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Living with or beyond lymphoma: A mixed methods investigation of the unmet needs of cancer survivors.

A dissertation submitted to the University of Dublin

for the Degree of Doctor of Philosophy

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Declaration

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Synopsis

Title: Living with or beyond lymphoma: A mixed methods investigation of the unmet needs of cancer survivors.

Background: The burden of cancer is set to increase thanks to success in treatment modalities and increasingly ageing populations. This is especially true for lymphoma survivors, the largest cohort of haematological malignancies. Mortality and survival rates for lymphoma continue to improve, with rising numbers of survivors living with or after a diagnosis of lymphoma after five years. However, lymphoma remains understudied in survivorship literature. Identifying problems during survivorship is a pressing concern for service planning and healthcare delivery. The anticipated surge in the annual numbers of new lymphoma cases over the coming decades is a clear signal for sound investment in survivorship planning and care delivery. Identifying the unmet needs of this cohort is required to ensure that future developments are tailored to meet their specific needs.

Aim: This study was designed to comprehensively investigate the unmet needs of adult lymphoma survivors. This research aims to examine the unmet needs of lymphoma survivors to guide policy, practice, and future research to be responsive in addressing these needs. This thesis strives to overcome previous research limitations and evaluate the unmet needs of lymphoma survivors using a quantitative survey and qualitative interviews to give a voice to the lymphoma survivor.

Methodology and Methods: A pragmatic mixed methods sequential explanatory design was considered the most suitable approach to address the research objectives and facilitate a comprehensive understanding of the magnitude and context of the unmet needs experienced by lymphoma survivors. In phase one, a purposive sample of adult lymphoma survivors (*N*=205) was recruited from five hospitals and via supplementary online recruitment through cancer support centres in Ireland. Lymphoma survivors one to five years post-diagnosis completed a survey including the Short-Form Survivor Unmet Needs Survey, Functional Assessment of Cancer Therapy-Lymphoma Survey and EuroQol Five-Dimension Five-Level Survey. The survey asked participants about their unmet needs and quality of life outcomes as a result of lymphoma. In phase two, a subsample of 14 survey participants participated in semi-structured interviews to add context to the unmet needs and experiences of lymphoma survivors in Ireland.

Findings: Integrated findings revealed a significant and directional link between unmet needs and quality of life outcomes among lymphoma survivors. Canonical correlational analysis confirmed that an increase in lymphoma survivors' quality of life is associated with a statistically significant decrease in unmet needs (p=<.001). Descriptive statistics showed the most prevalent concerns for higher unmet needs and lower quality of life were feeling tired (73-83%) and coping with a bad memory or focus (67-69%). Lymphoma survivors' narratives provided an enhanced understanding of the consequences on daily living, like the inconvenience of forgetfulness, a lack of focus, or sleep as a treatment for tiredness. Both datasets also

reported nausea and vomiting, weight changes and night sweats, but interview data provided further insights not captured by the phase one survey, such as reproductive health concerns and chemotherapy-induced alopecia. Inferential statistics found that being female, younger, not having private health insurance or having a more recent lymphoma diagnosis (one to three years post-diagnosis versus three to five years post-diagnosis) were consistent factors that contributed to higher unmet needs (all p=<.05). Interview data explained the experience of younger survivors who highlighted challenges associated with their life stage, including delayed diagnosis and perceived setbacks in achievements or milestones.

This study underscores the importance of timely cancer care, as evidenced by both survey responses and qualitative accounts. Unaddressed unmet physical needs contributed to unmet emotional and psychological needs due to the uncertainty experienced by survivors in seeking support to address their health concerns. This emphasises the importance of time in the journey to diagnosis and getting appointments or test results. After addressing physical health concerns, psychological and emotional needs were the dominant problems which survivors prioritised. Qualitative data revealed the importance of social support in coping with lymphoma-related challenges, although survivors often hesitated to burden their families. This study also highlights concerns about compromised immunity, infection risk, and feelings of isolation, particularly exacerbated by the pandemic. Financial problems, work-related challenges, and difficulties navigating the healthcare system further contributed to survivors' distress. While statistical analysis suggests a link between lower emotional and physical well-being and higher unmet informational needs (p=<.05), qualitative accounts shed light on insufficient awareness and understanding of lymphoma, leading to gaps in information provision and fragmented care.

Discussion and Conclusion: Lymphoma survivors have a myriad of interconnecting unmet needs which have reciprocal relationships with quality of life outcomes; better quality of life corresponds with fewer unmet needs. This study found consistent factors associated with higher unmet needs, yet a lymphoma diagnosis's heterogeneous and individualised nature requires thoughtful consideration. The problematic and often prolonged time to diagnosis spotlighted this inherent heterogeneity in the presentation of lymphoma, which can inadvertently be interpreted as not serious or cancer-related, and that this is a cancer that crosses the lifespan, which has inherent challenges relating to the nuances of life stage. These findings emphasise the importance of tailored support for lymphoma survivors. Yet, barriers to effective survivorship cancer care in identifying how it should be set up, who should monitor, assess, and develop the service and what specific patient groups will benefit from it. This research has identified that lymphoma would benefit from survivorship support in the period one to five years post-diagnosis, as participants reported dealing with a myriad of unmet needs across various domains. A tailored approach to follow-up care will likely be required, supported by an integrated care model for cancer care services. Effectively, cancer centres require access to a range of expertise, resources and joined-up thinking to meet the needs of the survivor population. The appropriate investment and infrastructure are fundamental to their efficiency and effectiveness. Multiple aspects of lymphoma survivorship would benefit from an enhanced understanding and awareness of lymphoma as a type of cancer. Clinically, survivorship services would benefit from the routine assessment of survivors' unmet needs; this study has provided evidence for

selecting valid and reliable instruments for use in this cohort. Future research should endeavour to address the sparse focus on lymphoma-specific research and disparate reporting, which to date has impaired the emphasis of this group at policy level with direct implications to practice and allocation of resources.

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Publications and Presentations Relating to this Thesis

Peer-Reviewed Publications

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Peer-Reviewed Published Abstracts

Boland, V., Drury, A., Brady. A-M. A qualitative exploration of lymphoma survivors' unmet need. Oct 2023. *Annals of Oncology.* European Medical Society for Oncology Congress, Madrid, Spain. https://doi.org/10.1016/j.annonc.2023.10.113

Boland, V., Drury, A., Brady, A-M. Uncovering the needs of lymphoma survivors: A cross-sectional study. Oct 2023. *Annals of Oncology.* European Medical Society for Oncology Congress, Madrid, Spain. https://doi.org/10.1016/j.annonc.2023.10.112

Boland, V., Drury, A., Brady, A-M. Mapping the measurement of lymphoma survivors' unmet needs and quality of life outcomes: evidence for a lymphoma-specific questionnaire. Sept 2022. *Annals of Oncology*. European Medical Society for Oncology Congress, Paris, France. *https://doi.org/10.1016/j.annonc.2022.07.381*

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Chapter 1 Background

1.1 Introduction

This thesis consists of a comprehensive investigation of the unmet needs of adult lymphoma survivors. This chapter introduces the fundamental concepts relevant to this body of work, facilitating an understanding of the context of this topic. Haematological malignancies and lymphoma are outlined to understand the population of interest. The primary outcome of interest for this thesis is unmet needs; this is defined and outlined in the context of this work. Next, the secondary outcome of interest, quality of life, is defined. The landscape of cancer survivorship and lymphoma is described nationally and internationally. An overview of the purpose of this study, as well as its aims and objectives, is then presented. The chapter concludes with an overview of the thesis's structure.

1.2 The Growing Burden of Cancer

Nationally, there has been an over fifty per cent increase in the number of cancer survivors compared to one decade ago (National Cancer Registry Ireland, 2022). Internationally, the burden of cancer is set to increase by more than sixty per cent by 2040, from 18.1 million new cases in 2018 to a predicted 29.4 million cases in the year 2040 (Ferlay et al., 2019). Cancer is a leading cause of death worldwide (Chhikara & Parang, 2023; Sung et al., 2021); however, the exponential advancements in cancer survival rates over the past fifty years have seen a departure from cancer being synonymous with a death sentence (Ferlay et al., 2019). Therefore, attention has been placed on attempts to reduce treatment toxicity with continued success in prognosis and survival, as many cancer survivors face problems secondary to their cancer, which neither standard cancer services nor society are well prepared to handle (Moser & Meunier, 2014).

Significant consequences have been evident from the physical, emotional, and financial strain on individuals and families burdened by cancer around the globe; prolonged disability, morbidity and premature mortality have a substantial economic impact (Ferlay et al., 2019; Prager et al., 2018). So, cancer is a significant public health issue; its burden is projected to spiral given the substantially increasing number of cancer survivors exerting significant strain on populations and health systems at all income levels (Ferlay et al., 2019; Luengo-Fernandez et al., 2013; Prager et al., 2018; Yabroff et al., 2011). Therefore, understanding how to guide the development of cancer services to address survivorship problems is urgently required in order to reduce the burden for the individual with cancer and the related dependency on health services to address late adverse effects (Ferlay et al., 2019). However, prioritising and addressing the growing cancer burden is challenging as cancer is not a single disease but a multitude of diseases (Prager et al., 2018). This thesis is focused on the survivorship experiences of individuals living with and beyond lymphoma, a cancer of the blood or haematological system.

1.3 Haematological Malignancies

Haematological malignancies are a diverse group of cancers which develop in the blood-forming tissue due to a disruption of normal haematopoietic function and encompass three broad categories: leukaemia, lymphoma, and myeloma (Brown & Cutler, 2012; Karagianni et al., 2021; Smith et al., 2011). Historically, the cancers have been grouped according to the location of the cancer involvement: leukaemia is a cancer of the blood, lymphoma of the lymph nodes and myeloma of the bone marrow (National Institute for Clinical Excellence, 2003a). Modern classifications refer to cell populations of the originating cancer: myeloid cells form in the blood system, and lymphoid cells are within the lymphatic system. Combined, haematological malignancies rank as the fourth most common cancer globally; this equates to 6.6% of all cancer incidence, with 1,278,362 new cases and 711,840 new deaths in 2020 (Sung et al., 2021).

Distinct from solid tumours, not only regarding their pathology, but haematological malignancies also differ in their potential disease presentation, progression, and outcome (Immanuel et al., 2019; Smith et al., 2011; Swerdlow et al., 2016). Some haematological malignancies can be highly acute, requiring urgent and aggressive treatment; others can be indolent, and slow growing, their detection is often by chance. Treatment is often complex and debilitating, with an increased risk of immune suppression and infection and the requirement of bone marrow support with transfusions (Brown & Cutler, 2012; Pallister & Watson, 2010). Typical symptoms vary by cancer type, with lumps commonly associated with lymphoma, bone fractures, pain, and kidney problems characteristic of myeloma and increased susceptibility to infection and fatigue commonly observed in leukaemia.

Haematological malignancies vary by gender, age, region, and the country's economic situation (Hemminki et al., 2022; Zhang et al., 2023). Haematological malignancies are a diverse group of diseases affecting people of all ages but with the highest incidence among older adults (Smith et al., 2011). Health systems internationally are challenged by a rapidly ageing population, which contributes to an increase in the burden of haematological malignancies (Chihara et al., 2014; Keykhaei et al., 2021; Kocarnik et al., 2022). These distinguishing factors contribute to a unique experience from diagnosis to chronic effects, with the potential for different needs to arise from these phases. A limitation of heterogeneous cancer investigations concerns that one size does not fit all. Furthermore, given the diversity among haematological malignancies, mixed haematological samples may be inappropriate, with subtype-specific research providing evidence for future care that is more responsive to survivors' needs (Chen et al., 2020; Esser et al., 2018; Oberoi et al., 2017b). Therefore, the largest cohort of haematological malignancies, lymphoma, is the focus of this thesis.

1.4 Lymphoma

Lymphomas are a heterogeneous group of cancers which involve the malignant proliferation of lymphocytes in the lymphatic system (Boffetta, 2011; Brown & Cutler, 2012; Sapkota & Shaikh, 2022). Lymphoma has two main types: Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL). Over ninety subtypes of lymphoma extend this heterogeneity (Swerdlow et al., 2016). This is reflected on a smaller

scale by cancer registries in Ireland and worldwide, where HL and NHL are grouped further by common subtypes (e.g., diffuse large B-cell lymphoma, follicular lymphoma) (Chihara et al., 2014; National Cancer Registry Ireland, 2022). The distinct types of lymphoma vary in morphology, immunophenotype, clinical features, and their response to therapy (Campo et al., 2011; Swerdlow et al., 2016). Lymphoma encompasses a variety of clinical presentations ranging from an indolent course to an aggressive disease (Nixon et al., 2020); the affected lymphatic system is so widespread that the malignancy can involve lymphatic tissue, bone marrow or extranodal sites (e.g., stomach, spleen central nervous system or skin) (Lewis et al., 2020; Paes et al., 2010; Swerdlow et al., 2016). In other words, lymphoma can affect any organ in the body (Lewis et al., 2020). Classification is based upon complex criteria from the World Health Organisation. Significant advancements in understanding lymphoid malignancies were acknowledged by the most recent publication in 2016 (Swerdlow et al., 2008; Swerdlow et al., 2016); the authors highlight the evolving landscape of lymphoma and its classification*: "Each time there is a new edition, it is simply a snapshot frozen at one moment in time. Along with accompanying technological advances and more basic investigations, each edition becomes outdated the moment it is published"* (Swerdlow & Cook, 2020, p. 73).

1.4.1 The Incidence of Lymphoma

The population of lymphoma survivors is substantially increasing thanks to the success of multimodal treatments (Frick et al., 2018). In 2020, there were an estimated 628,000 new lymphoma cases, with 283,000 new deaths worldwide (Sung et al., 2021). Ranked the eighth most common cancer in Europe and the world but the sixth most common in many countries such as Ireland, the United Kingdom, the United States and Australia (Baker & Mansfield, 2023; National Cancer Registry Ireland, 2022; Sung et al., 2021). Many survivors of lymphoma will have extended life expectancies but will live with treatment-related side effects (i.e., cardiac issues or secondary malignancies) (Adams et al., 2007; Epelbaum, 2000; Swerdlow et al., 2016; Van Leeuwen & Ng, 2016); resulting in increased risk for unmet needs and compromised quality of life. Continuous improvement in long-term survival for HL has resulted in 5-year survival currently around 90% in Western Europe (De Angelis et al., 2015), 89% in the United States (National Cancer Institute, 2023a), and 93% in Ireland (National Cancer Registry Ireland, 2022). The 5-year survival rate is lower for NHL at 74% in the United States and 71% in Ireland (National Cancer Institute, 2023b; National Cancer Registry Ireland, 2022). Gains in survival have been especially rapid for lymphoma because of improvements in treatment protocols, including the development of targeted therapies (Siegel et al., 2023).

About 207,000 cancer patients or former cancer patients were alive in Ireland at the end of 2020, affecting 1 in 24 of the Irish population, with NHL being the fifth most common cancer among survivors (4% of cases) (National Cancer Registry Ireland, 2022). The number of lymphoma survivors is projected to increase significantly by 160% in Ireland from 2015 to 2045, reflecting worldwide trends (National Cancer Registry of Ireland 2018). The incidence of NHL increases with age, while HL is more common in younger patients, resulting in significant differences in patient needs and quality of life outcomes (Rosenthal, 2022). Globally, 1 in 110 men and 1 in 161 women developed NHL over a lifetime, with a probability of 1 in 849 males and

1 in 1491 women developing HL (Fitzmaurice et al., 2017). Therefore, this is a heterogeneous cancer that is increasing in incidence, raising demand for complex healthcare services, specialisation, and technological innovation. Therefore, improved survival rates highlight the importance of recognising and managing the survivorship period for this group.

1.4.2 Non-Hodgkin Lymphoma

NHL is a general category of lymphoma which contains over sixty subtypes (Swerdlow et al. 2016). NHL accounts for approximately 90% of lymphoma incidence and can be divided into two groups, histologically indolent and aggressive forms, based on the prognosis of the disease (Harris et al., 1994; Sapkota & Shaikh, 2022). These aggressive (fast-growing or high-grade) lymphomas are treated with curative intent, while indolent (slow-growing or low-grade) lymphomas are managed as long-term chronic conditions. Their indolent nature means that many chemotherapy regimens will be ineffective until the disease transforms into a more aggressive form (Brown & Cutler, 2012); over two-thirds of patients present with painless peripheral lymphadenopathy. However, presentations are individual and vary according to the site involved, with extranodal site involvement occurring in nearly twenty-five per cent of NHL cases (Lewis et al., 2020). Indolent lymphomas, like follicular lymphoma, may present with waxing and waning lymphadenopathy for many years (Sapkota & Shaikh, 2022). The more aggressive forms or high-grade lymphomas can present as oncologic emergencies, such as structural compression from the enlarged tumour, creating respiratory and cardiology complications (Barré et al., 2022; Higdon et al., 2018). In the developed world, the most common NHL subtypes are diffuse large B cell lymphoma (DLBCL) (about 30%) and follicular lymphoma (around 20%). Aggressive lymphomas, like diffuse large B cell lymphoma or Burkitt lymphoma, can result in mortality within a few weeks without treatment (Sapkota & Shaikh, 2022). Systematic symptoms of fever, unexplained weight loss and night sweats occur in a subset of patients with more advanced disease (Lewis et al., 2020). Therefore, NHL is considered much less predictable than HL, which is outlined next.

1.4.3 Hodgkin Lymphoma

HL is an uncommon malignancy accounting for approximately 10% of all lymphomas. However, it is among the most common cancers affecting younger adults (Howlader et al., 2016; Miller et al., 2020; Swerdlow & Cook, 2020). A second peak of incidence is seen in patients over fifty-five years of age, with the pathophysiology of HL increasingly being understood (Eichenauer et al., 2014; Momotow et al., 2021). Hodgkin lymphoma is less common than NHL, with an average of 113 cases of Hodgkin Lymphoma per year in Ireland (National Cancer Registry Ireland, 2022). Most cases (95%) of HL are classified as classic Hodgkin lymphoma, which is distinguished from nodular lymphocyte-predominant HL (NLPHL) and is diagnosed in five per cent of all HL cases (Eichenauer et al., 2014). Supra-diaphragmatic presentation of HL is common (Gobbi et al., 2013). Systematic symptoms are present in approximately 35% of cases. The history of HL treatment represents remarkable success in progressing from a previously incurable disease to a cancer with an excellent prognosis and progressively declining mortality (Momotow et al., 2021). New treatment

concepts and regimens have continued to improve survivorship, with a necessary shift in focus required to the documented effects of HL and its treatment on the individual living with and beyond cancer. The rising incidence rate of 2% for HL per annum could lead to the burden doubling in two decades; this provides evidence and impetus for future research and strategies focused on the rising burden of HL now and in the coming decades (Singh et al., 2022). Although the number of HL cases and deaths is low relative to other cancer types, the disease is an increasing public health concern due to the extended survivorship and younger age profile of individuals diagnosed requiring healthcare services and support (Singh et al., 2022).

1.4.4 Challenges for Lymphoma

Lymphoma shares several experiences and challenges with other forms of cancer. However, lymphoma encompasses several experiences specific to the systematic impact and heterogeneity of the disease. Lymphomas often present a diagnostic challenge (Nixon et al., 2020). In comparison to many other cancers, the pathway to diagnosis of lymphomas can be fraught with difficulty and has been associated with excessive time between symptom onset, help-seeking behaviours, and diagnosis with multiple primary care consultations before referral to secondary care and an increased chance of being diagnosed after emergency admission (Howell et al., 2006, 2007; National Institute for Clinical Excellence, 2003a, 2003b; Skrabek et al., 2015; Summerfield et al., 2000). Prolonged time to diagnosis is often associated with lymphoma, despite the best efforts of patients, relatives, and healthcare professionals (Howell et al., 2020). Certain cancers may have specific symptoms that are often associated with local disease and frequently present at diagnosis, such as breast lumps in breast cancer. However, this may not always be the case with lymphoma. Patients with this disease are known to present with a wide range of symptoms according to the type and site of disease; these symptoms are also often seen in primary care in association with other more common and less potentially serious illnesses (i.e., influenza) (Sapkota & Shaikh, 2022). These circumstances pose challenges to direct haematology-oncology referral, with initial referral to other non-cancer disciplines common, particularly for those with symptoms that are not typical or include lymphadenopathy (Howell et al., 2007).

Diagnostic delay is usually defined as the time from symptom onset until the correct diagnosis; reducing the duration of the illness trajectory brings survival advantages (Howell et al., 2006). Diagnostic delay causes unfavourable outcomes among cancer patients; this has been widely analysed in solid tumours. However, data regarding haematological malignancies' diagnostic delay are scarce (Dapkevičiūtė et al., 2019). Various benign and malignant lymphoid proliferations can display histological features resembling HL (Wang et al., 2019). The GP experience of lymphoma diagnosis was variable in the UK (Howell et al., 2006), reflecting the wide range of symptoms associated with lymphoma, many of which are frequently seen in other more common minor illnesses (e.g., influenza) or lymphadenopathy that is localised or generalised which can pose confusion and unclear diagnosis, inhibiting swift suspicion for cancer services referral. Similarly, other medical conditions may mimic symptoms of NHL, like appendicitis, metastasis from a primary tumour (e.g., soft tissue sarcoma, nasopharyngeal carcinoma), autoimmune disorders (e.g., systemic lupus erythematosus) and some bacterial infections. Expert hematopathologists, flow cytometry,

and cytogenetics are required to aid the differentiation of various conditions (Sapkota & Shaikh, 2022), highlighting the high level of specialism required for lymphoma.

1.4.5 Treatment Options

The treatment for lymphoma varies considerably depending on various clinical factors and individual patient factors, such as age, symptom status and performance status (Sapkota & Shaikh, 2022). Treatment modalities for lymphoma can require in-patient hospital stays for several weeks and lifelong medical follow-up care (Amatya et al., 2021; Wilson, 2013). The most common treatment is chemotherapy, alone or combined with radiotherapy; immunotherapy and surgery are also commonly used. Chemotherapy regimens are relatively straightforward for HL, with the standard treatment being ABVD (adriamycin (doxorubicin), bleomycin, vinblastine and dacarbazine); other regimens are used. Given the numerous subtypes of NHL, multiple regimens are available. However, often treatments such as CHOP (cyclophosphamide, doxorubicin, vincristine, and prednisolone) with or without the targeted therapy, rituximab (R-CHOP), is considered (Edwards-Bennett et al., 2010; Torok et al., 2018; Wilson, 2013).

Advances in chemo-immunotherapy have improved outcomes in several lymphoma subtypes; however, the prognosis for many patients with relapsed and refractory disease remains poor (Ayyappan & Maddocks, 2019). Further advancements in cellular therapies and transplants provide more options for lymphoma patients, particularly for subsequent lines of treatment, such as the newly developed chimeric antigen receptor T-cells (CAR-T) (Poletto et al., 2022). This service for CAR-T is only emerging and in development in Ireland; the first patient received this treatment in December 2021 (St James's Hospital, 2023). The CAR-T programme is currently conducted at a single site nationally. It has limited eligibility criteria for specific types of lymphoma and leukaemia that are refractory (cancer cells do not respond to treatment) or in relapse (cancer cells grow again after a period of remission) (National Cancer Control Programme, 2023a). This evolving space of immunotherapy has revolutionised cancer treatment with CAR-T, which is important in future steps for treating lymphomas; improved approval, cost, and reimbursement will further enhance this advancement (Anderson & Mehta, 2019). For HL, high-dose chemotherapy followed by an autologous stem cell transplant (ASCT) is the standard of care for most patients who relapse following initial therapy (Ansell, 2020). Ultimately, optimal management of lymphoma requires accurate diagnosis, careful staging, and the identification of poor prognostic features to facilitate therapeutic versus toxic responses to treatment (Ansell, 2020; Ayyappan & Maddocks, 2019; Poletto et al., 2022)

1.4.6 Treatment Complications and Management

The pathology and the treatment for lymphoma induce several side effects long after therapy for survivors has ended, such as secondary malignancies, infertility, and increased susceptibility to infection (Brown & Cutler, 2012; Hodgson, 2008). The complications following treatment are variable depending on the type of treatment used. Previously, treating lymphoma was focused on merely achieving survival; now, there is a necessary interest in treatment which is less tolerant of high-risk toxicities. Myelosuppression, neutropenia, and immunosuppression are common adverse events of chemotherapy. Myelosuppression

requires transfusions (red cells and platelets) or the administration of colony-stimulating factors (e.g., granulocyte colony-stimulating factor) (Brown & Cutler, 2012). Lymphoma patients have acquired immune dysfunction. Neutropenia can pose a further risk of infections from bacterial, viral, and fungal contaminants. Its management depends on the degree of neutropenia, and if febrile, protective isolation and personal protective measures may be required to reduce the transmission of susceptible infections (Barré et al., 2022). Prophylactic therapies are incorporated into treatment regimens (i.e., anti-viral and anti-fungal medications). Similarly, anti-emetic serotonin receptor antagonists, among other agents, are used for the treatment and prophylaxis of chemotherapy-induced nausea and vomiting. Lymphoma survivors can experience several long-term and late effects, such as cancer-related fatigue, which may persist even years after treatment (Kreissl et al., 2020a; Liu et al., 2019). Survivors are also at risk of developing endocrine abnormalities such as gonadal dysfunction and hypothyroidism in men and women (Sapkota & Shaikh, 2022). Life-threatening emergent complications can occur, such as febrile neutropenia, tumour lysis syndrome, spinal cord or brain compression, or vena cava obstruction (Sapkota & Shaikh, 2022). Therefore, lymphoma survivors may experience an array of complications of treatment depending on the type of treatment, its level of toxicity and factors relating to individual patient response.

1.5 Cancer Survivorship

As therapeutic options advance and more people live longer, both with and beyond their cancer diagnosis, understanding how diagnosis and its treatment impact their needs and quality of life outcomes is fundamental to person-centred care (Muhsen et al., 2020; Rosenthal, 2022). Advances in modern cancer care and increased survival rates have sparked a necessary shift of attention toward survival management for researchers and healthcare professionals (Agostinelli et al., 2022; Watts, 2019). This increased growth of the number of survivors and recognition of physical and psychosocial challenges has stimulated the development of cancer survivorship as an important area for cancer care and research (Institute of Medicine, 2006; Jacobsen et al., 2017; Miller et al., 2020; Sung et al., 2021). However, cancer survivorship is a concept that is widely interpreted. By convention, a survivor is an individual who continues to function during and after severe adversity or life-threatening disease (Rodin et al., 2018). However, in cancer, there is broad recognition that cancer survivorship begins at diagnosis and continues until the end of life, involving the health and well-being of the individual with cancer (Denlinger et al., 2014; Drury et al., 2017a; Khan et al., 2012). A greater understanding of survivorship issues has generated momentum for practice change, enhanced education, and opportunities to make impactful points of intervention during the survivorship period (Department of Health, 2017; National Institute for Health and Care Excellence, 2016; Rosenthal, 2022). As the number of lymphoma survivors grows, enhanced awareness of issues to facilitate optimal survivorship care is paramount (Damlaj et al., 2019). In the literature, ‘patient’ and ‘survivor’ are used interchangeably; patient generally refers to the treatment period, while survivor often leans to the post-treatment period. Cancer survivorship can be summarised as ‘the experience of living with, through and beyond a diagnosis of cancer’ (Albreht et al., 2017; Department of Health, 2017). Therefore, reference to ‘living with or beyond cancer’, is often used for individuals who do not favour the use of patient or

survivor but to encompass anyone diagnosed with cancer including their entire cancer journey. For this thesis, the term survivor defines an individual living with a diagnosis of lymphoma, which encompasses their experiences from diagnosis to end of life.

While survivorship is recognised as a critical and distinct phase of the cancer care continuum (Department of Health, 2017; Institute of Medicine, 2006), this period can encompass different experiences for survivors, which differ by the timing or phase of survivorship (Miller et al., 2008). In practical terms, an individual's lymphoma experience can be broken down into three stages: the acute phase (the first-year post-diagnosis), the short-term phase (one to five years post-diagnosis) and the long-term phase (more than five years after diagnosis) (Campo et al., 2016). The acute phase occurs during the initial diagnosis and treatment. While long-term survivorship sees a more complete resumption of everyday life activities compared to the short-term phase, which often involves the transition from treatment completion to fear of cancer recurrence or receiving maintenance treatment, balanced with attempts to return to 'normal' life (Harrington et al., 2010; Institute of Medicine, 2006; Miller et al., 2008; Stanton, 2012). Understanding how a lymphoma diagnosis and its management impact an individual's needs and quality of life at each stage is critical for optimising cancer care (Rosenthal, 2022).

Post-treatment is a critical phase of adjustment with important implications for health services delivery; post-treatment, survivors require attention from healthcare systems and professionals as adverse events from cancer and treatment effects are prevalent (Institute of Medicine, 2006; Moser & Meunier, 2014; Page & Adler, 2008; Pongthavornkamol et al., 2019). More research is required on living with and beyond cancer to advance these subsequent stages for survivors. Survivorship in oncology and haematopoietic cell transplantation have flourished, yet the field of haematologic malignancy survivorship is considered comparatively still in its infancy (Muhsen et al., 2020). For lymphoma, optimising quality of life and identifying survivorship challenges is increasingly emphasised with continuous improvements in addressing survivorship issues required (Rosenthal, 2022; Troy et al., 2017; Vena & Copel, 2021a; Viscuse et al., 2019). Lymphoma survivorship care is complex involving relevant physical examination, careful consideration of potential health concerns (e.g., cardiovascular health, secondary malignancies) and infection risks (Henderson & Oeffinger, 2021). Furthermore, the implications for the follow-up of lymphoma survivors require consideration, with opportunities for future research sought to advance the evidence supporting practice for this group (Henderson & Oeffinger, 2021; Muhsen et al., 2020; Ng, 2014).

1.6 Unmet Needs

Cancer and the complex nature of treatment have a profound impact on the lives of survivors, making it a profoundly personal disease. Subsequently, this results in individuals living with and beyond cancer experiencing a wide range of needs, many of which are left unmet and unaddressed. As survival rates continue to increase, more individuals will live with the long-term implications of cancer (Miller et al., 2020; Sung et al., 2021). The best available evidence must be sought to meet the growing demands of cancer services (Evans Webb et al., 2021). Efforts to improve the availability of care and resources for cancer

survivors have been advanced by assessing survivors' needs (McDowell et al., 2010; Richardson et al., 2007). Therefore, the needs that are not being met must firstly be identified. Historically, conceptual uncertainties exist on what constitutes 'need' in healthcare (Asadi-Lari et al., 2003; Jordan & Wright, 1997; Priebe et al., 1999). Needs identify the requirements of an individual that enable them to achieve, maintain, or restore an appropriate level of independence or quality of life (Rosenberg et al., 2023; The Academy of Medical Sciences, 2017). Healthcare professionals consider needs in terms of healthcare services they can supply, while patients may consider what would make them healthier (e.g., a job, decent housing, or a bus route to the hospital).

Unmet needs distinguish between an individual's need or expectations for services and the actual experience of receiving them (Gauld et al., 2014); this operational definition forms the premise for this thesis's primary outcome of interest. Therefore, this study examines the spectrum of lymphoma survivors' needs that are not optimally met, as understanding where unmet needs lie can influence both the immediate support given to that patient and, cumulatively, by observing trends and patterns, can influence the overall provision of healthcare services and support for cancer care (Moghaddam et al., 2016; Swash et al., 2017; Swash et al., 2014). The direct assessment of an individual's perceived need for help enables an indication of required resources and the magnitude of the need for help or identification of those most at risk and vulnerable (Bonevski et al., 2000; Boyes et al., 2012; Hall et al., 2014). Understanding the unmet needs of lymphoma cancer survivors can enable informed decision-making relating to survivorship care to be achieved (Magalhães et al., 2020; O'Connor et al., 2019; Puts et al., 2012; Sanson-Fisher et al., 2000; Thomas et al., 2014). Most notably, failing to meet the needs of cancer survivors will inhibit the delivery of improved outcomes that are central to national and international focus and goals for cancer care (Albreht et al., 2017; Department of Health, 2017; Department of Health UK, 2013; Vaz-Luis et al., 2022).

1.7 Quality of Life

Like unmet needs, the secondary outcome of interest, quality of life (QOL), is a frequently used term in cancer survivorship research with several critical applications in research for cancer survivors (Jacobsen & Jim, 2011). The concept of QOL has been integral to evaluating the quality of health outcomes and is one of the core concepts within the field of patient-reported outcomes (Chassany et al., 2002; Costa et al., 2021; World Health Organisation, 1995). Quality of life is often assessed and reported but is rarely accompanied by a definition (Costa et al., 2021). QOL is a multidimensional concept that involves an individual's perception of their position in life, which is context-bound to their culture, values, and way of life (World Health Organisation, 1995). The term extends not only to the impact of cancer and its treatment but also to the recognition of the individual living with or beyond the diagnosis. QOL has been widely used to evaluate self-perceived feelings about well-being with a focus on favourable or adverse conditions (Kaur & Kaur, 2023), and so it is well-placed to evaluate the experience of cancer. Research on the QOL of cancer survivors has substantially increased over past decades, consistent with increasing recognition that life after cancer is often compromised by a broad spectrum of adverse events (Jacobsen & Jim, 2011; Moser &

Meunier, 2014). Moreover, this is reflected by a new focus on quality of life in European policy which was previously less explicit (Celis & Heitor, 2019; Celis & Pavalkis, 2017; European Commission, 2022). Quality of life measures an individual's sense of well-being and ability to function in the ordinary tasks of living (Gillen, 2009), and for this research, altered QOL resulting from a lymphoma diagnosis is the focus. This adds supplementary insights to investigating their unmet needs. Assessing the quality of life of lymphoma survivors can facilitate the improved health status of individuals with cancer and the quality of care available to them (Kaur & Kaur, 2023). This is important in informing healthcare service planning and delivery as contemporary cancer care focuses not only on cancer treatment but also on the holistic understanding of patient experiences and the impact on quality of life to inform the prioritisation of resource allocation (Adler & Page, 2008; National Institute for Health and Care Excellence, 2016, 2018; Page & Adler, 2008).

1.8 Cancer Policy in Ireland

The National Cancer Strategy in Ireland directs the development of cancer care to meet the needs of people living with and beyond cancer. It provides evidence-based recommendations for implementation at a national level. The first strategy was published almost three decades ago; its major goals were to reduce cancer incidence and mortality, ensure cancer care is effective and enhance quality of life to the greatest extent possible (Department of Health and Children, 1996). Reduced cancer mortality, improved cancer care coordination, recruitment and retention of cancer care professionals and enhanced implementation of available treatments (chemotherapy, radiotherapy, and surgery) were achieved. The following strategy in 2006 resulted in the restructuring of medical oncology services with the establishment of the National Cancer Control Programme (NCCP), a national screening initiative and the development of eight designated centres of excellence in cancer care; haematology cancers were neglected (Department of Health, 2006). The success of this strategy benefitted solid-tumour groups, particularly those requiring surgical interventions, as high-volume cancer surgeries were prioritised for centralisation; this began with breast cancer and was followed by less common cancers and then expansion to radiotherapy facilities (National Cancer Control Programme, 2014).

The subsequent and most recent strategy in 2017 saw several recommendations reflecting the advanced evidence and therapies available for cancer care. However, it was the first to acknowledge haematological malignancies or lymphoma (Department of Health, 2017). Subsequent work and reports stemming from this strategy reported the need for investigations seeking to understand the unmet needs of cancer survivors to meet the needs of people living with and beyond a cancer diagnosis (O'Connor et al., 2019). Current research on specific aspects of cancer survivors' unmet needs is lacking, including within particular cancer types that are underrepresented in existing literature, the impact of treatment side-effects on survivors, longitudinal data on unmet needs and socioeconomic status. Furthermore, the planning and design of survivorship strategies in Ireland would benefit from the routine collection of detailed information

with standardised survey instruments designed to measure specific unmet needs across multiple diseases (National Cancer Control Programme, 2019; O'Connor et al., 2019).

A recent implementation report outlined the present achievements of the current strategy (Department of Health, 2023). The NCCP has developed and implemented actions relating to their 'Early Diagnosis of Symptomatic Cancer Plan 2022-2025', including an eLearning programme for healthcare professionals in primary care to promote cancer awareness and early diagnosis (National Cancer Control Programme, 2022a). Rapid access clinics, early diagnosis pathways and electronic cancer referrals from general practitioners to hospitals have received funding, development, and resources (i.e., extended hours and locum support) (Department of Health, 2017; Saab, 2022). A Model of Care for Psycho-Oncology in 2020 has seen improved psycho-oncology development within our health services which has direct benefits to patients but also healthcare professionals in supporting individuals with cancer (National Cancer Control Programme, 2020). The Systematic Anti-Cancer Therapy (SACT) Model of Care guides the provision of quality treatment, safety, and standard of care for patients receiving SACT (National Cancer Control Programme, 2022b). While this highlights some of the advancements in cancer care nationally, colorectal, breast, lung and prostate cancer have been the main focus (Department of Health, 2017; O'Connor et al., 2019). However, the emerging development of haemato-oncology patient pathways directly responds to recommendation twenty-four of the NCS to develop national patient pathways for individual haematological malignancies (Department of Health, 2017; National Cancer Control Programme, 2023b, 2023c). Despite the rapidly increasing number of lymphoma cancer survivors, their needs and research priorities rarely receive attention or are addressed (Khimani et al., 2013; Ng, 2008; Payne et al., 2019). Previous national research by O'Connor et al. (2019) on the unmet needs of cancer survivors in Ireland found that prostate, colorectal and breast cancer survivors are most frequently studied; there was a lack of information on how needs vary by age, gender, and other sociodemographic details like employment status. Therefore, homogenous cancer-type investigations are needed to enhance our understanding, as one size does not fit all (O'Connor et al., 2019).

1.9 Lymphoma in the Irish Healthcare Context

Healthcare services in Ireland are delivered through a combination of public, private, and voluntary organisations governed by the Department of Health. Approximately half of the Irish population avail of private health insurance from several organisations purchased by those who can afford it (Health Insurance Authority, 2021). Irish residents (ordinarily residents living or intend to live in Ireland for at least one year) are entitled to receive health care through the public healthcare system, known as the Health Service Executive (HSE), regardless of insurance status. This public system is funded by general taxation and contributions for certain services, like emergency department visits or in-patient services (Citizens Information, 2022). Medical card holders are eligible for several free services such as general practitioner (GP) services, public hospital services, prescribed drugs, and medicines (subject to a charge for each item prescribed), ear and eye tests and dental checks (Health Service Executive, 2023b). Citizens aged seventy

or older may also qualify for a medical card, dependent on gross income (Health Service Executive, 2023a). Therefore, the public health system is accessible to all residents. However, the two-tier system means private health insurance allows people to gain preferential access to some services, and many public health services have substantial waiting lists.

Two main pathways to a diagnosis of lymphoma exist: through GP referral to hospital cancer services (i.e., investigation of suspected lymphoma) or direct presentation to hospital with signs and symptoms of lymphoma. From diagnosis, cancer care is predominantly provided and overseen by haematology-oncology doctors, cancer nurses and other health care professionals. The haematologist or oncologist commonly follows the lymphoma patient closely for several years post-treatment with a gradual reduction of frequency if appropriate and concurrent primary healthcare from general practitioners. A number of nurse-led follow-up clinics also provide this care (Drury et al., 2023). This transition period can be distressing, with miscommunication between even the most well-meaning providers (Sapkota & Shaikh, 2022).

Given the wide range of treatment modalities required for lymphoma cancers, the centralisation of these services is required and recommended by the current National Cancer Strategy: *"The NCCP will develop appropriate multidisciplinary teams, centralisation and treatment arrangements to meet the diverse needs of patients with haematological cancers"* (Department of Health, 2017, p. 86). The development and centralisation of haematological malignancies is recommended to be provided in four of eight cancer centres in Ireland. However, a limitation of this development is the scant evidence and data available to guide its direction. Current services for lymphoma survivors are provided in over twenty-six different sites, graded into three types of SACT hospitals. Community cancer support centres and services fill a substantial gap in patient services and have been recognised as an essential part of the cancer journey (National Cancer Control Programme, 2020). Core services provided by many centres relate to information and advice, psychological support, and survivorship programmes. Other services provided are transport and complementary therapies. Community cancer support centres are voluntary and charity organisations and, as such, receive funding through fundraising, philanthropy and, for a minority, limited public funding. The NCCP published best practice guidance for community cancer support centres and services in 2022 to assure that safe and quality services are provided but also to support championing person-centred and integrated approaches to care among designated cancer centres, SACT hospitals, primary care services and cancer support centres (Greally et al., 2022). This will provide a network of approved centres, providing a more comprehensive service for patients and their families over time (Greally et al., 2022; National Cancer Control Programme, 2020). Several informal support groups that provide psycho-social support to individuals with an array of cancer diagnoses are available, yet there is less awareness of what supports are tailored to lymphoma-specific needs.

1.10 Lymphoma Survivorship Internationally and Nationally

Among the necessary components of survivorship care identified in the seminal report from the Institute of Medicine (2006) was the delivery of interventions for the consequence of cancer and its treatment.

Improved care delivery required a fundamental shift in the goals for cancer control (Fil, 2022). Improved survival rates led to important questions relating to the survivorship concerns of individuals living with and beyond cancer, with HL seeing one of the most significant improvements in survival for malignancies of children and young adults (Ries et al., 1999; Rowland et al., 2013). The World Health Organisation provides the classification of lymphoma, which is complex and continuously evolving (Swerdlow et al., 2016). The National Comprehensive Cancer Network (NCCN) provide lymphoma guidelines for general recommendations on classifications, differential diagnosis, supportive care, and subtype-specific management (Hoppe et al., 2022; Zelenetz et al., 2021). Clinical practice guidelines for lymphoma are available from expert groups like the European Society for Medical Oncology (ESMO) (Eichenauer et al., 2018). Given the many subtypes and wide heterogeneity among lymphoma with variable prognosis, treatment modalities, and potential complications, the survivorship associated with this group is complex and challenging to predict (Alabdaljabar et al., 2022). International literature on survivorship has found lymphoma survivorship is associated with impaired QOL, possible physical health complications (including cardiovascular disease, infertility, and subsequent cancers), and the impact of novel treatments and their potential complications (Alabdaljabar et al., 2022; Andersson et al., 2021; Lekdamrongkul et al., 2021; Lo et al., 2021; Minoia et al., 2021; Vena & Copel, 2021b).

From diagnosis onwards, lymphoma survivors face challenges that can impact their physical and psychosocial well-being, resulting in unmet needs (Agostinelli et al., 2022; Enam et al., 2021; Kang et al., 2018; Kim et al., 2017; Noonan et al., 2020; Raphael et al., 2019). Most published work to date has placed focus on specific aspects of survivorship care, such as surveillance, or more recently late treatment effects and the psychosocial impacts experienced by lymphoma survivors. Yet, a gap remains for widely accepted lymphoma-specific recommendations to address follow-up survivorship care needs, like screening and management strategies of detriments to quality of life like anxiety, depression, sleep disturbances, and treatment-related fatigue (Powis et al., 2023). Additionally, there is a current gap for investigations to identify impactful points of service development, vulnerable groups within lymphoma and pathways for lymphoma-specific post-treatment and chronic survivorship (Rosenthal, 2022; Vena & Copel, 2021b).

Over one decade ago, Naidoo et al. (2013, p. 1) reported "*There is no published data on survivorship care in Irish patients. Knowledge of their survivorship needs and if these needs are currently met, is not known*". One decade later substantial developments have advanced cancer care nationally, resulting especially in increased research into various aspects of cancer survivorship for breast cancer, colorectal cancer, and prostate cancer from patient experiences to barriers to care (Algeo et al., 2022; Byrne et al., 2018; Droog et al., 2014; Drury et al., 2017b; Gavin et al., 2015; Maguire et al., 2018; Meade et al., 2017; O'Brien et al., 2018). Nationally, there is limited data in Ireland on the needs of lymphoma survivors; research is limited by small sample sizes (e.g., quantitative survey, *N=47*), recruitment sites (single or two sites), and a lack of attention on needs assessment (Hackett & Dowling, 2019; Holland et al., 2016; Pallin et al., 2023). Research would benefit from quantitative and mixed methods investigations of the needs of lymphoma survivors. Furthermore, the nature of the Irish healthcare system (Section 1.9) means the needs of survivors are likely

to be more nuanced. There is a need to evaluate evidence on the unmet needs of lymphoma in Ireland, to enhance the national picture of the experience of lymphoma survivors and to add to the growing international evidence on this issue.

1.11 Justification for this Research

Lymphoma, the largest cohort of haematological malignancies, is underserved by current literature. Mortality and survival rates for lymphoma continue to improve, with rising numbers of survivors, as more than seven out of ten individuals are living with or past a diagnosis of lymphoma after five years (Miller et al., 2020; National Cancer Registry Ireland, 2022; Sung et al., 2021). Identifying the problems during survivorship is a pressing concern for service planning and healthcare delivery; the anticipated surge in the annual numbers of new lymphoma cases over the coming decades is a clear signal for sound investment in survivorship planning and delivery of survivorship care (Department of Health, 2017; National Cancer Registry Ireland, 2014). The pressing issue of the growing numbers of lymphoma survivors and the support and attention they require makes survivorship a priority concern for this cancer type. Compared with other more common cancers such as breast, prostate, and colorectal cancer, lymphoma remains understudied in survivorship literature. While there is a high likelihood of overlap in some aspects of needs among different cancer types, there are known differences that make lymphoma-specific investigations valuable and, in some cases, necessary. A limitation of heterogenous cancer samples and mixed-haematological cancer samples is the flattening or diluting effect of findings and reduced generalisability to cancer type-specific concerns. The grouping of cancers into either solid tumours or haematological malignancies presents further challenges to the investigation of lymphoma as the care coordination and delivery are different regarding pathology, treatment, and prognosis. Inadequate service provision following treatment completion may lead to unmet needs along the survivorship continuum (De Leeuw & Larsson, 2013). Therefore, assessing the unmet needs of lymphoma survivors can help inform service development, inform future interventions during survivorship and direct support to those with the greatest need. Therefore, research is needed to advance and achieve informed decision-making relating to survivorship care, placing due attention to the needs and research priorities of lymphoma survivors.

1.12 Research Aims and Objectives

This research aims to investigate the unmet needs of lymphoma survivors to guide patients, policy, practice, and future research to be responsive in addressing these needs. This thesis strives to overcome previous research limitations and evaluate the unmet needs of lymphoma survivors using a quantitative survey and qualitative interviews to give a voice to the lymphoma survivor. The aim and objectives of this research study are clearly outlined in Table 1.1.

Table 1.1 The Aim and Objectives of this Research Study

Aim
To investigate the unmet needs of lymphoma survivors.
Objectives
1) To identify the unmet needs of lymphoma survivors.
2) To explore lymphoma survivors' quality of life outcomes and symptom experiences.
3) To evaluate the content and quality of instruments used with lymphoma survivors for assessing the constructs of interest, unmet needs, and quality of life outcomes
4) To identify what factors influence lymphoma survivors' unmet needs.
5) To inform the development of supportive care strategies and services to address the unmet needs of lymphoma survivors in Ireland.

1.13 Thesis Structure and Layout

This remaining thesis consists of seven chapters.

Chapter two provides an overview (background) of the evidence underpinning the rationale for this research through identified gaps in the literature. A rapid review methodology supports this chapter in providing a comprehensive background to the unmet needs of lymphoma survivors.

Chapter three utilises a systematic review to synthesise the available evidence guiding the assessment of unmet needs for lymphoma survivors. This content comparison facilitates the systematic selection of self-report measures for use with adult lymphoma survivors in phase one of this study.

Chapter four provides an understanding of this thesis's philosophical and methodological choices. How knowledge is generated within the philosophy and methodology of this research is explored. A justification for the study design and methodology is provided.

Chapter five outlines the roadmap undertaken for this two-phase, mixed methods study. The research methods applied to address the objectives of this study are outlined.

Chapter six presents the results of the quantitative phase with a detailed discussion of statistical analyses conducted to answer the relevant research objectives.

Chapter seven provides the findings directly from the voices of lymphoma survivors. The analysis of qualitative data is provided.

Chapter eight discusses the key findings in the context of relevant evidence. Integrating phase one quantitative and phase two qualitative findings is presented and comprehensively discussed to identify meta-inferences to inform the development of healthcare delivery and services for lymphoma survivors. The strengths and limitations of this research are described.

Chapter 2 Literature Review

2.1 Introduction

A literature review was conducted to underpin this thesis and establish an understanding of the unmet needs of people living with or after a lymphoma diagnosis. Lymphoma survivors are at increased risk of unmet needs due to toxicities arising from cancer and its treatment. Despite the rapidly increasing numbers of lymphoma cancer survivors, their needs and research priorities are often underserved and, therefore left largely unaddressed. This chapter presents the results of a rapid review undertaken to evaluate the unmet needs of people living with and beyond lymphoma, published in Psycho-Oncology. 2022;31(7): 1076- 1101. https://doi.org/10.1002/pon.5973) (Boland et al., 2022)[1]. This review of international literature was warranted to provide a comprehensive understanding of gaps in knowledge pertaining to the unmet needs of lymphoma survivors and to identify limitations to be addressed by future research efforts. Therefore, this publication adds to this thesis as it assimilates and evaluates evidence which supports the undertaking of this investigation. This directly corresponds with objective one of this thesis: to identify the unmet needs of lymphoma survivors.

2.2 Background

Haematological malignancies are a diverse group of cancers which develop in the blood-forming tissue, including three broad categories: leukaemia, lymphoma, and myeloma (Brown & Cutler, 2012; Smith et al., 2011). Haematological malignancies are distinct from solid tumours not only regarding their pathology, but also in their potential presentation, treatment, progression, and outcome (Smith et al., 2011; Swerdlow et al., 2016). These distinguishing factors contribute to an individualised experience from diagnosis to chronic effects with potential for different needs to arise from these phases. Given the diversity amongst haematological malignancies, mixed haematological samples may be inappropriate. Subtype-specific research is needed to ensure future care is responsive to survivors' needs (Chen et al., 2020; Esser et al., 2018; Oberoi et al., 2017c).

Therefore, this review is focused on lymphoma, the largest cohort of haematological malignancies, originating in the lymphatic system and encompassing a variety of distinct disease entities (Boffetta 2011). Given the widespread nature of the lymphatic system, lymphoma can affect any organ in the body with varying symptoms depending on where the cancer is (Armitage et al., 2017). Lymphomas are categorised by two types – Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL) (Fisher & Fisher 2004). Within the two subtypes many variations exist. Compared with HL, NHL is more heterogenous with more than sixty subtypes and division into indolent or aggressive forms (Ng et al., 2011; Swerdlow et al., 2016). The varied clinical features and histological appearances of lymphoma presents specific challenges such as difficult diagnosis, varied management strategies and assorted prognosis (Howell et al., 2019; Ng et al., 2011).

[1] **Boland, V.**, Drury, A., & Brady, A. M. (2023). Content comparison of unmet needs self-report measures for lymphoma cancer survivors: A systematic review. *PLOS ONE*, *18*(12): e0290729. https://doi.org/10.1371/journal.pone.0290729

The population of lymphoma cancer survivors is substantially increasing thanks to the success of multimodal treatments (Frick et al., 2018). In 2020, there was an estimated 628,000 new cases of lymphoma with 283,000 new deaths, worldwide (Sung et al., 2021). Furthermore, the late effects of lymphoma and its treatments are key determinants of long-term morbidity, mortality and quality of life and can pose challenges to survivorship (Ng et al., 2011). Many survivors of lymphoma will have extended life expectancies but may live with an increased risk for unmet needs resulting from late effects such as secondary malignancies, cardiac toxicity, pulmonary toxicity, and endocrine and gonadal dysfunction which raise concerns about fertility (Ng et al., 2011; Swerdlow et al., 2016; Van Leeuwen & Ng, 2016).

The concept of cancer survivorship is widely interpreted (Drury et al., 2017a; Feuerstein, 2007; Khan et al., 2012). However, it is broadly accepted that cancer survivorship begins at the time of diagnosis and continues until the end of life and can be referred to as 'living with and beyond cancer' (Jiao et al., 2015; National Cancer Control Programme, 2019). Similarly, some debate and conceptual uncertainties exist on what constitutes a 'need' in healthcare (Priebe et al., 1999; Sanson-Fisher et al., 2000). The term "unmet needs" is used to distinguish between concerns which survivors experience and wish for help in managing (Drury et al., 2017a; Hewitt et al., 2005; Reuben, 2004; Richardson et al., 2007; Sanson-Fisher et al., 2000).

Efforts to improve the availability of care and resources for survivors of cancer have been advanced by the assessment of survivors' needs (McDowell et al., 2010). The assessment of unmet needs enables the direct assessment of an individual's perceived need for help. This allows for a more direct indication of required resources and the magnitude of the need for help, therefore facilitating the prioritisation of health services (Bonevski et al., 2000; Boyes et al., 2012). While the identification of higher-level needs can quickly assist healthcare providers in identifying those most at risk and vulnerable (Hall et al., 2014). Quantifying the prevalence of survivors experiencing difficulties including poor outcomes, limitations and unmet needs is required to promote recovery and supportive self-management (Moghaddam et al., 2016; O'Connor et al., 2019; Richardson et al., 2007; Swash et al., 2014).

Understanding the unmet needs of lymphoma survivors can enable informed decision-making relating to survivorship care to be achieved (O'Connor et al., 2019; Puts et al., 2012; Sanson-Fisher et al., 2000). Survivorship issues are of particular importance to this population who often have long survival and can frequently be cured (Armitage et al., 2017). Yet despite the rapidly increasing number of lymphoma survivors, their needs and research priorities rarely receive attention or are addressed (Khimani et al., 2013; Payne et al., 2019). Therefore, a rapid review has been undertaken to assess and assimilate current knowledge (Tricco et al., 2015).

This review aims to establish an understanding of the unmet needs of people living with or beyond a diagnosis of lymphoma using a rapid review method and reflexive thematic analysis approach. The research question asks, '*What are the unmet needs of people living with a diagnosis of lymphoma cancer*?'.

2.1 Methods

2.1.1 Eligibility Criteria

To be eligible for review, publications must refer to individuals with a lymphoma diagnosis at any point of survival (from diagnosis onwards) and subtype or subgroup. Outcomes must refer to the needs of these individuals. Age criteria were applied to focus on the needs of adult survivors as opposed to childhood or adolescence (more than half of the sample aged 18 years or older at the time of data collection, i.e., survey). Detailed inclusion and exclusion criteria are provided in Table 2.1.

Table 2.1 Inclusion and Exclusion Criteria in PEOS Format

PEOS	Inclusion	Exclusion
Population	▪ Age 18 years or older ▪ Lymphoma cancer diagnosis ▪ Any subtype, subgroup, or stage ▪ At any point of survival ▪ Undergoing or completed any form of treatment for lymphoma	▪ Age 17 years or younger
Exposure	▪ Lymphoma cancer care/survivorship care	
Outcomes	Patient outcomes related to unmet needs which are a result of a diagnosis of lymphoma cancer including but not limited to: ▪ Survivorship care ▪ Patient health outcomes ▪ Late effects or consequences ▪ Quality of life or well-being ▪ Physical needs or concerns ▪ Psychosocial needs or concerns ▪ Socioeconomic needs or concerns ▪ Information needs	▪ Views of survivorship care ▪ Non-patient experience ▪ Patient outcomes relating to childhood or adolescent survivors of lymphoma cancer
Study Design	▪ Systematic reviews ▪ Qualitative & quantitative studies ▪ Mixed-methods studies ▪ Population-based studies ▪ Prospective & retrospective studies ▪ Cross-sectional studies ▪ Longitudinal studies ▪ Thesis/dissertations ▪ Grey literature	▪ Individual case studies ▪ Intervention studies or RCTs ▪ Survival statistics ▪ Opinion pieces ▪ Editorials ▪ Commentaries ▪ Narrative literature review
Reporting	▪ English language ▪ Sufficient detail on population, outcomes, and results	▪ Languages other than English

2.1.2 Rapid Review of the Evidence

A rapid review method is a variation of a systematic review; this method was selected as it balances time constraints and available resources with considerations of bias (Tricco et al., 2015). The literature on the needs of lymphoma cancer survivors includes a broad range of evidence. Therefore, this review uses a streamlined approach to synthesise the available evidence (Garritty et al., 2021; Tricco et al., 2015).

2.1.3 Sources and Searching

Five databases were systematically searched, including CINAHL, EMBASE, MEDLINE, PsycInfo, and Scopus in July 2021 and updated in February 2022. A restriction to literature published after 1st January 2006 was applied as the Institute of Medicine seminal report was published at this time (Institute of Medicine, 2006); this report has broadened the recognition of cancer survivorship in the cancer continuum resulting in progressive attention being placed on the unique challenges and needs of cancer and its subtypes (Nekhlyudov et al., 2017).

The search was filtered to English language only. Authors were contacted to source full text when required. Reference lists and grey literature (i.e., conference abstracts) were examined for relevance to the eligibility criteria. However, abstracts lacking sufficient detail on population, outcomes, or results were omitted. The search strategy and database searches were conducted by a researcher and an information specialist. Key search terms related to "lymphoma", "cancer survivors" and "needs" were searched, the resulting search string is outlined in Appendix 1.

2.1.4 Study Selection

First, duplicate references were removed from the review library. Second, the title and abstract of each study were assessed for their relevance to the PEOS eligibility criteria. Two independent reviewers performed screening, supported by COVIDENCE software. To minimise any selection bias, discrepancies were resolved through discussion and required consensus from both reviewers. Finally, the full texts of studies meeting the PEOS criteria were obtained for final screening by a single reviewer. Secondary sources, anecdotal, opinion, editorials, clinical papers, case studies and case reports were excluded to minimise bias. As the goal of this review was to understand the experience of unmet needs for lymphoma cancer survivors, rather than the effect of experimental interventions to improve outcomes, randomised controlled trials and intervention studies were also excluded.

2.1.5 Data Abstraction

Data abstraction was conducted by a reviewer and all studies received verification by a second reviewer. Data from studies were extracted using specific extraction templates as relevant to the quantitative, qualitative and review approaches included. Key information was recorded, such as authorship, country of origin, aim, design and method, recruitment method, instrument(s) used, sample size and response rate. If reported demographic information, such as sex, age, diagnosis, treatment, ethnicity/race, employment status, education level and partnership were extracted.

2.1.6 Quality Assessment

Methodological quality was assessed for all included studies using an appraisal tool developed by the Evidence for Policy and Practice Information and Coordinating (EPPI) Centre. Studies were assessed according to the tool's twelve quality appraisal criteria (Table 2.2). One reviewer independently assessed

each included study to establish to what extent each criterion was met, with independent verification of all judgements by a second reviewer as guided by Cochrane's interim rapid review guidance (Garritty et al., 2021). The twelve criteria provided a measure to the extent in which a study's findings provides valuable contribution to the review (Thomas et al., 2003).

Table 2.2 Needs Review Quality Appraisal Criteria Adapted from Thomas et al (2003)

Quality Appraisal Criteria
Quality of the study reporting:
A = Aims and objectives clearly reported
B = Adequately described the context of the research
C = Adequately described the sample *and sampling methods*
D = Adequately described the data collection methods
E = Adequately described the data analysis methods
There was good or some attempt to establish the:
F = Reliability of the data collection methods*/tools*
G = Validity of the data collection methods*/tools*
H = Reliability of the data analysis methods
I = Validity of the results of the data analysis
Appropriateness of the methods:
J = Used the appropriate data collection methods to allow for expression of views
K = Used the appropriate methods for ensuring the analysis was grounded in the views
L = Actively involved the participants in the design and conduct of the study

2.1.7 Data Analysis

Reflexive Thematic Analysis (TA) formed the basis for this review's analysis due to its aptitude to amass and analyse the heterogeneous body of included literature through the identification of patterns across the dataset (Braun & Clarke, 2006, 2019). The first step of familiarisation involves a deep immersion and analytical engagement with the data, the literature is seen as data rather than as information. Next, a code labels something of interest within the data using analysis software (NVivo version 12.0). The dataset was assessed twice to provide robust and coherent coding. Steps three to five involved the organisation of coded data into themes and the development of rich data analysis, represented by themes (Braun & Clarke, 2006, 2019).

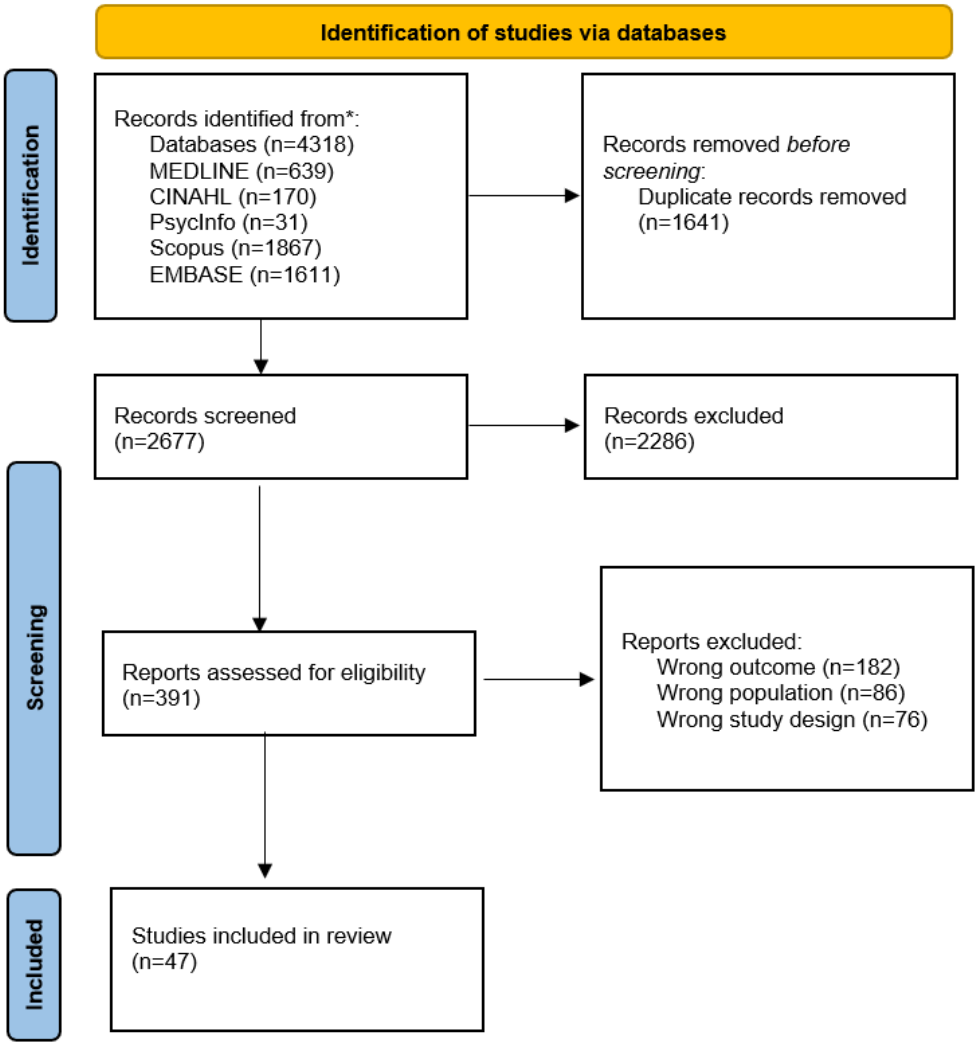
2.2 Results

2.2.1 Summary of Studies

2677 studies were screened with 391 requiring full-text eligibility review (Figure 2.1). Forty-seven studies met the inclusion criteria of which 57% were published in the last five years ago. Most studies employed quantitative approaches (*n=36*) and were more often cross-sectional (*n=24*). Studies originated from the

United States (*n=15*), Australia (*n=11*), United Kingdom (*n=4*), South Korea (*n=3*) and multiple other countries located in Asia, Europe, and Oceania (Table 2.2). This reflects current incidence rates of NHL which are highest in Australia, New Zealand, Northern America, and Europe (Sung et al., 2021).

Figure 2.1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Chart



Over thirty percent of included articles explicitly investigated unmet needs as the main outcome, while others explored closely related outcomes, such as quality of life (Table 2.3). Recruitment was mainly conducted via one or more cancer registries (*n=18*), at hospitals including single sites (*n=11*), two sites (*n=4*), three sites (*n=2*) and only two studies employing online recruitment strategies (Appendix 2). For quantitative surveys the most used instruments for assessing the needs (or associated outcomes, such as quality of life) of survivors included the European Organisation for Research and Treatment of Cancer Quality-of-life Questionnaire Core 30 (EORTC QLQ-C30), Survivor Unmet Needs Survey (SUNS), Hospital Anxiety and Depression Scale (HADS) and the Functional Assessment of Cancer Therapy – General (FACT-G) and Lymphoma subscale (FACT-LYM). Quantitative sample sizes ranged from small to large. The smallest

sample (*n=50*) was specified to a young age group (Zucchetti et al., 2017) and the largest sample (*n=4215*), a longitudinal study pooling data collected within clinical trials (Kreissl et al., 2020). The sample sizes of qualitative studies ranged from 6 to 51 (median=17).

Table 2.3 Summary Table of the Characteristics of Included Articles (N=47)

Characteristic	n	%
Methodology		
Quantitative	36	77
Qualitative	8	17
Review	3	6
Design		
Cross-sectional	24	67
Longitudinal	8	22
Cohort	4	11
Country		
United States	15	32
Australia	11	23
United Kingdom	4	9
South Korea	3	6
Germany	3	6
Other European countries	7	15
Other Asian countries	3	6
Other Oceania countries	1	2
Cancer site		
Lymphoma (total)	27	57
NHL and HL	12	26
NHL only	10	21
HL only	5	11
Mixed haematological malignancies (including >50% lymphoma)	18	38
Other cancers (including >50% lymphoma)	2	4
Method of data collection		
Questionnaire	36	77
Semi-structured interviews	6	13
Focus groups	2	4
Systematic review approach	3	6
Outcomes assessed by included articles		
Unmet needs	15	32
Health-related quality of life	8	17
Psychosocial	8	17
Quality of life	7	15
Post-treatment experiences	4	9
Care experiences	3	6
Physiological	2	4

A homogenous lymphoma-specific population was investigated by most included studies (60%). Heterogenous samples mostly included other haematological malignancies, such as leukaemia and multiple myeloma (Fauer et al., 2021; Hall et al., 2013; Hall et al., 2014; Oberoi et al., 2017; Parry et al., 2012; Parry et al., 2011; Tzelepis et al., 2018; Zucchetti et al., 2017). Male participants were slightly more common, and a diverse range of ages (young adulthood to more elderly) were captured. Chemotherapy was the most common treatment received by participants, with two studies focusing on outcomes relating to stem cell transplantation only (Arboe et al., 2017; Georges et al., 2020). Only fourteen studies discussed ethnicity or

race of participants, of these mainly White backgrounds were reported. Of the studies reporting the employment status of participants, a sizeable percentage (40-85%) were employed. A medium level of education (secondary school or equivalent) of participants in over half of studies reporting this sociodemographic factor (*n=24*) was found, while participants were mostly partnered (range 59-98%). However, disparity in reporting acute or chronic survivorship, time since diagnosis, stage of disease, socioeconomic status and sociodemographic details of current literature inhibits further analysis to generate a more substantive understanding of this cohort.

2.2.2 Quality Assessment

None of the included studies met all twelve quality criteria as this body of literature has not yet seen active involvement of participants in the design or conduct of studies as assessed by criterion L (Table 2.2). However, the literature included was of high methodological quality with most studies (*n=37*) meeting 11 of the 12 quality criteria. Followed by ten quality criteria being met by eight studies and the lowest number of criteria met being nine by two studies (Appendix 3). Reporting of sociodemographic information of participants varied amongst studies. Several studies supplied rich sociodemographic data, such as sex, age, diagnosis, time since diagnosis, treatment received, ethnicity, education level, employment status, and marriage/partnership status (Hall et al., 2014; Husson et al., 2017; Keegan et al., 2012; Kim et al., 2014; Kim et al., 2017; Smith et al., 2009). These quantitative studies differed in recruitment strategies, some used multiple cancer or state registries (Hall et al., 2014; Keegan et al., 2012; Smith et al., 2009), one used a national survivorship registry (Husson et al., 2017), others used three sites (Kim et al., 2014; Kim et al., 2017) and a single site (Kang et al., 2018). Reporting of participants' age was missing from two studies (Beaven et al., 2016; Swash et al., 2018), while two other studies only provided the age, sex, and diagnosis of participants (Khimani et al., 2013; Paul et al., 2017), limiting an adequate description of the study sample.

Studies using qualitative approaches were found to have made a good attempt to show rigour and credibility of data collection methods or analysis. This included detailed reporting of methods (framework used, recording device, transcribed verbatim, data analysis software) and details regarding the refinement of theme development (i.e., analysis conducted by one or more researcher, use of comprehensive field notes, reflexive diary) (Hackett & Dowling, 2019; Monterosso et al., 2017; Raphael et al., 2019). One qualitative study was found to require more detail in reporting data analysis as details pertaining to how analysis was conducted, such as the number of researchers involved, the coding process or how subthemes to major themes were formed was missing (Chen et al., 2020).

Most quantitative studies adequately described the use of statistical analysis (i.e., analysis of variance for comparing means of continuous variables). Most studies used validated and reliable tools (i.e., SUNS, FACT-LYM), with the exception of Parry et al. (2012) who used a tool that is not validated and Zucchetti et al. (2017) who used a tool appropriate to assess the study's main outcome of interest body image, yet not validated in the population of interest cancer survivors.

2.3 Reflexive Thematic Analysis

The active process of reflexive thematic analysis produced five major themes relating to the needs of lymphoma cancer survivors (Table 2.4). This includes disparity in health service delivery, psychological impact of cancer, impactful and debilitating concerns, the monetary cost of survival and insufficient provision of survivorship information. Study characteristics are outlined in Appendix 2.

Table 2.4 Theme Development

Subthemes	Themes
Theme One	
Transition from patient to survivor	Disparity in health service delivery
Disruption to continuity of care	
Lymphoma care as a speciality service	
Health care provider support	
Theme Two	
Psychosocial needs	Psychological impact of cancer
Impaired cognitive functioning	
The impact of anxiety, depression & stress	
The fear of recurrence	
Theme Three	
The continual burden of side effects during and after treatment	Impactful and debilitating concerns
Cancer-related fatigue	
Barriers to social reintegration	
Physical implications of lymphoma	
Theme Four	
Financial implications	The monetary cost of survival
The benefits of work	
Barriers to working	
Theme Five	
Inadequate information provisions	Insufficient Provision of Survivorship Information
Importance of communication from others	
Seeking survivorship advice	

2.3.1 Theme One Disparity in Health Service Delivery

The uncertainty and life transitions in the post-treatment period included what to do now, how to return to normal and receiving guidance or information relevant to this was important to survivors (Hackett & Dowling, 2019; Herrmann et al., 2020; Monterosso et al., 2017; Parry et al., 2011; Raphael et al., 2019). The transition away from the safety net of hospital interaction at the end of treatment was described as a sense of loss or abandonment by the health system, while others discussed the need for a new normal (Monterosso et al., 2017; Parry et al., 2011). Transitions to follow-up care in fragmented health service systems were reported (Chen et al., 2020). While a need to make sense of the experience of cancer was felt by survivors, some reported seeing others “survive and thrive” after cancer as empowering (Swash et al., 2018, p. 1470).

A lack of targeted and specialty services for lymphoma contributed to survivor distress (Chen et al., 2020; Parry et al., 2011). For lymphoma survivors, limited financial and psychosocial support was available compared to other cancer groups such as breast cancer (Parry et al., 2011). From a US perspective, speciality lymphoma care providers in smaller hometowns were scarce and contributed to negative experiences of diagnosis, including in some cases incorrect diagnosis (Chen et al., 2020). In addition, travel distance was a barrier to care for some survivors with long commutes and travel costs (Chen et al., 2020; Herrmann et al., 2020). Specific barriers to psychological wellbeing were found. The diagnosis of haematological malignancy in older persons is frequently delayed due to issues with referrals, general practitioners' limited knowledge of haematological pathologies and complications of comorbidities in masking symptoms (Fauer et al., 2021). Almost one-third of participants (*n=523*) who participated in a cross-sectional survey study indicated a need to avail of psychological health care, of which more than half indicated this need was left unmet (Keegan et al., 2012). Qualitative reports from participants show an acute awareness of the busy clinical environment and demands on healthcare professionals, this was a barrier to some survivors' in expressing their needs with health care professionals as they did not feel comfortable disturbing staff (Swash et al., 2018).

2.3.2 Theme Two The Psychological Impact of Cancer

The fear of cancer recurrence was a predominant concern reported by lymphoma survivors (Hackett & Dowling, 2019; Kang et al., 2018; Lobb et al., 2009; Monterosso et al., 2017; Posluszny et al., 2016; Raphael et al., 2019). For some lymphoma cancer survivors any physical symptom experienced instilled fear of recurrence between follow-up appointments. A heightened fear was experienced in the days before and of scheduled appointments (Hackett & Dowling, 2019). Help to manage the fear of recurrence was a frequently endorsed need in reviewed studies (Lobb et al., 2009; Posluszny et al., 2016; Raphael et al., 2019). The fear of recurrence was described as a common experience of living with uncertainty and fear for some focus group participants (n = 17) (Monterosso et al., 2017). However, the degree of fear of recurrence was not found to be different between stages of aggressive NHL (Kang et al., 2018). Other means of psychological distress was reported by many lymphoma cancer survivors, including depression, anxiety, and stress (Hall et al., 2014; Lekdamrongkul et al., 2021; Ng et al., 2016; Oberoi et al., 2017a; 2017b; 2017c; Paul et al., 2017; Raphael et al., 2019; Vargas-Román et al., 2020). Participants with above normal symptoms of depression and stress had statistically significant odds of reporting multiple high level unmet needs (Hall et al., 2014; Hall et al., 2015).

Younger participants reported better physical but worse mental health (Smith et al., 2010). Similarly, the initial delivery of the diagnosis was felt as important as the psychological adjustment was considered more difficult than the physical impact of disease (Swash et al., 2018). Perceived need for help was highest at diagnosis and escalated during cancer recurrence (Herrmann et al., 2020). One study reported on the psychosocial impact of body image for this cancer group; female survivors' body image is more impaired and markedly varies from their male counterparts with more concern relating to their physical appearance than males (Zucchetti et al., 2017). Similarly, more concerns relating to physical appearance was shown by

females compared with male survivors (Zucchetti et al., 2017). Furthermore, an interesting finding from focus groups in the UK was how survivors felt different to other cancer patients (Swash et al., 2018).

Many lymphoma survivors reported impaired neurocognitive functioning affecting younger survivors of both NHL and HL (Arden-Close et al., 2010; Husson et al., 2017; Kang et al., 2018; Kreissl et al., 2020). Impaired cognitive functioning at diagnosis for NHL survivors was significantly associated with a lack of life purpose in long-term survivors (Kang et al., 2018). Over forty percent of NHL survivors (n = 370) from South Korea reported they were not happy or satisfied with their life (Kang et al., 2018). While a US cross-sectional survey study found survivors with active disease had more negative impacts of cancer compared with disease-free survivors (Smith et al., 2009).

2.3.3 Theme Three Impactful and Debilitating Concerns

A substantial burden of cancer and its treatment has been reported by survivors of lymphoma, including many who are free of disease (Hackett & Dowling, 2019). In longitudinal study conducted over 7 years, over half of the survivors developed one or more late effects, with cardiac complications being the most common (Khimani et al., 2013). Other physiological issues identified included loss of energy, loss of strength, recurrent infections, neurocognitive decline, neuropathy, lymphadenopathy, pruritis, weight changes and secondary cancers (Arden-Close et al., 2010; Hackett & Dowling, 2019; Monterosso et al., 2017; Smith et al., 2009; Vena & Copel, 2021b). While this reflects the wide range of problems affecting lymphoma survivors it is important to note the great heterogeneity in reporting of what constitutes 'common' symptoms for this cohort. Worse physical health and worse fatigue compared to the general population were found for survivors of lymphoma (Arden-Close et al., 2010; Husson et al., 2017; Kim et al., 2014). Some survivors had physical complaints which impacted their daily lives, others felt an indescribable change in how they physically felt (Raphael et al., 2019). Survivors with active disease, long-term disease, comorbidities, of older age or rural residence were associated with worse physical functioning (Arden-Close et al., 2010; Noonan et al., 2020; Smith et al., 2010; Smith et al., 2009).

Cancer-related fatigue persistently affects individuals with lymphoma and impacts upon quality of life (Behringer et al., 2016; Hall et al., 2015; Husson et al., 2017). The frequency of general practitioner visits was higher (almost double) for participants experiencing severe cancer-related fatigue in comparison to those without severe fatigue (Behringer et al., 2016). Prevalence of severe cancer-related fatigue in HL survivors was reported to reduce over a period of five years, however, a limitation of this study is that the sample also reduced over this time (baseline *n=3759*; 5-year follow-up *n=1758*). Severe fatigue was found to be a barrier to social reintegration and impacted survivors' capacity for social events, work commitments or even family time (Behringer et al., 2016; Hackett & Dowling, 2019). Two studies compared groups of survivors (by survivors' residence, rural versus urban and by country, Australian survivors with Canadian survivors), and both reported that dealing with feeling tired was their most commonly reported unmet need (Hall et al., 2013a).

Given the mean age of most participants was greater than forty years of age there was scarce reporting on fertility concerns for lymphoma survivors. Although few, infertility concerns or the likelihood of remaining childless compared to a normative control population were discussed (Greaves et al., 2014; Hackett & Dowling, 2019). Two studies discussed the use of sperm banking by male participants prior to treatment (Greaves et al., 2014; Murphy-Banks et al., 2022), while no studies reported its gender counterpart of egg harvesting. Sexual issues were among the highest-rated unmet needs for one study (Parry et al., 2012), with sexual changes mentioned by others (Greaves et al., 2014). Furthermore, survivors reporting a negative impact on sexual function as a result of cancer was seen more often in women or survivors using anti-depressants or experiencing body image concerns (Greaves et al., 2014).

2.3.4 Theme Four The Monetary Cost of Survival

Unmet financial and work-related needs were reported by many lymphoma survivors (Chen et al., 2012; Hall et al., 2013a; Hall et al., 2014; Hall et al., 2015; Hernæs et al., 2021; Husson et al., 2017; Kang et al., 2018; Keegan et al., 2012; Kim et al., 2014; Kreissl et al., 2020; Parry et al., 2012). Survivors worried about earning money; trouble meeting daily expenses; relocating due to cancer caused difficulty paying bills and depleted savings and were associated with unmet needs (Hall et al., 2014; Hall et al., 2015). Over sixty-five percent of survivors (*n=370*) of a single centre cohort study reported not receiving enough support from others with financial difficulties more frequently associated with insufficient support (Kang et al., 2018).

Differences in financial needs related to care delivery internationally were evident. Participants in a US study reported a lack of transparency from the billing department at a university hospital, while a study conducted in China recommended medical professionals to select cost-effective treatments while ensuring the financial consequences of treatments are understood by patients (Chen et al., 2020; Xu et al., 2020). Conversely, in Denmark individual were financially supported through state benefits (Arboe et al., 2017). This highlights discrepancies in the financial implications for lymphoma survivors based on their country of residence, due to the availability or lack of financial support systems relating to lymphoma cancer care.

From Germany to China, a large percentage (40 – 85%) of lymphoma cancer survivors from multiple countries reported being members of the workforce. Staying employed from diagnosis throughout treatment is associated with a consistently higher likelihood of employment later in life, regardless of symptom burden (Hernæs et al., 2021). Working gave some survivors a sense of purpose and provided financial security, while flexible working arrangements were helpful in meeting psychological and practical needs (Herrmann et al., 2020). Sometimes cost implications were experienced by survivors when adjustments to work or school were made due to cancer care (Murphy-Banks et al., 2022). While patients on sick leave during relapse following autologous stem cell transplantation were found to have a poorer prognosis relating to returning to work and a higher rate of disability pension (Arboe et al., 2017). Lower income was associated with greater unmet needs relating to expenses for medical and living costs (Parry et al., 2012). Furthermore, lymphoma survivors may be immunocompromised which can be a significant barrier to the return to work (Hackett & Dowling, 2019). However, for some survivors a return to work was seen as a return to normal (Hackett & Dowling, 2019).

2.3.5 Theme Five Insufficient Provision of Survivorship Information

Unmet information needs were prevalent in lymphoma survivors from varying countries and research approaches (Arden-Close et al., 2011; Herrmann et al., 2020; Keegan et al., 2012; Kim et al., 2017; Monterosso et al., 2017; Oerlemans et al., 2012; Parry et al., 2011; Swash et al., 2018). A lack of sufficient information that was helpful for patients in understanding their care was reported by a number of survivors of one study (n = 17) (Herrmann et al., 2020). Being in receipt of information relating to survivorship, such as possible long term side effects of treatment, being informed about prevention of recurrence or recommended screening programmes were reported by few (Hackett & Dowling, 2019; Keegan et al., 2012; Kim et al., 2017). While explicit conversations about late effects were desired by all participants of semi-structured interviews (n = 17) (Murphy-Banks et al., 2022).

