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# **A Mixed-Methods Investigation of Unmet Needs, Symptom Experience, and Quality of Life in Individuals Living with Idiopathic Pulmonary Fibrosis**

A dissertation submitted to the University of Dublin for the Degree of Doctor of Philosophy

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## Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university, and it is entirely my own work. I confirm that the job has been completed in full compliance with relevant university policies, including the Academic Integrity policy, the Trinity Policy on Good Research Practice, and the guidance on AI and GenAI in Teaching, Learning, Assessment and Research.

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Carita Bramhill

## Summary

**Title:** A mixed-methods investigation of unmet needs, symptom experience, and quality of life in individuals with idiopathic pulmonary fibrosis.

**Background:** Idiopathic pulmonary fibrosis is a chronic, progressive and irreversible interstitial lung disease for which no curative treatment currently exists. While global prevalence continues to rise, recent improvements in median survival, particularly among those receiving antifibrotic therapy, highlight the growing need for standardised and equitable access to care. Despite its increasing incidence, IPF remains significantly underrepresented in national policy agendas, societal discourse and research funding priorities. The substantial burden imposed by IPF on both individuals and healthcare systems necessitates strategic investment, targeted service planning and consistent healthcare delivery models that address accessibility and resource allocation. A comprehensive understanding of the unmet needs of this population is essential to inform and optimise healthcare delivery for this under-recognised condition.

**Aim:** This study aimed to identify the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF. Specifically, it sought to explore the nature and extent of these unmet needs, examine the lived experience of symptoms and determine the factors that influence quality of life in this population. The findings of this research aimed to inform the ongoing development of healthcare services for individuals with IPF in Ireland, with implications for policy, education, health service provision, and future research initiatives.

**Methodology and Methods:** A sequential explanatory mixed-methods study was employed to address the research objectives in this study. This facilitated the integration of both quantitative and qualitative data, enabling comprehensive exploration of unmet needs, symptom experiences, and quality of life among individuals with IPF. This research was underpinned by a pragmatic philosophical stance and guided by the Levesque healthcare access theoretical framework, which provided a structured lens through which to examine the access-related dimensions of care. Phase one involved collecting audit data from a purposive sample of healthcare professionals (N = 16) across five hospitals, offering insight into service provision and care pathways. Phase two recruited a purposive sample of individuals diagnosed with IPF (N = 237) from the same five hospitals. Participants completed a comprehensive survey comprising the St. George Respiratory Questionnaire-IPF (SGRQ-IPF), IPF Patient-Reported Outcome Measure (IPF-PROM), and the Lung Information Needs Questionnaire (LINQ), which captured data on unmet needs, symptom experiences, and quality of life. Phase three consisted of semi-structured qualitative interviews (N = 20) designed to enrich and contextualise the quantitative findings. These interviews (N = 20) provided in-depth descriptive insights into the experiences of individuals with IPF, with a particular focus on unmet needs, symptom experiences, and perceptions of quality of life.

**Findings:** The integrated results of this sequential explanatory mixed-methods study reveal significant and widespread barriers in care for individuals living with IPF in Ireland. Notable heterogeneity exists in the composition and resourcing of multidisciplinary teams (MDT) across hospitals, with some centres better equipped than others. Over sixty per cent of healthcare professionals (HCPs) reported challenges in

accessing referrals to essential services, including counselling, lung transplantation assessment, pulmonary rehabilitation, and access to clinical trials. Many HCPs expressed concern about insufficient time allocated for patient consultations. Referral to palliative care was inconsistent and frequently delayed, contrary to international guidelines recommending early initiation. Discussion around palliative care was either absent or initiated too late to adequately capture patients' end-of-life care preferences, limiting their ability to benefit from symptom management and supportive services. Participants reported a high symptom burden with breathlessness, cough and fatigue being the most prevalent. Difficulties managing the side effects of medication were common, as too was the ability to access relevant supports.

Participants reported no access or prior referral to multiple healthcare supports, including an interstitial lung disease (ILD) nurse (28.3%), a dietitian (92.8%), a physiotherapist (52.3%), ILFA support groups (73.8%), pulmonary rehabilitation (60.8%), counselling services (95.8%), and palliative care (96.3%). Psychosocial challenges included anxiety, uncertainty and emotional distress related to disease progression. Participants also experienced delays in obtaining an accurate diagnosis. They highlighted the importance of the general practitioner, and that continuity of care was often disrupted due to difficulties in securing appointments with the same healthcare provider. Given the limited availability of formal support, many participants adopted self-directed coping mechanisms such as relying on family and friends, peer support, engaging in physical activity and participating in alternative therapies such as yoga, dancing and singing. Quantitative analysis identified statistically significant associations between poorer quality of life and the following variables: female gender, lack of health insurance, employment disruption due to IPF, living alone, presence of comorbid conditions and oxygen therapy use.

Participants also reported a lack of public awareness about IPF, inadequate information provision, and confusion navigating the healthcare system. Significant barriers, including poor building design, limited parking, financial strain, mobility challenges associated with oxygen equipment, infection risk (especially evident during the COVID-19 pandemic), and rural location further impeded access to care. Male participants and those living alone demonstrated higher information needs. Backward regression analysis using the SGRQ-I as the dependent variable identified several predictors of poorer quality of life, including having a comorbid condition ( $p = .004$ ), smoking history ( $p = .009$ ), living alone ( $p = .069$ ), and access to the Irish Lung Fibrosis Association peer support group ( $p = .085$ ).

**Discussion and Conclusion:** This study has yielded critical insights into the multifaceted and interconnected needs experienced by individuals with IPF. The findings highlight the complex relationship between symptom burden, unmet needs, and their cumulative impact on quality of life. Delays in obtaining an accurate and timely diagnosis were identified as a significant challenge, often resulting in postponed access to appropriate management and pharmaceutical interventions. A lack of public awareness and insufficient information further compounded these issues, leaving patients ill-equipped to navigate their care journey. Participants reported a high symptom burden, with secondary impacts on physical, functional, and emotional well-being. Persistent barriers to healthcare access, including inadequate resourcing of multidisciplinary teams, infrastructural limitations, and the financial strain associated with IPF, were shown to affect quality of life significantly. These systemic gaps contributed to



fragmented, inequitable, and unstandardised healthcare delivery. Addressing these challenges requires a multifaceted approach that integrates pharmacological treatment with patient-centred strategies aimed at enhancing quality of life. Such strategies may include peer support, social prescribing, and inclusion of patient and public involvement (PPI) in the development of standardised pathways of care. Furthermore, national policy directives are urgently needed to improve multidisciplinary retention and resourcing of healthcare staff, research, and programme development, ultimately ensuring that the needs of this underrepresented population are adequately met.

## Abstract

**Title:** A mixed-methods investigation of unmet needs, symptom experiences, and quality of life in individuals with idiopathic pulmonary fibrosis.

**Background and Aim:** Idiopathic pulmonary fibrosis (IPF) is a chronic, progressive, interstitial lung disease characterised by declining lung function and impaired quality of life. The burden on the healthcare system is expected to intensify given the global rise in the incidence and prevalence of idiopathic pulmonary fibrosis, and ongoing improvements in median survival among those receiving antifibrotic medication. Within this context, there is an urgent need to identify and address the unmet needs of those with IPF to ensure equitable, standardised, and patient-centred care. This study aimed to explore the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF.

**Methodology:** A sequential explanatory mixed-methods design was employed, underpinned by pragmatism, which provided the philosophical approach, and guided by the Levesque healthcare access theoretical framework.

**Methods:** Phase one involved an audit of healthcare professionals (N = 16) recruited from five national hospital sites. Phase two surveyed individuals diagnosed with IPF (N = 237) using validated instruments, including the St. George Respiratory Questionnaire-IPF (SGRQ-IPF), IPF Patient-Reported Outcome Measure (IPF-PROM) and the Lung Information Needs Questionnaire (LINQ). Phase three consisted of semi-structured interviews (N = 20) to gain deeper insights into unmet needs, symptom experiences, and quality of life.

**Findings:** Barriers to healthcare access were prominent, with significant challenges in referral to lung transplantation assessment, pulmonary rehabilitation, counselling, and clinical trials. Multidisciplinary team (MDT) provision varied significantly, with notable geographical disparity in equitable access to key supports. Palliative care discussions were often delayed or absent, limiting opportunities to plan for end-of-life care preferences. The most frequently reported symptoms were breathlessness, cough and fatigue. Poorer quality of life was significantly associated with female gender, oxygen use, lack of health insurance, employment disruption, living alone and having a comorbid condition. Participants also reported difficulties with obtaining an accurate diagnosis, navigating the healthcare system, and coping with the psychosocial impacts of IPF, including isolation, uncertainty and financial strain. Male participants and those living alone had higher information needs. Coping strategies were largely self-directed, involving family support, peer engagement and activities such as exercise, yoga and singing.

**Discussion and Conclusion:** This study highlights the substantial symptom burden and wide-ranging unmet needs experienced by individuals with IPF. Addressing gaps requires a multifaceted approach, including improved public awareness, early diagnosis, timely information provision, enhanced access to palliative care, pulmonary rehabilitation and lung transplantation assessment, self-management for symptoms, improved retention and better MDT resourcing. The implementation of a national registry, alongside innovative strategies such as enhanced peer support and social prescribing, is essential to optimise quality of life and inform further policy, research and service planning.

## Acknowledgement

I am deeply grateful to the participants in this study for their honest and thoughtful contributions, which form the very essence of this study. It has been a profound privilege to be welcomed into the deeply reflective spaces created during participants' interviews - spaces that offered me an opportunity to listen to the lived experiences of those affected by IPF. Thank you for placing your trust in me. I hope that the interview excerpts truly reflect your voices. I also wish to sincerely thank the many healthcare professionals who participated in this study. Your invaluable contributions, enthusiasm and unwavering support have been deeply appreciated.

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This PhD is dedicated to those who contributed to this study and to the many people who have lost their lives because of IPF.

## List of Abbreviations

**ACP:** Advance care Planning

**CHB:** Connolly Hospital, Blanchardstown

**COPD:** Chronic Obstructive Pulmonary Disease

**CUH:** Cork University Hospital

**COVID-19:** Coronavirus Disease 2019

**DoH:** Department of Health

**DPIA:** Data Protection Impact Assessment

**DPR:** Drug Payment Scheme

**GP:** General Practitioner

**GDPR:** General Data Protection Regulation

**GUH:** Galway University Hospital

**HCP:** Healthcare Professional

**HRCT:** High Resolution Computed Tomography

**HRQoL:** Health Related Quality of Life

**ICU:** Intensive Care unit

**I-CVI:** Item Content Validity Index

**ILD:** Interstitial Lung Disease

**ILFA:** Irish Lung Fibrosis Association

**IPF:** Idiopathic Pulmonary Fibrosis

**MDT:** Multidisciplinary Team

**MMUH:** Mater Misericordiae University Hospital

**NCP:** National Clinical Care Programme

**NHS:** National Health Service

**Nvivo:** Non-Versioned Information, Versatile Outcomes

**PIL:** Patient Information Leaflet

**PPI:** Patient and Public Involvement

**PR:** Pulmonary Rehabilitation

**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**QR:** Quick Response Code

**QoL:** Quality of Life

**S-CVI:** Scale Content Validity Index

**SPSS:** Statistical Package for the Social Sciences

**SVUH:** St Vincent's University Hospital

**TA:** Thematic Analysis

**TUH:** Tallaght University Hospital

**UHL:** University Hospital Limerick

**UK:** United Kingdom

**WHO:** World Health Organisation

## Publications and Presentations Related to This Thesis

### Peer-Reviewed Publications

**Bramhill, C.,** Langan, D., Mulryan, H., Eustace-Cook, J., Russell, A. M., & Brady, A. M. (2023). Exploration of the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis: a scoping review protocol. *BMJ open*, 13(5), e070513.

**Bramhill, C.,** Langan, D., Mulryan, H., Eustace-Cook, J., Russell, A. M., & Brady, A. M. (2024). A scoping review of the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis (IPF). *PloS one*, 19(2), e0297832.

### Non-Peer Reviewed Publications

**Bramhill, C.,** Brady, A-M. Pulmonary Fibrosis: Unmet Healthcare Needs. *Medical Independent*, 2024; 10 (4): 28-31

**Bramhill, C.** (2022) 'Living Beyond a Diagnosis of Idiopathic Pulmonary Fibrosis. A Mixed-Method Exploration of Patient Related Experience and Unmet Healthcare Needs'. *Irish Lung Fibrosis Association Newsletter*. 2022; 20 (2): 12

### Peer Reviewed Oral Presentations

**Bramhill, C.,** Russell, A-M., Brady, A-M. 'Navigating the Challenges of Unmet Needs: A Mixed Methods Study'. *Interstitial Lung Disease Network, Birmingham, United Kingdom*. 6-7 October 2024

**Bramhill, C.,** Brady, A-M. 'Living beyond a diagnosis of Idiopathic Pulmonary Fibrosis; a mixed methods study exploring patient related experience and unmet healthcare needs. *Trinity Health and Education International Conference, Dublin, Ireland*. 7-9 March 2023

### Non-Peer Reviewed Oral Presentations

**Bramhill, C.** 'An exploration of the unmet needs and quality of life of patients diagnosed with IPF. A PhD study'. *Boehringer Ingelheim Nurse Education Day. Athlone, Ireland*. 21 June 2023

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### Peer Reviewed Poster Presentations

**Bramhill, C.,** Langan, D., Mulryan, H., Russell, A-M., Brady, A-M. 'A scoping review of the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis (IPF)'. *Irish Thoracic Society Annual Scientific Meeting, Limerick, Ireland*. 9-11 November 2023

**Bramhill, C.,** Russell A.M, Brady A-M. 'Embedding patient and public involvement in a mixed-methods study, to explore the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis (IPF)'. *3<sup>rd</sup> European Pulmonary Fibrosis Summit, Barcelona, Spain*. April 26-28, 2024

**Bramhill, C.,** Russell A.M, Brady A-M. 'Patient and public involvement: creating opportunities for embedding PPI in doctoral research'. *Trinity Health and Education International Conference, Dublin, Ireland*. 4-6 March 2024

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# Chapter 1 Background

## 1.1 Introduction

This doctoral research study investigated the unmet needs, symptom experiences, and quality of life of people living with a diagnosis of idiopathic pulmonary fibrosis (IPF). This chapter introduces the aetiology of IPF, diagnostic criteria, epidemiological information (incidence and prevalence), and treatment modalities to foster a deeper understanding of the topic. Interstitial lung disease (ILD) is explained, and a description of pulmonary fibrosis follows. A detailed description of the symptoms of IPF is presented. Next, the primary outcome of interest, unmet needs and the secondary outcome, quality of life, are both defined, followed by the rationale for undertaking this study. The latter section of the chapter outlines both the aims and objectives of the research and the structure and layout of the thesis.

## 1.2 Interstitial Lung Disease

Interstitial lung disease (ILD) describes a heterogeneous group of at least two hundred disorders, each with their own clinical presentation and prognosis (Aielli et al., 2017; Wijsenbeek et al., 2019). These conditions are primarily defined by inflammation and/or fibrosis (scarring) of the lung interstitium – the tissue and space surrounding the alveoli (Smith & Jenkins, 2023). These changes can lead to breathlessness, dry cough, and fatigue, which may significantly impact quality of life (Kim et al., 2015; Wijsenbeek et al., 2022). The outlook for ILDs can vary widely. Some types respond better to specific therapies and have a favourable prognosis, while others have a much worse outcome (Grunewald et al., 2019). Some ILDs have known aetiologies (Athobiani et al., 2024; Raghu et al., 2011; Travis et al., 2002), while other ILDs of unknown cause are classified as '*idiopathic*' (Raghu et al., 2022).

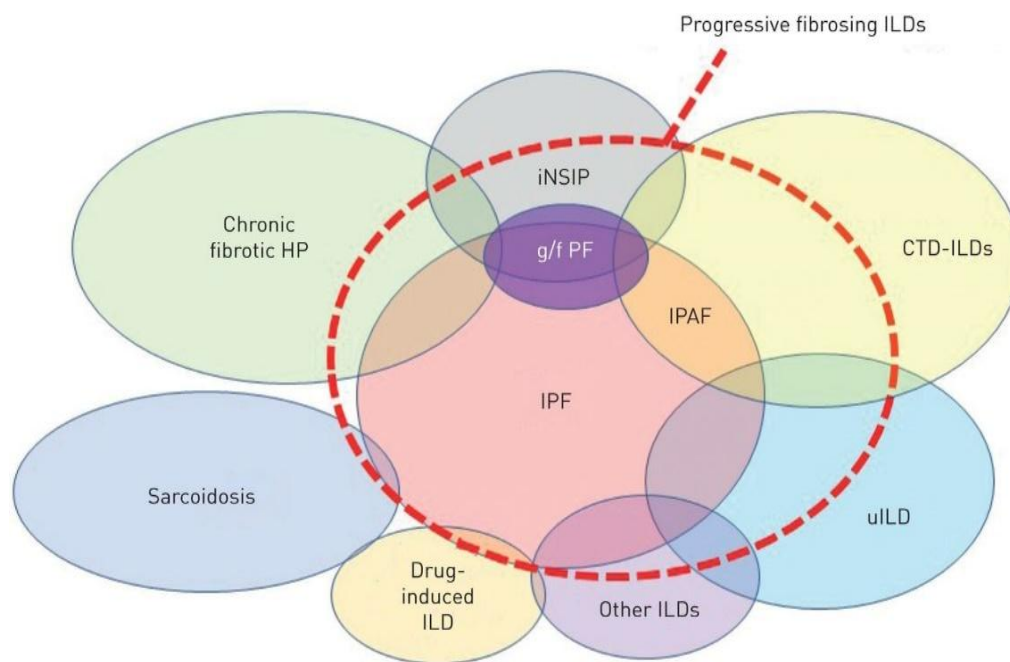
### 1.2.1 Idiopathic Pulmonary Fibrosis

Idiopathic pulmonary fibrosis is the most aggressive form of ILD, accounting for around 50% of all reported idiopathic interstitial pneumonia's (IIPs) (Athobiani et al., 2024; Holland et al., 2014; Raghu et al., 2011) (Figure 1.1). IPF is recognised as a chronic, progressive, and irreversible disease that can profoundly and devastatingly affect an individual's physical and psychological well-being, leading to negative impacts on quality of life (Holland et al., 2014; Sampson et al., 2015; Weatherald et al., 2017). IPF carries with it a poor prognosis and a median survival in those untreated of 3-5 years (Koudstaal & Wijsenbeek, 2023). IPF is thought to be characterised by the radiological and histological features of usual interstitial pneumonia (UIP) (Raghu et al., 2022). IPF is thought to arise from repeated minor injuries to the alveolar epithelium, in combination with abnormalities in the repair process (Wuyts et al., 2020). These abnormal processes result in damage to the normal structure of the lung (Thong et al., 2023), resulting in reduced lung volume and impaired gas exchange, which impacts quality of life (Wuyts et al., 2020, 2023).

IPF occurs most frequently in men and those aged over sixty years, with the incidence increasing with age (Collard, 2010; Fernández-Fabrellas et al., 2019; Jo et al., 2016; Lederer & Martinez, 2018) and is often

seen in those who have a history of smoking (Behr et al., 2015; Hyldgaard et al., 2014). The disease trajectory is believed to follow either a rapid or gradual decline (Ley et al., 2011). Individuals with IPF may experience extended periods of stability, which can be interrupted by acute exacerbations (AE) (Athobiani et al., 2024; Cho et al., 2020). Raghu et al. (2011) classified an exacerbation in IPF as a sudden deterioration of unknown cause, which is associated with an increased mortality rate (Collard et al., 2016). Individuals who require mechanical ventilation during an exacerbation often have a poor prognosis (Luo et al., 2020).

**Figure 1.1 Schematic Representation of Types of Interstitial Lung Disease (ILD)**



**\*Key:** Connective tissue disease (CTD)-ILDs include rheumatoid arthritis-associated ILD, systemic sclerosis-associated ILD, mixed CTD-associated ILD and other autoimmune ILDs. Other ILDs include exposure-related ILDs (asbestosis and silicosis), non-idiopathic pulmonary fibrosis (IPF), idiopathic interstitial pneumonias (desquamative interstitial pneumonia, etc.), and others. g/f PF: genetic and/or familial pulmonary fibrosis; HP: hypersensitivity pneumonitis; iNSIP: idiopathic nonspecific interstitial pneumonia; IPAF: interstitial pneumonia with autoimmune features; uILD: unclassifiable ILD. Schematic representation of types of interstitial lung disease (ILD) that may be associated with a progressive fibrosing phenotype. Reproduced with permission of the © ERS 2024: European Respiratory Review 28 (153) 190109; DOI: 10.1183/160006

### 1.2.2 Challenges for IPF Care

Over the past decade significant advances have been made in our understanding of IPF, although the underlying cause of the disease remains elusive (Raghu et al., 2011, 2018, 2022). Diagnostic delays in IPF are reported internationally and are often associated with common, non-specific symptoms of the condition, including cough, dyspnoea, and fatigue. The general symptoms of IPF can make diagnosis difficult, particularly when differentiating it from other types of ILD (Baddini-Martinez et al., 2025; McLean-Tooke et al., 2019; Raghu et al., 2011; Vega-Olivo & Criner, 2018). Current international guidelines (Raghu et al., 2011, 2022) provide a framework for clinicians diagnosing IPF and emphasise the critical role of the multidisciplinary team (MDT) in supporting diagnosis. Similarly, guidance from the UK National Institute for Health and Care Excellence (NICE, 2017) highlights the importance of MDT assessment, especially in situations where there is uncertainty regarding the diagnosis. The Irish Thoracic Society IPF



Position Statement echoes these sentiments (ITS, 2018). Harnessing the expertise of the MDT and integrating radiological and pathological information is considered the gold standard in the management of IPF to optimise patient outcomes (Cottin et al., 2022; Raghu et al., 2018).

Delays in diagnosis of more than one year (Hoyer et al., 2022) can lead to poorer outcomes for patients and are linked to a higher risk of an early death (Cosgrove et al., 2018; du Bois et al., 2011; Lamas et al., 2011; Richeldi et al., 2012). Delays in diagnosis often lead to delayed access to pharmaceutical treatments (Hoyer et al., 2022; Hoyer et al., 2019; Snyder et al., 2020). In addition, delays in diagnosis can impact opportunities for onward referral for lung transplantation assessment (Cosgrove et al., 2018). Accessing an early and accurate diagnosis is critical to enhancing the quality of life of individuals diagnosed with IPF (Aiello et al., 2017; Cassidy et al., 2015; Wijsenbeek et al., 2022). Current evidence indicates that there are still significant gaps in obtaining a prompt diagnosis, which represents an ongoing unmet need, often leading to delays in gaining access to appropriate treatment and significantly impacting quality of life (Bramhill et al., 2024).

### **1.2.3 Incidence and Prevalence of IPF**

Epidemiological information, such as incidence (number of new cases per year) and prevalence (total number of cases over time), is critical in IPF care as it can result in improvements in our understanding of the burden of disease. Additionally, it can provide a platform for future research and resource planning (Coggon et al., 2009). Challenges can persist in acquiring accurate epidemiological information in IPF, with broad variations observed depending on the case definition and methodology employed in data collection. While IPF is rare, the incidence of the condition is rising globally – a trend also seen in other ILDs (Sgalla et al., 2016). The global rise in IPF is thought to be attributable to several notable factors, including an ageing population, improved awareness about the condition, and better access to enhanced diagnostic tools such as computed tomography scans, culminating in earlier identification of the disease (Hoyer et al., 2019; Hutchinson et al., 2015; Maher et al., 2021). Broad variations in the incidence of IPF exist across several domains, including age, gender, ethnicity and geographical location (Wijsenbeek et al., 2022). Furthermore, international variations in data collection and recording of information hamper the interpretation of data, resulting in difficulties in assessing global trends (Maher et al., 2021). In Ireland, limited data exists on the incidence and prevalence of IPF, due to the absence of a national disease registry, impeding future healthcare planning for individuals affected by the disease (Irish Thoracic Society, 2018).

**International Data :** Maher et al. (2021) conducted a literature review to report on the incidence and prevalence of IPF globally from January 2009 to April 2020. They estimated that the adjusted incidence rates for the disease in each of the included countries ranged from 0.35 to 1.30 in Asia-Pacific nations, 0.09 to 0.49 in Europe and 0.75 to 0.93 in North America (per 10,000 population) (Maher et al., 2021).

**United Kingdom:** Strongman et al. (2018) present results from an extensive population-based study using data from 2000 to 2012 to explore the incidence, prevalence, and survival of patients with IPF in the UK.

They used the terminology IPF-CS (idiopathic pulmonary fibrosis clinical syndrome) rather than IPF to describe their population, reflecting the variability that exists in current coding practices. The overall number of cases of IPF-CS identified between 2000-2012 was 1491 using their narrow case definition, and 4527 using their broad case definition (Strongman et al., 2018). The overall incidence rate of the disease (incidence rate per 100,000 patient-years) was 2.85 (95% CI 2.71-3.00) using a narrow case definition and 8.65 (95% CI 8.40 - 8.90) using a broad case definition. They observed a 78% increase in the incidence of IPF-CS in 2012 compared with the year 2000 (Incidence rate ratio 1.78, 95% CI 1.50-2.11) (Strongman et al., 2018).

The prevalence of IPF-CS almost doubled over the study period 2000-2012, with a starting point of 19.94 per 100,00 patients (95% CI 18.48 - 21.47) in 2000 and rising to 38.82 per 100,000 patients (95% CI 37.04-40.66) in 2012 (Strongman et al., 2018). Significantly they found that the prevalence of IPF-CS in 2012 was significantly higher in males and increased with age. They also observed heterogeneity across health authority locations (Strongman et al., 2018). They observed no significant changes in survival, with a median survival using a broad case definition of three years (95% CI 2.8 - 3.1,  $N = 2168$ ) and in a narrow case definition of just under three years (95% CI 2.5 – 3.0,  $N = 996$ ) (Strongman et al., 2018).

**Ireland:** From an Irish perspective, IPF is estimated to affect around 1,000 people in Ireland, with a conservative estimate of at least 400 new cases diagnosed annually (ITS, 2018). The findings from the study conducted by Strongman et al. (2018) support the current literature that both the incidence and prevalence of IPF are increasing globally (Hutchinson et al., 2015; Maher et al., 2021). The exponential global rise in IPF poses a challenge for public health, placing a significant burden on already under-resourced health systems (Bramhill et al., 2024). The lack of standardised diagnostic coding for the condition, combined with the absence of a national IPF registry, hampers efforts to effectively plan and allocate resources to meet the needs of an IPF population, representing a persistent unmet need.

#### **1.2.4 Life Expectancy**

The introduction of antifibrotic therapy over a decade ago positively changed the landscape in IPF care, particularly in reducing the rate of disease progression (Bonella et al., 2023; Raghu et al., 2015). Pharmacological innovations over the last decade have made it increasingly necessary to address the unmet needs of this population (Maher & Strek, 2019). Mortality associated with IPF is high, notwithstanding the serious nature of this condition (Kim et al., 2015). Marshall et al. (2018) used the World Health Organisation (WHO) mortality database for the period 2001-2013 and found that mortality from the disease has increased in most European Union (EU) countries. IPF remains a serious and life-limiting condition, with a median life expectancy of between three and five years from diagnosis (Hutchinson et al., 2015; Olson et al., 2021) if untreated (Alsomali et al., 2023). Acute exacerbations in IPF are associated with increased mortality rates (Collard et al., 2016), representing devastating impacts to patients. Those who require invasive mechanical ventilation during an acute exacerbation can face a significant 86% mortality rate during inpatient stays (Luo et al., 2020). Other studies report a mortality rate during inpatient stays for acute exacerbation of 50% (Collard et al., 2016; Rush et al., 2018).

### 1.2.5 Symptoms of IPF

Individuals living with a diagnosis of IPF experience a significant symptom burden, coupled with an often-uncertain disease path and overall reduction in quality of life (QoL) (Overgaard et al., 2016b; Van Manen et al., 2017). There is a diverse range of symptoms associated with the condition, which can vary and worsen throughout the disease and includes progressively worsening breathlessness, often referred to as the '*hallmark of IPF*' (Swigris et al., 2005). Other symptoms include a dry, persistent cough, fatigue (Lancaster et al., 2021; Lindell et al., 2018; Wuyts et al., 2020), loss of appetite (Russell et al., 2016), and anxiety and depression (Van Manen et al., 2017).

Additionally, IPF symptoms include 'velcro'-like bibasilar crackles upon chest auscultation (Sellaes et al., 2016) and for some digital clubbing, where changes are observed in the appearance of fingers and toes (Raghu et al., 2011). Cough and dyspnoea are significant determinants of health-related quality of life (HRQoL) in patients with IPF (Glaspole et al., 2017; Kreuter et al., 2017). Dyspnoea is considered a significant predictor of disease progression and mortality in those with IPF (Musellim et al., 2009) and may contribute to the development of mental health impacts such as depression (De Vries et al., 2001). Chronic cough has been reported in 50% – 90% of patients with IPF (Saunders et al., 2023; Van Manen & Wijsenbeek, 2019), with limited treatment options available to manage this symptom (Musellim et al., 2009). Cough is a particularly challenging symptom for patients, which can negatively impact quality of life (Green et al., 2024).

Worsening symptoms over the course of the disease can contribute to difficulties with physical activities, engagement in social settings, and reduced employment, further limiting individuals' ability to participate fully in daily life. Symptom burden in IPF has been consistently shown in the literature to negatively affect quality of life. A diverse approach is required to alleviate symptom burden, address unmet needs, and improve patients' quality of life (Green et al., 2024; Russell et al., 2016; Swigris et al., 2005).

## 1.3 Management of IPF

### 1.3.1 Pharmacological Treatment Options for IPF

The last decade has witnessed a significant transformation in the care of patients diagnosed with IPF, facilitated by advancements in our understanding of the disease, enhancements in diagnostic criteria, and the introduction of new pharmacological treatments. Longitudinal safety and efficacy studies in both pirfenidone (Esbriet<sup>®</sup>) and nintedanib (Ofev<sup>®</sup>) have continued to foster confidence in their efficacy (Martinez et al., 2017; Ramadurai et al., 2018). Antifibrotic drugs (pirfenidone and nintedanib) can slow the rate of decline in lung function, but cannot cure IPF, and to date have demonstrated limited impact on quality of life (Bonella et al., 2023; Lancaster et al., 2021; Van Manen et al., 2017).

Available antifibrotic medications are often associated with adverse side effects, which can impact quality of life (Hadda & Guleria, 2020). The management of medication side effects should be discussed regularly with patients to help them manage these potential risks. The side effects most likely to occur with nintedanib (Ofev<sup>®</sup>) include nausea, vomiting, and diarrhoea (Richeldi et al., 2018). Pirfenidone (Esbriet<sup>®</sup>) is associated with gastrointestinal symptoms, coupled with reports of skin-related photosensitivity (Lancaster et al., 2017; Ren et al., 2017). The symptoms of IPF progressively worsen over the disease course, with many patients being prescribed oxygen to alleviate symptoms and improve quality of life (Akiyama et al., 2020; Johansson et al., 2017; Van Manen et al., 2017). However, barriers to oxygen therapy exist, including cost (Lacasse et al., 2015), difficulties associated with oxygen equipment and perceived negative impacts to self-image owing to the visibility of oxygen equipment when in use (Kelly & Maden, 2014; Khor et al., 2017). Lung transplantation remains the only option available to patients with IPF that can restore lung function and impact overall survival (Laporta et al., 2018; Thong et al., 2023). However, uptake of lung transplantation remains low, with many patients excluded from referral for assessment for surgery, often due to advanced age (King et al., 2023), therefore making symptom management imperative in this population.

### **1.3.2 Non-Pharmacological Treatment Options**

Non-pharmacological treatment options to support patients with IPF includes pulmonary rehabilitation (PR) (Cassidy et al., 2022). The National Institute for Health and Care Excellence Guidelines (NICE) (2017) recognise pulmonary rehabilitation as an essential component of non-pharmacological supportive treatment for patients with IPF, that support improvements in functional (Zamparelli et al., 2024) and respiratory capacity, positively impacting quality of life (Dowman et al., 2021; Gaunard et al., 2024; Glaspole et al., 2017; Guler et al., 2022; Nolan et al., 2022). Evidence suggests that pulmonary rehabilitation plays a critical role in preparing patients for lung transplantation surgery by addressing physical conditioning during lung transplantation assessment and the preoperative phase (Benton & Graham, 2017; De Sousa et al., 2021; Niu et al., 2024; Papathanasiou et al., 2021; Zamparelli et al., 2024).

Despite the recognised benefits, deficits remain in the implementation of pulmonary rehabilitation programmes both nationally (Cassidy et al., 2022) and internationally (Oliveira et al., 2023). Other novel supportive care options for functional and psychosocial well-being include mindfulness (Saketkoo et al., 2018), singing (Cahalan et al., 2022), and dance programmes (Niranjan et al., 2022). Health promotion measures which optimise a person's quality of life should be addressed with patients and should include smoking cessation and vaccination programmes (Vicol et al., 2024).

### **1.3.3 Palliative Care**

Palliative care is recommended to support patients in managing symptoms, pain relief, spiritual, and psychosocial well-being (Bonella et al., 2016; Irish Lung Fibrosis Association, 2015; Janowiak et al., 2022). Available literature suggests that referral to palliative care often occurs too late in the disease course

(Ahmadi et al., 2016; Lindell et al., 2017). Compared to patients who are experiencing cancer, individuals with IPF are less likely to receive early palliative care referral, representing an unmet need (Janowiak et al., 2022). Other supportive measures include advance care planning (ACP), which can provide an opportunity for patients and their caregivers to consider their preferences for end-of-life care (Koffman et al., 2023; Lindell et al., 2017). Despite national and international guidelines and patient charters (Bonella et al., 2016; ILFA, 2015; NICE, 2017; Raghu et al., 2022), which recommend early referral to palliative care services for those with the disease, its availability and accessibility remain poor, leading to unmet needs among patients and caregivers.

#### **1.4 Current Guidance on the Management of IPF in Ireland**

In Ireland the management of IPF is guided by several important guidelines and recommendations (ILFA, 2015; ITS, 2018). The Irish Thoracic Society's IPF Position Statement (2018) aims to provide guidance to healthcare professionals in the diagnosis and management of patients with IPF, and to inform policymakers about the necessary resources required to optimise quality of life. Meanwhile, the Irish Lung Fibrosis Association (ILFA) provides the backdrop for the National IPF Patient Charter (2015), which seeks to ensure fair and equitable care for those with the disease. The IPF Patient Charter outlines patients' needs, such as the requirement for a prompt diagnosis, clear information, access to pharmacological support, pulmonary rehabilitation, lung transplant assessment, and psychosocial support (ILFA, 2015, p.3). Additionally, ILFA provides a suite of support services to patients with IPF and their families, which include the provision of information and education regarding the condition, national support groups, patient-centred research underpinned by patient and public involvement, online classes, and advocacy work. In combination, these resources aim to enhance IPF care and advocate for standardised and equitable access to healthcare that meet the needs of patients nationally.

Currently, patients are predominantly treated in one of the eight specialist centres in Ireland: Galway University Hospital (GUH), Cork University Hospital (CUH), University Hospital Limerick (UHL), St. Vincent's University Hospital (SVUH), Tallaght University Hospital (TUH), Beaumont Hospital, Connolly Hospital, Blanchardstown (CHB), and the Mater Misericordiae University Hospital (MMUH). These centres offer services such as multidisciplinary assessments and access to diagnostic tools, including computed tomography scans and pulmonary function tests. Supportive treatment at these centres incorporates disease-modifying treatments, such as antifibrotic medications, access to oxygen therapy, and where available – pulmonary rehabilitation programmes and palliative care. However, persistent heterogeneity exists in the availability and provision of these supportive services, making them inaccessible for some patients (Cassidy et al., 2022). Unlike other chronic disease conditions, such as asthma and chronic obstructive pulmonary disease (COPD), patients with IPF often lack access to a dedicated clinical care pathway or programme of care, resulting in mainly hospital-based care (incorporating both inpatient and outpatient care provision), which is supported by their general practitioner in the community.

Nationally, the National Respiratory Clinical Programme (NCP) (Health Service Executive, 2010) was established in 2010 to enhance and standardise patient care in respiratory disease. The NCP aims to ensure early detection, disease management, and optimal treatment, aligned with the principles of Sláintecare to provide *“the right care, in the right place and at the right time”* (Department of Health Ireland [DOH], 2021). To date, the National Respiratory Clinical Programme (HSE, 2020) has largely excluded patients with IPF, instead mainly focusing on chronic obstructive pulmonary disease (COPD) and asthma.

The Health Service executive (HSE) is responsible for the delivery of healthcare services in Ireland through a range of public, private, and voluntary organisations operating under the governance of the Department of Health (Citizens Information, 2024). Access to healthcare services is provided through either public or private routes. Ireland operates a two-tier eligibility system to determine an individual’s entitlement to public services. This system defines the level of financial contribution required, the services available free of charge, and those for which individuals must pay out of pocket (HSE, 2024).

Within this framework, Category One applies to medical card holders. Individuals who qualify under this category are entitled to all public healthcare services free at the point of delivery (HSE, 2024). A medical card provides access to free general practitioner services, inpatient and outpatient public hospital care, as well as dental and optical services. Eligibility for a medical card is means-tested, with relatively low income thresholds. The HSE (2024) states that a single individual aged 66 years or over who lives alone must have a weekly income not exceeding 201.50 euro to qualify. Individuals who do not meet the criteria for a medical card, may be eligible for a General Practitioner Visit Card, which has a higher income threshold. However, this form of support is more limited, as it covers only general practitioner services (Citizens Information, 2024).

Category Two applies to individuals who are ordinarily resident in Ireland but do not hold a medical card (HSE, 2024). Under this category, individuals are entitled to access specialist public healthcare services, subject to partial coverage or applicable fees. Category Two residents are required to pay for general practitioner visits, most prescription medicines (unless eligible for the Drug Payment Scheme), and certain community and social care services (HSE, 2024).

Despite the universal availability of public healthcare services within the two-tier system, patients frequently experience long waiting times, limited choice, and capacity constraints. Consequently, almost half the population purchases private health insurance (Health Insurance Authority, 2021). One of the primary motivations for holding private health insurance in Ireland is the prolonged waiting times for appointments, diagnostic, procedures, and elective surgery within the public healthcare system. Delays can be particularly pronounced for non-urgent care, which can adversely affect individuals with chronic conditions. Private insurance provides faster access to specialist appointments and diagnostics.

Internationally, guidelines exist which provide a framework to support the management and diagnosis of IPF. These guidelines are regularly updated to reflect changes in clinical practice and advancements in diagnostics and pharmaceutical interventions (Behr et al., 2015; Cottin et al., 2017; Funke-Chambour et

al., 2017; NICE, 2017; Raghu et al., 2022; Skold et al., 2017; Xaubet et al., 2017). Additional guidance exists in the form of patient charters and position statements, which have been developed at both national and international levels (Bonella et al., 2016; ILFA, 2015; ITS, 2018). These aim to increase awareness of the condition, highlighting gaps in care and improving access to appropriate supports for all patients with IPF across Europe (Moor et al., 2019).

## **1.5 Quality of Life**

The secondary outcome of interest in this research is Quality of Life (QoL), which has become a central focus in IPF research due to the profound impact of this disease on patients' daily lives and overall well-being (De Vries et al., 2001; Van Manen et al., 2017; Kreuter et al., 2019). As IPF advances, patients may experience significant impacts on their physical and emotional health, making quality of life a critical outcome to assess in both clinical practice and research. There is increased recognition of the importance of incorporating patient-reported outcome measures (PROMs) into clinical research and routine outpatient care (Porter et al., 2016), reflecting a shift toward more patient-centred healthcare to optimise quality of life (Cox et al., 2020).

The concepts of quality of life (QoL) and health-related quality of life (HRQoL) are often used interchangeably, as they share several overlapping standard features (Karimi & Brazier, 2016). The shared commonalities inherent in these concepts can lead to confusion when applying these concepts in the context of research. Although QoL is frequently assessed in studies, it is often not clearly defined (Costa et al., 2021). The concept of health-related quality of life (HRQoL) is considered to operate at the intersection between health and QoL, bridging the gap between both (Sitlinger & Zafar, 2018). Research on the quality of life of patients with IPF has substantially increased in the last decade (Glaspole et al., 2017; Van Manen et al., 2017), with a growing emphasis on incorporating HRQoL measurement into clinical practice (Asadi-Lari et al., 2004). Frequently used HRQoL self-report measures used in IPF research include the St. George Respiratory Questionnaire (SGRQ) (Jones et al., 1991), Short Form (SF-36) (Ware Jr, 2000) and EuroQoL (EQ5D) (Herdman et al., 2011).

In essence, the concept of quality of life holds various meanings for people. It is defined by the World Health Organisation (WHO) (1995, p. 1045) as an "individual's perception of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards, and concerns". This definition reflects a diverse perspective, incorporating a broad range of contributory factors that include physical and emotional well-being, psychosocial factors, and environmental and cultural aspects. The literature outlines several other notable definitions of health-related quality of life (HRQoL), such as the one provided by Guyatt et al. (1993), who describe health-related quality of life as a range of factors that traditionally may not have been thought to relate to 'health', such as "income, freedom and quality of environment" (p. 622). They explain how nearly all aspects of life can become health-related when you are ill. This definition, like that provided by the world

health organisation adopts a broader perspective, by integrating physical, emotional, and social functioning.

Health-related quality of life in this study was anchored to the Ferrans et al. (2005, p. 338) model of HRQoL, which incorporates five domains which include: 'physical, biological and functional variables, assessment of symptoms and subjective experience of health, and an individual's overall quality of life'. The Ferrans et al. model supports this study's objective to explore the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF, using both objective patient-reported outcome measures (PROMs) and subjective data (semi-structured interviews) (Ferrans et al., 2005). Collecting HRQoL data can support healthcare professionals and policymakers in gaining a comprehensive understanding of the burden of the disease and informing improved health service planning and delivery. Management of patients with IPF requires a patient-centred, holistic approach that not only focuses on the clinical aspects of the condition but also prioritises resources to optimise patients' quality of life (Cox et al., 2020; Oliveira et al., 2023; Quinn et al., 2019).

## 1.6 Unmet Needs

Identifying unmet needs for individuals with IPF – which is the primary focus of this research – necessitates a comprehensive understanding of the multifaceted nature of 'needs' within a healthcare context. The concept of 'needs' spans physical, psychological, social, and system dimensions – each influencing patient outcomes and quality of life. Firstly, multiple conceptual definitions of 'need' exist, which have contributed to ongoing confusion and ambiguity in the literature due to the absence of a clear definition (Allin et al., 2010). The assertion that "it may be an illusion to suppose that there might ever be a consensus about the meaning of needs" (Culyer, 1998, p. 77) underscores the inherent complexity and subjectivity in defining 'need' within a healthcare context. This complexity is especially apparent in chronic conditions like IPF, where patients lived experiences and perceptions of their needs may overlap or differ significantly from those of healthcare professionals (Wells et al., 2024). Bradshaw's (1972, 1994) taxonomy of 'need' has been widely used in healthcare research to address the nuanced nature of the concept of 'need' by focusing on four types of need.

**Felt need (wants)** – needs that are dependent on an individual's perception of their needs encompassing their unique wants, wishes and desires.

**Expressed needs (demands)** – these are needs that are vocalised by individuals usually through health-seeking behaviours. Expressed needs can be impacted by certain variables, including the supply of services.

**Normative needs** – these needs relate to needs that are identified by healthcare professionals and that may not have been known to individuals themselves.



**Comparative needs** – addresses the needs that arise in one context and reflects how these may be similar or diverge from the needs of others in a similar context.

The concept of ‘health needs’ extends far beyond traditional clinical care, encompassing a broad range of supports and services, including health promotion measures, preventative medicine, treatment, rehabilitation, and supports that enable individuals to lead independent lives (Asadi-Lari & Gray, 2005; Asadi-Lari et al., 2004; Culyer, 1998). The concept of ‘need’ in healthcare is multifaceted, and while consensus remains elusive, one of the earliest conceptualisations is provided by Davies (1995). They employed a subjective approach to their definition, describing a ‘need’ as a personal feeling state that ignites an individual’s decision-making process regarding medical resources (Davies, 1995). In comparison, Green and Kreuter (1991) adopted a pragmatic lens to describe ‘need’ describing it as whatever an individual requires for their health, thereby incorporating multiple viewpoints. Healthcare needs are underscored by demand; the perception of need, which is broadly influenced by cultural and social factors. Demand also relates to the availability, affordability, and awareness of healthcare services (Grossman, 2017). On the other hand, supply concerns how many resources are available to meet demand (Stevens, 2004).

The endeavour to improve healthcare access and optimise patient needs in IPF has been significantly advanced through literature that prioritises the exploration of patient-centred experiences and perception of need (Jérnas et al., 2024; Lyu et al., 2021; Wells et al., 2024). Central to this approach is the recognition that a comprehensive review of patients’ needs must also include identification of patients’ unmet needs. Addressing the complex interplay that exists between patients and the broader healthcare system in which they interact requires identification of patients’ unmet needs to develop strategies to address persistent deficits. Unmet needs have been referred to as “the difference between those services judged necessary to deal appropriately with defined health problems and those services being received” (Carr & Wolfe, 1976, p. 418). Allin et al. describe the potential for an unmet need to arise based on the following categories of need: “unperceived (not noticed through self-reported data but probably identified clinically); chosen (based on what the patient prefers); unchosen (related to outside factors); clinician-validated (the patient feels they need care, but does not receive it, even if a clinician recommends it), and subjective unmet expectations (how individuals see the suitability of the treatment)” (2010, p. 466).

This study examines the spectrum of unmet needs among patients diagnosed with IPF, utilising the definition of unmet need supplied by Carr and Wolfe (1976) and drawing on Allin and colleagues (2010) categories of need to guide the assessment of unmet needs in this inquiry. The framework provided by Allin (2010) gives a broad base from which to view the diversity of needs identified by both patients and healthcare professionals in this study, enabling the recommendations for delivery of improved standards of care and optimising patient outcomes aligned with national (ILFA, 2015; ITS, 2018) and international best practice guidelines (NICE, 2017; Raghu et al., 2011; Raghu et al., 2018; Raghu et al., 2022).

## **1.7 Levesque Healthcare Access Framework**

Levesque's healthcare access framework (2013) provided the theoretical scaffolding for this research and was particularly suited to address the study's objectives. Levesque's framework helped to guide and inform the methods, analysis and final discussion in this study, supporting the integration of both quantitative and qualitative findings (2013). Levesque's framework (2013) incorporates both supply and demand considerations of healthcare access, underpinned by the following domains: approachability, acceptability, availability/accommodation, affordability and appropriateness. The domains are coupled with five corresponding abilities of the individual to seek healthcare, namely: perceive, seek, reach, pay and engage (Levesque et al., 2013). Incorporating Levesque's conceptual framework for healthcare access facilitated the exploration of the study's objectives, addressing the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF (2013). Levesque's framework provided a depth of clarity to the investigation, recognising the barriers and facilitators experienced by individuals when accessing healthcare (2013). The application of the Levesque healthcare access framework (2013) will be discussed in Chapter 3, Section 3.6.1 and again in Chapter 4, Section 4.9.1.5.

## **1.8 Personal Reflections on Selecting the Research Topic**

Having spent several years as the lead research nurse in a clinical research centre prior to undertaking my PhD, I was afforded a unique and invaluable opportunity to gain a deep insight into the care received by patients with IPF in Ireland. Several key factors guided my motivation to pursue a PhD, including, and most importantly, the opportunity to have direct engagement with patients at various stages of their disease trajectory, from initial diagnosis through to end-of-life care.

These often humbling and moving interactions allowed me to develop a deeper understanding of the lived experiences of those with IPF. I witnessed first-hand the impact that this chronic, progressive disease had on patients and their families. I fostered a deep awareness of the significant unmet needs patients faced when interacting with the healthcare system to address their needs. Patients' needs spanned multiple domains, including physical, psychological, and social areas. These experiences provided a platform from which I could make a meaningful contribution to the landscape of IPF care in Ireland and continue my commitment to advancing research in improving care for patients with the condition. My weekly attendance at respiratory outpatient clinics provided me with further insights into the patient experience and their evolving needs over the course of their illness.

My experience in providing care for individuals diagnosed with IPF was central to my decision to undertake the PhD. The focus of my research is to explore the unmet needs, symptom experiences, and quality of life of the growing population of patients living with IPF in Ireland. There is a critical need to develop a comprehensive understanding of the barriers and facilitators to address patients' unmet needs. Findings from this study aim to inform the development of patient-centred pathways and integration of holistic care for those diagnosed with IPF.

## 1.9 Justification for this Research Study

Prioritising the unmet needs of people diagnosed with IPF is considered a critical issue, particularly with the global rise in the incidence and prevalence of the disease. Addressing patients' needs and symptom experiences may improve the quality of life of those with the condition. Available evidence suggests a plethora of unmet needs and gaps in care that remain largely unaddressed (Bonella et al., 2016; Cassidy et al., 2022; Moor et al., 2019). Despite being the most prevalent interstitial lung disease, IPF continues to be underrepresented in current literature (Smith & Jenkins, 2023). The global rise in the incidence of IPF increases demand for healthcare services and underscores the urgent need to comprehensively understand the unmet needs, symptom experiences, and quality of life of sufferers (Maher et al., 2021; Maher et al., 2017). The exponential global growth in IPF represents an increased burden on healthcare services, whose demand will likely exceed supply, thereby creating a pressing concern for resource and service planning (Bramhill et al., 2024).

The Irish Thoracic Society's IPF Position Statement (2018), National Institute for Health and Care Excellence Guidelines (2017) and other international guidelines (Raghu et al., 2022) clearly outline standards of care required to optimise quality of life of individuals with IPF. However, these standards have not yet been fully implemented, and critical gaps in care still exist (Bonella et al., 2016; ILFA, 2015; Moor et al., 2019). The absence of investment in resources to support either a national registry or a clinical programme for pulmonary fibrosis in Ireland underscores the need for a review at national policy level, to address deficits in care and the unmet needs of this underrepresented group.

Current research in an Irish context has been hampered by a noticeable reliance on specific methodologies, notably the World Café approach and analysis of clinical outcomes (Brereton et al., 2020; Russell et al., 2019). Qualitative research in IPF is not widely available within an Irish context, with contemporary research mostly confined to online quantitative survey methods (Cassidy et al., 2022; Ryan & Meskeel, 2022). Current evidence has mostly relied on recruitment from single sites, often hampered by a small sample size (Ryan & Meskeel, 2022) or on mailing lists from patient support organisations (Cassidy, 2022). The limited pool of evidence in Ireland of unmet needs, symptom experiences, and quality of life for patients diagnosed with IPF would benefit from a mixed-methods approach that harnesses the strengths of multi-site recruitment.

When compared with other respiratory conditions, such as asthma and COPD, IPF remains an understudied area in the literature, and underrepresented at national policy level. There is some overlap in the 'needs' of those with IPF and other respiratory groups. However, given the chronic, progressive nature of IPF, the lack of curative treatment options, and the recognised severity of the disease, it is crucial that continued research focuses on patients' unmet needs and symptom experience to optimise quality of life.

The persistent inequalities in the provision of policy guidelines and healthcare resources for individuals with IPF, both nationally and globally, underscore the urgent need for robust research into patients' unmet needs. Addressing these gaps through a comprehensive, multi-site study is a research priority

which could inform the development of healthcare services and guide future interventions. Furthermore, it highlights the need to include patients with IPF in research, allowing for the integration of their lived experience and perception of needs and research priorities.

### 1.10 Research Aims and Objectives

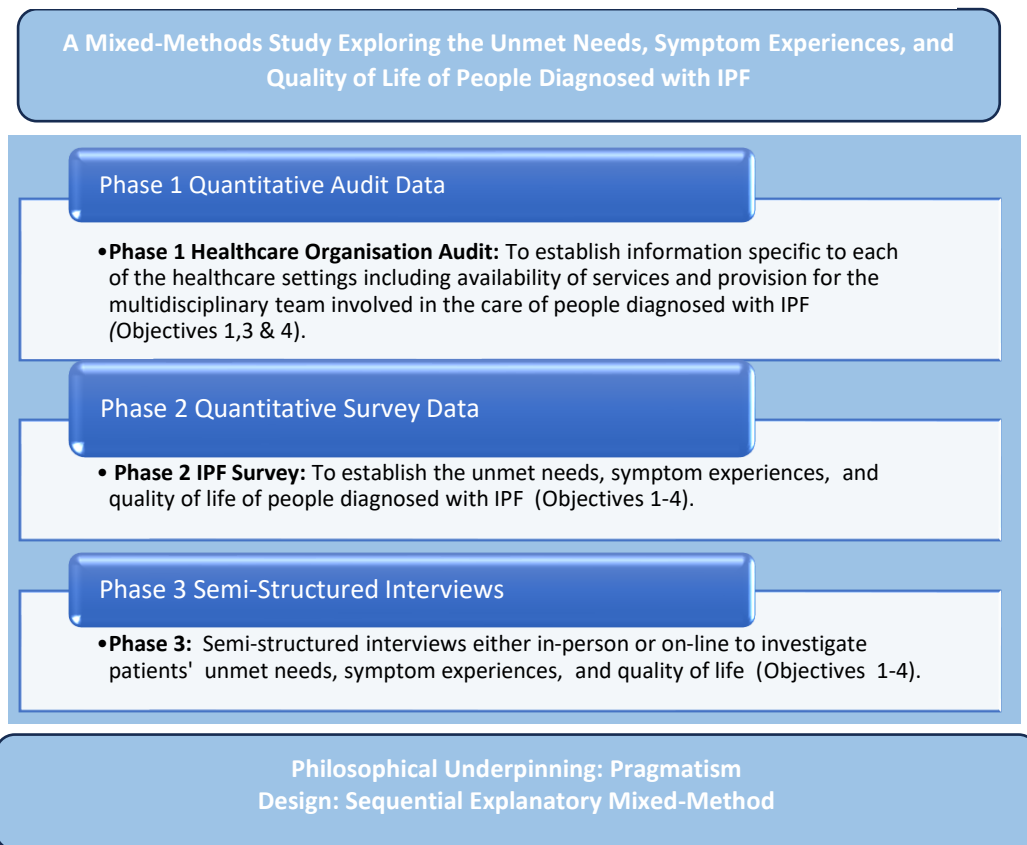
This research aims to identify the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF within an Irish healthcare system. Additionally, it aims to provide evidence to inform future policy, practice and research in addressing patients' unmet needs. The aims and objectives of this study are clearly outlined in Table 1.1, and the study phases are illustrated in Figure 1.2.

**Table 1.1 The Aim and Objectives of this Research Study**

| Aim                                                                                                   |                                                                                                                                   |
|-------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------|
| To investigate the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF |                                                                                                                                   |
| Objectives                                                                                            |                                                                                                                                   |
| i                                                                                                     | To identify the unmet needs of people diagnosed with IPF (QUANT and QUAL).                                                        |
| ii                                                                                                    | To explore the symptom experience and quality of life of people diagnosed with IPF (QUANT & QUAL).                                |
| iii                                                                                                   | To evaluate what factors, influence the quality of life of people diagnosed with IPF (QUANT & QUAL).                              |
| iv                                                                                                    | To inform the continuing development of healthcare access for people diagnosed with IPF in Ireland (Integration of QUANT & QUAL). |

To meet the study's aims and objectives, three phases were incorporated into the overall study design, which provided the scaffolding for this mixed-methods sequential explanatory design study (Figure 1.2).

**Figure 1.2 Study Phases Linked to the Study Aim and Objectives**



## 1.11 Thesis Structure and Layout

**The thesis consists of nine chapters.**

**Chapter one** introduces this research, outlining its aim and objectives. It also provides the framework for the study, including information about IPF, epidemiology, symptom burden, and both pharmaceutical and non-pharmaceutical supports. Lastly, it addresses the national and international policies concerning the management of IPF at the time of this research.

**Chapter two** presents a published scoping review of the literature exploring the unmet needs of people diagnosed with IPF.

**Chapter three** outlines the applicability of the chosen philosophical assumptions and justifies the mixed-methods research design.

**Chapter four** explains the methods used to answer the research aim and objectives in this three-phase mixed-methods sequential explanatory research design study.

**Chapter five** reports the results of the quantitative study phase and provides a detailed overview of the statistical analysis conducted to answer the research question.

**Chapter six** presents the findings of the qualitative interview phase, incorporating the voices of patients diagnosed with IPF.

**Chapter seven** provides a joint display, of meta-inferences drawn from both quantitative and qualitative findings.

**Chapter eight** discusses the key findings from this study, integrating evidence from both the quantitative and qualitative phases. The findings are discussed in the context of the Irish healthcare system and the delivery of care for people diagnosed with IPF, leading to the development of meta-inferences. Additionally, the study's strengths and limitations are addressed.

**Chapter nine** provides recommendations for future policy makers, health service provision, education, and research

## Chapter 2 Literature Review

### 2.1 Introduction

Chapter two presents the scoping review, which underpinned this research, and evaluated the unmet needs of people diagnosed with idiopathic pulmonary fibrosis (IPF), published in PLOS ONE <https://doi.org/10.1371/journal.pone.0297832> (Bramhill et al., 2024)<sup>1</sup>. The scoping review followed a scoping review protocol, previously published in the BMJ Open <http://bmjopen.bmj.com/> (Bramhill et al., 2023). The scoping review supported this study's objective which aimed to evaluate the unmet needs of people diagnosed with IPF. Additionally, it heightened our understanding of the symptom experience and quality of life of individuals diagnosed with IPF (Objective 2 and 3). This publication supported this thesis by synthesising available literature and highlighting gaps in our understanding of unmet needs among individuals with IPF and highlighting areas that warrant further investigation. In doing so, it informs this study's work and addresses objectives one, two and three.

### 2.2 Background

Interstitial lung disease (ILD) describes a range of heterogeneous lung conditions characterised by inflammation and fibrosis of the lung interstitium (Raghu et al., 2011; Salciccioli et al., 2022). In the last decade, there have been significant advances in our understanding of the pathophysiology of ILDs and the introduction of treatments that have significantly changed the landscape for many patients (Iribarnegaray et al., 2023). A large proportion of patients diagnosed with ILD have pulmonary fibrosis (PF), most commonly idiopathic pulmonary fibrosis (IPF), which represents around 17-37% of all ILDs (Aiello et al., 2017). IPF is a chronic, progressive, and irreversible disease which can profoundly and devastatingly impact the physical and psychological well-being of individuals (Sampson et al., 2015; Weatherald et al., 2017).

People living with IPF may experience debilitating symptoms, which vary in severity and disease course. Symptoms include progressively worsening breathlessness, impaired lung function, cough and fatigue (Lancaster et al., 2022; Lindell et al., 2017), with many patients and their carers experiencing anxiety and/or depression (Adkins & Collard, 2012; Van Manen et al., 2017). This high symptom burden (Delameillieure. et al., 2021; Raghu et al., 2011), coupled with social isolation for some, along with an inability to perform daily activities and the adjustment to a reduced life expectancy (median survival being 2-5 years), can impact quality of life (QoL) (Kalluri et al., 2020). Affecting predominantly older adults (Ramadurai et al., 2018) the incidence of IPF increases with age, and with higher rates seen in males (Bajwah & Yorke, 2017; Jo et al., 2016). Internationally, there has been a lack of standardisation in diagnostic coding, leading to an estimated reported prevalence of IPF ranging from 7 to 1650 per 100,000

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<sup>1</sup> **Bramhill C**, Langan D, Mulryan H, Eustace-Cook J, Russell AM, Brady AM. A scoping review of the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis (IPF). PLoS One. 2024 Feb 14;19(2): e0297832. doi: 10.1371/journal.pone.0297832. PMID: 38354191; PMCID: PMC10866483.

persons depending on whether narrow or broad case definitions are used (Shah Gupta et al., 2023). Patients living with a diagnosis of IPF have high unmet care needs and require a multidisciplinary team approach to care, which should include supports such as multidisciplinary team discussion at the time of diagnosis (Raghu et al., 2011; Tikellis et al., 2022).

Incongruence persists between the needs of patients with IPF, such as accurate and timely diagnosis (Moor et al., 2019), referral for lung transplantation assessment (Swaminathan et al., 2021; Tikellis et al., 2022), access to pulmonary rehabilitation (Moor et al., 2019; Van Manen et al., 2017), and the actual delivery of healthcare services to adequately meet these needs. Individual needs of patients with IPF are important, and so a person-centred approach encompassing the multiple components of the wider healthcare delivery system is needed. Addressing unmet needs for patients with IPF will contribute to improved quality of life (Bonella et al., 2016; Moor et al., 2019). Several studies, including systematic reviews, have previously investigated the care needs and experiences of patients with IPF (Bonella et al., 2016; Burnett et al., 2017; Duck et al., 2015; Lancaster et al., 2022; Lee et al., 2020; Lindell et al., 2017; Moor et al., 2019; Overgaard et al., 2016b; Sampson et al., 2015). However, many pre-COVID-19 studies have a broadly hospital-based focus with minimal recognition of the changing landscape of healthcare delivery, including community-based care.

Addressing unmet needs, particularly for patients with IPF, is deemed to be a critical issue and may facilitate the prioritisation of health services for this patient group and ultimately lead to improved quality of life (Bonella et al., 2016; Moor et al., 2019). Comprehensively understanding the unmet needs of patients with IPF can promote informed decision-making regarding patients' ongoing care and recognition of patient preferences. Despite advancements in our understanding of the pathogenesis of the disease and the ongoing delivery of antifibrotic treatment, deficits in our understanding of the needs and research priorities of patients with IPF prevail. Addressing the unmet needs of patients with IPF and designing services and patient-centred solutions around what patients want is essential to the future development of care for patients with IPF.

This review was guided by a central question, which was to map the available evidence related to the unmet needs of patients living with a diagnosis of IPF. The central research question was developed after several meetings with patient and public partners (PPI) comprising of patients diagnosed with IPF, their caregivers and healthcare professionals who collectively (a) described their research priorities and (b) identified the multi-dimensional component of their unmet needs. This was an iterative process, and over the course of three meetings, the research question took shape and led to the development of the scoping review protocol.

### **2.2.1 Aim**

This scoping review aimed to examine the unmet needs of patients living with a diagnosis of IPF.



### 2.2.2 Objectives

1. To synthesise the unmet needs of patients living with a diagnosis of IPF.
2. Define barriers and facilitators to meeting patients' needs.
3. Provide an overview of relevant concepts and terminology.

### 2.2.3 Scoping Review Protocol

The protocol for this study has been registered at Open Science Framework with its unique identifying number DOI 10.17605/OSF.IO/SY4KM.

## 2.3 Methods

### 2.3.1 Eligibility Criteria

For this review, patient needs have been defined from (a) PPI group input and (b) built on earlier work, which mapped patients' care needs identified by the European IPF patient charter (Bonella et al., 2016). New and emerging needs that were identified in the literature, and which to date have not been included in the European IPF patient charter (Bonella et al., 2016), were mapped within this scoping review. We utilised the 'PCC' framework, population (adult patients with IPF), concept (unmet needs), and context (all healthcare settings) to define the search strategy inclusion criteria (Peters et al., 2020). The PCC framework used to inform the search strategy is presented in Table 2.1. The 'PCC' mnemonic (population, concept, and context) is recommended as a guide to construct clear objectives and eligibility criteria for the scoping review (Pollock et al., 2023).

**Table 2.1 PCC Framework for Search Strategy Development**

| Framework | Element    | Key Terms                                             |
|-----------|------------|-------------------------------------------------------|
| PCC       | Population | Adults > 18 years of age who have a diagnosis of IPF. |
|           | Concept    | Healthcare needs.                                     |
|           | Context    | All care settings.                                    |

The core concept in this review is 'unmet needs'. Studies describing unmet needs, specifically of patients diagnosed with IPF were included. Inclusion and exclusion criteria are presented in Table 2.2 and 2.3.

**Table 2.2 Scoping Review Inclusion Criteria**

| Inclusion Criteria |                                                                                                                                              |
|--------------------|----------------------------------------------------------------------------------------------------------------------------------------------|
|                    | All geographical areas.                                                                                                                      |
|                    | All care settings.                                                                                                                           |
|                    | There are no language limits. Google translate will be used to translate non-English sources.                                                |
|                    | Sources must relate to patients with IPF.                                                                                                    |
|                    | Sources must be published between 2011-to 2022.                                                                                              |
|                    | Adults >18 years of age.                                                                                                                     |
|                    | We will include all review types, including systematic, scoping and literature reviews, which describe the unmet needs of our patient group. |

**Table 2.3 Scoping Review Exclusion Criteria**

| Exclusion criteria: |                                                                                                         |
|---------------------|---------------------------------------------------------------------------------------------------------|
|                     | Sources published prior to 2011.                                                                        |
|                     | Refers to human subjects < 18 years of age.                                                             |
|                     | Does not include reference to patients diagnosed with IPF.                                              |
|                     | This review will not include case reports, protocols, letters, posters, commentaries or opinion pieces. |

### 2.3.2 Patient and Public Involvement

Patient and public involvement (PPI) is recommended from the earliest research stages through to dissemination of the study findings (Boote et al., 2015). Patient and public involvement throughout the various stages of research is a valuable component of research activity and can contribute to improved quality and relevance of research (Health Service Executive, 2021). Patient and public representatives ( $N = 5$ ) from the Irish Lung Fibrosis Association PPI group were involved in reviewing the research protocol for this scoping review. The stakeholders comprise patient representatives, family members of patients diagnosed with IPF and experts and researchers in the field of IPF. The scoping review protocol was presented to the group for feedback and discussion during a Zoom call meeting. The scoping review findings were also presented to healthcare professionals in the field of IPF, in person, for further opportunities for discussion. The involvement of PPI in this scoping review has enriched the review and reflected the importance of including those impacted by IPF in the process.

## **2.4 Scoping Review of the Evidence**

This review was conducted in accordance with the Joanna Briggs Institute framework for scoping reviews and included the following steps: (i) identifying the research question, (ii) developing a search strategy, (iii) study selection and (iv) data analysis and presentation (Peters et al., 2020). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-ScR) checklist guides the reporting quality of this review (Tricco et al., 2018).

### **2.4.1 Sources & Searching**

The search strategy was developed with the assistance of a medical research librarian (JEC) and externally peer-reviewed by a second librarian as per the Peer Review of Electronic Search Strategies (PRESS) guidelines (McGowan et al., 2016). Six databases were systematically searched: Medline, CINAHL, APA PsycINFO, (EBSCO platform), Embase (Elsevier), Web of Science (Core Collection) and ASSIA (Applied Social Science Index) (Proquest), on 14<sup>th</sup> November 2022 and updated on 12<sup>th</sup> January 2023, to identify studies that met the review's inclusion criteria. Date limit criteria were applied at full-text review (2011-present). A restriction to literature published pre-2011 was applied, as this was the time that antifibrotic treatment for patients with IPF became available in the United Kingdom and Europe.

No language or geographic limits were applied. Grey literature and unpublished studies were included; sources included ProQuest Dissertations and Theses Global, Google Scholar, ClinicalTrials.gov, WHO International, Clinical Trials Registry Platform and OpenGrey. Furthermore, a comprehensive online search of key websites and a manual search of the reference lists of included studies was performed. Several international conference abstracts were reviewed, including those from the Irish Thoracic Society annual scientific meeting, the European Respiratory Society annual meeting and the British Thoracic Society meetings. A total of 100 abstracts were reviewed, with nine abstracts included in the final review.

The search strategy and database search were both conceptualised by the researcher (CB) and an information specialist (JEC). Key search terms related to 'IPF', 'unmet needs' and 'idiopathic pulmonary fibrosis' & 'pulmonary fibrosis' (The search string is available in Appendix 1).

### **2.4.2 Study Selection**

Initially, all identified records were collated and uploaded onto EndNote X9.3.3 (Clarivate Analytics, Pennsylvania, USA) and duplicates removed. Then all identified citations were transferred into Covidence software (Veritas Health Innovation, Melbourne, Australia), where any remaining duplicates were removed. The next step was to screen the titles and abstracts conducted by two independent reviewers (CB and DL) for assessment against the inclusion criteria. Potentially relevant studies which met the inclusion criteria were retrieved in full text and uploaded to Covidence. The full text of selected citations was assessed in detail against the inclusion criteria (PCC inclusion criteria) by the same two independent reviewers. Any disagreements which occurred about the inclusion or exclusion of a paper were discussed

by the reviewers until agreement was found. A third reviewer, HM, arbitrated when there was disagreement about the inclusion of a paper ( $n = 4$ ). We included all review types (systematic, scoping and narrative reviews), which described the unmet needs of our patient group. This review did not include case reports, protocols, letters, posters, commentaries or opinion pieces.

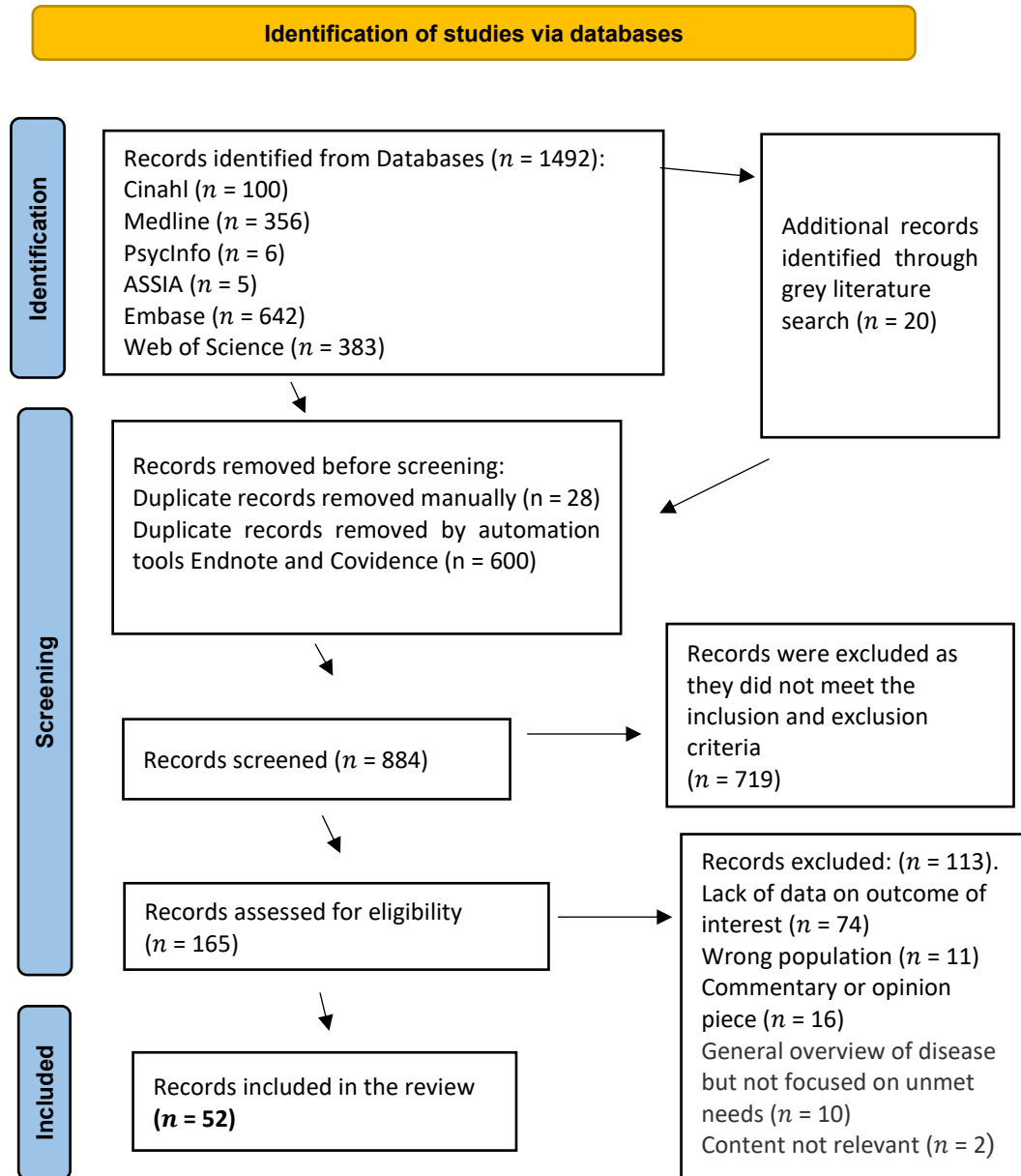
#### **2.4.3 Data Extraction**

Data was extracted from articles and other evidence sources included in the scoping review by one reviewer (CB), using a data extraction tool developed by the study's research team in adherence with the review objectives (Appendix 2). All studies received verification by another reviewer (AMB & AMR). Several important domains were included in the data capture tool, which adhered to the JBI guidelines.

#### **2.4.4 Data Analysis**

Data were analyzed utilizing the Braun and Clarke (2006, 2019) framework for reflexive thematic analysis (TA). This is a five-stage process for coding and data analysis and includes an initial step of data familiarisation through deep immersion with the information sources. Next, an iterative process of code development was supported by analysis software NVivo (NVivo version 12.0) (Braun & Clarke, 2006, 2019). The final three steps provided the backdrop for organising the codes into themes and fostered a rich in-depth analysis of the data, culminating in theme development. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) displays the identified sources (Figure 2.1).

Figure 2.1 PRISMA Flow Chart for Scoping Reviews (PRISMA-ScR)



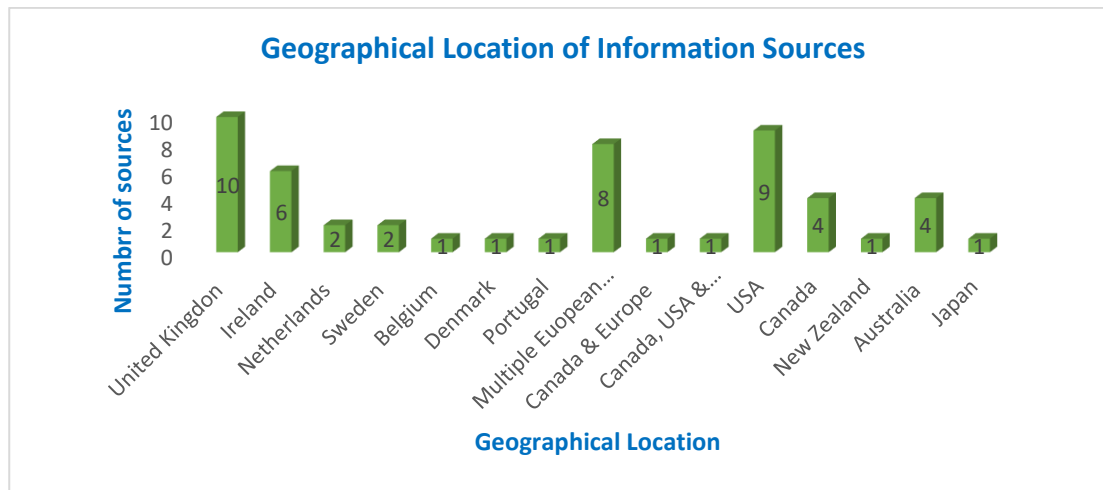
## 2.5 Results

### 2.5.1 Summary of the Studies

A total of 1492 information sources were identified through our database search, and a further 20 records were identified through a grey literature search, with 628 duplicates removed through manual and automated tools. After eliminating duplications, 884 unique citations were identified, with five of these representing non-English sources. Of these, 719 records were excluded after title/abstract screening, leaving 165 records for further assessment. After full text review, 113 records were deemed ineligible and were excluded. The primary reason for exclusion was the lack of data on the outcome of interest ( $n = 74$ ). Other common reasons for exclusion were the wrong population ( $n = 11$ ) and commentary or opinion piece ( $n = 16$ ). Fifty-two information sources met the inclusion criteria, of which ( $n = 30/58\%$ ) were

published in the last five years. All included articles were published between 2011 and 2022. Included sources were published in English and were from a wide geographical area, including several countries where English is not the dominant spoken language, and are presented in Figure 2.2.

**Figure 2.2 Geographical Location of Information Sources**



There was a total of thirty-eight studies included in this review, representing 73% of the included records, with the remaining ( $n = 14/27\%$ ) records being a mix of literature reviews ( $n = 6$ ), reports and guideline-type material, incorporating various methods ( $n = 8$ ). Of the studies ( $n = 38/73\%$ ), 50% of them employed quantitative approaches ( $n = 19$ ), with others using a qualitative design ( $n = 14/37\%$ ). While further studies employed a mixed-method methodology ( $n = 4/10.5\%$ ). Several literature reviews ( $n = 6/11.5\%$ ) were included in the overall review of fifty-two records and incorporated a range of methods. The remaining information sources ( $n = 8/15.3\%$ ) were diverse and included guideline documents ( $n = 2$ ), patient charters ( $n = 2$ ), framework documents ( $n = 1$ ), reports ( $n = 2$ ), and a position statement ( $n = 1$ ).

Of the thirty-eight studies (73%) included in the review, 31.6% ( $n = 12$ ) of these investigated care experiences, whilst a further 65.7% ( $n = 25$ ) explored palliative care needs and advance care planning. The remaining key areas of focus included in the thirty-eight studies predominantly explored information needs 71% ( $n = 27$ ), pharmaceutical treatments 65.8% ( $n = 25$ ), early and accurate diagnosis 47.3% ( $n = 18$ ), and psychological and emotional needs 52.6% ( $n = 20$ ). Other significant areas included the impact on relationships, 21.1% ( $n = 8$ ), physical burden of IPF 36.8% ( $n = 14$ ), oxygen needs 31.6% ( $n = 12$ ), pulmonary rehabilitation 36.8% ( $n = 14$ ), carer experience 39.5% ( $n = 15$ ), geographical location 15.8% ( $n = 6$ ), access to a tertiary centre 23.7% ( $n = 9$ ), the multidisciplinary team 15.8% ( $n = 6$ ), ILD nurse 23.7% ( $n = 9$ ), tele-health 10.5% ( $n = 4$ ), lung transplantation 31.6% ( $n = 12$ ), and clinical trial access 7.9% ( $n = 3$ ). Recruitment strategies within the literature were reported to be via single sites, 39.4% ( $n = 15$ ) or multiple sites ranging from two to fourteen sites, 60.5% ( $n = 23$ ). A homogenous IPF sample was investigated in most sources (84%). Remaining studies featured heterogeneous samples and included other ILDs, specifically fibrosing interstitial lung disease (F-ILD) (5.2%), pulmonary fibrosis (8.2%), and ILD (2.6%).

Male participants were significantly more frequently represented in all included studies (range 41.3%-87.7%). The fact that males were more frequently represented in our selected studies is aligned with international evidence that IPF is a disease predominantly seen in males (Sesé et al., 2021) accounting for ~70% of all IPF cases in international cohorts, which may in part be explained by the fact that men are more likely to present with a smoking history and having experienced occupational exposures more frequently than women with IPF (Jo et al., 2017). The study participants had an age range of 20-90 years. Studies which reported ethnicity or race of participants included white backgrounds ( $n = 5/13.1\%$ ). Only a limited number of studies included information on employment status ( $n = 2/5.2\%$ ), education ( $n = 4/10.5\%$ ), insurance ( $n = 3/7.8\%$ ), and marital status ( $n = 1/2.6\%$ ), a summary of these results is presented in Table 2.4.

**Table 2.4 Summary of the Characteristics of the Included Articles**

| Characteristics                   | N               | %             |
|-----------------------------------|-----------------|---------------|
| <b>Methodology</b>                | <b>(N = 52)</b> | <b>(100%)</b> |
| Quantitative                      | 19              | 36.5%         |
| Qualitative                       | 14              | 26.9%         |
| Mixed-Methods                     | 4               | 7.7%          |
| RCT                               | 1               | 1.9%          |
| Review                            | 6               | 11.5%         |
| Other                             | 8               | 15.3%         |
| <b>Design</b>                     | <b>(N = 38)</b> | <b>(100%)</b> |
| Cross sectional                   | 26              | 68.4%         |
| Cohort                            | 5               | 13.1%         |
| Longitudinal                      | 7               | 18.4%         |
| <b>Methods of Data Collection</b> | <b>(N = 38)</b> | <b>(100%)</b> |
| Questionnaire                     | 14              | 36.8%         |
| Semi-structured interviews        | 9               | 23.6%         |
| Focus group                       | 4               | 10.5%         |
| Registry data                     | 4               | 10.5%         |
| World cafe                        | 1               | 2.6%          |
| Chart Review                      | 2               | 5.2%          |
| Mixed methods                     | 4               | 10.5%         |

## 2.6 Reflexive Thematic Analysis

Several unmet needs and gaps in care were identified in the literature and are presented in Table 2.5.

**Table 2.5 Unmet Needs of Individuals Diagnosed with IPF**

| Unmet Needs of Individuals Diagnosed with IPF Identified in Included Evidence Sources |     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|---------------------------------------------------------------------------------------|-----|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Unmet Need                                                                            | No. | Evidence Source                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Carer experience</b>                                                               | 13  | Kalluri et al., 2021, Russell, Ripamonti and Vancheri, 2016; Overgaard et al., 2016b, Cassidy et al., 2024, Ramadurai et al., 2018a; Meadows et al., 2019; Masefield et al., 2019, Giot et al., 2012, Sampson et al., 2015, Tikellis et al., 2020, Bajwah and Yorke, 2017; Lee et al., 2020, Lindell et al., 2021.                                                                                                                                                                                           |
| <b>Pulmonary rehabilitation</b>                                                       | 15  | Moor et al., 2019, Weatherald, McFadden and Fell, 2017, Delameillieure et al., 2021; Duck et al., 2015, Burnett, Glaspole and Holland, 2019; Bonella et al., 2016; Masefield et al., 2019, Sampson et al., 2015; Tikellis et al., 2022, Kalluri et al., 2020, NICE, 2017, ITS, 2018, ILFA, 2015.                                                                                                                                                                                                             |
| <b>Information needs</b>                                                              | 23  | Moor et al., 2019, Brereton et al., 2020, Cassidy et al., 2024, Masefield et al., 2019, Overgaard et al., 2016a, Russell et al., 2016, Meadows et al., 2017; Ramadurai et al., 2018b, Kalluri et al., 2022, Delameillieure et al., 2021; Burnett et al., 2019; Bonella et al., 2016; van der Sar et al., 2021, Sampson et al., 2015, Tikellis et al., 2020, Maher et al., 2017, Kalluri et al., 2020, van Manen et al., 2017, Bajwah and Yorke, 2017; Lee et al., 2020, ILFA, 2015, Lindell et al., 2021.    |
| <b>Psychological/emotional needs</b>                                                  | 19  | Cove et al., 2015, Moor et al., 2019, Giot et al., 2012, Delameillieure et al., 2021, Duck et al., 2015b; Russell et al., 2016; Overgaard et al., 2016b, Cassidy et al., 2024, Schoenheit, Becattelli and Cohen, 2011; Masefield et al., 2019; van der Sar et al., 2021, EU-IPFF, 2020, Tikellis et al., 2022, Kalluri et al., 2020, van Manen et al., 2017, Bajwah and Yorke, 2017; Lee et al., 2020, ILFA, 2015, Lindell et al., 2021.                                                                     |
| <b>Physical burden of IPF</b>                                                         | 14  | Lancaster et al., 2022, Turnpenny et al., 2015, Duck et al., 2015b, Schoenheit et al., 2011, Burnett et al., 2019, Giot et al., 2012, Sampson et al., 2015, Kalluri et al., 2020, van Manen et al., 2017; Bajwah and Yorke, 2017; Chaaban et al., 2022; Lee et al., 2020, ITS, 2018, NICE, 2017.                                                                                                                                                                                                             |
| <b>Palliative care and advance care planning</b>                                      | 23  | Akiyama et al., 2020, Moor et al., 2019, Sharp et al., 2018, Weatherald et al., 2017, Moor et al., 2021, Ahmadi et al., 2016, Maher et al., 2017, Tyas, Boland and Gillon, 2019, Turnpenny et al., 2015, Kalluri et al., 2022, Cassidy et al., 2021, Delameillieure et al., 2021, Overgaard et al., 2016, Lindell et al., 2017, Bonella et al., 2016, Masefield et al., 2019, EU-PFF, 2020, Kalluri et al., 2020, van Manen et al., 2017, Chaaban et al., 2022, ILFA, 2015, ITS, 2018, Lindell et al., 2021. |

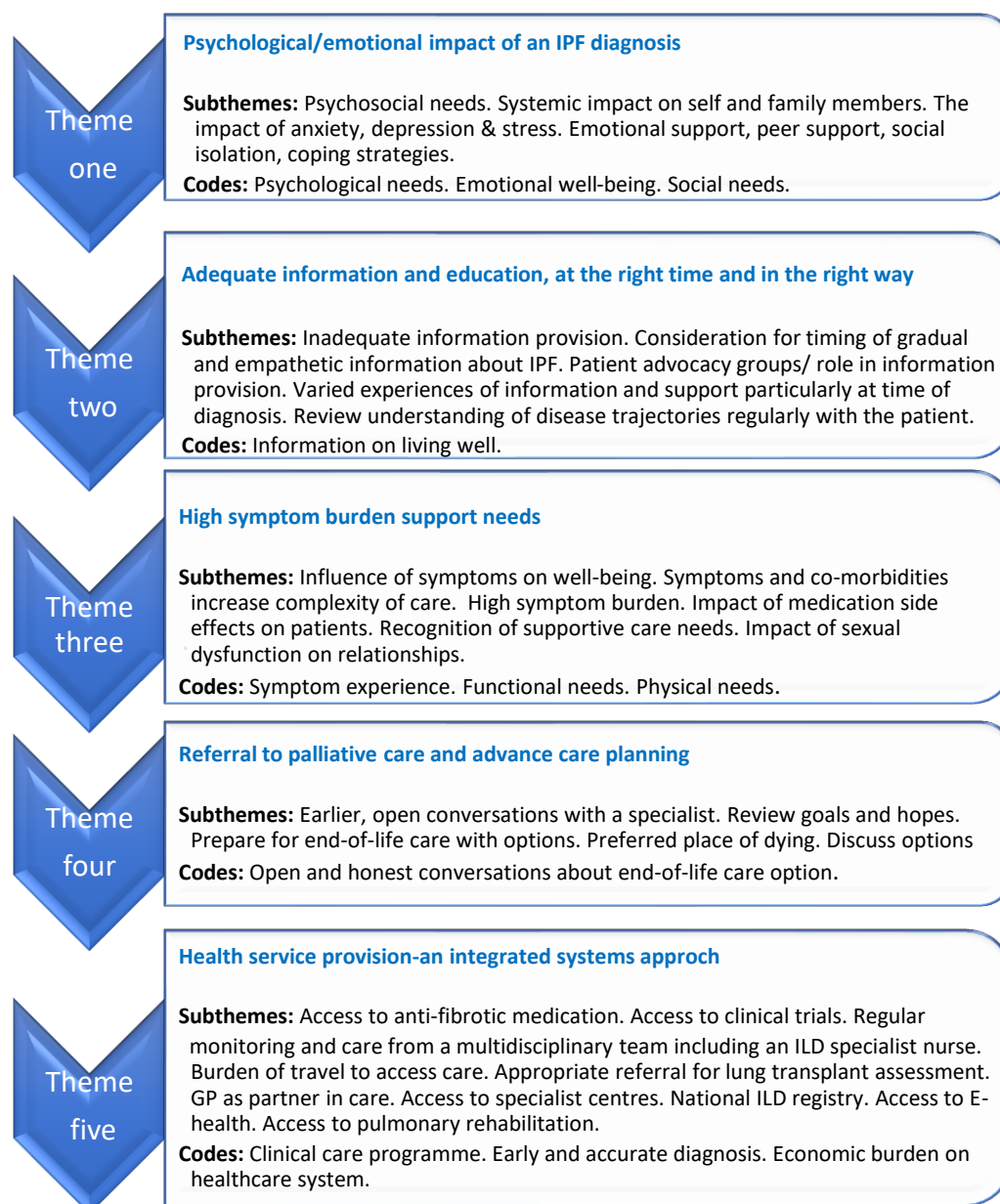


**Table 2.5 Unmet Needs of Individuals Diagnosed with IPF (Continued)**

| Unmet Needs of Individuals Diagnosed with IPF Identified in Included Evidence Sources |     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|---------------------------------------------------------------------------------------|-----|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Unmet Need                                                                            | No. | Evidence Source                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Impact on relationships</b>                                                        | 8   | Lancaster et al., 2022, Duck et al., 2015, Russell et al., 2016, Overgaard et al., 2016, Lindell et al., 2017, Schoenheit et al., 2011, Sampson et al., 2015, Lindell et al., 2021.                                                                                                                                                                                                                                                                                                 |
| <b>Oxygen needs</b>                                                                   | 11  | Maher et al., 2017, Duck et al., 2015b, Overgaard et al., 2016b, Burnett et al., 2019; Bonella et al., 2016; Meadows et al., 2017, Tikellis et al., 2022, Kalluri et al., 2020, van Manen et al., 2017, Bajwah and Yorke, 2017, ILFA, 2015.                                                                                                                                                                                                                                         |
| <b>Early &amp; accurate diagnosis</b>                                                 | 19  | Lancaster et al., 2022, Moor et al., 2019, Weatherald et al., 2017, Maher et al., 2017, Brereton et al., 2020, Schoenheit et al., 2011; Delameillieure et al., 2021, Overgaard et al., 2016b, Lindell et al., 2017; Burnett et al., 2019, Bonella et al., 2016; van der Sar et al., 2021, Duck et al., 2015, EU-IPFF, 2020, Sampson et al., 2015, Kalluri et al., 2020, ITS, 2018, ILFA, 2015; NICE, 2017.                                                                          |
| <b>E-health</b>                                                                       | 4   | Delameillieure et al., 2021, Ramadurai et al., 2018, Tikellis et al., 2020, Tikellis et al., 2022.                                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Care experiences</b>                                                               | 11  | Ncube, 2020, Lancaster et al., 2022, Moor et al., 2019, Burnett et al., 2019, Delameillieure et al., 2021, Overgaard et al., 2016b, Duck et al., 2015, Russell et al., 2016, Giot et al., 2012, Sampson et al., 2015, Kalluri et al., 2020.                                                                                                                                                                                                                                         |
| <b>Pharmaceutical treatment</b>                                                       | 22  | Lancaster et al., 2022, Pesonen et al., 2018, Picavet et al., 2017, Maher et al., 2017, Brereton et al., 2020, Moor et al., 2019, Weatherald et al., 2017, Maher et al., 2017, Burnett et al., 2019, Delameillieure et al., 2021, Russell et al., 2016, Bonella et al., 2016; Masefield et al., 2019, Maher et al., 2018, Tikellis et al., 2022, Lee et al., 2020, van Manen et al., 2017, Robalo-Cordeiro et al., 2017, Bajwah and Yorke, 2017, ILFA, 2015, ITS, 2018, NICE, 2017. |
| <b>Geographical location</b>                                                          | 6   | Dedent et al., 2022, Johannson et al., 2022, Swaminathan et al., 2022, Cassidy et al., 2024, Burnett et al., 2019.                                                                                                                                                                                                                                                                                                                                                                  |
| <b>Multi-disciplinary team</b>                                                        | 6   | Moor et al., 2019, Maher et al., 2017, Delameillieure et al., 2021, Burnett et al., 2019, Tikellis et al., 2022, ITS, 2018.                                                                                                                                                                                                                                                                                                                                                         |
| <b>E-Health</b>                                                                       | 3   | Ramadurai et al., 2018, Tikellis et al., 2020, Tikellis et al., 2022.                                                                                                                                                                                                                                                                                                                                                                                                               |
| <b>Lung transplant</b>                                                                | 11  | Swaminathan et al., 2022, Moor et al., 2019, Weatherald et al., 2017, Cassidy et al., 2024, Burnett et al., 2019; Bonella et al., 2016; Masefield et al., 2019, Tikellis et al., 2022, NICE, 2017, ITS, 2018, ILFA, 2015.                                                                                                                                                                                                                                                           |
| <b>ILD Nurse</b>                                                                      | 8   | Moor et al., 2019, Delameillieure et al., 2021, Russell et al., 2016, Tikellis et al., 2022, Kalluri et al., 2020, NICE, 2017, ITS, 2018, Lindell et al., 2021.                                                                                                                                                                                                                                                                                                                     |
| <b>Access to Tertiary Care Centre</b>                                                 | 8   | Lamas et al., 2011, Maher et al., 2017, Brereton et al., 2020, Moor et al., 2019, Dedent et al., 2021, Weatherald et al., 2017, Schoenheit et al., 2011, Giot et al., 2012.                                                                                                                                                                                                                                                                                                         |
| <b>Clinical Trials</b>                                                                | 3   | Maher et al., 2017, Burnett et al., 2019, Tikellis et al., 2020.                                                                                                                                                                                                                                                                                                                                                                                                                    |

The process of reflexive thematic analysis enabled the development of five themes related to the unmet needs of patients living with a diagnosis of IPF and presented in Figure 2.3.

**Figure 2.3 Theme Development**



### 2.6.1 The Psychological and Emotional Impact of an IPF Diagnosis

A need exists for psychological and emotional support throughout the disease course for patients diagnosed with IPF (Cove et al., 2015; Moor et al., 2019). The literature reports that the psychosocial needs of patients (Delameillieure et al., 2021) and their family carers are frequently being overlooked (Lindell et al., 2017; Russell et al., 2016) with a continued lack of psychological support for patients diagnosed with IPF (Russell et al., 2016; Van Manen et al., 2017). Psychological distress is reported by

many patients living with IPF, including worry, fear, anxiety, hopelessness and helplessness (Kalluri et al., 2020; Lindell et al., 2017; Overgaard et al., 2016; Russell et al., 2016). It is reported that many patients with IPF and their carers experience anxiety and or depression (Belkin et al., 2014; Overgaard et al., 2016; Russell et al., 2016; Van Manen et al., 2017).

Patients diagnosed with IPF report a loss of independence coupled with feelings of powerlessness and social isolation (Overgaard et al., 2016). The initiation of oxygen therapy is viewed as a particularly stressful time for patients (Overgaard et al., 2016), representing for some a distressing trajectory in the disease course and in some cases a loss of hope (Russell et al., 2016). In one study, oxygen initiation was associated with feelings of shame (Delameillieure et al., 2021), as the condition became externally visible to others (Russell et al., 2016). Patients can also experience increased anxiety related to worry associated with having adequate supplies of prescribed oxygen (Delameillieure et al., 2021).

Glaspole et al. (2017) explored the frequency of prolonged anxiety and depression among people living with IPF and factors contributing to their persistence. They reported that dyspnoea is a major contributor to anxiety and depression, followed by cough, which is also an important contributor. Moor et al. (2019) found that although patients were not being specifically asked about access to psychological support in their study, 10% of patients spontaneously reported a need for improved psychological support throughout the disease course. Van Manen and colleagues (2017) highlight the important role an ILD specialist nurse can play in helping patients to manage symptoms such as depression and anxiety, particularly as nurses will most likely have been involved in the patients' care for some time and may be viewed by patients as someone, they can confide in.

#### **2.6.1.1 Caregiver's Support Needs**

Significantly, the literature reported on the psychological impact of an IPF diagnosis on family caregivers who reported feelings of loneliness and anxiety (Overgaard et al., 2016; Russell et al., 2016), particularly associated with the fear of losing their loved one (Belkin et al., 2014; Overgaard et al., 2016). Caregivers are often not adequately prepared to help their loved ones and describe a sense of frustration and helplessness (Belkin et al., 2014). Ramadurai et al. (2018) coined the concept 'shrinking world syndrome', in relation to caregivers, to highlight the risk of social isolation, loneliness and a restricted lifestyle felt by some.

#### **2.6.2 Adequate Information and Education at the Right Time and in the Right Way**

Unmet information needs are prevalent for both patients with IPF and their caregivers in the presence of a varied disease trajectory (Bonella et al., 2016; Delameillieure et al., 2021; Sampson et al., 2015). The European IPF Patient Charter calls for "comprehensive and high-quality information about IPF, including its treatment, to be made available to patients" (Bonella et al., 2016, p. 605). Timely delivery of clinically appropriate information regarding diagnosis and treatment is an important cornerstone in the management of patients with a diagnosis of IPF (ITS, 2018). For effective communication, patients and carers want plain language, honesty and empathy (Masfield et al., 2019). Furthermore, patients and

carers want information with attention to timing (Masefield et al., 2019), content (Overgaard et al., 2016b), structure, and format (Sampson et al., 2015).

Practical information needs include information on medication use and potential side effects (Masefield et al., 2019), supplemental oxygen use, nutrition, exercise (Duck et al., 2015), management of cough and breathlessness (Sampson et al., 2015), insurance cover, travel advice [particularly for those on oxygen], trusted online information resources (Ramadurai et al., 2018), legal and practical advice for disease progression, end-of-life, and palliative care planning for patients (Akiyama et al., 2020; Bonella et al., 2016). Patients living alone expressed the most direct and urgent need for information about future care planning (Sampson et al., 2015). There is an emerging need for information on research related to the outcomes of clinical trials for IPF (Burnett et al., 2017; Ramadurai et al., 2018). Many patients and caregivers are not well informed about how their disease will progress. They require information on what to expect and how to prepare for the future (Bajwah et al., 2013; Kalluri et al., 2020; Ramadurai et al., 2018; Russell et al., 2016) with an emphasis on an individualised approach (Ramadurai et al., 2018; Schoenheit et al., 2011).

It is understood that access to information and education from a diverse range of sources enhances patients' and caregivers' coping strategies (Cassidy et al., 2024). Education and reliable information are the bedrock of patient care and help to empower patients to play an active role in their care (Duck, Spencer, et al., 2015; Van Manen et al., 2017). Patients regularly turn to online sources of information on IPF, but these can be of poor quality, outdated or not available in the patients' native language (Fisher et al., 2016; Russell et al., 2016). Russell and colleagues (2016) found that the level of disease awareness varied extensively among patients and reported that approximately one-third of patients felt inadequately aware of or informed about IPF. Caregivers often felt ill prepared for their caregiving role and expressed a need for information and education on strategies to help their family member manage IPF; for some, there was also a requirement for information on palliative care and advance care planning (ACP) (Cassidy et al., 2024; Russell et al., 2016).

Furthermore, there are increased calls for more awareness of IPF among general practitioners, nurses and physicians (Moor et al., 2019) and the public (Bonella et al., 2016). Healthcare professionals have expressed concern over a lack of time to discuss the diagnosis and treatment options (60%), with only 39% of healthcare professionals reporting that they had received any training in patient-centred communication (Moor et al., 2019).

### **2.6.3 High Symptom Burden**

A significant unmet need related to IPF is the burden associated with the physical and psychological impact of the condition. IPF remains an unpredictable disease of variable course, which could benefit from a systems approach to care, coordinated by a multidisciplinary team (Sampson et al., 2015). The deterioration in health-related quality of life for patients with IPF is highly correlated to worsening of symptoms, including increased breathlessness, cough and fatigue over time (Kalluri et al., 2020). Lindell

et al. (2017) analysed focus group data and highlighted that symptoms introduce an overwhelming burden for both the patient and carer, with cough being a particularly challenging symptom. For some patients, coughing led to distressing symptoms, such as incontinence (Duck et al., 2015). Patients report struggling with lethargy, which can impact even the simplest of tasks, such as reading or watching television (Duck et al., 2015). Several patients in Duck's study reported feeling depressed, which was associated with a lack of control and having to relinquish roles once held (Duck et al., 2015).

There is growing evidence that daily activities, recreation, pleasure and employment are significantly affected by the burden of symptoms like anxiety, depression and social isolation that relate to a diagnosis of IPF (Kalluri et al., 2020). There were also reported symptoms from the side effects of medication, particularly antifibrotic treatment, adding to the burden of symptoms already experienced by patients (Burnett et al., 2019). Sampson and colleagues call for a more pragmatic needs assessment to include components of physical and social functioning, nutrition and symptom burden, which would support patients' self-management and assist with their understanding of the illness and its varied disease trajectories (Sampson et al., 2015).

#### **2.6.4 Health Service Provision - A Systems Approach**

Reliance on healthcare services is immense for those living with IPF, with high healthcare costs in terms of resourcing and utilisation of services, provision of multidisciplinary care, and a recognised marked socio-economic burden for patients (Diamantopoulos et al., 2018; Lindell et al., 2017). Patients with IPF require regular routine monitoring and input from the multidisciplinary team, including provision for repeated hospitalisation. There is a need for increased supportive care, particularly at the end-of-life (Lindell et al., 2017). A significant unmet need in IPF care is the provision of timely and accurate diagnosis (Duck et al., 2015; Moor et al., 2019; Ramadurai et al., 2018). This is a recurrent deficit in health service provision. Several studies have highlighted the scope of the problem, with many patients diagnosed with IPF experiencing a protracted route to diagnosis (Bonella et al., 2016; Burnett et al., 2019; Delameillieure et al., 2021; Duck et al., 2015; Lindell et al., 2017; Moor et al., 2019; van Der Sar et al., 2021) which leads to unnecessary delays, including accessing pharmacological interventions and other supportive treatments (Vašáková et al., 2017).

There is an increasing recognition of the importance of having a well-resourced and appropriately staffed multidisciplinary team (MDT) in providing care to patients with IPF (Tikellis et al., 2022). Current guidelines call for multidisciplinary discussion involving expert respiratory physicians, radiologists and pathologists as the gold standard for IPF diagnosis (Raghu et al., 2011). However, evidence exists that suggests there can be gaps in staffing some of these multidisciplinary teams (Duck et al., 2012; Tikellis et al., 2022). Patients should have equal opportunities to access a variety of healthcare professionals encompassing a holistic approach to care and optimising their quality of life, with calls for equal access to non-pharmacological treatment options, including pulmonary rehabilitation, psychological support and transplant assessment referral (Bonella et al., 2016). Many studies continue to highlight that the myriad

of non-pharmacological treatment options are not equally available for patients in different geographical locations (Bonella et al., 2016; Cassidy et al., 2022).

Clinical nurse specialists are an essential component of the multidisciplinary team and are critical to the delivery of holistic care (Duck et al., 2015; ITS, 2018; NICE, 2017). Clinical nurse specialists play an essential role as part of the multidisciplinary team through several key channels of care, including supporting patients with IPF through the provision of expert knowledge and advice throughout the disease course (Duck et al., 2015; Russell et al., 2016) and coordinating care within the multidisciplinary team (Russell et al., 2018). However, there can be variability in access to specialist nursing across jurisdictions (British Thoracic Society, 2021; Cassidy et al., 2022). Furthermore, access to other supportive care services, such as pulmonary rehabilitation (Kalluri et al., 2020), can also be fragmented, with one study reporting that just 42% of patients had access to outpatient pulmonary rehabilitation, with similar findings reported for access to psychological support (58%) (Moor et al., 2019).

From a systems approach to healthcare, there is an urgent need for the establishment and recognition of national registries to capture epidemiological information on patients diagnosed with IPF (Pesonen et al., 2018). There is also a need reported by healthcare professionals to recognise the importance of giving patients the option of participating in research or clinical trials related to IPF (Duck et al., 2015; Moor et al., 2019).

#### **2.6.5 Referral to Palliative Care and Advance Care Planning**

The World Health Organisation recommends early palliative care intervention to improve the quality of life of patients and their families' facing problems associated with a life-threatening illness (2020). Since the course of IPF is unpredictable, early palliative care interventions can be beneficial in multiple ways, including symptom management (Bajwah et al., 2012; Bonella et al., 2016), emotional support, and the initiation of advance care planning conversations (Chaaban et al., 2022). The European IPF Patient Charter (Bonella et al., 2016) and the Irish Thoracic Society Position Statement on the management of IPF (2018) have identified an urgent need to involve palliative care in IPF. The National Institute for Health and Care Excellence (2017) guidance states that patients with IPF should have access to palliative and supportive care services to manage symptoms (Sharp et al., 2018). Startlingly, despite these recommendations, patients with IPF do not receive optimal palliative care over the course of their disease, resulting in high symptom burden and decreased quality of life for patients with ILD (Bajwah et al., 2012; Chaaban et al., 2022). There is increasing evidence that patients with IPF do not always have access to palliative care input, and when it is introduced, the timeline is rarely optimal (Cassidy et al., 2024; Moor et al., 2019). There continues to be poor referral and access to palliative care specialists, with some healthcare professionals reporting a lack of training in palliative care (Chaaban et al., 2022), insufficient communication training in facilitating end-of-life conversations, variations in the disease trajectory (Akiyama et al., 2020), and patients' preferences to support these conversations (Jabbarian et al., 2018; Kalluri et al., 2021; Lindell et al., 2017). In one study, healthcare professionals - specifically practising pulmonologists and nurses with ILD expertise - reported that palliative care was not initiated until the

later stages of pulmonary fibrosis/IPF, with a fifth reporting that palliative care was only initiated at the end of life (Moor et al., 2019). Lack of advance care planning leads to longer intensive care unit and overall hospital lengths of stay (Brown et al., 2016). Kalluri and colleagues (2021) in their qualitative study, revealed that advance care planning is desired by patients and caregivers early in their illness experience, with healthcare professionals citing a need to clarify role, scope and responsibility with a call for practical guidance and training for healthcare professionals to improve competency and confidence in these conversations.

## **2.7 Discussion**

This scoping review characterised the broad and varied unmet needs of patients living with a diagnosis of IPF. These unmet needs spanned five core domains, encompassing physical and psychological needs, palliative care needs, and finally needs related to information and health service provision (Appendix 3 summary of included studies). In recent years, our knowledge of the pathogenesis of IPF, coupled with an improved awareness of the complex disease burden associated with IPF, has rapidly improved; nevertheless, there remains a myriad of unmet needs and gaps in care for this patient population, which is reflected in several previous studies on the topic (Bonella et al., 2016; Moor et al., 2019; Sampson et al., 2015). Despite advancements in drug therapies, including the use of antifibrotic medication, which, when first introduced, heralded improved survival rates for many, there continues to be unmet needs and compromised quality of life for many patients living with IPF (Lee et al., 2020). A key element of the inequalities and gaps in care that continue to exist for many patients is timely access to these antifibrotic medications (Maher et al., 2016), with continued barriers to treatment, such as reimbursement restrictions evidenced internationally, despite the various calls which support early initiation of these treatments (Moor et al., 2019).

### **2.7.1 The Psychological and Emotional Impact of an IPF Diagnosis**

Psychological distress was reported by many patients living with IPF and their caregivers and incorporated several key elements, including anxiety, depression, fear and worry (Lindell et al., 2017; Overgaard et al., 2016b; Russell et al., 2016). The continued need for improved access and reimbursement to psychological and emotional support throughout the disease course for both patients and their caregivers was evident throughout the literature (Cassidy et al., 2024; Delameillieure et al., 2021; Duck et al., 2015; Giot et al., 2012; Masefield et al., 2019; Overgaard et al., 2016b; Russell et al., 2016; Schoenheit et al., 2011; Van Manen, Geelhoed, et al., 2017). The psychosocial needs of patients and their family carers represents a critical issue as regards the incorporation of psychological support into existing and newly developed clinical care pathways for patients with IPF, with a focus on eliminating cost and access issues to this important resource. The literature supports a broad scope of adjunct psychological supports for patients, including the requirement for a respiratory nurse specialist, peer support programmes and pulmonary rehabilitation (Tikellis et al., 2020). However, there remains continued disparate access to these resources internationally (Delameillieure et al., 2021; Tikellis et al., 2020).

### **2.7.2 Adequate Information and Education at the Right Time and in the Right Way**

Patients have specific requirements regarding the delivery of appropriate and bespoke information at specific time points during the disease trajectory, a need which remains largely unmet (Bonella et al., 2016; Sampson et al., 2015; Schoenheit et al., 2011). Support groups and patient organisations were highlighted as a potential resource for information delivery in conjunction with the patient's hospital-based team during outpatient clinic visits. Addressing information needs has been identified as a key cornerstone in international patient charters, but a gap between information needs and their actual delivery remains (Bonella et al., 2016; ILFA, 2015).

### **2.7.3 High Symptom Burden**

Patients living with IPF report a high symptom burden impacting both physical and psychological well-being, coupled with the management of drug side-effects, and a call for support in managing these disabling symptoms. The literature reported that there are further unmet needs for patients with IPF, not least the need for appropriately resourced multidisciplinary teams (Tikellis et al., 2021), including the requirement for a respiratory nurse specialist (Duck et al., 2015; ITS, 2018). Furthermore, access to specialist interstitial lung disease centres with bespoke expertise to help manage patients' symptoms and facilitate access to supportive care, such as pulmonary rehabilitation, represents a significant requirement for patients with IPF.

### **2.7.4 Referral to Palliative Care and Advance Care Planning**

A critical unmet need for patients with IPF is timely referral to palliative care as part of their overall management plan and care package. Despite calls from several patient charters and international IPF position statements (Bonella et al., 2016; Cassidy et al., 2024), highlighting the importance of access to palliative and supportive care services to manage symptoms (NICE, 2017; Sharp et al., 2018), there continues to be poor palliative care referral and access to palliative care specialists, directly impacting patients' quality of life (Bajwah et al., 2012; Chaaban et al., 2022).

### **2.7.5 Health Service Provision -A Systems Approach**

Patients living with IPF rely heavily on the healthcare system, representing a significant need for an integrated health systems approach to providing supportive care. Equal access to supportive care and non-pharmacological treatment remains problematic, with reports of inequitable availability of services for patients in different European countries (Bonella et al., 2016; Cassidy et al., 2022). Internationally and across several healthcare systems, there remain deficits in providing patients with an early and accurate diagnosis (Duck et al., 2015; Moor et al., 2019; Ramadurai et al., 2018), representing a recurrent gap in health service provision. These delays have significant impacts on patients, including accessing pharmacological interventions and other supportive treatments (Vašáková et al., 2017).



In summary, the findings of this review expand our current understanding of the broad scope of unmet needs for patients with IPF, extending our depth of awareness of patient experiences and requirements for support and access to essential services across multiple domains. Equally, it identifies the diverse and nuanced approach to care which is required for this population. Furthermore, it identifies an urgent unmet need globally, which is the call for the establishment of IPF patient registries to capture epidemiological information (Pesonen et al., 2018), coupled with additional benefits such as ease of identification of patients who may wish to participate in research or clinical trials related to IPF (Duck et al., 2015; Moor et al., 2019). Registry data will provide opportunities to improve our understanding of this complex condition and to adequately prepare for appropriately resourced care provision.

## **2.8 Study Limitations**

The core limitations of this scoping review involve the diverse and varying quality of available evidence, with only one randomised controlled trial included. Similarly, mixed-methods studies were underrepresented in the review, comprising just 7.7% of the overall included resources. Furthermore, there were limited longitudinal studies, with just 18.4% represented in this review. The methodological quality of studies was high; however, many excluded some important demographic variables, including stage of disease, oxygen use, socioeconomic status and employment status. Given the varied disease trajectory, the interpretation of the findings from some studies may have been impacted. This review included non-English language articles in its inclusion criteria but cannot claim to have exhausted all non-English resources despite utilising a systematic approach to the review.

## **2.9 Conclusion**

In recent years, we have seen significant advances in relation to our understanding of the pathogenesis of IPF, coupled with the introduction of antifibrotic medication and their recognised contribution to patient survival. The concept of unmet needs and quality of life is intrinsically linked. Yet, there remain deficits in the literature as regards comprehensively investigating these concepts, for patients with IPF, representing a need for future research to focus on examining this relationship. This review will extend the knowledge base of the multidisciplinary team regarding the diverse range of needs that patients with IPF have, signalling the requirement to continue to target research toward this underrepresented population. The literature highlights the continued lack of integrated clinical care programmes in many jurisdictions for the management of IPF, which can result in unstructured and fragmented care delivery for patients. This review also highlights that patients living with a diagnosis of IPF experience a diverse range of unmet needs across various areas and requires a comprehensive multidisciplinary approach to care, with equal access to services and tailored information to support them over the course of the disease. These are key areas for future research.

### 2.9.1 Integration of the Scoping Review

This scoping review publication contributes valuable insights into the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF. This extensive review of the literature highlighted a range of unmet needs spanning a diverse scope of areas, representing a heightened need for further investigation. The scoping review facilitated the identification of survey instruments that had been used in previous studies to evaluate unmet needs. This provided a structured evaluation of their psychometric properties and appropriateness for this study in assessing unmet needs, symptom experiences, and quality of life of those with IPF, strengthening the selection of survey instruments.

The scoping review revealed several limitations in the literature; many studies employed single-site recruitment rather than multiple sites and were often hindered by small sample sizes (Ryan & Meskell, 2022). Other sources tended to be heavily reliant on a narrow selection of methodologies, such as the ‘*World Café*’ approach and retrospective analyses (Brereton et al., 2020; Russell et al., 2019). There was minimal evidence of patient and public involvement (PPI) in many of the included studies, representing another need for this current study, which prioritises PPI in the overall research design. Overall, these limitations underscore the necessity of this thesis, which aims to investigate the unmet needs, symptom experiences, and quality of life of individuals with IPF using a mixed-method sequential explanatory design.

This approach seeks to address existing gaps in evidence and actively involve patient and public partners in a meaningful way to enrich the research design (Chapter 3, Section 3.7). To mitigate some of the limitations observed in previous research, this mixed-methods study incorporates a multi-site recruitment strategy (Chapter 4, Section 4.4) and integrates PPI throughout the study. This approach aligns with best research practices, ensuring that the perspectives of those directly affected by the condition inform the research process (Chapter 4, Section 4.9.1.4). Furthermore, the study employs patient-centred instruments (Chapter 4, Section 4.7.2) to collect data on the phenomenon of interest, contributing to the literature on the applicability of these instruments in an IPF population. The scoping review underpinning this thesis highlights the myriad of unmet needs experienced by individuals with IPF and emphasises the importance of incorporating the lived experience and active contribution of PPI. This maximises opportunities to ensure that the research reflects the research priorities and unique perspective of individuals with IPF.

## Chapter 3 Methodological and Philosophical Considerations

### 3.1 Introduction

This chapter details the methodological and philosophical influences considered in the planning and implementation of this mixed-methods sequential explanatory design study. A discussion on paradigms is provided in Section 3.2, followed by an overview of this study's philosophical underpinning, pragmatism (Section 3.2.1). The mixed methods typology used in this study is introduced in Section 3.3, followed by an assessment of quality in mixed methods (Section 3.4). The justification for mixed methods is provided in Section 3.5. The research aim and objectives are explicitly outlined in Chapter 4, Section 4.2. The study objectives underpin the overall study and guide subsequent decisions within the study's methodological framework. Section 3.6 outlines the theoretical framework informing this research, followed by a reflection on the incorporation of patient and public involvement (PPI) (Section 3.7). Ethical considerations are discussed in Section 3.8, with the conclusion provided in Section 3.9.

### 3.2 An Exploration of Paradigms

A critical cornerstone of research involves positioning one's work within a particular paradigm, acknowledging that personal beliefs contribute to the chosen methodological approach (Guba & Lincoln, 1994; Houghton et al., 2012). Kuhn was one of the earliest contributors to describe paradigms as an accepted philosophical movement concerning "beliefs that direct research" (1962, p. 23). Guba and Lincoln expanded on Kuhn's original definition defining paradigms as a "basic set of beliefs, principles and assumptions that guide the actions of the researcher", (1994, p. 107). Fundamentally, a paradigm is the philosophical lens through which researchers interpret the world, acquire knowledge, form an understanding of the nature of reality and guides the methodological approach (Creswell & Plano Clark, 2018; Guba & Lincoln, 1994). Research paradigms are distinguished by unique philosophical elements regarding epistemology (how we gain knowledge), ontology (beliefs about the nature of reality), axiology (the role ethics and values play in research), and methodology (strategies to be employed using the chosen methods to examine the research questions) (Creswell, 2013; Creswell & Plano Clark, 2018; Crotty, 1998; Guba & Lincoln, 1994).

Historically, a dichotomy existed between positivism/post-positivism and interpretivism/constructivism paradigms. This contentious debate fuelled the 'paradigm wars' with purists arguing for the superiority of their preferred paradigm over others (Denison, 1996; Doyle et al., 2016; Guba & Lincoln, 1994; Howe, 1988; Johnson & Onwuegbuzie, 2004; Weaver & Olson, 2006). Positivism and post-positivism are grounded in the belief that a singular, objective reality exists, maintaining that truth can be uncovered through measurable data (Creswell & Plano Clark, 2018; Kincheloe & Tobin, 2009; Lincoln, 1985; Morgan, 2007; Teddlie & Tashakkori, 2009). Constructionism, by contrast, argues that reality is not singular but multiple, socially and culturally constructed, and shaped by environmental contexts and personal experiences (Christensen, 2022; Denison, 1996; Denscombe, 2008; Guba & Lincoln, 1994; Morgan, 2014).

Purists argue that quantitative and qualitative methodologies are at opposite ends of a continuum which are fundamentally incompatible, a conundrum commonly referred to as the “incompatibility thesis” (Liu, 2022, p. 1). These diverse methodological approaches are believed to represent ontological and epistemological perspectives regarding the nature of reality and knowledge acquisition, underpinned by underlying values and beliefs that guide the investigation (Scotland, 2012). Although grounded in contrasting philosophical foundations, quantitative and qualitative approaches offer distinct orientations from which to view the research question and advance knowledge (Denzin & Lincoln, 2011). Knowledge generation in quantitative research is grounded in objective, empirical and impartial methods, aimed at producing broad and generalisable data (Morgan, 2007). In contrast, qualitative approaches acknowledge the subjective and contextual nature of reality, framed within a social and cultural setting utilising qualitative inquiry and interpretive analysis (Morgan, 2007).

To resolve the historical debate regarding contrasting paradigms, a mixed-methods approach was adopted combining both quantitative and qualitative methods, and their underlying philosophical underpinnings. The introduction of mixed methods is commonly referred to as a ‘*third research paradigm*’ (Christensen, 2022; Denison, 1996; Denscombe, 2008; Greene, 2007; Guba & Lincoln, 1994; Morgan, 2014). This study benefited from a mixed-methods research design which contributed to the coherence of the investigation and strengthened the rigor and credibility of the research while recognising the underlying philosophical and theoretical orientations that guided methodological decisions (Tashakkori & Teddlie, 1998).

This study’s epistemological stance adopts a holistic approach that recognises the complexity and individuality of participants’ lives and avoids the contentious issues of the ‘*incompatibility thesis*’. This study prioritises the complementary strengths of both quantitative and qualitative methods. By employing a mixed-methods study design, this study aimed to generate new knowledge about people diagnosed with IPF and their unmet needs, symptom experiences, and quality of life. Integration of diverse ontological perspectives facilitated a comprehensive exploration of the phenomenon of interest.

### **3.2.1 Philosophical Underpinning**

Pragmatism was chosen as the guiding paradigm for this study, reflecting the researcher’s stance concerning the nature of reality and the process of acquiring new knowledge. Pragmatism emerged as a philosophical movement in the late nineteenth century in the United States, in response to the historical ‘*paradigm wars*’, which had divided methodological purists. Influential figures to the development of pragmatism as a philosophical movement included Charles Sanders Pierce, William James, John Dewey, and Richard Rorty, along with other contemporaneous contributors such as Morgan (Creswell & Plano Clark, 2018; Morgan, 2007; Tashakkori & Teddlie, 2003).

Pragmatism was a salient choice for this research study, given its problem-focused orientation and emphasis on practical outcomes and flexibility in the research approach oriented toward a ‘what works’ approach. Adopting this philosophy, valued the integration of both objective and subjective knowledge (Mitchell & Education, 2018; Molina-Azorin, 2016), and is particularly suited to mixed-methods research.

Pragmatism asserts that knowledge and reality are not fixed, but rather contextual and ever-evolving, shaped by our lived experiences (Coghlan & Brydon-Miller, 2014). Pragmatism views reality as a normative construct shaped by social interactions and shared practices, rather than as an absolute or fixed truth (Creswell, 2011; Kaushik & Walsh, 2019). Additionally, pragmatism acknowledges the active role of the researcher, acknowledging that individualised experiences, preconceptions, and interpretations may influence the research design (Johnson & Onwuegbuzie, 2004).

This mixed-methods study was grounded in the philosophical principles of pragmatism which provided the necessary scaffolding to address the research aim and objectives. Pragmatism facilitated flexibility to oscillate between diverse methods in response to the unique needs of each phase of the research. The justification for choosing pragmatism to underpin this research study was informed by several factors. First, pragmatism focuses on a '*what works*' approach, enabling oscillation between deductive and inductive reasoning, while acknowledging abductive reasoning, which facilitates a deeper reflection of the research question (Morgan, 2007). Pragmatism provided an adaptable approach which prioritises the integration of both quantitative and qualitative methods to address the research question and accommodate diverse worldviews. Next, pragmatism recognises that truth is personal and contextual, favouring practicality over a fixed interpretation of reality. This orientation is especially relevant in the context of this study, which seeks to explore complex phenomena concerning the unmet needs of individuals diagnosed with IPF, where participants' unique narratives are central to achieving the study's objectives. The following section outlines the ontological, epistemological, axiological and methodological underpinnings used in this study.

### **3.2.2 Ontology**

Ontology concerns the nature of reality and is often framed within two contrasting domains: objectivism and subjectivism. Ontological assumptions focus on what constitutes reality (Scotland, 2012) and are described by Crotty as "the study of being" (Crotty, 1998, p. 10). The ontological positioning of this study adopts a nuanced position, that recognises the complexity of human experience and views reality as context dependent, constructed through our experiences, interactions with others and wider social and cultural influences. This study avoids confining reality to a singular objective truth, instead this study favours the integration of both singular and multiple interpretations of reality (Maarouf, 2019; Morgan, 2014). Adopting this stance, enhanced our understanding of the phenomena of interest and contributed to the legitimacy of the inquiry (Creswell, 2007). In the quantitative phases of this study (phase one and phase two) an objective view of reality was adopted which acknowledged the existence of a singular reality. This position paved the way for the collection of quantifiable and generalisable data to address objectives 1-3. Subsequently, adopting a subjective ontology, in phase three, acknowledged that reality is interpreted through observation and individualised experience. Integrating qualitative methods (phase three) enabled the investigation of the multidimensional and diverse perspectives of those living with IPF, which facilitated a rich, in-depth contextual space for the inclusion of participants' unique interpretations of their lived experiences to address and further expand on objectives 1-3 (Morgan, 2007).

### **3.2.3 Epistemology**

Epistemology may be considered a branch of philosophy related to questions about “how we gain knowledge about what we know” (Creswell & Plano Clark, 2018, p. 37). Pragmatism views objectivity and subjectivity on a continuum, which facilitates oscillation between both at varying points of the research process (Maarouf, 2019). This study’s epistemology benefited from the flexible integration of both quantitative and qualitative methods and their associated philosophies, allowing the researcher to flow between both paradigms for a more nuanced understanding of the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF. Pragmatism prioritises the research question rather than becoming embroiled in philosophical assumptions about truth and reality; it therefore recognises that quantitative or qualitative methods alone would not have sufficiently portrayed the lived experience of individuals diagnosed with IPF (Maxcy, 2003).

### **3.2.4 Axiology**

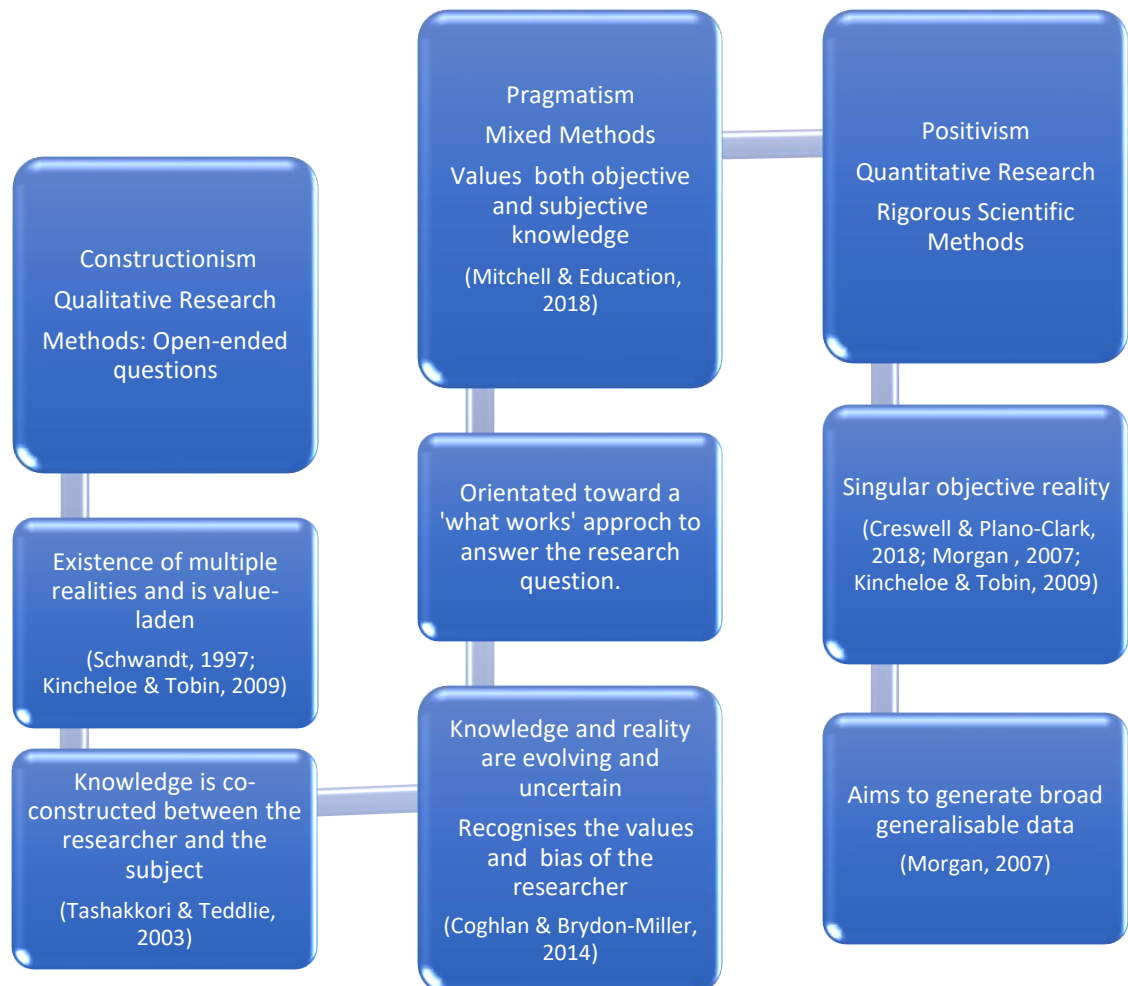
Axiology as an element of worldview focuses on the role of values and bias in the research process, recognising that these are context dependent (Allemang et al., 2022; Creswell & Plano Clark, 2018). Existing literature suggests that an objective approach to research is often associated with a value-free position, underpinned by rigorous quality control measures intended to avoid bias. In contrast, a subjective approach is generally considered to be value-laden, with the researcher viewed as intrinsically connected to the research process (Gobe et al., 2013; Lim, 2025). Pragmatism facilitates the adoption of a value-oriented approach, recognising that bias is an unavoidable element of research. This study’s axiological position appreciates the role values play in the selection of the research question and subsequent research design, while acknowledging the existence of the researcher’s unique values, personal experiences, and potential bias (Johnson & Onwuegbuzie, 2004; Kaushik & Walsh, 2019). The axiological position taken in this study sought to minimise the risk of bias, through transparent and ethical practices guided by the Belmont Report (Ryan, 1979), which underpins the ethical considerations in this study (Creswell, 2007). Several steps were employed to mitigate against bias in the collection and analysis of data, including managing validity and reliability in the quantitative data analysis phase (Section 4.7.2.6-4.7.2.8) and credibility and rigour in the qualitative phase (Section 4.7.3.3).

### **3.2.5 Methodology**

Methodology is concerned with the overall strategies employed concerning data collection and analysis and research decisions made relating to what data should be collected, from where, when and how, and is influenced by the purpose of the research and the epistemological position of the researcher (Scotland, 2012). In contrast, methods concern the techniques required to implement the methodology (Crotty, 1998). Methodology is generally situated in either quantitative or qualitative paradigms, supporting either deductive or inductive reasoning (Kaushik & Walsh, 2019). Pragmatism bridges the gap between these methodological approaches and the methods employed to address the research question (Johnson & Onwuegbuzie, 2004; Kaushik & Walsh, 2019). In this study, pragmatism harnesses the strength of both

quantitative (deductive) and qualitative (inductive) reasoning, applying a practical lens to '*what works*', to address the research problem (Figure 3.1).

**Figure 3.1 Philosophical Underpinning**



### 3.3 Research Study Design-Sequential Explanatory Mixed Methods

A myriad of mixed-methods typologies have emerged over the years (Greene, 2007b; Morgan, 1998; Patton, 1990; Tashakkori & Teddlie, 1998). Mixed-methods studies incorporate a range of typologies in which the timing of methods influences the relationship between research phases and the sequencing of quantitative and qualitative components. The premise underlying mixed methods typologies is their capacity to organise and simplify complex constructs, arranging them into coherent and understandable systems (Curry, 2015). Such typologies facilitate researchers' ability to plan and implement the various components of the mixed-methods design and support the synthesis and comparison of evidence generated through the research process (Curry, 2015). Additionally, these typologies serve to legitimise mixed-methods designs by clarifying that they are distinct from either qualitative or quantitative designs

alone (Tashakkori & Teddlie, 2003). Creswell and Plano Clark (2018) outline three core mixed methods typologies: convergent, explanatory sequential and exploratory sequential (Table 3.1). Each of these typologies provides a roadmap that enables researchers to anchor key aspects of their research design, including data collection, analysis and the integration or mixing of their data.

**Table 3.1 Mixed Methods Research Design Typologies**

|                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Convergent</b>             | <ul style="list-style-type: none"> <li>• This design is characterised by the intention of the researcher to bring together the results of both the quantitative and qualitative data analysis for the purpose of comparing or combining them.</li> <li>• The fundamental rationale behind a convergent design is to compare the two results so that the researcher can obtain a more comprehensive understanding of the problem.</li> <li>• Create opportunities to validate one set of findings with the other.</li> </ul>                                                                     |
| <b>Explanatory sequential</b> | <ul style="list-style-type: none"> <li>• This design is characterised by the fact that data is collected in two distinct phases. The first phase commences with the collection and analysis of data quantitatively.</li> <li>• This is followed by a second phase which aims to collect and analyse qualitative data. The purpose of this second phase is to explain or expand on the first quantitative phase.</li> </ul>                                                                                                                                                                      |
| <b>Exploratory sequential</b> | <ul style="list-style-type: none"> <li>• This design typically prioritises the collection and analysis of qualitative data. This is followed by the development phase where a quantitative feature based on the qualitative results is designed.</li> <li>• The final phase in this design, involves the researcher quantitatively testing the new feature.</li> <li>• The researcher then interprets how the quantitative results have built on the initial qualitative results or how the quantitative results have provided a clearer understanding of the phenomena of interest.</li> </ul> |

### 3.3.1.1 Rationale for a Mixed Methods Design

After reviewing established mixed methods typologies and considering the study objectives (Chapter 4, Section 4.2), an explanatory sequential mixed methods design was adopted. Conceptualised as both a method and a broader methodological orientation (Creamer, 2018), this approach enabled the purposeful integration of the complementary strengths of both quantitative and qualitative inquiry. This design facilitated a more comprehensive and nuanced understanding of the unmet needs, symptom experiences, and quality of life of individuals living with IPF than could be achieved through the use of a single



methodological approach alone (Creswell & Plano Clark, 2018; Doyle et al., 2016; Teddlie & Tashakkori, 2009).

By enabling the integration of multiple data sources, the research design supported the generation of new knowledge, that could have been constrained by singular methodological approaches alone (Curry & Nunez-Smith, 2014; Gurenlian, 2023; Morgan, 2014). The explanatory sequential design acknowledges that knowledge and truth are pluralistic, context-dependent and dynamic whilst simultaneously supporting the systematic collection and analysis of data. The explanatory sequential design was selected as the most appropriate methodological approach for addressing the research objectives due to its structured process: quantitative data are first collected and analysed in phase one and phase two, followed by the collection of qualitative data in a subsequent phase to further explain, enrich and expand upon the initial quantitative findings (Curry & Nunez-Smith, 2014; Halcomb, 2019). The suitability of this approach is further reinforced by its capacity to integrate the philosophical and theoretical underpinnings of the research, thereby ensuring methodological coherence and alignment with the research aims (Creswell & Plano Clark, 2018).

At a national level, there is a paucity of data relating to individuals living with IPF, attributable in part to the absence of a national IPF patient registry. This limitation necessitated an initial nationwide quantitative phase of data collection, prior to undertaking qualitative inquiry, thereby further justifying the use of a sequential explanatory mixed methods design. Consequently, this study was conducted across three phases to operationalise the selected research design.

The Irish Thoracic Society *Position Statement on IPF* (2018) and the *Respiratory Health of the Nation Report* (Irish Thoracic Society, 2018b) both highlight a lack of Ireland-specific evidence regarding the impact of IPF within the Irish healthcare system. Identified deficits include limited epidemiological data, national inconsistencies in patient care pathways, and inadequate data collection related to healthcare access. These gaps underscore the ongoing need for research situated within an Irish context to better understand the unmet needs of individuals with IPF. This mixed methods study is therefore positioned to address these evidence gaps by facilitating a deeper understanding of the lived experiences of people diagnosed with IPF, including the challenges encountered when accessing healthcare services within nationally representative tertiary hospitals in Ireland.

### **3.3.1.2 Phase one (Quantitative)**

Phase one employed quantitative methods through a healthcare organisation audit to assess the unmet needs of individuals diagnosed with IPF, as observed by healthcare professionals with specialist expertise in this area. This phase addressed objective 1,3 and 4 by capturing healthcare professionals' perspectives on service provision, care pathways, and perceived gaps in healthcare delivery for people living with IPF.

#### **3.3.1.3 Phase two (Quantitative)**

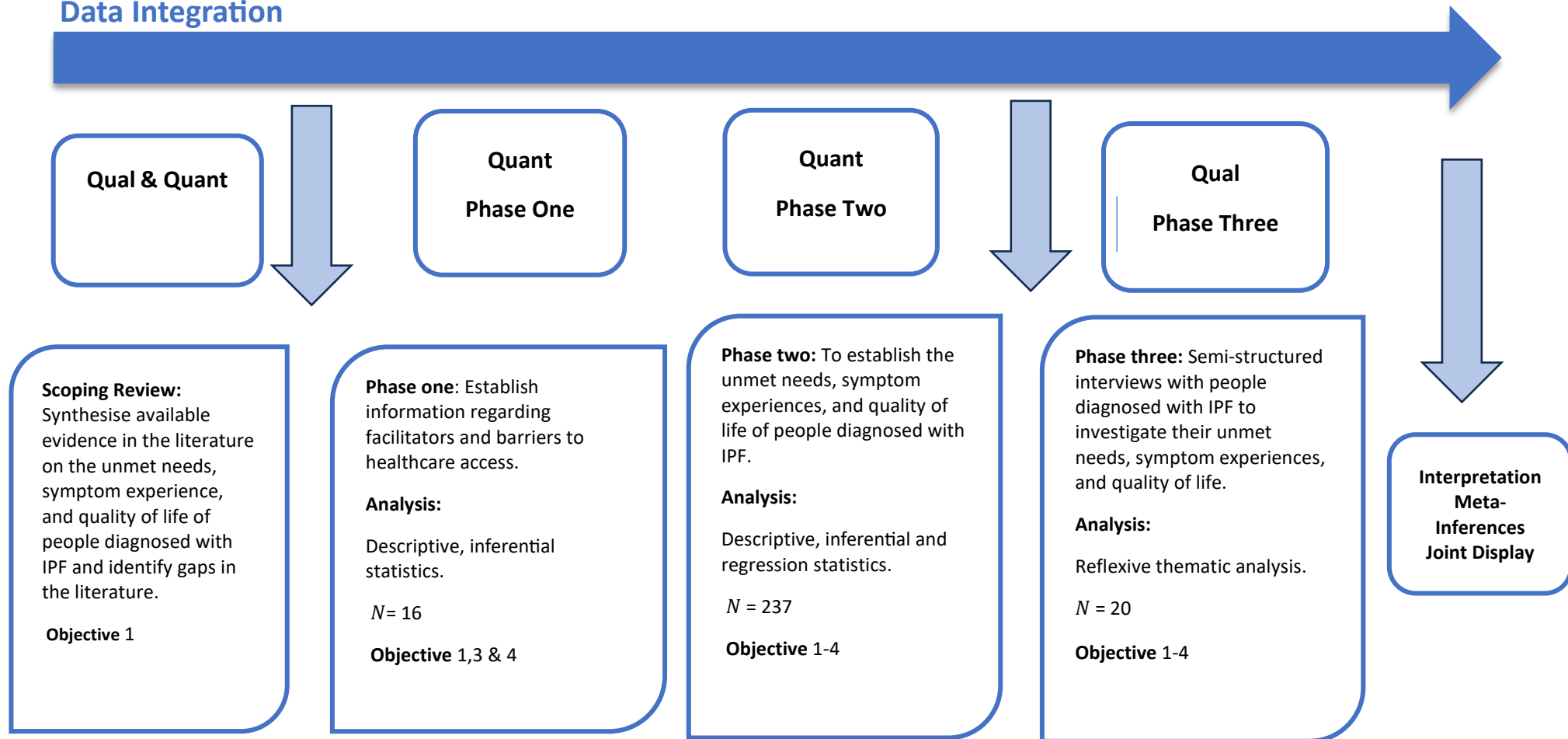
Phase two employed quantitative methods, using an IPF survey to explore the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF, addressing objectives 1-4. This study utilised readily available, validated instruments with strong psychometric properties, the St. George-IPF questionnaire (SGRQ-IPF), the IPF-Patient Reported Outcome Measure (IPF-PROM), and the Lung Information Needs Questionnaire (LINQ), to measure the constructs of interest, thereby optimising both time and resource efficiency.

#### **3.3.1.4 Phase three (Qualitative)**

Phase three employed qualitative, semi-structured interviews to generate rich, in-depth insights into the phenomenon of interest and to address objectives 1-4. This phase enabled deeper exploration of findings from the preceding quantitative phases, thereby enhancing contextual understanding. Collectively, the mixed methods design adopts a pluralistic stance that leverages the strengths of individual methodologies to offset their inherent limitations and create methodological synergy, resulting in a more holistic understanding of the phenomenon of interest (Ahmed et al., 2024). The mixed methods design is outlined in Figure 3.2.

Figure 3.2 Explanatory Sequential Design

## Data Integration



### 3.4 Assessing Quality in Mixed Methods Research

Historically, mixed methods research has faced criticism for its lack of transparent reporting regarding quality standards (Creswell & Clark, 2017; Fàbregues et al., 2021; Teddlie & Tashakkori, 2009). Quantitative and qualitative research have traditionally benefitted from individualised quality criteria. This divergence in quality appraisal has created a challenge for mixed methods researchers to reconcile these differences concerning quality appraisal. This study sought to provide transparent information which clearly articulated the rationale for adopting a mixed-methods design. Additionally, this study aimed to explicitly document points of integration, a core component of mixed-methods research. Opportunities for integration were clearly documented to ensure the methodological quality and to enhance the reliability and credibility of this mixed-methods study (O'Cathain et al., 2007). Prioritising credibility in this study, given the use of diverse methods and their underlying philosophical assumptions was considered critical in the delivery of this research (Plano Clark & Ivankova, 2016). Bryman (2015) developed the quality appraisal framework which was selected for this mixed-methods study to address quality appraisal. The selection of their quality framework was a pragmatic choice due to its simplicity and applicability to the current study (Bryman, 2014). An overview of Bryman's six core criteria and applicability to relevant sections in this thesis is provided in Table 3.2.

**Table 3.2 Mixed Methods Core Quality Criteria**

| Guideline<br>(Adapted from Bryman, 2014, p.125)                                                                                             | Appraisal Criteria                                                                                                                     | Chapter and Section                                                                                                                                                                                                                                    |
|---------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| (1) Need for the quantitative and qualitative components of a mixed-methods project to be implemented in a technically competent manner.    | Have the standards for the qualitative and quantitative methods (sampling, data collection, analysis etc.) been executed proficiently? | <ul style="list-style-type: none"> <li>✓ Chapter 3, Section 3.3 and Chapter 4, Section 4.3 (Study Design)</li> <li>✓ Chapter 4, Section 4.5, (Population and Sample).</li> <li>✓ Figure 3.2, (Mixed Methods Sequential Explanatory Design).</li> </ul> |
| (2) Need for transparency. Have the structure, sequencing and phases of the qualitative and quantitative components been clearly described? | Have the structure, sequencing and phases of the qualitative and quantitative components been clearly described?                       | <ul style="list-style-type: none"> <li>✓ Chapter 3, Section 3.3 and Chapter 4, Section 4.3 (Study Design)</li> <li>✓ Figure 3.2, (Mixed Methods Sequential Explanatory Design).</li> </ul>                                                             |
| (3) Need for mixed methods to be linked to research questions.                                                                              | Is the use of mixed methods rooted in the research questions?                                                                          | <ul style="list-style-type: none"> <li>✓ Chapter 3, Section 3.3 and Chapter 4, Section 4.3 (Research Design).</li> <li>✓ Chapter 4, Section 4.2 (study aims and objectives).</li> </ul>                                                                |

**Table 3.2 Mixed Methods Core Quality Criteria (Continued)**

| Guideline                                                                  | Appraisal Criteria                                   | Chapter and Section                                                         |
|----------------------------------------------------------------------------|------------------------------------------------------|-----------------------------------------------------------------------------|
| (4) Need to be explicit about the nature of mixed methods design employed. | What is the specific mixed-method design?            | ✓ Chapter 3, Section 3.3 (sequential explanatory mixed methods design).     |
| (5) Need for a rationale for the use of mixed methods research.            | Is there a clear rationale for using mixed methods?  | ✓ Chapter 3, Section 3.5 (justification for mixed methods research design). |
| (6) Need for integration.                                                  | Have points of integration been clearly articulated? | ✓ Chapter 4, Section 4.9, Integration.                                      |

In summary, quality appraisal in this study addresses the research design, the methods and integration, transparency of interpretation and use of a mixed methods design (Curry, 2014). Justification for mixed methods in this study is described in the next Section 3.5.

### 3.5 Justification for Mixed Methods Research

A mixed-methods approach was chosen for this inquiry due to its ability to incorporate “*multiple ways of seeing*” (Greene, 2007, p. 20). This strategy created opportunities to view the research question through multiple lens. This study used quantitative (audit and survey) and qualitative (semi-structured interview) methods, which are subsequently integrated to provide a comprehensive analysis of the research question (Creswell, 2011). The decision to employ a mixed-methods design is embedded in the complexity of the phenomenon of interest, which sought to explore the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF. The methodological considerations for this study, including philosophical and theoretical underpinnings, have been described in Section 3.2 and Section 3.6. The next chapter (Chapter 4) will focus on the methods employed in this study (Section 4.7). Additionally, both quantitative (Section 4.7.1-4.7.2) and qualitative (Section 4.7.3) data collection methods will be described, along with the integration techniques employed in this study (Section 4.9). Harnessing the strengths of two opposing paradigms (positivism and constructionism) and integrating these worldviews through a mixed-methods design, strengthens the depth of knowledge available to comprehensively answer the research question, where the use of single methods alone would not have been sufficient. Employing a mixed-methods sequential explanatory design for this study warranted the inclusion of a clearly articulated rationale for selecting a mixed-methods research design to address the research question (Creswell & Plano Clark, 2018). Bryman’s justification for using mixed methods was employed to outline the rationale for its use in this current study (Table 3.3) (Bryman, 2006, p. 10).

**Table 3.3 Justification for Employing a Mixed Methods Research Design**

|                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
|-------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Triangulation</b>          | <ul style="list-style-type: none"><li>Quantitative and qualitative findings are combined to enhance the validity of findings (triangulate) and assess for convergence or divergence in the findings. Triangulation enables a comprehensive understanding of the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF.</li></ul>                                                                                                                                              |
| <b>Completeness</b>           | <ul style="list-style-type: none"><li>Using both quantitative (deductive) and qualitative (inductive) methods provides a more complete understanding of the phenomenon of interest, than could have been achieved using one method alone.</li><li>Quantitative surveys provide statistical data to extend the breadth of our understanding of the phenomenon of interest. Meanwhile, qualitative interviews fostered a rich, contextual understanding of the lived experience of those with IPF.</li></ul> |
| <b>Explanation</b>            | <ul style="list-style-type: none"><li>Qualitative interviews can help to explain and expand on the quantitative survey findings, providing a deeper analysis of the unmet needs, symptom experiences, and quality of life of those with IPF.</li></ul>                                                                                                                                                                                                                                                     |
| <b>Instrument Development</b> | <ul style="list-style-type: none"><li>Quantitative findings helped develop the interview guide and informed the sampling strategy utilised in phase three (maximum variation sampling).</li></ul>                                                                                                                                                                                                                                                                                                          |

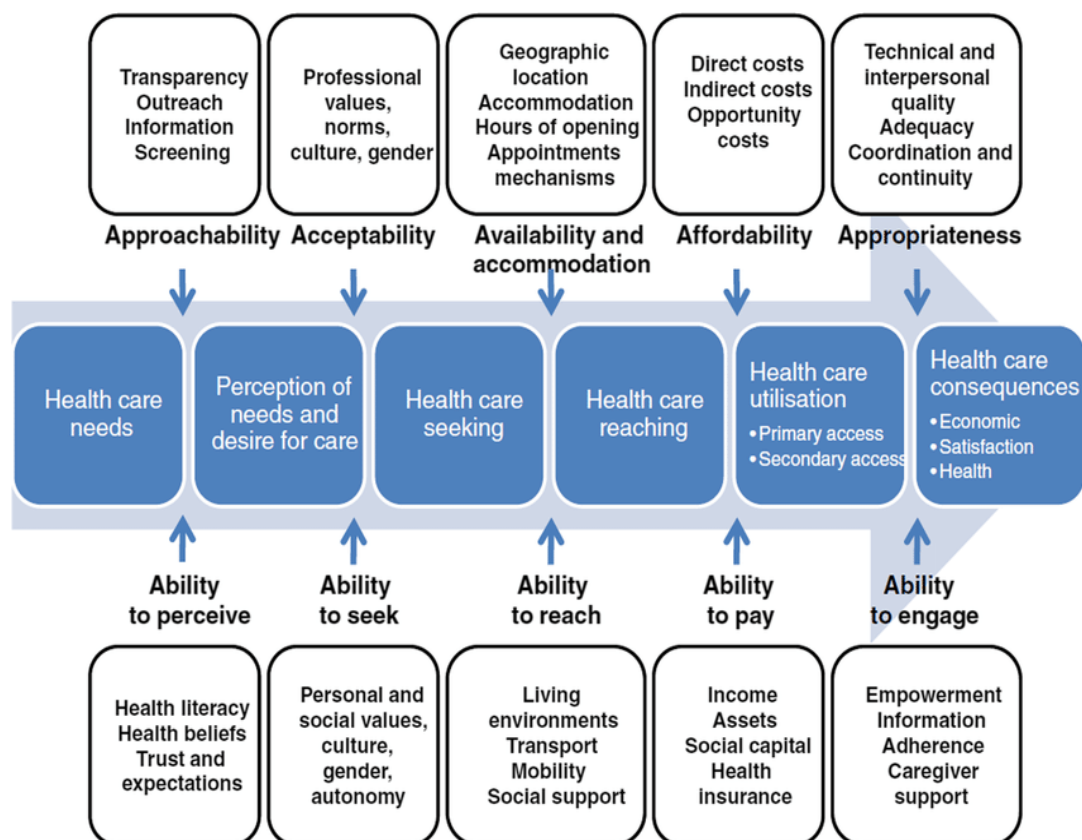
### 3.6 Theoretical Framework

This study reviewed several theoretical frameworks prior to selecting the Levesque healthcare access framework (2013). Lysaght describes a researcher's choice of theoretical framework as being grounded in "personal beliefs and understandings about the nature of knowledge, how it exists (in the metaphysical sense) concerning the observer, and the possible roles to be adopted by the researcher in his/her work" (2011, p. 572). In alignment with this perspective, Levesque's framework (2013) served as the theoretical blueprint for the overall research design and informed the methods, analysis, and interpretation of the findings in this present study. Alternative theoretical frameworks were considered for this study, including Bronfenbrenner's Socioecological Framework (1977), which gained prominence in the 1970s, and Andersons behavioural Model of Health Services Use (Anderson et al., 2001). Bronfenbrenner's socioecological framework (1977) offers valuable insight into the multiple contextual layers shaping healthcare access, however its primarily descriptive nature provides limited guidance on how individuals progress through the stages of access within healthcare systems. Similarly, Andersons Behavioural Model (2001) conceptualises access largely in terms of healthcare utilisation patterns, rather than as a dynamic and interactive driven experience.

In contrast, Levesque's Healthcare Access (2013) framework was selected as the most suitable theoretical foundation for this study because it offers a comprehensive, process-orientated conceptualisation of access that integrates both healthcare system level characteristics and individuals' ability to engage with care. Levesques framework (2013) delineates five dimensions of access: approachability, acceptability, availability/accommodation, affordability, and appropriateness, paired with five corresponding abilities of the individual to seek healthcare (perceive, seek, reach, pay and engage) (Figure 3.3). This dual system and individual perspective enable a nuanced examination of barriers and facilitators across the care continuum while also identifying specific critical junctures at

which targeted interventions may be effectively introduced. Employing Levesque’s framework (2013) provided a clear theoretical structure for the study and supported the research objectives by facilitating the systematic identification of barriers and facilitators to healthcare access relevant to the unmet needs of individuals diagnosed with IPF (Bramhill et al., 2024).

**Figure 3.3 Levesque Healthcare Access Framework**



### 3.6.1 Levesque’s Healthcare Access Framework

Integrating Levesque’s conceptual framework for healthcare access (2013) supported this study objective to explore the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF within the context of the complex healthcare systems they navigate. The framework acknowledges that healthcare access extends beyond ‘simply *using services*’ and is concerned with the ability to access services, institutions and providers of services (Levesque et al., 2013; Whitehead, 1992). Patients with IPF can experience barriers when accessing essential supports and services. The scoping review (chapter two) highlighted challenges, such as difficulties in obtaining an accurate and timely diagnosis (Moor et al., 2019), limited access to a multidisciplinary team, supportive care, and related services (Cassidy et al., 2022). Additional barriers include inadequate referral for lung transplantation assessment (Tikellis et al., 2022), pulmonary rehabilitation (Moor et al., 2019; Van Manen et al., 2017), psychological supports (Van Manen et al., 2017) and access to specialist nursing (Bramhill et al., 2024; Cassidy et al., 2022). The widening gap between patients’ needs and the actual delivery of healthcare services highlights a critical

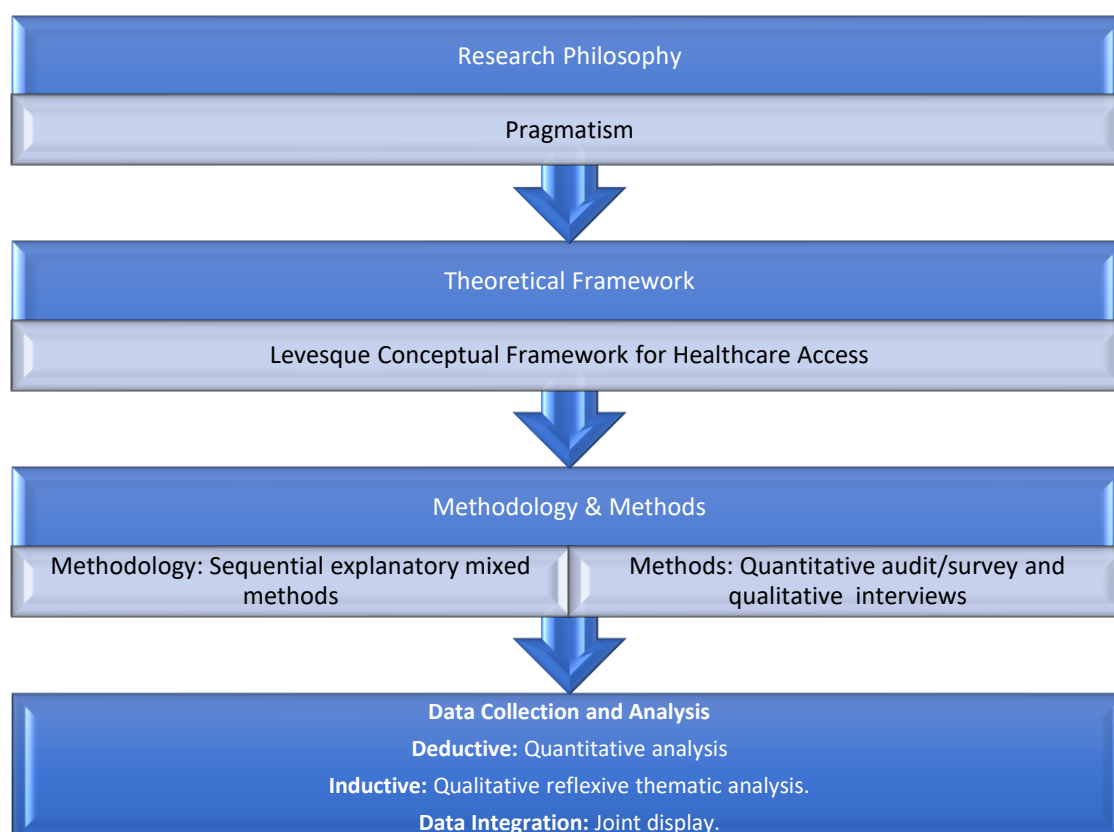
shortfall in the provision of services. Guided by Levesque's healthcare access framework (2013), this study aims to explore the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF, and in the process acknowledge the barriers and facilitators to care that exist.

Levesque's framework invites a broader conceptualisation of healthcare access, that moves beyond a unidimensional view, instead encompassing geographical, economic and social determinants which inhibit or facilitate healthcare access (Corscadden et al., 2017; Levesque et al., 2013). Levesque's framework encourages enhanced understanding of the complex interplay among various dimensions of healthcare access, incorporating individual characteristics such as cultural, societal, and ethical considerations, and extending to other factors which concern healthcare access such as location, financial aspects and health literacy (Levesque et al., 2013). Levesque's framework has previously been applied in several other studies, including a study conducted by Schwarz et al. (2022) who sought to identify barriers to healthcare access in Austria for people living with chronic conditions. Schwarz et al. (2022) hypothesised that access to healthcare transcends multiple domains, encompassing not only individual characteristics but extending to wider societal factors, a finding that has relevance for this study given the complex interplay between individuals and the healthcare system. Access to healthcare requires understanding the five core dimensions in Levesque's framework (2013) concerning approachability, acceptability, availability/accommodation, affordability, and appropriateness of services (Cu et al., 2021). Recognising how these dimensions interact and the complex healthcare systems that individuals with IPF navigate is essential.

The first domain in the framework is approachability, which involves recognising and understanding the availability of healthcare services. This is crucial for those living with IPF, who often rely upon multiple forms of healthcare support. Acceptability involves cultural and societal elements which impact engagement with healthcare services, and includes factors such as gender, social norms and beliefs (Levesque et al., 2013). Availability and accommodation relate to the infrastructure and service delivery characteristics available at healthcare sites (Levesque et al., 2013). Additionally, affordability considers the financial impacts which could affect engagement with healthcare services (Levesque et al., 2013). Finally, appropriateness addresses bespoke patient needs and the quality and availability of services (Krishnan, 1999; White et al., 1992). Levesque's framework (2013) supported the development of this research study which was underpinned by the philosophical underpinning of pragmatism and aligned with Crotty's framework for developing a research study (Figure 3.4).



**Figure 3.4 Crotty's Framework for Developing a Research Study**



### 3.7 Patient and Public Involvement

Patient and public involvement (PPI) in research is defined as conducting research, '*with or by members of the public*' (Hayes et al., 2012; HSE, 2021). Patient and public involvement (PPI) in research aims to positively contribute to the quality, relevance, and impact of the investigation (Jones et al., 2021) and is considered a key competency in doctoral-level research (Pierce et al., 2023). Despite its inherent challenges concerning time commitment and researcher's ark of learning, it is a critical component of contemporaneous research and often an ethical requirement in research ethics committee applications. Engaging PPI in this current study was motivated by a primary aim to actively integrate feedback and contributions from PPI partners into several aspects of this study. Involving PPI in this research improved the appropriateness and applicability of the findings. The application of PPI is described in detail in Chapter 4 (Section 4.9.1.4).

### 3.8 Ethical Considerations

Ethical approval for the conduct of this study was sought and subsequently granted by relevant research ethics committees at the selected five hospital recruitment sites (Appendix 4). Ethical approval was also secured from the Faculty of Health Sciences, Trinity College Dublin (Appendix 4). In addition, a Data Protection Impact Assessment (DPIA) was supplied, which aimed to review potential data protection issues in consultation with relevant data protection officers (DPOs) in Trinity College Dublin and respective

hospital sites. A study protocol was developed to outline procedures and ensure adherence to ethical principles maintained throughout the research. A consultative process with the clinical leads from each of the five hospital sites facilitated access to respiratory outpatient clinics before data collection began. This study included personal and health information and was compliant with the EU General Data Protection Regulation (EU) 2016/679 (GDPR) and the Data Protection Act 1988-2018 and the Health Research Regulations (Section 36 (2) 2018).

### **3.8.1 Ethical Framework**

The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Science) (Ryan, 1979) is a pivotal framework which guides this inquiry. The report prioritises the rights of research participants, building upon the Nuremberg Code, Declaration of Helsinki and other laws (Ryan, 1979; Sims, 2010). The core priorities in the report include respect, justice and beneficence and were considered and applied throughout all aspects of this research (Ryan, 1979). The following section outlines the comprehensive approach to ethical considerations in this study.

### **3.8.2 Respect for Persons/Autonomy**

Respect for persons is a concept that carries two core principles: firstly, recognising autonomy and secondly, the inherent need to protect those with diminished autonomy (Łuków & Różyńska, 2014). The Belmont Report specifies instances where respect for a person's autonomy should be addressed, including access to participants, informed consent and confidentiality (Ryan, 1979). Autonomy in research advises that participants should be given appropriate information to make their own decisions about their participation (Beauchamp & Childress, 2019). Informed consent is central to the principle of respect and autonomy and occurs when a person is informed about the potential risks and benefits of the research and subsequently consents to participate (Dooley & McCarthy, 2005). Respect for persons and autonomy in this study was addressed in the participant information leaflet and consent form by informing participants about the study aim and procedures in a clear, unambiguous manner (Appendix 5 and 6). Participant packs provided comprehensive information on the particulars of the study, including the procedures, the risks and benefits, the right to withdraw, the right to decline to answer any question and the contact details of the researcher in the event of participants wishing to discuss the study in more detail. Participants were encouraged to take their time to consider their involvement and to ask any questions. Those indicating a wish to take part in the study were asked to read and sign a consent form, indicating their consent to participate in the study. Participants who opted for a follow-up interview were advised of the voluntary nature of the study and provided with a participant pack, which provided details about follow-up interviews. To safeguard participants from coercion during interview recruitment, an additional measure was applied, i.e. any participant who deferred their interview more than twice was omitted.

### 3.8.3 Beneficence and Non-Maleficence

In accordance with the Belmont Report (Beauchamp, 1990; Ryan, 1979), the principle of beneficence requires that researchers align their work in such a way as to benefit others while promoting participants' welfare and safety. The principle of beneficence encompasses non-maleficence, which emphasises the responsibility of researchers to protect participants from harm (Barrow et al., 2022). The principle of beneficence outlined in the Belmont report includes two specific criteria:

1. Participants' right to freedom from harm and discomfort (Ryan, 1979).
2. Participants' right to protection from exploitation (Johansen et al., 2008; Ryan, 1979).

This study recruited participants who may be considered vulnerable due to their life-limiting diagnosis (Jacobson, 2005). To minimise the risk of harm, particularly exploitation or coercion, gatekeepers were used as a point of contact before study participation (Chapter 4, Section 4.6.2.1). The informed consent process, which included a detailed participant information leaflet (PIL) and consent form, reinforced the principles of justice. Participants who declined to participate were treated fairly, a sentiment aligned with the principle of justice (Cassell, 2000).

Participant packs included information on participants' rights, procedures, risks, benefits, and their right to withdraw from taking part at any time. The following sentence was included in the participant information leaflet (PIL): *"Your participation is entirely voluntary. If you initially decide to take part, you can subsequently change your mind without difficulty. This will not affect your future treatment in any way"* (p.1). The well-being of participants was prioritised throughout. Information on available support was provided, including support groups facilitated by the Irish Lung Fibrosis Association (ILFA), mental health support lines such as 'AWARE' and the contact details of the consultant-led hospital team (Polit, 2010). A distress protocol (Qualitative Research Distress Protocol) was developed to guide the researcher and to provide steps to be taken in the event of participants becoming distressed (Appendix 7) (Whitney et al., 2022).

### 3.8.4 Justice

Justice is the ethical obligation of researchers to treat research participants with fairness and equality (Tappen, 2022). The Belmont Report outlines the right to justice, emphasising the researcher's responsibility to consider the distribution of both the benefits and the burden of research (Ryan, 1979). Provision was made for protecting participants' privacy and ensuring fair treatment by providing study information in a timely manner. This study was guided by the research question, with efforts made to include a representative sample of the target population, aligned with the principle of justice. Multiple methods were utilised to maximise participation in this study, including the use of online, in-person and postal communication methods. Participants were given time to ask questions and to obtain the researcher's contact details (phone and email) during their routine outpatient clinic visit.

Confidentiality was maintained through rigorous standards of data protection and security of study records, aligned with national legislative measures including GDPR. Audit data collected in phase one (healthcare Organisation Audit) did not include any identifying details, with each returned audit assigned a unique identification code to link the audit with the healthcare site for analysis purposes. Next, phase two survey data were assigned unique identification codes, allowing the researcher to link participants' contact details with surveys to facilitate the process of maximum variation sampling in phase three (qualitative interviews) (Chapter 4, Section 4.5.4). Hard copy survey and consent forms were stored securely in a locked cabinet in a storage facility when not in use. The researcher, who had previously completed training on data protection, was the only person who had access to the study data. All hard copy personal details (phase one and phase two), SPSS data, audio recordings (phase three) and consent forms were subsequently scanned onto a secure, encrypted database and held on a university server on an encrypted laptop. Files were held individually to prevent any unauthorised linkage of data.

Additionally, interviews were recorded on a digital recorder on the researcher's laptop and transcribed by the researcher with unique identification codes applied to each transcript. The participants' confidentiality and anonymity were maintained by removing any identifiable information, such as names and hospital details, from source data. The audio recordings were destroyed once the interview transcripts had been checked and verified by the researcher and the analysis had been completed. The data related to this study will be stored for five years, which is aligned with the Faculty of Health Sciences, Trinity College Dublin guidelines.

### **3.9 Conclusion**

This chapter has explored the philosophical and methodological considerations that underpin this current study. Pragmatism was selected as the philosophical underpinning to address the research aim and objectives. The mixed-methods sequential explanatory design facilitated the collection of both quantitative and qualitative information, comprising three study phases. This mixed methods study design provided a robust framework to answer the research objectives. The epistemological, ontological and axiological assumptions connected to this body of work have been articulated (Section 3.2). This inquiry follows a pluralistic methodology which aligns with the study's philosophical position of pragmatism, thereby emphasising a '*what works*' approach (Section 3.2.1). Additionally, Levesque's healthcare access framework (2013) is outlined, providing a theoretical foundation from which to examine the research question and guide multiple aspects of the study, including the scoping review, the selection of survey instruments, the development of the interview guide, and the interpretation and analysis of the data (Section 3.6). Ethical considerations relevant to this study were discussed in Section 3.8, followed by the conclusion of Chapter 3.

## Chapter 4 Methods

### 4.1 Introduction

This chapter presents the research design and methods used to address the research question. Section 4.2 describes the study aim and objectives. Section 4.3 introduces the sequential explanatory design employed to explore the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF and receiving follow-up care in a tertiary hospital setting in Ireland. The study setting is described in Section 4.4, followed by the study population and sampling procedures in Section 4.5. A description of the recruitment strategy is provided in Section 4.6. An explanation of data collection procedures applied in the quantitative phase (phase one & phase two) and in the qualitative phase (phase three) is provided in Section 4.7. Reflexivity is addressed in Section 4.7.3.6, while data management and analysis is described in Sections 4.8. A detailed overview of integration opportunities is provided in Section 4.9. Finally, Section 4.10 provides a chapter summary.

### 4.2 Study Aims and Objectives

This study aims to investigate the unmet needs, symptom experiences, and quality of life among individuals with IPF who are receiving treatment in a tertiary care hospital in Ireland.

#### Study Objectives:

- To identify the unmet needs of people diagnosed with IPF (QUANT and QUAL).
- To explore the symptom experience and quality of life of people diagnosed with IPF (QUANT & QUAL).
- To evaluate what factors, influence the quality of life of people diagnosed with IPF (QUANT & QUAL).
- To inform the continuing development of healthcare access for people diagnosed with IPF in Ireland (Integration of QUANT & QUAL).

### 4.3 Study Design

A mixed-method sequential explanatory research design was used to comprehensively investigate the research phenomenon and address the research objectives (Creswell & Plano Clark, 2018; Hafsa, 2019). This study employed three phases to address the research objectives. The application of a sequential explanatory design in this study began with phase one, which used a quantitative audit method to assess the unmet needs of people diagnosed with IPF from the perspective of healthcare professionals representing the five hospital recruitment sites. Quantitative survey methods were utilised in phase two to assess the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF. Finally, qualitative semi-structured interviews (phase three) provided a rich in-depth contextual insight

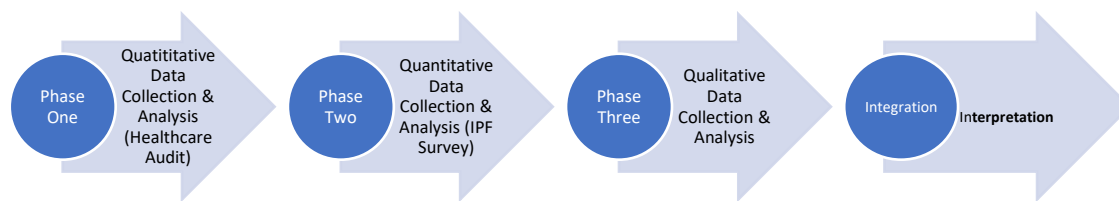
into participants' perception of their unmet needs, symptom experiences, and quality of life, facilitating a deeper understanding of the earlier quantitative findings. The employment of mixed methods allowed for the combination of diverse methods and their underlying philosophical assumptions to advance, "a more rounded, more complete understanding of the phenomenon of interest being studied than would otherwise occur" (Bazeley, 2017, p. 2). The following table (Table 4.1) outlines the research objectives and how they are addressed in this mixed methods sequential explanatory study through both quantitative (audit and survey) and qualitative (interview) study phases.

**Table 4.1 Study Methods Applied to the Integrated Study Objectives**

|                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                           |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Objective 1: To identify the unmet needs of people diagnosed with IPF (Addressed in phases 1,2, and 3).</b>                                                                                                                                                                    |                                                                                                                                                                                                                           |
| <b>Phase One Health Care Organisation Audit</b>                                                                                                                                                                                                                                   |                                                                                                                                                                                                                           |
| <b>Quantitative Phase</b>                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                           |
| Descriptive data collected to comprehensively understand the unmet needs and healthcare access of individuals diagnosed with IPF in a nationally representative sample of healthcare organisations.                                                                               |                                                                                                                                                                                                                           |
| <b>Phase Two IPF Survey</b>                                                                                                                                                                                                                                                       | <b>Phase Three Semi-Structured Interviews</b>                                                                                                                                                                             |
| <b>Quantitative Phase</b>                                                                                                                                                                                                                                                         | <b>Qualitative Phase</b>                                                                                                                                                                                                  |
| What are the most frequently reported unmet needs identified by individuals with IPF?<br><b>Instrument</b> : Lung Information Need Questionnaire (LINQ) and sociodemographic questions.<br><b>Analysis:</b> Descriptive & inferential statistics followed by regression analysis. | What are the most frequently reported unmet needs identified by individuals with IPF?<br><b>Data collection:</b> Semi-structured interviews.<br><b>Analysis:</b> Reflexive thematic analysis.                             |
| <b>Objective 2: To explore the symptom burden and quality of life of individuals diagnosed with IPF (Addressed in phases 2 and 3).</b>                                                                                                                                            |                                                                                                                                                                                                                           |
| <b>Phase Two IPF Survey</b>                                                                                                                                                                                                                                                       | <b>Phase Three Semi-Structured Interviews</b>                                                                                                                                                                             |
| <b>Quantitative Phase</b>                                                                                                                                                                                                                                                         | <b>Qualitative Phase</b>                                                                                                                                                                                                  |
| What are the most frequently reported symptoms and impacts on quality of life identified by individuals with IPF.<br><b>Instrument:</b> SGRQ-I & IPF-PROM<br><b>Analysis:</b> Descriptive & inferential statistics followed by regression analysis.                               | What are the most frequently reported symptoms and impacts on quality of life identified by individuals with IPF.<br><b>Data collection:</b> Semi-structured interviews.<br><b>Analysis:</b> Reflexive thematic analysis. |
| <b>Objective 3: To evaluate what factors, influence the quality of life of individuals diagnosed with IPF (Addressed in Phases 2 and 3).</b>                                                                                                                                      |                                                                                                                                                                                                                           |
| <b>Phase Two IPF Survey</b>                                                                                                                                                                                                                                                       | <b>Phase Three Semi-Structured Interviews</b>                                                                                                                                                                             |
| <b>Quantitative Phase</b>                                                                                                                                                                                                                                                         | <b>Qualitative Phase</b>                                                                                                                                                                                                  |
| What variables demonstrate a statistically significant impact on the quality of life of individuals diagnosed with IPF?<br><b>Analysis:</b> Descriptive, correlational and inferential statistical analysis followed by regression analysis.                                      | What factors impact the quality of life of individuals diagnosed with IPF?<br><b>Data collection:</b> Semi-structured interviews.<br><b>Analysis:</b> Reflexive thematic analysis.                                        |
| <b>Objective 4: To inform future healthcare priorities for people diagnosed with IPF to address their unmet needs (Addressed in Phases 1, 2, and 3).</b>                                                                                                                          |                                                                                                                                                                                                                           |
| <b>Quantitative Phase One and Two</b>                                                                                                                                                                                                                                             | <b>Qualitative Phase Three</b>                                                                                                                                                                                            |
| What findings from phases one and two inform future priorities nationally to address patients' unmet needs?<br>Mixing of both quantitative and qualitative findings.<br><b>Analysis:</b> Integration and meta-inferences illustrated in a joint display (Chapter 7).              | What qualitative findings inform future priorities for healthcare access?<br><b>Analysis:</b> Integration and meta-inferences illustrated in a joint display (Chapter 7).                                                 |

Survey data collection was completed in January 2024, followed by qualitative interview data collection (phase three) in April 2024. The research design was enhanced by the intentional integration of both qualitative and quantitative data occurring at several points during data collection, analysis and interpretation (Section 4.9). This mixed methods approach facilitated new insights, which would not have been possible using a single method alone (Moseholm & Fетters, 2017). This section provides an overview of the study methods applied to both study phases and outlines the integrated research objectives that are addressed in each phase (Figure 4.1).

**Figure 4.1 Mixed Methods Explanatory Sequential Design**



#### **4.3.1.1 Phase One-Healthcare Organisation Audit**

Phase one (Healthcare Organisation Audit) employed a cross-sectional audit of resources and services, as identified by healthcare professionals providing care to people with IPF across the five tertiary hospital sites included in this study (Section 4.4.1). Clinical audit is described as a “quality improvement process that aims to improve patient care and outcomes, by reviewing care against explicit standards and acting to improve care when standards are not met” (Health Service Executive, 2025, p. 6). Current standards for the management of individuals with IPF are outlined in the Irish Thoracic Society IPF Position Statement (2018) and were used as a framework to guide phase one audit data collection, analysis and interpretation and discussed further in Chapter 6.

#### **4.3.1.2 Phase Two-IPF Survey**

Phase two (IPF Survey) employed a descriptive cross-sectional survey design. A cross-sectional study is an observational process in which exposure and outcome are determined simultaneously for each subject, akin to taking a ‘*snapshot*’ of a group of individuals (Carlson & Morrison, 2009). Advantages include its efficient design, which is suited to comprehensively understanding the prevalence of the variable of interest and highlighting any factors that may be associated with such outcomes (Carlson & Morrison, 2009; Wang et al., 2020). This approach was chosen because it effectively estimates the prevalence of unmet needs and symptoms for individuals with IPF and supports the identification of any independent factors which may influence participants’ quality of life.

#### **4.3.1.3 Phase Three-Interviews**

Phase three utilised a qualitative descriptive design to gain a rich, in-depth insight of the experiences of individuals with IPF, focusing on their unmet needs, symptom experiences, and quality of life (Sandelowski, 2010). This study aimed to prioritise the participants’ voice, unique perspectives and lived experiences,



thereby contributing to a better understanding of the phenomenon of interest. Information gathered in the quantitative stage (phase one and phase two) was used to inform the development of the qualitative interview guide (phase three), which complemented PPI contributions and purposeful sampling procedures (Creswell & Plano Clark, 2018). Open-ended questions and intermediate probing questions were employed to elicit a rich depth of information from participants, facilitated by semi-structured interviews. The use of semi-structured interviews provided a scaffolding for consistent questions and the incorporation of the participants' own words and preferred language, using direct verbatim quotations, which honoured the approach to rhetoric in this study (Chapter 6) (Patton, 2002).

## 4.4 Study Setting

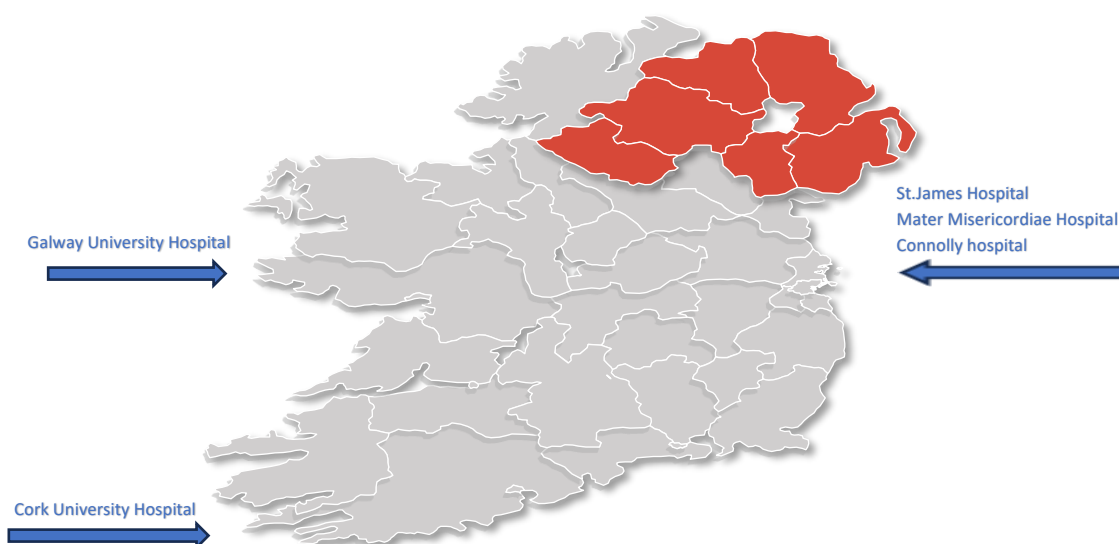
### 4.4.1 Study Setting (Phase One & Phase Two)

This national research study was conducted across five hospital sites (phase one and phase two) with a specific focus on respiratory outpatient departments, complemented by a targeted recruitment strategy that leveraged patient support groups and online outreach. The selected sites included Cork University Hospital, St. James's Hospital, Connolly Hospital, Blanchardstown, Mater Misericordiae Hospital, Dublin, and Galway University Hospital. These hospitals are all considered centres of excellence with dedicated clinics and services for patients with IPF, spanning multiple HSE regions; these sites ensured a broad national representation of patients with IPF (Figure 4.2).

### 4.4.2 Study Setting (Phase Three)

The setting for qualitative interviews was the same five hospital sites used in phase one and phase two (Section 4.4.1). Qualitative interviews took place in a dedicated space (patient consultation room) at each of the five hospital respiratory outpatient departments.

**Figure 4.2 Healthcare Organisation Sites**



The five hospital sites were selected for their high patient volume, optimising participant recruitment and ensuring geographical diversity across both urban and rural settings (Table 4.2). Nationwide patient support groups supported by the Irish Lung Fibrosis Association also aided recruitment in phase two (IPF Survey).

**Table 4.2 Characteristics of Hospital Recruitment Sites**

| Site       | Hospital type   | Services                                            | Model of Care                                            |
|------------|-----------------|-----------------------------------------------------|----------------------------------------------------------|
| Hospital 1 | Public hospital | Diagnosis, pulmonary function testing, & follow-up. | Consultant-led follow-up, combined with nursing support. |
| Hospital 2 | Public hospital | Diagnosis, pulmonary function testing, & follow-up. | Consultant-led follow-up, combined with nursing support. |
| Hospital 3 | Public hospital | Diagnosis, pulmonary function testing, & follow-up. | Consultant-led follow-up, combined with nursing support. |
| Hospital 4 | Public hospital | Diagnosis, pulmonary function testing, & follow-up. | Consultant-led follow-up, combined with nursing support. |
| Hospital 5 | Public hospital | Diagnosis, pulmonary function testing, & follow-up. | Consultant-led follow-up, combined with nursing support. |

## 4.5 Study Population and Sample

### 4.5.1 Population (Phase One)

The target population in phase one (Healthcare Organisation Audit) included respiratory consultants, specialist respiratory registrars, advanced nurse practitioners or respiratory nurse specialists. These healthcare professionals were selected to provide essential insights into outpatient care, addressing gaps in available supports and services. Unlike other conditions, IPF lacks a national clinical programme or national patient registry, further limiting knowledge of this population (Bramhill et al., 2024). All eligible respiratory clinical leads at the five hospital recruitment sites were invited to complete the audit.

### 4.5.2 Population (Phase Two)

The unmet needs of people with IPF remain under-researched, particularly in an Irish context, despite the rising global incidence of IPF (Maher et al., 2021). Incidence rates have surged from 73 per 100,000 persons in 2010 to 210 cases per 100,000 persons in 2019 (Kaul et al., 2022). This study aims to address gaps in the literature by examining the unmet needs, symptom experiences, and quality of life of individuals with IPF receiving care in the Irish healthcare system. Previous European studies have either lacked sufficient representation of Irish patients (Moor et al., 2019) or relied upon limited data collection methods, such as focus groups (Cassidy et al., 2024) or online survey methods alone (Cassidy et al., 2022). To ensure a comprehensive understanding of the phenomenon of interest, participants in phase two were adults aged >18 years, diagnosed with IPF, who were at least 3 months post-diagnosis, and were receiving care in tertiary hospital settings in Ireland. Participants were selected at different stages of the disease trajectory (time since diagnosis) to capture a range of healthcare needs and dependencies.

#### **4.5.3 Sampling Strategy - Phase One & Phase Two**

##### ***4.5.3.1 Sampling Approach (Phase One)***

Phase one (Healthcare Organisation Audit) employed a purposive sampling strategy to collect information from healthcare professionals concerning healthcare access and unmet needs of individuals diagnosed with IPF. All eligible healthcare professionals (Medical and Nursing) working at the five recruitment sites were invited to participate in the phase one audit (Table 4.2). Equal opportunities to participate in this study were afforded to all eligible healthcare professionals in these settings. Convenience sampling in phase one was conducted at each of the five recruitment sites, and commenced in May 2022 and was completed in November 2023, to obtain a representative sample of participants nationally.

##### ***4.5.3.2 Sampling Approach (Phase Two)***

Phase two (IPF Survey) used a purposive sample of individuals diagnosed with IPF who were receiving care in tertiary hospitals nationally. Sampling for this study took place during the Covid-19 pandemic, during which Ireland experienced heightened restrictive public health measures, including mandatory face coverings, reduced hospital visiting and social distancing. These restrictions were introduced to limit the spread of COVID-19, and were first introduced in March 2020, before gradually easing periodically over the following three years (O'Reilly et al., 2023). Extensive efforts to include a comprehensive and representative sample of individuals diagnosed with IPF were employed in this study to ensure that all eligible participants were given equal opportunities to participate. Several sampling strategies were employed, which considered factors such as geographical location and participant preferences.

##### ***4.5.3.3 Sampling Criteria (Phase Two)***

The eligibility criteria for this study are clearly outlined in Table 4.3 for both phase one (Healthcare Organisation Audit) and phase two (IPF Survey). Phase three utilised a subset of participants from phase two and used the same inclusion and exclusion criteria.

**Table 4.3 Study Inclusion and Exclusion Criteria**

| <b>Healthcare Organisation Audit (Phase One)</b>                                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                              |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Inclusion Criteria</b>                                                                                                                                                                                                                                                                                                                                                  | <b>Exclusion Criteria</b>                                                                                                                                                                                                                                                    |
| <ul style="list-style-type: none"> <li>• Eligible healthcare staff, including clinical leads (Respiratory Consultant/specialist respiratory Registrar or registered respiratory Nurse Specialist or registered respiratory (Candidate) Advanced Nurse Practitioner.</li> <li>• Healthcare organisations must be providing care for patients diagnosed with IPF.</li> </ul> | <ul style="list-style-type: none"> <li>• Individuals who are not respiratory clinical leads.</li> <li>• Healthcare organisation sites which are not involved in the care of patients diagnosed with IPF.</li> </ul>                                                          |
| <b>IPF Survey (Phase Two)</b>                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                              |
| <b>Inclusion Criteria</b>                                                                                                                                                                                                                                                                                                                                                  | <b>Exclusion Criteria</b>                                                                                                                                                                                                                                                    |
| <ul style="list-style-type: none"> <li>• Diagnosis of IPF must follow the guidelines outlined by the *ATS/ERS/JRS/ALAT 2018.</li> <li>• An individual over 18 years of age.</li> <li>• An individual who has the capacity to give informed consent.</li> <li>• Men and women are targeted for recruitment equally.</li> </ul>                                              | <ul style="list-style-type: none"> <li>• Diagnosis of IPF did not follow the guidelines outlined by the *ATS/ERS/JRS/ALAT 2018.</li> <li>• An individual under 18 years of age.</li> <li>• An individual who does not have the capacity to give informed consent.</li> </ul> |

\*Key: ATS (American Thoracic Society), ERS (European Respiratory Society), JRS (Japanese Respiratory Society), ALAT (Latin American Thoracic Society)

#### **4.5.3.4 Sample Size (Phase Two)**

To obtain a nationally representative sample of individuals diagnosed with IPF, estimates (incidence and prevalence) from the Irish Thoracic Society IPF position statement were utilised. The Irish Thoracic Society (2018) estimates the incidence of IPF in Ireland to be in the region of 400 new cases diagnosed annually with an estimated prevalence of 1000 individuals living with IPF in Ireland (Table 4.4). Determining the sample size for this cross sectional study proved challenging due to the limited epidemiological information available at national level concerning IPF. The absence of a national IPF registry further complicates accurate incidence and prevalence estimates. Current estimates are widely believed to be underestimated, with actual cases likely to be higher, given the rising global incidence of IPF (ITS, 2018; Maher et al., 2021). This study estimated that a sample of 211 participants diagnosed with IPF was required (Table 4.5).

**Table 4.4 Prevalence Calculation Used for the Sample**

| Prevalence Calculation Used for the Sample (Daniel, 1999) |                                                                                                                                                                                                                                                               |
|-----------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| $n = \frac{Z^2 P(1-P)}{d^2}$                              | <p><math>n</math> = Sample size</p> <p><math>Z</math> = Zstatistic for a level of confidence (1.96 for a 95% confidence level)</p> <p><math>P</math> = Expected prevalence or proportion</p> <p><math>D</math> = Precision (corresponding to effect size)</p> |

A sample size calculation based on the estimated prevalence of IPF provided by the Irish Thoracic Society (2018a) was completed using Daniels' Formula (Daniel, 1999; ITS, 2018). A confidence interval of  $\pm 6\%$  and a confidence level of 95% requires a sample of  $N = 211$  (Table 4.5).

**Table 4.5 Sample Size Calculation**

| Confidence Interval Precision (Daniel, 1999) | Sample Required |
|----------------------------------------------|-----------------|
| $\pm 0.04$                                   | 376             |
| $\pm 0.05$                                   | 278             |
| $\pm 0.06$                                   | <b>211</b>      |
| $\pm 0.07$                                   | 164             |

#### **4.5.3.5 Maximising Survey Response Rate**

In addition to the in-person recruitment strategy at the five hospital recruitment sites, supplementary methods were used to maximise participant recruitment. An online campaign across Facebook, Twitter, and Instagram helped reach a broad audience. In addition, a targeted campaign at six national patient support groups for people with IPF was implemented at various intervals throughout the recruitment phase. This approach was further supported by phone calls to group leaders ( $N = 6$ ) to strengthen relationships and provide study information. Additionally, attendance at several support group meetings allowed the distribution of participant information packs, which contained a participant information leaflet outlining the aims and objectives of the study.

#### **4.5.4 Sampling Strategy (Phase Three)**

##### **4.5.4.1 Sampling Approach**

Phase three (qualitative interviews) employed an integrated, purposeful and strategic sampling approach with maximum variation stratification to ensure that selected participants captured a range of lived experiences. Phase two, quantitative data collection, aimed to compile information from a large cohort to obtain broad generalisable information, whereas qualitative methods (phase three) prioritised contextually rich data (Palinkas et al., 2015). Meaningful integration of both quantitative and qualitative

data reinforced the sequential explanatory mixed method design. This strategic approach maximised opportunities for the collection of diverse perspectives and generation of rich data (Braun & Clark, 2021; Onwuegbuzie & Collins, 2017). Maximum variation sampling was employed to ensure the intentional and integrated selection of a diverse participant sample, thereby enhancing our understanding of the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF (Figure 4.3) (Patton, 2002; Sandelowski, 2010). The variables guiding maximum variation sampling, which aimed to achieve maximum variation, included age, gender, time since diagnosis, antifibrotic medication use, oxygen use, insurance status, residence and living arrangements (Table 4.6). Utilising this approach enhanced our understanding of the barriers, facilitators and strategies for improving healthcare access to address patients' unmet needs. Survey participants from phase two (IPF survey) could opt in to a follow-up interview (phase three) by providing their contact details when completing the IPF survey (phase two) and indicating their consent to be contacted for an interview in phase three. Information about follow-up interviews was included in participant packs or online via Qualtrics. Integrating maximum variation sampling enhanced the diversity of the sample in phase three and facilitated the identification of shared patterns and themes to enhance the overall coherence of the study and enriched the study findings.

**Figure 4.3 Integrated Sampling Strategy**



**Table 4.6 Maximum Variation Sampling Stratification**

| Variable                 | Variations                                         |
|--------------------------|----------------------------------------------------|
| Age group                | 50-60 years, 60-70 years, 70-80 years, 80-90 years |
| Gender                   | Female or Male                                     |
| Time since diagnosis     | Less than 1 year, 2-3 years, 4-5 years, >5 years   |
| Anti-fibrotic medication | Yes or no                                          |
| Oxygen use               | Yes or no                                          |
| Insurance status         | Private health insurance and/or medical card       |
| Residence                | Urban/Rural                                        |
| Living arrangements      | Living alone or living with others                 |

#### **4.5.4.2 Sampling Criteria**

Phase three participants were selected based on the variables identified for use in the maximum variation sampling approach to ensure relevance and to build opportunities for further exploration and expansion of phase two data (Table 4.6). Inclusion and exclusion criteria were aligned with previously determined eligibility criteria described in phase two (IPF Survey) (Table 4.3). In addition, participants had to have completed the IPF survey to be considered for phase three qualitative interviews

#### **4.5.4.3 Sample Size and Data Saturation**

A total of 230 participants in phase two agreed to be considered for a follow-up interview in phase three, representing 97% of the total quantitative sample. Interviews were scaffolded by maximum variation stratification ensuring that participants were selected deliberately, based on their ability to provide in-depth information capturing their lived experience and offering diverse perspectives (Patton, 2002). The researcher assessed potential interviewees against the study's eligibility criteria and the variables identified for the study's maximum variation sampling approach to identify potential participants in phase three. Gatekeepers were utilised to support recruitment in phase three by providing information regarding deceased participants from phase two, to avoid inadvertently contacting them and causing distress to families. A subset of participants who participated in phase two (IPF Survey) were invited to provide their contact details if they wished to be considered for a follow up interview in phase three. Eligible participants were contacted by either phone or email depending on their preference. Potential participants were given further information about the study and an opportunity to have any questions they may have answered prior to arranging a follow up interview. A purposive sample of 20 participants were selected by maximum variation sampling stratification.