Monterosso et al. (2017) suggested some health care professionals did not anticipate the required information and support needed post-treatment leaving survivors' information needs unmet. While survivors from another study felt health care providers were unprepared to help them with survivorship concerns, including physical and psychosocial issues in the posttreatment period (Parry et al., 2011). The delivery and the personalisation of information that was relevant to the individual was considered important (Swash et al., 2018). Moreover, comprehensive verbal information supplemented with written take-home information was appreciated by survivors (Herrmann et al., 2020).

There were gender differences in the provision of information needs, with males being more likely to report unmet information needs (Keegan et al., 2012). Men wanted to discuss more topics than they did, while women managed to discuss the topics which they wished to discuss (Arden-Close et al., 2011). However, one study found satisfaction with information provision was relatively good in two-thirds of survivors with HL being the most satisfied (74%) (Oerlemans et al., 2012). The use of technology was seen as favourable for improved communication with clinical teams by survivors (Chen et al., 2020). Similarly, the use of Survivorship Care Plans may provide opportunities for good information provision regarding the ongoing sequelae of survivorship concerns between healthcare professionals and survivors (Oerlemans et al., 2012).

2.4 Discussion

Research surrounding the needs of lymphoma survivors is emerging and increasing. However, a heavy focus on quantitative approaches is evident which lacks in-depth qualitative exploration and limited mixed methods and longitudinal data. Most of this research has been conducted at single sites, limiting generalisability. In addition, there is wide-ranging use of varying instruments to assess the needs or associated factors (i.e., quality of life outcomes) of lymphoma survivors with only one instrument designed and validated for a lymphoma-specific population (FACT-LYM). Wider literature reporting on lymphoma heavily emphasises the increased risk of infection for this group (Andersson et al., 2011; Miller et al., 2016). Yet limited literature included in this review reflects this concern. This spotlights the importance of using validated instruments that are sensitive to the needs and side effects relative to lymphoma-specific populations.

Methodological quality of included articles was high, yet key details relating to sociodemographic information, socioeconomic status, time since diagnosis, stage of disease and the stage of survivorship require improved reporting to improve understanding. The varied and inconsistent reporting of included literature has impaired the ability to quantify this research question through meta-analytical approaches. However, despite the advancement and positive associations with lymphoma survivorship, it is not without consequences as survivors are living with and beyond a lymphoma diagnosis with a myriad of needs and compromised quality of life.

Disparity in the delivery of health services involved an individualised response to the transition after treatment, ranging from a sense of abandonment to a welcomed change. Limited evidence suggests health service delivery is fragmented for lymphoma survivors with a lack of available speciality services. Furthermore, survivors of one qualitative study felt different to other cancers while survivors of another noted more supports were available for breast cancer as opposed to lymphoma. Moreover, lymphoma diagnosis can often be delayed which may negatively impact patient outcomes. While evidence on the factors influencing the timing of diagnosis is limited, they may include the complexity of older age and delayed recognition by non-haematological specialty health providers such as general practitioners (Fauer et al., 2021; Howell et al., 2019). Yet, it is important to acknowledge the complexities of these issues which may be multifactorial, involving both patient and health service provider-related problems and solutions (Frick et al., 2018).

Similar to a systematic review conducted on factors associated with fear of recurrence in cancer patients (over half of included studies focused on breast cancer), there was an association between physical symptoms for lymphoma survivors and fear of cancer recurrence (Crist & Grunfeld, 2013). Additionally, there is a need for better information provision for patients on the cost of ongoing treatment relative to quality of life. Mitigating against the delivery of toxicities with potentially little gain to survival, especially for elderly populations (Bron et al., 2017; Niscola et al., 2015). More research into the challenging concern of toxicity versus quality of life in this population is needed to support healthcare professionals and health systems.

Financial hardship among survivors is well documented; however, substantial heterogeneity in its prevalence has been found by a systematic review of mixed cancer types (Mehnert et al., 2013). For lymphoma, this rapid review found that many survivors are among our workforce internationally and financial and work-related concerns are commonly associated with unmet needs. Of the included studies reporting the employment status of participants, a sizeable percentage (40 – 85%) of lymphoma cancer survivors are in the global work force. Therefore, an enhanced awareness for the occupational wellbeing of lymphoma survivors is required of employers, colleagues, and insurance companies as the effects of cancer and its treatment can linger long past treatment completion (Duijts et al., 2014).

Fertility is one concern specific to younger lymphoma survivors. Survivors may feel uncertain about their fertility post treatment and available preservation strategies (i.e., egg harvesting, sperm banking)

(Hodgson, 2015). Being cognisant of survivors' preferences is important in developing novel survivorship services to optimise engagement (Mayo et al., 2021). However, the current evidence on fertility needs and sexual needs of lymphoma cancer survivors is scarce which limits capacity to direct care and support systems for this group. Themes contain layers they are textured and nuanced, and this review has used them to capture the rich diversity of the needs of lymphoma cancer survivors. The findings of this review extend our current understanding of lymphoma cancer survivors who experience of myriad of unmet needs from diagnosis to survivorship.

2.4.1 Limitations

The key limitations of current literature involve the lack of qualitative, mixed methods and longitudinal approaches with the overall heterogeneity of included articles inhibiting deeper analysis or a meta-analytical approach to improve understanding of this research problem. There is extremely limited evidence on the spiritual needs of this population. No included studies reported the needs of lymphoma cancer survivors from Africa or South America. While the rapid review method has been found to be used inconsistently and with poor quality reporting in the literature (Tricco et al., 2015), this rapid review employed several recommendations from Cochrane's interim rapid review guidance including search strategy involvement of an information specialist and two independent reviewers for dual screening of abstracts with conflict resolution. However, it is important to acknowledge that reviews can only be as good as the quality of the primary research on which it is based. Despite drawing on systematic approaches, this review cannot claim to have exhausted all relevant evidence and did not include literature published in languages other than English.

2.4.2 Clinical Implications

Future research is required to address the sparse focus on lymphoma-specific research and disparate reporting which impairs a comprehensive understanding of lymphoma cancer survivors' needs. Moreover, the concepts of unmet needs and quality of life are closely related. This review identifies a need for further clarification on the relationship between unmet needs and quality of life to help guide future research and enhance meta-analytical approaches in this area. This review shows that lymphoma cancer survivors experience a myriad of unmet needs across multiple domains, reinforcing the need for lymphoma-specific research. Lymphoma survivors have reported their desire for more holistic and survivorship-oriented research relating to quality of life and guidance for health and wellbeing (Payne et al., 2019). Therefore, the findings of this review may offer input for the development of supportive interventions for these survivors.

2.5 Conclusion

Despite advances in the survival rates of lymphoma survivors, the treatment of cancer is unfortunately not without consequence. This often contributes to various needs that are frequently long-term. Lymphoma survivors are largely active in our global workforce yet experience a significant burden of financial and work-

related concerns. They experience disruption to psychosocial wellbeing including fear of cancer recurrence, fragmented health services and insufficient provision of information relating to survivorship. This review identified important and timely information which can aid the improvement of survivorship care for this growing, diverse, and underserved population.

2.5.1 In the Context of this Thesis

This review identified that various instruments were used to measure the unmet needs of lymphoma survivors with limited consideration of their psychometric quality, this warrants further investigation. Therefore, the next chapter explores this further to develop this current thesis to meet its aim to comprehensively investigate the unmet needs of lymphoma survivors. Other limitations included previous studies' samples recruited from single hospital sites or registries and lymphoma included within mixed cancer samples. The quality assessment found that this body of literature did not include active involvement of participants in the design or conduct of studies, showing a lack of public and patient involvement (PPI) in this field of research. As a consequence of these limitations, the understanding of lymphoma survivors' unmet needs is limited. This thesis builds on these limitations in subsequent chapters, through a comprehensive review of instruments for this population and constructs of interest (Chapter 3), a multi-site lymphoma-specific investigation and engagement with individuals with lived experience of lymphoma (Chapter 5). Therefore, this publication adds to this thesis as it contributes to placing due attention on the needs and research priorities of lymphoma survivors.

Chapter 3 Measuring Lymphoma Survivors' Unmet Needs

3.1 Introduction

There is increasing recognition of the complex impact of a cancer diagnosis and its treatment, which has led to efforts to develop instruments to reflect survivors' needs accurately. The literature review underpinning this thesis found that there is a limited understanding of the decision-making involved in the selection of instruments used to measure lymphoma survivors' unmet needs, especially regarding their psychometric quality (Boland et al., 2022). Building on this limitation of current evidence, this chapter outlines the fully integrated publication arising from this thesis entitled 'Content comparison of unmet needs self-report measures for lymphoma cancer survivors: A systematic review', which was published in PLOS ONE (2023, 18(12): e0290729. https://doi.org/10.1371/journal.pone.0290729)[2]. The goal of this publication was to evaluate the psychometric properties and comprehensiveness of available self-report instruments to assess unmet needs and quality of life with adult lymphoma survivors. This directly corresponds with objective three of this thesis: to evaluate the content and quality of instruments used with lymphoma survivors for assessing the constructs of interest. Assimilating this evidence is warranted to inform the development of this mixed methods study, including the selecting of instruments and development of the phase one survey. To enable evidence-based recommendations for this thesis, this involved identifying available instruments, conducting a content comparison of the selected instruments, appraising the pertinent psychometric measurement properties.

3.2 Background

Measurement is central to health research and clinical practice (De Vet et al., 2011). The centrality of the patient perspective in cancer care is critical to achieving meaningful research outcomes. Patient-reported outcome measures assist in identifying the most prevalent concerns for a target population (Wen & Gustafson, 2004). Optimal cancer care requires an adequate understanding of the needs of survivors and the factors that influence them (Richardson et al., 2007; Wen & Gustafson, 2004). Efforts to improve the availability of care and resources for cancer survivors have been advanced by assessing survivors' needs (McDowell et al., 2010). As the number of cancer survivors continues to rise, healthcare services and policymakers must understand this population's needs and quality of life outcomes (Campbell et al., 2011). This information can focus on the most problematic or prevalent concerns for cancer survivors or facilitate the detection of problems that might otherwise be overlooked (Valderas et al., 2008). Instruments that accurately measure the influence of cancer on quality of life and the level of unmet needs in the expanding population of cancer survivors are needed. Various instruments are available to measure cancer survivors' diverse outcomes, yet guidance on optimising their selection and recommendations for use is scarce. Selecting appropriate instruments for measuring outcomes of interest is challenging given the vast proliferation of such questionnaires over the past decades (Ahmed et al., 2012), which have been

[2] **Boland, V.**, Drury, A., & Brady, A. M. (2023). Content comparison of unmet needs self-report measures for lymphoma cancer survivors: A systematic review. *PLOS ONE*, *18*(12): e0290729. https://doi.org/10.1371/journal.pone.0290729

associated with a general lack of clarity in their intended applications (Marshall et al., 2006; Valderas et al., 2008).

A cancer diagnosis poses a potential threat to life, disrupts daily functioning and is a barrier to psychological health and well-being (Pereira et al., 2020). Tumour site-specific research is required to advance future research and healthcare delivery that is responsive to survivors' needs (Chen et al., 2020; Esser et al., 2018). Lymphoma, the most prevalent haematological cancer, affects an estimated 628,000 new annual cases worldwide across all age groups (Sung et al., 2021). Originating in the lymphatic system, the widespread nature of lymphoma can affect any organ in the body, creating a range of symptoms depending on the location (Armitage et al., 2017; Swerdlow et al., 2016). It is categorised into two types, Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL), with indolent and aggressive forms (Swerdlow et al., 2016).

The varied clinical features and histological appearances of lymphoma present challenges such as difficult diagnosis, complex management strategies and assorted prognoses (Howell et al., 2019; Ng et al., 2011). Moreover, long-term morbidity and mortality impact quality of life and can pose challenges associated with lymphoma survivorship (Ng et al., 2011). Lymphoma survivors are substantially increasing due to success in treatment modalities, producing a growing dependency on health care services from diagnosis and treatment to follow-up and survivorship care (Frick et al., 2018). Despite improvements in survival rates, treatment toxicities are endured by patients (Hlubocky et al., 2013). Therefore, assessing needs and quality of life outcomes among people living with and after lymphoma is important to understand better lymphoma survivorship and its influencing factors (Lekdamrongkul et al., 2021).

Scant guidance is currently available on measuring lymphoma survivors' needs and quality of life outcomes. Numerous quality-of-life instruments are used in the current literature on lymphoma survivors, demonstrating a largely non-standardised approach to measuring different quality-of-life outcomes. This has impaired opportunities for meta- analysis to form conclusions and recommendations for this population (Boland et al., 2022). Moreover, Goswami et al. (2019) reviewed the quality of life instruments available for haematological malignancies; of the thirty instruments identified, only one was a lymphoma-specific tool (Functional Assessment of Cancer Therapy - Lymphoma).

Conceptual uncertainties exist as to what constitutes a healthcare need. 'Unmet needs' discriminate between the needs experienced by survivors and those they wish for help in managing. 'Quality of life' involves an individual's perception of their position in life, which is context-bound to their culture, values, and way of life (World Health Organisation, 1995). The two constructs of interest share an interrelation and are commonly used in cancer survivorship research, a period that begins at diagnosis and continues until the end of life (Drury et al., 2017a; Khan et al., 2012). However, the factors that have the greatest impact on unmet needs and overall quality of life outcomes are often not routinely captured. Thus, the most prevalent survivorship issues may not always be the most impactful (Drury et al., 2022).

An issue for healthcare research is the range of available outcome measurement instruments measuring the same constructs with further patient-reported outcome measures in development. The diversity of

available instruments leads to heterogeneity in the evidence generated, which is problematic for evidence-based recommendations. Choosing the most suitable and applicable instrument is vital, as selecting inappropriate or poor-quality instruments may present bias in the conclusions of studies (Mokkink et al., 2016). As the availability of generic, cancer-related, and tumour-site-specific outcome measures increases, a review is required to assimilate evidence on available instruments.

This research aims to evaluate the content and quality of instruments used with lymphoma survivors for assessing the constructs of interest (unmet need and quality of life). The Consensus-based Standards for selecting health Measurement Instruments (COSMIN) methodology was developed explicitly for studies on health-related patient-reported outcomes (De Vet et al., 2011) and will support evidence for lymphoma-specific research in this current review. The objectives are:

i) To identify available instruments measuring the unmet needs and quality of life outcomes of lymphoma survivors in current literature.

ii) To conduct a content comparison of the included instruments and appraise the pertinent psychometric measurement properties.

iii) To provide evidence-based recommendations for applying patient-reported lymphoma-specific outcome measurements in future research.

3.3 Methods

3.3.1 Study Design

This systematic review was conducted and reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Guidelines (Moher et al., 2009; Page et al., 2021). The ten-step procedure developed by COSMIN for conducting a systematic review of outcome measures further guides this study (Prinsen et al., 2018). The COSMIN-validated Risk of Bias checklist supports evaluation of patient-reported outcome measures, and a user manual provides a step-by-step guide to instrument appraisal (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). Measurement properties are only assessed if presented in the selected article.

3.3.2 Search strategy

The author of this thesis conducted a recent review using a rapid review methodology and reflexive thematic analysis to gather current evidence on lymphoma survivors' unmet needs and quality of life outcomes (Chapter Two). The study focused on adult lymphoma survivors of any subtype or stage. Five databases: CINAHL, EMBASE, Medline, PsycInfo and Scopus, were systematically searched from 2006 – February 2022, limiting the search to English-language articles. A researcher and an information retrieval specialist performed the search strategy and database searches. Two independent reviewers screened and assessed the methodological quality of all included studies. The full review methodology and methods are discussed elsewhere (Boland et al., 2022).

Articles included in this rapid review and their extracted data (i.e., details on the instruments used) provided a list of instruments relevant to the construct and population of interest. Thirty-six studies included in this review used thirty-one different outcome measurement instruments in a population with at least fifty per cent lymphoma survivors. Next, the published articles reporting the original development or validation of these instruments were retrieved based on the citation(s) provided for each paper. In addition, the COSMIN Database of Systematic Reviews of Outcome Measurement Instruments was searched to cross-check the completeness of identified instruments for this population. The search terms for this database included: "lymphoma", "non-Hodgkin lymphoma", "Hodgkin lymphoma", "haematological malignancy", and "blood cancer". All papers identified via this process were then imported into Covidence for screening according to the inclusion and exclusion criteria of the review.

3.3.3 Eligibility criteria

The eligibility criteria are outlined in Population, Issue, Comparison, Outcome, Study (PICOS) format in Table 3.1. Peer-reviewed articles reporting the evaluation of the psychometric properties of relevant self-reported measures for unmet need or quality of life was restricted to studies concentrating on the development or validation of a single instrument. One researcher initially screened the instruments, with verification by two other researchers; discrepancies were resolved through discussion to achieve consensus to minimise selection bias. Studies evaluating an instrument of interest but using a validation process with another instrument were excluded from the review for two reasons: 1) difficulty identifying such articles systematically and 2) interpreting their results (De Vet et al., 2011).

Table 3.1 Eligibility Criteria in PICO Format

PICO	Inclusion Criteria	Exclusion Criteria
Population	Lymphoma survivors of any stage and subtype. Studies were included if they included lymphoma survivors (>50%) in homogenous or heterogeneous groups.	Populations that are not lymphoma cancer specific.
Issue	Instruments that collect data directly from participants. Content for patient-reported outcomes questionnaires.	Experimental measurements or interventions. Not patient-reported outcomes-based.
Comparison	NA	NA
Outcome	The instrument should address one of two multidimensional constructs of interest i) unmet need or ii) quality of life.	Constructs that do not meet the definition of needs and quality of life or measure only a single aspect (i.e., anxiety or depression).
Study	Development of validation studies on a single instrument. English language only. Full-text reports.	Validation or comparison studies on more than one instrument. Abstracts that need more information to enable adequate data extraction.

3.3.4 Conceptual Framework and Content Analysis

The Supportive Care Framework for Cancer Care was designed to conceptualise what type of support cancer patients might require and how to approach planning for service delivery (Fitch, 1994; Fitch, 2008). The framework appropriately focuses on distinguishing between concerns experienced by individuals with cancer. Identifying unmet needs offers informed evidence to guide where help is required. The

framework's domains encompass the physical, psychological, emotional, social, practical, informational, and spiritual needs of an individual with cancer (Fitch, 2008). Individual mapping of items within the included instruments against the framework's domains was conducted to illustrate the content and fundamental domains of unmet needs addressed by each instrument.

3.3.5 Assessment of Measurement Properties

The consensus-based standards for selecting health measurement instruments (COSMIN) methodology guided this evaluation (Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018). If a study meets the standards for good methodological quality, the risk of bias is minimal (De Vet et al., 2011). The COSMIN taxonomy of measurement properties distinguishes consensus-based definitions of measurement properties and their order of importance. Each present measurement property (structural validity, internal consistency, reliability, measurement error, construct validity, and responsiveness) was evaluated for risk of bias, so the prominent measurement properties identified received appraisal by one reviewer with verifications by two reviewers.

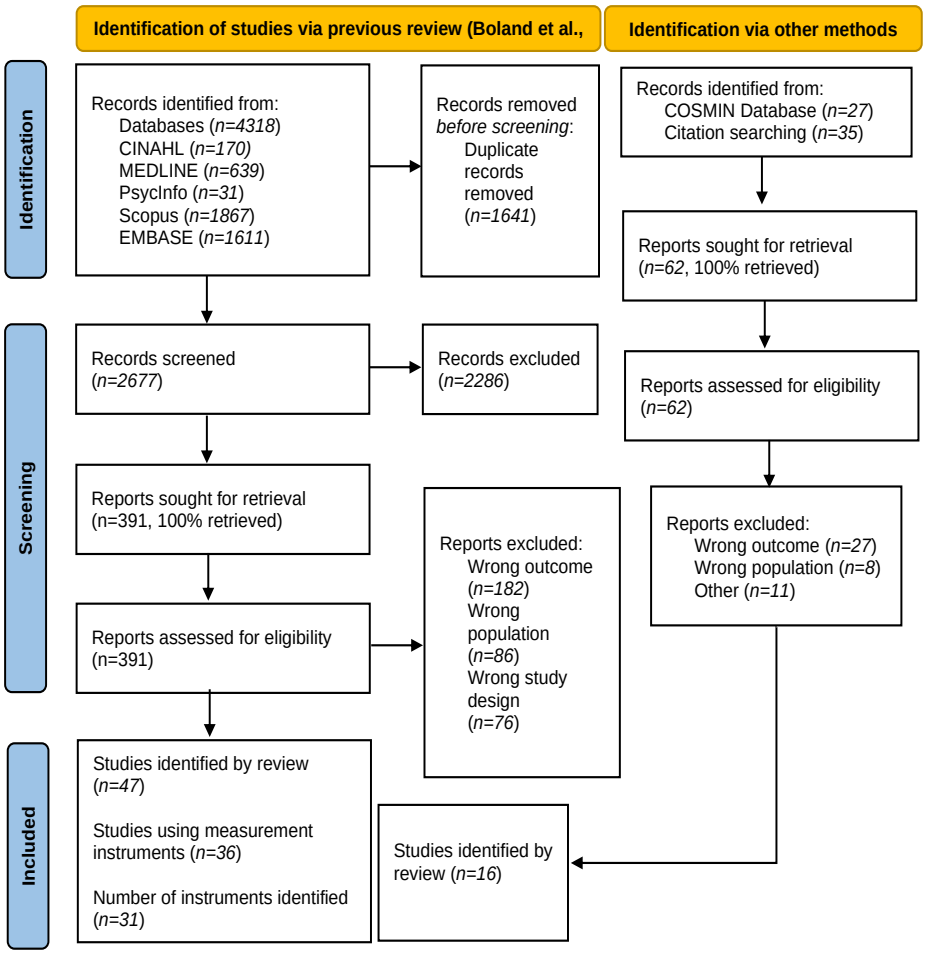
3.4 Results

Thirty-one instruments were identified (Boland et al., 2022). Several were excluded (*n=19*); some were too specific (i.e., Functional Assessment of Chronic Illness Therapy – Fatigue, or Hospital Anxiety and Stress Scale) (*n=9*); others had the wrong outcome (i.e., Profile of Mood States) (*n=7*) or wrong population (i.e., Support Persons Unmet Needs Survey) (*n=2*) (Appendix 4). Therefore, twelve instruments were identified across the reviewed studies that met the inclusion criteria: four measured unmet needs and eight measured quality of life. The PRISMA flow diagram (Figure 3.1) outlines the complete results process.

3.4.1 Study Characteristics

Citation screening identified sixteen original articles reporting on developing and validating the twelve included instruments. Characteristics of the instruments (e.g., purpose, indication) and the study properties (e.g., sample characteristics, country of origin, instrument administration) were extracted to facilitate comparison and analysis. Most instruments (*n=9*) had a generic cancer indication; two were generic quality of life measures (SF-36 and EQ-5D-5L) commonly used with cancer survivors (Herdman et al., 2011; Ware & Sherbourne, 1992), and one was lymphoma-specific (FACT-LYM) (Hlubocky et al., 2013). Four different instruments focused on the construct of need: Cancer Survivor Unmet Needs (CaSUN), 34-item Short-form Supportive Care Needs Survey (SCNS-SF34), Survivor Unmet Needs Survey (SUNS), and Short-form Survivors Unmet Needs Survey (SF-SUNS). Eight instruments focused on quality of life: EuroQol 5-Dimension, 5-Level instrument (EQ-5D-5L), European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), The Functional Assessment of Cancer Therapy – General (FACT-G), The Functional Assessment of Cancer Therapy – Lymphoma (FACT-LYM), Impact of Cancer (IOC), Impact of Cancer Version 2 (IOCv2), and Quality of Life – Cancer Survivor (QoL-CS).

Figure 3.1 PRISMA Flow Chart



The total number of items for instruments varied considerably from five items (EQ-5D-5L and a visual analogue scale) to 89 items (SUNS). The recall period for instruments included the last month (*n=3*), the past week (*n=2*), and today (*n=1*), but some did not clearly define this. Likert scales with five points were mainly used, with a higher score indicating more problems or a greater need for most instruments. The completion time for instrument questionnaires ranged from 5 to 24 minutes (mean = 12 minutes); a completion time was not retrieved for four instruments (IOC, IOCv2, QoL-CS SF-SUNS). Quality-of-life instruments were primarily developed in the USA, with the EORTC QLQ-C30 and EQ-5D-5L developed across multiple countries (Aaronson et al., 1993; Herdman et al., 2011). Needs instruments originated from Australia (55%) and Canada (45%) (Boyes et al., 2009; Campbell et al., 2014; Campbell et al., 2011; Hodgkinson et al., 2007), with one study for the SUNS developed in both countries (Hall et al., 2013a). Sample sizes of the included studies ranged from 40 to 3,919 participants (Table 3.2-3.3). More than half of the articles (56%) had lymphoma participants in the validation and development studies, with almost 20% using a homogenous lymphoma sample (Crespi et al., 2010; Hlubocky et al., 2013; Taylor et al., 2018). Two articles recruited participants with heterogeneous haematological cancers (Hall et al., 2013a; Hall et al., 2014). Instruments varied in their targeted survivorship trajectory, including longer-term survivors (CaSUN, IOC, IOCv2 and QoL-CS), more acute (EORTC QLQ-C30, FACT-G and FACT-LYM), and a specified

period of one to five years post-diagnosis (SUNS and SF-SUNS). Statistical pooling of results for meta-analysis was not performed as there were not enough studies or sufficiently similar studies to combine results (De Vet et al., 2011). Therefore, this study's approach to synthesis is the best evidence synthesis. This qualitative analysis considers the methodological quality of studies, the homogeneity of studies, and a content comparison of the instruments (De Vet et al., 2011).

Table 3.2 Summary Characteristics of Unmet Needs Instruments

Instrument	Original development study (author, year)	Population	Sample characteristics (% lymphoma)	Disease duration	Survivorship stage	Instrument administration	Country
CaSUN	Hodgkinson (2007)	*n=353*	Heterogenous cancer survivors	Diagnosed one or more years earlier and disease-free	1 to 15 years post-diagnosis	Two hospital outpatient clinics (breast cancer, mixed cancers)	Australia
SCNS-SF34	Boyes (2008)	*n=888*	Heterogenous cancer survivors	Unclear	Unclear	Secondary analysis from nine cancer treatment centres in one Australian state	Australia
SF-SUNS	Campbell (2014)	*n=1589*	Heterogenous cancer survivors (5.3% NHL)	12 to 60 months post-cancer diagnosis	1 to 5 years post-diagnosis	Three population-based cancer registries	Canada
	Taylor (2018)	*n=40*	Homogenous lymphoma patients (72.5% NHL, 27.5% HL)	Three months post-treatment completion	1 to 5 years post-diagnosis	One tertiary hospital in Australia	Australia
SUNS	Campbell (2011)	*n=550*	Heterogenous cancer survivors	12 to 60 months post-cancer diagnosis	1 to 5 years post-diagnosis	Population-based cancer registry	Canada
	Hall (2013a)	*n=437*	Heterogenous haematological cancer survivors (>50% lymphoma)	1 to 60 months post-cancer diagnosis	1 to 5 years post-diagnosis	Australian and Canadian cancer registries	Australia, Canada
	Hall (2014)	*n=715*	Heterogeneous haematological cancer survivors (59% NHL, 6.2% other lymphoma)	Median time since diagnosis was 35 months	1 to 5 years post-diagnosis	Four Australian state population-based cancer registries	Australia

Key: CaSUN= Cancer Survivor Unmet Needs, SCNS-SF34=34-item Short-form Supportive Care Needs Survey, SF-SUNS=Short-Form Survivor Unmet Needs Survey, SUNS=Survivor Unmet Needs Survey, NHL-Non-Hodgkin Lymphoma.

Table 3.3 Summary Characteristics of Quality of Life Instruments

Instrument	Original development study (author, year)	Population	Sample characteristics (% lymphoma)	Disease duration	Survivorship stage	Instrument administration	Country
EQ 5D-5L	Janssen (2012)	*n=3919*	Patients with chronic conditions	NA	NA	Various administrations in 5 countries	Denmark, England, Italy, the Netherlands, Poland and Scotland
EORTC QLQ-C30	Aaronson (1993)	*n=305*	Homogenous nonresectable lung cancer	Unclear	Unclear	Health centres in 13 countries	USA
FACT-G	Cella (1993)	*n=854*	Heterogenous cancer patients (8% lymphoma and leukaemia)	Unclear	Unclear	Medical centre, support centre and from an intervention study	USA
FACT-LYM	Hlubocky (2012)	*n=84*	Homogenous NHL patients (100% NHL)	At least two months after diagnosis of NHL	Unclear	Three medical centres in one city	USA
IOCv2	Crespi (2008)	*n=1840*	Breast cancer survivors and non-Hodgkin lymphoma survivors (35% NHL)	Five to ten years post-diagnosis, disease-free	Long-term survivors	Cancer registries, members of the previous study	USA
	Crespi (2010)	*n=652*	Homogenous NHL survivors (100% NHL)	At least two years post-diagnosis	Long-term survivors	Cancer registries	USA
IOC	Zebrack (2006)	*n=193*	Heterogenous long-term cancer survivors (25% lymphoma)	Five to ten years post-diagnosis, disease-free, off treatment	Long-term survivors	One university cancer registry	USA
QoL-CS	Ferrell (1995)	*n=686*	Heterogenous cancer patients (9% lymphoma, 8% HL)	4 to 538 months post-diagnosis	Long-term survivors	Cancer survivorship mailing list	USA
SF-36	McHorney (1994)	*n=3445*	Patients with chronic medical and psychiatric conditions	NA	NA	Various health centres in three cities	USA

Key: EQ 5D-5L=EuroQoL Five Dimension Five Level, EORTC QLQ-C30=European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire, FACT-G=Functional Assessment of Cancer Therapy-General, FACT-LYM=Functional Assessment of Functional Therapy-Lymphoma, IOCv2=Impact of Cancer Version Two, IOC=Impact of Cancer, QoL-CS=Quality of Life-Cancer Survivor, SF-36=Thirty-six Item-Short Form Survey, NHL=Non-Hodgkin Lymphoma, HL=Hodgkin Lymphoma.

3.4.2 Content Comparison

Comparison of instrument content helps appraise a measure's relevance for a specific purpose. Each domain of the Supportive Care Framework (SCF) by Fitch (1994) was addressed by at least four instruments (Table 3.4). All of the SCF frameworks domains are covered by the CaSUN. Six instruments (SCNS-SF34, SUNS, SF-SUNS, IOC, IOCv2 and QoL-CS) had greater than 70% coverage with the domains. Four instruments addressed more than half of the domains (EORTC QLQ-C30, FACT-G, FACT-LYM and SF-36), with a generic instrument, the EQ-5D-5L, only covering three domains, physical, emotional, and practical. All included instruments addressed the emotional domain, and a majority (*n=11*, 92%) covered the practical domain. The physical and social domains were represented by ten instruments each. The item content of seven instruments related to the psychological domain but a minority of instruments (*n=4*; 33%) specifically addressed either informational (CaSUN, SCNS-SF34, SUNS and SF-SUNS) or spiritual (CaSUN, IOC, IOCv2, QoL-CS) needs within their items.

Table 3.4 Supportive Care Framework's Domains Addressed by Each Included Instrument (Fitch, 2008)

Supportive Care Framework's Domains – Instruments													
	1	2	3	4	5	6	7	8	9	10	11	12	%
Physical	X	X			X	X	X	X	X	X	X	X	83
Psychological	X	X	X	X					X	X	X		58
Emotional	X	X	X	X	X	X	X	X	X	X	X	X	100
Social	X		X	X		X	X	X	X	X	X	X	83
Practical	X	X	X	X	X	X	X	X	X	X		X	92
Informational	X	X	X	X									33
Spiritual	X								X	X	X		33
% Covered	100	71	71	71	43	57	57	57	87	87	71	57	

Key: X=present. 1=CaSUN, 2=SCNS-SF34, 3=SUNS, 4=SF-SUNS, 5=EQ-5D-5L, 6=EORTC QLQ-C30, 7=FACT-G, 8=FACT-LYM, 9=IOC, 10=IOCv2, 11=QoL-CS, 12=SF36.

3.4.3 Validity

The validation of psychometric tools ensures that measurements are accurate and meaningful for their target population (Aldridge et al., 2017). Content validity refers to the extent to which an instrument measures what it is intended to measure (Lynn, 1986; Polit & Beck, 2004; Waltz et al., 2010). Content validity was adequately reported by 30% of included studies (Campbell et al., 2011; Ferrell et al., 1995; Herdman et al., 2011; Hodgkinson et al., 2007; Zebrack et al., 2006). For instance, the IOC appropriately reported its concept elicitation in a large qualitative sample of long-term cancer survivors (*n=47*) (Zebrack et al., 2006). However, some studies provided limited reporting of qualitative methods undertaken for item generation, while others only utilised quantitative survey methods. Short-form instruments usually derive from an original longer-form instrument; the reporting of the newer adapted instrument must reorientate the reader to what the construct is; this is a limitation of the initial reporting for the SCNS-SF34 (Boyes et

al., 2009). A construct is a broad topic for a study; it contains related dimensions (or subscales) treated as a single theoretical concept. Structural validity measures the degree to which the scores of a measurement instrument reflect the construct's dimensionality (Mokkink et al., 2010). The included instruments mainly incorporated a multidimensional and discriminative approach. Confirmatory factor analysis is preferred over explorative factor analysis when a strong theory about the instrument's structure is known, although both are useful in evaluating structural validity (Mokkink et al., 2018). Several studies (44%) clearly described the use of exploratory factor analysis; its overarching goal is to identify the underlying relationships between measured variables (Campbell et al., 2014; Campbell et al., 2011; Crespi et al., 2008; Crespi et al., 2010; Hall et al., 2014; Hodgkinson et al., 2007; Zebrack et al., 2006).

3.4.4 Reliability

Reliability involves the degree to which the measurement is free from error (Kimberlin & Winterstein, 2008; Mokkink et al., 2010). Test-retest reliability measures the consistency of the same test over time (Mokkink et al., 2010) and helps us understand how dependable a measurement instrument is. If the correlation between the results at different time points is high, this is considered evidence for good test-retest reliability. Intraclass correlation coefficients describe how strongly units in the same group resemble each other (Landis & Koch, 1977). Intraclass coefficients for all subscales of the following instruments were calculated and inferred that the reliability for the FACT-G (0.81-0.92) was excellent, FACT-LYM (0.61-0.87) was good to excellent, and SF-SUNS (0.45-0.74) was fair to good (Cella et al., 1993; Hlubocky et al., 2013; Taylor et al., 2018). The Kappa (k) statistic's strength of agreement ranges from <0.40 (fair), 0.41-0.60 (moderate), 0.61-0.80 (substantial) and >0.81 (almost perfect) and provides a benchmark for interpretation (Landis & Koch, 1977). The test-retest reliability was low for the CaSUN (mean *k=0.13*) and moderate for the SUNS (mean *k=0.58*). While statistical outputs, as outlined above, are reported as verifications, the methods used to provide evidence for this reliability are mostly insufficiently explained to validate their use or evidence in the context of a wider population (i.e., no confidence intervals).

Internal consistency relates to how well an instrument measures what it aims to measure, or in other words, the degree of interrelatedness among items (Mokkink et al., 2010). Internal consistency only requires one data set (i.e., calculated without repeating the test) and is assessed by Cronbach's alphas which quantifies the level of agreement on a standardised scale (0 to 1). Higher values show higher agreement between items. Excellent internal consistency statistics (α=>0.70) were found in all subscales for half of the included studies; this indicates a high degree of homogeneity among the items with respective instruments (Tables 3.5-3.6) (Boyes et al., 2009; Campbell et al., 2014; Campbell et al., 2011; Crespi et al., 2008; Ferrell et al., 1995; Hall et al., 2014; Hlubocky et al., 2013).

Table 3.5 The Reliability and Validity of Unmet Needs Instruments Used with Adult Lymphoma Survivors

Unmet Needs Measure (Author)	Reliability	Validity
CaSUN (Hodgkinson et al., 2007)	Internal consistency: Cronbach's alpha value=0.96 for the multidimensional total scale and ranged between 0.78 and 0.93 for subscales. Reproducibility: Time interval = approximately three weeks. Mean test-retest reliability (Kappa coefficient) score=0.13.	Content validity: Based on previous qualitative research and literature review. Quantitative survey methods. Construct validity: Exploratory factor analysis, five factors.
SCNS-SF34 (Boyes et al., 2009)	Internal consistency: Cronbach's alpha values ranged from 0.86 to 0.96 for subscales.	Content validity: Derived from the original SCNS-LF59, the origin of the construct is not clearly described. Quantitative survey methods. Construct validity: Confirmatory factor analysis, five factors. Convergent validity: correlation with three other measures assessing psychosocial well-being, Distress Thermometer, Hospital Anxiety and Depression Scale and EORTC QLQ-C30 (r = 0.48-0.56).
SUNS (Campbell et al., 2011; Hall et al., 2013a; Hall et al., 2014)	Internal consistency: All Cronbach's alpha values were greater than 0.9 for subscales. Reproducibility: Time interval = around 28 days. High item test-retest reliability was stated without data shown (Hall et al., 2013a). Weighted Kappa coefficients between item responses from Time 1 and Time 2 ranged from 0.25 to 0.76 (mean = 0.58; SD = 0.09) (Hall et al., 2014). Cross-cultural reliability: face and content validity for Canadian and Australian haematological cancer patients (Hall et al., 2013a).	Content validity: Literature review, cancer survivor input, professional input, and a pilot test with feedback. Construct validity: Exploratory factor analysis, five factors. Convergent validity: correlation with all three subscales of the Depression Anxiety and Stress Scale (range 0.44-0.73).
SF-SUNS (Campbell et al., 2014; Taylor et al., 2018)	Internal consistency: All Cronbach's alpha values were greater than 0.85 for subscales (Campbell et al., 2014). Cronbach's alpha values ranged from 0.65 to 0.94 for subscales (Taylor et al., 2018). Reproducibility: Time interval = 5 days. Test-retest reliability (intraclass correlation with 95% confidence interval) scores = 0.45-0.74 (Taylor et al., 2018).	Content validity: Derived from the SUNS. Construct validity: Exploratory factor analysis, five factors. Intraclass correlations with the original domains of the SUNS were greater than 0.9, closely reflecting the original structure (Campbell et al., 2014).

Key: CaSUN= Cancer Survivor Unmet Needs, SCNS-SF34=34-item Short-form Supportive Care Needs Survey, SF-SUNS=Short-Form Survivor Unmet Needs Survey, SUNS=Survivor Unmet Needs Survey, NHL-Non-Hodgkin Lymphoma.

Table 3.6 The Reliability and Validity of Quality of Life Instruments Used with Adult Lymphoma Survivors

Quality of Life Measure (Author)	Reliability	Validity
EQ-5D-5L (Herdman et al., 2011)	Intraclass correlation coefficient: range reported by a systematic review (*n=9*) >0.7 shows good reliability (Feng et al. 2020).	Content validity: Derived from the EQ-5D-3L. Focus groups were used to investigate the face and content validity of the new version.
EORTC QLQ-C30 (Aaronson et al., 1993; Hjermstad et al., 1995)	Internal consistency: Cronbach's alpha values were 0.54-0.86 for pre-treatment and 0.52-0.89 for post-treatment. Reproducibility: Test-retest reliability (Pearson's correlation coefficient) scores = 0.82-0.91 (Hjermstad et al., 1995).	Content validity: Derived from the original EORTC QLQ-C36. Quantitative survey methods.
FACT-G (Cella et al., 1993)	Internal consistency: Cronbach's alpha values ranged from 0.65-0.89 for subscales. Reproducibility: Time interval = 3 to 7 days. Test-retest reliability (intraclass correlation) scores = 0.82-0.92.	Content validity: interviews with cancer patients and oncology professionals for item generation, item review/reduction and pilot test/evaluation. Convergent correlations: correlations performed with multiple tools, highest with the Functional Living Index-Cancer (r=0.79) and lowest with the Marlowe-Crowne Social Desirability Scale (r=0.22).
FACT-LYM (Hlubocky et al., 2013)	Internal consistency: Cronbach's alpha values were 0.70-0.95 at all time points. Reproducibility: Time interval = three-time points (baseline, 3-7 days, and 8-12 weeks). Test-retest reliability (intraclass correlation) scores = 0.61-0.87.	Content validity: item generation using semi-structured interviews with cancer patients and oncology professionals, item review/reduction and pilot test/evaluation. Convergent validity: correlation between the FACT-LYM and other FACT scales with the POMS total score (range = -0.42 to 0.68), SF-36 mental (r = 0.48, p=*<0.001*) and physical (r=0.62, p=*<0.001*).
IOC (Zebrack et al., 2006)	Internal consistency: Cronbach's alpha values were 0.67-0.89 for subscales.	Content validity: qualitative methods, nurse and social worker input, content analysis, pilot test.
IOCv2 (Crespi et al., 2008; Crespi et al., 2010)	Internal consistency: Cronbach's alpha values were 0.76-0.89 for breast cancer participants and 0.59-0.91 for non-Hodgkin lymphoma participants (Crespi et al., 2010).	Content validity: derived from the original IOC. Construct validity: De novo exploratory factor analysis. Concurrent validity: lack of correlation between the IOCv2 positive scale and the FACT-G, FACT-LYM and SF-36, showing the IOCv2 content is distinct from these scales.
QoL-CS (Ferrell et al., 1995)	Internal consistency: Cronbach's alpha values were 0.71-0.89 for subscales. Reproducibility: time interval = approximately two weeks. Overall test-retest reliability was 0.89.	Content validity: in-depth interviews, quality of life researcher and nurse input. Construct validity: Exploratory factor analysis. Concurrent validity: the overall correlation with the FACT-G was 0.78.
SF-36 (McHorney et al., 1994; Ware & Sherbourne, 1992)	Internal consistency: Cronbach's alpha values were 0.78-0.93 for subscales (McHorney et al., 1994).	Content validity: Medical Outcome Study previous literature and wider literature review on instruments (Ware & Sherbourne, 1992).

Key: EQ 5D-5L=EuroQoL Five Dimension Five Level, EORTC QLQ-C30=European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire, FACT-G=Functional Assessment of Cancer Therapy-General, FACT-LYM=Functional Assessment of Functional Therapy-Lymphoma, IOCv2=Impact of Cancer Version Two, IOC=Impact of Cancer, QoL-CS=Quality of Life-Cancer Survivor, SF-36=Thirty-six Item-Short Form Survey, NHL=Non-Hodgkin Lymphoma, HL=Hodgkin Lymphoma.

3.4.5 Other Measurement Properties

The prominent measurement properties of these instruments have been outlined above. However, other aspects warrant consideration, such as responsiveness, which aims to detect change over time in the construct to be measured. A barrier to assessing responsiveness is the need for more clarity about this measurement property in the literature (De Vet et al., 2011). One key aspect of responsiveness is its application; it is relevant for measurement instruments using an evaluative application (i.e., a longitudinal study measuring change over time) (De Vet et al., 2011). Many of the included studies in this review discriminated between participants at a single time-point, and therefore responsiveness is not an issue. Cross-cultural validity should be considered when an instrument is used in culturally different populations (i.e., ethnicity, language) and refers to the performance of a culturally adapted instrument (Mokkink et al., 2010). For example, one study found that haematological survivors (greater than half had a lymphoma diagnosis) from Australia and Canada responded similarly to items on the SUNS using logistic regression analysis (Hall et al., 2013a). However, few of the included tools have been subject to cross-cultural testing.

3.5 Discussion

To provide optimal supportive cancer care, identifying patients' perceived concerns and the level of support needed is required (Campbell et al., 2014). Standardisation in selecting outcome measurement instruments in specific research areas is warranted as it contributes to improved consistency in reporting, enables comparisons, and synthesises findings (Mokkink et al., 2016). The overarching purpose of this review was to address the gap in current knowledge for adult lymphoma survivors by appraising and comparing the available unmet needs and quality of life self-report measures for use with this population. As the number of lymphoma survivors continues to rise, so does their dependency on health systems and services. However, current literature for this population is disparate, and only one of the twelve included instruments was explicitly designed for use with lymphoma survivors (FACT-LYM).

Several instruments were found to measure unmet needs and quality of life outcomes in this population. This implies a need for more consensus on the most suitable instrument for this group. This heterogeneity of instruments makes conducting a comparison of studies challenging. Furthermore, it poses limitations for international research efforts focused on improving or responding to the needs of lymphoma survivors. The principal psychometric measurement properties reported in the reviewed studies are structural validity, internal consistency, reproducibility, and content validity (Tables 3.5-3.6). The psychometric data in the published literature needs to be more comprehensive, and the validity and reliability of evidence for available needs assessment tools are limited (Jiao et al., 2015; Jiao et al., 2018; Taylor & Monterosso, 2016).

Similar to other systematic reviews on instrument selection, the included instruments for this review were not examined for all psychometric properties, and evidence for responsiveness was scarce (Rezai et al., 2020; Wang et al., 2021). The COSMIN methodology aims for more standardisation in using outcome measurement instruments (Mokkink et al., 2016). Improved reporting of the aims and related methods is

required to permit a greater level of interpretation regarding the precision and the applicability of results in instrument development. Thus, providing a better indication of the suitability and strength of the results.

It was difficult to discern conclusively which measure was the most valid and reliable given that no study assessed all psychometric properties with variation in the psychometric properties they selected to assess. However, the tools with the most comprehensively reported psychometric properties were the SUNS and SF-SUNS (Campbell et al., 2014; Campbell et al., 2011). All included unmet needs instruments were developed in Australia or Canada. The FACT-G and its module for lymphoma, FACT-LYM, have been identified for lymphoma survivors. The original study for its development was conducted with a non-Hodgkin lymphoma sample (Hlubocky et al., 2013). All included quality of life instruments were developed in the USA except one (EQ-5D-5L). Therefore, the psychometric testing for included instruments outside the countries they were developed is limited. Cultural relevance is an important factor in instrument selection as popularity may not consider the sustainability of the instrument's relevance as treatments and models of care evolve, and new technology becomes available. The awareness surrounding the cultural relevance of an instrument and the cultural nuances which might affect cancer survivors' capacity to communicate their needs and quality of life via self-reported outcome measures requires attention (Fawcett, 2011).

The acceptability of the selected instrument to the study's population stage of survivorship should be considered. There are several options for long-term survivorship (IOC, IOCv2, QoL-CS, and CaSUN), while the SUNS and SF-SUNS are specific to one to five years post-diagnosis. Cancer survivors are prone to fatigue and impaired cognitive functioning. Therefore, the feasibility of instruments (i.e., fewer items and shorter time to completion) should receive prominent attention; the EQ-5D-5L, EORTC QLQ-C30 and SF-SUNS are the shortest included instruments with thirty or fewer items. By using shorter instruments, there may be fewer participant burdens, potentially a higher response rate, and fewer missing values (Cheung et al., 2004). There was significant variation between the number of items and domains across instruments. Half of the included quality-of-life instruments were developed in the 1990s, compared to the development of unmet needs instruments published from 2007 onwards. The reporting of unmet needs instruments was more comprehensive than the quality of life instruments, allowing more clarity in the extraction of the aims and methods of psychometric analysis. The domains of informational needs and spiritual needs received the least attention, with the CaSUN having the most coverage of domains of need (Fitch, 2000; Hodgkinson et al., 2007).

In the reviewed literature, statistical tests are common to evaluate reliability. However, the rationale for selecting specific reliability tests and assumptions and parameters underpinning the selected test often needs to be stated, representing a significant limitation of the literature. Statements like 'reliability were assessed using intraclass correlation coefficient' are made without noting important distinctions in its assumptions and evidence for its selection to facilitate appropriate interpretation. For instance, vague statements are made on the range of results rather than the specific subscale and overall scale results (Prinsen et al., 2018).

The COSMIN methodology provides comprehensive resources to assess instruments' psychometric measurement properties (Mokkink et al., 2010; Prinsen et al., 2018). These resources are significant for researchers developing research projects and evaluating their choice of the measurement instrument. However, barriers to its implementation exist, including the time, skill and knowledge base required to assess the COSMIN checklist (Kwok et al., 2021). The checklist has 114 items; ninety-six are related to psychometric properties; thus, considerable time is required to become acquainted with the COSMIN taxonomy and tools. Its use is a complex activity with limited or not sufficiently similar studies to enable the effective combination of results (i.e., statistical pooling). The complexity of this tool may limit the application and use of COSMIN to compare instruments across diverse health issues. An exploration of how the tool has been applied to date is recommended to establish whether there are opportunities to develop short-form versions of the tool to support rapid decision-making for tools in clinical environments.

3.5.1 Limitations

While efforts were made to comprehensively review all relevant instruments for the population and outcomes of interest, this review is not exhaustive. Instruments may have extensive validation within studies not detected in this review. The review was limited to English language publications, and instruments in other languages (i.e., studies examining cross-cultural acceptability) may have been missed. A prospective protocol registration for this review was not conducted. However, a rigorous and systematic approach was conducted to identify instruments and evaluate their content and psychometric properties for lymphoma cancer patients and survivors.

3.6 Conclusion

Standardisation in selecting outcome measurement instruments in specific research areas is warranted as it contributes to improved consistency in reporting and reduces difficulties in comparing and synthesising findings (Mokkink et al., 2016). There is a continued need to work in partnership with lymphoma survivors to ensure that future care is responsive to the concerns of this population. Like other tumour-site-specific research, lymphoma survivors, a substantially increasing cohort, will benefit from focused research. Healthcare professionals endeavour to ensure that physical or mechanical tools (i.e., a sphygmomanometer) provide accurate information with each use (i.e., correct blood pressure reading). This concern should be granted to using measurement instruments about their validity and reliability in research and broader clinical practice. However, selecting outcome measures for specific purposes is complex, involving conceptual considerations (i.e., defining the construct and population), practical aspects (i.e., the burden for patients and costs) and quality aspects assessed by different measurement properties. Future studies are warranted to assess the measurement properties of existing instruments, especially for structural validity, cross-cultural validity, and reliability. This review provides a platform for instrument comparisons for adult lymphoma survivors, with suggestions for important factors to consider in systematically selecting unmet needs and quality of life self-report measures. Primarily focused on approaches for research, this review has provided steps to consider for clinical applications. In selecting

measurement instruments, researchers should consider research objectives, study design, psychometric properties, feasibility, and the pros and cons of using more than one measure.

3.6.1 In the Context of This Thesis

A variety of instruments were found for use in measuring lymphoma survivors' unmet needs with little attention to their psychometric properties and quality (Boland et al., 2022). Therefore, this subsequent publication (Boland et al., 2023) was warranted to assimilate evidence to, firstly, identify what instruments are being used to measure the unmet needs and quality of life outcomes of lymphoma survivors, and secondly, to evaluate the psychometric properties and quality of selected instruments. This information was valuable in enabling the decision-making and development of the quantitative phase one survey (e.g., selection of instruments outlined in Chapter 5) and so, enhances the quality of the findings resulting from the study. Next, the philosophical and methodological approaches to this research are outlined in Chapter 4, followed by a detailed discussion of study methods in Chapter 5.

Twelve instruments met the inclusion criteria; only one was explicitly developed for lymphoma (Functional Assessment of Cancer Therapy – Lymphoma). Four instruments focused on the construct of need, and eight focused on quality of life. The psychometric data in the published literature is not comprehensive; there is heterogeneity in their development, content, and quality. No included instrument was examined for all COSMIN measurement properties, and methodological quality was variable; all instruments measured at least four domains of need. The emotional domain was reviewed by all instruments (n=12), and the spiritual and informational domains received the least focus (n=4 each). This review provides a platform for instrument comparison, with suggestions for important factors to consider in systematically selecting unmet needs and quality of life self-report measures for adult lymphoma survivors. Considering the various discrepancies and limitations of the available instruments, using more than one instrument is recommended. In selecting measurement instruments, researchers should consider research objectives, study design, psychometric properties and the pros and cons of using more than one measure. Evaluating the participant burden and feasibility of completing the selected instrument is important for lymphoma survivors, a group burdened by cancer-related fatigue and cognitive impairment.

Chapter 4 Philosophical and Methodological Approaches

4.1 Introduction

This chapter examines the influence of philosophy and methodology on the consideration and decision-making for this research. All research is grounded in philosophical foundations with underlying beliefs and approaches to inform decision-making. This chapter will discuss the underlying research philosophy informing this study, pragmatism. Selection of research methods requires careful consideration of how knowledge is generated. A definition of mixed methods research is outlined to justify the sequential explanatory mixed methods design. The potential limitations of mixed methods research are described. Lastly, the theoretical frameworks informing this research are presented.

4.2 Philosophical Underpinnings

It is essential to make strategic decisions about research methods in any research endeavour (Creswell & Plano-Clark, 2017; Patton, 2014). Researchers are also encouraged to position their research within a chosen paradigm. A worldview (or paradigm) is a "basic belief system" Guba and Lincoln (1994, p. 107), that is, a fundamental collection of beliefs and values that direct actions (Guba, 1990; Guba & Lincoln, 1982). The researchers' worldview underpins a research study and permeates the entirety of the study. Therefore, the worldview is a 'thinking framework' that guides the researcher's behaviour (Morgan, 2007). This belief and value system encompasses ontological, epistemological, and methodological assumptions. The first distinct element, ontology, refers to the nature of reality (and being) and asks *what do we know?* Next, epistemology is the nature of knowledge and asks *how we can know what we know?* Methodology asks *what is considered an appropriate approach to enquiry?* focusing on the process, practicalities, and strategies of conducting research (Mackenzie & Knipe, 2006). Therefore, worldview, ontology, epistemology, and methodology must be harmonious and coherent (Clarke & Braun, 2021). The conceptualisation of the nature of *axiology* (ethics and values) is also pertinent to an inquiry of research.

Diverse worldviews bring different perspectives on reality, knowledge, values, and methodology in research. In the past, researchers approached and addressed questions about ontology, epistemology, and methodology dualistically. Positivists/post-positivists held their beliefs in a single, objective reality measurable through quantitative, *deductive* methods (Creswell & Creswell, 2018; Mackenzie & Knipe, 2006; Morgan, 2007; Tashakkori & Teddlie, 2010). Whereas interpretivists believed in multiple, subjective realities best comprehended using inductive, qualitative approaches (Clarke & Braun, 2021; Creswell & Creswell, 2018; Parahoo, 2014; Tashakkori & Teddlie, 2010). Quantitative and qualitative approaches offer pros and cons, with distinct orientations towards addressing appropriate research questions and objectives.

Quantitative research measures the breadth of a topic, while qualitative research delves into the topic's depth (Morgan, 2007). Quantitative research tests and validates theories and hypotheses and yields generalisability. Quantitative approaches can swiftly collect and analyse data but risk misalignment with

the researcher's understanding of the phenomenon and participants' perspectives. Qualitative research excels in providing rich, profound insights into intricate and dynamic phenomena, exploring participant interpretations within their local contexts with adaptable research processes as results emerge; even small qualitative samples yield illuminating findings.

The relationship to the research process differs for quantitative (objective) and qualitative (subjective) strands (Morgan, 2007). Objectivity is maintaining impartial and unbiased approaches; findings rely on evidence and rigorous methods rather than subjective opinion to strengthen credibility. Subjectivity is the quality of being based on the influence of self-conscious perspective rather than the external world. Similarly, inferences from data differ for the two approaches: quantitative uses generality; qualitative applies context (Morgan, 2007). While generalisability (the extent to which study findings can be applied to other situations) is not a goal of qualitative research, it is often referred to as a limitation of this approach, as is the time-intensive nature of qualitative data collection and analysis. Contextualisation, a strength of qualitative research rather than quantitative research, involves framing something in its context or situation within which it exists. Purists of either the quantitative or qualitative paradigms subscribe to a belief system that either supports quantitative research (positivist/postpositivist worldview) or upholds qualitative research (naturalist or constructivist worldview); there is no middle ground (Denzin, 2012; Slife et al., 1995). They argue that quantitative and qualitative approaches are so different that it is impossible to intermingle the two. Yet, they both share an overarching goal to generate and advance knowledge.

This study epistemologically believes that there are parts of reality which can be measured (i.e., captured by valid and reliable measurement tools). However, ontologically, one single truth (or reality advocated by positivists) delimits the holistic, comprehensive, and integrated nature of healthcare and the cancer care continuum experience for survivors. This is because we create, interpret, rationalise, and reshape knowledge through human reasoning. In this sense, we make knowledge by interpreting the world and our experiences within it. The self is not an object but a process (Rosenbaum & Dyckman, 1995). Therefore, the significance of the human experience is not confined solely to the external objective reality or the internal realm of the individual's mind but instead emerges through interaction or transaction (Morgan, 2014). Thus, this way of thinking denies the notion of the incompatibility thesis, where different paradigms cannot coincide within the same research (Onwuegbuzie & Leech, 2005). The dominance of one paradigm over the other (positivist/post-positivist or anti-positivist) is delimiting and perhaps unnecessarily divisive as diverse approaches can be complementary with legitimate influence over knowledge generation (Morgan, 2014). By approaching lymphoma survivors' unmet needs from both philosophical perspectives, a greater depth of knowledge about the experience can be harnessed, resulting in *'more complete accounts of social reality'* (Bryman, 1988, p. 126).

4.3 Worldview

In response to this duality, pragmatism emerged and extended the choice beyond traditional positivist/post-positivist or interpretivism (Morgan, 2007). An influential philosophical movement in the

late 19th and early 20th centuries in America, its origins are often attributed to philosophers Charles Saunders Peirce, William James and John Dewey (Dewey, 1929; Dewey, 1938; James, 1907; Peirce, 1905). This philosophy moved away from questioning the nature of the mind's relationship to reality (Rorty 1980). Therefore, truth is armed by reflexive and rational reasoning using eclectic tools to find solutions to the research question (Goodman, 2005). Pragmatism focuses on the consequences of research and the importance of the research question under investigation, orientated towards "what works" and its pluralistic approach to real-world problems and solutions (Creswell & Plano-Clark, 2017; Morgan, 2007). Pragmatism sees knowledge as rooted in our real-life experiences (our reality) and how we interpret them (our construction of it). This approach endorses eclecticism and emphasises the importance of selecting needs-based research methods and concepts, enabling this research to determine what best answers its research questions. Furthermore, pragmatism gives way to the complementary nature of various perspectives on ontological, epistemological, and methodological concerns (Johnson & Onwuegbuzie, 2004; Morgan, 2007).

Diverse approaches that value objective and subjective knowledge are paramount to this worldview (Creswell & Plano-Clark, 2017). Furthermore, pragmatism incorporates the belief that theories can be objective and generalised or subjective and contextualised through appropriate analysis of transferability to a selected situation (Morgan, 2007; Shannon-Baker, 2015). In other words, objectivity involves judgement, perception, interpretation or understanding of the world from a third-person point of view (he, she, it), distinct from subjectivity (me). Yet, within this worldview, there is interplay between the two. It is facilitating this research to be adaptable to strategies that support and strengthen this inquiry process. Although fluid and flexible, it is based on an ethical basis of what is reasonable (Moran-Ellis et al., 2006).

Moreover, human reasoning is a sufficiently complex and flexible process (Patton, 2014) that aligns with the theoretical drive (or direction) within mixed methods research, which moves back and forth between deduction and induction, creating abduction. Therefore, the pragmatic approach to conducting research is informed by research that cannot be exclusively driven by theory (deductive) or formed from data (inductive). Abductive reasoning facilitates movement back and forth between induction and deduction during inquiry (Morgan, 2007; Shannon-Baker, 2015). This pragmatic study uses abductive reasoning, intersubjectivity and transferability (Table 4.1) (Morgan, 2007). The latter term, transferability, emphasises becoming entwined with generalisability less than the practical implementation of research within specific situations, contexts, or environments (Morgan, 2007).

For this current research, the worldview of pragmatism is seen as a way of thinking that is not prescriptive in its approach to conducting research. This is a philosophy of progress, continuity, and change, not of absolutes, which allows action to pervade existence (Dewey, 1932). Furthermore, this research is founded on recognising that truth is personal, prioritising practicality over a rigid reality, favouring actions and practical considerations over ideation that is not exclusively reliant on evidence (Rescher, 2000). Through a pragmatic worldview, the combination or 'integration' of quantitative and qualitative approaches permits a more comprehensive approach to address the research question (Morgan, 2007), that is cognisant of the

complex context of the lymphoma survivor experience. Pragmatism's assumptions drive this research to be practical and applied, not abstract; this corresponds with the practical use of human reasoning and critical thinking in addressing cancer survivorship.

Table 4.1 Pragmatic Approaches in Research Methodology (Morgan, 2007)

Approach	Qualitative	Quantitative	Pragmatic
Connection of theory and data	Induction	Deduction	Abduction
Relationship to the research process	Subjectivity	Objectivity	Intersubjectivity
Inference from data	Context	Generality	Transferability

For this pragmatic study, individuals (lymphoma survivors) are deeply intertwined with their contexts (the cancer care continuum) in which they are simultaneously acting and being acted upon. Lymphoma survivors are not static but ever evolving; they are made up of circumstances in which they must contemplate with even the most passive events calling for action or change. Consequently, this research design, a mixed methods sequential explanatory design, reflects the attempt to engage with the different worldview perspectives among lymphoma survivors across follow-up cancer care services in Ireland. Pragmatism provides a versatile worldview that can effectively support the mixed methodology employed within it.

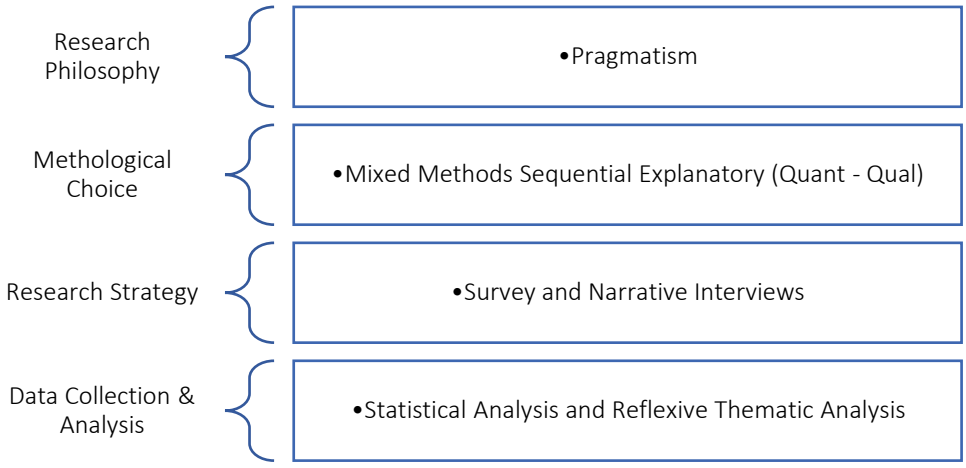
4.4 Study Design

After carefully considering different methodologies to address the research question, a pragmatic mixed methods approach was chosen; mixed methods research is an inquiry approach that combines quantitative and qualitative forms of research involving their philosophical assumptions (Figure 4.1) (Creswell & Creswell, 2018; Moran-Ellis et al., 2006; Tashakkori & Creswell, 2007). Therefore, the mixed methods approach provided the necessary depth to comprehend the unmet needs of lymphoma survivors and the breadth to explore the context of their experiences. This presents a platform to acknowledge diverse thoughts and interpretations of knowledge, extending the delimiting nature of a singular approach (i.e., quantitative, or qualitative alone).

Ultimately, the goal of understanding complex human phenomena can be accomplished in several ways using mixed methods research, which is both a method and a methodology (Creamer, 2018). This means that mixed methods research is a design with philosophical assumptions (guiding the direction of the research process) and methods of inquiry (focusing on the action of the research process). Diverse approaches that value objective and subjective knowledge are paramount to this worldview (Creswell & Plano-Clark, 2017). The central premise of this mixed methods study is that using quantitative or qualitative

approaches alone cannot provide a more substantive understanding of research problems than in combination (Creamer, 2018; Creswell & Plano-Clark, 2017). Under the philosophy of pragmatism, mixed methods exploit the strengths of quantitative and qualitative research methodologies to answer the research question (Morgan, 2014).

Figure 4.1 The Philosophical and Methodological Approaches Underpinning this Research



Addressing the underserved research focus on lymphoma survivors' unmet needs is the central principle guiding this study. To achieve this overarching aim, the mixed methods sequential explanatory design was selected as the most appropriate method to address this research question, enabling the development of a complete understanding of the unmet needs of lymphoma survivors. Collecting both data types from the participants allowed a richer interpretation of the survey results. It elucidated the experiences and viewpoints of lymphoma survivors, thereby permitting factors affecting their unmet needs to be comprehensively explored.

The researcher determines the utility of the research. The mixed methods approach employed by this research can respond to the interests and needs of diverse stakeholders in lymphoma survivorship, like policymakers, healthcare professionals, support persons or societies and, of course, the individual with lymphoma. Healthcare policymakers, for example, seek concrete evidence to support the planning, development, implementation, and evaluation of services. The most recent national cancer strategy supports the necessity for this inquiry into lymphoma survivors who are underserved by current literature (Department of Health, 2017). Therefore, this mixed methods research can respond to the call for evidence on this group, reporting on the context of their needs that remain unmet.

4.5 Theoretical Framework

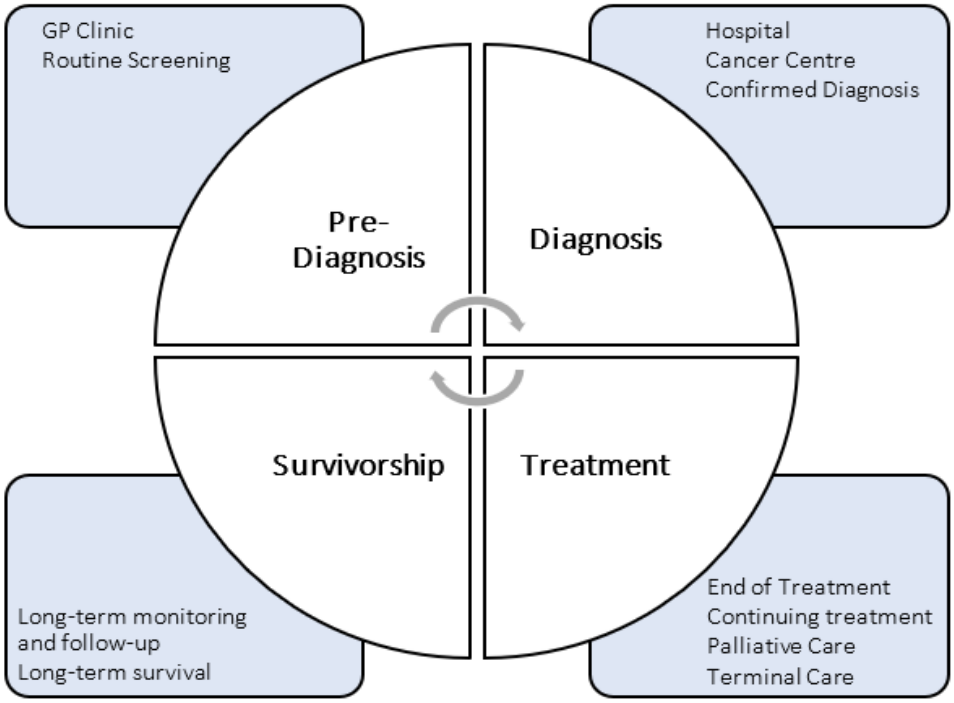
A theoretical framework provides a grounding base for the methods and analysis of this research, informed by theory (Grant & Osanloo, 2014), providing structure and rationale for this study and the purpose and significance of the research investigation. The magnitude of the impact of cancer on the individual living

with cancer extends past physical considerations (Afiyanti et al., 2018). Many factors important to daily living for individuals living with cancer may be affected, including emotional, informational, practical, psychological, social, and spiritual needs (Fitch, 2008). Cancer supportive care comprises an integrative field of multidisciplinary services necessary for people affected by cancer to manage the impact of their disease and treatment and achieve optimal health outcomes. Therefore, the rationale for the selection and application of the Supportive Care Framework for Cancer Care by Fitch (2008).

4.5.1 Supportive Care Framework

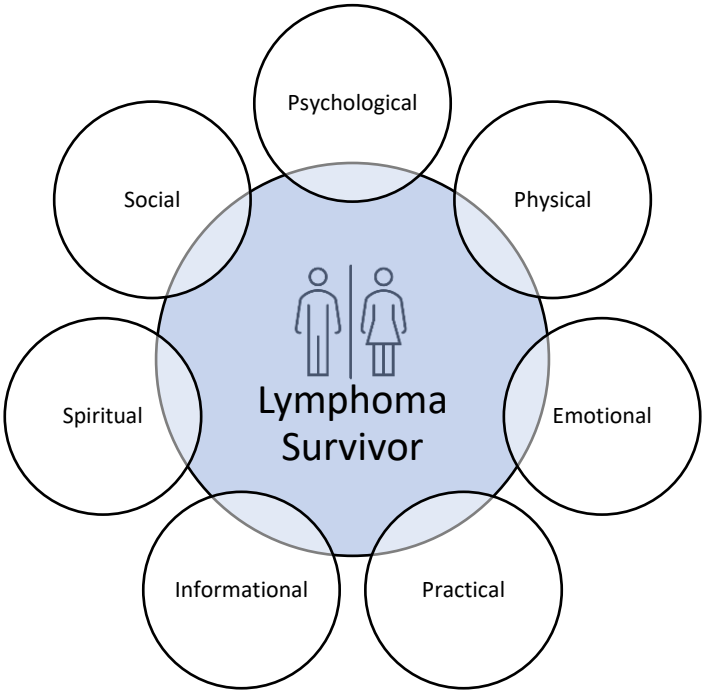
The Supportive Care Framework (SCF) is the major model underlying the conceptualisation of supportive cancer care; it was initially constructed two decades ago to help conceptualise the help and services cancer patients may require (Fitch, 1994; Fitch, 2008). This person-centred framework highlights seven key domains that must be routinely assessed and supported across the entire cancer pathway to deliver optimal patient experiences and outcomes: emotional, informational, practical, physical, psychological, social, and spiritual (Fitch, 2008). The original intent of the framework was to provide health service planners with a conceptual platform to plan and deliver services. The framework details that supportive care is provided at all stages of the patient cancer pathway from before diagnosis onwards (Fitch, 2008). A map of the cancer patient's pathway begins with the journey to diagnosis at the general practitioner clinic or through routine screening. Hospitals or cancer centres are required to undergo tests and confirm a diagnosis of cancer. Some patients may undergo a period of active surveillance (e.g., watchful waiting). A period of treatment is likely required with various possible outcomes (e.g., relapse and continued treatment or remission and end of treatment). Long-term monitoring and follow-up may accompany long-term survival. While some patients may require palliative care or terminal care (Figure 4.2).

Figure 4.2 Map of the Cancer Patient's Pathway by Fitch (2008) Adapted



This pathway is broad, as the diagnosis and treatment of cancer can be conceptualised as an unexpected life event or a series of events across a spectrum of experiences with cancer (Fitch, 2008). For some, cancer may be felt as a single event with a clearly defined beginning and end. For others, the experience of cancer may be more chronic in nature. For all, a spectrum of events, interactions and experiences because of cancer occurs prior to diagnosis, and through diagnosis, treatment, and follow-up (survivorship). Individuals with a cancer diagnosis may enter the cancer care system at various points, and experience diverse care, provided at a different pace along their pathway (e.g., remission and long-term follow-up versus relapse and palliative care) (Figure 4.2). Regardless of the necessary pathway, cancer-related events are embedded into the daily lives of individuals living with or beyond cancer (Fitch, 2008). Effective supportive care delivery requires collaborative efforts of various disciplines, healthcare settings and cancer organisations with integrated approaches to person-centred compassionate cancer care (Fitch, 2008). However, a person's ability to meet their needs may be compromised because of cancer. Living with unmet needs adds to the burden of living with and beyond cancer, the SCF's seven domains provide examples of areas of needs for individuals with cancer (Figure 4.3). Notably, the framework is focused on the potential for supportive care at all parts of the cancer journey, from screening to diagnosis, treatment, and follow-up cancer care (Fitch, 2008). Therefore, it provides a theoretical basis for optimal cancer care delivery that entails and impacts the totality of a patient's experiences and outcomes.

Figure 4.3 Supportive Care Framework by Fitch (2008) Adapted – Domains of Needs for Lymphoma Survivors



4.5.2 Application of Framework

The SCF directly influenced the development of this research. The framework is aptly suited to the population of interest, lymphoma survivors, a group substantially increasing due to success in advancing

outcomes, with growing concerns about survivorship. This framework places emphasis on the whole trajectory of cancer as an entirety rather than contributing factors which supplement the treatment phase. Previous applications of the SCF show the framework have been used as an instrument for service or program development, as well as a foundational approach to cancer care education and as a model for research project design (Fitch, 2008). Moreover, the SCF has provided the conceptual understanding for research relating to different cancer types, such as breast, gynaecological and prostate, and expanded to use in other areas of health care to assist in recognising needs and attempts to address them (Afiyanti et al., 2018; Davies et al., 2019; Gray et al., 2000; Loughery & Woodgate, 2019; Pelentsov et al., 2015).

Closely related to this research, the SCF was used to qualitatively explore the unmet needs of haematological cancer survivors (71% of lymphoma participants) in Australia. The SCF was used to guide data collection and analysis to help understand patients' unmet needs as *"to provide optimal, patient-centred care to all cancer survivors, we must first identify what survivors would like help with"* (Herrmann et al., 2020, p. 2). Like this current research, the authors reported the SCF was particularly suited to examining patients' unmet needs as it conceptualises the help and services cancer patients may require. This is because the SCF theorises that a cancer diagnosis may affect an individual's ability to meet and satisfy their needs across multiple domains of life (Fitch, 2008). Various changes may occur throughout an individual's cancer journey, impacting their needs and requirements for additional support outside their resources and beyond those offered by routine cancer care services (Howell et al., 2012). Herrmann et al. (2020) used qualitative content analysis where codes and categories were grouped around but not restricted to the SCF domains.

Quality cancer supportive care must be conceptualised by its impact on patient experience and care outcomes. The framework is influenced by a focus on value-based healthcare, value defined as outcomes that matter to survivors (Lee & Porter, 2013). Therefore, this framework provides an appropriate match for this research in investigating the unmet needs of lymphoma survivors. Needs do not manifest in isolation, and unmet needs may be interrelated, so the framework provided a structured way of assessing survivors' unmet needs through domains (i.e., psychological, and social). This helps to facilitate the current mixed methods study to inform future planning and delivery of cancer services for this group, as current practices in Ireland are non-centralised and fragmented.

The SCF is appropriate to frame the examination of survivors' unmet needs and the help that individuals living with or beyond lymphoma may require. This study provides insights into the experiences of lymphoma survivors one to five years post-diagnosis, reflecting their concerns from diagnosis to survivorship and aligning with the premise that supportive care encompasses all aspects of cancer care delivery. Therefore, the SCF closely aligns with the population and the primary outcome of interest in this line of inquiry and provide a basis to uncover the needs of lymphoma survivors, which can inform patients, policy, healthcare services and research (Fitch, 2008). The framework is integrated throughout this study (Table 4.2)

Table 4.2 Application of the Supportive Care Framework to this Research

Framework's Influence	
Aspect of Research	Supportive Care Framework's Influence
Key concepts	The conceptualisation of supportive care within the SCF further extends the context and understanding of the study's key concept, unmet needs (Section 1.6 and extended within this current Chapter 4).
Systematic review (Chapter Three)	The systematic review used the SCF to facilitate content comparison and analysis (Section 3.3.4). An overview of what domains of needs were captured by available instruments was provided (Section 3.4.2).
Interview guide development (Chapter Five)	The SCF and previous qualitative work using the SCF informed the development of the interview guide for phase two interviews.
Analysis and Interpretation (Chapter Eight)	See section 8.5 which discusses the theoretical implications of this research.

4.6 Conclusion

Due to the intricate nature of healthcare research, there is a growing need for more sophisticated research designs, emphasising incorporating mixed methods in healthcare and cancer care research. This study generates knowledge through a pragmatic, pluralist approach which recognises the validity of various viewpoints and forms of knowledge. Ontologically, reality is actively created, based on ever-changing human nature, but orientated towards solving practical, real-world problems. The epistemological assumption of this research believes that the research problem can be viewed through numbers and text. The sequential explanatory design used in this study provides a robust framework for inquiry to explore the study's objectives. The issues surrounding lymphoma survivorship and unmet needs are multifaceted, rendering the necessity for a research approach that can reach both the depth and breadth required to address the research question. The theoretical framework, SCF, underpins this research as a template for integrated cancer survivorship service planning and delivery.

Chapter 5 Methods

5.1 Introduction

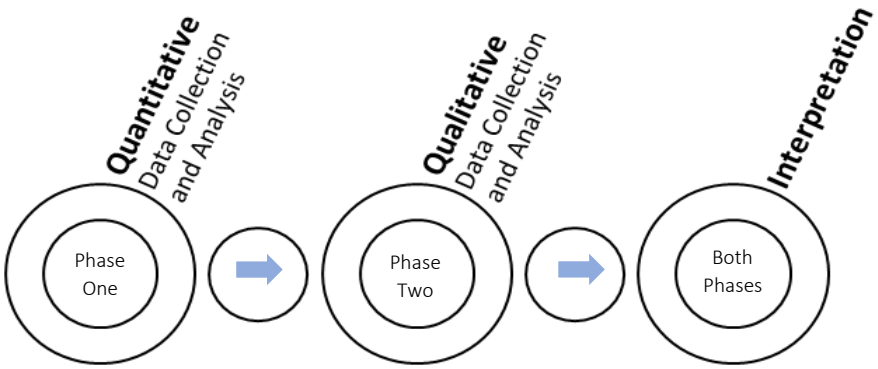
The previous chapter outlined the methodology for the conduct of this research study, applying the underlying beliefs of pragmatism to guide method selection (Jonker & Pennink, 2010). This mixed methods study aimed to investigate the unmet needs of lymphoma cancer survivors receiving follow-up care in tertiary haematology-oncology healthcare settings in Ireland between one- and five-years following diagnosis. This chapter will outline the research methods applied to address the objectives of this study and provide a justification for their use. Using a sequential explanatory design, the phases are presented in a logical, sequential manner.

5.2 Design

5.2.1 Sequential Explanatory Design

The study design is mixed methods with a sequential explanatory design to investigate the unmet needs of lymphoma survivors. This mixed-methods sequential explanatory design study consists of a quantitative-driven methodological core followed by a qualitative investigation to comprehensively evaluate this research problem (Creswell & Plano-Clark, 2017). Two distinct phases were explored; quantitative data were collected and analysed in the first phase to evaluate the unmet needs of lymphoma survivors and their influencing factors. In the subsequent qualitative phase, data was collected and analysed to build upon phase one findings and elicit a deeper understanding of unmet needs' impact on survivors' quality of life (Creswell & Plano-Clark, 2017) (Figure 5.1).

Figure 5.1 Mixed Methods Sequential Explanatory Design



The quantitative results from a questionnaire are explained through follow-up interview data to better understand it and add new meaning directly from participants' voices (Creswell et al., 2011; Doyle et al., 2016). This design allows the research problem to be viewed from different perspectives (quantitative and qualitative) to enhance and enrich the meaning of a singular perspective – the unmet needs of lymphoma survivors. Merging quantitative and qualitative data develops a more complete understanding of this research problem, which could not be achieved by one approach alone (Creswell et al., 2011; Creswell &

Plano-Clark, 2017). The findings of both phases were integrated during the interpretation of results. The methods of the study as they respond to the integrated objectives of the study are presented in Table 5.1; the objectives are divided into two strands, quantitative and qualitative, delineating their distinct yet interconnected focus areas.