This study prioritised '*data saturation*', focusing on the quality, depth and relevance of data, ensuring that sufficient information was gathered, to replicate the study if required and when no new information was generated (Fusch & Ness, 2015; Braun & Calrk, 2013). The sample size for the qualitative phase was determined iteratively, guided by interpretation of data richness, depth, and alignment to the study's objectives (Braun & Clarke, 2021). In phase three, quality took precedence over quantity, ensuring there was sufficient depth to address the research question effectively (Fusch & Ness, 2015). Data collection ceased when twenty interviews were completed. Data saturation may be considered to be context

dependent (Rahimi, 2024), influenced by the researcher's interpretation of the data (Fusch & Ness, 2015; Rahimi, 2024) therefore requiring methodological rigour and transparency (Mason, 2010). Braun and Clarke (2021) assert that meaning is not merely derived from the data but is constructed through interpretation in reflexive thematic analysis. Acknowledging researcher bias and reflexivity through reflective journaling and discussion with supervisors, enhanced the credibility, methodological rigour, and transparency of the findings.

## **4.6 Recruitment Procedures**

### **4.6.1 Phase One**

Recruitment for phase one (healthcare professional audit) began with preliminary discussions with clinical leads via Microsoft Teams calls to outline the study aim and objectives and the proposed recruitment strategy for phase one. Recruitment took place across the five national respiratory outpatient clinics selected for inclusion in this study (Figure 4.2). Hard copies of the audit tool were distributed to potential participants in a research pack containing an information leaflet, consent form and pre-paid self-addressed envelope for return of completed audits. Gatekeepers at each site invited eligible healthcare professionals to take part and referred Interested individuals to the researcher (Section 4.6.2.1). These individuals were offered the opportunity to ask questions, seek clarification about the study and take time to consider their participation. Participants who chose to enrol were given two options for returning the completed audit to the researcher; either handing it directly to the researcher at the end of the outpatient clinic or posting it using the pre-paid envelope provided.

### **4.6.2 Phase Two**

Recruitment for phase two required substantial collaboration and project management skills to build trust and engagement among clinical teams. This phase also began with early discussions with clinical leads via Microsoft Teams calls. A pre-prepared presentation was delivered to healthcare professionals attending the online meeting outlining the study's aims and objectives, sampling and data collection procedures (September 2021-December 2021). Ongoing dialogue with clinical staff, subsequently supported the identification and confirmation of suitable recruitment sites. The five hospital sites selected are considered centres of excellence in respiratory care in Ireland. These sites reflect the typical hospital environments in which patients with IPF receive routine care and were chosen to ensure a mix of both urban and rural sites capturing diverse sociodemographic contexts. Recruitment sites were also selected based on their caseloads, prioritising hospitals with the highest number of patients diagnosed with IPF. Recruitment for this study was significantly influenced by the restrictions associated with the Covid-19 pandemic. These constraints necessitated the adoption of creative and flexible recruitment strategies, including the development of an online social media campaign to support participant engagement. Regular meetings with staff at each recruitment site facilitated the ethical approval process by enabling familiarity with the site specific procedures and processes for ethics committee submissions.



Following sustained collaboration with the clinical leads at the five selected sites, each respiratory team gave their permission to participate in this study, contingent on approval from respective research ethics committees. Ethical approval was subsequently granted at each of the five sites and TCD Faculty Research Ethics Committee prior to commencing recruitment (Appendix 4). Once approvals were obtained, clinical leads and study gatekeepers were contacted to support implementation of the recruitment plan. This included disseminating recruitment posters (Appendix 8) at each site and distributing participant information packs during respiratory outpatient clinics (Appendix 5). To maximise recruitment, a multi modal recruitment approach was adopted, combining in-person strategies with an online supplementary recruitment strategy via Qualtrics (accessible via a QR code). Employing a targeted recruitment strategy was essential to ensuring adequate representation within the sample and strengthening the potential for statistical generalisations of the study findings (Onwuegbuzie, 2007; Teddlie & Yu, 2007).

Phase two recruitment was undertaken at each of the five hospital sites, specifically within their respective respiratory outpatient clinics. Study information posters were displayed in the waiting room of all five outpatient clinics, displaying a QR code that enabled participants to access and complete the online survey if preferred. Hard copies of the survey were also made available in the participant pack along with an invitation letter, information leaflet, consent form and pre-paid self-addressed envelope for return of completed surveys. As in phase one, gatekeepers at each site introduced the study to eligible individuals with IPF. Those who expressed interest and wished to gain more information about the study, were directed to the researcher, who provided further information, answered questions and allowed sufficient time to consider participation. Participants were encouraged to read the information leaflet and to discuss with family members if they wished. Participants were given flexibility regarding how and when they completed the survey. Some participants chose to complete their survey during the outpatient clinic visit and to return the completed survey directly to the researcher. Others opted to take their participant pack home and to return the survey at a later date using the pre-paid envelope.

A pilot study for the phase two survey was conducted in June 2022 and included 7 participants from two of the selected sites. The purpose of conducting the pilot study was to assess the study processes and procedures, including evaluation of the survey instrument and the feasibility of implementing the proposed online survey for the main study. A detailed description of the pilot study is provided in Section 4.6.2.2. Data collected in the pilot study was not used in the main study, as the aim of the pilot study was to assess the procedures involved in the recruitment strategy. Consequently, pilot participants were excluded from the main study. Phase two recruitment commenced at the first hospital site in late July 2022, with all sites fully operationalised by August 2022. Recruitment continued until January 2024, encompassing an 18-month period of quantitative data collection across Ireland. Recruitment ceased once the sample size was reached.

#### **4.6.2.1 Gatekeepers**

This study employed gatekeepers at each of the five hospital recruitment sites to help with various aspects of the recruitment strategy and ensure ongoing communication with hospital personnel (McFadyen &

Rankin, 2016). The gatekeepers, including administrative, nursing and medical staff, all proved to be invaluable and supported the recruitment strategy in the following ways:

- Alerting the researcher to the days and times that outpatient clinics were running.
- Supporting the researcher with administration tasks, including postal surveys.
- Informing patients about the study by placing study posters in prominent clinic areas.

#### **4.6.2.2 Pilot Study Phase Two**

The reliability of the current study was enhanced by piloting the survey instrument and conducting extensive data cleaning prior to analysis (Curry, 2014). A pilot study was conducted to establish the validity of the survey instrument used in phase two (IPF Survey) after feedback from PPI contributors. The pilot study aimed to evaluate a range of study procedures and processes, including the recruitment strategy, and assessment of study materials such as clarity of the invitation letter, the participant information sheet and consent form. The pilot study took place over four weeks in late June 2022, with seven participants included. The pilot study was designed to replicate the recruitment conditions anticipated for phase two of the research. The pilot study tested various data collection methods (paper-based or online). Three participants opted to complete the pilot survey online using Qualtrics (accessible via a QR code). Feedback from the pilot study included a concern that was raised about the accessibility of the QR code, as some participants were unfamiliar with using QR codes. In response to this feedback, clear instructions and training on QR code use was provided at the Annual Irish Lung Fibrosis Association (ILFA) patient information day and highlighted in an ILFA newsletter (ILFA, 2022). Additionally, a technical issue with a drop-down option in the online survey was identified, which allowed participants to proceed without answering; once highlighted, this was corrected.

#### **4.6.3 Phase Three**

This mixed methods sequential explanatory design study enabled survey participants from phase two who expressed an interest in further involvement to be invited to participate in a semi-structured interview, using a stratified maximum variation sampling approach. Survey participants (phase two) from each of the five recruitment sites received information about the semi-structured interview component at the time of completing the phase two IPF Survey. The phase two information leaflet and consent form included a dedicated section for participants to indicate whether they wished to opt in to a follow-up semi-structured interview. Those who consented to be contacted were asked to leave their contact details, including their name and phone number or email address. Participants were informed that expressing interest did not guarantee an interview invitation, as recruitment would conclude once sampling targets had been reached. The researcher's phone number was given to all participants to allow them to ask any questions about the study or information that they had received.

A total of 230 participants selected to be contacted for a follow-up interview. Utilising a stratified maximum variation sampling strategy (Section 4.5.4) a subset of survey participants who had completed a survey in phase two were sequentially invited to participate in a qualitative semi-structured interview between February 2024 and April 2024. A total of 20 participants were purposively selected from phase two. They were contacted by phone and provided with information about the study along with having any of their questions answered. Interested participants were scheduled for a semi-structured interview at that point and selected a time and date that was convenient for them. Ten interviews were conducted in-person at each of the five outpatient respiratory clinics and a further ten were completed online, depending on an individual's preference. On the day of the interview, participants were given more information about the study, along with having any of their questions answered.

## **4.7 Data Collection**

### **4.7.1 Phase One Quantitative Data Collection**

Data in phase one was collected anonymously via an anonymised audit tool using paper and pen format and commenced in May 2022. Participant information packs were dispensed by gatekeepers at each of the five hospital recruitment sites; the packs comprised a letter of invitation, participant information sheet, consent form, and the audit tool. Comprehensive and clear instructions accompanied the participant packs to facilitate completion of the audit, along with the researcher's phone number in the event of requiring assistance or need for further information. Completed audits could either be returned in person at respiratory outpatient clinics or via a postal route, with each pack containing a freepost envelope. Some participants chose to complete their audit on the day of the respiratory clinic while others chose a postal return method for completed audits. Due to the quantitative strategy employed to collect data in this study it is not possible to establish how many participant packs were distributed by gatekeepers or how many healthcare professionals were approached and given information about the study. Furthermore, it is not possible to determine the non-response rate of participants in phase one.

#### **4.7.1.1 Audit Development**

The audit tool used in phase one, benefited from the inclusion of questions initially developed for the EU-PFF survey (Moor et al., 2019) and aligned with the standards of care for patients with IPF highlighted in the Irish Thoracic Society IPF Position Statement (Appendix 9) (ITSa, 2018; Moor et al., 2019). Permission was secured from the European Pulmonary Fibrosis Federation (EU-PFF) to use an amended version of a previously utilised survey 'EU-PFF Survey' (Appendix 10), which had been developed through expert collaboration with healthcare professionals and patient/support group representatives (Moor et al., 2019). Information in the EU-PFF survey related to respiratory/IPF clinics; time allocated for patients during outpatient clinic visits, access to pharmacological treatment, access to clinical trials, access to non-pharmacological treatments such as pulmonary rehabilitation and palliative care, psychological support, and referral for lung transplantation assessment.

#### **4.7.2 Phase Two Quantitative Data Collection**

Quantitative data in phase two was collected via a self-administered survey (Appendix 11) using either paper and pen format or through an online survey using the digital platform 'Qualtrics' (accessible via a QR code). Considering factors such as the older age profile of potential participants and widespread geographical location, it was deemed appropriate to select paper, postal and electronic survey completion options, aligned with participant preferences for the IPF Survey. Gatekeepers informed potential participants about the study and interested individuals were directed to the researcher who dispensed the participant packs at each of the five recruitment sites. For the paper (and postal return) options, participant packs contained a letter of invitation, participant information sheet, consent form and survey. All packs included a pre-paid envelope, giving the option to return the survey by post if required. Clear instructions on survey completion were dispensed to participants, along with the researcher's phone number in the event of any difficulties; this information was also available to those accessing the survey online. For the online options (electronic survey via Qualtrics), a QR code for accessing the online survey was displayed on a poster available to view in the hospital respiratory outpatient departments and online via social media, linking participants to the participant pack information (letter of invitation, participant information sheet, consent form and survey). Extensive efforts to maintain the anonymity and confidentiality of participants aligned with the Health Research Regulations, (2018). The study made significant efforts to maintain the confidentiality of participants and did not store an 'internet protocol' (IP) tracking address for those who completed their survey online using the digital platform 'Qualtrics'.

##### **4.7.2.1 Phase Two Survey Development**

An extensive review of the literature was completed to identify available survey instruments to be employed in phase two (IPF Survey), supported by an extensive content analysis. The literature search was guided by Levesque's healthcare access framework (2013) and sought to examine available instruments which addressed the key concepts in this study, namely '*unmet needs*', '*symptom experience*' and '*quality of life*', and this yielded several instruments. Selecting the most suitable and applicable instruments for this study was critical to capture the concepts of interest and to strengthen the findings (Mokkink et al., 2016). Disease-specific instruments have emerged in abundance in some health areas but remain limited in IPF, particularly instruments which address unmet needs. Currently, limited guidance and ongoing ambiguity remains, concerning the selection of the most appropriate measurement tools to assess unmet needs, symptom experiences, and quality of life, thereby hampering the identification of suitable instruments. Further ambiguity exists regarding what constitutes a '*healthcare need*' in the population of interest, with conceptual uncertainty surrounding '*unmet needs*'. To overcome this uncertainty, the Irish Lung Fibrosis Association (ILFA) IPF Patient Charter (2015) was used as a roadmap for key terms and areas of interest regarding patients' unmet needs.

The Consensus-based Standards for selecting health measurement instruments (COSMIN) methodology (De Vet et al., 2011) is widely used in studies that focus on health-related patient-reported outcomes and guided the instrument selection in the literature review. The three survey instruments selected for this

study included the St. George Respiratory Questionnaire-IPF (SGRQ-I) (Yorke et al., 2010), the IPF-Patient Reported Outcome Measure (IPF-PROM) (Russell et al., 2018) and finally the Lung Information Needs Questionnaire (LINQ) (Hyland et al., 2006). Permission to use the three selected survey instruments and a modified version of the EU-PFF European PF patient survey was granted by the relevant authors (Moor et al., 2019) (Appendix 10). Criteria for instrument selection are listed below:

- ✓ Disease-specific - designed for use in the population of interest in this study (people diagnosed with IPF).
- ✓ Ability to be used as a self-report measure.
- ✓ Must be easy to understand, clear, and concise and completed in a short timeframe.
- ✓ Be reliable and valid.

#### **4.7.2.2 The St. George Respiratory Questionnaire IPF (SGRQ-I)**

The original St. George Respiratory Questionnaire (SGRQ) was designed and validated for use in patients with chronic obstructive pulmonary disease (COPD) and has been in existence for nearly three decades (Jones et al., 1991). Jones and colleagues revised the original SGRQ to develop an IPF-specific version, the St. George Respiratory Questionnaire IPF (SGRQ-I) (King et al., 2008; Yorke et al., 2010). The 34-item SGRQ-I assesses quality of life over a three-month recall period across three subscales: symptoms (6 items), activity (10 items) and impacts (18 items) (Yorke et al., 2010). Likert scales are used to capture responses, which are designed to facilitate participants to select their own unique response within a scale (Likert, 1932). Scores range from 0 to 2718.3 on the SGRQ-I, with higher scores indicating more impaired HRQoL (Prior et al., 2019).

Internal reliability (Cronbach alpha ( $\alpha$ )) for each SGRQ-I component (Symptoms 0.62; Activities 0.80; Impacts 0.85) in this study was comparable to the original SGRQ (Yorke et al., 2010). Furthermore, intraclass correlation coefficients (ICC) achieved in this study (Symptoms 0.72; Activities 0.84; Impacts 0.80) were similar to those found in Prior and colleagues' study (2019). The SGRQ-I has been translated into several languages, including Spanish, demonstrating adequate internal consistency, reliability, and validity (Capparelli et al., 2018). Further validation testing was completed by Prior et al. (2019), who aimed to translate the SGRQ-I into Danish for patients with IPF. Their study concluded that the internal consistency of SGRQ-I was high (Cronbach's  $\alpha = 0.92$ ) and had good test-retest reliability with high ICC values  $>0.78$  and a Bland-Altman plot when comparing answers at baseline and after two weeks (Prior et al., 2019) (Table 4.7).

**Table 4.7 Internal Consistency of SGRQ-I**

| SGRQ-I (Prior et al., 2019) | Cronbach's $\alpha$ | ICC  |
|-----------------------------|---------------------|------|
| Total SGRQ-I Score          | 0.92                | 0.97 |
| Subscale 1 Symptoms         | 0.77                | 0.78 |
| Subscale 2 Activities       | 0.86                | 0.94 |
| Subscale 3 Impacts          | 0.84                | 0.96 |

#### 4.7.2.3 IPF-Patient Reported Outcome Measure (IPF-PROM)

The IPF-PROM (Russell et al., 2018) is a 12-item questionnaire designed to measure the health status of people diagnosed with IPF and contains four subscales: physical experience of breathlessness (3 items), psychological experiences of breathlessness (3 items), emotional well-being (3 items), and energy levels (3 items). The IPF-PROM generates information to evaluate health status over a two-week recall period, using a Likert scale (Likert, 1932). Higher scores represent lower health status, and vice versa. The scores range from 12 to 48, where 48 represents a poorer health status. Eighty-five patients with IPF participated in the 12-month IPF-PROM validation study, using a mixed methods approach (Russell et al., 2018). The IPF-PROM has also demonstrated high test-retest reliability, as indicated by the intraclass correlation coefficient ( $>0.80$ ) (Russell et al., 2018) (Table 4.8). The IPF-PROM achieved a very high Cronbach's alpha ( $\alpha$ ) score of 0.92 and demonstrated good face and content validity in the original validation study (Russell et al., 2018). In this study, the overall Cronbach's  $\alpha$  for the IPF-PROM score was of 0.85. The subscales demonstrated the following Cronbach's  $\alpha$  values: physical experience of breathlessness (0.87), psychological experiences of breathlessness (0.81), emotional well-being (0.86), and energy levels (0.92). Although the IPF-PROM is a relatively new outcome measure, it has demonstrated good reliability and validity and has been successfully utilised in several studies (Davis et al., 2021; Tziraki et al., 2024). The IPF-PROM was specifically chosen for this study to provide a score for the item 'energy', given that low energy/fatigue was highlighted as an area of 'need' and an under-researched symptom in the initial literature review, and a concept that was not explicitly included in the SGRQ-I (Bloem et al., 2020).

**Table 4.8 Internal Consistency of IPF-PROM**

| IPF-PROM (Russell et al., 2018)                         | Cronbach's $\alpha$ | ICC     |
|---------------------------------------------------------|---------------------|---------|
| Total IPF-PROM Score                                    | 0.92                | $>0.80$ |
| Subscale 1 (Psychological experience of breathlessness) | 0.87                | 0.83    |
| Subscale 2 (Physical experience of breathlessness)      | 0.87                | 0.89    |
| Subscale 3 (Emotional well-being)                       | 0.90                | 0.81    |
| Subscale 4 (Energy)                                     | 0.84                | 0.86    |

#### 4.7.2.4 Lung Information Needs Questionnaire (LINQ)

The Lung Information Needs Questionnaire (LINQ) (Hyland et al., 2006) is designed to assess the current need for information from a patient's perspective. The LINQ is a self-complete questionnaire with multiple-choice or binary-style questions. The LINQ contains 16 questions with six subscales: disease knowledge (4

items), medication (3 items), self-management (2 items), exercise (3 items), smoking (3 items), and diet (1 item). Scores range from 0 to 25 (sum of all items), with higher scores indicating a need for greater information. The total LINQ score provides an overview of the patient's information needs, and the individual subscale scores, identify specific information needs (Wakabayashi et al., 2011).

The LINQ demonstrated an internal consistency of Cronbach's  $\alpha = 0.62$  (Hyland et al., 2006). This study achieved a similar Cronbach's  $\alpha = 0.60$ . The LINQ performed well in test-retest reliability for the six subscales, with seventy patients included in the original analysis (Table 4.9). Intraclass correlation coefficients varied between .066 and 0.98. The LINQ authors achieved an intraclass correlation calculated for the total score of 0.89, and for each of the six subscales: disease knowledge = 0.77, medicines = 0.72, self-management = 0.66, smoking = 0.98, exercise = 0.78 and diet = 0.75 (Hyland et al., 2006). Further studies, which utilised the LINQ, have confirmed that it is a practical tool for detecting areas where patients' need education and is sensitive to change after pulmonary rehabilitation (PR) (Jones et al., 2008). The LINQ has been translated into several languages, including Spanish and Italian (Sauro et al., 2008; Wilches Luna et al., 2014). Kim and colleagues translated the LINQ into Korean, verifying the LINQ's validity and reliability. Their study revealed good test-retest reliability (performed within 2 weeks) for the total LINQ score and subscale scores (Kim et al., 2022). Kim and colleagues reported that the overall K-LINQ score, as well as the disease knowledge, smoking and self-management subscales, demonstrated high internal consistency, with coefficients of 0.70 or higher (2022). The remaining subscales, medicine, exercise and diet, showed moderate reliability, with intraclass correlation (ICC) coefficients ranging 0.5–0.7 (Kim et al., 2022).

**Table 4.9 Internal Consistency of LINQ**

| LINQ (Hyland et al., 2006) | ICC | Cronbach's $\alpha$ |
|----------------------------|-----|---------------------|
| Total LINQ Score           | .89 | .62                 |
| Disease knowledge          | .77 |                     |
| Medication                 | .72 |                     |
| Self-Management            | .66 |                     |
| Smoking                    | .98 |                     |
| Exercise                   | .78 |                     |
| Diet                       | .75 |                     |

#### **4.7.2.5 Sociodemographic Information**

In this study, sociodemographic data were collected to capture participant characteristics, supporting inclusivity and ensuring diverse representation of the target population (Roberts & Mortenson, 2023). Over 89% of the sociodemographic information used in this study was adapted from a previous European-wide survey conducted by the EU-PFF (Moor et al., 2019) and included demographic variables such as sex, ethnicity, year of birth, and time since diagnosis (questions 1-4). Additional variables covered health insurance status, geographical location (urban/rural), and private/public hospitals (questions 5-8). The survey also assessed antifibrotic medication use, oxygen therapy use (questions 9-16), access to supports

and services, awareness of clinical trials, and employment status (17-20). There was a total of 20 items in the sociodemographic section in the final survey instrument which were loyal to the wording in the original survey developed by the EU-PFF (Moor et al., 2019).

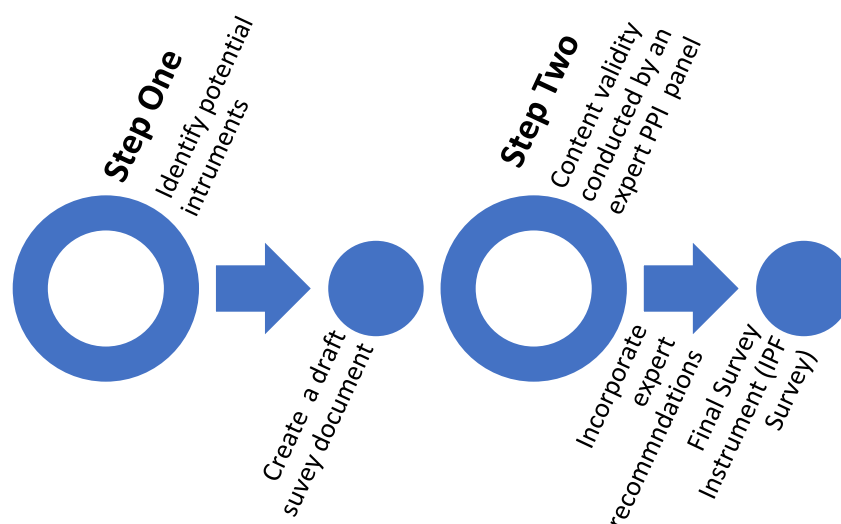
#### 4.7.2.6 Validity

Validity is a vital tool to enhance the quality of research. Several definitions of validity exist, with one defining validity as *“the extent to which a concept is accurately measured”* (Heale & Twycross, 2015, p. 1). Content validity is considered an essential step in verifying how well the survey instrument measures what it intended to measure (Elangovan & Sundaravel, 2021; Polit & Beck, 2006). To ensure the quality of the selected instruments in this study, employing a previously validated survey instrument supported the objective to address validity in the quantitative phase of this study. This also brought additional benefits, such as saving time and limited the need for increased resources (Elangovan & Sundaravel, 2021).

#### 4.7.2.7 Content Validity

Assessing content validity is an important step in the development of a survey instrument and concerns the degree to which selected items in an instrument reflect the phenomenon that is intended to be measured (Allen et al., 2023; Zamanzadeh et al., 2014). It requires a comprehensive process to generate information on both the representativeness, clarity, and relevance of items (Polit & Beck, 2006). Guiding principles to support the content validity process in this study included identification of content relevance, content clarity, and content representation (Figure 4.4) (Lynn, 1986). This study adhered to an adapted version of Lynn’s content validity recommendations, utilising a structured process (Lynn, 1986). Additionally, content validity was supported by Polit and colleagues content validity appraisal recommendations (Polit & Beck, 2006; Polit et al., 2007).

**Figure 4.4 Stages of Content Validity**





Stages of Content Validity Adapted from the Framework Developed by Lynn 1986.

**Step one** involved an extensive literature review to identify a range of available instruments addressing the concepts of interest, unmet needs, symptom experiences, and quality of life of people diagnosed with IPF. Concurrently with the literature review, a consultation process occurred with academic staff in the field of chronic disease to gain expert feedback on the process of selecting items that best suited the study objectives. Individual mapping of items within the included instruments against the Irish Lung Fibrosis IPF Patient Charter (2015) items was conducted to illustrate the content and bespoke aspects of unmet needs, symptom experiences, and quality of life addressed by each instrument and displayed in a table to visualise the results.

**Step two** harnessed the expertise of the PPI panel, which was made up of healthcare professionals and people with lived experience of IPF ( $N = 4$ ) who were tasked with an overall assessment of the practicality and feasibility of the proposed survey instrument. The panel had an opportunity to review each of the selected instruments independently (SGRQ-I, IPF-PROM, LINQ and the sociodemographic questions). A LIKERT scale was employed to facilitate this process, evaluating key aspects such as clarity (how clear is the language used for the items), relevance (assessing how accurately the questions represented the phenomena of interest) and representativeness (focusing on the extent to which the item reflects the target construct) (Cobern & Adams, 2020).

The content validity index (CVI) is a widely used method for assessing the content validity of survey instruments, ensuring they generate high-quality data, and has been widely used in healthcare research (Haynes et al., 1995; Polit et al., 2007; Souza et al., 2017) (Appendix 12). The PPI contributors rated the overall IPF survey instrument content validity, using the scale content validity index (S-CVI) and item content validity index level (I-CVI), guided by instructions provided by Polit and Beck (2006, 2007) (Appendix 13).

The items in a survey are determined to be relevant if the I-CVI  $> 0.79$ . The I-CVI in this study was determined through consultation with the PPI panel and calculated as 0.91, indicating a high level of agreement that items were relevant to the topic. The expert panel rated the IPF-Survey as clear (S-CVI/AVE = 0.90 excellent), relevant (S-CVI/AVE = 0.92 excellent) and representative (S-CVI/AVE = 0.91 excellent) of the phenomenon of interest in this case, unmet needs, symptom experiences, and quality of life. The kappa score supported this analysis and was considered to have a high level of agreement  $k^* > .74$ . The survey instrument benefitted from further review by the expert panel, who rated their universal agreement of the items in the survey instrument as excellent (S-CVI/UA = 0.80 excellent). The high levels of universal agreement and the inclusion of three patients diagnosed with IPF in the content validity process further strengthened the utility of the survey.

The expert panel suggested minor revisions to the survey, including updating gender response options. Consequently, the original distinctions of 'male' or 'female' were subsequently expanded to 'male' 'female' or 'prefer to self-describe', with a text box included for additional input. Feedback from PPI contributors recommended incorporating the phrase 'previous use of antifibrotic medication' as previous

use of anti-fibrotic medication could impact symptom experience and quality of life. PPI contributors' feedback resulted in the following questions being added: '*Were you previously prescribed nintedanib?*' and '*Were you previously prescribed pirfenidone?*'.

#### **4.7.2.8 Reliability**

Reliability concerns the accuracy, stability and consistency of a survey measure, and relates to participants achieving the same response each time they complete the survey instrument (Heale & Twycross, 2015). There are several considerations when discussing reliability, including the internal consistency of an instrument. This can be measured using a '*Cronbach's alpha coefficient*' and measures the degree to which the sets of items are associated in the survey instrument (Creswell & Plano Clark, 2018). The Cronbach's  $\alpha$  result is a number between 0 and 1, where a score of 0.7 or higher is considered acceptable (LoBiondo-Wood et al., 2014; Shuttleworth, 2015). Reliability can also be tested using test-retest, over different timepoints to assess the consistency of scores over time (Mokkink et al., 2010). Other options for testing reliability include interrater reliability (repetition over persons) and intrarater reliability (repetition over occasions) (Polit & Beck, 2017). Reliability for each of the study's included instruments is discussed using Cronbach's  $\alpha$  test and test-retest results (Section 4.7.2.1).

#### **4.7.2.9 Finalised Survey**

The finalised survey (phase two) was organised into the following sections to maximise its coherency and accessibility: section one comprised sociodemographic items (20 items), section two concerned lung information needs (LINQ, 16 items), section three captured information on quality of life (SGRQ-I, 34 items), and again in section four which also focused on quality of life, with the addition of the subscale '*energy*' (IPF-PROM, 12 items). The final survey instrument (IPF Survey) is available in Appendix 11.

### **4.7.3 Phase Three Qualitative Data Collection**

#### **4.7.3.1 Qualitative Interview Guide Development**

This study employed semi-structured interviews for the qualitative phase, with a purposive sample of phase two participants (IPF Survey). In a mixed-method study, semi-structured interviews are considered a practical approach for the qualitative phase, due to their "ability to explore new concepts, to generate hypotheses and explain results which warrant follow-up from the quantitative phase of the research" (DeJonckheere & Vaughan, 2019, p. 2). The interview guide was developed over several steps; firstly, by considering the objectives of the study and selecting questions that best addressed them. Insights derived from the scoping review supported this process, for example, DeLamilleure and colleagues' (2021), qualitative study on patient and health care professionals' perspectives on the IPF care journey was an invaluable resource for planning the semi-structured questions. Additionally, the Levesque healthcare access theoretical framework (2013) informed the interview design, whilst aligning with the study's focus on unmet needs, symptom experiences, and quality of life. The final interview guide is available in Appendix 14. The interview guide contained six sections which served as prompts for interviewees, and included sections on diagnosis, living with IPF, information needs, healthcare access, healthcare supports,

and decision making. The structure of interviews was planned to start with orientating participants to the interview procedures and explanations as to the purpose of the interview. After initial introductions, an invitation to participants to share their personal experiences of living with IPF was offered with the question: '*Can you share your experience of living with IPF?*' The next section focused on the diagnostic journey, followed by a section concerning the participants experience of IPF. The third section referenced unmet information needs, given the gaps identified in earlier study findings (phase one and phase two), warranting further explanation. This was followed by a section on healthcare access and supports following a diagnosis of IPF, which was also guided by findings from the quantitative phase and PPI feedback. The final section focused on participants capacity for self-management. The interview concluded by asking participants if they wished to share further information or to clarify previously made points during the conversation.

The interview guide was developed using a flexible and iterative approach, drawing on multiple sources of evidence. These included findings from phase one (Healthcare Organisation Audit) and phase two (IPF survey), insights from the scoping review (Chapter 2), feedback from PPI contributors, and discussions with the supervisory team (Bryman, 2012). The final interview guide was informed by an in-depth content analysis of survey data from phases one and phase two, which identified key areas for further qualitative exploration. These areas included information needs, the impact of physical symptoms on quality of life, delayed diagnosis, and referral pathways, and access to supportive services such as palliative care, counselling, and pulmonary rehabilitation.

#### **4.7.3.2 Procedures for Qualitative Interviews**

Semi-structured interviews took place between February 2024 and April 2024. Participants were given the choice to have their interview conducted online via video link ( $n = 10$ ) or face-to-face ( $n = 10$ ). The interviews took place during the latter stage of the COVID-19 pandemic, and some participants were naturally reluctant to meet in person. Hospital gatekeepers were asked to confirm if participants were alive or deceased before making contact. This information was critical to avoid causing any distress to family members. Before the interviews began, digital recording equipment was checked, and the participants' comfort was prioritised. Interviews were recorded using voice recorder software on the researcher's encrypted laptop. All interviews were audio-recorded with participants' consent and transcribed later by the researcher. The interviews were conducted sequentially, adopting a flexible and pragmatic approach, using the interview guide. Interviews were pseudonymised, using a unique identifier to protect the identity of each participant. At the outset of the interview, an introduction and explanation of the study aim, background and demographic information were confirmed with the participants followed by administration and collection of the participants consent form.

The ability to build trust and rapport with a participant during an interview is an essential ingredient of the interview process (Kvale & Brinkmann, 2009). The researcher utilised helpful skills such as empathy and effective communication techniques, previously developed from both her psychology and psychotherapy training, which supported both face-to-face and online interviews. A distress protocol

(Appendix 7) was developed prior to interviews taking place; however, the protocol was not required (Braun & Clarke, 2013). Field notes supported audio-recordings and facilitated any observations made in the interview space, such as displays of emotion that may not have been detected in the audio recording.

Having an interview guide provided a structure to the interview process, whilst maintaining an iterative and flexible approach to address the research objectives. Further consideration included recognition of my clinical experience. My experience has shaped my perception and beliefs about IPF. However, it may have unintentionally introduced a degree of bias into the interview process, which I reflected on in voice notes I made and in reflective journalling, creating a more reflective, nuanced and comprehensive approach to data collection. It was also helpful to engage with supervision to reflect on the interview process, creating opportunities to de-brief and review reflective notes to guide discussion.

#### **4.7.3.3 Credibility and Rigour**

A fundamental aspect of the research design was to appraise the quality of the qualitative approach by using established standards of credibility and rigour. Considerable care was taken in this inquiry to optimise rigour, aligned to the practical framework offered by Lincoln and Guba (1985). Lincoln and Guba proposed a framework for addressing trustworthiness in qualitative research, which includes credibility, transferability, confirmability and dependability (1985). Trustworthiness, a term often used interchangeably with rigour, was facilitated by prolonged engagement in the field. The researcher had the opportunity to immerse herself within the context and culture of the multi-site nationally representative healthcare environments. Trustworthiness was also complemented by ongoing engagement with PPI partners and healthcare professionals through attendance at outpatient clinics, multidisciplinary team meetings and conference presentations, a process collectively referred to as '*persistent observation*'. Meanwhile, a reflective journal was maintained to record this information (Tashakkori & Teddlie, 1998; Tobin & Begley, 2004). Credibility in this study relates to how well the integrated mixed methods findings explain the phenomena of interest and how accurately they provide a description and interpretation of the data (Lincoln, 1985). Ensuring methodological transparency is a critical element in the research process to ensure that findings are robust and meaningful (Cresswell and Poth, 2016).

Methodological transparency is essential to ensure robust and meaningful findings (Creswell & Poth, 2016). This study employed established strategies to ensure rigour, as outlined by Lincoln and Guba (1985). These included triangulation, member checking, peer review, rich description and reflexivity. Triangulation was used to enhance validity through the integration of multiple data sources and theoretical perspectives. Data was collected across diverse healthcare settings, geographical regions in Ireland, and professional roles, enabling cross validation of findings and a comprehensive understanding of the phenomenon of interest.

Credibility in this study relates to how well the integrated mixed methods findings explain the phenomena of interest and how accurately they provide a description and interpretation of the data (Lincoln, 1985). Maintaining a reflexive journal aided decisions taken in respect of the interview guide development and

data analysis. The researcher conducted, transcribed and analysed all interviews, which supported the credibility of the research through prolonged engagement with the data and accuracy of the findings. Interviewees were offered opportunities to member-check the transcript findings, a critical component of credibility according to Lincoln and Guba (1985) to confirm if the interviews were representative of their experience. One interviewee requested their transcript after interview completion, with no further amendments or changes requested. Credibility was reinforced in the interviews by repeating back sentences or phrases to participants; both rephrasing and elaboration helped ensure that the correct information was recorded. Peer review contributed to confirmability and dependability, with research design, data collection, analysis, interpretation, and write-up regularly reviewed by academic supervisors. Reflexivity was embedded throughout the research process to acknowledge researcher positionality, address potential bias, and maintain transparency.

#### **4.7.3.4    *Transferability and Dependability***

In qualitative research, transferability can be described as the extent to which various aspects of the research processes can be generalised to another population or context (Cope, 2014; Curry, 2014; Lincoln, 1985; Streubert & Carpenter, 2011). Transferability and dependability were supported through the use of rich, thick description clearly outlining the study procedures, setting, gatekeeper roles, sampling strategy, detailed information regarding the theoretical foundations, specifically the Levesque healthcare access framework (2013) along with providing details of pragmatism, this studies philosophical underpinning. A detailed procedural diagram to facilitate a rich visual description of the study and opportunities for transferability is provided (Figure 4.5). Dependability refers to how processes are facilitated logically and transparently (Patton, 1990). Dependability was factored into the qualitative interview analysis using coding and annotation functions in NVivo software to document decision-making, providing a transparent audit trail to accurately record processes and procedures in this study (Tobin & Begley, 2004). Additionally, attendance at PPI meetings was recorded to maintain a record of engagement with PPI partners, further enhancing dependability (Creswell, 2007).

#### **4.7.3.5    *Confirmability***

Confirmability is concerned with ensuring that the findings are representative of the data collected, confirmed by an audit trail that records the decisions made in the study (Lincoln, 1985). A reflective journal and interview notes fostered a space to consider and reflect on self-reflexivity and potential influence on each stage of the research process. Journaling provided a reflective space to consider how representative the qualitative findings are of participants personal narratives (Curry, 2014; Lincoln, 1985). Integration of participants' direct quotations to support the interpretation of qualitative interview findings offered further opportunities to apply the principle of confirmability. A portion of the transcribed interviews ( $n = 8$ ) were selected to undergo an audit by the supervisory team, creating further opportunities to review the application of reflexive, thematic analysis. This process helped to ensure that the themes were relevant and assessed for their explanatory power concerning the collected data (Lincoln, 1985). Analysis of the

interview transcripts was anchored to a rigorous process to ensure credibility. It included discussion with the supervisory team, coupled with an audit trail that maximised credibility during qualitative analysis. Maintaining an accurate log of decisions made and actions taken was critical to the process (Lincoln, 1985).

#### **4.7.3.6 Reflexivity**

Maintaining a reflexive journal aided decisions taken in respect of the interview guide development and data analysis. Reflexivity is a fundamental component of qualitative research, integrated into the overall research design. Reflexivity incorporates, “continuous, collaborative, and multifaceted practice” through which researchers critically evaluate how their subjectivity and positionality may influence the research process (Olmos-Vega et al., 2023, p. 241). According to Braun and Clark (2021), who emphasise that reflexivity is a continuous process interwoven into the fabric of the inquiry; enhancing our awareness of the researcher’s engagement with the data as they bring with them their own positionality and personal perspectives (Braun & Clarke, 2021). As Finlay (2002) notes, the subjective nature of qualitative research may expose the researcher’s inherent biases, underscoring the critical importance of reflexivity and transparency in the research process.

Several key factors framed my motivation to commence a PhD in the field of IPF. One contributory factor was my experience of working as the lead research nurse in a clinical research centre, where my day-to-day work involved coordinating a range of clinical trials related to IPF. This experience provided a diverse scope of opportunities to gain a broader insight into the experiences of people diagnosed with IPF in Ireland, at various stages of their disease. This experience gave me an insight into the journey people with IPF take and the severe impact this chronic progressive condition has on patients and their families across diverse aspects of their lives.

My journey into reflexivity started many years before my PhD, when I embarked on several training pathways, including nursing, psychology and subsequently psychotherapy training, which served to develop my curiosity and explore my own worldview, subjectivity and inherent biases. This journey sparked a personal motivation to utilise skills acquired to contribute in a meaningful way to the body of research related to people diagnosed with IPF and their families through pursuing a PhD.

My previous professional role enabled me to prioritise and focus on the research objectives to create a space to illuminate the lived experience of people diagnosed with IPF. To minimise the risk of my own bias and preconceptions about IPF, I actively engaged in reflexivity. I recorded my personal musings relating to my experience of caring for people with IPF and how that might influence the study and impact my interpretation of the findings. I also used these reflective notes to review and interpret my contribution to the data. In qualitative interviews (phase three), I actively sought to amplify participants’ voices and incorporate their unique lived experience and perception of reality by using techniques and methods, such as active listening and non-verbal cues, to create a safe space which fostered conversation. I anchored myself to the pre-prepared interview guide to minimise the risk of bias.

Reflexivity strengthened my awareness of the professional roles we inhabit and how my prior role as a research nurse might inherently carry a risk of creating a power imbalance, which could negatively impact qualitative interviews (phase three). Having never previously worked in any of the five included hospital sites, I occupied a 'visitor' role, which positioned me as both an insider and an outsider, which may have influenced how participants perceived me. I considered whether participants might hesitate to discuss negative healthcare experiences due to concern about possible repercussions, should they be seen to complain. To address this, the information leaflet and consent form clearly outlined the participants' rights and how they were safeguarded in the study. Fostering an appreciation for reflective practices and awareness of my own positionality supported the endeavour to facilitate a deeper understanding of the experiences of people diagnosed with IPF.

## **4.8 Data Management and Analysis**

This study utilised a sequential explanatory mixed methods design. Data from both quantitative and qualitative methods were analysed sequentially and reported separately, addressing the study's aims and objectives (Section 4.2). The results were then integrated and discussed in Chapter 8. Meta-inferences derived from the integration of both methods were summarised in Section 8.1. The following section will outline the data management and analysis procedures for the quantitative data.

### **4.8.1 Phase One & Phase Two**

Survey data were collected via Qualtrics an online data collection platform or in paper copy, with raw data exported to SPSS (The Statistical Package for the Social Sciences, version 27) for statistical analysis. Paper survey data responses were manually entered into Qualtrics software. A file was created in SPSS with the complete data set, where all variables and response choices were labelled and assessed for specific measurement type (nominal, categorical or scale). Where necessary, variables were recoded or transformed using numerical values to facilitate statistical analysis. Dummy variables were utilised, where required, in procedures such as regression analysis. Prior to data analysis, a sample of data was independently checked with a second member of the supervisory team to ensure accuracy of data entry. Data accuracy and consistency were assessed at multiple timepoints, including during the data cleaning process, throughout data analysis and through random spot checks. These random checks were completed to identify any errors, missing values or outliers, and to maintain data integrity. A 10% subset of data (every third participant) was cross-checked for accuracy with the corresponding paper copy to ensure the accuracy of data entry. Validation procedures were also completed to ensure total subscale scores aligned with the manualised survey instructions. Any errors detected were corrected as they occurred. Internal consistency of the three instruments and their subscales was assessed using Cronbach's Alpha. Open-ended questions were checked for errors, and any identifiable information was removed. Open-ended questions from the quantitative survey data were handled in the qualitative chapter (Chapter 6, Section 6.3) using reflexive thematic analysis (Braun & Clarke, 2021).

#### **4.8.1.1 Management of Missing Data**

A series of systematic checks on the total data set was conducted prior to data analysis to check for missing data.

**Phase One (Healthcare Organisation Audit):** The data collected in phase one, predominantly consisted of descriptive information. A review of data collected indicated no missing data in the closed-ended responses, with two missing responses in the optional open-ended questions, resulting in the complete data set deemed suitable for inclusion in statistical analysis ( $N = 16$ ).

**Phase Two (IPF survey):** There were several strands of data collection methods used in phase two, including paper and pen methods and an online electronic survey using Qualtrics software. Initially, all returned surveys in the study dataset were included, with missingness checked in separate analyses ( $N = 237$ ). Utilising the forced response function on Qualtrics yielded a high survey response rate and minimal observation of missing cases. The sample size and valid proportions deemed eligible in each data analysis procedure are provided throughout Chapter 5.

In the case of the St. George Respiratory Questionnaire-IPF (SGRQ-I), IPF-Patient Reported Outcome Measure (IPF-PROM) and the Lung Information Needs Questionnaire (LINQ) survey instruments, the developers included manualised guidance on how to manage missing data. These instructions were applied to the dataset using the SPSS syntax program, which calculated appropriate scoring options aligned with the developers' guidelines. An overall response rate of at least 80% was deemed acceptable for data analysis in this study. No underlying issues of concern were identified with any of the missing values. The structure of the survey necessitated several conditional responses, which were dependent on pre-defined criteria.

#### **4.8.1.2 Descriptive Statistical Analysis**

The first step in data analysis involved data cleaning in SPSS. Then, data items were relabelled with numerical values, followed by the calculation of subscale and total scores for the three survey instruments (LINQ, SGRQ-I and IPF-PROM), using manualised instructions provided by respective authors. Statistical analysis began with descriptive statistics to explore the characteristics of survey participants, and served to summarise the dataset, including percentages, means or medians, range and standard deviations. Recoding occurred in several instances; for example, data related to the item '*comorbid conditions*' was recoded into '*systems disorders*' for clarity purposes. Descriptive frequency statistics facilitated the identification of differences and patterns in categorical data, which benefited from further statistical analysis, including inferential statistics. The dataset mainly contained categorical variables.

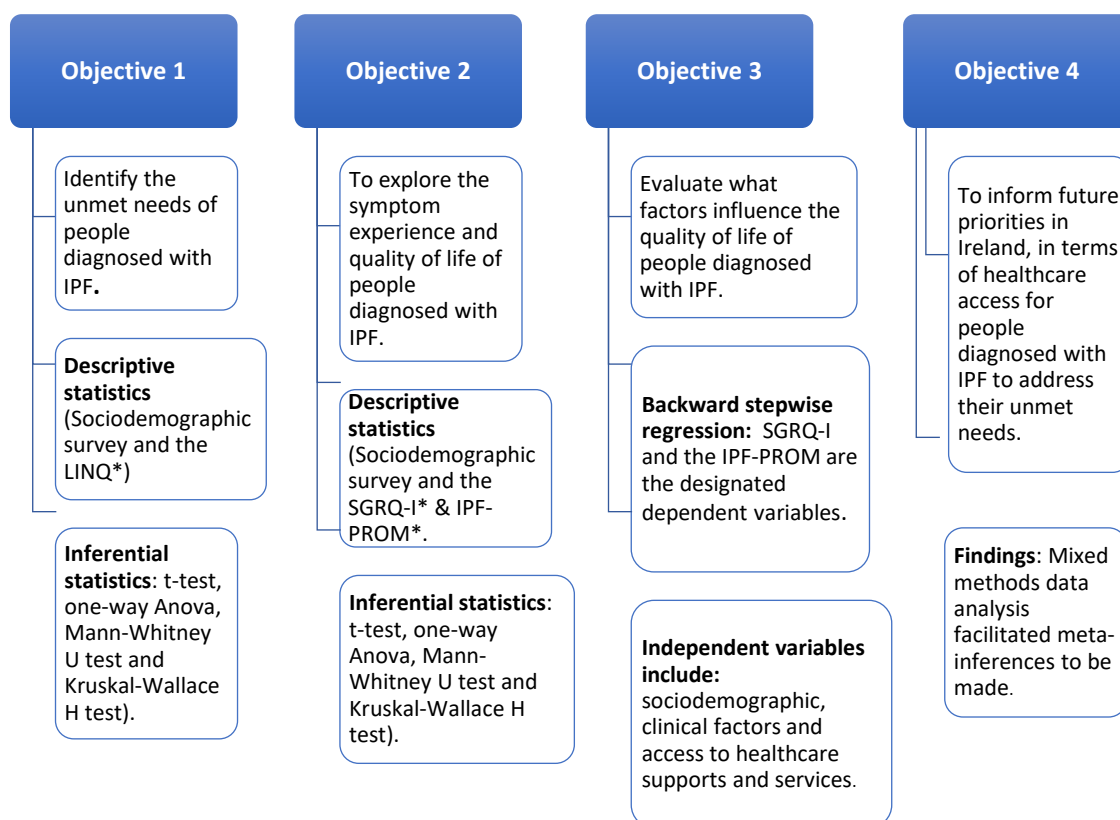
#### **4.8.1.3 Inferential Statistical Analysis**

Inferential statistics were utilised to identify any associations or variation between variables of interest, including sociodemographic and clinical factors, access to healthcare supports and services and items from the three survey instruments. Independent samples *t*-tests were used to compare the variance in mean values between two groups, and for more than two groups, one-way ANOVA was employed. Non-parametric tests were utilised when data were considered not normally distributed and when the Shapiro-



Wilk test of normality revealed  $p$  values that were outside the expected range ( $p < 0.5$  was considered normal). Furthermore, visual inspection of QQ (Quantile Quantile) plots generated for quantitative data that did not have a normal distribution warranted the selection of non-parametric tests (Mann-Whitney  $U$  tests and Kruskal-Wallis  $H$  Tests) to characterise the significance of variation between subgroups within the sample (i.e., age, gender and health insurance status). The Mann-Whitney  $U$  Test compares the mean rank value between two independent groups (Sundjaja et al., 2023), while the Kruskal-Wallis  $H$  Test facilitates statistical analysis for more than two groups (Xia, 2020). All  $p$ -values were two-sided, and statistical significance was defined as  $p < 0.05$ . Pearson's correlations were used to describe any correlation between significant variables of interest and the primary quality-of-life instrument used in this study, the SGRQ-I. Statistical analysis in this section served to address objectives one, two and three. Backward stepwise regression analysis was used to examine the explanatory factors that meaningfully contribute to the quality of life of people diagnosed with IPF (Figure 4.5).

**Figure 4.5 Statistical Analysis Used to Address the Study Objectives**



**\*Key:** LINQ (Lung Information Needs Questionnaire), SGRQ-I (St. George Respiratory Questionnaire), IPF-PROM (IPF Patient Reported Outcome Measure)

#### 4.8.1.4 Backward Stepwise Regression

Backward stepwise regression analysis was employed as a reliable method to provide greater insight into the predictive power of independent variables (IV) on the dependent variable (DV) being addressed in this study, 'quality of life' (DV: SGRQ-I & IPF-PROM) (Field, 2013). The independent variables were selected

based on statistically significant results from the inferential statistical analysis (Chapter 5). These variables include sociodemographic and clinical factors, healthcare access, and information needs. The underlying principle for regression analysis is that you can fit a predictive model to your data and use that model to predict values of the dependent variable (DV) based on one or more significant independent variables (IVs) (Field, 2013).

Backward stepwise regression requires that all independent predictor variables be input into the model. The contribution of these variables to the model is then assessed by evaluating the t-test value to determine its statistical significance (Field, 2013). Variables that do not meet the p value threshold defined as  $p \leq 0.05$ , often referred to as ' $p$  -to remove' are eliminated from the model (Chowdhury & Turin, 2020). This process is then repeated to assess which predictor variable makes a significant contribution to the model (Field, 2013). The value is computed against a removal criterion value, which was set at a probability of  $F$ -to remove greater than or equal to .100 (Ratner, 2010). Backward stepwise regression analysis specifies several assumptions to ensure the robustness of the analysis, outlined in Table 4.10 (Field, 2013, p.170).

**Table 4.10 Backward Stepwise Regression Assumptions**

| Assumptions               | Definition of Assumptions                                                                                                                                                                                                                                                                                   |
|---------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Linearity                 | The relationship between the predictor variable and the outcome variable should be linear. The mean value of the outcome variable at each value of the predictor variable should be situated on a straight line. This can be assessed through a visual inspection of the scatterplot (Field, 2013, p. 170). |
| Homoscedasticity          | Residuals should demonstrate homoscedasticity, where the variance should be constant across all levels of the predictor variable (Field, 2013, p. 170).                                                                                                                                                     |
| Normality of residuals    | Normality of residuals can be inspected by visual inspection of the P-P plots or the histogram (Field, 2013, p. 170).                                                                                                                                                                                       |
| No multicollinearity      | There should be no perfect multicollinearity which in effect means that two or more predictor variables should not demonstrate a perfect linear relationship (Field, 2013, p. 170).                                                                                                                         |
| No outliers               | The data should not contain any outliers that could distort the results (Field, 2013, p. 170).                                                                                                                                                                                                              |
| Independence of residuals | The values of the outcome variable should be independent (Field, 2013, p. 170).                                                                                                                                                                                                                             |

#### 4.8.2 Phase Three

Audio recordings of participant interviews were transcribed and pseudonymised until analysis was completed and verified. Once this task was completed, transcripts of participant interviews were fully anonymised (phase three). Computer software for the management of qualitative data, NVivo, supported qualitative data analysis.

#### 4.8.2.1 Reflexive Thematic Analysis

Qualitative data were analysed using reflexive thematic analysis, guided by Braun and Clarke's analytical framework (Braun & Clarke, 2006, 2021). They define thematic analysis as a method for identifying themes or patterns in qualitative data (2006). Their most recent version is referred to as '*reflexive thematic analysis*' (TA), which highlights researcher reflexivity and subjectivity (Braun & Clarke, 2021). Reflexive thematic analysis (TA) has been described as a '*theoretically flexible interpretative*' approach (Byrne, 2022), which highlights the active role the researcher plays in producing knowledge (Braun & Clarke, 2021; Finlay, 2002). The premise of reflexivity argues that qualitative researchers are aware of their self-influence on the research (Probst, 2015) and the impact their positionality and subjectivity may have on several aspects of the study, from the research design, data collection, data analysis and interpretation (Finlay, 2002).

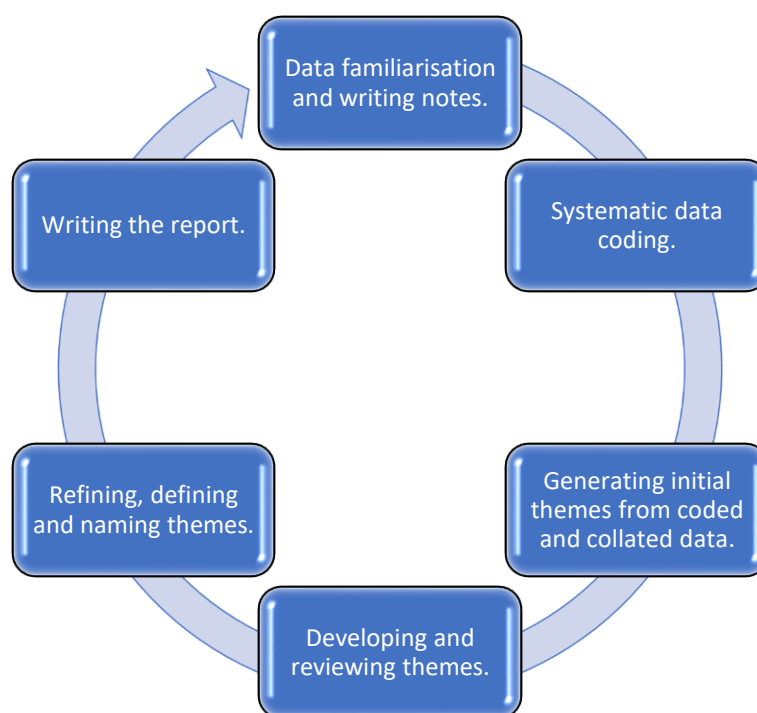
This research is informed by epistemological and ontological assumptions, with pragmatism providing the foundation for the qualitative analysis, guided by Levesque's theoretical healthcare access framework (2013). The sequential explanatory design used in this study was underscored by pragmatism, which prioritises research outcomes and the practical application of research aligned with a '*what works*' approach. The participant's voice is prioritised while, acknowledging the researcher's subjective interpretation of the data. Qualitative analysis was supported by an audit trail of decisions made, reading and re-reading the data and taking time to reflect on participant interviews prior to writing, grounded in transparent methods (Green et al., 2007).

Reflexive thematic analysis (TA) was adopted in this study given its transparent and flexible approach to qualitative data analysis. This method facilitated the use of semantic codes which captured participants' perceptions of reality using their own expressions and preferred language to describe their lived experiences (Byrne, 2022; Lim, 2025). Additionally, latent coding was employed, which aimed to deepen our understanding of the material through a deep exploration of underlying meanings within the data (Byrne, 2022). This additional layer enriched the study findings by reflecting on less explicit themes and hidden meanings in the data. Reflexive thematic analysis is commonly viewed as both a descriptive and interpretive process, where the researcher's role in the interpretation of the data is acknowledged. The analysis occurs at the intersection of the data, theoretical framework and the researchers' skills and personal reflexivity (Braun & and Clarke, 2019).

Reflexive thematic analysis used both inductive and deductive approaches, which aligned with the study's mixed-methods design (Fereday & Muir-Cochrane, 2006). Deductive coding was guided by the research aim and objectives. While inductive coding which was primarily utilised in the initial stages during code development, through open-coding, with direct participant quotations to scaffold findings that are grounded in the data (Braun & Clarke, 2021; Fereday & Muir-Cochrane, 2006).

Braun and Clarke (2021) developed a six-step guide to reflexive thematic analysis (Figure 4.6). The six phases are organised in sequential order; however, the two authors state that analysis is not linear but rather an iterative and recursive process, which incorporates deep immersion in the data and enhanced awareness of one's own subjectivity (Braun & Clarke, 2021).

**Figure 4.6 Braun and Clarke Reflexive Thematic Analysis**



**Data Familiarisation** is considered an important ingredient in TA, contributing to the depth and richness of the analysis (Braun & Clarke, 2021). In this study, the familiarisation process was facilitated by engaging in repeated active listening to audio recordings, thereby creating an immersive experience with the data, allowing space to capture reflective notes. Reading and re-reading the pseudonymised interview transcripts further deepened this immersion while also creating opportunities to verify the accuracy of the transcriptions. Particular attention was given to noticing subtle nuances such as pauses, moments of emotion and changes in tone. One example of this was a participant who became visibly emotional at the end of her interview and asked if she could hug me, as she wanted to thank me for creating a space for her to tell her story for the first time. A reflective journal helped me to capture these nuances while documenting my reflections during interviews, and again during data analysis.

**Data Coding** represented the next step in this iterative, reflexive analytical process. A complete coding perspective was utilised at this stage, which involved identifying all data segments of relevance to answering the research question (Braun & Clarke, 2013, p. 206). The complete data set was examined broadly to capture data segments that were of interest particularly those that aligned with the research objectives. Each relevant data segment was assigned a descriptive code label to support the development of meaningful insights related to the research objectives and that might be useful in addressing the research question (Byrne, 2022). This coding process was facilitated by NVivo software with examples of this form of coding including 'psychological needs' and 'information needs', (Appendix 15).

**Generating Initial Themes from Coded and Collated Data** Braun and Clarke describe reflexive TA as “patterns of shared meaning, united by a central concept or idea” (2021). Analysis shifted from initial codes to aggregated codes, grouped together based on conceptual similarities (Byrne, 2022). This stage involved a recursive process moving from a descriptive approach to coding toward an interpretive one, which involved the synthesis of similar codes with shared meaning into candidate themes which served to address the research question.

**Developing and Reviewing Themes** involved analysing the entire dataset alongside the candidate teams in a recursive manner. This stage required critically reflecting on how effectively the candidate themes captured patterns of shared meaning and supported interpretation of the data. At this stage of analysis, specific candidate themes which lacked sufficient depth or relevance, were either discarded or merged into other valid themes to enhance the coherency of the entire dataset.

**Refining, Defining and Naming Themes** was the next step in this active process. It involved reviewing the candidate themes generated in the previous step and then reflecting on the accuracy of interpretation. Refinement and further development of themes, to support the research objectives, continued.

**Writing up** formed an important element of the reflexive thematic analysis used in this study, culminating in a coherent narrative of participants’ experiences which addressed the research question. Patton (1990) describes specific criteria for writing up TA results, including the requirement for themes to provide a meaningful and coherent description of the data. The process of writing was woven into the overall tapestry of this analysis, from the inclusion of a reflective journal, developing awareness of my subjectivity, to analytical notes, capturing key moments during analysis. Incorporation of direct quotes from participants, sought to embed the authentic narrative of people diagnosed with IPF. The final report derived from a process of reviewing and writing up the results under the guidance of the supervisory theme.

## 4.9 Integration

The integration of quantitative and qualitative data was prioritised in this study and considered a critical component of the mixed-methods design. Integration involves the intentional mixing of both quantitative and qualitative elements leveraging the strengths of both to create a comprehensive understanding of the phenomenon of interest (Creamer, 2018; Halcomb, 2019). Integration benefits the overall design by connecting different data types which can complement and enhance each other and can occur at multiple levels, including the philosophical and research design level (Creswell & Clark, 2017). Integration in mixed methods refers to the process of linking both qualitative and quantitative approaches to generate a “holistic understanding” of the research problem, which could not have been achieved by using a single method alone (Fetters & Molina-Azorin, 2017, p. 293). Integration distinguishes mixed methods from either quantitative or qualitative research approaches alone and should be intentionally designed and purposefully incorporated into a mixed methods study (Fetters et al., 2013; Teddlie & Tashakkori, 2009). The timing of data collection in a sequential explanatory mixed methods research design, dictates that quantitative research precedes and informs qualitative research (Hafsa, 2019). The levels of integration in

this study were planned at several points throughout the sequential explanatory design, creating opportunities to demonstrate the purposeful connection between quantitative and qualitative data (Curry, 2014; Moseholm & Fetters, 2017). The findings in this study reflect the information generated during the quantitative and qualitative phases, framed by Levesque's theoretical framework (2013) and underpinned by the studies philosophy of pragmatism. Opportunities to integrate quantitative and qualitative approaches at multiple points are aligned with Fetters' typology of integration procedures (Fetters et al., 2013; Fetters & Molina-Azorin, 2017) (Table 4.11). In the current study integration occurs at multiple levels to facilitate a comprehensive understanding of the phenomenon of interest, leveraging the strengths of both quantitative numerical data and qualitatively rich contextual data to address the research objectives (Figure 4.7).

#### **4.9.1.1    *Integration at the Design Level***

The study objectives were addressed through the selection of a sequential explanatory mixed methods design which supported the aim to investigate the unmet needs, symptom experiences, and quality of life among those living with a diagnosis of IPF. This research design facilitated the collection of quantitative data which proceeded and informed the next study phase employing qualitative data collection methods (Fetters et al., 2013). Qualitative data provided rich contextual information which helped to explain, expand, and contextualise the preceding quantitative findings.

#### **4.9.1.2    *Integration at the Method level***

Integration of both quantitative and qualitative approaches was supported by several integration techniques, including connection/building (phase one & phase two) and merging (phase three) (Fetters et al., 2013). This study built on feedback from PPI members and literature review findings to inform the development of the quantitative survey (phase two). Connection occurred through the integrated sampling strategy, using maximum variation sampling, where variables of interest highlighted in the findings from the quantitative data analysis (phase one and two) helped to inform the next phase of data collection which used semi-structured interviews (phase three). The integration technique of 'building' facilitates the endeavour to use the results from one method as a building block for the subsequent methods, facilitating a more rounded and comprehensive understanding of the phenomenon of interest (Fetters et al., 2013). Further opportunities to build on earlier findings occurred during the development of the interview guide which built on the proceeding quantitative survey findings and integration of PPI feedback. The sequential mixed methods design facilitated the integration of multiple methods facilitating a more comprehensive understanding of the unmet needs, symptom experiences, and quality of life of individuals with IPF then would have occurred using a single method alone. Analysing quantitative and qualitative data separately before integrating them helped to identify confirmation, discordance or expansion of results between quantitative data and qualitative data (Creswell, 2007; Fetters et al., 2013).

#### 4.9.1.3 Integration at the Interpretation and Reporting Level

Finally, data from both the quantitative (phase one and phase two) and qualitative analyses (phase three) were merged and presented side-by-side in a visual joint display (chapter 7) to facilitate interpretation and exploration of meta-inferences (Guetterman et al., 2015; O'Cathain et al., 2007). Analysis of the integrated findings in the joint display revealed where convergence, divergence or expansion of results between the quantitative and qualitative phases occurred (Bazeley, 2017; Fetters, 2019; Younas et al., 2020). Guided by the Levesque healthcare access framework (2013), qualitative interview findings were examined alongside survey-mapped quantitative data, enabling deeper interpretation and expansion of the earlier quantitative results. The process of expansion enabled new understanding to emerge and clarified areas where the data converged or diverged (Creswell & Plano Clark, 2017). Meta-inferences were generated through the examination of patterns identified in the quantitative data, integrated with the contextually rich themes derived from the qualitative narratives. This integrative approach resulted in a comprehensive, in-depth and holistic analysis of the phenomenon under investigation, thereby strengthening the overall validity of the findings (Tashakkori & Teddlie, 2010; Cresswell and Clark, 2017). Systematically mixing quantitative and qualitative data added to the overall coherence of this study and highlighted patterns of convergence, divergence and elaboration across the datasets which added legitimacy to this inquiry.

**Table 4.11 Integration Opportunities**

| Integration          | Integration Opportunities (Adapted from Fetters, 2017)                                                                                                                                                                                                                                                                      |
|----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Building</b>      | <b>Selection of a mixed methods sequential explanatory design</b> to answer the integrated study objectives, building on the strength of both quantitative and qualitative methods (Chapter 4, Section 4.3).                                                                                                                |
|                      | Integrated <b>research objectives</b> building on findings from the scoping review (Chapter 4, Section 4.2) and PPI feedback.                                                                                                                                                                                               |
|                      | Building on the extensive <b>scoping review</b> to inform the choice of survey instruments in phase one and phase two (Chapter 2).                                                                                                                                                                                          |
|                      | Quantitative data collection (phase one and phase two) informed the development of the interview guide (phase three), building on interesting findings from the quantitative phase (Chapter 4, Section 4.7.3.1). Additionally, the interview guide development was supported by building on feedback from PPI contributors. |
| <b>Connecting</b>    | Connecting two epistemological positions (objective and subjective). Selection of pragmatism as the epistemology for this inquiry, leveraging the strengths of both epistemological positions (Chapter 3, Section 3.2.1) (Moseholm & Fetters, 2017).                                                                        |
|                      | Integrated sampling strategy using maximum variation sampling. A subset of participants from phase two (IPF Survey) were selected to participate in phase three (qualitative interview phase) connecting the sample from phase two with phase three (Chapter 4, Section 4.5.3-4.5.4).                                       |
| <b>Joint display</b> | Quantitative findings from phase one and phase two (Chapter 5) and qualitative findings from phase three were analysed separately (Chapter 6) before being integrated. Observation of where convergence, divergence, or expansion of integrated findings occurred in this mixed-methods study are outlined in Chapter 7.    |
|                      | Meta-inferences are drawn from the integration of both quantitative and qualitative study findings (Chapter 8, Section 8.2-8.5).                                                                                                                                                                                            |
|                      | A joint display was used to facilitate the visual display of integrated quantitative and qualitative findings, followed by a discussion of meta-inferences from these findings (Chapter 7).                                                                                                                                 |

Furthermore, opportunities for integration occurred at the theory level, where Levesque's healthcare access theory (2013) informed both the quantitative and qualitative phases of this study, including the study design, data collection and analysis. The integration of Levesque's theoretical framework (2013) provided an opportunity to harness the strength of mixed methods integration, facilitating an in-depth understanding of the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF. The integrated findings, which influence the interpretation of results, are discussed in detail in Chapter 8.

#### **4.9.1.4    *Integration of Patient and Public Involvement***

My role as the co-chair of a newly formed Patient and Public Involvement (PPI) network, supported by the Irish Lung Fibrosis Association, provided the backdrop for the inclusion of PPI in this doctoral research and was fundamental to ensuring its relevance. Engaging with an existing PPI network benefited this study and enabled opportunities to engage with more experienced PPI partners and to learn from their expertise (Tomlinson et al., 2019). Extensive literature exists on the positive contribution that PPI can bring to research by drawing on the lived experience of PPI contributors (Nilsen et al., 2006). The principles of PPI commonly include respect, support, transparency, and accountability and were central components to the application of PPI in this study (Brett et al., 2014). PPI engagement also aligned with the values and ethical principles of this research, which aimed to include the unique perspectives of people diagnosed with IPF. Having assessed opportunities for PPI engagement within the overall research design and the potential time constraints involved in the implementation of the study methods, a decision was made early on to select specific time points where the strengths of PPI could be leveraged to maximise its potential. Throughout the project's four-year duration, the PPI group was responsible for guiding and shaping various aspects of the research. PPI group meetings were conducted online via Zoom. There were six scheduled sessions during the project. The PPI contributions encompassed a range of activities, including:

- 1. Identifying research priorities:** Engagement with PPI partners at the initial study conceptualisation stage allowed me to refine and develop my research aims and objectives in line with the panel selecting 'unmet needs' as a research priority.
- 2. Scoping review protocol:** I used the established communication channels to disseminate study progress and invite participants to contribute to the draft scoping review search strategy and subsequent write-up.
- 3. Scoping review publication:** PPI contributions facilitated the development and subsequent publication of the scoping review through frequent feedback concerning language and interpretation of findings (Chapter 2).
- 4. Determining preferred language:** The PPI group were instrumental in informing the language used in the study publications and thesis write-up, embedding their preferences within this body of work, while remaining loyal to the preferred informal rhetoric used in this study.
- 5. Review of the interview guide:** PPI partners were involved in critically reviewing the interview guide, creating opportunities for them to give feedback about potential changes which could benefit the overall interview process. PPI engagement supported my aim to carry out research



that focuses on issues that matter to those immediately impacted by IPF, maximising this study's relevance through the integration of patients' preferred language and research priorities

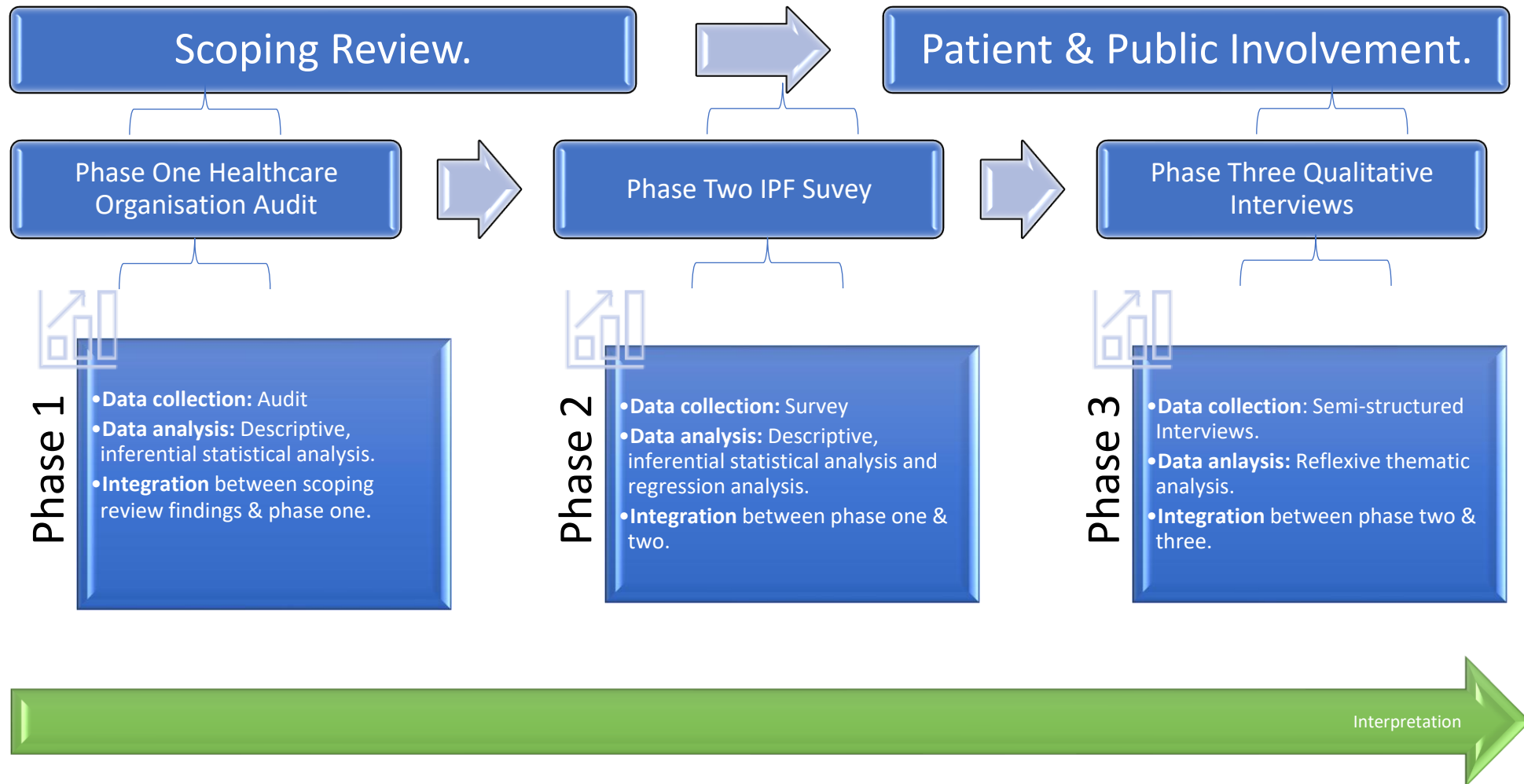
#### 4.9.1.5 Integration of Levesque's Theoretical Framework for Healthcare Access

This study integrated Levesque's Healthcare Access Framework (2013) which served as the theoretical foundation for this study, previously described in Chapter 1 (section 1.7). Levesque's framework supported earlier phases of this research by informing the overall research design and subsequent phases of this research, as described in Table 4.12. Levesque's framework supported the selection of survey instruments to address the research objectives. Similarly, the interview guide incorporated important references to healthcare access such as affordability, accessibility and approachability (Appendix 14). Opportunities for integration in this study are displayed in Figure 4.7.

**Table 4.12 Application of Levesque's Theoretical Framework for Healthcare Access**

| Research Process                                  | Integration of the Levesque framework                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|---------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Core concept</b>                               | The concept of 'unmet needs' may be viewed through the lens of healthcare access, which acknowledges the individual and their ability to access healthcare, extending to broader determinants of healthcare access. Factors that may inhibit, or permit healthcare access include the availability of services, geographical, economic and social determinants. Additionally, exploring unmet needs supports the other research objectives, <i>namely</i> 'symptom experience' and 'quality of life', both of which can be viewed through the consequences of access to healthcare. |
| <b>Phase one : Quantitative Audit (Chapter 5)</b> | Levesque's framework (2013) guided the inclusion of questions related to healthcare access to address unmet needs in phase one of the study. The five domains of affordability, acceptability, approachability, availability, accommodation, and appropriateness from Levesque's healthcare access framework (2013) underscore the selection of survey questions to assess unmet needs.                                                                                                                                                                                             |
| <b>Phase two: Quantitative Survey (Chapter 5)</b> | Levesque's five domains of access were utilised to guide the selection of survey questions in the IPF Survey. They provided a comprehensive awareness of the barriers to healthcare access that were addressed in the IPF Survey.                                                                                                                                                                                                                                                                                                                                                   |
| <b>Interview guide (Chapter 6)</b>                | Levesque's framework guided the development of the interview guide by ensuring that questions concerning healthcare access highlighted in quantitative data findings were incorporated into the interview guide (Chapter 4, Section 4.7.3.1).                                                                                                                                                                                                                                                                                                                                       |
| <b>Analysis and interpretation (Chapter 8)</b>    | Chapter eight (Section 8.2) discusses the application of Levesque's theoretical framework during data analysis and subsequent implications for the research findings. Applying a theoretical framework facilitated a move beyond a descriptive analysis of unmet needs, extending to a comprehensive explanatory position, which facilitated the identification of unmet needs and target areas for future research and interventions to enhance patient outcomes.                                                                                                                  |

Figure 4.7 Mixed Methods Explanatory Sequential Design: Point of Integration



#### **4.10 Conclusion**

This chapter has outlined the methods used in this mixed-methods sequential explanatory study. The procedures and justification for using a mixed-methods study design have been presented. A description of data collection procedures in phase one (Healthcare Organisation Audit), phase two (IPF Survey) and phase three (qualitative interviews) was provided along with points of integration. Relevant information includes the study's recruitment strategy, sampling procedures, data collection methods, the inclusion of pilot study and data analysis.

This chapter has outlined the methodological approach taken across all three study phases of this sequential explanatory mixed-methods study. The study setting (Section 4.4), population and integrated sampling strategy (Section 4.5) and recruitment procedures (Section 4.6), have been described in detail. Phase one detailed the development of the audit tool (Section 4.7.1), while the survey instrument used in phase two are described with an overview of their reliability and validity (4.7.2), coupled with information on methods of distribution. Development of the qualitative interview guide, which was informed by findings from the preceding quantitative phase was described in Section 4.7.3.1. The statistical plan for quantitative data was outlined, with a rationale for the selection of statistical tests and the assumptions underpinning them (Section 4.8.1). Qualitative interviews were analysed, using reflexive thematic analysis allowing for deeper exploration of the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF, while leveraging the strength of participants' voices. The six phases of reflexive thematic analysis are explored in detail (Section 4.8.2.1). Overall, this chapter has provided a comprehensive step-by-step account of the methods used in this sequential explanatory mixed-methods study. Integration in this study was described in Section 4.9. The next chapter will present the results of data analysis, firstly for the quantitative phase (Chapter 5), followed by qualitative data (Chapter 6).

## Chapter 5 Quantitative Findings

### 5.1 Introduction

This chapter presents the research findings from the quantitative phase of this sequential explanatory mixed-method study, which aimed to investigate the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF. The findings from phase one (Healthcare Organisation Audit) and phase two (IPF Survey) are presented in this chapter. A description of the survey instruments used to address the study objectives are provided in Table 5.1.

**Overview of the data collected in phase one (Healthcare Organisation Audit)** (Section 5.2). This chapter commences with phase one data analysis (Healthcare Organisation Audit). Firstly, sample characteristics are provided, followed by descriptive and frequency statistics (Section 5.2.1-5.2.3).

**Overview of the data collected in phase two (IPF Survey)** (Section 5.3). This section focuses on the findings from the IPF survey (phase two). Firstly, recruitment and response rates for phase two are provided (Section 5.3.1). Next, descriptive statistics of survey data are provided, reporting on the unmet needs of people diagnosed with IPF (Section 5.3.2-5.3.3). Furthermore, an assessment of the information needs of the population of interest, using descriptive statistical analysis are provided (Section 5.3.4). Figures and tables illustrate the findings.

**An exploration of the symptom burden and quality of life (QoL) of people diagnosed with IPF** Section 5.4 reports on the secondary aim of this research, to explore the symptom experience and quality of life of people diagnosed with IPF using the St. George Respiratory Questionnaire-IPF (SGRQ-I). Descriptive statistics illustrated by figures and tables are supplied for this purpose (Section 5.4.1-5.4.2). Additionally, the most frequently reported impacts on quality of life are outlined (Section 5.4.3). The results of parametric and non-parametric statistical tests selected for this analysis are provided (Section 5.4.4-5.4.5).

**Secondary exploration of the symptom experience and quality of life (QoL) of people diagnosed with IPF** (Section 5.5). The IPF-PROM is used as a supplementary quality of life assessment tool. Descriptive statistics are supplied (Section 5.5.1-5.5.5), as too are the results of non-parametric statistical analysis (5.5.6-5.5.7).

**An evaluation of the explanatory factors that influence the quality of life (QoL) of people diagnosed with IPF** (Section 5.6). The results of Section 5.3-5.5 informed the development of a backward stepwise regression model, which explored the explanatory factors that influence participants' with IPF quality of life (dependent variable) assessed using the SGRQ-I and IPF-PROM. The independent variables selected for backward stepwise regression were statistically significant variables identified from the inferential statistical analysis findings. They included sociodemographic factors, clinical characteristics, access to supports and services and information needs.

**Table 5.1 Instruments Used to Address Study Aims and Objectives**

| <b>Aim and Objectives</b>                                                                                                                                                        |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Instrument</b>                                                                                                                                                                |
| <b>Objective 1: To identify the Unmet Needs of People Diagnosed with IPF</b>                                                                                                     |
| <b>Instrument</b>                                                                                                                                                                |
| <ul style="list-style-type: none"> <li>• <b>Instrument:</b> Healthcare Organisation Audit (phase one).</li> </ul>                                                                |
| <ul style="list-style-type: none"> <li>• <b>Instrument:</b> IPF Survey (phase two).</li> </ul>                                                                                   |
| <ul style="list-style-type: none"> <li>• <b>Instrument:</b> Lung Information Needs Questionnaire (LINQ) (phase two).</li> </ul>                                                  |
| <b>Objective 2: To explore the Symptom Experience and Quality of Life of People Diagnosed with IPF</b>                                                                           |
| <b>Instrument</b>                                                                                                                                                                |
| <ul style="list-style-type: none"> <li>• <b>Instrument:</b> St. George Respiratory Questionnaire-IPF (SGRQ-I) (phase two).</li> </ul>                                            |
| <ul style="list-style-type: none"> <li>• <b>Instrument:</b> IPF-PROM (phase two).<br/>(supplementary quality of life instrument to support findings from the SGRQ-I).</li> </ul> |

### 5.1.1 Missing Data Management Procedures

The management of missing data has previously been discussed in Chapter 4 (Section 4.8.1.1). Data cleaning was performed prior to analysis and identified missing values for the IPF-PROM survey instrument, with three participants identified as having missing values (0.8%). On further inspection of the dataset, there was minimal evidence of any further missing data. Only three participants had more than three missing cells (<1%), with missing values occurring randomly, resulting from non-completion of the survey, with no obvious trend observed in the missing values. It is reasonable to assume that the observed missing values occurred randomly rather than owing to a particular trend. Self-administered survey response items typically observe non-response to some items, which is usually attributed to a question missed due to, being overlooked, misunderstood, or intentionally skipped or forgotten (Groves & Peytcheva, 2008). To retain as much of the data as possible, it was decided to exclude cases pairwise during statistical analysis to maximise the full potential of participant responses where appropriate. Eliminating data pairwise ensures that data is included for analysis and only excluded if the missing data is required for analysis at that time (Kang, 2013).

## 5.2 Phase One (Healthcare Organisation Audit)

### 5.2.1 Phase One Summary Characteristics of the Sample

The healthcare professional sample in phase one were recruited from five national hospital sites across three healthcare regions (Public Health HSE West and Northwest, Southwest and Dublin and Midlands) (Chapter four, Figure 4.2). This national sample included a diverse group of healthcare professionals ( $N = 16/100\%$ ) consisting of respiratory nurse specialists/advanced nurse practitioners ( $n = 7/43.75\%$ ), consultant respiratory physicians and specialist respiratory registrars ( $n = 9/56.25\%$ ). Eighteen participant packs were distributed, with sixteen returned, representing a response rate of 88.8% between May 2022 to November 2023.

### 5.2.2 Phase One Descriptive Statistics

Descriptive statistical analysis (frequency values are represented by both numerical and percentage values) for the healthcare organisation audit (Table 5.2). Descriptive statistics were conducted to explore characteristics of the clinical environment, multidisciplinary team, access to pharmacological and non-pharmacological supports and overall healthcare access. Variability in access was evident, with several barriers affecting the availability of and referral to key supports and services. These included differences in access to pulmonary rehabilitation, lung transplantation assessment, clinical trials, and palliative care.

**Table 5.2 Healthcare Organisation Descriptive Statistics**

| Healthcare Organisation Audit Questions (N = 16)                                          | Yes        | No         |
|-------------------------------------------------------------------------------------------|------------|------------|
| Variable                                                                                  | Yes (n/%)  | No (n/%)   |
| <b>Clinical Environment</b>                                                               |            |            |
| Are patients involved in developing their personalised treatment plan?                    | 16 (100%)  | 0          |
| Are both face-to-face & telehealth consultation options available?                        | 14 (87.5%) | 2 (12.5%)  |
| Is there dedicated time for consultations with new patients?                              | 12 (75 %)  | 4 (25%)    |
| Is there a need to improve the consultation time at clinic for new patients?              | 10 (62.5%) | 6 (37.5%)  |
| <b>Access to Pharmacological Supports</b>                                                 |            |            |
| Ambulatory oxygen is fully re-imbursed                                                    | 10 (62.5%) | 6 (37.5%)  |
| Ambulatory oxygen is partially re-imbursed                                                | 3 (18.7%)  | 13 (81.2%) |
| Ambulatory oxygen is not re-imbursed                                                      | 3 (18.7%)  | 13 (81.2%) |
| <b>Availability and Referral to Supportive Services</b>                                   |            |            |
| Referral to lung transplantation assessment?                                              | 14 (87.5%) | 2 (12.5%)  |
| Barriers in referral to lung transplantation assessment?                                  | 6 (37.5%)  | 10 (62.5%) |
| Referral to pulmonary rehabilitation?                                                     | 13 (81.3%) | 3 (18.7%)  |
| Barriers in referral to pulmonary rehabilitation?                                         | 7 (43.8%)  | 9 (56.2%)  |
| Barriers in referral to counselling services?                                             | 12 (75%)   | 4 (25%)    |
| Barriers to clinical trial participation?                                                 | 8 (50%)    | 8 (50%)    |
| <b>Referral Practices to Palliative Care</b>                                              |            |            |
| Are end-of-life discussions had with patients and their families?                         | 15 (93.7%) | 1 (3.8%)   |
| Referral to palliative care between year one and two                                      | 3 (18.7%)  | 13 (81.3%) |
| Referral to palliative care between year two and three                                    | 5 (31.2%)  | 11 (68.3%) |
| Referral to palliative care between year three and five                                   | 4 (25%)    | 12 (75%)   |
| <b>Educational support/information options offered to patients with IPF at the clinic</b> |            |            |
| Educational written material                                                              | 13 (81.3%) | 3 (18.7%)  |
| Signposting to ILFA website                                                               | 10 (62.5%) | 6 (37.5%)  |
| Information on ILFA peer support groups                                                   | 11 (68.7%) | 5 (31.3%)  |
| Information on educational conferences/meetings                                           | 6 (37.5%)  | 10 (62.5%) |
| Telephone support lines                                                                   | 9 (56.3%)  | 7 (43.7%)  |

Healthcare professionals were asked to describe the composition of the multidisciplinary team who were available to care for patients with IPF at their centre (Table 5.3).

**Table 5.3 Healthcare Organisation Multidisciplinary Teams**

| Healthcare Organisation Audit Questions                       | Yes               | No              |
|---------------------------------------------------------------|-------------------|-----------------|
| <i>Variable</i>                                               | <i>Yes (N /%)</i> | <i>No N /%)</i> |
| <b><i>Healthcare Organisation Multidisciplinary Teams</i></b> |                   |                 |
| Consultant respiratory physician or pulmonologist             | 16 (100%)         | 0               |
| Consultant pathologist                                        | 12 (75%)          | 4 (25%)         |
| Rheumatologist                                                | 10 (65.3%)        | 6 (43.7%)       |
| Respiratory nurse specialist                                  | 6 (37.5%)         | 10 (62.5%)      |
| Physiotherapist                                               | 6 (37.5%)         | 10 (62.5%)      |
| Advanced nurse practitioner (respiratory)                     | 5 (31.3%)         | 11 (68.5%)      |
| Pharmacist                                                    | 2 (12.5%)         | 14 (87.5%)      |
| Medical social worker                                         | 0                 | 16 (100%)       |
| Psychologist/counsellor                                       | 0                 | 16 (100%)       |
| Occupational therapist                                        | 0                 | 16 (100%)       |
| <b><i>Frequency of Multidisciplinary Team Meetings</i></b>    |                   |                 |
| Weekly/biweekly                                               | 6 (37.5%)         | 10 (62.5%)      |
| Once a month or more                                          | 10 (62.5%)        | 6 (37.5%)       |

### 5.2.3 Phase One Summary

This section presented the results of the descriptive statistical analysis of the phase one healthcare organisation audit data ( $n = 16$ ), which aimed to understand the supports and services available to patients with IPF at each of the five healthcare organisation sites included in this study. Findings revealed that twelve healthcare professionals (HCPs) (75%) reported having dedicated clinic time for consultations with new patients diagnosed with IPF. However, 62.5% ( $n = 10$ ) of them believed improvements could be made to the allocated clinic time, as they felt there was insufficient time to spend on consultations with their patients. Most centres offered both face-to-face clinic visits and telehealth options (87.5%,  $n = 14$ ) with just two hospitals offering face-to-face clinic visits only (12.5%). HCPs reported that all patients with IPF are involved in developing their personalised treatment plan (100%,  $N = 16$ ).

Widespread national variability was observed in the provision of healthcare staff comprising the multidisciplinary team (MDT) providing care for people diagnosed with IPF. None of the included sites had provision for a social worker, occupational therapist, or psychologist/counsellor on their multidisciplinary team. A further 62.5% ( $n = 10$ ) of HCPs reporting no respiratory nurse specialist and 87.5% ( $n = 14$ ) reported no pharmacist on their multidisciplinary team. The frequency of multidisciplinary team meetings

varied, with some centres reporting weekly/biweekly meetings (37.5%,  $n = 6$ ) and others reporting the frequency of these meetings as monthly (62.5%,  $n = 10$ ). In most centres, ambulatory oxygen is fully reimbursed (62.5%,  $n = 10$ ), partially re-imbursed (18.7%,  $n = 3$ ) or in some cases not reimbursed (18.7%,  $n = 3$ ).

Most HCPs (87.5%,  $n = 14$ ) reported that they refer patients with IPF to specialist centres for lung transplantation assessment, although 37.5% of participants ( $n = 6$ ) reported barriers to such referrals. Most HCPs (81.3%,  $n = 13$ ) reported that patients are routinely referred for pulmonary rehabilitation, with barriers identified in this referral pathway by 43.8% ( $n = 7$ ). Nationally, there was limited provision for counselling services in the outpatient clinic with 75% of HCPs reporting barriers to this form of support ( $n = 12$ ). Timing of referral to palliative care differed, with most reporting that referrals take place in year two and year three post an IPF diagnosis (31.2%,  $n = 5$ ), followed by years three to five (25%,  $n = 4$ ). Referrals occurring in year one and two account for (18.7%,  $n = 3$ ) and similarly for those which occur in the first twelve months following an IPF diagnosis (18.7%,  $n = 3$ ). A further 6.3% ( $n = 1$ ) of referrals to palliative care occur more than five years after an IPF diagnosis. Most HCPs (93.7%,  $n = 15$ ) reported that end-of-life care is discussed with patients and their families, over the course of their disease. Deficits existed in clinical trial participation, with eight HCPs (50%) reporting that they do not invite patients to participate in clinical trials due to barriers in accessing clinical trial facilities. Signposting to a range of information resources varied with most HCPs (81.3%,  $n = 13$ ) offering patients with IPF educational written material, followed by information about the Irish Lung Fibrosis Association (ILFA), peer support groups (68.7%,  $n = 11$ ) and a further 62.5% ( $n = 10$ ) provided signposting to educational websites.

## **5.3 Phase Two (Idiopathic Pulmonary Fibrosis Survey)**

### **5.3.1 Phase Two Recruitment**

This section relates to survey data collected from people diagnosed with idiopathic pulmonary fibrosis (IPF) in phase two (IPF Survey). A total of two hundred participant recruitment packs were distributed at the five hospital recruitment sites (Chapter four, Figure 4.2), with a total of one hundred and seventy completed surveys returned, resulting in a raw response rate of >85% during the recruitment phase (July 2022 to January 2024) (Table 5.4). In addition, twenty-seven participants were recruited through online methods via Qualtrics, an online data collection platform used to collect the survey data, and forty additional participants chose to use postal methods to complete their survey. Due to the nature of the recruitment strategy, it is not possible to provide detailed information on participants who were either missed or declined to take part in the study. The breakdown of the response rate, including dispatched and returned surveys at each of the five hospital recruitment sites, is outlined in Table 5.5.



**Table 5.4 Methods Used for Participant Recruitment**

| Methods Used for Participant Recruitment           | <i>N</i> | % of the total sample |
|----------------------------------------------------|----------|-----------------------|
| Hospital recruitment sites (in-person recruitment) | 170      | 71.7                  |
| Postal recruitment                                 | 40       | 16.8                  |
| Online recruitment                                 | 27       | 11.39                 |
| Total recruitment                                  | 237      | 100                   |

Most participants were recruited from sites two and three, representing 50% of the total sample recruited from the five sites.

**Table 5.5 Survey Response Rates by Recruitment Sites**

| Healthcare Organisation   | Dispatched | Returned | Response Rate (%) |
|---------------------------|------------|----------|-------------------|
| Healthcare organisation 1 | 25         | 25       | 100               |
| Healthcare organisation 2 | 50         | 45       | 90                |
| Healthcare organisation 3 | 40         | 40       | 100               |
| Healthcare organisation 4 | 35         | 30       | 85.7              |
| Healthcare organisation 5 | 35         | 30       | 85.7              |
| Total response            | 185        | 170      | 91.8              |

### 5.3.2 Phase Two Descriptive Statistics

Descriptive statistical analysis (with frequency reported as both numerical counts and percentages) for the IPF Survey are presented in Table 5.6. The following sections will provide numerical data on sociodemographic variables along with data concerning healthcare access to address unmet needs. Descriptive analysis of the unmet needs of those with IPF will be guided by the Levesque healthcare access framework (2013). Unmet needs in this section relate to healthcare access, health insurance status, access to pharmacological/non-pharmacological supports, clinical trial access, geographical location (rural/urban), information needs, and additional support needs required by specific cohorts such as those living alone. Unmet needs in this study are defined as “the differences between those services judged necessary to deal appropriately with defined health problems and those services actually being received (Carr & Wolfe, 1976, p. 418). The mean age of participants was 75 years ( $SD = 9.2$ ,  $N = 237$ ) with an age range of 50 - >90 years.

One hundred and sixty-two participants were male (68.4%), representing a significantly larger representation of males than females (31.6%,  $n = 75$ ). Participants were mainly 'White Irish' (97.8%,  $n = 232$ ) with five participants identifying as 'any other white background' (2.1%). There were no other ethnic groups reported within this category. Participants were mainly retired (83%,  $n = 196$ ). Of all the participants, 27% had worked in manual labour jobs with potential occupational exposure such as dust particles, chemicals, fungal spores, and animal droppings ( $n = 64$ ).