Table 5.1 Study Methods Applied to the Integrated Objectives of this Research's Primary Data

<table>
<tr><td colspan="2">Objective 1: To identify the unmet needs of lymphoma survivors.
Research Question 1: What are the unmet needs of lymphoma survivors?</td></tr>
<tr><td>Quantitative Phase</td><td>Qualitative Phase</td></tr>
<tr><td>What are the most common or problematic unmet needs reported by survey data.
● Instrument: SFUNS
● Descriptive statistical analysis</td><td>What are the most common or problematic concerns voiced by interview participants.
● Data collection: semi-structured interview guide
● Reflexive thematic analysis</td></tr>
<tr><td colspan="2">Objective 2: To explore lymphoma survivors' quality of life outcomes and symptom experiences.
Research Question 2: What are lymphoma survivors' self-reported quality of life outcomes and symptom experiences?</td></tr>
<tr><td>Quantitative Phase</td><td>Qualitative Phase</td></tr>
<tr><td>What are the most common or problematic quality of life outcomes or symptom experiences reported by survey data.
● Instruments: FACT-LYM and EQ-5D-5L
● Descriptive statistical analysis</td><td>What are the most common or problematic concerns (QoL or symptom experience) voiced by interview participants.
● Data collection: semi-structured interview guide
● Reflexive thematic analysis</td></tr>
<tr><td colspan="2">Objective 4: To evaluate what factors influence lymphoma survivors' unmet needs.
Research Question 4: What explanatory factors influence lymphoma survivors' unmet needs?</td></tr>
<tr><td>Quantitative Phase</td><td>Qualitative Phase</td></tr>
<tr><td>What factors are associated with unmet needs for lymphoma survivors?
● Statistical analysis: Univariate Analysis, Hierarchical Multiple Regression and Canonical Correlational Analysis</td><td>What factors are linked to unmet needs for lymphoma survivors?
● Reflexive thematic analysis</td></tr>
<tr><td colspan="2">Objective 5: To inform the development of supportive care strategies and services to address the unmet needs of lymphoma survivors in Ireland.
Research Question 5: How can the development of supportive care strategies and services be informed to address the unmet needs of lymphoma survivors in Ireland?</td></tr>
<tr><td>Quantitative Phase</td><td>Qualitative Phase</td></tr>
<tr><td>What quantitative findings inform strategy or service developments to address the unmet needs of lymphoma survivors in Ireland?
● Inferences from quantitative findings</td><td>What qualitative findings inform strategy or service developments to address the unmet needs of lymphoma survivors in Ireland?
● Inferences from qualitative findings</td></tr>
</table>

The first quantitative phase provides several contributions to addressing this study's objectives, from the design of the questionnaire to its data collection and analysis. The subsequent second phase offers the opportunity to return to the quantitative findings and drive further analysis but also allows for insights unique to the qualitative approach. Employing a mixed methods design involves thoughtfully combining methods to advance *"a more rounded, more complete, and better-developed understanding of the phenomenon being studied than would otherwise occur"* (Bazeley, 2017, p. 2).

5.2.2 Phase One Quantitative Design

Phase one employs a quantitative descriptive correlational design which is an appropriate approach for creating a comprehensive understanding of a phenomenon, including explanatory factors like unmet needs that contribute to the diverse experiences of individuals living with or beyond cancer. Considered an efficient and effective method for quantifying a problem, the descriptive correlational study obtains information to establish whether two or more variables of interest are related (Creswell, 2002; LoBiondo-Wood et al., 2014; Wood & Ross-Kerr, 2010). The descriptive correlational study has many advantages, including accuracy of data, increased flexibility when investigating complex relationships among variables, its ability to obtain a wealth of information from a large population, and the economical manner in which it can be conducted (LoBiondo-Wood et al., 2014). This study design is also suitable for establishing reliable estimates of lymphoma cancer survivors' unmet needs and examining factors (i.e., gender or age) influencing higher levels of unmet needs.

5.2.3 Phase Two Qualitative Design

Through illuminating meaning, this qualitative inquiry cultivates the capacity to learn about the unmet needs of lymphoma survivors (Patton, 2014). Phase two used a qualitative descriptive design employing interviews to reveal those meanings and their implications. This descriptive work aimed to give a voice to lymphoma survivors, focusing on the meaning they attach to their experiences. Given the aim to capture the distinct voices of individual lymphoma survivors, this research favoured individual interviews over group interviews (such as focus groups). Interviews are ideally suited to experience-type research questions with individuals with a personal stake in the topic (Braun & Clarke, 2013). This allowed individual perspectives to be heard and understood, contributing to a better understanding of lymphoma and its compounding unmet needs.

Interviews involve open-ended questions and probes yield in-depth responses about people's experiences, perceptions, opinions, feelings, and knowledge (Patton, 2014). The interviews were semi-structured, allowing for a balance between providing a framework for consistent questioning and enabling participants to express their experiences and viewpoints in their own words (Braun & Clarke, 2013). The semi-structured format encourages participants to elaborate their thoughts and experiences, this provides flexibility to address ambiguities and gather more profound insights as participants could discuss personally relevant topics beyond the interview guide (Morse, 2016). The data collected consist of verbatim quotations with sufficient context to be interpretable (Patton, 2014).

5.2.4 Integration

Mixed methods research is a powerful approach which combines quantitative and qualitative research methods to gain a more comprehensive understanding of a particular research question or topic (Fetters et al., 2013). By leveraging the strengths of both approaches, mixed methods studies can yield unique insights and produce knowledge that may not be accessible by one method alone. However, despite its potential benefits, there are challenges in fully realising the advantages of mixed methods research due to a failure to adequately integrate the findings (Bazeley, 2017). Integration in mixed methods research is a core principle (Creswell & Plano-Clark, 2017). Maximising the potential of mixed methods research lies in effectively integrating the quantitative and qualitative components, creating a synergy where the different data types complement and enhance each other. This study was focused on achieving multiple levels of integration throughout from design to interpretation (Figure 5.2).

Figure 5.2 Points of Integration within this Study

Points of Integration

- Sequential explanatory design (Section 5.2.1).
- Integrated research objectives (Section 1.12).
- Integrated sampling strategy: a subsample of survey participants were invited to participate in follow-up interviews (Section 5.4).
- Quantitative findings informed the development of the qualitative interview guide (Section 5.5.3).
- Quantitative results informed the development of the maximum variation sampling strategy used to identify interview participants (Section 5.4.3).
- The integrated findings responding to the mixed methods objectives identify convergence and divergence of results between quantitative and qualitative phases (Section 8.1.1).
- Meta-inferences drawn from the integration of quantitative and qualitative findings are summarised and discussed (Section 8.2).

Firstly, integration at the study design level occurred through the mixed methods sequential explanatory design. Next, at the methods level, the quantitative sample links to the qualitative sample through an integrated sampling strategy. Next, through building, the quantitative results informed the qualitative data collection approach – the interview guide. Next, integration is presented as the findings of the first and second phases are reported; the fit of integration describes the extent to which the qualitative and quantitative findings cohere (Fetters et al., 2013). The integrated findings respond to the mixed methods objectives and identify convergence and divergence of results between quantitative and qualitative phases. Finally, the integrated findings of this study influence the interpretation which receives detailed discussion in the final Chapter 8 of this research. The findings from this mixed methods study reflect the needs articulated in the supportive care framework by Fitch (2008); this framework provided a guide for this work in both quantitative and qualitative phases. The framework specifically informed planning, study design, data collection (literature review, the systematic review of survey instruments, the interview guide) and data analysis. Therefore, this integration process allows for a comprehensive and nuanced understanding of the research question.

5.3 Population and Sample

5.3.1 Population

While the needs and research priorities of lymphoma survivors have been given limited attention, the rising number of these survivors has sparked an increasing interest in comprehending survivorship issues (Alabdaljabar et al., 2022; Khimani et al., 2013; Payne et al., 2019; Rosenthal, 2022; Viscuse et al., 2019). The survivorship period can encompass different experiences for survivors, which differ by stage or time since diagnosis (Department of Health, 2017; Institute of Medicine, 2006; Miller et al., 2008). Evidence for acute (up to the first-year post-diagnosis), treatment-focused or long-term (five years or more post-diagnosis) follow-up care exist for lymphoma; this research aims to address the literature gap in delineating the short-term survivorship phase (Ciavarella et al., 2017; Damlaj et al., 2019; Hashmi et al., 2015; Mols et al., 2007; A. K. Ng, 2014; Vena & Copel, 2021a). Therefore, the inclusion criteria for this research study are adults (aged 18 years or older), with a diagnosis of lymphoma (inclusive of all subtypes but specific to the period of one to five years post-diagnosis) who have received cancer care in Ireland. This period of one to five years post-diagnosis often involves the transition from treatment completion to fear of recurrence, or receiving maintenance treatment, balanced with attempts to return to 'normal' life (Campo et al., 2016; Harrington et al., 2010; Institute of Medicine, 2006; Miller et al., 2008; Stanton, 2012). Given the high five-year net survival rate for this group and their growing numbers, one to five years post-diagnosis encompasses a large group of survivors living with or beyond lymphoma with varying dependency on health services.

5.3.2 Quantitative Sample Size

Using the best available evidence for lymphoma cases in Ireland, from 2015 to 2019, there were 577 individuals alive with Hodgkin lymphoma and 3,020 with non-Hodgkin lymphoma (National Cancer Registry Ireland, 2019). Therefore, 3,597 cases represent the population of interest (Table 5.2). A sample size of approximately 249 is required from a population of roughly 3,597 lymphoma survivors diagnosed within the last five years (National Cancer Registry Ireland, 2019). A sample size calculation based on the prevalence of lymphoma was undertaken using Naing et al. (2006) calculator, which is underpinned by the formula outlined in Table 5.3 (Daniel, 1999; Naing et al., 2022). A confidence interval of ±6% for a confidence level of 95% requires a sample of 249 (Table 5.4) (Naing et al., 2006).

Table 5.2 Lymphoma Cases in Ireland. Source: Personal Correspondence with the NCRI

Lymphoma	Alive on 31/12/2019
C81 (Hodgkin's Lymphoma)	577
C82 – 85 (Non-Hodgkin's Lymphoma)	3,020
Total (*C81 – 85*)	3,597*

**Vital status (on 31/12/2019) of cases diagnosed with lymphoma during 2015 – 2019, all of whom had attained 18th birthday (>=18) at the time of diagnosis, by type of lymphoma and period of diagnosis.*

Table 5.3 Prevalence Calculation Used for the Sample Size (Daniel & Cross, 2018)

$$n = \frac{Z^2 P(1-P)}{d^2}$$	
Where	n = Sample size Z = Z statistic for a level of confidence (1.96 for 95% confidence level) P = Expected prevalence or proportion D = Precision (corresponding to effect size)

Table 5.4 Sample Size Calculation for Confidence Interval Precision for Prevalence (Naing et al. 2006)

Confidence Interval Precision	Sample Required
±0.04	515
±0.05	348
±0.06	**249**
±0.07	186

5.3.3 Qualitative Sample Size

Determining an appropriate sample size for the qualitative phase is necessary, although the means for determining it differs from that of the quantitative phase (Malterud et al., 2016; Morse, 1995; Sandelowski, 1995). Nonetheless, there is no simple way to determine the right size of a qualitative dataset (Clarke & Braun, 2021). Sandelowski (1995, p. 179) discusses sample size in qualitative research as *"neither small nor large, but too small or too large"*. This alludes to the appropriateness of the sample to the research question, the study's theoretical aims, and providing adequate data to comprehensively analyse the topic and answer the research question (Morse & Field, 2013; Sandelowski, 1995). Moreover, an in-depth understanding of a few cases can provide a novel and richly textured account of an experience (Creswell et al., 2011; Sandelowski, 1995).

For this descriptive qualitative research study, the concept theoretical sufficiency was used to guide and determine the sample size (Dey, 1999). This differs to data saturation, the prevailing concept for sample size in qualitative research. Data saturation refers to 'informational redundancy', which signifies the juncture where the collection of new information stops (Lincoln & Guba, 1985). Theoretical sufficiency captures the notion that data collection for this research stopped when a sufficient depth of understanding was achieved to advance the research objectives. Theoretical sufficiency focuses in on the quality of data collected and the extent to which it encapsulated the richness, depth, diversity, and intricacy of the needs of lymphoma survivors (Braun & Clarke, 2021). This created a focus on quality over quantity concerning the sufficiency or adequacy of the data (Fusch & Ness, 2015). Therefore, the final sample size was determined during the data collection process, influenced by the sufficiency and depth of the data in tackling the

research question while adopting a practical stance towards an acceptable sample size (Braun & Clarke, 2021).

5.3.4 Eligibility Criteria

The eligibility criteria are clearly defined in Table 5.5.

Table 5.5 Inclusion and Exclusion Criteria

Inclusion and Exclusion Criteria	
Eligible to take part if:	**Not eligible** to take part if:
They were diagnosed with lymphoma between one year and five years ago.	They received their lymphoma cancer treatment in another country.
They are over 18 years of age and can supply written informed consent.	They decline participation or are unable to supply informed consent.
They are living with early or advanced disease, or if they are disease-free at the time of the study.	They are unconscious or acutely unwell at the time of the study.
They are residents of Ireland.	They have cognitive impairment that would limit the patient's ability to participate in the study.
They can speak, read and write in English.	They are terminally ill and in the last three months of life.

5.4 Recruitment and Sampling Strategy

5.4.1 Phase One Recruitment and Sampling Strategy

The survey sample was achieved via the primary method of recruitment at hospital sites or the supplementary method of online recruitment. The sample comprised of lymphoma survivors attending follow-up care at five hospitals. A supplementary viral (recruited online) sample of lymphoma survivors who volunteered in response to online and print advertisements of the study. This study's recruitment occurred during peak waves of the COVID-19 pandemic, in which significant public health measures and restrictions were implemented in March 2020 to mitigate the pandemic's impact (O'Reilly et al., 2023). However, one world has many lenses, and so research designs may emerge or evolve as a research study progresses due to issues arising or as the researcher's knowledge develops (Creswell et al., 2011). Multiple recruitment approaches were considered to maximise the sample potential of lymphoma survivors. Discussion with the National Cancer Registry of Ireland revealed the sites with the greatest numbers of lymphoma survivors. Therefore, access and permission via five hospital sites encompassing a critical mass of lymphoma patients and survivors were sought and granted. These five hospitals, including two designated cancer centres, were located within two of Ireland's hospital groups (RSCI Hospital group and Dublin Midlands Hospital group). These hospitals reflect the healthcare environments in Ireland where lymphoma survivorship care takes place. The wide catchment areas of these sites, reflecting cancer centres and regional hospitals, serve urban and rural populations with varying socio-economic circumstances, enabling a critical mass of lymphoma survivors to be reached. Recruitment commenced at the first site in

December 2020 and continued until September 2021 at the final site. Six months of recruitment was carried out at each site or until sufficiency was achieved (i.e., no new eligible participants were found). In phase one of the study, potential participants who met the inclusion criteria were identified by gatekeepers at each site's Haematology–Oncology Department while attending their routine follow-up clinics or cancer services.

5.4.2 Maximising Sample Potential

In addition to recruitment processes at five hospital sites, supplementary online recruitment was used to maximise the study's reach for potential participants. As outlined previously, direct recruitment occurred through haematology-oncology services at five hospital sites. Study posters (Appendix 10) were displayed in clinical areas to inform patients about the study's eligibility criteria. Social media platforms (Facebook, Twitter, Instagram, LinkedIn) were targeted with study posters and descriptive text to reach a broad age range of lymphoma survivors. Currently, there is no dedicated lymphoma cancer organisation or society in Ireland. Alternatives such as, the Irish Cancer Society, a cancer organisation, were approached to promote the study online. Additionally, thirty-two cancer support groups in Ireland were contacted, leading to further promotion through newsletters and social media accounts and maximising the awareness of the study among potential participants.

5.4.3 Phase Two Recruitment and Sampling Strategy

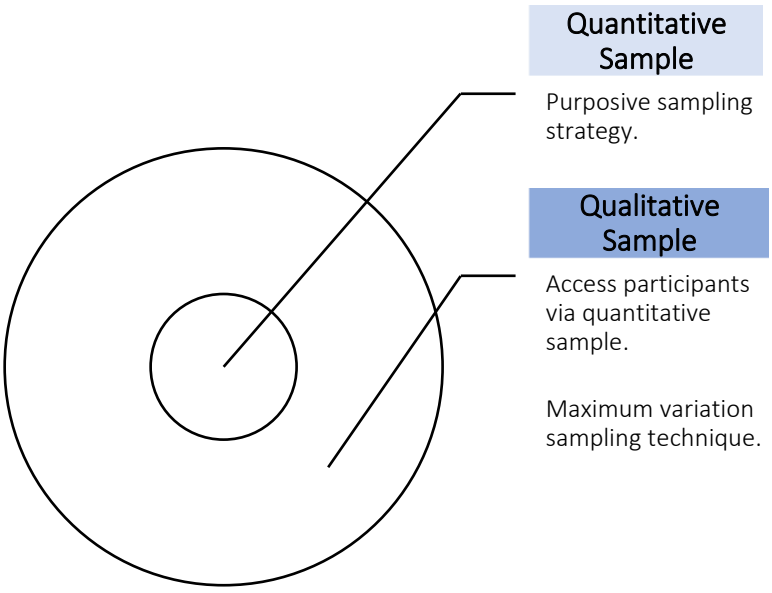
An integrated and purposeful sampling strategy was the most practical and efficient means to access interview participants. Since the explanatory sequential design aimed to explain the initial quantitative results, the individuals best suited to provide more detail on the quantitative results are the ones who contributed to the quantitative dataset (Creswell & Plano-Clark, 2017). Survey participants from five hospital sites were invited to participate in the interview. Access emerged sequentially as survey participants received information on the interview phase of the study in the research packs (in both electronic and paper formats) and were requested to return their contact details if they wished to participate. The selection of interviewees was determined through maximum variation; using this purposive approach allows for the intentional and careful selection of participants based on their ability to offer in-depth and insightful data and ensures a comprehensive and focused understanding of the unmet needs of lymphoma survivors (Coyne, 1997; Sandelowski, 1995, 2000). The sampling strategy sought to achieve variation by lymphoma sub-type, time since diagnosis, age, gender, residence, insurance status, ethnicity and living arrangements (Table 5.6).

Table 5.6 Maximum Variation Sampling Stratifications for Phase Two Interviews

Variable	Variations
Lymphoma type	Hodgkin lymphoma or non-Hodgkin lymphoma
Time since diagnosis	1-3 years post-diagnosis or 3-5 years post-diagnosis
Age group	18-45 years, 46-69 years, 70+ years
Gender	Female or Male
Residence	Rural or Urban
Insurance status	Private health insurance and/or medical card
Living arrangements	Living with others or living alone
Ethnicity	Irish or non-Irish

Talking to a wide variety of lymphoma survivors with different backgrounds and experiences enables an understanding of diversity and a more complete understanding of the research phenomenon. More specifically, the goal is to select participants who represent all strata of key variables. By including a wide range of viewpoints, important patterns and ideas can be uncovered and the wider population can be represented (Bowling, 2014); gaining a greater insight into this research phenomenon by looking at it from all angles (Bowling, 2014; Patton, 2014) . The maximum variation sampling strategy was drawn from the survey sample recruited via five hospital sites (*N=205*); seventy percent of participants consented to a follow-up interview (*n=144*). The interviews followed a purposive sampling approach, meaning participants were deliberately chosen because they are 'information rich' and illuminative due to their lived lymphoma experience (Patton, 2014). This allows for the integration of both strands at the sampling stage and facilitates insights about the phenomenon of interest (Figure 5.3).

Figure 5.3 Integrated Sampling Strategy



5.5 Data Collection

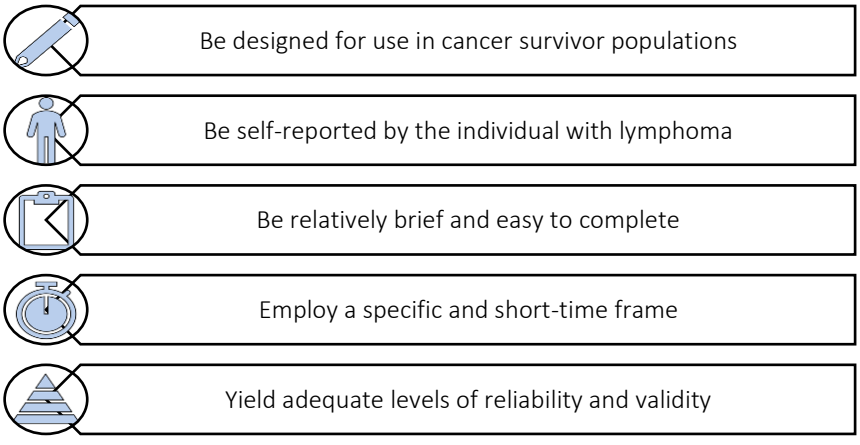
5.5.1 Quantitative Data Collection

Considering the broad age range of lymphoma survivors, both paper and electronic survey formats were employed and allowed for the individual preference of the participant. The study pack comprised a letter of invitation, a participant information sheet, the questionnaire, and a consent form. Clear instructions were provided to minimise participant burden. The distribution approach for all sites was related to the personal preference of the individual participant. For the paper (and postal return) format, a paper research pack was provided to the participant and returned by post via a pre-paid addressed envelope (included in the pack to facilitate postage). For the online (and electronic submission) survey format, a poster was provided to the participant with access (via the survey link or quick response (QR) code) to the contents of the research pack, information leaflet and questionnaire.

5.5.2 Survey Development

The limited available evidence to guide the selection of survey instruments for use with lymphoma survivors was addressed by a systematic review in Chapter 3. The review evaluated available self-report instruments, their psychometric properties, and their comprehensiveness in assessing the unmet needs of adult lymphoma survivors (Boland et al., 2023). This evidence supports the selection of instruments for data collection in phase one of this research. Three instruments were selected which met the criteria outlined in Figure 5.4: Short-Form Survivor Unmet Needs Survey (SF-SUNS), Functional Assessment of Cancer Therapy – Lymphoma (FACT-LYM) and the EuroQol 5D-5L (EQ 5D-5L).

Figure 5.4 Selection Criteria for Instruments



The Survivor Unmet Needs Survey (SUNS) developed by Campbell et al. (2011) was found to have the strongest psychometric properties, however it is lengthy with 89-items, making the shorter version SF-SUNS, a 30-item tool, more appropriate (Boland et al., 2023; Jiao et al., 2018). Psychometric evidence is not decisive in a recommendation for the EORTC QLQ-C30 over the FACT-G, or vice-versa (Luckett et al., 2011). However, studies should employ a survivor-specific and general measure of quality of life (Arden-

Close et al., 2010), therefore the integrated and lymphoma-sensitive FACT-LYM provides a more appropriate choice, as an equivalent EORTC survivor-specific tool was not available at this time. The FACT-LYM was identified as the only appropriate instrument for a lymphoma-specific population (Boland et al., 2023; Goswami et al., 2019). These instruments have demonstrated reliability and validity with cancer survivors as shown in Table 5.7.

Table 5.7 Selected Outcome Assessment Instruments

Sample	Use	Reliability	Validity	Other
Short Form-Survivor Unmet Needs Survey (SF-SUNS) (Campbell et al., 2014; Taylor et al., 2018)				
Trail data: Canada (*n=1589*, NHL 5%). **Test-retest reliability:** Australia (*n=40*, NHL/HL 100%). Timeframe = last month.	Developed for cancer survivors to assess unmet needs. Assess the gap between patient self-reported concerns and the level of support they require.	**Internal Consistency** Cronbach's alpha scores for all domains were ≥0.85. **Test-Retest Reliability** ICC across all domains were high ≥ 0.9.	Derived from the SUNS. **Discriminant Validity** Survivors who received treatment had significantly higher median scores than survivors without treatment.	Validated in cancer survivors 1 – 5 years post-diagnosis and in lymphoma cancer survivor populations (Taylor et al., 2018). Sensitive to change: responsive to the changing needs of lymphoma cancer survivors.
Functional Assessment of Cancer Therapy – lymphoma (FACT-LYM) (Hlubocky et al., 2013)				
Trail data: USA (*n=84*, NHL 100%) Timeframe = past week.	Developed for assessing unique issues of a lymphoma diagnosis. Assess the quality of life and symptoms/ side effects associated with lymphoma cancer survivors.	**Internal Consistency** Cronbach's alpha > 0.7 at all three times. **Test-Retest Reliability** ICC range for all subscales is 0.61–0.87. Overall ICC for FACT-LYM= 0.87.	**Content Validity** Items were content valid, relevant, comprehensive, and self-explanatory. **Convergent Validity** Moderately high correlation with other instruments: POMS total score (0.42-0.68), SF-36 (r=0.48, *p=<0.001*) and PCS (r=0.62, *p=<0.001*).	Sensitive to change: differentiated patients in each of the three groups (*p=<0.001*)
EuroQoL-Five Dimension-Five Level (EQ-5D-5L) (Herdman et al., 2011)				
Trail data: UK (*n=40*), Spain (*n=37*) Timeframe = today.	Developed as a generic instrument for describing and valuing health. Designed to be self-administered and short enough for use in conjunction with other measures.	**Test-Retest Reliability** ICC range from a systematic review (*n=9*) >0.7 (Feng et al. 2020).	**Convergent Validity** with the WHO-5, all Spearman rank order coefficients were significant (*p=<0.001*)	Moderate effect sizes for responsiveness (Feng et al., 2020).

5.5.2.1 Unmet Needs Instrument

The 30-item SF-SUNS measures the degree of unmet need as perceived by an individual at one time point (Taylor et al., 2018). Unmet needs are assessed from the following four domains: information needs (3 items), work and financial needs (8 items), access and continuity of care needs (6 items), and coping, sharing, and emotional needs (13 items). Participants' self-reported concerns, and the level of support they require are measured using a Likert-type scale, ranging from 0 (no unmet need) to 4 (very high unmet

need). Scores from domains are generated by adding each item score and dividing by the total number of domain items (Taylor *et al.* 2018). SF-SUNS derives from the original 89-item SUNS and is validated for cancer survivors one to five years post-diagnosis and has been tested with HL and NHL populations (Campbell et al. 2014; Taylor *et al.* 2018). Initial testing involved a mixed-cancer sample (*n=1589*) including NHL participants (5%) (Campbell et al., 2014). Further reliability test-retesting was conducted in an NHL and HL sample (n = 40) (Taylor et al., 2018). SF-SUNS has demonstrated reliability and validity (Campbell et al. 2011, Carey et al. 2012, Hall et al. 2015). All Cronbach's alphas were >0.85 showing strong internal consistency for all four domains and intra-class correlations (ICC) >0.9 indicates the SF-SUNS is a reliable in measuring levels of unmet need (Taylor et al., 2018). Mixed test-retest reliability was found (fair to good, 0.45-0.74) (Taylor *et al.* 2018). Discriminant validity showed successful differentiation between groups of cancer survivors experiencing varying levels of unmet need (Campbell et al., 2014).

5.5.2.2 Cancer-specific Instrument

The FACT-LYM is a valid and reliable is a lymphoma specific measurement instrument that is responsive to changes in health status (Hlubocky et al., 2013). Participants' self-reported quality of life outcomes are measured using a Likert-type scale, ranging from 0 (not at all) to 4 (very much). The FACT-LYM is a 42-item tool covering questions relating to quality of life and symptoms and side effects commonly associated with lymphoma during the past week. The general component (FACT-G) covers four subscales: Physical Wellbeing (7 items), Social/Family Wellbeing (7 items), Emotional Wellbeing (6 items), and Functional Wellbeing (7 items). The Additional Concerns subscale or 'LYM' component (15 items) addresses issues typically associated with lymphoma (e.g., fevers, night sweats, itching). Initial psychometric testing was validated and developed utilising comprehensive input from a sample of NHL participants (*n=84*) (Hlubocky et al., 2013). Expert interviews and literature review informed the content of items (Hlubocky et al., 2013). The use of this measure for disease-related symptoms and concerns is supported by high internal consistency (α=>0.70) at all time points. Convergent validity was tested by examining Spearman's correlation coefficients among FACT-Lym (subscales and total scores) and related measures, finding moderately high correlations with the Profile of Mood States (POMS) total score (r=0.42 to 0.68) and 36-item Short Form Survey (SF-36) mental component score (r=0.48, *p=<0.001*) were shown (Hlubocky et al., 2013).

5.5.2.3 Generic Health Instrument

The purpose of the standardised EQ 5D-5L is to describe and value health (Herdman et al., 2011). This generic instrument consists of the thermometer-like visual analogue scale (VAS), which rates health from the worst imaginable health (0) and the best imaginable health (100). The EQ-5D descriptive system includes five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (Feng et al., 2020). The 5-level version was introduced to improve the instrument's sensitivity and to reduce ceiling effects when compared with the previous 3-level version (EQ 5D-3L). The EQ 5D-5L was designed to be self-administered and short enough to complement the use of other measures (Coons et al., 2000; Feng et al., 2020). Therefore, the EQ-5D is complimentary of the FACT-LYM and SF-SUNS which address cancer-

related outcomes. Extensive psychometric testing has been conducted internationally, with face and content validity and strong reliability among English-speaking cancer patients (Herdman et al., 2011; Pickard et al., 2007). Preliminary testing was conducted using response scaling and focus groups (Herdman et al., 2011). Further testing showed convergent validity with another validated instrument (WHO-5) using Spearman's coefficients were significant (*p=<0.001*), and discriminatory power (Shannon index) showed information richness (Janssen et al., 2013). A systematic review of the psychometric properties of the EQ-5D-5L reported that nine studies addressed test-retest reliability, finding good to excellent intraclass correlation coefficient (>0.7) (Feng et al., 2020).

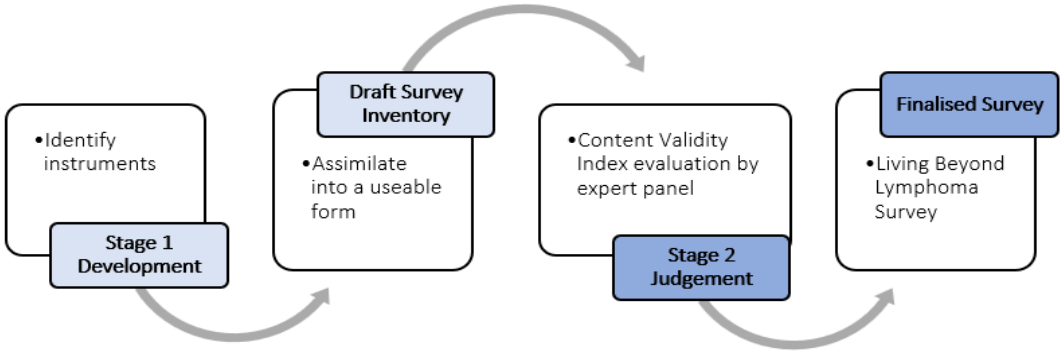
5.5.2.4 Demographic Characteristics

Demographic information is necessary for generalisation purposes (Salkind, 2010). A national review identified limited information on how needs differ by age, sex, and education level in the Irish cancer context (O'Connor et al., 2019). Self-report questions regarding participants' gender, year of birth, region of residence (urban or rural), origin of ethnicity, type of lymphoma diagnosis and time since diagnosis will be included. Items on the demographic scale were extracted and adapted from two sources: first, the Department of Health (UK) Quality of Life of Cancer Survivors in England Patient Reported Outcomes Measures (2012) and second, the most recent National Census of Ireland (2016) form.

5.5.2.5 Content Validity

The assessment of content validity is a crucial step in instrument development and refers to the extent to which an instrument measures what it is intended to measure (Beck & Gable, 2001; Lynn, 1986; Polit & Beck, 2004; Waltz et al., 2010). For this study, content validity involves determining the content relevance, content clarity and content representativeness of the selected instruments' items. Relevance relates to how essential or important the items are to be used in the survey, clarity refers to how clear a question is and how easy it is to understand, while representativeness refers to what extent the items represent the target construct (Abd Gani et al., 2020). A construct refers to the basis of the survey items, which may be reflected in the context of the study (Abd Gani et al., 2020). The application of a two-stage process that incorporates rigorous instrument development and quantifies content validity is vital to the validation of instrumentation (Lynn, 1986) (Figure 5.5).

Figure 5.5 Stages of Content Validity Determination, Adapted (Lynn, 1986)



Stage one was discussed in detail in Chapter 3 (systematic review identifying instruments); this current Section 5.6 outlines the assimilation of instruments into a useable questionnaire. In stage two, an expert panel was formed, encompassing clinical (nursing, medicine, and pharmacy), academic and lived experience of lymphoma. This wide variation in experts' backgrounds is advantageous in being holistic, involving patient participation and its multi-disciplinary content validity approach. However, this variation may reduce control over item agreement (Rodrigues et al., 2017). The principal goal of the expert review was to assess the clarity (is the item clear and easy to understand), relevance (are the questions appropriate and relevant), and representativeness (are the questions characteristic and representative) of the survey to the lymphoma survivors and to reveal any issues that exist in the instrument prior to the distribution to the target population (Abd Gani et al., 2020). A structured procedure for evaluating content validity was prepared and given to experts, consisting of instructions and a rating system (Appendix 13). They independently reviewed items on each instrument (EQ-5D-5L, FACT-LYM, SF-SUNS, Demographics) using a 4-point Likert scale to assess relevance, clarity, and representativeness. This evaluation was conducted using the survey software Qualtrics.

The experts rated the Living Beyond Lymphoma survey as clear (S-CVI/Ave=0.94 excellent), relevant (S-CVI/Ave=0.96 excellent) and representative (S-CVI/Ave=0.94 excellent), the scoring manual adapted from Polit and Beck (2006); Polit et al. (2007) is outlined in Appendix 14. Universal agreement for the scale (S-CVI/UA) was lower (range S-CVI-UA=0.58 – 0.75 fair - good). Items with poor validity scores were expected to be deleted. However, all individual items were rated fair or higher, receiving I-CVIs >0.625 (more than five experts rated the item with a 3 or 4) and k^*>0.52. Strong evidence supported the content validity of the survey, including evaluation and feedback from two lymphoma survivors. Given the excellent average scale agreement but fair to good universal agreement for the scale, the wide variation in experts' backgrounds and experiences could be considered inadvertently reducing control over item agreement.

Suggestions from experts were considered valuable (this change would add value to the survey) or not valuable (this change would not add value to the survey). Most suggestions were deemed not valuable when considered in the context of the whole survey for demographics, the original question for age was problematic as it included a four-digit box to input birth year. This was changed to *'What is your age in years?'* as age was more practical than birth year. Similarly, the question asking participants about gender received comments from three experts. E1: *'Not really clear as to the difference between prefer to self-describe and prefer not to say'.* E5: *'Put Female before Male (alphabetical order). Could also consider including Transgender Female and Transgender Male'.* E6: '*Not sure what prefer to self-describe means, is this a known term (is it gender-fluid?)'.* The most practical approach to rationalising this question *('What gender do you identify with? Tick one)* involved the removal of *'prefer not to say',* leaving three options instead of four 'Female', 'Male', or 'Prefer to self-describe' with a text box for description (no participants used the self-describe option). The expert panel added value to the question about treatment ('What treatments have you received for your lymphoma cancer? Tick all that apply'). Immunotherapy (e.g., Rituximab), stem cell transplantation, and other cellular therapy (e.g., CAR-T therapy) were added to

chemotherapy, radiotherapy, surgery and other (please specify) to provide a better overview of potential treatment options for lymphoma survivors.

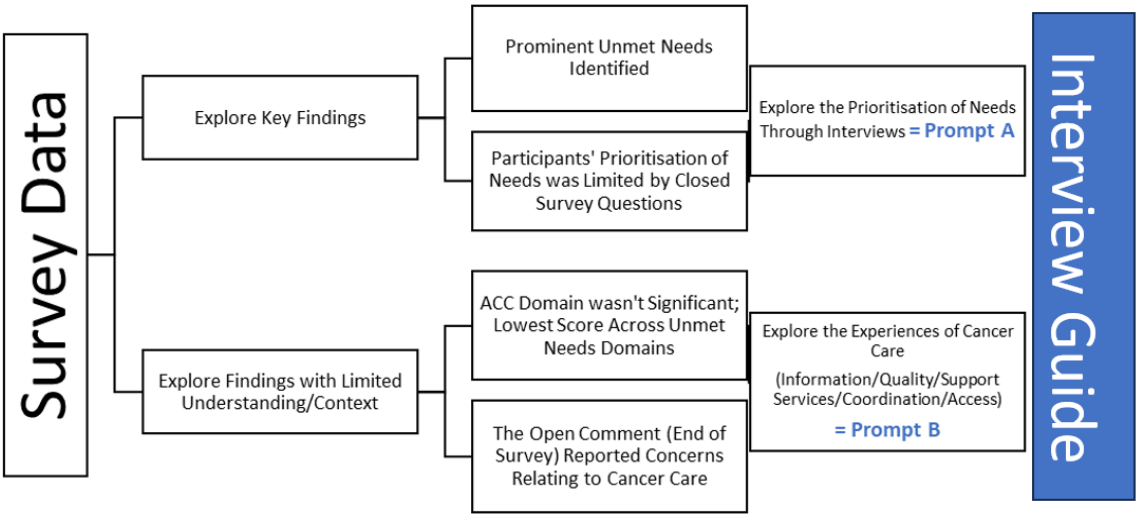
5.5.2.6 Finalised Survey

The finalised survey was organised into four sections: section one, generic health (EQ 5D-5L, five items and a visual analogue scale); section two, quality of life (FACT-LYM, forty-two items); section three, unmet needs (SF-SUNS, thirty items); and lastly section four, demographics (twelve questions and one open-text box). The survey is available in Appendix 12.

5.5.3 Interview Guide Development

The semi-structured interview was designed to yield in-depth insights into the personal and sensitive nature of the lived experience of lymphoma (Gill et al., 2008). The interview guide was developed over several steps. Initially, the research objectives were reviewed, and questions were considered to address the identified important aspects of this research (Table 5.1). The research issues distilled from the literature review guided further formation of the semi-structured interview questions. Specifically, a qualitative study by Herrmann et al. (2020) used semi-structured interviews to explore haematological cancer survivors' (*N=17*, 59% NHL, 12% other lymphoma) unmet need; the Supportive Care Framework by Fitch (2008) guided their data collection interview guide and analysis. Given the similar population, purpose and theoretical framework, their semi-structured interview guide was reviewed to extract or inform this research. The main contribution to the development of the interview guide came from the phase one quantitative survey findings, which were evaluated systematically to identify areas where further qualitative explanation or understanding was needed. A content analysis was conducted to identify the survey's key findings and to explore the findings with limited understanding requiring further context. Two key aspects were identified from the survey findings which warranted further explanation in the subsequent interview. The process of interview guide development is illustrated in Figure 5.6.

Figure 5.6 Integration Process: Quantitative Findings Inform the Qualitative Interview Guide Development



ACC=Unmet Needs Domain for Access and Continuity of Care

The final interview guide is available in Appendix 15. This section discusses the specific key survey findings which informed the interview guide development. Survey participants consistently reported prominent unmet needs, however, the closed nature of the survey items delimited the prioritisation of unmet needs as the options were predetermined. An exploration of the prioritisation of needs for lymphoma survivors through phase two interviews was warranted. The opening interview question was broad: 'Could you tell me about your experiences with lymphoma cancer?'. To provide more structure and to capture the prioritisation of needs, Prompt A was devised: 'Since being diagnosed what have been the top three things that you needed help with?'. This facilitated the ability for interview data to confirm the survey's key findings and allowed for a more novel understanding of lymphoma survivors' unmet needs to be explored.

The domain of unmet needs for access and continuity of care was statistically insignificant and scored the lowest across unmet needs domains. An explanation for this finding was not clearly understood, therefore this warranted further explanation to understand lymphoma survivors' experiences of cancer care. In addition, the optional open comment at the end of the survey ('Is there anything further you would like to tell us about living with or beyond a lymphoma diagnosis?') found concerns relating to cancer care reported by lymphoma survivors. Therefore, an exploration of the experiences of cancer care through phase two interviews was warranted. Five key aspects were considered using data from the SFSUNS and narrative data provided by open comment answers, these included information, quality, support services, coordination, and access to cancer care for lymphoma survivors. Prompt B was formed and encompassed five questions relating to specific features of cancer care: 'What types of information should be provided during cancer care?', 'What things should hospitals do to provide quality treatment during cancer care?', 'What type of support services should be offered during cancer care?', 'What things do you think are needed for cancer care to be coordinated?', and 'What type of care should cancer patients be able to access?'.

5.5.3.1 Interview Procedure

Interviews were undertaken over ten weeks in the summer of 2022, at a time of mutual convenience for the participant and researcher. Participants were asked where they would like to be interviewed; all interviews took place online via video or by phone. Notably, this period coincided with the pandemic, which posed risks to this population. This might explain the absence of a preference for in-person interviews over convenient online or phone options. Given participants' dispersed locations across the island of Ireland, travel factors could have further impacted their preferences. Interviews were conducted systematically yet flexibly using a semi-structured guide (Section 5.6.8 and Appendix 15) developed from brainstorms about the topic, the literature review, informed by previous literature and the phase one survey findings.

All interviews were audio-recorded with permission and transcribed later by the researcher. Background and demographic information provided via the quantitative survey was confirmed with the participants at the start of the interview. Each interview participant was pseudonymised using a unique identifier before the interview to maintain confidentiality. Rapport was established through initial survey recruitment during participants' routine follow-up appointments or via hospital gatekeepers. Next, to arrange the interview,

contact was made via the participant's preferred and chosen means of communication by phone or email. A brief introduction outlining the background and aim of the study was provided to the interviewees. Rapport was further developed during interviews as time was provided for pre-interview conversation to put the participant at ease. Rapport and a well-planned interview guide are two important factors for generating rich and detailed accounts relevant to this research, as the participant feels comfortable disclosing personal information (Braun & Clarke, 2013). The capacity to build rapport was not felt to differ drastically between phone or online (virtual face-to-face) interviews as the participants appeared comfortable with their choice of communication, which in turn comforted the researcher, facilitating this 'professional conversation' (Kvale, 2007).

The interview guide was used to provide a general structure to the interview. The researcher's social skills, knowledge, and training were utilised to conduct an interview that appropriately met the demands of the research question and methodological approach. Using intuition throughout the interview process, the researcher used probes like head nodding (for online interviews) or sounds like 'uh-huh' (for phone interviews), silence and repeating the interviewees' words back to provide depth to the interview. Potential participant distress due to sensitive topics was anticipated (Braun & Clarke, 2013). A distress pathway was established (Appendix 9), and while sensitive discussions occurred, the pathway was not required.

Field notes to complement audio-taped interviews were maintained, allowing comments upon impressions, behaviours, emotions, or nonverbal cues that may not be adequately captured through the audio recording. Online (virtual face-to-face) participants were advised of the purpose of this notetaking to maintain comfort and trust. Reflective notes were added after each interview, guiding subsequent discussions and aiding analysis. These notes were used during interpretation to help remind the researcher of situational factors that may be important during data analysis.

5.6 Quality and Rigour

Rigour in research is characterised by the robustness of the research design and the suitability of the methods employed to address the research questions (Morse, 2016). Within qualitative research, the term trustworthiness is often used interchangeably with rigour, presenting a challenge because of the approach's contextual and subjective nature (Smith et al., 2014). To ensure the trustworthiness of qualitative inquiries, researchers commonly adopt four criteria: credibility, transferability, confirmability, and dependability (Lincoln & Guba, 1985). The criteria for establishing trustworthiness in qualitative research evolved from those used in empirical research and are used to frame the considerate care taken to ensure rigour in this research inquiry. This section also examines the quality of this mixed methods research and the reflexivity conducted by the author.

5.6.1 Credibility

Credibility concerns the accuracy of descriptions or interpretations of the experiences under investigation (Lincoln & Guba, 1985). *"It is not possible to understand any phenomenon without reference to the context*

in which it is embedded" (Lincoln & Guba, 1985, p. 302); it is therefore imperative that the researcher spends enough time becoming oriented to the situation. An element of prolonged engagement was conducted by the researcher, who was immersed in learning the culture and context of the lymphoma experience as a haematology nurse (the reflexivity surrounding this is discussed further in Section 5.7.5). Moreover, interview transcripts underwent two rounds of scrutiny for accuracy, accompanied by the maintenance of an audit trail and a reflexive journal to enhance credibility. An audit trail in qualitative research involves a process of ensuring clarity in the justification of actions carried out through step-by-step records (Lincoln & Guba, 1985). The reflexive journal aided decision-making about the development of the interview guide and, subsequently, data analysis. Credibility was reinforced during the interview process itself by employing techniques such as rephrasing, elaboration, and repetition of questions in varied contexts, fostering in-depth responses. The incorporation of mock interviews with fellow PhD peers (to test the interview guide and enhance interview skills) and previous focus group interview training served to further fortify and ensure credibility throughout the qualitative phase of the study.

5.6.2 Transferability and Dependability

Transferability pertains to the ability to apply findings to different contexts; this allows the reader to draw on the applicability to their own context or situation (Lincoln & Guba, 1985; Lincoln & Guba, 1988). To make this judgement possible, there must be a thick description so the reader can make sense and establish clear levels of meaning (Geertz, 1973). To ensure this, detailed descriptions of the research context, actions taken, and justifications for arriving at the findings are provided within this current chapter and in the qualitative findings (Chapter 7). This clarity enables other researchers to determine the suitability of applying these findings elsewhere. Dependability refers to the efforts made to ensure a logical and transparent process which facilitates the examination of methods, decisions and outcomes undertaken for the research process. A reflexive journal maintained a report of actions carried out to arrive at conclusive findings and to provide a trail of transparency of the process and decisions.

5.6.3 Confirmability

Confirmability delves into a deeper understanding and investigation, ensuring the findings are clearly derived from the data and determined by appropriate audit trail linkages (Lincoln & Guba, 1985). In reviewing the findings of data analysis, unusual findings or findings which lacked interpretive value were linked back to the raw data via the audit trail (raw data, interview notes, reflexive journal notes and NVivo memos and annotations). Judgements were made about whether inferences based on the data are logical, looking carefully at the application of reflexive thematic analysis, the appropriateness of theme development, the quality of interpretations and the possibility of equally attractive alternatives (Lincoln & Guba, 1985). Next, the selected themes were evaluated for their utility, clarity, explanatory power, and appropriate fit to the data. Additionally, half of the interview transcripts (*n=7*) were subjected to independent verification by another researcher (supervisory team). Codes and developing themes were

discussed until a consensus was agreed; this further enhanced the validity and reliability of qualitative data analysis.

5.7 Quality of Reporting Mixed Methods Research

To ensure the credibility of a mixed methods study, it is essential to provide a clear rationale for adopting a mixed methods design, including both quantitative and qualitative components, as well as points of integration (O'Cathain et al., 2008). A common criticism of mixed methods research is the lack of explicit documentation and transparency in the reporting of mixed methods studies (Cameron, 2013). The Good Reporting of a Mixed Methods Study (GRAMMS) checklist was developed as a quality framework to address this problem, aiding the evaluation of the quality of mixed methods studies (O'Cathain et al., 2008). This section discusses the GRAMMS criteria and how they apply to this research is outlined in Table 5.8.

5.7.1 Justification for Mixed Methods Research

The decision to employ a mixed methods approach in this study is grounded in the complexity of the research question, which seeks to explore the multifaceted needs of lymphoma survivors. Chapter 4 explores the methodological and philosophical approaches underpinning this research, specifically Section 4.4 on study design, while Chapter 5 details the methods employed, their rationale and the choice of study design (Section 5.2). A mixed methods design was chosen to leverage the strengths of both quantitative and qualitative data, allowing for a more comprehensive understanding to advance the knowledge of lymphoma survivors' unmet needs, that could not be achieved by a single approach. Quantitative data offers a broad overview of unmet needs which is expanded upon by the qualitative data through gaining deeper insights into individual experiences and contextual factors.

5.7.2 Research Design and Methods

The research design is detailed in Chapter 5, Section 5.2.1. The mixed methods sequential explanatory design was selected to first quantify the unmet needs of lymphoma survivors through surveys (phase one), followed by in-depth semi-structured interviews with a subset of the survey sample to explore these needs in more detail (phase two). This approach is suitable for enhancing the understanding of the unmet needs of lymphoma while building on previous evidence which informed the decision-making on the variables to be measured (e.g., instruments validated for this population). Sections 5.2.2 through 5.2.4 outline the steps of each phase, including how the findings from the initial survey guided the focus of the interviews. The sampling strategies for both the quantitative and qualitative phases are described in Chapter 5, providing a representative sample of lymphoma survivors. Data collection methods are detailed, including comprehensive reporting on survey development, processes, and procedures for both quantitative and qualitative phases. This comprehensive reporting in Chapter 5 enhances the transparency of this research and shows the development of this mixed methods study from conception to later findings and interpretation.

5.7.3 Integration

The integration of quantitative and qualitative data is a critical component of the mixed methods approach. Section 5.2.4 explains how integration occurs at multiple points within this study, from the sequential explanatory design to the integrated research objectives, integrated sampling strategy and development of the interview guide and maximum variation sampling strategy. For example, for the interview guide development, two key areas were identified from the quantitative findings which required further qualitative explanation: a) understanding was sought as to how lymphoma survivors prioritised their unmet needs and b) investigation as to what specific features of cancer care were important to lymphoma survivors or would be helpful to other individuals in their position with a lymphoma diagnosis. This was prompted to enable participants to list their top unmet needs and decide on the level of prioritisation due to their lived experience, without the constraints of the predetermined nature of the first phase survey. Prompt B was informed by the limited insight into the context of cancer care within the survey results. This integration is detailed in Section 5.5.3 and the resulting interview guide is available in Appendix 15. A narrative integration of results combines statistical trends with personal narratives to provide a richer understanding of the unmet needs of lymphoma survivors in Chapter 8.

Underpinned by pragmatism, the pluralistic research design, employed in this study appreciates different paradigms (i.e., post-positivism in phase one and interpretivism in phase two) to facilitate an integrated and more nuanced understanding of this research problem. The integrated analysis of quantitative and qualitative findings required in-depth considerations from methodological and analytical perspectives. Analytically, integration was achieved, by juxtaposing the findings of phase one and phase two for congruence and/or divergence. This resulted in similarities, or novel qualitative findings being grouped to facilitate a rich discussion of this study's findings. For example, cancer-related fatigue was reported by many survey participants, while interviews provided a contextual understanding of the experience of this problem (e.g., fatigue impacted their daily living; sleep was used as a treatment for fatigue). Other findings in phase two were novel (e.g., experiences of chemotherapy-induced alopecia and reproductive concerns for lymphoma survivors).

5.7.4 Limitations

Acknowledging the limitations of this research is essential to a balanced discussion, specifically, Section 8.6 on strengths and limitations provides this. Integration of both quantitative and qualitative data provided unique insights that would not be possible from either method alone. These insights are woven throughout the discussion chapter, highlighting that the combined methods enriched the understanding of lymphoma survivors' unmet needs. Furthermore, this dual approach allows for more targeted recommendations for support services.

Table 5.8 Good Reporting of a Mixed Methods Study Checklist Applied to this Research (O'Cathain et al., 2008)

Guideline	Location (Chapter, Section)
Describe the justification for using a mixed methods approach to the research question.	▪ Chapter 4 (Methodological and Philosophical Approaches), Section 4.4 Study Design. ▪ Chapter 5 (Methods), Section 5.2 Design.
Describe the design in terms of the purpose, priority, and sequence of the methods.	▪ Section 5.2.1 Sequential Explanatory Design. ▪ Sections 5.2.2-5.2.4 Phase One, Two, and Integration.
Describe each method in terms of sampling, data collection and analysis.	▪ Described in detail throughout Chapter 5 – Methods.
Describe where integration has occurred, how it has occurred and who has participated in it.	▪ Chapter 5.2 Study Design, Section 5.2.4 Integration.
Describe any limitation of one method associated with the presence of the other method.	▪ Chapter 8 (Discussion), strengths and limitations, Section 8.6.
Describe any insights gained from mixing or integrating methods.	▪ Throughout Chapter 8 (Discussion).

5.8 Reflexivity

Reflexivity involves routinely reflecting on the researcher's assumptions, expectations, choices, and actions throughout the research process. This means being aware of how the researcher's position inevitably shapes her research and engagement with data; this is ongoing rather than a final process of reflection (Clarke & Braun, 2021). My professional experience as a nurse in haematology and my personal experience caring for a family member with a haematological malignancy have immense potential to influence my views. This family cancer experience inspired me to become a nurse, and my experience working in haematology compelled my aspiration to understand, upskill and contribute to research focused on improving patient outcomes in this area. Therefore, a process of reflexivity was necessarily undertaken throughout this research.

Within my research design, I was conscious of the importance of involving diverse perspectives by seeking input from individuals with different backgrounds through employing a maximum variation sampling strategy. This approach facilitated a more comprehensive understanding of unmet needs, as it ensured the inclusion of voices from individuals not occupying positions of social privileges, such as non-Irish or marginalised groups like the Irish travelling community.

My background as a nurse with clinical experience working with lymphoma survivors could potentially lead to certain assumptions and perspectives relating to this research topic. I might assume that my clinical experience provides me with a deep understanding of the challenges and needs faced by lymphoma

survivors, equipping me to detect and identify unmet needs more accurately. While this knowledge is beneficial in achieving a comprehensive understanding of this research, I employed practices to ensure it did not distort or overshadow the lived experiences provided by the lymphoma survivors. During interviews, I made efforts to create safe and inclusive environments to encourage participants to share their lymphoma experiences. This included using culturally sensitive language, active listening, and being open to participants' viewpoints. This was particularly important given my background as a nurse, as many participants often sought validation for their experiences by asking questions like 'Is that what it is meant to be like?' or 'Is that what other people experience at other hospitals?'. I refrained from engaging in complex conversations outside the interviewer's position to avoid causing any undue harm to the participants, such as providing conflicting answers to their current understanding.

I considered how lymphoma survivors might perceive me given my clinical nurse background, which was subtly made known to the participants through information leaflets and invitation letters. Positive perceptions might include seeing me as empathetic and understanding due to my clinical experience working with patients as I can relate to their experiences and challenges. Participants might also view me as knowledgeable about lymphoma, such as their treatment journey and potential issues they have encountered, leading to more informed discussions. However, participants might hesitate to express certain opinions or concerns, such as complaints or bad experiences of healthcare delivery, fearing the power dynamic of my clinical nursing background. To mitigate these challenges, I engaged in ongoing reflexivity, critically examining how I should adopt reflexive practices that acknowledge and address potential biases, ensuring a more holistic and nuanced understanding of the unmet needs of lymphoma survivors. Therefore, this section has outlined how reflexivity was approached in my research.

5.9 Ethical Considerations in the Design of this Study

Greater awareness of ethical research issues and their implications can lead to advancements in healthcare (Crico et al., 2022). The research protocol was developed to protect participants from harm and to ascertain the appropriate measures to take to reduce risks. This research was submitted for ethical review by the Ethics Committees of Trinity College Dublin and hospital sites to enhance the ethical considerations and acceptability of this study. Ethical approval was granted from five relevant committees (Appendix 5) in advance of proceeding with the study. Permission for use of the quantitative data collection instruments was obtained from the corresponding authors or organisations (Appendix 6). In addition to ethical considerations, data protection impact assessments (DPIA) were undertaken to assess and manage the data protection risks of this research; they were reviewed and developed with relevant Data Protection Officers (DPO) affiliated with the university and hospital sites. As this research used personal and health data, it complied with EU and national data protection laws (EU General Data Protection Regulation 2016 (GDPR) and Data Protection Acts 1988-2018) and the Health Research Regulations 2018, including the 2021 amendments. Most ethical research guidelines are founded upon the principle of honouring participants'

human rights, emphasising that research involving human subjects must adhere to universally applicable ethical standards (World Medical Association, 1964).

5.9.1 Ethical Framework

The Belmont Report is a critical document for researchers as its purpose is to protect the rights of research participants. The Belmont Report uses and builds upon the Nuremberg Code, Declaration of Helsinki and other laws (Ryan et al., 1979; Schmidt & Brown, 2024; Sims, 2010). Considering the ethical considerations in the design and conduct of this research, the Belmont Report was used as an ethical framework. The three major components include respect for persons, beneficence, and justice. There is overlap among the principles, however this section is focused on providing an overview of how ethical issues received appropriate consideration in the context of this study.

5.9.2 Respect for Persons

Respect for persons involves two moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy (Department of Health, 2014; Sims, 2010). Autonomous individuals have the right to make their own choices and decisions (Beauchamp & Childress, 2001; Kitchener & Kitchener, 2009). However, some individuals may not be completely autonomous for a variety of reasons (i.e., intellectual disabilities or psychological illness); allowances must be made for vulnerable people who require additional protection (Department of Health, 2014; Miracle, 2016). An autonomous person provided with appropriate information has the right to make their own decisions which must be honoured and respected (Beauchamp & Childress, 2001). In the case of individuals who are not completely autonomous, additional safeguards must be considered and put in place (Kitchener & Kitchener, 2009; Schmidt & Brown, 2024). This means that individuals capable of deliberation about their personal choices require respect for their capacity for self-determination, while persons with diminished capacity should be protected. Informed consent implies two related actions: first, comprehension, and second, voluntary participation. The research participant must understand the nature of the research and their role within it.

Participants were recruited through hospital sites (described in Section 5.5). Respect for persons was addressed by the following aspects of this research. Initial information about the study was provided to potential participants by clinical gatekeepers (nurses and doctors). In addition, prior to deciding whether to participate in the study, all potential participants received an invitation letter and a detailed participant information leaflet (PIL) (Appendix 7). Potential participants were encouraged to take time in considering their participation in this research and to discuss their participation with people they trust, *"Before you decide whether you wish to take part, please read this information sheet carefully. Ask any questions you may have. Don't feel rushed or under pressure to make a quick decision. You should 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 may wish to discuss it with your family, friend, or healthcare professional.".* These materials provided comprehensive information about the study, including a

description of the research procedure, and potential benefits and risks. Additionally, the booklet contained contact details for the researcher, encouraging participants to reach out for queries or further clarification. A consent form was completed and returned by the participant, submitted online or via pre-paid postage (Appendix 8).

Information about the subsequent interview was included in the PIL and consent form, as survey participants were asked to indicate if they were willing to receive potential future contact about participating in a follow-up interview. Participants who completed the survey but who did not wish to participate in a follow-up interview did not 'opt in' for follow up (e.g., no contact details were sought). Participants who agreed and returned their written contact information (and were selected for interview, study recruitment is outlined in Section 5.5) were contacted about the interview. The participant's preferred contact method was used (e.g., email or telephone). During this correspondence, participants were informed of the purpose of the interviews, the topics to be discussed and the process of conducting the interview and participant's questions were addressed. A convenient time and place were arranged to conduct the interview, participants were given the choice of in-person, by telephone or online. All participants selected either online or by telephone due to the pandemic. The written consent provided by participants was verbally confirmed prior to starting the interview. The interview participants were reassured that they could pause, stop, or withdraw from the interview before its completion.

5.9.3 Beneficence

Beneficence incorporates the principle of doing good (Schmidt & Brown, 2024). While certain scientific research endeavours may carry the risk of physical harm to participants, in the realm of social science research, the notion of harm primarily pertains to psychological distress, discomfort, social disadvantage, or breaches of privacy (Israel, 2014). For both research and clinical care this involves two general rules or beneficent actions: doing no harm and maximising possible benefits and minimising possible harms (Ryan et al., 1979; Schmidt & Brown, 2024; Sims, 2010). Awareness and knowledge of known or possible harm is required before providing consent for research studies or nursing and medical procedures. This information is required to enable an informed autonomous decision (Miracle, 2016). One measure undertaken to protect participants was a written informed consent form and PIL outlining the purpose of the study, a description of the research procedure, and the potential benefits and risks (Sims & Miracle, 2002). The PIL included the clear message that participation is voluntary without fear of reprisal, "*You don't have to take part in this study. If you decide not to take part, it won't affect your future cancer care. You can change your mind about taking part in the study. You don't have to give us a reason. If you opt out, rest assured it won't affect your cancer care in the future*." (Appendix 7).

Other efforts were made by this research project to protect participants from harm through reducing risks and increasing benefits. This study delves into the sensitive subject of the experience of cancer which is personal to participants and could evoke emotional reactions. Consequently, this study had the potential to cause psychological distress, particularly when participants were voicing their experiences in phase two

interviews. To address this concern, a plan was devised at the beginning of the study to provide support and protection for participants. Within the PIL, this potential risk to participants was outlined including the support available should distress occur (e.g., Irish Cancer Society Daffodil Centres or Nurse Lines). A research interview and distress protocol to manage distress in the context of the study interview was developed, adapted from Draucker et al. (2009) (Appendix 9). Additionally, the exclusion criteria excluded individuals who were terminally ill in the last three months of life, unconscious or unwell at the time of survey or with cognitive impairment inhibiting informed consent, from participating in this study to cause no harm. In keeping with respect for persons, the decisions of individuals were respected, and efforts made to keep them from harm. There were no direct benefits to participants for being involved in this study, however this research provided participants with a platform to express their experiences of lymphoma. This is compatible with the broad understanding of beneficence in improving comprehension or providing indirect developments or benefits (Iphofen, 2020).

5.9.4 Justice

Justice demands equal treatment and fairness for all (Schmidt & Brown, 2024; Sims, 2010). Ensuring fair allocation of both the challenges and advantages of participating in research, is often the focus of justice in social science research (Kitchener & Kitchener, 2009). Justice questions who ought to receive the benefits of research or bear its burdens; it is an ethical obligation to treat each person morally right. To facilitate this, information was provided to all participants in a timely manner and in an accessible format, with additional supports available for individuals who need it (e.g., time to ask the research team questions). Participants had access to the researcher's contact details for inquiries, which were promptly and respectfully addressed.

Protection of participants' privacy was upheld; many steps were taken to protect confidentiality and keep data safe through secure encryption and handling of survey data so that it can no longer be attributed to participants (anonymisation). The questionnaires were devoid of any participant-identifying information except for a unique identification code, enabling researcher identification necessary to allow the maximum variation sampling technique (Section 5.5.3). All data accompanying a complete and returned survey were handled confidentially. Paper questionnaires were securely stored, and electronic data were entered into a password protected, encrypted computer programme, managed solely by the researcher. Access to data, both electronic and paper-based was restricted to the researchers and her academic supervisors. Interviews were recorded on an encrypted, password protected audio device. The audio recordings were uploaded on to a password protected and encrypted laptop and stored in a password protected folder. Only the researcher had access to this data. Identifying information was removed from interview transcripts (e.g., named hospitals, services, or locations), transcripts were numbered forming pseudonymised data. Audio recorded interviews were destroyed when accuracy of transcripts was confirmed, and analysis was complete.

The study operated without deception; participants were informed of the intent to publish findings in peer-reviewed journals and conference presentations. Assurances were given regarding anonymity

preservation. Research that is of interest to the public, such as advancements in the knowledge of cancer survivorship (i.e., the understanding of experience and development of services), should be shared accordingly (Miracle, 2016; Sims, 2010). Dissemination of research with participants and society, such as lay person summaries of peer-reviewed publications and presentations, were important considerations relating to the principle of justice and this research. Therefore, the Belmont Report protects the rights of participants through respect for persons, justice and beneficence and has framed the discussion of ethical considerations in the context of this research.

5.10 Data Management and Analysis Procedure

The quantitative and qualitative data were analysed sequentially and reported separately using appropriate analytic techniques for each dataset in keeping with the sequential explanatory design. This section outlines the data analysis strategies for this study's quantitative and qualitative phases.

5.10.1 Quantitative Survey Data Management

Survey data was collected in Qualtrics and then data was entered into SPSS to facilitate data analysis. The raw survey data was imported into SPSS. The data entry was double-checked to verify its accuracy. Within SPSS v27.0, each variable was defined by specifying its name, data type, level of measurement (i.e., nominal, ordinal, scale) and any applicable labels or value ranges to ensure clarity. Checks for errors or inconsistencies in the data (e.g., data entry mistakes) were conducted. Detected errors were corrected in consultation with the participant's questionnaire responses. Variables were recoded or transformed to make them suitable for analysis (i.e., dummy variables were created for regression analysis). Throughout the data management process, validation checks were conducted to ensure the accuracy and integrity of the data (e.g., verifying that the data falls within the expected ranges). One open-ended item on the survey was screened, removing potentially identifiable information, such as the names of places, hospitals, or healthcare professionals. The open-ended responses at the end of the survey provided textual data which lent itself to qualitative analysis and therefore were included the open-ended responses for reflexive thematic analysis.

5.10.2 Descriptive Statistical Analysis

After data cleaning, subscale and total scores were calculated for responses to the SF-SUNS, FACT-LYM and EQ-5D-5L, following manual scoring templates provided by the corresponding authors for each standardised instrument. In addition, the authors of the FACT-LYM provided a syntax for use in SPSS. Firstly, the collected data underwent a descriptive exploration to understand the unmet needs of lymphoma survivors. Descriptive statistics, such as percentages, means or medians, range, and standard deviations, were used to summarise and describe the dataset. This process identified patterns and relationships for subsequent inferential statistical analysis. Univariate descriptive frequencies were computed to summarise

categorical data, enabling the description, comparison, and characterisation of relationships present within the dataset (Gorard, 2021).

5.10.3 Inferential Statistical Analysis

Inferential statistics enable inferences to be made based on the data set (Field, 2018; Gorard, 2021). Initially, hypothesis testing (*t*-tests, Chi-square tests and Wald tests) was conducted to observe statistically significant associations between sociodemographic or clinical characteristics and lymphoma subtype. This provides important insights into the differences between Hodgkin lymphoma and non-Hodgkin lymphoma. The *t*-test is used when comparing the differences between the means of two groups. At the same time, Chi-squared (symbolised as χ^2) is a test of significance used with two (or more) categorical variables when trying to decide if they are related (Gorard, 2021). Nonparametric inferential statistics (Mann-Whitney *U* tests and Kruskal-Wallis *H* tests) were used to characterise the significance of differences in unmet needs scores between subgroups within the sample (i.e., age groups or lymphoma type). These tests were focused on addressing objectives one, two and four of this research (Table 5.9).

Table 5.9 Statistical Analysis Used to Address the Relevant Study's Objectives

Objective 1 Identify unmet needs.	▪ Descriptive statistics (SF-SUNS) ▪ Hypothesis testing (SF-SUNS) (Mann-Whitney tests and Kruskal-Wallis tests)
Objective 2 Explore QOL and symptom experiences.	▪ Descriptive statistics (FACT-LYM and EQ-5D-5L) ▪ Hypothesis testing (FACT-LYM) (Mann-Whitney tests and Kruskal-Wallis tests)
Objective 4 Evaluate factors influencing unmet needs.	▪ Hierarchical Multiple Regression (dependent variable = unmet needs; independent variables = demographics, clinical characteristics and QOL) ▪ Canonical Correlation Analysis
Objective 5 Inform service development to address unmet needs.	▪ Informed by meta-inferences

Key: QOL = quality of life; SF-SUNS=Short-Form Survivor Unmet Needs Survey; FACT-LYM=Functional Assessment of Cancer Therapy-Lymphoma; EQ-5D-5L=EuroQoL-Fie Dimension-Five Level. Note: Objective 3 does not apply.

Nonparametric tests were used in the univariate analysis because the data were not from a normal distribution (Shapiro-Wilk tests of normality showed *p* values <.001; with >.05 considered normal. Quantile-quantile plots were observed as not linear). The Mann-Whitney *U* test determines the number of times a score from one of the samples is ranked higher than a score from the other sample (Cramer, 1994). Similarly, the Kruskal-Wallis *H* test ranks cases in the different samples together in one series except this test can be used with more than two unrelated samples (Cramer, 1994). Hierarchical multiple regression and canonical correlation analysis were used to examine and elicit the explanatory factors that influence lymphoma survivor's unmet needs. Unless otherwise stated, all statistical tests were assessed for significance at confidence level α=≤.05. The rationale for selection and assumptions underpinning the statistical techniques are discussed in subsequent sections.

5.10.3.1 Rationale for Hierarchical Multiple Regression

Hierarchical multiple regression was used to explore whether specific blocks of variables increased the model's explanatory power regarding unmet needs (Keith, 2014). Each block represents one step (or model). In the hierarchical regression, each block of variables was added to the model in sequential steps to determine if the additional variable(s) in each block significantly improved the model's explanatory power (Keith, 2014). It allows for a systematic examination of the contribution of different sets of predictors in explaining the unmet needs of lymphoma survivors. By introducing predictor variables in sequential blocks or stages, you can assess the unique contribution of each set of predictors while controlling for other variables (Fein et al., 2022). This stepwise approach helps build a nuanced understanding of the factors influencing unmet needs in individuals with a lymphoma diagnosis. Hierarchical multiple regression enables a systematic control of potential confounding variables (Pourhoseingholi et al., 2012). By introducing covariates in earlier blocks of the regression model, their effects can be accounted for before examining the impact of subsequent sets of predictors. This enhances the accuracy of assessing the independent effects of each set of predictors on unmet needs. It also enables the evaluation of the additional variance explained by each set of predictors. By comparing the R^2 and/or adjusted R^2 values across different blocks of the model, an assessment can be made of the extent to which each set of predictors contributes to explaining the variation in unmet needs over and above what has already been accounted for (Frost, 2020). This helps identify the unique contribution of specific predictors and provides insights into their incremental effects on unmet needs. The steps involved are outlined in Appendix 11. To proceed with the hierarchical multiple regression model described above, the assumptions for this model must be met (Table 5.10).

Hierarchical multiple regression offers a framework for examining moderation effects. By introducing potential moderators (or interactions) in the later block of the regression model, their role in the relationship between earlier predictors and unmet needs can be assessed. Finally, it facilitates a systematic approach to model refinement and validation (Barido et al., 2008). By comparing the goodness-of-fit indices, such as the change in adjusted R^2, as each variable is removed from the complete model, the improvement in model fit with the addition of different sets of predictors can be evaluated (Frost 2020).

This helps iteratively refine the model and ensure that the final model provides a robust representation of the relationships between predictors and unmet needs. The selection of the independent variables in each block and the order in which they are entered are based on a combination of previous research evidence, the specific aims of the current thesis and the adjusted R^2 values. Adjusted R^2 measures how well the selected variables in a regression model explain the variation in the dependent variable, adjusted for the number of predictors and sample size. It considers both the goodness of fit and the complexity of the model.

Table 5.10 Hierarchical Multiple Regression Assumptions

Hierarchical Multiple Regression Assumptions
Linearity: A linear relationship between the independent and dependent variables should exist. This can be assessed by visual inspection of scatterplots between studentised residuals and unstandardised predicted values and partial regression plots showing a linear relationship between the continuous independent variables and each dependent variable.
Homoscedasticity: The variances of the residuals should be constant across all levels of the independent variables. This assumption implies that the spread of the residuals should be the same across the range of predicted values. This can be assessed by visual inspection of scatterplots between studentised residuals and unstandardised predicted values.
Normality of residuals: The residuals (the differences between the observed and predicted values) should be normally distributed. The distribution of residuals should be symmetric and centred around zero. Visual inspections of the residuals' histogram or a P-P plot assess if they follow a normal distribution.
No multicollinearity: The independent variables should not be highly correlated. High multicollinearity can make it difficult to determine the unique contribution of each predictor variable. By inflating the variance and type II error (e.g., a false negative), multicollinearity renders the coefficient of a variable consistent but unreliable. There are two elements to ensure there are no multicollinearity issues. Firstly, inspection of correlation tables checks that none of the independent variables have correlations greater than 0.7. Secondly, tolerance values (which measure how much beta coefficients are affected by the presence of other predictor variables in a model) should be ≥0.1. Tolerance values less than 0.1 correspond to a Variance Inflation Factor (VIF) greater than 10, which may indicate a collinearity problem (Hair et al., 2014).
No outliers: There should not be any outliers that disproportionately influence the regression results. Outliers can distort the regression line and affect the estimation of coefficients. Outliers can be assessed by checking that the minimum and maximum values of the standardised residuals lie within ±3 standard deviations.
Independence of residuals: The assumption of independence means that the residuals, which are the differences between the observed and predicted values of the dependent variable, should not be systematically related or correlated with each other. A value of approximately 2 indicates no correlation between residuals, as assessed by the Durbin-Watson statistic.

5.10.3.2 Rationale for Canonical Correlation Analysis

Canonical correlation analysis (CCA) is a multivariate analysis of correlation used to explore complex relationships between multiple variables (Hair, 2014; Hotelling, 1992; Sherry & Henson, 2005). As outlined in the previous section, hierarchical multiple regression was concerned with the relationship between a single dependent variable and a set of independent variables. CCA extends this work by exploring multiple dependent and independent variables. The underlying principle of CCA investigates the relationship between variables by developing independent canonical functions that maximise the correlation between the weighted linear composites, known as canonical variates (Hair, 2014; Hardoon et al., 2004; Sherry & Henson, 2005). In multivariate analysis, a variate is a linear combination of variables with empirically determined weights (Hair, 2014). In other words, CCA aims to identify and measure the associations among two sets of variables, where each set of variables is combined into a single variate. CCA aims to evaluate the simultaneous relationships between each variate so that the relative contribution of each variable within each set can be assessed (Sherry & Henson 2005).

The canonical correlation coefficient measures the strength of association between the variable sets (Alpert & Peterson, 1972; Hair, 2014). This means that CCA was used to identify and measure the simultaneous associations between each set of observed variables (or variates) so that the relative contribution of each variable within each set (or variate) can be assessed. CCA permits the simultaneous comparisons among independent and dependent variables (Thompson, 1991). The cut-off of 0.45 identifies meaningful coefficient correlations or loadings (Sherry & Henson 2005). CCA overcomes many limitations of other statistical techniques, such as univariate analysis, bivariate correlations, and multiple regression analysis (Laessig & Duckett, 1979). Unlike bivariate correlation, CCA can handle two sets of data rather than two variables and can handle multiple dependent variables, unlike multiple regression, which is restricted to one dependent variable (Laessig & Duckett, 1979). As a multivariate technique, the probability of committing a Type I error is limited (Thompson, 1991). CCA is robust to possible violations of normality as it can measure multiple intercorrelated outcome variables; statistical significance in the canonical correlations is attached to each latent canonical variable (Sherry & Henson 2005). Finally, and most importantly, CCA is best suited to research that aims to determine outcomes based on multiple interconnected variables. Since CCA investigates simultaneous relationships between variables that are typically scored separately in survey instruments, the true nature of the critical variables is more likely to be extracted (Sherry & Henson, 2005).

The relevant assumptions of the CCA model included linearity and homoscedasticity (using scatter plots), normality checked for each subscale (using P-P plots), and multicollinearity checked using Variance Inflation Factor (VIF values); more detailed insights into these assumptions were outlined previously in Table 5.10.

5.11 Qualitative Interview Data Management

As described previously, qualitative interview data was transcribed; participant transcripts were pseudonymised. Computer-aided qualitative data management software, NVivo, facilitated the phase two data analysis.

5.11.1 Reflexive Thematic Analysis

Descriptive analysis employs a semantic approach that aims to investigate, document, and describe the nature of a research problem (Braun & Clarke, 2013). The concept semantic was understood to mean participant-driven and descriptive, an approach capable of giving a voice to the lymphoma survivor. The goal of data analysis was to see the world from the perspective of the participant and to produce meaning that is true to the participant. Reflexive thematic analysis (TA) is a robust method for developing, analysing, and interpreting patterns across a qualitative dataset, which involves systematic data coding processes to develop themes (Clarke & Braun, 2021). The open and organic procedures and process of reflexive TA are grounded by qualitative values that support and set the limits for the flexible and organic approach (Clarke & Braun, 2021; Grant & Giddings, 2002; Kidder & Fine, 1987; Madill & Gough, 2016). Like the statistical techniques applied in the first phase of quantitative analysis (Table 5.10), reflexive thematic analysis has its core assumptions outlined by Clarke and Braun (2021).

1. A primary tool for reflexive TA is researcher subjectivity, as knowledge generation is inherently subjective and situated. Research subjectivity is a resource for analysis, not a problem to be managed (Gough & Madill, 2012).
2. Data analysis and interpretation can be weaker (e.g., unconvincing) or more substantial (e.g., compelling), rather than accurate or objective.
3. Quality codes and themes result from deep engagement and giving the analysis some distance (i.e., taking a break from the process).
4. Themes are conceptualised as patterns anchored by a shared idea, meaning or concept, not summaries of a topic. Themes are built from codes and are not identified before the analytic process. Through systematic engagement with the dataset, themes are actively produced (themes do not *emerge* from the data).
5. Theoretical assumptions underpin data analysis.
6. Reflexivity, an essential part of high-quality analysis, entails researchers thoroughly grasping their standpoint.

For this phase two qualitative study, subjectivity was viewed as valuable rather than problematic, as "the researcher becomes the instrument for analysis" (Nowell et al., 2017, p. 2). Practising reflexivity in reflexive TA entailed consistent contemplation about assumptions, expectations, decisions, and activities throughout the research journey (Finlay & Gough, 2003). Following the quantitative first phase of this mixed methods study, avoidance of 'positivism creep' in the second qualitative phase was consciously sought; this refers to the unknowing importation of quantitative values, such as objectivity, control of bias and the search for ultimate truth. Instead, qualitative skills were honed, including enhanced subjectivity

and reflexivity practice (Clarke & Braun, 2021). This means that the analysis aims to capture reality as expressed within the dataset through the exploration of participant's perspectives and understandings. Using an inductive approach, the analysis is located within the data and coding and theme development are driven by the data content (Clarke & Braun, 2021). It is moving from a complex problem to a general theory of understanding to improve or address a given situation (i.e., the unmet needs of lymphoma survivors). The reflexive thematic analysis flow within this research is outlined in Figure 5.6. In pragmatism, fallibilism is central to understanding knowledge, as neither knowledge nor belief is certain. This means that empirical knowledge can be accepted even though it cannot be scientifically proven. Pragmatism emphasises explanation aptly suited to this research design (sequential explanatory) and employs the qualitative values of this second phase. This reflexive approach to TA involved a six-phase process, offering guidance rather than rules for the analysis process (Braun & Clarke, 2019; Clarke & Braun, 2021).

A progressive, recursive process was approached which was not strictly linear. The initial stage of familiarisation involved engagement and immersion in the data that was not yet systematic, this was followed by more systematic and engaged procedures through coding, generating initial themes; developing and reviewing themes; refining, defining, and naming themes; and writing up. Each step is outlined below in the context of this research.

Familiarisation with the dataset involved becoming deeply familiar with the dataset's content, through immersion (Clarke & Braun, 2021). In practice, this involved listening to the audio recordings three times (the first time to capture reflexive notes, the second to transcribe and the third time to clarify the accuracy of the transcription). Then, reading and re-reading the data, making brief notes about analytic ideas or insights that came to mind regarding data items or the dataset as whole. The pseudonymised transcripts were uploaded to NVivo to facilitate the analysis.

Coding involved working though the dataset in a fine-grained way, identifying data segments that appear potentially interesting, relevant, or meaningful to the research question. Code labels (analytically meaningful descriptions) were applied to these segments with a detailed and specific focus on capturing single meanings or concepts (i.e., 'care coordination', 'physical needs'). Semantic codes were used which captured the explicitly expressed meaning of data; often this involved staying close to the language of participants or the overt meanings of data but avoiding a 'topic summary' style to coding (i.e., 'body image', 'fear of recurrence') (Clarke & Braun, 2021). Code labels were then collated and complied into relevant data segments for each code, facilitated by NVivo.

Generating initial themes involved identifying shared patterned meaning across the dataset. Codes that appeared to share a core idea or concept were clustered together. The focus remained on generating potentially meaningful answers or insights to the research question. This active process constructed initial themes based around the data, the research questions and the researcher's knowledge and insights (i.e., clinical nursing background in lymphoma survivorship) (Clarke & Braun, 2021). Codes initially captured a

specific meaning (i.e., 'psychological needs', 'psychosocial support', 'social response to a lymphoma diagnosis'), themes developed broader description of shared meanings (i.e., 'the psycho-social burden of lymphoma). When potential themes were reviewed, a list of candidate themes was collated to capture the data and address the research question. All coded data was collated to the relevant candidate theme.

Developing and reviewing themes involved assessing candidate themes for their viability to the overall analysis by looking at the full dataset. This development involved checking that themes make sense about both the coded extracts and the full dataset. Each theme was considered using the following question: does this theme tell a convincing and compelling story about an important pattern of shared meaning related to the dataset? The themes were also reviewed to see if they highlighted the most important patterns across the dataset in relation to the research question. Certain candidate themes were collapsed together, split into new themes, or discarded to strengthen the sense of captured meaning. The themes were considered central organising concepts with each theme needing its own core focus or idea and its scope to the broader dataset. Relationships between themes started to be considered, including their relation to existing knowledge, clinical practice, and policy for this research area.

Refining, defining, and naming themes involved fine-tuning the analysis, focusing on a strong core for each theme. Understanding what story each theme told and how they fit into the overarching story about the data was developed. Brief synopsis of each theme was created to facilitate this. Decision-making on concise, punchy, and informative names for each theme was conducted. On reflection, letting the analysis go was essential at one point as more development of this refining process was needed. Time was taking away from this process. This enabled a fresh perspective to be applied on return to the process, which was beneficial in finalising theme names.

Writing up, an integral phase to the analytic process for TA. Writing began early on from familiarisation notes and reflexive journaling to more analytic writing from the initial generation of themes. This notetaking and writing all fed into the formal write up. The aim was to weave together the analytical narrative using compelling data extracts to provide the reader with a coherent story about the dataset which addresses the research question. The value of editing was understood as the write up was extensively revised to produce the final report.

5.12 Conclusion

This chapter discussed the chosen study design, a sequential explanatory mixed methods study, selected to provide a more complete understanding of this research problem that could not be achieved by one approach alone. The understanding and application of ethical considerations for this research were framed by the Belmont Report. The various aspects of the phase one survey and subsequent phase two interviews were outlined, including the points of integration within this research design. Rationales were provided for the selection of the population and the sampling strategy. The detailed development of the phase one

survey was described involving considerations of validity and reliability; a content validity evaluation was conducted with lymphoma experts, including those with lived experience of lymphoma. A finalised survey was provided and the procedures for its distribution. A detailed quantitative data analysis was presented, and selected statistical tests were introduced and defined with the rationale for relevant assumptions. The phase two interviews aimed to capture the distinct voices of individual lymphoma survivors; the interview procedures were described, and the development of the interview guide was discussed. This included how it was directly informed by the quantitative findings and literature review. Reflexive thematic analysis aimed to identify themes through patterns of meaning across the dataset. The assumptions and six phases of TA were explored within the context of this study. The quality and rigour within this research study were given due consideration and the reflexive practices of the author were outlined. Therefore, a comprehensive presentation of the methods of this mixed methods research has been provided.