**Table 5.6 Phase Two Descriptive Statistics**

| <b>IPF Survey (N = 237)</b>                               |                  |                 |
|-----------------------------------------------------------|------------------|-----------------|
| <b>Variable</b>                                           | <b>Yes N (%)</b> | <b>No N (%)</b> |
| <b>Gender</b>                                             |                  |                 |
| Male                                                      | 162 (68.4%)      | 75 (31.6%)      |
| Female                                                    | 75 (31.6%)       | 162 (68.4%)     |
| Prefer to self-describe                                   | 0                | 0               |
| <b>Age</b>                                                |                  |                 |
| 50-59 years                                               | 13 (5.4%)        | 224 (94.5%)     |
| 60-69 years                                               | 50 (21%)         | 187 (78.9%)     |
| 70-79 years                                               | 111 (46.8%)      | 126 (53%)       |
| 80-89 years                                               | 58 (24.4%)       | 179 (75.5%)     |
| 90 years                                                  | 5 (2.1%)         | 232 (97.8%)     |
| <b>Ethnicity</b>                                          |                  |                 |
| White Irish                                               | 232 (97.8%)      | 5 (2.1%)        |
| Any other white background                                | 5 (2.1%)         | 232 (97.8%)     |
| <b>Employment</b>                                         |                  |                 |
| Manual labour                                             | 80 (33.7%)       | 157 (66.2%)     |
| Manual labour with potential occupational exposures       | 64 (27%)         | 173 (72.9%)     |
| Transport work                                            | 38 (16%)         | 199 (83.9%)     |
| Administration                                            | 30 (12.6%)       | 207 (87.3%)     |
| Other                                                     | 25 (10.5)        | 212 (89.4%)     |
| <b>Geographical location</b>                              |                  |                 |
| Urban Location                                            | 167 (70.5%)      | 70 (29.5%)      |
| Rural location                                            | 70 (29.5%)       | 167 (70.5%)     |
| <b>Living within 20km of the tertiary hospital centre</b> |                  |                 |
| Living within 20km of the tertiary hospital centre        | 151 (63.7%)      | 86 (36.3%)      |
| Living >20km of the tertiary hospital centre              | 86 (36.3%)       | 151 (63.7%)     |

**Table 5.6 Phase Two Descriptive Statistics (Continued)**

| IPF Survey (N = 237)                                  |                  |                 |
|-------------------------------------------------------|------------------|-----------------|
| <i>Variable</i>                                       | <i>Yes N (%)</i> | <i>No N (%)</i> |
| <b>Living arrangements</b>                            |                  |                 |
| Living alone                                          | 121 (51%)        | 116 (49%)       |
| Living with others                                    | 116 (49%)        | 121 (51%)       |
| <b>Health Insurance</b>                               |                  |                 |
| Private health Insurance                              | 91 (38.3%)       | 146 (61.7%)     |
| Medical card                                          | 92 (38.8%)       | 145 (61.2%)     |
| Both a medical card & private health insurance        | 41 (17.3%)       | 196 (82.7%)     |
| Neither a medical card & private health insurance     | 13 (5.5%)        | 224 (94.5%)     |
| <b>Public or private hospital</b>                     |                  |                 |
| Attending a public hospital for treatment             | 207 (87.3%)      | 30 (12.6%)      |
| Attending a private hospital for treatment            | 8 (3.4%)         | 229 (96.6%)     |
| Attending both a public hospital & a private hospital | 22 (9.2%)        | 215 (90.7%)     |

Participants were asked to report their experience of access, to oxygen therapy and clinical trial access represented by binary yes/no responses (Table 5.7). Difficulties were reported by some participants regarding the reimbursement of portable oxygen therapy (37.1%,  $n = 26$ ). Access to research related to IPF was positively reported by 16.8% ( $n = 40$ ) of the sample. Whilst a further 83.1% ( $n = 197$ ) reported that they were not aware of research in this field.

**Table 5.7 Healthcare Access**

| IPF Survey (N = 237)                   |                  |                 |
|----------------------------------------|------------------|-----------------|
| <i>Variable</i>                        | <i>Yes N (%)</i> | <i>No N (%)</i> |
| Currently prescribed oxygen therapy?   | 70 (29.5%)       | 167 (70.4%)     |
| Is portable oxygen re-imbursed?        | 211 (89%)        | 26 (37.1%)      |
| Access to clinical trial/IPF research? | 40 (16.8%)       | 197 (83.1%)     |

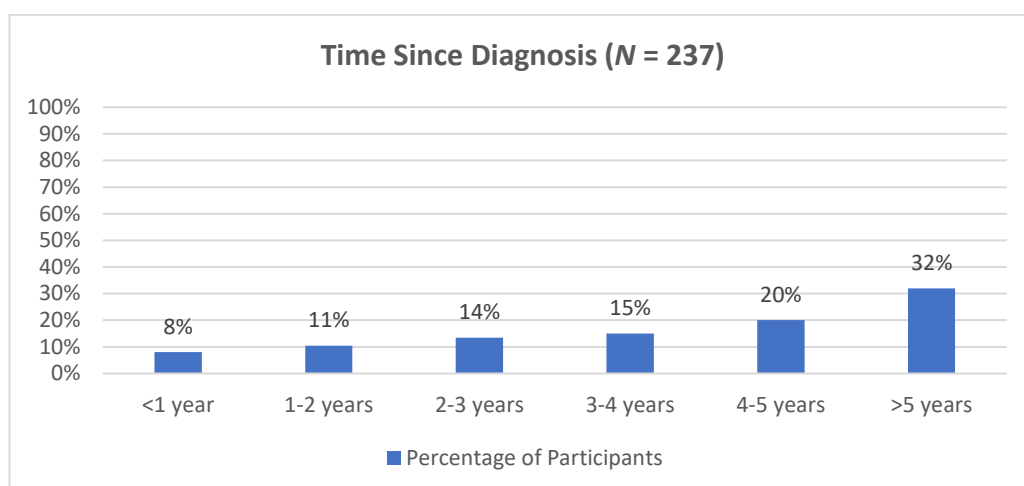
Participants were asked to report their experience of healthcare access, concerning prior referral and access to a range of healthcare professionals defined by binary yes/no responses (Table 5.8).

**Table 5.8 Self-Reported Experience of Healthcare Access**

| <b>Healthcare Access (N = 237)</b>  |          |          |
|-------------------------------------|----------|----------|
| <b>Variable</b>                     | <b>N</b> | <b>%</b> |
| <b>Specialist respiratory nurse</b> |          |          |
| Yes                                 | 170      | 71.7%    |
| No                                  | 67       | 28.3%    |
| <b>Physiotherapist</b>              |          |          |
| Yes                                 | 113      | 47.7%    |
| No                                  | 124      | 52.3%    |
| <b>Pulmonary rehabilitation</b>     |          |          |
| Yes                                 | 93       | 39.2%    |
| No                                  | 144      | 60.8%    |
| <b>ILFA support group</b>           |          |          |
| Yes                                 | 62       | 26.2%    |
| No                                  | 175      | 73.8%    |
| <b>Dietician</b>                    |          |          |
| Yes                                 | 17       | 7.2%     |
| No                                  | 220      | 92.8%    |
| <b>Psychologist/Counsellor</b>      |          |          |
| Yes                                 | 10       | 4.2%     |
| No                                  | 227      | 95.8%    |
| <b>Occupational therapist</b>       |          |          |
| Yes                                 | 10       | 4.2%     |
| No                                  | 227      | 95.8%    |
| <b>Palliative care</b>              |          |          |
| Yes                                 | 9        | 3.8%     |
| No                                  | 228      | 96.2%    |

Most participants were diagnosed more than five years ago (32%,  $n = 76$ ). Some, forty seven (20%) were diagnosed within the last four to five years. A further thirty five (15%) were diagnosed in the previous three to four years, with a combined seventy eight diagnosed in the last 0 -2 years (33%) (Figure 5.1).

**Figure 5.1 Time Since Diagnosis of IPF**



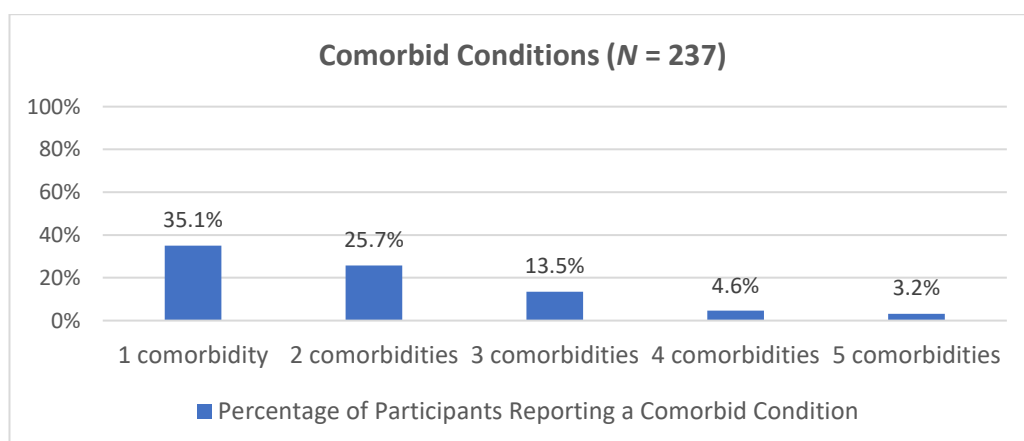
A total of 67.9% ( $n = 161$ ) of participants were currently prescribed antifibrotic medication (Table 5.9).

**Table 5.9 Treatment Interventions**

| Variable                | Response ( $N = 237$ )           | N  | %    |
|-------------------------|----------------------------------|----|------|
| Antifibrotic medication | Currently prescribed pirfenidone | 89 | 37.5 |
| Antifibrotic medication | Prior use of pirfenidone         | 37 | 15.6 |
| Antifibrotic medication | Currently prescribed nintedanib  | 72 | 30.4 |
| Antifibrotic medication | Prior use of nintedanib          | 32 | 13.5 |

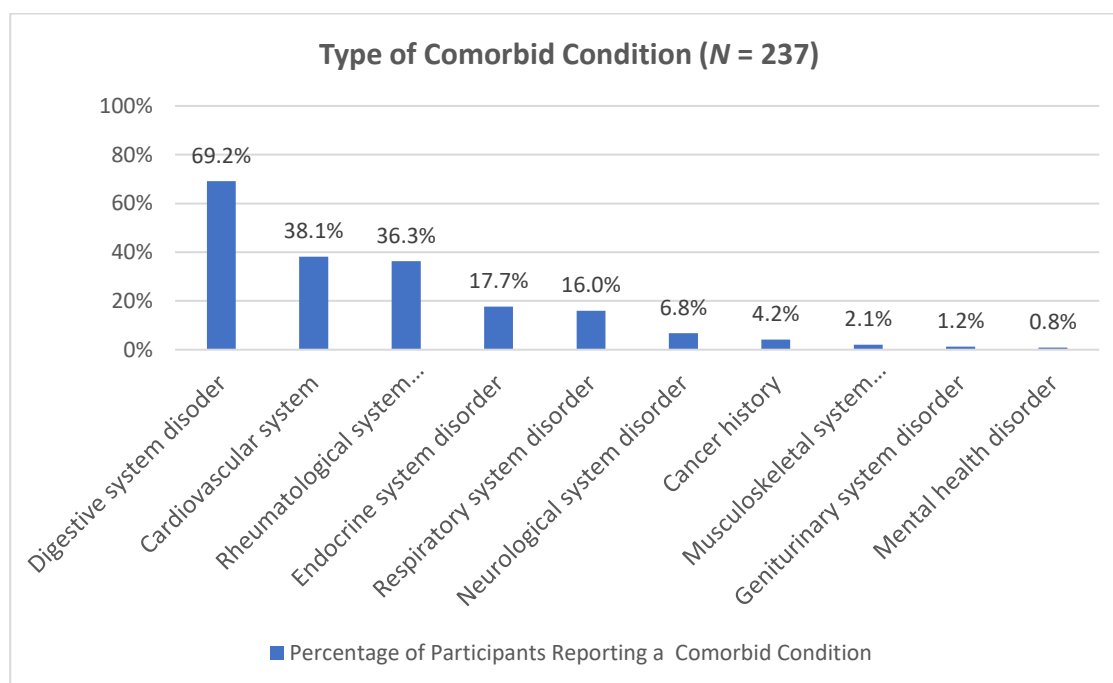
A total of 82.1% ( $n = 194$ ) of participants reported between one and five comorbid conditions (range 1-5 comorbid conditions). Eighty-three participants (35.1%) reported at least one comorbid condition, followed by two comorbid conditions (25.7%,  $n = 61$ ). A further 13.5% ( $n = 32$ ) reported three comorbid conditions, with 17.7% reporting no comorbid conditions ( $n = 42$ ) (Figure 5.2).

**Figure 5.2 Number of Comorbid Conditions Reported by Participants**



The most prevalent comorbid conditions were digestive system disorders (69.2%,  $n = 164$ ), cardiovascular system disorders (38.1%,  $n = 90$ ), rheumatological system disorders (36.3%,  $n = 86$ ) and endocrine system disorders (17.7%,  $n = 42$ ) (Figure 5.3).

**Figure 5.3 Classification of Comorbid Conditions**



### 5.3.3 Phase Two Descriptive Analysis of the Lung Information Needs Survey

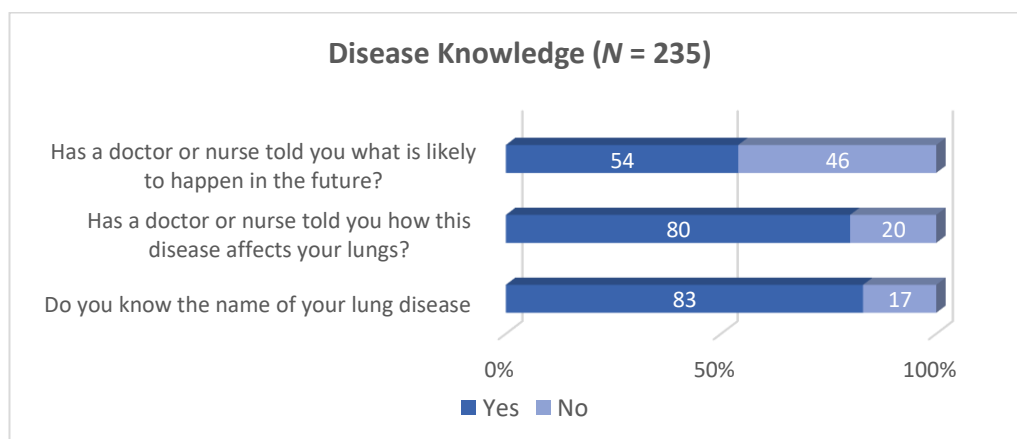
The Lung Information Needs Questionnaire (LINQ) was used to assess the information needs of people diagnosed with IPF in this study (Table 5.10). The highest theoretical score in the LINQ is 25 (range 0-25), with higher scores representing a greater information need. There are six subscales in the LINQ (disease knowledge, medication, self-management, exercise, smoking and diet). A total of 235 participants completed the LINQ (99.15%).

**Table 5.10 Lung Information Needs Questionnaire Subscale Items**

| LINQ Survey Instrument<br>(N = 235) | No. of Items | Median Score | SD   |
|-------------------------------------|--------------|--------------|------|
| LINQ TOTAL                          | 16           | 10           | 3.29 |
| Subscale 1: Disease knowledge       | 4            | 1            | 1.10 |
| Subscale 2: Medicines               | 3            | 2            | .892 |
| Subscale 3: Self-management         | 2            | 2            | 1.39 |
| Subscale 4: Exercise                | 3            | 2            | 1.04 |
| Subscale 5: Smoking                 | 3            | 1            | 1.13 |
| Subscale 6: Diet                    | 1            | 2            | .651 |

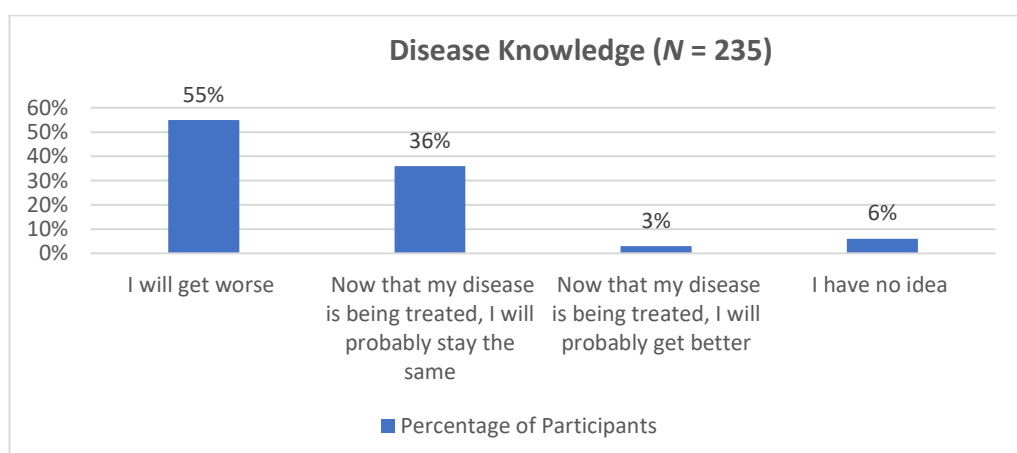
The following section provides a summary of descriptive survey data obtained from responses to the Lung Information Needs Questionnaire (LINQ). Participants were first asked to indicate their unmet information needs regarding **disease knowledge**. There are four questions in this subscale. Most participants reported that they knew the ‘name of their lung disease’ (83%,  $n = 195$ ), with a further 80% ( $n = 188$ ) reporting that a ‘doctor or nurse had told them how their disease affects their lungs’. Over half of the participants in this study reported that a healthcare professional had explained to them what is likely to happen in the future as regards their IPF (54%,  $n = 126$ ) (Figure 5.4).

**Figure 5.4 Subscale One Disease Knowledge**



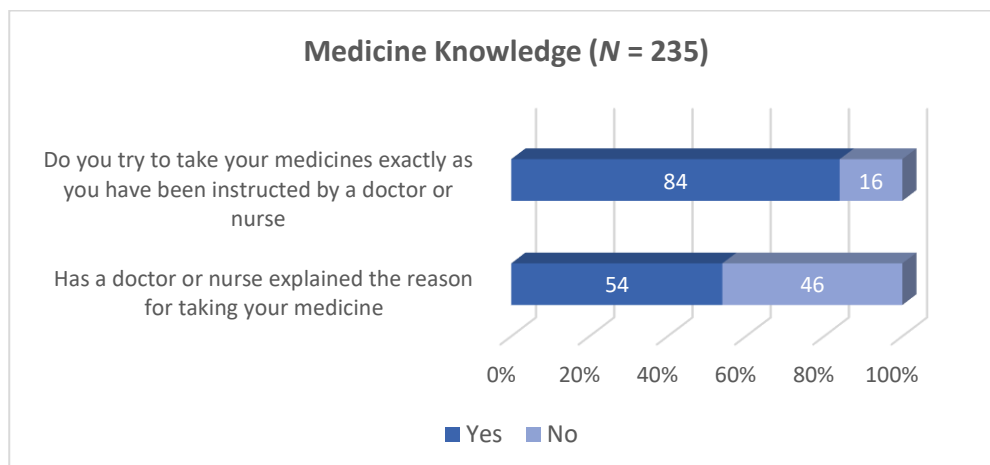
Information gaps were highlighted in the next section of the ‘**disease knowledge**’ subscale, regarding disease progression, with several response options offered. Over half (55%,  $n = 129$ ) of the sample reported that their disease will ‘get worse’, with a further 36% reporting that their disease will stay the same ( $n = 85$ ). A further 3% reported that they will ‘get better’ ( $n = 7$ ), with 6% reporting that they ‘have no idea’ about what will happen ( $n = 14$ ) (Figure 5.5).

**Figure 5.5 Subscale One Disease Knowledge**



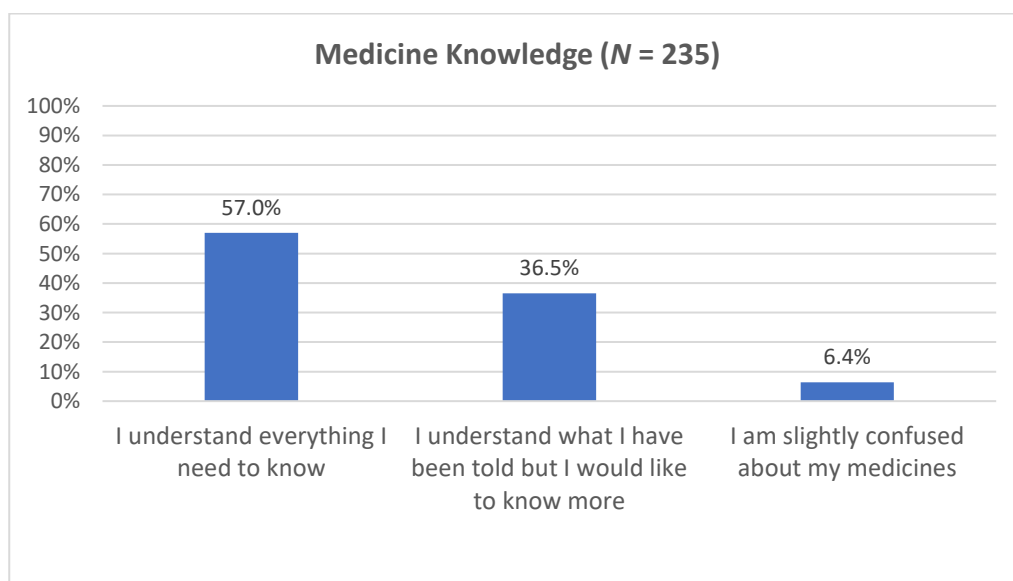
Participants were asked to report their unmet **medicine** information needs (three items). Some 54% ( $n = 126$ ) reported that a doctor or nurse had explained to them the reasons for taking their medicines. However, almost half (46%,  $n = 109$ ) reported that they had not been given this information. Despite this gap in information provision, a high percentage of participants reported that they tried to take their medicines as instructed (84%,  $n = 197$ ) (Figure 5.6).

**Figure 5.6 Subscale Two Medicine Knowledge**



Significantly 36.5% ( $n = 86$ ) of participants reported that they understood what they had been told about their medicines, but expressed a need to know more. A small proportion of participants (6.4%  $n = 15$ ) reported that they were still slightly confused about their medication. Over half of the sample (57%,  $n = 134$ ), reported that they understood everything they needed to know about their medication (Figure 5.7.).

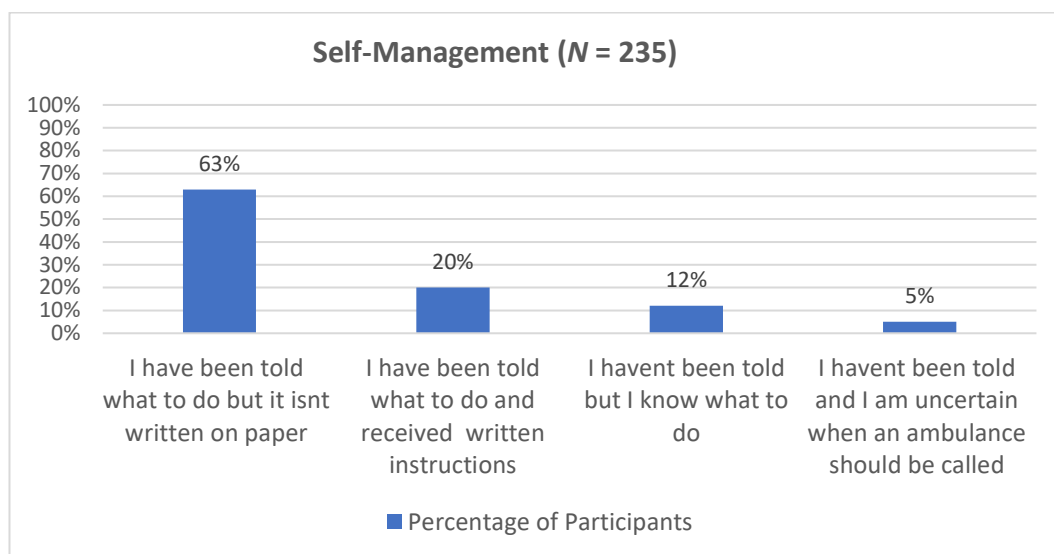
**Figure 5.7 Subscale Two Participants' Medicine Knowledge**





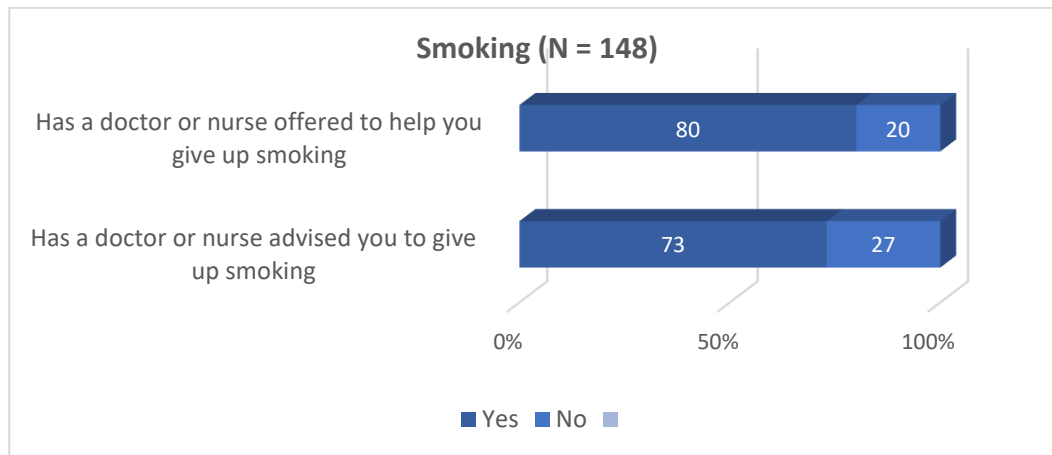
Many participants reported that they knew when to call an ambulance in the event of worsening breathlessness, but had not been given written instructions (63%,  $n = 148$ ). A further 20% reported that this information had been provided to them in written format ( $n = 47$ ). Additionally, 12% ( $n = 28$ ) reported that they hadn't been told what to do if they experienced worsening breathlessness but believed they would know what to do if this did happen. A small proportion (5%,  $n = 12$ ) reported that they had not been told what to do and were uncertain about when to call an ambulance in the event of requiring an ambulance due to worsening breathlessness (Figure 5.8).

**Figure 5.8 Subscale Three Self-Management Information Needs**



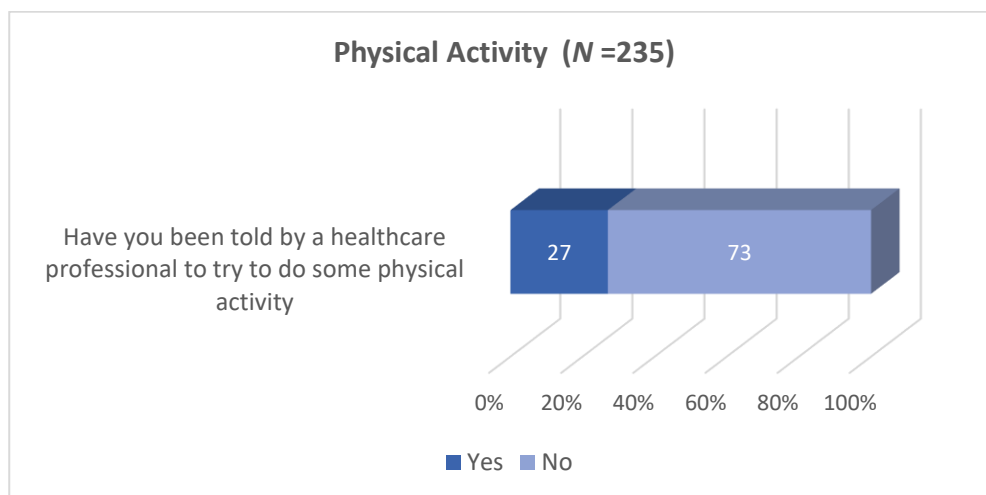
Participants were asked to identify **smoking** information needs in the fourth subscale, containing two items. Many participants reported being previous smokers (60%,  $n = 141$ ), while a much smaller number were still smoking (3%,  $n = 7$ ). A further 37% ( $n = 87$ ) reported that they had never smoked. Of those who had smoked or were still smoking ( $n = 148$ ), 27% ( $n = 40$ ) reported that they had never been advised to give up smoking by a healthcare professional, while 20% ( $n = 30$ ) had never been offered any help to give up smoking (Figure 5.9).

**Figure 5.9 Subscale Four Smoking Information Needs**



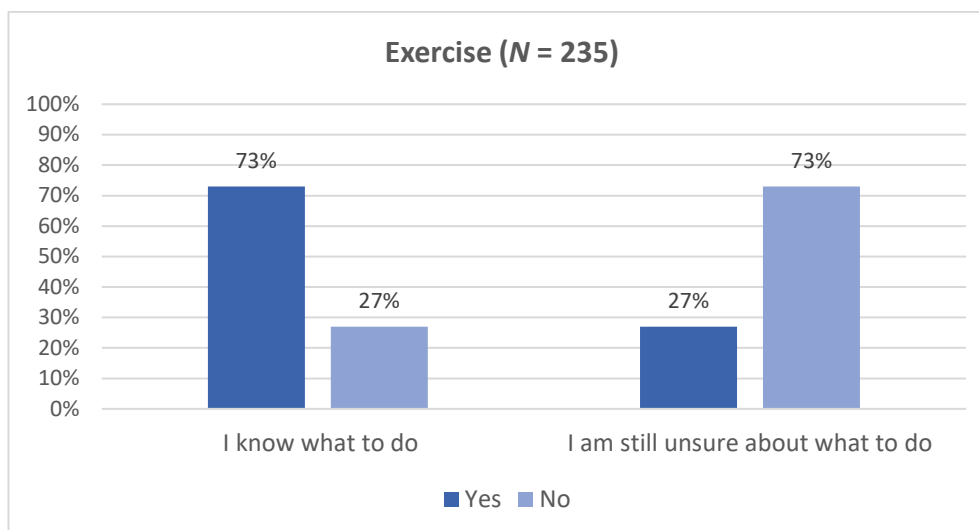
Participants were asked about their **exercise** information needs in the fifth subscale, containing three items, with 73% ( $n = 171$ ) of participants reporting that a doctor or nurse had not told them to do any physical activity (Figure 5.10).

**Figure 5.10 Subscale Five Exercise Information Needs**



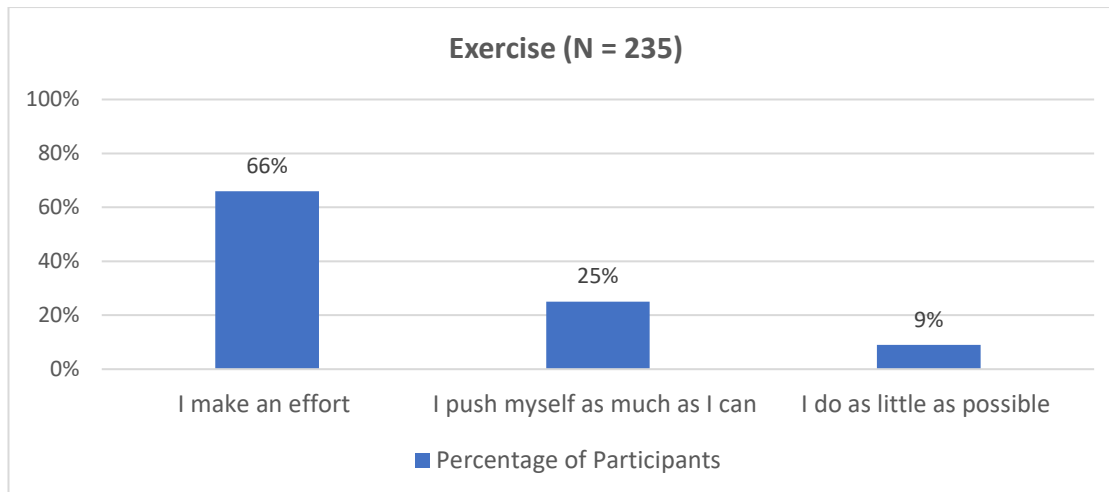
Most participants (73%,  $n = 171$ ) reported that they knew what to do regarding exercise. However, 27% ( $n = 63$ ) were still unsure about what exercises to do, indicating an information gap (Figure 5.11).

**Figure 5.11 Subscale Five Exercise Information Needs**



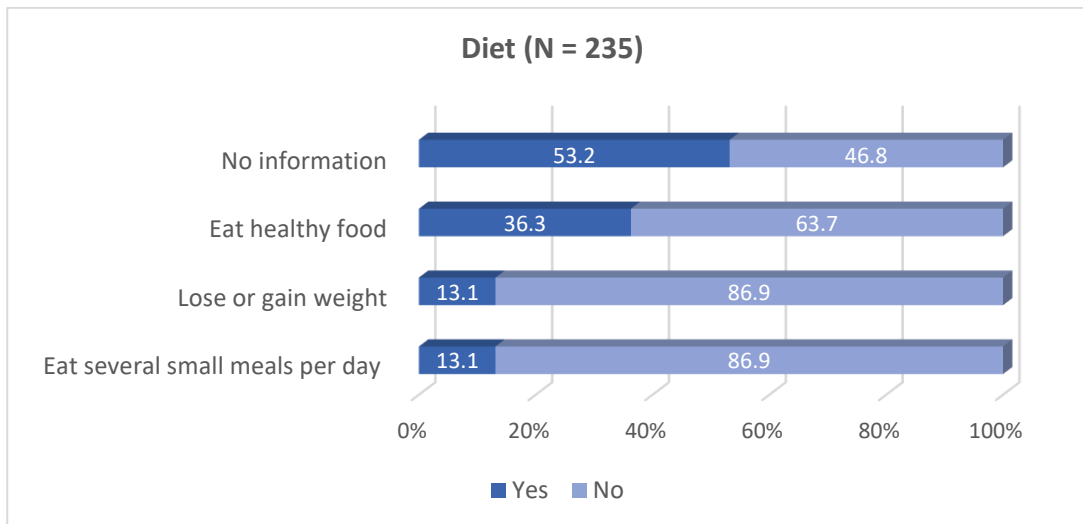
Participants were asked to select a response that best matched their approach to exercise. Participants reported that they either ‘made an effort’ with exercise (66%,  $n = 155$ ) or that they ‘pushed themselves as much as they could’ (25%,  $n = 59$ ). A smaller number reported that they did ‘as little exercise as possible’ (9%,  $n = 21$ ) (Figure 5.12).

**Figure 5.12 Subscale Five Exercise Information Needs**



The final subscale in the LINQ related to **diet** and included one item. Participants selected from multiple statements that best matched their situation as regards ‘diet’. Over half (53.2%  $n = 125$ ) reported that they had not been given information relating to their diet. Additionally, 36.3% ( $n = 85$ ) reported that a healthcare professional had advised them to eat healthy food. Some (13.1%  $n = 31$ ) wished to lose or gain weight. Another, 13.1% ( $n = 31$ ) opted to eat several small meals per day (Figure 5.13).

**Figure 5.13 Subscale Six Dietary Information Needs**



### 5.3.4 Lung Information Needs Inferential Data Analysis

A series of Mann-Whitney *U* tests were conducted to determine if there were statistically significant differences between lung information needs (dependent variable) and several independent variables of interest (Table 5.11).

#### 5.3.4.1 Lung Information Needs and Gender

Compared to being female, males had higher lung information needs in three of the six LINQ subscales, including smoking ( $p = .044$ ), diet ( $p = .019$ ) and disease knowledge subscales ( $p = .007$ ). Females, on the other hand, had higher information needs when compared to males in just one LINQ subscale, the self-management subscale ( $p = .009$ ). The other two subscales in the LINQ (exercise and medicine subscales) did not demonstrate statistically significant differences when compared with gender.

#### 5.3.4.1 Lung Information Needs and Living Arrangements

Compared to living with others, those who lived alone demonstrated higher disease knowledge information needs ( $p = .012$ ). In contrast, the self-management subscale found that those living with others had more information needs than those who lived alone ( $p = .012$ ). All other subscales in the LINQ did not demonstrate statistically significant differences when compared with living arrangements.

## 5.4 Phase Two Quality of Life and Symptom Experience

The secondary objective in this research was to understand the symptom experience and quality of life of people diagnosed with IPF. The primary quality of life measure in this study was the St. George Respiratory Questionnaire-IPF (SGRQ-I), and the secondary measure to assess quality of life is the IPF-patient-reported outcome measure (IPF-PROM). In both instruments, higher scores represent a poorer quality of life. Statistical analysis of the SGRQ-I will be reported first.

#### **5.4.1 Descriptive Statistics (SGRQ-I)**

The SGRQ-I provides an in-depth exploration of the quality of life and symptom burden of people diagnosed with IPF and supplements the assessment of unmet need previously discussed in Section 5.3 (Table 5.11). A total of 99.5% ( $N = 236$ ) of participants completed all three subscales in the SGRQ-I. The total theoretical scores for the SGRQ-I ranged from .00-2718.3 where higher scores represented poorer quality of life, with scores achieved in this study ranging from .00-2718.3 (median = 1377.30,  $SD = 544.65$ ) (Table 5.12). Descriptive statistics of the SGRQ-I subscales will be presented next.

**Table 5.11 Inferential Statistics to Examine Differences in Information Needs and Independent Variables**

| LINQ Subscales                   | <i>N</i> | Disease knowledge                                          | Medicines                                     | Self-Management                                             | Smoking                                                    | Exercise                                            | Diet                                                       |
|----------------------------------|----------|------------------------------------------------------------|-----------------------------------------------|-------------------------------------------------------------|------------------------------------------------------------|-----------------------------------------------------|------------------------------------------------------------|
| Gender <sup>a</sup>              |          | Mean Rank                                                  | Mean Rank                                     | Mean Rank                                                   | Mean Rank                                                  | Mean Rank                                           | Mean Rank                                                  |
| Male                             | 162      | 126.31                                                     | 123.36                                        | 111.26                                                      | 124.34                                                     | 117.69                                              | 124.79                                                     |
| Female                           | 74       | 101.39                                                     | 107.86                                        | 134.36                                                      | 105.71                                                     | 120.27                                              | 104.74                                                     |
| Test statistic                   |          | z=-2.71<br>( <i>U</i> =4728.00)<br><b><i>p</i> = .007*</b> | z =-1.76<br>( <i>U</i> =5207.00)<br>P = .078  | z =-2.60<br>( <i>U</i> =4820.50)<br><b><i>p</i> = .009*</b> | z =-2.01<br>( <i>U</i> =5047.50)<br><b><i>p</i> =.044*</b> | z =-.282<br>( <i>U</i> =5863.00)<br><i>p</i> = .778 | z =-2.34<br>( <i>U</i> =4975.0)<br><b><i>p</i> = .019*</b> |
| Living Arrangements <sup>a</sup> |          | Mean rank                                                  | Mean rank                                     | Mean rank                                                   | Mean rank                                                  | Mean rank                                           | Mean rank                                                  |
| Living alone                     | 100      | 130.45                                                     | 125.78                                        | 106.01                                                      | 108.14                                                     | 121.41                                              | 122.36                                                     |
| Living with others               | 135      | 108.78                                                     | 112.24                                        | 126.89                                                      | 117.90                                                     | 115.77                                              | 114.77                                                     |
| Test statistic                   |          | z =-2521<br>( <i>U</i> -505.00)<br><b><i>p</i> = .012*</b> | z =-1.646<br>( <i>U</i> =5972.50)<br>P = .100 | z =-2.52<br>( <i>U</i> =5550.50)<br><b><i>p</i> = .012*</b> | Z=-.027<br>( <i>U</i> =6736.50)<br><i>p</i> =.978          | z =-.693<br>( <i>U</i> =6409.00)<br><i>p</i> =.488  | z =-.949<br>( <i>U</i> =6314.00)<br><i>p</i> = .343        |

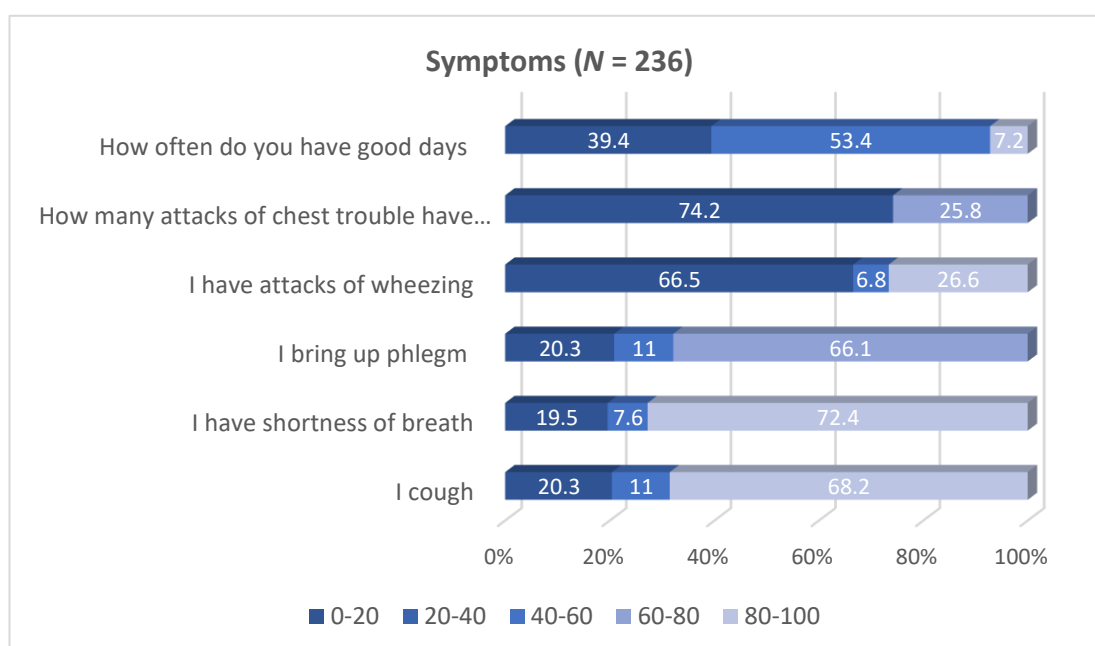
Key: \*  $p < 0.05$ , <sup>a</sup> Mann-Whitney U tests for binary categorical variables

**Table 5.12 SGRQ-I Scoring**

| SGRQ-I             | N   | Range of Scores | Median Score | SD     | No. of Items |
|--------------------|-----|-----------------|--------------|--------|--------------|
| <b>Total score</b> | 236 | .00-2720.30     | 1377.30      | 544.65 | 34           |
| <b>Symptoms</b>    | 236 | .00-490.30      | 246.85       | 116.30 | 6            |
| <b>Activity</b>    | 236 | .00-746.50      | 500.70       | 217.83 | 10           |
| <b>Impacts</b>     | 236 | .00-1483.50     | 601.90       | 320.43 | 18           |

#### 5.4.1.1 Symptoms Subscale

Symptoms experienced almost every day by participants included cough (68.2%,  $n = 161$ ), production of phlegm (66.1%,  $n = 156$ ), and shortness of breath (72.4%,  $n = 171$ ), observed in the distribution of scores mostly in the upper 60-80 and 80-100 range, respectively (range 0-100). A notable proportion of participants have attacks of wheezing almost daily (26.6%,  $n = 63$ ). A smaller percentage, 25.8% reported attacks of chest trouble almost every day ( $n = 61$ ). Some 39% of participants reported that they experienced no 'good days' ( $n = 92$ ) (Figure 5.14).

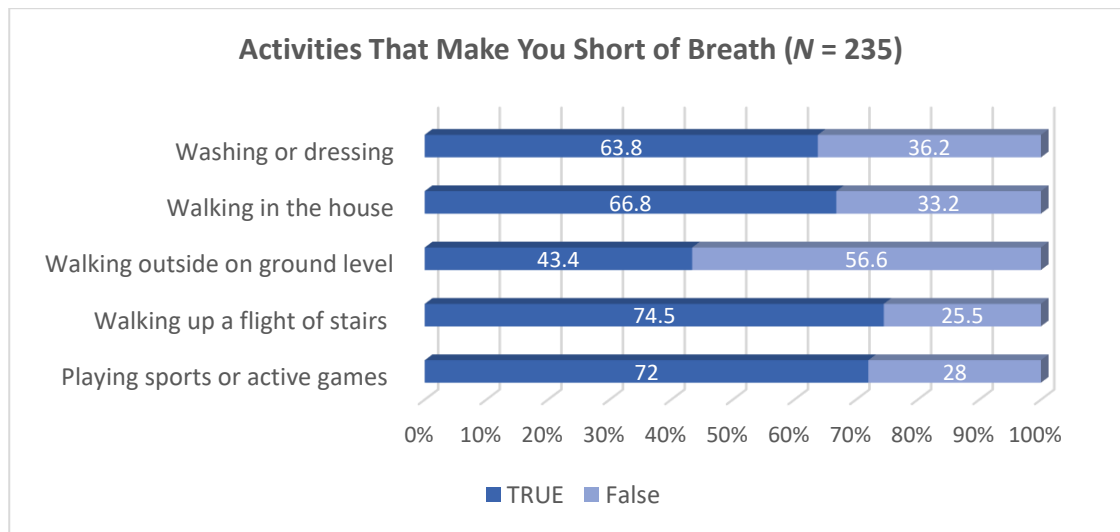
**Figure 5.14 Symptoms Subscale**

#### 5.4.1.2 Activities Subscale

Most participants reported that playing sports or games (72%,  $n = 170$ ) and walking up a flight of stairs (74.5%,  $n = 176$ ) were the most difficult activities due to their experience of breathlessness. Indeed, a significant proportion experienced breathlessness even when walking on a level surface outside the house (43.4%,  $n = 102$ ) and when walking within their homes (66.8%,  $n = 158$ ). Daily activities such as hygiene

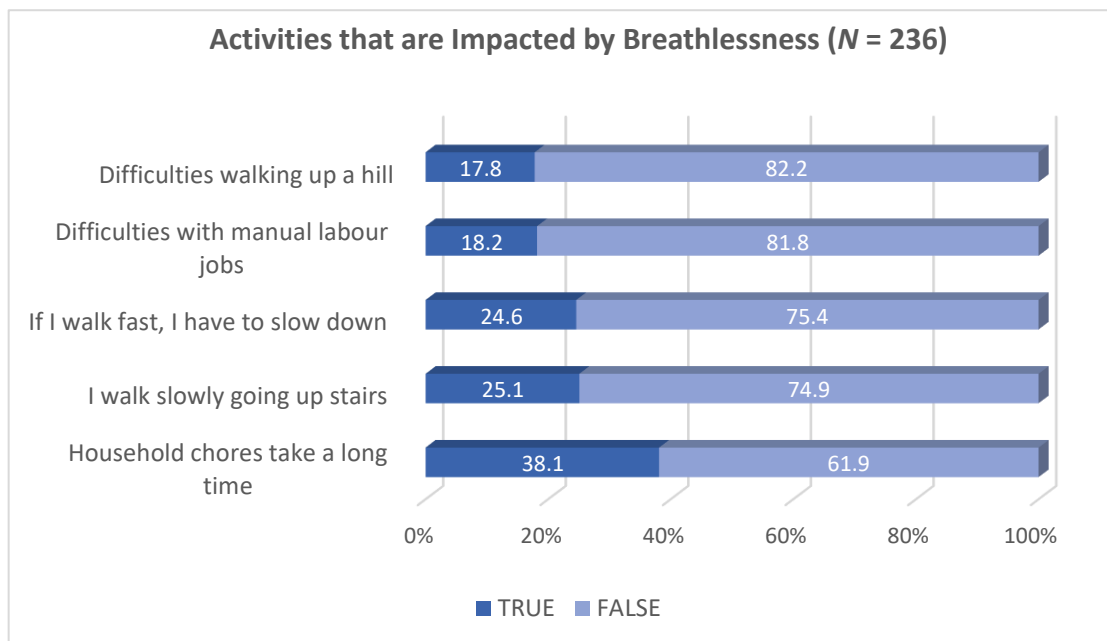
was associated with breathlessness for just over a third of participants, indicating significant debilitation from shortness of breath (63.8%,  $n = 150$ ) (Figure 5.15).

**Figure 5.15 Activities Subscale**



Participants reported that their breathing problems impacted their ability to do a variety of activities, including walking up a hill (17.8%,  $n = 42$ ) or manual labour (18.2%,  $n = 43$ ). Participants reported having to go slowly walking up a flight of stairs (25.1%,  $n = 59$ ). Almost a quarter of participants (24.6%) reported that if they hurried or walked fast, they would have to slow down or stop due to breathlessness ( $n = 58$ ). Household chores were impacted by breathlessness in a significant proportion of the sample (38.1%,  $n = 90$ ) (Figure 5.16).

**Figure 5.16 Activities Subscale**





#### 5.4.1.3 Impacts Subscale

A significant portion of participants reported that their lung condition interfered or made them stop work (53.3%,  $n = 126$ ) with 83% reporting that they were retired ( $n = 196$ ). Almost 70% ( $n = 165$ ) of participants reported that they got exhausted easily with a further 40% ( $n = 94$ ) reporting that their cough made them tired. Sleep disturbances impacted by cough or breathing problems were reported by 68% of participants ( $n = 160$ ). Breathlessness (50%,  $n = 118$ ) was an issue when bending or talking (50%,  $n = 118$ ). A large portion of participants (84%,  $n = 198$ ) reported that their cough did not hurt.

Many participants found their cough or breathing to be embarrassing in public (35.1%,  $n = 83$ ) and a further 36% ( $n = 85$ ) reported that they thought their chest trouble was a nuisance to family or friends. Significantly, a large proportion of participants reported that everything seemed too much of an effort (55%,  $n = 130$ ) with a further 42% ( $n = 99$ ) believing that exercise was not safe for them. Moreover, 38% ( $n = 89$ ) of participants felt panic or were afraid when they could not breathe, and 48% ( $n = 113$ ) reported that they believed they were not in control of their chest problem. Most people reported that leaving the house to do shopping (80%,  $n = 188$ ), household chores (80%,  $n = 188$ ) and moving from bed to a chair (100%,  $n = 236$ ) were not problematic in terms of breathlessness. However, the ability to play sports or games was reported as challenging by participants (75%,  $n = 177$ ) (Figure 5.17).

#### 5.4.2 Quality of life Experiences of Participants (SGRQ-I)

The top six responses in the category 'true' for binary response items (true or false) were situated across the 'activity' and 'impacts' subscales of the SGRQ-I and are presented in Table 5.13. Responses in the symptom's subscale were not collected as binary responses in the first instance and, therefore, not included in the table. However, data from the symptom's subscale suggests that the highest scoring symptoms reported by participants were shortness of breath (72.4%,  $n = 171$ ), followed by cough (68.2%,  $n = 161$ ).

**Table 5.13 Highest Scoring Items on the SGRQ-I**

| Top Six Highest Scoring Items (SGRQ-I) ( $N = 236$ ) | $N$ | %    | Subscale |
|------------------------------------------------------|-----|------|----------|
| Walking up a flight of stairs                        | 176 | 74.5 | Activity |
| I cannot play sports                                 | 177 | 75   | Impact   |
| Playing sports or other games                        | 170 | 72.1 | Activity |
| I become exhausted easily                            | 165 | 70   | Impact   |
| My cough or breathing disturbs my sleep              | 160 | 68   | Impact   |
| Walking in the house                                 | 158 | 66.8 | Activity |

### 5.4.3 Inferential Analysis (SGRQ-I)

Inferential statistical analysis was conducted to identify significant differences between participants with IPF' quality of life (dependent variable) and several independent variables, including sociodemographic, clinical factors, information needs and access to healthcare supports and services (Section 5.4.4). Considering first the total scale score for the SGRQ-I, visual inspection of the boxplot indicates that the data does not have any outliers, and variances are concluded to be homogenous after assessment of Levene's test for equality of variances (Levene, 1960). Normality tests indicate that the SGRQ-I satisfied the criteria for normality of the data, and therefore, parametric tests were selected for data analysis, including one-way ANOVA and independent samples *t*-test (Table 5.14).

The distribution of values for the SGRQ-I subscales (symptoms, impacts and activity) was assessed as irregular and did not follow a normal distribution. Therefore, non-parametric statistics, including Mann-Whitney *U* tests for binary categorical data and Kruskal-Wallis *H* tests for more than two categorical variables, were used for data analysis. Mean rank scores were used rather than median scores, where significant differences in scores were investigated. Findings from inferential data analysis informed a backward stepwise regression model presented in Section 5.6. The results of both parametric and non-parametric tests are presented throughout this section.

**Figure 5.17 Impacts Due to IPF Reported by Participants by Item**

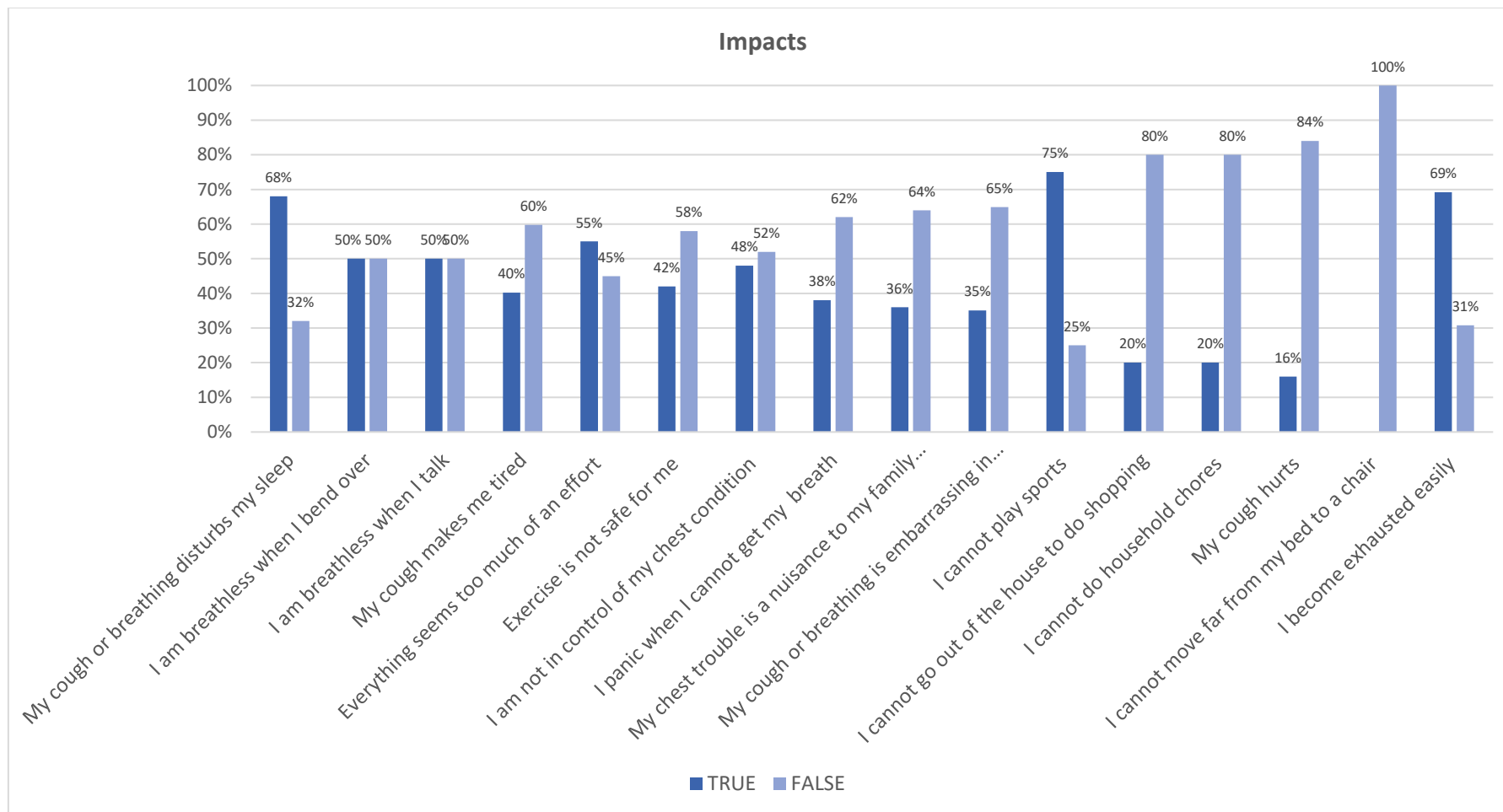


**Table 5.14 SGRQ-I Normality Tests**

| SGRQ-I            | Mean    | Standard Deviation | 5% Trimmed Mean | Skewness | Kurtosis | Kolmogorov-Smirnov Sig. | Shapiro-Wilk Sig. |
|-------------------|---------|--------------------|-----------------|----------|----------|-------------------------|-------------------|
| Symptoms subscale | 258.59  | 115.09             | 258.68          | .055     | -.716    | .062 (0.36)             | .979 (.003)       |
| Activity subscale | 468.27  | 215.67             | 478.82          | -.482    | -.599    | .121 (<.001)            | .933 (<.001)      |
| Impacts subscale  | 598.13  | 320.43             | 588.62          | .371     | -.208    | .071 (.009)             | .978 (.002)       |
| Total Scale       | 1324.99 | 544.65             | 1323.84         | .024     | -.177    | .050 (.200)             | .994 (.551)       |

#### 5.4.4 St. George Respiratory Questionnaire IPF (SGRQ-I)

The primary measurement instrument for quality of life in this study was the St. George Respiratory Questionnaire-IPF (SGRQ-I). A series of parametric tests, including One-Way ANOVA and independent sample *t*-tests were utilised to compare the data (Table 5.15-5.17). The variables of interest selected for analysis were those identified in phase two (IPF Survey) and included sociodemographic factors, clinical factors, information needs and access to healthcare supports and services.

**One-way ANOVA:** The relevant variables that demonstrated statistically significant differences between independent variables assessed against total quality of life scores using a One-way ANOVA ( $p < .05$ ,  $N = 236$ ) were health insurance status ( $F(3,217) = 3.12$ ,  $p = .027$ ), having a comorbid condition ( $F(6,214) = 2.61$ ,  $p = .018$ ) and having previously been prescribed pirfenidone ( $F(2,218) = 3.16$ ,  $p = .044$ ) or having previously been prescribed nintedanib ( $F(2,218) = 6.27$ ,  $p = .002$ ).

Further analysis of comorbid conditions and health insurance status using Tukey's Honestly Significant Differences post-hoc tests was undertaken. This test helped to determine what number of participants who self-reported a comorbid condition(s) demonstrated the highest and lowest changes in reported mean scores. Comorbid conditions in this study ranged from zero to six comorbid conditions. Participants who reported having at least three comorbid conditions ( $n = 32$ ) had significantly worse quality of life compared to those who reported having just one comorbid condition ( $n = 83$ ) ( $p = .015$ ).

Similarly, a Tukey's Honestly Significant Differences post-hoc test was used to determine what combination of health insurance status (public, private, a combination of both or neither) represented a statistically significant mean difference in scores. This test indicated that participants who had private health insurance ( $n = 91$ ) had significantly better quality of life than those who reported having only a medical card ( $n = 92$ ) ( $p = .047$ ).

**Independent Samples T-Test:** Further analysis of the data using an independent samples *t*-test revealed that those who lived more than 20km from their treatment centre (mean = 1418.39, SD = 527.39,  $n = 85$ ) compared to those that lived within a 20km radius of their treatment centre (mean = 1269.91, SD = 549.02,  $n = 151$ ) demonstrated statistically significant, worse quality of life scores ( $t(219) = 1.99$ ,  $p = .048$ ). Females (mean = 1461.94, SD = 474.30,  $n = 74$ ) compared to males (mean = 1265.62, SD = 565.52,  $n = 162$ ) had statistically significant worse quality of life scores ( $t(148.7) = -2.66$ ,  $p = .009$ ). Finally, those who had previously been asked to participate in a clinical trial (mean = 1136.89, SD = 588.75,  $n = 40$ ) had a better quality of life compared to those that had not been asked to participate in a clinical trial (mean = 1362.82, SD = 529.00,  $n = 196$ ), ( $t(219) = -2.32$ ,  $p = .021$ ). Similarly, participants with an awareness of clinical trials (mean = 1113.00, SD = 500.62,  $n = 46$ ) compared to participants not aware of clinical trials (mean = 1371.85, SD = 544.13,  $n = 190$ ) reported better quality of life ( $t(219) = -2.76$ ,  $p = .006$ ).

At the time of data collection, there were seventy people who reported that they were prescribed ambulatory oxygen (mean = 1627.17, SD = 510.20). Participants who had been prescribed oxygen therapy ( $n = 70$ ) had significantly worse quality of life ( $t(219) = 5.62$ ,  $p < .001$ ) compared to participants who had

not been prescribed oxygen therapy (mean = 1201.82, SD = 510.39,  $n = 166$ ). Those who reported having an endocrine system disorder (mean = 1112.44, SD = 584.74,  $n = 42$ ) demonstrated better quality of life ( $t(219) = 2.13$ ,  $p = .034$ ) compared to those who didn't have an endocrine system disorder (mean = 1353.33, SD = 534.72,  $n = 195$ ).

Participants who lived with others (mean = 1262.54, SD = 543.90,  $n = 115$ ) had statistically significant better quality of life compared to those that lived alone (mean = 1406.31, SD = 537.62,  $n = 121$ ), ( $t(219) = 1.96$ ,  $p = .050$ ). None of the eight disease areas (history of cancer, respiratory system, musculoskeletal system, digestive system, genitourinary system, neurological system, mental health or 'other') demonstrated statistically significant differences in overall mean scores except for 'endocrine system disorder'  $p < 0.05$ .

**Table 5.15 Inferential Statistical Analysis to Identify Sociodemographic Factors Associated with Differences in Participants' SGRQ-I Scores**

| St. George Respiratory Questionnaire-IPF (SGRQ-I) |          |         |        |                 |           |          |          |              |
|---------------------------------------------------|----------|---------|--------|-----------------|-----------|----------|----------|--------------|
| Groups                                            | <i>N</i> | Mean    | SD     | CI              | <i>df</i> | <i>F</i> | <i>t</i> | <i>P</i>     |
| <b>Gender <sup>b</sup></b>                        |          |         |        | -342.16, -50.46 | 148.7     |          | -2.66    | <b>.009*</b> |
| Male                                              | 162      | 1265.62 | 565.52 |                 |           |          |          |              |
| Female                                            | 74       | 1461.94 | 474.39 |                 |           |          |          |              |
| <b>Age Groups <sup>a</sup></b>                    |          |         |        |                 | 4,216     | .698     |          | .594         |
| 50-59                                             | 13       | 1411.26 | 580.98 |                 |           |          |          |              |
| 60-69                                             | 50       | 1269.59 | 522.99 |                 |           |          |          |              |
| 70-79                                             | 111      | 1336.19 | 585.60 |                 |           |          |          |              |
| 80-89                                             | 58       | 1479.98 | 102.25 |                 |           |          |          |              |
| >90                                               | 4        | 1450.80 | 101.20 |                 |           |          |          |              |
| <b>Health Insurance Status <sup>a</sup></b>       |          |         |        |                 | 3,217     | 3.12     |          | <b>.027*</b> |
| Private health insurance                          | 91       | 1233.90 | 554.43 |                 |           |          |          |              |
| Medical card                                      | 92       | 1449.32 | 543.77 |                 |           |          |          |              |
| Both medical card/ private health insurance       | 41       | 1202.32 | 554.59 |                 |           |          |          |              |
| Neither medical card/ private health insurance    | 12       | 1397.84 | 156.83 |                 |           |          |          |              |
| <b>Residence Area <sup>b</sup></b>                |          |         |        | -274.59, 48.166 | 219       |          | -1.39    | .167         |
| Urban                                             | 166      | 1291.70 | 537.36 |                 |           |          |          |              |
| Rural                                             | 70       | 1404.92 | 557.86 |                 |           |          |          |              |
| Living alone                                      | 121      | 1406.31 | 537.62 |                 |           |          |          |              |

Key: \* $P < .05$ , <sup>a</sup> one-way ANOVA for more than two categorical variables, <sup>b</sup> independent samples t-tests for binary categorical variable

**Table 5.15 Inferential Statistical Analysis to Identify Socio-Demographic Factors Associated with Differences in Participants' SGRQ-I Scores (Continued)**

| St. George Respiratory Questionnaire-IPF (SGRQ-I)           |     |         |        |              |       |      |      |              |
|-------------------------------------------------------------|-----|---------|--------|--------------|-------|------|------|--------------|
| Groups                                                      | N   | Mean    | SD     | CI           | df    | F    | t    | P            |
| <b>Living More than 20km from the Hospital <sup>b</sup></b> |     |         |        | 1.31, 295.64 | 219   |      | 1.99 | <b>.048*</b> |
| Yes                                                         | 85  | 1418.39 | 527.39 |              |       |      |      |              |
| No                                                          | 151 | 1269.91 | 549.02 |              |       |      |      |              |
| <b>Living Arrangements <sup>b</sup></b>                     |     |         |        | -.80, 288.34 | 219   |      | 1.96 | <b>.050*</b> |
| Living with others                                          | 115 | 1262.54 | 543.90 |              |       |      |      |              |
| Living alone                                                | 121 | 1406.31 | 537.62 |              |       |      |      |              |
| <b>Hospital Type <sup>a</sup></b>                           |     |         |        |              | 3,217 | .521 |      | .668         |
| Public hospital                                             | 207 | 1332.48 | 556.36 |              |       |      |      |              |
| Private hospital                                            | 8   | 1467.98 | 612.85 |              |       |      |      |              |
| Both private and public                                     | 21  | 1211.07 | 365.53 |              |       |      |      |              |

Key: \*P<0.05, <sup>a</sup> one-way ANOVA for more than two categorical variables, <sup>b</sup> independent samples t-tests for binary categorical variables



**Table 5.16 Inferential Statistical Analysis to Identify Clinical Factors Associated with Differences in Participants' SGRQ-I Scores**

| St. George Respiratory Questionnaire-IPF (SGRQ-I)     |          |         |        |               |           |          |          |          |
|-------------------------------------------------------|----------|---------|--------|---------------|-----------|----------|----------|----------|
| Groups                                                | <i>N</i> | Mean    | SD     | CI            | <i>df</i> | <i>F</i> | <i>t</i> | <i>P</i> |
| <b>Prescribed Ninetedanib <sup>b</sup></b>            |          |         |        | -304.33, 6.55 | 2,215     |          | 1.88     | .827     |
| Yes                                                   | 72       | 1221.23 | 549.89 |               |           |          |          |          |
| No                                                    | 164      | 1370.11 | 536.85 |               |           |          |          |          |
| <b>Previously Prescribed Ninetedanib <sup>a</sup></b> |          |         |        |               | 2,218     | .6273    |          | .002*    |
| Yes                                                   | 32       | 1393.12 | 479.15 |               |           |          |          |          |
| No                                                    | 195      | 1296.36 | 536.78 |               |           |          |          |          |
| Not sure                                              | 9        | 2136.24 | 565.90 |               |           |          |          |          |
| <b>Prescribed Pirfenidone <sup>b</sup></b>            |          |         |        | 17.84, 280.50 | 217       |          | 1.73     | .042*    |
| Yes                                                   | 89       | 1402.59 | 485.12 |               |           |          |          |          |
| No                                                    | 147      | 1271.26 | 573.32 |               |           |          |          |          |
| <b>Previously Prescribed Pirfenidone <sup>a</sup></b> |          |         |        |               | 2,218     | 3.16     |          | .044*    |
| Yes                                                   | 37       | 1321.92 | 680.64 |               |           |          |          |          |
| No                                                    | 190      | 1308.39 | 511.82 |               |           |          |          |          |
| Not sure                                              | 9        | 1870.58 | 824.40 |               |           |          |          |          |
| <b>History of an Endocrine Disorder <sup>b</sup></b>  |          |         |        | 18.57, 463.21 | 219       |          | 2.135    | .034*    |
| Yes                                                   | 41       | 1112.44 | 581.74 |               |           |          |          |          |
| No                                                    | 195      | 1353.33 | 534.72 |               |           |          |          |          |

Key: \*P<0.05, <sup>a</sup> one-way ANOVA for more than two categorical variables, <sup>b</sup> independent samples t-tests for binary categorical variables

**Table 5.16 Inferential Statistical Analysis to Identify Clinical Factors Associated with Differences in Participants' SGRQ-I Scores (Continued)**

| St. George Respiratory Questionnaire-IPF (SGRQ-I)      |     |         |         |               |       |      |      |        |
|--------------------------------------------------------|-----|---------|---------|---------------|-------|------|------|--------|
|                                                        | N   | Mean    | SD      | CI            | df    | f    | t    | p      |
| <b>Prescribed Oxygen <sup>a</sup></b>                  |     |         |         | 276.18,574.51 | 219   | ~    | 5.62 | <.001* |
| Yes                                                    | 70  | 1627.16 | 510.20  |               |       |      |      |        |
| No                                                     | 166 | 1201.82 | 510.39  |               |       |      |      |        |
| <b>Cost of Portable Oxygen Reimbursed <sup>b</sup></b> |     |         |         | ~             | 3,60  | .388 | ~    | .792   |
| Yes                                                    | 44  | 1571.65 | 569.04  |               |       |      |      |        |
| No                                                     | 17  | 1713.45 | 477.44  |               |       |      |      |        |
| Yes, in part                                           | 9   | 1724.59 | 288.98  |               |       |      |      |        |
| <b>Comorbid Condition <sup>b</sup></b>                 |     |         |         | ~             | 6,214 | 2.61 | ~    | .018*  |
| 0                                                      | 42  | 1258.46 | 527.66  |               |       |      |      |        |
| 1                                                      | 83  | 1252.47 | 536.10  |               |       |      |      |        |
| 2                                                      | 61  | 1357.44 | 501.12  |               |       |      |      |        |
| 3                                                      | 32  | 1635.01 | 504.35  |               |       |      |      |        |
| 4                                                      | 11  | 1169.18 | 473.71  |               |       |      |      |        |
| 5                                                      | 7   | 984.50  | 1029.09 |               |       |      |      |        |

Key: \*P<0.05, <sup>a</sup> Independent sample t-test for binary categorical variables, <sup>b</sup>one-way ANOVA for more than two categorical variables

**Table 5.17 Inferential Statistical Analysis to Identify Clinical Factors Associated with Differences in Participants' SGRQ-I Scores**

| St. George Respiratory Questionnaire-IPF (SGRQ-I)                                   |     |          |        |                  |       |      |       |                  |
|-------------------------------------------------------------------------------------|-----|----------|--------|------------------|-------|------|-------|------------------|
| Groups                                                                              | N   | Mean     | SD     | CI               | df    | F    | t     | P                |
| <b>Asked to Participate in Clinical Trial/Research Related to IPF? <sup>b</sup></b> |     |          |        | -435.69, -16.15  | 219   | ~    | -2.32 | <b>0.21*</b>     |
| Yes                                                                                 | 40  | 1136.89  | 588.75 |                  |       |      |       |                  |
| No                                                                                  | 196 | 1362.822 | 529.00 |                  |       |      |       |                  |
| <b>Awareness of Clinical Trials <sup>b</sup></b>                                    |     |          |        | -436.58, -81.10  | 219   | ~    | -2.76 | <b>.006*</b>     |
| Yes                                                                                 | 40  | 1113.00  | 500.62 |                  |       |      |       |                  |
| No                                                                                  | 196 | 1371.85  | 544.13 |                  |       |      |       |                  |
| <b>Did IPF Interfere With your Job or Make you Leave Your Job <sup>b</sup></b>      |     |          |        | -560.52, -293.78 | 219   | ~    | -6.31 | <b>&lt;.001*</b> |
| Yes                                                                                 | 126 | 1526.01  | 518.57 |                  |       |      |       |                  |
| No                                                                                  | 110 | 1098.85  | 482.93 |                  |       |      |       |                  |
| <b>Type of Work <sup>a</sup></b>                                                    |     |          |        | ~                | 4,216 | .087 | ~     | .986             |
| Administration                                                                      | 30  | 1322.93  | 553.35 |                  |       |      |       |                  |
| Manual labour with potential occupational exposures                                 | 64  | 1320.60  | 508.38 |                  |       |      |       |                  |
| Manual labour                                                                       | 80  | 1265.25  | 535.93 |                  |       |      |       |                  |
| Transport work                                                                      | 38  | 1356.69  | 566.15 |                  |       |      |       |                  |
| Other work                                                                          | 24  | 1355.68  | 639.87 |                  |       |      |       |                  |

Key: \*P<0.05, <sup>a</sup> one-way ANOVA for more than two categorical variables, <sup>b</sup> independent samples t-tests for binary categorical variable

#### 5.4.5 St. George Respiratory Questionnaire-IPF Subscales

The SGRQ-I subscales (symptoms, activity and impacts) violated the assumptions underpinning parametric analysis; therefore, non-parametric tests were employed (Mann-Whitney  $U$  tests for binary variables and Kruskal-Wallis  $H$  tests for more than two categorical variables), to identify differences in SGRQ-I subscale scores (Table 5.18-Table 5.22).

##### 5.4.5.1 Symptoms Subscale

Participants were asked to rate their symptom experience in the first subscale on the SGRQ-I. Those who reported having a medical card (mean rank = 131.82) experienced worse symptom experience than those in the other three insurance categories ( $X^2(3) = 11.34, p = 0.10, n = 236$ ) which included private health insurance (mean rank = 119.98), both a medical card and private health insurance (mean rank = 96.85) or neither a medical card/private health insurance (mean rank = 83.31). Participants living more than 20km from their treatment centre (mean rank = 133.41) had worse quality of life on the symptom's subscale compared to those living within a 20km radius of the hospital (mean rank = 110.11), ( $X^2(1) = 6.351, p = .012, n = 236$ ). Having access to a peer support group (mean rank = 134.84) represented worse symptom experience compared to those who didn't have access to a peer support group (mean rank = 113.39), ( $U = 4441.50, z = 2.06, p = .039, n = 236$ ). Participants who reported that their IPF had interfered or made them stop work (mean rank = 138.88) reported worse symptom experience compared with those whose employment had not been impacted (mean rank = 91.68), ( $U = 4015.50, z = -5.33, p < .001, n = 236$ ).

Participants who were prescribed oxygen (mean rank = 143.32) were more likely to be impacted by IPF compared to those who were not prescribed oxygen therapy (mean rank = 108.03), ( $U = 4072.50, z = 3.63, p < .001, n = 236$ ). Having been prescribed nintedanib (mean rank = 99.00), represented less impacts compared to those who were not prescribed nintedanib (mean rank = 124.38), ( $U = 4500.00, z = -2.66, p = .008, n = 236$ ). Those who had previously been prescribed pirfenidone (mean rank = 129.00) reported worse symptom experience compared with those who reported that they had not previously been prescribed pirfenidone (mean rank = 114.69), ( $X^2(2) = 8.61, p = .013, n = 236$ ).

Participants diagnosed with IPF living with at least one comorbid condition (mean rank = 108.00) compared with those with no comorbid conditions (mean rank = 106.00) reported worse symptom experience when comparing mean rank scores ( $X^2(5) = 14.5, p = .028, n = 236$ ). Participants who reported a history of a digestive system disorder (mean rank = 45.13) reported less symptom impairment compared with those who didn't have a digestive system disorder (mean rank = 119.77), ( $U = 170.50, z = -2.17, p = .030$ ). Similarly, those who have an endocrine system disorder (mean rank = 89.64) compared to those who didn't have an endocrine system disorder (mean rank = 122.54) were observed to have less symptom impairment ( $U = 2164.50, z = -2.43, p = .015, n = 236$ ).

#### **5.4.5.2 Activity Subscale**

Females reported greater limitations to physical activities, impacting quality of life (mean rank = 137.92) compared to males (mean rank = 108.43), ( $U = 4362.00$ ,  $z = -3.08$ ,  $p = .002$ ,  $n = 235$ ). Rural dwellers (mean rank = 136.73) experienced greater limitations to physical activities compared to urban dwellers (mean rank = 101.21), ( $U = 4434.50$ ,  $z = -2.73$ ,  $p = .006$ ,  $n = 235$ ). Having access to a peer support group supported by the Irish Lung Fibrosis Association (mean rank = 134.52) represented greater limitations to physical activities compared to those without access to this form of support (mean rank = 113.50), ( $U = 4457.50$ ,  $z = -1.97$ ,  $p = .048$ ,  $n = 235$ ). Those who reported having access to a physiotherapist (mean rank = 107.01) reported fewer limitations to physical activities compared to those who didn't have access to a physiotherapist (mean rank = 127.10), ( $U = 5769.00$ ,  $z = -2.15$ ,  $p = .031$ ,  $n = 235$ ).

Participants who were prescribed oxygen (mean rank=152.45) were observed to have worse impacts to their physical activities when compared to those who were not prescribed oxygen (mean rank = 103.38), ( $U = 3363.50$ ,  $z = -5.07$ ,  $p < .001$ ,  $n = 235$ ). Participants who were prescribed pirfenidone (mean rank = 130.35) experienced greater limitations to physical activities compared to those who had not been prescribed pirfenidone (mean rank = 110.88) ( $U = 5302.00$ ,  $z = -2.14$ ,  $p = .032$ ,  $n = 235$ ).

Participants living with at least three comorbid conditions (mean rank = 148.20) consistently reported worse impacts to their quality of life compared to those with no comorbid conditions (mean rank = 126.82) ( $X^2(5) = 21.64$ ,  $p = .001$ ,  $n = 235$ ). Having an endocrine system disorder (mean rank = 88.07) represented less impairment compared to those who didn't have an endocrine system disorder (mean rank = 122.21), ( $U = 2119.00$ ,  $z = -2.54$ ,  $p = .011$ ,  $n = 235$ ). Those who reported that IPF had interfered or made them stop work (mean rank = 129.50) had statistically significantly greater limitations to physical activities compared to those whose employment had not been impacted (mean rank = 102.53), ( $U = 5187.00$ ,  $z = -3.05$ ,  $p = .002$ ,  $n = 235$ ).

#### **5.4.5.3 Impacts Subscale**

Females reported greater psychosocial impacts due to IPF (mean rank = 130.11) compared to males (mean rank = 101.91), ( $U = 3811.50$ ,  $z = -3.02$ ,  $p = .002$ ,  $n = 236$ ). Participants who lived alone (mean rank = 130.88) experienced greater psychosocial impacts due to IPF than those who lived with others (mean rank = 108.46), ( $U = 4783.00$ ,  $z = -2.58$ ,  $p = .010$ ,  $n = 236$ ). Participants with a medical card (mean rank = 124.06) reported greater psychosocial impacts due to IPF compared to those who had private health insurance (mean rank = 101.21), ( $X^2(3) = 8.75$ ,  $p = .033$ ,  $n = 236$ ). Additionally, those who reported that IPF had interfered or caused them to stop work (mean rank = 140.47) experienced greater psychosocial impacts than those whose employment was not impacted (mean rank = 89.83), ( $U = 3816.00$ ,  $z = -5.71$ ,  $p < .001$ ,  $n = 236$ ).

Participants who were prescribed oxygen therapy (mean rank = 142.06) were more likely to experience greater psychosocial impacts compared to those who were not prescribed oxygen therapy (mean rank = 98.34), ( $U = 3036.00$ ,  $z = -4.61$ ,  $p < .001$ ,  $n = 236$ ). Those who had previously been prescribed pirfenidone

(mean rank = 109.34) experienced greater psychosocial impacts compared with those who reported that they had not been prescribed pirfenidone (mean rank = 107.09), ( $X^2(2) = 6.93, p = .031, n = 236$ ). Similar results were seen for those that had previously been prescribed nintedanib (mean rank = 109.07) who experienced greater psychosocial impacts compared with those who reported that they had not been prescribed nintedanib (mean rank = 108.83), ( $X^2(2) = 10.73, p = .005, n = 236$ ). Participants living with at least three comorbid conditions (mean rank = 150.16) consistently reported greater psychosocial impacts due to IPF compared to those with zero comorbid conditions (mean rank = 100.97), ( $X^2(5) = 13.73, p = .033, n = 236$ ).

Participants who were not aware of clinical trials in IPF (mean rank = 115.60) reported worse psychosocial impacts compared to those who had been made aware of clinical trials (mean rank = 90.180), ( $U = 2787.00, z = -2.27, p = .023, n = 236$ ). Similarly, participants who had been asked to participate in a clinical trial (mean rank = 92.05) reported fewer psychosocial impacts compared to those who had not been invited to participate in a clinical trial (mean rank = 114.81), ( $U = 2703.00, z = -1.97, p = .048, n = 236$ ).

**Table 5.18 Inferential Statistical Analysis to Identify Socio-Demographic Factors Associated with Differences in Participants' SGRQ-I Subscale Scores**

| SGRQ-I Subscales             | Symptoms          |           |                              |          | Activities        |           |                              |              | Impacts           |           |                              |              |
|------------------------------|-------------------|-----------|------------------------------|----------|-------------------|-----------|------------------------------|--------------|-------------------|-----------|------------------------------|--------------|
|                              | <i>N</i><br>(236) | Mean Rank | Test statistic               | <i>P</i> | <i>N</i><br>(235) | Mean Rank | Test statistic               | <i>P</i>     | <i>N</i><br>(236) | Mean Rank | Test statistic               | <i>P</i>     |
| <b>Gender<sup>a</sup></b>    |                   |           | $Z=.548$<br>( $U=5649.00$ )  | .584     |                   |           | $Z=-3.08$<br>( $U=4362.00$ ) | <b>.002*</b> |                   |           | $Z=-3.02$<br>( $U=3811.50$ ) | <b>.002*</b> |
| Male                         | 162               | 119.63    |                              |          | 162               | 108.43    |                              |              | 162               | 101.91    |                              |              |
| Female                       | 74                | 114.38    |                              |          | 73                | 137.92    |                              |              | 74                | 130.11    |                              |              |
| <b>Age<sup>b</sup></b>       |                   |           | $\chi^2(5) = 7.54$           | .183     |                   |           | $\chi^2(4) = 7.06$           | .132         |                   |           | $\chi^2(5) = 5.36$           | .373         |
| 50-59                        | 13                | 300.82    |                              |          | 12                | 148.15    |                              |              | 13                | 106.11    |                              |              |
| 60-69                        | 50                | 289.02    |                              |          | 50                | 119.44    |                              |              | 50                | 124.32    |                              |              |
| 70-79                        | 111               | 244.12    |                              |          | 111               | 115.23    |                              |              | 111               | 102.46    |                              |              |
| 80-89                        | 58                | 249.09    |                              |          | 58                | 120.25    |                              |              | 58                | 112.37    |                              |              |
| >90                          | 4                 | 295.80    |                              |          | 4                 | 73.00     |                              |              | 4                 | 160.50    |                              |              |
| <b>Residence<sup>a</sup></b> |                   |           | $Z=-1.14$<br>( $U=5217.50$ ) | .253     |                   |           | $Z=-2.73$<br>( $U=4434.50$ ) | <b>.006*</b> |                   |           | $Z=-.994$<br>( $U=4639.40$ ) | .320         |
| Urban                        | 166               | 115.23    |                              |          | 166               | 110.21    |                              |              | 166               | 108.24    |                              |              |
| Rural                        | 70                | 125.61    |                              |          | 69                | 136.73    |                              |              | 70                | 117.62    |                              |              |

Key: \* $p < 0.05$ , <sup>a</sup> Mann-Whitney U tests for binary categorical variables, <sup>b</sup> Kruskal-Wallis H tests for more than two categorical variables

**Table 5.18 inferential Statistical Analysis to Identify Socio-Demographic Factors Associated with Differences in Participants' SGRQ-I Subscale (Continued)**

| Subscales of SGRQ-I                     | Symptoms |           |                           |              | Activity |           |                          |      | Impacts |           |                          |              |
|-----------------------------------------|----------|-----------|---------------------------|--------------|----------|-----------|--------------------------|------|---------|-----------|--------------------------|--------------|
|                                         | N (236)  | Mean Rank | Test Statistic            | P            | N (235)  | Mean Rank | Test Statistic           | P    | N (236) | Mean Rank | Test Statistic           | P            |
| <b>Living Arrangements <sup>a</sup></b> |          |           | Z=-1.121<br>(U=6173.00)   | .262         |          |           | Z=-.587<br>(U=6448.50)   | .557 |         |           | Z=-2.58<br>(U=4783.00)   | <b>.010*</b> |
| Living alone                            | 121      | 123.77    |                           |              | 121      | 121.02    |                          |      | 121     | 130.88    |                          |              |
| Living with others                      | 115      | 113.73    |                           |              | 114      | 115.77    |                          |      | 115     | 108.46    |                          |              |
| <b>Health Insurance <sup>b</sup></b>    |          |           | X <sup>2</sup> (3) =11.34 | <b>0.10*</b> |          |           | X <sup>2</sup> (3) =5.64 | .131 |         |           | X <sup>2</sup> (3) =8.75 | <b>.033*</b> |
| Private                                 | 91       | 119.98    |                           |              | 91       | 106.04    |                          |      | 91      | 101.21    |                          |              |
| Medical card                            | 92       | 131.82    |                           |              | 92       | 129.94    |                          |      | 92      | 124.06    |                          |              |
| Both                                    | 41       | 96.85     |                           |              | 41       | 116.94    |                          |      | 41      | 95.64     |                          |              |
| Neither                                 | 12       | 83.31     |                           |              | 11       | 118.69    |                          |      | 12      | 128.25    |                          |              |

Key: \*p<0.05, <sup>a</sup> Mann-Whitney U tests for binary categorical variables, <sup>b</sup> Kruskal-Wallis H tests for more than two categorical variables



**Table 5.19 Inferential Statistical Analysis to Identify Clinical Factors Associated with Differences in Participants' SGRQ-I Subscale Scores**

| SGRQ-I Subscales                                      | Symptoms |           |                          |                  | Activity |           |                          |                  | Impacts |           |                          |                  |
|-------------------------------------------------------|----------|-----------|--------------------------|------------------|----------|-----------|--------------------------|------------------|---------|-----------|--------------------------|------------------|
|                                                       | N (236)  | Mean Rank | Test Statistic           | P                | N (235)  | Mean Rank | Test Statistic           | P                | N (236) | Mean Rank | Test Statistic           | P                |
| <b>Prescribed Pirfenidone <sup>a</sup></b>            |          |           | Z=-.731<br>(U=6043.00)   | .465             |          |           | Z=-2.14<br>(U=5302.00)   | <b>.032*</b>     |         |           | Z=-1.722<br>(U=4835.50)  | .085             |
| Yes                                                   | 89       | 122.30    |                          |                  | 88       | 130.35    |                          |                  | 89      | 119.87    |                          |                  |
| No                                                    | 147      | 115.60    |                          |                  | 147      | 110.88    |                          |                  | 147     | 104.53    |                          |                  |
| <b>Previously Prescribed Pirfenidone <sup>b</sup></b> |          |           | X <sup>2</sup> (2) =8.61 | <b>.013*</b>     |          |           | X <sup>2</sup> (2) =.590 | .745             |         |           | X <sup>2</sup> (2) =6.93 | <b>.031*</b>     |
| Yes                                                   | 37       | 129.00    |                          |                  | 37       | 110.21    |                          |                  | 37      | 109.34    |                          |                  |
| No                                                    | 199      | 114.69    |                          |                  | 190      | 118.44    |                          |                  | 190     | 107.09    |                          |                  |
| Not sure                                              | 9        | 184.13    |                          |                  | 8        | 130.31    |                          |                  | 9       | 178.67    |                          |                  |
| <b>Prescribed Ninetedanib <sup>a</sup></b>            |          |           | Z=-2.668<br>(U=4500.00)  | <b>.008*</b>     |          |           | Z=-1.021<br>(U=5245.50)  | .307             |         |           | Z=-1.88<br>(U=4295.50)   | .060             |
| Yes                                                   | 72       | 99.00     |                          |                  | 72       | 109.35    |                          |                  | 72      | 97.25     |                          |                  |
| No                                                    | 164      | 124.38    |                          |                  | 163      | 119.01    |                          |                  | 164     | 114.48    |                          |                  |
| <b>Prescribed Oxygen <sup>a</sup></b>                 |          |           | Z=-3.63<br>(U=4072.50)   | <b>&lt;.001*</b> |          |           | Z=-5.07<br>(U=3363.50)   | <b>&lt;.001*</b> |         |           | Z=-4.61<br>(U=3036.00)   | <b>&lt;.001*</b> |
| Yes                                                   | 70       | 143.32    |                          |                  | 70       | 152.45    |                          |                  | 70      | 142.06    |                          |                  |
| No                                                    | 166      | 108.03    |                          |                  | 165      | 103.38    |                          |                  | 166     | 98.34     |                          |                  |

Key: \*P<0.05, <sup>a</sup>Mann-Whitney U test for binary categorical variables, <sup>b</sup> Kruskal-Wallis H test for more than two categorical variables

**Table 5.19 Inferential Statistical Analysis to Identify Clinical Factors Associated with Differences in Participants' SGRQ-I Subscale Scores (Continued)**

| SGRQ-I Subscales                                     | Symptoms |           |                                  |                  | Activities |           |                                  |              | Impacts |           |                                  |                  |
|------------------------------------------------------|----------|-----------|----------------------------------|------------------|------------|-----------|----------------------------------|--------------|---------|-----------|----------------------------------|------------------|
|                                                      | N (236)  | Mean Rank | Test statistic                   | P                | N (235)    | Mean Rank | Test statistic                   | P            | N (236) | Mean Rank | Test statistic                   | P                |
| <b>Time Since Diagnosis<sup>b</sup></b>              |          |           | $\chi^2(6) = 3.29$               | .771             |            |           | $\chi^2(6) = 9.33$               | .155         |         |           | $\chi^2(6) = 2.11$               | .909             |
| < 1 year                                             | 19       | 119.05    |                                  |                  | 19         | 97.55     |                                  |              | 19      | 106.94    |                                  |                  |
| 1-2 years                                            | 26       | 113.62    |                                  |                  | 26         | 116.99    |                                  |              | 26      | 104.75    |                                  |                  |
| 2-3 years                                            | 33       | 123.98    |                                  |                  | 33         | 141.33    |                                  |              | 33      | 121.98    |                                  |                  |
| 3-4 years                                            | 35       | 107.39    |                                  |                  | 35         | 121.77    |                                  |              | 35      | 107.34    |                                  |                  |
| 4-5 years                                            | 47       | 121.26    |                                  |                  | 48         | 99.39     |                                  |              | 48      | 117.40    |                                  |                  |
| >5 years                                             | 76       | 130.40    |                                  |                  | 75         | 125.32    |                                  |              | 76      | 115.52    |                                  |                  |
| <b>Employment Impact<sup>a</sup></b>                 |          |           | $Z = -5.33$<br>( $U = 4015.50$ ) | <b>&lt;.001*</b> |            |           | $Z = -3.05$<br>( $U = 5187.00$ ) | <b>.002*</b> |         |           | $Z = -5.71$<br>( $U = 3816.00$ ) | <b>&lt;.001*</b> |
| No                                                   | 126      | 91.68     |                                  |                  | 126        | 102.53    |                                  |              | 126     | 89.83     |                                  |                  |
| Yes                                                  | 110      | 138.88    |                                  |                  | 109        | 129.50    |                                  |              | 110     | 140.47    |                                  |                  |
| <b>Previously Prescribed Ninetedanib<sup>b</sup></b> |          |           | $\chi^2(2) = 5.91$               | .052             |            |           | $\chi^2(2) = 4.79$               | .091         |         |           | $\chi^2(2) = 10.73$              | <b>.005*</b>     |
| Yes                                                  | 32       | 123.31    |                                  |                  | 31         | 140.91    |                                  |              | 32      | 109.07    |                                  |                  |
| No                                                   | 195      | 116.11    |                                  |                  | 195        | 114.18    |                                  |              | 195     | 108.83    |                                  |                  |
| Not sure                                             | 9        | 190.20    |                                  |                  | 9          | 149.20    |                                  |              | 9       | 203.60    |                                  |                  |

Key: \* $P < 0.05$ , <sup>a</sup>Mann-Whitney U tests for binary categorical variables, <sup>b</sup>Kruskal-Wallis H tests for more than two categorical variables

**Table 5.20 Inferential Statistical Analysis to Identify if Comorbidity Factors are Associated with Differences in Participants' SGRQ-I Subscale Scores**

| SGRQ-I Subscales                              | Symptoms          |              |                                |              | Activity          |              |                                |              | Impacts           |              |                                |              |
|-----------------------------------------------|-------------------|--------------|--------------------------------|--------------|-------------------|--------------|--------------------------------|--------------|-------------------|--------------|--------------------------------|--------------|
|                                               | <i>N</i><br>(236) | Mean<br>Rank | Test Statistic                 | <i>P</i>     | <i>N</i><br>(235) | Mean<br>Rank | Test Statistic                 | <i>P</i>     | <i>N</i><br>(236) | Mean<br>Rank | Test Statistic                 | <i>P</i>     |
| <b>Digestive System Disorder <sup>a</sup></b> |                   |              | $Z = -2.17$<br>( $U=170.50$ )  | <b>.030*</b> |                   |              | $Z = -.930$<br>( $U=337.00$ )  | .352         |                   |              | $Z = -.777$<br>( $U=335.50$ )  | .437         |
| Yes                                           | 164               | 45.13        |                                |              | 164               | 86.75        |                                |              | 164               | 86.38        |                                |              |
| No                                            | 72                | 119.77       |                                |              | 71                | 118.54       |                                |              | 72                | 111.45       |                                |              |
| <b>Endocrine System Disorder <sup>a</sup></b> |                   |              | $Z = -2.43$<br>( $U=2164.50$ ) | <b>.015*</b> |                   |              | $Z = -2.54$<br>( $U=2119.00$ ) | <b>.011*</b> |                   |              | $Z = -1.17$<br>( $U=2175.50$ ) | .240         |
| Yes                                           | 29                | 89.64        |                                |              | 28                | 88.07        |                                |              | 29                | 97.17        |                                |              |
| No                                            | 207               | 122.54       |                                |              | 207               | 122.21       |                                |              | 207               | 112.84       |                                |              |
| <b>Number of Comorbidities <sup>b</sup></b>   |                   |              | $X^2(5) = 14.5$                | <b>.028*</b> |                   |              | $X^2(5) = 21.64$               | <b>.001*</b> |                   |              | $X^2(5) = 13.73$               | <b>.033*</b> |
| 0                                             | 42                | 106.00       |                                |              | 41                | 126.82       |                                |              | 42                | 100.97       |                                |              |
| 1                                             | 83                | 108.00       |                                |              | 83                | 110.68       |                                |              | 83                | 98.86        |                                |              |
| 2                                             | 61                | 123.83       |                                |              | 61                | 110.49       |                                |              | 61                | 121.80       |                                |              |
| 3                                             | 32                | 148.06       |                                |              | 32                | 148.20       |                                |              | 32                | 150.16       |                                |              |
| 4                                             | 11                | 143.36       |                                |              | 11                | 120.23       |                                |              | 11                | 73.64        |                                |              |
| 5                                             | 7                 | 119.67       |                                |              | 7                 | 58.08        |                                |              | 8                 | 83.60        |                                |              |

Key: \* $P < 0.05$ , <sup>a</sup>Mann-Whitney U tests for binary categorical variables, <sup>b</sup>Kruskal-Wallis H tests for more than two categorical variables.

**Table 5.21 Inferential Statistical Analysis to Identify if Clinical Trial Factors are Associated with Differences in Participants' SGRQ- Subscale Scores**

| SGRQ-I<br>Subscales                                                     | Symptoms   |              |                        |      | Activity   |              |                         |      | Impacts    |              |                         |              |
|-------------------------------------------------------------------------|------------|--------------|------------------------|------|------------|--------------|-------------------------|------|------------|--------------|-------------------------|--------------|
|                                                                         | N<br>(236) | Mean<br>Rank | Test Statistic         | P    | N<br>(235) | Mean<br>Rank | Test Statistic          | P    | N<br>(236) | Mean<br>Rank | Test Statistic          | P            |
| <b>Previously asked to Participate in a Clinical Trial <sup>a</sup></b> |            |              | Z=-.470<br>(U=3716.00) | .638 |            |              | Z=-1.566<br>(U=3271.50) | .117 |            |              | Z-1.975<br>(U=2703.00)  | <b>.048*</b> |
| Yes                                                                     | 40         | 113.40       |                        |      | 39         | 102.29       |                         |      | 40         | 92.05        |                         |              |
| No                                                                      | 196        | 118.94       |                        |      | 196        | 120.64       |                         |      | 188        | 114.81       |                         |              |
| <b>Awareness of Clinical Trials in IPF <sup>a</sup></b>                 |            |              | Z=-643<br>(U=4241.00)  | .520 |            |              | Z=-1.90<br>(U=3628.50)  | .057 |            |              | Z=-2.276<br>(U=2787.00) | <b>.023*</b> |
| Yes                                                                     | 47         | 112.85       |                        |      | 47         | 101.20       |                         |      | 47         | 90.18        |                         |              |
| No                                                                      | 189        | 119.94       |                        |      | 188        | 122.20       |                         |      | 189        | 115.60       |                         |              |

Key: \*P<0.05, <sup>a</sup>Mann-Whitney *U* tests for binary categorical variables

**Table 5.22 Inferential Statistical Analysis to Identify if Healthcare Access is Associated with Differences in Participants' SGRQ-I Subscale Scores**

| SGRQ-I Subscales                                  | Symptoms |           |                         |       | Activity |           |                           |       | Impacts |           |                         |      |
|---------------------------------------------------|----------|-----------|-------------------------|-------|----------|-----------|---------------------------|-------|---------|-----------|-------------------------|------|
|                                                   | N (236)  | Mean Rank | Test Statistic          | P     | N (235)  | Mean Rank | Test Statistic            | P     | N (236) | Mean Rank | Test Statistic          | P    |
| <b>Access to a Psychologist <sup>a</sup></b>      |          |           | Z=-.109<br>(U=1107.00)  | .913  |          |           | Z=-.234<br>(U=1076.00)    | .815  |         |           | Z=-.679<br>(U=826.50)   | .497 |
| Yes                                               | 10       | 121.80    |                         |       | 10       | 115.00    |                           |       | 10      | 137.45    |                         |      |
| No                                                | 226      | 118.88    |                         |       | 225      | 119.18    |                           |       | 226     | 118.19    |                         |      |
| <b>Access to a Respiratory Nurse <sup>a</sup></b> |          |           | Z=-.360<br>(U=5441.00)  | .710  |          |           | Z=-.556<br>(U=5266.50)    | .578  |         |           | Z=-.900<br>(U=4350.50)  | .368 |
| Yes                                               | 170      | 118.49    |                         |       | 170      | 121.47    |                           |       | 170     | 118.81    |                         |      |
| No                                                | 66       | 120.29    |                         |       | 65       | 112.74    |                           |       | 66      | 119.48    |                         |      |
| <b>Access to ILFA Support Group <sup>a</sup></b>  |          |           | Z=-2.066<br>(U=4441.50) | .039* |          |           | Z=-1.978<br>(U=4457.50)   | .048* |         |           | Z=-1.067<br>(U=4073.00) | .286 |
| Yes                                               | 62       | 134.84    |                         |       | 61       | 134.52    |                           |       | 62      | 122.39    |                         |      |
| No                                                | 174      | 113.39    |                         |       | 174      | 113.50    |                           |       | 174     | 117.80    |                         |      |
| <b>Access to a Physiotherapist <sup>a</sup></b>   |          |           | Z=-.722<br>(U=6571.5)   | .470  |          |           | Z=-2.157,<br>(U= 5769.00) | .031* |         |           | Z=-1.84<br>(U=5220.5)   | .066 |
| Yes                                               | 113      | 108.01    |                         |       | 113      | 107.01    |                           |       | 113     | 119.50    |                         |      |
| No                                                | 123      | 127.10    |                         |       | 122      | 127.50    |                           |       | 123     | 103.40    |                         |      |

Key: \*P<0.05, <sup>a</sup>Mann-Whitney U tests for binary categorical variable.

#### 5.4.6 Inferential Analysis Summary

Several factors were identified that highlighted differences in quality of life across the SGRQ-I subscales. Females tended to have greater limitations to physical activity observed in the activity subscale ( $p = .002$ ) and greater psychosocial impacts ( $p = .002$ ). Those living alone had higher psychosocial impacts compared to those living with others ( $p = .010$ ). Having private health insurance represented fewer limitations to physical activity and psychosocial impacts compared to those who only had a medical card in the activity subscale ( $p = .010$ ) and impacts subscale ( $p = .033$ ) (Table 5.18). Significantly, those participants who were prescribed oxygen therapy were more likely to be negatively impacted by IPF and reported worse quality of life on all three subscales (symptoms ( $p < .001$ ), activity ( $p < .001$ ) and impacts ( $p < .001$ ) (Table 5.19). Similarly, participants who reported that IPF had impacted their employment experienced worse quality of life scores across all three subscales, symptoms ( $p < .001$ ), activity ( $p = .002$ ) and impacts ( $p < .001$ ) compared to those participants whose employment had not been affected (Table 5.19).

Participants who had access to a support group supported by the Irish Lung Fibrosis Association (ILFA) were more likely to report greater symptom impacts compared to those who did not attend a support group ( $p = .039$ ) with similar results seen in the activity subscale ( $p = .048$ ) (Table 5.22). Participants without access to a physiotherapist reported worse quality of life compared to those who did have access to this form of support in the activity subscale ( $p = .031$ ) (Table 5.22).

Having a comorbid condition was associated with worse quality of life across all three subscales, symptoms ( $p = .028$ ), activity ( $p = .001$ ) and impacts ( $p = .033$ ). Participants who reported at least three comorbid conditions, had lower quality of life across all three subscales compared to participants who reported no comorbid conditions (Table 5.20). Additionally, participants with a history of an endocrine system disorder tended to have better quality of life in the symptoms ( $p = .015$ ) and activities subscales ( $p = .011$ ) than those without such a disorder (Table 5.20).

Having no awareness of clinical trials in IPF represented greater psychosocial impacts ( $p = .023$ ). This finding is reflected again for participants who were never asked to participate in a clinical trial, who reported greater psychosocial impacts compared to those who had been invited to participate in a clinical trial ( $p = .048$ ) (Table 5.21). Those who were currently prescribed pirfenidone reported greater limitations to physical activity ( $p = .032$ ) on the 'activity' subscale and observed again in those who had previously been prescribed pirfenidone on the 'symptoms' ( $p = .013$ ) and 'impacts' ( $p = .031$ ) subscales. Conversely, the opposite finding was observed in those who were currently prescribed nintedanib who reported better quality of life on the 'symptoms' subscale ( $p = .008$ ). However, having previously been prescribed nintedanib, represented worse psychosocial impacts ( $p = .005$ ) (Table 5.19).

These findings provide further empirical evidence of the extensive symptom experience, psychosocial burden, limitations to physical activities and unmet needs experienced by people diagnosed with IPF, impacting their quality of life and outlined in both the scoping review (Chapter two) and in previous sections of this analysis (Section 5.2-5.3).

#### 5.4.7 Lung Information Needs Questionnaire and the SGRQ-I

The results of non-parametric correlations examining the relationship between the lung information needs questionnaire subscales (LINQ) and overall quality of life scores from the SGRQ-I are presented in Figure 5.18. Spearman's rank-order ( $R_s$ ) correlations were statistically significant for the subscale's 'exercise' ( $R_s = .227^{**}$ ,  $p < .001$ ) and 'smoking' ( $R_s = .160^*$ ,  $p = .017$ ) on the LINQ when plotted against the total SGRQ-I score. These results suggest that unmet information needs in the areas of 'exercise' and 'smoking' are associated with poorer overall quality of life. Further correlation analysis between the SGRQ-I subscales and LINQ scores was found to be minimal, leading to the decision not to pursue further correlational analysis on this data.

### 5.5 Investigating Quality of Life and Symptom Experience (IPF-PROM)

The secondary quality of life measure in this study was the IPF-patient-reported outcome measure (IPF-PROM). The variables included for analysis were the same as those selected for the previously described analysis (Section 5.4.3-5.4.6) and included sociodemographic, clinical factors, information needs and access to healthcare supports and services. A total of 99.15% ( $n = 235$ ) of participants completed all 12 items in the IPF-PROM (Figure 5.19). The total theoretical score ranged from 0-48, with scores achieved in this study between 12-48 (median = 24.00,  $SD = 7.17$ ) where higher scores represent worse quality-of-life (Table 5.23).

**Table 5.23 IPF-PROM Scoring**

| IPF-PROM      | Response rate<br><i>N</i> (%) | Range of<br>scores | Median | SD   | No. of<br>items |
|---------------|-------------------------------|--------------------|--------|------|-----------------|
| Psychological | 235 (99.15)                   | 1-4                | 6      | 1.99 | 3               |
| Physical      | 235 (99.15)                   | 1-4                | 6      | 1.99 | 3               |
| Emotional     | 235 (99.15)                   | 1-4                | 6      | 2.54 | 3               |
| Energy        | 235 (99.15)                   | 1-4                | 6      | 2.04 | 3               |
| Total score   | 235 (99.15)                   | 0-48               | 24     | 7.17 | 12              |

The total score for the IPF-PROM did not meet the requirements for parametric testing (Table 5.24), supported by visual inspection of the histogram and normal probability plots (Q-Q plot) generated for the total IPF-PROM and its subscales which demonstrated a departure from normality. Kruskal-Wallis  $H$  tests and Mann-Whitney  $U$  tests were employed to display the data for the overall IPF-PROM and relevant scores from each of the subscales (Table 5.25-5.27).

**Figure 5.18 Results of Spearman's Rank Order Correlations**

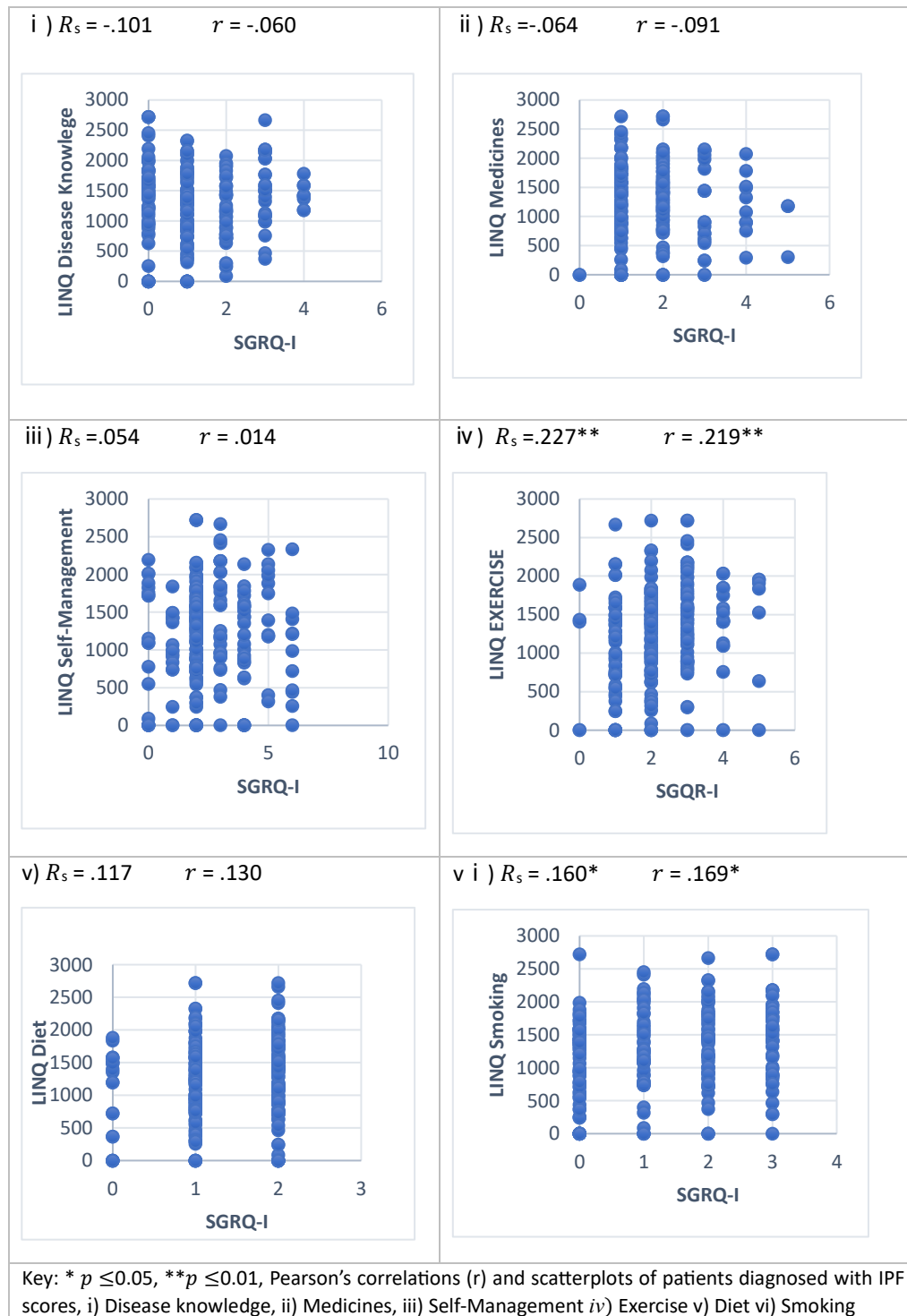
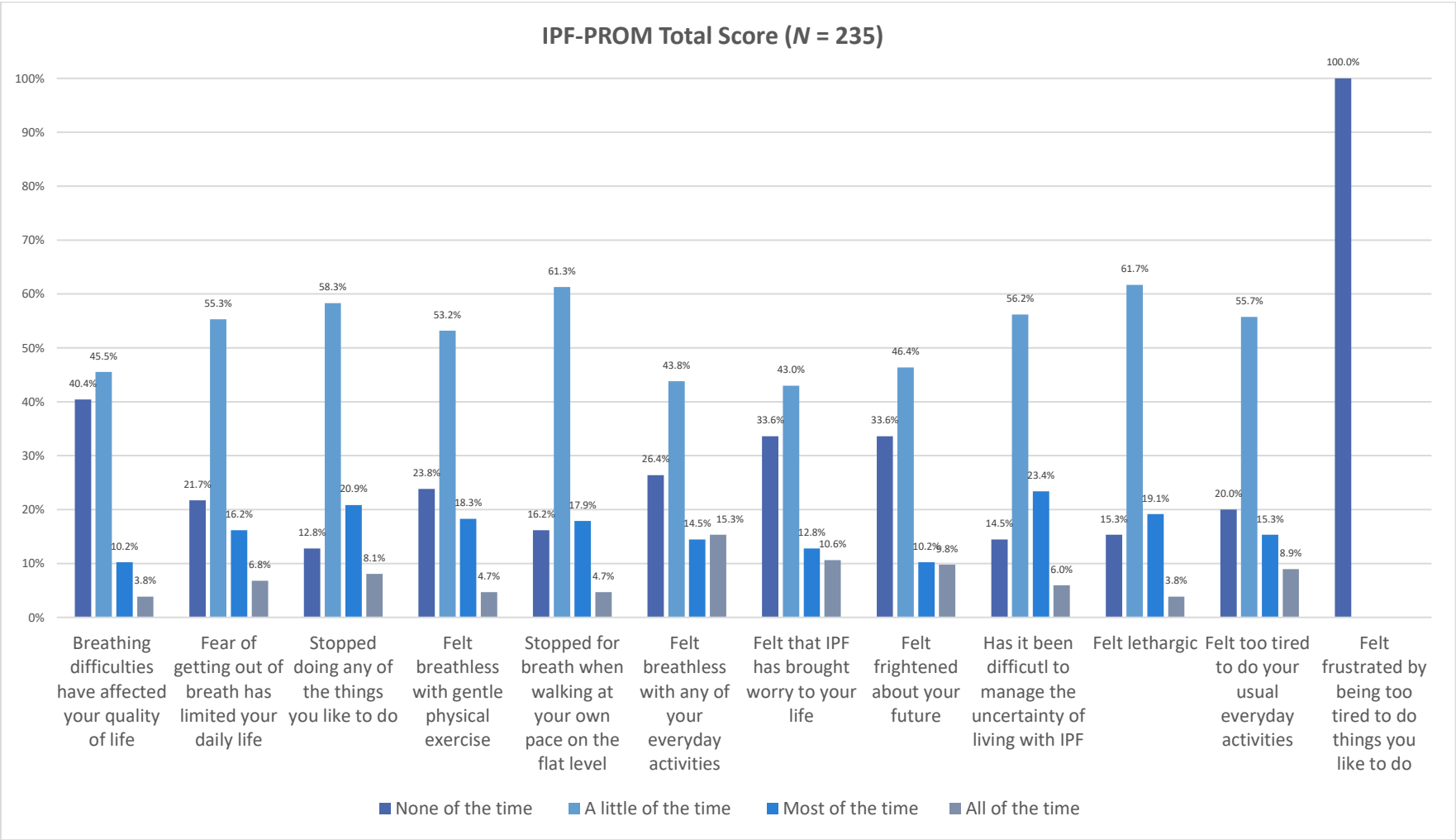




**Table 5.24 Normality Tests For the IPF-PROM**

| IPF-PROM                      | Mean  | Median | Standard Deviation | Skewness | Kurtosis | Kolmogorov-Smirnov (Sig.) | Shapiro-Wilk (Sig.) |
|-------------------------------|-------|--------|--------------------|----------|----------|---------------------------|---------------------|
| <b>IPF PROM Total</b>         | 24.90 | 24.00  | 7.17               | .924     | .937     | .158 (<0.001)             | .913 (<0.001)       |
| <b>Psychological subscale</b> | 5.91  | 6.00   | 1.99               | .778     | .920     | .204 (<0.001)             | .900 (<0.001)       |
| <b>Physical subscale</b>      | 6.39  | 6.00   | 1.99               | .671     | .564     | .266 (<0.001)             | .904 (<0.001)       |
| <b>Emotional subscale</b>     | 6.15  | 6.00   | 2.54               | .729     | -.229    | .208 (<0.001)             | .908 (<0.001)       |
| <b>Energy subscale</b>        | 6.45  | 6.00   | 2.04               | .587     | .251     | .260 (<0.001)             | .937 (<0.001)       |

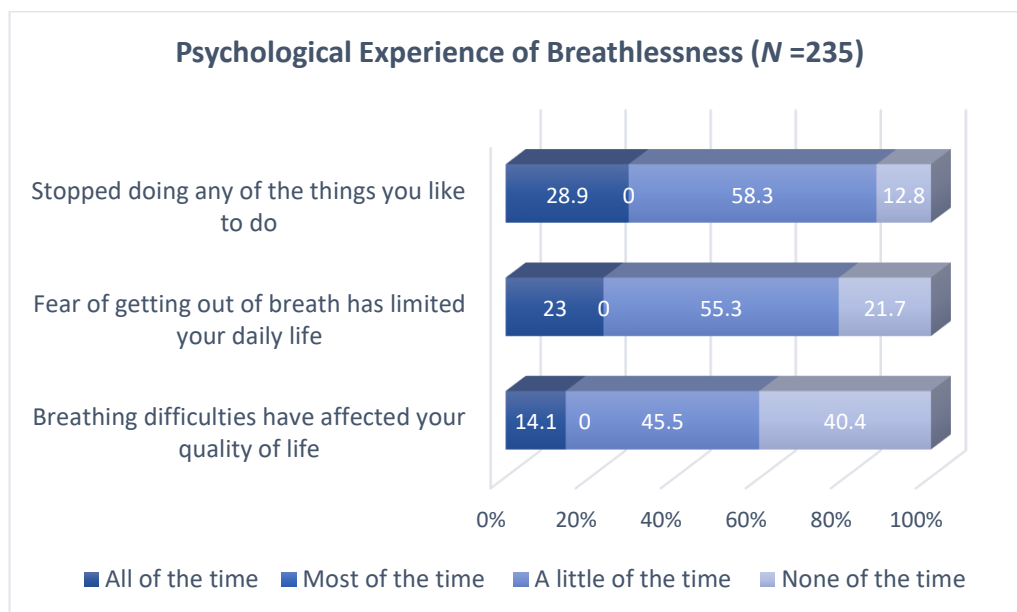
Figure 5.19 IPF-PROM



### 5.5.1 Psychological Experience of Breathlessness (IPF-PROM)

Participants were asked to indicate their psychological experience of breathlessness with 14.1% ( $n = 33$ ) of participants indicated that their breathing difficulties affected their quality of life 'all of the time'. Other common responses in the 'all of the time' response category included 'fear of getting out of breath has limited daily life' (23%,  $n = 54$ ), with a further 28.9% of participants reporting IPF had stopped them from doing the things they liked to do ( $n = 68$ ) (Figure 5.20).

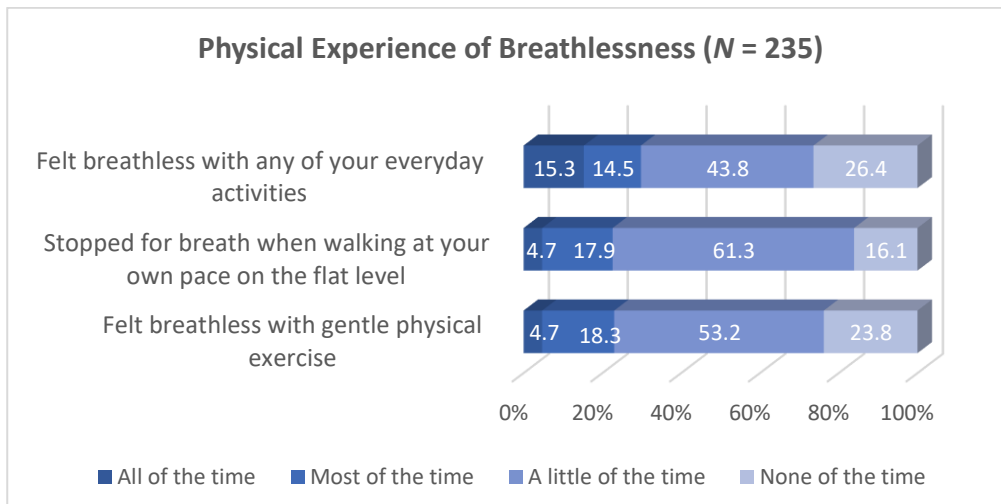
**Figure 5.20 Participants' Psychological Experience of Breathlessness**



### 5.5.2 Physical Experience of Breathlessness (IPF-PROM)

Participants were asked to rate their physical experience of breathlessness, where responses indicating lower quality of life were combined using response items 'all of the time' or 'most of the time' and are reflected in the following items, 'felt breathless with gentle physical activity' (23%,  $n = 54$ ), 'stopped for breath when walking at your own pace on the flat level' (22.6%,  $n = 53$ ) and 'felt breathless with any of your everyday activities' (29.8%,  $n = 70$ ). A further 61.3% ( $n = 144$ ) of participants reported that they had to stop for breath when walking on a flat surface 'a little of the time' (Figure 5.21).

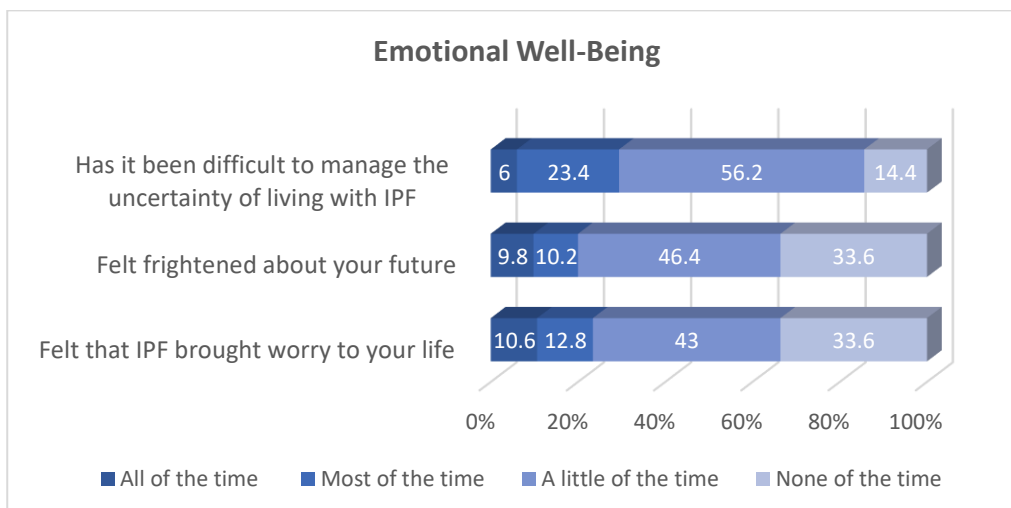
**Figure 5.21 Participants' Physical Experience of Breathlessness**



### 5.5.3 Emotional Well-Being (IPF-PROM)

The emotional well-being subscale showed a similar pattern of responses to the previous two subscales, with two response categories combined 'most of the time' or 'all of the time' reflected in the following items, 'it has been difficult to manage the uncertainty of living with IPF' (29.4%,  $n = 69$ ), 'felt frightened about your future' (20%,  $n = 47$ ) and 'felt that IPF has brought worry to your life' (23.4%,  $n = 55$ ). Over 50% of participants reported that managing the uncertainty of living with IPF occurred 'a little of the time' (56.2%,  $n = 132$ ) (Figure 5.22).

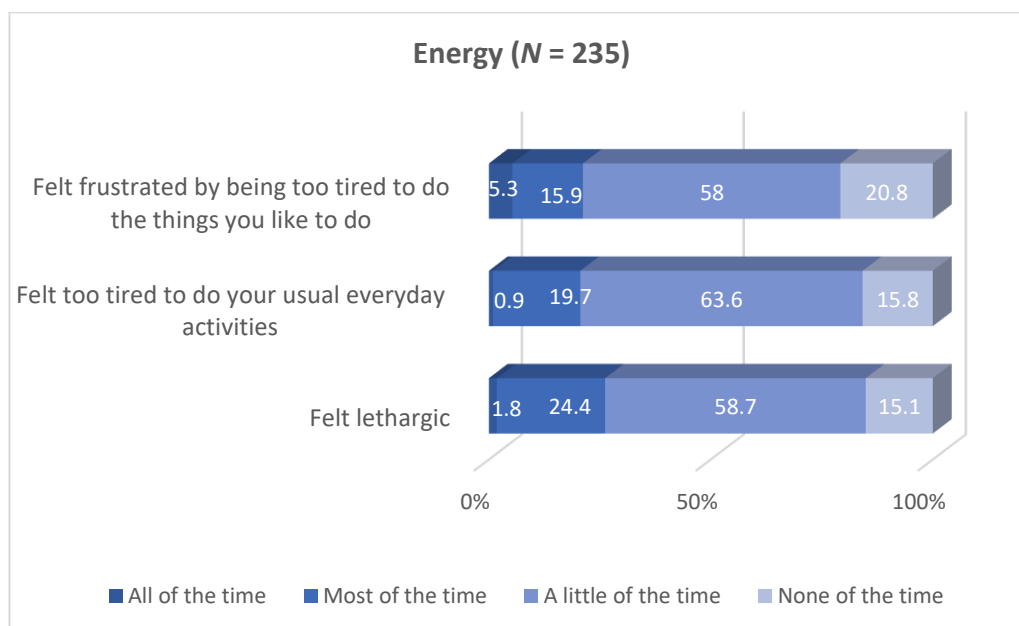
**Figure 5.22 Participants' Emotional Well-Being**



#### 5.5.4 Energy (IPF-PROM)

The next subscale featured in the IPF-Prom is the energy subscale, where responses at the higher end of the scale, 'most of the time' or 'all of the time' were combined for items, 'felt frustrated by being too tired to do the things you like to do', (21.2%,  $n = 50$ ), 'felt too tired to do your usual everyday activities' (20.6%,  $n = 48$ ) and 'felt lethargic' (26.2%,  $n = 61$ ). Furthermore, over 60% of participants reported that they felt too tired to do their usual everyday activities 'a little of the time' (63.6%,  $n = 149$ ) (Figure 5.23)

**Figure 5.23 Participants' Energy**



#### 5.5.5 Quality of Life Experienced by People with IPF (IPF-PROM)

Responses were combined in the categories 'all of the time' and 'most of the time' to provide a comprehensive understanding of the quality of life experience of participants across the four subscales. The six highest reported items in these combined categories are presented in Table 5.25. The three highest scoring items, representing lower quality-of-life, were distributed across three subscales (physical, emotional and psychological) and included, 'felt breathless with any of your everyday activities' (30.4%,  $n = 71$ ), 'it has been difficult to manage the uncertainty of living with IPF' (29.4%,  $n = 69$ ) and 'stopped doing any of the things you like to do' (28.9%,  $n = 68$ ).

**Table 5.25 Highest Scoring Items on the IPF-PROM**

| Highest Scoring Top Six Items (N = 236)              | N  | %    | Subscale      |
|------------------------------------------------------|----|------|---------------|
| Felt breathless with any of your everyday activities | 70 | 29.8 | Physical      |
| Difficult to manage the uncertainty of life with IPF | 69 | 29.4 | Emotional     |
| Stopped doing any of the things you like to do       | 68 | 28.9 | Psychological |
| Felt lethargic                                       | 62 | 26.2 | Energy        |
| Felt IPF has brought worry into your life            | 55 | 23.4 | Emotional     |
| Fear of getting out of breath has limited daily life | 54 | 23   | Psychological |

### 5.5.6 IPF-PROM Quality of Life Inferential Analysis

Inferential statistics were conducted to explore differences in overall IPF-PROM scores (dependent variable) and a range of independent variables. The results indicated that females (mean rank = 134.59) reported poorer quality of life compared to males (mean rank = 109.90), ( $U = 4601.50$ ,  $z = -2.58$ ,  $p = .010$ ,  $n = 235$ ) (Table 5.26). Age group significantly impacted quality of life ( $\chi^2(5) = 16.77$ ,  $p = .005$ ,  $n = 235$ ). Participants in the 50-59 age group (mean rank = 154.31) reported worse overall quality of life compared to other age group categories (Table 5.26). Participants who reported that IPF interrupted or made them stop work (mean rank = 129.29) had poorer quality of life compared to those whose work was unaffected (mean rank = 101.82), ( $U = 5110.50$ ,  $z = -3.118$ ,  $p = .002$ ,  $n = 235$ ) (Table 5.28).

Those prescribed oxygen (mean rank = 145.24) reported worse quality of life compared to those not prescribed oxygen (mean rank = 106.45), ( $U = 3868.50$ ,  $z = -4.011$ ,  $p < .001$ ,  $n = 235$ ) (Table 5.27). Access to palliative care support was associated with worse quality of life (mean rank = 164.50) compared to those without access to this support (mean rank = 116.36), ( $U = 536.00$ ,  $z = -1.97$ ,  $p = .048$ ,  $n = 235$ ) (Table 5.28). Furthermore, participants previously prescribed nintedanib (mean rank = 119.52) reported worse quality of life compared to those who were not previously prescribed nintedanib (mean rank = 107.96), ( $\chi^2(2) = 8.735$ ,  $p = 0.13$ ,  $n = 235$ ) (Table 5.27). Finally, the item 'comorbid condition' was associated with poorer quality of life, having three comorbid conditions in particular represented worse quality of life ( $\chi^2(6) = 20.10$ ,  $p = .003$ ,  $n = 235$ ) (Table 5.27).

**Table 5.26 Inferential Statistical Analysis to Identify Sociodemographic Factors Associated with Differences in Participants' IPF-PROM Scores**

| IPF-Patient Reported Outcome Measure (IPF-PROM)     |         |           |                          |              |
|-----------------------------------------------------|---------|-----------|--------------------------|--------------|
| IPF-PROM                                            | N (235) | Mean Rank | Test statistic           | P            |
| <b>Gender <sup>a</sup></b>                          |         |           | Z = -2.581 (u = 4601.50) | <b>.010*</b> |
| Male                                                | 161     | 109.90    |                          |              |
| Female                                              | 74      | 134.59    |                          |              |
| <b>Age <sup>b</sup></b>                             |         |           | $\chi^2(5) = 16.77$      | <b>.005*</b> |
| 50-59                                               | 13      | 154.31    |                          |              |
| 60-69                                               | 50      | 139.70    |                          |              |
| 70-79                                               | 111     | 115.23    |                          |              |
| 80-89                                               | 58      | 99.75     |                          |              |
| >90                                                 | 3       | 101.23    |                          |              |
| <b>Living Arrangements <sup>a</sup></b>             |         |           | Z = -.712 (u = 6384.00)  | .476         |
| Living with others                                  | 115     | 115.29    |                          |              |
| Living alone                                        | 120     | 121.66    |                          |              |
| <b>Health Insurance <sup>b</sup></b>                |         |           | $\chi^2(3) = 4.359$      | .225         |
| Private health insurance                            | 91      | 115.13    |                          |              |
| Medical card                                        | 92      | 127.85    |                          |              |
| Both a medical card and private health insurance    | 41      | 102.09    |                          |              |
| Neither a medical card nor private health insurance | 11      | 118.15    |                          |              |

Key: \*p<0.05, <sup>a</sup> Mann-Whitney U tests for binary categorical variables, <sup>b</sup> Kruskal-Wallis H test for more than two categorical variables

**Table 5.27 Inferential Statistical Analysis to Identify Clinical Factors Associated with Differences in Participants' IPF-PROM Scores**

| IPF-Patient Reported Outcome Measure (IPF-PROM)       |         |           |                            |                  |
|-------------------------------------------------------|---------|-----------|----------------------------|------------------|
| IPF-PROM                                              | N (235) | Mean Rank | Test statistic             | P                |
| <b>Previously Prescribed Ninetedanib <sup>b</sup></b> |         |           | $\chi^2(2) = 8.735$        | <b>.013*</b>     |
| Yes                                                   | 31      | 119.52    |                            |                  |
| No                                                    | 195     | 107.96    |                            |                  |
| Not sure                                              | 9       | 109.23    |                            |                  |
| <b>Prescribed Oxygen <sup>a</sup></b>                 |         |           | $Z = -4.011$ (U = 3868.50) | <b>&lt;.001*</b> |
| Yes                                                   | 70      | 145.24    |                            |                  |
| No                                                    | 165     | 106.45    |                            |                  |
| <b>Comorbid Conditions <sup>b</sup></b>               |         |           | $\chi^2(6) = 20.10$        | <b>.003*</b>     |
| 0                                                     | 42      | 102.36    |                            |                  |
| 1                                                     | 83      | 100.38    |                            |                  |
| 2                                                     | 61      | 116.34    |                            |                  |
| 3                                                     | 32      | 152.61    |                            |                  |
| 4                                                     | 11      | 89.73     |                            |                  |
| 5                                                     | 6       | 65.40     |                            |                  |

Key: \*p<0.05, <sup>a</sup> Mann-Whitney U test for binary categorical variables, <sup>b</sup> Kruskal-Wallis H tests for more than two categorical variables



**Table 5.28 Inferential Statistical Analysis to Identify Healthcare Access Factors Associated with Differences in Participants' IPF-PROM Scores**

| IPF-Patient Reported Outcome Measure (IPF-PROM)                                      |         |           |                         |              |
|--------------------------------------------------------------------------------------|---------|-----------|-------------------------|--------------|
|                                                                                      | N (235) | Mean rank | Test statistic          | P            |
| <b>Has IPF Interfered with your Job or made you Stop Work <sup>a</sup></b>           |         |           | Z =-3.118 (U = 5110.50) | <b>.002*</b> |
| Yes                                                                                  | 125     | 129.29    |                         |              |
| No                                                                                   | 110     | 101.82    |                         |              |
| <b>Were you Ever Asked to Participate in a Clinical Trial/ Research <sup>a</sup></b> |         |           | Z =-.175 (U = 3812.00)  | .861         |
| Yes                                                                                  | 39      | 115.80    |                         |              |
| No                                                                                   | 196     | 117.85    |                         |              |
| <b>Do you have Access to Palliative Care Support <sup>a</sup></b>                    |         |           | Z =-1.974 (U = 536.00)  | <b>.048*</b> |
| Yes                                                                                  | 9       | 164.50    |                         |              |
| No                                                                                   | 226     | 116.36    |                         |              |
| <b>Do you have Access to a Specialist Nurse <sup>a</sup></b>                         |         |           | Z =-1.117 (U = 5005.50) | .264         |
| Yes                                                                                  | 169     | 114.94    |                         |              |
| No                                                                                   | 66      | 125.99    |                         |              |
| <b>Do you have Access to ILFA National Patient Support Group <sup>a</sup></b>        |         |           | Z =-1.699 (U = 4584.50) | .089         |
| Yes                                                                                  | 61      | 130.54    |                         |              |
| No                                                                                   | 174     | 113.50    |                         |              |

Key: \*p<0.05, <sup>a</sup> Mann-Whitney U test for binary categorical variables, <sup>b</sup> Kruskal-Wallis H test for more than two categorical variables

### 5.5.7 Inferential Statistical Analysis of the IPF-PROM Subscales

Inferential statistical analysis was conducted between the dependent variable (DV); IPF-PROM subscales (psychological experience of breathlessness, physical experience of breathlessness, emotional well-being and energy levels) and several independent variables, including sociodemographic, clinical factors and access to supports and services, to identify statistically significant differences in quality of life scores (Table 5.29-5.31).

#### 5.5.7.1 Psychological Experience of Breathlessness

Females (mean rank = 131.79) reported worse psychological experience of breathlessness impacting quality of life compared to males (mean rank = 110.39) ( $U = 4731.00$ ,  $Z = 2.297$ ,  $p = .022$ ,  $n = 235$ ) (Table 5.29). Participants who were prescribed oxygen (mean rank = 148.56) reported worse psychological experience of breathlessness compared to those who were not prescribed oxygen (mean rank = 104.24), ( $U = 3566.00$ ,  $Z = -4.70$ ,  $p = .001$ ,  $n = 70$ ) (Table 5.30). Not being financially reimbursed for portable oxygen (mean rank = 47.24) represented poorer quality of life compared to those who were fully reimbursed (mean rank = 32.60), ( $X^2(3) = 8.71$ ,  $p = .033$ ,  $n = 70$ ) (Table 5.30). Participants who reported that their lung condition (IPF) interfered with their job or made them stop work (mean rank = 138.88) had worse psychological experience of breathlessness when compared with those whose employment had not been impacted (mean rank = 91.68), ( $U = 4608.00$ ,  $Z = -4.29$ ,  $p < .001$ ,  $n = 235$ ) (Table 5.30).

#### 5.5.7.2 Physical Experience of Breathlessness

Females reported worse physical experience of breathlessness (mean rank = 131.11) compared to males (mean rank = 111.45), ( $U = 2852.00$ ,  $Z = -2.145$ ,  $p = .032$ ,  $n = 235$ ). In the 'age' category, those in the 60-69 age group (mean rank = 142.55) reported worse quality of life compared to other age categories ( $X^2(5) = 13.25$ ,  $p = .020$ ,  $n = 235$ ) (Table 5.29). Living in a rural location (mean rank = 132.36) was associated with worse physical experiences of breathlessness compared with those living in an urban area (mean rank = 112.03), ( $U = 4736.50$ ,  $Z = -2.185$ ,  $p = .029$ ,  $n = 235$ ) (Table 5.29). Participants who reported that their lung condition (IPF) interfered with their job or made them stop work (mean rank = 129.50) reported worse physical experience of breathlessness when compared with those whose employment had not been impacted (mean rank = 102.53), ( $U = 5691.50$ ,  $Z = -2.00$ ,  $p = .045$ ,  $n = 235$ ) (Table 5.30).

Access to healthcare supports and services was associated with differences in quality of life. Participants with access to a dietitian (mean rank = 152.18) reported worse physical experience of breathlessness compared to those who did not have this access (mean rank = 115.33), ( $U = 1272.00$ ,  $Z = -2.253$ ,  $p = .024$ ,  $n = 235$ ) (Table 5.31). Having access to palliative care services (mean rank = 162.31) represented worse physical experience of breathlessness compared to those without such access (mean rank = 116.44), ( $U = 553.50$ ,  $Z = -1.964$ ,  $p = .050$ ,  $n = 235$ ) (Table 5.31). Participants who were prescribed oxygen (mean rank = 138.26) reported worse physical experience of breathlessness compared to those who were not prescribed oxygen (mean rank = 109.41), ( $U = 4357.00$ ,  $Z = -3.11$ ,  $p = .002$ ,  $n = 235$ ) (Table 5.30).

### **5.5.7.3 Emotional Well-Being**

Females (mean rank = 130.78) reported worse emotional well-being compared to males (mean rank = 111.60), ( $U = 4876.00$ ,  $z = -2.03$ ,  $p = .042$ ,  $n = 235$ ). Mean rank emotional well-being scores were statistically significant across different age groups (50-59 years, 60-69 years, 70-79 years, 80-89 years, >90 years), ( $X^2(5) = 13.35$ ,  $p = .020$ ,  $n = 235$ ). Significantly, being in the 50-59 age group (mean rank = 169.96) represented worse emotional well-being compared to all other age categories (Table 5.29). Those who had a medical card (mean rank = 133.32) reported worse emotional well-being than those with private health insurance (mean rank = 109.53) or those with neither health insurance nor a medical card (mean rank = 114.27), ( $X^2(3) = 8.289$ ,  $p = .040$ ,  $n = 235$ ) (Table 5.29). Additionally, mean rank emotional well-being scores were statistically significant across comorbid conditions (range 0-6 comorbid conditions) ( $X^2(6) = 13.15$ ,  $p = .041$ ,  $n = 235$ ) (Table 5.30).

Those with access to a physiotherapist (mean rank = 107.00) reported better emotional well-being compared to those who did not have this access (mean rank = 128.02), ( $U = 5656.00$ ,  $z = -2.40$ ,  $p = .016$ ,  $n = 236$ ) (Table 5.31). Finally, having access to an Irish Lung Fibrosis Association peer support group (mean rank = 134.14) represented worse emotional well-being compared to those who didn't have access to this type of support (mean rank = 112.22), ( $U = 4362.50$ ,  $z = -2.213$ ,  $p = .027$ ,  $n = 235$ ) (Table 5.31). Participants who were prescribed oxygen (mean rank = 142.14) reported worse emotional well-being compared to those who were not prescribed oxygen (mean rank = 107.76), ( $U = 4085.50$ ,  $Z = -3.60$ ,  $p < .001$ ,  $n = 235$ ) (Table 5.30).

### **5.5.7.4 Energy**

There were no statistically significant findings identified between patients' quality of life and selected independent variables (sociodemographic, clinical factors and access to services and supports) on the energy subscale.

### **5.5.7.5 Inferential Statistical Analysis (IPF-PROM)**

Several factors were observed to have a statistically significant impact on quality of life for people diagnosed with IPF. Significantly, females demonstrated worse quality of life across three subscales, psychological ( $p = .022$ ), physical ( $p = .032$ ) and emotional ( $p = .042$ ) (Table 5.29). Age also demonstrated significant impairment to quality of life on two subscales, physical ( $p = .020$ ) and emotional ( $p = .020$ ). Living in a rural location was associated with a lower quality of life in the physical subscale ( $p = .029$ ) (Table 5.29). Health insurance items demonstrated statistically significant differences in the emotional well-being category ( $p = .040$ ) (Table 5.29). Participants who reported that their lung condition had interfered or made them stop work using binary response items 'yes or no' demonstrated statistically significantly worse quality of life scores across two subscales, psychological ( $p < .001$ ) and physical ( $p = .045$ ) (Table 5.30). Participants who had been prescribed oxygen therapy reported worse quality of life compared to those not prescribed oxygen across three subscales, psychological ( $p < .001$ ), physical ( $p = .002$ ) and emotional ( $p < .001$ ). Portable oxygen that was not fully reimbursed represented worse quality of life in the

psychological subscale ( $p = .033$ ) (Table 5.30). Having a comorbid condition was associated with lower emotional well-being ( $p = .041$ ) (Table 5.30). Overall, this inferential statistical analysis highlights several independent factors which contribute to quality of life among people diagnosed with IPF.

**Table 5.29 Inferential Statistical Analysis to Identify if Socio-demographic Factors are Associated with Differences in Participants' Subscale Scores**

| IPF-Patient Reported Outcome Measure Subscales (IPF-PROM) |                   |              |                                   |              |              |                                  |              |              |                                  |              |              |                                 |          |
|-----------------------------------------------------------|-------------------|--------------|-----------------------------------|--------------|--------------|----------------------------------|--------------|--------------|----------------------------------|--------------|--------------|---------------------------------|----------|
| Variable                                                  | Psychological     |              |                                   |              | Physical     |                                  |              | Emotional    |                                  |              | Energy       |                                 |          |
|                                                           | <i>N</i><br>(235) | Mean<br>Rank | Test statistic                    | <i>P</i>     | Mean<br>Rank | Test statistic                   | <i>P</i>     | Mean<br>Rank | Test statistic                   | <i>P</i>     | Mean<br>Rank | Test statistic                  | <i>P</i> |
| <b>Gender <sup>a</sup></b>                                |                   |              | $Z = -2.297$<br>( $U = 4731.00$ ) | <b>.022*</b> |              | $Z = -2.145$<br>( $U = 2852.0$ ) | <b>.032*</b> |              | $Z = -2.03$<br>( $U = 4876.00$ ) | <b>.042*</b> |              | $Z = -1.74$<br>( $U = 5031.5$ ) | .081     |
| Male                                                      | 161               | 110.39       |                                   |              | 111.45       |                                  |              | 111.60       |                                  |              | 112.56       |                                 |          |
| Female                                                    | 74                | 131.79       |                                   |              | 131.11       |                                  |              | 130.78       |                                  |              | 128.62       |                                 |          |
| <b>Age <sup>b</sup></b>                                   |                   |              | $\chi^2(5) = 10.91$               | .053         |              | $\chi^2(5) = 13.2$               | <b>.020*</b> |              | $\chi^2(5) = 13.35$              | <b>.020*</b> | .            | $\chi^2(5) = 3.33$              | .648     |
| 50-59                                                     | 13                | 136.50       |                                   |              | 137.27       |                                  |              | 169.96       |                                  |              | 136.73       |                                 |          |
| 60-69                                                     | 50                | 135.79       |                                   |              | 142.55       |                                  |              | 140.76       |                                  |              | 127.40       |                                 |          |
| 70-79                                                     | 111               | 118.65       |                                   |              | 109.67       |                                  |              | 117.26       |                                  |              | 112.15       |                                 |          |
| 80-89                                                     | 58                | 96.52        |                                   |              | 111.39       |                                  |              | 95.55        |                                  |              | 115.44       |                                 |          |
| >90                                                       | 3                 | 95.70        |                                   |              | 73.10        |                                  |              | 33.70        |                                  |              | 132.90       |                                 |          |

Key: \* $p < 0.05$ , <sup>a</sup> Mann-Whitney U test for binary categorical variables, <sup>b</sup> Kruskal-Wallis H tests for more than two categorical variables

**Table 5.29 Inferential Statistical Analysis to Identify if Sociodemographic Factors are Associated with Differences in Participants' Subscale Scores (Continued)**

| IPF-Patient Reported Outcome Measure Subscales (IPF-PROM) |                   |               |                                     |          |              |                                     |              |              |                                    |              |              |                                    |          |
|-----------------------------------------------------------|-------------------|---------------|-------------------------------------|----------|--------------|-------------------------------------|--------------|--------------|------------------------------------|--------------|--------------|------------------------------------|----------|
| Variable                                                  |                   | Psychological |                                     |          | Physical     |                                     |              | Emotional    |                                    |              | Energy       |                                    |          |
|                                                           | <i>N</i><br>(235) | Mean<br>Rank  | Test Statistic                      | <i>P</i> | Mean<br>Rank | Test Statistic                      | <i>P</i>     | Mean<br>Rank | Test Statistic                     | <i>P</i>     | Mean<br>Rank | Test Statistic                     | <i>P</i> |
| <b>Residence<sup>b</sup></b>                              |                   |               | $Z = -1.337$<br>( $U = 5\,077.00$ ) | .181     |              | $Z = -2.185$<br>( $U = 4\,736.50$ ) | <b>.029*</b> |              | $Z = -1.841$<br>( $U = 4\,867.0$ ) | .066         |              | $Z = -1.363$<br>( $U = 5\,106.0$ ) | .173     |
| Urban                                                     | 167               | 113.77        |                                     |          | 112.03       |                                     |              | 114.26       |                                    |              | 114.26       |                                    |          |
| Rural                                                     | 68                | 126.42        |                                     |          | 132.36       |                                     |              | 1230.46      |                                    |              | 127.00       |                                    |          |
| <b>Health Insurance<sup>b</sup></b>                       |                   |               | $X^2(3) = 7.015$                    | .071     |              | $X^2(3) = 4.140$                    | .247         |              | $X^2(3) = 8.289$                   | <b>.040*</b> |              | $X^2(3) = 4.328$                   | .228     |
| Private Insurance                                         | 90                | 123.51        |                                     |          | 123.80       |                                     |              | 109.53       |                                    |              | 108.44       |                                    |          |
| Medical card                                              | 92                | 121.95        |                                     |          | 121.38       |                                     |              | 133.32       |                                    |              | 127.18       |                                    |          |
| Both                                                      | 41                | 92.76         |                                     |          | 100.59       |                                     |              | 103.20       |                                    |              | 121.99       |                                    |          |
| Neither                                                   | 12                | 123.42        |                                     |          | 109.31       |                                     |              | 114.27       |                                    |              | 105.92       |                                    |          |

Key: \*  $p < 0.05$ , <sup>a</sup> Mann-Whitney U tests for binary categorical variables, <sup>b</sup> Kruskal-Wallis H tests for more than two categorical variable

**Table 5.30 Inferential Statistical Analysis to Identify if Clinical Factors are Associated with Differences in Participants Subscale Scores**

| IPF-Patient Reported Outcome Measure Subscales (IPF-PROM) |                   |               |                                  |          |              |                                  |          |              |                                 |          |              |                                  |          |
|-----------------------------------------------------------|-------------------|---------------|----------------------------------|----------|--------------|----------------------------------|----------|--------------|---------------------------------|----------|--------------|----------------------------------|----------|
|                                                           |                   | Psychological |                                  |          | Physical     |                                  |          | Emotional    |                                 |          | Energy       |                                  |          |
|                                                           | <i>N</i><br>(235) | Mean<br>Rank  | Test statistic                   | <i>P</i> | Mean<br>Rank | Test statistic                   | <i>P</i> | Mean<br>rank | Test statistic                  | <i>P</i> | Mean<br>Rank | Test statistic                   | <i>P</i> |
| Number of Comorbidities <sup>b</sup>                      |                   |               | $X^2(6) = 2.77$                  | .836     |              | $X^2(6) = 2.340$                 | .886     |              | $X^2(6) = 13.15$                | .041*    |              | $X^2(6) = 8.15$                  | .237     |
| 0                                                         | 42                | 120.36        |                                  |          | 122.38       |                                  |          | 115.87       |                                 |          | 122.92       |                                  |          |
| 1                                                         | 83                | 114.49        |                                  |          | 111.51       |                                  |          | 101.12       |                                 |          | 103.65       |                                  |          |
| 2                                                         | 61                | 121.45        |                                  |          | 122.99       |                                  |          | 134.68       |                                 |          | 131.62       |                                  |          |
| 3                                                         | 32                | 124.70        |                                  |          | 125.11       |                                  |          | 135.13       |                                 |          | 128.77       |                                  |          |
| 4                                                         | 11                | 107.82        |                                  |          | 109.64       |                                  |          | 98.73        |                                 |          | 106.59       |                                  |          |
| Prescribed Oxygen <sup>a</sup>                            |                   |               | $Z = -4.70$<br>( $U = 3566.00$ ) | <.001*   |              | $Z=-3.11$<br>( $U = 4357.00$ )   | .002*    |              | $Z=-3.60$<br>( $U = 4085.50$ )  | <.001*   |              | $Z=-1.28$<br>( $U = 5187.50$ )   | .199     |
| Yes                                                       | 70                | 148.56        |                                  |          | 138.26       |                                  |          | 142.14       |                                 |          | 126.39       |                                  |          |
| No                                                        | 165               | 104.24        |                                  |          | 109.41       |                                  |          | 107.76       |                                 |          | 114.44       |                                  |          |
| Reimbursed <sup>c</sup> Port. Oxygen <sup>b</sup>         |                   |               | $X^2(3) = 8.71$                  | .033*    |              | $X^2(3) = 1.69$                  | .639     |              | $X^2(3) = 1.83$                 | .607     |              | $X^2(3) = 3.56$                  | .313     |
| Yes                                                       | 44                | 32.60         |                                  |          | 33.26        |                                  |          | 33.38        |                                 |          | 34.08        |                                  |          |
| In part                                                   | 9                 | 26.78         |                                  |          | 36.67        |                                  |          | 34.44        |                                 |          | 27.94        |                                  |          |
| No                                                        | 17                | 47.24         |                                  |          | 40.41        |                                  |          | 38.82        |                                 |          | 40.85        |                                  |          |
| Has IPF Impacted Work <sup>a</sup>                        |                   |               | $Z = -4.29$<br>( $U = 4608.00$ ) | <.001*   |              | $Z = -2.00$<br>( $U = 5691.50$ ) | .045*    |              | $Z= -.854$<br>( $U = 6278.00$ ) | .393     |              | $Z = -.854$<br>( $U = 6278.00$ ) | .393     |
| No                                                        | 111               | 91.68         |                                  |          | 102.53       |                                  |          | 89.83        |                                 |          | 112.63       |                                  |          |
| Yes                                                       | 124               | 138.88        |                                  |          | 129.50       |                                  |          | 140.47       |                                 |          | 119.87       |                                  |          |

Key: \*\*p<0.05, <sup>a</sup> Mann-Whitney U test for binary categorical variables, <sup>b</sup> Kruskal-Wallis H test for more than two categorical variables, <sup>c</sup> Port (Portable)

**Table 5.31 Inferential Statistical Analysis to Identify if Healthcare Access Factors are Associated with Differences in Participants' Subscale Scores**

| IPF-Patient Reported Outcome Measure Subscales (IPF-PROM) |                   |               |                                          |          |           |                                          |              |           |                                          |              |           |                                         |          |
|-----------------------------------------------------------|-------------------|---------------|------------------------------------------|----------|-----------|------------------------------------------|--------------|-----------|------------------------------------------|--------------|-----------|-----------------------------------------|----------|
|                                                           |                   | Psychological |                                          |          | Physical  |                                          |              | Emotional |                                          |              | Energy    |                                         |          |
|                                                           | <i>N</i><br>(235) | Mean Rank     | Test statistic                           | <i>P</i> | Mean Rank | Test statistic                           | <i>P</i>     | Mean rank | Test statistic                           | <i>P</i>     | Mean Rank | Test statistic                          | <i>P</i> |
| <b>Access to a Physiotherapist</b>                        |                   |               | <i>Z</i> =-.744<br>( <i>U</i> =6451.50)  | .457     |           | <i>Z</i> =--.158<br>( <i>U</i> =6809.50) | .875         |           | <i>Z</i> =-2.40<br>( <i>U</i> =5656.00)  | <b>.016*</b> |           | <i>Z</i> =-1.29<br>( <i>U</i> =6243.00) | .197     |
| Yes                                                       | 113               | 120.88        |                                          |          | 117.30    |                                          |              | 107.00    |                                          |              | 112.24    |                                         |          |
| No                                                        | 122               | 114.45        |                                          |          | 118.64    |                                          |              | 128.02    |                                          |              | 123.24    |                                         |          |
| <b>Access to ILFA Support Group <sup>a</sup></b>          |                   |               | <i>Z</i> =-1.282<br>( <i>U</i> =4761.00) | .200     |           | <i>Z</i> =-1.757<br>( <i>U</i> =4592.00) | .079         |           | <i>Z</i> =-2.213<br>( <i>U</i> =4362.50) | <b>.027*</b> |           | <i>Z</i> =-.809<br>( <i>U</i> =5200.50) | .418     |
| Yes                                                       | 62                | 126.71        |                                          |          | 130.44    |                                          |              | 134.14    |                                          |              | 120.62    |                                         |          |
| No                                                        | 173               | 114.18        |                                          |          | 113.54    |                                          |              | 112.22    |                                          |              | 117.06    |                                         |          |
| <b>Access to Palliative Care<sup>a</sup></b>              |                   |               | <i>Z</i> =-1.55<br>( <i>U</i> =618.00)   | .119     |           | <i>Z</i> =-1.964<br>( <i>U</i> =553.50)  | <b>.050*</b> |           | <i>Z</i> =-1.196<br>( <i>U</i> =685.50)  | .232         |           | <i>Z</i> =-1.860<br>( <i>U</i> =570.50) | .063     |
| Yes                                                       | 8                 | 153.25        |                                          |          | 162.31    |                                          |              | 145.81    |                                          |              | 160.19    |                                         |          |
| No                                                        | 227               | 116.23        |                                          |          | 116.44    |                                          |              | 117.02    |                                          |              | 116.51    |                                         |          |
| <b>Access to a Dietitian<sup>a</sup></b>                  |                   |               | <i>Z</i> =-1.078<br>( <i>U</i> =1562.00) | .281     |           | <i>Z</i> =-2.253<br>( <i>U</i> =1272.00) | <b>.024*</b> |           | <i>Z</i> =-.312<br>( <i>U</i> =1770.00)  | .755         |           | <i>Z</i> =-.750<br>( <i>U</i> =1658.50) | .453     |
| Yes                                                       | 17                | 134.12        |                                          |          | 152.18    |                                          |              | 122.88    |                                          |              | 129.44    |                                         |          |
| No                                                        | 218               | 116.20        |                                          |          | 115.33    |                                          |              | 117.62    |                                          |              | 117.11    |                                         |          |

Key: \**p*<0.05, <sup>a</sup> Mann-Whitney U test for binary categorical variable



### **5.5.8 Correlational Analysis of Quality of Life and Information Needs**

Correlational analysis between the LINQ and the IPF-PROM subscale scores was not recorded as significant; therefore, no further analysis was performed to examine the relationship between the IPF-PROM subscale scores and the Lung Information Needs Questionnaire (LINQ) subscale scores.

## **5.6 Explanatory Factors Influencing Quality of Life**

### **5.6.1 Backward Stepwise Regression Analysis**

Backward stepwise regression was utilised to support the identification of the most likely combination of variables that could best explain participants' quality of life using the SGRQ-I, followed by the IPF-PROM survey instruments. The assumptions underlying the regression model have previously been described and were adhered to, ensuring that linearity, multicollinearity, homoscedasticity, and normality of residuals were not violated, thus maintaining the robustness of the analysis (Cohen et al., 2013; Stevens, 2002) (Chapter four, Section 4.8.1.4). Firstly, the relationship between the dependent variable (SGRQ-I) and the independent variables was inspected and found to broadly follow a linear distribution. Visual inspection of the normal *P-P* plot for the SGRQ-I revealed no clear outlying residuals or evidence of skewness, indicating a good model fit, supporting the selection of the backward regression model (Appendix 16). Further validation came from the scatterplot, where residuals followed a horizontal band indicating homoscedasticity (Appendix 16). The histogram for the SGRQ-I also supported a broadly normal distribution (Appendix 16). Additionally, a Durbin-Watson score of 1.416 suggested that the residuals were largely independent. It is accepted that scores between  $> 1$  and  $< 3$ , indicate the assumption of independent errors, are tenable (Field, 2013).

The relationship between the secondary quality of life measure in this study, IPF-PROM (dependent variable) and the independent variables followed a linear distribution. Visual inspection of the normal *P-P* plot for the IPF-PROM revealed no clear outlying residuals or evidence of skewness, suggesting a good model fit (Appendix 16). The histogram also showed no clear outliers and broadly followed a normal distribution (Appendix 16). Additionally, the scatterplot demonstrated that residuals adhered to broadly normal homoscedasticity (Appendix 16). Additionally, a Durbin-Watson score of 1.818, which is within the acceptable range  $> 1$  and  $< 3$ , indicating no evidence to invalidate the assumption of independent errors (Field, 2013).

### **5.6.2 Multicollinearity Checks**

Multicollinearity checks were performed on the independent variables of interest, with levels of multicollinearity ranging between 5 and 10 in the case of both the SGRQ-I and the IPF-PROM for several variables (Table 5.32). Following consultation with a statistician, it was decided to retain the variables, given that VIF values ranged between  $> 5$  and  $< 10$  in the case of the six items from both the SGRQ-I and

the IPF-PROM, indicating a moderate correlation within acceptable boundaries. James et al. (2013) suggest that a VIF between 5 and 10 reflects a moderate correlation of model predictors.

**Table 5.32 Multicollinearity Checks for SGRQ-I and the IPF-PROM**

| <b>Instrument &amp; Variable</b>                                                  | <b>Tolerance</b> | <b>VIF</b>  |
|-----------------------------------------------------------------------------------|------------------|-------------|
| <b>SGRQ-I:</b> Is the cost of portable oxygen reimbursed?                         | Tolerance = .132 | VIF = 7.601 |
| <b>SGRQ-I:</b> Is the cost of home oxygen reimbursed?                             | Tolerance = .123 | VIF = 8.099 |
| <b>SGRQ-I:</b> Previously asked to participate in a clinical trial or research.   | Tolerance = .109 | VIF = 9.166 |
| <b>IPF-PROM:</b> Is the cost of portable oxygen reimbursed?                       | Tolerance = .116 | VIF = 8.658 |
| <b>IPF-PROM:</b> Is the cost of home oxygen reimbursed?                           | Tolerance = .107 | VIF = 9.351 |
| <b>IPF-PROM:</b> Previously asked to participate in a clinical trial or research. | Tolerance = .117 | VIF = 8.574 |

### **5.6.3 Backward Stepwise Regression Procedures**

A total of twenty-seven variables, which demonstrated statistically significant differences in quality of life scores in prior inferential statistical analysis (Section 5.4 & 5.5), met the criteria for inclusion in the regression modelling analysis (Table 5.33). All items from the lung information needs (LINQ) survey instrument relating to information needs were retained, regardless of significance, as an exploratory approach was employed in the regression analysis to identify unmet needs which may impact participants' quality of life. All independent variables were categorical. The selected variables facilitated our objective to gain a comprehensive understanding of the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF.

**Table 5.33 Variables Included in the Backward Regression Model**

| Variables Included in the Backwards Stepwise Regression Model |                                                                                           | Area of Need                            |
|---------------------------------------------------------------|-------------------------------------------------------------------------------------------|-----------------------------------------|
| I.                                                            | Access to a physiotherapist, dietician, palliative care or an ILFA patient support group. | Healthcare access needs                 |
| II.                                                           | Are you aware of any ongoing clinical trials/research studies in IPF?                     | Clinical trial participation needs      |
| III.                                                          | Were you ever asked to be involved in a clinical trial/research study                     | Clinical trial awareness needs          |
| IV.                                                           | Are you currently taking a medicine called pirfenidone for your lung condition?           | Access to antifibrotic medication needs |
| V.                                                            | If no, were you treated with pirfenidone medication for your lung condition in            | Access to antifibrotic medication needs |
| VI.                                                           | Age Category                                                                              | Sociodemographic information            |
| VII.                                                          | Is the cost of home oxygen paid for by your health insurance?                             | Access to oxygen needs                  |
| VIII.                                                         | Is the cost of portable oxygen paid for by your health insurance?                         | Access to oxygen needs                  |
| IX.                                                           | Are you currently taking a medicine called nintedanib for your lung condition?            | Access to antifibrotic medication needs |
| X.                                                            | If no, were you treated with nintedanib for your lung condition?                          | Access to antifibrotic medication needs |
| XI.                                                           | Do you have a digestive system disorder?                                                  | Clinical Factors                        |
| XII.                                                          | Do you have an endocrine system disorder?                                                 | Clinical Factors                        |
| XIII.                                                         | Do you live on your own?                                                                  | Sociodemographic information            |
| XIV.                                                          | Do you live >20 km from the hospital you attend for IPF treatment?                        | Health care centre access needs         |
| XV.                                                           | Gender                                                                                    | Sociodemographic information            |
| XVI.                                                          | Health Insurance status                                                                   | Sociodemographic information            |
| XVII.                                                         | Comorbid condition                                                                        | Clinical Factors                        |
| XVIII.                                                        | Prescribed oxygen                                                                         | Access to oxygen needs                  |
| XIX.                                                          | LINQ subscales: disease knowledge, self-management, medicine, smoking, exercise, diet.    | Information needs                       |

#### 5.6.4 Backward Stepwise Regression (SGRQ-I)

The first backward regression model was conducted using the St. George Respiratory Questionnaire-IPF (SGRQ-I) (dependent variable) to explore which of the twenty-seven independent variables significantly predicted quality of life in participants with IPF. The analysis used a backward elimination method, with variables removed if the probability of  $F$ -to remove was greater than or equal to 0.100. The final model, model 20, included six predictor variables and was statistically significant ( $F(6,51) = 7.593$ ,  $p < 0.01$ ,  $R^2 = 0.410$ ). The adjusted  $R$ -squared of 0.410 indicates that approximately 41% of the variance in SGRQ-I scores was explained by the model containing the remaining six predictor variables. The six predictor variables that remained in the final model were:

- ✓ History of an endocrine system disorder ( $p = .007$ ).
- ✓ Previous treatment with nintedanib ( $p = .036$ ).
- ✓ Presence of a comorbid condition ( $p = .004$ ).
- ✓ Smoking history ( $p = .009$ ).
- ✓ Living arrangements (living alone) ( $p = .069$ ).
- ✓ Access to the Irish Lung Fibrosis Association peer support group ( $p = .085$ ).

The unstandardised coefficients indicated significant contributions from the following: having an endocrine disorder ( $\beta = -455.031$ ,  $t = -2.789$ ,  $p = .007$ ), presence of a comorbid condition ( $\beta = 138.48$ ,  $t = 3.04$ ,  $p = .004$ ), and smoking ( $\beta = 142.65$ ,  $t = 2.71$ ,  $p = .009$ ) and further highlighted the robust fit of the model. The findings indicate the strong predictive power that certain needs such as healthcare access, psychosocial needs and clinical factors have on the quality of life of individuals with IPF. The remaining fourteen independent variables included in the regression model did not contribute to the model in a statistically significant, meaningful way. In summary, the backward stepwise regression model identified that having a comorbid condition ( $\beta = 138.48$ ,  $t = 3.04$ ,  $p = .004$ ) was the most significant predictor for quality of life when assessed against the SGRQ-I instrument (Table 5.34).

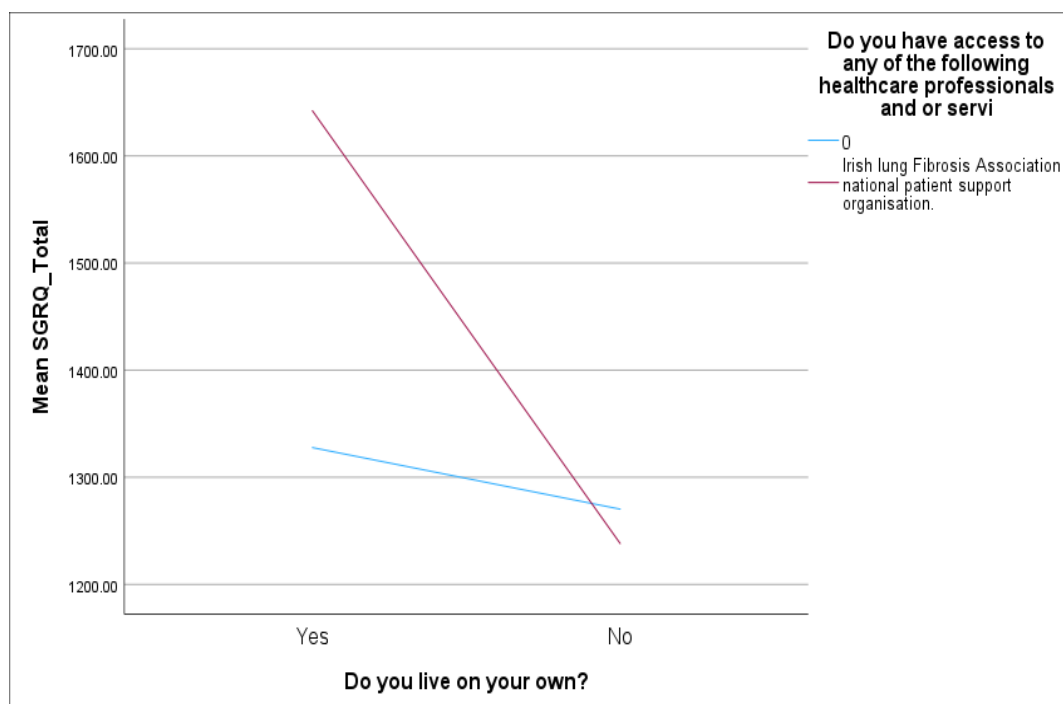
**Table 5.34 Backwards Stepwise Regression Model SGRQ-I**

| Backward Stepwise Regression<br>Dependent Variable SGRQ-I |                                               |                                |            |        |      |                         |             |
|-----------------------------------------------------------|-----------------------------------------------|--------------------------------|------------|--------|------|-------------------------|-------------|
|                                                           |                                               |                                |            |        |      | 95% Confidence Interval |             |
| Model                                                     | Parameter                                     | Unstandardized coefficient (B) | Std. Error | t      | Sig. | Upper Bound             | Lower Bound |
| 20                                                        | Do you have an endocrine system disorder      | -455.031                       | 163.154    | -2.789 | .007 | -782.577                | -127.485    |
|                                                           | Previous treatment with ninetedanib?          | 302.884                        | 140.963    | 2.149  | .036 | 19.889                  | 585.879     |
|                                                           | Comorbid condition                            | 138.487                        | 45.495     | 3.044  | .004 | 47.153                  | 229.821     |
|                                                           | Smoking                                       | 142.654                        | 52.624     | 2.711  | .009 | 37.007                  | 248.302     |
|                                                           | Living alone                                  | -218.786                       | 117.646    | -1.860 | .069 | -454.971                | 17.398      |
|                                                           | Access to the Irish Lung Fibrosis Association | 234.214                        | 133.150    | 1.759  | .085 | -33.096                 | 501.525     |
|                                                           | Constant                                      | 963.487                        | 335.609    | 2.871  | .006 | 289.724                 | 1637.250    |

### 5.6.5 Interaction Effect

Further analysis was conducted to explore if there was an interaction effect between statistically significant variables of interest observed in the backward regression model. Two variables from prior analysis indicated a significant interaction effect, namely 'living alone' and 'attending an Irish Lung Fibrosis Association Peer (ILFA) support group. Those who live alone and who attend an ILFA peer support group have significantly lower quality of life (captured by higher SGRQ-I scores) compared to those who do not attend this form of support. Among those who live with others, there is less difference observed in quality of life between those who do and do not attend ILFA support group meetings ( $F(1,221) = 4.205, p = .042$ ) (Figure 5.24).

**Figure 5.24 Interaction Relationship (Living Arrangements and Support Group Attendance)**



### 5.6.6 Backward Stepwise Regression (IPF-PROM)

A second backward stepwise regression model was generated for the IPF-PROM (dependent variable) to explore which of the independent variables significantly predicted participants with IPF quality of life (Table 5.35). The same guidelines and criterion used for the SGRQ-I were employed in this analysis. The final model, model 16 identified ten statistically significant independent variables ( $F(10,51) = 6.820, p < .001, R^2 = 0.488$ ). The ten variables are outlined in Table 5.35.

**Table 5.35 IPF-PROM Backward Regression Model**

| Independent Variables                             |                                                 |
|---------------------------------------------------|-------------------------------------------------|
| Age category ( $p < .001$ )                       | Awareness of clinical trials ( $p = .008$ )     |
| Previous treatment with nintedanib ( $p < .001$ ) | Access to an ILFA support group ( $p = .003$ )  |
| Smoking history ( $p < .001$ )                    | History of an endocrine disorder ( $p = .014$ ) |
| Disease knowledge ( $p = .002$ )                  | Currently prescribed pirfenidone ( $p = .012$ ) |
| Exercise ( $p = 0.20$ )                           | Living > 20km from the hospital ( $p = .022$ )  |

The adjusted  $R$  square of .488 suggested that approximately 49% of the variance in IPF-PROM scores was explained by the ten predictor variables listed above, highlighting the robust fit of the model. In summary, the backward regression analysis identified ten predictor variables, with three of these variables being highly significant predictors of quality of life assessed by the IPF-PROM, namely, age category ( $\beta = -3.88$ ,  $t = -4.30$ ,  $p < .001$ ), previous treatment with nintedanib ( $\beta = 7.35$ ,  $t = 3.47$ ,  $p < .001$ ), and smoking history ( $\beta = 2.97$ ,  $t = 3.94$ ,  $p < .001$ ) indicating the significant role of these variables on overall quality of life using the IPF-PROM (Table 5.36).

**Table 5.36 Backward Stepwise Regression IPF-PROM**

| Backward Stepwise Regression/ Dependent Variable Patient Reported Outcome Measure- IPF (IPF-PROM) |                                                                                 |                                |            |        |       |                         |             |
|---------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------|--------------------------------|------------|--------|-------|-------------------------|-------------|
| Model                                                                                             |                                                                                 |                                |            |        |       | 95% Confidence Interval |             |
| 16                                                                                                | Parameter                                                                       | Unstandardized coefficient (B) | Std. Error | t      | Sig.  | Upper Bound             | Lower Bound |
|                                                                                                   | Age Category                                                                    | -3.881                         | .902       | -4.302 | <.001 | -5.692                  | -2.070      |
|                                                                                                   | Do > 20km from the hospital you attend for your IPF treatment?                  | 3.862                          | 1.629      | 2.371  | .022  | .592                    | 7.132       |
|                                                                                                   | Do you have a history of an endocrine system disorder                           | -5.729                         | 2.247      | -2.550 | .014  | -10.239                 | -1.218      |
|                                                                                                   | Are you currently taking a medicine called pirfenidone for your lung condition? | -4.509                         | 1.739      | -2.592 | .012  | -8.000                  | -1.017      |
|                                                                                                   | If no, were you treated with nintedanib medication in the past?                 | 7.359                          | 2.119      | 3.473  | .001  | 3.106                   | 11.612      |
|                                                                                                   | Smoking                                                                         | 2.978                          | .755       | 3.944  | <.001 | 1.462                   | 4.493       |
|                                                                                                   | Exercise                                                                        | -2.700                         | 1.119      | -2.411 | .020  | -4.947                  | -.452       |
|                                                                                                   | Disease Knowledge                                                               | -2.439                         | .749       | -3.255 | .002  | -3.944                  | -.935       |
|                                                                                                   | Are you aware of any clinical trials related to IPF?                            | 6.666                          | 2.420      | 2.755  | .008  | 1.808                   | 11.524      |
|                                                                                                   | Do you have access to the Irish Lung Fibrosis Association                       | 11.701                         | 3.700      | 3.163  | .003  | 4.274                   | 19.128      |
|                                                                                                   | Constant                                                                        | 21.926                         | 6.049      | 3.624  | <.001 | 9.781                   | 34.071      |



## 5.7 Conclusion

This chapter presented the results of the statistical analysis of quantitative survey data, which addressed the study's objectives. First, the healthcare organisation audit (phase one) was presented, followed by analysis of the IPF survey data (phase two), offering opportunities to gain greater insight into the unmet needs, symptom experiences, and quality of life of people diagnosed with IPF attending nationally representative tertiary hospitals. Sixteen healthcare professionals completed the audit in phase one across five healthcare sites. Widespread variability existed regarding the timely provision of care and access to supports and services to address the unmet needs of individuals with IPF. Half of the sample reported no access to clinical trial facilities (50%), and a further 43.7% referenced barriers to pulmonary rehabilitation. An additional 37.7% reported barriers to lung transplantation assessment. Furthermore, 62.5% of participants reporting a lack of time to spend on consultations with patients with IPF during outpatient clinics. Deficits existed regarding satisfactory availability of healthcare staff to care for patients with IPF, including a social worker, occupational therapist, psychologist/counsellor, respiratory nurse specialist and pharmacist. Variability existed in palliative care input, with referrals most commonly occurring in years two and three post an IPF diagnosis (31.2%). Reimbursement for ambulatory oxygen therapy remain problematic, with some patients out of pocket when prescribed oxygen therapy, representing a financial burden.

Next analysis was performed on the IPF Survey data (phase two). Descriptive statistics found that males were more frequently represented in the sample (68.4%), followed by females (31.6%). White ethnicities (97.8%) were the most frequently represented group. Participants were aged between fifty and ninety years, with the highest number of participants represented in the seventy to seventy-nine age group (46.8%), with 70.5% residing in either urban or rural areas (29.5%). Variability existed in insurance status, with 38.3% of participants having private health insurance and a further 38.8% having only a medical card. A mix of living arrangements existed (51% lived alone and 49% lived with others). Most participants attend a public hospital for their treatment (87.3%). Participants were predominantly retired (83%). The highest number of participants were diagnosed more than five years ago (32%), followed by those diagnosed four to five years ago (20%). A total of 29.5% of the sample were currently prescribed oxygen therapy. Access to healthcare supports varied widely, with deficits observed in availability, affordability and accessibility of services.

Unmet needs were broad and varied, and included widespread information deficits, with males generally having higher information needs than females. Gaps in information provision were identified in several of the lung information needs questionnaire subscales, particularly medicines, diet and exercise, with a lack of written instructions evident in the event of requiring an ambulance due to worsening breathlessness (63%). Several participants believed that their IPF would stay the same or they would get better (39%), representing an unmet information need. Information deficits existed regarding smoking cessation, with 27% of those who had previously smoked having never been advised to give up smoking and 20% having never been offered any help to quit. Further information needs existed around dietary advice, with 53.2%

reporting that a healthcare professional had not given them dietary advice. This trend existed for information regarding physical activity, where 27% of participants reported that they were unsure as to how much exercise to do.

The two most frequently endorsed symptoms reported by participants were shortness of breath (72.9%) and cough (68.6%), resulting in impacts to quality of life. Symptom burden and quality of life were investigated using both the SGRQ-I and IPF-PROM. Females tended to report poorer quality of life than males observed in both the SGRQ-I and the IPF-PROM. The top six highest reported impacts to quality of life using the SGRQ-I instrument were situated in two subscales (impacts and activity) and related to inability to engage in sports (75%) or other games (72.1%), difficulties walking up a flight of stairs (74.5%), exhaustion (70%), sleep disturbances (68%) and walking in the house (66.8%). The most endorsed concerns impacting quality of life using the IPF-PROM were situated in both the physical and psychological subscales and included difficulty managing the uncertainty of life (29.4%), felt IPF has brought worry into your life (23.4%) and fear of getting out of breath which had limited daily life (23%), felt breathless with everyday activities (29.8%), stopped doing things previously enjoyed (28.9%) and feeling lethargic (26.2%).

These findings were supported by inferential statistics, which identified twenty-seven variables that were independently associated with statistically significant differences in individuals diagnosed with IPF quality of life scores on both the SGRQ-I and the IPF-PROM. Backward stepwise regression was completed using these significant independent variables, which incorporated sociodemographic, clinical factors, information needs and access to supports and services, resulting in sixteen predictor variables combined across both survey instruments that contributed to the variance observed in quality of life scores.

These findings supported earlier descriptive and inferential conclusions and found that having a history of an endocrine system disorder, previously treated with either nintedanib/pirfenidone, having a comorbid condition, smoking history, living alone, access to an Irish Lung Fibrosis peer support group, age category, disease knowledge, exercise, awareness of clinical trials related to IPF, currently prescribed pirfenidone, exercise, and living more than 20km from the hospital significantly predicted quality of life. Further analysis to assess the interaction relationship found that those who lived alone and attended an Irish Lung Fibrosis peer support group had significantly lower quality of life (SGRQ-I) compared to those who lived with others and participated in this form of support.

Chapter 6 will now examine the qualitative interviews, which formed a central component of this mixed methods explanatory sequential study to explore the quality of life, symptom burden and unmet needs of people diagnosed with IPF, to foster greater knowledge of participants' unique experience of accessing healthcare to address their needs.

## Chapter 6 Qualitative Findings

### 6.1 Introduction

Chapter 6 presents the qualitative findings for this mixed-methods study. These findings extend the quantitative results outlined in Chapter 5, and provide an in-depth investigation of the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF. The inclusion of interviews in this study enabled participants to use their preferred rhetoric, enhancing the credibility of the findings through the inclusion of quotes. This chapter will begin with a description of the findings from phase three (qualitative interviews). A conceptual map is provided to illustrate the key findings, which reveal four themes (Figure 6.1).

#### **Theme One: Navigating the complex IPF journey**

This theme captures participants' experience at the time of diagnosis, illustrating the complexities of their journey. It also highlights the emotional impact of receiving an IPF diagnosis and reveals widespread gaps in the knowledge and public awareness about the disease.

#### **Theme Two: The burden of living with IPF**

Theme two provides a detailed insight into the lived experience of the symptoms of IPF, coupled with participants' fears and anxieties about how their disease will progress and end-of-life care. It also illustrates the notable impact of the COVID-19 pandemic and reviews the significant barriers faced when oxygen therapy is prescribed.

#### **Theme Three: Addressing psychosocial needs**

Theme three focuses on the relational, emotional, and psychological components of living with an IPF diagnosis. This theme explores participants' worries and concerns about palliative care and illustrates the need for a holistic person-centred approach to care.

#### **Theme Four: Engaging with a complicated healthcare system**

This final theme outlines the challenges participants encounter in accessing healthcare, identifying both the barriers and facilitators that shaped their engagement with health services.

Considerable care was taken in this inquiry to optimise the quality and rigour in the qualitative interviews aligned with the practical framework offered by Lincoln and Guba (1985), which addresses the issues of credibility, transferability, confirmability and dependability, as discussed in detail in Chapter 4 (Section 4.7.3). Findings from open-ended questions in phase one (Healthcare Organisation Audit) are presented in Section 6.3.

## 6.2 Presentation of Qualitative Findings

The methods for qualitative analysis are described in section 4.8.2 and relate to the semi-structured interviews conducted with people diagnosed with IPF. Interviews took place between February 2024 and April 2024, averaging 55 minutes (range 39 minutes to 1 hour 3 minutes). A total of twenty interviews were completed. Direct quotes from participant interviews are provided to illustrate the themes. Interview transcripts are assigned a numerical code in place of real names, coupled with each participant's gender and age.

### 6.2.1 Qualitative Findings

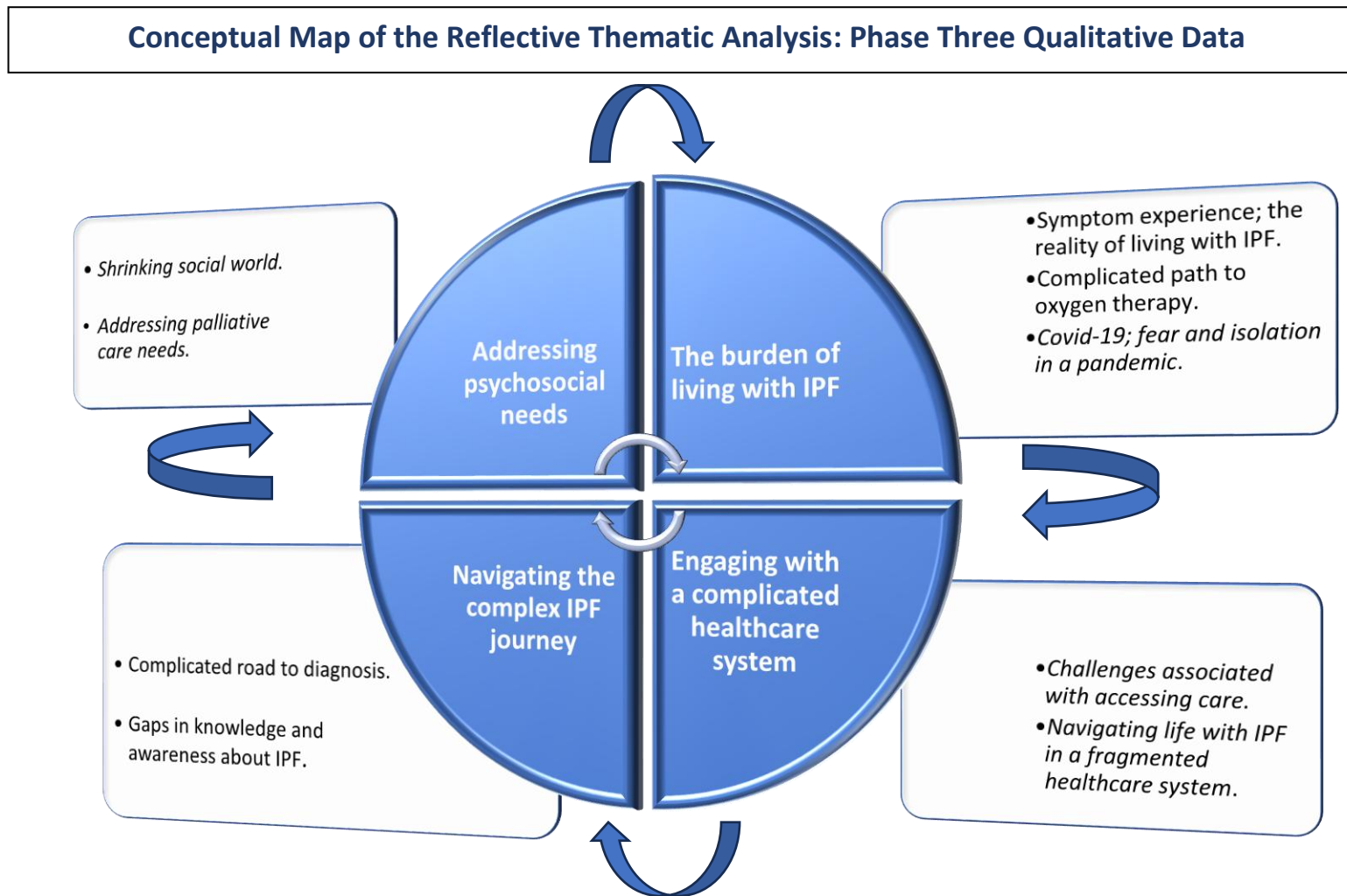
All participants had a diagnosis of IPF ( $N = 20$ ) and received their diagnosis at one of the five national hospital sites included in this study. Summary characteristics of the sample are provided in Table 6.1. The mean age of participants was 79 years (range 50 - 86 years). Females comprised 40% ( $n = 8$ ) and males 60% ( $n = 12$ ) of the interview sample. Participants diagnosed in the last 3-4 years ( $n = 10$ , 50%) represented the largest group, followed by those diagnosed more than five years ago ( $n = 4$ , 20%). Participants predominately resided in urban locations ( $n = 16$ , 80%) with the remainder residing in rural areas ( $n = 4$ , 20%). Most participants were White-Irish ( $n = 19$ , 95%). Many participants had a medical card, or general practitioner visit card ( $n = 11$ , 55%), while others had private health insurance ( $n = 9$ , 45%). Most participants were prescribed antifibrotic medication ( $n = 13$ , 65%). A significant proportion were prescribed oxygen ( $n = 8$ , 40%).

Qualitative data analysis was conducted using Braun and Clarke's reflexive thematic analysis (Braun & Clark, 2006, 2018), grounded in Levesque's theoretical framework of access to healthcare (2013). Both frameworks provided the scaffolding from which to anchor this inquiry. Although heterogeneity exists between interviews due to the unique lives of people with IPF, the concepts of this study, unmet needs, symptom experiences, and quality of life, were considered broadly within the context of Levesque's theoretical framework (2013). This framework considers the facilitators and barriers to accessing healthcare from multiple perspectives, including individual, societal, cultural and system levels, to address unmet needs. The four themes developed in this qualitative analysis represent the lives of people diagnosed with IPF. They aim to contextualise their experience of navigating a complex healthcare system, providing valuable insights into their experiences (Figure 6.1).

**Table 6.1 Summary Characteristics of the Interview Sample**

| Variable ( <i>N</i> = 20)                      | <i>N</i> | %   |
|------------------------------------------------|----------|-----|
| <b>Gender</b>                                  |          |     |
| Female                                         | 8        | 40  |
| Male                                           | 12       | 60  |
| <b>Age groups</b>                              |          |     |
| 50-59 years                                    | 1        | 5   |
| 60-69 years                                    | 3        | 15  |
| 70-79 years                                    | 11       | 55  |
| 80-86 years                                    | 5        | 25  |
| <b>Time since diagnosis</b>                    |          |     |
| < 1 year                                       | 3        | 15  |
| 1-2 years                                      | 3        | 15  |
| 3-4 years                                      | 10       | 50  |
| 5 years or more                                | 4        | 20  |
| <b>Ethnicity</b>                               |          |     |
| Irish                                          | 19       | 95  |
| Other                                          | 1        | 20  |
| <b>Residence</b>                               |          |     |
| Urban                                          | 16       | 80  |
| Rural                                          | 4        | 20  |
| <b>Living arrangement</b>                      |          |     |
| Living with others (partner, family & friends) | 13       | 65  |
| Alone                                          | 7        | 35  |
| <b>Employment status</b>                       |          |     |
| Employment (full-time, part-time)              | 4        | 20  |
| Retired                                        | 16       | 80  |
| Unemployed                                     | n/a      | n/a |
| <b>Insurance status</b>                        |          |     |
| Private health insurance                       | 5        | 25  |
| Medical card or GP only card                   | 11       | 55  |
| Both private health insurance & medical card   | 4        | 20  |
| <b>Oxygen therapy</b>                          |          |     |
| Yes                                            | 8        | 40  |
| No                                             | 12       | 60  |
| <b>Antifibrotic therapy</b>                    |          |     |
| Yes                                            | 13       | 65  |
| No                                             | 7        | 35  |

Figure 6.1 Conceptual Map of the Reflexive Thematic Analysis Findings in the Qualitative Data



## **6.2.2 Theme One: Navigating the Complex IPF journey**

Navigating the complex IPF journey from symptoms to diagnosis underscores the challenges participants encountered on their way to a diagnosis of IPF. Participants reported significant difficulties in obtaining an early and accurate diagnosis. Many described feelings of shock and worry at that time, highlighting the emotional burden associated with a diagnosis of IPF. Participants' emotional distress was often worsened by receiving insufficient information about their diagnosis, often leading them to turn to the internet in search of answers. Further gaps existed regarding public awareness about the condition, illustrating the challenges participants faced on their IPF journey.

### **6.2.2.1 Subtheme 1.1: Complicated Road to Diagnosis**

Many participants described the journey to an IPF diagnosis as prolonged and complicated. Obtaining an accurate and timely diagnosis represented a significant challenge for participants, which frequently affected both physical and psychological well-being. Delayed diagnosis was a common concern experienced by several participants, who described prolonged periods of frustration caused by inconclusive clinical investigations that left them uncertain about the cause of their persistent symptoms. Two-thirds of participants reported frequent visits to a general practitioner and multiple specialist referrals, as they searched for an accurate diagnosis. The symptoms of IPF closely resemble those of various other conditions, which resulted in some people initially receiving an inaccurate diagnosis.

"Nothing showed up, and at the end of the day we were questioning adult-onset asthma, so I was put on inhalers. At times, if I got a bad dose of the coughing, I'd be overdosing on the inhalers (laughing)." (P12, Male, Age 78)

"I kept saying I'm tired. And then after a while I was saying why am I so tired all the time. I was finding it hard to breathe as well. I got it checked out, and the doctor said, 'Yeah, it sounds like menopause symptoms.'" (P17, Female, Age 58)

Delayed diagnosis led to further complications in accessing timely healthcare and appropriate treatments, a challenge experienced across all age and gender subgroups in the interview sample. Some individuals expressed frustration at the missed opportunities for early access to available treatment and support due to delayed diagnosis. Additionally, delayed diagnoses often affected participants' ability to develop trust and rapport with their clinical team, which was occasionally fractured due to the complicated road to diagnosis.

"I had been attending the hospital here for maybe fifteen years and the GP\* (\*general practitioner) who thought maybe I had asthma. That went on until about maybe three years ago, when they did the breathing tests, and the doctor called me in, and he said we think you have fibrosis." (P02, Female, Age 70)

Participants described the investigative process to identify the cause of their symptoms as both emotionally and physically exhausting. Extensive investigations, which resulted in inconclusive results,

often led to frustration and uncertainty for participants. Diagnostic uncertainty increased participants' worries, complicating an already challenging diagnostic journey. Participants described varying levels of tolerability for clinical investigations, with surgical lung-biopsy often regarded as an especially difficult and burdensome procedure.