Chapter 6 Phase One Quantitative Findings

6.1 Introduction

This chapter presents the results of the quantitative phase of this mixed-method sequential explanatory design study. Four main sections group the relevant findings.

Summary and exploration of the collected data (Section 6.2). Firstly, this section provides an overview of the sample characteristics in sociodemographic terms, primarily as percentages of the total sample for characteristics of interest and using figures as appropriate. How missing data was handled is outlined.

Identifying the unmet needs of lymphoma survivors (Section 6.3). The primary aim of this research is to provide an understanding of the unmet needs of lymphoma survivors. This section provides the descriptive and univariate statistical analysis of the Short-Form Survivors Unmet Needs Survey (SF-SUNS), a cancer-specific instrument, in which survivors self-report their needs that remain unmet on a scale of 0 (no unmet need) to 4 (very high unmet need). Figures and tables illustrate the findings that identify the prevalent unmet needs of this sample.

Understanding lymphoma survivors' quality of life (QOL) outcomes (Section 6.4). The secondary aim of the research is to provide an understanding of the QOL outcomes of lymphoma survivors. The QOL survey used for this research, the Functional Assessment of Cancer Therapy – Lymphoma (FACT-LYM), is a lymphoma-specific instrument in which survivors self-report their quality of life on 42 questions relating to physical, social, emotional, and functional well-being and the symptom experience of lymphoma. The EuroQoL Five-Dimension Five-Level (EQ 5D-5L) is used as a supplementary assessment of lymphoma survivors' health status. Descriptive and univariate statistical analyses of the FACT-LYM and EQ 5D-5L were tabulated.

Evaluating the explanatory factors that influence lymphoma survivors' unmet needs (Section 6.5). This final section explores the explanatory factors that influence lymphoma survivors' unmet needs (dependent variable), QOL outcomes, sociodemographic characteristics, and clinical characteristics (independent variables). Hierarchical multiple regression was used to understand meaningful variables in the data and evaluate the explanatory factors influencing lymphoma survivors' unmet needs. Canonical Correlation Analysis was subsequently applied to understand the relationships between the unmet needs and quality of life outcomes.

6.2 Summary and Exploration of the Collected Data

6.2.1 Description of Variables

A description of the study's variables, including the ordinal data, nominal data, and continuous data, is outlined in Appendix 16.

6.2.2 Missing Data

Missing data are an inevitable problem in research that threatens the validity and generalisability of study results and leads to issues affecting the interpretation and inferences of research results (Little & Rubin 2002, Sterne *et al.* 2009). To examine determinants of missingness for this study, complete cases and missing values were evaluated for systemic differences. Many participants completed an online electronic survey via the platform Qualtrics; its function 'forced response' was used which resulted in a high rate of complete cases and low missing data. All returned questionnaires were included in the study dataset; missingness was handled separately in the analyses (e.g., the same default for all tests). The sample size eligible for analysis is reported for each analysis procedure, and valid proportions are presented. The 'Survivor Unmet Needs Survey User Guide' provided guidance for coding the SF-SUNS data. The 'Instructions for the FACIT SPSS Scoring Programmes' was provided by the authors of the FACT-LYM and adhered to. These instructions were applied to this study's data using the SPSS syntax program provided which calculated relevant scoring options, where calculating reverse scored items and prorating for missing data has been integrated. In cases where individual items were skipped, subscale scores were prorated using the average of the other answers in the scale. This was acceptable as long as more than 50% of the items were answered in the subscale (e.g., a minimum of 4 of 7 items, 4 of 6 items, etc.) as subscale scores were prorate for missing items. An overall item response rate of greater than 80% is considered an acceptable indicator of quality of life. There was no clear systemic issue with the small number of missing values observed. Missing values for three participants were a result of not completing the survey. Only four items on the survey had missing values of six or more. Moreover, missing values per participant were observed. Twenty-six participants (12.6%, *N*=205) provided missing values (>1 cell missing), of which only five had more than ten missing cells. Three participants had significant missing cells, including three to four SF-SUNS domains and all sociodemographic items (71-74 items). There was no trend across survey items with missing values for participants. Therefore, it is reasonable to assume that this is missing completely at random. Item nonresponse frequently occurs during self-administered questionnaires and may be due to a question not being understood or seen, a question being skipped and forgotten, the topic being uncomfortable or having a negative connotation for the participant, a question being asked in such a way that a participant was unable to respond or the participant's slow reading or loss in interest may be a factor (Sterne *et al.* 2009).

6.2.3 Summary Characteristics of Total Sample

Three hundred and seventeen lymphoma survivors were deemed eligible to participate in the phase one survey from December 2021 to August 2022. Three hundred and nine questionnaire packs were distributed, of which 185 were returned. Nine participants declined participation at the point of recruitment (5%), resulting in a response rate of 58%. In addition, 20 participants responded to the online study advertisements, providing a total survey sample size of *N*=205 (Table 6.1). Due to the nature of the online recruitment process, it was not possible to ascertain how many participants were reached, missed, or declined participation. Over half of the participants were recruited from two cancer centres (54%), with

thirty-six per cent recruited from three regional hospitals. The phase one survey sample's gender distribution was almost equal, with 51% female participants. Nearly seventy per cent of female participants (68.1%, *n*=62) and over half of male participants (51.6%, *n*=47) were recruited from cancer centres. More male participants (48.4%, *n*=44) were recruited from regional hospitals than female participants (31.9%, *n*=29). The mean age of participants was 53.7 years (*SD*=17.9, *n*=196), and the age range was 19 – 88 years, with an even distribution across the lifespan (Table 6.2). Participants ranged from one to five years post-diagnosis. For analysis, this was dichotomised into two groups: one to three years post-diagnosis and three to five years post-diagnosis. Almost three in five participants were one to three years post-diagnosis (57.9%, *n*=113), with the remaining eighty-two participants diagnosed between three and five years ago (42.1%).

Table 6.1 Questionnaire Response Rate by Recruitment Sites

Site	Site Type	Dispatched	Returned	Response Rate
1	Cancer centre	89	54	61%
2	Cancer centre	97	57	59%
3	Regional	38	27	71%
4	Regional	43	23	54%
5	Regional	42	24	57%
6	Online	n/a	20	n/a
Total	Hospital sites	317	185	58%
Total	All	205		

Over half of the participants had private health insurance (55.2%), and less than half had a medical card (45.8%). Participants were mainly in employment (42.6% full-time, 10.9% part-time) or education (5% students). Of those in employment (53.4%), many worked their usual hours (29.7%), fewer hours (17.8%) or more hours (3%) than before a lymphoma diagnosis. Participants (*N*=202) resided across Ireland; their areas of residence included urban dwellings (67.3%, *n*=136) and rural dwellings (32.7%, *n*=66). In the original survey, no participants reported living in a nursing home or other long-term care home. Living arrangement was dichotomised into living with others (partner/spouse/family/friends) and alone. Most participants lived with other people (79.7%, *n*=161); twenty per cent lived alone (20.3%, *n*=41), *N*=202.

Almost 9 in 10 lymphoma participants were 'White Irish' (87.6%, *n*=177). Eight per cent were 'Any other White background' (8.3%, *n*=17). Due to the small cell numbers for other groups (i.e., Asian background, *n*=2), the cells within the variable 'ethnicity' were dichotomised into White Irish and other (12.4%, *n*=25). 'Other' is inclusive of Any other white background (8.3%, *n*=17), any other Black background (1%, *n*=2), any other Asian background (1%, *n*=2), African (0.5%, *n*=1) and Irish Traveller (0.5%, *n*=1), *N*=202. Within this sample, sixty-six per cent of participants also had a comorbid diagnosis, such as a cardiac condition (24.6%, *N*=195). Fifty-nine participants (30.2%) reported musculoskeletal disorders such as arthritis and long-term back pain. Fifty-five (28.2%) lymphoma survivors reported cardiovascular system disorders, including angina and high blood pressure. Fifteen (7.7%) participants reported hearing impairment. Few participants (5.1%, *n*=10) of the total sample and only three HL participants reported respiratory system disorders such as asthma or other chronic respiratory issues or having a mental health disorder (2.5%).

6.2.4 Summary Characteristics by Lymphoma Subtype

Statistically significant associations by lymphoma subtype are outlined in Table 6.2.

Table 6.2 Sociodemographic Characteristics of the Sample by Lymphoma Subtype in %

	HL	NHL	Total	Test Statistic	*p*-value
	n=51	*n*=144	*N*=195		
Age, mean % (*SD*)					
	41.7 (18.8)	57.5 (15.6)	53.7 (17.9)	$t(193)=5.798$	**<.001[c,*]**
Age Categories %					
18-39	56.0	15.8	26.5	$\chi^2(2)=30.51$	**<.001[a,*]**
40-69	30.0	58.3	50.8		
70 or older	14.0	25.9	22.8		
Gender %					
Female	51.0	50.0	50.3	$\chi^2(1)=0.01$	.904[a]
Male	49.0	50.0	49.7		
Residence %					
Rural	25.5	36.1	33.3	$\chi^2(1)=1.91$	.167[a]
Urban	74.5	63.9	66.7		
Living status %					
Living with others	84.3	77.8	79.5	$\chi^2(1)=0.99$	.321[a]
Living alone	15.7	22.2	20.5		
Ethnicity %					
Irish	80.4	92.4	89.2	$\chi^2(1)=5.62$	**.018[a,*]**
Other	19.6	7.6	10.8		
Employment status %					
Full-time/Part-time	60.8	52.8	54.9	$\chi^2(3)=19.16$	**<.001[a,*]**
Retired/Homemaker	17.6	42.4	35.9		
Student	13.7	2.1	5.1		
Unemployed	7.8	2.8	4.1		
Employment hours %					
Working less hours than before	26.7	35.5	33.0	$\chi^2(3)=19.16$	.240[a]
Working usual hours	63.3	53.9	56.6		
Working more hours than before	10.0	3.9	5.7		
Not working	0.0	6.6	4.7		
Time since diagnosis %					
1 to 3 years	51.0	60.4	57.9	$\chi^2(1)=1.38$	.241[a]
3 to 5 years	49.0	39.6	42.1		
Sites %					
Cancer centre	65.2	57.4	59.4	$\chi^2(1)=0.87$	.352[a]
Regional	34.8	42.6	40.6		
Medical card %					
	51.0	43.4	45.4	$\chi^2(1)=0.88$	.348[a]
Private health insurance %					
	49.0	58.7	56.2	$\chi^2(1)=1.44$	.230[a]

Key: ***p=<.05**; HL = Hodgkin lymphoma; NHL = non-Hodgkin lymphoma; [a] Pearson Chi-Square; [b] Fisher's Exact test; [c] t-test.

Table 6.2 Sociodemographic Characteristics of the Sample by Lymphoma Subtype in %, Continued

	HL	NHL	Total	Test Statistic	*p*-value
	n=51	*n*=144	*N*=195		
Treatment %					
Chemotherapy	92.2	91.7	91.8	$\chi^2(1)=0.01$	.913[a]
Immunotherapy	11.8	35.4	29.2	$\chi^2(1)=10.19$	**.001[a,*]**
Radiotherapy	45.1	20.1	26.7	$\chi^2(1)=12.00$	**<.001[a,*]**
Surgery	29.4	15.4	19.1	$\chi^2(1)=4.79$	**.029[a,*]**
Other cellular therapy	2.0	0.0	0.5	N/A	.262[b]
Stem Cell Transplant	5.9	3.5	4.1	N/A	.433[b]
Medical conditions %					
Arthritis	11.8	18.1	16.4	$\chi^2(1)=1.09$	.297[a]
Respiratory conditions	5.9	4.9	5.1	$\chi^2(1)=0.08$	.723[a]
Diabetes	0.0	4.2	3.1	$\chi^2(1)=2.19$	.139[a]
Epilepsy	0.0	2.1	1.5	N/A	.568[b]
Kidney disease	2.0	3.5	3.1	$\chi^2(1)=0.29$	.591[a]
Liver disease	0.0	2.1	1.5	N/A	.568[b]
Cardiac conditions	9.8	29.9	24.6	$\chi^2(1)=8.17$	**.004[a,*]**
Hearing or visual impairments	5.9	10.4	9.2	$\chi^2(1)=0.94$	.412[a]
Other chronic conditions	17.6	23.6	22.1	$\chi^2(1)=0.17$	.377[a]
Cognitive conditions	3.9	2.8	3.1	$\chi^2(1)=0.16$	.653[a]
None of these conditions	58.8	38.9	44.1	$\chi^2(1)=6.07$	**.014[a,*]**

Key:***p=<.05**; HL = Hodgkin lymphoma; NHL = non-Hodgkin lymphoma; [a] Pearson Chi-Square; [b] Fisher's Exact test; [c] t-test.

One hundred and forty-four participants (71.3%) had a diagnosis of non-Hodgkin lymphoma (NHL), and fifty-one (25.2%) had Hodgkin lymphoma (HL). A small number of participants (3.5%, *n*=7) reported that they did not know or remember their subtype. Fifty-one per cent of participants were one to three years post-diagnosis and forty-nine per cent three to five years post-diagnosis. For NHL, participants were mostly one to three years post-diagnosis (60.4%, *n*=87), with over forty per cent three to five years post-diagnosis (39.6%, *n*=61). The number of males and females was equal for subtypes NHL (male *n*=72, female *n*=72) and almost equal for HL (male *n*=25, female *n*=26).

There were a few significant differences between the groups (HL and NHL, Table 6.2). The mean age for non-Hodgkin lymphoma survivors was 57.5 years (*SD*=15.6), with 73% of NHL participants aged 55 years or older. HL participants were statistically significantly younger (41.6 years, *SD*=18.8) than NHL survivors (57.5 years, *SD*=15.6) ($t(193)=5.798$ $p=<.001$); the data had no outliers, as assessed by inspection of a boxplot, and variances were homogeneous as assessed by Levene's test for equality of variances (Levene, 1960). Since a diagnosis of cancer, the employment status was significantly different between groups ($\chi^2(3)=19.16$, $p=<.001$), yet there was no significant difference between their working hours. Working hours varied since before a cancer diagnosis for lymphoma survivors as most participants continued working their usual hours post-diagnosis (56.6%, *n*=60), while one-third worked fewer hours (33.1%, *n*=35). Almost half of HL survivors reported having private health insurance (49.0%, *n*=25) and nearly sixty per cent of NHL survivors

(58.7%, *n*=84). Over forty per cent of NHL survivors (43.4%, *n*=25) and over half of HL survivors (51%, *n*=26) had a medical card. Three in four survivors aged seventy or older were in receipt of a medical card (75.6%, *n*=34).

6.3 Identifying Lymphoma Survivors' Unmet Needs

6.3.1 Unmet Needs Descriptive Analysis

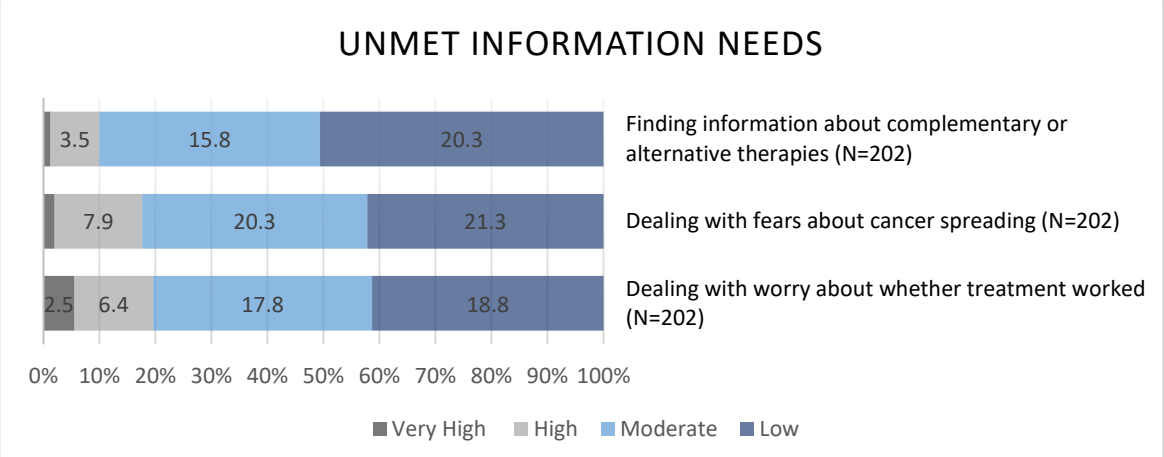
Unmet needs distinguish between an individual's need or expectations for services and the actual experience of receiving them (Gauld et al., 2014). In other words, these are needs that currently lack the level of support required for an individual to achieve optimal well-being. The SF-SUNS subscales demonstrated high levels of internal reliability (range α=0.84-0.95, Table 6.3) (Nunnally & Bernstein, 1994; Terwee et al., 2007). The mean SF-SUNS sub-domain scores ranged from 0.67–1.07, with Coping, Sharing and Emotional Needs domain achieving the highest score overall.

Table 6.3 SF-SUNS by Domain with Mean Scores and Cronbach's Alpha Scores

Domain (Range 0-4)	*N*	Cronbach's alpha score	Mean Score	*SD*
Information needs (INF)	202	.84	0.79	0.88
Work and financial needs (FIN)	201	.91	0.85	0.92
Access and continuity of care needs (ACC)	201	.92	0.67	0.86
Coping, sharing and emotional needs (COP)	201	.95	1.07	0.93

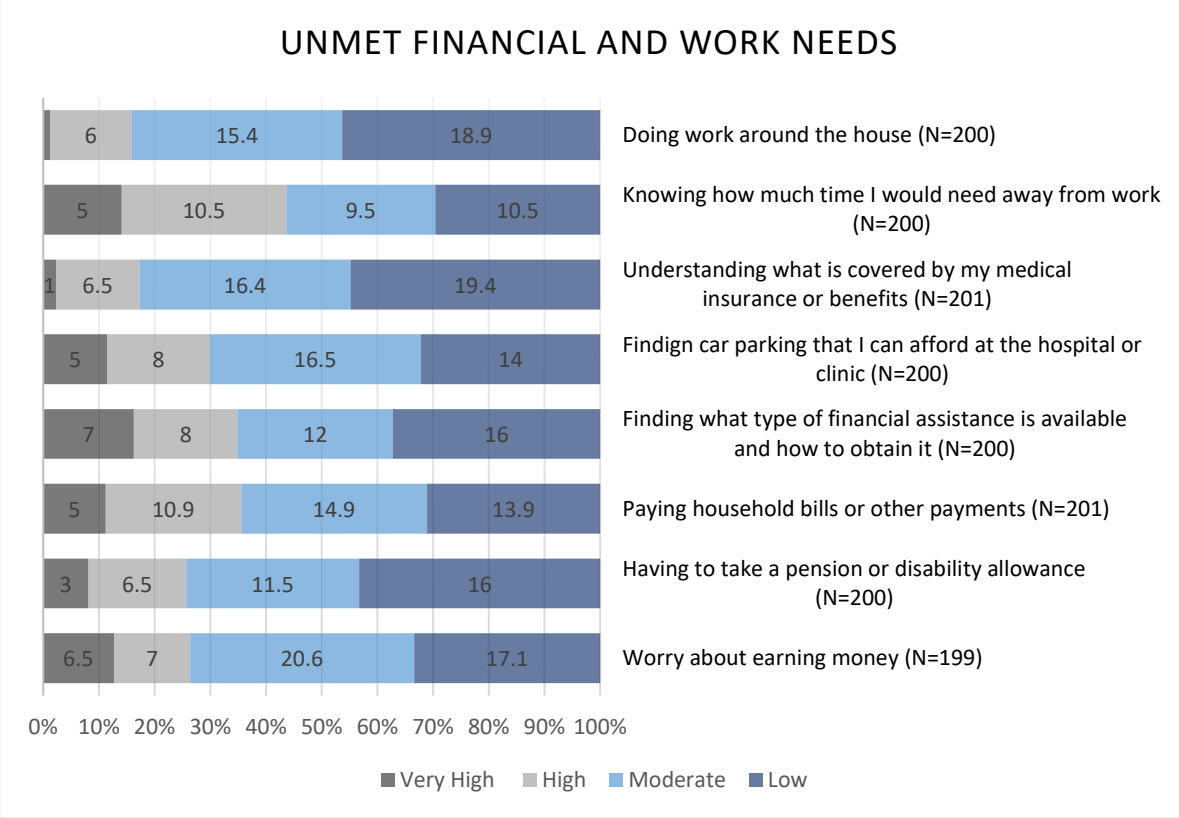
Participants were asked to indicate their **unmet information needs (INF)** in the past month on three items. Half of the participants reported unmet information needs in 'dealing with fears about cancer spreading' (50.5%, *n*=101). Less than half of the participants reported 'dealing with worry about whether the treatment has worked' (45.5%, *n*=92) or 'finding information about complementary or alternative therapies' as concerns (40.1%, *n*=81) (Figure 6.1).

Figure 6.1 Participants' Unmet Information Needs by Item



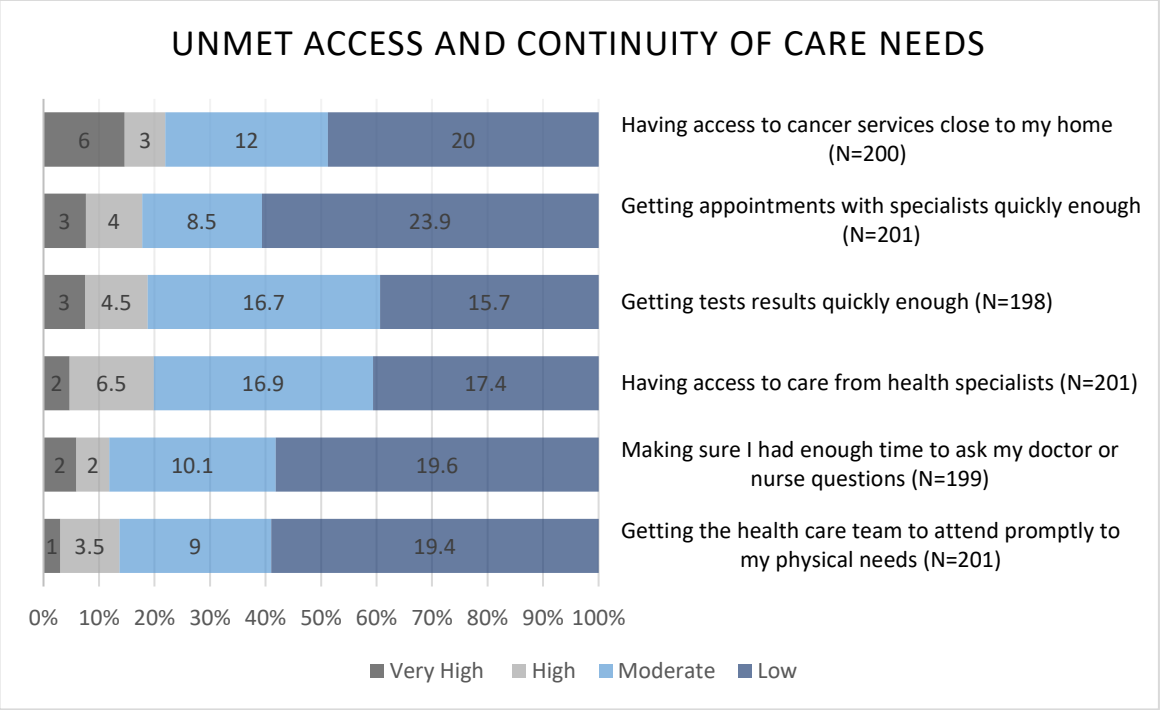
Participants were asked to report their **unmet work and financial needs (FIN)** over the last month across eight items. The most prevalent item within this subscale for some level (low to very high) of unmet need was 'worry about earning money' (51.3%, *n*=199) (Figure 6.2). Unmet needs of high to very high importance were most prevalent for three items, 'paying household bills or other payments' (15.9%, *n*=32), 'knowing how much time I would need away from work' (15.5%, *n*=31), and 'finding what type of financial assistance is available and how to obtain it' (15%, *n*=30). 'Finding car parking that I can afford at the hospital or clinic' was a concern for eighty-seven participants (43.5%, *N*=200), with 30.5% reporting low to moderate unmet needs for this item.

Figure 6.2 Participants' Unmet Financial and Works Needs by Item



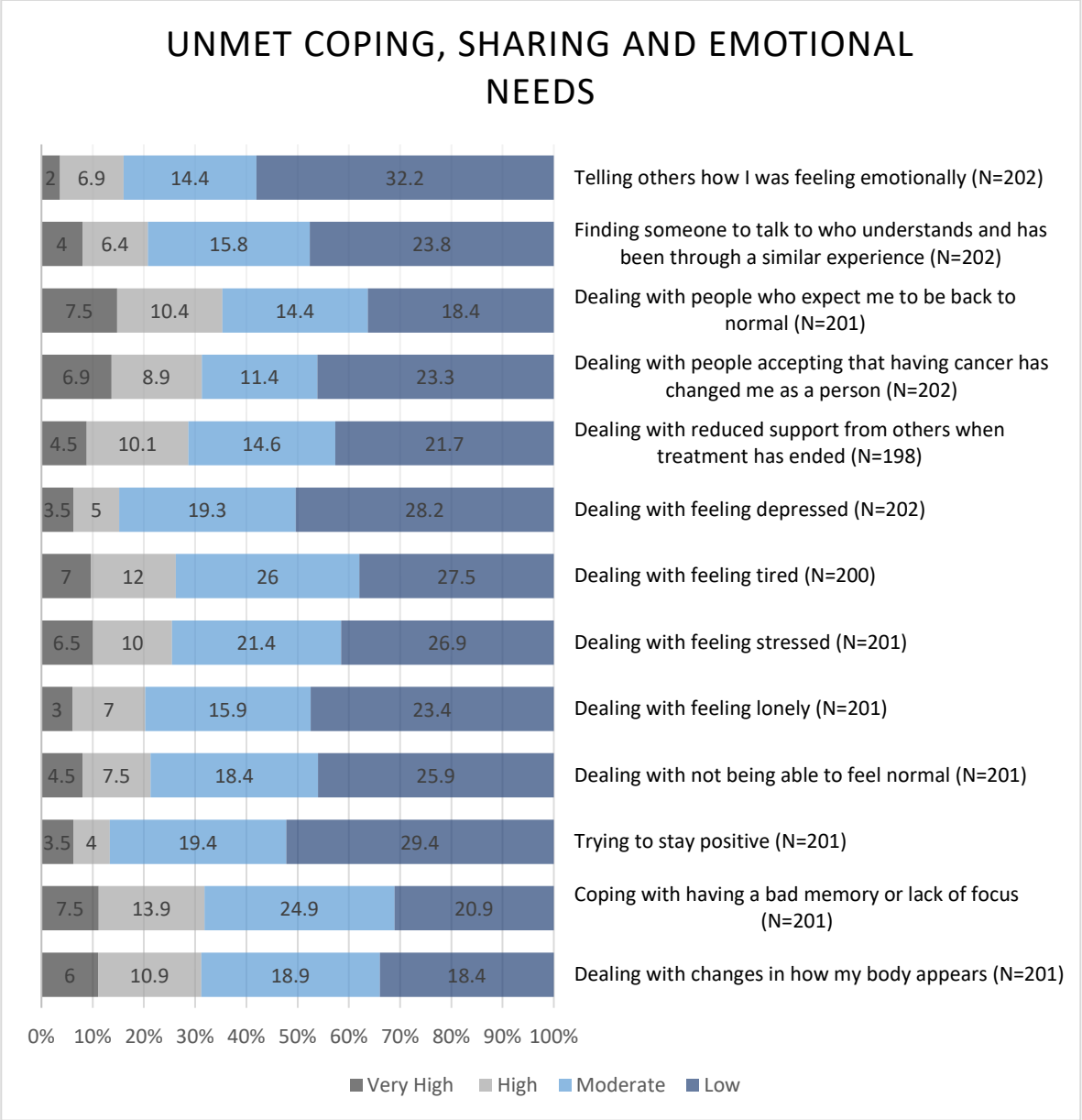
The **unmet access and continuity of care needs (ACC)** domain had the lowest level of unmet needs ('no unmet needs' range 57.2%-67.2% per item). This domain included six items relating to unmet access and continuity of care needs due to having cancer now or in the past over the last month (Figure 6.3). The least endorsed unmet need item was related to 'getting the healthcare team to attend to my physical needs promptly' (67.2% of participants reported 'no unmet needs', *n*=135). However, approximately thirty per cent of lymphoma survivors reported low to moderate unmet needs for five of the six items within this domain, such as 'having access to care from health specialists' (34.4%, *n*=68), 'getting tests results quickly enough' (32.4%, *n*=64), and 'getting appointments from specialists quickly enough' (32.4%, *n*=65).

Figure 6.3 Participants' Unmet Access and Continuity of Care Need by Item



The **unmet coping, sharing and emotional needs (COP)** domain had the highest level of unmet needs across the four domains. Across all survey items, 'dealing with feeling tired' was the most frequent unmet need, reported by 72.5% (*n*=145) of lymphoma survivors. Next, 'coping with having a bad memory or lack of focus' was reported by 67.2% (*n*=135) of lymphoma survivors, of which over half reported moderate to very high unmet needs (53.7%, *n*=108). 'Dealing with feeling stressed' was also reported by many survivors (64.7%, *n*=130), with almost half reporting low to moderate unmet needs (48.3%, *n*=97). Six of the thirteen items of this domain had more than 15% of the sample reporting high to very high unmet needs, such as 'dealing with people who expect me to be back to normal (17.9%, *n*=36) and 'dealing with changes in how my body appears' (16.9%, *n*=34) (Figure 6.4).

Figure 6.4 Participants' Unmet Coping, Sharing and Emotional Needs by Item



6.3.2 High/Very High Unmet Needs by Item

By consolidating the participants' responses for "high unmet needs" and "very high unmet needs," a comprehensive understanding of unmet needs categorised by higher levels of severity can be provided. The ten most frequently endorsed 'high/very high' unmet needs for the sample (*N=202*) are presented in Table 6.4. This illustrates what specific needs lymphoma survivors are at increased risk of needing help. Seven of the topmost frequently endorsed 'high/very high' unmet needs were from within the coping, sharing and emotional needs domain and three from the unmet work and financial needs domain. 'Coping with having a bad memory or lack of focus' was the most frequently reported unmet need for 'high/very high' responses (21.4%, *n*=43). The following four most endorsed items involved dealing with: 'feeling tired', 'people who expect me to be "back to normal", 'changes in how my body appears', and 'feeling stressed'.

Table 6.4 The Ten Most Frequently Endorsed High/Very High' Unmet Needs Items (n=202)

Top Items	*N*	%	Domains
Coping with having a bad memory or lack of focus	43	21.4	COP
Dealing with feeling tired	38	19.0	COP
Dealing with people who expect me to be "back to normal"	36	17.9	COP
Dealing with changes in how my body appears	34	16.9	COP
Dealing with feeling stressed	33	16.4	COP
Paying household bills or other payments	32	16.0	FIN
Dealing with people accepting that having cancer has changed me as a person	32	15.8	COP
Knowing how much time I would need away from work	31	15.5	FIN
Finding what type of financial assistance is available and how to obtain it	30	15.0	FIN
Dealing with reduced support from others when treatment has ended	29	14.6	COP

Key: COP=Coping, sharing and emotional needs; FIN=Work and financial needs

6.3.2.1 High/Very High Unmet Needs by Subtype

A *z*-test was conducted to determine if there was a statistically significant difference between the percentages of HL survivors having High or Very high unmet needs compared to NHL survivors (Table 6.5). HL survivors were more likely to report 'dealing with not being able to feel normal' compared to NHL survivors (z=4.03, p<.001). Similarly, HL survivors were more likely to have higher unmet needs for 'having access to cancer services close to my home' (z=2.60, p=.009), 'dealing with feeling lonely' (z=3.20, p=.001) and 'dealing with people who expect me to be back to normal' (z=2.04, p=.04) compared with NHL survivors.

Table 6.5 High/Very High Unmet Needs by Subtype (N=202)

Top Items	% HL	% NHL	*Test Statistic*	*p*-value
Dealing with people who expect me to be "back to normal"	27.5	14.7	z=2.04	**.04***
Dealing with not being able to feel 'normal'	25.5	7.7	z=4.03	**<.001***
Having access to cancer services close to my home	17.6	5.6	z=2.60	**.009***
Dealing with feeling lonely	17.6	7.0	z=3.20	**.001***

Key: ***p*=<.05,** *z*-test.

6.3.2.2 High/Very High Unmet Needs by Gender

A *z*-test was conducted to determine if there was a statistically significant difference between the percentages of female survivors having High or Very high unmet needs compared to male survivors (Table 6.6). Compared to being male, being female was associated with higher unmet needs for 'dealing with reduced support from others when treatment has ended' (p=.01), 'dealing with people who expect me to

be back to normal' (p=.01), 'coping with having a bad memory or lack of focus' (p=.02) and 'dealing with people accepting that having cancer has changed me as a person' (p=.03). A statistically significant gender difference for the most frequently reported unmet need item 'dealing with feeling tired' was not found (p=.35).

Table 6.6 High/Very High Unmet Needs by gender (N=202)

Top Items	% Female	% Male	*p*-value
Coping with having a bad memory or lack of focus	28.2	14.3	**.02***
Dealing with people who expect me to be "back to normal"	25.5	10.1	**.01***
Dealing with reduced support from others when treatment has ended	22.0	7.1	**.01***
Dealing with feeling tired	21.6	16.3	.35

Key: ***p*=<.05,** *z*-test.

6.3.3 No Unmet Needs

Thirteen per cent of the sample reported 'no unmet needs' across all thirty items (n=26). The mean age for these participants was 58.2 years (range 38 – 88 years). Almost ninety per cent of those participants reporting no unmet needs across all items had a diagnosis of NHL (88.5%, n=23), a large portion were male (65.4%, n=17) or lived in an urban setting (61.5%, n=16).

6.4 Univariate Analysis of Lymphoma Survivors' Unmet Needs

A univariate analysis between lymphoma survivors' sociodemographic and clinical characteristics and unmet needs was conducted to provide greater insights into significant associations for individual variables. The results of this analysis are presented at the end of this section in Table 6.7-6.8 and explained in the subsequent sections (Sections 6.4.1-6.4.4). As outlined in Section 5.10.3, Mann-Whitney U tests for binary categorical variables and Kruskal-Wallis H tests for more than two categorical variables were used. Distributions of unmet needs scores for each of the subscales were not similarly shaped for all the groups associated with each independent variable, as assessed by visual inspection of the boxplots. Accordingly, no inferences can be drawn about differences in medians between groups, but significant differences can be investigated using mean ranks.

6.4.1 Unmet Information Needs (INF)

Females (mean rank=114.3) had significantly higher unmet information needs scores than males (mean rank=87.1), U= 3681.5, z=-3.452, p=.001, N=201. Being diagnosed with lymphoma for one to three years (mean rank=109.1) was associated with significantly higher unmet information needs than being three to five years post-diagnosis (mean rank=88.1), U=904.5, z=-2.530, p=.011, N=200. Not having a hearing or visual impairment (mean rank=103.6) was associated with significantly higher unmet information needs than having the impairment (mean rank=74.2), U=1164, z=-2.137, p=.033, N=201.

6.4.2 Unmet Work and Financial Needs (FIN)

Females (mean rank=109.4) were associated with higher unmet work and financial needs than males (mean rank=92.2), *U*=4183.5, *z*=1.470, *p*=.034, *N*=201. Being diagnosed one to three years ago (mean rank=107.5) was associated with significantly higher unmet work and financial needs than being three to five years post-diagnosis (mean rank=91.0), *U*=4080, *z*=4.276, *p*=.044, *N*=200. Not having private health insurance was associated with higher unmet work and financial needs than having private health insurance (*U*=4126.5, *z*=-2.022, *p*=.043, *N*=200). Mean rank unmet work and financial needs scores were highly statistically significantly different between age groups (18 – 39 years, 40 – 69 years and 70 years or older), $\chi^2(2)=14.018$, *p*=.001, *N*=195; being younger was associated with significantly higher unmet work and financial needs than being older. A Bonferroni correction for multiple comparisons was made with statistical significance accepted at the *p*=<.05 level. This post hoc analysis revealed statistically significant differences in unmet work and financial needs scores between the 70 years or older group (mean rank=73.6) and 18 to 39 years group (mean rank=115.8), *p*=.001 and 70 years or older group and 40 to 69 years group (mean rank=100.4), *p*=.022 but not with the 19 to 39 years and 40 to 69 years group, *p*=.111. Similarly, mean rank unmet work and financial needs scores were highly statistically significantly different between employment status ($\chi^2(3)=9.267$, *p*=.018, *N*=201); being unemployed (mean rank=136.1) or employed (mean rank=109.0) was associated with higher unmet work and financial needs than being retired/homemaker (mean rank=86.2). Post hoc analysis revealed no statistically significant differences within pairwise comparisons.

6.4.3 Unmet Needs for Access and Continuity of Care (ACC)

There were no statistically significant findings between lymphoma survivors' unmet needs for access and continuity of care and demographic or clinical characteristics.

6.4.4 Unmet Coping, Sharing and Emotional Needs (COP)

A high level of unmet coping, sharing and emotional needs for lymphoma survivors was indicated by the highest mean score of 1.07 (*SD*=0.93) among the four domains (Table 6.3). This univariate analysis revealed several statistically significant associations between demographic characteristics and unmet coping, sharing and emotional needs. Like previous domains, being female (mean rank=113.2) was associated with higher unmet coping, sharing and emotional needs than being male (mean rank=88.1), *U*=3785.5, *z*=-3.066, *p*=.002, *N*=201. Not having private health insurance (mean rank=112.5) was associated with more unmet needs for this domain than having insurance (90.9), *U*=3875.5, *z*=-2.621, *p*=.009, *N*=200. Being younger was associated with more unmet coping, sharing and emotional needs than being older, $\chi^2(2)=9.505$, *p*=.009, *N*=195. Subsequently, pairwise comparisons were performed using Dunn's (1964) procedure that revealed statistically significant differences in unmet coping, sharing and emotional needs scores between the 70 years or older group (mean rank=79.1) and 18 to 39 years group (mean rank=114.6) (*p*=.006), but not for the other two groups.

Table 6.7 Univariate Analysis of Associations Between Lymphoma Survivors' Unmet Needs and Sociodemographic Characteristics

Domains of Unmet Needs		Information Needs (INF)			Financial and Work Needs (FIN)			Access and Continuity of Care Needs (ACC)			Coping, Sharing & Emotional Needs (COP)		
	N	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*
Gender[a]			Z = -3.45	**<.001***		Z = -2.12	**.034***		Z = -1.66	.096		Z = -3.07	**.002***
Female	102	114.3			109.4			107.4			113.2		
Male	98	87.1			92.2			94.3			88.1		
Age[b]			$\chi^2(2)$=4.72	.094		$\chi^2(2)$=14.02	**<.001***		$\chi^2(2)$=4.95	.084		$\chi^2(2)$=09.50	**.009***
18-39 years	50	106.5			115.8			108.3			114.6		
50-69 years	99	100.4			100.4			99.4			98.4		
70 years or older	46	83.5			73.6			83.9			79.1		
Residence[a]			Z = -0.04	.969		Z = -0.08	.936		Z = -0.68	.497		Z = -0.71	.478
Rural	66	100.8			101.5			104.8			96.8		
Urban	135	101.1			100.8			99.1			103		
Living Arrangement[a]			Z = -1.55	.121		Z = -1.04	.299		Z = -0.71	.478		Z = -0.10	.096
Living with others	160	97.9			98.9			99.58			97.6		
Living alone	41	113.1			109.3			106.55			114.5		

Key: ***p*=<0.05**, [a]Mann-Whitney *U* Tests for binary categorical variables, [b]Kruskal-Wallis *H* tests for more than two categorical variables.

Table 6.7 Univariate Analysis of Associations Between Lymphoma Survivors' Unmet Needs and Sociodemographic Characteristics Continued

Domains of Unmet Needs		Information Needs (INF)			Financial and Work Needs (FIN)			Access and Continuity of Care Needs (ACC)			Coping, Sharing & Emotional Needs (COP)		
	N	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*
Ethnicity[a]			$Z = 1.11$	.267		$Z = 2.09$	.383		$Z = 1.47$	.606		$Z = -0.01$	.075
Irish	177	99.4			98.7			99.48			96.87		
Other	24	112.9			107.6			104.58			115.04		
Employment Status[b]			$\chi^2(3)=0.48$	.924		$\chi^2(3)=10.09$	**.018***		$\chi^2(3)=1.46$	.692		$\chi^2(3)=3.54$	.316
Full-time/Part-time	108	102.8			109.0			103.50			101.93		
Retired/Homemaker	76	99.5			86.2			95.68			94.74		
Student	10	91.4			99.6			103.00			115.30		
Unemployed	8	102.6			136.1			115.69			130.19		
Employment Hours[b]			$\chi^2(3)=0.95$	.815		$\chi^2(3)=2.18$	.536		$\chi^2(3)=0.87$	.834		$\chi^2(3)=1.12$	.773
Working less hours	35	55.8			57.6			50.71			54.65		
Working usual hours	61	52.4			50.6			54.23			51.80		
Working more hours	6	45.5			49.3			53.83			53.50		
Not working	5	59.3			66.5			63.20			66.40		

Key: ***p*=<0.05**, [a]Mann-Whitney *U* Tests for binary categorical variables, [b]Kruskal-Wallis *H* tests for more than two categorical variables.

Table 6.7 Univariate Analysis of Associations Between Lymphoma Survivors' Unmet Needs and Sociodemographic Characteristics Continued

Domains of Unmet Needs		Information Needs (INF)			Financial and Work Needs (FIN)			Access and Continuity of Care Needs (ACC)			Coping, Sharing & Emotional Needs (COP)		
	N	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*
Medical Card[a]			*Z* = 0.42	.675		*Z* = 1.27	.205		*Z* = 0.40	.690		*Z* = -0.25	.801
No	109	102.0			98.7			99.48			96.87		
Yes	92	98.7			107.6			104.58			115.04		
Private Health Insurance[a]			*Z* = 1.50	.135		*Z* = 2.02	**.043***		*Z* = 0.78	.438		*Z* = 2.62	**.009***
No	90	107.0			109.0			103.50			101.93		
Yes	111	95.2			86.2			95.68			94.74		

Key: ***p*=<0.05**, [a]Mann-Whitney *U* Tests for binary categorical variables, [b]Kruskal-Wallis *H* tests for more than two categorical variables.

Table 6.8 Univariate Analysis of Associations Between Lymphoma Survivors' Unmet Needs and Clinical Characteristics

Domains of Unmet Needs		Information Needs (INF)			Financial and Work Needs (FIN)			Access and Continuity of Care Needs (ACC)			Coping, Sharing & Emotional Needs (COP)		
	N	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*
Lymphoma Type[a]			*Z* = 0.23	.817		*Z* = 1.36	.174		*Z* = 1.77	.077		*Z* = 1.95	.064
HL	51	99.0			106.6			109.0			110.0		
NHL	143	97.0			94.3			93.4			93.1		
Time Since Diagnosis[a]			*Z* = 2.53	**.011***		*Z* = 2.02	**.044***		*Z* = 0.84	.400		*Z* = 1.32	.187
1 to 3 years	115	109.1			107.5			103.4			105.1		
3 to 5 years	85	88.9			91.0			96.6			94.2		
Chemotherapy[a]			*Z* = 1.00	.318		*Z* = 1.52	.129		*Z* = 1.65	.098		*Z* = -0.48	.633
No	17	113.9			121.2			122.5			94.6		
Yes	184	99.8			99.1			99.0			101.6		
Immunotherapy[a]			*Z* = -0.23	.824		*Z* = -0.56	.574		*Z* = -1.05	.293		*Z* = -0.16	.877
No	144	100.5			99.6			98.4			100.6		
Yes	57	102.4			104.6			107.6			102.0		

Key: ***p*=<0.05**, [a]Mann-Whitney *U* Tests for binary categorical variables, [b]Kruskal-Wallis *H* tests for more than two categorical variables.

Table 6.8 Univariate Analysis of Associations Between Lymphoma Survivors' Unmet Needs and Clinical Characteristics Continued

Domains of Unmet Needs		Information Needs (INF)			Financial and Work Needs (FIN)			Access and Continuity of Care Needs (ACC)			Coping, Sharing & Emotional Needs (COP)		
	N	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*	Mean Rank	Test statistic	*p*
Radiotherapy [a]			*Z* = 0.85	.396		*Z* = 1.60	.109		*Z* = 1.01			*Z* = 1.23	.220
No	148	103.0			104.9			103.4		.312	104.0		
Yes	53	95.4			90.2			94.3			92.6		
Surgery [a]			*Z* = 1.96	.050		*Z* = -0.99	.324		*Z* = 1.29	.196		*Z* = -0.69	.488
No	163	104.2			98.6			102.9			99.2		
Yes	37	84.3			108.9			89.8			106.5		
No Conditions [a]			*Z* = -1.85	.064		*Z* = -0.99	.324		*Z* = -1.02	.309		*Z* = 0.15	.877
No	114	94.6			97.5			97.5			101.6		
Yes	87	109.3			105.6			105.6			100.3		

Key: ***p*=<0.05**, [a]Mann-Whitney *U* Tests for binary categorical variables, [b]Kruskal-Wallis *H* tests for more than two categorical variables.

6.4.5 Unmet Needs Univariate Analysis Summary

Several factors were associated with higher unmet needs across domains. One significant finding was that being female was consistently associated with higher unmet needs across three domains. Similarly, being younger was associated with higher unmet financial and work needs and unmet coping, sharing and emotional needs. Insurance coverage also emerged as a relevant factor; those without private health insurance reported higher unmet needs. The timing of diagnosis was another influential factor; those with a more recent diagnosis (one to three years ago) experienced higher unmet needs. Furthermore, a hearing or visual impairment was associated with fewer unmet needs. The employment status of lymphoma survivors also played a role; being retired or a homemaker was associated with lower unmet needs compared to being unemployed, employed or in education. Overall, this univariate analysis sheds light on various factors that contribute to unmet needs among lymphoma survivors.

6.5 Understanding Lymphoma Survivors' Quality of Life and Symptom Experiences

A secondary objective of this research was to understand lymphoma survivors' quality-of-life outcomes and symptom experiences. To accomplish this, an overview of the participants' responses to the FACT-LYM and EQ-5D-5L questionnaires is presented. These instruments were used to supplement the assessment of unmet needs carried out by the SF-SUNS. They offer valuable insights into the impaired quality of life outcomes and the specific symptoms experienced by individuals with lymphoma. Relevant findings from the FACT-LYM will be reported first; responses refer to no problems with well-being or some problems ('a little bit', 'somewhat', 'quite a bit' and 'very much') unless otherwise stated. The FACT-LYM subscales demonstrated high levels of internal reliability (range α=0.75-0.89, Table 6.9) (Nunnally & Bernstein, 1994; Terwee et al., 2007).

Table 6.9 FACT-LYM by Domain with Mean Scores and Cronbach's Alpha Scores

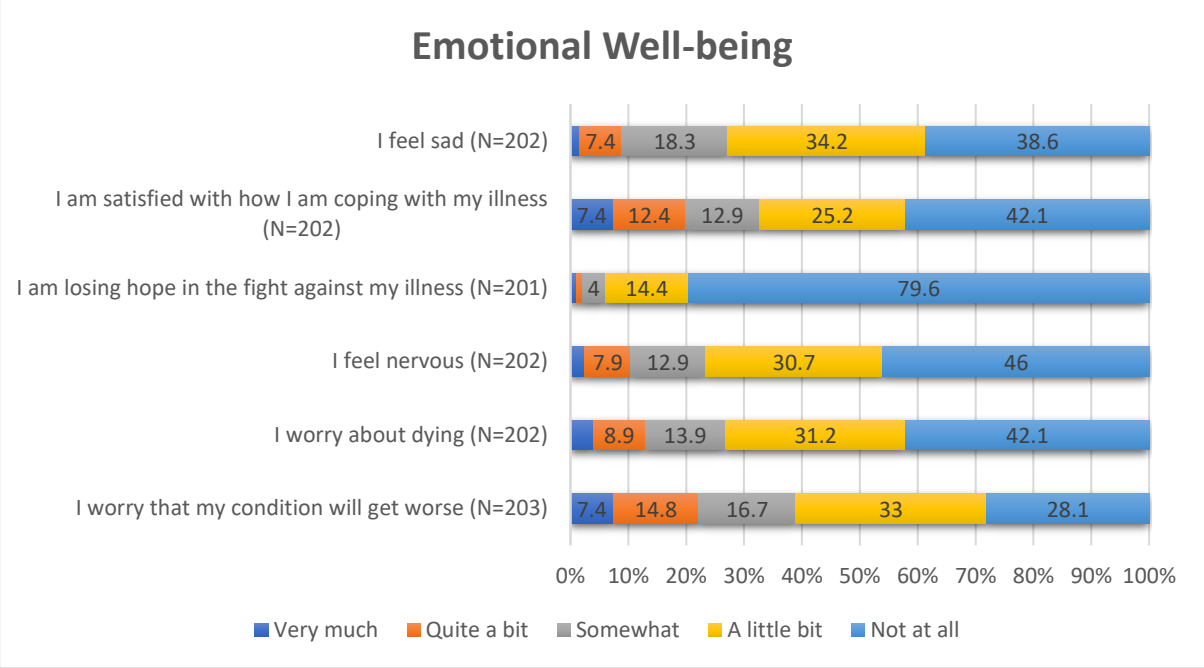
Domain (Score Range)	*N*	Cronbach's alpha score	Mean Score	*SD*
Physical Well-being (PWB) (0-28)	200	.81	22.60	4.55
Social Well-being (SWB) (0-28)	201	.82	19.49	4.57
Emotional Well-being (EWB) (0-24)	199	.75	18.23	4.38
Functional Well-being (FWB) (0-28)	201	.89	19.30	6.24
Lymphoma-Specific Concerns (LYM) (0-60)	198	.86	41.06	9.99

6.5.1 Emotional Well-being (EWB)

Lymphoma survivors were asked to rate their emotional well-being on six items over the last week on the FACT-LYM questionnaire. The most prominent concern about emotional well-being was 'I worry that my condition will get worse'; this was shared in varying degrees ('very much' and 'quite a bit' responses = 22.2% and 'somewhat' and 'a little bit' responses = 49.7%) by over seventy per cent of participants (71.9%, *N*=203). Two in five lymphoma survivors were unsatisfied with how they were coping with their illness

(42.1%, *N*=202). Yet almost eighty per cent of participants reported 'not at all' to 'I am losing hope in the fight against my illness' (79.6%, *N*=202). Feeling nervous (46%, *N*=202) and worrying about dying (57.9%, *N*=202), and feeling sad (61.4%, *N*=202) were concerns shared by many lymphoma survivors (Figure 6.5).

Figure 6.5 Lymphoma Survivors' Concerns for Emotional Well-being by Item



6.5.2 Physical Well-being (PWB)

Participants were asked to rate their physical well-being over seven items over the past week on the FACT-LYM questionnaire. Over eighty per cent of lymphoma survivors (83.4%, *N*=205) experienced 'a lack of energy', with one in five rating its severity at the higher end of the scale ('quite a bit' to 'very much' 21.5%). Almost sixty per cent of lymphoma survivors were bothered by the side effects of treatment (57.4%, *N*=204), while two in five were forced to spend time in bed (40.2%, *N*=204). Feeling ill was a concern for one-third of lymphoma survivors (34.3%, *N*=204), as were two other items: 'because of my physical condition, I have trouble meeting the needs of my family' (32.7%, *N*=205) and 'I have pain' (32.7%, *N*=203) (Figure 6.6).

6.5.3 Functional Well-being (FWB)

Lymphoma survivors were asked to report their functional well-being on seven FACT-LYM items over the past week. Functional well-being can broadly provide insight into practical concerns faced by survivors. Participants reported being able to work (91.2%, *N*=204) and found their work fulfilling (94.6%, *N*=203). Nearly seventy per cent positively responded to 'I am able to enjoy my life' ('quite a bit' responses = 30.9% and 'very much' responses = 37.7%). Over half of lymphoma survivors had 'very much' accepted their illness (53%, *N*=202). Nearly twenty per cent of participants reported sleep disturbance, reporting they only slept well 'a little bit 'or 'not at all' (19.2%, *N*=203) (Figure 6.7).

Figure 6.6 Lymphoma Survivors' Concerns for Physical Well-being by Item

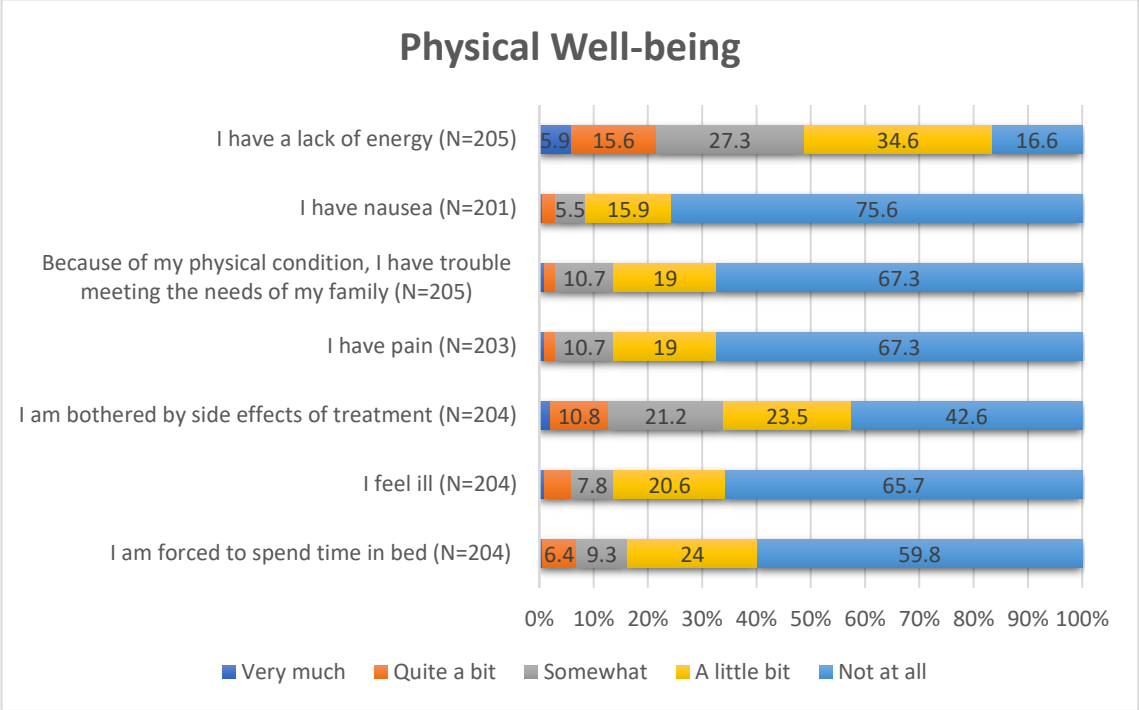
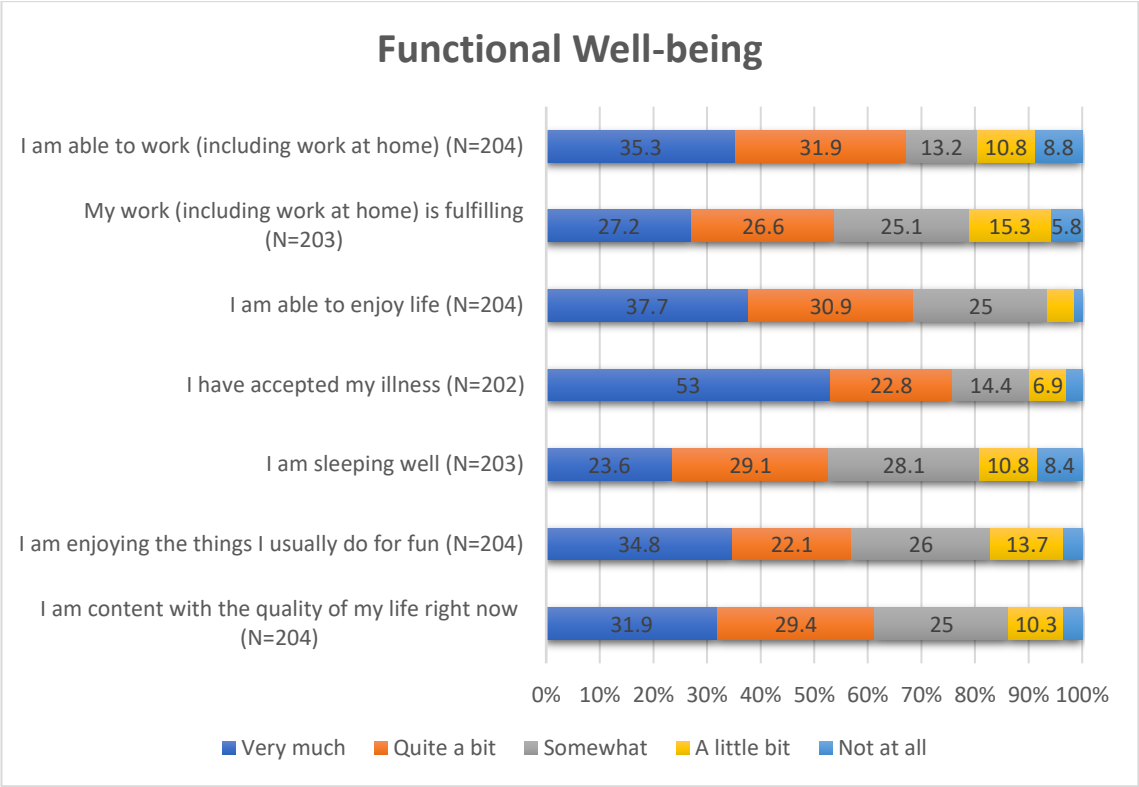


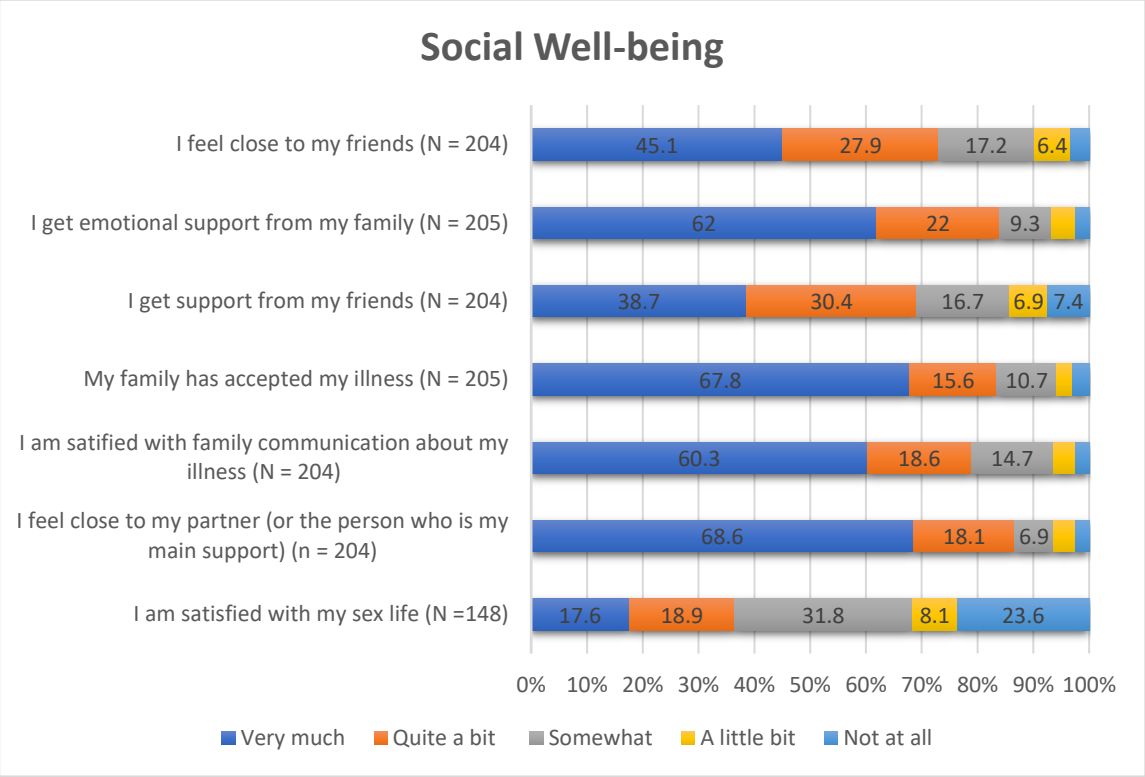
Figure 6.7 Lymphoma Survivors' Concerns for Functional Well-being by Item



6.5.4 Social Well-being (SWB)

Participants reported their social and family well-being for seven items (including one about sex which participants could opt out of if they felt uncomfortable) of the FACT-LYM questionnaire. Almost every participant reported feeling close to their partner or main support person (97.5%, *N*=204). Similarly, participants said that they get emotional support from their family (97.6%, *N*=205), and participants felt their family had accepted the illness (97.1%, *N*=204). The one optional item for this domain, 'I am satisfied with my sex life", was answered by one hundred and forty-eight participants with varied responses (Figure 6.8).

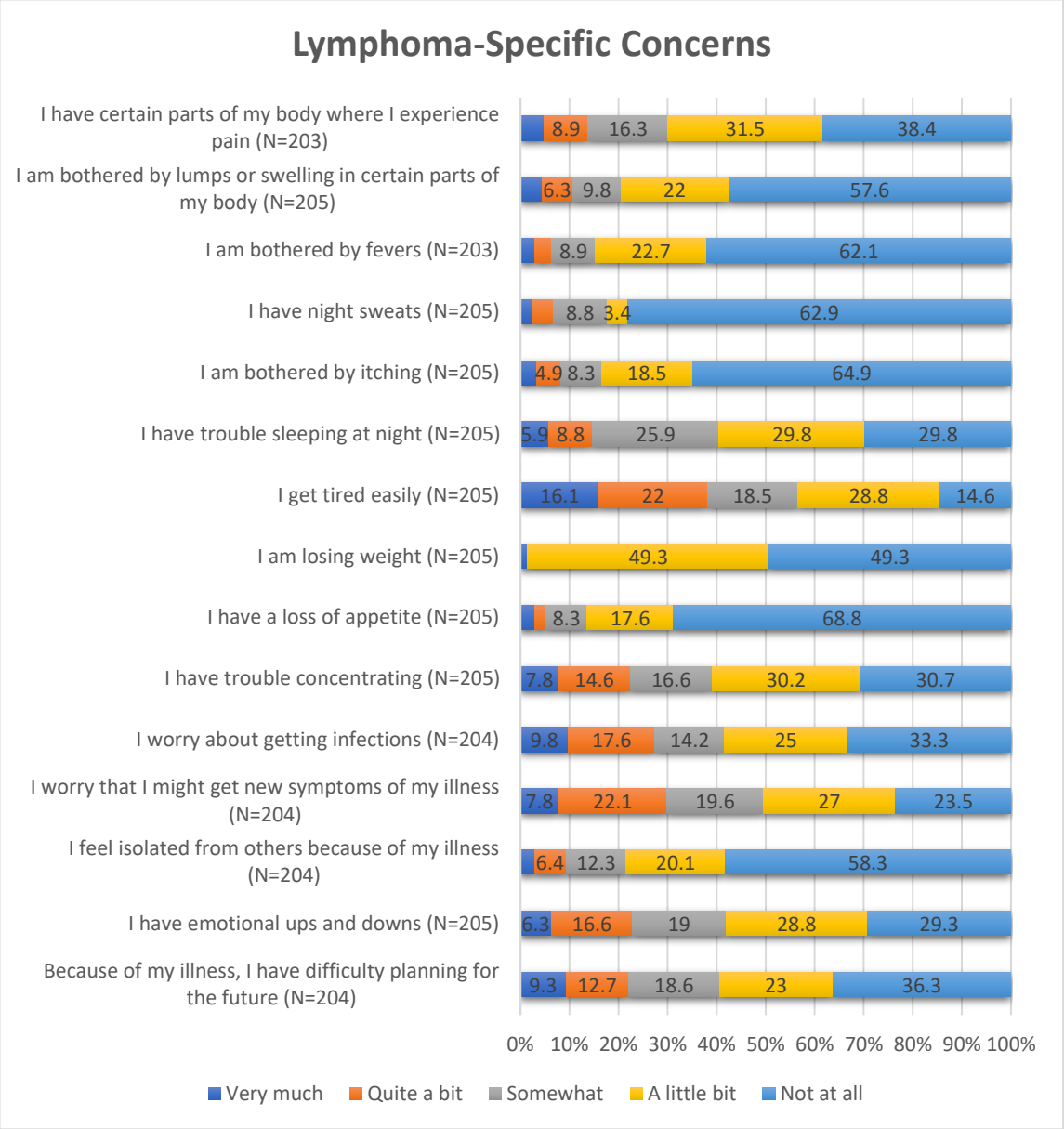
Figure 6.8 Lymphoma Survivors' Concerns for Social Well-being by Item



6.5.5 Lymphoma-Specific Concerns (LYM)

Lymphoma survivors were asked to rate their lymphoma-specific concerns on six items over the last week on the FACT-LYM questionnaire. Seven out of ten lymphoma survivors had trouble sleeping at night (70.2%, *N*=205) and experienced 'emotional ups and downs' (70.7%, *N*=205). Over three-quarters of lymphoma survivors worried 'they might get new symptoms of their illness' (76.5%, *N*=204) or 'about getting infections' (66.7%, *N*=204), while a large portion had difficulty planning for the future (63.7%, *N*=204) and difficulty concentrating (69.3%, *N*=205). Four out of ten lymphoma survivors felt 'isolated from others because of their illness' (41.7%, *N*=204) (Figure 6.9).

Figure 6.9 Lymphoma Survivors' Lymphoma-Specific Concerns by Item



6.5.6 EQ 5D-5L Findings

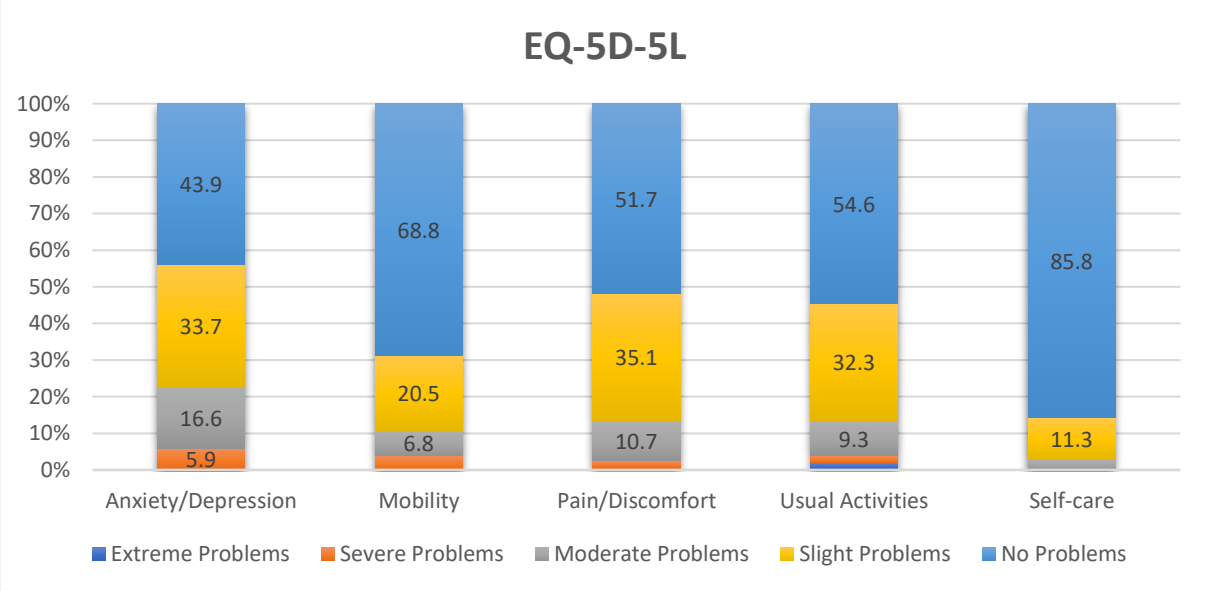
'Anxiety/depression' were the most endorsed problems reported on the EQ-5D-5L questionnaire, with fifty-six per cent of participants (*n*=115) reporting some problems with anxiety and depression. This is higher than the other four health statuses: pain/discomfort (48%, *n*=99), usual activities (45%, *n*=93), mobility (31.2%, *N*=205), and self-care (14.2%, *n*=29) (Figure 5.14). Participants were asked to indicate their difficulty level with mobility and pain/discomfort on the day they completed the EQ-5D-5L survey. Pain and discomfort were reported by nearly half of the lymphoma survivors (48%, *n*=99), showing a higher rating for 'pain/discomfort' on the EQ-5D-5L on the day of the survey compared to 'I have pain' on the FACT-LYM over the past week. Less than one-third of the total sample (31.2%, *N*=205) reported some problems with mobility. The EQ-5D-5L questionnaire asked participants to indicate their difficulty level with self-care and usual activities. Participants reported the least problems with self-care (13.9%, *n*=28), while forty-five per

cent of participants (*N*=205) had problems with their usual activities. A summary of EQ-5D-5L responses is provided in Table 6.10 and Figure 6.10.

Table 6.10 EQ 5D-5L Some Problems Responses by Health State in Number and % of the Sample (N=205)

Health State	*n*	% Respondents reporting some problems
Mobility	64	31.2
Self-care	29	14.2
Usual activities	93	45.4
Pain/discomfort	99	48.3
Anxiety/depression	115	56.1

Figure 6.10 EQ 5D-5L Problems in % Reported by Lymphoma Survivors



6.5.6.1 Visual Analogue Scale Findings

The Visual Analogue Scale (VAS) of the EQ-5D-5L allowed participants to self-rate their health status on the day of the survey from 0 to 100, the worst to best health imaginable. The mean VAS score across all participants was 73.77 (*SD*=17.37) and range (25 to 100), *N*=204. The minimum VAS score increased with age (18–39 years minimum VAS = 25, 40 – 69 years minimum VAS=30 and 70 years or older minimum VAS=40). One in six lymphoma survivors reported a VAS score of 50 or lower (16.6%, *n*=34), while half reported a score of 80 or greater (49.5%, *n*=101).

6.5.7 Summary of QOL and Symptom Experience Findings

Half of the participants rated their health positively on the day of completing the survey (VAS $\bar{x}$=73.77, *SD*=17.37). Anxiety and depression were the most frequently endorsed problems on the EQ-5D-5L by over half of the participants. Problems with emotional and physical well-being and lymphoma-specific concerns were reported. Like the analysis of unmet needs, many (eight out of ten) survivors reported a lack of energy.

Seven out of ten survivors worried their condition would get worse, worried about new symptoms, had trouble sleeping, difficulty concentrating or had emotional ups and downs. Over half of the survivors had concerns about getting infections, had difficulty planning for the future, or were bothered by the side effects of treatment. Functional and social well-being were rated positively by participants (>90%) as they reported good support and rapport with the family and were able to work, which was fulfilling. Many survivors were able to enjoy life (70%) and accepted their illness (53%). These findings provide insights into the QOL outcomes and symptom experiences of lymphoma survivors.

6.5.8 Higher Unmet Needs and Quality of Life Outcomes

A univariate analysis examined the relationship between QOL outcomes and sociodemographic/clinical characteristics to identify significant variables associated with lower quality of life outcomes for physical, social, emotional, and functional well-being on the FACT-LYM subscales. Higher scores on the survey indicate a higher quality of life. Being female was associated with worse physical well-being (p=.001) and worse emotional well-being (p=.046) than being male. Not having private health insurance was associated with worse physical well-being (p=.002) and worse functional well-being (p=.047). Regarding employment status, being a student was associated with worse social well-being (p=.008), while being in employment (full-time or part-time) was associated with higher physical well-being and social well-being (p=.008). No significant associations were found between age and quality of life outcomes. These findings provide empirical evidence that variables (e.g., being female, being employed or a student and not having private health insurance) associated with lower quality of life outcomes are similar to those associated with higher unmet needs outlined in the previous section (Section 6.4). Further insight into the factors influencing unmet needs will be gained from subsequent regression analysis (Section 6.6).

6.6 Explanatory Factors Influencing Survivors' Unmet Needs

6.6.1 Hierarchical Multiple Regression Analysis

Hierarchical multiple regression was used to identify the factors that best explained participants' unmet needs. The assumptions underlying this model have been previously described (Section 5.8.4). The model was used to explore whether specific blocks of variables increased the model's explanatory power regarding unmet needs, each block represents one step (or model). Each block of variables was added to the model in sequential steps to determine if the additional variable(s) in each block significantly improved the model's explanatory power (Keith 2014).Four exploratory hierarchical multiple regression analyses were conducted to describe the relative contribution of patient demographics, clinical factors, QOL attributes and possible moderation effects as assessed by patient responses measured by the SF-SUNS, FACT-LYM and EQ-5D-5L instruments. The four subscales of unmet needs (SF-SUNS, i.e., INF, FIN, ACC, COP), the five quality of life subscales (FACT-LYM, i.e., PWB, SWB, EWB, FWB, LYMS), the VAS of the EQ-5D-5L, sociodemographic and clinical characteristics form the variables of interests in evaluating the explanatory factors influencing lymphoma survivors' unmet needs.

The hierarchical multiple regression analysis assumptions outlined in Table 5.10 were fulfilled to ensure normality, linearity, multicollinearity, and homoscedasticity were not violated. Inspections of scatterplots, partial regression plots, p-p plots and correlation tables were conducted and accompany each model (Appendix 19), distinguished by the dependent variables (INF, FIN, ACC, COP). The relationship between the dependent variables (INF, FIN, ACC and COP) and the independent variables can be assumed to be linear, as inspected by the scatterplot (the residuals roughly form a horizontal band) and partial regression plots. Homoscedasticity was assessed by visual inspection of the same scatterplot. Inspection of the normal P-P plot revealed minor deviations from normality. However, multiple regression is robust against departures from normality. Correlation tables show no multicollinearity issues as no independent variables have correlations greater than 0.7, and all tolerance values are greater than 0.1 (lowest=0.116). There were no outliers as the standardised residuals were greater than ±3 standard deviations. Residuals were independent as assessed by a Durbin-Watson statistic of 2.030 (INF), 2.036 (FIN), 1.976 (ACC), and 2.098 (COP) as a value of approximately 2 indicates no correlation between residuals.

6.6.1.1 Procedures

The selection of the independent variables in each block and the order in which they are entered was based on a combination of previous research evidence, the specific aims of this current research and the adjusted R^2 values. The variable selection for blocks is outlined next.

The first block controls the potential influence of particular variables before examining the primary predictor and outcome variables. Therefore, the first block was entered into the hierarchical regression, including the sociodemographic variables to act as control variables. This accounted for variability by removing the effect of sociodemographic variables before analysing the relationship between the predictors (clinical factors and QOL variables) and the outcome (unmet needs). This provided a more focused analysis of the relationships of interest to the research question while keeping the sociodemographic factors constant. This approach can help to reveal whether the associations between unmet needs and clinical characteristics and QOL variables are independent of the effects of the sociodemographic variables (i.e., constants like age), a typical application used in health research.

Therefore, by systematically entering blocks of variables in hierarchical regression, an investigation of the incremental variance explained by each block of variables can be conducted. Univariate analysis investigated combinations of possible interaction effects for each subscale, resulting in only two interactions: i) Lymphoma Type (HL or NHL) and Age Group (18 – 39 years, 40 – 69 years and 70+ years), and ii) EWB and PWB, which were considered for further analysis. The four hierarchical regression analyses identified the independent predictors in each block of the four unmet needs subscales: INF, FIN, ACC, and COP. The following models were constructed:

1. Model one: consisted of the participants' sociodemographic characteristics, providing information about the lymphoma survivor sample like gender, age, residence, employment status and health insurance status.

2. Model two: provided information on lymphoma, cancer care and its treatment. These clinical characteristics include lymphoma diagnosis, time since diagnosis, sites (cancer centre or regional hospital), treatment (i.e., chemotherapy, immunotherapy, radiotherapy, surgery), and comorbidities (i.e., cardiac conditions).

3. Model three: comprised of the quality-of-life outcomes (i.e., PWB, SWB, EWB, FWB, LYMS, VAS).

4. Model four: concerned with the interaction effects between i) Emotional Well-being and Physical Well-being and ii) Lymphoma Type and Age Group. The first involves emotional well-being as a potential moderator between participants' physical well-being and the outcome variables for unmet needs (i.e., INF, FIN, ACC and COP); motivated by the link between body and mind for lymphoma survivors. Similarly, for the second, participants' age groups were investigated as a potential moderator between their lymphoma diagnosis (NHL or NHL) and each outcome variable; motivated by the age difference between subtypes.

Therefore, participant sociodemographic details were entered in the first step (model one); clinical characteristics were added for the second step (model two); quality of life attributes were entered in step three (model 3) after centring on offsetting possible multicollinear effects. The final step (model four) introduces the two interactions as potential moderators.

6.6.1.2 Unmet Information Needs (INF)

Table 6.11 (at the end of this section) summarises the results of the hierarchical multiple regression analysis of the first dependent subscale, unmet information needs (INF). Model 1 was statistically significant (R^2=.119, F(9, 172)=2.578, p=.008). The model showed that being female and not having private health insurance significantly increased unmet information needs (β=-.210, p=.008; β=-.208, p=.013).

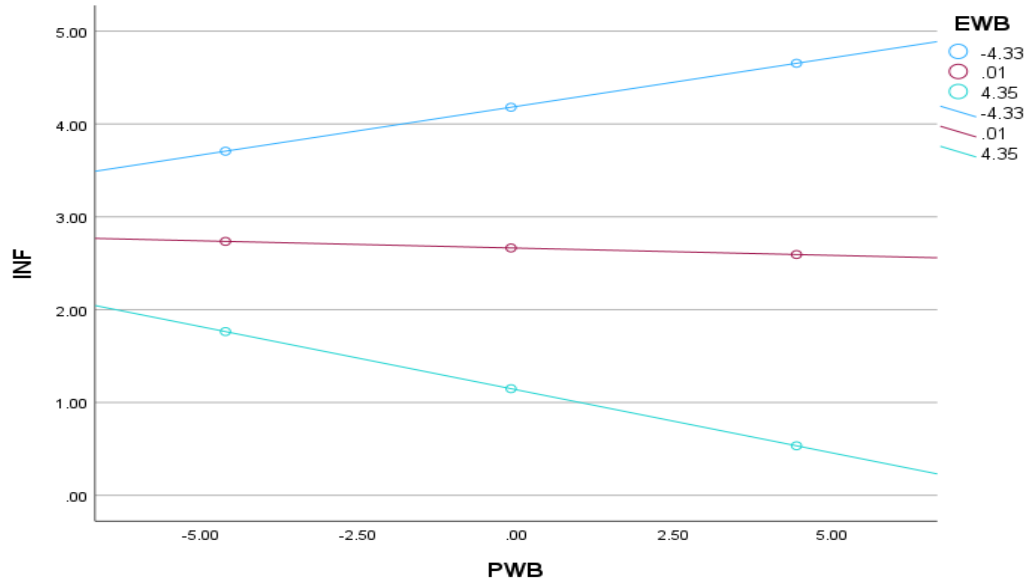
Adding clinical characteristics to predict unmet information needs in Model 2 led to a statistically significant increase in R^2 of .093, F(10, 162)=1.911, p=.047. After adjusting for sociodemographic characteristics, being male, having private health insurance, being 3 - 5 years post-diagnosis (β=-.178, p=.021) and having surgery (β=-.183, p=.015) led to a significant decrease in unmet information needs. Being retired and/or a homemaker resulted in a statistically significant (β=.244, p=.024) increase in unmet information needs compared to those in full-time or part-time employment.

In Model 3, the addition of the QoL variables was statistically significant (R^2=.479, F(25, 156)=5.726, p<.001; adjusted R^2=.395). Being female, retired and/or a homemaker (compared to those in employment) and having surgery were statistically significant, however, the variable that contributes most to an increase in unmet information needs was physical well-being (PWB) with a beta coefficient of 0.254 and a p-value of

0.009. In other words, PWB has the most decisive influence on the extent to which individuals experience unmet information needs. Interestingly, an increase in EWB, FWB and VAS scores led to a significant reduction in unmet information needs (β=-.248, *p*=.006, β=-.233, *p*=.038, β=-.182, *p*=.048), respectively, after adjusting for sociodemographic and clinical characteristics.

In **Model 4**, adding the interaction terms resulted in a significant increase in R^2 of .027, $F(3, 153)=2.791$, *p*=.042. Being retired and/or a homemaker remained statistically significant (β=.212, *p*=.019) compared to being employed for increased unmet information needs while having surgery (β=-.147, *p*=.018) led to a decrease in unmet information needs. In this model, an examination was conducted to explore the relationship between PWB, and unmet information needs (INF). The results indicated a significant moderator effect of EWB on PWB scores (β=-.171, *p*=.015) (Figure 6.11). This interaction term (EWB*PWB) accounted for an additional 2.7% of the total variance in the model, further supporting the statistical significance of the moderator effect. The findings indicate that their EWB score influences the relationship between a participant's PWB score and unmet information needs. In other words, the impact of PWB on unmet information needs varies depending on the level of EWB. Participants who reported EWB scored higher than average (one standard deviation above the mean) displayed significantly higher PWB scores, which increased unmet information needs. In comparison, individuals with EWB scores that were average or below average (one standard deviation below) demonstrated significantly higher PWB scores but reduced unmet information needs. No significant moderation effect was observed between age and lymphoma diagnosis (HL or NHL).

Figure 6.11 The Interaction Relationship Between Emotional Well-being, Physical Well-being and Unmet Information Needs



Key: EWB=emotional well-being; PWB=physical well-being; INF=unmet information needs.

6.6.1.3 Unmet Work and Financial Needs (FIN)

Table 6.12 summarises the results of the second dependent variable, unmet work and financial needs (FIN). **Model 1** was statistically significant (R^2=.159, F(9, 172)=3.605, p<.001; adjusted R^2=.115) and explained 15.9% of the variance in the FIN subscale. The model showed that being female, younger, and not having private health insurance contributed significantly to unmet work and financial needs (β=-.157, p=.033; β=-.299, p=.016; β=-.166, p=.042), respectively.

Adding clinical variables to **Model 2** did not significantly improve the overall prediction of FIN beyond those included in Model 1 (F(10, 162)=1.086, p=.376).

In **Model 3**, the addition of the QoL variables was statistically significant (R^2=.550, F(25, 156)=7.632, p<.001; adjusted R^2=.478). Being a student significantly reduced unmet work and financial needs (β=-.141, p=.029) compared to those working full-time or part-time hours. An increase in the lymphoma-specific (LYMS) variable scores made the most significant contribution (β=-.377, p<.001) to a decrease in unmet work and financial needs, followed by an increase in FWB scores (β=-.251, p=.012), after adjusting for sociodemographic and clinical characteristics.

Although adding the interaction terms in **Model 4** resulted in a nonsignificant increase in R^2 of .006, F(3, 153)=0.673, p=.570, being a student (β=-.143, p=.028) compared to being in employment and having higher FWB and LYMS scores, led to a reduction in FIN. Neither interaction term indicated a significant moderator in Model 4.

6.6.1.4 Unmet Needs for Access and Continuity of Care (ACC)

Table 6.13 summarises the results of the third dependent variable, unmet needs for access and continuity of care. **Model 1** was not statistically significant (R^2=.036, F(9, 172)=0.709, p=.700; adjusted R^2=.015), explaining 3.6% of the variance in the unmet needs for access and continuity of care (ACC) domain.

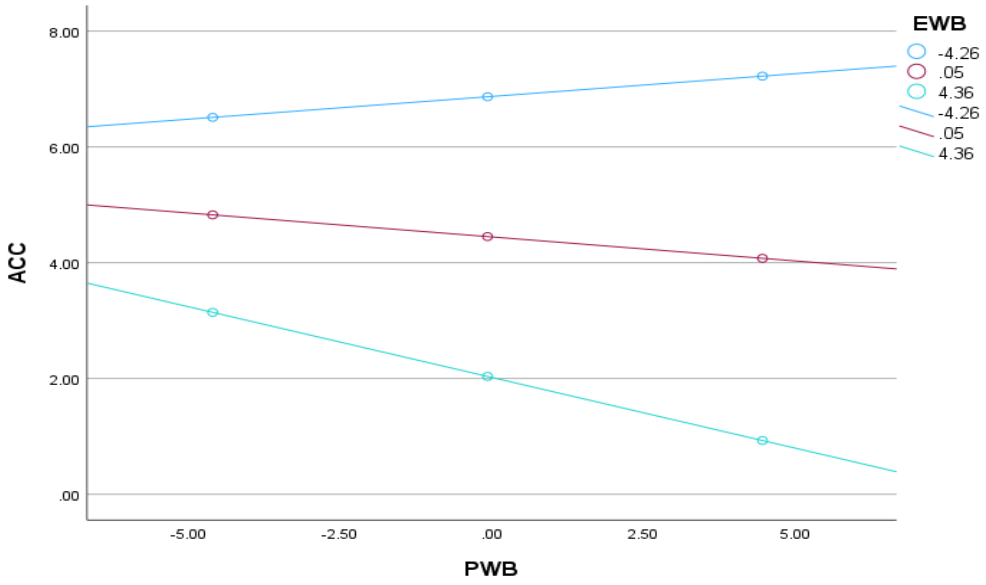
Adding clinical variables in **Model 2** to predict ACC led to a statistically nonsignificant increase in R^2 of .092, F(10, 162)=1.718, p=.081. Having surgery (β=-.163, p=.038) and a hearing or visual impairment was significant, β=-.209, p=.011), leading to a decrease in ACC after adjusting for sociodemographic characteristics.

In **Model 3**, the addition of the QoL variables was statistically significant (R^2=.550, F(25, 156)=2.718, p<.001; adjusted R^2=.303). Having non-Hodgkin's lymphoma (β=-.165, p=.045) and a hearing or visual impairment (β=-.190, p=.013) significantly reduced ACC. An increase in EWB made the most significant contribution (β=-.352, p<.001) to decreased unmet needs for access and continuity of care after adjusting for sociodemographic and clinical characteristics.

For **Model 4**, adding the interaction terms resulted in a significant increase in R^2 of .041, F(3, 153)=3.169, p=.026. A hearing or visual impairment (β=-.162, p=.042) significantly decreased ACC. An investigation of the relationship between PWB and unmet needs for access and continuity of care needs

revealed a statistically significant moderator effect of EWB on PWB scores (β=-.229, *p*=.005), as evidenced by the interaction term explaining an additional 4.1% of the total variance, *p*=.026 (Figure 6.15). This finding suggested that participants reporting higher-than-average (one standard deviation above the mean) EWB scores had significantly higher PWB scores associated with increased unmet needs for access and continuity of care. While those with average or lower-than-average (one standard deviation below) EWB scores resulted in significantly higher PWB scores, reducing ACC. No significant moderation effect was observed between age and lymphoma diagnosis (HL or NHL).

Figure 6.12 The Interaction Relationship Between Emotional Well-being, Physical Well-being and Unmet Needs for Access and Continuity of Care



Key: EWB=emotional well-being; PWB=physical well-being; ACC=unmet needs for access and continuity of care.

6.6.1.5 Unmet Coping, Sharing and Emotional Needs (COP)

Finally, Table 6.14 summarises the results of the fourth dependent variable, unmet coping, sharing and emotional needs (COP). Model 1 was statistically significant (R^2=.123, F(9, 172)=2.671, *p*=.006; adjusted R^2=.077), explaining 12.3% of the variance in the COP domain. The model showed that being male, having private health insurance and being 70 years or older (compared to the youngest age group, 18 – 39 years) significantly decreased unmet coping, sharing and emotional needs (β=-.185, *p*=.014; β=-.184, *p*=.027; β=-.281, *p*=.026), respectively.

Adding the clinical variables to predict unmet coping, sharing, and emotional needs in Model 2 led to a statistically nonsignificant increase in R^2 of .082, F(10, 162)=1.095, *p*=.369. After adjusting for sociodemographic characteristics, being male, having private health insurance, being 70 years or older (compared to the youngest age group) and having no conditions (β=-.174, *p*=.025; β=-.171, *p*=.044; β=-.275, *p*=.046; β=-.183, *p*=.043, respectively) led to a significant decrease in COP.

Table 6.11 The Hierarchical Regression Models for Unmet Information Needs (INF)

Unmet Information Needs (INF)	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
Gender								
Female	-	-	-	-	-	-	-	-
Male	-.210	**.008****	-.183	**.016***	-.132	**.047***	-.083	.215
Age								
18 - 39 years	-	-	-	-	-	-	-	-
40 - 69 years	-.124	.202	-.062	.550	.035	.691	.165	.230
70+ years	-.289	**.022***	-.217	.107	-.075	.506	.060	.709
Residence								
Rural	-	-	-	-	-	-	-	-
Urban	.019	.797	.017	.822	.008	.900	.010	.870
Employment status								
Full-time/Part-time	-	-	-	-	-	-	-	-
Retired/Homemaker	.160	.130	.244	**.024***	.185	**.040***	.212	**.019***
Student	-.121	.142	-.116	.155	-.093	.177	-.081	.235
Unemployed	-.017	.823	.009	.902	-.097	.139	-.084	.194
Medical Card								
No	-	-	-	-	-	-	-	-
Yes	.113	.184	-.110	.192	-.048	.502	-.061	.389
Private Health Insurance								
No	-	-	-	-	-	-	-	-
Yes	-.208	**.013***	-.215	**.010***	-.109	.125	-.109	.121
Lymphoma Type								
Hodgkin Lymphoma			-	-	-	-	-	-
Non-Hodgkin Lymphoma			-.086	.310	-.107	.132	.015	.885
Time Since Diagnosis								
1 to 3 years			-	-	-	-	-	-
3 to 5 years			-.178	**.021***	-.138	**.036***	-.111	.093
Site								
Regional Hospital			-	-	-	-	-	-
Cancer Centre			.078	.290	-.002	.972	-.018	.783
Chemotherapy								
No			-	-	-	-	-	-
Yes			-.062	.393	-.060	.330	-.083	.180
Immunotherapy								
No			-	-	-	-	-	-
Yes			-.001	.989	-.046	.476	-.043	.504
Radiotherapy								
No			-	-	-	-	-	-
Yes			-.005	.952	.020	.755	.029	.648
Surgery								
No			-	-	-	-	-	-
Yes			-.183	**.015***	-.154	**.014***	-.147	**.018***

Table 6.11 The Hierarchical Regression Models for Unmet Information Needs (INF) Continued

Unmet Information Needs (INF)	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
No Conditions								
No			-	-	-	-	-	-
Yes			.097	.271	.128	.084	.127	.081
Quality of Life								
PWB					.254	**.009***	.209	**.034***
SWB					-.011	.882	.004	.957
EWB					-.248	**.006***	-.319	**.001***
FWB					-.223	**.038***	-.197	.070
LYMS					-.192	.095	-.198	.080
VAS					-.182	**.048***	-.140	.125
Interactions								
EWB*PWB							-.171	**.015***
Lymphoma type*Age Group1							-	-
Lymphoma type*Age Group 2							-.208	.206
Lymphoma type*Age Group3							-.247	.133

	Model 1	Model 2	Model 3	Model 4
R^2	.119	.212	.479	.506
Adjusted R^2	.073	.119	.395	.415
ΔR^2	.119	.093	.267	.027
ΔF	2.578*	1.911*	13.297**	2.791*

Key: ***p*=<.05**. β = Standardised coefficient (reference level). PWB = Physical Well-being; SWB = Social/Family Well-being; EWB = Emotional Well-being; FWB = Functional Well-being; LYMS = Lymphoma-specific; VAS = Visual Analogue Scale; Age Group1 = 19 - 39 years; Age Group2 = 40 - 69 years; Age Group3 = 70+ years.

In **Model 3**, the addition of the QoL variables was statistically significant (R^2=.627, F(25, 156)=10.498, p<.001; adjusted R^2=.567). An increase in QoL variables: SWB (β=-.148, p<.001), EWB (β=-.335, p<.001), and LYMS (β=-.363, p<.001) significantly resulted in decreased unmet coping, sharing and emotional needs after adjusting for sociodemographic and clinical characteristics.

Although adding the interaction terms in **Model 4** resulted in a nonsignificant increase in R^2 of .002, F(3, 153)=0.311, p=.817, increased SWB, EWB, and LYMS scores resulted in reduced COP (β=-.140, p=.033; β=-.348, p<.001; β=-.367, p<.001, respectively).

Table 6.12 The Hierarchical Regression Models for Unmet Work and Financial Needs (FIN)

Unmet Work and Financial Needs (FIN)	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
Gender								
Female	-	-	-	-	-	-	-	-
Male	-.157	**.033***	-.120	.113	.013	.825	.002	.975
Age								
18 - 39 years	-	-	-	-	-	-	-	-
40 - 69 years	-.130	.169	-.166	.113	-.106	.198	-.086	.507
70+ years	-.299	**.016***	-.281	**.038***	-.187	.076	-.076	.621
Residence								
Rural	-	-	-	-	-	-	-	-
Urban	.005	.947	.028	.710	.026	.656	.023	.687
Employment status								
Full-time/Part-time	-	-	-	-	-	-	-	-
Retired/Homemaker	-.029	.776	-.033	.761	-.076	.359	-.081	.342
Student	-.115	.152	-.138	.091	-.141	**.029***	-.143	**.028***
Unemployed	.138	.064	.131	.088	-.007	.908	-.009	.888
Medical Card								
No	-	-	-	-	-	-	-	-
Yes	-.125	.133	-.120	.157	-.077	.246	-.072	.286
Private Health Insurance								
No	-	-	-	-	-	-	-	-
Yes	-.166	**.042***	-.179	**.032***	-.042	.528	-.053	.427
Lymphoma Type								
Hodgkin Lymphoma			-	-	-	-	-	-
Non-Hodgkin Lymphoma			-.032	.710	-.052	.434	.014	.890
Time Since Diagnosis								
1 to 3 years			-	-	-	-	-	-
3 to 5 years			-.081	.282	-.005	.935	-.003	.962
Site								
Regional Hospital			-	-	-	-	-	-
Cancer Centre			.101	.171	-.033	.581	-.025	.675
Chemotherapy								
No			-	-	-	-	-	-
Yes			-.102	.158	-.104	.071	-.110	.061
Immunotherapy								
No			-	-	-	-	-	-
Yes			.090	.237	.025	.671	.035	.560
Radiotherapy								
No			-	-	-	-	-	-
Yes			-.102	.191	-.060	.326	-.063	.300
Surgery								
No			-	-	-	-	-	-
Yes			-.005	.943	.032	.581	.026	.658

Table 6.12 The Hierarchical Regression Models for Unmet Work and Financial Needs (FIN) Continued

Unmet Work and Financial Needs	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
No Conditions								
No			-	-	-	-	-	-
Yes			-.092	.293	-.029	.670	-.031	.655
Quality of Life								
PWB					-.061	.495	-.051	.581
SWB					.127	.073	.113	.114
EWB					-.091	.275	-.067	.445
FWB					-.251	**.012***	-.234	**.024***
LYMS					-.377	**<.001***	-.370	**.001***
VAS					-.036	.670	-.049	.573

	Model 1	Model 2	Model 3	Model 4
R^2	.159	.212	.550	.556
Adjusted R^2	.115	.119	.478	.475
ΔR^2	.159	.053	.339	.006
ΔF	3.605**	1.086	19.571**	.673

Key: ***p*=<.05**. β = Standardised coefficient (reference level). PWB = Physical Well-being; SWB = Social/Family Well-being; EWB = Emotional Well-being; FWB = Functional Well-being; LYMS = Lymphoma-specific; VAS = Visual Analogue Scale.

Table 6.13 The Hierarchical Regression Models for Unmet Needs for Access and Continuity of Care (ACC)

Access and Continuity of Care Needs (ACC)	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
Gender								
Female	-	-	-	-	-	-	-	-
Male	-.086	.274	-.027	.743	.035	.647	.095	.219
Age								
18 - 39 years	-	-	-	-	-	-	-	-
40 - 69 years	-.054	.591	-.013	.908	.044	.667	.251	.113
70+ years	-.225	.088	-.132	.352	-.064	.624	-.073	.696
Residence								
Rural	-	-	-	-	-	-	-	-
Urban	-.034	.651	-.056	.475	-.052	.468	-.050	.477
Employment status								
Full-time/Part-time	-	-	-	-	-	-	-	-
Retired/Homemaker	.119	.283	.169	.134	.131	.208	.177	.089
Student	-.036	.677	-.074	.388	-.064	.420	-.046	.556
Unemployed	.003	.971	.008	.918	-.084	.267	-.072	.331
Medical Card								
No	-	-	-	-	-	-	-	-
Yes	-.033	.715	-.057	.520	-.050	.549	-.060	.466
Private Health Insurance								
No	-	-	-	-	-	-	-	-
Yes	-.085	.331	-.105	.230	-.017	.833	-.003	.972

Table 6.13 The Hierarchical Regression Models for Unmet Needs for Access and Continuity of Care (ACC) Continued

Access and Continuity of Care Needs (ACC)	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
Lymphoma Type								
Hodgkin Lymphoma			-	-	-	-	-	-
Non-Hodgkin Lymphoma			-.174	.053	-.165	**.045***	-.062	.610
Time Since Diagnosis								
1 to 3 years			-	-	-	-	-	-
3 to 5 years			-.043	.590	.025	.741	.038	.614
Site								
Regional Hospital			-	-	-	-	-	-
Cancer Centre			.051	.509	-.033	.653	-.049	.503
Chemotherapy								
No			-	-	-	-	-	-
Yes			-.133	.080	-.110	.126	-.128	.074
Immunotherapy								
No			-	-	-	-	-	-
Yes			.012	.879	.003	.964	.002	.979
Radiotherapy								
No			-	-	-	-	-	-
Yes			-.067	.411	-.055	.463	-.045	.547
Surgery								
No			-	-	-	-	-	-
Yes			-.163	**.038***	-.121	.092	-.111	.118
No Conditions								
No			-	-	-	-	-	-
Yes			-.066	.478	.003	.976	.003	.970
Quality of Life								
PWB	-.086		.442		-.129		.253	
SWB	.006		.949		.031		.717	
EWB	-.352		**.001***		-.436		**<.001***	
FWB	.013		.916		.007		.952	
LYMS	-.082		.532		-.092		.478	
VAS	-.008		.941		.044		.675	
Interactions								
EWB*PWB							-.229	**.005***
Lymphoma type*Age Group1							-	-
Lymphoma type*Age Group2							-.282	.136
Lymphoma type*Age Group3							-.083	.659

	Model 1	Model 2	Model 3	Model 4
R^2	.036	.128	.303	.344
Adjusted R^2	.015	.026	.192	.224
ΔR^2	.036	.092	.175	.041
ΔF	.709	1.718	6.542**	3.169*

Key for Table 6.10: ***p*=<.05**. β = Standardised coefficient PWB = Physical Well-being; SWB = Social/Family Well-being; EWB = Emotional Well-being; FWB = Functional Well-being; LYMS = Lymphoma-specific; VAS = Visual Analogue Scale; Age Group1 = 19 - 39 years; Age Group2 = 40 - 69 years; Age Group3 = 70+ years.

Table 6.14 The Hierarchical Regression Models for Unmet Coping, Sharing and Emotional Needs (COP)

Unmet Coping, Sharing and Emotional Needs (COP)	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
Gender								
Female	-	-	-	-	-	-	-	-
Male	-.185	**.014***	-.174	**.025***	-.047	.397	-.043	.457
Age								
18 - 39 years	-	-	-	-	-	-	-	-
40 - 69 years	-.126	.193	-.118	.267	-.057	.448	-.103	.385
70+ years	-.281	.026*	-.275	**.046***	-.164	.088	-.222	.115
Residence								
Rural	-	-	-	-	-	-	-	-
Urban	.028	.699	.060	.427	.081	.123	.083	.117
Employment status								
Full-time/Part-time	-	-	-	-	-	-	-	-
Retired/Homemaker	.079	.455	.060	.581	-.004	.956	-.007	.926
Student	-.027	.740	-.046	.578	-.082	.159	-.083	.159
Unemployed	.128	.091	.097	.215	-.060	.273	-.059	.287
Medical Card								
No	-	-	-	-	-	-	-	-
Yes	-.039	.647	-.037	.666	.013	.827	.008	.892
Private Health Insurance								
No	-	-	-	-	-	-	-	-
Yes	-.184	**.027***	-.171	**.044***	.009	.878	.015	.812
Lymphoma Type								
Hodgkin Lymphoma			-	-	-	-	-	-
Non-Hodgkin Lymphoma			-.111	.200	-.090	.136	-.146	.114
Time Since Diagnosis								
1 to 3 years			-	-	-	-	-	-
3 to 5 years			-.098	.209	-.027	.618	-.026	.645
Site								
Regional Hospital			-	-	-	-	-	-
Cancer Centre			.135	.073	-.047	.383	-.053	.339
Surgery								
No			-	-	-	-	-	-
Yes			-.020	.795	.055	.299	.058	.271
No Conditions								
No			-	-	-	-	-	-
Yes			-.183	.043*	-.078	.214	-.077	.222

Table 6.14 The Hierarchical Regression Models for Unmet Coping, Sharing and Emotional Needs Continued

Unmet Coping, Sharing and Emotional Needs (COP)	Model 1		Model 2		Model 3		Model 4	
	β	*p*	β	*p*	β	*p*	β	*p*
Quality of Life								
PWB					-.115	.160	-.123	.146
SWB					-.148	**.022***	-.140	**.033***
EWB					-.335	**.000***	-.348	**.000***
FWB					-.050	.583	-.056	.552
LYMS					-.363	**.000***	-.367	**.000***
VAS					.131	.090	.137	.084

	Model 1	Model 2	Model 3	Model 4
R^2	.123	.178	.627	.629
Adjusted R^2	.077	.082	.567	.562
ΔR^2	.056	.056	.449	.002
ΔF	**2.671****	1.095	**31.316****	.311

Key: ***p*=<.05**; β=standardised coefficient (reference level); PWB=physical well-being; SWB=social well-being; EWB=emotional well-being; FWB=functional well-being; LYMS=lymphoma-specific; VAS=visual analogue scale.

6.6.1.6 Hierarchical Multiple Regression Findings Summary

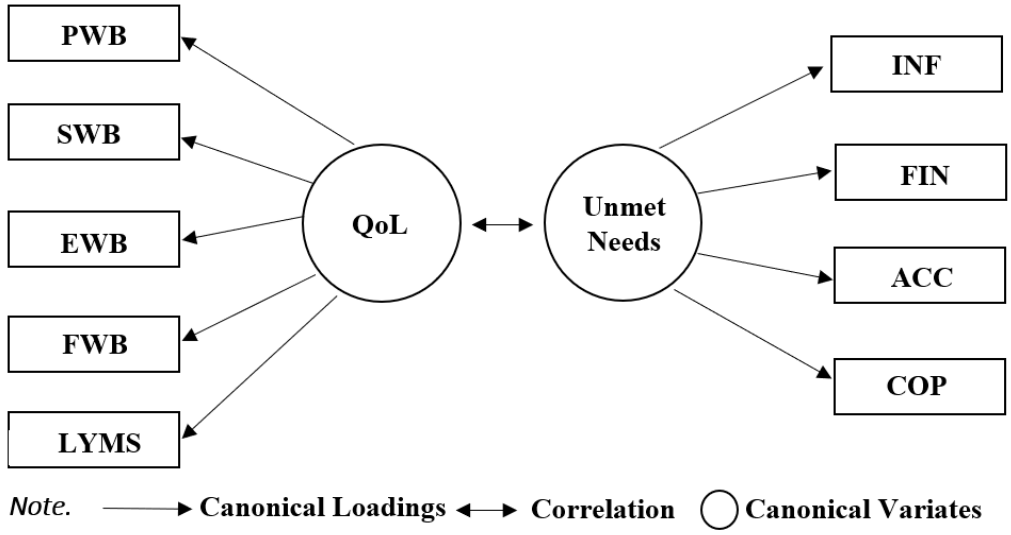
The hierarchical multiple regression identified several factors which influence unmet needs. Being female, not having private health insurance, having a recent lymphoma diagnosis (1-3 years post-diagnosis), being retired or a homemaker and having better physical well-being influenced unmet information needs. Unmet financial and work needs, being female, not having private health insurance, being younger, and being in employment (full-time or part-time) contributed to higher needs. Participants with better functional well-being or fewer lymphoma-specific concerns were associated with lower unmet financial and work needs. Participants who had surgery, a hearing or visual impairment, a diagnosis of non-Hodgkin lymphoma or better emotional well-being were associated with lower unmet access and continuity of care needs. Higher unmet coping, sharing and emotional needs were found in female participants, younger participants, those without private health insurance or those with one or more conditions. Better social well-being, emotional well-being or fewer lymphoma-specific problems were associated with lower unmet coping, sharing and emotional needs. The results also indicated that lymphoma survivors' level of emotional well-being influenced the relationship between their physical well-being and unmet needs.

6.6.2 Canonical Correlation Analysis

As described in Chapter 5, Section 5.8.5, canonical correlation analysis (CCA) is a multivariate analysis of correlation used to explore complex relationships between multiple variables (Hair, 2014; Hotelling, 1992; Sherry & Henson, 2005). The canonical correlation coefficient measures the strength of association between the variable sets (Alpert & Peterson, 1972; Hair, 2014). CCA provides the opportunity to explore the complexity of multiple relationships of constructs of interest (Sherry & Henson, 2005). Therefore, CCA

was used to explore the relationships between two sets of variables, the unmet needs variate and the QOL variate, quantifying the strength of the linear relationship between this pair of variables. The aim was to identify which specific QOL characteristics were statistically significantly associated with attributes of unmet needs using CCA. The first step of CCA is to derive one or more canonical functions. The number of canonical functions equals the number of variables in the smaller set (Sadoughi et al., 2016); for this study, the unmet needs variate is the smaller set with four variables (CV1, CV2, CV3 and CV4). The FACT-LYM scale (using variables PWB, SWB, EWB, FWB and LYMS) measures the QOL variate and the SF-SUNS scale (using variates INF, FIN, ACC, and COP) measures and the Unmet Needs variate (Figure 6.13). Assumptions of linearity and homoscedasticity were evaluated using scatter plots, normality was checked for each subscale variable using p-p plots, and multicollinearity was checked using Variance Inflation Factor (VIF), values (Appendix 19). The cut-off of 0.45 identifies meaningful coefficient correlations or loadings (Sherry & Henson 2005).

Figure 6.13 Conceptual Model of Proposed Canonical Correlation Analysis of the Relationship Between Unmet Needs and Quality of Life



6.6.2.1 Hypothesis

It is hypothesised that an increase in lymphoma survivors' QOL will be associated with a statistically significant decrease in unmet needs.

6.6.2.2 Results

The CCA supports the hypothesis for a significant association between QOL and patients' unmet needs. Table 6.15 shows descriptive statistics for the SF-SUNS and FACT-LYM scales used for this sample.

Table 6.15 Descriptive Statistics for Quality of Life and Unmet Needs Subscales

Subscales	*N*	Mean	*SD*
Quality of Life			
Physical Well-being (PWB)	205	22.53	4.54
Social Well-being (SWB)	205	21.79	5.28
Emotional Well-being (EWB)	202	18.23	4.36
Functional Well-being (FWB)	204	19.42	6.27
Lymphoma-Specific Subscale (LYMS)	205	40.91	10.03
Unmet Needs			
Unmet Information Needs (INF)	202	2.38	7.36
Unmet Financial and Work Needs (FIN)	201	6.81	7.36
Unmet Needs for Access and Continuity of Care (ACC)	201	3.99	5.13
Unmet Coping, Sharing and Emotional Needs (COP)	201	13.87	12.05

CCA resulted in four canonical functions with squared correlations R_c^2 of .587, .159, .060 and .022. Two of the four canonical functions (CV1 and CV2) are significant, and these measures of overall model fit with correlations shown in Table 6.16. The relationship between QOL and unmet needs variates was statistically significant, using Wilk's λ=.320, $F(20, 627.79)=12.873$, $p<.001$. Functions 2 to 4 and 3 to 4 were also statistically significant, $F(12, 502.98)=4.275$, $p<.001$ and $F(6, 382.00)=2.718$, $p=.013$, respectively. Function 4 was not statistically significant. The four functions yielded a full model effect size of 1 – λ=.68, indicating that the full model explained about 68% of the variance shared by the two variates.

Table 6.16 Measures of Overall Model Fit for Canonical Correlation Analysis for the Hypothesis of Interest

Canonical Function	Canonical Correlation	Canonical R^2	Wilk's	*F* Statistic	*p*
1	.766	.587	.320	12.873	**<.001***
2	.399	.159	.773	4.275	**<.001***

Key: ***p*=<.05**

The R_c^2 effects for each variate indicate that only the first two functions (CV1 and CV2) should be considered, with each showing 58.7% and 15.9% of the shared variance, respectively. The other two functions (CV3 and CV4) contributed only 6% and 2.2% shared variance and were not considered for further analysis. The first relationship, canonical variate CV3 ($p<.001$), indicated that participants with an increased QoL across all the variables (except (SWB)) were more likely to experience significantly lower unmet needs across all outcome variables with unmet work and financial needs (FIN) and unmet coping, sharing and emotional needs (COP) being particularly strong, followed by ACC. The second relationship, CV4 ($p<.001$), revealed that none of the variables exceeded the significant threshold of 0.45. (Table 6.17).

Table 6.17 Canonical correlations and standardised variate coefficients for the first and second canonical variates

	CV1		CV2	
Subscales	COR	COE	COR	COE
Quality of Life				
Physical Well-being (PWB)	**.728***	-0.014	.184	0.702
Social Well-being (SWB)	.418	0.022	.218	0.774
Emotional Well-being (EWB)	**.874***	0.369	.178	0.608
Functional Well-being (FWB)	**.720***	0.126	-.426	-1.375
Lymphoma-Specific Subscale (LYMS)	**.955***	0.615	-.023	-0.393
Unmet Needs				
Unmet Information Needs (INF)	**-.687***	-0.160	.279	0.690
Unmet Financial and Work Needs (FIN)	**-.837***	-0.380	.386	0.971
Unmet Needs for Access and Continuity of Care (ACC)	**-.558***	0.068	-.189	-0.702
Unmet Coping, Sharing and Emotional Needs (COP)	**-.939***	-0.649	-.315	-0.953

Key: ***Significant correlations=≥ .45**; COR=canonical loadings; COE=standardised canonical loadings variate coefficient; CV1=canonical variate 1; CV2=canonical variate 2.

The first significant canonical variate demonstrated that those participants with increased scores in LYMS (0.615) and EWB (0.369) were significantly associated with lower unmet work and financial needs (FIN) (-0.380) and lower unmet coping, sharing and emotional needs (COP) (-0.649). However, both PWB (-0.014) and SWB (0.022) had a reduced impact across all the unmet needs variables. The second significant canonical variate showed a large decrease in the FWB score (-1.375) resulting in a significant increase in unmet work and financial needs (FIN) (0.971), but a large significant reduction in unmet coping, sharing and emotional needs (COP) (-0.953).

6.6.2.3 Canonical Correlation Analysis Findings Summary

An increase in lymphoma survivors' quality of life is associated with a statistically significant decrease in unmet needs. Survivors with better emotional well-being or less lymphoma-specific concerns had lower unmet needs relating to work, finances and emotional health. Worse functional well-being was associated with higher unmet needs in financial and work-related concerns but lower unmet needs for coping and emotional health concerns.

6.7 Conclusion

This chapter has provided evidence for the study's objectives from 205 lymphoma survivors across multiple hospital sites in Ireland. Participants were one to five years post diagnosis of NHL (71%) or HL (25%). The sample consisted of equal gender distribution (51% female), a wide age range (19 – 88 years), varied residence (67% urban; 33% rural), different insurance statuses, different living arrangements (80% lived with others; 20% lived alone) and included different ethnicities (88% White Irish). One in nine participants received chemotherapy; NHL survivors were more likely to have received immunotherapy while HL survivors were more likely to have received radiotherapy. Over half of the total sample and three in four HL survivors (mean age 41.6 years) were in employment.

While one in two lymphoma survivors rated their health positively on the day they completed the survey, large numbers of survivors reported unmet needs (over the last month) and impaired quality of life and symptom experiences (over the past week). The unmet needs of lymphoma survivors were identified; dealing with feeling tired was the most endorsed unmet need item by over seventy per cent of survivors. Followed by coping with a bad memory/focus and dealing with feeling stressed. Dealing with feeling depressed, sharing feelings with others, body changes, worry about earning money, and fears of cancer spreading were unmet needs reported by over half of lymphoma survivors. However, one in ten lymphoma survivors (mostly NHL, male or lived in an urban setting) reported no unmet needs across all items.

Descriptive statistics revealed the most frequently reported 'high/very high' unmet needs items were within the domains of unmet coping, sharing and emotional needs and unmet financial and work needs. HL survivors reported statistically significant higher unmet needs in dealing with not feeling 'normal' than NHL survivors. Female survivors reported statistically significant higher unmet needs than males in dealing with reduced support when treatment ended, people expecting them to be 'back to normal' or coping with a bad memory/focus. This was supported by findings of the univariate analysis for unmet needs, as being female was consistently associated with higher unmet needs. Being younger, not having private health insurance or having a more recent lymphoma diagnosis (one to three years post-diagnosis) contributed to higher unmet needs. Being retired or a homemaker was associated with lower unmet needs compared to those unemployed, in employment or in education.

The quality of life outcomes and symptom experiences of lymphoma survivors were explored. Like, the unmet needs investigation, a lack of energy and difficulty concentrating were top concerns for over seventy percent of lymphoma survivors. Around three in four participants worried their condition would get worse or worried about new symptoms. Trouble sleeping, emotional difficulties, worry about getting infections and difficulty planning for the future were also endorsed by large numbers of lymphoma survivors. Anxiety and depression were the most endorsed health state on the EQ-5D-5L as over half of participants reported some problems with these aspects of emotional well-being. Problems with pain and discomfort or usual activities were reported by over forty per cent of survivors. The univariate analysis for quality of life outcomes found similar variables (e.g., being female and not having private health insurance) associated with lower quality of life outcomes to that of the separate univariate analysis results for higher unmet needs. Those in employment or education were associated with better social well-being.

Univariate, hierarchical multiple regression and canonical correlational analyses were used to systematically investigate significant relationships between the dataset's demographic, clinical and quality of life variables and provided evidence for the factors influencing the unmet needs of lymphoma survivors. Hierarchical regression and CCA analyses supported the univariate findings that being female or younger were significant variables in relation to unmet emotional needs or unmet financial and work needs, suggesting that gender and age have a significant role in explaining the variations in these specific domains. Consistent with previous findings, being female, not having private health insurance or having a more recent diagnosis (1-3 years ago) were associated with higher unmet needs.

The quality-of-life variables PWB, EWB, FWB and LYMS were significantly related to all four unmet needs domains in the CCA analysis. Hierarchical regression revealed that functional well-being was significantly related to unmet information needs, unmet financial needs, and unmet emotional needs; emotional well-being was significantly related to unmet emotional needs; and lymphoma-specific concerns was significantly related to unmet financial needs. Better social well-being was associated with lower unmet emotional needs. Unmet emotional needs and unmet financial and work needs were the predominant domains of unmet needs significantly associated with key independent variables identified by descriptive, univariate and regression analyses. CCA confirmed an increase in lymphoma survivors' quality of life is associated with a statistically significant decrease in unmet needs.

Chapter 7 Phase Two Qualitative Findings

7.1 Introduction

This chapter provides the qualitative findings of this mixed methods study. It extends the results of the quantitative first phase (Chapter 6) to offer an in-depth investigation of the individual experiences and complexities of lymphoma survivors' unmet needs. This insight can provide a voice to lymphoma survivors through additional in-depth exploration and elaboration, which is especially valuable for this group as an underserved population in current literature. The rationale and relevant considerations relating to the qualitative phase and selection of reflexive thematic analysis are provided in detail elsewhere (Chapter 5). This mixed methods study benefits from the qualitative phase in its ability to understand the meaning embedded in lymphoma survivors' experiences through an open-ended and subjective approach (Lincoln & Guba 1985). A challenge of qualitative inquiry involves the voluminous amounts of text-based data, which requires reduction to a manageable form without losing its embedded meaning. Additionally, the data analysis process must be transparent, credible, and trustworthy (Lincoln & Guba 1985) (section 5.7). Concept maps provide one strategy to deal with the methodologic challenges of qualitative research. A conceptual map was used to illustrate the development of the main themes (Figure 7.1), focusing on establishing meaning in the context of the unmet needs of lymphoma survivors. A detailed presentation of the phase two findings corresponding with the conceptual map is then presented.

7.2 Qualitative Findings

Through providing a platform to voice their experiences, a rich discussion of lymphoma survivors' unmet needs was uncovered. The interview sample (*N*=14) summary characteristics are presented in Table 7.1. The participants received their cancer care at five clinical sites of recruitment across Ireland; this included cancer centres and regional hospitals. Most participants had non-Hodgkin lymphoma (NHL) (*n*=11, 79%); three participants had a diagnosis of Hodgkin lymphoma (HL). The average age of the interview participants was 52 years old (range 24-81); the mean age was younger for HL (29.7 years) and older for NHL (58.2 years). The sample had an even representation of gender and time since diagnosis, with seven participants either one to three years or three to five years post-diagnosis. Slightly more participants resided in urban areas (*n*=8, 57%) than in rural settings (*n*=6, 43%). Most participants were of White Irish background (*n*=12, 83%); two participants reported other ethnicities from Europe and South America. Nearly all participants (*n*=13, 93%) had a medical card or equivalent (e.g., General Practitioner Visit Card), while four participants had both private health insurance and a medical card (*n*=4). Participants were in employment (*n*=7, 50%), retired (*n*=6, 43%) or unemployed (*n*=1). Their working hours since diagnosis varied, with seventy-five per cent working more or continuing to work their usual hours. The mean interview duration was 32 minutes.

Figure 7.1 The Conceptual Map of the Reflexive Thematic Analysis of Phase Two Qualitative Data

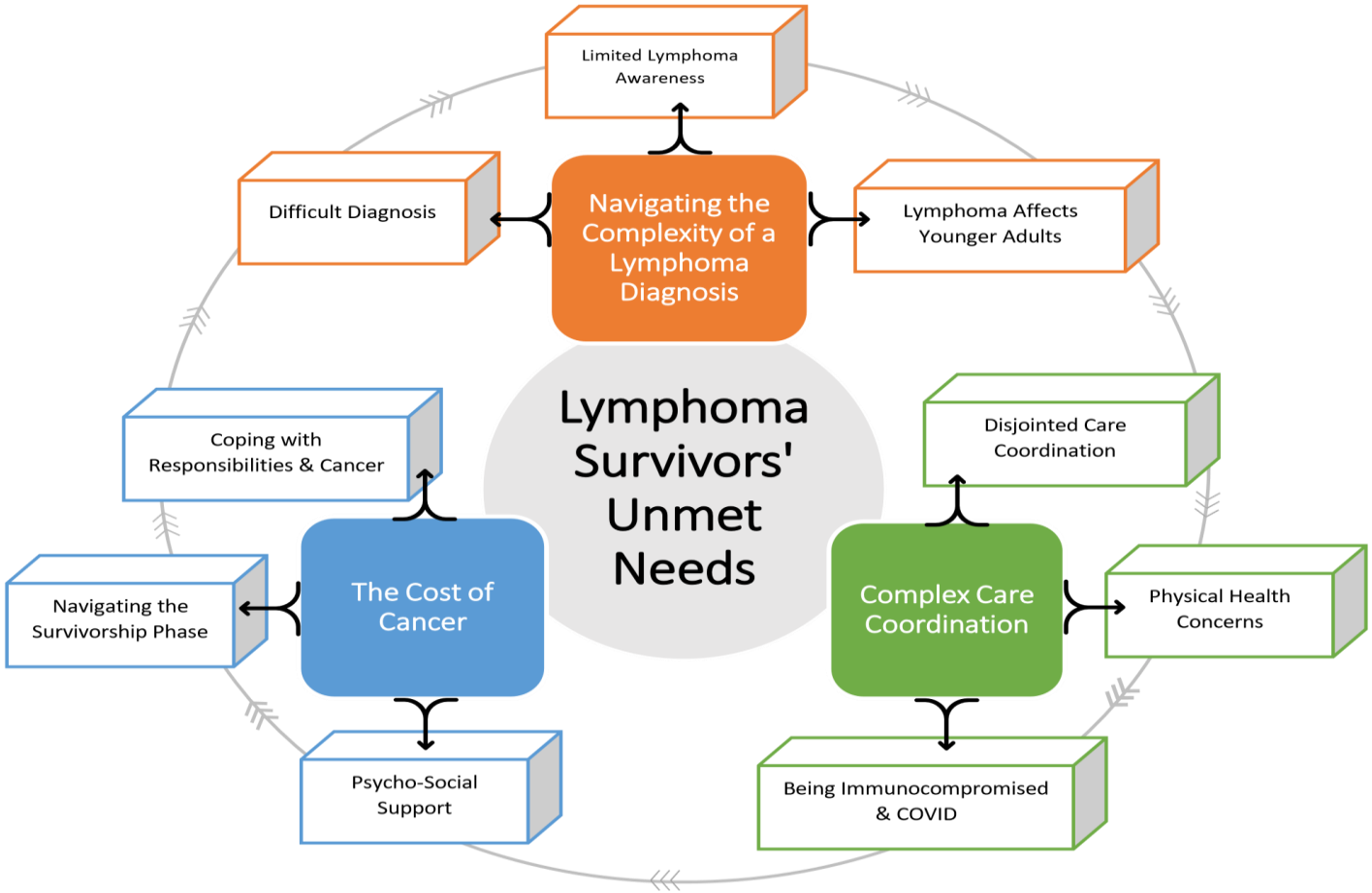


Table 7.1 Summary Characteristics of the Interview Sample (N=14)

Variable	n	%
Lymphoma Type		
Hodgkin lymphoma	3	21.0
Non-Hodgkin lymphoma	11	79.0
Time Since Diagnosis		
1 – 3 years	7	50.0
3 – 5 years	7	50.0
Gender		
Female	7	50.0
Male	7	50.0
Age Groups		
18-25	3	21.0
26-45	4	29.0
46-65	2	14.0
66+	5	36.0
Ethnicity		
Irish	11	78.5
Other	3	21.5
Residence		
Rural	6	43.0
Urban	8	57.0
Living Arrangement		
With others (partner, family, friends)	12	83.0
Alone	2	17.0
Insurance Status		
Medical card/Public	13	93.0
Private health insurance	4	29.0
Employment Status		
Employed (full-time/part-time)	7	50.0
Retired	6	43.0
Unemployed	1	7.0
Working Hours (Since a Lymphoma Diagnosis) (*n*=8)		
Fewer hours	3	37.5
More hours	2	25.0
Usual hours	3	37.5
Comorbidities		
0	6	43.0
1	3	21.0
2 or more	5	36.0

Patterns of shared meaning across this dataset are evident as the three themes interconnect, and all provide information valuable to this investigation of lymphoma survivors' unmet needs. Theme one groups together the shared experiences of survivors' navigating the complexities presented by lymphoma from the challenges in diagnosis, lymphoma awareness and specifically for younger adults. Theme two outlines lymphoma survivors' experiences of complex care coordination, including disjointed cancer care, and how physical health concerns and the immunocompromised nature of lymphoma contribute to its challenges. Finally, theme three found that cancer is both literally and figuratively costly, highlighting the challenges in

balancing life responsibilities with cancer, concerns specific to the survivorship phase, and dealing with psycho-social problems.

7.2.1 Theme One Navigating the Complexity of a Lymphoma Diagnosis

Patterns of shared meaning were evident from participants reporting their journey to a lymphoma diagnosis and the complex navigation of experiences this entailed. The challenges associated with a problematic lymphoma diagnosis and the prolonged waiting are presented. A deficit of awareness around lymphoma as a type of cancer contributed to further difficulties, so participant accounts of limited lymphoma awareness are outlined. The final subtheme illustrates the challenging nature of navigating lymphoma for younger adults; their accounts provide insights into age-specific needs.

Subtheme 1.1: Difficult Diagnosis

The complexity of a lymphoma diagnosis and cancer journey, along with its wide range of symptoms, posed challenges for both survivors and healthcare professionals. Specifically, the difficulty in diagnosing lymphoma was voiced by participants. Delays in receiving a lymphoma diagnosis were experienced by participants, which negatively impacted their well-being, as the prolonged wait for answers was emotionally and psychologically taxing. When asked the main interview question, 'Could you tell me about your experiences with lymphoma cancer?', many survivors began to report their problematic diagnosis experience and highlighted the lengthy time it took to get to a diagnosis.

> *"Getting there was the guts of a year from the first time I went to the doctor to being sat in front of the consultant, being told I had cancer." (P04, Female, Age 43, Interview)*

The diagnostic experience was problematic in varied ways for survivors across ages and gender as the complexity of a lymphoma diagnosis is compounded by the fact that it can be challenging to differentiate lymphoma from other conditions with similar symptoms. As lymphoma can affect any organ in the body, various presentations were evident from survivors' experience of diagnosis, from impaired respiratory function to many other signs and symptoms. For a cancer of the blood, blood test results were not reported as the primary cause for concern leading to diagnosis; instead, it was in combination with other unwanted signs and symptoms of poor health that required multiple lines of investigation (i.e., physical examinations, imaging tests).

> *"It was an 11-centimetre tumour in my chest. That had been pressing on my heart and my lungs. I couldn't actually breathe properly." (P02, Female, Age 24, Interview)*

> *P6: "My exams, blood exams, usually were really, really good. I just feel pain, so this made it hard to find out the correct diagnosis." (P06, Female, Age 41, Interview)*

Medical investigations used to diagnose lymphoma typically include imaging tests like ultrasound, CT scans, or PET scans, as well as blood tests and biopsies. However, sometimes, these investigations can be inconclusive, meaning they still need to confirm or rule out the presence of lymphoma definitively. This was a cause of concern for lymphoma survivors and their healthcare practitioners because it hindered

diagnosis and treatment planning. Additionally, it was frustrating, as this left participants and their healthcare practitioners uncertain and unsure whether they had lymphoma and its best course of action.

> *"I remember the ultrasound came back showing nothing." (P10, Male, Age 81, Interview)*

The presentation of lymphoma for participants was not straightforward as their signs and symptoms did not fit the characteristics commonly understood for lymphoma. Even though healthcare professionals understood these characteristics better, some participants sympathised with the complexity and difficulty of diagnosing lymphoma. Given their first-hand experience of complications which preceded their lymphoma diagnosis (i.e., a stomach bleed for one participant and misdiagnosis for another), participants understood the reason for delays. Still, they endured unmet psychological and emotional needs during this period of uncertainty.

> *"The GP, in fairness, would think, how am I supposed to know there was anything wrong with your stomach when you didn't tell me anything was wrong with your stomach? It must be difficult to diagnose." (P10, Male, Age 81, Interview)*

> *"I was misdiagnosed at the start… they thought it was pancreatic cancer." (P05, Male, Age 40)*

Proactively seeking medical attention can help identify potential health issues early on. However, this led to one participant considering how her experience could have been grossly worse had she not been so proactive in her healthcare. An individual's awareness of their health supports the identification of changes that may warrant investigation. The capacity for patients to articulate their concerns is also important to patient outcomes, as is the skill of extracting the required information by healthcare professionals.

> *"I caught it at stage 2B, had I not been as forceful as I was, would I have been at stage 4? It grows so quickly." (P04, Female, Age 43, Interview)*

Some participants with unclear or inconclusive diagnoses sought a specialist's opinion, often resulting in multiple visits to doctors or different medical specialities. These specialists had expertise in diagnosing and treating lymphoma and could provide valuable input in determining the correct diagnosis. Survivors shared a sense of relief in finally receiving their lymphoma diagnosis. It enabled a course of action to be chosen, easing the prolonged uncertainty and unknown surrounding their health concerns.

> *"I had to visit many different doctors to discover the lymphoma finally. People ask me how my reaction was when I found out about the cancer. For me, I feel happy because finally, now, I know what I have." (P06, Female, Age 41, Interview)*

> *"When I got told I got cancer, I told them thank you because it was a year of waiting for an answer." (P03, Male, Age 24, Interview)*

Systemic delays were also related to the overall health service rather than individual healthcare professionals as participants voiced system issues but complementary of staff. While survivors navigated barriers to care outlined above, the cancer care received was reported as excellent. Participants voiced the barriers to care and observed resource and staffing problems require careful consideration.

"I would think a people and number issue. The patient-to-consultant ratio is probably way too big." (P03, Male, Age 24, Interview)

"The cancer care is excellent; it is the barriers that are in place to that care that needs to be looked at." (P12, Female, Age 80, Interview)

A prominent issue for lymphoma survivors is the difficulty in diagnosing lymphoma and the challenging journey they face when seeking answers to their health concerns. The heterogeneity of experiences is noted from the interview sample, with varied presentations, signs, and symptoms of lymphoma, which contributed to inconclusive or unclear results. In addition, this subtheme identified that delayed diagnosis results in a heightened potential for unmet psychological and emotional needs due to unresolved physical health concerns. Similarly, delays in cancer services created a prolonged sense of waiting for survivors. The journey to diagnosis was complex and uncertain for half of the participants, and it shows diagnosing lymphoma poses challenges for patients and healthcare professionals. Therefore, a difficult diagnosis journey contributes to a complex experience navigating lymphoma.

Subtheme 1.2: Limited Lymphoma Awareness

One contributing aspect of difficult lymphoma diagnosis is the limited awareness surrounding this cancer among the general public. Indeed, half of the qualitative study participants reported that they did not realise that lymphoma is a cancer. Many survivors were unfamiliar with lymphoma as a type of cancer until they received their diagnosis. Even upon receiving a diagnosis, some survivors didn't understand lymphoma to mean a cancer diagnosis. These experiences describe a lack of knowledge and understanding about lymphoma as a type of cancer. In comparison, a better awareness of other cancers, like breast cancer, was voiced by participants, highlighting the dissociation of lymphoma as a cancer for some survivors.

"Turns out I had lymphoma cancer. I hadn't heard of it before, or if I had, I didn't realise it was cancer." (P12, Female, Age 80, Interview)

"All the big buzzword cancers like breast cancer and so on, but I hadn't heard much about lymphoma." (P04, Female, Age 43, Interview)

Some survivors voiced a sense of surprise at the gravity of a lymphoma diagnosis. The lack of awareness surrounding lymphoma and the immediate implications a lymphoma diagnosis placed on their daily lives contributed to this surprise. This shock was compounded by the need to adapt quickly, and cope with the uncertainty of diagnosis.

"I didn't realise my diagnosis was so serious." (P11, Female, Age 71, Interview)

Similarly, some survivors initially perceived lymphoma to be relatively more straightforward to treat than other cancers. However, the experiences proved to be more challenging and complex than anticipated; the communication received about their diagnosis set them up for unrealistic expectations. An oversimplification in the explanation of lymphoma from healthcare professionals contributed to unmet

expectations regarding treatment and timelines associated with the cancer. A narrative that lymphoma is more straightforward than others was felt to undermine survivors' challenges and warped their expectations for their cancer journey, leading to unmet information needs.

> *"I thought it was going to be not as hard as, let's say, other ones [cancers] because they kind of say it's a good one to get because it's so treatable and stuff. But it still was really difficult" (P01, Female, Age 24, Interview)*

> *"The first day that I had Hodgkin's lymphoma, two doctors in the emergency department said to me… and I had just been diagnosed… 'if you are going to get cancer, lymphoma is the best one to get'. It is curable and all that. If you are going to get cancer, that's the one… it ended up not being that simple." (P02, Female, Age 24, Interview)*

This subtheme of limited lymphoma awareness speaks to the unmet information needs experienced by participants and the deficit of awareness surrounding lymphoma as a type of cancer. Unlike other cancers, lymphoma was not associated with the umbrella term of cancer. This caused difficulties in understanding what a lymphoma diagnosis involved, its seriousness, and managing expectations based on incomplete information and communication. While lymphoma and its association with cancer may be unclear to some, this lack of awareness extends past patients to the public and some healthcare professionals.

Subtheme 1.3: Lymphoma Affects Young Adults

Navigating the complexities of lymphoma was challenging for younger survivors. Four younger adults articulated that their symptoms were not taken seriously due to their younger age, leading to missed chances for early diagnosis and treatment opportunities. The previous subtheme, 'difficult diagnosis', discussed the difficult road to diagnosis for participants; the specific challenges for younger people are illuminated here. Younger survivors were considered fit and 'healthy' by general practitioners; this youthful barrier imposed inadequate prioritising of their health concerns, which required diagnostic investigations. To the detriment of the participants, their health concerns were dismissed due to their younger age. This delayed addressing unmet physical needs, which negatively impacted psychological and emotional well-being, as more invasive procedures or surgeries could have been avoided if their symptoms had been taken more seriously and sooner.

> *"If I had only been sent for that MRI in the first place, I wouldn't have maybe had to do surgery on my head. So being listened to in the first place, not being dismissed." (P03, Male, Age 24, Interview)*

> *"'Oh, she is young, she is fit and healthy, it could not be anything serious… but I looked up the symptoms, and I think this should have been taken seriously a little bit earlier." (P04, Female, Age 43, Interview)*

Younger adults with lymphoma voiced unmet social needs from a lack of support and resources tailored to their age group. Cancer services and supports were felt to be geared towards older demographics, leaving younger individuals feeling out of place. Waiting rooms and hospital wards had predominantly older people

attending them, making it difficult for younger survivors to relate to or find support from peers who share similar experiences. A more personalised approach to cancer supportive care for younger persons was desired.

> *"Maybe something a bit more personalised… I felt like it was aimed towards older people." (P01, Female, Age 24, Interview)*

> *"Even at times in the waiting rooms when I would be waiting to get my chemo, I would look around at people who are a lot older than me." (P03, Male, Age 24, Interview)*

Additionally, younger people face challenges in navigating life experiences distinct from those of older people. Specifically, survivors transitioning from teens into young adulthood may consider seeking support through social media platforms and connecting with others online who have undergone similar experiences. However, a lack of information on handling social situations and relationships was voiced, such as navigating how to bring cancer up with someone.

> *"What I have come across is you are either a child or you are an old person. By an old person, I mean a proper adult with kids and a mortgage. Or you are still seven years old, still colouring a book… There is a lot of talk of play therapists and stuff. Sure, no twenty-year-old needs a play therapist… There is no information on how to navigate social things. Even relationships, how to approach cancer, how to bring it up with someone." (P03, Male, Age 24, Interview)*

> *"I ended up reaching out to people on Instagram that were my age. I would literally look up Hodgkin lymphoma on Instagram and Twitter." (P02, Female, Age 24, Interview)*

The previous subtheme of limited lymphoma awareness is further extended as younger survivors expressed surprise when they realised lymphoma is common among younger people. Age matters in diverse ways, and in the case of younger participants, age was an integral way healthcare professionals perceived them when attending to their health concerns and further imposing the complexity of navigating a lymphoma diagnosis.

> *"The amount of young and younger girls than me, young men and women, that have this." (P04, Female, Age 43, Interview)*

This subtheme reported the problems experienced by younger lymphoma survivors due to their age. The unmet physical needs of younger lymphoma survivors stemmed from their dismissed health concerns, resulting in worse outcomes potentially affecting psychological and emotional well-being. A need for tailored resources and support for younger adults was voiced by participants, who may turn to online platforms to find connections to meet their unmet social needs.

The three subthemes have collectively illustrated various aspects of navigating the complexities of a lymphoma diagnosis. Difficult and delayed paths to diagnosis for participants were compounded by unmet psychological and emotional needs and prolonged periods of unknown, uncertainty, and unanswered questions about health concerns that contributed to impaired well-being. The complexity of a 'difficult

diagnosis' involved varied presentations and inconclusive investigations, while the survivor's ability to articulate their concerns to medical professionals may also be a contributing factor. Participant accounts highlight that lymphoma awareness is limited. The needs important to younger survivors were identified, highlighting that the health concerns of young people need to be taken seriously.

7.2.2 Theme Two: Complex Care Coordination

Complex care coordination involves lymphoma survivors' experiences of disjointed cancer care, managing physical health concerns and being immunocompromised. The accounts from participants provide their first-hand experience of care coordination and insights into identifying challenges and potential solutions. The prominent side effects and symptoms of lymphoma and its treatment are outlined. The barriers to care coordination due to the immunocompromised nature of lymphoma and the pandemic are provided.

Subtheme 2.1: Disjointed Cancer Care

Lymphoma survivors perceived a gap or disconnect in the healthcare system, specifically regarding the coordination of cancer services between hospitals and primary care. They sensed that something was missing with their continuity of cancer care. The participant accounts emphasise the need for better collaboration and integration between healthcare providers to promote a more seamless experience throughout their cancer journey. A more united approach and better communication between hospital-based cancer services and primary care was suggested to help address these issues.

> *"There was a missing link there." (P11, Female, Age 71, Interview)*

> *"I don't know what the solution is, but there needs to be a bit of joint-up thinking." (P04, Female, Age 43, Interview)*

The varied presentation associated with lymphoma (outlined in the subsequent subtheme, 'Physical Health Concerns') necessitated a multidisciplinary approach of input from diverse medical teams for survivors. Participant accounts required input from haematology, oncology, and other specialities like endocrinology and cardiology. This can contribute to the patient feeling at risk of being overlooked within a complex system. Further challenges exist in the communication between specialist hospital services and ongoing care arrangements in the community. Therefore, the patient can feel they must act as a conduit for information regarding their illness and treatment pathways, which can contribute to unmet information needs. This unanticipated responsibility can be further complicated when there is variance between the treating physicians regarding care, again placing responsibility on the person with lymphoma to act as a go-between regarding their care and treatment.

> *"I know they have to look after thousands of people. Then you have to explain your case, the whole rigmarole again. And then, one consultant thinks one thing, another person tells you that you are fine, and the third person tells you to go somewhere else. You are left chasing your tail." (P03, Male, Age 24, Interview)*

> *"You also had to go to an Endocrinologist… and then you'd go to your GP, and you'd have to kind of relay everything, and you know it was a lot of to and frow and different people." (P01, Female, Age 24, Interview)*

There was potential for greater attention to patient-centred care arrangements as participants identified the challenge associated with repeat visits to acute hospital settings to access phlebotomy services. Participants specifically suggested a greater opportunity to respond to unmet practical needs for localising aspects of care. Some participant accounts pointed to an anomaly in barriers to integration of care as follow-up phlebotomy is free at the point of service when the service is accessed through hospital-based speciality services. In contrast, access such as surveillance in the primary care setting can result in unanticipated costs (e.g., blood tests in the GP practice).

> *"The support afterwards, like getting your bloods done but not having to go all the way in there [to the hospital]. Not having to pay a premium for getting them done by your local doctors... There should be clinics closer" (P04, Female, Age 43, Interview)*

Participants reported relying on cancer specialist centres as they developed familiarity with service arrangements. There was evidence that the completion of treatment was a notable transition period for survivors. The transition period was associated with increased anxiety regarding losing the 'safety net' attached to the familiarity with the routine of such services and interactions. This necessitated participants to adjust to increased independence from the healthcare facility where they received treatment; this helped to manage or reduce anxiety and unmet emotional needs.

> *"I would have liked to know what to do after treatment. I felt I should be happy to be finished, but maybe I felt alone. I remember when I finished chemotherapy, I checked with my doctor if I could have a little bit more chemotherapy." (P06, Female, Age 41, Interview)*

> *P14: "I was really dependent on the hospital. I needed them. I needed them to make me well again." (P14, Male, Age 63, Interview)*

The limited hospital space, particularly in waiting areas, made bringing someone along for support during appointments challenging and shed light on the physical environment's impact on the overall care experience. The constraints on physical space, particularly during times of crisis such as the pandemic, add further complexities to the coordination of care and can affect the emotional well-being of patients and their families. The physical environment of hospitals was seen as a barrier to care coordination and is outlined further within the subsequent subtheme, 'Being Immunocompromised and COVID'. Therefore, these accounts from lymphoma survivors describe unmet practical needs and a missing link for their care coordination. Lymphoma often requires multidisciplinary and specialist approaches to care, while a desire for localised services was evident. Yet, the person with lymphoma was responsible for mediating between different care providers, resulting in unmet information needs. The transition after treatment can result in losing the safety net of routine care and the interactions accompanying this. Participants experienced an adjustment in letting go of their dependency on health services to address unmet emotional needs. The factors identified contribute to the complexity of care coordination for this group.

Subtheme 2.2: Physical Health Concerns

The prominent symptoms and side effects of lymphoma and its treatment were shared by participants, showing several acute unmet physical needs with some longer-term or permanent effects. The most reported symptoms and side effects included cancer-related fatigue, impaired cognitive function, and reproductive health concerns. Cancer-related fatigue was a prominent concern voiced by half of the participants, but the reported severity varied by individual. This physical concern had a knock-on effect on the daily living of participants, disrupting sleep and social activities. Tiredness was experienced physically within the body for most and impacted speech in one severe case. Participants recounted the need for sleep, a necessary response to fatigue.

> *"Oh, exhaustion on the legs. Exhaustion, exhaustion, no energy." (P10, Male, Age 82, Interview)*

> *"I have to preserve my energy to drive home. I know that when I get tired, I will slur my words. That is when I knew I needed to sleep. I don't care where I am, what is happening, what occasion it is. I need to go home and sleep." (P03, Male, Age 24, Interview)*

Similarly, one-third of survivors reported impaired cognitive function, such as memory issues or reduced focus. Participants experienced their brain 'slow-down' in contrast to their normal capacity for functioning before cancer, creating a different self of sense, which was hoped to be a temporary rather than permanent change. This was reflected in participants' accounts, which questioned the cause of their impaired cognitive function, with lymphoma, its treatment or stress considered, while older participants also considered if the ageing process was at fault.

> *"The memory is not so good. I don't know whether that is getting older or if cancer and treatment are to blame. I am more forgetful; the focus isn't there." (P13, Male, Age 80, Interview)*

> *"My brain is a little bit fuzzy. But I don't know if that is from all the treatment or is it just because there is so much going on?" (P01, Female, Age 24, Interview)*

The perception of appearing weaker was another aspect discussed by older participants. They recounted experiences of being perceived as frail and in need of assistance by others due to the physical toll of the treatment. This perception, although well-intentioned, affected their self-esteem. The contrast between their previous appearance and post-treatment self was a source of discomfort. Participant accounts showed a shared experience of the negative impact of appearing 'unwell' to others. This made social interactions difficult for participants as cancer became the focal point of their identity, contributing to unmet social needs.

> *"After my treatment, I was pretty shook. I was very weak. People said they saw me crossing the road and wanted to help me. Later on, they told me that they had seen better corpses. When you look back at yourself in the mirror a year afterwards. I looked a wreck and twenty years older than I do now." (P10, Male, Age 82, Interview)*

Side effects are commonly managed pharmaceutically with other drugs that interact (aim to reduce adverse events) with additional side effects as participants recounted treatment-related side effects. Nausea and vomiting, a common side effect of chemotherapy, were troublesome as some participants experienced prolonged sickness despite taking prescribed anti-emetics or remedies.

"I got sick for four hours, constantly." (P02, Female, Age 2, Interview)

"Side effects, yeah, there were many. There was lots of stuff they could give me to try and counter the side effects, but they, in turn, gave me side effects. So, it was trying to get the balance right… They gave me anti-sickness (medications), so I didn't physically get sick, but I felt it." (P04, Female, Age 43, Interview)

Almost half of the sample reported weight changes; some participants lost weight, and others gained it due to lymphoma or its treatment (i.e., steroids). For some, dietitian intervention was required to assist with balancing weight issues. One participant highlighted the sensitivity needed when discussing weight change during cancer, as it can be problematic for younger individuals or those sensitive about their weight. A loss of strength and impaired healing, as a result of chemotherapy were also outlined by participants. Night sweats were debilitating for older male participants due to perfuse sweating, which disturbed sleep.

"There was actually one other thing that I think is important for young people… Weight is mentioned a lot. There were times when I would get weighed, and they would be like Oh my god, you have gained a lot of weight!… I feel like they could be a bit more sensitive." (P2, Female, Age 24, Interview)

"I would saturate the bed sheets with sweat at night." (P13, Male, Age 80, Interview)

While many side effects voiced by participants resolved after treatment, some were left with lasting effects long after the end of treatment and into survivorship. The impaired immune defence was noted as the common cold became routinely problematic for some survivors, and this perceived weakness to susceptible infections persisted long after treatment. Half of the interview participants shared concerns related to sexuality or reproductive health concerns. Men reported impaired testosterone levels and a desire to regain pre-chemotherapy baselines.

P5: "I am on my second round of testosterone. The chemo destroyed … my testosterone levels. It attacks everything. I am close to building it up… Many men would say, 'Ah, sure, this is just how it is'. I want to get back to the way I was. I will never get fully, but I will try to get as close as I can." (P05, Male, Age 45, Interview)

Female participants expressed their challenges finding appropriate support and information regarding their reproductive concerns, like fertility and family planning. The area of reproductive health was seen as quite specialised and outside the realm of cancer care professionals, posing risks to unmet information needs for survivors. Treatment side effects can extend beyond physical health and affect survivors' plans to start or expand their families. Perspectives of people with and without children (including survey data responses) are represented and share the emotional toll of experiencing premature menopause, closing opportunities for creating or building families.

"So now I am in ovarian failure. You know, so obviously kids and all that, I feel there is no one to link in with properly about that sort of thing now. Because I feel like your cancer care nurses, they wouldn't know much about that area." (P01, Female, Age 24, Interview)

"I am in perimenopause at the moment. So, it brought on the menopause, so emotionally, it has been hard to deal with the fact that my family was finished. I thought we would have more." (P04, Female, Age 43, Interview)

Time constraints associated with lymphoma treatment, particularly for aggressive forms of the disease, further compound the reproductive health challenges for both men and women. Limited time for fertility preservation measures, such as egg freezing or sperm banking, can leave survivors with few options. One participant voiced not having enough time to undergo egg freezing, while another expressed relief in already harvesting eggs before treatment.

> *"I only had one week to treatment; I didn't have a chance to get egg freezing done." (P02, Female, Age 24, Interview)*

> *"So, and it is nice to know I have them [harvested eggs] there." (P01, Female, Age 24, Interview)*

The egg-freezing process was challenging, requiring careful preparation, including hormone treatment and injections, which can have their own physical and emotional toll. Egg harvests yielding fewer eggs than expected caused disappointment, especially given the time and effort invested in the preparation. In addition, survivors may face financial difficulties in addressing their reproductive needs. A significant financial burden for those not qualifying for financial assistance with egg harvesting was voiced by one survivor as the cost of egg harvesting is significant (e.g., several thousand euros per harvest). This exacerbates the challenges lymphoma survivors face and underscores the need for more accessible and affordable options for fertility preservation.

> *"Getting eggs frozen takes so long. I started on one cycle of it, and it didn't work. That included two months of preparation and injections, everything. I think I got one egg, which is poor. Even they were like, this was bad." (P02, Female, Age 24, Interview)*

> *"The hormone treatment was quite tough. I suppose it made you go a bit funny feeling, then with everything else going on it was hard." (P01, Female, Age 24, Interview)*

Survival became the primary concern for persons with lymphoma during the initial diagnosis and treatment phase. Decision-making regarding fertility preservation may take a backseat as individuals focus on fighting for their lives. This underscores the importance of timely discussions and comprehensive support to help individuals make informed decisions about their reproductive health before treatment begins.

> *"I remember they asked me if I wanted to freeze my eggs. I had just had a baby, and I was thinking I am just going to fight for my life. I remember my husband asking are you sure? Later, whatever happens, you know, but I was lucky I had no problems conceiving." (P07, Female, Age 31, Interview)*

The physical concerns of lymphoma survivors included a wide range of issues caused by lymphoma and its treatment. Unmet physical needs can be divided into acute side effects of treatments and issues that do not resolve long after treatment has ended. Common acute concerns, cancer-related fatigue and cognitive decline negatively impacted daily living, such as sleep and capacity for social interactions, resulting in unmet practical and social needs for some participants. The challenges of reproductive concerns contributed to the unmet emotional needs of lymphoma survivors, a group crossing the age spectrum of childbearing potential. Collectively, the treatment, management, and follow-up care for the physical health needs of this group requires complex care coordination.

Subtheme 2.3: Being Immunocompromised and COVID

> *"During COVID, you could see how difficult it was for staff to organise areas to keep people safe. There was no space." (P13, Male, Age 80, Interview)*

Being immunocompromised posed barriers to the complex navigation of a lymphoma diagnosis. The COVID pandemic imposed further restrictions and threats for lymphoma survivors, a group at high risk for susceptible infections due to compromised immune systems. The limited space available made it challenging to maintain appropriate physical distancing and safety measures, further exacerbating the already constrained physical environment of hospitals and creating additional hurdles for patients and healthcare providers. Pandemic measures restricted survivors, as no visitors for inpatients and no accompanying persons were allowed at outpatient appointments. This contributed to unmet psycho-social needs as necessary protective measures (i.e., closed curtains and restricted interactions) resulted in increased feelings of isolation and loneliness. Protective measures resulted in limited physical contact with family members and loved ones and restricted interactions with healthcare professionals and staff.

> *"It was during COVID, so you had no one else with you." (P11, Female, Age 71, Interview)*

> *"…with COVID, I was in there on my own. I thought that was probably the hardest part… your curtains were closed, and everyone was in their own space. It was really isolating." (P01, Female, Age 24, Interview)*

Not being allowed to physically see family was particularly challenging for survivors. Participants had to adapt to new changes as the pandemic unfolded in Ireland. Participants experienced a heightened period of restricted social interactions while concurrently navigating their lymphoma journey. The pandemic disrupted normal routines accustomed by participants at their routine cancer care appointments, like having a support person present. Unmet psycho-social needs were particularly experienced after milestone events such as a diagnosis or major interventions like surgery. This was challenging for participants at different stages (i.e., active treatment, post-treatment and follow-up survivorship).

> *"There was no getting in to see me. Yeah, covid was a thing, but you know you're allowed to see your mam and dad or my brother. A lot happened between the time I got to see them, ten-hour surgery; you've got the diagnosis, you've no idea what is about to happen." (P03, Male, Age 24, Interview)*

The physical environment in hospital outpatient departments can be crowded and busy. Participants spoke about how too few chairs often existed, making for a prolonged and unpleasant wait for necessary and scheduled appointments. This problem was exacerbated by the pandemic but existed before it as some participants noted the changes during this period, most prominently in restrictions to non-patients (i.e., family or support persons accompanying survivors). A shared upset for family contact was desired by inpatients who couldn't have family visits and outpatients who couldn't bring family to appointments. Having support persons present was expressed as a need for survivors when receiving news about their cancer. Facilities to accommodate survivors' accompanying support persons at appointments were left desired, with access to a small comfort area or tearoom suggested by one participant.

"I was lucky; when COVID started, I only had three sessions left, but it was hard because my wife always came with me. I always had someone to talk to. It changed to you can't have anyone there; that was the hardest part. More room should be made to accommodate people who come with you… Even to have a separate area for visitors, they are there for hours. They are not just coming in. A small tearoom area, things like that." (P05, Male, Age 45, Interview)

"There isn't much room to bring someone with you, but that is what you need when you get this sort of news about cancer; you need someone with you. They have to stand beside you and wait it out. You can wait a long time to be seen." (P12, Female, Age 80, Interview)

This subtheme reflects another barrier to care coordination for this group. Participants at various stages of their journey faced challenges due to being immunocompromised. These challenges were exacerbated by the pandemic, resulting in unmet needs relating particularly to psycho-social well-being. Physical restrictions to social interactions with family or support persons challenged the psychological well-being of survivors, as loneliness and isolation were experienced. The physical environment of hospitals (including pre-pandemic) hindered the unmet psychosocial needs of survivors due to overcrowding and lack of facilities for survivors and their support persons.

This second theme shows lymphoma cancer care requires a connecting link for care coordination as the individual with lymphoma is often left to mediate between different care providers in other settings. Reproductive health concerns, cancer-related fatigue and cognitive decline were common physical concerns for lymphoma survivors and ones they sought help with (i.e., sufficient information and communication). The treatment, management, and follow-up care of physical health needs of lymphoma survivors required complex care coordination. This complexity was exacerbated by the challenges of immunocompromised survivors, as evidenced by the pandemic. Participant accounts voiced unmet psychosocial needs due to restrictive infection control procedures necessary for their protection. However, the physical environment of hospitals was a barrier to meeting survivors' psycho-social needs.

7.2.3 Theme Three: The Cost of Cancer

Participants voiced several issues that collectively portray the cost of cancer, which involved more than just financial implications. The first subtheme deals with life responsibilities (i.e., finances, work, and travel concerns) that had a costly impact on survivors' well-being. Next, the survivorship phase is unpacked as participant accounts provide insights into how they coped and navigated this period. Finally, psycho-social issues reveal what was important to lymphoma survivors and the barriers to addressing their needs.

Subtheme 3.1: Coping with Responsibilities and Cancer

Many participants conveyed financial considerations arising from prolonged engagement with treatment, but the life stage of the participants shaped the impact and associated worry. For younger participants, delays in achieving financial milestones were a dominant concern, like securing a mortgage or career progression. In comparing themselves to their peers not going through cancer, they felt like they had some catching up to do. For others, finance was not as dominant a worry, but this was attributed to the financial

security associated with being at the end of a career or within retirement. Therefore, younger persons with lymphoma are at particular risk for financial toxicity and unmet financial needs.

> *"I would have worked for a year already; I would have had this much saved. I will never be able, you know, if I wanted to buy a house, I am a year behind." (P03, Male, Age 24, Interview)*

> *"I had money and no interest in it, which is dangerous. I had worked for forty years, so I was all right financially. I didn't think about money because it wasn't a problem once, but that could be different. You need money to do things." (P09, Male, Age 58, Interview)*

The cumulative impact of costs associated with attending hospitals and treatment were reported by participants, such as wigs, car parking and toll charges. The expense of cancer came as a surprise to survivors. Managing and planning money was never seen as a simple task, yet it became significantly more challenging with cancer and when feeling unwell. Some participants felt the burden of financial toxicity, with one participant voicing that cancer felt like something she 'chose'.

> *"Financial worries were a thing for me. Bad timing was the main cause of this, but when you are sick and not feeling well, planning your money becomes a lot harder." (P14, Male, Age 63, Interview)*

> *"Yeah, the other thing there was a financial challenge. That was a huge thing, a huge challenge. I didn't realise how expensive cancer could be. You are made to feel like it is something you 'chose', you know… Even trying to get a wig was, like, a half-decent wig was over a thousand euros because I wanted to try and look normal." (P04, Female, Age 43, Interview)*

Returning to work for participants was seen as a significant milestone in the recovery process, heralding a return to a sense of normalcy and routine. Building strength back up was a key focus for survivors trying to get back into the workforce. Participants anticipated a return to work and voiced concerns about potential health risks from working in the workplace or considered whether they could return to their previous line of work.

> *"What is the risk if I start back working? Am I increasing my risk a huge amount? But I couldn't find a huge amount of information on it either." (P01, Female, Age 24, Interview)*

Some survivors required an extended period off work to recover from lymphoma and its treatment. A significant gap in employment history can impact career progression and financial stability. Participant accounts from middle-aged survivors showed a shift in perspectives and a new vulnerability due to being out of work. Building on the findings presented in theme two, follow-up appointments kept survivors busy, with one participant requiring frequent annual leave from work to attend them.

> *"Being out of work was hard. It changes your whole aspect of life; you look at life differently. You could get very vulnerable." (P09, Male, Age 58, Interview)*

> *"I think I feel quite busy. I have all these follow-up appointments, and I have to take annual leave off work for them. That is so much of your annual leave gone, like five or six of them, that is so much." (P02, Female, Age 24, Interview)*

The cost of cancer extended past financial concerns as the interview participants identified travel distance to healthcare facilities and treatment as a significant burden. Many of them expressed that the burden of travel fell on themselves, their support persons, and family members. The dependency on others for transportation highlights the logistical challenges patients face when accessing cancer care. The

participants who personally experienced the impact of travel distance acknowledged the importance of having a support system. For others, the toll of travel contributed to a dependency on health services and a life which revolved around cancer care appointments.

> *"I had a brother-in-law who would bring me up to the [cancer centre] in the city. That was for scans and stuff, and it was in my car. If he couldn't do it, my son would do it. Good family support. Plenty there." (P08, Female, Age 73, Interview)*

> *The inconvenience of the dependency on hospital visits. Life is dependent on appointments. (P21, Male, Age 81, Survey Data)*

Some participants were not personally impacted by travel distance to treatment or cancer care appointments. Still, empathy for others who had to travel was evident in recognition of the inequities in access to cancer care based on geographical location. Individuals living in rural areas may experience difficulties accessing timely and convenient care due to the long distances they must travel and restricted transportation options. Therefore, the cost of travel can mean more than just financial implications as it impacts the time and resources available to survivors and can lead to an array of unmet needs.

> *"I think if I lived somewhere rural, how would I do it? I am lucky my husband has a van. I had a car for myself if I ever needed it, and I had my mom with the baby, so I was free, if I felt well enough, to go whenever needed." (P01, Female, Age 24, Interview)*

> *"I got the best. But I will say this, I was near hand, I was lucky. I was sad for other people who had to come from far places." (P09, Male, Age 58, Interview)*

Several participants experienced the financial implications of lymphoma as they described the expense associated with cancer. This was heightened for younger survivors as they aimed to achieve financial success in their careers or get on to the property ladder like their peers; however, these goals were postponed due to cancer. Anticipation of a return to work heralded a return to normalcy. Yet, uncertainty underpinned it as new cancer-related health concerns became a worry; they sought reassurance. Moreover, whether or not travel was a problematic factor, the inconvenience of hospital visits and the dependency on appointments and healthcare services was widely felt by survivors.

Subtheme 3.2: Navigating the Survivorship Phase

The cost of cancer was also noted during survivorship for participants. Once the physical threat of cancer subsided, survivors attended to various psychological problems. The following participant accounts present a shift in their focus during survivorship. From one year after diagnosis, most participants experienced a decrease in the physical threat of lymphoma, yet issues that brought emotional or psychological needs to the forefront remained. The psychological impact of lymphoma was far-reaching as survivors experienced new uncertainties and a change in priorities as they progressed past diagnosis and treatment to living with and beyond lymphoma. Survivors had to process how cancer impacted them to deal with or meet their unmet emotional and psychological needs. This was highlighted by the definition of lymphoma as an 'event', one which was disruptive to the lives of participants across ages.

"There are a lot of mental issues to deal with; it is not just the physical, the physical has gone. It is how cancer impacted you." (P04, Female, Age 43, Interview)

"It is a life upset; it is an event that disrupts living" (P14, Male, Age 63, Interview)

Participant accounts showed the lingering fear and anxiety associated with the possibility of cancer returning. A desire for normality was driven by a need to regain control and stability in this uncertainty, yet this was difficult to attain when participants experienced a fear of recurrence. The fear of needing additional treatment was a constant worry for some survivors, leading to heightened anxiety and unease. Moving on was not a simple matter for some participants as they feared setting themselves up for upset; putting things off became a coping mechanism for others.

"I was afraid to move on from anything. Even I remember that I was not even going back to college because I thought, oh, I will have to drop out again. That would be so much more devastating than not starting." (P02, Female, Age 24, Interview)

"We thought, what was the point? It could just come back. Now, at year five, it is starting to dissipate. I would put everything off for the first few years instead of getting on with my life, but it is not that cut and dry." (P04, Female, Age 43, Interview)

The survivorship period brought new cancer care routines for participants regarding follow-up appointments, surveillance, or intermittent therapies (i.e., transfusions or maintenance treatment in response to blood works or scan results). Therefore, waiting for follow-up appointments was a cause of concern for survivors. The frequency of follow-up appointments varied from case to case; participant accounts voiced fear while awaiting their appointments. Potentially worrying signs and symptoms of disease or recurrence were a particular cause for concern (i.e., new onset of itchiness). Rapid access to healthcare became a primary need for participants with reason to suspect or fear cancer recurrence.

"Let's say, my leg was very itchy, I have a rash, and you fear is there a lump is it coming back, but I wouldn't have access until February." (P11, Female, Age 71, Interview)

Ongoing surveillance and follow-up care were necessary to address the fear of recurrence. Expert medical opinion and investigation (i.e., scans) were immediately required, so a return to dependency on healthcare professionals and services in the survivorship period was evident from participant accounts. A proactive approach from healthcare professionals in responding to potential symptoms of recurrence was clear from participant accounts; timely medical evaluations helped manage survivors' anxiety, providing reassurance and reducing unmet psychological or emotional needs. Participants voiced fear, which stemmed from concerns about going through the physical and emotional challenges of treatment again and the potential impact on their plans, relationships, and overall well-being.

"I had one or two scares after; sometimes you are afraid it is coming back. I had one or two scares, and they would immediately arrange PET scans and act on everything very quickly." (P05, Male, Age 45, Interview)

Participants experiencing fear of recurrence were driven by an urgency to obtain information to answer or find solutions to participants' concerns. Hopeful to relieve their worries, a few female participants were drawn to the internet, highlighting unmet information needs can result from a fear of recurrence.

Participants reported their awareness of the limitations of using online sources for this reason but felt compelled to investigate their concerns.