"I had to get a procedure where they drilled into my side. They took pieces of my lung in a biopsy. I have to be honest; it was the most painful thing I've ever had." (PO6, Male, Age 68)

Participants who failed to receive a timely and accurate diagnosis through the public healthcare system, despite multiple appointments with physicians, often opted to explore alternative options. Many individuals proactively sought a specialist opinion in the private healthcare system at great personal expense. Respiratory specialists, especially those with expertise in IPF, were viewed as an essential resource, playing a pivotal role in the diagnosis of the condition due to their specialised training and in-depth knowledge of the disease. Participants described the relief they experienced once they received an accurate diagnosis, resulting in an end to a prolonged period of uncertainty. A confirmed diagnosis enables timely access to suitable treatment, including antifibrotic therapy, which can slow disease progression, and support better health outcomes for patients.

"After waiting for several tests for some time, I arranged an appointment privately with the Consultant, and I had the \*PFTs (\*pulmonary function test) done, and he said it looks to me like IPF. He said idiopathic pulmonary fibrosis." (P10, Male, Age 72)

Many participants reported significant delays in their diagnostic journey, which led to dissatisfaction with the healthcare system and prolonged uncertainty. Diagnostic delays were frustrating and were largely attributed to the complexity of the healthcare system rather than to individual healthcare professionals. The most frequently cited factors believed to contribute to diagnostic delays resulted from a lack of resources and a shortage of healthcare staff. Participants mainly reported positive interactions with healthcare staff, particularly in the early stages of their disease, frequently referring to them as '*excellent*'.

"And everybody was very kind, and you just felt you could talk to them. My life has changed. Now I didn't realise just how much my life had changed. It had changed radically." (P01, Female, Age 83)

#### **6.2.2.2 Subtheme 1.2: Gaps in Knowledge and Awareness about IPF**

Having navigated the complex journey from initial symptoms to an IPF diagnosis, one-third of participants expressed dissatisfaction with how information about their condition and its progression was communicated to them. Many described the experience as distressing, citing a lack of empathy and sensitivity during consultation with healthcare staff. A perceived lack of sensitivity during communication of an IPF diagnosis added to the emotional burden experienced by participants.

"I think it was just the initial appointment and the way it was said to me. I didn't think it was the right way to say it. I mean, it was just very blunt, and it was just totally unexpected." (P18, Female, Age 64)



A prominent concern for participants was the lack of information provided to them about IPF, particularly at the time of diagnosis. Insufficient information often resulted in a sense of bewilderment and uncertainty amongst participants. Many noted that they were unfamiliar with the disease before diagnosis. The shock of receiving an IPF diagnosis, combined with a lack of reliable information, left many feeling ill-informed and confused about the disease. As a result, participants often left their hospital appointments unable to comprehend the breadth and impact of an IPF diagnosis.

“I was told I had fibrosis in my lung. And that’s about all I was told.” (P03, Male, Age 86)

A third of participants expressed dissatisfaction with how information about their diagnosis was communicated to them during their outpatient clinic appointment. Several participants noted the limited availability of options for the provision of information, including a general lack of paper-based resources. This absence of variability in information resources further contributed to the uncertainty many experienced, making it more challenging to comprehend the diagnosis. This absence of standardised information provision further compounded participants’ sense of uncertainty, underscoring their bewilderment and general overwhelm.

“I wasn’t given any more information, only what the doctor told me that day. I wasn’t even given a leaflet. I was given nothing. I was told the nurse would be in touch with me. That was it.” (P02, Female, Age 70)

Some participants described a sense of discomfort at not being fully informed about the seriousness of their diagnosis. Others recounted how their diagnosis was oversimplified by their healthcare team, often leading to unrealistic expectations about recovery. For others, they described living in a state of limbo, wondering if they would get better or deteriorate. This sense of uncertainty was further exacerbated when participants received limited or no follow-up information beyond the initial diagnosis regarding disease progression or survival time, further adding to an unmet information need.

“I left the hospital after getting a diagnosis, but nobody fully explained it; they couldn’t tell me how bad it was, and I was wondering if I would get better.” (P04, Female, Age 77)

Participants’ uncertainty was underscored by a need to understand the contributory factors that resulted in the development of IPF in the first instance. Several participants described how their questions often went unanswered, compounding their bewilderment regarding their health, and the nature of their diagnosis.

“And I was told it was idiopathic, and they was no obvious explanation as to why I had it, but it wasn’t gone into too much. I would have liked it if he had gone into it with me, like what could have contributed to this.” (P01, Female, Age 83)

There was an overarching sense that information delivery at the time of the diagnosis was often dichotomised into one of two camps, either too little or too much information, ‘*the goldilocks phenomenon*’, leading to some participants seeking information via the internet. Personal preferences regarding the type and volume of information was often not prioritised by healthcare staff. In some

instances, participants described their experience of being overwhelmed by the excessive amount of information communicated to them, often leading to shock and worry. Most participants highlighted a preference for gradual provision of information rather than excessive information particularly at the initial diagnosis stage.

“Well, I think the initial diagnosis wasn’t great. I would say you know it was a bit too much information, a both of a shock, but it was like he was reading it from a script.” (P17, Female, Age 58)

For others, insufficient information provision exacerbated the uncertainty and difficulties they faced in fully comprehending their diagnosis of IPF. Several participants noted the lack of take-home information, such as leaflets or other information resources - as an unmet need, often leading to a sense of confusion and ambiguity about their condition.

“No, they didn’t explain basically ever about my IPF. They just said come back in 6 weeks’ time or 3 months.” (P20, Male, Age 83)

The internet was frequently used as an information resource, particularly when participants encountered limited information provision from their healthcare team. Some participants recounted how they had experienced a steep learning curve as they sought information via the internet, which represented a challenging experience. Many had to acquire new skills to help them navigate online resources, with many recalling this experience as challenging and lonely, and often feeling they had been ‘*left on their own*’, believing they had nowhere to turn for help.

“Everybody goes to Google, and that’s our biggest downfall, really, you know and looking at the prognosis and all of that. You’re pretty much left on your own, it is a rare disease, and it’s like, well, where do you turn from there. That really was the biggest issue.” (P16, Female, Age 64)

Others were more cautious and chose to avoid the internet, fearing inaccurate and unreliable information.

“So no, I don’t look up the internet, there’s too much false stuff.” (P12, Male, Age 78)

Other information resources included those available through the Irish Lung Fibrosis Association (ILFA), which some participants had previously accessed. Participants highlighted the variety of resources available from ILFA including peer support groups, which were described by participants as ‘*very helpful*’. ILFA support groups were generally viewed as a reliable information resource and support. However, a gap in awareness about ILFA existed within the hospital setting, representing an unmet need. Many participants reported that they were not signposted to ILFA and had to take a proactive approach to discover this form of support themselves.

“Nobody told me about ILFA, I discovered it. I got involved with their presentations and a lot of their information and found it was excellent.” (P10, Male, Age 72)

A widespread lack of public awareness about IPF was particularly evident amongst family and friends, further exacerbating the difficulties participants faced as they attempted to comprehend their new

diagnosis. Additionally, participants reported frustration connected to the general lack of public awareness about the condition, noting that the public did not fully appreciate the seriousness of the disease. This lack of public awareness about the serious nature of IPF often resulted in an unrealistic oversimplification of the condition, which affected how participants themselves viewed the disease.

“Ah, nobody knew. My family didn’t know. I mean, I never heard of IPF, and none of my colleagues ever heard of it, and there are only some people I would tell. All I ever get from people is: ‘Look at you, you look gorgeous, you’d never think there was anything wrong with you.’” (P17, Female, Age 58)

### **6.2.3 Theme Two: The Burden of Living with IPF**

This theme addresses the reality of adjusting to a diagnosis of IPF. The first subtheme addresses participants’ experience of adapting to a ‘*new normal*’ and the complexities of living with IPF, including the barriers and facilitators to accessing healthcare to help manage symptoms and medication side effects. The second subtheme describes participants’ experiences of worsening breathlessness, necessitating the use of prescribed oxygen. An overview is provided of the complex journey experienced by many participants when accessing oxygen therapy. The third subtheme highlights the added difficulties of living through the COVID-19 pandemic, which introduced an additional layer of complexity to an already challenging journey. Participants recalled how the pandemic had worsened barriers to care and heightened disruptions to the coordination of their care.

#### **6.2.3.1 Subtheme 2.1: Symptom Experience; the Reality of Living with IPF**

Participants described prominent IPF symptoms and medication side effects, highlighting several unmet healthcare needs that negatively affected quality of life. Worsening breathlessness, cough and fatigue were the most frequently reported symptoms. Breathlessness significantly affected participants’ ability to perform certain activities, often leading to avoidance of tasks that might exacerbate their experience of breathlessness. Breathlessness further impacted participants’ social world as it frequently affected their ability to fully engage with certain tasks, a situation that generally worsened over the course of the disease.

“The breathing situation stops me doing some of the things I’d like to do; I’d have a fear of getting too breathless. My breathing isn’t getting any better; it’s hard not being able to do some of the things that I used to do.” (P04, Female, Age 77)

Participants recounted how they experienced cough, a common symptom of IPF, which profoundly impacted both physical and emotional well-being. Excessive coughing frequently affected sleep quality, and had secondary impacts on social activities, due to participants’ experience of lethargy and exhaustion. Excessive coughing had impacted several participants’ ability to socialise, as it affected their ability to hold a conversation during particularly bad coughing episodes.

“It’s certainly inconvenient, anyway. It’s generally worse when I’m talking, particularly if I’m on the telephone. I’d hardly be able to talk; I’d just keep coughing.” (P08, Male, Age 76)

“I had a coughing fit last night that lasted half an hour. I have water beside me all the time, but then I’m up and down to the toilet. I could be up five times a night to go to the toilet.” (P02, Female, Age 70)

Coughing, particularly in public, was recounted by participants as a particularly bothersome symptom. Many participants reported feelings of shame and embarrassment when coughing fits occurred. These concerns were especially heightened during the COVID-19 pandemic due to stigma associated with coughing. Sufferers recounted embarrassment in public settings when they could not control their coughing.

“If I’m coughing in public, it’s a bit of an embarrassment.” (P03, Male, Age 86)

Fatigue was described as a persistent and overwhelming concern, frequently escalating into extreme exhaustion. Participants shared vivid examples of how fatigue impacted their day-to-day activities, with some recounting how they had fallen asleep during conversations, and others recounting how they required frequent breaks during physical activities. Fatigue routinely affected participants’ ability to engage in social activities, resulting in many withdrawing from social engagements as they attempted to prevent exacerbation of their symptoms, resulting in isolation. Participants generally attributed their experience of fatigue to either their IPF diagnosis or to the natural ageing process.

“There are times when I haven’t the energy to participate in a conversation at the table. I need more energy to be part of that, so there are times when I feel I need to sit and not talk, just let other people carry on. That’s when I feel low.” (P01, Female, Age 83)

Sleep disturbances were a frequent cause for concern, often exacerbating the experience of fatigue and lack of energy. Participants recounted the negative impacts of sleep deprivation on routine activities such as housework and outdoor tasks, including gardening. The unpredictability of sleep quality and duration represented a distressing symptom for participants. Many expressed overwhelming anxiety due to the uncertainty associated with their sleep which further added to their overall distress.

“And like some nights I would sleep great and other nights I would sleep badly. I might sleep for three hours and that’s it; I don’t sleep any more than that.” (P02, Female, Age 70)

Moreover, impacts to appetite and weight loss featured in over two-thirds of participant interviews. The symptoms of IPF and medication side effects at times affected participants’ appetite. Some, recounted changes in their weight, which were often initially welcomed; however, the retention of weight quickly became a more prevalent concern, necessitating active intervention and support from healthcare professionals. Dietary support was cited by many participants as frequently unavailable, representing an unmet healthcare need.

“My appetite is gone, which was a good thing; I tended to eat too much. But the girls said at the beginning that you will lose your appetite, but make sure to eat. They didn’t tell me what to eat, though. So yes, some advice would have been helpful at that stage.” (P12, Male, Age 78)

“I think I probably don’t eat as much as I used to. I think my weight has dropped a bit.” (P08, Male, Age 76)

Participants recounted experiences of medication side-effects, included nausea, diarrhoea and vomiting, which were collectively described as being “hugely inconvenient,” disrupting daily lives and negatively affecting overall well-being. Prolonged medication side effects impacted compliance and adherence to treatment protocols as participants sought to minimise the risk of experiencing adverse side effects. Some participants described their experience of feeling unprepared to manage medication side effects, representing additional unmet healthcare needs.

“Unfortunately, I was one of the unlucky people who got severe diarrhoea from my medication.” (P14, Female, Age 76)

“Eventually I agree to go on medication, and I stuck it out for a year, and it nearly killed me. I mean, I just had the worst side effects.” (P16, Female, Age 64)

Medication side effects, such as faecal urgency and/or diarrhoea, were described as distressing and often led to some embarrassing situations, culminating in many choosing to avoid socialising, further isolating them from family and friends. Medication side effects were often viewed as especially problematic and frequently led to participants viewing social engagements as intolerable, negatively affecting emotional well-being and quality of life.

“You’d be very embarrassed. I lost control twice when I was out walking, and I said God, just don’t let me meet somebody on the way home. I couldn’t go anywhere, and the frustration you felt because you had to take the medication to help your symptoms. But the side effects they were having on you were inhibiting your whole life. I couldn’t go anywhere, you know, it was very depressing.” (P18, Female, Age 64)

#### **6.2.3.2 Subtheme 2.2: Navigating the Complicated Path to Oxygen Therapy**

IPF is characterised by a progressive deterioration in lung function, leading to worsening breathlessness, eventually resulting in the requirement for prescribed oxygen. The initiation of oxygen therapy was viewed through a range of lenses, from a supportive one, enabling a person to live independently, to a dependent position, which represented a visible sign of significant deterioration in health. Participants recounted their experience of prescribed oxygen therapy and continual adjustments to a new way of life. For many, the initiation of oxygen was viewed negatively. It ignited profound feelings of powerlessness and anxiety, representing a significant decline in their condition and marking a new milestone on their IPF journey.

“You fall off a cliff in this transition. You are going off a cliff, and you know you are falling, and you are looking around, and you are trying to grab onto some tufts of grass as you are falling. And eh, it’s pretty painful.” (P01, Female, Age 83)

The transition to oxygen therapy represented a steep learning curve as participants adapted to managing their oxygen equipment and related procedures associated with oxygen usage. The introduction of oxygen therapy was a visible indicator of their health status, leading to an often-distressing reality for participants as their condition was now publicly visible. Many recounted how they often worried about how others might perceive them, particularly in social situations, with many fearing that they would be perceived negatively.

“I didn’t want to be publicly identified as an invalid. I felt this canula\* (\*nasal prongs) is bad enough that people can see that. I had to work on myself with that. I would have been very conscious of how I presented myself to the world. And that was my own personal struggle.” (P01, Female, Age 83)

Participants described the challenge of adjusting to a ‘*new normal*’ as they adapted to increasing reliance on oxygen therapy and often struggled with their changing roles, especially in their own relationships as they became dependent on others. Adherence to oxygen therapy was a concern for many, given their experience of stigma when using oxygen equipment in public.

“It is a bit much of an adjustment, and up until now, I have been avoiding using it.” (P03, Male, Age 86)

Several participants who were prescribed oxygen described a diverse range of experiences from being appropriately supported to feeling lost at sea. Many recounted challenges in accessing support with their oxygen needs to facilitate assessment and clinically appropriate adjustments to oxygen requirements, representing a critical unmet need.

“There’s very little support in this whole area of oxygen. There’s nobody following up with you to check that you’re on the right amount of oxygen, and it’s critical. I spent all summer absolutely shattered, no energy. I didn’t feel like eating, just feeling horrible, low in myself and you know the physiotherapist that I eventually saw said you weren’t getting enough oxygen, that’s why you felt so bad.” (P16, Female, Age 64)

Furthermore, the transition to oxygen therapy limited participants’ opportunities for social engagement due to the difficulties associated with oxygen equipment, particularly when mobilising - which was often described as overly burdensome. Participants believed that the initiation of oxygen therapy robbed them of their spontaneity, as the amount of planning required was considered very challenging and hindered their ability to socialise.

“So anyway... (upset...) I found that tank terribly hard to take in. Extremely difficult to live with. My life became very restricted. Very small and not very much socially, it would have taken too

much in relation to organising the oxygen tank and then getting into a car and all that, I didn't want to do it." (P01, Female, Age 83)

"It wouldn't be the visible part that bothers me, it would be the curtailment of doing things." (P07, Male, Age 77)

The introduction of oxygen therapy signalled interruptions to sleep, given the intrusiveness and noise associated with the equipment, leading to some participants expressing poor adherence to their oxygen therapy, especially when their sleep had been impacted.

"The machine is running, and then I take off the machine and try and sleep, and then you are thinking I really should have that machine on, I really should." (P02, Female, Age 70)

The supply and delivery of home oxygen to individuals was sometimes complicated by financial and logistical challenges. Participants who did not have a medical card and had to independently arrange their own oxygen supply recounted the challenges they experienced with this task. Difficulties were associated with the supply, delivery and reimbursement of oxygen therapy, representing an unnecessarily complicated path to an essential support, and underscoring the requirement to address this unmet need.

"There has to be a better way of being reimbursed, but I can't imagine how simple things like that take so much time." (P12, Male, Age 78).

"At the moment, my bill is nearly up to €400 every month, and I'm about three months behind in reimbursements, you know. So, like you're never fully up to speed on your reimbursements, you're always behind. It's a pain in the neck; you would imagine you just send in the form and bang; it's done. There must be a better way." (P16, Female, Age 64)

Others described how their clinical team had advised them to commence oxygen therapy, leaving some participants feeling reluctant to do so, given their fear of it negatively impacting their independence, social connections and day-to-day activities.

"It would mean a lot of things I couldn't do. I couldn't even play golf. I'd feel uncomfortable going around with an oxygen bottle. And I know I've seen people with them, and they look awkward with them, like they're embarrassed. I'd do anything not to have to take it." (P10, Male, Age 72)

Participants recalled significant information gaps regarding the supply of oxygen while travelling abroad, often culminating in heightened anxiety and worry. Travelling abroad with ambulatory oxygen frequently carried an additional cost, representing an increased financial burden and an additional challenge associated with self-management. Several participants had made the difficult decision to cease travelling abroad, given the complexities involved with travelling with oxygen equipment. Collectively, the initiation of supplementary oxygen represented psychological, social, and financial impacts, affecting participants' quality of life.

“I suppose I found it took a very long time to truly grow into the acceptance of how much I’m going to be tethered to oxygen. I just thought I couldn’t travel with a tank. It had no attraction for me. I decided no, I’m never going to fly again.” (P01, Female, Age 83)

“It was basically an additional €600 to go on your holiday between travel insurance and oxygen.” (P18, Female, Age 64)

### **6.2.3.3 Subtheme 2.3: COVID-19; Fear and Isolation in a Pandemic**

The COVID-19 pandemic presented significant challenges for those living with IPF, owing to their compromised lung function, further compounding the difficulties faced by participants navigating a complex healthcare system. Individuals with IPF were considered a high-risk group during the pandemic, owing to their chronic lung disease. Many described their fears of becoming seriously unwell in the event of contracting COVID-19 at that time. Widespread restrictions nationally at the height of the pandemic compounded already reduced social networks, further isolating participants. Many participants employed various coping strategies at this time to mitigate the risk of contracting the infection, including efforts to significantly limit socialising with family and friends.

“You do get lonely at times when things get on top of you or something (tearful), and of course, my social life was way better before COVID, but you know it’s the same for everybody. COVID just did things to people, all that keeping away from each other. It was very isolating.” (P14, Female, Age 76)

Participants described how the COVID-19 pandemic restrictions had significantly affected their physical conditioning and functional ability.

“I did like to walk, but I stopped doing that. I would go out and meet friends, but I stopped doing that. We would occasionally go to a dance, which I couldn’t do anymore. And then I just got stiffer and stiffer.” (P10, Male, Age 72)

“I think it was the physio who said to me when I was doing the walking test that I needed to walk and do some exercises to strengthen my legs, as they had become weak, and to help me to go up the stairs or whatever.” (P02, Female, Age 70)

Participants described the difficulties they faced once pandemic restrictions had been lifted, resulting in several individuals experiencing long-term psychological impacts long after national restrictions had been rescinded. Many described their challenge in reconnecting with a fulfilling social world and resuming previously enjoyed hobbies and social activities after restrictions were lifted.

“I’m used to it now; I haven’t gone to my choir since COVID-19, so that means I haven’t gone into a choir since 2020. So that’s three years ago now, unfortunately. I really miss it.” (P14, Female, Age 76)



Participants recalled the struggles they had experienced when accessing necessary supports, such as their general practitioner and pulmonary rehabilitation classes, during the COVID-19 pandemic. Participants described widespread disruptions to essential supports and services, as frustrating, particularly as their health deteriorated and their need for multiple interventions and symptom management support increased.

“But anyway, I had COVID, so of course, the \*GP (\*general practitioner) wouldn’t see me, so then when I rang the nurse who prescribed whatever I had to be on. She said, ‘Isolate, stay in your room.’ I was in my room for three weeks.” (P02, Female, Age 70)

Many perceived hospitals as high-risk environments for contracting COVID-19, culminating in heightened worry for participants associated with fear of contracting the infection while in hospital. These fears related to crowded emergency departments, due to a lack of adequate infrastructure, such as individual clinical assessment cubicles, appropriate infection control measures and protocols to ensure compliance with social distancing. These worries often culminated in participants avoiding the emergency department, which delayed access to healthcare supports to address their health needs.

“Actually, it would frighten me to come into hospital, it’s so crowded.” (P07, Male, Age 77)

Participants who had engaged with the Irish Lung Fibrosis Association (ILFA) benefited from access to a small number of online supports during pandemic restrictions, which many recalled as helpful. Online classes hosted by ILFA not only supported participants’ lung health, but also provided a social outlet, which was described as hugely important given the heightened social distancing restrictions that existed at that time.

“I do the exercises in the house \*online (\* pulmonary rehabilitation classes), but I was very nervous about going out, I didn’t even go to Mass. I basically became a recluse. It was very hard (tearful).” (P02, Female, Age 70)

“I started doing their \*pulmonary rehab (\*pulmonary rehabilitation) class twice a week on Zoom with ILFA, and they were great.” (P10, Male, Age 72)

This second theme, adjusting to a new normal, highlights the unmet needs of people living with IPF, given the complexities associated with care coordination. Prominent concerns, related to the symptoms of IPF and medication side effects, were described along with their impact on quality of life. Participants described having to navigate often complex pathways alone, with access to oxygen therapy described as particularly troublesome. The adjustment to a ‘*new normal*’ upon initiation of oxygen therapy represented a significant challenge and often resulted in a plethora of unmet needs. Complex care coordination required by participants was particularly challenging during the COVID-19 pandemic. Participants recounted their experience of isolation at that time, and difficulties they experienced when

accessing healthcare, such as general practitioner consultations and pulmonary rehabilitation classes to address their symptoms.

#### **6.2.4 Theme Three: Addressing Psychosocial Needs**

Participants described psychological and social adjustments to their lives following a diagnosis of IPF. The shock of diagnosis and ensuing uncertainty about their prognosis were prominent in participant interviews. Participants shared their experience of disconnection from previously enjoyed hobbies, employment opportunities and family and friends, affecting their psychological and emotional well-being. Adjusting to a '*new normal*' was a phenomenon that also extended to family members, who often experienced evolving and changing roles within their family, and significant worry for their loved ones. Participants employed a range of coping strategies, including attendance at fitness classes and yoga, to help manage the uncertainty that IPF introduced into their lives. End-of-life care, and the ability to recognise a significant deterioration in their health, were frequently cited as a source of concern. Participants expressed a need for dignified and compassionate end-of-life support that prioritised person-centred care and pain management, underscoring the necessity for palliative care intervention over the course of an IPF diagnosis.

##### **6.2.4.1 Subtheme 3.1: Shrinking Social World**

The psychological impact of an IPF diagnosis was extensive, affecting participants on multiple levels as they transitioned into what many described as a '*new normal*'. Participants recounted the shock of diagnosis, followed by a period of fear and uncertainty at the enormity of their situation, with many becoming increasingly aware that IPF was a serious, progressive and irreversible lung condition.

"I went in for my appointment, and I was told I have lung fibrosis. Then there was this big launch into lung transplants, all kinds of things. I was like a rabbit in the headlights because I didn't know where this had come from." (P17, Female, Age 58)

Participants experienced a shift in their priorities as they came to terms with the seriousness of IPF and its far-reaching consequences, often culminating in a sense of disconnection and loss from previously enjoyed social connections and/or employment, which negatively affected their psychosocial well-being.

"Well, it has been challenging and disappointing. You know that I can't do the things I want to do, but you know, I'm very aware that I need to look after my health, and I need to look after my lung condition." (P14, Female, Age 76)

"It's a real illness, it's not something that you can take for granted. You've got to do what's right for it. Obviously, scaling back at work so that I can spend more time with my family is a priority. I wouldn't like to give up work completely, I'd like to do two/three days a week and then have long weekends away to do things." (P06, Male, Age 68)

Adapting to a '*new normal*' was further complicated by participants' difficulties in maintaining their independence. Impacts to participants' sense of autonomy often came from concerned family members

who sought to step in and lend their support, frequently robbing them of their independence in the process. Participants recounted how they often found themselves engaging in difficult conversations with family members to address concerns about their loss of independence as they sought to maintain their autonomy despite the challenges that IPF had brought.

“I’m able to drive and go to the supermarket on my own. They used to come with me, and I said this is getting too much, because I feel I’m giving up my independence. I said I can go and get a trolley and lean on the trolley.” (P02, Female, Age 70)

Other described a reduction in their social connections due to the physical symptoms of IPF, frequently culminating in frustration and isolation for them. Fatigue and a lack of energy often hampered participants’ ability to socialise, which in turn affected their relationships, usually resulting in increased frustration experienced by their family members and partners. Participants’ relationships within their family were often impacted due to their altered role and frequent inability to engage in social settings.

“I’m sure it must be frustrating for \*her (\*wife), now we can’t do a lot of things, you know, that you would want to do, she would want to do. I say to her I’m sorry, but I don’t feel like going here or there.” (P12, Male, Age 78)

The use of ambulatory oxygen frequently impacted individuals’ self-image, which was especially concerning for both male and female participants. Additionally, impacts to self-image were often linked to the experience of breathlessness, especially in social situations, which many described as embarrassing. Several participants feared that friends held an altered view of them as ‘*frail*’, with others sharing embarrassing social experiences where people incorrectly perceived them as being incapacitated due to alcohol or drugs, leading to shame and stigma and further affecting their self-esteem.

“I do try now to get out for a walk, but I might have to stop and catch my breath, and it’s embarrassing. You have to stop and catch your breath (tearful). You think people are looking at you and maybe thinking, what’s wrong with her? Is she drunk?” (P02, Female, Age 70)

“It’s generally worse when I’m talking. It used to be particularly bad if I went on the telephone; I’d hardly be able to talk, and I’d just keep coughing. In certain situations, it would be embarrassing, particularly these days when people are worried about flu and COVID. And you start coughing, and somebody is thinking he shouldn’t be here.” (P08, Male, Age 76)

Participants described a persistent, lingering worry associated with the seriousness of their condition, leading to a state of continuous hypervigilance, and uncertainty about their health, finances, and family, which contributed to heightened anxiety. Participants lived with the distressing reminder that their condition was chronic, progressive, ultimately fatal, and found that it shifted personal priorities.

“Well, I suppose worries are different for everyone, you know. There are bigger worries that we might have to do with finances; there might be worries to do with our health and worries for our family.” (P14, Female, Age 76)

Participants employed various coping strategies to mitigate the psychological impacts of IPF, which could otherwise negatively affect their lives. Coping strategies, frequently cited to ameliorate negative thoughts, included engaging in physical fitness, yoga, and completing chores such as grocery shopping. For some, introducing spirituality and religion into their lives helped them cope with the frequent uncertainty they experienced. Physical activity was described by participants as benefitting both their physical health and psychological well-being.

“You are reading about IPF online, and people are talking about depression and how IPF can seriously affect people’s lives and lifestyle, so I felt that the one thing I could do for myself was to stay as fit as I could for as long as I could.” (P19, Male, Age 75)

A prevailing lack of psychological support was reported by several people, citing the requirement for mental health support as a critical healthcare need. Uncertainty associated with living with IPF impacted the psychological well-being of participants, who reported a gap in services to address these needs. Many described how they were rarely offered any mental health support from their healthcare providers, with those who failed to access local mental health services often turning to online resources or private practitioners to bridge this gap. Many participants described the positive benefits they had gained from online resources, including yoga and singing, in the absence of locally available in-person supports.

“There is nothing really, you know, around where I live of any supports, so I think it’s fantastic for people to go online. You could do your exercise, you can do your yoga, you can do your signings, and I think it’s a great help.” (P14, Female, Age 76)

“There’s a huge lack of psychological support for people with IPF, you know, and I’ve seen so many people struggling with this, and myself included, from time to time. It’s one day at a time, you know.” (P16, Female, Age 64)

National peer support groups were reported as being helpful, providing opportunities to share their lived experience and gain peer support. Peer support groups frequently created a sense of community and were mainly regarded as a valuable source of information about IPF. Many expressed a need for specialist centres to routinely inform patients about peer support groups.

“They did a six-week yoga class. It was every Friday for six weeks, and I have to say I thought it was fantastic. Yeah, a lot of breathing techniques, I mean it wasn’t high impact now or anything like that, but it was really good. I’m going to do more of it. That was done with ILFA. Yeah, they were very helpful, I just think I’d be lost without it really.” (P18, Female, Age 64)

“You know ILFA is the biggest source of information in Ireland, and I think if consultants suggested to patients to contact ILFA, because that’s what I’d do initially, it would be brilliant.” (P16, Female, Age 64)

The support received from patient support groups was largely viewed as positive, offering opportunities to learn more about IPF and supporting participants to adapt to a ‘*new normal*’. However, some participants had differing views with some perceiving peer support groups as unhelpful, given the fact

that attendees were at varying stages of the disease, reflecting the changes that occur over time with IPF. Participants often found that seeing others further along in their disease course could be frightening, as it provided a visible insight into what lay ahead in relation to the progression of IPF. Witnessing others experiencing significant physical symptoms could be confronting, forcing them to face a difficult truth.

“Sitting around listening to each other now that we’ve lost our quality of life and are a shadow of our former selves, I’m not sure I would want to be a part of that.” (P01, Female, Age 83)

Many participants turned to family and friends to support them with their health worries, as family members were generally closely involved in the management of IPF and its symptoms. Family members were generally viewed as critical in providing psychosocial support, which hugely benefited participants. For individuals who had either lost loved ones or lived far away from family, their circle of friends often stepped in and took on supportive roles, which aimed to bridge the gap in psychosocial support.

“If I were to be honest, I get lonely at times, but I have a wonderful circle of friends. I’ve wonderful friends. I have cousins and they’re wonderful and I’m in touch with them and I have good, very good friends where I live, and I’m in touch with them and we socialise.” (P14, Female, Age 76)

For others, they recounted how family members frequently struggled to fully understand the disease, often finding it difficult to accept. Given the complex nature of IPF, some participants selected to withhold details of their prognosis from family, choosing instead to shield them from the worry associated with a difficult diagnosis. Many participants described how family members would excessively worry about them, which had detrimental impacts on their personal freedom, as family members sought to inhibit their independence - a reality that many found frustrating.

“I haven’t told any family or friends that I have this condition. There’s nothing they can do to help. They wouldn’t understand, I find it hard to understand it myself. I’d find it hard to try and explain what it is to them.” (P20, Male, Age 83)

“One of my brothers annoys me every day, ringing me asking how I am.” (P07, Male, Age 77)

Other participants delayed telling people about their diagnosis, not wishing to attract sympathy, instead preferring to maintain a sense of normality despite the prevailing challenges and disruption to their daily lives. Participants recounted taking time for themselves to reflect on their diagnosis and process the news, prior to sharing this information with others.

“It took me time to tell people because I didn’t want sympathy.” (P17, Female, Age 58)

Participants described how they employed various strategies to help them cope and manage the experience of living with a chronic condition, with many turning to spirituality and religious rituals such as prayer. These strategies were described by participants as comforting, particularly during times of uncertainty or worry.

“I just go into the chapel for an hour, and I like to sit there and not go through any big prayers or anything like that, just quietly be there, present.” (P01, Female, Age 83)

#### **6.2.4.2 Subtheme 3.2: Addressing Palliative Care Needs**

The third subtheme, ‘addressing palliative care needs’, introduces us to the fears and uncertainties which exist for many people diagnosed with IPF concerning death and dying.

Participants described ongoing anxiety and worry while navigating a complex healthcare system, alongside persistent uncertainty about disease progression. They reported living with a heightened fear of significant deterioration, coupled with growing anxiety about the speed at which IPF might worsen. Concerns regarding the level of care required when their condition deteriorated were especially evident among those who were living alone.

“I suppose the biggest worry is how quickly it will progress, how much care are you going to need, how you are going to manage it, because I live on my own, and of course, obviously you’re worried about dying as well. You just want some life between now and dying and you don’t want to just die too young either. But, I mean, there’s a good possibility it will happen.” (P18, Female, Age 64)

Significant information gaps were highlighted regarding advance care planning and the role of palliative care. Participants expressed concern over the limited availability of information on how to recognise an acute deterioration in their condition. The limited time available during outpatient clinic appointments to discuss end-of-life care and associated concerns about their worsening condition resulted in participants frequently relying on the internet to obtain information concerning disease progression.

“I have looked up life expectancy and this sort of stuff. I looked up something recently, I don’t know why I did, I looked for signs you’re at the end of your time.” (P12, Male, Age 78)

Fears about coping with a deterioration in health intermittently flooded the consciousness of participants. Worsening breathlessness was a prominent concern, accompanied by a pronounced fear of losing the ability to breath. One third of participants articulated their fear of dying by suffocation, a particularly harrowing image, given participants’ experience of worsening breathlessness and the increasingly impossible task of simply ‘*breathing*’ as the disease progressed.

“I remember thinking my biggest fear was that I would suffocate, and I wondered if I was going to die gasping. I thought, I’m going to suffocate to death, that’s my biggest fear, to die struggling for breath.” (P17, Female, Age 58)

Many participants envisioned what their end-of-life care might look like, with differing accounts conveyed regarding personal preferences at end-of-life. A general sentiment shared by several participants was their wish to simply ‘slip away’ at the time of their death, an option that was described as optimal given the alternatives. Overwhelmingly, participants expressed their wish to die with dignity, with some people having considered the option of assisted dying to ensure a dignified death.

“I think I’d be in Switzerland or away, I’d rather leave this world with dignity, and that’s it. That’s probably selfish of me to say that, but that’s the way I feel.” (P06, Male, Age 68)

Other participants chose to focus on day-to-day activities rather than looking too far into the future and end-of-life care, preferring instead to maintain a sense of normality. Others expressed discomfort with having conversations which related to end-of-life care, although they generally recognised the inevitability of death.

“But everybody passes on, and I don’t think too much about it, but it will be a major, major event for me and for others.” (P20, Male, Age 83)

“I have three things I would prefer: God takes me, I don’t want to be with a box of oxygen. I just don’t feel that that’s me, or a lung transplant. That’s it, like God take me or a lung transplant, one or the other.” (P06, Male, Age 68)

A common sentiment expressed by participants was their hope for comfortable and dignified end-of-life care, particularly in terms of symptom management and alleviation of pain. Participants who had previously engaged with palliative care services recounted a largely positive experience and subsequent improvements to their lives. However, some participants were reluctant to participate in conversations about advance care planning, preferences for end-of-life care, funeral arrangements, or writing a will. Despite these core beliefs and challenges, most participants acknowledged the critical importance of advance care planning for the future.

“I think I should really look more into it, it’s very difficult to sit down, some people are wonderful, and they decide what they want for their funeral. I would hope that I’d be cared for, it’s highly unlikely that I’ll be cared for at home because I don’t have support at home, but there is hospital care. There is palliative care, which is very good, and I think that would be my wish if I’m at that stage, that I would be looked after by a palliative care team.” (P14, Female, Age 76)

The third theme, ‘*addressing psychosocial needs*’, encompasses two core subthemes as participants sought to navigate their ‘*new normal*’ and cope with the psychological and social impact of living with a chronic progressive disease. Participants recounted their experience of a ‘*shrinking social world*’, as they navigated the complexities associated with IPF, often culminating in reduced social networks. Many participants described challenges conveying the serious nature of IPF to family and friends, pointing out that family members often worried excessively, depriving participants of their autonomy. Participants spoke about their fears associated with death and dying, a particularly prominent concern for those living alone.

#### **6.2.5 Theme Four: Engaging with a Complicated Healthcare System**

The challenges associated with engaging with a complex healthcare system were widespread, with difficulties often attributed to healthcare access to address unmet needs. Collectively, participants expressed concerns about the burden of living with IPF, which included the financial burden and additional difficulties associated with healthcare access. Concerns regarding infrastructure, such as the distance of

outpatient departments from the carpark, insufficient parking bays and expensive parking charges, were outlined in the first subtheme. The next subtheme addresses challenges experienced by participants when navigating a complex healthcare system, including difficulties associated with access to supports and services, such as the general practitioner, psychological support and peer support.

#### **6.2.5.1 Subtheme 4.1: Challenges Associated with Accessing Care**

A prominent concern reported by participants was the financial burden of living with IPF, leaving many feeling inadequately supported as they faced challenges meeting the cost of care. The cumulative financial burden associated with outpatient clinic appointments, diagnostic investigations, and inpatient hospitalisations, including toll charges, hospital parking fees, and, for some, loss of income, negatively impacted participants. Many participants were retired or had been forced to leave their employment due to their IPF diagnosis and frequently found themselves requiring a diverse range of health-related supports, which routinely necessitated out-of-pocket expenses. Access to surveillance, such as phlebotomy services accessed via their general practitioner, often incurred charges, as did frequent general practitioner visits. This was especially concerning for those who did not qualify for a medical card or other forms of free fees. Expenses associated with medication and oxygen therapy use, including electricity costs, further deepened the financial burden associated with IPF.

“And then there are parking charges, which can really add up.” (P03, Male, Age 86)

“It’s very frustrating, the scheme is that you pay 80 euro a month, and you get your drugs. I mean, oxygen is a drug. You paid your 80 euro, you know you shouldn’t be getting a bill for maybe 400 euro a month and forking that money out, it’s crazy.” (P16, Female, Age 64)

Half of the participants had private health insurance, which was described as very reassuring, particularly in the event of requiring healthcare support. Participants generally viewed private health insurance as a priority, offering a safety net against unnecessary worry when medical investigations or timely access to a specialist were required. However, despite having private health insurance, many participants still reported having several out-of-pocket expenses after accessing private specialist care, further adding to the cost of living with IPF. There was widespread recognition that not everyone can afford private health insurance, with several participants expressing concern for those who do not have this ‘*luxury*’.

“I’d be afraid to let the private health insurance go.” (P04, Female, Age 77)

“I do feel health insurance is very important, it’s very expensive, and we know that, but you know, if you have private health insurance, you have your peace of mind set at ease. I’m very aware that there are a lot of people who, unfortunately, can’t afford private health insurance.” (P14, Female, Age 76)

Those who had been successful in obtaining a general practitioner visit card or medical card, which enabled access to healthcare services at no cost, expressed relief at the reduced financial burden associated with living with IPF. Additionally, recent reductions in the national monthly drug payment scheme had significantly eased participants’ financial burden.



"I have a GP visit card, and it's brilliant, and the drug repayment scheme means everything over 80 euro a month is covered. It's brilliant given the price of the medication that I'm on. I'm very grateful to have it." (P19, Male, Age 75)

Others, particularly those recently retired, expressed disappointment at having been refused a general practitioner visit card, believing that this would have eased some of the financial worry they had experienced. Those living with a diagnosis of IPF regularly required frequent visits, representing a significant financial burden.

"I really do think it's very unfair, I mean I have worked all my life, I only retired this year and that was mainly because of this condition, and I worked all these years, I paid my taxes, everything, and I'm on a very small pension. But according to them I'm on too much." (P17, Female, Age 58)

"I think that there should be more back-up, such as a medical card and things like that, because it's a terminal illness. I mean, you don't recover from it." (P18, Female, Age 64)

Infrastructure at hospital sites was identified as a significant challenge for participants, given their experience of impaired mobility and breathlessness. Almost all participants reported difficulties with parking when attending outpatient clinics, with some arriving up to two hours early to obtain suitable parking. Others turned to family members for help, often necessitating them to take time off work to facilitate an outpatient appointment. The distance of parking bays to the hospital entrance was a source of distress for several participants, as they recounted having to walk significantly long distances from the carpark to their clinic, often arriving at the clinic feeling stressed and experiencing increased breathlessness.

"Today was the worst ever for parking. I have to take my time walking up to the hospital." (P04, Female, Age 77)

"That's the problem, parking is impossible up there. I get the bus now; I wouldn't take the car here." (P11, Male, Age 75)

Concerns regarding parking and difficulties accessing a parking bay at hospital outpatient departments not only affected patients but also extended to healthcare staff. Participants noted how some staff were unable to fulfil their duties in a timely manner, as they too were experiencing difficulties with parking.

"When she went, she had to do home visits, she had to sit in the carpark, she couldn't come in to do her work because there was no parking space." (P07, Male, Age 77)

Another troubling issue raised by several participants during hospital outpatient visits was the frequent disregard for no-smoking policies, particularly around the hospital entrance, causing distress for individuals who often had to pass through a '*cloud of smoke*' as they entered the hospital, something that was particularly problematic given their compromised lung function.

“People are smoking at the front door of the hospital; this needs to be looked at. They know people will smoke, so why can’t they ask them to smoke somewhere else, in a dedicated area.”  
(P02, Female, Age 70)

Participants generally reported high levels of satisfaction with the public healthcare system despite several shortcomings. These shortcomings were usually attributable to deficits within the healthcare system rather than attributable to healthcare professionals. Participants generally described their experience with the respiratory team as positive, with many viewing the care they had received as ‘*excellent*’ and noting the professionalism and reassurance they had received.

“I found the public healthcare system to be by far the better system because at the support group meetings I’ve come across people who have been treated privately and who didn’t have any access to support services like I’ve had.” (P19, Male, Age 75)

#### **6.2.5.2 Subtheme 4.2: Navigating Life with IPF in a Fragmented Healthcare System**

People with IPF often require complex care coordination involving multiple healthcare systems and associated resources. Due to the chronic and progressive nature of IPF, participants acknowledged an increasing reliance on supports and services to help with daily activities over the course of their disease. Participants shared their experience of navigating an often-complex healthcare system to optimise their health, highlighting several barriers they had encountered when accessing healthcare. Barriers to care represented a pattern of unmet need, with many noting multiple layers of complexity in the healthcare system, where supports were not easily accessible and often incurred limited availability.

“But you still feel there isn’t the support you need; the nurse is great, but there’s only so much she can do. There’s a long waiting list for \*PR (\*Pulmonary Rehabilitation) classes, and I was lucky enough to get on them. I do feel for people waiting to get into those classes.” (P09, Male, Age 72)

There were geographical disparities concerning the ability to access supportive services and multidisciplinary care. Some participants reported limited access, whilst others experienced more optimal access to services with minimal difficulties. Psychological support was frequently cited as difficult to access, with one-third of participants noting a lack of available mental health services in their treatment centre. Consequently, many had to seek private care at their own expense, representing a significant unmet need.

“I think psychological services are critical for many of us, you know. I’ll turn around next week. I’m going to have to start paying out €75 euro a week for the next couple of weeks for therapy. I mean, it’s a lot of money when you’re paying out all the other stuff as well, but it’s crucial.” (P16, Female, Age 64)

Lung transplantation is a critically important treatment option for IPF, especially given the limited options available to treat this condition. However, difficulties were recalled by some participants in their ability to access lung transplantation assessment. Some participants found the referral process unnecessarily

complicated and difficult to navigate. Others believed they had been excluded from onward referral for this form of support, due to their age or the severity of their lung disease, highlighting the need for more equitable access to these critically important treatment options.

“Two things I was told: number one, I was too well, I wasn’t bad enough. Number two, I was too old.” (P12, Male, Age 78)

Participants referenced supports available to them through ILFA, including peer support, online exercise classes, and access to educational resources facilitated by patient information conferences and workshops. However, deficits existed in how information about these supports was communicated to patients, with many reporting limited awareness of their existence.

“I just found the back-up with ILFA and the classes and all that to be very helpful. I just think I’d be lost without it really.” (P18, Female, Age 64)

“I never heard of ILFA, but it would be of interest to me.” (P03, Male, Age 86)

Participants expressed concern for people diagnosed with IPF, citing anecdotal reports from patient support groups about heterogeneity and variability in access to supportive care. Many participants noted significant differences between public and private healthcare, emphasising a lack of standardisation in the provision of reliable and up-to-date information. In addition, participants expressed variability in healthcare access which was often associated with geographical location.

“I’ve come across some people who have private insurance and see their doctor privately and don’t know about the support services that are out there that they currently have no access to.” (P19, Male, Age 75)

Many participants expressed disappointment with inadequacies they perceived in the healthcare system, specifically deficits in the provision of onward referral to essential supports and services such as psychology, dietetics, lung transplant assessment and palliative care services. As a result, many participants were often left with the responsibility of arranging these referrals themselves, which significantly added to the burden they experienced when navigating a complex healthcare system.

“I would have liked a referral to a dietician. I think psychological services are critical for many of us. Another service that would have benefited me is \*OT (\*occupational therapy) to organise things that will make our lives a bit easier.” (P16, Female, Age 64)

Many participants highlighted the strong rapport they had established with healthcare staff, emphasising the significant benefits of these relationships. Others valued a sense of familiarity during clinic appointment, which was described as comforting, especially given the uncertainty they often experienced when navigating the healthcare system. Participants were particularly grateful for the professional and caring approach they frequently received.

“I think the team in the hospital, I couldn’t say enough about them. I think they’re brilliant, and then the respiratory nurse as a back-up is just fantastic, really. You can call her if you need

something, or if you've a question, you can call her. I just find that little bit of back-up, that you can just contact her, I think that's fantastic." (P18, Female, Age 64)

However, concern was raised that healthcare teams, especially nursing staff, were often understaffed and '*run off their feet*'. This frequently led to worries about inconveniencing staff, with some participants hesitant to contact staff and add to their workload, with others fearing they might be viewed as a nuisance.

"I try not to burden X because I know she's very busy. I know she's there; I don't want to bother her because I know she's busy." (P07, Male, Age 77)

General practitioners were frequently referenced as an essential source of support, often serving as the point of contact with healthcare services when early symptoms of IPF appeared. General practitioners play a critical role in the care of people diagnosed with IPF, both at the time of diagnosis and throughout their healthcare journey, often bridging the gap between community and hospital-based care. However, barriers existed when accessing primary care, with two-thirds of participants reporting significant delays in obtaining an appointment with their general practitioner, resulting in frustration and uncertainty.

"It was frustrating not to get a quicker appointment with the \*GP (\*general practitioner). That is a problem for older people and people with this lung condition." (P05, Male, Age 77)

Participants expressed frustration when asked to see a new general practitioner at their primary care appointment, indicating a sense of disjointed and fragmented care. These experiences revealed a lack of continuity, often requiring participants to repeatedly recount their past medical history to each new primary care doctor, which many described as distressing.

"You don't have one-to-one with the \*GP (\*general practitioner) that used to be available. When you are in the system, you wouldn't necessarily see the same GP twice. They are doing their best, but we could do with more access." (P05, Male, Age 77)

Participants experienced communication deficits when important clinical information was shared between healthcare providers, with some recounting instances of poor communication between their hospital team and their general practitioner. Participants frequently found themselves '*caught in the middle*', often having to bridge the communication gap themselves, representing a challenging and unfavourable situation.

"I don't know if the hospital gives feedback to the \*GP (\*general practitioner), I know they tell the GP about my medication, but I don't know if they will inform her about my progression. For example, if I get blood tests done here, my GP will say she wasn't given those results, and she will ask me to go and get the blood tests done again. Like, why is there no communication between them? It would save an awful lot of hassle." (P02, Female, Age 70)

Participants frequently experience a diverse range of symptoms due to the chronic and progressive nature of their condition, often requiring complex care coordination. Many participants expressed fears about

receiving uncoordinated and sub-optimal care, given the diverse scope of their needs and their experience of the frequent barriers they encountered in accessing healthcare.

“I think the most important thing now for people is that there is a register and of course the other important thing is there should be a care pathway so that every consultant and every doctor and every \*GP (\*general practitioner), will follow, so that everybody in the country can access the same treatment because certainly from what I have heard, when we have been talking in the pulmonary fibrosis society things are very different all over the country.” (P14, Female, Age 76)

This final theme, ‘engaging with a complicated healthcare system’, highlighted several barriers to healthcare access. The interconnectedness of the healthcare system, coupled with its barriers and facilitators to care, was illuminated as a significant healthcare need. The first subtheme identified the challenges associated with healthcare access, including the cost of care, which extended beyond the financial burden to structural barriers to care. The second subtheme outlined the challenges associated with navigating life with IPF. Access to supportive care continued to represent an unmet need given the deficits which exist in accessing essential supports and services, including lung transplant assessment. The critical role of patient support networks and access to online information resources, including exercise programmes and psychological support, was highlighted as an essential component of care. Participants also emphasised the central role of the general practitioner in coordinating care and providing ongoing support.

### **6.3 Healthcare Organisation Survey Questions**

The following section addresses the four open-ended questions from the healthcare organisation audit (phase one) discussed in Chapter 5.

#### **6.3.1 Sample Demographics (phase one)**

Sixteen healthcare professionals (HCPs) completed the healthcare organisation audit respiratory consultants or respiratory registrars ( $n = 9$ ); respiratory nurses or advanced nurse practitioners ( $n = 7$ ), previously discussed in Chapter 5.

#### **6.3.2 Presentation of the Findings**

Methods for analysing open-ended questions in the healthcare organisation audit (phase one) benefited from Braun and Clarkes (2006, 2019) reflexive thematic analysis framework described in Chapter 4, Section 4.8.2. The findings from open-ended questions in the quantitative audit facilitated opportunities for participants to share details of their experiences that may not have been captured in the predefined survey questions, generating a more nuanced view of the data.

### **6.3.2.1 Service Improvements for Patients with IPF**

In the healthcare organisation audit, HCPs were asked how outpatient services might be improved for patients with IPF. Recommendations for service enhancement focused on the need for an adequately resourced multidisciplinary team with sufficient time to deliver person-centred care. Additionally, there was consensus on the need for improved hospital infrastructure to support access to specialist clinics and optimise care.

“We need more staff at the clinic, including physiotherapy.” (P11)

“There is a difficulty in increasing the number of clinics due to a lack of outpatient department space.” (P05)

Healthcare staff often referenced long intervals between routine outpatient appointments and extended waiting times for onward referrals as unsatisfactory. Those delays directly affected patients who required timely access to supports and services.

“There are often times when patients have to wait prolonged periods in between clinic visits, which, if there were more staff, would not need to be the case.” (P01)

Healthcare professionals overwhelmingly reported the need for more dedicated time during clinic appointments to discuss patients’ care needs. Increased clinic time would allow greater opportunity to address access to supports and services, including patients’ preferences concerning end-of-life care.

“I am lucky to have dedicated clinic time for patients; this should be a requirement in all centres.” (P07)

### **6.3.2.2 Barriers to Care**

The healthcare audit also provided information regarding barriers that healthcare providers had observed when prescribing antifibrotic medication. Despite access to the drug payment scheme (DPS) for non-medical cardholders, the affordability of medicine was frequently referenced as an ongoing concern due to the financial burden associated with accessing these medications.

“Medicines are not totally free. Most patients are using their \*drug payment scheme (\*DPS), requiring them to pay eighty euros per month out of their own pocket.” (P03)

The audit also inquired about barriers to services such as pulmonary rehabilitation and palliative care. Most HCPs expressed concern regarding long waiting lists for pulmonary rehabilitation and the lack of appropriately skilled staff to facilitate such interventions. A shortage of physiotherapists due to attrition or retirement from the public healthcare system was cited as exacerbating existing deficits in care provision, particularly in the acute healthcare setting.

“It would be really important to reduce pulmonary rehabilitation waiting times.” (P08)

“Wait times to see a physiotherapist need to change drastically.” (P09)

Healthcare professionals believed that palliative care should be prioritised within a dedicated care pathway for patients with IPF, a finding that was corroborated in phase three qualitative interviews. However, significant differences in healthcare professionals' attitudes regarding the timing of palliative care interventions were observed. Some believed that palliative care should be initiated at the time of diagnosis, emphasising its importance regarding symptom management. Others recommended a more nuanced approach, suggesting that the timing and delivery should depend heavily on the severity of the disease. Additionally, some healthcare professionals felt that patient preferences should guide the initiation of palliative care conversations.

"Difficult question, it depends on how severe the disease is when they first meet the team." (P14)

"It is highly individualised - you have to take into consideration decline in pulmonary function tests, symptoms and patient preferences." (P10)

### **6.3.2.3 Priority Areas for Improvement**

The final open-ended question asked HCPs to identify priority areas for improvement to address the needs of those with IPF. A prominent concern was connected to deficits in the national provision of supports and services. The lack of clinical trial infrastructure nationwide was highlighted as a significant gap in patient care, with the lack of staff resources and clinical trial facilities highlighted as a significant barrier to access.

"We don't run clinical trials as we don't have the resources for that." (P09)

"There is no clinical trial facility at our centre." (P14)

Almost all participants emphasised the need for IPF to be included in an integrated national clinical programme. Other priorities were connected to addressing staff deficits on multidisciplinary teams, with psychological support highlighted as an example of a critical gap in care, requiring urgent resourcing.

"We need to have IPF included in the national clinical programme (scheme) to ensure the best supportive care for patients." (P15)

"There is currently little to no provision for psychology in our service; this is a major deficit." (P10)

## **6.4 Phase One Summary of Healthcare Audit**

The responses from healthcare professionals to the open-ended questions used in the phase one audit provide valuable insights into the attitudes and views of participants from a nationally representative sample of healthcare organisations. Nationally, there are deficits in timely access to supports and services, including pulmonary rehabilitation and palliative care. Almost all healthcare professionals shared concerns about the need to improve staff resourcing and retention to support the multidisciplinary team. They also emphasised the importance of offering more frequent outpatient clinic visits and dedicated time

at their clinics to address patient preferences. Future priorities included establishing a national clinical programme and ILD registry, along with improving clinical trial infrastructure.

## 6.5 Conclusion

Chapter 6 sought to provide an in-depth understanding of the unmet needs, symptom experiences, and quality of life of people living with a diagnosis of IPF. Additionally, qualitative insights from healthcare professionals' responses to open-ended questions in phase one (Healthcare Organisation Audit) supported the qualitative phase in this study. Phase three findings revealed several gaps in care, particularly at the time of diagnosis, with many participants feeling like they were '*stepping into the unknown*' without adequate support at a time of great uncertainty. Widespread gaps in information provision were observed, representing a prominent concern. The limited availability of diverse information resources and the absence of a standardised approach to information provision made it difficult for participants to comprehensively understand their diagnosis.

Many expressed disappointments at not being fully informed about the serious nature of their disease, leading to unrealistic expectations about survival and potential recovery. Personal preferences for the timing, method, and amount of information required by participants were rarely recognised, further complicating the journey. As a result, many participants turned to unreliable internet resources to bridge the information gap. Additionally, there was a lack of public awareness about IPF, with the Irish Lung Fibrosis Association frequently cited as bridging this gap in the provision of practical and helpful information. However, many participants reported how they had not been made aware of this form of support, representing a continued unmet need.

The symptoms associated with IPF, including worsening breathlessness, cough, and fatigue, impacted both the physical and psychological well-being of participants, further complicating the IPF journey. Many participants described embarrassing situations when their symptoms were very visible in social situations, often leading to stigma, and frequently resulting in a reduction in social connections to avoid further embarrassment. The initiation of supplemental oxygen was considered a significant milestone in the trajectory of the disease. Oxygen therapy often heralded a shift in how others viewed those with IPF, as participants' symptoms became increasingly visible, representing a substantial deterioration in their condition and resulting in increased dependency.

Participants recounted their experiences of the COVID-19 pandemic and the impact of isolating from friends and family at that time, signalling a particularly challenging mental health toll for many. The psychological impact of IPF often affected participants' social connections and relationships, significantly shrinking their social worlds. Participants frequently described their worries about the progression of their disease, with particular concern about how end-of-life care would be managed to ensure a dignified and pain-free death.



Many expressed concerns about the overall cost of living with IPF, which included an increased financial burden and other challenges, such as travelling long distances to outpatient clinics, car parking charges, and insufficient parking bays. Barriers and facilitators to optimal healthcare were highlighted and represented several deficits in care provision. Access to healthcare highlighted significant geographical disparities, and inequities between those who could afford private health insurance or pay for care and those who could not. These differences resulted in unequal access to services for individuals living with IPF. Despite these barriers, general practitioners were frequently identified as a valuable source of support, although there were challenges in accessing this service and overwhelming concerns about one's ability to pay.

Qualitative interview findings extend the quantitative survey data results (phase one and phase two) and shed light on the disparities which exist from the onset of the disease right through to end-of-life care, which can negatively impact participants' healthcare experience. These findings also highlighted significant healthcare access concerns that align with the domains referenced in the Levesque healthcare access framework (2013): approachability, acceptability, affordability, appropriateness, availability and accommodation, outlined in Chapter 3, Section 3.5.1.

## Chapter 7 Integrated Findings

### 7.1 Joint Display of Integrated Findings

This mixed methods study integrated data from both quantitative and qualitative findings using a range of techniques including comparing, combining and interpretation of the data (Fetters et al., 2013). Integrating both approaches culminated in an integrated report of the mixed methods results which created a rich, contextual and comprehensive understanding of the unmet needs, symptom experiences, and quality of life of individuals with IPF. Integration of data in this study has previously been described in Chapter 4 (Section 4.9) and occurred at the design level, methodology level, and reporting of the study findings (Creswell & Clark, 2017). This chapter presents findings at the interpretation and reporting stage, using a joint display to visually represent integrated quantitative and qualitative approaches, which can be viewed simultaneously, enabling comparison of findings (Table 7.1). Chapter 8 will facilitate a narrative approach to the interpretation and reporting of study findings (Fetters et al., 2013). Findings in this study have been enhanced by the inclusion of a joint display to support meta-inferences made by visually representing both quantitative and qualitative results (Creswell & Clark, 2017; Guetterman et al., 2015).

**Table 7.1 Joint Display of Integrated Findings**

| Theme                    | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Integrated Inferences                     |
|--------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| <b>Delayed Diagnosis</b> | <p><b>Phase One:</b></p> <p>Variability existed in the composition of the multidisciplinary team (MDT) to facilitate an accurate and timely diagnosis of IPF.</p> <p>Variability in MDT meetings with 62.5% (<math>n = 10</math>) reporting a frequency of meetings &gt; weekly/biweekly which could limit access to the expertise necessary to make a prompt diagnosis of IPF.</p> <p><b>Phase Two:</b></p> <p>Delayed diagnosis is a considerable concern for individuals with IPF, impacting onward referral to experts in the field and delayed access to pharmacological and non-pharmacological supports and services.</p> <p>Financial implications existed for those attending private healthcare to obtain an accurate diagnosis, with 12.6% (<math>n = 30</math>) of participants reporting that they attend a private hospital for their care, with a further 55.6% (<math>n = 104</math>) reporting that they had private health insurance.</p> | <p><b>Phase Three:</b></p> <p>“I had been attending the hospital here for maybe fifteen years because the GP thought I had asthma. That went on, until about maybe three years ago, when they did the breathing tests, and the Doctor called me in, and he said, we think you have fibrosis.” (P02, Female, Age 70)</p> <p>“After waiting for several tests for some time, I arranged an appointment privately with the consultant, and I had the pulmonary function tests (PFTs) done, and he said it looks to me like IPF. He said idiopathic pulmonary fibrosis.” (P10, Male, Age 72)</p> | <p><b>Confirmation and Expansion.</b></p> |

| Theme                                     | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Integrated Inferences             |
|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|
| <b>Lack of Public Awareness about IPF</b> | <p><b>Phase Two:</b></p> <p>17% of participants did not know the name of their lung disease. A further 20% reported that a healthcare professional had not explained to them how their disease affects their lungs.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | <p><b>Phase Three:</b></p> <p>“Ah, nobody knew, my family didn't know, I mean, I never heard of IPF, and none of my colleagues ever heard of it, and there's only some people I would tell. All I ever get off people is look at you, you look gorgeous, you'd never think there was anything wrong with you.” (P17, Female, Age 58).</p> <p>“I left the hospital after getting a diagnosis, but nobody fully explained it to me, and I was wondering if it would be bad.” (P04, Female, Age 77).</p>                                                                                                                                                                                                                                                         | <b>Confirmation and Expansion</b> |
| <b>Impact of IPF Symptoms</b>             | <p><b>Phase Two:</b></p> <p>Quantitative analysis highlighted the existence of widespread symptoms with shortness of breath (72.4%, <math>n = 171</math>) being the most reported symptom, followed by fatigue 70% (<math>n = 165</math>). Cough was reported by almost 68.25% (<math>n = 161</math>) of participants.</p> <p>Symptoms impacted daily activities with 20% (<math>n = 47</math>) of participants reporting an inability to complete household chores, 42% (<math>n = 99</math>) reported that exercise was not safe, and 50% (<math>n = 118</math>) reported that breathlessness when talking limited their ability to engage in social situations. The most frequently reported concerns in the IPF-PROM were 'breathlessness with everyday activities' (29.8%, <math>n = 70</math>), 'lethargy' (26.2%, <math>n = 62</math>), and 'fear of becoming excessively breathless' (23%, <math>n = 54</math>).</p> | <p><b>Phase Three:</b></p> <p>“The breathing situation stops me from doing some of the things I'd like to do; I'd have a fear of getting too breathless. My breathing isn't getting any better; it's hard not being able to do some of the things I used to do.” (P04, Female, Age 77).</p> <p>“I had a coughing fit last night that lasted half an hour. I have water beside me all the time, but then I'm up and down to the toilet.” (P02, Female, Age 70).</p> <p>“There are times when I haven't the energy to participate in a conversation at the table. “I need more energy to be part of that, so there are times when I need to sit and not talk, just let other people carry on. That's when I feel like I'm a burden.” (P01, Female, Age 83).</p> | <b>Confirmation and Expansion</b> |

| Theme                | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Integrated Inferences      |
|----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|
| Information Deficits | <p><b>Phase One:</b></p> <p>Widespread gaps in information provision existed, with over 31% of healthcare professionals (<math>n = 5</math>) reporting that they did not signpost patients to the Irish Lung Fibrosis Association (ILFA) patient support groups.</p> <p><b>Phase Two:</b></p> <p>Quantitative analysis revealed a range of areas where information gaps existed, including disease knowledge, medicines, exercise, diet, and smoking cessation, with a notable lack of paper-based information resources provided to patients. Higher information needs were frequently associated with poorer quality of life.</p> <p><b>Disease Knowledge:</b> 36% reported that their IPF will stay the same (<math>n = 85</math>), a further 3% reported that they will 'get better' (<math>n = 7</math>) and 6% reporting that they 'have no idea' (<math>n = 14</math>).</p> <p><b>Medicines:</b> 46% of participants reported that they had not been given written information about their medicines (<math>n = 109</math>).</p> <p>Significantly, 36.5% (<math>n = 86</math>) of participants reported that they understood what they had been told about their medicines but expressed a need to know more, and 6.4 % reported that they were still slightly confused about their medicines.</p> | <p><b>Phase Three:</b></p> <p>"Everybody goes to Google, and that's our biggest downfall, really, you know and looking at the prognosis and all of that. You're pretty much left on your own, it is a rare disease, and it's like, well, where do you turn from there, that really was the biggest issue." (P16, Female, Age 64).</p> <p>"No. They didn't explain basically ever about my IPF. They just said come back in 6 weeks' time or 3 months." (P20, Male, Age 83).</p> <p>"Nobody told me about ILFA, I discovered it. I got involved with their presentations and a lot of their information and found that it was excellent." (P10, Male, Age 72).</p> | Confirmation and Expansion |

| Theme                                   | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Integrated Inferences             |
|-----------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|
| <b>Information Deficits (Continued)</b> | <p><b>Self-Management:</b> 5% (<math>n = 12</math>) reported that they had not been told what to do in the event of becoming excessively breathless and were uncertain about when to call an ambulance.</p> <p><b>Smoking:</b> 27% (<math>n = 40</math>) reported that they had never been advised to give up smoking by a healthcare professional.</p> <p><b>Exercise:</b> 73% (<math>n = 171</math>) of participants reported that a doctor or nurse had not advised them to try to do some physical activity.</p> <p><b>Diet:</b> Over half (53.2%; <math>n = 125</math>) of the participants reported that they had not been given information relating to their diet.</p>                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | <b>Confirmation and Expansion</b> |
| <b>Fragmented Healthcare Access</b>     | <p><b>Phase One:</b></p> <p>62.5% (<math>n = 10</math>) of HCPs reported no respiratory nurse specialist and 87.5% (<math>n = 14</math>) reported no pharmacist on their multidisciplinary team.</p> <p>Most HCPs (87.5%, <math>n = 14</math>) reported that they refer patients with IPF to specialist centres for lung transplant assessment with some reporting barriers to this process (37.5%, <math>n = 6</math>). Most HCPs (81.25%, <math>n = 13</math>) reported that patients are referred for pulmonary rehabilitation. Gaps in this referral pathway were identified by 43.75% (<math>n = 7</math>). Nationally, there was limited provision for counselling services in the OPD (100%, <math>n = 16</math>).</p> | <p><b>Phase One</b></p> <p>"We need more staff at the clinic, including physiotherapy." (P11).</p> <p>"There is difficulty in increasing the number of clinics due to a lack of outpatient department space." (P05).</p> <p><b>Phase Three:</b></p> <p>"But you still feel there isn't the support you need; the nurse is great, but there's only so much she can do. There's a long waiting list for PR* (*pulmonary rehabilitation) classes, and I was lucky enough to get in on time. I do feel sorry for people waiting to get into those classes." (P09, Male, Age 72)</p> | <b>Confirmation and Expansion</b> |

| Theme                                           | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | Integrated Inferences             |
|-------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|
| <b>Fragmented Healthcare Access (Continued)</b> | <p><b>Phase Two:</b></p> <p>Almost equal proportion of participants had either private health insurance (38.3%, <math>n = 91</math>) or a medical card (38.8%, <math>n = 92</math>). A further 17.3% (<math>n = 41</math>) had both a medical card and private health insurance, with just 5.5% (<math>n = 13</math>) having neither of these.</p> <p>Participants reported not having been referred to or had access to an ILD specialist nurse (28.3%), pulmonary rehabilitation (60.8%), physiotherapist (52.3%), dietician (92.8%), or palliative care (96.2%).</p> | <p><b>Phase Three:</b></p> <p>"I think psychological services are critical for many of us, you know. I'll turn around next week. I'm going to have to start paying out seventy-five euros a week for the next couple of weeks for therapy. I mean, it's a lot of money when you're paying out all the other stuff as well, but it's crucial." (P16, Female, Age 64).</p> <p>"I would have liked a referral to a dietitian. I think psychological services are critical for many of us. Another service that would have benefited me is *OT (*occupational therapy) to organise things that will make our lives a little bit easier." (P16, Female, Age 64).</p> <p>"It was frustrating not to get a quicker appointment with the GP. That is a problem for older people and for people with this lung condition." (P05, Male, Age 77).</p> <p>"I have a GP visit card and its brilliant, and the drug repayment scheme means everything over eighty euros a month is covered, its brilliant given the price of the medication that I'm on." (P19, Male, Age 75).</p> | <b>Confirmation and Expansion</b> |

| Theme                                           | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                             | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Integrated Inferences             |
|-------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|
| <b>Fragmented Healthcare Access (Continued)</b> |                                                                                                                                                                                                                                                                                                                                                                                                                               | <p><b>Phase Three:</b><br/> “I think that there should be more backup such as a medical card and things like that because it is a terminal illness, I mean you don't recover from it.” (P18, Female, Age 64).</p> <p><b>Phase One:</b><br/> “It would be really important to reduce pulmonary rehabilitation waiting times.” (P08).</p> <p>“Wait times to see a physiotherapist need to change drastically.” (P09).</p> <p>“Medicines are not totally free. Most patients are using their drug payment scheme (DPS), requiring them to pay eighty euros per month out of their own pocket.” (P03).</p> <p>“We need to have IPF included in the national clinical programme scheme to ensure best supportive care for patients.” (P15).</p> <p>“There is currently little to no provision for psychology in our service; this is a major deficit.” (P10).</p> | <b>Confirmation and Expansion</b> |
| <b>Covid-19 Pandemic</b>                        | <p><b>Phase One and Phase Two:</b><br/> Participants reported not having been referred to or had access to an ILD specialist (28.3%), pulmonary rehabilitation physiotherapist (52.3%), dietician (92.8%) , or palliative care (96.2%). A total of 26.2% (<math>n = 62</math>) of patients had previously accessed an ILFA support group ,and just 4.2% (<math>n = 10</math>) had access to a psychologist or counsellor.</p> | <p><b>Phase Three:</b><br/> “‘But anyway, I had COVID. So, of course, the GP* (*general practitioner) wouldn't see me, so then when I rang the nurse who prescribed whatever I had to be on, she said Isolate, stay in your room. I was in my room for three weeks.” (P02, Female, Age 70).</p> <p>“‘Actually, it would frighten me to come into the hospital, it's so crowded.” (P07, Male, Age 77)</p> <p>“‘I'm used to it now; I haven't gone to my choir since COVID, so that means I haven't gone into a choir since 2020, so that's three years ago now, unfortunately. I really miss it.” (P14, Female, Age 76)</p>                                                                                                                                                                                                                                   | <b>Expansion</b>                  |



| Thme                         | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Integrated Inferences             |
|------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|
| <b>Palliative Care Needs</b> | <p><b>Phase One:</b></p> <p>Variability in referral practices concerning palliative care existed, with some referrals taking place in the first twelve months after diagnosis, 18.7% (<math>n = 3</math>), years two to three 31.2% (<math>n = 5</math>) and years three to five 25% (<math>n = 4</math>).</p> <p><b>Phase Two:</b></p> <p>Just 3.8% (<math>n = 9</math>) of participants reported that they had been referred to or had access to palliative care.</p> <p>A total of 36% of participants reported that their condition will stay the same (<math>n = 85</math>), representing an unmet information need which may inhibit the introduction of palliative care if patients themselves don't perceive a need for this form of support.</p> | <p><b>Phase One:</b></p> <p>"Difficult question, it depends on how severe the disease is when they first meet the team." (P14).</p> <p>"It is highly individualised, you have to take into consideration decline in pulmonary function tests, symptoms, and patient preferences." (P10).</p> <p><b>Phase Three:</b></p> <p>"I remember thinking my biggest fear was that I would suffocate, and I wondered if I was going to die gasping. I thought, I'm going to suffocate to death, that's my biggest fear, to die struggling for breath." (P17, Female, Age 58).</p> <p>"But everybody passes on, and I don't think too much about it, but it will be a major, major event for me and for others." (P20, Male, Age 83).</p> <p>"I think I should really look more into it, it's very difficult to sit down, some people are wonderful, and they decide what they want for their funeral. I would hope that I'd be cared for, it's highly unlikely that I'll be cared for at home because I don't have support at home, but there is hospital care. There is palliative care, which is very good, and I think that would be my wish if I'm at that stage, that I would be looked after by a palliative care team." (P14, Female, Age 76).</p> | <b>Confirmation and Expansion</b> |

| Theme                                                                     | Quantitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                            | Qualitative Data                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | Integrated Inferences |
|---------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|
| <b>Clinical Trials and Access to Novel Therapeutics and Treatments</b>    | <p><b>Phase One:</b></p> <p>Deficits existed in clinical trial participation, with eight HCPs reporting that they do not invite patients to participate in clinical trials, as they do not have access to clinical trial facilities (<math>n = 8</math>, 50%).</p> <p><b>Phase Two:</b></p> <p>83.1% % (<math>n = 197</math>) of participants were not aware of or research related to IPF.</p>                                                              | <p><b>Phase One:</b></p> <p>"We don't run clinical trials as we don't have the resources for that." (P09).</p> <p>"There is no clinical trial facility at our centre." (P14).</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | <b>Confirmation</b>   |
| <b>Addressing Challenging and Evolving Needs - A Coordinated Approach</b> | <p><b>Phase One:</b></p> <p>A total of 31.3% (<math>n = 5</math>) of healthcare professionals did not signpost patients with IPF to ILFA community supports.</p> <p><b>Phase Two:</b></p> <p>Participants highlighted gaps in the provision and uptake of community-based support. Some participants had poor access to some supports, with just 26.2% (<math>n = 62</math>) had previously accessed peer support through an ILFA patient support group.</p> | <p><b>Phase Three:</b></p> <p>Insufficiencies in the provision of support and services, especially those that are community-based, often led to participants relying heavily on family and friends to bridge this gap.</p> <p>"There is nothing really you know around where I live of any supports, so I think it's fantastic for people to go online, you could do your exercises, you can do your yoga, you can do your singing, and I think it's a great help." (P14, Female, Age 76).</p> <p>"There's a huge lack of psychological support for people with IPF, you know, and I've seen so many people struggling with this, and myself included, from time to time. It's one day at a time, you know." (P16, Female, Age 64).</p> <p>"I never heard of ILFA, but it would be of interest to me." (P03, Male, Age 86).</p> | <b>Build</b>          |

## **7.2 Conclusion**

This chapter has presented a joint display of integrated quantitative and qualitative findings from this mixed-methods study. The incorporation of the various approaches employed in this study facilitated data interpretation to investigate convergence, divergence and expansion of results (Guetterman et al., 2015). This study benefited from leveraging the strengths of both quantitative and qualitative methodologies to provide an in-depth and comprehensive understanding of the phenomenon of interest. The joint display also supports the development of meta-inferences, which could not have been facilitated using a single method alone. Chapter 8 will provide a narrative interpretation of the integrated findings.

## Chapter 8 Discussion

### 8.1 Introduction

This chapter provides a discussion of the integrated findings from this thesis. It presents the meta-inferences that are supported by the quantitative (Chapter 5) and qualitative (Chapter 6) findings. First, an overview of the key findings from this mixed-methods study are presented, which address the overall aim and objectives of this research. This is followed by a discussion on the application of Levesque's healthcare access framework (2013), which was utilised in this study. The integrated findings from phase one, phase two (quantitative findings) and phase three, (qualitative findings) provide valuable information concerning the opportunities to improve health service provision to address the unmet needs of individuals diagnosed with IPF. Additionally, meta-inferences from this mixed-methods study highlight the range of symptoms experienced by individuals with IPF, and the barriers to care that exist to address their needs and optimise quality of life. Finally, this chapter offers a discussion on the current deficits that exist in IPF care and highlights opportunities to develop and improve health services to enhance the quality of life of individuals with IPF. This chapter concludes with a discussion of the overall strengths and limitations of this research.

#### 8.1.1 Overview of Key Findings

This study, using a mixed-methods sequential explanatory design, aimed to identify the unmet needs of individuals with IPF and assess symptom experiences and impacts on quality of life. Guided by Levesque's healthcare access framework (2013), the findings from chapters 5 (Healthcare Organisation Audit and IPF Survey) and 6 (Interviews) revealed considerable variation in access to timely and affordable care. The analysis highlighted barriers to care, particularly when accessing pulmonary rehabilitation, lung transplantation assessment, and psychological services. Over half of healthcare professionals noted limited access to clinical trials, and referral practices to palliative care varied, partly due to its local availability. Gaps were also evident in the recruitment and retention of multidisciplinary professionals, with over 60% of healthcare providers reporting insufficient consultation time with patients. Financial burdens related to oxygen and antifibrotic medications were a significant concern, as confirmed in the qualitative interviews (phase three).

Phase two survey findings, underpinned by Levesque's healthcare access framework (2013), revealed frequent disruptions in accessing healthcare services, including dietetics, physiotherapy, pulmonary rehabilitation, palliative care, psychology/counselling, and ILFA's range of supports. Quantitative findings were expanded on in the qualitative interviews, which found that geographical and financial factors were key contributors to barriers to care. Inferential statistics showed that shortness of breath, fatigue, and cough, were the most frequently reported symptoms, severely impacting sleep, mobility, and social connections. These symptoms, often exacerbated by medication side effects, hindered patients' ability to seek, reach, and engage with services.

Significant differences in quality of life, measured by the SGRQ-I, were found across various demographic and clinical factors. Poorer quality of life was linked to living alone, being female, residing in rural areas,

having comorbidities, using prescribed oxygen, and lacking access to key services. In contrast, a better quality of life was associated with private health insurance, living with others and being male. Men were found to have greater information needs, especially regarding medicine, diet and exercise information needs compared to females. Qualitative findings emphasised that patient preferences for timing and method of information delivery were crucial.

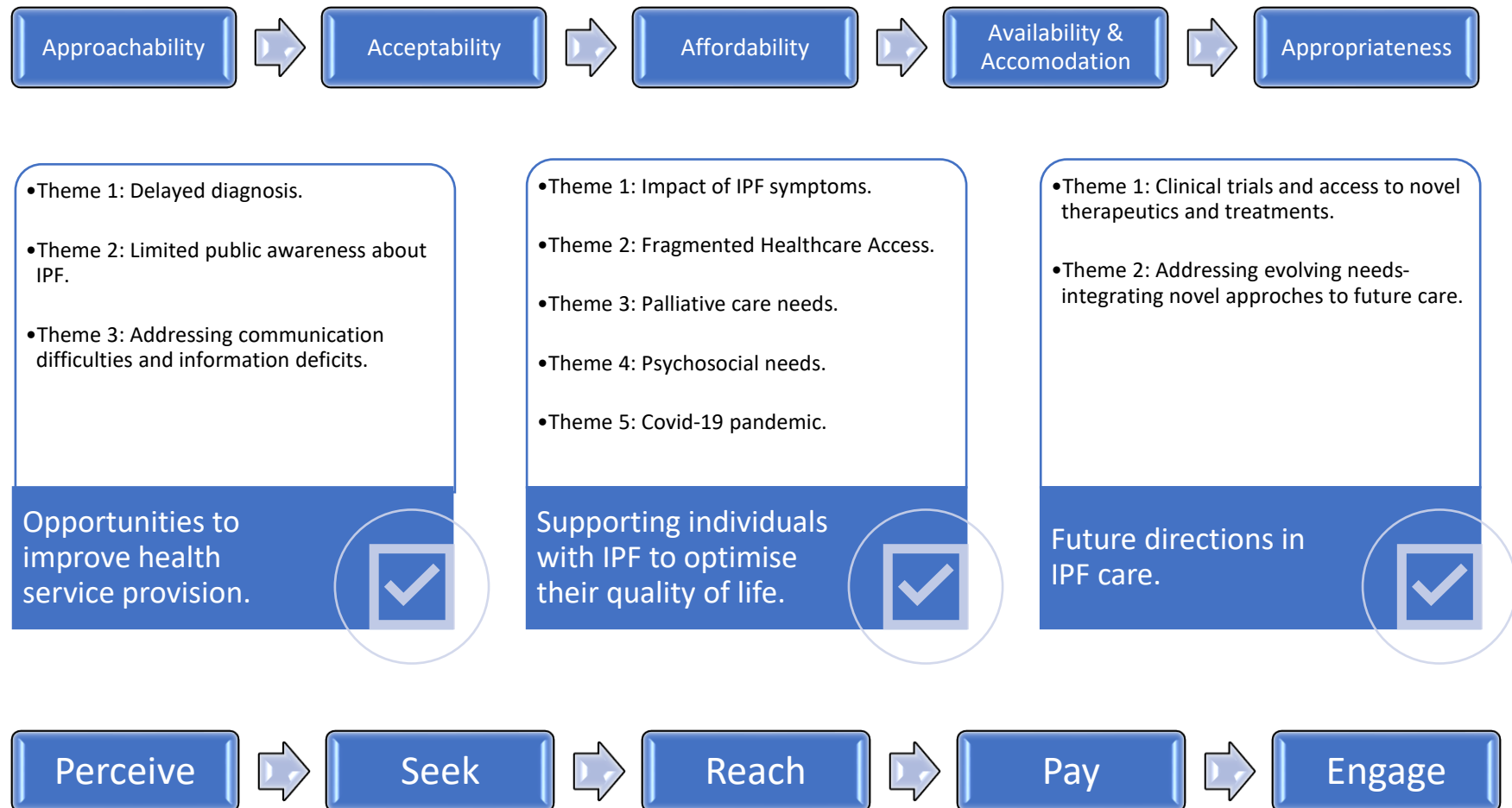
Participants frequently cited limited public awareness of IPF as a significant issue, leading to feelings of isolation. The COVID-19 pandemic further exacerbated these challenges, with restrictions impacting social connections and healthcare access. Poor hospital infrastructure, long waiting lists, and insufficient support often prompted patients to seek private healthcare to bridge these gaps. Notable predictors of quality of life included comorbidities, smoking, living alone, older age, living further from the patients' treatment centre, and limited access to information or services. These predictors were confirmed in interviews, which underscored the significant inverse relationship that exists between unmet needs and quality of life.

## **8.2 Theoretical Framework: Levesque Healthcare Access Framework**

The application of the Levesque healthcare access framework (2013) served as the theoretical underpinning for this study and facilitated meaningful exploration of unmet needs, symptom experiences, and quality of life of individuals with IPF. This framework has not previously been used in research concerning those with IPF, making a novel and original contribution of the framework in this context. The five domains of accessibility integrated into the model are approachability, acceptability, affordability, appropriateness, availability/accommodation (Levesque et al., 2013). These domains are coupled with the five corresponding abilities: the ability to perceive, seek, reach, pay, and engage (Levesque et al., 2013). The combined strengths of the domains and the corresponding ability to access healthcare supported the identification and categorisation of unmet needs in this current study. The application of Levesque's theoretical framework (2013) informed the overall research design from its inception in 2021 to its completion in 2025. Levesque's framework (2013) influenced the development of the quantitative (audit and survey data collection) and qualitative methods (interviews) used in this mixed-methods study (Chapter 4).

Study findings (chapter 5 and chapter 6) were integrated (chapter 7) and synthesised, resulting in meta-inferences being drawn. A discussion of the integrated findings will follow, situated within the Levesque healthcare access framework (2013), with each of its five domains facilitating a discussion of the findings. Levesque's framework (2013) accurately depicts the complex interplay between the healthcare system and individuals with IPF who experience varying degrees of dependency on the healthcare system from acute to primary care services, typified by repeated hospitalisation, complex investigations and regular outpatient consultations. New evidence to extend the Levesque framework will be provided along with a visual representation of how findings from this study were incorporated into the framework (Figure 8.1).

**Figure 8.1 Integrated Findings Using Levesque Healthcare Access Framework**



### 8.3 Opportunities to Improve Health Service Provision

#### 8.3.1 Delayed Diagnosis

Qualitative findings in this study indicated that delayed diagnosis is a significant concern that adversely affects individuals with IPF. Access to prompt and accurate diagnosis is crucial in the management of IPF, enabling earlier initiation of antifibrotic therapy and prompt access to other supportive measures such as oxygen therapy, pulmonary rehabilitation and lung transplantation assessment to optimise better health outcomes (Cosgrove et al., 2018; 2022; Lamas et al., 2011; Oldham & Noth, 2014). Many participants described an arduous journey to diagnosis, impacting both physical and psychological well-being, which was often financially challenging. These findings are consistent with previous research, which highlighted persistent delays in the diagnostic journey for those with IPF (Cosgrove et al., 2018; Hoyer et al., 2019; van Der Sar et al., 2021). A Danish cohort study reported on the impact of delayed diagnosis in IPF, indicating that a diagnostic delay of over one-year worsened progression-free survival, quality of life, and hospitalisation rates in patients with IPF (Hoyer et al., 2022). Current evidence underscores this worrying pattern of diagnostic delays following the onset of symptoms, with current trends indicating a median time of over two years to obtain a diagnosis (IQR 0.9 – 5.0) (Hoyer et al., 2019). Qualitative findings in this study revealed that participants experienced similar delays in diagnosis, from symptom onset to confirmed diagnosis. Diagnosing IPF is often complicated by the frequently nonspecific nature of symptoms, which are regularly attributed to advancing age or other respiratory conditions, further complicating the diagnostic journey and delaying access to care (Hoyer et al., 2022; Hoyer et al., 2019; Schoenheit et al., 2011).

Levesque's concept of the '**ability to perceive**' a healthcare need is particularly relevant in this context, as the non-specific nature of IPF symptoms and limited public awareness hinder timely recognition of IPF, and reduce individuals '**ability to engage**' with primary care services for early assessment. Additionally, evidence suggests that delayed diagnosis can result in delayed access to pharmaceutical therapies, with one European study ( $n = 286$ ), indicating that more than a quarter of participants ( $n = 74$ , 26%) had unsatisfactory delays in commencing antifibrotic therapy of more than six months (Moor et al., 2019).

IPF is considered a rare disease with often limited awareness among general practitioners about the early signs and symptoms, further complicating the task of prompt and accurate diagnosis. The lack of awareness among general practitioners corresponds to Levesque's domain of '**approachability**' in healthcare access, which highlights the recognition and visibility of a health need by patients' and their healthcare providers. Several participants in this current study recounted their distressing experience of being initially misdiagnosed, resulting in delayed access to healthcare. These findings are mirrored in an extensive cohort study among six hundred participants with interstitial lung disease in the United States, where 55% ( $n = 330$ ) of participants reporting more than one misdiagnosis, and 38% reported more than two misdiagnoses prior to receiving an accurate diagnosis (Cosgrove et al., 2018). Diagnostic delays were further complicated when the patients' general practitioner dismissed or oversimplified the diagnosis or

symptoms. These findings are mirrored in several other studies (Ahmed et al., 2023; Hoyer et al., 2019; Schmidt, 2020), highlighting the need for greater public awareness and education about IPF.

International guidelines (NICE, 2017; Raghu et al., 2011; Raghu et al., 2022) aim to support accurate and timely diagnosis of IPF. They consistently emphasise the importance of skilled multidisciplinary teams in the care and management of those with IPF. Despite these guidelines, delays in diagnosis persist, often due to insufficient investment in recruiting and retaining skilled staff with the necessary expertise and proficiency to assess and diagnose IPF. The Irish Thoracic Society IPF Position Statement (2018) underscores these concerns. It emphasises the urgent need for improved staff resourcing within centres of excellence in pulmonary fibrosis across Ireland to ensure the delivery of high-quality care for patients. At present, the lack of integrated pathways of care and the absence of a National Pulmonary Fibrosis Clinical Programme of care contribute to significant barriers for individuals with IPF, who must navigate a fragmented health care system to obtain an accurate diagnosis and **appropriate** access to support and services.

Participants who failed to receive a prompt and accurate diagnosis within the public healthcare system often turned to private specialist care to obtain an expert assessment of their symptoms. Leveque's (2013) domain of '**affordability**' and corresponding '**ability to pay**' for healthcare is relevant in this case, as patients faced a substantial financial burden due to the perceived requirement to access private healthcare. Diagnostic delays and misdiagnosis persist as significant problems in the management of IPF. Collaborative solutions should focus on improving access to expedited diagnosis, better public awareness and general practitioner education, investment in appropriately resourced multidisciplinary teams, and improved diagnostic tools delivered through an integrated pathway of care to optimise outcomes for patients (Table 8.1).

**Table 8.1 Delayed Diagnosis**

|                         |                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>Diagnostic challenges underscore the unmet needs of individuals with IPF, who require timely access to diagnosis and referral to services.</li> <li>Factors influencing participants' complex diagnostic journey include inadequate retention and resourcing of the multidisciplinary team.</li> <li>Delayed diagnosis significantly affects the quality of life of those with IPF.</li> </ul> |
| <b>Recommendation</b>   | <ul style="list-style-type: none"> <li>Investment in a National Pulmonary Fibrosis Clinical Programme that could standardise the provision of equitable care and address deficits in access to timely and accurate diagnosis.</li> </ul>                                                                                                                                                                                              |
| <b>Recommendation</b>   | <ul style="list-style-type: none"> <li>Implementation of a National ILD Registry to collect data on diagnostic pathways, observe trends and invest in improved care.</li> </ul>                                                                                                                                                                                                                                                       |

### 8.3.2 Limited Public Awareness about IPF

Limited public awareness exists regarding IPF nationally, which often impedes a patient's ability to recognise a need for healthcare, or **to seek** medical evaluation, particularly when early symptoms are vague or non-specific. This challenge aligns with the **approachability** domain in Levesque's framework



(2013), which relates to the visibility and existence of healthcare services relevant to an individual's needs. The gap in public awareness about IPF highlighted in this study extended beyond patients to general practitioners, who may experience limited familiarity with the condition, necessitating an urgent requirement to improve public awareness about the early signs of IPF (Aiello et al., 2017; Bonella et al., 2016; Cottin et al., 2017). The Irish Lung Fibrosis Patient Charter (2015) emphasises the critical need for improved, clear, and concise information about IPF, to enhance public awareness. In a previous observational cross-sectional study in Portugal, findings indicated that only 21.9% of general practitioners had satisfactory self-perceived knowledge about interstitial lung disease, representing a need for improved education and heightened awareness about this disease among primary care services (Silva et al., 2022).

Greater awareness of IPF could support timely referral to specialist centres for further investigations, a process that, according to findings from this study, is frequently hampered by delays. Participants in this current study recounted delayed onward referral for specialist care, as their symptoms were either dismissed or misdiagnosed in the early stages of their disease by their general practitioner. These findings are consistent with those found in other studies across Europe, the United States and Japan (Lancaster et al., 2021; Purokivi et al., 2017; van Der Sar et al., 2021). A novel approach to support general practitioners in primary care to recognise the early symptoms of IPF, is a symptom-based algorithm to help identify patients who warrant onward referral for specialist assessment (Thickett et al., 2014). General practitioners require support through investment, resourcing, and bespoke training to support their learning, particularly as the demands upon the primary care system continue to grow. A recent economic and social research institute (ESRI) report predicts that there will be an upward trend in demand for general practitioner consultations from 19.4 million in 2023 to around 24–25 million by 2040, representing an increase of 23–30% (Connolly et al., 2025). This upward trend is expected to place additional strain on an already overwhelmed primary care system, posing significant challenges for future healthcare delivery. Investment at the primary care level through enhanced resourcing and targeted information campaigns could support general practitioners in recognising the early symptoms of IPF in a timely manner. This would facilitate prompt referral to specialist centres guided by a national programme for IPF that outlines a clearly articulated care pathway for those suspected of having IPF.

The widespread lack of public awareness about IPF has had a significant impact on patients, many of whom struggle to fully comprehend the diagnosis themselves, due to limited prior knowledge of the condition. Collaborating with patient support organisations to develop public awareness campaigns could play a role in improving understanding about IPF and supporting the critical need for earlier detection of IPF within primary care settings. The European Pulmonary Fibrosis Federation (EU-PFF) addresses public awareness through annual campaigns each September, aligned with global efforts to raise awareness of pulmonary fibrosis. The EU-PFF, '*Breathing Life*', campaign underscores the persistent lack of public understanding of IPF, a critical unmet need that, if addressed, could support earlier diagnosis and better referral pathways (Bonella et al., 2016; Purokivi et al., 2017) (Table 8.2).

**Table 8.2 Limited Public Awareness about IPF**

|                         |                                                                                                                                                                                                                                                                                                                                                              |
|-------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>• A widespread lack of public awareness about IPF exists, among healthcare professionals in acute and primary care settings.</li> <li>• Improved public awareness may positively impact the path to diagnosis by educating the public and healthcare practitioners on the early signs and symptoms of IPF.</li> </ul> |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>• Investment is required for public awareness campaigns to increase awareness about IPF and particularly its early signs and symptoms.</li> </ul>                                                                                                                                                                     |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>• Targeted investment in training general practitioners about the early signs and symptoms of IPF to improve prompt onward referral for specialist assessment.</li> </ul>                                                                                                                                             |

### 8.3.3 Addressing Communication Difficulties and Information Deficits

The European Patient Charter advises that patients should have access to comprehensive and reliable information about IPF (Bonella et al., 2016). Information provision is the bedrock of high-quality patient care that can assist patients with self-management and optimise their quality of life (Bramhill et al., 2024). A general lack of information about IPF and supportive services, deemed necessary throughout the disease course, further adds to the burden of the disease, representing an unmet need and contributing to barriers in an individual's **ability to engage** with services. Applying Levesque's healthcare access framework (2013), in this section focuses on several domains within the framework, starting with **appropriateness**, which concerns the alignment of services with patient preferences, including timeliness, quality, and effective communication. Participants' **ability to engage** and interact with healthcare services depends on several factors, including trust, motivation, and effective communication.

Communication deficits were observed in this study between healthcare professionals and patients. These concerns were closely linked to clinical consultations, at times, described as 'rushed' or 'unempathetic', contributing to a distressing experience, particularly at the time of diagnosis. Poor communication between healthcare professionals and patients contributed to the emotional burden of living with IPF. Despite this important finding, few studies have explored effective communication throughout the diagnostic journey, highlighting a significant unmet need (Graham et al., 2025; Masefield et al., 2019; Wuyts et al., 2014). Within Levesque's healthcare access framework (2013), these deficits can be considered within the context of **acceptability**, which may impact an individual's willingness **to seek** care due to ineffective and unempathetic clinician communication.

Both national (ILFA, 2015) and international (Bonella et al., 2016) patient charters emphasise the importance of providing standardised, reliable and up-to-date information to support individuals with IPF. Both qualitative and quantitative analyses highlight the gaps that exist in the provision of standardised and reliable information for individuals with IPF, particularly at the time of diagnosis, where limited resources left individuals with IPF feeling uninformed and unprepared for the challenges that an IPF diagnosis brought. The literature suggests that patients prefer balanced information that offers elements of hope and honesty (Masefield et al., 2019). These findings align with previous research in this area using qualitative interview methods across Australia, Denmark and the United Kingdom (Burnett et al., 2017;

Overgaard et al., 2016b; Senanayake et al., 2018). Participants provided with oversimplified information often had unrealistic expectations about recovery from IPF.

Quantitative and qualitative analysis revealed a range of areas where information gaps existed, including disease knowledge, medicines, exercise, diet, smoking cessation, travel advice, and advance care planning, with a notable lack of paper-based information resources provided to patients. Higher information needs were frequently associated with poorer quality of life. Participants often turned to the internet, seeking information, especially when there was a gap in information provision, a finding corroborated in several other studies across Australia, Canada and the United States (Burnett et al., 2017; Fisher et al., 2016; Graham et al., 2025). Graham et al. (2025) indicated that 68% of participants in their study from the United States ranked the internet in their top three most prioritised sources of information, confirming its importance to patients.