> *"My neck got very itchy, and you're just looking on the internet; I am. I know I shouldn't, but I am looking on the internet to see if the symptoms of cancer are coming back or different forms of lymphoma." (P11, Female, Age 71, Interview)*

> *"What is normal, and what is not normal, you know? Because you can go to Doctor Google and drive yourself mad." (P04, Female, Age 43, Interview)*

Participants' accounts showed a recurrent sense of waiting, extending past the initial diagnosis phase outlined in theme one into more routine cancer services. There was a sense that one must adapt to the system of waiting within their natural routines, such as routine bloodwork used to inform clinical decision-making at follow-up appointments. The prolonged waiting dragged out events (i.e., treatment administration) that participants wished to get over with quickly.

> *"I remember waiting for the doctor and waiting for the test to happen. I felt like I was waiting, and there was probably no need to be there." (P07, Female, Age 31, Interview)*

> *"It was always like you need to get your bloods. You need to wait for that, then there is two hours wait before the chemo is ready... You'd be waiting afterwards. It felt like a long, drawn-out process. When you want to get it over with." (P01, Female, Age 24, Interview)*

Participant accounts showed a sense of loss and disconnection from the person they were before lymphoma. Isolation, loneliness, and a loss of identity summed up this disconnection and were contributing factors to unmet emotional needs. Identity, or the sense of being an individual, was disrupted by a lymphoma diagnosis and the demands it entailed from treatment, time for recovery or lasting effects. Participants elaborated on their experiences of losing their sense of self, discussing how the consequences of cancer placed limitations on their capacity to engage in work, social activities, and physical pursuits. Cancer often brings about a wide range of emotions; one participant felt he lost the permission or the ability to experience positive emotions, such as laughter. The constant focus on one's illness and challenges can overshadow the ability to find joy and engage in activities that once brought them joy. This sense of deprivation and the perceived loss of permission to experience positive emotions can pose further unmet emotional needs.

> *"Sometimes, I guess it feels like you are the only one." (P02, Female, Age 24, Interview)*

> *"My whole identity is gone... No one told me I was still allowed to laugh" (P03, Male, Age 24, Interview)*

As the number of lymphoma survivors continues to increase, survivorship issues are becoming increasingly important. Participants provided insights into what was important during this period, adding to the care coordination findings in theme two. A shift from physical concerns emphasised a focus on caring for the mind. The survivorship period involved unmet emotional and psychological needs, which participants were eager to address; the fear or signs of cancer recurrence was a significant challenge to this.

Subtheme 3.3: Psycho-social Support

Participants voiced how their family support helped them to cope with cancer. Some participants highlighted the importance of having family support; others acknowledged that not everyone has access to such support systems and that coping would be more difficult without family support. Participant accounts showed that family support positively influenced participant's psychological well-being, providing emotional comfort, practical help, and a sense of security.

> *"That is one thing, you would need excellent support." (P09, Male, Age 58, Interview)*

> *"Not everyone has family support as I did. There are other burdens other than health and COVID." (P07, Female, Age 31, Interview)*

Lymphoma placed an emotional burden on the family and friends of survivors as participant accounts showed concern about causing further distress to their loved ones. They wanted to protect their families from experiencing additional emotional distress. Sometimes, this involved withholding their feelings and avoiding discussing their cancer experience with family members, highlighting the interplay between survivors' unmet social, psychological, and emotional needs. The following quotes illustrate the impact of cancer on the individual with lymphoma and the family.

> *"Protecting my loved ones from worry is important, so I worry alone." (P19, Female, Age 63, Survey Data)*

> *"A lot of the time you have your family there, but they are upset that you were sick. I would be afraid to bring this up to my mam or my dad, you know, it is harder." (P02, Female, Age 24, Interview)*

Barriers to the uptake of supportive cancer services included the lack of attention to lymphoma survivors specifically and the lack of age-appropriate sensitivity experienced. A need for dedicated support groups closer to home was voiced by female participants. Many existing support groups are located in other countries, which felt far away. This highlights the need for support networks tailored to Irish lymphoma survivors. A local support network was desired as it was felt to offer survivors a sense of community, understanding, and shared experiences, allowing survivors to connect with others who have gone through the challenges of lymphoma within the same country.

> *"There are so many in America, it seems, support groups and stuff there, but I mean so far away." (P01, Female, Age 24, Interview)*

> *"There is no support group in Ireland, so I found an English lymphoma support group, and I receive regular emails from them." (P19, Female, Age 63, Survey Data)*

Psycho-social concerns impacted how participants felt about themselves and how others perceived them. Self-image was one factor affected by cancer treatment for some survivors. Several male and female interview participants and survey data quotes showed hair loss and loss of hair from the face negatively impacted their sense of self and confidence. A disconnection from their former identity before cancer was evident in the mirror.

> *"Losing my hair had a massive negative impact on me." (P22, Male, Age 73, Survey Data)*

Hair loss, particularly from the head, was a common concern expressed by participants. Hair loss was experienced differently; some survivors embraced their hair loss by using headscarves and accessories to

feel comfortable and confident. Others felt that even hair regrowth pointed to the individual's illness in social settings such as work or university. The process of regrowth and waiting for hair to return was a journey that took time, with one participant expressing excitement when their hair finally started to grow back, emphasising the significance of hair as a symbol of identity and self-image. While men also provided their accounts, an in-depth sense of the challenges posed by hair loss was particularly articulated by younger women. The impact of hair loss challenged participant's emotional and psycho-social well-being and contributed to unmet needs in these areas.

> *"So, my with actual hair, I didn't even mind because you know you had nice head scarves and everything." (P01, Female, Age 24, Interview)*

> *"When you have to go back to work, or college and your hair is short, and you know everyone thinks – oh, she was sick" (P02, Female, Age 24, Interview)*

Participants expressed difficulties coping with the loss of eyebrows and eyelashes, as it altered their facial expression and affected their overall appearance. The absence of these facial features made them appear tired and sick, requiring more time and effort to apply makeup or recreate their former appearance. This process added challenges and highlighted the need to adjust daily routines and self-care practices.

> *"The eyebrows and eyelashes were the worst part because it just made you look so tired and sick. Doing your make-up without any eyebrow hair, I had a tiny little shadow, and that was it. It was hard; you just felt like you had to add more time to everything. I'd say that was definitely the worst part." (P01, Female, Age 24, Interview)*

Participants voiced the visual changes in their exterior, including physical changes like scars, as challenging. Like the findings from theme two related to weight gain and loss these changes had a psychological impact, making survivors feel like they no longer recognised themselves. This adjustment involved accepting the physical changes and reconciling the emotional and psychological aspects associated with them. The following participant quotes highlight the unwanted and undesirable nature of the effects of cancer and its treatment, impacting how individuals feel about themselves.

> *"Even the mental side of things, my body doesn't look the same. I have a big scar on my head, my head feels different." (P03, Male, Age 24, Interview)*

> *"Hate how I look, lost so much weight, nothing fits me. I don't want to go out to mix with people. My hair got thin; I just hate myself." (P25, Female, Age 74, Survey Data)*

Psycho-social needs were evident from the account of one survivor from the travelling community in Ireland who shared insights on the lack of understanding about cancer for this minority group. The participant's account highlights that minority groups may face further unmet psychosocial needs if there is a limited understanding of cancer in their community. This participant had high unmet psychological needs and reported the community's difficulty understanding how poor mental health was linked to cancer.

> *"Yes, they wouldn't understand that. They can't understand. They see one person getting cured of cancer one time. They are convinced that it works if you get it at the right time. And you are trying to tell them that is not*

how it works… To explain that to the traveller people, that there is nothing you can do about it, they couldn't understand it." (P09, Male, Age 58, Interview)

Therefore, the complexity and psychological-expense of meeting psycho-social needs was evident from participant accounts. This subtheme reported that family support was critical to helping participants cope with lymphoma, but survivors wished to shield their loved ones from further distress due to this life upset. Participant's sense of self was impacted by changes in their appearance which altered their self-perception of themselves and led to concern about how others perceived them (i.e., hair loss highlighting cancer). Additionally, individuals from minority groups may experience further psycho-social problems.

This theme, the cost of cancer, identified several unmet needs. Financial, practical, emotional, and psycho-social issues were voiced by participants with interplay evident between the needs (i.e. financial and psychological). The first subtheme highlighted unmet financial, work, and practical needs as participants voiced their experiences coping with life responsibilities inevitably touched by cancer. The financial toxicity associated with cancer negatively impacted survivors, especially younger adults, without the financial security attained at the end of their careers or retirement. The toll of travelling to cancer care was problematic, inconvenient, and time-intensive for survivors, especially those further from facilities. Unmet psychological needs were prominent concerns for survivors during survivorship. The fear of recurrence was a barrier to addressing needs, making participants afraid to move on. Like the waiting for initial diagnosis in theme one, some survivors also awaited follow-up appointments during the survivorship phase, seeking reassurance. Some participants were burdened by their external appearance due to cancer; this negatively impacted how they felt inside and how they thought others perceived them. Therefore, the impact of cancer extends past the individual with lymphoma to their family.

7.3 Conclusion

The primary aim of this second qualitative phase was to provide an understanding of lymphoma survivors' unmet needs. The secondary interest was to understand the quality of life outcomes and symptom experiences voiced by interview participants. Through semi-structured interviews with lymphoma survivors, a more nuanced understanding of their experiences was uncovered, focusing on the meaning of their experiences. The findings of this phase provide insights into the challenges lymphoma survivors face and highlight areas where healthcare services and support services can be developed to meet their unmet needs and enhance their quality of life.

Lymphoma survivors experienced several unmet needs one to five years post-diagnosis. Delays addressing physical needs impacted the emotional and psychological well-being of individuals with lymphoma. So, ongoing, or unaddressed unmet physical needs contributed to unmet emotional and psychological needs. This is due to the uncertainty experienced by survivors in seeking support to address their health concerns related to late effects and symptoms of potential recurrence. After addressing physical health concerns, psychological and emotional needs were dominant problems and extended into the survivorship phase for survivors up to five years post-diagnosis. Physical problems such as symptoms of lymphoma or its treatment

also contributed to unmet practical needs as survivors' capacity for daily tasks or social interactions was diminished (e.g., cancer-related fatigue and sleep deprivation). Older survivors experienced heightened concerns about their physical needs and whether they were experiencing the ageing process versus cancer.

Unmet practical and information needs were experienced from disjointed cancer care coordination; a missing link was evidenced by individuals with lymphoma who had to lead the communication regarding their cancer between different care settings. Participants wanted to be well-informed about their lymphoma; healthcare professionals' appropriate communication was critical to avoiding oversimplifying lymphoma and better-managing expectations. Cancer can be expensive, unwanted costs associated with cancer contributed to financial worries, and life responsibilities (e.g., travel) negatively impact survivors' well-being due to pending financial and practical concerns. Younger survivors were susceptible to unmet psycho-social, emotional, and financial needs as they articulated the unwanted focus lymphoma posed on their lives, impacting their sense of self. Barriers to social interactions like infection control measures are not restricted to the COVID virus, as people living with and after lymphoma are a potentially immunocompromised group, which posed further problems for psycho-social needs. Family support was critical for survivors, yet survivors did not want to burden family members. Addressing unmet psycho-social needs may involve helping survivors facilitate or work with the changing landscape of their needs through supportive care and family support. A limited awareness surrounding lymphoma can be attributed to many of the unmet needs experienced by survivors, as improved awareness would improve the information, communication, resources and support available to address the various unmet needs identified from participant accounts. The experiences of lymphoma survivors were guided by life stage rather than subtype (NHL or HL) or gender.

Therefore, this qualitative investigation has identified the unmet needs of lymphoma survivors and their impact on their well-being. This study provides insights into the challenges lymphoma survivors encounter and highlights the areas where healthcare services, policymakers and support services can focus their attention on for this group. Enhanced awareness of lymphoma as a type of cancer is needed to improve the advancements of available support and services for this group.

Chapter 8 Discussion

8.1 Introduction

This chapter presents the discussion for this thesis and draws on inferences formed from the quantitative results (Chapter 6) and qualitative findings (Chapter 7). Initially, this chapter outlines how the objectives and overarching aim of this research were addressed. The integrated findings of this mixed methods study provide insights into the development of lymphoma survivorship services, the assistance required to help lymphoma survivors live a normal life and the factors to consider in keeping pace with the evolving landscape of lymphoma survivorship. The integrated discussion is supplemented with a summary of key findings and recommendations. The overall strengths and limitations of this research are presented. Finally, recommendations for policy, lymphoma survivors, future research and practice are provided.

8.1.1 Overview of Key Findings

This section highlights the key findings of this mixed methods study. The objectives of this research are addressed as the unmet needs of lymphoma survivors are identified, including their influencing factors and the impact on quality of life outcomes and symptom experiences. The survey's key findings are outlined with a description of how the interviews built upon and/or facilitated a more novel and in-depth understanding of the unmet needs of lymphoma survivors.

The phase one survey findings identified significant unmet needs among lymphoma survivors, with over seventy per cent reporting feeling tired as a primary concern, followed by reports of coping with memory issues, stress, and depression. Quality of life outcomes echoed these findings, with fatigue, concentration issues, and fears about a worsening condition being prevalent. Emotional difficulties, sleep troubles, infection worries, and challenges in planning for the future, with anxiety and depression affecting over half of the participants. Pain, discomfort, and activity limitations impacted over forty per cent of survivors. The phase two interview study affirmed these concerns and added contextual understanding as to how cancer-related fatigue affected survivors' daily tasks and social interactions. Indeed, they also illuminated how delays in addressing physical needs significantly impacted emotional, psychological, and practical well-being.

Quality of life outcomes from the survey analysis showed physical, emotional, and functional well-being were inversely related to unmet needs, particularly in emotional and financial domains. Sharing feelings, body changes, financial worries, and fears of cancer spreading were common with over half of the survey participants reporting these issues. Interviews further revealed that financial worries were common due to the high costs associated with cancer, affecting younger survivors more profoundly as they dealt with the impact of lymphoma on their lives and sense of self. Younger age was statistically significantly associated with higher unmet needs across domains for survey participants. However, the interviews revealed that older survivors struggled to differentiate between ageing and cancer symptoms, heightening their concerns about physical needs. One in ten survivors, (primarily NHL, male, or urban residents), reported no unmet needs on the phase one survey.

Higher social well-being was statistically correlated with lower unmet emotional needs. Interviews gave insight into barriers to social interactions, especially for immunocompromised individuals, further complicated psycho-social needs. The participant accounts illustrated the complexity of unmet psycho-social needs. Notably family support was critical to coping, but survivors were hesitant to burden their loved ones. Participants emphasised the importance of being well-informed about their lymphoma, with appropriate communication from healthcare professionals being crucial to managing expectations. Interviews provided a novel understanding of unmet practical and informational needs which stemmed from disjointed cancer care coordination, forcing survivors to manage communication about their care between different care settings. Furthermore, limited awareness of lymphoma contributed to unmet needs, highlighting the need for improved information provision, resources, and support.

Survey findings established the factors influencing higher unmet needs for lymphoma survivors. Female survivors reported higher unmet needs, particularly regarding reduced post-treatment support, societal expectations of normalcy, and cognitive difficulties. Younger age, lack of private health insurance, and recent diagnosis were linked to higher unmet needs while being retired or a homemaker was associated with lower unmet needs. Consistent associations emerged in univariate and multivariate analyses, highlighting that being female, younger, uninsured, or recently diagnosed were significant predictors of higher unmet needs. However, the interview findings explained that lymphoma survivors' experiences were influenced by life stage (i.e., younger age and less life experience) than gender or lymphoma subtype. Finally, canonical correlational analysis of survey data confirmed that enhancing lymphoma survivors' quality of life significantly reduces their unmet needs; interview accounts echoed this interconnection between unmet needs and quality of life as unmet needs were voiced with impaired quality of life.

8.2 Developing Lymphoma Survivor Services

8.2.1 Survivorship Stage – A Fundamental Factor

In determining the responsiveness of survivorship services to the needs of lymphoma survivors, the stage of survivorship is a fundamental consideration. The rapid review of international literature (Chapter 2) conducted for this study spotlights the scarcity of literature investigating the short-term phase of survivorship for lymphoma survivors (Boland et al., 2022), as the mean time since diagnosis ranged from 6.3 years to 12.8 years for the included studies (Arden-Close et al., 2011; Beaven et al., 2016; Chen et al., 2012; Georges et al., 2020; Greaves et al., 2014; Hernæs et al., 2021; Kang et al., 2018; Kim et al., 2014; Kim et al., 2017; Lekdamrongkul et al., 2021; Lobb et al., 2009; Ng et al., 2016; Zucchetti et al., 2017). The wide inclusion criteria used by these studies for longer survivorship encompasses a larger potential sample size than the period of one to five years post-diagnosis used in this current study. Participants ranged from one to five years post-diagnosis and represented the experiences of navigating the short-term period following a lymphoma diagnosis and its treatment through to survivorship. Over half of the participants were one to two years post-diagnosis; this initial period after diagnosis reflects a time in which lymphoma survivors are highly dependent on healthcare services, which may have increased the availability of this group during study recruitment.

Given the growing numbers of lymphoma survivors, the survivorship stage is an important aspect to consider as it dictates, to a large extent, how an individual experiences their cancer (i.e., active treatment experience versus post-treatment experience). This study presents insights into the short-term period of lymphoma survivors, a period associated with a transition from treatment completion to maintenance treatment or monitoring for cancer recurrence, balanced with an attempt to return to 'normal' living (Institute of Medicine, 2006; Miller et al., 2008; Mullan, 1985; Stanton, 2012). The period of one to five years post-diagnosis is important for active surveillance but also the observation of unmet needs and planning of survivorship care; this transition period from active treatment to post-treatment is key to maintaining health and well-being among cancer survivors (Hackett & Dowling, 2019; Institute of Medicine, 2006). Lymphoma survivors one to three years post-diagnosis experienced higher unmet needs and lower quality of life, suggesting this is a particularly difficult time to adjust to a 'new normal' or way of living and to achieve optimal quality of life. This research highlights the importance of enhanced survivorship care and support for lymphoma survivors in this period. Therefore, the time after treatment completion is a critical factor for interventions to support this cohort.

Findings from this study show a negative association between a more recent diagnosis of lymphoma and quality of life. The findings from the canonical correlation analysis show a reduction in unmet needs can improve quality of life among lymphoma survivors; this is consistent with other studies (Kim et al., 2017; Lekdamrongkul et al., 2021). The reprioritisation and rethinking of survivorship cancer care planning is required to address unmet needs and overcome the challenges in delivering optimal supportive care (Molassiotis et al., 2017). A cross-sectional study of NHL survivors in Thailand suggested ongoing survivorship care beyond ten years post-diagnosis is required to improve the quality of life among NHL survivors (Lekdamrongkul et al., 2021).

In the Irish context, doctors provide follow-up care for lymphoma survivors, which is often focused on physical assessments and surveillance of cancer recurrence. Nurse-led clinics specialising in cancer survivorship, encompassing survivors' physical and psychosocial needs, have emerged in a minority of Irish hospitals over the past number of years. Given the success of treatment and extended survivorship for lymphoma, many of these clinics now include lymphoma survivors. Despite limited national guidance, clinical nurse specialists and advanced nurse practitioners lead in developing these services to benefit patient outcomes. Wider literature has shown nurse-led care to be effective and beneficial to patient outcomes (Chan et al., 2023; Monterosso et al., 2019; Taylor et al., 2019). Nationally, an evaluation of advanced nurse practitioners (ANPs) demonstrated many benefits including reduced hospital admissions, reduced specialist waiting lists and reduced patient waiting time in emergency care areas with ANPs (Department of Health, 2020). Therefore, a recent expert review of nursing nationally recommended policy to progress a revised target of 3% of the nursing (and midwifery) workforce practising in advanced practice (Department of Health, 2022).

The findings of this mixed methods study support the recent introduction of individual haemato-oncology patient pathways in 2023 in line with Recommendation 24 of the National Cancer Strategy 2017-2026 (National Cancer Control Programme, 2023a, 2023b). These pathways include clear follow-up timelines for

specific subtypes (currently available for leukaemia subtypes and acute lymphoblastic lymphoma). The standardisation of cancer survivorship services nationally is required to benefit a greater number of cancer survivors in Ireland. A longitudinal study assessing the needs and quality of life of survivors at different time points post-treatment should be conducted to see changes over time in the adaptation process throughout the survivorship trajectory. This would provide empirical evidence on the impact of these follow-up and survivorship clinics for lymphoma survivors to support the standardisation of survivorship services across the country. In addition, longitudinal data would be valuable in identifying the specific needs for this service to aid the development and implementation of these services for the healthcare professionals and healthcare systems involved in its progress. Further development and publications of pathways for lymphoma subtypes would be beneficial.

Key Findings
Unmet needs and quality of life outcomes relating to lymphoma survivorship were identified (Objectives 1 and 2). A more recent diagnosis was identified as a factor for higher unmet needs and lower quality of life (Objective 4). The development of policy and services to address the unmet needs of lymphoma survivors in Ireland is provided (Objective 5).
Recommendation 1.1
Investigate the changes over time for post-treatment lymphoma survivors receiving follow-up or survivorship care services to inform developments.

8.2.2 Addressing Difficult Diagnosis and Limited Lymphoma Awareness

The challenges voiced by participants began with the complexities of the initial diagnosis of lymphoma but were negatively underpinned by a lack of awareness of lymphoma as a cancer. Prompt diagnosis and treatment are critical to cancer survival and improving quality of life outcomes (Skrabek et al., 2015). However, the heterogeneity and variation noted from participant accounts reflect previous evidence which points to disease onset with a wide range of presenting symptoms, which can be inadvertently interpreted as not serious or cancer-related (Howell et al., 2020; Howell et al., 2008; Howell et al., 2006; Skrabek et al., 2015). Lymphoma crosses the lifespan, this is of particular importance as qualitative accounts from younger survivors spotlighted shared experiences of being dismissed as *'young, fit and healthy'*, which contributed to prolonged time to diagnosis, worse outcomes, and more significant unmet needs during their cancer journey. Integral to the immune system, lymphomas are essentially tumours of lymphocytes; they can mimic infection and inflammation. Therefore, the planning of treatment for each case relies on accurate diagnosis and staging with input from trained haematopathologists making the initial assessments vital in the management of this disease (Iyengar, 2020). The persistent problem of difficult diagnosis for lymphoma survivors requires urgent solutions; investment and resources in specialists, diagnostic equipment, and a collaborative and integrated way to guide the delivery of this care is warranted.

The accurate detection and precise assessment of therapeutic responses is critical to the optimal management of patients with lymphoma (Cunningham et al., 2017). Consistency and accuracy of diagnosis are fundamental to improving outcomes in haematological cancers, yet there are significant challenges

around implementation (Ireland, 2011; National Institute for Clinical Excellence, 2003; National Institute for Health and Care Excellence, 2016). A challenging recommendation from the National Institute for Clinical Excellence (2003) was the requirement to develop integrated laboratory services for accurate diagnosis of haematological malignancies and its implementation. This continues to be important given the significant human and financial cost of potential diagnostic errors (Ireland, 2011). In the UK's National Health Service, Specialist Integrated Haematological Malignancy Diagnostic Services (SIHMDS) were introduced as a standard of care to reduce diagnostic error and improve clinical outcomes (Dalley et al., 2015; Howell et al., 2020; National Institute for Clinical Excellence, 2003; National Institute for Health and Care Excellence, 2016; Snowden et al., 2016). The aim of the SIHMDS is to offer high-quality, reliable, and affordable services which can provide a comprehensive assessment of patients with diagnosed or suspected haematological malignancies. The service incorporates all the pathology specialisms associated with haematological malignancy diagnosis (morphology, histology etc) in a unified process that covers all investigational pathways with a central reception and single integrated report.

While the service delivery of SIHMDS models has been successfully implemented in the UK, its implementation has been varied likely due to inequity of access, standardisation, and quality in haemato-oncology diagnostics (Cartwright et al., 2022). However, building on the findings from this mixed-method study, this model is of notable interest to inform future national interventions. The original and revised NICE recommendations did not specify the configuration of SIHMDS services in the UK and so, two broad models of service delivery were established, 'co-located' services operating from a single-site, and 'networked' services, where geographically separated laboratories are linked by common management and information systems (Dalley et al., 2015; National Institute for Clinical Excellence, 2003; National Institute for Health and Care Excellence, 2016). This study's findings on variance across interdisciplinary care (i.e., primary care to cancer care services in hospitals) for lymphoma survivors provide further evidence to support the development of national haematology services from its current hub and spoke configuration to an appropriate number of cancer centres to provide comprehensive care for all patients with haematological malignancies, facilitating centralisation (Department of Health, 2017). This is timely considering the centralisation of haematological cancer services is under review in Ireland (Department of Health, 2023). Therefore, there is potential to adapt the SIHMDS model to advance haematological cancer services and practice in Ireland. However, this is not without its inherent challenges. In addition to logistical challenges in this service redesign, a recent report of current pathology services in Ireland identified substantial workforce gaps across a range of service areas and sites in haematology with concerns about filling these specialised posts and impending retirements (National Doctors Training and Planning, 2023). One solution involves additional advanced nurse practitioners to alleviate the demand for laboratory experience and ensure routine care needs are met. A review should be undertaken to assess the capacity to adapt a model to advance the consistent and accurate diagnosis of haematological malignancies to begin to address difficult lymphoma diagnosis.

Enhanced cancer awareness can improve psycho-social support for individuals with a cancer diagnosis through a greater understanding. The overall deficit of awareness around lymphoma as a cancer found by the phase two qualitative study extends past patients and healthcare professionals to the public. The

qualitative accounts from this study echo the findings from focus groups of NHL survivors in England who felt different to other cancer patients (Swash et al., 2018). Like previous studies, the participants of this current study compared the limited awareness of lymphoma to the advanced awareness of breast cancer (Parry et al., 2011; Swash et al., 2018); suggesting lymphoma has far to go to attain the same perceived benefits of other more recognised cancer types. Notably, enhanced awareness, education and support for primary care are required to advance the prompt recognition and referral for further investigations when lymphoma is suspected. However, general practitioners in Ireland experience challenges, such as limited access to fast-track systems for haematological cancers at their local hospitals with 26% experiencing unacceptable delays (O'Shea & Collins, 2016). Additionally, before diagnosis, better awareness of lymphoma can lead to enhanced help-seeking behaviours, which can lead to rapid cancer investigation and identification, directing healthcare professionals and patients towards a timelier diagnosis (Howell et al. 2020). The increased promotion of cancer awareness is needed. Therefore, this study reflects previously identified issues of difficult diagnosis and limited cancer awareness (Canadian Cancer Society, 2003; Fitch et al., 2020; Institute of Medicine, 2001), which continue to be a significant unmet need voiced by survivors. Time to diagnosis is often prolonged, despite the best efforts of patients, their support persons and healthcare professionals (Howell et al., 2020). Investments are needed to improve lymphoma diagnosis, such as an adaptation of the identified SIHMDS model to address practical needs in cancer care coordination. Promotional cancer awareness campaigns for the public can reduce psycho-social needs, while healthcare settings require enhanced awareness and education on lymphoma.

Key Findings
Unmet needs and quality of life outcomes were identified relating to the challenging journey to a lymphoma diagnosis and surrounding awareness of this cancer (Objectives 1 and 2). A need for enhanced lymphoma cancer awareness was identified (Objective 1). The factors influencing unmet needs for lymphoma diagnosis are related to system barriers and challenges (Objective 4). The development of services for lymphoma survivorship was informed through direction for policy and service planning (Objective 5).
Recommendation 1.2
A review should be undertaken to assess the capacity to adapt a model to advance the consistent and accurate diagnosis of haematological malignancies to begin to address difficult lymphoma diagnosis.
Recommendation 1.3
National cancer awareness campaigns should target i) public awareness, ii) advocate for health-seeking behaviours, and iii) guidance and support for primary healthcare professionals.

8.2.3 Factors for Better Lymphoma Care Coordination

Complex care coordination was found for lymphoma survivors which often required a multitude of multidisciplinary team members (differing specialties and fields) from diagnosis to follow-up survivorship care. Qualitative accounts found lymphoma care is often grouped under 'haematology-oncology', yet haematology and oncology are distinct subfields which present ambiguity for patients surrounding the

speciality of their care. Participants attended a haematologist or oncologist. The reasons behind this are complex and not well-defined. However, this study found varied and complex treatment programs required for lymphoma pose challenges to the delivery of these services. There are known pathological differences between haematological malignancies and solid tumours which can affect treatment, but this can also extend to organisational differences within services (National Institute for Health and Care Excellence, 2016). The distinct features of services for haematological malignancies have been identified by the National Institute for Health and Care Excellence (2016) from a range of laboratory skills to diagnostic and clinical management skills under the speciality of clinical haematology with less use of palliative services than solid tumours.

Moreover, the 'missing link' voiced by participants also reflects the lack of integration between different interdisciplinary sites providing cancer services, which imposes challenges to care coordination for both survivors and healthcare professionals. This aligns with broader cancer care literature for lymphoma and haematological cancer survivors which highlights poor continuity of care across the patient-survivor transition paved by uncertainty, with unmet informational needs requiring improved patient-centred communication (Hackett & Dowling, 2019; Herrmann et al., 2020; Parry et al., 2011; Raphael et al., 2019). Learning from this mixed methods study's findings suggests the structure of the Irish healthcare system may have contributed to these issues. The national move from a hub and spoke model (outlined in section 8.2.2) to centralisation of services in haematological malignancies may be an influential factor in addressing care coordination issues for lymphoma survivors. This also provides further support for the growing need for nurse-led services in the care of haematological malignancies, to provide multi-faceted support, coordinated care and necessary information to survivors throughout the course of their illness (National Institute for Health and Care Excellence, 2016). As outlined in section 8.2.2, the effectiveness of nurse-led services has been shown to advance healthcare delivery and patient outcomes nationally and internationally. While preparing service guidance for haematological malignancies is challenging, it represents a significant and necessary change to develop services, develop care coordination and reduce unmet needs.

Key Findings
The unmet needs and well-being of lymphoma survivors are related to their current care coordination (Objectives 1 and 2). Fragmented and non-centralisation services may be influencing factors (Objective 4). Informed direction for the development of care coordination for lymphoma survivorship was provided (Objective 5).
Recommendation 1.4
The identification of the barriers to integrated care among interdisciplinary cancer care is required to support further endeavours to address these challenges.
Recommendation 1.5
The findings support the advanced development of nurse-led services to support survivors of haematological malignancies, including lymphoma.

8.3 Assisting Lymphoma Survivors to Live a Normal Life

8.3.1 Symptom Burden

This mixed methods study adds to the evidence on symptom burden, including cancer-related fatigue for post-treatment lymphoma survivors. Fatigue was the most prevalent symptom experienced by participants and shows fatigue is problematic for lymphoma survivors one to five years post-diagnosis; this was consistent with findings from other studies of lymphoma survivors (LeBlanc et al., 2022; Lee et al., 2023; Oerlemans et al., 2013). The consolidation of high/very high unmet needs showed 19% of lymphoma participants of this current study reported a top unmet need, tiredness; this reflected the results of other studies from Australia and Canada in which 15-18% of survivors endorsed tiredness as the top high/very high unmet need (Hall et al., 2013a; Hall et al., 2014; Tzelepis et al., 2018). While longitudinal studies of fatigue in lymphoma are rare, research studies from the US and the Netherlands found worsening fatigue over time for NHL survivors (LeBlanc et al., 2022; Oerlemans et al., 2013). This highlights the need for healthcare professionals to screen for fatigue in lymphoma survivors, even those many years from diagnosis and treatment.

Further statistical analysis showed higher unmet needs relating to fatigue were associated with lower quality of life outcomes; the qualitative analysis provided additional meaning to this impaired quality of life as participants voiced the severity of fatigue interrupted daily living impacting the physical and psycho-social needs of individuals. Strategies to cope with fatigue were not apparent from participants' accounts, like the physical necessity (rather than a strategy) to rest and sleep to manage fatigue. Participants' preparedness for common effects like fatigue was difficult to ascertain, as they discussed what was necessary to manage their fatigue rather than strategical actions carried out - which would reflect educational advice commonly received in preparation for treatments like chemotherapy and radiotherapy (e.g., gentle exercise, good diet and managing physical exertion to optimise the impact of fatigue). Therefore, this mixed methods study adds to the evidence on the prevalence and impact for many survivors one to five years post-diagnosis, while additional evidence suggests it may persist longer than this.

Cancer-related fatigue in survivorship is infrequently addressed by healthcare practitioners with inconsistent management, and its impact on quality of life is underestimated (Minton et al., 2013; Pearson, 2022; Pearson et al., 2016). A 'quick fix' is not readily available with limited time to complete a comprehensive fatigue assessment or management plan within a standard cancer care consultation (Berger et al., 2015). International guidelines for managing cancer-related fatigue recommend a comprehensive assessment of modifiable contributing factors as a first step for moderate or severe fatigue; the aim of managing perpetuating factors is to lower fatigue to a point where interventions like exercise conditioning become feasible (Berger et al., 2015; Roila et al., 2019). An appraisal by Pearson et al. (2016) compared existing guidelines for cancer-related fatigue and found the Canadian Association of Psychosocial Oncology (CAPO) guidance has the strongest evidence for use worldwide (Howell et al., 2015). CAPO guidelines recommend screening cancer patients using a numerical scale for fatigue severity. Positive screenings trigger focused assessments, addressing onset, duration, patterns, and identifying contributing factors and

relevant blood values. Managing fatigue involves interventions like education, physical activity, cognitive-behavioural therapy, and mind-body techniques.

Although these clinical guidelines advise health professionals on what strategies to recommend to individuals experiencing cancer-related fatigue; they do not guide how health professionals can support survivors to adopt these management strategies (Agbejule et al., 2023). A recent systematic review of fifty-one papers found that self-management support that is delivered after cancer treatment, facilitated by health professionals, and incorporating at least one in-person contact appears to produce the most favourable outcomes for cancer-related fatigue (Agbejule et al., 2022). Symptoms of cancer-related fatigue deserve attention because they are associated with adverse effects on psychological well-being and everyday life (Kreissl et al., 2020). However, national evidence is currently limited (Department of Health, 2017; Greally et al., 2022; O'Connor et al., 2019), therefore a standardised approach to cancer-related fatigue is needed to address this prevalent issue for cancer survivors. In addition to standardised guidelines for healthcare professionals, standardised self-management guidelines should be identified and promoted for cancer survivors. Future research should focus on improving the national assessment and management of cancer-related fatigue, utilising international guidance to support healthcare professionals and improve patient outcomes.

A closely associated symptom of tiredness or fatigue is mental exhaustion and 'brain fog' (Pearson, 2022). Most participants (67%) reported 'coping with having a bad memory or lack of focus' as the second most endorsed unmet need; the prevalence of lymphoma survivors' self-reported cognitive impairment was lower in other studies at 20-40% (Krolak et al., 2017; Oerlemans et al., 2022). The effects of cancer and its treatment on cognitive functioning have mostly been studied in similarly sized samples to this study (<250 participants), but focus has been placed on treatment effects (lymphoma survivors up to two years after diagnosis only) or the long-term impacts (Franceschetti et al., 2021; Mariegaard et al., 2021; Muzzatti et al., 2021; Zimmer et al., 2015). A recent study from the Netherlands found almost one-third of patients with lymphoma report persistent cognitive impairment which remains present up to eight years post-diagnosis; this was twice as high compared to the normative population (Ekels et al., 2023). This current study spotlights many lymphoma survivors who are dealing with issues of cognition or fatigue within the short-term period of one to five years following diagnosis. Like the findings for fatigue, additional evidence for impaired cognition suggests this may be a persistent symptom which extends past the short-term survivorship period.

Key Findings

The symptom burden of fatigue and impaired cognition were identified and were associated with a high level of unmet needs and lower quality of life for lymphoma survivors (Objectives 1 and 2). The development of supportive services for cancer-related fatigue was informed through direction for policy and service planning (Objective 5).

Recommendation 1.6

Investigate helpful factors in advancing the assessment and management of cancer-related fatigue and impaired cognition during survivorship nationally.

8.3.2 Supporting Immunocompromised Experiences

Malignant lymphomas mirror the complexity of the immune system; the revised WHO classification of tumours and haematopoietic and lymphoid tissues reflects our deepening understanding of the immune system (Swerdlow et al., 2016). The immunocompromised nature of lymphoma was highlighted through participants' experiences of cancer care during the pandemic, impacting psycho-social needs. As a particularly vulnerable group to the effects of COVID-19 (Yang et al., 2021; Zomerdijk et al., 2022), lymphoma survivors feared increased risk of morbidity or mortality during this time. Participants used the word '*isolating*' to describe their experience during the pandemic. This is echoed by previous research as social isolation, loneliness, and a fractured experience of human connectivity were described as a consequence of time spent alone in a hospital room or through self-isolation in the community (Deckx et al., 2014; El-Jawahri et al., 2015; ElSadr et al., 2009; Krüger et al., 2001; Lee et al., 2011; Tecchio et al., 2013; Vottero & Rittenmeyer, 2012). During the pandemic, lymphoma survivors were considered clinically highly vulnerable; it was necessary to 'cocoon', make changes to treatment and follow-up care and for a major reorganisation of haematology and cancer services (Drury et al., 2021; El-Sharkawi & Iyengar, 2020). While the immunocompromised nature of lymphoma was predominantly spotlighted through the experience of the pandemic, it is a feature of this disease regardless, as previous evidence conducted pre-pandemic found recurrent infections were persistent for participants for a number of years post-treatment and prolonged recovery time (Hackett & Dowling, 2019).

Social support was substantially curtailed during the pandemic to protect individuals from the inherent risks of the virus through social distancing measures and quarantine and visitor limitations, which restricted opportunities for family support (Weinkove et al., 2020). Protective isolation is used because of severe immunodeficiency to minimise the high risk of being infected by the hospital environment, other patients, visitors, or their own flora (Letrecher, 2023). This practice is commonly associated with blood cancer patients including lymphoma survivors and is not unique to the COVID-19 pandemic (Annibali et al., 2017); however, for many participants of this study, their cancer experiences took place during the pandemic. Protective isolation or self-isolation, although necessary to mitigate risk, may increase patients' psychosocial distress and highlights the importance of healthcare providers in monitoring the psychosocial implications of isolation practice (Annibali et al., 2017; Biagioli et al., 2016; Letrecher, 2023; Tecchio et al., 2013). Validating survivors' increased distress during periods of uncertainty and providing the appropriate supportive care is required to help lymphoma survivors navigate the changing landscape of their needs (Barré et al., 2022; Zomerdijk et al., 2022). Moreover, this study's findings show the physical hospital environment was voiced as a barrier to meeting survivors' needs. Future healthcare infrastructure and design should consider the psycho-social well-being of patients in addition to the requirements to meet their physical health needs, maximising opportunities for recreational activities, safe social interactions,

and capacity for physical activity (Annibali et al., 2017). In service development of acute hospitals for haematological malignancies, there is a need for increased numbers of single isolation rooms to service the unavoidable and predicted need of this patient group for isolation.

Key Findings
Unmet needs and impaired quality of life were identified from the immunocompromised experiences associated with a lymphoma diagnosis (Objectives 1 and 2). Information for the development of services was provided to address the unmet needs of lymphoma experiences of necessary immunocompromised practices (Objective 5).
Recommendation 1.7
Future design of healthcare settings should consider the psycho-social well-being of patients in addition to the necessary requirements for their physical health. Increased capacity to adequately respond to the needs of immunocompromised patients is required, such as increased numbers of single isolation rooms.

8.3.3 Coping with Lymphoma is Age-related

In Ireland, recent figures show the median age at diagnosis for all cancers combined (excluding non-melanoma skin cancers) was sixty-eight (National Cancer Registry Ireland, 2022). Both lymphoma subtypes fall considerably below this average, while HL is well-documented for occurring in younger people (National Cancer Registry Ireland, 2022; Sung et al., 2021). Shaped over time, an individual's perception of illness differs across the lifespan at different ages, including their ability to cope with illness (Leventhal & Crouch, 2013). Younger lymphoma participants were associated with higher unmet needs and lower quality of life compared to older survivors, especially regarding work and financial needs, and emotional needs. Similarly, studies from other countries have reported young adults with lymphoma have significantly decreased quality of life (Leak et al., 2013; Vena & Copel, 2021). Lymphoma presents a challenge to healthcare service delivery as it requires sensitivity to the nuances of different age groups, from young adults to gerontological considerations. The findings of this mixed-method study suggest younger survivors may have fewer coping skills to manage their diagnosis than older survivors. This reflects previous evidence as young adult cancer survivors were unprepared for re-entering everyday life after cancer treatment with a mismatch of expectations with reality and the holistic impact of cancer effects (Hauken et al., 2013). Evidence from this mixed methods study found the context of Irish healthcare services and cancer support groups is geared towards its predominant users, older adults. These findings align with a previous national study of younger colorectal cancer survivors' perceptions of cancer services as being designed for older people (Drury et al., 2020). This contextual understanding may be an influential factor in determining the level of needs of lymphoma survivors but also a contributing factor to survivors not seeking or receiving help to address their needs as outlined in Section 8.4.3. Younger adults with cancer have been found to perceive their cancer knowledge as limited before their diagnosis, which is a direct result of their age, life experiences and exposure to cancer up until that point (Hart et al., 2021). Wider evidence suggests a need for developmentally targeted cancer care for this population of young adults with cancer with proactive

approaches to characterising and eliminating barriers needed to obtain the appropriate and optimal care (Burkart et al., 2019; Janssen et al., 2021; Jones et al., 2020; May et al., 2018). Therefore, this study adds to this emerging literature on the needs and quality of life outcomes of Irish lymphoma survivors; younger survivors may require additional support in the period one to five years post-diagnosis. Future research should explore the helpful factors and supportive care interventions to improve the coping skills of younger adults with lymphoma.

Key Findings
Unmet needs and quality of life outcomes related to lymphoma survivors' age were identified (Objectives 1 and 2). Being younger was identified as a factor influencing higher unmet needs and lower quality of life (Objective 4). There is a need for age-sensitive services and support for cancer survivors (Objective 5).
Recommendation 1.8
Understand what factors are directly impactful for making cancer care services and supportive care services age-inclusive.
Recommendation 1.9
Explore the helpful factors and supportive care interventions to improve the coping skills of younger adults with lymphoma.

8.4 Keeping Pace with Evolving Practice

8.4.1 Measuring Unmet Needs: Next Steps

Enhancing the reporting of the study's objectives and associated methods is necessary to facilitate a more in-depth understanding of the accuracy and relevance of the results in instrument development (Mokkink et al., 2018). For example, in selecting specific reliability tests, the rationale, assumptions and parameters underpinning the tests need to be reported (Prinsen et al., 2018). This, in turn, would offer a clearer indication of the suitability and robustness of the findings. The COSMIN methodology used to guide the systematic review (Chapter 3) offers extensive tools for evaluating the instruments' psychometric measurement properties (Mokkink et al., 2018; Prinsen et al., 2018). These resources hold considerable value for researchers involved in research and facilitates scrutinising the selection of instruments. Evidence from this study's systematic review and wider literature supports the use of more than one instrument as a recommendation to address the research question; while evaluating known discrepancies and limitations of available instruments (Boland et al., 2023; Mokkink et al., 2016; Prinsen et al., 2018; Terwee et al., 2018). When choosing measurement tools, researchers should consider their research objectives, study design, and psychometric properties, assessing the advantages and disadvantages of using multiple measures. For cancer survivors, a population found to face a myriad of unmet needs, it is necessary to assess the participant burden and feasibility of completing selected instruments. The feasibility of instruments should be cognisant of the number of included items and the time for completion; shorter instruments may present less participant burden and could yield higher response rates and fewer missing values (Cheung et al., 2004). The stage of survivorship, outlined previously within this chapter (Section 8.2.1) requires

consideration in decision-making for measuring outcomes. The acceptability of selected instruments to a specific group (e.g., one to five years post-diagnosis) can be assessed through content validity index evaluations, assessing how relevant, responsive, and clear the questionnaire is in relation to the population of interest (Beck & Gable, 2001; Lynn, 1986; Polit & Beck, 2006; Polit et al., 2007). This facilitates an evaluation to support or reject the use of a specific instrument, including direction of improvements from experts associated with the population of interest. Patient and public (PPI) involvement in health research is increasing worldwide, but PPI needs to be integrated more broadly into the cancer research process (Boote et al., 2015; Pii et al., 2019). Therefore, the involvement of individuals with lived experience of cancer in the development and evaluation of questionnaires is valuable and ensures measurement instruments are acceptable to people living with and beyond cancer (Drury et al., 2024). Additionally, this systematic review has provided a platform to facilitate instrument comparison; guidance that is especially useful for early career researchers and clinical healthcare professionals embarking upon this complex research area. Future research should endeavour to provide accessible and feasible guidance for early career researchers and clinical healthcare professionals involved in cancer survivorship research.

Key Findings
The content and quality of instruments used with lymphoma survivors to assess the constructs of interest, unmet needs, and quality of life outcomes, were assessed through a systematic review of available evidence (Objective 3).
Recommendation 1.10
Standardisation in selecting outcome measurement instruments for specific research areas (e.g., lymphoma cancer survivorship) requires improvements in the consistency of reporting. The COSMIN methodology is one comprehensive approach which can be considered, however, its application to research with disparate reporting on the psychometric properties of instruments requires attention to enhance its application and feasibility.
Recommendation 1.11
Content validity index evaluations are useful for smaller research projects in assessing the applicability of a questionnaire to a population of interest. Accessible guidance on this application for clinical healthcare professionals and early career researchers is needed to advance the quality of cancer survivorship research.

8.4.2 Emerging Treatment Experiences Require Investigation

The treatment delivered to this cohort reflects expected treatment patterns internationally, including chemotherapy, radiotherapy, immunotherapy, and surgery (Chircop & Scerri, 2018; Hoppe et al., 2022; Horwitz et al., 2020; Zelenetz et al., 2021). Around 160 patients receive transplants to treat many types of haematological or rare solid-organ tumours in the national stem cell transplantation service each year in Ireland (St James's Hospital, 2023). Few study participants reported receiving stem cell transplants (4.1%, n = 8), despite attending the same recruitment clinics as patients receiving other treatments (e.g., chemotherapy). However, international literature shows the patient outcomes of this treatment-specific

group are often explored exclusively given its complexity (Al Khabori et al., 2011; Persoon et al., 2019; Rashidi et al., 2016; Sezgin & Bektas, 2023; Sureda et al., 2020). The study's timeline did not allow for the recruitment of patients receiving chimeric antigen receptor (CAR) T-cell therapy as this is newly available in Ireland. A recent qualitative paper in the European Journal of Oncology Nursing was the first to report on how patients (lymphoma survivors, *N=14*) experience this novel treatment (Leinemann & Krutter, 2024); the findings show the patient experience of CAR-T therapy differs from those of other cancer patients. Yet additional research is warranted to enrich the available evidence on this group. To advance the understanding of the needs of lymphoma survivors and the heterogeneity among lymphoma survivors, insights into novel treatment experiences must be investigated. An exploration of the nuanced differences among lymphoma survivors receiving different treatments would enhance the development of survivorship services, highlighted in Section 8.2.

Key Findings
The unmet needs and quality of life of lymphoma survivors undergoing novel treatments were not captured by this sample (Objectives 1 and 2). Future research is warranted which is inclusive of emerging treatment to add further insights to this current mixed methods study on lymphoma survivors (Objective 5).
Recommendation 1.12
Understand the experiences of lymphoma survivors undergoing more novel approaches to treatment, including chimeric antigen receptor T-cell therapy.
Recommendation 1.13
Understand the future direction of grouping lymphoma survivors by treatment types to inform health services (e.g., is treatment-specific research required for transplant or CAR-T therapy survivors?).

8.4.3 Alleviating Demand: Utilising Cancer Networks

The substantially increasing number of lymphoma survivors is not an isolated issue specific to hospitals alone. In Ireland and many other countries, cancer survivors can avail of a wide network of psychosocial support services, from within hospitals to cancer organisations (e.g., Irish Cancer Society) or local support groups or networks. Evidence from this mixed methods study suggests these services are often underutilised; like previous research which has outlined the low uptake of psychosocial support services in people living with cancer (Bauwens et al., 2014; Clover et al., 2013; Funk et al., 2016). Due to the complexities of cancer, its treatment and recovery, survivors were often reliant on the ancillary support often rendered by family and friends. This is not without its challenges as the qualitative accounts of lymphoma survivors voiced wanting to protect their families from further emotional distress caused by cancer, often withholding expressing their feelings. Qualitative analysis found a lack of participants availing of these supplementary supportive services. One barrier to the uptake of their use nationally or locally included survivors feeling services were not tailored or related to lymphoma, this contrasted with lymphoma-specific organisations, networks and support groups noted as available in countries outside Ireland. Another barrier previously outlined (Section 8.3.3) involved the sensitivity of these supportive

services or networks to younger survivors. This adds lymphoma-specific considerations to the findings of a qualitative study by Sheridan et al. (2020) on the non-use of cancer information services among people experiencing cancer in Ireland. Barriers to the provision of psychosocial supportive care noted from broader cancer survivorship literature found survivors' preference for self-management, not viewing distress levels as severe or lack of information or awareness about the service were key factors (Clover et al., 2015; Dilworth et al., 2014; Sheridan et al., 2020). Individuals with positive attitudes towards psychological support or who demonstrate more positive coping styles were found to have greater use of psychosocial supports; mental health literacy, knowledge and patient empowerment were seen as important influencing factors for the uptake of supportive care services (Tondorf et al., 2018). One randomised controlled trial found the uptake of support services was highest for strategies employing outreach procedures for connecting the support service to male cancer patients, telephone-based information and support program outcalls exhibited an engagement rate of ninety percent for those referred (Livingston et al., 2010).

A disconnection exists between the level of unmet needs in cancer survivors and their engagement with services that may help in addressing those needs. As demand for cancer care services increases, known problems are impacting our health services including the recruitment and retention of staff and concerns for safe staffing levels (Department of Health, 2022; National Doctors Training and Planning, 2023). There are additional problems with the lengthy time necessary to gain experience, qualification, and competence as a healthcare professional in the speciality of cancer care and survivorship. This creates pressurised problems for healthcare professionals, the individual navigating a cancer diagnosis and their supportive circles of family and friends. Survivors should be directed towards the wide range of external supportive care available to them including cancer organisations and support groups, counselling or psychological support, emerging psycho-oncology support services and chaplaincy or spiritual services. Concerted efforts to enhance the visibility and awareness of services available nationally should be continued (Sheridan et al., 2020). However, future research is needed to ascertain helpful factors to increase the uptake of valuable supportive services as they play a role in alleviating demands for hospitals and healthcare settings, which are consistently at full capacity and often prioritise the physical needs of survivors as a necessity.

Novel approaches could be considered to assist people living with or beyond cancer and their family caregivers through health technology like eHealth and telemedicine (Chan et al., 2021; Darley et al., 2021; Furlong et al., 2019), as this has the potential to alleviate burdens for the patient, their families, healthcare professionals and supportive services. Evidence suggests digital health technology can *"act as a bridge from uncertainty to an understanding regarding a cancer diagnosis and its treatment"* (Darley et al., 2023, p. 1). A review by Taylor et al. (2020) demonstrates that the clinical management and survivorship of haematological malignancies presents opportunities to explore eHealth approaches to advance patient outcomes. A randomised controlled trial evaluating a remote monitoring system for chemotherapy side effects, including HL and NHL survivors, found reductions in symptom burden which support the use of such systems versus standard cancer centre care (Maguire et al., 2021). While health technology is a promising modality for cancer care, it is essential to address barriers that could widen health disparities as mass application of eHealth and telemedicine have the potential to exclude marginalised groups such as,

older people and individuals with digital or literacy issues (Chan et al., 2021; Kreps & Neuhauser, 2010). Older adults with cancer and their caregivers have been associated with low self-perceived eHealth literacy and less confidence in evaluating online health information for their cancer care and decision-making; collaborative efforts considering minimal approaches to credible digital health applications are warranted (Verma et al., 2022).

Key Findings
Unmet psycho-social needs were identified relating to supportive services, and influencing factors were barriers to the uptake of these services (Objectives 1 and 4). The development of services was informed to enhance the psycho-social needs of survivors (Objective 5).
Recommendation 1.14
Review the barriers and helpful factors impacting the uptake of supportive services by adult cancer survivors nationally or locally, including a comprehensive understanding of available interdisciplinary supportive care services from within hospitals to cancer support groups. Consider potential digital and literacy issues or other barriers relevant to the Irish population in the development of health technologies nationally.

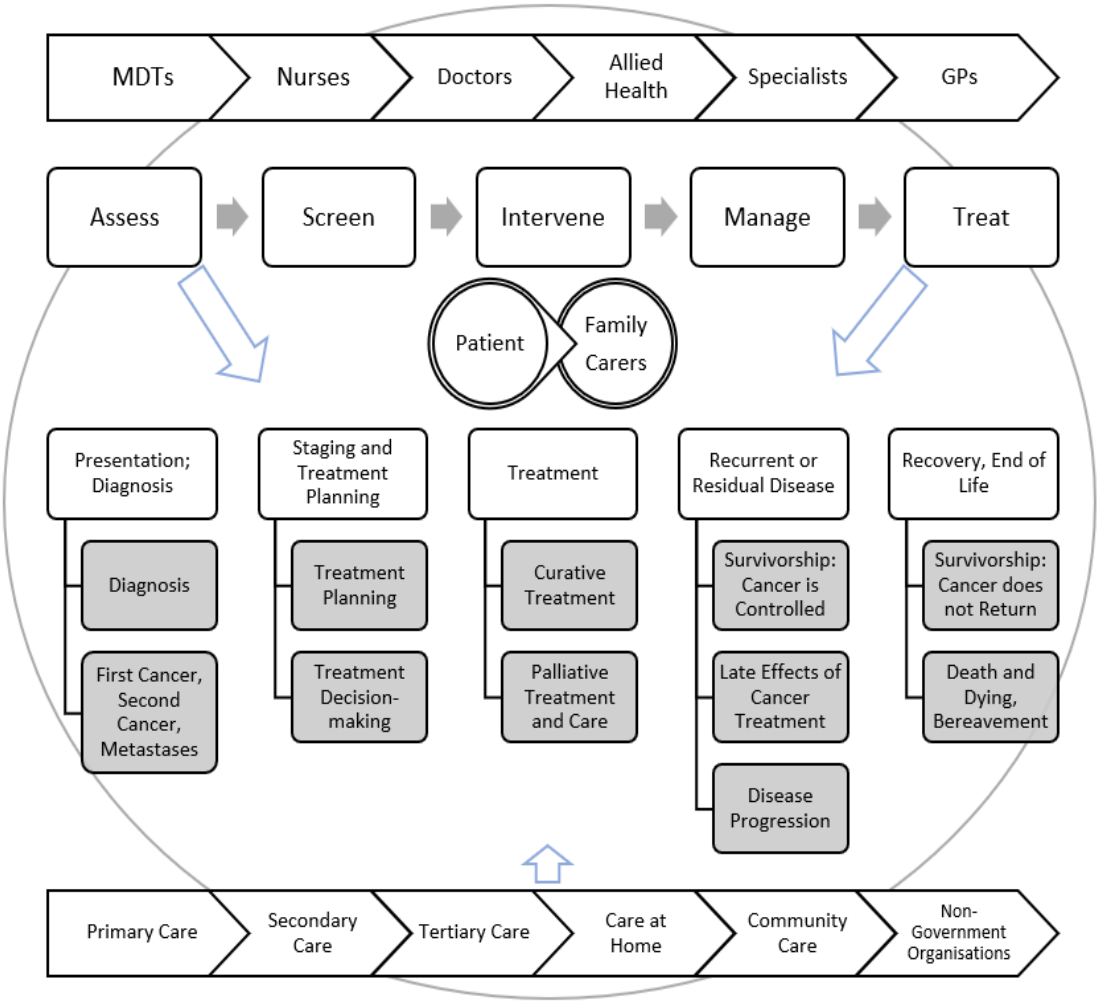
8.5 The Theoretical Implications of this Research

There is heterogeneity in how the term supportive care was defined in published literature, dictionaries, and textbooks, with some having a narrow interpretation and describing supportive care as mostly the management of treatment and side effects by oncology teams (Cherny et al., 2009; Hui et al., 2013). A recent study by Krishnasamy et al. (2023), including the original Supportive Care Framework (SCF) author Margaret Fitch, aimed to explore a refreshed supportive care definition and framework to refocus the dialogue about supportive care, establishing the Integrated Cancer Care Framework (ICCF). Their refocused framework highlighted one critical issue: that supportive care is more than a series of individual services that coincide within cancer services; it is a conceptual framework that guides planning, resourcing, and the delivery of cancer care. The ICCF was underpinned by a series of supportive care assumptions developed using the Theory of Change (e.g., how, and why an initiative works) (De Silva et al., 2014). The framework offers insight into meaningful outcomes for supportive cancer care research focusing on maximising health outcomes that matter to people affected by cancer and the system within which care is delivered.

Health service demand has grown exponentially as people live longer with the consequences of cancer and its treatment. The impact of insufficient supportive care is increasingly apparent and presents challenges to survivors' recovery. Importantly, insights provided by individuals affected by cancer contribute to a significant understanding of where and why improvements are warranted (Krishnasamy et al., 2023). Treatment delivery was long considered the primary activity of cancer care, with other components of care seen as supplementary. The refreshed views from Krishnasamy et al. (2023) support a shift in thinking away from targeting singular aspects of care at the individual patient level to realise the importance of supportive care as a basis for the delivery of integrated cancer care (Sanson-Fisher et al., 2019; Sturmberg et al., 2010). Many professional cancer organisations share this view of supportive care (Jordan et al., 2018;

Multinational Association of Supportive Care in Cancer, 2023; National Cancer Institute, 2023c). The refreshed approach of the ICCF is outlined in Figure 8.1.

Figure 8.1 Integrated Cancer Care Framework by Krishnasamy et al. (2023)



Given the paper by Krishnasamy was published in 2023, the original SCF informed the development of this research (conducted 2020-2024). The SCF directly influenced the development of data collection methods (Chapter 5), and the ICCF adds value to the thought process in analysis and interpreting the study's results (this current chapter) which builds on the SCF which is limited by its age and detail. The framework is aptly suited to the population of interest, lymphoma survivors, a group substantially increasing due to success in advancing outcomes, with growing concerns about survivorship. This framework places emphasis on the whole trajectory of cancer as an entirety rather than contributing factors which supplement the treatment phase. Therefore, the application of the Integrated Cancer Care Framework (ICCF) in the context of this mixed methods research aimed to conceptualise the findings through the impact on patient experience and care outcomes.

The original ICCF figure (Figure 8.1) by Krishnasamy et al. (2023) has been adapted to incorporate significant integrated findings from this mixed methods study which have been discussed in detail in the previous

sections (8.2-8.4). This adapted Figure 8.2 illustrates that the cancer care of lymphoma survivors cannot rely on haematologists or oncologists alone, their care is multifaceted and complex, requiring the broader knowledgebase of multidisciplinary teams, nurses, doctors allied health care professionals, additional specialists, and general practitioners. This provision of care cannot be isolated to hospitals (secondary care) or cancer centres (tertiary care); primary care is vital to the prompt recognition and diagnosis of lymphoma, while community care and supportive care delivered by non-government organisations and local groups are essential to meet the unmet needs and coping mechanisms required to live well with and beyond lymphoma. No two journeys are the same, the framework accurately depicts the nature of being in and out of hospital required of individuals living with and beyond lymphoma as they often have periods of dependency on healthcare professionals and services.

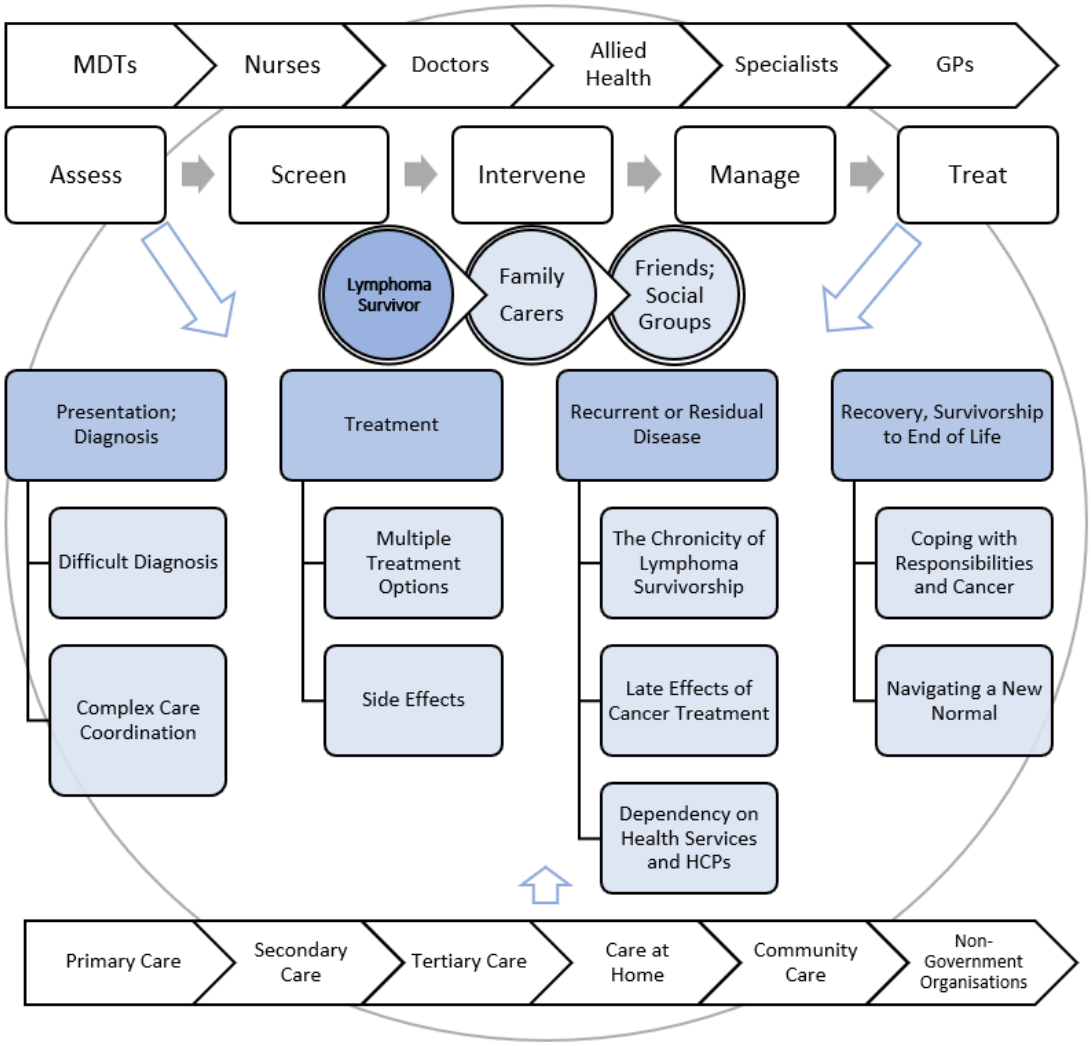
The linear expectations of the SCF have been advanced and complimented by the ICCF to show the relevant different stages which entail different levels of support. The presentation of lymphoma was paved with difficult journeys to diagnosis for many survivors. Complex care coordination was a significant finding which noted the need for integrated cancer care and that collaborative interdisciplinary care is necessary for its development and successful implementation. Treatment for lymphoma includes multiple treatment options including emerging therapies thanks to the continued success of research developments. Increased success brings enhanced survival rates, substantially increasing the number of lymphoma survivors but also the trajectory for potential problems including known side effects like fatigue and impaired cognitive functioning.

Cancer is increasingly considered a chronic disease; this is especially relevant to certain experiences of lymphoma. This study encompasses the ICCF's way of thinking, where each component of cancer care occurs within supportive care, as this accurately represents the patient's cancer experience. The ICCF demonstrates that delivering acute care, survivorship practices, and palliative and end-of-life care interconnect with each other framed within supportive care. This conceptualisation aligns with this research investigation interested in how lymphoma survivors experience their lives, as a result of cancer. Rather than focusing on discrete events or issues (which have been mainly separated for the convenience of healthcare professionals and researchers in managing descriptions and measurement of problems), the integration of various aspects of their cancer care is evident (Berman et al., 2020; Krishnasamy et al., 2023; Olver et al., 2020). Ultimately, there is a greater focus on person-centred care in delivering cancer care (Afiyanti et al., 2018; Fitch, 2008).

Recurrent or residual disease speaks to the chronicity of lymphoma survivorship which involves monitoring and managing the late effects of cancer and its treatment which includes a continued dependency on health services and healthcare professionals. As defined for this research, a cancer survivor includes a person with lymphoma from the time of diagnosis until the end of life. For the participants of this research, one to five years post-diagnosis, this involved living beyond lymphoma which included coping with responsibilities outside of the sphere of cancer and navigating their new normal. At the heart of this is the individual with lymphoma closely accompanied by their families, carers, and friends within their supportive circles. Rather than a series of discrete events or problems during the cancer trajectory, an appropriate

integrated understanding of the complexities of lymphoma survivors' unmet needs has been facilitated by the ICCF. Overall, an understanding of the theoretical implications of this research has benefitted from the contemporary views of the ICCF which builds upon the seminal SCF to enhance and better reflect the present-day lymphoma cancer care experience in Ireland.

Figure 8.2 Integrated Cancer Care Framework by Krishnasamy et al. (2023) Adapted - to this Study's Mixed Methods Findings for Lymphoma Survivors' Unmet Needs



8.6 Overall Limitations and Strengths

This section identifies the constraints affecting this research and an overview of the strengths of this research. To begin, there are limitations to the current study which should be considered when drawing conclusions from the results.

Non-respondent data was not available for this study's sample, so the representativeness to lymphoma survivors has been presented through congruence with the findings of previous research and with demographic data for Ireland which provides reassurance. There were minimal differences in the response rates among the five different sites and the sample sizes recruited were relevant to the size and scale of the individual site, however, it is impossible to ascertain if non-responses introduced bias into the findings.

Through rapport with gatekeepers, efforts were made to ensure that all lymphoma survivors eligible for the study were offered study information. However, from the outset, the surveys were available in the English language only, while not highlighted by gatekeepers at clinical sites this may have precluded the recruitment of participants who did not read or understand English. The sample included largely white and English-speaking participants and therefore, the findings may not be transferable to different settings or cultures. The sample provides several fundamental demographic and clinical factors of lymphoma survivors facilitated by the maximum variation sampling technique, but while efforts were made to include minority groups (e.g., Irish Traveller, unemployed), the sample could not be exhaustive of all potential factors and the substantial findings come from the common majority. Similarly, this study provides extremely limited insights into the experience of lymphoma for patients undergoing stem cell transplants and no insights into the experience associated with CAR-T therapy. These developing areas may warrant further investigation in the future.

While supplementary online recruitment was conducted in addition to recruitment via hospitals, it was extremely challenging to reach eligible participants online. A total of twenty lymphoma survivors completed the survey online, recruited through established cancer organisations and local cancer networks who distributed the study information via their newsletters and social media accounts. Lymphoma-specific organisations and networks outside of Ireland, which appear active in various countries, could not be utilised as the study excluded the experience of lymphoma cancer care received outside of Ireland. Strategies to improve recruitment, like offering a small unconditional monetary incentive, have been associated with increased participation in surveys (Edwards et al., 2005), this was not possible due to the financial constraints of this study.

There were two key disruptions to the normal research process during the undertaking of this study, the COVID pandemic and the cyber-attack on the national health service IT systems. The COVID pandemic occurred in various severity (involving different waves, peaks, and national restrictions) throughout the recruitment period. This also affected the ethical approval process, with delays and discrepancies between sites in the capacity for recruitment procedures. This was coupled with reluctance among survivors to attend clinic, due to concerns of contracting the virus or being unable to attend having contracted it. This was further compounded by a cyber-attack on the national health service IT systems on May 14th, 2021, (O'Reilly et al., 2023), which imposed further recruitment delays as clinics were cancelled with potential participants rescheduled to a later date. In addition, the capacity for gatekeeping and recruitment procedures with the rise of virtual and telephone appointments was noticeably reduced, compared to the traditional in-person clinic. Therefore, a potentially significant influential factor is that this study was conducted during COVID. This is a limitation of this research as the findings related to being immunocompromised are likely to be influenced by this experience. If the study was repeated now, there is potential for the findings to be different.

The journey from novice to expert is an inherent limitation of this PhD research. The learning curve at the start led to challenges in decision-making for study design and participant recruitment, potentially affecting the timeline. Reliance on guidelines and established methodologies limited flexibility and discretionary

judgment. The progression from novice to expert facilitated growth but introduced limitations impacting the research. For instance, mastering complex data analysis techniques may have influenced early analyses. Expert guidance was availed of to ensure the accuracy of this research through supervisors who are mixed methods experts, as well as, statisticians, and expert groups (e.g., Cochrane guidance for rapid review methodology). Acknowledging these limitations provides a balanced account of the research process and the continuous learning involved. A reflection on being a novice researcher, guided by Benner's (1982) theory is outlined in Section 8.9.1.6.

Next, there **strengths** of this research are outlined.

Firstly, the use of a rapid review in Chapter 2 to provide an overview of the existing research on lymphoma survivors' unmet needs is a strength of this thesis as it facilitates the contextualised synthesis of the findings from previous evidence. This provided an evidence-based foundation for decision-making for this study and to cement the appropriateness of the study's overarching aim and objectives. Secondly, a systematic review in Chapter 3 provided an in-depth evaluation of the content and psychometric quality of instruments used to measure the unmet needs of lymphoma survivors. This provided a structured examination of existing evidence to inform the decision-making regarding the phase one survey which ultimately enhances the overall rigour and quality of this study.

The mixed methods study provides comprehensive data on the unmet needs of lymphoma survivors, meeting this study's aim and objectives. The attempt to both quantify and narrate the problems experienced by lymphoma survivors with integrated evidence is a unique feature of this study in informing the development of services and healthcare delivery. Quantitative and qualitative data demonstrate that the vast majority of lymphoma survivors experience a myriad of unmet needs in the period of one to five years following diagnosis. This study has shown the factors are complex but not dissimilar to other cancer groups, so multifaceted approaches that have shown success for other cancers should be considered. The mixed methods design allowed for the integration of quantitative and qualitative findings to provide deep insights into factors influencing the unmet needs of lymphoma survivors. For instance, despite the survey facilitating elements of cancer care delivery, it was the qualitative accounts which brought the important issues of difficult diagnosis and complex coordination to light. The use of one-to-one semi-structured interviews facilitated in-depth discussions with lymphoma survivors who disclosed deeply personal experiences as a result of cancer and its treatment which may have not been possible in a group session, like a focus group. The findings of this study indicate the need for service development and areas for further research to establish interventions to address the unmet needs of lymphoma survivors; the comprehensive nature of the study's findings would not have been established with a single method alone. Therefore, the knowledge gained from the mixed methods sequential explanatory design has justified the use of a mixed methods methodology.

Lymphoma survivors recruited from five hospitals in Ireland enhanced the generalisability of the findings. The majority of previous evidence included in this study's literature review (Chapter 2) used samples generated in single or two sites, often academic medical centres in Australia or the US, which may not be

representative of the majority of lymphoma survivors' experiences (Boland et al., 2022). This study captured participants across Ireland, encompassing a critical mass of lymphoma survivors. The sites chosen included publicly funded hospitals including designated cancer centres and regional centres with full-time and part-time haematology/oncology consultants to reflect the currently non-centralised and fragmented services available for lymphoma. The hospital groups used for recruitment had large catchment areas spanning urban and rural areas across different provinces and counties in Ireland. The non-centralisation of lymphoma cancer care in Ireland makes recruiting participants a logistical challenge as they are dispersed across twenty-six different hospital sites. Within the hospital setting, lymphoma survivors may be under the supervision of a consultant haematologist or oncologist, which contributes to further division in the care provided to this group. Navigating this landscape was both a challenge and a success of this study as five different hospital sites across Ireland are represented by participants.

Looking at previous national literature, one cross-sectional survey study by Holland et al. (2016) was conducted on the quality of life outcomes of non-Hodgkin lymphoma survivors at two hospital sites (different to this current study) in Ireland and reported a sample size of 47 (response rate 54%), making this current study the largest investigation of lymphoma survivors to date in Ireland. International studies investigating lymphoma survivors' unmet needs via hospital site recruitment ranged from the UK to China, with a sample size range of 50 – 837 participants (Arden-Close et al., 2011; Beaven et al., 2016; Chen et al., 2012; Georges et al., 2020; Greaves et al., 2014; Hernæs et al., 2021; Kang et al., 2018; Kim et al., 2014; Kim et al., 2017; Lekdamrongkul et al., 2021; Lobb et al., 2009; Ng et al., 2016; Zucchetti et al., 2017). In comparison to other countries publishing research in this area (i.e., Australia, the UK and the US), the population of Ireland is significantly smaller with just over 5 million citizens compared to a population of 26 million in Australia, 68 million in the UK and over 340 million in the US (Australian Institute of Health and Welfare, 2021; Baker & Mansfield, 2023; National Cancer Registry Ireland, 2022; Sung et al., 2021). Therefore, this study's sample contributes to the existing body of evidence regarding lymphoma survivors and emerging national evidence.

While not necessarily a strength, it is worth noting that some individuals diagnosed with slow-growing lymphomas will initially necessitate a regime of watchful waiting and will not require treatment for many years after diagnosis. The power sample for this sample used the best available evidence from the national cancer registry for its calculation which could not distinguish between survivors who were watchful waiting or post-treatment. Therefore, the power calculation overestimates the sample size required and may increase the study's capacity for generalisation.

The maximum variation sampling technique used to obtain the qualitative interview sample formed from a subset of the quantitative survey sample was a strength of this study. This facilitated a point of mixed methods integration as well as incorporating broad perspectives from diverse demographic characteristics. The demographic data showed that participants were broadly representative of lymphoma survivors across the lifespan (age range 19-88 years). An individual's perception of illness varies over settings and over time, this shapes their ability to cope with the illness and its management which varies across the lifespan at different ages (Leventhal and Crouch 1997). Lymphoma presents a challenge to healthcare service delivery

as it requires sensitivity to the nuances of different age groups from young adults to gerontological considerations, and so the age distribution of this sample shows a strength of the maximum variation sampling technique. Furthermore, diversity in cancer research is important and while the findings may not be transferable to all settings or cultures, the sample is representative of the normative general population regarding ethnicity and cultural background in Ireland including non-Irish participants (Central Statistics Office, 2016). Additionally, participants resided across Ireland; their areas of residence included urban and rural dwellings. This reflects the general population in Ireland, with just over three in ten people (31.4%) living in a rural area, above the rate of 27.3% in the European Union (Eurostat, 2019).

As outlined in Section 8.2.1, this study presents insights into the short-term period of lymphoma survivors, a period associated with a transition from treatment completion to maintenance treatment or monitoring for cancer recurrence, balanced with an attempt to return to 'normal' living (Miller et al., 2008; Stanton, 2012). These insights contribute to enhanced understanding of the lymphoma experience for this period of survivorship, a period which is significant to healthcare planning and delivery given the increased dependency on health services during this time for many individuals with a lymphoma diagnosis.

Consultation with medical, nursing, pharmacy and other allied health care professionals providing cancer care to individuals with lymphoma was carried out to advance this research, particularly in the initial design to data collection stages of this study. This provided a deep engagement with the relevance of this research study for practice as rich and robust discussions with healthcare professionals working in this area expected and warranted this. Furthermore, the involvement of an expert group of academics and clinicians working with lymphoma survivors and individuals with lived experience of lymphoma was a strength of this research. The expert group was directly involved in the content validity evaluation of the phase one survey, providing valuable insights to improve the relevance, representativeness, and clarity of survey questions to lymphoma survivors. The lived experience of lymphoma is valuable in terms of practical contribution to enhancing the research process (Pii et al., 2019; Thompson et al., 2014).

8.7 Recommendations

This section presents areas for recommendations for the development of service provision for lymphoma survivorship care and for future research. The key findings informing these recommendations were discussed in the previous section, this section builds upon this by grouping the recommendations by relevance for policy, the patient, practice and future research.

Policy

It is recommended that policy influencing the development and improvement of lymphoma survivorship care, including governing national bodies, the Health Service Executive and National Cancer Control Programme:

- Should assess the capacity to adapt a model to advance the consistent and accurate diagnosis of haematological malignancies to begin contributing to address the difficult diagnosis associated with lymphoma.
- Should incorporate national cancer awareness campaigns that target i) public awareness, ii) advocacy for health-seeking behaviours, and iii) enhanced guidance and support for primary healthcare professionals.
- Should advance the development of nurse-led models which can support survivors of haematological malignancies, including lymphoma. Continuous development of workforce planning is needed to be responsive to the evolving needs and demands of the substantially growing number of cancer survivors.
- Should assess the current and future design of healthcare settings for adherence to the following concerns for adult cancer patients (especially relevant for lymphoma and haematological malignancies), (i) considering the psycho-social well-being of patients in addition to the necessary requirements for their physical health, and (ii) the increased capacity to adequately respond to the needs of immunocompromised patients, such as increased numbers of single isolation rooms or capacity for chairs.

Patient

It is recommended that individuals living with and beyond lymphoma:

- Are well placed to contribute to the development of services for lymphoma survivorship through advocacy, participation, and involvement in research.
- Should be consulted for their input regarding the development or evaluation of services for lymphoma survivorship care.
- Can advocate and voice the need for lymphoma-specific cancer networks, initiate or lead this development.

Future Research and Practice

It is recommended that future research (including direction for practice):

- Incorporates standardisation in the selection of outcome measurement instruments, including improved and consistent reporting. The COSMIN methodology and content validity index evaluations may be useful to tailored and adapted for use in future research projects to advance the quality of cancer survivorship research.
- Investigates and responds to the emerging needs of lymphoma survivors, given the evolving treatments and care available, including the appropriate grouping of lymphoma survivors (e.g., by subtype or treatment types) for research and practice purposes.
- To investigate the changes over time for post-treatment lymphoma survivors receiving follow-up or survivorship care services to (i) evaluate current practice and (ii) provide evidence to inform future practice. This is timely given the continuously increasing numbers of lymphoma survivors and growing demand for haematological cancer services.
- To identify the barriers to integrated care among interdisciplinary cancer care nationally.
- To investigate helpful factors to advance the assessment and management of cancer-related fatigue and impaired cognition during survivorship nationally.
- To understand what factors are directly impactful for making cancer care services and supportive care services age-inclusive.
- To explore what factors and supportive care interventions are helpful in improving the coping skills of younger adults with lymphoma.
- To understand the experience of lymphoma survivors undergoing more novel approaches to treatment. This will inform services to be responsive to the potentially different needs arising from varied treatment approaches.

8.8 Original Contribution to Knowledge

This research makes several original contributions to knowledge relating to lymphoma survivors, their unmet needs and quality of life. Like all research, this work draws on previous work, which helped to identify and steer what this research should build upon. Guided by pragmatism, this is an authentic piece of work with originality seen in the different approaches and insights provided within this thesis. As a PhD with publication, the publications have added to the literature, providing a synthesis of information relevant to lymphoma survivors. First, a rapid review provided a synthesis of the evidence for lymphoma survivors' unmet needs and identified a limited understanding of this problem, particularly in the Irish context. Second, a systematic review investigated the content and psychometric quality of available instruments for use in measuring the unmet needs of lymphoma survivors, providing evidence for the validity and reliability of the survey findings. Next, this study advanced a unique understanding of two important concepts to cancer survivorship, unmet needs, and quality of life, from the carefully considered

statistical methods (especially the canonical correlational analysis) which were enhanced by the voice of survivors in interviews. Next, this research has provided evidence to support the use of the Supportive Care Framework by Fitch (2008) and the more recent Integrated Cancer Framework by Krishnasamy et al. (2023) to underpin research examining needs in a sample requiring increasingly integrated and multidisciplinary care to address their multifaceted needs. Finally, this study has provided new and timely evidence about the experiences of lymphoma survivors receiving follow-up care in haemato-oncology settings. For the first time in Ireland, a comprehensive understanding of the unmet needs and quality of life outcomes of lymphoma survivors through a pragmatic mixed methods approach was explored. To date, this is the largest national investigation of lymphoma survivors' unmet needs.

8.8.1 Clinical Implications

The advancement of knowledge in this area is most notable in its clinical implications. This thesis has outlined several factors and recommendations that require attention to support lymphoma survivors in addressing their unmet needs, but what is needed to make them happen? The enhanced knowledge gained from this research's findings is important to nursing practice. There is growing support and demand for survivorship services nationally and internationally. Nurse-led care has been found as effective and beneficial to patient outcomes and the investment in nurse-led models of care for cancer services can contribute to ameliorating the increasing demands on healthcare systems. The identification of unmet needs can be the first step in providing supportive care that addresses survivors' concerns. This study has identified the short-term period of one to five years following diagnosis as a key point for the observation of unmet needs in the planning and consideration of lymphoma survivorship care. However, unmet needs are not routinely assessed in nursing practice. There is opportunity to build upon this study's evaluation of instruments for measuring unmet needs in lymphoma survivors and adopt the identified, validated, and reliable instruments for clinical use with lymphoma survivors.

8.9 Reflection

The research question underpinning this PhD was initiated during my clinical work as a nurse in haematology cancer services in Ireland. I identified a gap in the attention placed on patients with haematological malignancies. A group that appears separate from solid tumours in many aspects, from attending a haematologist rather than an oncologist to the systemic rather than localised nature accompanying haematological malignancies. I focused my efforts on the biggest cohort, lymphoma survivors, which was supported by limitations of previous research on haematological malignancies involving insufficient reporting of subtype-specific concerns. Like in clinical practice, I sought to advocate for the individual living with lymphoma, for whom the landscape for post-treatment experiences was often not clear. This evolved into an investigation of the unmet needs of lymphoma survivors one to five years post-diagnosis. I was drawn to the concept of unmet needs as it emphasises the actual experiences of meeting an individual's needs or expectations for services. This mixed methods study has provided insights into the unmet needs of lymphoma survivors, while the process of undertaking this study has been a

valuable experience. I have developed an in-depth appreciation and enhanced understanding of the research process, which I don't believe is possible to this degree without the undertaking of a PhD. I feel that the pragmatic approach to this study aptly served this research; mimicking the approaches required of health services to achieve optimal patient outcomes within the constraints of knowledge, resources, and infrastructure.

8.9.1 Critical Findings from the Reflexivity Process

Engaging in reflexivity throughout this PhD research has been instrumental in maintaining the integrity and quality of this research. Reflecting on one's values, biases, and influence on the research was critical in several aspects of this study: personal and professional biases, participant interactions, methodological choices, data interpretation and application of theoretical frameworks.

8.9.1.1 Personal and Professional Biases

Coming from a clinical background in haematology, I was aware that my professional experiences and personal commitment to improving patient care could introduce biases. These biases might manifest in how I interpreted data or interacted with participants. To mitigate this, I maintained a reflexive journal, documenting my thoughts, feelings, and decisions throughout the research process. This practice helped me remain cognisant of my biases and strive for objectivity, ensuring that the findings accurately represented the participants' experiences rather than my preconceived notions. I challenged my reflexivity through peer review, which involved discussing my notes with my supervisory team to further check my active reflexivity.

8.9.1.2 Participant Interactions

My role as a nurse could have influenced how participants responded during interviews, potentially viewing me as an authority figure or healthcare professional rather than an impartial researcher. Being reflexive about this dynamic, I consciously adopted a neutral and empathetic approach during interviews, encouraging participants to share their experiences openly without feeling judged or guided by my clinical background. This helped in eliciting genuine and rich qualitative data.

8.9.1.3 Methodological Choices

Reflexivity played a critical role in the choice and implementation of the mixed methods design. Recognising the balance required of both approaches was necessary from the conception of the design to careful implementation to meet the timeframe required of this comprehensive two-phase study. Ensuring the qualitative subsequent phase was equally robust and comprehensive provided the necessary balance to provide a holistic understanding of lymphoma survivors' unmet needs, which could not be captured fully by one approach alone.

8.9.1.4 Data Interpretation

Reflexive practice was particularly important during data analysis. Regular discussions with my supervisory team and peer debriefing sessions provided opportunities to challenge my interpretations and consider

alternative perspectives. This collaborative approach helped mitigate the risk of biased interpretations and enhanced the credibility of the findings.

8.9.1.5 Reflexive Application of Theoretical Frameworks

Throughout the research process, my reflexive practice was influenced by the application of the theoretical frameworks, the Supportive Care Framework (SCF) and the subsequent Integrated Cancer Care Framework (ICCF). The SCF influenced the evidence synthesis and design of this study, while the ICF published during this study in 2023 evolved the critical thinking of this research topic, especially for the integration analysis and interpretation of findings. Initially, I viewed supportive care primarily in terms of managing and prioritising physical symptoms and side effects in a more singular approach to cancer care, with an often unclear connection between multidisciplinary care services. However, as I engaged with the ICCF, I recognised the importance of a more comprehensive approach that includes the wider considerations of an individual's level of needs (e.g., psychological, social, emotional, financial). This shift in perspective was critical during data analysis, in which integrated findings developed to reflect the broader aspects of supportive care, such as assisting lymphoma survivors to live a normal life which encompassed symptom burden, supporting immunocompromised experiences, and coping with lymphoma being age-related. The ICCF also prompted me to reflect on the systemic aspects of care delivery. For example, when analysing data related to care coordination, I initially focused on the interactions between patients and their primary care providers. The ICCF encouraged me to consider the entire healthcare system, including the roles of secondary and tertiary care, non-government organisations, and community support groups. This broader view helped to identify gaps in care coordination and informed recommendations for more integrated and seamless care pathways. Visually, this development is presented in Figures 8.1 and 8.2.

The reflexive process and the application of the SCF and the ICCF were intertwined, each informing and enriching the other. The framework provided a structured approach to understanding and addressing the unmet needs of lymphoma survivors, while reflexivity ensured that my biases and assumptions were continually examined and addressed. This dynamic interplay ultimately enhanced the rigour and depth of the research, contributing to a more comprehensive and actionable understanding of the lymphoma survivors' experiences and needs.

8.9.1.6 From Novice to Expert, A Reflection

Benner's (1982) theory of novice to expert describes my PhD journey, involving the development of skills and knowledge over time through experience and reflection. The novice level represents beginners with no prior experience in the tasks they are expected to perform. This stage aptly describes the initial phases of my PhD journey, where I navigated the unfamiliar terrain of conducting primary research. Tasks such as designing the study, applying for ethical approvals, and recruiting participants were new and a significant learning curve. At this stage, my actions were largely driven by rules and guidelines, with limited ability to apply discretionary judgment. As I gained more experience, enhanced skills, and recognition of patterns, I progressed to the advanced beginner stage. Through iterative experiences such as preparing peer-reviewed publications, presenting at conferences, drafting sections of the thesis, and successfully navigating ethical approvals, my competency grew. Reaching competency**,** I managed the research process

more effectively, making informed decisions and handling complexities with greater confidence. Finally, at the expert stage, I developed a deep understanding of the subject matter, marked by an expert awareness of the literature and appropriate application of theoretical frameworks and underpinning philosophical assumptions.

8.10 Conclusion

This chapter has presented a discussion of the findings of this mixed methods study. A clear direction regarding how the study's objectives were addressed was provided throughout. Therefore, the overarching research question has been comprehensively addressed. Further insights informed the development of services for lymphoma cancer survivors through the direction of recommendations relevant to lymphoma survivorship. This study presented the opportunity to build on previous work through a mixed methods design identifying the unmet needs of lymphoma survivors and the factors associated with higher unmet needs such as specific groups or impactful areas for intervention during survivorship. The results of this current study highlight gaps in the delivery of cancer care to adult lymphoma survivors in the short-term period following diagnosis; by identifying areas in need of improvement, these findings can guide the development of services that respond to survivors' needs and improve care. The key findings from this research suggest that lymphoma survivors have a myriad of interconnecting unmet needs which have reciprocal relationships with quality of life outcomes (e.g., better quality of life corresponds with fewer unmet needs).

The findings from this study reflect the needs articulated in the Supportive Care Framework by Fitch (2008), including physical, psychosocial, emotional, and practical domains, as well as within reports concerning unmet needs from other investigators (Bron et al., 2017; Burg et al., 2015; Hall et al., 2013; Herrmann et al., 2020; Kim et al., 2017; Lobb et al., 2009). The application of the Integrated Cancer Care Framework in the context of this mixed methods' integrated findings incorporated the variable and nuanced experiences of individuals undergoing a lymphoma cancer journey. Therefore, the theoretical implications of this research have received detailed consideration in this chapter.

Despite the growing bodies supporting survivorship as a critical period in the cancer trajectory, the short-term period has been largely underserved by current literature. This is especially evident for lymphoma survivors, a heterogeneous group of cancer which crosses the lifespan with extended survivorship in which literature has predominantly focused on the treatment phase or long-term impacts. Furthermore, when focusing on lymphoma-specific evidence, the bolus of research focuses on treatment and late effects or reflects the experiences of children and adolescents as it is one of the most commonly diagnosed cancers for these younger age groups (Miller et al., 2022; Wu et al., 2022). One of the barriers to effective survivorship cancer care is identifying how this should be set up, who should monitor, assess, and develop the service and what specific patient groups will benefit from it (Powel & Seibert, 2017; Rosenzweig et al., 2017). This research has identified that lymphoma would benefit from survivorship support in the period one to five years post-diagnosis as participants reported dealing with a myriad of unmet needs across various domains. Yet not every lymphoma survivor will need the same services or necessarily have access

to the same services. It is likely a tailored approach to follow-up care will be required, supported by an integrated care model for cancer care services. Effectively, cancer centres require access to a range of expertise, resources and joined-up thinking to meet the needs of the survivor population. The appropriate investment and infrastructure are fundamental to their efficiency and effectiveness. Multiple aspects of lymphoma survivorship would benefit from enhanced understanding and awareness of lymphoma as a type of cancer. Future research should endeavour to address the sparse focus on lymphoma-specific research and disparate reporting, which to date has impaired the emphasis of this group at the policy level with direct implications to practice and allocation of resources. Lastly, the original contribution of this research has been outlined, including the clinical implications.

Reference List

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., de Haes, J. C., & et al. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst*, *85*(5), 365-376. https://doi.org/10.1093/jnci/85.5.365

Abd Gani, N. I., Rathakrishnan, M., & Krishnasamy, H. N. (2020). Development and Content Validity of an Instrument: Perspectives from Expert Reviewers. *Solid State Technology*, *63*(3), 269-279.

Adams, M. J., Constine, L. S., & Lipshultz, S. E. (2007). Late effects of therapy for Hodgkin's lymphoma. *Current hematologic malignancy reports*, *2*(3), 143-150. https://doi.org/10.1007/s11899-007-0020-4

Adler, N. E., & Page, A. (2008). Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. *In Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*.

Afiyanti, Y., Milanti, A., & Putri, R. H. (2018). Supportive care needs in predicting the quality of life among gynecological cancer patients. *Canadian Oncology Nursing Journal*, *28*(1), 22-29. https://doi.org/10.5737/236880762812229

Agbejule, O. A., Hart, N. H., Ekberg, S., Crichton, M., & Chan, R. J. (2022). Self-management support for cancer-related fatigue: A systematic review. *International Journal of Nursing Studies*, *129*, 104206. https://doi.org/https://doi.org/10.1016/j.ijnurstu.2022.104206

Agostinelli, G., Muzzatti, B., Serpentini, S., Spina, M., & Annunziata, M. A. (2022). Cancer-Related Psychological Distress in Lymphoma Survivor: An Italian Cross-Sectional Study [Original Research]. *Frontiers in Psychology*, *13*. https://doi.org/10.3389/fpsyg.2022.872329

Ahmed, S., Berzon, R. A., Revicki, D. A., Lenderking, W. R., Moinpour, C. M., Basch, E., Reeve, B. B., & Wu, A. W. (2012). The Use of Patient-reported Outcomes (PRO) Within Comparative Effectiveness Research: Implications for Clinical Practice and Health Care Policy. *Medical Care*, *50*(12), 1060-1070. http://www.jstor.org/stable/41714633

Al Khabori, M., de Almeida, J. R., Guyatt, G. H., Kuruvilla, J., & Crump, M. (2011). Autologous Stem Cell Transplantation in Follicular Lymphoma: a Systematic Review and Meta-analysis. *JNCI: Journal of the National Cancer Institute*, *104*(1), 18-28. https://doi.org/10.1093/jnci/djr450

Alabdaljabar, M. S., Durani, U., Thompson, C. A., Constine, L. S., & Hashmi, S. K. (2022). The forgotten survivor: A comprehensive review on <scp>Non-Hodgkin</scp> lymphoma survivorship. *American Journal of Hematology*, *97*(12), 1627-1637. https://doi.org/10.1002/ajh.26719

Albreht, T., Andrés, J. B., Dalmas, M., De Lorenzo, F., Ferrari, C., Honing, C., Huovinen, R., Kaasa, S., Kiasuwa, R., & Knudsen, A. (2017). Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States. *European Guide on Quality Improvement in Comprehensive Cancer Control. Scientific Institute of Public Health, National Institute of Public Health, Brussels*.

Aldridge, V. K., Dovey, T. M., & Wade, A. (2017). Assessing test-retest reliability of psychological measures: Persistent methodological problems. *European Psychologist*, *22*(4), 207.

Algeo, N., Bennett, K., & Connolly, D. (2022). Breast cancer survivorship and employment in Ireland: Legislative systems and the return to work of women with breast cancer. *Work*, *71*, 927-939. https://doi.org/10.3233/WOR-205044

Alpert, M. I., & Peterson, R. A. (1972). On the interpretation of canonical analysis. *Journal of marketing Research*, *9*(2), 187-192.

Amatya, B., Khan, F., Lew, T. E., & Dickinson, M. (2021). Rehabilitation in patients with lymphoma: An overview of Systematic Reviews. *J Rehabil Med*, *53*(3), jrm00163. https://doi.org/10.2340/16501977-2810

Anderson, J. K., & Mehta, A. (2019). A review of chimeric antigen receptor T-cells in lymphoma. *Expert Review of Hematology*, *12*(7), 551-561.

Andersson, A., Enblad, G., Erlanson, M., Johansson, A. S., Molin, D., Tavelin, B., Näslund, U., & Melin, B. (2021). High risk of cardiovascular side effects after treatment of Hodgkin's lymphoma – Is there a need for intervention in long-term survivors? [Review]. *Upsala Journal of Medical Sciences*, *126*(1), Article e6117. https://doi.org/10.48101/ujms.v126.6117

Andersson, A., Enblad, G., Gustavsson, A., Erlanson, M., Hagberg, H., Molin, D., Tavelin, B., & Melin, B. (2011). Long term risk of infections in Hodgkin lymphoma long-term survivors. *British Journal of Haematology*, *154*(5), 661-663. https://doi.org/10.1111/j.1365-2141.2011.08638.x

Annibali, O., Pensieri, C., Tomarchio, V., Biagioli, V., Pennacchini, M., Tendas, A., Tambone, V., & Tirindelli, M. C. (2017). Protective Isolation for Patients with Haematological Malignancies: A Pilot Study Investigating Patients' Distress and Use of Time. *Int J Hematol Oncol Stem Cell Res*, *11*(4), 313-318.

Ansell, S. M. (2020). Hodgkin lymphoma: A 2020 update on diagnosis, risk-stratification, and management. *American Journal of Hematology*, *95*(8), 978-989. https://doi.org/https://doi.org/10.1002/ajh.25856

Arboe, B., Olsen, M. H., Goerloev, J. S., Duun-Henriksen, A. K., Johansen, C., Dalton, S. O., & de Nully Brown, P. (2017). Return to work for patients with diffuse large B-cell lymphoma and transformed indolent lymphoma undergoing autologous stem cell transplantation. *Clinical Epidemiology*, *9*, 321-329. https://doi.org/10.2147/CLEP.S134603

Arden-Close, E., Absolom, K., Greenfield, D. M., Hancock, B. W., Coleman, R. E., & Eiser, C. (2011). Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. *Psycho-Oncology*, *20*(11), 1202-1210. https://doi.org/10.1002/pon.1835

Arden-Close, E., Pacey, A., & Eiser, C. (2010). Health-related quality of life in survivors of lymphoma: a systematic review and methodological critique. *Leukemia & lymphoma*, *51*(4), 628-640. https://doi.org/10.3109/10428191003587263

Armitage, J. O., Gascoyne, R. D., Lunning, M. A., & Cavalli, F. (2017). Non-Hodgkin lymphoma. *The Lancet*, *390*(10091), 298-310. https://doi.org/10.1016/s0140-6736(16)32407-2

Asadi-Lari, M., Packham, C., & Gray, D. (2003). Need for redefining needs. *Health Qual Life Outcomes*, *1*, 34. https://doi.org/10.1186/1477-7525-1-34

Australian Institute of Health and Welfare. (2021). *Cancer in Australia* (cancer series no. 133). Australian Institute of Health and Welfare, Australia.

Ayyappan, S., & Maddocks, K. (2019). Novel and emerging therapies for B cell lymphoma. *Journal of Hematology & Oncology*, *12*(1). https://doi.org/10.1186/s13045-019-0752-3

Baker, C., & Mansfield, Z. (2023). *Cancer statistics for England*. House of Commons Library, London.

Barido, G. T., Campbell-Gauthier, G. D., Mang-Lawson, A. M., Mangelsdorff, A. D., & Finstuen, K. (2008). Patient satisfaction in military medicine: model refinement and assessment of continuity of care effects. *Military medicine*, *173*(7), 641-646.

Barré, S., McElwee, J., Calhoun, C., Weant, K. A., Maldonado, A., & Bell, C. M. (2022). Review of Hematological and Oncological Emergencies. *Advanced Emergency Nursing Journal*, *44*(2). https://journals.lww.com/aenjournal/fulltext/2022/04000/review_of_hematological_and_oncological.3.aspx

Bauwens, S., Baillon, C., Distelmans, W., & Theuns, P. (2014). Systematic screening for distress in oncology practice using the Distress Barometer: the impact on referrals to psychosocial care. *Psycho-Oncology*, *23*(7), 804-811.

Bazeley, P. (2017). Integrating analyses in mixed methods research. *Integrating Analyses in Mixed Methods Research*, 1-344.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. Oxford University Press, USA.

Beaven, A. W., Samsa, G., Zimmerman, S., & Smith, S. K. (2016). Quality of Life is Similar between Long-term Survivors of Indolent and Aggressive Non-Hodgkin Lymphoma. *Cancer Investigation*, *34*(6), 279-285. https://doi.org/10.1080/07357907.2016.1194427

Beck, C. T., & Gable, R. K. (2001). Ensuring Content Validity: An Illustration of the Process. *Journal of Nursing Measurement* (2), 201-215. https://doi.org/10.1891/1061-3749.9.2.201

Behringer, K., Goergen, H., Müller, H., Thielen, I., Brillant, C., Kreissl, S., Halbsguth, T. V., Meissner, J., Greil, R., Moosmann, P., Shonukan, O., Rueffer, J. U., Flechtner, H.-H., Fuchs, M., Diehl, V., Engert, A., & Borchmann, P. (2016). Cancer-Related Fatigue in Patients with and Survivors of Hodgkin Lymphoma: The Impact on Treatment Outcome and Social Reintegration. *Journal of Clinical Oncology*, *34*(36), 4329-4337. https://doi.org/10.1200/jco.2016.67.7450

Benner, P. (1982). *From novice to expert*. American Journal of Nursing, 402-7.

Berger, A. M., Mitchell, S. A., Jacobsen, P. B., & Pirl, W. F. (2015). Screening, evaluation, and management of cancer-related fatigue: Ready for implementation to practice? *CA: a cancer journal for clinicians*, *65*(3), 190-211.

Berman, R., Davies, A., Cooksley, T., Gralla, R., Carter, L., Darlington, E., Scotté, F., & Higham, C. (2020). Supportive care: an indispensable component of modern oncology. *Clinical Oncology*, *32*(11), 781-788.

Biagioli, V., Piredda, M., Mauroni, M. R., Alvaro, R., & De Marinis, M. G. (2016). The lived experience of patients in protective isolation during their hospital stay for allogeneic haematopoietic stem cell transplantation. *European Journal of Oncology Nursing*, *24*, 79-86. https://doi.org/https://doi.org/10.1016/j.ejon.2016.09.001

Boffetta, P. (2011). I. Epidemiology of adult non-Hodgkin lymphoma. *Annals of oncology*, *22*(Supplement 4), 27-31. https://doi.org/10.1093/annonc/mdr167

Boland, V., Drury, A., & Brady, A.-M. (2023). Content comparison of unmet needs self-report measures for lymphoma cancer survivors: A systematic review. *Plos one*, *18*(12), e0290729.

Boland, V., Drury, A., Sheaf, G., & Brady, A. M. (2022). Living with or beyond lymphoma: A rapid review of the unmet needs of lymphoma survivors. *Psycho-Oncology*, *31*(7), 1076-1101.

Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., Boyes, A., & Group, S. C. R. (2000). Evaluation of an instrument to assess the needs of patients with cancer. *Cancer*, *88*(1), 217-225.

Boote, J., Wong, R., & Booth, A. (2015). 'Talking the talk or walking the walk?'A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. *Health Expectations*, *18*(1), 44-57.

Bowling, A. (2014). *Research methods in health: investigating health and health services* (4 ed.). McGraw-hill Education.

Boyes, A., Girgis, A., & Lecathelinais, C. (2009). Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *Journal of evaluation in clinical practice*, *15*(4), 602-606.

Boyes, A. W., Girgis, A., D'Este, C., & Zucca, A. C. (2012). Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: A population-based cross-sectional study. *BMC Cancer*, *12*. https://doi.org/10.1186/1471-2407-12-150

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage Publications.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597.

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 201-216. https://doi.org/10.1080/2159676x.2019.1704846

Bron, D., Aurer, I., André, M. P. E., Bonnet, C., Caballero, D., Falandry, C., Kimby, E., Soubeyran, P., Zucca, E., Bosly, A., & Coiffier, B. (2017). Unmet needs in the scientific approach to older patients with lymphoma [Editorial]. *haematologica*, *102*(6), 972-975. https://doi.org/10.3324/haematol.2017.167619

Brown, M., & Cutler, T. (2012). *Haematology nursing*. John Wiley & Sons.

Bryman, A. (1988). Quantity and quality in social research. Routledge, London.

Burkart, M., Sanford, S., Dinner, S., Sharp, L., & Kinahan, K. (2019). Future health of AYA survivors. *Pediatric Blood & Cancer*, *66*(2), e27516. https://doi.org/https://doi.org/10.1002/pbc.27516

Byrne, J., Campbell, H., Gilchrist, M., Summersby, E., & Hennessy, B. (2018). Barriers to care for breast cancer: A qualitative study in Ireland. *European Journal of Cancer Care*, *27*(5), e12876. https://doi.org/https://doi.org/10.1111/ecc.12876

Cameron, R. (2013). Lessons from the field: Applying the good reporting of a mixed methods study (GRAMMS) framework. *Electronic Journal of Business Research Methods*, *11*(2), 55-66.

Campbell, H. S., Hall, A. E., Sanson-Fisher, R. W., Barker, D., Turner, D., & Taylor-Brown, J. (2014). Development and validation of the Short-Form Survivor Unmet Needs Survey (SF-SUNS). *Supportive Care in Cancer*, *22*(4), 1071-1079. https://doi.org/10.1007/s00520-013-2061-7

Campbell, H. S., Sanson-Fisher, R., Turner, D., Hayward, L., Wang, X. S., & Taylor-Brown, J. (2011). Psychometric properties of cancer survivors' unmet needs survey. *Supportive Care in Cancer*, *19*(2), 221-230. https://doi.org/10.1007/s00520-009-0806-0

Campo, E., Swerdlow, S. H., Harris, N. L., Pileri, S., Stein, H., & Jaffe, E. S. (2011). The 2008 WHO classification of lymphoid neoplasms and beyond: evolving concepts and practical applications. *Blood, The Journal of the American Society of Hematology*, *117*(19), 5019-5032.

Campo, R. A., Leniek, K. L., Gaylord-Scott, N., Faurot, K. R., Smith, S., Asher, G., Porterfield, D., & Gaylord, S. A. (2016). Weathering the seasons of cancer survivorship: mind-body therapy use and reported reasons and outcomes by stages of cancer survivorship. *Supportive Care in Cancer*, *24*(9), 3783-3791. https://doi.org/10.1007/s00520-016-3200-8

Canadian Cancer Society. (2003). Breaking down the barriers: study of cancer patient and caregiver needs in Ontario. The Canadian Cancer Society, Toronto, Canada.

Cartwright, A., Snowden, J. A., Whitehouse, H., Scott, S., & Whitby, L. (2022). Implementation of the updated NICE haematological cancers (NG47) improving outcomes guidelines across Specialist

Integrated Haematological Malignancy Diagnostic Services (SIHMDS) in England: a UK NEQAS LI survey. *Journal of Clinical Pathology*.

Celis, J. E., & Heitor, M. (2019). Towards a mission-oriented approach to cancer in Europe: an unmet need in cancer research policy. *Molecular oncology*, *13*(3), 502-510.

Celis, J. E., & Pavalkis, D. (2017). A mission-oriented approach to cancer in Europe: a joint mission/vision 2030. *Molecular oncology*, *11*(12), 1661-1672.

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S. B., Winicour, P., & Brannon, J. (1993). The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of Clinical Oncology*, *11*(3), 570-579.

Central Statistics Office. (2016). *Census 2016 Summary Results - Part 1*. https://www.cso.ie/en/csolatestnews/presspages/2017/census2016summaryresults-part1/

Chan, R. J., Crawford-Williams, F., Crichton, M., Joseph, R., Hart, N. H., Milley, K., Druce, P., Zhang, J., Jefford, M., Lisy, K., Emery, J., & Nekhlyudov, L. (2023). Effectiveness and implementation of models of cancer survivorship care: an overview of systematic reviews. *Journal of Cancer Survivorship*, *17*(1), 197-221. https://doi.org/10.1007/s11764-021-01128-1

Chan, R. J., Crichton, M., Crawford-Williams, F., Agbejule, O. A., Yu, K., Hart, N. H., de Abreu Alves, F., Ashbury, F. D., Eng, L., Fitch, M., Jain, H., Jefford, M., Klemanski, D., Koczwara, B., Loh, K., Prasad, M., Rugo, H., Soto-Perez-de-Celis, E., van den Hurk, C., & Chan, A. (2021). The efficacy, challenges, and facilitators of telemedicine in post-treatment cancer survivorship care: an overview of systematic reviews. *Annals of Oncology*, *32*(12), 1552-1570. https://doi.org/https://doi.org/10.1016/j.annonc.2021.09.001

Chassany, O., Sagnier, P., Marquis, P., Fullerton, S., Aaronson, N., & Group, E. R. I. o. Q. o. L. A. (2002). Patient-reported outcomes: the example of health-related quality of life—a European guidance document for the improved integration of health-related quality of life assessment in the drug regulatory process. *Drug Information Journal*, *36*(1), 209-238.

Chen, A. B., Feng, Y., Neuberg, D., Recklitis, C., Diller, L. R., Mauch, P. N., & Ng, A. K. (2012). Employment and insurance in survivors of Hodgkin lymphoma and their siblings: a questionnaire study. *Leukemia & lymphoma*, *53*(8), 1474-1480. https://doi.org/10.3109/10428194.2012.660629

Chen, L., Payne, J. B., Dance, K. V., Imbody, C. B., Ho, C. D., Ayers, A. A., & Flowers, C. R. (2020). Priorities for Rural Lymphoma Survivors: A Qualitative Study. *Clinical Lymphoma, Myeloma and Leukemia*, *20*(1), 47-52. https://doi.org/10.1016/j.clml.2019.09.599

Cherny, N. I., Abernethy, A. P., Strasser, F., Sapir, R., Currow, D., & Zafar, S. Y. (2009). Improving the methodologic and ethical validity of best supportive care studies in oncology: lessons from a systematic review. *Journal of Clinical Oncology*, *27*(32), 5476-5486.

Cheung, Y. B., Goh, C., Wong, L. C., Ng, G. Y., Lim, W. T., Leong, S. S., Tan, E. H., & Khoo, K. S. (2004). Quick-FLIC: validation of a short questionnaire for assessing quality of life of cancer patients. *British journal of cancer*, *90*(9), 1747-1752. https://doi.org/10.1038/sj.bjc.6601782

Chhikara, B. S., & Parang, K. (2023). Global Cancer Statistics 2022: the trends projection analysis. *Chemical Biology Letters*, *10*(1), 451-451.

Chircop, D., & Scerri, J. (2018). The lived experience of patients with non-Hodgkin's lymphoma undergoing chemotherapy. *European Journal of Oncology Nursing*, *35*, 117-121. https://doi.org/https://doi.org/10.1016/j.ejon.2018.07.003

Chihara, D., Ito, H., Matsuda, T., Shibata, A., Katsumi, A., Nakamura, S., Tomotaka, S., Morton, L. M., Weisenburger, D. D., & Matsuo, K. (2014). Differences in incidence and trends of haematological

malignancies in Japan and the United States. *British Journal of Haematology*, *164*(4), 536-545. https://doi.org/10.1111/bjh.12659

Ciavarella, S., Minoia, C., Quinto, A. M., Oliva, S., Carbonara, S., Cormio, C., Cox, M. C., Bravo, E., Santoro, F., Napolitano, M., Spina, M., Loseto, G., & Guarini, A. (2017). Improving Provision of Care for Long-term Survivors of Lymphoma. *Clinical Lymphoma Myeloma and Leukemia*, *17*(12), e1-e9. https://doi.org/https://doi.org/10.1016/j.clml.2017.08.097

Citizens Information. (2022). *Health system*. Retrieved 27/11/23 from https://www.citizensinformation.ie/en/health/health-system/entitlement-to-public-health-services/

Clarke, V., & Braun, V. (2021). *Thematic analysis: a practical guide*. Sage Publications, London.

Clover, K., Kelly, P., Rogers, K., Britton, B., & Carter, G. L. (2013). Predictors of desire for help in oncology outpatients reporting pain or distress. *Psycho-Oncology*, *22*(7), 1611-1617.

Coons, S. J., Rao, S., Keininger, D. L., & Hays, R. D. (2000). A Comparative Review of Generic Quality-of-Life Instruments. *PharmacoEconomics*, *17*(1), 13-35. https://doi.org/10.2165/00019053-200017010-00002

Costa, D. S., Mercieca-Bebber, R., Rutherford, C., Tait, M.-A., & King, M. T. (2021). How is quality of life defined and assessed in published research? *Quality of Life Research*, *30*, 2109-2121.

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*, *26*(3), 623-630.

Cramer, D. (1994). *Introducing statistics for social research: Step-by-step calculations and computer techniques using SPSS*. Routledge, London.

Creamer, E. G. (2018). *An Introduction to Fully Integrated Mixed Methods Research*. Sage Publications. https://doi.org/10.4135/9781071802823

Crespi, C. M., Ganz, P. A., Petersen, L., Castillo, A., & Caan, B. (2008). Refinement and psychometric evaluation of the impact of cancer scale. *JNCI: Journal of the National Cancer Institute*, *100*(21), 1530-1541.

Crespi, C. M., Smith, S. K., Petersen, L., Zimmerman, S., & Ganz, P. A. (2010). Measuring the impact of cancer: a comparison of non-Hodgkin lymphoma and breast cancer survivors. *Journal of Cancer Survivorship*, *4*(1), 45-58.

Creswell, J. W. (2002). *Educational research: Planning, conducting, and evaluating quantitative*. Pearson.

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5 ed.). Sage Publications.

Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Smith, K. C. (2011). Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health*, *2013*, 541-545.

Creswell, J. W., & Plano-Clark, V. L. (2017). *Designing and Conducting Mixed Methods Research*. SAGE Publications.

Crico, C., Sanchini, V., Casali, P. G., & Pravettoni, G. (2022). Ethical issues in oncology practice: a qualitative study of stakeholders' experiences and expectations. *BMC Medical Ethics*, *23*(1), 67. https://doi.org/10.1186/s12910-022-00803-x

Crist, J. V., & Grunfeld, E. A. (2013). Factors reported to influence fear of recurrence in cancer patients: a systematic review. *Psycho-Oncology*, *22*(5), 978-986. https://doi.org/10.1002/pon.3114

Cunningham, J., Iyengar, S., & Sharma, B. (2017). Evolution of lymphoma staging and response evaluation: current limitations and future directions. *Nature Reviews Clinical Oncology*, *14*(10), 631-645. https://doi.org/10.1038/nrclinonc.2017.78

Dalley, C., Basarir, H., Wright, J., Fernando, M., Pearson, D., Ward, S., Thokula, P., Krishnankutty, A., Wilson, G., & Dalton, A. (2015). Specialist integrated haematological malignancy diagnostic services: an Activity Based Cost (ABC) analysis of a networked laboratory service model. *Journal of Clinical Pathology*.

Damlaj, M., El Fakih, R., & Hashmi, S. K. (2019). Evolution of survivorship in lymphoma, myeloma and leukemia: Metamorphosis of the field into long term follow-up care. *Blood Reviews*, *33*, 63-73. https://doi.org/10.1016/j.blre.2018.07.003

Daniel, W. W. (1999). *Biostatistics: a foundation for analysis in the health sciences* (7 ed.). Wiley.

Daniel, W. W., & Cross, C. L. (2018). *Biostatistics: a foundation for analysis in the health sciences*. Wiley.

Dapkevičiūtė, A., Šapoka, V., Martynova, E., & Pečeliūnas, V. (2019). Time from Symptom Onset to Diagnosis and Treatment among Haematological Malignancies: Influencing Factors and Associated Negative Outcomes. *Medicina*, *55*(6), 238. https://doi.org/10.3390/medicina55060238

Darley, A., Coughlan, B., & Furlong, E. (2021). People with cancer and their family caregivers' personal experience of using supportive eHealth technology: a narrative review. *European Journal of Oncology Nursing*, *54*, 102030.

Darley, A., Coughlan, B., Maguire, R., McCann, L., & Furlong, E. (2023). A bridge from uncertainty to understanding: The meaning of symptom management digital health technology during cancer treatment. *DIGITAL HEALTH*, *9*, 20552076231152163. https://doi.org/10.1177/20552076231152163

Davies, E. L., Gordon, A. L., Pelentsov, L. J., & Esterman, A. J. (2019). The supportive care needs of individuals recovering from first episode psychosis: A scoping review. *Perspectives in Psychiatric Care*, *55*(1), 6-14. https://doi.org/10.1111/ppc.12259

De Angelis, R., Minicozzi, P., Sant, M., Dal Maso, L., Brewster, D. H., Osca-Gelis, G., Visser, O., Maynadié, M., Marcos-Gragera, R., & Troussard, X. (2015). Survival variations by country and age for lymphoid and myeloid malignancies in Europe 2000–2007: Results of EUROCARE-5 population-based study. *European Journal of Cancer*, *51*(15), 2254-2268.

de Leeuw, J., & Larsson, M. (2013). Nurse-led follow-up care for cancer patients: what is known and what is needed. *Supportive Care in Cancer*, *21*(9), 2643-2649. https://doi.org/10.1007/s00520-013-1892-6

De Silva, M. J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C., & Patel, V. (2014). Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials*, *15*(1), 267. https://doi.org/10.1186/1745-6215-15-267

De Vet, H. C., Terwee, C. B., Mokkink, L. B., & Knol, D. L. (2011). *Measurement in medicine: a practical guide*. Cambridge university press.

Deckx, L., van den Akker, M., & Buntinx, F. (2014). Risk factors for loneliness in patients with cancer: A systematic literature review and meta-analysis. *European Journal of Oncology Nursing*, *18*(5), 466-477. https://doi.org/https://doi.org/10.1016/j.ejon.2014.05.002

Denlinger, C. S., Carlson, R. W., Are, M., Baker, K. S., Davis, E., Edge, S. B., Friedman, D. L., Goldman, M., Jones, L., & King, A. (2014). Survivorship: introduction and definition. *Journal of the National Comprehensive Cancer Network*, *12*(1), 34-45.

Denzin, N. K. (2012). Triangulation 2.0. *Journal of Mixed Methods Research*, *6*(2), 80-88.

Department of Health. (2006). *National Cancer Strategy*. Dublin, Ireland: Department of Health.

Department of Health. (2017). *National Cancer Strategy 2017 - 2026*. Dublin, Ireland Department of Health.

Department of Health. (2020). *Evaluation of the Impact of Implementing a Draft Policy to Develop Advanced Nurse Practitioners (cANPs/RANPs) to Meet Health Service Needs*. Ireland Retrieved from https://healthservice.hse.ie/filelibrary/onmsd/final-evaluation-report-on-the-impact-of-implementing-the-draft-policy-on-graduate-specialist-and-advanced-nursing-practice.pdf

Department of Health. (2022). *Report of the Expert Review Body on Nursing and Midwifery*. Ireland Retrieved from https://www.gov.ie/pdf/?file=https://assets.gov.ie/219846/ea2cf1ee-ec4c-4a55-aeb7-2e5504e62c5d.pdf#page=null

Department of Health. (2023). *National cancer strategy 2017-2026 implementation report 2022*. Department of Health, Dublin, Ireland: Department of Health Retrieved from https://www.gov.ie/pdf/?file=https://assets.gov.ie/259707/2d7d2291-b190-41be-86ab-2645ddb45c94.pdf#page=null

Department of Health and Children. (1996). *Cancer Services in Ireland: A National Strategy*. Department of Health and Children, Dublin, Ireland.

Department of Health (2014). National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *The Belmont Report. Ethical principles and guidelines for the protection of human subjects of research.* Department of Health, Education and Welfare, Indiana.

Department of Health UK. (2013). *Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)*. https://assets.publishing.service.gov.uk/media/5a74c301e5274a3f93b489b6/9333-TSO-2900664-NCSI_Report_FINAL.pdf

Dewey, J. (1929). *The Quest for Certainty.* Minton Balch and Company, New York.

Dewey, J. (1932). Philosophy and civilization. *Philosophical review*, *41*(a).

Dewey, J. (1938). *Logic: The Theory of Enquiry.* Henry Holt & Co, New York.

Dey, I. (1999). *Grounding grounded theory: Guidelines for qualitative inquiry.* Academic Press.

Dilworth, S., Higgins, I., Parker, V., Kelly, B., & Turner, J. (2014). Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review. *Psycho-Oncology*, *23*(6), 601-612.

Doyle, L., Brady, A.-M., & Byrne, G. (2016). An overview of mixed methods research – revisited. *Journal of Research in Nursing*, *21*(8), 623-635. https://doi.org/10.1177/1744987116674257

Draucker, C. B., Martsolf, D. S., & Poole, C. (2009). Developing distress protocols for research on sensitive topics. *Archives of Psychiatric Nursing*, *23*(5), 343-350.

Droog, E., Armstrong, C., & MacCurtain, S. (2014). Supporting Patients During Their Breast Cancer Journey: The Informational Role of Clinical Nurse Specialists. *Cancer Nursing*, *37*(6), 429-435. https://doi.org/10.1097/ncc.0000000000000109

Drury, A., Boland, V., and Dowling, M. 2024. Optimising the use of Patient Reported Outcome Measures in Symptom Management: What is the role of Advanced Practice Nurses? *Seminars in Oncology Nursing*, *40*(3), 151632.

Drury, A., Payne, S., & Brady, A.-M. (2017a). Cancer survivorship: advancing the concept in the context of colorectal cancer. *European Journal of Oncology Nursing*, *29*, 135-147.

Drury, A., Payne, S., & Brady, A.-M. (2017b). The cost of survival: an exploration of colorectal cancer survivors' experiences of pain. *Acta Oncologica*, *56*(2), 205-211.

Drury, A., Payne, S., & Brady, A.-M. (2020). Colorectal cancer survivors' quality of life: a qualitative study of unmet need. *BMJ Supportive & Palliative Care*, bmjspcare-2020-002190. https://doi.org/10.1136/bmjspcare-2020-002190

Drury, A., Payne, S., & Brady, A.-M. (2022). Prevalence vs impact: a mixed methods study of survivorship issues in colorectal cancer. *Quality of Life Research*, *31*(4), 1117-1134. https://doi.org/10.1007/s11136-021-02975-2

Drury, A., Sheila, P., & Anne-Marie, B. (2023). Adapting the pillar integration process for theory development: the theoretical model of healthcare factors influencing quality of life in cancer survivorship. *Journal of Mixed Methods Research*, *17*(3), 264-287.

Duijts, S. F. A., Van Egmond, M. P., Spelten, E., Van Muijen, P., Anema, J. R., & Van Der Beek, A. J. (2014). Physical and psychosocial problems in cancer survivors beyond return to work: A systematic review. *Psycho-Oncology*, *23*(5), 481-492. https://doi.org/10.1002/pon.3467

Edwards-Bennett, S., Jacks, L., Moskowitz, C., Wu, E., Zhang, Z., Noy, A., Portlock, C., Straus, D., Zelenetz, A., & Yahalom, J. (2010). Stanford V program for locally extensive and advanced Hodgkin lymphoma: the Memorial Sloan-Kettering Cancer Center experience. *Annals of Oncology*, *21*(3), 574-581.

Eichenauer, D. A., Aleman, B. M., André, M., Federico, M., Hutchings, M., Illidge, T., Engert, A., & Ladetto, M. (2018). Hodgkin lymphoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*, *29*, iv19-iv29.

Eichenauer, D. A., Engert, A., André, M., Federico, M., Illidge, T., Hutchings, M., & Ladetto, M. (2014). Hodgkin's lymphoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*, *25*, 70-75.

Ekels, A., Oerlemans, S., Schagen, S. B., Issa, D. E., Thielen, N., Nijziel, M. R., van der Poel, M. W. M., Arts, L. P. J., Posthuma, E. F. M., & van de Poll-Franse, L. V. (2023). The course of self-perceived cognitive functioning among patients with lymphoma and the co-occurrence with fatigue and psychological distress. *Journal of Cancer Survivorship*. https://doi.org/10.1007/s11764-023-01458-2

El-Jawahri, A., Traeger, L., Kuzmuk, K., Eusebio, J., Vandusen, H., Keenan, T., Shin, J., Gallagher, E. R., Greer, J. A., & Pirl, W. F. (2015). Prognostic understanding, quality of life and mood in patients undergoing hematopoietic stem cell transplantation. *Bone Marrow Transplantation*, *50*(8), 1119-1124.

El-Sharkawi, D., & Iyengar, S. (2020). Haematological cancers and the risk of severe COVID-19: Exploration and critical evaluation of the evidence to date. *British Journal of Haematology*, *190*(3), 336-345. https://doi.org/https://doi.org/10.1111/bjh.16956

ElSadr, C. B., Noureddine, S., & Kelley, J. (2009). Concept analysis of loneliness with implications for nursing diagnosis. *International Journal of Nursing Terminologies and Classifications*, *20*(1), 25-33.

Enam, N., Chou, K., & Stubblefield, M. D. (2021). Prevalence of function-limiting late effects in Hodgkin lymphoma survivor. *Physical Medicine and Rehabilitation,* *14*(7), 811-817. https://doi.org/10.1002/pmrj.12662

Epelbaum, R. (2000). Non-Hodgkin's lymphoma: long-term survivors and adverse effects. *Annals of Oncology*, *11*(3), 123-130. https://doi.org/10.1093/annonc/11.suppl_3.123

Esser, P., Kuba, K., Mehnert, A., Johansen, C., Hinz, A., Lordick, F., & Götze, H. (2018). Quality of life in survivors of hematological malignancies stratified by cancer type, time since diagnosis and stem cell transplantation. *European journal of haematology*, *101*(3), 340-348. https://doi.org/10.1111/ejh.13104

European Commission. (2022). *Europe's Beating Cancer Plan: Communication from the Commission to the European Parliament and the Council*. Brussels: Commission of the European Communities. Retrieved from https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf

Eurostat. (2019). Distribution of Population by Degree of Urbanisation, Dwelling Type and Income Group—EU-SILC Survey. Retrieved from https://ec.europa.eu/eurostat/web/degree-of-urbanisation/database

Evans Webb, M., Murray, E., Younger, Z. W., Goodfellow, H., & Ross, J. (2021). The Supportive Care Needs of Cancer Patients: a Systematic Review. *Journal of Cancer Education*, *36*(5), 899-908. https://doi.org/10.1007/s13187-020-01941-9

Fauer, A., Choi, S. W., Wallner, L. P., Davis, M. A., & Friese, C. R. (2021). Understanding quality and equity: patient experiences with care in older adults diagnosed with hematologic malignancies. *Cancer Causes and Control*, *32*(4), 379-389. https://doi.org/10.1007/s10552-021-01395-4

Fawcett, J. (2011). The cultural relevance of research instruments. *Journal of Advanced Nursing*, *67*(10), 2079-2079. https://doi.org/10.1111/j.1365-2648.2011.05818.x

Fein, E. C., Gilmour, J., Machin, T., & Hendry, L. (2022). *Statistics for Research Students: An Open Access Resource with Self-Tests and Illustrative Examples*. University of Southern Queensland.

Feng, Y.-S., Kohlmann, T., Janssen, M. F., & Buchholz, I. (2020). Psychometric properties of the EQ-5D-5L: a systematic review of the literature. *Quality of Life Research*, *1*(27). https://doi.org/10.1007/s11136-020-02688-y

Ferlay, J., Ervik, M., Lam, F., Colombet, M., Mery, L., Piñeros, M., Znaor, A., Soerjomataram, I., & Bray, F. (2019). Global cancer observatory: cancer today. *International Journal of Cancer*, *8*(144), 1941-1953.

Ferrell, B. R., Hassey Dow, K., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of Life Research*, *4*(6), 523-531. https://doi.org/10.1007/bf00634747

Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving integration in mixed methods designs—principles and practices. *Health Services Research*, *48*(6pt2), 2134-2156.

Feuerstein, M. (2007). Defining cancer survivorship. *Journal of cancer survivorship: research and practice*, *1*(1), 5-7. https://link.springer.com/article/10.1007%2Fs11764-006-0002-x

Field, A. (2018). Discovering statistics using IBM SPSS statistics 5th ed. In. Thousand Oaks, California: Sage.

Fil, M. (2022). Cancer care: beyond survival [Editorial]. *The Lancet, Cancer Survivorship Series*, *399*.

Finlay, L., & Gough, B. (Eds.). (2003). *Reflexivity: a practical guide for researchers in health and social sciences.* Blackwell Science.

Fisher, S. G., & Fisher, R. I. (2004). The epidemiology of non-Hodgkin's lymphoma. *Oncogene*, *23*(38), 6524-6534. https://doi.org/10.1038/sj.onc.1207843

Fitch, M. (1994). Providing supportive care for individuals living with cancer. *Toronto: Ontario Cancer Treatment and Research Foundation*, *23*.

Fitch, M. (2000). Supportive care for cancer patients. *Hosp Q*, *3*(4), 39-46. https://doi.org/10.12927/hcq..16542

Fitch, M. (2008). Supportive care framework. *Canadian Oncology Nursing Journal*, *18*(1), 6-14.

Fitch, M. I., Coronado, A. C., Schippke, J. C., Chadder, J., & Green, E. (2020). Exploring the perspectives of patients about their care experience: identifying what patients perceive are important qualities in cancer care. *Supportive Care in Cancer*, *28*, 2299-2309.

Fitzmaurice, C., Allen, C., Barber, R. M., Barregard, L., Bhutta, Z. A., Brenner, H., Dicker, D. J., Chimed-Orchir, O., Dandona, R., Dandona, L., Fleming, T., Forouzanfar, M. H., Hancock, J., Hay, R. J., Hunter-Merrill, R., Huynh, C., Hosgood, H. D., Johnson, C. O., Jonas, J. B., . . . Global Burden of Disease Cancer, C. (2017). Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 32 cancer groups, 1990 to 2015: A Systematic Analysis for the Global Burden of Disease Study Global Burden of Disease Cancer Collaboration. *JAMA oncology*, *3*(4), 524-548. https://doi.org/10.1001/jamaoncol.2016.5688

Franceschetti, S., Annunziata, M. A., Agostinelli, G., Gerardi, C., Allocati, E., Minoia, C., & Guarini, A. (2021). Late Neurological and Cognitive Sequelae and Long-Term Monitoring of Classical Hodgkin Lymphoma and Diffuse Large B-Cell Lymphoma Survivors: A Systematic Review by the Fondazione Italiana Linfomi. *Cancers*, *13*(14), 3401. https://www.mdpi.com/2072-6694/13/14/3401

Frick, M. A., Vachani, C. C., Hampshire, M. K., Bach, C., Arnold-Korzeniowski, K., Metz, J. M., & Hill-Kayser, C. E. (2018). Patient-Reported Survivorship Care Practices and Late Effects After Treatment of Hodgkin and Non-Hodgkin Lymphoma. *JCO Clinical Cancer Informatics*, *2*, 1-10. https://doi.org/10.1200/CCI.18.00015

Frost, J. (2020). Regression analysis: an intuitive guide for using and interpreting linear methods. In: Jim Publishing.

Funk, R., Cisneros, C., Williams, R. C., Kendall, J., & Hamann, H. A. (2016). What happens after distress screening? Patterns of supportive care service utilization among oncology patients identified through a systematic screening protocol. *Supportive Care in Cancer*, *24*, 2861-2868.

Furlong, E., Darley, A., Fox, P., Buick, A., Kotronoulas, G., Miller, M., Flowerday, A., Miaskowski, C., Patiraki, E., & Katsaragakis, S. (2019). Adaptation and implementation of a mobile phone–based remote symptom monitoring system for people with cancer in Europe. *Journal of Medical Internet Research Cancer*, *5*(1), e10813.

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, *20*(9), 1408-1416.

Garritty, C., Gartlehner, G., Nussbaumer-Streit, B., King, V. J., Hamel, C., Kamel, C., Affengruber, L., & Stevens, A. (2021). Cochrane Rapid Reviews Methods Group offers evidence-informed guidance to conduct rapid reviews. *Journal of clinical epidemiology*, *130*, 13-22. https://doi.org/10.1016/j.jclinepi.2020.10.007

Gauld, R., Raymont, A., Bagshaw, P. F., Nicholls, M. G., & Frampton, C. M. (2014). The importance of measuring unmet healthcare needs. *New Zealand Medical Journal*, *127*(1404), 63-67.

Gavin, A., Drummond, F. J., & Sharp, L. (2015). Long-term physical effects reported by prostate cancer survivors in Ireland. *Cancer Professional*. https://www.researchgate.net/profile/Frances-Drummond/publication/277715806_Long-term_physical_effects_reported_by_prostate_cancer_survivors_in_Ireland/links/55753e3308ae7536374ff7c5/Long-term-physical-effects-reported-by-prostate-cancer-survivors-in-Ireland.pdf

Geertz, C. (1973). *Thick Description: Towards an Interpretive Theory of Culture*. Routledge.

Georges, G. E., Bar, M., Onstad, L., Yi, J. C., Shadman, M., Flowers, M. E., Carpenter, P. A., Stewart, S., Lee, S. J., & Holmberg, L. A. (2020). Survivorship after Autologous Hematopoietic Cell Transplantation for Lymphoma and Multiple Myeloma: Late Effects and Quality of Life: Late Effects and QOL after Auto-HCT. *Biology of Blood and Marrow Transplantation*, *26*(2), 407-412. https://doi.org/10.1016/j.bbmt.2019.10.002

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal*, *204*(6), 291-295. https://doi.org/10.1038/bdj.2008.192

Gillen, G. (2009). Managing Executive Function Impairments to Optimise Function. *Cognitive and Perceptual Rehabilitation*, 245-283. https://doi.org/https://doi.org/10.1016/B978-0-323-04621-3.10001-4

Gobbi, P. G., Ferreri, A. J. M., Ponzoni, M., & Levis, A. (2013). Hodgkin lymphoma. *Critical Reviews in Oncology/Hematology*, *85*(2), 216-237. https://doi.org/https://doi.org/10.1016/j.critrevonc.2012.07.002

Goodman, R. B. (2005). *Pragmatism: Critical concepts in philosophy*. Taylor & Francis.

Gorard, S. (2021). How to make sense of statistics. *How to Make Sense of Statistics*, 1-296.

Goswami, P., Khatib, Y., & Salek, S. (2019). Haematological malignancy: Are we measuring what is important to patients? A systematic review of quality-of-life instruments. *European Journal of Haematology*, *102*(4), 279-311.

Gough, B., & Madill, A. (2012). Subjectivity in psychological science: from problem to prospect. *Psychological Methods*, *17*(3), 374.

Grant, B. M., & Giddings, L. S. (2002). Making sense of methodologies: A paradigm framework for the novice researcher. *Contemporary nurse*, *13*(1), 10-28.

Grant, C., & Osanloo, A. (2014). Understanding, selecting, and integrating a theoretical framework in dissertation research: Creating the blueprint for your "house". *Administrative Issues Journal*, *4*(2), 4.

Gray, R. E., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). Managing the impact of illness: The experiences of men with prostate cancer and their spouses. *Journal of Health Psychology*, *5*(4), 531-548.

Greally, H., Love, D., & O'Loughlin, B. (2022). *NCCP Best practice guidance for community cancer support centres*. Health Service Executive, Ireland.

Greaves, P., Sarker, S.-J., Chowdhury, K., Johnson, R., Matthews, J., Matthews, R., Smith, M., Korszun, A., Gribben, J. G., & Lister, T. A. (2014). Fertility and sexual function in long-term survivors of haematological malignancy: using patient-reported outcome measures to assess a neglected area of need in the late effects clinic. *British Journal of Haematology*, *164*(4), 526-535. https://doi.org/10.1111/bjh.12651

Guba, E. G. (1990). *The Paradigm Dialogue*. Alternative Paradigms Conference, Indiana. School of Education, San Francisco, CA, US.

Guba, E. G., & Lincoln, Y. S. (1982). Epistemological and methodological bases of naturalistic inquiry. *Educational Technology Research and Development, 30*(4), 233-252.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of Qualitative Research*, *2*(163-194), 105.

Hackett, F., & Dowling, M. (2019). Lymphoma survivors' experiences at the end of treatment. *Journal of Clinical Nursing, 28*(3/4), 400-409. https://doi.org/10.1111/jocn.14658

Hair, J. (2014). *Multivariate Data Analysis (MVDA).* (7 ed.). Pearson Education Limited.

Hall, A., Campbell, H. S., Sanson-Fisher, R., Lynagh, M., D'Este, C., Burkhalter, R., & Carey, M. (2013a). Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology*, *22*(9), 2032-2038.

Hall, A., D'Este, C., Tzelepis, F., Lynagh, M., & Sanson-Fisher, R. (2014). Factors associated with haematological cancer survivors experiencing a high level of unmet need across multiple items of supportive care: a cross-sectional survey study. *Supportive Care in Cancer*, *22*(11), 2899-2909. https://doi.org/10.1007/s00520-014-2264-6

Hall, A., Lynagh, M., Bryant, J., & Sanson-Fisher, R. (2013c). Supportive care needs of hematological cancer survivors: A critical review of the literature. *Critical Reviews in Oncology/Hematology*, *88*(1), 102-116. https://doi.org/10.1016/j.critrevonc.2013.03.008

Hall, A. E., Sanson-Fisher, R. W., Lynagh, M. C., Tzelepis, F., & D'Este, C. (2015). What do haematological cancer survivors want help with? A cross-sectional investigation of unmet supportive care needs. *BMC research notes*, *8*(1), 1-6.

Hardoon, D. R., Szedmak, S., & Shawe-Taylor, J. (2004). Canonical correlation analysis: An overview with application to learning methods. *Neural Computation*, *16*(12), 2639-2664.

Harrington, C. B., Hansen, J. A., Moskowitz, M., Todd, B. L., & Feuerstein, M. (2010). It's not over when it's over: long-term symptoms in cancer survivors—a systematic review. *The International Journal of Psychiatry in Medicine*, *40*(2), 163-181.

Harris, N. L., Jaffe, E. S., Stein, H., Banks, P. M., Chan, J. K., Cleary, M. L., Delsol, G., Falini, B., & Gatter, K. (1994). A revised European-American classification of lymphoid neoplasms: a proposal from the International Lymphoma Study Group. *Blood*, *84*(5), 1361-1392.

Hart, R. I., Cowie, F. J., Jesudason, A. B., & Lawton, J. (2021). Adolescents and young adults' (AYA) views on their cancer knowledge prior to diagnosis: Findings from a qualitative study involving AYA receiving cancer care. *Health Expectations*, *24*(2), 307-316. https://doi.org/https://doi.org/10.1111/hex.13170

Hashmi, S., Carpenter, P., Khera, N., Tichelli, A., & Savani, B. N. (2015). Lost in Transition: The Essential Need for Long-Term Follow-Up Clinic for Blood and Marrow Transplantation Survivors. *Biology of Blood and Marrow Transplantation*, *21*(2), 225-232. https://doi.org/https://doi.org/10.1016/j.bbmt.2014.06.035

Hauken, M. A., Larsen, T. M. B., & Holsen, I. (2013). Meeting Reality: Young Adult Cancer Survivors' Experiences of Reentering Everyday Life After Cancer Treatment. *Cancer Nursing*, *36*(5), E17-E26. https://doi.org/10.1097/NCC.0b013e318278d4fc

Health Insurance Authority. (2021). *Health insurance in Ireland market report 2021*. Retrieved from https://www.hia.ie/sites/default/files/HIA%20Market%20Report%20-%20Final.pdf

Health Service Executive. (2023a, 20 January 2023). *Medical card for over 70s*. Health Service Executive. Retrieved from https://www2.hse.ie/services/schemes-allowances/medical-cards/other-types-of-medical-card/over-70s/

Health Service Executive. (2023b). *Medical cards*. Retrieved from https://www2.hse.ie/services/schemes-allowances/medical-cards/about-the-medical-card/what-it-covers/

Hemminki, K., Hemminki, J., Försti, A., & Sud, A. (2022). Survival trends in hematological malignancies in the Nordic countries through 50 years. *Blood Cancer Journal*, *12*(11), 150.

Henderson, T. O., & Oeffinger, K. C. (2021). Hodgkin Lymphoma Survivors: We Need to Do Better. *Journal od the National Cancer Institute*, *113*(6), 654-655. https://doi.org/10.1093/jnci/djaa196

Herdman, M., Gudex, C., Lloyd, A., Janssen, M., Kind, P., Parkin, D., Bonsel, G., & Badia, X. (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of Life Research*, *20*(10), 1727-1736. https://doi.org/10.1007/s11136-011-9903-x

Hernæs, K. H., Smeland, K. B., Fagerli, U.-M., & Kiserud, C. E. (2021). Post-treatment work patterns amongst survivors of lymphoma treated with high-dose chemotherapy with autologous stem-cell transplantation. *BMC Cancer*, *21*(1), 143. https://doi.org/10.1186/s12885-021-07836-2

Herrmann, A., Mansfield, E., Tzelepis, F., Lynagh, M., & Hall, A. (2020). Use of the supportive care framework to explore haematological cancer survivors' unmet needs: a qualitative study. *BMC Health Services Research*, *20*(1). https://doi.org/10.1186/s12913-020-05927-7

Hewitt, M., Greenfield, S., & Stovall, E. (2005). *From cancer patient to cancer survivor: lost in transition*. National Academies Press.

Higdon, M. L., Atkinson, C. J., & Lawrence, K. V. (2018). Oncologic emergencies: Recognition and initial management [Article]. *American family physician*, *97*(11), 741-748B. https://www.scopus.com/inward/record.uri?eid=2-s2.0-85047860571&partnerID=40&md5=4d3d39d1a2bfa0ca19fc4b10b8c61e63

Hjermstad, M. J., Fossa, S. D., Bjordal, K., & Kaasa, S. (1995). Test/retest study of the European Organization for Research and Treatment of Cancer Core Quality-of-Life Questionnaire. *Journal of Clinical Oncology*, *13*(5), 1249-1254.

Hlubocky, F. J., Webster, K., Cashy, J., Beaumont, J., & Cella, D. (2013). The Development and Validation of a Measure of Health-Related Quality of Life for Non-Hodgkin's Lymphoma: The Functional Assessment of Cancer Therapy—Lymphoma (FACT-Lym). *Lymphoma*, *2013*, 147176. https://doi.org/10.1155/2013/147176

Hodgkinson, K., Butow, P., Hunt, G., Pendlebury, S., Hobbs, K., Lo, S. K., & Wain, G. (2007). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *16*(9), 796-804.

Hodgson, D. C. (2008). Hodgkin Lymphoma: The Follow-Up of Long-Term Survivors. *Hematology/Oncology Clinics of North America*, *22*(2), 233-244. https://doi.org/10.1016/j.hoc.2008.01.004

Hodgson, D. C. (2015). Long-term toxicity of chemotherapy and radiotherapy in lymphoma survivors: optimizing treatment for individual patients. *Clinical Advances in Hematology & Oncology : H&O*, *13*(2), 103-112. https://elib.tcd.ie/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=25774480&site=ehost-live

Holland, R. A., Bird, B. R., Cahill, M., Murphy, C. G., O'Reilly, S., O'Connor, E., Boyce, M., & Crotty, R. (2016). Assessing the quality of life of non–Hodgkin lymphoma survivors: A population-based study. *Journal of Clinical Oncology*, *34*(3_suppl), 227-227. https://doi.org/10.1200/jco.2016.34.3_suppl.227

Hoppe, R. T., Advani, R. H., Ai, W. Z., Ambinder, R. F., Armand, P., Bello, C. M., Benitez, C. M., Chen, W., Dabaja, B., & Daly, M. E. (2022). NCCN Guidelines® insights: Hodgkin lymphoma, version 2.2022: Featured updates to the NCCN Guidelines. *Journal of the National Comprehensive Cancer Network*, *20*(4), 322-334.

Hotelling, H. (1992). Relations between two sets of variates. In *Breakthroughs in statistics: methodology and distribution* (pp. 162-190). Springer.

Horwitz, S. M., Ansell, S., Ai, W. Z., Barnes, J., Barta, S. K., Clemens, M. W., Dogan, A., Goodman, A. M., Goyal, G., & Guitart, J. (2020). NCCN guidelines insights: T-cell lymphomas, version 1.2021: Featured updates to the NCCN guidelines. *Journal of the National Comprehensive Cancer Network*, *18*(11), 1460-1467.

Howell, D., Hart, R., Smith, A., Macleod, U., Patmore, R., & Roman, E. (2020). 'Unpacking' pathways to lymphoma and myeloma diagnosis: Do experiences align with the Model of Pathways to

Treatment? Findings from a UK qualitative study with patients and relatives. *BMJ open*, *10*(2), e034244. https://doi.org/10.1136/bmjopen-2019-034244

Howell, D., Mayo, S., Currie, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Collacutt, V., & McLeod, D. (2012). Psychosocial health care needs assessment of adult cancer patients: a consensus-based guideline. *Supportive Care in Cancer*, *20*, 3343-3354.

Howell, D. A., Hart, R. I., Smith, A. G., Roman, E., Macleod, U., & Patmore, R. (2019). Disease-related factors affecting timely lymphoma diagnosis: A qualitative study exploring patient experiences. *British Journal of General Practice*, *69*(679), E134-E145. https://doi.org/10.3399/bjgp19X701009

Howell, D. A., Smith, A. G., & Roman, E. (2006). Lymphoma: variations in time to diagnosis and treatment. *European Journal of Cancer Care*, *15*(3), 272-278. https://doi.org/10.1111/j.1365-2354.2006.00651.x

Howell, D. A., Smith, A. G., & Roman, E. (2007). Referral pathways and diagnosis: UK government actions fail to recognize complexity of lymphoma. *European Journal of Cancer Care*, *16*(6), 529-532. https://doi.org/10.1111/j.1365-2354.2007.00789.x

Howlader, N., Noone, A., Krapcho, M., Miller, D., Bishop, K., Altekruse, S., Kosary, C., Yu, M., Ruhl, J., & Tatalovich, Z. (2016). SEER cancer statistics review, 1975–2013. *Bethesda, MD: National Cancer Institute*, *19*.

Hui, D., De La Cruz, M., Mori, M., Parsons, H. A., Kwon, J. H., Torres-Vigil, I., Kim, S. H., Dev, R., Hutchins, R., & Liem, C. (2013). Concepts and definitions for "supportive care,""best supportive care,""palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Supportive Care in Cancer*, *21*, 659-685.

Husson, O., Prins, J. B., Kaal, S. E. J., Oerlemans, S., Stevens, W. B., Zebrack, B., van der Graaf, W. T. A., & van de Poll-Franse, L. V. (2017). Adolescent and young adult (AYA) lymphoma survivors report lower health-related quality of life compared to a normative population: results from the PROFILES registry. *Acta Oncologica*, *56*(2), 288-294. https://doi.org/10.1080/0284186X.2016.1267404

Immanuel, A., Hunt, J., McCarthy, H., van Teijlingen, E., & Sheppard, Z. A. (2019). Quality of life in survivors of adult haematological malignancy. *European Journal of Cancer Care*, *28*(4), e13067. https://doi.org/https://doi.org/10.1111/ecc.13067

Institute of Medicine. (2001). *Committee on Quality of Health Care in America Institute of Medicine Staff. Crossing the quality chasm: a new health system for the 21st century.* National Academies Press.

Institute of Medicine. (2006). From cancer patient to cancer survivor: Lost in transition. In: The National Academies Press Washington, DC.

Iphofen, R. (2020). Ethics and integrity in research. *Handbook of Research Ethics and Scientific Integrity*, 739-749.

Ireland, R. (2011). Haematological malignancies: the rationale for integrated haematopathology services, key elements of organization and wider contribution to patient care. *Histopathology*, *58*(1), 145-154. https://doi.org/10.1111/j.1365-2559.2010.03697.x

Israel, M. (2014). *Research Ethics and Integrity for Social Scientists: Beyond Regulatory Compliance*. SAGE Publications Ltd. http://digital.casalini.it/9781473909151

Jacobsen, P. B., & Jim, H. S. L. (2011). Consideration of Quality of Life in Cancer Survivorship Research. *Cancer Epidemiology, Biomarkers & Prevention*, *20*(10), 2035-2041. https://doi.org/10.1158/1055-9965.Epi-11-0563

Jacobsen, P. B., Nipp, R. D., & Ganz, P. A. (2017). Addressing the survivorship care needs of patients receiving extended cancer treatment. *American Society of Clinical Oncology Educational Book*, *37*, 674-683.

James, W. (1907). *Pragmatism: a new name for some old ways of thinking: popular lectures on philosophy*.

Janssen, M. F., Pickard, A. S., Golicki, D., Gudex, C., Niewada, M., Scalone, L., Swinburn, P., & Busschbach, J. (2013). Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study. *Quality of Life Research*, *22*(7), 1717-1727. https://doi.org/10.1007/s11136-012-0322-4

Janssen, S. H. M., van der Graaf, W. T. A., van der Meer, D. J., Manten-Horst, E., & Husson, O. (2021). Adolescent and Young Adult (AYA) Cancer Survivorship Practices: An Overview. *Cancers*, *13*(19), 4847. https://www.mdpi.com/2072-6694/13/19/4847

Jiao, M., Hall, A., Jefford, M., & Piper, A. (2015). Needs assessment tools for post-treatment cancer survivors: literature review. *Melbourne: Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre*.

Jiao, M., Hall, A., Nolte, L., Piper, A., Lisy, K., & Jefford, M. (2018). A rapid review of needs assessment tools for post-treatment cancer survivors. *European Journal of Cancer Care*, *27*(2), e12764.

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, *33*(7), 14-26.

Jones, J. M., Fitch, M., Bongard, J., Maganti, M., Gupta, A., D'Agostino, N., & Korenblum, C. (2020). The Needs and Experiences of Post-Treatment Adolescent and Young Adult Cancer Survivors. *Journal of Clinical Medicine*, *9*(5), 1444. https://www.mdpi.com/2077-0383/9/5/1444

Jonker, J., & Pennink, B. (2010). *The essence of research methodology: A concise guide for master and PhD students in management science*. Springer Science.

Jordan, J., & Wright, J. (1997). Making sense of health needs assessment. *The British Journal of General Practice*, *47*(424), 695.

Jordan, K., Aapro, M., Kaasa, S., Ripamonti, C., Scotté, F., Strasser, F., Young, A., Bruera, E., Herrstedt, J., & Keefe, D. (2018). European Society for Medical Oncology (ESMO) position paper on supportive and palliative care. *Annals of Oncology*, *29*(1), 36-43.

Kang, D., Cho, J., Kim, I. R., Kim, M. K., Kim, W. S., & Kim, S. J. (2018). Health-Related Quality of Life in Non-Hodgkin Lymphoma Survivors: A Prospective Cohort Study. *Cancer Research and Treatment*, *50*(4), 1051-1063. https://doi.org/10.4143/crt.2017.207

Karagianni, P., Giannouli, S., & Voulgarelis, M. (2021). From the (Epi) genome to metabolism and vice versa; examples from hematologic malignancy. *International Journal of Molecular Sciences*, *22*(12), 6321.

Kaur, M., & Kaur, S. (2023). Concept of quality of life in health care research: a review. *International Journal Of Community Medicine And Public Health*, *10*(10), 3931-3937. https://doi.org/10.18203/2394-6040.ijcmph20232869

Keegan, T. H., Lichtensztajn, D. Y., Kato, I., Kent, E. E., Wu, X. C., West, M. M., Hamilton, A. S., Zebrack, B., Bellizzi, K. M., Smith, A. W., Keegan, T. H. M., Lichtensztajn, D. Y., Kato, I., Kent, E. E., Wu, X.-C., West, M. M., Hamilton, A. S., Zebrack, B., Bellizzi, K. M., & Smith, A. W. (2012). Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *Journal of Cancer Survivorship*, *6*(3), 239-250. https://doi.org/10.1007/s11764-012-0219-9

Keith, T. Z. (2014). *Multiple regression and beyond: An introduction to multiple regression and structural equation modelling*. Routledge.

Keykhaei, M., Masinaei, M., Mohammadi, E., Azadnajafabad, S., Rezaei, N., Saeedi Moghaddam, S., Rezaei, N., Nasserinejad, M., Abbasi-Kangevari, M., & Malekpour, M.-R. (2021). A global, regional, and national survey on burden and Quality of Care Index (QCI) of hematologic malignancies; global burden of disease systematic analysis 1990–2017. *Experimental Hematology & Oncology*, *10*, 1-15.

Khan, N. F., Rose, P. W., & Evans, J. (2012). Defining cancer survivorship: a more transparent approach is needed. *Journal of Cancer Survivorship*, *6*(1), 33-36.

Khimani, N., Chen, Y. H., Mauch, P. M., Recklitis, C., Diller, L., Silver, B., & Ng, A. K. (2013). Influence of new late effects on quality of life over time in hodgkin lymphoma survivors: A longitudinal survey study. *Annals of Oncology*, *24*(1), 226-230. https://doi.org/10.1093/annonc/mds243

Kidder, L. H., & Fine, M. (1987). Qualitative and quantitative methods: When stories converge. *New Directions for Program Evaluation*, *1987*(35), 57-75.

Kim, S. H., Kim, I.-R., Kim, S. H., Lee, S., Ok, O., Kim, W. S., Suh, C., & Lee, M. H. (2014). Health-related quality of life in Korean lymphoma survivors compared with the general population. *Annals of Hematology*, *93*(9), 1531-1540. https://doi.org/10.1007/s00277-014-2091-3

Kim, S. H., Lee, S., Kim, S. H., Ok, O. N., Kim, I.-R., Choi, E., Kang, Y.-K., Kim, S. J., & Lee, M. H. (2017). Unmet needs of non-Hodgkin lymphoma survivors in Korea: prevalence, correlates, and associations with health-related quality of life. *Psycho-Oncology*, *26*(3), 330-336. https://doi.org/10.1002/pon.4136

Kimberlin, C. L., & Winterstein, A. G. (2008). Validity and reliability of measurement instruments used in research. *American Journal of Health-System Pharmacy*, *65*(23), 2276-2284. https://doi.org/10.2146/ajhp070364

Kitchener, K. S., & Kitchener, R. F. (2009). Social science research ethics: Historical and philosophical issues. *The Handbook of Social Research Ethics*, *5(22).*

Kocarnik, J. M., Compton, K., Dean, F. E., Fu, W., Gaw, B. L., Harvey, J. D., Henrikson, H. J., Lu, D., Pennini, A., & Xu, R. (2022). Cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life years for 29 cancer groups from 2010 to 2019: a systematic analysis for the global burden of disease study 2019. *JAMA oncology*, *8*(3), 420-444.

Kreissl, S., Hagenbeek, A., Knoop, H., & Borchmann, P. (2020a). Cancer-Related Fatigue in Hodgkin Lymphoma. *Hodgkin Lymphoma: A Comprehensive Overview*, 501-509.

Kreissl, S., Müller, H., Goergen, H., Meissner, J., Topp, M., Sökler, M., Markova, J., Bernhard, J., Greil, R., von Tresckow, B., Behringer, K., Rüffer, J.-U., Flechtner, H.-H., Möstl, M., Fuchs, M., Engert, A., Diehl, V., & Borchmann, P. (2020b). Health-Related Quality of Life in Patients With Hodgkin Lymphoma: A Longitudinal Analysis of the German Hodgkin Study Group. *Journal of Clinical Oncology*, *38*(25), 2839-2848. https://doi.org/10.1200/JCO.19.03160

Kreps, G. L., & Neuhauser, L. (2010). New directions in eHealth communication: Opportunities and challenges. *Patient Education and Counseling*, *78*(3), 329-336. https://doi.org/https://doi.org/10.1016/j.pec.2010.01.013

Krishnasamy, M., Hyatt, A., Chung, H., Gough, K., & Fitch, M. (2023). Refocusing cancer supportive care: a framework for integrated cancer care. *Supportive Care in Cancer*, *31*(1). https://doi.org/10.1007/s00520-022-07501-9

Krolak, D., Collins, B., Weiss, L., Harris, C., & Van der Jagt, R. (2017). Cognitive function and its relationship to other psychosocial factors in lymphoma survivors. *Supportive Care in Cancer*, *25*(3), 905-913. https://doi.org/10.1007/s00520-016-3480-z

Krüger, W., Hornung, R., Hertenstein, B., Kern, W., Kröger, N., Ljungman, P., & Zander, A. (2001). Practices of infectious disease prevention and management during hematopoietic stem cell

transplantation: a survey from the European group for blood and marrow transplantation. *Journal of Hematotherapy & Stem Cell Research*, *10*(6), 895-903.

Kvale, S. (2007). Doing interviews. In. London: Sage.

Kwok, E. Y. L., Rosenbaum, P., Thomas-Stonell, N., & Cunningham, B. J. (2021). Strengths and challenges of the COSMIN tools in outcome measures appraisal: A case example for speech–language therapy. *International Journal of Language and Communication Disorders*, *56*(2), 313-329. https://doi.org/10.1111/1460-6984.12603

Laessig, R. E., & Duckett, E. J. (1979). Canonical correlation analysis: potential for environmental health planning. *American Journal of Public Health*, *69*(4), 353-359.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 159-174.

Leak, A., Smith, S. K., Crandell, J., Jenerette, C., Bailey Jr, D. E., Zimmerman, S., & Mayer, D. K. (2013). Demographic and disease characteristics associated with non-Hodgkin Lymphoma survivors' quality of life. *Oncology Nursing Forum, 40*(2), 157.

LeBlanc, M. R., Zimmerman, S., LeBlanc, T. W., Bryant, A. L., Hudson, K. E., & Smith, S. K. (2022). Persistent fatigue among long-term non-Hodgkin lymphoma survivors. *Leukemia & Lymphoma*, *63*(2), 344-352. https://doi.org/10.1080/10428194.2021.1984450

Lee, I. T., Wang, Y.-J., Lin, M.-W., Chiou, T.-J., & Wu, C.-J. (2023). Symptom clusters and predominant symptoms in lymphoma survivorship: a cross-sectional study using trend analysis. *Supportive Care in Cancer*, *32*(1), 40. https://doi.org/10.1007/s00520-023-08249-6

Lee, T., & Porter, M. (2013). *The strategy that will fix healthcare*. Harvard Business Review, Boston.

Lee, Y. M., Lang, D., & Tho, P. C. (2011). The experience of being a neutropenic cancer patient in an acute care isolation room: a systematic review of qualitative evidence. *JBI Evidence Synthesis*, *9*(12), 400-416.

Leinemann, V., & Krutter, S. (2024). 'The last bridge'- How patients experience the CAR T-cell therapy. A qualitative study. *European Journal of Oncology Nursing*, *68*, 102494. https://doi.org/https://doi.org/10.1016/j.ejon.2023.102494

Lekdamrongkul, P., Pongthavornkamol, K., Molassiotis, A., Sriyuktasuth, A., Siritanaratkul, N., & Chansatitporn, N. (2021). Exploring health-related quality of life among non-Hodgkin's lymphoma survivors after completion of primary treatment: a cross-sectional study in Thailand. *Supportive Care in Cancer*, *29*, 6511-6522. https://doi.org/10.1007/s00520-021-06246-1

Letrecher, S. (2023). The impact of protective isolation in a hematology unit on staff, patients, and their families. *International Journal of Applied Psychoanalytic Studies*, 1-26. https://doi.org/https://doi.org/10.1002/aps.1812

Leventhal, E. A., & Crouch, M. (2013). Are there differences in perceptions of illness across the lifespan? In *Perceptions of health and illness*. *Psychology Press,* 77-102.

Levene, H. (1960). Robust tests for equality of variances. *Contributions to probability and statistics*, 278-292.

Lewis, W. D., Lilly, S., & Jones, K. L. (2020). Lymphoma: diagnosis and treatment. *American family physician*, *101*(1), 34-41.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.

Lincoln, Y. S., & Guba, E. G. (1988). Criteria for Assessing Naturalistic Inquiries as Reports. Sage Publications.

Liu, L., He, X., & Feng, L. (2019). Exercise on quality of life and cancer-related fatigue for lymphoma survivors: a systematic review and meta-analysis. *Supportive Care in Cancer*, *27*(11), 4069-4082. https://doi.org/10.1007/s00520-019-04983-y

Livingston, P. M., White, V. M., Hayman, J., Maunsell, E., Dunn, S. M., & Hill, D. (2010). The psychological impact of a specialist referral and telephone intervention on male cancer patients: a randomised controlled trial. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *19*(6), 617-625.

Lo, A. C., Chen, B., Samuel, V., Savage, K. J., Freeman, C., & Goddard, K. (2021). Late effects in survivors treated for lymphoma as adolescents and young adults: a population-based analysis [Article in Press]. *Journal of Cancer Survivorship : research and practice*. https://doi.org/10.1007/s11764-020-00976-7

Lobb, E. A., Joske, D., Butow, P., Kristjanson, L., Cannell, P., Cull, G., & Augustson, B. (2009). When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. *Patient education and counseling*, *77*(1), 103-108.

LoBiondo-Wood, G., Haber, J., Cameron, C., & Singh, M. (2014). *Nursing research in Canada-E-book: methods, critical appraisal, and utilization*. Elsevier Health Sciences.

Loughery, J., & Woodgate, R. L. (2019). Supportive care experiences of rural women living with breast cancer: An interpretive descriptive qualitative study. *Canadian Oncology Nursing Journal*, *29*(3), 170.

Luckett, T., King, M. T., Butow, P. N., Oguchi, M., Rankin, N., Price, M. A., Hackl, N. A., & Heading, G. (2011). Choosing between the EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical research: issues, evidence and recommendations. *Annals of Oncology*, *22*(10), 2179-2190. https://doi.org/10.1093/annonc/mdq721

Luengo-Fernandez, R., Leal, J., Gray, A., & Sullivan, R. (2013). Economic burden of cancer across the European Union: a population-based cost analysis. *The Lancet Oncology*, *14*(12), 1165-1174.

Lynn, M. (1986). Determination and Quantification Of Content Validity. *Nursing Research*, *35*(6), 382-386. https://journals.lww.com/nursingresearchonline/Fulltext/1986/11000/Determination_and_Quantification_Of_Content.17.aspx

Mackenzie, N., & Knipe, S. (2006). Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research*, *16*(2), 193-205.

Madill, A., & Gough, B. (2016). Qualitative research and its place in psychological science. In A. E. Kazdin (Ed.), *Methodological issues and strategies in clinical research* (4th ed., pp. 437–458). American Psychological Association. https://doi.org/10.1037/14805-028

Magalhães, B., Fernandes, C., Lima, L., Martinez-Galiano, J. M., & Santos, C. (2020). Cancer patients' experiences on self-management of chemotherapy treatment-related symptoms: A systematic review and thematic synthesis. *European Journal of Oncology Nursing*, 101837.

Maguire, R., Hanly, P., Hyland, P., & Sharp, L. (2018). Understanding burden in caregivers of colorectal cancer survivors: what role do patient and caregiver factors play? *European Journal of Cancer Care*, *27*(1), e12527.

Maguire, R., McCann, L., Kotronoulas, G., Kearney, N., Ream, E., Armes, J., Patiraki, E., Furlong, E., Fox, P., Gaiger, A., McCrone, P., Berg, G., Miaskowski, C., Cardone, A., Orr, D., Flowerday, A., Katsaragakis, S., Darley, A., Lubowitzki, S., Donnan, P. T. (2021). Real time remote symptom monitoring during chemotherapy for cancer: European multicentre randomised controlled trial (eSMART). *British Medical Journal*, *374*, n1647. https://doi.org/10.1136/bmj.n1647

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research*, *26*(13), 1753-1760. https://doi.org/10.1177/1049732315617444

Mariegaard, J., Wenstrup, J., Lim, K. Z. M., Bidstrup, P. E., von Heymann, A., Johansen, C., Knudsen, G. M., Law, I., Specht, L., & Stenbæk, D. S. (2021). Prevalence of cognitive impairment and its relation to mental health in Danish lymphoma survivors. *Supportive Care in Cancer*, *29*, 3319-3328.

Marshall, S., Haywood, K., & Fitzpatrick, R. (2006). Impact of patient-reported outcome measures on routine practice: a structured review. *Journal of Evaluation in Clinical Practice*, *12*(5), 559-568.