Few international studies have comprehensively investigated information needs across the care continuum, from initial diagnosis of IPF to end-of-life care. The lack of continuous and personalised information often leaves patients and their families without reliable information to support them at critical touchpoints over the course of the disease (Masefield et al., 2019; Wuyts et al., 2014). Additionally, deficits existed in the provision of information and support to manage the debilitating side effects of medication, which negatively impacted medication adherence and quality of life, findings corroborated in several other studies across the United States and Italy (Graham et al., 2025; Levra et al., 2022; Provenzani et al., 2025).

Quantitative findings indicated that being male, living alone, and being on oxygen were significantly associated with greater information needs when compared with other groups in the study. These results were corroborated in qualitative interviews, where individuals who were prescribed oxygen reported higher information needs that frequently remained largely unaddressed, a finding consistent with several other studies in Australia and the United Kingdom (Burnett et al., 2019; Khor et al., 2017; Sampson et al., 2015). An Australian study conducted by Tikellis et al. (2022), found that those receiving supplementary oxygen often felt unprepared for its impact on their daily lives and **ability** to socialise, often reporting high levels of information needs related to its use.

Patient support organisations were positively viewed, representing a reliable source of information provision; however, just 26.2% of participants in this study had previously accessed the Irish Lung Fibrosis Association (ILFA) resources. Findings from this mixed-method study have identified key areas where information gaps persist, highlighting the need for improved and standardised information provision on topics such as oxygen use and travel, advance care planning, palliative care, managing symptoms, medication side effects, improved awareness about peer support facilitated by the Irish lung fibrosis association, information regarding diet, and exercise and information on clinical trial access (Table 8.3).

**Table 8.3 Addressing Communication Difficulties and Information Deficits**

|                         |                                                                                                                                                                                                                                                                                                                       |
|-------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>• Ineffective communication at the time of diagnosis can negatively impact individuals, representing an unmet need.</li> <li>• A lack of standardised information at the time of diagnosis, coupled with limited variability of resources represents an unmet need.</li> </ul> |
| <b>Recommendation</b>   | <ul style="list-style-type: none"> <li>• Consider the timing and variability of resources aligned with patient preferences to address information needs.</li> </ul>                                                                                                                                                   |
| <b>Recommendation</b>   | <ul style="list-style-type: none"> <li>• Investment in developing standardised information resources. Engaging with patient support organisations and the Health Service Executive (HSE) to facilitate the dissemination of reliable and standardised information.</li> </ul>                                         |

## 8.4 Supporting Individuals with IPF to Optimise their Quality of Life

### 8.4.1 Impact of IPF Symptoms

This mixed-methods study contributes to the growing body of evidence regarding the symptom experience of those with IPF (Table 8.4). In this current study, shortness of breath (72.4%,  $n = 171$ ) was the most common symptom, followed by fatigue 70% ( $n = 165$ ) and cough (68.25%,  $n = 161$ ). Comparable findings were reported in a study conducted by Graham et al. (2025), in the United States, which also employed a mixed-methods approach exploring the perspective of individuals diagnosed with IPF ( $n = 106$ ). Their study reported that 87% of individuals with IPF experienced shortness of breath; among them, 41% considered shortness of breath to be very burdensome (Graham et al., 2025). Additionally, 77% of participants in their study experienced cough, with 30% indicating that this symptom was also very burdensome (Graham et al., 2025). In this current study, participants similarly described their experience of debilitating symptoms that significantly affected their lives. Notably, 39% of participants in this study reported experiencing ‘*no good days*’ ( $n = 92$ ) as they struggled to navigate the challenges associated with their symptoms. Qualitative findings indicated that worsening breathlessness was associated with increased anxiety and often led to avoidance of activities and situations that might exacerbate symptoms. Avoidance of activities directly impacted quality of life, often isolating individuals from family and friends. Numerous other studies across Germany, Australia, and Canada have highlighted that avoidance of physical activities is inversely related to worsening deconditioning, which can, in turn, exacerbate symptoms (Bahmer et al., 2017; Hanada et al., 2020; Prasad et al., 2021). Evidence in the literature highlights that symptoms such as cough and dyspnoea are highly correlated with worsening anxiety and depression (Pink et al., 2014; Tzouvelekis et al., 2020; Uzer et al., 2024) and other psychological impacts, such as isolation and loneliness (Bajwah et al., 2013; Hofman et al., 2024; Senanayake et al., 2018).

Fatigue was reported by almost 70% ( $n = 165$ ) of participants in this study. These results mirror those in other studies in the United Kingdom and Sweden (Jernås et al., 2024; Senanayake et al., 2018). The experience of fatigue is often not recognised and insufficiently addressed by healthcare providers in clinical practice, exacerbating its burden on patients (Graham et al., 2025; Pascoe et al., 2025). However, this trend is changing with increasing attention on the experience of fatigue observed in contemporary research (Kahlmann et al., 2020; Swigris et al., 2018). For example, a Dutch study reported that 48% ( $n =$

28) of individuals with IPF experienced fatigue, which was strongly correlated ( $p = < 0.5$ ) with severe impairment, highlighting the significant impact of fatigue on participants' daily lives (Bloem et al., 2020). Qualitative findings in this study revealed that fatigue was closely linked to challenges in maintaining social connections, often resulting in isolation and difficulties in engaging with routine activities. Persistent coughing frequently disrupted sleep, not only for participants but for their partners, resulting in increased lethargy, an issue that has been documented in previous studies across the United States (Belkin et al., 2014; Klein et al., 2021; Lindell et al., 2018). The quality and duration of participants' sleep was often negatively impacted by cough and dyspnoea, with 68% of participants in this study reporting this as a problem ( $n = 160$ ).

Applying the Levesque healthcare access framework (2013) deepens our understanding of the **'acceptability'** domain within the framework, particularly in relation to how individuals interpret and respond to persistent symptoms. Participants frequently reported feelings of shame, discomfort and embarrassment, an underrecognized consequence of IPF, mainly due to the visibility of symptoms such as coughing and dyspnoea. These findings are consistent with previous research conducted in Europe, Australia and the United States which generated a diverse geographical spread of data (Green et al., 2024; Mann et al., 2023; Swigris et al., 2021). Strategies to alleviate the symptoms of IPF were largely initiated by patients rather than recommended by healthcare professionals. Commonly cited approaches included taking regular breaks, incorporating daytime naps, and avoidance of activities and social situations that could exacerbate participants' symptoms. While these strategies offered some symptom relief, they often contributed to further isolating participants from family and friends. Limited time during outpatient consultations, which are often pressurised due to time-constraints and are generally focused on clinical investigations, leave limited opportunities to engage in symptom management strategies. One study in Belgium highlighted that healthcare professionals had limited or no knowledge of self-management strategies, limiting **approachability**, which, combined with a lack of time and administrative workload, contributed to a gap in care (Delameillieure et al., 2021). Lee et al. (2023) conducted a recent scoping review of eighty-seven papers and found that standalone pulmonary fibrosis self-management programmes remained largely unexplored. One potential solution is the expansion of the interstitial lung disease nurse specialist role, who could support the development and/or expansion of self-management strategies for patients with IPF.

Other less well-known impacts due to IPF symptoms include loss of income due to the cessation of employment. In this present study, 53.3% ( $n = 126$ ) of participants reported that their lung condition interfered with or prevented them from continuing in employment. Limited research has explored this phenomenon, with one observational study in Canada indicating a significant association between cough severity and workplace productivity loss among individuals with fibrotic interstitial lung disease, including IPF (Algamdi et al., 2019). IPF is associated with an older population, some of whom may potentially experience age-related discrimination in their employment due to their advanced age, which may add to the burden of managing a complex condition in the workplace. This phenomenon is observed in several other reports on older adults in the workplace, who experience age-related stereotypes negatively impacting their opportunities for employment (Burn et al., 2023; Cadiz et al., 2017; Marchiondo et al.,

2019; McConatha et al., 2022). Moreover, age-related discrimination and chronic symptoms that result in impacts to employment further contribute to the disease burden.

International guidelines and patient charters (Bonella et al., 2016; ILFA, 2015; ITSa, 2018; NICE, 2017; Raghu et al., 2022) consistently highlight the importance of symptom management in IPF to enhance functional capacity and quality of life. These recommendations traditionally emphasise supports such as pulmonary rehabilitation, psychological support, palliative care services, access to multidisciplinary teams, medication and oxygen. However, a notable gap remains, where current guidelines often overlook the broader impacts of IPF symptoms on the individual, including loss of employment, financial burden associated with access to healthcare, diminished social connections and stigma associated with visible symptoms. These challenges highlight a gap in patient-centred care that warrants greater attention. Nationally, there are gaps in the standardisation of care pathways that could improve symptom management. This is particularly concerning given the absence of a National Clinical Programme for pulmonary fibrosis, highlighting an unmet need for equitable and standardised care (Bramhill et al., 2024; Cassidy et al., 2022; ITSa, 2018) (Table 8.4).

**Table 8. 4 Impact of IPF Symptoms**

|                         |                                                                                                                                                                                                                                                                                                                      |
|-------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>• Cough, breathlessness and fatigue were the most commonly reported symptoms, that negatively impacted quality of life.</li> <li>• Deficits exist in the provision of self-management strategies.</li> <li>• Persistent deficits exist in standardised guidelines.</li> </ul> |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>• Consider the use of patient reported outcome measures to assess unmet needs concerning symptom management.</li> </ul>                                                                                                                                                       |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>• Enhanced guidelines to include assessment of less explored symptoms such as fatigue.</li> </ul>                                                                                                                                                                             |

#### **8.4.2 Fragmented Healthcare Access**

Qualitative findings offered a profound insight into the challenges participants frequently face when accessing healthcare, which is often disjointed, unstandardised, and inequitable across geographical regions. Participants in this study who lived further from their tertiary treatment centre reported poorer quality of life. Similarly, in a retrospective cohort study conducted in the United States, rurality was found to be a barrier to specialist care (DeDent et al., 2022). Complex care coordination was evident among those with IPF **engaging** with the healthcare system, with reports of limited **availability** of supports such as pulmonary rehabilitation, palliative care, psychology/counselling, dietetics, and occupational therapy. These findings align with several other studies in Ireland and across Europe, which point to a persistent issue with healthcare access (Cassidy et al., 2022; DeDent et al., 2022; Moor et al., 2019). International best practice guidelines recommend the provision of multidisciplinary care in IPF to optimise patient outcomes, given the necessity for coordinated care provision and healthcare access due to the complexity of the disease (Bonella et al., 2016; ITSa, 2018; Raghu et al., 2011; Raghu et al., 2022).

The variation in multidisciplinary team composition observed in this study often led to inequitable healthcare access to specialist services across hospital sites, suggesting a lack of standardisation in care delivery nationally. Ireland compares unfavourably with other countries, with evidence from the British Thoracic Society ILD registry, further underscoring existing insufficiencies in access to care within an Irish context (BTS, 2021). The United Kingdom consistently performs better than Ireland for access to physiotherapy for example for those with interstitial lung disease, which is reported to be 60% in Britain, compared to 47.7% in the present study (BTS, 2021; Cassidy et al., 2022). Additionally, previous research in Ireland indicates that only 58% ( $n = 65$ ) of patients with pulmonary fibrosis have access to an interstitial lung disease nurse specialist, with considerable geographical variation, representing an unmet need (Cassidy et al., 2022). Internationally, this trend continues with Ireland comparing unfavourably with several other countries. Australia, for example, offers a structured multidisciplinary team approach, with findings from a study by Tikellis et al. (2022) indicating that 97% ( $n = 38$ ) of included centres have regular multidisciplinary team meetings to support the diagnosis of IPF, incorporating a diverse team of highly skilled professionals offering patient-centred care. Similarly, in Denmark, their approach entails the integration of highly skilled multidisciplinary teams within several centres of excellence that have the capacity to provide both routine and complex interstitial lung disease care (Bendstrup et al., 2015).

Qualitative findings from this study highlight the considerable strain placed on a limited number of healthcare staff in delivering patient-centred care, often resulting in overreliance and increased pressure that could overwhelm staff and lead to attrition if left unaddressed. International evidence points to a broader shortage of nurses, raising concerns about the sustainability of skilled staffing (Russell et al., 2018). In Ireland, the shift towards community-based care under the Sláintecare programme (Department of Health, 2021) may further impact staff retention in acute hospitals, as healthcare professionals transition into community-based roles, potentially fuelling attrition in acute services.

Participants in this study experienced difficulties when accessing primary care support, particularly general practitioner services, with limited **availability** of appointments and frequent concerns about continuity of care which may fail to **accommodate** patients' preferences. These findings are corroborated in a Canadian cross-sectional study, which exposes shortfalls in access and continuity in primary care (Dewille-Stoetzel et al., 2024). In the Canadian study, it was found that 32% ( $n = 121$ ) of participants with chronic conditions encountered difficulty in obtaining a primary care appointment (Dewille-Stoetzel et al., 2024).

Applying Levesque's framework (2013) with a focus on the **availability and accommodation** of services, underscores a novel contribution from this study, highlighting infrastructural barriers within hospital settings, including inaccessible buildings, limited capacity for social distancing, a lack of hospital isolation rooms, inadequate parking facilities, as well as the financial burden of parking charges. These factors further compound the challenges faced by individuals with IPF, intensifying the burden of disease and impeding individuals' **ability to reach** essential supports and services.

Lung transplantation can extend the survival of patients with IPF, with evidence of increased survival despite the higher risk profile of these patients (Thabut et al., 2003). Access to lung transplantation assessment for those with IPF is widely recognised by both national and international guidelines, which

emphasise its importance (Bonella et al., 2016; Cassidy et al., 2016; Raghu et al., 2011). Despite these guidelines, some participants reported being excluded from lung transplantation assessment, based on age or severity of disease, echoing findings in other studies (Sterclova et al., 2024; Swaminathan et al., 2022). The International Society for Heart and Lung Transplantation indicates that median survival post-lung transplantation for those with IPF is 4.1 years (Stehlik et al., 2012).

Levesque's healthcare access framework (2013) highlights challenges in accessing lung transplantation assessment for patients with IPF, with limited information provided to participants regarding this option, making it difficult for them **to perceive** it as a suitable pathway. One study from the United States highlights the need for improved information for patients about lung transplantation to educate them about this option (King et al., 2023). International guidance, like that from the International Society for Heart and Lung Transplantation (ISHLT) (Leard et al., 2021) supports clinicians in assessing transplant suitability, high-risk assessments and survival rates post-surgery, as well as consideration for the particularly onerous surgical work-up experienced by patients (Christie et al., 2011). Ramirez et al. (2024) explored survival after a lung transplant for those with IPF (n = 416) using retrospective data from 2012-2023. Age of the lung transplant recipient has been found to impact survival post lung transplantation (P = .039) (Ramirez et al., 2024). Additionally, a retrospective analysis of registry data, between 2006 and 2022, found that older lung transplantation recipients (n = 30,494) aged seventy years and over had poorer long-term survival outcomes compared with those who were younger (Meyer et al., 2024).

IPF remains underrepresented in national clinical programmes, unlike asthma and chronic obstructive pulmonary disease (COPD), which have dedicated care programmes. The prevalence of IPF is much lower than that for asthma and COPD. However, its impact is significant, given patients' advancing age, existence of multiple comorbidities and significant symptom burden causing increased reliance on healthcare supports and services (ITSb, 2018). Ireland ranks fourth worldwide for asthma, with an estimated prevalence of 470,000 and impacting all ages (ITSb, 2018). COPD affects an estimated 500,000 adults aged over forty in Ireland (ITSb, 2018). The high prevalence of both COPD and asthma necessitates community-based care, via the Sláintecare programme, which does not include provision for IPF, highlighting the inequitable access to care that exists in Ireland. The national clinical care programme (NCP) initiative began in Ireland in 2010, after a period of economic recession and austerity measures (Darker et al., 2018). The NCP embarked on reconfiguring healthcare delivery that incorporates hospital-based acute care, coupled with community-based initiatives. One such national clinical programme is the National Programme for Older Persons (2010), which places particular importance on recognising the needs of older adults, such as frailty, polypharmacy, and multiple comorbidities, supporting these individuals to live independently and with dignity. Consideration could be given to the inclusion of IPF in this program, where access to suitable supports may be more readily available, given the poor integration of IPF into current respiratory programs.

This study revealed that many participants faced a substantial financial burden, with half relying on private health insurance to offset limited access to public services, highlighting issues of **affordability and ability to pay**. These concerns were reflected in counselling costs, medication expenses, travel with oxygen



equipment, as well as increased electricity costs due to home oxygen use, which contributed to an additional financial burden, particularly for those no longer in paid employment. Hidden costs associated with private healthcare, including frequent consultant-led appointments and diagnostic imaging costs (HRCT scans and pulmonary function tests), also contributed to their financial burden. These findings echo international evidence, such as those from a Greek cohort study involving individuals with IPF ( $n = 123$ ), where almost half of the participants reported increased expenses relating to medication costs, and the ability to access physician visits, hospital services and medical investigations (Naoum et al., 2020). The underexplored economic burden of IPF requires further investigation, given its significant impact on patients' lives and their ability to access care (Kreuter et al., 2022; Morell et al., 2016; Wong et al., 2022). Quantitative analysis revealed that those with private health insurance experienced better quality of life compared to the uninsured. Interviews revealed that individuals prioritised health insurance expenditure, due to future orientated fears of medical costs and inability to afford care. A database study in the United States among patients hospitalised with pulmonary fibrosis indicated that those with poorer insurance coverage, or lower income, were significantly disadvantaged in terms of access to optimal healthcare and were much less likely to receive lung transplantation or rehabilitation (Gaffney et al., 2018).

Findings from this study highlight that inequalities in care and existing barriers in accessing supports and services are highly dependent on the provision of an appropriately resourced multidisciplinary team, geographical factors and financial inequalities to access supports and services, coupled with difficulties experienced when navigating an often-complex health system. The findings of this study support the need for a coordinated approach in IPF care to address individuals' unmet needs (Table 8.5).

**Table 8.5 Fragmented Healthcare Access**

|                         |                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>Widespread inequitable access to healthcare was evident in this current study, with the availability and consistency of supports and services varying from one centre to another. Some centres were better resourced than others, leading to inequitable access to care.</li> <li>Individuals with IPF often experienced financial hardship when accessing supports and services.</li> </ul> |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>Development of a National Pulmonary Fibrosis Clinical Programme that could standardise care and lead to equitable healthcare access.</li> </ul>                                                                                                                                                                                                                                              |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>Investment in a National Pulmonary Fibrosis Registry that could support resource planning to optimise patient care.</li> </ul>                                                                                                                                                                                                                                                               |

#### **8.4.3 Palliative Care Needs**

The World Health Organisation (World Health Organisation, 2020) has defined palliative care as an intervention that can help improve quality of life, particularly for those with life-limiting conditions, using a range of psychological, physical, social, and spiritual supports. The Levesque healthcare access framework (2013) supported the exploration of current practices and barriers to integrating palliative care in IPF. IPF is a chronic, progressive disease, making palliative care essential in supporting patients to manage symptoms and maintain quality of life (Bajwah & Yorke, 2017; Kreuter et al., 2017; Wijssenbeek et

al., 2023). Several studies have highlighted its essential role in IPF, to alleviate symptoms, improve quality of life and support advance care planning (Pihlaja et al., 2023; Rajala et al., 2016; Smallwood et al., 2018). This importance is further reinforced by both international and national patient charters, which advocate for early integration of palliative care into the care pathway and not limited to end of life care only (Bonella et al., 2016; ILFA, 2015). Healthcare professionals who responded to the audit in this study estimated that approximately half of referrals to palliative care occurred within three years following an IPF diagnosis. However, discordant findings were reported in the IPF survey, with less than 4% of participants indicating that they had ever been referred to palliative care. This finding is worrying, given that over fifty per cent of participants in this study were diagnosed more than four years ago, with most reporting that they had not received any palliative care support. Current guidelines recommend early initiation of palliative care, which did not routinely occur in this present study. Similarly, lower-than-anticipated rates of referral to palliative care were evident in the data drawn from international patient registries from the United States, Germany, and Spain, which reported that referral to palliative care occurred in just twenty per cent of cases for those with IPF (Oliveira et al., 2023).

Utilising Levesque's concept of **acceptability** (2013), it was found that palliative care acceptability was poor in this study. Many healthcare professionals held differing views on the timing of its initiation, while some patients perceived it as primarily focused on end-of-life care only. Cultural sensitivity and societal norms may impact the referral processes to palliative care, given widespread misconceptions about its scope, with many frequently associating it primarily with death and dying, with limited awareness of its broader role in symptom management. Kim et al. (2019) conducted a scoping review of barriers to palliative care for patients with interstitial lung disease and found that the frequency of referrals ranged from 0% to 38%. Their findings indicated that barriers to palliative care referral and uptake included patients' fears concerning their future, confusion about the role of palliative care, and uncertainty about the nature of their disease (Kim et al., 2019).

Current guidelines for those with chronic obstructive pulmonary disease (COPD) and interstitial lung disease recommend initiating palliative care when patients experience physical, psychological, social and or spiritual/existential needs (Janssen et al., 2023). Notable publications (ITSa, 2018; NICE, 2017) advocate for the early initiation of palliative care in IPF to maximise its benefits for patients. Despite these recommendations, evidence indicates that referral to palliative care services remains underutilised. Studies indicate that such care is most often introduced during the final month before death, typically in response to an acute respiratory exacerbation (Cassidy et al., 2024; Liang et al., 2017; Lindell et al., 2017). This delay frequently results in those with IPF dying in acute hospital settings, regardless of their personal preferences for end-of-life care (Liang et al., 2017; Lindell et al., 2017).

Qualitative analysis in this current study highlighted information gaps in the provision of reliable information about palliative care services, resulting in many participants turning to the internet to address their end-of-life information needs. Individuals with IPF often have unique fears regarding the nature of and imminence of death, observed in this study where participants frequently experienced frightening mental imagery of how death might translate for them, with images of '*death by suffocation*', a frequently

reported concern. Participants often found themselves unable to discuss these sensitive care needs due to current care arrangements. This represents a missed opportunity due to variability in referral patterns and access to expertise in palliative care. Some participants had mulled over travelling abroad to avail of assisted dying, given their fears of an unsupported, undignified and uncomfortable death. Others preferred not to dwell on end-of-life matters, instead opting to live in the moment and take each day as it came, a finding consistent with other research (Liang et al., 2017).

A national quantitative survey on pulmonary fibrosis ( $N = 112$ ) using the Irish Lung Fibrosis Association membership and a targeted social media campaign, indicated the existence of widespread heterogeneity and variations in referral practices to palliative care, with most referrals occurring more than 12 months after diagnosis ( $n = 6$ , 86%), representing a gap in care (Cassidy et al., 2022). These findings are consistent with international literature, which demonstrates poor referral practices to palliative care in IPF, particularly when compared with other conditions such as lung cancer (Ahmadi et al., 2016). Several other studies highlight the underutilisation of palliative care in IPF, such as that from Zou et al. (2019), which looked at referral patterns in a retrospective single-speciality centre cohort study in the United States. Their findings concluded that just 13.5% of their sample ( $n = 828$ ) had been referred to palliative care (Zou et al., 2019). In a retrospective cohort study spanning ten years in the United States, only 3.8% of patients with IPF admitted to the intensive care unit (ICU) received a palliative care referral prior to ICU admission (Liang et al., 2017). Alarming, 77% of those patients died in the ICU, highlighting a critical gap in appropriate supportive care (Liang et al., 2017). These findings highlight the urgent need for targeted interventions to address information deficits, as stigma and misconceptions surrounding palliative care persist. Many still equate it exclusively with end-of-life care only, rather than recognising its broader scope in improving quality of life throughout the disease trajectory (Table 8.6).

**Table 8.6 Palliative Care Needs**

|                         |                                                                                                                                                                                                                                         |
|-------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>Widespread variation and heterogeneity exist in the referral of patients with IPF to palliative care services, representing an unmet need.</li> </ul>                                            |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>Investment in information resources for healthcare professionals and patients to address information gaps and develop awareness of the role palliative care services can have in IPF.</li> </ul> |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>Include palliative care within a newly developed clinical care programme for IPF to standardise inclusion of this intervention.</li> </ul>                                                       |

#### **8.4.4 Psychosocial Needs**

IPF is associated with debilitating symptoms, including persistent cough, fatigue, and breathlessness, all of which can negatively impact quality of life. Beyond the physical burden, these symptoms often result in emotional, social, and psychological challenges, leading to heightened psychosocial needs (Bramhill et al., 2024; Moor et al., 2019; Oliveira et al., 2023). Quantitative findings from this study highlight the significant psychosocial burden that exists among individuals with IPF, particularly for specific subgroups within the sample who reported poorer quality of life, including those with comorbidities, those who lived alone, and

females. This points to the need for targeted interventions that address the unique vulnerabilities of these subgroups, such as mental health supports, social integration groups, peer support, and gender sensitive support strategies to support their psychosocial well-being. Participants experienced constant and evolving shifts in their priorities, as they were forced to adjust their daily lives to a '*new normal*', often limiting social connections due to the symptoms of IPF, such as fatigue and dyspnoea. For some, further impacts on psychosocial well-being were highlighted through their experience of loss of employment. Quantitative findings revealed that over 50% of participants reported that their lung condition interfered with or made them stop work (53.3%,  $n = 126$ ), representing further impacts on social connections, and echoed in other studies across Europe and the United States (Algamdi et al., 2019; Chaudhuri et al., 2024; Swigris et al., 2005). Furthermore, a Canadian study by Algamdi et al. (2019) revealed that individuals with interstitial lung disease, aged fifty-five or more, had 18% lower employment rates compared to a matched population (20% vs 38%,  $P < .001$ ).

Quantitative analysis indicated that nearly 30% of participants in the present study struggled with the uncertainty surrounding their diagnosis, often experiencing heightened anxiety and persistent fear of worsening breathlessness (23%,  $n = 54$ ), adding to the psychosocial burden of this disease. These emotional stressors contributed to a reduction in their social world and intensified the burden already experienced by individuals as they navigated the complexity of managing a chronic progressive condition, a phenomenon seen in several other studies across Europe and the United States (Russell et al., 2016; Schoenheit et al., 2011; Swigris et al., 2005). This present study highlighted the undercurrent of worry and anxiety that exists for those with IPF, findings that have been demonstrated in other studies across Asia, Australia and the United States, which indicate that depression and anxiety are common in patients with pulmonary fibrosis (Holland et al., 2014; Lee et al., 2017; Ryerson et al., 2011). Evidence from a literature review conducted by Yohannes (2020) in the United States, that explored the prevalence of depression among those with IPF, found that depression rates range from 14% to 49% and anxiety rates range from 21% to 60% respectively. Despite the high prevalence of depression and anxiety among those with IPF (Glaspole et al., 2017; Lee et al., 2017; Spagnolo et al., 2021), these mental health concerns are often overlooked or inadequately treated, contributing to negative impacts affecting quality of life, increased hospital admissions, dependency on caregivers and reduced social interactions (Coelho et al., 2010; Hofman et al., 2024; Holland et al., 2012; Yohannes, 2020).

Individuals with the condition often find themselves employing a range of coping mechanisms to ameliorate the psychological effects associated with IPF. Coping strategies identified in this present study included physical exercise, yoga, singing, completing household chores, and engaging with spirituality and religion. Others sought private mental health supports at great personal expense due to the lack of locally available supports. Several papers have highlighted the persistent lack of psychological support, such as counselling, representing a significant unmet need (Belkin et al., 2014; Janssen et al., 2023; Schoenheit et al., 2011). Others reached out to the national patient support organisation (ILFA) and found this form of peer support to be generally invaluable; however, this sentiment was not shared by all participants. Participants were dichotomised into one of two camps regarding the **acceptability** of peer support, for example, those who wished to attend peer support, viewing it as beneficial and helpful in managing their

condition. While others, experienced psychological barriers concerning the issue of seeing others who might be in poorer health than themselves, which could be confronting and inhibited them from engaging in peer support. These findings are reported in several other papers that used both mixed-methods and qualitative interviews to collect data across the United Kingdom (Dean et al., 2021; Senanayake et al., 2018). Findings from a qualitative study in the United Kingdom, reported that attendance at a peer support group for those with IPF could positively impact patients' ability to cope with their illness (Senanayake et al. 2018).

This study also showed that the psychological burden of IPF affects not only patients but also family caregivers, a group often overlooked, in both clinical care and research. Previous studies (Bonella et al., 2016; Lee et al., 2020) highlight the importance of involving family members throughout the disease course, as they are crucial in supporting patients' psychosocial needs. A recent scoping review highlighted a critical gap in psychological support for both patients and family caregivers (Klein et al., 2021). Adjustments made to control the symptoms of IPF, manage medication side effects, and handle the burden of oxygen equipment often reshape family dynamics (Belkin et al., 2014; Shah et al., 2018). A recurring theme among participants was the loss of independence, resulting in family members often stepping in to help manage participants' needs, which sometimes fractured relationships and altered roles within the household. This studies mixed-methods findings mirror those from other studies that have documented increased stress, reduced intimacy and strained relationships among those with IPF and other family members (Russell et al., 2016; Swigris et al., 2005; Wells et al., 2024).

Participants in this study reported poor access to psychological and counselling services, with repeated calls for better access to counselling as part of an integrated care package, a finding consistent with other studies using a mix of survey and interview methods across Europe and the United States (Belkin et al., 2014; Giot et al., 2012; Schoenheit et al., 2011). Taken together, these insights point to the necessity of developing comprehensive psychosocial care models that not only manage clinical aspects of IPF but actively support patients in coping with uncertainty, fear, isolation and potential risk of anxiety or depression. Future research should investigate the effectiveness of such interventions and consider longitudinal approaches to understand better how psychosocial challenges evolve. Consideration for a broader view of psychosocial support should include integration into clinical care programmes and pathways of care for social prescribing to alleviate symptoms of isolation and social disconnection. This section has demonstrated the current situation regarding the availability of limited psychosocial support for individuals with IPF to address their needs (Table 8.7).

**Table 8.7 Psychosocial Needs**

|                         |                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|-------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>• Participants in this study experienced psychological impacts such as anxiety and depression. Study findings revealed poor access and referral practices to counselling services.</li> <li>• Isolation and loss of identity significantly impacted quality of life, often affecting family caregivers too.</li> <li>• Coping strategies included physical exercise, peer support and yoga.</li> </ul> |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>• Investment in the provision of mental health supports, such as psychology and counselling services. Signposting to adjunct supports such as peer support and integrated social prescribing practices to help patients with their psychosocial well-being.</li> </ul>                                                                                                                                 |

#### 8.4.5 COVID-19 Pandemic

The COVID-19 pandemic had a profound impact on the psychological well-being of individuals with IPF, who were considered a high-risk and vulnerable group due to their compromised lung function. National restrictions on social gatherings at that time led to increased social isolation as participants limited their social interactions to protect themselves from infection. Levesque's framework (2013) supports the discussion on COVID-19 in those with IPF. Levesque's **approachability** domain underscores how the pandemic significantly affected participants' ability to recognise and access available services. Many reported increased difficulties obtaining healthcare during heightened restrictions particularly due to reduced **availability** of general practitioner appointments and pulmonary rehabilitation services. These disruptions were particularly concerning given that individuals with IPF lack access to a dedicated clinical programme of care, unlike patients with conditions such as cancer, COPD, and asthma. Existing deficits in care pathways for those with IPF exacerbated the vulnerability of individuals with IPF due to the absence of a standardised and equitable care pathway during the pandemic, highlighting a critical gap in service provision. Participants experienced heightened emotions during the initial phase of the COVID-19 pandemic, when the visible signs of IPF, particularly coughing, often led to social stigma, which intensified feelings of embarrassment, as observed in qualitative interviews.

Infrastructure concerns were particularly problematic at that time, with many expressing a significant fear of contracting COVID-19 if hospitalisation was required. This fear reflects broader cultural and societal sensitivity that impacted participants' willingness to engage in healthcare services. Consistent with Levesque's framework (2013), these prominent concerns regarding the risk of infection impacted participants' **acceptability** of services, as well as their **ability to engage** in these supports, especially when required to meet in person. Despite national and international recommendations (Bonella et al., 2016; ITSa, 2018) that highlight a holistic approach to managing those with IPF, incorporating social, practical, and emotional support, a sentiment that was often not operationalised during heightened restrictions. The provision of such services was significantly disrupted during the COVID-19 pandemic. This finding is consistent with another study conducted in Ireland, which indicated increased worry among patients and caregivers associated with hospitalisation during the COVID-19 pandemic (Cassidy et al., 2022).

Lessons learned from the pandemic have enabled innovative healthcare initiatives, including hybrid models that blend face-to-face and virtual care, tailored to patient preferences. Additional approaches included online exercise/ pulmonary rehabilitation programmes, and other strategies such as yoga and singing for lung health, which supported patients’ physical conditioning and reduction in the risk of infection. These measures could be considered for ongoing care packages into the future (Table 8.8).

**Table 8.8 COVID-19 Pandemic**

|                         |                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>• The COVID-19 pandemic had a significant effect on individuals with IPF, with many describing impacts to their quality of life at that time.</li> <li>• Learnings should focus on preparedness for future pandemics.</li> </ul>                                                                                                                                                             |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>• Future healthcare settings could integrate PPI in hospital infrastructure design and planning to ensure that patients’ spaces in hospital settings are attuned to the preferences and needs of those with IPF.</li> <li>• Measures to enhance infection control in hospitals could include single-occupancy rooms and telehealth, as well as E-health outpatient consultations.</li> </ul> |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>• Improved provision for access to online supports such as online exercise/ pulmonary rehabilitation programmes to support the physical health of individuals with IPF.</li> </ul>                                                                                                                                                                                                           |

## 8.5 Future Direction in IPF Care Provision

### 8.5.1 Clinical Trials and Access to Novel Therapeutics and Treatments

New and emerging pharmaceutical treatments for IPF are currently in development, with several active phase III studies in progress (Sgalla et al., 2023). As the global incidence of IPF continues to rise, and given the high symptom burden experienced by patients, there is a pressing need for novel therapeutics to improve outcomes and quality of life. With no known cure for IPF, apart from lung transplantation and only two established licensed antifibrotic drugs available, pirfenidone (Esbriet®) and nintedanib (Ofev®), early access to novel therapeutics through clinical trial participation is essential. In this study, a significant lack of awareness and engagement with clinical trials was associated with poorer quality of life, underscoring the need to improve trial accessibility and integration into routine care pathways in Ireland. A recent report by the Irish Lung Fibrosis Association (2025) highlighted that Ireland compares unfavourably to other countries, particularly Canada and Denmark, in clinical trial infrastructure and access. Both Canada and Denmark have established registries, ‘CARE-PF’ in Canada (Ryerson et al., 2016) and ‘DANILDA’ in Denmark (Bendstrup et al., 2019), which facilitate the recruitment of clinical trial participants. Internationally, a previous Australian study (Tikellis et al., 2021) indicated that participation in clinical trials was poor, with only 58% of centres having readily available access to this option. Geographical location, poor trial infrastructure, and insufficient clinical trial expertise were notable barriers (Tikellis et al., 2021). These findings support existing international literature, which prioritises

patients' perspectives in clinical trial design to enhance participation (Collard et al., 2015; Frost et al., 2025; Jalbert et al., 2022). Notably, the current study found that only half of healthcare professionals refer patients to clinical trials; barriers to referral included a lack of clinical trial infrastructure, representing an unmet need.

Inequalities in trial participation associated with geographical limitations have been creatively addressed in Australia by the Clinical Oncology Society of Australia (COSA) (Graffini et al., 2024; Sabesan & Zalcborg, 2018). COSA adopted a tele-trials initiative to overcome geographical barriers to clinical trial participation (Sabesan & Zalcborg, 2018). This novel approach to clinical trial access could be extended to IPF trials, maximising opportunities for patients located in rural areas to access novel therapeutics via clinical trial participation (Tikellis, 2021). Lessons learned in other disease areas, particularly oncology, should be leveraged to inform and improve trial design and enhance recruitment strategies. Adapting standard operating procedures from cancer clinical trials could remove existing barriers to trial participation identified in this study (Table 8.9).

**Table 8.9 Clinical Trials and Access to Novel Therapeutics and Treatments**

|                          |                                                                                                                                                                                                                                                                                                                                              |
|--------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point:</b> | <ul style="list-style-type: none"> <li>Participants in this study who were either unaware or had not been invited to participate in a clinical trial tended to have poorer quality of life.</li> <li>Addressing inequitable access to clinical trials should be a priority for future policy makers and healthcare professionals.</li> </ul> |
| <b>Recommendation:</b>   | <ul style="list-style-type: none"> <li>Consider novel opportunities for engaging broader involvement in clinical trials such as tele-health options, remote monitoring, virtual consultations and wearable monitoring devices.</li> </ul>                                                                                                    |
| <b>Recommendation:</b>   | <ul style="list-style-type: none"> <li>Development of a national registry that could serve as a recruitment platform to support wider inclusion of patients with IPF.</li> </ul>                                                                                                                                                             |

### 8.5.2 Addressing Evolving Needs – Integrating Novel Approaches to Future Care

Findings from this mixed-methods study underscore the limited **availability** of diverse healthcare supports, with a particular emphasis on community-based services, leading to an overreliance on acute hospital care. The increasing incidence of IPF globally (Maher et al., 2021) is anticipated to place considerable strain on an already overstretched and fragmented healthcare system, as the disease progresses. There exists a critical need to enhance healthcare **accessibility** for individuals with IPF, particularly through community-oriented or novel approaches, considering the current scarcity of supportive services (Duck et al., 2015). Contemporaneous research has predominantly concentrated on hospital-based care arrangements (Bonella et al., 2016; Burnett et al., 2017; Lee et al., 2020; Tikellis et al., 2022; van Manen, Kreuter, et al., 2017), with limited focus on Levesque's concept of **approachability** and **acceptability** concerning community-based programmes such as pulmonary rehabilitation and digital health monitoring (2013). Levesque's (2013) concept of **accommodation** can be applied to infrastructure barriers concerning transportation and parking. Furthermore, financial obstacles continue to be a



significant barrier to accessing community-based supports and services, impacting participants' **ability to reach and pay** for such services (Cassidy et al., 2015; Cassidy et al., 2022; Moor et al., 2019). International evidence reflects similar challenges, including reports of community-based supports which are either non-existent or poorly accessible (Collard et al., 2007; Lindell et al., 2021; Morisset et al., 2016). Despite the life-limiting nature of an IPF diagnosis, this study underscores the persistent deficiencies in community-based support that often does not align with patient preferences.

Nationally, the Irish Lung Fibrosis Association provides a broad range of supports, including information, peer support, and online programs. This study identified low patient awareness and utilisation of these services. While nearly 70% (n = 11) of healthcare professionals reported that they signpost patients to the Irish Lung Fibrosis Association, only 26.2% (n = 62) of participants in this study had previously accessed this form of support. Given the increasing incidence of IPF, there is an urgent need to expand capacity for out-of-hospital services (Maher et al., 2021) and enhance awareness and engagement with existing community supports. A qualitative study by Senanayake et al. (2018) highlighted that peer support groups promote emotion-focused and problem-focused coping, positively contributing to patient well-being. Future research could investigate the barriers that prevent patients' **ability to engage** with patient support networks. Peer support groups could foster and develop a peer-led approach to normalise participation and to enhance **approachability**, thereby supporting patients with IPF in **seeking** this form of support.

Contemporary evidence supports the integration of digital technologies, such as virtual multidisciplinary teams, remote monitoring, and home spirometry, to enhance quality of life for individuals with IPF and reduce the burden on healthcare systems (Moor & Wijsenbeek, 2023; Nakshbandi et al., 2023). The COVID-19 pandemic accelerated the shift toward remote care and home-based monitoring (Tikellis et al., 2023), yet E-health remains underutilised in IPF care despite national policy endorsement through programmes such as Sláintecare (Moor et al., 2020; Nakshbandi et al., 2023). Opportunities to creatively integrate digital technology into the routine management of those with IPF are still limited and represent an unmet need. Digital health and home-based monitoring programs may have a secondary positive impact on the environment by reducing motor car use (Moor & Wijsenbeek, 2023; Nakshbandi et al., 2023). International evidence suggests that E-health has demonstrated promising results, providing accessible and affordable care to those with IPF (Cerdán-de-Las-Heras et al., 2021; Moor et al., 2020; Moor et al., 2018). Levesque's framework (2013) highlights that healthcare depends on both **availability and accommodation**. This is particularly relevant in digital healthcare, where failing to address these factors can further increase barriers especially for vulnerable populations, such as older adults who may face challenges with digital literacy and navigating online health resources (Cerdán-de-Las-Heras et al., 2021; Moor & Wijsenbeek, 2023). Participants in this current study described the steep learning curve they had to undertake as they turned to online resources to obtain reliable and up-to-date information on their disease, particularly during the COVID-19 pandemic restrictions, highlighting the necessity to support patients as they engage with online support and services.

Community-based activities encompassed mindfulness (Saketkoo et al., 2018), singing (Cahalan et al., 2022; Lewis et al., 2016), yoga and dancing (Niranjan et al., 2022) which present promising opportunities to improve the well-being of individuals with IPF. Social prescribing aims to support people in a holistic way to address “non-medical social determinants of health and well-being” (Wilson et al., 2025, p. 2) by connecting patients to community and voluntary services tailored to individual needs (Drinkwater et al., 2019; Wilson et al., 2025). Although still gaining recognition, particularly among those with chronic conditions, social prescribing has the potential to bridge gaps in psychosocial support and decrease reliance on acute hospital care. Existing literature highlights a range of activities available through the social prescribing programme, including exercise and walking groups (Bertotti et al., 2020), mindfulness (Palmer et al., 2017), ‘men’s shed’ (Chesterman & Bray, 2018), gardening (Moffatt et al., 2023) that could relieve pressure on healthcare systems and enhance individuals’ quality of life (Table 8.10).

**Table 8.10 Addressing Evolving Needs – Integrating Novel Approaches to Future Care**

|                         |                                                                                                                                                                                                                   |
|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Discussion Point</b> | <ul style="list-style-type: none"> <li>There is a persistent lack of and underutilisation of community-based psychosocial and healthcare supports and services for individuals with IPF.</li> </ul>               |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>There is a need to enhance the availability, accessibility and awareness of community-based supports and services to address the needs of individuals with IPF.</li> </ul> |
| <b>Recommendation:</b>  | <ul style="list-style-type: none"> <li>Future research efforts are required to determine the often-poor uptake of community-based services.</li> </ul>                                                            |

## 8.6 Summary of Key Findings

In this sequential explanatory mixed methods study, the qualitative findings expanded on and contextualised the quantitative results by illuminating the unmet needs, symptom experiences, and quality of life challenges experienced by individuals with IPF. These integrated findings are presented side by side in the joint display in Chapter 7, enabling visual comparison of quantitative and qualitative datasets and facilitating the identification of any areas of concordance, discordance and expansion. Quantitative data provided numerical insight into difficulties associated with obtaining timely and accurate diagnosis. For example, 13% of patients reported turning to private healthcare to expedite the diagnostic process ( $n = 30$ ), while a further 56% acquired private health insurance to improve access to healthcare ( $n = 104$ ). These findings were deepened and contextualised through qualitative interviews, in which participants described prolonged diagnostic journeys, and experiences of misdiagnosis often leading to a necessity to seek private health insurance in order to reach an accurate diagnosis. One participant captured this experience of misdiagnosis stating:

“I kept saying I’m tired. And then after a while I was saying why am I so tired all the time? I was finding it hard to breath as well, I got it checked out, and the doctor said, ‘Yeah, it sounds like menopause symptoms.’” (P17, Female, Age 58).

Quantitative findings identified shortness of breath ( $n = 171$ , 72.4%) as the most prevalent symptom, followed by fatigue ( $n = 165$ , 70%) and cough ( $n = 161$ , 68.25%). Qualitative narratives expanded on these results by offering rich first-person accounts of living with these symptoms. Participants described the substantial burden imposed on daily functioning, sleep quality, social participation, and interpersonal relationships. As one participant explained:

“The breathing situation stops me from doing some of the things I’d like to do. I’d have a fear of getting too breathless.” (P04, Female, Age 77).

Quantitative analysis identified several factors associated with poorer quality of life, including female gender, lack of health insurance, comorbidities, living alone, and greater distance from a tertiary referral centre. The qualitative findings illuminated the mechanism underlying these associations by revealing fragmented care pathways, geographical inequities, and inconsistent access to specialist supports. During phase three interviews, participants described substantial variability in referral practices, echoing findings from phases one and two. Reported inconsistencies included unequal access to pulmonary rehabilitation, psychological support, clinical trials, and palliative care. These gaps further compounded psychosocial distress and symptom burden. Quantitative data demonstrated heterogeneity in palliative care referral practices, with most occurring in years two to three of illness ( $n = 5$ , 31.2%) followed by years three to five ( $n = 4$ , 25%). Qualitative accounts expanded on these trends by highlighting participants’ fears around death and their desire for compassionate and dignified end of life care.

Qualitative insights also enriched understanding on the widespread information gaps identified quantitatively, particularly among male participants and those living alone. Participants described compensating for these gaps through self-directed coping strategies, peer support and family involvement. Others reported seeking information online despite concerns regarding unreliable or outdated sources. Overall, the qualitative findings deepened interpretation of the quantitative trends by capturing the lived experience of IPF and shedding light on the interrelated influence of healthcare access, symptom burden, and quality of life.

## **8.7 Strengths and Limitations**

### **8.7.1 Strengths**

This section outlines the strengths and limitations of this mixed-methods study. The integration of quantitative and qualitative approaches served as a key strength, enabling the study to achieve its objectives. The mixed-methods design provides both a narrative and quantifiable account of the lived experience of those with IPF, addressing the study's objectives. Combining quantitative and qualitative approaches provided insights into the unmet needs, symptom experiences, and quality of life for

individuals with IPF informing future practice and highlighting research priorities. Relying on a single method alone would not have sufficiently addressed the complexity of the research problem.

This study incorporated public and patient involvement (PPI) throughout each study phase, strengthening the design and ensuring alignment with patient and family carer priorities. PPI involvement helped ensure the study remained patient-focused and accessible to a broader population. PPI played a vital role in enhancing each phase of the study, from design to dissemination of findings. Feedback from PPI partners informed the scoping review, development of the survey instruments and interview guide, ensuring alignment with patient priorities and the study's objectives. PPI involvement also strengthened dissemination efforts, including support with plain language summaries for publication and presentations, such as the development of a poster at the Pulmonary Fibrosis Patient Summit in Barcelona in 2024, ensuring findings reached those most affected. Overall, integrating PPI enriched the study's relevance, impact, and reach.

Participants were recruited from five of the eight national specialist centres in interstitial lung disease, complemented by an extensive online recruitment strategy to reach a broader population. This enhanced the generalisability of the findings. Unlike prior research that relied on a single method alone, a smaller sample size or fewer recruitment sites, this study prioritised an extensive multi-site recruitment campaign to address the research objectives and provide valuable new evidence to the area of unmet needs, symptom experiences, and quality of life among those with IPF. This study included a large sample of participants ( $N = 237$ ) in phase two (IPF survey), making it the most extensive mixed-methods study conducted in Ireland addressing the phenomenon of interest. Prior to this study, a national quantitative study in Ireland explored access to specialist and multidisciplinary healthcare for patients ( $N = 112$ ) with pulmonary fibrosis (Cassidy et al., 2022). Previously, international studies exploring gaps in care for those with IPF and were poorly represented by patients from Ireland, with one European study of patients with pulmonary fibrosis ( $N = 286$ ) notably having just five representatives from an Irish population (Moor et al., 2019).

Navigating the complex healthcare system across the island of Ireland was both a challenge and a strength of this study. Recruiting from hospitals across multiple provinces and hospital groups enabled a broad geographical reach, which is a key strength in this study, especially given the difficulty in accessing hard-to-reach individuals with IPF due to the complexity of their disease and its symptoms. Utilising gatekeepers at each site strengthened this study by including individuals with insider knowledge of the culture and practical elements of each outpatient clinic, creating trust in the study. Fostering relationships with hospital staff (medical, nursing, physiotherapy, hospital administration and allied healthcare professionals) who support patients with IPF and their families prior to study commencement helped to build strong engagement with experts in the field. Fostering engagement with national respiratory teams helped this study significantly, both during the recruitment and data analysis phase and in subsequent publications and dissemination of the findings. Enhanced sampling techniques used in this study included maximum variation sampling, which sought to strengthen the inclusion of diverse perspectives in qualitative

interviews, recognising the variability in patient's experiences and stages of disease, creating a sample that was broadly representative of patients with IPF across the disease course.

### **8.7.2 Limitations**

The recruitment strategy employed in this study did not facilitate the collection of information concerning those who selected not to participate in the study, and, indeed, why they did not participate. However, the findings do bear similarity to the results of other international studies (Lancaster et al., 2021; Moor et al., 2019; Tikellis et al., 2022). Surveys used in this study were limited to English language only and potentially excluded non-English speakers from participation. Participants were predominantly White, English speakers, which may have limited inclusion of a more culturally diverse sample and may inhibit the ability to compare findings to other contexts or cultures internationally. This study used maximum variation sampling in its recruitment strategy for qualitative interviews to maximise the diversity of the participants, despite this, the recruited sample consisted largely of male participants. The study design relied upon self-report survey data followed by semi-structured interviews. Data collection did not extend to clinical factors such as pulmonary function testing (PFT) results, which might have provided insight into the individual's health status and further depth to the analysis of the findings.

Participants in this study were recruited through the five national hospital sites. The online recruitment campaign did not extend the sample greatly. Employing an online recruitment strategy was challenging due to the older target population who may not regularly engage with social media. International patient support organisations were excluded to ensure the experiences of those with IPF receiving care in a hospital in Ireland was prioritised. Contact was made with each of the pulmonary fibrosis peer support groups nationally ( $N = 6$ ), and paper copies of surveys were distributed to them.

This PhD commenced in September 2021, where intermittent interruptions regarding national restrictions were still being deployed in Ireland, due to the COVID-19 pandemic. Recruitment was challenging, given the various restrictions in place at that time. On a practical level, it impacted recruitment as face masks were mandatory for much of the recruitment phase. Some hospitals initiated additional efforts to shield patients from the risk of infection by requesting that healthcare professionals wore face masks long after national restrictions had been rescinded, reflecting the need to protect those with IPF from contracting the infection. The COVID-19 pandemic further impacted the recruitment strategy as some outpatient clinics operated a hybrid system, with clinic visits alternating at times between in-person and telehealth options, hampering recruitment efforts. Similarly, some patients were reluctant to attend the clinic in person, fearing the risk of contracting COVID-19.

Secondary impacts from COVID-19 resulted in changes in submission arrangements to respective research ethics committees, followed by delays in research ethics approval, which hampered the commencement of the study. It is difficult to assess whether the study would generate similar results if conducted again, given the diverse challenges that existed over the duration of this PhD particularly during the recruitment phase. In addition to the impact from COVID-19 on this study there was an unexpected cyber-attack on

the national health service computer systems, on May 14<sup>th</sup>, 2021, which further impacted commencement of the study as there were ongoing impacts to outpatient clinics long after the cyber-attack ended.

## **8.8 Conclusion**

Chapter 8 presented a discussion of the meta-inferences made from integrated quantitative and qualitative findings. The sequential explanatory mixed-methods research design supported the study's aim to provide a comprehensive investigation of the unmet needs, symptom experiences, and quality of life of individuals diagnosed with IPF. A discussion has been provided, presenting findings from both quantitative data, which highlighted the myriad of symptoms and unaddressed needs of patients which impacted their quality of life, complemented by qualitative interviews, that helped explain and extend earlier quantitative analysis. Participant interviews provided rich insights into the lived experience of individuals with IPF, which helped to enhance our understanding of the healthcare barriers that exist and hamper efforts to address patients' unmet needs. A discussion was provided of the difficulties experienced by participants in obtaining a prompt and accurate diagnosis a finding that was corroborated in both quantitative and qualitative analysis. This was followed by an overview of the impact of the symptoms associated with the condition. The barriers to palliative care and psychosocial support required by those with IPF were illustrated. Prominent concerns regarding the barriers to healthcare access were presented. The impact of COVID-19, resulting in isolation and difficulties in accessing care, were described in quantitative findings and expanded on in qualitative interviews. The future direction of the management of IPF was described and included better access to novel therapeutics through clinical trial participation, followed by a discussion on novel community support measures to address unmet needs.

The application of the Levesque healthcare access framework (2013) in this study provided a meaningful backdrop to support an integrated understanding of the complex interplay that exists when individuals with IPF seek healthcare to address their needs and optimise their quality of life. Utilising Levesque's theory (2013) provided the scaffolding to address issues concerning healthcare access, including approachability, acceptability, availability/accommodation, affordability and appropriateness. Levesque's theory facilitated a broader view of healthcare access that incorporates multiple domains, encompassing factors related to both supply and demand of services. Additionally, Levesque's framework (2013) acknowledged the various systems involved in the care of individuals with IPF, incorporating the healthcare system, policy, and healthcare staff, placing the person with IPF at the centre of care. Findings from this study were supported by existing literature in the field. Notwithstanding contemporaneous research in IPF, this study generated novel insights from a nationally representative sample of individuals with the condition, adding to the current body of literature addressing unmet needs, symptom experiences, and quality of life. Levesque's framework (2013) supported this study's aim to inform future care planning, policy and research. This chapter concluded with a discussion of the strengths and limitations of this study. Recommendations developed from the study's findings are discussed in Chapter 9.

## **Chapter 9 Recommendations and Conclusion**

### **9.1 Introduction**

This chapter builds upon the discussion of the findings in chapter 8, offering recommendations for policy, education and training, health service delivery and future research. These recommendations address the wide-ranging and interconnected services within the healthcare system that continue to fall short in meeting the needs of individuals diagnosed with IPF. The Levesque healthcare access framework (2013) guides this chapter, which outlines the domains of healthcare access (approachability, acceptability, availability/accommodation, affordability and appropriateness) alongside the five corresponding abilities to access healthcare, i.e. ability to perceive, seek, reach, pay, and engage. Recommendations are mapped to these domains and corresponding abilities, to inform future policy, healthcare delivery, training and research. This chapter also includes an outline of the plans for disseminating this body of work. It concludes with a final personal reflection on the researcher's journey.

### **9.2 Implications and Recommendations from this Thesis**

This section provides a summary of the key findings from this study and discussed in the preceding chapters. The results have important implications for policymakers, education and training, research and future practice. It is hoped that these recommendations will be considered by the Health Service Executive (HSE) particularly by departments involved in implementing the National Clinical Programmes, as well as Higher Education Institutes (HEIs) and researchers in the field, to encourage the adoption and application of these recommendations.

#### **9.2.1 Implications and Recommendations for Policy**

The findings from this mixed-methods study highlight the persistent deficits in care experienced by individuals with IPF. The Irish Thoracic Society Position Statement on IPF (2018) previously emphasised the need for an early and accurate diagnosis for those with IPF, a priority echoed in the Irish Lung Fibrosis Association Patient Charter on IPF (2015); however, these recommendations frequently remain unmet. The prolonged and often complex diagnostic pathway results in delays in access to essential healthcare, leaving many patients without an integrated and comprehensive care pathway. The Levesque healthcare access framework (2013) provides an appropriate lens through which to make recommendations, given its recognition of the diverse barriers to healthcare access that exist. Difficulties persist in providing precise incidence and prevalence of IPF due to the absence of national registry data. Consequently, a key recommendation arising from this study is the establishment of the National Pulmonary Fibrosis Registry. This aligns with Levesque's (2013) domain of availability and accommodation, where a registry could enhance access to care by providing data on gaps in care, demand for services, monitor patient outcomes, and inform future workforce and capacity planning.

To improve care provision, policy recommendations should promote collaboration with key stakeholders, including the Health Service Executive (HSE) National Chronic Disease Programme, the National Programme for Older Persons, the Sláintecare programme, the Irish Thoracic Society and Irish Lung Fibrosis Association. Inequalities in access to care persist for individuals with IPF, particularly regarding access to specialist healthcare professionals. This remains the case despite international guidelines emphasising the importance of an appropriately resourced multidisciplinary team to deliver the complex care required by patients with IPF (Raghu et al., 2011; Raghu et al., 2022). Furthermore, the findings, highlight the substantial financial burden frequently experienced by individuals living with IPF. Accordingly, this section also outlines recommendations for policymakers aimed at alleviating the financial burden associated with IPF.

#### **Study Recommendations:**

- **National Patient Registry:** National policy should prioritise the development of a National Patient Registry to improve understanding of the disease prevalence, enable international comparisons through standardised coding, monitor patient outcomes, and inform future resource allocation and multidisciplinary service provision planning.
- **National Clinical Programme:** Efforts should be accelerated to establish a National Pulmonary Fibrosis Clinical Programme, supported by dedicated national health service funding to ensure standardised and equitable care for individuals with IPF.
- **Financial Burden:** National policy should address the financial burden associated with IPF by reviewing eligibility thresholds for medical and general practitioner cards and provide targeted financial support for medication costs and prescribed oxygen use, including associated electricity Expenses

#### **9.2.2 Recommendations for Health Service Provision**

The data from this study highlight the breadth of symptoms experienced by individuals with IPF, including cough, dyspnoea, fatigue, and mental health challenges such as anxiety and depression. Despite this, services to support symptom management remain limited. Recommendations include the prioritisation of alternative supports, such as peer-led local support groups, particularly for individuals living alone who often report poorer quality of life. Innovative approaches to optimising quality of life could also incorporate social prescribing to enhance psychosocial well-being.

Health service planning should actively engage with patient and public involvement (PPI) to inform the design and implementation of hospital infrastructure that supports patient needs. Meaningful PPI engagement can ensure that the physical environment, diagnostic pathways and services are more responsive to the needs of patients. Integrating patient perspectives can reduce the burden of frequent hospital visits and improve patients overall experience and quality of care concerning the health service.



Despite its recognised value, PPI remains underutilised in health service planning, representing a missed opportunity to better reflect real-world experiences.

#### **Study Recommendations:**

- **Hospital Infrastructure:** Health service planning should incorporate lessons from the COVID-19 pandemic by strengthening hospital infrastructure and infection control measures to better meet the needs of those with IPF during future public health emergencies.
- **PPI:** Health service planning could be enhanced through PPI engagement to ensure services and care pathways are responsive to the evolving needs of patients.
- **Oxygen Services for IPF:** Health services should ensure timely and equitable access to specialist oxygen clinics for individuals with IPF, integrated into multidisciplinary care pathways to support appropriate assessment, education, and ongoing review of oxygen therapy.
- **Social prescribing:** Healthcare professionals should facilitate patient engagement with social prescribing, to reduce isolation and enhance quality of life with integration into clinical assessment and treatment in line with the National Framework for Social Prescribing.

#### **9.2.3 Education and Training Recommendations**

Recommendations for education and training are informed by the scoping review findings (Chapter 2) and the overall integrated study findings, which identified significant public awareness gaps about IPF and widespread information deficits relating to IPF. Improving awareness of the early signs and symptoms of IPF may support earlier and more accurate diagnosis, addressing a key challenge highlighted in this research, while also contributing to the destigmatisation of the condition. Delayed diagnosis was most frequently associated with general practice, where early symptoms were frequently misattributed to other respiratory conditions or aging, resulting in delayed access to essential healthcare. Enhanced education programmes for general practitioners, alongside capacity for specialist registrars in interstitial lung disease and advanced nurse practitioners may improve diagnostic accuracy and patient outcomes. Applied through Levesque's (2013) healthcare access framework, these recommendations underscore the importance of **accessible**, culturally sensitive healthcare that **accommodates** patient preferences. Education and training initiatives should also target specific care touchpoints highlighted in this study, particularly the initiation and management of oxygen therapy.

#### **Study Recommendations:**

- **Public Awareness:** Develop national IPF awareness campaigns to improve understanding of IPF, reduce stigma, and promote early recognition of symptoms.
- **Education and Training:** Strengthen IPF education within undergraduate and postgraduate medical, nursing and allied health programmes, with particular emphasis on general practitioner training.

- **Patient Information:** Provide tailored patient-centred information delivered at key touchpoints in the disease trajectory, particularly at the time of oxygen therapy initiation.
- **Peer Support:** Support the continued expansion of peer-led support groups through the Irish Lung Fibrosis Association to enhance information sharing and psychosocial support.

#### 9.2.4 Future Research and Practice Innovations

The integrated findings of this research have informed the future research priorities outlined in this section. Strategic planning is essential to address current deficits in care and prioritise enhanced support for the physical, psychological, social and spiritual well-being of individuals with IPF. Future research focus could leverage the strengths of Levesque's healthcare access framework (2013) to guide and prioritise investigations aimed at improving access to care. Building on the findings of this study, future research should focus on several core areas, including improving public awareness and addressing information deficits, particularly in relation to early symptom recognition of the condition, self-management, financial awareness, and palliative care needs. Future studies should also prioritise populations identified as being at higher risk of poorer quality of life, including individuals living alone, females, those prescribed oxygen therapy, uninsured individuals and those with multiple comorbidities. Research exploring symptom management and medication related side effects is warranted to further enhance the quality of life of individuals with IPF. Patient-focused research initiatives should leverage the established strengths, organisations such as the Irish Lung Fibrosis Association and the Irish Thoracic Society have, to facilitate collaboration between patients and healthcare professionals and to advance research efforts. Meaningful patient and public involvement in future research will be critical to ensuring its relevance and impact.

#### Study Recommendations:

- **Patient and Public Involvement:** Individuals with IPF should be actively involved in research design, to ensure research is representative of those with lived experience.
- **Evaluate Psychoeducation Interventions** that address the information needs identified in this study including financial concerns, peer support, medication, oxygen therapy, managing multiple comorbidities, and advance care planning. Such interventions could improve patient knowledge, self-management and overall quality of life.
- **Adopt a phenomenological approach** in future research to explore the lived experience of individuals with IPF, particularly regarding social stigma and its impact on quality of life. Understanding these experience can inform interventions that target psychosocial well-being and social support.
- **Develop a national programme of research** to examine the effects of geographical disparities, particularly in rural areas, where access to supports and services may be limited. Such research could inform strategies to reduce inequalities in healthcare access and improve outcomes for patients living in underserved regions.

### 9.3 Dissemination Plan

Dissemination of the findings from this research was a key priority throughout the study. To date, the study has resulted in two peer-reviewed research outputs and two additional non-peer-reviewed publications. Research findings have been presented in a poster presentation at two international conferences. I have been invited to present at both national and international conferences, including the Interstitial Lung Disease Network in the United Kingdom, and at a respiratory training conference for advanced nurse practitioners in Ireland. Additionally, I was asked to present an oral presentation at a patient information day hosted by the Irish Lung Fibrosis Association. Furthermore, I was invited to write an opinion piece in the Medical Independent in Ireland outlining the unmet needs of those with IPF. These dissemination activities have helped ensure the voices and experiences of individuals with IPF reach a broad audience across clinical, academic and patient communities. The study findings will be shared further through journal publications, conference presentations and workshops and seminars.

#### Future manuscript plans/in progress:

1. **Manuscript title:** Addressing the palliative care needs of patients with IPF, a qualitative exploration of the barriers and facilitators to palliative care.
2. **Manuscript title:** A mixed methods investigation of the unmet needs of patients with IPF.
3. **Manuscript title:** A qualitative exploration of social stigma, psychosocial isolation, and shame experienced by patients with IPF.
4. **Manuscript title:** A qualitative investigation into the experiences of patients living with IPF and their use of prescribed oxygen.

#### In addition:

- Dissemination plans also include oral presentations at both national and international conferences.
- Poster presentation at both national and international conferences.
- Dissemination of study findings through publication in the Irish Lung Fibrosis Association newsletter and social media channels.
- Distribution of study findings at each of the five national recruitment sites included in this study, to inform future practice.

### 9.4 Original Contribution to Knowledge

This mixed-methods study has added an authentic and original body of work to the field of IPF. Incorporating both quantitative and qualitative methods enhanced the utility and applicability of findings, thereby improving our understanding of the unmet needs, symptom experiences, and quality of life of those with IPF. Employing the Levesque healthcare access theoretical framework (2013) underpinned this research, supporting the development of findings in both quantitative and qualitative approaches, to

expand our knowledge on the phenomenon of interest and address the barriers to healthcare access that exist.

This study built on current evidence in the field and developed the concept of '**unmet need**', integrating a broader conceptualisation of its use and enhancing awareness of current gaps in care that exist nationally for those with IPF. The PhD was guided by its philosophical underpinning of pragmatism to address the research problem. Firstly, a protocol was published, providing a framework for developing the final scoping review, which was subsequently published, advancing our current understanding of the unmet needs of individuals with IPF. Secondly, patient and public contributions enhanced this study by ensuring that the research was aligned with the research priorities of those with lived experience, incorporating their feedback periodically to inform each phase of the study. Thirdly, careful consideration of the instruments used in this research, has added to the body of literature, providing vital information concerning their applicability in an extensive national, multi-site study. This PhD, with publication, has contributed to the body of literature that exists, offering a new perspective on the current management and care of those with IPF in Ireland. The study's findings have clinical implications and advance knowledge regarding the phenomenon of interest by highlighting areas of need that require attention in the clinical setting. To date, this is the largest national mixed-methods study investigating the unmet needs, symptom experiences, and quality of life of those with IPF, providing an enhanced awareness of the current landscape of IPF care in Ireland.

## **9.5 Reflection**

My arrival to the PhD programme in September 2021 was the result of several years of clinical work in a research centre, where my role predominantly focused on clinical trials related to those with IPF. My early interactions with patients with IPF was a profoundly impactful experience, and I subsequently spent several years musing about how I might make a meaningful contribution to this field. My opportunity came in the form of a PhD scholarship and a conversation with Professor Anne-Marie Brady, from the School of Nursing and Midwifery, Trinity College Dublin, who encouraged and supported my first steps into academia. Completing a PhD during a worldwide pandemic, COVID-19, required a pragmatic, adaptive, and solution-focused approach to meet the challenges encountered. Adjusting to social distancing, online and telecommunication methods necessitated the acquisition of new skills and novel solutions to advance my research. I was supported by excellent graduate peer support provided by the School of Nursing and Midwifery, where I happily found myself among a community of researchers striving to make meaningful contributions in their chosen fields of research. I am deeply grateful to each of the five hospital recruitment sites for placing their trust in me. Their flexibility and willingness to adapt to changes were crucial in supporting my recruitment efforts.

Theoretically, I was initially unfamiliar with the philosophy underpinning this research, namely pragmatism, which presented a steep learning curve in developing knowledge and proficiency to ensure its applicability in this study. Likewise, using a mixed-methods design was an approach I had not previously used. I read extensively in the early stage of the research process to become familiar with mixed-methods

research, and this heightened awareness consolidated my choice of using a sequential explanatory mixed-methods design in this study. This study design allowed for the use of both quantitative and qualitative approaches, leveraging the strengths of both.

My development as a researcher spanned the course of this research from its inception in 2021 to the present. Engaging in a PhD has been personally transformative, facilitating a diverse range of skills and learning that I will take forward as I progress my career. Skills acquired include deep immersive learning in a mixed-methods research design and integration and analysis of quantitative and qualitative data. Inclusion of a scoping review supported the acquisition of new skills in systematic evidence synthesis. Critical skills have been harnessed to address the research objectives. Embracing reflexivity enhanced my ability to conduct this research ethically, grounded in the philosophy of pragmatism, to address this study's objectives. The learning gained from this PhD has reinforced my commitment to prioritise the voices of those with lived experience and to integrate their unique contribution into the research process. My confidence has flourished as regards decision-making for large-scale projects with multiple stakeholders and has been one of the most pivotal learnings and one that will facilitate future research endeavours.

Integrating strong patient and public involvement from the beginning in this research has taught me a wealth of knowledge. Firstly, involving those with lived experience was both a meaningful and thought-provoking experience, which in turn enhanced the applicability of the research findings. My experience of working side-by-side with patients with IPF was both humbling and thought-provoking and equipped me with skills that will benefit my future work.

Interacting with the respiratory multidisciplinary teams across Ireland for over two years of data collection provided a deep insight into the national landscape of IPF care. Each centre has its own way of supporting and managing its patients, very much dancing to the beat of its own drum, which I came to appreciate as I spent time each week attending the respective respiratory outpatient clinics. Adapting to the nuances that exist among respiratory teams as they work to provide care to patients with IPF became a source of deep learning for me as I watched, observed and listened to the clinical teams. I am forever grateful to have had this opportunity, which was only possible through the generosity of the national respiratory teams.

Participant interviews provided this study with a depth of information relating to the unmet needs, symptom experience, and quality of life of individuals diagnosed with IPF in Ireland. Thoughtful conversations with patients during the interview process often become a space of deeply emotional reflection on life before IPF and after diagnosis. I learned to listen with my ears and my heart as I was invited into the narrative of people's lives, which was both a privilege and an honour. Conducting all aspects of this research from its inception to completion created a space for immersive learning, skill acquisition and reflection, which I hope will significantly advance knowledge in this area.

## **9.6 Conclusion**

Drawing on the integrated findings, this chapter presents recommendations related to policy, health service provision, education and training and future research. These recommendations highlight the complex coordination of care and unmet needs that exist for individuals with IPF, which significantly impact their quality of life. Recommendations were guided by Leveque's healthcare access theoretical framework (2013), recognising the complexity of the healthcare systems that patients with IPF must navigate to address their unmet needs. Integration of the domains of healthcare access (approachability, acceptability, availability/accommodation, affordability and appropriateness), coupled with the five abilities to access healthcare (ability to perceive, seek, reach, pay and engage) provided the backdrop to provide integrated recommendations that reflect the complex interplay that exists within the healthcare system to address patients' unmet needs.

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## Appendices

### Appendix 1 Scoping Review Search Strategy

| Search | Query (Medline (EBSCO) example).                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Records Retrieved |
|--------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| S1     | TI ("Idiopathic pulmonary fibros*" OR "Idiopathic interstitial pneumonia*" OR "Familial Idiopathic Pulmonary Fibrosis*" OR "Usual Interstitial Pneumon*" OR "fibrosing interstitial lung disease" OR "progressive fibrosis" OR "nonspecific interstitial pneumonia" OR "pulmonary fibros*") OR AB ( "Idiopathic pulmonary fibros*" OR "Idiopathic interstitial pneumonia*" OR "Familial Idiopathic Pulmonary Fibrosis*" OR "Usual Interstitial Pneumon*" OR "fibrosing interstitial lung disease" OR "progressive fibrosis" OR "nonspecific interstitial pneumonia" OR "pulmonary fibros*") | 23,354            |
| S2     | (MH "Idiopathic Pulmonary Fibrosis") OR (MH "Idiopathic Interstitial Pneumonias+") OR (MH "Pulmonary Fibrosis+")                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | 26,041            |
| S3     | S1 OR S2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | 35,660            |
| S4     | TI ( (servic* OR need* OR support* OR care* OR caring OR nurs* OR pathway*) N4 (access* OR barrier* OR disparit* OR demand* OR gap* OR unmet* OR lack* OR challenge* OR obstacle* OR limit* OR difficult* OR capacit* OR burden* OR benefit*) ) OR AB ( (servic* OR need* OR support* OR care* OR caring OR nurs* OR pathway*) N4 (access* OR barrier* OR disparit* OR demand* OR gap* OR unmet* OR lack* OR challenge* OR obstacle* OR limit* OR difficult* OR capacit* OR burden* OR benefit*))                                                                                           | 411,640           |
| S5     | (MH "Health Services Needs and Demand+") OR (MH "Health Services Accessibility") OR (MH "Healthcare Disparities")                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | 150,631           |
| S6     | S4 OR S5                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | 516,375           |
| S7     | S3 AND S6                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | 356               |

## Appendix 2 Data Extraction Tool

| Evidence source details and characteristics                       |  |
|-------------------------------------------------------------------|--|
| Author                                                            |  |
| Year                                                              |  |
| Title                                                             |  |
| Country                                                           |  |
| Aims/Purpose                                                      |  |
| Study Population and sample Size                                  |  |
| Concept                                                           |  |
| Context or setting                                                |  |
| Study Design                                                      |  |
| Methodology                                                       |  |
| Unmet Needs Identified (Physical, Psychological, Social or Other) |  |
| Examples of PROMs Used                                            |  |
| Summary of Key Findings                                           |  |
| Limitations                                                       |  |

### Appendix 3 Study Characteristics of Included Studies

| Reference<br>Country (N=52)         | Aim                                                                                                                                                                                                                                                    | Sample<br>(N)         | Participants                                                                     | Setting                                                                                                                                                                                | Age range (mean)                                                                                                    | Methodology                                                    | Summary of key findings                                                                                                                                                                                                                                                                                                                                                                            |
|-------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|----------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1) Akiyama<br>2020<br>Japan         | This study aimed to characterize the practice of pulmonologists regarding palliative care and end-of-life communication for patients with IPF and identify perceived difficulties and barriers to this.                                                | 135<br><br>Multi-site | HCP:<br>Representative sample of pulmonologists from Shizuoka prefecture, Japan. | Pulmonologists working at up to 15 general hospitals in the region.                                                                                                                    | Age range between 20 and 60 with highest percentage (41.5%) in their 30's                                           | Quantitative study utilising self-administered questionnaires. | Findings reported that patients with IPF complained of dyspnoea and cough. However, less morphine was prescribed for IPF than for lung cancer.<br><br>Participants experienced greater difficulty in providing palliative care for IPF patients than for lung cancer patients.<br><br>End of life discussions in patients with IPF were conducted later than the physician-perceived ideal timing. |
| 2) Brereton<br>2020<br>UK & Ireland | The objective of this study was to investigate, within primary care healthcare systems, the time taken from the first primary care physician referral for symptom investigation to ILD specialist centre review and antifibrotic therapy commencement. | 247<br><br>Multi-site | Patients diagnosed with IPF                                                      | Recruitment took place at two specialist ILD clinics in two countries (University Hospital Southampton, Southampton, UK, and Mater Misericordiae University Hospital, Dublin, Ireland) | First group (n=142) mean age 72 mean SD + 8.8 years.<br>Second group (n=41) mean age 73.5 SD + 7.39 SD + 6.6 years. | Quantitative study using electronic case note review.          | Patients reviewed in the ILD clinic within 12 months of primary care referral had a significantly preserved mean forced vital capacity (FVC) (83±22% predicted) compared to those reviewed between 12 and 24 months (75±22%, p=0.036), and >24 months (71±17%, p≤0.001), respectively.                                                                                                             |
| 3) Cove<br>2015<br>UK               | Pilot study to characterise the psychological needs of patients and carers and test the feasibility of a workshop.                                                                                                                                     | 29<br><br>Single site | 13 patients with IPF<br>16 family members                                        | Workshop                                                                                                                                                                               | unknown                                                                                                             | Quantitative questionnaire post workshop attendance            | Preliminary data suggests attendance at a workshop addressing psychological issues is feasible and is perceived to be a positive experience by patients diagnosed with IPF and their families.                                                                                                                                                                                                     |



| Reference Country                                                  | Aim                                                                                                                                                                           | Sample (N)                                                    | Participants                                                       | Setting                                                                                                                                                | Age range (mean)      | Methodology                                                           | Summary of key findings                                                                                                                                                                                                                                                                                         |
|--------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------|--------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|-----------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 4) Dedent<br>2021<br>United States                                 | Assess the geographic differences in mortality and baseline pulmonary function in participants with IPF.                                                                      | 849<br><br>Single site                                        | Patients diagnosed with IPF.                                       | UCSF ILD Clinic                                                                                                                                        | Unknown               | Retrospective cohort study<br>Online data capture system.             | Rural participants have decreased baseline pulmonary function and increased mortality within their first year of presentation to a tertiary care centre compared to suburban participants, independent of individual-level characteristics.                                                                     |
| 5) Johansson<br>2022<br>Canada                                     | To test the hypothesis that greater travel distance to access ILD clinical care would be associated with more severe disease at time of referral and worse clinical outcomes. | 1162<br><br>Multi-site                                        | Patients with fibrotic Interstitial lung disease                   | Canadian Registry for Pulmonary Fibrosis (CARE-PF) which is a multicentre prospective registry of patients from ILD subspecialty clinics across Canada | 49%<br>(Total sample) | Quantitative study<br>Online data capture system using registry data. | Patients with fibrotic ILD with a longer travel distance to their ILD clinic had better prognostic indices at baseline but had a higher risk of death or lung transplant in the total cohort and in patients with connective tissue disease related ILD.                                                        |
| 6) Lancaster<br>2021<br><br>United states, Japan, France, Germany. | To gain physician and patient perspectives on the pathway to care from symptom recognition to diagnosis and disease burden.                                                   | Physicians (n=244)<br>Patients with IPF (n=1249)<br>Muti-site | Healthcare professionals and patients diagnosed with IPF (n = 739) | Adelphi IPF II Disease Specific Programme, with the following countries included France, Germany, Japan and the United States.                         | 68% (total sample)    | Quantitative point-in-time study using an online survey.              | Misdiagnosis and delayed diagnosis were common in this study; examples included a diagnostic delay of 0.8 years in Germany to 2.0 years in Japan after symptom onset was reported. Patients reported low quality of life with only 50% of patient with moderate/severe IPF were satisfied with their treatment. |

| Reference Country                  | Aim                                                                                                                                                                                    | Sample (N)                    | Participants                                                                                 | Setting                                                                                                                                                                                                      | Age range (mean)                                                    | Methodology                                                                                      | Summary of key findings                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|----------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 7) Lamas<br>2011<br>USA            | To examine the association between delayed access to subspecialty care and survival time in Idiopathic Pulmonary Fibrosis.                                                             | 129<br><br>Single centre      | Patients who met American Thoracic Society criteria for idiopathic pulmonary fibrosis        | New York Presbyterian/Columbia University Medical Center (New York, NY)                                                                                                                                      | 76%                                                                 | Prospective cohort study using a questionnaire                                                   | The results of this single-centre prospective study demonstrate that delayed access to a tertiary care centre is associated with a higher rate of death from IPF independent of disease severity.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| 8) Lindell<br>2021<br>USA          | To determine the feasibility, acceptability and efficacy of a nurse-led early palliative care intervention entitled "A Program of SUPPORT", in patients with IPF and their caregivers. | 76 dyads<br><br>Single centre | Patients with IPF (diagnosed in the year before their initial centre visit)<br><br>Caregiver | University of Pittsburgh                                                                                                                                                                                     | Patients intervention group: males, 80%<br>Control group: males 85% | Randomized controlled trial.                                                                     | Efficacy demonstrated a significant improvement in caregiver's knowledge, disease preparedness, and confidence in caring for the patient as well as an improvement in knowledge and advance care planning completion in patient participants.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| 9) Maher<br>2017<br>United Kingdom | To investigate treatment patterns of European patients with IPF to understand antifibrotic prescribing and identify unmet needs in IPF treatment practice.                             | 290<br><br>Multi-site         | Respiratory physicians.                                                                      | The questionnaire was developed by Elma Research, an independent market research agency, on behalf of F. Hoffmann-La Roche Ltd and distributed to physicians from France, Germany, Italy, Spain, and the UK. | Unknown                                                             | Quantitative Study.<br><br>Patient chart review followed by an online questionnaire (35-40 min). | This audit highlights the high proportion of patient's diagnosed with IPF, who do not receive approved antifibrotic treatment. Overall, 54% of patients with IPF did not receive treatment with an approved antifibrotic. Of patients with a confirmed diagnosis, 40% did not receive treatment. The treated population was younger than the untreated population (67 vs 70 years, respectively; $p \leq 0.01$ ), with more frequent multidisciplinary team evaluation (83% vs 57%, respectively; $p \leq 0.01$ ). A higher proportion of untreated patients had forced vital capacity > 80% at diagnosis versus treated patients. Of patients with 'mild' IPF, 71% did not receive an approved antifibrotic versus 41% and 60% of patients with 'moderate' and 'severe' IPF, respectively. |

| Reference Country                                                                                                                                       | Aim                                                                                                                                                                                                                                                                    | Sample (N)                                                                     | Participants                                                                                                                 | Setting                                                                                                                                       | Age range (mean)                | Methodology                                                                            | Summary of key findings                                                                                                                                                                                                                                                                                                                       |
|---------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------|----------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 10) Moor<br>2019<br>Denmark, Ireland, UK, Bulgaria, Czech Republic, Poland, Greece, Italy, Spain, Austria, Belgium, France, Germany and the Netherlands | The aim of the development of the joint expert and patient statement was to highlight the most pressing common unmet needs of patients with PF/IPF. Putting forward recommendations to improve the quality of life and health outcomes throughout the patient journey. | Patients (n=286) and HCP's (n=69)<br><br>Multi-site                            | Patient survey completed by: Patients 79%, Caregivers 21%<br><br>HCP 69: 56 physicians (81%) and 13 specialist nurses (19%). | Online survey distribution by the European Idiopathic Pulmonary Fibrosis and Related Disorders Federation (EU-IPFF) in 14 European countries. | 70 % of the total patient group | Quantitative study using online surveys.                                               | Delays in diagnosis and timely access to interstitial lung disease specialist and pharmacological treatment were identified as important gaps in care.<br><br>Patients and HCPs reported that a greater focus on symptom-centred management, adequate information including trial information and increasing awareness of PF/IPF is required. |
| 11) Moor<br>2021<br>Netherlands                                                                                                                         | The aim of this study was to evaluate the predictive value of the surprise question for 1-year mortality in IPF.                                                                                                                                                       | Questions answered by 140 HCPS in relation to 140 patients.<br><br>Single site | Patients with IPF (n=140)                                                                                                    | A prospective cohort study at the Erasmus Medical Center.                                                                                     | 87% (Total population)          | Quantitative study Prospective cohort study using a paper questionnaire                | The surprise question can accurately predict 1-year mortality in IPF using a multivariable model (OR 3.69; 95% CI 1.24–11.02; $p = 0.019$ ). The C-statistic of the surprise question to predict mortality was 0.75 (95% CI 0.66–0.85).                                                                                                       |
| 12) NCUBE<br>2020<br>New Zealand                                                                                                                        | To create a nurse-led clinic to support, guide and optimise therapy for patients with IPF.                                                                                                                                                                             | Patients with IPF (n=9)<br><br>Single site                                     | Patients diagnosed with IPF.                                                                                                 | Single site nurse led clinic.                                                                                                                 | Unknown                         | Creation of a nurse led clinic: including a quantitative pre/post clinic questionnaire | Needs amongst this small group varied from one patient who was close to end of life and another patient who had just been diagnosed. Patient feedback at initial analysis was positive.                                                                                                                                                       |

| Reference Country                   | Aim                                                                                                                                                                 | Sample (N)                                                                   | Participants                                                 | Setting                                                            | Age range (mean)                                                          | Methodology                                                                         | Summary of key findings                                                                                                                                                                                                                                                              |
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| 13) Personen<br>2018<br>Sweden      | This cohort study was performed to explore potential differences in the care of IPF in two Nordic countries.                                                        | 312<br>Finish registry (n=152)<br>Swedish registry (n=160)<br><br>Multi-site | Finnish IPF Registry (n=152)<br>Swedish IPF registry (n=160) | Two national registries.                                           | Finnish registry. mean age (SD) 74.6 (8.3)<br>Swedish registry 72.5 (8.0) | Quantitative study utilizing two patient registries using online data capture tool. | This study highlighted that there are differences in how patients are treated with antifibrotic drugs in Finland and Sweden.<br><br>To be resident in Sweden was the main determinant for receiving antifibrotic drugs (OR 5.48, 95%CI 2.65-11.33, P< 0.0001).                       |
| 14) Sharp<br>2017<br>United Kingdom | To investigate the current practices around palliative and supportive care and to explore the impact of a supportive care decision aid tool.                        | 73<br><br>Single site                                                        | The decision aid was prospectively assessed with 73 patients | UK ILD centre.                                                     | Pre-tool: 80.9%<br>Deceased: 82.8%<br>After-tool: 78.1%                   | Quantitative study using a data capture tool.                                       | The decision aid tool was completed for 49.3% of patients and resulted in significant increases in documented discussion of referral to palliative care (11.2% vs 53.6%, p<0.01).<br><br>Tool completion led to an increase in referral for palliative care (2.7% vs 16.7%, p<0.01). |
| 15) Swaminathan<br>2022<br>USA      | To identify clinical characteristics and social determinants of health that differentially associate with lung transplant compared with death in patients with IPF. | 955<br><br>Multi-site                                                        | Patients diagnosed with IPF                                  | IPF-PRO Registry (A multi-centre US registry of patients with IPF) | Male 75.5% (total sample)                                                 | Quantitative study evaluating registry data.                                        | For patients on the IPF-PRO Registry, median Zip code, income and access to a lung transplant centre differentially impact the risk of lung transplantation compared with death, irrespective of disease severity measures or other transplant eligibility factors.                  |

| Reference Country                 | Aim                                                                                                                                                       | Sample (N)                                                                                   | Participants                                                                                                                               | Setting                                                                                                                        | Age range (mean)                    | Methodology                                                 | Summary of key findings                                                                                                                                                                                                                                                                      |
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| 16) Turnpenny<br>2015<br>UK       | This study aimed to explore chest clinicians' experiences in delivering care in advanced IPF.                                                             | 57<br><br>Single site                                                                        | Chest consultants (n=17), chest registrars (n=28), physiotherapists (11), and nurse clinician (n=1).                                       | Questionnaires were distributed at a regional respiratory meeting.                                                             | unknown                             | Quantitative study utilising questionnaire.                 | Less than 10% of all respondents felt they had significant training in initiating End-of-Life discussions or palliating symptoms.                                                                                                                                                            |
| 17) Tyas<br>2019<br>UK            | To explore if the introduction of severity criteria improved palliative care provision for patients with idiopathic pulmonary fibrosis.                   | 47<br><br>Single site                                                                        | Patients diagnosed with IPF.                                                                                                               | Clinic setting                                                                                                                 | Unknown                             | Quantitative clinical audit tool.                           | Introducing IPF disease specific markers of severity, following the intervention from a SPCT consultant in 2016, along with having a respiratory consultant with a specialist interest in palliative care, has improved access to palliative care and symptom control for patients with IPF. |
| 18) Van der Sar<br>2021<br>Europe | Aim to evaluate the time to diagnosis of pulmonary fibrosis and identify reasons for delays.                                                              | 273<br><br>Multi-site                                                                        | Patients with a self-reported diagnosis of pulmonary fibrosis.                                                                             | EU-PFF and its member patient organisations in Europe.                                                                         | Unknown                             | Quantitative study utilizing surveys.                       | The time to diagnose pulmonary fibrosis varies widely across Europe. Forty percent of individuals took $\geq 1$ year to receive a final diagnosis. Delays occur at each stage of the diagnostic pathway.                                                                                     |
| 19) Wysham<br>2015<br>Sweden      | To compare end of life care in oxygen-dependent Pulmonary Fibrosis patients compared to patients who died from cancer: A national population-based study. | Total: 57,128 patients with PF 285 & patients with terminal cancer 56,843<br><br>Multi-site. | Patients with pulmonary fibrosis who died from January 1, 2011, through October 14, 2013 & Patients who died from cancer at the same time. | Nationwide Swedish Registries of long-term oxygen (LTOT) and EOL care: Swedevox and Swedish Registry of Palliative Care (SRPC) | PF 61% males<br>Cancer patients 51% | Quantitative study utilising nationwide Swedish registries. | PF patients access fewer palliative care services and experience greater symptom burden at the end of life than patients with terminal cancer.                                                                                                                                               |

| Reference Country                                                        | Aim                                                                                                                                                                 | Sample (N)                                                                                  | Participants                                                                                                                        | Setting                                                                                                                                   | Age range (mean)                      | Methodology                                                             | Summary of key findings                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
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| 20) Weatherald 2017<br>Canada                                            | To describe the practice patterns of Canadian respirologists on the diagnosis and management of IPF and to determine if these patterns reflect current guidelines   | 112 respondents to the 2009 survey<br>107 respondents to the 2013 survey.<br><br>Multi-site | Canadian Thoracic Society (CTS) members who are academic or community physicians, or respirology fellows-in-training were surveyed. | Canadian Thoracic Society (CTS) member email addresses used for survey distribution.                                                      | Unknown                               | Online quantitative surveys.                                            | Practice patterns for diagnosis and treatment of IPF in Canada evolved in concordance with the publication of international guidelines in 2011.<br><br>Access to palliative care, lung transplantation referral, multidisciplinary diagnosis discussion, and specialty IPF clinics were identified as gaps in IPF care in Canada.                                                                                                                                                                                          |
| 21) Maher 2018<br>Canada, France, Germany, Italy, Spain, United Kingdom. | The aim of this study was to investigate the views of patients with IPF and pulmonologists on the diagnosis and management of IPF to understand treatment patterns. | Physician group: (n = 287)<br>Patient group: (n=68)<br><br>Multi-site                       | Survey:<br>Patients with IPF (n=60)<br>Pulmonologists (n=287)<br><br>Interview<br>Patients (n = 68)<br>Pulmonologists (n = 61)      | Patients recruited via physician referrals, patient groups, or market research panels.<br><br>HCPs recruited from market research panels. | 72% (of total sample of patients)     | Mixed method Interview (in person and telephone).<br><br>Online survey. | This study identified several barriers to antifibrotic treatment, principally reflecting the differing views and values of patient and physician were identified in this study suggesting a need for better patient - physician communication about pharmacological therapy for IPF.                                                                                                                                                                                                                                       |
| 22) Sampson 2015<br>UK                                                   | This study addresses the care needs of patients and carers at different stages of the IPF disease trajectory.                                                       | 48<br><br>Multi-site                                                                        | Patients diagnosed with IPF and paired carers.                                                                                      | Two UK specialist interstitial lung disease clinics                                                                                       | Patients: 18 males<br>Carers: 6 males | Cross sectional mixed methods study including interviews.               | Patients diagnosed with IPF have a clear understanding of their prognosis but little understanding of how their disease will progress and how it will be managed. Patients and carers outlined key elements of MDT activity capable of having significant impact on the care experience. They were structured around: focus on clinical encounters; timely identification of changes in health status and functional activity.; understanding of symptoms and medical interventions and coping strategies and carer roles. |

| Reference Country                                                                                 | Aim                                                                                                                                                                     | Sample (N)                                                                                        | Participants                                                 | Setting                                                                                                                                                                                                       | Age range (mean) | Methodology                                                                             | Summary of key findings                                                                                                                                                                                                                                                                                                                     |
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| 23) Tikellis<br>2020<br>Australia                                                                 | Report the experiences of people who participated in the Peer Connect Service and to document the resources required to support such a service.                         | 32<br><br>Multi-site                                                                              | Patients diagnosed with pulmonary fibrosis.                  | The Peer Connect Service managed by LFA, a national organization that provides support to people with a lung disease in Australia.                                                                            | 56%              | Mixed methods study involving qualitative semi-structured interviews with Participants. | Major themes included the value of shared experiences, providing mutual support and the importance of shared personal characteristics (e.g. gender and hobbies) in allowing information and emotional support needs to be met.                                                                                                              |
| 24) Tikellis<br>2022<br>Australia                                                                 | Examine the organization of IPF care across Australia, how it aligns with guidance for best practice, and identified barriers and facilitators to best care.            | 39<br><br>Multi-site                                                                              | Purposive sampling of respiratory Physicians.                | Hospitals and health networks with respiratory medicine services was identified through various sources that include the Australian Institute of Health and Welfare, the TSANZ website and internet searches. | unknown          | Mixed Methods Online questionnaire and semi-structured telephone interviews.            | Approaches to diagnosis, treatment and access to referral services were generally consistent with best practice guidance.<br><br>Barriers related to inadequate staffing, lack of a nurse coordinator, inadequate access to clinical trials and funding models.<br><br>Telehealth technologies were perceived as facilitators to best care. |
| 25) Bonella<br>2016<br>Austria, Belgium, France, Germany, Ireland, Italy, Spain, UK, Netherlands. | The aim of this study was to gather perceptions from European patient advocacy groups regarding inequalities and unmet needs in IPF care, to develop a Patient Charter. | Patient advocacy group members interviewed from 11 PG's (n-12) Working group (n-16).<br>Muti-Site | Healthcare professionals and patient advocacy group members. | 11 Patient advocacy groups                                                                                                                                                                                    | unknown          | Qualitative interviews<br><br>Individual telephone interview.                           | Five key themes were identified, the need for improved diagnosis, treatment access, holistic care, disease awareness and palliative care.                                                                                                                                                                                                   |

| Reference Country                     | Aim                                                                                                                                                                                | Sample (N)                                                                            | Participants                                                                                                                                                                         | Setting                                      | Age range (mean)                              | Methodology                                                                                | Summary of key findings                                                                                                                                                                                                                                                                                                     |
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| 26) Burnett<br>2019<br>Australia      | The aim of this study was to assess the patient experience of modern IPF care.                                                                                                     | 100<br>Registry<br>Multi-site                                                         | Patients diagnosed with IPF.                                                                                                                                                         | The Australian IPF Registry,                 | 61% (total sample)                            | A Qualitative study using semi-structured interviews. (telephone).<br><br>Grounded theory. | Dissatisfaction with information received particularly at the time of diagnosis.<br><br>The burden of travel to specialist centres and costs of treatment were significant.                                                                                                                                                 |
| 27) Cassidy<br>2024<br>Ireland.       | Explore the palliative care and future health and social care planning requirements of individuals and families living with fibrotic interstitial lung disease (F-ILD) in Ireland. | 60 delegates attended with 39 stakeholders participating in discussion<br>Single site | 39 stakeholders participating in discussion: patients (n=12), caregivers (n=13), healthcare and adjunct professionals (n=9), industry representatives (n=4) and clergy member (n=1). | World Café setting.                          | Patients (n=5 male), caregivers (n=6 male)    | World-Café qualitative research approach using a constructivist paradigm.                  | Palliative care is fundamental to the care and treatment of F-ILD's, regardless of disease progression.<br><br>Unmet palliative care needs were identified as psychological and social support, disease education, inclusion of caregivers and practical and legal advice for disease progression and end-of-life planning. |
| 28) Delameillieure<br>2021<br>Belgium | To understand the care trajectory for patients with IPF based on the perspectives of patients and HCPS.                                                                            | 18<br><br>Single site                                                                 | Healthcare professionals (n-9). Patients (n-9)                                                                                                                                       | IPF disease management program at UZ Leuven. | Patient group (67%) and caregiver group (40%) | Qualitative study using interviews.                                                        | Overall findings identified pitfalls and suggestions for improvement covering all elements of the chronic care model (CCM), primarily at the level of the individual patient and the care team.<br>Self-management support.<br>Patient reported outcomes and eHealth tools.                                                 |