May, E. A., McGill, B. C., Robertson, E. G., Anazodo, A., Wakefield, C. E., & Sansom-Daly, U. M. (2018). Adolescent and young adult cancer survivors' experiences of the healthcare system: A qualitative study. *Journal of Adolescent and Young Adult Oncology*, *7*(1), 88-96.

Mayo, S. J., Ajaj, R., & Drury, A. (2021). Survivors' preferences for the organisation and delivery of supportive care after treatment: an integrative review. *European Journal of Oncology Nursing*, 102040.

McDowell, M. E., Occhipinti, S., Ferguson, M., Dunn, J., & Chambers, S. K. (2010). Predictors of change in unmet supportive care needs in cancer. *Psycho-Oncology*, *19*(5), 508-516. https://doi.org/10.1002/pon.1604

McHorney, C. A., Ware Jr, J. E., Lu, J. R., & Sherbourne, C. D. (1994). The MOS 36-item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care*, 40-66.

Meade, E., McIlfatrick, S., Groarke, A. M., Butler, E., & Dowling, M. (2017). Survivorship care for postmenopausal breast cancer patients in Ireland: What do women want? *European Journal of Oncology Nursing*, *28*, 69-76. https://doi.org/10.1016/j.ejon.2017.03.003

Mehnert, A., De Boer, A., & Feuerstein, M. (2013). Employment challenges for cancer survivors. *Cancer*, *119*, 2151-2159. https://doi.org/10.1002/cncr.28067

Miller, K., Merry, B., & Miller, J. (2008). Seasons of Survivorship Revisited. *The Cancer Journal*, *14*(6), 369-374. https://doi.org/10.1097/PPO.0b013e31818edf60

Miller, K. D., Fidler-Benaoudia, M., Keegan, T. H., Hipp, H. S., Jemal, A., & Siegel, R. L. (2020). Cancer statistics for adolescents and young adults, 2020. *CA: A Cancer Journal for Clinicians*, *70*(6), 443-459. https://doi.org/10.3322/caac.21637

Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R., & Jemal, A. (2016). Cancer treatment and survivorship statistics, 2016. *CA Cancer Journal for Clinicians*, *66*(4), 271-289. https://doi.org/10.3322/caac.21349

Minoia, C., Gerardi, C., Allocati, E., De Sanctis, V., Franceschetti, S., Viviani, S., Annunziata, M. A., Bari, A., Skrypets, T., Oliva, S., Puzzovivo, A., Di Molfetta, S., Caccavari, V., Di Russo, A., Loseto, G., Daniele, A., Nassi, L., Gini, G., & Guarini, A. (2021). Late toxicities and long-term monitoring in classical Hodgkin lymphoma and diffuse large B-cell lymphoma survivors: A series of systematic reviews of the fondazione italiana linfomi. *Hematological Oncology*, *39*(2), 478-479. https://doi.org/10.1002/hon.2881

Minton, O., Berger, A., Barsevick, A., Cramp, F., Goedendorp, M., Mitchell, S. A., & Stone, P. C. (2013). Cancer-related fatigue and its impact on functioning. *Cancer*, *119*, 2124-2130.

Miracle, V. A. (2016). The Belmont Report: The Triple Crown of Research Ethics. *Dimensions of Critical Care Nursing*, *35*(4), 223-228. https://doi.org/10.1097/dcc.0000000000000186

Moghaddam, N., Coxon, H., Nabarro, S., Hardy, B., & Cox, K. (2016). Unmet care needs in people living with advanced cancer: a systematic review. *Supportive Care in Cancer*, *24*(8), 3609-3622. https://doi.org/10.1007/s00520-016-3221-3

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *British Medical Journal, 339*(1), 2535-2535. https://doi.org/10.1136/bmj.b2535

Mokkink, L., Prinsen, C., Patrick, D., Alonso, J., Bouter, L., Vet, H., & Terwee, C. (2018). Guideline for systematic reviews of outcome measurement instruments. *Quality of Life Research*, *25*, 21.

Mokkink, L., Terwee, C., Patrick, D., Alonso, J., Stratford, P., Knol, D., Bouter, L., & De Vet, H. (2010). International consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes: results of the COSMIN study. *Journal of Clinical Epidemiology, 63*(7), 737-745.

Mokkink, L. B., Prinsen, C. A. C., Bouter, L. M., Vet, H. C. W. D., & Terwee, C. B. (2016). The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) and how to select an outcome measurement instrument. *Brazilian Journal of Physical Therapy*, *20*(2), 105-113. https://doi.org/10.1590/bjpt-rbf.2014.0143

Molassiotis, A., Yates, P., Li, Q., So, W., Pongthavornkamol, K., Pittayapan, P., Komatsu, H., Thandar, M., Yi, M., & Chacko, S. T. (2017). Mapping unmet supportive care needs, quality-of-life perceptions and current symptoms in cancer survivors across the Asia-Pacific region: results from the International STEP Study. *Annals of Oncology*, *28*(10), 2552-2558.

Mols, F., Aaronson, N. K., Vingerhoets, A. J. J. M., Coebergh, J.-W. W., Vreugdenhil, G., Lybeert, M. L. M., & van de Poll-Franse, L. V. (2007). Quality of life among long-term non-Hodgkin lymphoma survivors. *Cancer*, *109*(8), 1659-1667. https://doi.org/https://doi.org/10.1002/cncr.22581

Momotow, J., Borchmann, S., Eichenauer, D. A., Engert, A., & Sasse, S. (2021). Hodgkin Lymphoma—Review on Pathogenesis, Diagnosis, Current and Future Treatment Approaches for Adult Patients. *Journal of Clinical Medicine*, *10*(5), 1125. https://www.mdpi.com/2077-0383/10/5/1125

Monterosso, L., Taylor, K., Platt, V., Lobb, E., Krishnasamy, M., Musiello, T., Bulsara, C., Stratton, K., & Joske, D. (2017). A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, *28*, 62-68. https://doi.org/10.1016/j.ejon.2017.03.002

Monterosso, L., Platt, V., Bulsara, M., & Berg, M. (2019). Systematic review and meta-analysis of patient reported outcomes for nurse-led models of survivorship care for adult cancer patients. *Cancer Treatment Reviews*, *73*, 62-72. https://doi.org/https://doi.org/10.1016/j.ctrv.2018.12.007

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research*, *6*(1), 45-59.

Morgan, D. L. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*, *1*(1), 48-76.

Morgan, D. L. (2014). Pragmatism as a paradigm for social research. *Qualitative Inquiry*, *20*(8), 1045-1053.

Morse, J. M. (1995). The significance of saturation. In (Vol. 5, pp. 147-149): Sage Publications, Thousand Oaks, CA.

Morse, J. M. (2016). *Mixed method design: Principles and procedures*. Routledge.

Morse, J. M., & Field, P.-A. (2013). *Nursing Research: The Application of Qualitative Approaches*. Springer.

Moser, E. C., & Meunier, F. (2014). Cancer survivorship: a positive side-effect of more successful cancer treatment. *European Journal of Cancer Supplements*, *12*(1), 1-4.

Muhsen, I. N., Bar, M., Savani, B. N., Estey, E. H., & Hashmi, S. K. (2020). Follow-up issues in survivors of hematologic malignancies – Current stance and future perspectives. *Blood Reviews*, *44*, 100674. https://doi.org/https://doi.org/10.1016/j.blre.2020.100674

Multinational Association of Supportive Care in Cancer. (2023). *Definition of supportive care: Multinational Association of Supportive Care in Cancer*. Retrieved 13/09/23 from https://mascc.org/what-is-supportive-care/

Murphy-Banks, R., Kumar, A. J., Lin, M., Savidge, N., Livne, E., & Parsons, S. K. (2022). Hodgkin lymphoma survivor perspectives on their engagement in treatment decision-making and discussion of late effects. *Supportive Care in Cancer*, *30*(2), 1399-1405.

Muzzatti, B., Cattaruzza, N., Piccinin, M., Flaiban, C., Agostinelli, G., Berretta, M., & Annunziata, M. A. (2021). Cognitive function in long-term lymphoma survivors: relationship between subjective reports and objective assessments and with quality of life. *Psychology, Health & Medicine*, *26*(8), 968-979.

Naidoo, J., Hayes, E., Teo, M., Horgan, A., Calvert, P., & O'Connor, M. (2013). An Irish breast cancer survivorship study: are we meeting our patients' needs? *Irish Medical Journal.* https://www.lenus.ie/handle/10147/303571

Naing, L., Nordin, R. B., Abdul Rahman, H., & Naing, Y. T. (2022). Sample size calculation for prevalence studies using Scalex and ScalaR calculators. *BMC Medical Research Methodology*, *22*(1), 209. https://doi.org/10.1186/s12874-022-01694-7

Naing, L., Winn, T., & Rusli, B. (2006). Practical issues in calculating the sample size for prevalence studies. *Archives of Orofacial Sciences*, *1*, 9-14.

National Cancer Control Programme. (2014). *Report on the implementation of 'A Strategy for Cancer Control in Ireland 2006'*. National Cancer Control Programme, Dublin, Ireland.

National Cancer Control Programme. (2019). *National Cancer Survivorship Needs Assessment: Living with and beyond cancer in Ireland*. National Cancer Control Programme, Dublin, Ireland.

National Cancer Control Programme. (2020). *Hospital and community-based psychosocial care for patients with cancer and their families: a model of care for Psycho-Oncology*. Dublin, Ireland: National Cancer Control Programme Retrieved from https://www.hse.ie/eng/services/list/5/cancer/profinfo/psycho-oncology-programme/model%20of%20care.pdf

National Cancer Control Programme. (2022a). *Early diagnosis of symptomatic cancer plan 2022-2025*. Dublin, Ireland: National Cancer Control Programme Retrieved from https://www.hse.ie/eng/services/list/5/cancer/prevention/nccp-early-diagnosis-of-cancer-plan-2022-2025-web-version.pdf

National Cancer Control Programme. (2022b). *NCCP Systemtic Anti-Cancer Therapy Model of Care*. Dublin, Ireland: National Cancer Control Programme Retrieved from https://www.hse.ie/eng/services/list/5/cancer/profinfo/medonc/nccp-systemic-anti-cancer-therapy-model-of-care.pdf

National Cancer Control Programme. (2023a). *CAR-T Therapy*. National Cancer Control Programme. Retrieved from https://www.hse.ie/eng/services/list/5/cancer/profinfo/chemoprotocols/car-t-therapy/

National Cancer Control Programme. (2023b). *Haemato-oncology adult patient pathway: acute myeloid leukaemia (AML)*. NCCP Haemato-oncology Clinical Leads Group, Ireland.

National Cancer Control Programme. (2023c). *National Haemato-oncology Adult Patient Pathway: Acute Lymphoblastic Leukaemia (ALL) / Acute Lymphoblastic Lymphoma (LBL) V2*. Health Service Executive, Ireland.

National Cancer Institute. (2023a). *Cancer Stat Facts: Hodgkin Lymphoma*. Retrieved from https://seer.cancer.gov/statfacts/html/hodg.html

National Cancer Institute. (2023b). *Cancer Stat Facts: Non-Hodgkin Lymphoma*. Retrieved from https://seer.cancer.gov/statfacts/html/nhl.html

National Cancer Institute. (2023c). *Supportive care: National Cancer Institute*. Retrieved from https://www.cancer.gov/publications/dictionaries/cancer-terms/def/supportive-care

National Cancer Registry Ireland. (2014). *Cancer projections for Ireland 2015-2040*. https://ncri.ie/sites/ncri/files/pubs/Cancer%20projections%20for%20Ireland%202015%20-%202040.pdf

National Cancer Registry Ireland. (2019). *Cancer in Ireland 1994-2017 with estimates for 2017-2019: Annual report of the national cancer registry*. National Cancer Registry, Ireland.

National Cancer Registry Ireland. (2022). *Cancer in Ireland 1994-2020: Annual statistical report of the National Cancer Registry*. National Cancer Registry, Ireland.

National Doctors Training and Planning. (2023). *Medical workforce planning for the specialties of pathology: an expert stakeholder informed review*. https://www.hse.ie/eng/staff/leadership-education-development/met/plan/specialty-specific-reviews/pathology%20specialty%20review.pdf

National Institute for Clinical Excellence. (2003a). *Guidance on cancer services improving outcomes in haematological cancers: the manual*. National Service Executive, London.

National Institute for Clinical Excellence. (2003b). *Improving outcomes in haematological cancers: the manual*. National Service Executive, London.

National Institute for Health and Care Excellence. (2016). *Haematological cancers: improving outcomes (NG47).* London: National Institute for Clinical Excellence Retrieved from http://www.nice.org.uk/guidance/ng47

National Institute for Health and Care Excellence. (2018). *People's experience in adult social care services: improving the experience of care and support for people using adult social care services [NG86]*. Retrieved from https://www.nice.org.uk/guidance/ng86

Nekhlyudov, L., Ganz, P. A., Arora, N. K., & Rowland, J. H. (2017). Going Beyond Being Lost in Transition: A Decade of Progress in Cancer Survivorship. *Journal of Clinical Oncology*, *35*(18), 1978-1981. https://doi.org/10.1200/jco.2016.72.1373

Ng, A. K. (2008). Late complications after treatment for Hodgkin lymphoma. *Current Hematologic Malignancy Reports*, *3*(3), 119-125. https://doi.org/10.1007/s11899-008-0018-6

Ng, A. K. (2014). Current survivorship recommendations for patients with Hodgkin lymphoma: Focus on late effects. *Hematology*, *2014*(1), 488-494. https://doi.org/10.1182/asheducation-2014.1.488

Ng, A. K., LaCasce, A., & Travis, L. B. (2011). Long-term complications of lymphoma and its treatment [Review]. *Journal of Clinical Oncology*, *29*(14), 1885-1892. https://doi.org/10.1200/JCO.2010.32.8427

Ng, D., Leong, Y., Gan, G., Ng, D. L. C., Leong, Y. C., & Gan, G. G. (2016). Quality of life amongst lymphoma survivors in a developing country. *Supportive Care in Cancer*, *24*(12), 5015-5023. https://doi.org/10.1007/s00520-016-3364-2

Niscola, P., Tendas, A., Giovannini, M., Scaramucci, L., Perrotti, A., de Fabritiis, P., & Howell, D. A. (2015). Caring for terminal patients in haematology: the urgent need of a new research agenda. *Supportive Care in Cancer*, *23*(1), 5-7. https://doi.org/10.1007/s00520-014-2489-4

Nixon, S., Bezverbnaya, K., Maganti, M., Gullane, P., Reedijk, M., Kuruvilla, J., Prica, A., Kridel, R., Kukreti, V., Bennett, S., Rogalla, P., Delabie, J., Pintilie, M., & Crump, M. (2020). Evaluation of Lymphadenopathy and Suspected Lymphoma in a Lymphoma Rapid Diagnosis Clinic. *JCO Oncology Practice*, *16*(1), e29-e36. https://doi.org/10.1200/jop.19.00202

Noonan, D., LeBlanc, M., Conley, C., Benecha, H., Leak-Bryant, A., Peter, K., Zimmerman, S., Mayer, D., & Smith, S. (2020). Quality of Life and Impact of Cancer: Differences in Rural and Nonrural Non-Hodgkin's Lymphoma Survivors. *Journal of Rural Health*, *36*(4), 536-542. https://doi.org/10.1111/jrh.12420

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 1609406917733847.

Nunnally, J., & Bernstein, I. (1994). *Psychometric Theory* (3 ed.). McGraw-Hill.

O'Cathain, A., Murphy, E., & Nicholl, J. (2008). The quality of mixed methods studies in health services research. *Journal of Health Services Research & Policy*, *13*(2), 92-98.

O'Reilly, S., Kathryn Carroll, H., Murray, D., Burke, L., McCarthy, T., O'Connor, R., Kilty, C., Lynch, S., Feighan, J., Cloherty, M., Fitzpatrick, P., Falvey, K., Murphy, V., Jane O'Leary, M., Gregg, S., Young, L., McAuliffe, E., Hegarty, J., Gavin, A., . . . Mullooly, M. (2023). Impact of the COVID-19 pandemic on cancer care in Ireland – Perspectives from a COVID-19 and Cancer Working Group. *Journal of Cancer Policy*, *36*, 100414. https://doi.org/https://doi.org/10.1016/j.jcpo.2023.100414

O'Brien, K. M., Mooney, T., Fitzpatrick, P., & Sharp, L. (2018). Screening status, tumour subtype, and breast cancer survival: a national population-based analysis. *Breast Cancer Research and Treatment*, *172*(1), 133-142. https://doi.org/10.1007/s10549-018-4877-9

O'Connor, M., Drummond, F., O'Donovan, B., & Donnelly, C. (2019). *The unmet needs of cancer survivors in Ireland: A Scoping Review 2019.* National Cancer Registry Ireland, Cork.

O'Shea, M. T., & Collins, C. (2016). Access to diagnostics used to detect cancer. *Irish College of General Practitioners (ICGP),* http://hdl.handle.net/10147/615148.

Oberoi, D., White, V., Seymour, J., Miles, P., Harrison, S., Jefford, M., Winship, I., Hill, D., Bolton, D., Kay, A., Millar, J., Doo, N., & Giles, G. (2017a). The influence of unmet supportive care needs on anxiety and depression during cancer treatment and beyond: a longitudinal study of survivors of haematological cancers. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, *25*(11), 3447-3456. https://doi.org/10.1007/s00520-017-3766-9

Oberoi, D., White, V., Seymour, J., Prince, H., Harrison, S., Jefford, M., Winship, I., Hill, D., Bolton, D., Kay, A., Millar, J., Doo, N., Giles, G., Prince, H. M., & Doo, N. W. (2017b). The course of anxiety, depression and unmet needs in survivors of diffuse large B cell lymphoma and multiple myeloma in the early survivorship period. *Journal of Cancer Survivorship*, *11*(3), 329-338. https://doi.org/10.1007/s11764-016-0591-y

Oberoi, D., White, V., Seymour, J. F., Prince, H. M., Harrison, S., Jefford, M., Winship, I., Hill, D. J., Bolton, D., Millar, J., Wong Doo, N., Kay, A., & Giles, G. (2017c). Distress and unmet needs during treatment and quality of life in early cancer survivorship: A longitudinal study of haematological cancer patients. *European journal of haematology*, *99*(5), 423-430. https://doi.org/10.1111/ejh.12941

Oerlemans, S., Husson, O., Mols, F., Poortmans, P., Roerdink, H., Daniels, L. A., Creutzberg, C. L., & van de Poll-Franse, L. V. (2012). Perceived information provision and satisfaction among lymphoma and

multiple myeloma survivors--results from a Dutch population-based study. *Annals of Hematology*, *91*(10), 1587-1595. https://doi.org/10.1007/s00277-012-1495-1

Oerlemans, S., Mols, F., Issa, D. E., Pruijt, J., Peters, W. G., Lybeert, M., Zijlstra, W., Coebergh, J. W. W., & van de Poll-Franse, L. V. (2013). A high level of fatigue among long-term survivors of non-Hodgkin's lymphoma: results from the longitudinal population-based PROFILES registry in the south of the Netherlands. *Haematologica*, *98*(3), 479.

Olver, I., Keefe, D., Herrstedt, J., Warr, D., Roila, F., & Ripamonti, C. I. (2020). Supportive care in cancer—a MASCC perspective. *Supportive Care in Cancer*, *28*, 3467-3475.

Onwuegbuzie, A. J., & Leech, N. L. (2005). Taking the "Q" out of research: Teaching research methodology courses without the divide between quantitative and qualitative paradigms. *Quality and Quantity*, *39*, 267-295.

Paes, F. M., Kalkanis, D. G., Sideras, P. A., & Serafini, A. N. (2010). FDG PET/CT of extranodal involvement in non-Hodgkin lymphoma and Hodgkin disease. *Radiographics*, *30*(1), 269-291. https://doi.org/10.1148/rg.301095088

Page, A. E., & Adler, N. E. (2008). *Cancer care for the whole patient: Meeting psychosocial health needs.* National Academies Press.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., & Brennan, S. E. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *International Journal of Surgery*, *88*, 105906.

Pallin, N. D., O'Connor, M., Gannon, A., Browne, J., Cahill, M. R., & O'Shea, D. (2023). Experiences of and preferences for self-management among low grade non-Hodgkin's lymphoma survivors: A qualitative interview study. *European Journal of Oncology Nursing*, *66*, 102378. https://doi.org/https://doi.org/10.1016/j.ejon.2023.102378

Pallister, C., & Watson, M. (2010). *Haematology*. Scion Publishing Ltd.

Parahoo, K. (2014). *Nursing research: principles, process and issues*. Macmillan International Higher Education.

Parry, C., Lomax, J. B., Morningstar, E. A., & Fairclough, D. L. (2012). Identification and Correlates of Unmet Service Needs in Adult Leukemia and Lymphoma Survivors After Treatment. *Journal of Oncology Practice*, *8*(5), e135-141. https://doi.org/10.1200/JOP.2011.000464

Parry, C., Morningstar, E., Kendall, J., & Coleman, E. A. (2011). Working Without a Net: Leukemia and Lymphoma Survivors' Perspectives on Care Delivery at End-of-Treatment and Beyond. *Journal of Psychosocial Oncology*, *29*(2), 175-198. https://doi.org/10.1080/07347332.2010.548444

Patton, M. Q. (2014). *Qualitative research & evaluation methods: Integrating theory and practice*. Sage Publications.

Paul, C., Hall, A., Oldmeadow, C., Lynagh, M., Campbell, S., Bradstock, K., Williamson, A., Carey, M., & Sanson-Fisher, R. (2017). Dyadic interdependence of psychosocial outcomes among haematological cancer survivors and their support persons. *Supportive Care in Cancer*, *25*(11), 3339-3346. https://doi.org/10.1007/s00520-017-3751-3

Payne, J. B., Dance, K. V., Farone, M., Phan, A., Ho, C. D., Gutierrez, M., Chen, L., & Flowers, C. R. (2019). Patient and caregiver perceptions of lymphoma care and research opportunities: A qualitative study. *Cancer, 125*(22), 4096-4104. https://doi.org/10.1002/cncr.32401

Pearson, E. J. (2022). Fatigue – a substantial problem in hematology, but what can be done? *Leukemia & Lymphoma*, *63*(2), 263-264. https://doi.org/10.1080/10428194.2021.1992767

Pearson, E. J., Morris, M. E., & McKinstry, C. E. (2016). Cancer-related fatigue: appraising evidence-based guidelines for screening, assessment and management. *Supportive Care in Cancer*, *24*, 3935-3942.

Persoon, S., Buffart, L. M., Chinapaw, M., Nollet, F., Frings-Dresen, M., Koning, S., Kersten, M., & Tamminga, S. (2019). Return to work experiences of patients treated with stem cell transplantation for a hematologic malignancy. *Supportive Care in Cancer*, *27*, 2987-2997.

Peirce, C. S. (1905). What pragmatism is. *The Monist*, 161-181.

Pelentsov, L. J., Laws, T. A., & Esterman, A. J. (2015). The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disability and Health Journal*, *8*(4), 475-491.

Pereira, M. G., Vilaça, M., Pereira, M., Ferreira, G., Monteiro, S., Coelho, H., Geraldes, C., Gonçalves, C., da Costa, F. L., Marques, H., & Bacalhau, R. (2020). The mediator role of unmet needs on quality of life in myeloma patients. *Quality of Life Research*, *29*(10), 2641-2650. https://doi.org/10.1007/s11136-020-02511-8

Pickard, S. A., De Leon, M. C., Kohlmann, T., Cella, D., & Rosenbloom, S. (2007). Psychometric Comparison of the Standard EQ-5D to a 5 Level Version in Cancer Patients. *Medical Care*, *45*(3), 259 - 263. https://doi.org/10.2307/40221410

Pii, K. H., Schou, L. H., Piil, K., & Jarden, M. (2019). Current trends in patient and public involvement in cancer research: A systematic review. *Health Expectations*, *22*(1), 3-20. https://doi.org/10.1111/hex.12841

Poletto, S., Novo, M., Paruzzo, L., Frascione, P. M. M., & Vitolo, U. (2022). Treatment strategies for patients with diffuse large B-cell lymphoma. *Cancer Treatment Reviews*, *110*, 102443. https://doi.org/https://doi.org/10.1016/j.ctrv.2022.102443

Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods*. Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2006). The content validity index: are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health*, *29*(5), 489-497.

Polit, D. F., Beck, C. T., & Owen, S. V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in Nursing & Health*, *30*(4), 459-467.

Pongthavornkamol, K., Lekdamrongkul, P., Pinsuntorn, P., & Molassiotis, A. (2019). Physical Symptoms, Unmet Needs, and Quality of Life in Thai Cancer Survivors after the Completion of Primary Treatment. *Asia-Pacific Journal of Oncology Nursing*, *6*(4), 363-371. https://doi.org/10.4103/apjon.apjon_26_19

Posluszny, D. M., Dew, M. A., Beckjord, E., Bovbjerg, D. H., Schmidt, J. E., Low, C. A., Lowery, A., Nutt, S. A., Arvey, S. R., & Rechis, R. (2016). Existential challenges experienced by lymphoma survivors: Results from the 2010 LIVESTRONG Survey. *Journal of Health Psychology*, *21*(10), 2357-2366. https://doi.org/10.1177/1359105315576352

Pourhoseingholi, M. A., Baghestani, A. R., & Vahedi, M. (2012). How to control confounding effects by statistical analysis. *Gastroenterology and Hepatology from Bed to Bench*, *5*(2), 79.

Powis, M., Hack, S., Fazelzad, R., Hodgson, D., & Kukreti, V. (2023). Survivorship care for patients curatively treated for Hodgkin's and non-Hodgkin's lymphoma: a scoping review. *Journal of Cancer Survivorship*. https://doi.org/10.1007/s11764-023-01500-3

Prager, G. W., Braga, S., Bystricky, B., Qvortrup, C., Criscitiello, C., Esin, E., Sonke, G. S., Martínez, G., Frenel, J.-S., Karamouzis, M., Strijbos, M., Yazici, O., Bossi, P., Banerjee, S., Troiani, T., Eniu, A., Ciardiello, F., Tabernero, J., Zielinski, C. C., . . . Ilbawi, A. (2018). Global cancer control: responding to the growing burden, rising costs and inequalities in access. *ESMO Open*, *3*(2), e000285. https://doi.org/https://doi.org/10.1136/esmoopen-2017-000285

Priebe, S., Huxley, P., & Burns, T. (1999). Who needs needs? *European Psychiatry*, *14*(4), 186-188.

Prinsen, C. A., Mokkink, L. B., Bouter, L. M., Alonso, J., Patrick, D. L., De Vet, H. C., & Terwee, C. B. (2018). COSMIN guideline for systematic reviews of patient-reported outcome measures. *Quality of Life Research*, *27*(5), 1147-1157.

Puts, M. T. E., Papoutsis, A., Springall, E., & Tourangeau, A. E. (2012). A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. *Supportive Care in Cancer*, *20*(7), 1377-1394. https://doi.org/10.1007/s00520-012-1450-7

Raphael, D., Frey, R., & Gott, M. (2019). The nature and timing of distress among post-treatment haematological cancer survivors. *European Journal of Cancer Care*, *28*(1), e12951. https://doi.org/10.1111/ecc.12951

Rescher, N. (2000). Realistic pragmatism: An introduction to pragmatic philosophy. *Transactions of the Charles S. Peirce Society*, *36*(3).

Reuben, S. H. (2004). *Living beyond cancer: finding a new balance. President's cancer panel 2003-2004 annual report.* Department of Health and Human Services, Maryland.

Rezai, M., Kolne, K., Bui, S., & Lindsay, S. (2020). Measures of Workplace Inclusion: A Systematic Review Using the COSMIN Methodology. *Journal of Occupational Rehabilitation*, *30*(3), 420-454. https://doi.org/10.1007/s10926-020-09872-4

Richardson, A., Medina, J., Brown, V., & Sitzia, J. (2007). Patients' needs assessment in cancer care: a review of assessment tools. *Supportive Care in Cancer*, *15*(10), 1125-1144.

Ries, L., Smith, M., Gurney, J., Linet, M., Tamra, T., & Young, J. (1999). *Cancer incidence and survival among children and adolescents: United States SEER Program, 1975-1995.* National Cancer Institute.

Rodin, G., Chudak, A., Jhung, E., Trypuc, J., & Gospodarowicz, M. (2018). *Clinical Services: Supportive Care*. Princess Margaret Cancer Centre, University Health Network.

Rodrigues, I. B., Adachi, J. D., Beattie, K. A., & MacDermid, J. C. (2017). Development and validation of a new tool to measure the facilitators, barriers and preferences to exercise in people with osteoporosis. *BMC Musculoskeletal Disorders*, *18*(1), 1-9.

Roila, F., Fumi, G., Ruggeri, B., Antonuzzo, A., Ripamonti, C., Fatigoni, S., Cavanna, L., Gori, S., Fabi, A., Marzano, N., Graiff, C., De Sanctis, V., Mirabile, A., Serpentini, S., Bocci, C., Pino, M. S., Cilenti, G., Verusio, C., Ballatori, E., . . . on behalf of, N. (2019). Prevalence, characteristics, and treatment of fatigue in oncological cancer patients in Italy: a cross-sectional study of the Italian Network for Supportive Care in Cancer (NICSO). *Supportive Care in Cancer*, *27*(3), 1041-1047. https://doi.org/10.1007/s00520-018-4393-9

Rosenbaum, R., & Dyckman, J. (1995). Integrating Self and System: An Empty Intersection? *Family Process*, *34*(1), 21-44. https://doi.org/https://doi.org/10.1111/j.1545-5300.1995.00021.x

Rosenberg, M., Kowal, P., Rahman, M. M., Okamoto, S., Barber, S. L., & Tangcharoensathien, V. (2023). Better data on unmet healthcare need can strengthen global monitoring of universal health coverage. *British Medical Journal, 382*.

Rosenthal, A. (2022). Quality of Life and Survivorship in Lymphoma. *Current Oncology Reports*, *24*(9), 1113-1120. https://doi.org/10.1007/s11912-022-01283-3

Rowland, J. H., Kent, E. E., Forsythe, L. P., Loge, J. H., Hjorth, L., Glaser, A., Mattioli, V., & Fosså, S. D. (2013). Cancer survivorship research in Europe and the United States: Where have we been, where are we going, and what can we learn from each other? *Cancer*, *119*(S11), 2094-2108. https://doi.org/https://doi.org/10.1002/cncr.28060

Ryan, K., Brady, J., Cooke, R., Height, D., Jonsen, A., King, P., & Turtle, R. (1979). *Ethical principles and guidelines for the protection of human subjects of research. The Belmont Report.* Washington DC.

Saab, M. M., O'Driscoll, M., Sahm, L. J., Leahy-Warren, P., Noonan, B., Fitzgerald, S., Kilty, C., McCarthy, M., O'Malley, M., Lyons, N., & Hegarty, J. (2022). *Barriers, Facilitators, and Strategies to Recognise and Refer High-Risk Individuals with Lung Cancer 'Alarm' Signs and Symptoms: A Study with Primary Healthcare Professionals in Ireland - Report*. Retrieved from https://www.hse.ie/eng/services/list/5/cancer/prevention/summary-report.pdf

Sadoughi, F., Afshar, H. L., Olfatbakhsh, A., & Mehrdad, N. (2016). Application of canonical correlation analysis for detecting risk factors leading to recurrence of breast cancer. *Iranian Red Crescent Medical Journal*, *18*(3).

Salkind, N. J. (2010, 2021/03/03). *Encyclopedia of Research Design*. Retrieved from https://methods.sagepub.com/reference/encyc-of-research-design

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, *18*(2), 179-183. https://doi.org/10.1002/nur.4770180211

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in nursing & health*, *23*(4), 334-340. https://doi.org/https://doi.org/10.1002/1098-240X(200008)23:4

Sanson-Fisher, R., Hobden, B., Watson, R., Turon, H., Carey, M., Bryant, J., & Freund, M. (2019). The new challenge for improving psychosocial cancer care: shifting to a system-based approach. *Supportive Care in Cancer*, *27*(3), 763-769. https://doi.org/10.1007/s00520-018-4568-4

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., Cook, P., & Supportive Care Review, G. (2000). The unmet supportive care needs of patients with cancer. *Cancer*, *88*(1), 226-237.

Sapkota, S., & Shaikh, H. (2022). *Non-Hodgkin Lymphoma*. Retrieved from http://europepmc.org/abstract/MED/32644754

Schmidt, N. A., & Brown, J. M. (2024). *Evidence-based practice for nurses: Appraisal and application of research* (6 ed.). Jones & Bartlett Learning.

Sezgin, M. G., & Bektas, H. (2023). A retrospective study of treatment and outcomes of patients with lymphoma undergoing hematopoietic stem cell transplantation: A single-center experience. *Transplant Immunology*, *79*, 101855. https://doi.org/https://doi.org/10.1016/j.trim.2023.101855

Shannon-Baker, P. (2015). "But I Wanted to Appear Happy": How using Arts-Informed and Mixed Methods Approaches Complicate Qualitatively Driven Research on Culture Shock. *International Journal of Qualitative Methods*, *14*(2), 34-52. https://doi.org/10.1177/160940691501400204

Sheridan, A., Kemple, M., Hyde, A., Fox, P., Furlong, E., Coughlan, B., Bell, M., Naughton, C., Carberry, S., & Drennan, J. (2020). Non-use of cancer information services among people experiencing cancer in Ireland. *European Journal of Oncology Nursing*, *44*, 101700.

Sherry, A., & Henson, R. K. (2005). Conducting and interpreting canonical correlation analysis in personality research: A user-friendly primer. *Journal of Personality Assessment*, *84*(1), 37-48.

Siegel, R. L., Miller, K. D., Wagle, N. S., & Jemal, A. (2023). Cancer statistics, 2023. *Cancer Journal for Clinicians*, *73*(1), 17-48.

Sims, J., & Miracle, V. A. (2002). Elements of an informed consent. *Dimensions of Critical Care Nursing*, *21*(6), 242-245.

Sims, J. M. (2010). A brief review of the Belmont report. *Dimensions of Critical Care Nursing*, *29*(4), 173-174.

Singh, D., Vaccarella, S., Gini, A., De Paula Silva, N., Steliarova-Foucher, E., & Bray, F. (2022). Global patterns of Hodgkin lymphoma incidence and mortality in 2020 and a prediction of the future burden in 2040. *International Journal of Cancer*, *150*(12), 1941-1947. https://doi.org/10.1002/ijc.33948

Skrabek, P., Bucher, O., Seftel, M. D., & Turner, D. (2015). Time to Diagnosis and Treatment of Lymphoma: A Canadian Population Based Study. *Blood*, *126*(23), 2098-2098. https://doi.org/10.1182/blood.V126.23.2098.2098

Slife, B. D., Williams, R. N., & Williams, R. N. (1995). *What's behind the research?: Discovering hidden assumptions in the behavioral sciences*. Sage Publications.

Smith, A., Howell, D., Patmore, R., Jack, A., & Roman, E. (2011). Incidence of haematological malignancy by sub-type: a report from the Haematological Malignancy Research Network. *British Journal of Cancer*, *105*(11), 1684-1692. https://doi.org/10.1038/bjc.2011.450

Smith, S. K., Crespi, C. M., Petersen, L., Zimmerman, S., & Ganz, P. A. (2010). The impact of cancer and quality of life for post-treatment non-Hodgkin lymphoma survivors. *Psycho-Oncology*, *19*(12), 1259-1267.

Smith, S. K., Zimmerman, S., Williams, C. S., Zebrack, B. J., Smith, S. K., Zimmerman, S., Williams, C. S., & Zebrack, B. J. (2009). Health status and quality of life among non-Hodgkin lymphoma survivors. *Cancer (0008543X)*, *115*(14), 3312-3323. https://doi.org/10.1002/cncr.24391

Smith, V., Coughlan, M., & Cronin, P. (2014). Understanding nursing and healthcare research. *Understanding Nursing and Healthcare Research*, 1-224.

Snowden, J. A. (2016). Now patients are living longer, we need to think about long-term sequelae and not just short term-term impact. *Hematology*, *21*(1), 44. https://doi.org/10.1080/10245332.2016.1166729

St James's Hospital. (2023). *CAR-T and Stem Cell Transplant Service*. Retrieved from https://www.stjames.ie/services/hope/car-tstemcelltransplant/#:~:text=The%20Stem%20Cell%20Transplantation%20(SCT,about%20160%20patients%20each%20year.

Stanton, A. L. (2012). What Happens Now? Psychosocial Care for Cancer Survivors After Medical Treatment Completion. *Journal of Clinical Oncology*, *30*(11), 1215-1220. https://doi.org/10.1200/JCO.2011.39.7406

Sturmberg, J. P., O'Halloran, D. M., & Martin, C. M. (2010). People at the centre of complex adaptive health systems reform. *Medical Journal of Australia*, *193*(8), 474-478.

Summerfield, G., Carey, P., Galloway, M., & Tinegate §, H. (2000). An audit of delays in diagnosis and treatment of lymphoma in district hospitals in the northern region of the United Kingdom. *Clinical & Laboratory Haematology*, *22*(3), 157-160.

Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2021). Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *A Cancer Journal for Clinicians*, *71*(3), 209-249. https://doi.org/10.3322/caac.21660

Sureda, A., André, M., Borchmann, P., da Silva, M. G., Gisselbrecht, C., Vassilakopoulos, T. P., Zinzani, P. L., & Walewski, J. (2020). Improving outcomes after autologous transplantation in relapsed/refractory Hodgkin lymphoma: a European expert perspective. *BMC Cancer*, *20*(1), 1088. https://doi.org/10.1186/s12885-020-07561-2

Swash, B., Bramwell, R., & Hulbert-Williams, N. J. (2017). Unmet psychosocial supportive care needs and psychological distress in haematological cancer survivors: The moderating role of psychological

flexibility. *Journal of Contextual Behavioral Science*, *6*(2), 187-194. https://doi.org/https://doi.org/10.1016/j.jcbs.2017.02.005

Swash, B., Hulbert-Williams, N., & Bramwell, R. (2014). Unmet psychosocial needs in haematological cancer: a systematic review. *Supportive Care in Cancer*, *22*(4), 1131-1141. https://link.springer.com/article/10.1007%2Fs00520-014-2123-5

Swash, B., Hulbert-Williams, N., & Bramwell, R. (2018). 'Haematological cancers, they're a funny bunch': A qualitative study of non-Hodgkin's lymphoma patient experiences of unmet supportive care needs. *Journal of Health Psychology*, *23*(11), 1464-1475. https://doi.org/10.1177/1359105316660179

Swerdlow, S. H., Campo, E., & Harris, N. L. (2008). WHO classification of tumours of haematopoietic and lymphoid tissues. *World Health Organisation Classification of Tumours*, 358-360.

Swerdlow, S. H., Campo, E., Pileri, S. A., Harris, N. L., Stein, H., Siebert, R., Advani, R., Ghielmini, M., Salles, G. A., & Zelenetz, A. D. (2016). The 2016 revision of the World Health Organization classification of lymphoid neoplasms. *Blood, 127*(20), 2375-2390.

Swerdlow, S. H., & Cook, J. R. (2020). As the world turns, evolving lymphoma classifications–past, present and future. *Human Pathology*, *95*, 55-77. https://doi.org/https://doi.org/10.1016/j.humpath.2019.08.019

Tashakkori, A., & Creswell, J. W. (2007). *Exploring the nature of research questions in mixed methods research.* Sage Publications, Los Angeles, CA.

Tashakkori, A., & Teddlie, C. (2010). *Handbook of Mixed Methods in Social & Behavioral Research* (2 ed.). Sage Publications. https://doi.org/10.4135/9781506335193

Taylor, S., Bellhouse, S., Allsop, M., Radford, J., & Yorke, J. (2020). The role of e-Health in the delivery of care for patients with hematological cancers: a systematic literature review. *Telemedicine and e-Health*, *26*(9), 1093-1105.

Taylor, K., Bulsara, M., & Monterosso, L. (2018). Test-Retest Reliability of the Short-Form Survivor Unmet Needs Survey. *Asia-Pacific Journal of Oncology Nursing*, *5*(2), 165-171. https://doi.org/10.4103/apjon.apjon_4_18

Taylor, K., Chivers, P., Bulsara, C., Joske, D., Bulsara, M., & Monterosso, L. (2019). Care After Lymphoma (CALy) trial: A phase II pilot pragmatic randomised controlled trial of a nurse-led model of survivorship care. *European Journal of Oncology Nursing*, *40*, 53-62. https://doi.org/10.1016/j.ejon.2019.03.005

Taylor, K., & Monterosso, L. (2016). Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. *Australian Journal of Cancer Nursing, The*, *17*(1), 6-13.

Tecchio, C., Bonetto, C., Bertani, M., Cristofalo, D., Lasalvia, A., Nichele, I., Bonani, A., Andreini, A., Benedetti, F., Ruggeri, M., & Pizzolo, G. (2013). Predictors of anxiety and depression in hematopoietic stem cell transplant patients during protective isolation. *Psycho-Oncology*, *22*(8), 1790-1797. https://doi.org/https://doi.org/10.1002/pon.3215

Terwee, C. B., Bot, S. D., de Boer, M. R., van der Windt, D. A., Knol, D. L., Dekker, J., Bouter, L. M., & de Vet, H. C. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology*, *60*(1), 34-42.

Terwee, C. B., Prinsen, C. A., Chiarotto, A., Westerman, M. J., Patrick, D. L., Alonso, J., Bouter, L. M., De Vet, H. C., & Mokkink, L. B. (2018). COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. *Quality of Life Research*, *27*(5), 1159-1170.

The Academy of Medical Sciences. (2017). *Unmet need in healthcare: Summary*. Retrieved from https://acmedsci.ac.uk/file-download/430378

Thomas, J., Sutcliffe, K., Harden, A., & et al. (2003). Children and healthy eating: a systematic review of barriers and facilitators. *Database of Abstracts of Reviews of Effects (DARE): Quality Assessed Reviews.*

Thomas, L. P. M., Meier, E. A., & Irwin, S. A. (2014). Meaning-Centered Psychotherapy: A Form of Psychotherapy for Patients With Cancer. *Current Psychiatry Reports*, *16*(10). https://doi.org/10.1007/s11920-014-0488-2

Thompson, B. (1991). A primer on the logic and use of canonical correlation analysis. *Measurement and Evaluation in Counseling and Development*.

Thompson, J., Bissell, P., Cooper, C. L., Armitage, C. J., & Barber, R. (2014). Exploring the Impact of Patient and Public Involvement in a Cancer Research Setting. *Qualitative Health Research*, *24*(1), 46-54. https://doi.org/10.1177/1049732313514482

Tondorf, T., Grossert, A., Rothschild, S., Koller, M., Rochlitz, C., Kiss, A., Schaefert, R., Meinlschmidt, G., Hunziker, S., & Zwahlen, D. (2018). Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study. *Psycho-Oncology*, *27*(6), 1656-1663.

Torok, J. A., Wu, Y., Chino, J., Prosnitz, L. R., Beaven, A. W., Kim, G. J., & Kelsey, C. R. (2018). Chemotherapy or combined modality therapy for early-stage Hodgkin lymphoma. *Anticancer Research*, *38*(5), 2875-2881.

Tricco, A. C., Antony, J., Zarin, W., Strifler, L., Ghassemi, M., Ivory, J., Perrier, L., Hutton, B., Moher, D., & Straus, S. E. (2015). A scoping review of rapid review methods. *BMC Medicine*, *13*(1), 1-15.

Troy, J. D., Locke, S. C., Pupa, M. R., Feliciano, J., Richhariya, A., & LeBlanc, T. W. (2017). Patient-reported distress in hodgkin lymphoma patients on active therapy vs. long-term survivors. *Blood*, *130*. http://www.embase.com/search/results?subaction=viewrecord&id=L620335758&from=export

Tzelepis, F., Paul, C. L., Sanson-Fisher, R. W., Campbell, H. S., Bradstock, K., Carey, M. L., & Williamson, A. (2018). Unmet supportive care needs of haematological cancer survivors: rural versus urban residents. *Annals of Hematology*, *97*(7), 1283-1292. https://doi.org/10.1007/s00277-018-3285-x

Valderas, J. M., Kotzeva, A., Espallargues, M., Guyatt, G., Ferrans, C. E., Halyard, M. Y., Revicki, D. A., Symonds, T., Parada, A., & Alonso, J. (2008). The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Quality of Life Research*, *17*(2), 179-193. https://doi.org/10.1007/s11136-007-9295-0

Van Leeuwen, F. E., & Ng, A. K. (2016). Long-term risk of second malignancy and cardiovascular disease after Hodgkin lymphoma treatment. *Hematology*, *2016*(1), 323-330. https://doi.org/10.1182/asheducation-2016.1.323

Vargas-Román, K., Díaz-Rodríguez, C. L., Cañadas-De la Fuente, G. A., Gómez-Urquiza, J. L., Ariza, T., & De la Fuente-Solana, E. I. (2020). Anxiety prevalence in lymphoma: A systematic review and meta-analysis. *Health Psychology: 39*(7), 580-588. https://doi.org/10.1037/hea0000869

Vaz-Luis, I., Masiero, M., Cavaletti, G., Cervantes, A., Chlebowski, R. T., Curigliano, G., Felip, E., Ferreira, A. R., Ganz, P. A., Hegarty, J., Jeon, J., Johansen, C., Joly, F., Jordan, K., Koczwara, B., Lagergren, P., Lambertini, M., Lenihan, D., Linardou, H., . . . Pravettoni, G. (2022). ESMO Expert Consensus Statements on Cancer Survivorship: promoting high-quality survivorship care and research in Europe. *Annals of Oncology*, *33*(11), 1119-1133. https://doi.org/https://doi.org/10.1016/j.annonc.2022.07.1941

Vena, J. A., & Copel, L. C. (2021a). Cancer survivorship and quality of life outcomes of adolescents and young adults with lymphoma: An integrative review. *European Journal of Oncology Nursing*, *52*, 101948. https://doi.org/https://doi.org/10.1016/j.ejon.2021.101948

Vena, J. A., & Copel, L. C. (2021b). A Meta-Ethnography of the Experiences of Adults with Lymphoma During Acute and Chronic Survivorship. *Seminars in Oncology Nursing*, *37*(2), 151142. https://doi.org/10.1016/j.soncn.2021.151142

Verma, R., Saldanha, C., Ellis, U., Sattar, S., & Haase, K. R. (2022). eHealth literacy among older adults living with cancer and their caregivers: A scoping review. *Journal of Geriatric Oncology*, *13*(5), 555-562. https://doi.org/https://doi.org/10.1016/j.jgo.2021.11.008

Viscuse, P., Yost, K. J., Jenkins, S., Lackore, K., Habermann, T., Thanarajasingam, G., & Thompson, C. (2019). Impact of lymphoma survivorship clinic visit on patient-centered outcomes. *Journal of Cancer Survivorship*, *13*(3), 344-352. https://doi.org/10.1007/s11764-019-00756-y

Vottero, B., & Rittenmeyer, L. (2012). The hospitalised patients' experience of being in protective/source isolation: A systematic review of qualitative evidence. *JBI Evidence Synthesis*, *10*(16), 935-976.

Waltz, C. F., Strickland, O. L., & Lenz, E. R. (2010). *Measurement in nursing and health research*. Springer Publication.

Wang, H.-W., Balakrishna, J. P., Pittaluga, S., & Jaffe, E. S. (2019). Diagnosis of Hodgkin lymphoma in the modern era. *British Journal of Haematology*, *184*(1), 45-59. https://doi.org/10.1111/bjh.15614

Wang, Y., Yin, M., Zhu, S., Chen, X., Zhou, H., & Qian, W. (2021). Patient-reported outcome measures used in patients undergoing total knee arthroplasty. *Bone & Joint Research*, *10*(3), 203-217. https://doi.org/10.1302/2046-3758.103.Bjr-2020-0268.R1

Ware, J. E., Jr., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care*, *30*(6), 473-483.

Watts, E. (2019). Cancer survivorship: living with and beyond cancer. *Trends in Urology & Men's Health*, *10*(5), 28-31.

Weinkove, R., McQuilten, Z. K., Adler, J., Agar, M. R., Blyth, E., Cheng, A. C., Conyers, R., Haeusler, G. M., Hardie, C., Jackson, C., Lane, S. W., Middlemiss, T., Mollee, P., Mulligan, S. P., Ritchie, D., Ruka, M., Solomon, B., Szer, J., Thursky, K. A., Teh, B. W. (2020). Managing haematology and oncology patients during the COVID-19 pandemic: interim consensus guidance. *Medical Journal of Australia*, *212*(10), 481-489. https://doi.org/https://doi.org/10.5694/mja2.50607

Wen, K.-Y., & Gustafson, D. H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes*, *2*(1), 1-12.

Wilson, W. H. (2013). Treatment strategies for aggressive lymphomas: what works? *Hematology*, *2013*(1), 584-590. https://doi.org/10.1182/asheducation-2013.1.584

Wood, M. J., & Ross-Kerr, J. (2010). *Basic Steps in Planning Nursing Research: From Question to Proposal: From Question to Proposal*. Jones & Bartlett Publishers.

World Health Organisation. (1995). The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Social Science and Medicine, 41*(10), 1403-1409. https://doi.org/10.1016/0277-9536(95)00112-k

World Medical Association. (1964). *Declaration of Helsinki: Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects. Retrieved from https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/*

Xu, R. H., Wong, E. L.-Y., Su, Y., Zhang, H., Zhang, W., & Dong, D. (2020). Quantifying the Effect of Financial Burden on Health-Related Quality of Life among Patients with Non-Hodgkin's Lymphomas. *Cancers, 12*(11), 3325. *https://doi.org/10.3390/cancers12113325*

Yabroff, K. R., Lund, J., Kepka, D., & Mariotto, A. (2011). Economic Burden of Cancer in the United States: Estimates, Projections, and Future Research. *Cancer Epidemiology, Biomarkers & Prevention, 20*(10). *https://doi.org/10.1158/1055-9965.Epi-11-0650*

Yang., Chai, P., Yu, J., & Fan, X. (2021). Effects of cancer on patients with COVID-19: a systematic review and meta-analysis of 63,019 participants. *Cancer Biol Med*, *18*(1), 298-307. https://doi.org/10.20892/j.issn.2095-3941.2020.0559

Zebrack, B. J., Ganz, P. A., Bernaards, C. A., Petersen, L., & Abraham, L. (2006). Assessing the impact of cancer: development of a new instrument for long-term survivors. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *15*(5), 407-421.

Zelenetz, A. D., Gordon, L. I., Chang, J. E., Christian, B., Abramson, J. S., Advani, R. H., Bartlett, N. L., Budde, L. E., Caimi, P. F., & De Vos, S. (2021). NCCN Guidelines® insights: b-cell lymphomas, version 5.2021: featured updates to the NCCN guidelines. *Journal of the National Comprehensive Cancer Network*, *19*(11), 1218-1230.

Zhang, N., Wu, J., Wang, Q., Liang, Y., Li, X., Chen, G., Ma, L., Liu, X., & Zhou, F. (2023). Global burden of hematologic malignancies and evolution patterns over the past 30 years. *Blood Cancer Journal*, *13*(1), 82. https://doi.org/10.1038/s41408-023-00853-3

Zimmer, P., Mierau, A., Bloch, W., Strüder, H. K., Hülsdünker, T., Schenk, A., Fiebig, L., Baumann, F. T., Hahn, M., & Reinart, N. (2015). Post-chemotherapy cognitive impairment in patients with B-cell non-Hodgkin lymphoma: a first comprehensive approach to determine cognitive impairments after treatment with rituximab, cyclophosphamide, doxorubicin, vincristine and prednisone or rituximab and bendamustine. *Leukemia & Lymphoma*, *56*(2), 347-352.

Zomerdijk, N., Jongenelis, M., Yuen, E., Turner, J., Huntley, K., Smith, A., McIntosh, M., & Short, C. E. (2022). Experiences and needs of people with haematological cancers during the COVID-19 pandemic: A qualitative study. *Psycho-Oncology*, *31*(3), 416-424.

Appendices

Appendix 1 Search String Used in Database Searches

Terms relating to lymphoma
(MH "Lymphoma+")
TI(Lymphoma*)
AB(Lymphoma*)
CI(Lymphoma*)
Terms relating to cancer survivorship
(MH "Cancer Survivors")
TI(surviv* OR (after N2 cancer)) / (W/2) / (NEAR/2)
AB(surviv* OR (after N2 cancer))
CI(surviv* OR (after N2 cancer))
Terms relating to needs
(MH “Needs Assessment”) / (DE “Needs Assessment”)
TI(((unmet OR unfulfil* OR overlook* OR perceived OR "supportive care" OR physiological OR physical OR psychological OR emotional OR spiritual OR economical OR social OR psychosocial OR practical OR informational) N2 (need* OR concern*)) OR "late effect*" OR "patient outcome*")
AB(((unmet OR unfulfil* OR overlook* OR perceived OR "supportive care" OR physiological OR physical OR psychological OR emotional OR spiritual OR economical OR social OR psychosocial OR practical OR informational) N2 (need* OR concern*)) OR "late effect*" OR "patient outcome*")
CI(((unmet OR unfulfil* OR overlook* OR perceived OR "supportive care" OR physiological OR physical OR psychological OR emotional OR spiritual OR economical OR social OR psychosocial OR practical OR informational) N2 (need* OR concern*)) OR "late effect*" OR "patient outcome*")
Limitations
English language Adults Post January 2006 (Institute of Medicine report)

Appendix 2 Study Characteristics of Included Studies (N=47)

Quantitative							
Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Arboe 2017 *Denmark*	369 *National registry*	Describe the social outcomes after ASCT in terms of return to work.	60%	100% NHL	22-73 (Median=58, SD=NR)	NR	▪ Following ASCT, there was an impaired association between return to work for patients on sick leave at the time of relapse. ▪ Older patients (>55 years) were more likely to return to work compared to younger patients.
Arden-Close 2011 *United Kingdom*	115 *Single site*	Evaluate gender differences in HRQoL, late effects, perceived vulnerability, and satisfaction with care.	49%	100%	18-45 (Mean=37.3, SD=5.6)	12.8 years (SD=5.0)	▪ No gender differences were found in self-reported late effects or perceived vulnerability, however, men with more late effects reported worse psychological HRQoL. ▪ Men wished to talk about more topics than they did, while women were able to talk about the topics they wanted.
Beaven 2016 *United States*	553 *Two sites*	Evaluate differences in QoL between incurable indolent lymphoma and potentially cured aggressive NHL.	50%	100% NHL	(Mean=61.9, SD=13.5)	10.6 years (SD=6.9)	▪ Aggressive and indolent lymphoma survivors were found to have similar overall QoL, however differences were greater in short-term survivors. ▪ Longer-term indolent lymphoma survivors had higher QoL scores than shorter-term survivors.
Behringer 2016 *Germany*	3,759 (5 year follow up n=1,758) *Database*	Investigate the persistence of severe fatigue in HL survivors up to 9 years after primary therapy and its relationship with social reintegration.	56%	100% HL	18-60 (Median=34)	Unclear	▪ Baseline severe fatigue was often younger, more often female, and had a higher stage of disease compared to patients without a baseline of severe cancer-related fatigue. ▪ Five years post-therapy, 84% of survivors without severe fatigue were working or in education, compared to 57% of survivors' experiencing severe fatigue.
Chen 2012 *United States*	511 *Single site*	Evaluate the disparities in employment and insurance between HL survivors and their non-diagnosed peers.	49.5%	100% HL	16-82 (Median=44)	Median 15 years (Range 5-32)	▪ HL survivors were more likely to report job denial, difficulty obtaining insurance due to medical history, and difficulty changing jobs due to fear of losing insurance. ▪ Male gender, income, and scarring of the head and neck were associated with job denial (multivariate analysis).
Esser 2018 *Germany*	922 *Two cancer registries*	Compare adjusted levels of QoL across different subsamples of survivors with haematological malignancies versus the general population.	57% (total sample)	57%	(Mean=63.9, SD=13.4)	9.1 years (SD=4.2)	▪ Worse QoL predictors included: being female, not being in remission at the time of the survey, number of comorbidities, and having a history of relapse. ▪ Compared with the general population, haematology cancer survivors scored significantly lower in functioning and higher in symptom burden.

Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Fauer 2021 *United States*	1,151 *Database (NCI SEER)*	Examine factors influencing patient experiences in care during the first year of diagnosis in older adults diagnosed with leukaemia and lymphoma.	46% (lymphoma sample)	63%	65-85+	Median 6 months	▪ Completing the survey 8 to 12 months after diagnosis compared to 0 to 3 months was associated with a higher global rating of care (fully adjusted models). ▪ Each additional comorbidity (β 0.26, p=0.003) and being dually eligible for Medicaid (β 0.43, p = 0.03) were significantly associated with a higher adjusted personal doctor rating.
Georges 2020 *United States*	389 *Single site*	Explore the late effects and QoL in long-term survivors after autologous hematopoietic cell transplantation.	59% (lymphoma sample)	69%	22-88 (median 63)	NR	▪ Lymphoma survivors were more likely to report post-traumatic stress symptoms (6% versus 1%) and problems with sexual desire, erection, ejaculation, or vaginal dryness or pain (62% versus 51%) compared to myeloma survivors. ▪ Worse mental functioning was associated with younger age and treatment for anxiety, depression, or pain.
Greaves 2014 *United Kingdom*	718 *Single site*	Determine the impact of haematological malignancy on fertility and sexual function based on the patient's report of their experience.	59% (total sample)	84%	(Mean HL 53.1, SD 11.9; NHL 45.0, SD 13.0)	HL 25.1 years (SD 10.0); NHL 16.8 (SD 8.5)	▪ Fertility support services were attended by few (12%). ▪ Of the HL patients who did not store a sperm sample, the majority (52%) reported that they were not offered the chance to store a sperm sample, whereas among NHL patients most (55%) of those who did not store a sperm sample did not intend to have any children after treatment.
*Hall 2015 *Australia*	715 *Four cancer registries*	Identify the most prevalent unmet needs of haematological cancer survivors.	59% (total sample)	64%	15-80	35 months (SD 18.5)	▪ "Dealing with feeling tired" (17%), was the most frequently endorsed "high/very high" unmet need. ▪ Higher levels of psychological distress (e.g., anxiety, depression, and stress) and indicators of financial burden because of cancer were consistently identified as characteristics associated with the three most prevalent "high/very high" unmet needs.
*Hall 2014 *Australia*	696 *Four cancer registries*	Identify subgroups of haematological cancer survivors who report a high level of multiple unmet needs.	59% (total sample)	64%	15-70+	1-60+ months	▪ "High/very high" level of unmet need on seven or more items of the SUNS were reported by 25% of participants. ▪ Survivors who: had relocated due to their cancer, had difficulty paying bills, had used up their savings because of cancer, and were classified as having above-normal symptoms of depression and stress had statistically significantly higher odds of reporting seven or more "high/very high" unmet needs.
Hall 2013 *Australia*	437 *Two national registries*	Assess and compare the unmet needs of Australian (A) and Canadian (C) haematological cancer survivors.	59% (A); 54% (C)	>50% (A); >52% (C)	15-60+	1-60 months	▪ 'Dealing with feeling tired' was identified as the highest concern by survivors. ▪ Having a personal expense in the last month because of having cancer, younger age at diagnosis, female sex, vocational or other level education, and consulting a health care professional for cancer treatment or concerns about cancer in the last month were associated with multiple areas of need.

Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Hernaes 2021 *Norway*	225 *Hospital registry*	Investigate post-treatment work patterns amongst survivors of lymphoma treated with high-dose chemotherapy and ASCT.	61%	100%	(Mean 52, SD 11.6)	NR	▪ Eighty-five per cent of participants were employed when diagnosed, 77% before high-dose chemotherapy and autologous stem-cell transplantation and 69% at the survey. ▪ Employment before HDT-ASCT positively corresponds with a higher probability of employment at survey for a given symptom burden.
Husson 2017 *The Netherlands*	198 *National survivorship registry*	Examine differences in HRQoL between AYA lymphoma survivors and a normative population and to determine sociodemographic, clinical, and long-term symptom-related factors associated with HRQoL.	57%	100%	(Mean 34.7, SD 7.4)	4.2 years (SD 2.7)	▪ Poorer HRQoL for AYA lymphoma survivors was observed in seven domains: physical, role, cognitive, emotional, social functioning, fatigue, and financial difficulties compared to the normative population sample. ▪ Being unemployed, female gender, having one or more comorbid conditions, high levels of fatigue and psychological distress were most strongly associated with HRQoL.
Kang 2018 *South Korea*	370 *Single site*	Compare HRQoL at diagnosis to that of long-term follow-up among survivors of aggressive and indolent NHL.	55.5%	100% NHL	18-82 (median 51)	Median 4.0 years (range 1.7-17.4 years)	▪ The HRQOL of long-term survivors with aggressive NHL improved to a similar level of indolent NHL during the follow-up survey. However, survivors of NHL were found to fear the probability of relapse and second malignancy. ▪ More than 65% of survivors thought they did not receive sufficient support from others, and patients who had financial difficulties at diagnosis were more frequently associated with suffering from insufficient support.
Keegan 2012 *United States*	523 *Multiple registries*	Describe unmet information and service needs of AYA survivors and identify sociodemographic and health-related factors associated with unmet information and service needs.	63% (total sample)	52%	15-39	Median 11 months	▪ Half of survivors have unmet information needs (about cancer treatments, long-term effects, cancer returning or new cancer type). ▪ Unmet needs included: staying physically fit (30%), financial support (>50%), fertility or reproductive concerns about having children in the future (>40%).
Khimani 2013 *United States*	273 *Not clear*	Determine changes in QoL and the development of new late effects over 7 years in a cohort of long-term HL survivors.	50%	100%	31-78	NR	▪ Over 7 years, a significant physical decline was noted, decline was greater among survivors experiencing new cardiac or pulmonary complications compared with those without any new complications. ▪ There were no differences in changes in QoL scores over time between survivors who did or did not develop a new infectious complication or a new second malignancy.

Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Kim 2017 *South Korea*	826 *Three hospital registries*	Describe the prevalence and correlates of unmet needs among lymphoma survivors and to identify their association with HRQoL.	58%	100% NHL	(Mean 56, SD 12.0)	6.3 years (SD 3.2)	▪ The most reported unmet needs domains: 'treatment and prognosis' (38.3%) and 'keeping mind under control' (30.5%). ▪ The three most often reported individual unmet needs: 'being informed about prevention of recurrence' (50.7%), 'being informed about prevention of metastasis' (49.7%), and 'having self-confidence of overcoming cancer' (42.7%).
Kim 2014 *South Korea*	837 *Three hospital registries*	Examine the association between HRQOL and sociodemographic and clinical factors and identify predictors of HRQoL in the survivor population.	57%	100%	(Mean 54.6, SD 12.6)	6.3 years (SD 3.2)	▪ Overall, the HRQoL in both HL and NHL survivors and the general population were comparable, but clinically meaningful worse social functioning in NHL survivors ($p<0.001$) and more severe fatigue in HL survivors ($p<0.001$) than in the general population was observed. ▪ Survivors who received peripheral blood stem cell transplants showed clinically meaningful worse role ($p=0.001$) and social ($p<0.001$) functioning than those who were treated with first-line chemotherapy alone.
Kreissl 2020 *Germany*	4,215 *Pooled secondary analysis*	Analyse longitudinal HRQoL data prospectively collected within trials.	55%	100%	18-60 (median 34)	0-5 years	▪ During survivorship, cognitive, emotional, role, and social functioning and fatigue, dyspnoea, sleep, and financial problems were severely and persistently affected. ▪ Financial problems were the most affected domain of HRQoL in the first year after treatment.
Lekdamrongkul 2021 *Thailand*	312 *Two sites*	Exploring HRQoL among non-Hodgkin's lymphoma survivors after completion of primary treatment.	45%	100% NHL	18-89 (mean 58, SD 14.67)	NR	▪ NHL survivors in phase I (<6 months post-treatment) had significantly lower physical well-being and functional well-being scores than longer-term survivors; and significantly lower lymphoma domain scores than those in phase III (>4 – 9 years after completion of primary treatment). ▪ Physical symptom distress, anxiety, depression, unmet supportive care needs, poor adaptation, and receiving chemotherapy disrupted HRQoL (all $p<0.001$).
Lobb 2009 *Australia*	66 *Two sites*	Determine patients' information, emotional and support needs after treatment for haematological malignancy.	NR	59%	24-82 (mean 54, SD 14.07)	NR	▪ The most often endorsed unmet needs included: managing the fear of recurrence, the need for a case manager and the need for communication between treating doctors. ▪ Predictors of unmet needs included younger patients ($p=0.01$), marital status ($p=0.03$) and employment ($p=0.03$).
Ng 2016 *Malaysia*	156 *Single site*	Determine the prevalence of anxiety and depression of lymphoma survivors and to investigate associations between these disorders and QoL.	40%	100%	18-85 (median 52.06, SD 16.8)	6.82 years (SD 5.5), median 26 (range 1-27)	▪ 18 % of patients had symptoms of anxiety and 10 % had symptoms of depression. ▪ Patients with anxiety were associated with lower overall QOL score, lower emotional and cognitive functioning and complained more of fatigue and insomnia ($p<0.05$). Patients who had depression were associated with lower physical functioning and complained more of insomnia ($p<0.05$).

Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Noonan 2020 *United States*	566 *Pooled secondary analysis*	Evaluate QoL and impact of cancer difference in rural and non-rural non-Hodgkin lymphoma survivors.	48%	100% NHL	23-65+	15.2 years (SD 7.19)	▪ Rural residence was independently associated with lower SF-36 physical part summary scores and the physical function subscale (all p<0.05). ▪ Rural residence was also associated with higher IOCv2 positive impact scores and the subscales of altruism/empathy and meaning of cancer scores in the adjusted models (all p<0.05).
*Oberoi 2017A *Australia*	414 *Cancer registry*	Examine the influence of anxiety, depression, and unmet supportive care needs on future QoL in MM and DLBCL.	57% (total sample)	57% NHL (DLBCL)	(Mean 63.82, SD 11.08)	6.7 months (SD 1.98)	▪ Except for physical well-being, all other QoL subscales and overall QoL were significantly associated with T1 (on average 7 months post-diagnosis) anxiety. ▪ All QoL subscales and overall QoL were significantly associated with T1 depression. Only patient care needs were associated with physical and social well-being and overall QoL.
*Oberoi 2017B *Australia*	414 *Cancer registry*	Examine the cross-sectional and longitudinal associations between patient-reported unmet needs and anxiety and depression for survivors.	57% (total sample)	57% NHL (DLBCL)	(Mean 63.82, SD 11.08)	6.7 months (SD 1.98)	▪ At T1 (on average 7 months post-diagnosis), 30% of participants reported at least one moderate to high unmet need in the psychological needs and the physical and daily living needs domains, 24% information needs, 9% sexuality needs and 11% patient care needs. ▪ At T2 (on average 15 months post-diagnosis), 23% reported at least one moderate to high unmet need in the psychological and physical and daily living needs domains, 14% information needs and 8% sexuality and patient care needs.
*Oberoi 2017C *Australia*	414 *Cancer registry*	Examine the course of anxiety, depression, and unmet needs in survivors in the first two years post-diagnosis.	57% (total sample)	57% NHL (DLBCL)	(Mean 63.82, SD 11.08)	6.7 months (SD 1.98)	▪ Course of anxiety differed (p< 0.01) with the rate increasing in Diffused Large B Cell Lymphoma (14 to 22%) while staying stable for Multiple Myeloma (15 to 12%). ▪ Change in unmet needs was similar for the two cancer groups, except for moderate to high psychological needs (p < 0.05).
Oerlemans 2012 *The Netherlands*	1,135 *National registry*	Measure the perceived level of satisfaction with information received by survivors of lymphoma and MM.	60% (total sample)	86%	(Mean 61.6, SD 14)	3.7 years (SD 2.7)	▪ Two-thirds of survivors were satisfied with the amount of received information, with HL survivors being most satisfied (74 %). At least 25 % of survivors wanted more information. ▪ Younger age, having had chemotherapy, having been diagnosed more recently, using the internet for information, and having no comorbidities were key factors associated with higher perceived levels of information provision.
Parry 2012 *United States*	477 *Cancer registry*	Characterise the psychosocial and health service needs of adult leukaemia and lymphoma survivors after treatment.	54% (total sample)	79%	18-85 (mean 56, SD NR)	NR	▪ The rate of unmet needs was highest for sexual issues, handling medical and living expenses, emotional difficulties, employment, and health insurance. ▪ Women were more likely to report unmet childcare needs than men; younger individuals were more likely to report needing help with emotional difficulties and family problems, and lower income was related to greater unmet needs for medical and living expenses.

Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Paul 2017 *Australia*	787 *Five state cancer registries*	Explore the dyadic relationships between unmet needs, depression, and anxiety in people diagnosed with haematological cancer and their support persons.	58% (total sample)	56% NHL	(Mean 57, SD 13)	NR	▪ Survivor unmet needs were significantly related to support person depression (p = 0.0036). ▪ Survivor unmet needs did not have a significant relationship to supporting person anxiety (p = 0.78). Higher anxiety scores for survivors were significantly associated with greater support person's unmet needs.
Posluszy 2016 *United States*	429 *Online survey*	Examine the existential challenges that lymphoma cancer survivors may experience.	44%	100%	18-78 (mean 44.2, SD 12.7)	7 years (SD 7.4)	▪ Most survivors (73–86%) endorsed existential concerns, with 30–39% reporting related perceived functional impairment. ▪ Concerns were associated with being female, younger, unmarried, and having undergone stem cell transplantation.
Smith 2010 *United States*	652 *Two cancer registries*	Examine the association between the impact of cancer and QoL post-treatment for NHL survivors.	50%	100% NHL	(51.9, SD 14.2)	10.8 years (SD 7.5)	▪ Survivors with comorbidities and negative appraisals of life threat and treatment intensity reported worse physical and mental health and QOL (all p<0.05). ▪ After controlling for demographic and clinical characteristics, younger respondents reported better physical but worse mental health and QoL (all p<0.01).
Smith 2009 *United States*	761 *Two cancer registries*	Compare the QoL status of individuals with active NHL with those who were disease-free.	50%	100% NHL	25-92 (mean 52.3, SD 14.1)	10.4 years (SD 7.2)	▪ Survivors with active disease (n = 109) demonstrated worse physical and mental health functioning, worse QOL, and less positive and more negative impacts of cancer compared with disease-free survivors (n = 652; all p<0.01). ▪ No significant differences were seen between short-term survivors (2 – 4 years post-diagnosis) and long-term survivors (>5 years post-diagnosis).
Tzelepis 2018 *Australia*	1511 (Urban n=1145, Rural n=272) *Five cancer registries*	Examine the unmet supportive care needs among rural versus urban haematological cancer survivors.	57% (total sample)	67%	(Mean 58, SD 13)	3.4 years (SD 1.5)	▪ Dealing with feeling tired was the most common "high/very high" unmet need for rural (15%) and urban (15%) survivors. The emotional health domain had the highest mean unmet need score for rural and urban survivors. ▪ Rurality was associated with a decreased unmet emotional health domain score while travelling for more than 1 hour to treatment was associated with increased unmet financial concerns and unmet access and continuity of care.
Xu 2020 *China*	1,549 *Online survey*	Assess the association of HRQoL with financial burden among patients with NHL in China.	52%	100% NHL	(Mean 43.3, SD NR)	Not clear	▪ Sixty per cent of respondents reported suffering moderate to high financial burdens. ▪ A significant relationship between increased financial burden and reduced HRQoL scores, including the EQ-Index, physical, emotional, and social functioning, was found.
Zuchchetti 2017 *Italy*	50 *Single site*	Investigate the experience of possible body image discomfort among AYA haematological cancer survivors.	52% (total sample)	52%	15-23 (mean 17.7, SD 2.53)	NR	▪ No significant differences in body image were found between leukaemia and lymphoma survivors or between the off-therapy and long-term groups. ▪ More females were in the risk category of impaired body image than males.

Qualitative							
Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Chen 2020 *United States*	12 *Single site and via conferences*	Determine the perceived unmet needs regarding lymphoma care in rural areas.	50%	100%	21-73 (median 54)	NR	▪ The greatest barrier to care was the travel distance. The participants described difficulty navigating between local clinics and larger cancer centres. ▪ The lack of communication between the local and specialized clinics complicated the process, and participants had difficulty contacting or seeking advice from the team at the larger cancer centres.
Hackett 2018 *Ireland*	14 *Single site*	Explore lymphoma survivors' experiences on their end of treatment and follow-up care.	64%	100%	18-65+	3-60 months	▪ Themes found: (i) dealing with uncertainty, (ii) changing relationships, (iii) returning to work, (iv) extended recovery time and (v) concerns for the future. ▪ Some participants were unaware that their treatment had ended, many experienced recurrent infections which prolonged recovery time, and many had no recall of discussions on healthy lifestyle behaviours or recommended screening programmes at their follow-up visits.
Herrmann 2020 *Australia*	17 *One state cancer registry*	Explore the unmet needs experienced by haematological cancer survivors as a result of their disease and treatment and helpful strategies.	59% (total sample)	71%	19-76 (mean 57, SD 13)	0-2+ years	▪ Themes found: (i) changes in unmet needs across the care trajectory; (ii) informational unmet needs requiring improved patient-centred communication; (iii) uncertainty about treatment and the future; (iv) coordinated, tailored, and documented post-treatment care planning as a strategy for optimal care delivery; and (v) ongoing support services to meet psychosocial and practical unmet needs.
Monterosso 2017 *Australia*	17 *Single site*	Explore the post-treatment experiences and preferences for follow-up support of lymphoma survivors.	53%	100%	27-85 (mean 63.8, SD 14.5)	6-29 months	▪ Themes found: (i) information; (ii) loss and uncertainty; (iii) family, support and post-treatment experience; (iv) transition, connectivity and normalcy, and (v) person-centred post-treatment care. ▪ Participants described a sense of loss as they transitioned away from regular interaction with the hospital at the end of treatment, but also talked about the need to find a "new normal".
Murphy-Banks 2022 *United States*	17 *Not clear*	Understand how survivors in active survivorship care perceived their role in treatment decision-making and when they acquired an understanding of late effects.	47%	100% HL	18-39+	5-36 years (mean 19 years)	▪ Role in initial treatment decision-making fluctuated between passive and active engagement with providers identified as being crucial to this process. ▪ Half of the interviewees (53%) expressed unmet information needs. Most participants (71%) reflected on fertility discussions; more than half of those participants cited fertility discussions occurring primarily before or during treatment.

Reference *Country*	Sample Size *Recruitment*	Aim	% Male	% Lymphoma	Age Range in years	Mean Time Since Diagnosis	Key Findings
Parry 2011 *United States*	51 *Cancer support organisations*	Explore patient's experiences on care delivery during the end-of-treatment transition to survivorship for leukaemia and lymphoma survivors.	45% (total sample)	76%	20-82 (Mean 50.3, SD NR)	Not clear	▪ Survivors reported poor continuity of care across the patient–survivor transition, difficulty finding proper information/services, lack of preparation, lack of support for survivorship issues, and inadequate or poorly timed follow-up as factors contributing to adjustment difficulties at end of treatment and beyond.
Raphael 2017 *New Zealand*	23 *National registry*	Explore the nature and timing of psychosocial distress experienced by haematological cancer survivors.	44% (total sample)	74%	33-77	0-8 years	▪ Themes found: (i) apprehension about leaving the safety of the health care system (ii) uncertainty and life transitions in the post-treatment period (iii) distress associated with ongoing physical problems or impairment, and (iv) fear of recurrence.
Swash 2018 *United Kingdom*	6 *Single site*	Investigate the experiences of psychosocial needs in haematological cancer patients, the importance, and impact of their unmet needs.	83%	100% NHL	NR	NR	▪ Themes found: (i) concerns for family, (ii) information needs, and (iii) the need for psychological support. ▪ NHL patients perceive themselves as different from other cancer survivors or patients (i.e., treated by haematologists rather than oncologists; lymphoma can be described as a chronic health condition, rather than acute cancer).

Reviews				
Reference	Country	No. of Articles	Aim	Key findings
Arden-Close 2010	*United Kingdom*	18	Determine HRQoL in survivors of HL and NHL.	▪ Survivors of lymphoma experienced worse physical but comparable mental HRQoL to the general population. ▪ No conclusions could be drawn about the association between different treatments and HRQoL.
Vargas-Roman 2020	*Spain*	15	Examine the prevalence of anxiety among lymphoma patients.	▪ The meta-analysis sample was n = 2,138 and the overall prevalence of anxiety in lymphoma patients was 19% (95% CI [12%, 25%]).
Vena 2021	*United States*	9	Appraise the experiences of adults with lymphoma at the acute and chronic survivorship phases.	▪ Themes found: (i) the challenges and burden of treatment, (ii) communication and support from others, and (iii) moving forward with life.

*Merged databases

Key: NR=not reported; HRQoL=Health-Related Quality of Life; QoL=Quality of Life; HL=Hodgkin Lymphoma; NHL=non-Hodgkin Lymphoma; AL=Acute Leukaemia; MM=multiple myeloma; DLBC=diffused large b-cell lymphoma; AYA=Adolescent and Young Adult; NCI SEER=National Cancer Institute (NCI) Surveillance, Epidemiology and End-Results Registry; HDT-ASCT=high dose chemotherapy and autologous stem cell transplantation; SF-36 V2.0=Medical Outcomes Study Short Form-3; IOCv2=Impact of Cancer version 2; CI=Confidence Interva; SD=standard deviation.

Appendix 3 Quality Criteria Met by Included Studies

Author	Design / Method	Quality Criteria Met	Total
Arboe et al (2017)	Cohort	A, B, C, D, E, G, H, I, J, K	10
Arden-Close et al (2011)	Cohort	A, B, C, D, E, F, G, H, I, J, K	11
Arden-Close et al (2010)	Systematic review	A, B, C, D, E, F, G, H, I, J, K	11
Beaven et al (2016)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Behringer et al (2016)	Longitudinal	A, B, C, D, E, F, G, H, I, J, K	11
Chen et al (2020)	SSI	A, B, C, D, E, F, G, H, J, K	10
Chen et al (2012)	Cross-sectional	A, B, C, D, E, G, H, I, J, K	10
Esser et al (2018)	Cohort	A, B, C, D, E, F, G, H, I, J, K	11
Fauer et al (2021)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Georges et al (2020)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Greaves et al (2014)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Hackett & Dowling (2018)	SSI	A, B, C, D, E, F, G, H, I, J, K	11
*Hall et al (2015)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
*Hall et al (2014)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Hall et al (2013)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Hernaes et al (2021)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Herrmann et al (2020)	SSI	A, B, C, D, E, F, G, H, I, J, K	11
Husson et al (2017)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Kang et al (2018)	Longitudinal	A, B, C, D, E, F, G, H, I, J, K	11
Keegan et al (2012)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Khimani et al (2013)	Longitudinal	A, B, D, F, G, H, I, J, K	9
Kim et al (2017)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Kim et al (2014)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Kreissl et al (2020)	Longitudinal	A, B, C, D, E, F, G, H, I, J, K	11
Lekdamrongkul et al (2021)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Lobb et al (2009)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Monterosso et al (2017)	Focus groups (two)	A, B, C, D, E, F, G, H, I, J, K	11
Murphy-Banks et al (2022)	SSI	A, B, D, E, F, G, H, I, J, K	10
Ng et al (2016)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Noonan et al (2020)	Cohort	A, B, C, D, E, F, G, H, I, J, K	11
*Oberoi et al (2017A)	Longitudinal	A, B, C, D, E, F, G, H, I, J, K	11
*Oberoi et al (2017B)	Longitudinal	A, B, C, D, E, F, G, H, I, J, K	11
*Oberoi et al (2017C)	Longitudinal	A, B, C, D, E, F, G, H, I, J, K	11
Oerlemans et al (2012)	Longitudinal	A, B, C, D, E, F, G, H, I, J, K	11
Parry et al (2012)	Cross-sectional	A, B, C, D, E, H, I, J, K	9
Parry et al (2011)	SSI	A, B, C, D, E, F, G, H, I, J, K	11
Paul et al (2017)	Cross-sectional	A, B, D, E, F, G, H, I, J, K	10
Posluszy et al (2016)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Raphael et al (2017)	SSI	A, B, C, D, E, F, G, H, I, J, K	11
Smith et al (2010)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Smith et al (2009)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Swash et al (2018)	Focus groups (three)	A, B, D, E, F, G, H, I J, K	10
Tzelepis et al (2018)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Vargas-Roman et al (2020)	Systematic review & MA	A, B, C, D, E, F, G, H, I, J, K	11
Vena et al (2021)	Meta-ethnography	A, B, C, D, E, F, G, H, I, J, K	11
Xu et al (2020)	Cross-sectional	A, B, C, D, E, F, G, H, I, J, K	11
Zucchetti et al (2017)	Cross-sectional	A, B, C, D, E, F, G, H, J, K	10

Key: SSI=Semi structured interviews, MA=Meta analysis.
*Merged datasets

Appendix 4 Rationale for Excluded Instruments

Exclusion reason	Instrument name
Wrong population (*n*=2)	• Support Persons Unmet Needs