| Reference Country                                                                     | Aim                                                                                                                                                                                                                 | Sample (N)                                         | Participants                                                                      | Setting                                                                                                                                                                                                     | Age range (mean)                         | Methodology                                         | Summary of key findings                                                                                                                                                                                                                                                                                                                                                                                                                |
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| 29) Duck<br>2015<br>United Kingdom                                                    | To understand the perceptions, needs and experiences of patients with IPF.                                                                                                                                          | Patients (n=17)<br><br>Single site                 | Patients with confirmed diagnosis of Idiopathic Pulmonary Fibrosis.               | University Hospital of South Manchester Foundation Trust.                                                                                                                                                   | 7 Males                                  | Qualitative study. Semi-Structured Interviews.      | Three main themes were identified: 'Struggling to get a diagnosis'; 'Loss of the life I previously had'; and 'Living with Idiopathic Pulmonary Fibrosis'. Patients reported struggling to get a diagnosis and coping with a life-limiting, rapidly progressive illness with no good treatment and few support structures.                                                                                                              |
| 30) Giot<br>2012<br>Switzerland<br>Germany,<br>France,<br>Italy, Spain<br>and the UK. | Researchers conducted a European survey of diagnosed IPF patients to identify unmet needs in the management of patients diagnosed with IPF and opportunities to improve care.                                       | Patients (n=45)<br>Carers (n=18)<br><br>Multi-site | Patients diagnosed with IPF and in some interview's carers were also interviewed. | European wide survey of patients in Germany, France, Italy, Spain and the UK.                                                                                                                               | Unknown                                  | Qualitative study utilizing structured interviews.  | In 58% of cases, diagnosis was protracted due to dismissal of symptoms and misdiagnosis.<br><br>Patients treated in specialist centres reported better satisfaction with care than those treated by generalists.<br><br>The patients cited negative impacts of IPF on almost all aspects of their lives, which could lead to depression.                                                                                               |
| 31) Kalluri<br>2021<br>Canada                                                         | To explore the perspectives, experiences and needs of patients with IPF, family caregivers, and healthcare professionals on ACP-related experiences to understand and inform a framework for advance care planning. | 20<br><br>Multi-site                               | HCP (N=10)<br>Patients (n=5) and caregivers (n=5).                                | Patients with IPF and family caregivers (PFCs) were recruited through the local Pulmonary Fibrosis Association. HCPs were recruited through email invitation letters to home care (HC) and acute care (AC). | Patients<br>60%<br><br>Caregivers<br>20% | Qualitative study using semi-structured interviews. | Participant perceptions included insufficient information and conversations occur late. Recommendations were to have earlier conversations; have open conversations; provide detailed information; and plan for end-of-life. Professionals related delayed timing to poor end-of-life care and distressing deaths. Acute care professionals perceived lack of clarity of roles and described personal, patient and caregiver distress. |

| Reference Country                                         | Aim                                                                                                                                                | Sample (N)            | Participants                                                                                                                                                                                                                       | Setting                                                                                                      | Age range (mean)                               | Methodology                                                                                 | Summary of key findings                                                                                                                                                                                                                                                                                        |
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| 32) Lindell<br>2017<br>United States                      | Exploration of the perception of palliative care (PC) needs in patients with Idiopathic Pulmonary Fibrosis (IPF) and their family caregivers.      | 13<br><br>Single site | Convenience sample of patients (n=5) and family caregivers (n=5) & family caregivers of decedent IPF patients (n=3).                                                                                                               | The University of Pittsburgh Dorothy P. and Richard P. Simmons Centre for Interstitial Lung Disease at UPMC. | Male patient's 100%                            | Qualitative study of patients and family caregivers using thematic analysis of focus group. | Four themes described 1) frustration with the diagnostic process and education received 2) overwhelming symptom burden, 3) hesitance to engage in advance care planning, and 4) comfort in receiving care from pulmonary speciality centre because of resources.                                               |
| 33) Masfield<br>2019<br>UK<br>Ireland<br>Belgium<br>Italy | The aim of this study was to identify the communication challenges reported by patients and carers across Europe and elicit ideas for improvement. | 58<br><br>Multi-Site  | Focus group participants: five patients and three carers in England; seven patients and four carers in Italy (two focus groups); six patients in Belgium; and twenty-three patients and ten carers in Ireland (five focus groups). | Four national patient organisations in Europe held focus groups:                                             | Unknown                                        | Qualitative focus group study.                                                              | Patients and carers in Europe have unmet communication needs, which could be met by specialist physicians and specialist centres providing more effective information and signposting to support services, including support groups and patient organisations.                                                 |
| 34) Meadows<br>2017<br>USA                                | This study aimed to develop a new IPF patient/provider communication and disease education program.                                                | 16<br><br>Single site | Patients diagnosed with IPF (n=12)<br>Caregivers (n=4).                                                                                                                                                                            | The National Jewish Health (NJH) Interstitial Lung Disease (ILD) program                                     | Patients (n=8 males)<br>Caregivers (n=2 males) | Qualitative focus groups.                                                                   | Patients desired information on improving their own quality of life and caregivers desired information on acquiring knowledge and skills they felt necessary to improve their efficacy as caregivers of a patient with IPF.<br><br>Patient and caregiver directed information should come in multiple formats. |

| Reference Country                                     | Aim                                                                                                                                                                                                                                                                          | Sample (N)             | Participants                                                                                               | Setting                                                                                                                        | Age range (mean)               | Methodology                                                                   | Summary of key findings                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
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| 35) Overgaard<br><br>2016<br><br>Denmark              | The aim of this study was to increase knowledge of life with IPF for patients and family caregivers.                                                                                                                                                                         | 49<br><br>Multi-site.  | Patients (n=25)<br>Family Carers (n=24)                                                                    | Specialist clinics at two University Hospitals                                                                                 | 15 male participants with IPF  | Qualitative descriptive design using in-depth dyadic interviews               | The following six themes were developed: information and disclosure, reactional desynchrony, perpetual vigilance, emotional ambivalence, gradual and tacit role shift, and adapted coping strategies.                                                                                                                                                                                                                                                                                                                                                     |
| 36) Ramadurai<br><br>2018<br><br>USA                  | This study sought to improve understanding of the informational needs of patients and their caregivers.                                                                                                                                                                      | 17<br><br>Single site. | Patients diagnosed with IPF (n=13)<br>Caregivers (n=4)                                                     | Interstitial Lung Disease Programme at National Jewish Health                                                                  | Patients 54%<br>Caregivers 50% | Qualitative study using focus groups.                                         | Patients wanted information on how to live well despite having IPF, practical information on how they could remain active and travel and how they could preserve their quality of life despite living with a life-threatening disease like IPF.<br><br>Caregivers wanted information on the general aspects of IPF.                                                                                                                                                                                                                                       |
| 37) Russell<br><br>2016<br><br>UK<br>Italy<br>Germany | The aim of survey was to probe the impact of IPF on patients' quality of life; the role of healthcare professionals and caregivers; the information needs of both patients and their caregivers; and patients' perceptions of pirfenidone as a new treatment option for IPF. | 45<br><br>Multi-site.  | Multidisciplinary team-confirmed diagnosis of IPF with disease duration >3 months. Patient with IPF (n=45) | Patients were invited to enrol through patient support groups (UK), specialist centres (Italy) or an advocacy group (Germany). | Male: 71%                      | Semi-structured, qualitative, in-depth patient interviews of 1-hour duration. | 87 % of patients reported that diagnosis took >1 year.<br><br>Patients reported that IPF had a significant physical and emotional impact on their quality of life.<br>The beneficial role played by caregivers and interstitial lung disease specialist nurses (where available) was specifically highlighted.<br><br>Information was often of poor quality, out of date, or in English only.<br>Patients' perceptions of pirfenidone were largely positive and associated with 'hope' but were also influenced by the level of side effects experienced. |

| Reference Country                                                   | Aim                                                                                                                                                 | Sample (N)            | Participants                                                                                                                          | Setting                           | Age range (mean)       | Methodology                                 | Summary of key findings                                                                                                                                                                                                                                                                                                                 |
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| 38) Schoenheit<br><br>2011<br><br>Germany, France, Italy, Spain, UK | To gain further insights regarding patients' perspectives on the diagnostic process, disease education, emotional well-being, and quality of life.  | 45<br><br>Multi-site. | Patients (20% from each country) with physician confirmed diagnosis of IPF.<br><br>Caregivers participated in 18 (40%) of interviews. | Germany, France, Italy, Spain, UK | 49 % of patient sample | Qualitative In-depth interview (in person). | The median reported time from initial presentation to confirmed diagnosis of IPF was 1.5 years (range 1 year between initial presentation and a confirmed diagnosis of IPF).<br><br>The most common unmet needs cited by participants were disease education resources, access to centres of excellence, and familial support programs. |
| 39) Bajwah<br><br>2017<br><br>United Kingdom                        | This review presents evidence for the epidemiology and management of the main symptoms of ILD and includes psychological needs and palliative care. | N/A                   | PF-ILD<br>ILD                                                                                                                         | N/A                               | N/A                    | Literature Review.                          | People living with ILD often suffer unmet physical and psychological needs throughout the disease journey.<br><br>Recent recommendations from the National Institute of Clinical Excellence promote the use of a new palliative care needs assessment tool.                                                                             |
| 40) Chaaban<br><br>2021<br><br>USA                                  | Literature review to highlight the palliative care needs of patients with ILD.                                                                      | N/A                   | ILD                                                                                                                                   | N/A                               | N/A                    | Literature Review.                          | Palliative care addresses symptoms in diseases where cure is unlikely or impossible, especially chronic diseases. Palliative care can, and should, be implemented early to addresses goals of patients and caregivers.                                                                                                                  |

| Reference<br>Country                    | Aim                                                                                                                                                                                                                | Sample<br>(N) | Participants | Setting | Age<br>(mean)<br>range | Methodology        | Summary of key findings                                                                                                                                                                                                                                                                                                                                                                                                                            |
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| 41) Kalluri<br>2019<br>Canada           | This review sought to summarize the care pathway from the patient's perspective and identify current gaps in care, education, support and communication among patients with IPF, their caregivers, and care teams. | N/A           | N/A          | N/A     | N/A                    | Literature review. | The ability to assess and control symptoms; develop self-efficacy; access to psychosocial, emotional, and spiritual support; and information on the disease and its course are important unmet needs for both patients with idiopathic pulmonary fibrosis and caregivers. There, is a huge need to support the multidisciplinary work focused on identifying gaps across the patient journey and PREMS and PROMs can be instrumental to this goal. |
| 42) Lee<br>2020<br>Australia            | The supportive care needs of people with pulmonary fibrosis and their caregivers: A systematic review.                                                                                                             | N/A           | N/A          | N/A     | N/A                    | Systematic Review. | A total of 35 studies were included in this review. The most frequently reported needs were in the domain of information/education and psychosocial/emotional needs. An additional domain 'access to care' was identified, this included access to peer support, psychological support, specialist centres and support for families of people with pulmonary fibrosis.                                                                             |
| 43) Robalo-Cordeiro<br>2017<br>Portugal | Manuscript preparation which was the outcome of a multidisciplinary meeting between pulmonology, radiology, and pathology clinicians on the use of antifibrotic agents in IPF.                                     | N/A           | N/A          | N/A     | N/A                    | Review.            | Based on the available data from clinical trials and extension studies, the authors concluded that both pirfenidone and nintedanib have a significant effect on FVC decline.<br><br>Since IPF is a progressive lung disease, early diagnosis and treatment are crucial for slowing functional decline, reducing symptoms, and improving quality of life.                                                                                           |

| Reference Country                                | Aim                                                                                                                                                                 | Sample (N)                                     | Participants                                          | Setting                                                                                                                            | Age range (mean) | Methodology                                   | Summary of key findings                                                                                                                                                                                                    |
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| 44) Van Manen<br><br>2017<br><br>Netherlands     | Literature review to summarise the evidence regarding quality of life for patients with IPF and discusses challenges in the management of this devastating disease. | N/A                                            | N/A                                                   | N/A                                                                                                                                | N/A              | Literature Review.                            | The review summarises the most recent insights into measuring and improving quality of life for patients with IPF.<br><br>The authors propose a new model for continuous care in IPF – the ‘ABCDE’ of IPF care.            |
| 45) EU-IPFF Report<br><br>2020<br><br>UK         | EU-IPFF benchmarking report on access to Idiopathic Pulmonary Fibrosis (IPF) care in Europe                                                                         | 19 patient organisations involved in the study | Patient representatives and healthcare practitioners. | EU-IPFF member organisations and partners were invited to take part. There were 19 patient organisations from 17 EU Member States. | Unknown          | Qualitative study utilising phone interviews. | The Benchmarking Report outlines the current state of IPF care and management in Europe. It identifies best-performing countries along with challenges that require greater political attention and an immediate response. |
| 46) HSE<br><br>2020<br><br>Ireland               | National Framework for the Integrated Care Programme for the Prevention and Management of Chronic Disease in Ireland.                                               | N/A                                            | N/A                                                   | N/A                                                                                                                                | N/A              | HSE National Framework.                       | This report sets out the national framework which will describe an integrated approach to the prevention and management of chronic disease in Ireland over the coming years (2020-2025).                                   |
| 47) Nice guideline<br><br>2017<br>United Kingdom | Idiopathic pulmonary fibrosis in adults: diagnosis and management.                                                                                                  | N/A                                            | N/A                                                   | N/A                                                                                                                                | N/A              | Guideline Document.                           | This guideline contains recommendations on the diagnosis of idiopathic pulmonary fibrosis and delivery of care to people with idiopathic pulmonary fibrosis.                                                               |

| Reference Country                                | Aim                                                                                           | Sample (N) | Participants | Setting | Age range (mean) | Methodology                                  | Summary of key findings                                                                                                                                                                                                                                                                                                                                                       |
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| 48) The Irish Thoracic Society 2018 Ireland      | Irish Thoracic Society Position Statement on the Management of idiopathic pulmonary fibrosis. | N/A        | N/A          | N/A     | N/A              | Position statement.                          | The standards of diagnosis and management of IPF need to be radically improved as outlined in the position statement.<br><br>All patients with IPF should have access to specialist centres and all appropriate treatments without undue delay                                                                                                                                |
| 49) The Irish Thoracic Society 2018 Ireland      | Respiratory Health of the Nation 2018.                                                        | N/A        | N/A          | N/A     | N/A              | Review of Respiratory conditions in Ireland. | Future research direction: Research needs to be focused on people and patients to identify barriers in terms of diagnosis, self-care and access to health services.<br>Research is also needed to focus on quality-of-life outcomes as well as evaluation focused on implementation of interventions.                                                                         |
| 50) Irish Lung Fibrosis Association 2015 Ireland | National Patient Charter for Idiopathic Pulmonary Fibrosis                                    | N/A        | N/A          | N/A     | N/A              | Patient Charter.                             | Six key patient entitlements outlined:<br>Early and accurate diagnosis.<br>Clear information about IPF.<br>Access to appropriate medicines and oxygen therapy.<br>Access to pulmonary rehabilitation and exercise programmes.<br>Early referral to the National Lung Transplant Unit for lung transplant assessment.<br>Access to psychological and palliative care services. |
| 51) Matthews 2018 Ireland                        | Patient charter on dying, death and bereavement in Ireland.                                   | N/A        | N/A          | N/A     | N/A              | Patient Charter.                             | The importance of reforming health and social care systems and wider societal structures to ensure that dying people have access to appropriate care and psychological and spiritual supports is being increasingly recognised.                                                                                                                                               |
| 52) Raghu 2022 United States                     | Idiopathic Pulmonary Fibrosis (an Update) and Progressive Pulmonary Fibrosis in Adults.       | N/A        | N/A          | N/A     | N/A              | Clinical Practice Guidelines.                | Recommendations for future research include the following: optimize strategies for addressing quality of life, including treatment of comorbidities, physical activity, emotional well-being, and palliation of symptoms.                                                                                                                                                     |

## Appendix 4 Ethical Approvals from Research Ethics Committees

### COISTE EITICE UM THAIGHDE CLINICIÚIL Clinical Research Ethics Committee of the Cork Teaching Hospitals

Tel: +353-21-4901901  
Email: [crec@ucc.ie](mailto:crec@ucc.ie)

University College Cork  
Lancaster Hall  
6 Little Hanover Street  
Cork  
Ireland

CREC Review Reference Number: ECM 4 (mm) 11/01/2022  
& ECM 3 (rr) 22/02/2022

Date: 7<sup>th</sup> February 2022

Dr Michael Henry  
Consultant Respiratory Physician  
Cork University Hospital  
Wilton  
Cork

**Study Title: Living beyond a diagnosis of idiopathic pulmonary fibrosis: a mixed method exploration of patient related experience and unmet healthcare needs.**

Dear Dr Henry

The following documents have been approved:

| Document                                        | Date                                                                                    |
|-------------------------------------------------|-----------------------------------------------------------------------------------------|
| Cover Letter                                    | 27 <sup>th</sup> January 2022                                                           |
| Application Form                                | 27 <sup>th</sup> January 2022                                                           |
| Patient Invitation Letter                       | Include "Version 2.0" as a header or footer on this document prior to use               |
| Patient Information Leaflet                     | Change "Version 1.0 dated 01/12/2021" to "Version 2.0 dated January 2022" prior to use. |
| Information Leaflet for Healthcare Professional | Change "Version 1.0 dated 01/12/2021" to "Version 2.0 dated January 2022" prior to use. |
| Healthcare Professional Questionnaire           | Change "Version 1.0 dated 01/11/2021" to "Version 2.0 dated January 2022" prior to use. |

Full approval is now granted to carry out the above study. The date of this letter is the date of authorization of the study.

Please keep a copy of this signed approval letter in your study master file for audit purposes. The study must be carried out in accordance with General Data Protection Regulation and Health Research Regulation 2018/2021.

You should note that ethical approval will lapse if you do not adhere to the following conditions:

1. Submission of an Annual Progress Report/Annual Renewal Survey (due annually from the date of this approval letter). **We would encourage you to keep note of this date as the CREC will not issue a reminder.**
2. Report unexpected adverse events, serious adverse events or any event that may affect ethical acceptability of the study
3. Submit any change to study documentation (minor or major) to CREC for review and approval. Amendments must be submitted on an amendment application form and revised study documents must clearly highlight the changes and contain a new version number and date. Amendments cannot be implemented without written approval from CREC.
4. Notify CREC of discontinuation of the study
5. Submit an End of Trial Declaration Form and Final Study Report/Study Synopsis when the study has been completed.

Yours sincerely



Professor David Kerins  
Chairman  
Clinical Research Ethics Committee  
of the Cork Teaching Hospitals





*Mater Misericordiae*  
*University Hospital*

Sisters of Mercy

Eccles Street, Dublin D07 R2WY, Ireland

Tel: +353 1 8032000

*Ospidéal Ollscoile*

*Mater Misericordiae*

Siúracha na Trócaire

Sráid Eccles, Baile Átha Cliath D07 R2WY, Éire

Web: [www.mater.ie](http://www.mater.ie)



Not for prescription purposes

Dr Katherine O'Reilly  
Consultant Respiratory Physician  
Mater Misericordiae University Hospital  
Eccles Street  
Dublin 7

2<sup>nd</sup> March 2022

Institutional Review Board Reference: 1/378/2285

**RE: Living beyond a diagnosis of Idiopathic Pulmonary Fibrosis. A mixed exploration of patient related experience and unmet healthcare needs**  
**Standard Application Form (Version 1.0, 1<sup>st</sup> December 2021)**  
**Study Protocol (Version 1.0, 1<sup>st</sup> November 2021)**  
**Narrative Summary**  
**Adult Participant Information Leaflet and Consent Form (Version 1.0, 1<sup>st</sup> December 2021)**  
**Invitation Letter**  
**Healthcare Professional Participant Information Leaflet and Consent Form (Version 1.0, 1<sup>st</sup> December 2021)**  
**Patient Interview Guide for the Study**  
**Participant Questionnaire**  
**Healthcare Professional Questionnaire**  
**Idiopathic Pulmonary Fibrosis Study recruitment poster**

Dear Dr. O'Reilly,

The Mater Misericordiae University Hospital and Mater Private Hospital Institutional Review Board (IRB) at its meeting of Wednesday 2<sup>nd</sup> March 2022 discussed the above research study to be carried out at Mater Misericordiae University Hospital (MMUH).

Approval for this research study to proceed at the MMUH is granted.

It is your responsibility to adhere to the approved research protocol and ensure the following:

1. Only Investigators named on the approved IRB application form are involved in the research;
2. All investigators involved with the research only use the approved documents without deviation (unless they have been approved by the IRB);
3. To submit annual reports setting out the progress of the research;
4. To notify the IRB when the research is concluded.

It is your responsibility to comply with your legal obligations under Data Protection Law and the Health Research Regulations. You should consult with the research study site Data Protection Officer on any data protection issues in particular in relation to the sharing of any personal data outside of the MMUH. Detailed GDPR Guidance for research is available on the HRB website: <https://www.hrb.ie/funding/gdpr-guidance-for-researchers/>.

Yours sincerely

Prof. Georgina Flood  
Acting Chairperson  
Institutional Review Board

Cc: Ms. Carita Bramhill, PhD in the School of Nursing and Midwifery, Trinity College Dublin

*Commitment to Excellence*



Carita Bramhill,  
School of Nursing & Midwifery,  
Trinity College Dublin,  
24 D'Olier Street,  
Dublin 2,  
Ireland

21st July 2022

**Ref:** 220601  
**Title of Study:** Living beyond a diagnosis of Idiopathic Pulmonary Fibrosis,  
a mixed method exploration of patient related experience  
and unmet healthcare needs.

Dear Carita,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in June 2022. We are pleased to inform you that the above project has ethical approval to proceed.

This study has been ethically approved. We would advise you to seek review and comments on your DPIA from the DPO if required prior to study commencement'

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

Prof. Jacintha O'Sullivan  
Chairperson  
Faculty Research Ethics Committee



**Tallaght  
University  
Hospital**

Ospidéal  
Ollscoile  
Thamhlachta

An Academic Partner of Trinity College Dublin



## Research Office

Project ID: 0538

Ms carita bramhill,  
Trinity College Dublin

Dr Ruairi Fahy,  
St. James's Hospital

Approval Date: 13 June 2022  
Submission Number: 924

Submission Title: Living beyond a diagnosis of Idiopathic Pulmonary Fibrosis; a mixed method exploration of patient related experience and unmet health care needs.  
Submission Date: 23.May.2022 13:34

Dear Ms bramhill,

On behalf of the Chair and members of the SJH/TUH Joint Research Ethics Committee I wish to inform you that your study has received **FULL APPROVAL**. Your study can now proceed.

The following documents were reviewed and approved:

| Document Type               | File Name                                                             | Date        | Version |
|-----------------------------|-----------------------------------------------------------------------|-------------|---------|
| Insurance Certificate       | TCD Insurance Certificate (Research Activities)                       |             |         |
| Default                     | Revised Appendix One PIL for Interview participants                   | 04.Oct.2021 | 1.0     |
| Survey/Questionnaire        | Patient questionnaire JREC                                            | 01.Nov.2021 | 1.0     |
| Principle Investigator C.V. | Ruairi J Fahy CV March.2021                                           | 01.Nov.2021 | 1.0     |
| Default                     | JREC Additional Documents for submission                              | 01.Nov.2021 | 1.0     |
| Participant Consent Form    | Revised Appendix Five Participant Consent form for optional Interview | 01.Nov.2021 | 1.0     |
| Default                     | Revised Appendix Four Participant Information leaflet Healthcare      | 04.Nov.2021 | 1.0     |

Page 1 of 2

|                                 |                                                               |             |     |
|---------------------------------|---------------------------------------------------------------|-------------|-----|
|                                 | professionals                                                 |             |     |
| Default                         | Revised Appendix Two Participant contact sheet                | 23.Jan.2022 | 1.0 |
| Default                         | Reply to the JREC regarding amendments Jan 2022               | 24.Jan.2022 | 1.0 |
| Participant Information Leaflet | REVISED Appendix Three Version 1 PIL JREC tracked changes (3) | 01.Sep.2022 | 1.0 |
|                                 | 16.5.22                                                       |             |     |

Please note that ethical approval for this study is only active under the following conditions:

1. Applicants must submit an annual report for ongoing projects.
2. Applicants must submit an end of study declaration/end of study report upon completion of the study.
3. All adverse events must be reported to the JREC.
4. All changes (minor and substantial) to documentation/study must be submitted to the JREC using the amendment request form and the changes must be tracked/highlighted clearly. Approval from the JREC is required before implementation of the changes.

It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection regulation (GDPR), Health Research Regulations and the Data Protection Act 2018.

Yours sincerely,

**Dr Sadhbh O'Neill**

**Research Ethics & Clinical Trials Manager,**

**SJH/TUH Joint Research Ethics Committee**

The SJH/TUH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

Clinical Research Ethics Committee  
2<sup>nd</sup> Floor  
Room 2  
HR Building  
Merlin Park Hospital  
Galway.

10<sup>th</sup> March, 2022.

Ms. Carita Bramhill  
School of Nursing & Midwifery  
Trinity College  
24 D'Olier Street  
Dublin 2.

**Ref: C.A. 2787      *Living beyond a diagnosis of Idiopathic Pulmonary Fibrosis, a mixed method exploration of patient related experience and unmet healthcare needs***

Dear Ms. Bramhill,

The Clinical Research Ethics Committee approved and ratified the above submission at it's meeting on Wednesday 9<sup>th</sup> March, 2022.

The date of this letter is the date of authorization of the study.

Please keep a copy of this signed approval letter in your study master file for audit purposes. The study must be carried out in accordance with General Data Protection Regulation and Health Research Regulation 2018.

You should note that ethical approval will lapse if you do not adhere to the following conditions:

1. Submission of an Annual Progress Report/Annual Renewal Survey (due annually from the date of this approval letter). **We would encourage you to keep note of this date as the CREC will not issue a reminder.**
2. Report unexpected adverse events, serious adverse events or any event that may affect ethical acceptability of the study.
3. Submit any change to study documentation (minor or major) to CREC for review and approval. Amendments must be submitted on an amendment application form and

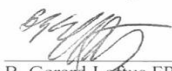
Ospidéal na h-Ollscoile, Gaillimh, UNIVERSITY HOSPITAL GALWAY,  
Galway, Ireland.

revised study documents must clearly highlight the changes and contain a new version number and date. Amendments cannot be implemented without written approval from CREC.

4. Notify CREC of discontinuation of the study
5. Submit an End of Trial Declaration Form and Final Study Report/Study Synopsis when the study has been completed.

*This application has been reviewed from an Ethical perspective. It remains the responsibility of the Principal Investigator to ensure that data processes are compliant with National Data Protection Regulations and local policies.*

Yours sincerely,



B. Gerard Loftus FRCPI, MD  
Emeritus Professor of Paediatrics, NUI, Galway  
Chair, Galway Clinical Research Ethics Committee.

22<sup>nd</sup> July 2022

Dr Eoin Judge  
Connolly Hospital  
Blanchardstown  
Dublin 15

Re: Study CHB 001/22 - Living beyond a diagnosis of Idiopathic Pulmonary Fibrosis:  
A mixed method of exploration of patient related experience and un-met healthcare  
needs.

Dear Eoin,

Thank you for your re-submission documents to Connolly Hospital Research Ethics Committee. Your study has been approved by the Connolly Hospital Research Ethics Committee.

If you require any further information, please do not hesitate to contact me.

Yours sincerely,



---

Dr Eamon Dolan  
Clinical Director, Chairperson, Research Ethics Committee

CC: Carita Bramhill

## Appendix 5 Participant Information Leaflet and Consent Form



**Trinity College Dublin**  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

### Adult Participant Information Leaflet

#### Principal Investigator:

[Redacted]  
[Redacted]  
[Redacted]

#### Consultant co-investigator's name:

Professor Anne-Marie Brady; Professor in the School of Nursing & Midwifery, Trinity College Dublin. Tel: 01-896 3004 E-mail: [abrady4@tcd.ie](mailto:abrady4@tcd.ie)

Ms. Carita Bramhill; PhD Candidate Trinity College Dublin. Tel: 087-784 3705  
E-mail: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie)

#### Data Controller's/joint Controller's Identity:

Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland.

[Redacted]

#### Data Controller's/joint Controller's Contact Details:

Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie) Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy)

#### Date Handlers Identity:

Ms. Carita Bramhill  
Professor Anne-Marie Brady

#### Data Processors:

Ms. Carita Bramhill.  
Professor Anne-Marie Brady.

#### Data Processors Contact Details:

[Bramhilc@tcd.ie](mailto:Bramhilc@tcd.ie) or [abrady4@tcd.ie](mailto:abrady4@tcd.ie)

#### Data Protection Officer's Identity:

Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie)

Before you decide whether you wish to take part, please read this leaflet carefully. If you have any questions about this research study please contact Ms. Carita Bramhill, PhD candidate on email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or phone: 087-784 3705 or you can contact Professor Anne-Marie Brady, email: [abrady4@tcd.ie](mailto:abrady4@tcd.ie) Tel: 01-896 3004.

You are being invited to take part in a research study to be carried out by researchers at Trinity College Dublin and at [REDACTED] University Hospital and the research team named above.

The aim of this study is to understand the needs and quality of life of patients living with Idiopathic Pulmonary Fibrosis. The results of this study will help to inform the development of healthcare and support services that are important for patients with a diagnosis of Idiopathic Pulmonary Fibrosis.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'. You don't have to take part in this study. If you decide not to take part, it won't affect your future medical care.

You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don't have to give us a reason. If you do opt out, rest assured it won't affect the quality of treatment you get in the future. If you wish to opt out, please contact Carita Bramhill, PhD candidate, TCD. Email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or phone: 087-784 3705, who will be able to organise this for you.

## **PART 1 – THE STUDY**

### **Why is this study being done?**

The results of the study will be used to inform health care professionals and policy makers about the needs of patients with Idiopathic Pulmonary Fibrosis and to use this information to develop healthcare services that support patient's needs.

### **Why am I being asked to take part?**

You are being asked to take part in this study as you are a patient with a diagnosis of Idiopathic Pulmonary Fibrosis and are attending the Respiratory Department in the Mater Misericordiae University Hospital. You're experience means you may have important

information about the needs of people living with a diagnosis of Idiopathic Pulmonary Fibrosis. We are also interested to know about your quality of life.

**Do I have to take part? What happens if I say no? Can I withdraw?**

Your participation in this study is entirely voluntary and it is up to you to decide whether or not to take part. If you decide not to take part, you do not have to give us a reason and your decision will not affect your current or future medical care.

If you decide to take part and then change your mind, you can leave the study at any time up to data being anonymised. You do not have to give us a reason.

Should you wish to withdraw from the study, we will destroy any personal data, which could be used to identify you. If you withdraw after the interview data has been anonymised, then we will keep the anonymised data already collected as we need to manage your information in a specific way to ensure the research is accurate and reliable. You may withdraw from the study by contacting Ms. Carita Bramhill, email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie)

### How will the study be carried out?

This study will be conducted between the Mater Misericordiae University Hospital outpatient respiratory Department and Trinity College Dublin, School of Nursing and Midwifery. This study will use patient questionnaires and an optional follow-up patient interview to understand the needs of patients and quality of life of those living with a diagnosis of Idiopathic Pulmonary Fibrosis.

It is anticipated to include a total of 231 patients nationally in the patient questionnaire. The other

The optional follow-up patient interview will be conducted in an agreed location [REDACTED] [REDACTED] Dublin or Trinity College Dublin or in your home or on TCD approved Zoom Technology if you wish at a mutually convenient time. The Interview will last approximately 45 minutes. It is anticipated to include 20 patients in the optional follow up interview.

There will also be a healthcare professional questionnaire to be completed nationally by healthcare workers who work with patients who have been diagnosed with Idiopathic Pulmonary Fibrosis. It is anticipated to include 12 healthcare professionals nationally in the healthcare professional audit.



|                                                        |
|--------------------------------------------------------|
| <b>What will happen to me if I agree to take part?</b> |
|--------------------------------------------------------|

If you agree to take part in the study, you will be asked to sign a consent form. The research team will invite you to complete a questionnaire. The questionnaire will ask questions about your health, well-being and about your needs and quality of life. You will be invited to answer the questions based on your own personal experience. Your answers will be confidential. The questionnaire will take approximately 20 minutes to complete. The questionnaire can be completed at your routine outpatient clinic visit.

There is also the option to post the questionnaire back to the researcher if you do not have time to complete at your out-patient clinic visit. You will also have a third option to complete the questionnaire online via TCD approved Qualtrics software. You will also have the option to agree to be contacted after completing your questionnaire for a follow-up interview.

You will be invited to answer interview questions based on your personal experiences of IPF and how this has affected your quality of life. During the interview, the researcher will ask questions about your healthcare needs including physical needs, emotional needs, and specific needs associated with your diagnosis including access to services specific to your healthcare needs. You can refuse to answer any questions which make you feel uncomfortable, and you can leave the interview at any time.

If you become upset when completing the questionnaire or the interview, please inform the researcher Ms. Carita Bramhill or a member of your clinical team in [REDACTED]

The interview conversation will be audio recorded. The purpose of the recording is to allow the researchers to capture all the information discussed during the interview which is important for them to analyse later. The interview will last approximately 45 minutes.

After the interview, we will use the tape recording to transcribe the interview conversation. Interview transcripts will be pseudonymised and identifying information including your name will be removed from the transcript. Should you wish to review the audio transcript this can be arranged by contacting Carita Bramhill, email [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie).

The recording and transcript of your interview will be stored in a password protected file on a secure, encrypted server in the School of Nursing and Midwifery, Trinity College Dublin to which only members of the research team will have access.

Hard copy consent forms will be stored in a locked filing cabinet in the School of Nursing and Midwifery, Trinity College Dublin and only the research team will have access to these files.

**Are there any benefits to me or others if I take part in the study?**

There are no direct benefits to you from participating in this study. We hope that the information we gain from you and other participants of the study will provide an understanding of the needs and quality of life of patients living with a diagnosis of Idiopathic Pulmonary Fibrosis.

**Are there any risks to me or others if I take part in the study?**

There is a risk that you may be identified by your comments in the optional follow-up interview. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low.

There is a risk that you may become upset by questions in either the questionnaire or the interview. If you become upset or distressed during the interview you may pause the interview at any time. Your wish to continue or not to continue will be respected by the researcher. Please speak to the researcher: Carita Bramhill; email [bramhile@tcd.ie](mailto:bramhile@tcd.ie) or a member of your clinical team or your GP. Alternatively, you can seek support from the Irish Lung Fibrosis Association, by contacting 086-8715264 or email: [info@ilfa.ie](mailto:info@ilfa.ie)

**Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?**

The results of the study will be reported in a study report, medical/scientific journals, student thesis, and disclosed at medical/scientific conferences. No information which reveals your identity will be disclosed. The information collected from this research will be provided to stakeholders and policy makers in respiratory medicine to provide evidence in relation to the care needs and quality of life of patients diagnosed with Idiopathic Pulmonary Fibrosis.

**PART 2 – DATA PROTECTION**

**What information about me (personal data) will be used as part of this study? Will my medical records be accessed?**

We will collect anonymous information from you in the patient questionnaire. The information collected in the questionnaire relates to your needs, access to healthcare supports and quality of life.

If you opt-in to be contacted for the optional follow-up interview after completing the patient questionnaire, we will ask you to provide your contact details (name, email, phone-number) in order to contact you to arrange the interview, time and date. We will not keep your name or contact information once your direct participation in the study has ceased.

The healthcare professional audit will be completely anonymous.

|                                           |
|-------------------------------------------|
| <b>What will happen my personal data?</b> |
|-------------------------------------------|

Only the researchers will access the personal data that you provide as part of this study.

For those who opt-in to the follow up interview your name and contact information will be stored in a password protected database on a secure, encrypted server in the School of Nursing and Midwifery, Trinity College Dublin to which only members of the research team will have access. We will not keep your name or contact information once your direct involvement in the study has ceased. After this time, your personal information will be removed from the participant database.

Interviews conducted on TCD approved Zoom technology will be downloaded and saved to the TCD One Drive and then deleted from Zoom cloud storage. The researcher Carita Bramhill will store all audio files on TCD OneDrive server in a password protected format. Once the transcripts are checked for accuracy, the audio files will be deleted from TCD One Drive. Only the lead Investigator and researcher Carita Bramhill will have access to the audio files.

Your consent form will be retained for seven years after completion of the study. After that time, the principal investigator will ensure all data relating to the study is destroyed.

Every effort will be made to maintain your contact details securely and in compliance with GDPR. There is a low risk of a data breach occurring.

|                                                                        |
|------------------------------------------------------------------------|
| <b>Who will access and use my personal data as part of this study?</b> |
|------------------------------------------------------------------------|

Your data will be treated in a confidential manner. Only members of the study team will have access to your data. Only anonymised data in the case of patient questionnaires and pseudonymised data in the case of follow up interview contact details will leave the clinic and be securely held in Trinity College Dublin. Your data will not be stored or transferred outside the EU.

|                                                                                   |
|-----------------------------------------------------------------------------------|
| <b>Will my personal data be kept confidential? How will my data be kept safe?</b> |
|-----------------------------------------------------------------------------------|

Your privacy is important to us. Your participation in this study will be kept strictly confidential, and we will not be informing anyone that you took part in this study. We take many steps to make sure that we protect your confidentiality and keep your data safe. A data protection impact assessment has been undertaken and identified that the risk of a data breach where your personal data could be accessed by a third party was low.

All members of the research team and transcription team who will have access to your data have received data protection training and have signed a confidentiality agreement as part of their employment.

Only the researchers will have access to the tape recording of the patient Interviews. The interview transcript will be coded and pseudonymised by members of the research team.

The information we have collected in paper format will be stored in a locked filing cabinet in the School of Nursing and Midwifery, Trinity College Dublin. Only members of the research team will have access to these files. Electronic data will be stored in password protected files, on a secure, encrypted server in the School of Nursing and Midwifery, Trinity College Dublin to which only members of the research team will have access to this data.

|                                                          |
|----------------------------------------------------------|
| <b>What is the lawful basis to use my personal data?</b> |
|----------------------------------------------------------|

Your identity will be protected by assigning your interview a code. Information that might identify you will not be used in any presentation or publication arising from this study.

We are carrying out this research in the public interest and will process personal data for scientific research purposes under Articles 6(1)(e) and 9(2)(j) of the General Data Protection Regulations (2018). This means that we will only use your data in the ways needed to conduct the research study.

|                            |
|----------------------------|
| <b>What are my rights?</b> |
|----------------------------|

As a participant of this research study, you have a number of rights under data protection (GDPR) regulations:

You have a right to lodge a complaint about the research study with the Data protection Commissioner. You have a right to request access to your data and a copy of it, unless your request would make it impossible or make it very difficult to conduct the research. You have a right to restrict or object to processing, unless your request would make it impossible or make it very difficult to conduct the research.

You have a right to have any inaccurate information about you corrected or deleted, unless their request would make it impossible or make it very difficult to conduct the research.

You have a right to have your personal data deleted, unless your request would make it impossible or make it very difficult to conduct the research.

You have a right to data portability, meaning you have a right to move your data from one controller to another in a readable format.

There will be no automated decision making or profiling using your data.

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise any of these rights by contacting

Ms Carita Bramhill email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or Prof Anne-Marie Brady email: [abrady4@tcd.ie](mailto:abrady4@tcd.ie)  
Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you have the right to lodge a complaint with the Data Protection Commissioner at: <https://www.dataprotection.ie/>.

### PART 3 – COSTS, FUNDING & APPROVAL

#### Will it cost me anything if I agree to take part?

You may incur expenses to travel to the location of the Interview. Should you incur costs, you will be refunded up to €10 for travel costs within the Dublin region, and up to €30 for travel costs from outside the Dublin region. A receipt for the costs of travel must be provided to the investigators as evidence of travel to ensure refund of travel expenses. Interviews can also be conducted in your home if you would prefer, and this will be accommodated by the researcher Ms. Carita Bramhill.

#### Who is funding this study? Will the results study be used for commercial purposes?

This study is being conducted by staff from the [REDACTED] University Hospital and the School of Nursing and Midwifery Trinity College Dublin named on this information leaflet. This work is supported by a PhD student scholarship (TCD Ussher award).

#### Has this study been approved by a research ethics committee?

This study has received ethical approval from the Joint Research Ethics Committee for [REDACTED] in [2<sup>nd</sup> March 2022] (1/378/2285) and the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin on [21/07/2022] (220601). Reports on

this project will be submitted to the Research Ethics Committee on an annual basis until the project is completed.

#### **PART 4 – FUTURE RESEARCH**

**Will my personal data and/or biological material be used in future studies?**

The data collected for the purpose of this study will not be used in future studies.

#### **PART 5 – FURTHER INFORMATION**

**Where can I get further information?**

If you have any concerns or questions, you can contact:

Ms Carita Bramhill on E: mail: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or phone 087-7843705

#### **Data Handlers:**

Ms. Carita Bramhill, PhD Candidate, School of Nursing and Midwifery, Trinity College Dublin. Tel: 087-7843705; E-mail: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie)

Professor Anne-Marie Brady Professor of Nursing and Midwifery, School of Nursing and Midwifery, Trinity College Dublin. Tel: 018963004; E-mail: [abrady4@tcd.ie](mailto:abrady4@tcd.ie)

#### **Data Protection Officers:**

#### **Data Controller's/joint Controller's Contact Details:**

Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie) Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy)

**What happens if I wish to make a complaint?**

If you wish to make a complaint, you can contact Ms Carita Bramhill, [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or Prof Anne-Marie Brady email: [abrady4@tcd.ie](mailto:abrady4@tcd.ie) who will direct you as appropriate.

**Will I be contacted again?**

You will only be contacted if you agree to the follow up interview. The researcher will contact you to set up the interview at a time and day that is suitable for you.



## CONSENT FORM

**Living beyond a Diagnosis of Idiopathic Pulmonary Fibrosis. A mixed method exploration of patient related experience and unmet healthcare needs.**

There are two sections in this form. Each section has a statement and asks you to indicate if you agree with the statement (yes/no). On the next page, you are asked to sign the form to indicate your consent. The end of this form is for the researchers to complete.

**Please ask any questions you may have when reading each of the statements.**

| Part 1: General                                                                                                                                                                                                                                                             |                              |                             |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|-----------------------------|
| I confirm that I had read and understood the information leaflet for the above study and the information within the leaflet has been fully explained to me.                                                                                                                 | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I have had the opportunity to discuss the study, ask questions about the study and I have received satisfactory answers to all my questions.                                                                                                                                | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I understand that the study is entirely voluntary and, if I decide that I do not want to take part, I can stop taking part in this study at any time up to the interview without giving a reason. I understand that not taking part will not affect my future medical care. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I understand that I will not be paid for taking part in the study                                                                                                                                                                                                           | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| <i>I know how to contact the research team if I need to</i>                                                                                                                                                                                                                 | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I agree to be contacted by researchers by (email/phone) as part of this study.                                                                                                                                                                                              | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I consent to take part in this research study having been fully informed of the risks, benefits and purpose of the study as set out in the information leaflet which I have been provided with.                                                                             | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me.                                                                                          | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| Part 2: Data Protection                                                                                                                                                                                                                                                     |                              |                             |
| I give my consent to give my contact details to be contacted for an optional follow up interview in the next six months                                                                                                                                                     | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I understand the researchers will protect my data using all available resources.                                                                                                                                                                                            | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I give my explicit consent to have my data processed as part of this research study                                                                                                                                                                                         | YES <input type="checkbox"/> | NO <input type="checkbox"/> |

**Participant Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**To be completed by the Principal Investigator or nominee**

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team.

|                                                                                                                                                                                                                          |                              |                             |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|-----------------------------|
| I have fully explained the purpose and nature (including benefits and risks) of this study to the participant in a way that he/she could understand. I have invited him/her to ask questions on any aspect of the study. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I confirm that I have given a copy of the information leaflet and consent form to the participant.                                                                                                                       | YES <input type="checkbox"/> | NO <input type="checkbox"/> |

**Researcher's Name:** \_\_\_\_\_

**Researchers Title and Qualifications:** \_\_\_\_\_

**Researchers Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_



## Appendix 6 Healthcare Professional Information Leaflet and Consent Form



**Trinity College Dublin**

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Healthcare Professional

Participant Information leaflet

**A Mixed-Methods Investigation of Unmet Needs, Symptom Experiences, and Quality of Life in Individuals Living with Idiopathic Pulmonary Fibrosis**

### Principal Investigator:

[Redacted]

[Redacted]

[Redacted]

### Study co-investigator's name:

Professor Anne-Marie Brady; Professor in the School of Nursing & Midwifery, Trinity College Dublin. Tel: 01-896 3004 E-mail: [abrady4@tcd.ie](mailto:abrady4@tcd.ie)

Ms. Carita Bramhill; PhD Candidate Trinity College Dublin.

Tel: 087-784 3705

E-mail: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie)

### Data Controller's/joint Controller's Identity:

Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland.

### Data Controller's/joint Controller's Contact Details:

Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie) Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy)

### Data Handlers Identity:

Ms. Carita Bramhill

Professor Anne-Marie Brady

### Data Protection Officer's Identity:

[dataprotection@tcd.ie](mailto:dataprotection@tcd.ie)

Before you decide whether you wish to take part, please read this leaflet carefully. If you have any questions about this research study, please contact Ms. Carita Bramhill, PhD candidate on Email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or phone: 087-784 3705 or you can contact Professor Anne-Marie Brady, Email: [abrady4@tcd.ie](mailto:abrady4@tcd.ie) Phone 01-8963004.

You are being invited to take part in a research study to be carried out by researchers at Trinity College Dublin. The Mater Misericordiae University Hospital is the recruitment site. However, staff at the Mater Misericordiae University Hospital are not involved in carrying out the study (e.g. conducting interviews, collating data, analysing data, etc.).

The aim of this study is to understand the needs and quality of life of patients living with Idiopathic Pulmonary Fibrosis. It is anticipated that the results of this study will help to inform the development of healthcare and support services that are important for patients with a diagnosis of Idiopathic Pulmonary Fibrosis.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'. You don't have to take part in this study.

You can change your mind about taking part in the study any time you like. If you wish to discuss this further, please contact Ms. Carita Bramhill, PhD candidate, TCD. Email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or phone: 087-784 3705.

## PART 1 – THE STUDY

Why is this study being done?

The results of the study will be used to inform health care professionals and policy makers about the needs of patients diagnosed with Idiopathic Pulmonary Fibrosis and to use this information to develop healthcare services that support patient's needs.

Why am I being asked to take part?

You are being asked to take part in this study as you are involved in the care of people with a diagnosis of Idiopathic Pulmonary Fibrosis.

Do I have to take part? What happens if I say no? Can I withdraw?

Your participation in this study is entirely voluntary and it is up to you to decide whether or not to take part. You do not have to give us a reason if you choose not to participate.

As this is an anonymous audit questionnaire it will not be possible to remove your questionnaire once submitted as it is anonymised. You may discuss this further if you wish by contacting Ms. Carita Bramhill, email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie)

How will the study be carried out?

This study will be conducted between the [REDACTED] respiratory department and Trinity College Dublin, School of Nursing and Midwifery. This study will use an anonymous survey to collect data from healthcare workers. It is anticipated to include a total of 12 healthcare workers nationally in the patient questionnaire.

There will also be information collected from patients living with a diagnosis of IPF and involves a questionnaire and optional follow up interview. It is anticipated to include a total of 231 patients in the patient questionnaire and 20 patients in the optional follow-up interview.

This is a national study involving the following Hospital sites, Mater Misericordiae University Hospital, Connolly Hospital, Galway University Hospital, Cork University Hospital and St. James's Hospital.

What will happen to me if I agree to take part?

If you agree to take part in the study, you will be asked to sign a consent form. You will then be asked to complete a questionnaire. The questionnaire will take approximately 20 minutes to complete using paper and pen format. You will be invited to answer questions based on your personal experience of caring for patients with IPF. Questions relate to service delivery and the needs as identified by you of patients living with a diagnosis of IPF.

Are there any benefits to me or others if I take part in the study?

There are no direct benefits to you from participating in this study. We hope that the information we gain from you and other participants of the study will provide an understanding of the needs and quality of life of patients living with a diagnosis of Idiopathic Pulmonary Fibrosis. This study will make recommendations to inform the oversight, strategic planning and implementation of services for patients with Idiopathic Pulmonary Fibrosis.

Are there any risks to me or others if I take part in the study?

This is a low-risk study. If you have any questions about the study, please contact a member of the study team at any stage. Contact details are provided at the end of this document.

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

The results of the study will be reported in a study report, student thesis, medical/scientific journals and disclosed at medical/scientific conferences. No information which reveals your identity will be disclosed. The information collected from this research will be provided to stakeholders and policy makers in respiratory medicine in order to provide evidence in relation to the care needs and quality of life of patients diagnosed with Idiopathic Pulmonary Fibrosis.

## PART 2 – DATA PROTECTION

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

We will collect anonymous information from you in the healthcare professional questionnaire. The information collected in the questionnaire relates to the needs of patients living with a diagnosis of IPF.

What will happen my personal data?

You will be asked to complete an anonymous questionnaire using paper and pen format. Your response will be anonymous and scanned onto a secure drive on an encrypted TCD computer. All data collected in this study will only be used to achieve the aims of the study and will not be shared with anyone other than members of the research team without your consent. Data collected in this study will be destroyed after seven years by the Principal Investigator.

Who will access and use my personal data as part of this study?

Your data will be treated in a confidential manner. Only members of the study team will have access to your anonymised Questionnaire. Your data will not be stored or transferred outside the EU.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. Data will be kept confidential. Electronic data will be encrypted, password protected and stored on a secure server in Trinity College Dublin. Only researchers in Trinity College Dublin will have access to this folder. As you are not asked to include your name or personal data details in the questionnaire, the data will be anonymous and cannot be linked back to you.

What is the lawful basis to use my personal data?

We are carrying out this research in the public interest and will process personal data for scientific research purposes under Articles 6(1)(e) and 9(2)(j) of the General Data Protection Regulations (2018). This means that we will only use your data in the ways needed to conduct the research study.

#### What are my rights?

As a participant of this research study, you have a number of rights under data protection (GDPR) regulations:

1. You have a right to lodge a complaint about the research study with the Data Protection Commissioner.
2. You have a right to request access to your data and a copy of it unless your request would make it impossible or make it very difficult to conduct the research.
3. You have a right to restrict or object to processing unless your request would make it impossible or make it very difficult to conduct the research.
4. You have a right to have any inaccurate information about you corrected or deleted, unless their request would make it impossible or make it very difficult to conduct the research.
5. You have a right to have your personal data deleted unless your request would make it impossible or make it very difficult to conduct the research.
6. There will be no automated decision making or profiling using your data.

By law you can exercise the following rights in relation to your personal data unless the request would make it impossible or very difficult to conduct the research. You can exercise any of these rights by contacting:

Ms. Carita Bramhill email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or Prof. Anne-Marie Brady email: [abrady4@tcd.ie](mailto:abrady4@tcd.ie)  
Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you have the right to lodge a complaint with the Data Protection Commissioner at: <https://www.dataprotection.ie/>.

#### Part 3: Costs, Funding & Approval

Will it cost me anything if I agree to take part?

It will not cost you anything if you agree to take part in this study.

Who is funding this study? Will the results study be used for commercial purposes?

This study is being conducted by staff from the School of Nursing and Midwifery Trinity College Dublin named on this information leaflet. This work is supported by a PhD student scholarship (TCD Ussher award). Results will not be used for any commercial purposes.

Has this study been approved by a research ethics committee?

This study has received ethical approval from the Research Ethics Committee for Mater Misericordiae University Hospital, Dublin 7, on [2<sup>nd</sup> March 2022] and the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin on [21/07/2022] (220601). Reports on this project will be submitted to the Research Ethics Committee on an annual basis until the project is completed

#### PART 4 – FUTURE RESEARCH

Will my personal data and/or biological material be used in future studies?

The data collected for the purpose of this study will not be used in future studies.

#### PART 5 – FURTHER INFORMATION

Where can I get further information?

If you have any concerns or questions, you can contact:

**Co-Investigator:**

Ms. Carita Bramhill at 087-7843705 Email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie)

**Data Controller:**

Email: [dataprotection@tcd.ie/](mailto:dataprotection@tcd.ie/) Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy)

**Data Handlers:**

Ms. Carita Bramhill, PhD Candidate, School of Nursing and Midwifery, Trinity College Dublin. Tel: 087-7843705; E-mail: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie)

Professor Anne-Marie Brady, Professor of Nursing and Midwifery, School of Nursing and Midwifery, Trinity College Dublin. Tel: 018963004; E-mail: [abrady4@tcd.ie](mailto:abrady4@tcd.ie)

**Data Protection Officers:**

Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie). Website: [www.tcd.ie/privacy](http://www.tcd.ie/privacy).

What happens if I wish to make a complaint?

If you wish to make a complaint, you can contact Ms Carita Bramhill, [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or Prof Anne-Marie Brady email: [abrady4@tcd.ie](mailto:abrady4@tcd.ie) who will direct you as appropriate.

If you wish to make a complaint to someone outside of this research project, please find the relevant contact details below:

Prof. Maria Brennan, Director of Research, School of Nursing and Midwifery, Trinity College Dublin,  
Tel: 01-8963901 E-mail: [brennan@tcd.ie](mailto:brennan@tcd.ie)

|                            |
|----------------------------|
| Will I be contacted again? |
|----------------------------|

You will not be contacted again as part of this research study.



## CONSENT FORM HEALTH CARE PROFESSIONALS

Living beyond a Diagnosis of Idiopathic Pulmonary Fibrosis. A mixed method exploration of patient related experience and unmet healthcare needs.

There are two sections in this form. Each section has a statement and asks you to indicate if you agree with the statement (yes/no). On the next page, you are asked to sign the form to indicate your consent. The end of this form is for the researchers to complete.

**Please ask any questions you may have when reading each of the statements.**

| Part 1: General                                                                                                                                                                                 |                              |                             |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|-----------------------------|
| I confirm that I had read and understood the information leaflet for the above study and the information within the leaflet has been fully explained to me.                                     | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I have had the opportunity to discuss the study, ask questions about the study and I have received satisfactory answers to all my questions.                                                    | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I understand that the study is entirely voluntary and, if I decide that I do not want to take part, I can do so without giving a reason.                                                        | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I understand that I will not be paid for taking part in the study                                                                                                                               | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| <i>I know how to contact the research team if I need to</i>                                                                                                                                     | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I consent to take part in this research study having been fully informed of the risks, benefits and purpose of the study as set out in the information leaflet which I have been provided with. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me.              | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| Part 2: Data Protection                                                                                                                                                                         |                              |                             |
| I understand the researchers will protect my data using all available resources.                                                                                                                | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I give my explicit consent to have my data processed as part of this research study                                                                                                             | YES <input type="checkbox"/> | NO <input type="checkbox"/> |

**Participant Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_



**To be completed by the Principal Investigator or nominee**

|                                                                                                                                                                                                                          |                              |                             |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|-----------------------------|
| I have fully explained the purpose and nature (including benefits and risks) of this study to the participant in a way that he/she could understand. I have invited him/her to ask questions on any aspect of the study. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| I confirm that I have given a copy of the information leaflet and consent form to the participant.                                                                                                                       | YES <input type="checkbox"/> | NO <input type="checkbox"/> |

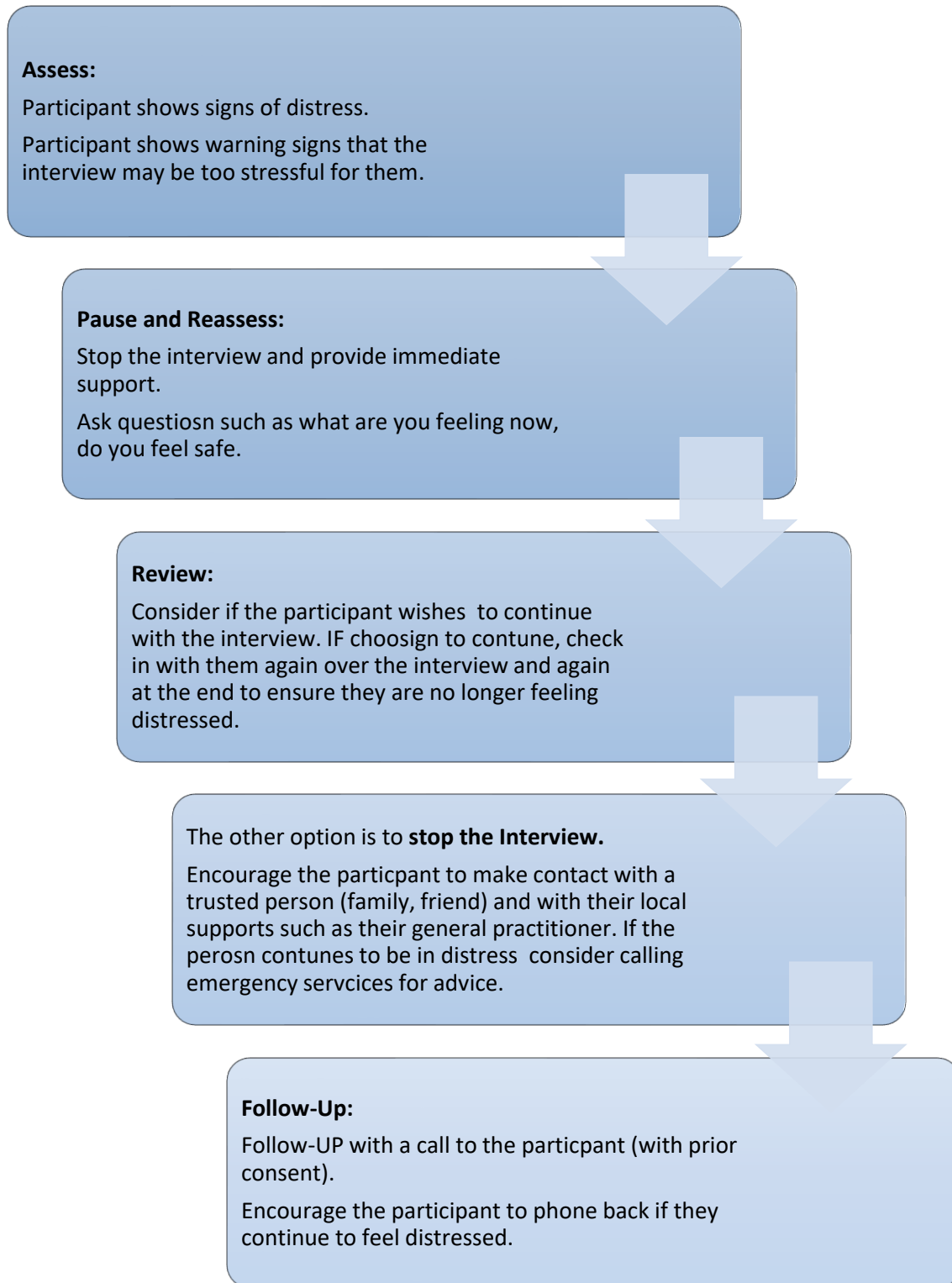
**Researcher's Name:** \_\_\_\_\_

**Researchers Title and Qualifications:** \_\_\_\_\_

**Researchers Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

Research Interview and Distress Protocol, Adapted (Whitney et al., 2022)



## IDIOPATHIC PULMONARY FIBROSIS STUDY

Researchers at Trinity College Dublin invite you to take part in a survey at clinic or online  
about your experience of Idiopathic Pulmonary Fibrosis

The aim of this study is to investigate the unmet needs and quality of life outcomes of patients living with Idiopathic Pulmonary Fibrosis.

This study will be carried out in order to enhance the knowledge base of those working directly with patients with Idiopathic Pulmonary Fibrosis and policy makers to be better informed of the unmet needs of this population.

**How do I take part?**



**You can scan the QR code and go to:**

[www.Qualtracs.ie](http://www.Qualtracs.ie)

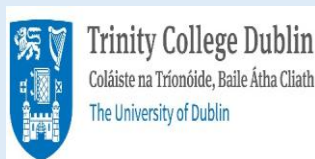
**We would like to hear from you if you:**

Have you been diagnosed with Idiopathic Pulmonary fibrosis  
in the last five years?



For more information about this study, or to take part, please contact:

Carita Bramhill, Email: [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie), Phone: 087-7843705





Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

### Healthcare professional Audit

#### A) General Information

I am a healthcare professional caring for patients with Interstitial lung Disease:

☐ Yes

☐ No

What is your Professional role?

☐ Nurse (including Respiratory Nurse specialist and (Candidate) Advanced Nurse Practitioner (Respiratory))

☐ Doctor (Consultant Respiratory Physician)

#### B) Interactions between Healthcare Professionals and Patients

3) Do you have a specific time allocation at clinic for consultations for new IPF patients?

☐ Yes

☐ No

☐ N/A

4) Do you feel you don't always get to spend as much time as you would like to with IPF patients at the outpatient clinic?

Yes ☐

No ☐

N/A ☐

5) How might services be improved for patients during their routine outpatient clinic visit?

---

---

6) Does your center currently offer both in-person clinic visits and online visits to patients diagnosed with IPF?

☐ Both in person and online (including telephone visits) visits

☐ In person visits only

☐ Online visits only (including telephone visits)

☐ Other, \_\_\_\_\_ please \_\_\_\_\_ specify:  
\_\_\_\_\_  
\_\_\_\_\_

### C) Screening

7) Does your Centre have a multidisciplinary team available to assess and diagnose patients for IPF?

- ☐ Yes  
☐ No  
☐ Not sure  
☐ N/A

8) On average how often do the Multidisciplinary team meet to discuss IPF patient cases?

- ☐ Once a week  
☐ Twice a month  
☐ Once a month  
☐ Every 3 months  
☐ Greater than 3 months  
☐ Other (please specify): \_\_\_\_\_  
☐ Not sure  
☐ N/A

### D) Referral pathway

9) Which of the following professionals are part of the multidisciplinary team in your centre caring for patients with a diagnosis of IPF?

(Please tick all that apply)

- ☐ Consultant respiratory physician or pulmonologist  
☐ Consultant thoracic radiologist  
☐ Consultant pathologist  
☐ Respiratory nurse specialist  
☐ Advanced Nurse practitioner (respiratory)  
☐ Physiotherapist  
☐ Rheumatologist

- ☐ Immunologist
- ☐ Thoracic Surgeon
- ☐ Pharmacist
- ☐ Medical social worker
- ☐ Psychologist/Counsellor
- ☐ Occupational Therapist
- ☐ Nurse
- ☐ Other (please describe)
- 
- 

**10) Are IPF patients involved in developing their personalized treatment plan in your centre?**

- ☐ Yes
- ☐ No
- ☐ Not sure

**11) What support/information options do you offer to patients with IPF at clinic?**

- ☐ Educational written material
- ☐ Educational DVD's
- ☐ Signposting to useful websites
- ☐ Information on ILFA patient support groups
- ☐ Information on IPF patient educational conferences/meetings
- ☐ Telephone support lines
- ☐ Information on pharmacological treatment options within 3 months of diagnosis of IPF
- ☐ None
- ☐ Other:

If you chose **other** please specify:

---



---

**12) Do you refer patients to a specialist centre for lung transplant assessment?**

- ☐ Yes
- ☐ No
- ☐ N/A

**13) Are there any barriers to lung transplant assessment referral?**

- ☐ Yes

☐ No

☐ Not sure

If you answered yes please specify:

---

---

14) Does your center have access to free psychological support such as counselling for IPF patients?

☐ Yes

☐ No

☐ Not sure

☐ N/A

### E) Access to Pharmacological Treatment.

15) Are there any barriers to prescribing anti-fibrotic medications at your centre?

☐ Yes

☐ No

☐ Not sure

16) If you answered yes, please specify what the barriers to prescribing anti-fibrotic medication are:

---

---

17) Is anti-fibrotic medication fully re-imbursed for ALL patients with IPF at your centre?

☐ Yes

☐ No

☐ Not sure

## F) Access to Non-Pharmacological Treatment.

**18) Does your Centre prescribe ambulatory oxygen for IPF patients?**

- ☐ Yes  
☐ No  
☐ Not sure

**19) Is ambulatory oxygen reimbursed?**

- ☐ Yes  
☐ No  
☐ Partially re-imbursed  
☐ Not sure

**20) Do you refer patients with IPF for pulmonary rehabilitation?**

- ☐ Yes  
☐ No  
☐ N/A  
☐ Not sure

**21) Are there any barriers to accessing Pulmonary rehabilitation at your centre?**

- ☐ Yes  
☐ No  
☐ Not sure

If you answer yes, please specify:

---

**22) When do you start palliative care referral for patients with IPF?**

- ☐ Within the first 12 months after a patient has been diagnosed with IPF  
☐ Year 2-3 after a patient has been diagnosed with IPF  
☐ Year 3-5 after a patient has been diagnosed with IPF  
☐ N/A  
☐ Not sure  
☐ Other, please specify: \_\_\_\_\_

**23) Is end of life care discussed by the team with IPF patients and their families?**

- ☐ Yes  
☐ No  
☐ Not sure



## G) Research

24) Do you ask patients with IPF if they would wish take part in clinical trials?

- ☐ Yes
- ☐ No
- ☐ Not sure
- ☐ N/A

25) Does your center participate in clinical trials related to IPF?

- ☐ Yes
- ☐ No
- ☐ Not sure
- ☐ N/A

## H) General recommendations:

Please share your suggestions for improving the patient's experience of the IPF journey:

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---

## Appendix 10 IPF Survey Approval for use of Phase One and Two Instruments



Medicine, Biomedical Sciences, Health and Social Care Sciences

15 April 2021

Cranmer Terrace  
London SW17 0RE  
Switchboard  
+44 (0)20 8672 9944  
[www.sgul.ac.uk](http://www.sgul.ac.uk)

### To Whom It May Concern:

This is to confirm that St George's, University of London (St George's Hospital Medical School) has given permission for Carita Bramhill, University College Dublin to use the SGRQ-I in a study to explore quality of life and unmet healthcare needs for patients living with an IPF diagnosis in Ireland.

**Professor Paul Jones, PhD FRCP**  
**Professor of Respiratory Medicine**

P.W. Jones, PhD FRCP  
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## **Permission to use the Lung Information Needs Questionnaire (LINQ)**

### **Email from Professor Michael Hyland**

Wed, 4 May 2022, 10:20

Carita Bramhill has the permission of Rupert Jones and Michael Hyland to use the Lung Information Needs Questionnaire for any purpose. This questionnaire has been made open access by the authors. Permission from the authors is not needed for the use of this questionnaire.

Regards,

Michael Hyland

## IPF PROM Permissions



Russell, Anne-Marie <A.Russell4@exeter.ac.uk>

Tue, 9 Nov 2021,  
11:52

Dear Carita

As the developer of the IPF-PROM – a patient reported outcome measure validated for use in IPF populations I write to confirm that I grant permissions for use in your study:

Living Beyond a Diagnosis of Idiopathic Pulmonary Fibrosis; A mixed method study to explore gaps in care and unmet healthcare needs.

Best Wishes

Anne-Marie

Dr. Anne-Marie Russell

Senior Lecturer

University of Exeter

Medical School | College of Medicine and Health | St Lukes' Campus | South cloisters | Exeter  
EX1 2LU

## EU-PFF Sociodemographic Questionnaire

Dear Carita,

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED].

On use of the questionnaire, I am the person who would grant permission so I hereby permit it on behalf of the EU-IPFF. [REDACTED]

[REDACTED]  
[REDACTED]  
[REDACTED]

Warmest Regards,

Liam Galvin,

Secretary,

EU-IPFF.

## Appendix 11 IPF Survey



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

Your experience of living with Idiopathic Pulmonary Fibrosis (IPF) Survey

**We thank you in advance for your time and effort in completing this survey**



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

Your experience of living with Idiopathic Pulmonary Fibrosis (IPF) Survey

**We thank you in advance for your time and effort in completing this survey**

This questionnaire is designed to help us learn more about how Idiopathic Pulmonary Fibrosis affects your life. The information and the answers you give will be treated with the utmost confidentiality. There are no right or wrong answers. Please read each item and place a tick (✓) in the box that best matches your experience.

The survey will take approximately 20 minutes to complete, and the answers are confidential.

If you have any questions about the questionnaire or study, please do not hesitate to contact me, the researcher Ms. Carita Bramhill by email [bramhilc@tcd.ie](mailto:bramhilc@tcd.ie) or phone on 087-7842705.

### How to Fill in the Questionnaire

Many of the questions will ask you to select **one option** and can be answered by placing a tick (✓) in the box next to the answer.

1) An example of a tick box response:

#### MOBILITY

- ☐ I have no problems in walking about
- ☐ I have slight problems in walking about
- ☒ I have moderate problems in walking about
- ☐ I have severe problems in walking about
- ☐ I am unable to walk about

**This answer represents someone who has moderate problems with walking.**

2) Some questions ask you to fill in your answer in blank boxes for example

**What year were you born?**

1962

**A) Section One:**

**This section asks questions about you**

**1A) What year were you born?**

|  |  |  |  |
|--|--|--|--|
|  |  |  |  |
|--|--|--|--|

**2A) How long ago did you receive your Idiopathic Pulmonary Fibrosis (IPF) diagnosis**

**(Tick (✓) one box only)**

- ☐ 1-2 years ago
- ☐ 2-3 years ago
- ☐ 3-4 years ago
- ☐ 4-5 years ago
- ☐ More than 5 years ago
- ☐ I don't know when I was diagnosed

**3A) What gender do you identify with? (Tick (✓) one box only)**

- ☐ Male
- ☐ Female
- ☐ Prefer to self-describe

**4A) Do you have: (Tick (✓) one box only)**

- ☐ Private Health Insurance.
- ☐ Medical card.
- ☐ Both a medical card & private health insurance.

☐ Neither a medical card or private health insurance.

**5A) Do you live in an urban or rural area? (Tick (✓) one box only)**

☐ Urban

☐ Rural

**6A) Do you live more than 20 km from the hospital you attend for your IPF treatment?  
(Tick (✓) one box only)**

**7A) What  
type of  
hospital  
do you  
attend  
for your  
treatment?**

☐ Yes

☐ No

**(Tick (✓) one box only)**

|         |                          |                                      |
|---------|--------------------------|--------------------------------------|
| Public  | <input type="checkbox"/> | Hospital                             |
| Private | <input type="checkbox"/> | Hospital                             |
| Both    | <input type="checkbox"/> | public hospital and private hospital |
| Don't   | <input type="checkbox"/> | know                                 |

**8A) What if any of the following conditions do you have? (Tick (✓) one box only)**

**Select all that apply**

- ☐ Heart disease.
- ☐ Gastro oesophageal reflux (GER).
- ☐ Arthritis.
- ☐ Asthma or other chronic chest problems **not including your IPF.**
- ☐ Alzheimer disease or dementia.
- ☐ Obstructive sleep apnoea.
- ☐ Pulmonary hypertension.



☐

Other Please specify:

**Information about your IPF? (Tick (✓) one box only)**

9A) Are you currently taking a medicine called **pirfenidone** for your lung condition?

☐ Yes ☐ No ☐ Not sure

10A) If no, were you treated with **pirfenidone** medication for your lung condition in the past?

☐ Yes ☐ No ☐ Not sure

11A) Are you currently taking a medicine called **nintedanib** for your lung condition?

☐ Yes ☐ No ☐ Not sure

12A) If no, were you treated with **nintedanib** medication in the past?

☐ Yes ☐ No ☐ Not sure

13A) If you are taking either **pirfenidone or nintedanib**, how long have you been taking this medication for? **(Tick (✓) one only)**

- ☐ Less than 6 months?
- ☐ 6-12 months?
- ☐ 1-2 years?
- ☐ More than 2 years?

14A) Has your Doctor prescribed any form of **oxygen therapy** for you?

Yes ☐ No ☐

**If NO please skip to next question 18**

15A) Is the cost of **portable oxygen** paid for by your health insurance? **(Tick (✓) one only)**

- ☐ Yes, fully paid
- ☐ Yes, in part
- ☐ No
- ☐ Not applicable

16A) Is the cost of **home oxygen paid for by your health insurance?** (Tick (✓) one box only)

- ☐ Yes, fully paid
- ☐ Yes, in part
- ☐ No
- ☐ Not applicable

17A) Which of the following best describes your ability to access portable oxygen and/or home oxygen?

(**TICK** all that apply).

- ☐ No problem accessing oxygen
- ☐ High cost
- ☐ No availability of portable liquid oxygen
- ☐ No availability of portable oxygen concentrators
- ☐ Oxygen therapy was not prescribed
- ☐ Other

Please specify) \_\_\_\_\_

#### Access to Multi-Disciplinary Care

18A) Do you have access to any of the following healthcare professional and or services to support you?

(please **tick** ALL that **APPLY**)

- ☐ Dietician.
- ☐ Physiotherapist.
- ☐ Pulmonary (lung) rehabilitation/exercise programme?

☐ Palliative care support?

☐ Psychologist/Counsellor?

☐ Specialist Respiratory (Lung) Nurse.

☐ Occupational Therapist

☐ Irish lung Fibrosis Association national patient support organisation.

☐ Have you attended a virtual class hosted by ILFA? (Tick if your answer is yes)

19A) Have you attended a virtual clinic for your appointment in the last three months?

☐ Yes ☐ No

20 A) If you answered yes, to QUESTION 19A) which of the following would you prefer?

☐ In person outpatient clinic visit.

☐ A mix of both online/phone consultation and in person outpatient clinic?

☐ All virtual (online/phone) clinics?

### Research

21A) Are you aware of any ongoing clinical trials/research medicine study in Idiopathic Pulmonary Fibrosis? **(Tick (✓) one box only)**

☐ Yes

☐ No

☐ Not sure

22A) Were you ever asked to be involved in a clinical trial/research medicine study in Idiopathic Pulmonary Fibrosis? **(Tick (✓) one box only)**

☐ Yes

☐ No

☐ Not sure

23A) What was the last employment/work you held? (please specify)

24A) Are their other family members who have also had a diagnosis of IPF?

☐

Yes

☐

No

☐

Not sure

Please

specify:

---

### Part 1

**Questions about how much chest trouble you currently have. Please tick (✓) in one box for each question.**

|                  |                            |            |
|------------------|----------------------------|------------|
| Almost every day | Only with chest infections | Not at all |
|------------------|----------------------------|------------|

26B). I cough:

27B). I bring up phlegm (sputum):

28B). I have shortness of breath:

29B). I have attacks of wheezing:

30B) In a typical week how many attacks of chest trouble do you have? **Please tick (✓) one:**

☐

More than 1 attack

☐

No attacks

31B). In a typical week how often do you have good days? **Please tick (✓) one:**

☐

None

☐

A few days

☐

Every day is a good day

**Section 1:**

32B) If you have ever had paid employment:

Please tick (✓) one:

- ☐ My lung condition interferes or made me stop work
- ☐ My lung problem does not affect my job

33B) **Section 2: Questions about what activities usually make you feel breathless.**

**Please tick (✓) in each box that applies to you these days.**

Please tick (✓) in *each box* that applies to you *these days*:

|                               | True                     | False                    |
|-------------------------------|--------------------------|--------------------------|
| Getting washed or dressed     | <input type="checkbox"/> | <input type="checkbox"/> |
| Walking around the home       | <input type="checkbox"/> | <input type="checkbox"/> |
| Walking outside on the level  | <input type="checkbox"/> | <input type="checkbox"/> |
| Walking up a flight of stairs | <input type="checkbox"/> | <input type="checkbox"/> |
| Playing sports or games       | <input type="checkbox"/> | <input type="checkbox"/> |

**34B) Section 3: Some more questions about your cough and breathlessness. Please tick in each box that applies to you these days.**

Please tick (✓) in *each box* that applies to you *these days*:

|                                         | True                     | False                    |
|-----------------------------------------|--------------------------|--------------------------|
| My cough hurts                          | <input type="checkbox"/> | <input type="checkbox"/> |
| My cough makes me tired                 | <input type="checkbox"/> | <input type="checkbox"/> |
| I am breathless when I talk             | <input type="checkbox"/> | <input type="checkbox"/> |
| I am breathless when I bend over        | <input type="checkbox"/> | <input type="checkbox"/> |
| My cough or breathing disturbs my sleep | <input type="checkbox"/> | <input type="checkbox"/> |
| I get exhausted easily                  | <input type="checkbox"/> | <input type="checkbox"/> |

**35B) Section 4: Questions about other effects that your chest trouble may have on you. Please tick in each box that applies to you these days.**

Please tick (✓) in *each box* that applies to you *these days*:

True    False

|                                                                    |                          |                          |
|--------------------------------------------------------------------|--------------------------|--------------------------|
| My cough or breathing is embarrassing in public                    | <input type="checkbox"/> | <input type="checkbox"/> |
| My chest trouble is a nuisance to my family, friends or neighbours | <input type="checkbox"/> | <input type="checkbox"/> |
| I get afraid or panic when I cannot get my breath                  | <input type="checkbox"/> | <input type="checkbox"/> |
| I feel that I am not in control of my chest problem                | <input type="checkbox"/> | <input type="checkbox"/> |
| Exercise is not safe for me                                        | <input type="checkbox"/> | <input type="checkbox"/> |
| Everything seems too much of an effort                             | <input type="checkbox"/> | <input type="checkbox"/> |

**36B) Section 5: These are questions about how your activities might be affected by your breathing. Please tick in each box which you think applies to you because of your breathing**

|                                                                                                                                                                 |                          |                          |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|--------------------------|
|                                                                                                                                                                 | True                     | False                    |
| Jobs such as housework take a long time, or I have to stop for rests                                                                                            | <input type="checkbox"/> | <input type="checkbox"/> |
| If I walk up one flight of stairs, I have to go slowly or stop                                                                                                  | <input type="checkbox"/> | <input type="checkbox"/> |
| If I hurry or walk fast, I have to stop or slow down                                                                                                            | <input type="checkbox"/> | <input type="checkbox"/> |
| My breathing makes it difficult to do things such as walk up hills, carrying things up stairs, light gardening such as weeding, dance, play bowls or play golf. | <input type="checkbox"/> | <input type="checkbox"/> |
| My breathing makes it difficult to do things such as very heavy manual work, run, cycle, swim fast or play competitive sports                                   | <input type="checkbox"/> | <input type="checkbox"/> |

**37B) Section 6: We would like to know how your chest usually affects your daily life. Please tick in each box that applies to you because of your chest trouble**

|                                                 |                          |                          |
|-------------------------------------------------|--------------------------|--------------------------|
|                                                 | True                     | False                    |
| I cannot play sports or games                   | <input type="checkbox"/> | <input type="checkbox"/> |
| I cannot go out of the house to do the shopping | <input type="checkbox"/> | <input type="checkbox"/> |
| I cannot do housework                           | <input type="checkbox"/> | <input type="checkbox"/> |
|                                                 | <input type="checkbox"/> | <input type="checkbox"/> |

I cannot move far from my bed or chair

**38B) Now, would you tick in the box (one only) which you think best describes how your chest affects you:**

|                                                         | True                     | False                    |
|---------------------------------------------------------|--------------------------|--------------------------|
| It does not stop me doing anything I would like to do   | <input type="checkbox"/> | <input type="checkbox"/> |
| It stops me doing one or two things I would like to do  | <input type="checkbox"/> | <input type="checkbox"/> |
| It stops me doing most of the things I would like to do | <input type="checkbox"/> | <input type="checkbox"/> |
| It stops me doing everything I would like to do         | <input type="checkbox"/> | <input type="checkbox"/> |

### Section 3: Your IPF diagnosis and your Health

Please read each question and place a tick (✓) in the box that best describes your experience in the last two weeks.

If you do not experience an item please place a tick (✓) in the 'none' box

39C) During the last two weeks how would you rate your overall quality of life?

| Excellent                | Good                     | Fair                     | Poor                     | Very poor                |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

During the last **two weeks**, because of IPF, how much of the time have you....

40C) Felt that your breathing difficulties have affected your quality of life?

| None of the time         | A little of the time     | Most of the time         | All of the time          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

41C) Felt that your fear of getting out of breath has limited your daily life?

| None of the time         | A little of the time     | Most of the time         | All of the time          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

42C) Stopped doing any of the things you like to do?

| None of the time         | A little of the time     | Most of the time         | All of the time          |
|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**During the last two weeks, because of IPF, how much of the time have you.....**

43C) Felt breathless with gentle physical exercise?

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

44C) Stopped for breath when walking at your own pace on the flat level (e.g. along the pavement, at home

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

45C) Felt breathless with any of your everyday activities

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

**During the last two weeks, because of IPF, how much of the time have you .....**

46C) Felt that IPF has brought worry to your life?

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

47C) Felt frightened about the future?

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

48C) Has it been difficult to manage the uncertainty of living with IPF?

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

**During the last two weeks, because of IPF, how much of the time have you?**



49C) Felt lethargic?

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

50C) Felt too tired to do your usual everyday activities?

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

51C) Felt frustrated by being too tired to do the things you like to do?

None of the time

A little of the time

Most of the time

All of the time

☐☐☐☐

**D) Section 4: The next section asks questions about your**

52D) Do you know the name of your lung disease?

☐

YES

☐

NO

53D) Has a doctor or nurse told you how this disease affects your lungs?

☐

YES

☐

NO

54D) Has a doctor or nurse told you what is likely to happen in the future?

☐

YES

☐

NO

55) Which of the following statements best describes what will happen to you over the next few years? **TICK ONE ONLY**

☐ Now that my disease is being treated, I will probably get better

☐ Now that my disease is being treated, I will probably stay the same

☐ I will get worse

☐ I have no idea

56D) Has a doctor or nurse explained the reason for taking your medicines?

☐ YES

☐ NO

57D) Do you try to take your medicines exactly as you have been instructed by a doctor or nurse?

☐ YES

☐ NO

58D) Are you satisfied with the information doctors and nurses have given you about your inhalers or medicines? **TICK ONE ONLY**

☐ I understand everything I need to know

☐ I understand what I have been told but I would like to know more

☐ I am slightly confused about my medicines

☐ I am very confused about my medicines

59D) What sentence best describes what you have been told to do if your breathing gets worse? **TICK ONE ONLY**

☐ I have been told what to do and the doctor/nurse has given me written instructions

☐ I have been told but it is not written on paper

☐ I haven't been told but I know what to do

☐ I haven't been told and I don't know what to do

60D) Have you been told when you should call an ambulance if your breathing worsens? **TICK ONE ONLY**

☐ I have been told what to do and the doctor/nurse has given me written instructions

☐ I have been told but it isn't written on paper

☐ I haven't been told but I know what to do

☐ I haven't been told and I am uncertain when an ambulance should be called

61D) What best describes you? **TICK ONE ONLY**

☐ Never smoked (go to question 58D)

☐ Used to smoke but don't now (go to question 58D)

☐ Still smoking (go to question 56D)

62D) Has a doctor or nurse advised you to give up smoking?

☐ YES

☐ NO

63D) Has a doctor or nurse offered to help you to give up smoking (e.g., given you nicotine gum or patches or referral to a Smoking Cessation clinic)?

☐ YES

☐ NO

64D) Have you been told by a doctor or nurse to try to do some physical activity (e.g., walking, brisk walking and other forms of exercise)?

☐ YES

☐ NO

65D) Has a doctor or nurse told you how much physical activity (e.g., walking, brisk walking and other forms of exercise) you should do

☐ Yes and I know what to do

☐ Yes but I am unsure what to do

☐ Yes but I am unable to do it

☐ No

66D) How much physical activity do you do?

☐ As little as possible

☐ I make an effort

☐ I push myself as much as I can

67D) What have doctors or nurses told you about your diet or eating? (please tick all that apply)

☐ Eat several small meals per day "(eg., 6 small meals per day instead of 3 large ones)"

☐ Lose or gain weight

☐ Eat healthy food

☐ Nothing

68D) Have you any questions or comments about your lung disease? "If so, write them in the space below"

---

---

69D) Do you live on your own?

☐ YES

☐ NO

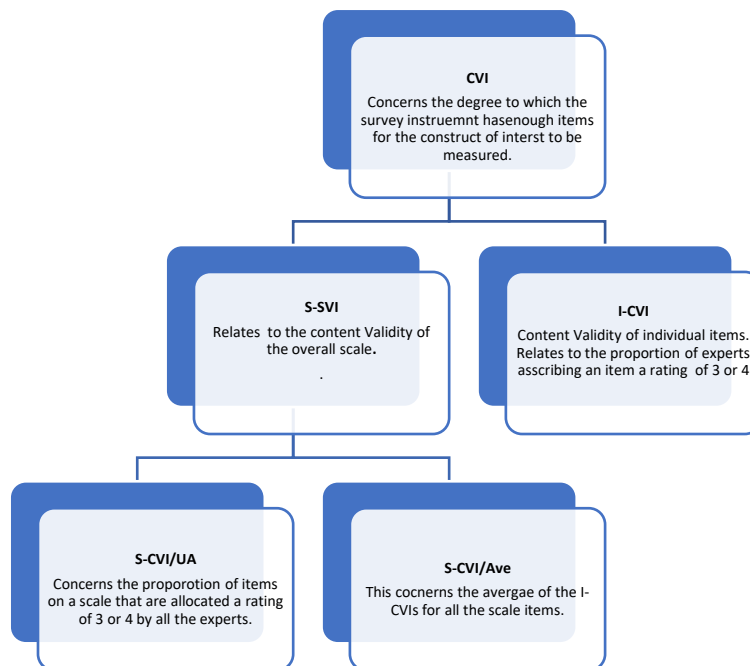
## Appendix 12 Content Validity Guide

Expert reviewers were asked to score items from the IPF survey for clarity, relevance and representativeness using a pre-defined rating scale. The expert panel members were also asked to provide any additional feedback they wished to give about the IPF Survey and were provided with an opportunity to do so.

|                                                                                    |                                                                                                                                                                                                                         |
|------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Clarity: Experts were asked to rate each item on a scale of 1-4.</b>            | <b>1 = Item is not clear</b><br><b>2 = Item needs major revisions to be clear.</b><br><b>3 = Item needs minor revisions to be clear.</b><br><b>4 = Item is clear.</b>                                                   |
| <b>Relevance: Experts were asked to rate each item on a scale of 1-4.</b>          | 1 = Item is not necessary in the survey.<br>2 = Item provides some information but is not essential in the survey.<br>3 = Item is not useful but is deemed essential.<br>4 = Item is deemed essential.                  |
| <b>Representativeness: Experts were asked to rate each item on a scale of 1-4.</b> | 1= Item is deemed not representative.<br>2 = Item required major revisions to be deemed not representative.<br>3 = Item required minor revisions to be deemed not representative.<br>4 = Item is deemed representative. |

## Appendix 13 Content Validity Index Scoring Manual

The Content Validity index was adapted from Polit & Beck, 2006 p. 493



|                                                  |                                                                                                                                                  |
|--------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Scoring</b>                                   | <b>Rating of 3 or 4 on a scale = 1</b><br><b>Rating of 1 or 2 on a scale = 0</b>                                                                 |
| <b>Experts in Agreement</b>                      | Sum up the rating provided by the experts for each item.                                                                                         |
| <b>Universal Agreement (UA)</b>                  | Score '1' assigned to the item that achieved 100% expert agreement.<br><br>Score '0' assigned to an item if it failed to achieve 100% agreement. |
| <b>Item-Level Content Validity Index (I-CVI)</b> | To find the I-CVI you must take the value for the experts in agreement and divide by the number of experts.                                      |



**Trinity College Dublin**  
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The University of Dublin

### **Introduction and Welcome**

- Welcome participant.
- Provide information about the aim of the study.
- Provide the information leaflet and provide answers to any questions the participant has.
- Confirm consent and record in notes.
- Test recording equipment.
- Ensure the participant is comfortable prior to commencing interview questions.

### **Topic Guide:**

**Main Interview question:** Can you tell me about your experience of living with IPF?

### **Prompts include:**

### **Probing questions:**

- Please tell me more about ...
- What does that mean to you?
- Could you please give me an example?
- Could you describe what that was like for you?

### **Focused Interview Question:**

**1. Diagnosis: Can you tell me about your journey to an IPF diagnosis?**

**Consider:** Symptoms, general practitioner visits, investigations.

**2. Living with IPF: How does having IPF affect you day to day?**

**Consider:** Relationship with family and friends, social connections.

**3: Information source: Can you tell me about the types of information you believe should be provided to those with IPF?**

**Consider:** Information needs at diagnosis, treatment information, medication side effects, information about supports and services, public awareness about IPF.

**4. Health care system? Can you describe how the hospital could support you with your IPF?**

**Consider:** Access to multidisciplinary team, symptom management, access to the hospital building, waiting times.

**4. Healthcare supports: What kinds of supports do you think are required for those with IPF?**

**Consider:** Care coordination between the hospital and the general practitioner, affordable care, geographical location, peer support, emotional support needs, physical support needs, financial supports, transport needs.

**5. Decision Making: Can you tell me about how involved you feel in your care?**

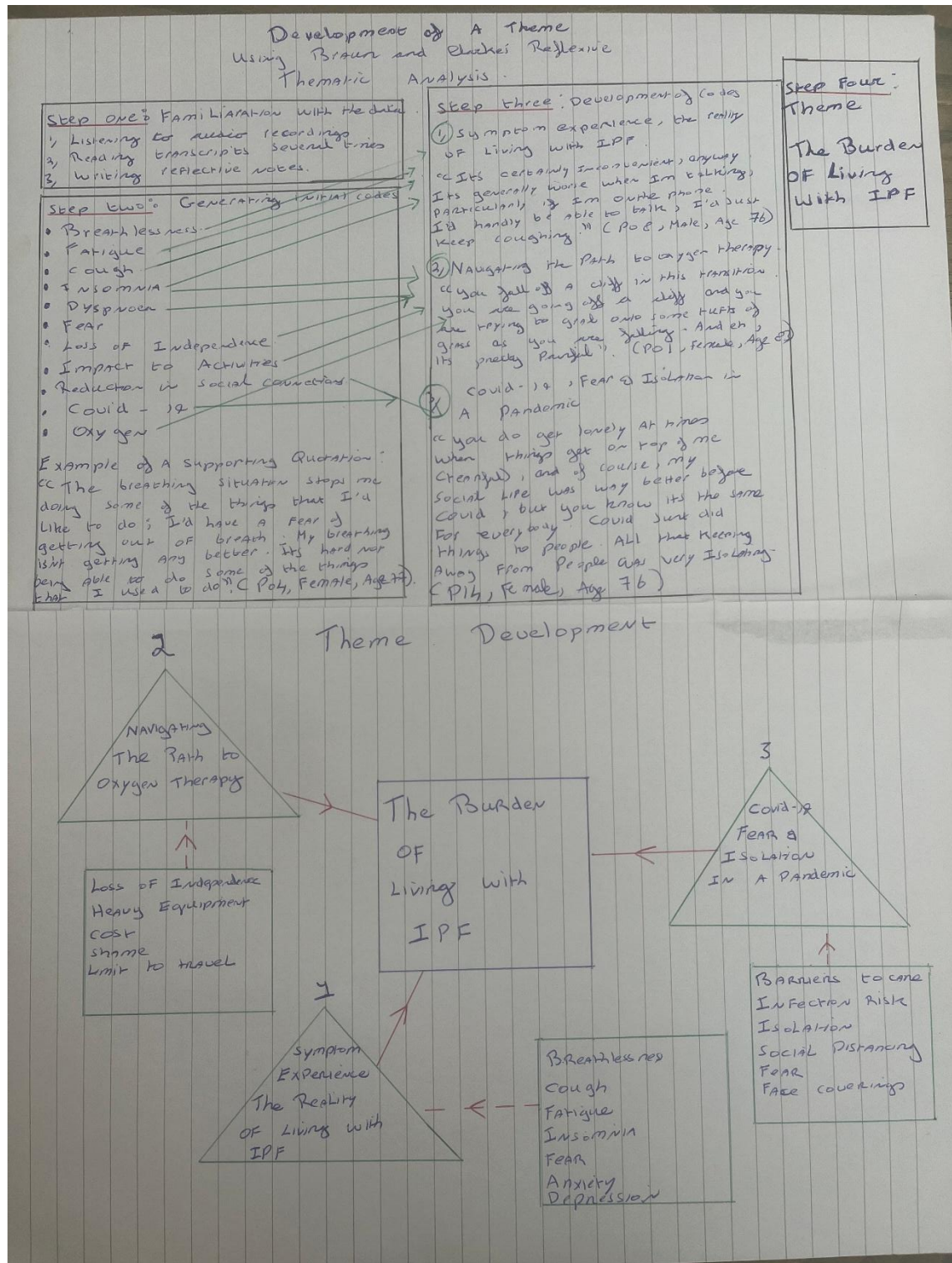
**Consider:** Care planning, self- management support,

**6. Close out Question**

- Is there anything else that might be relevant that we have not talked about today that you would like to add?

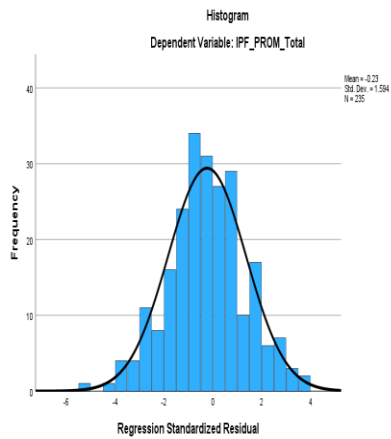
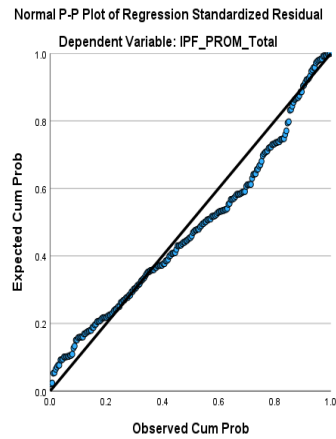


## Appendix 15 Coding for the Qualitative Theme



## Appendix 16 Assumptions of Inferential Statistical Tests

### 1) Backward Stepwise Regression for Variables predicting Quality of Life using the IPF-PROM (Histogram and PP-Plot)



### 1) Backward Stepwise Regression for Variables predicting Quality of Life using the SGRQ-I (Histogram and PP-Plot)

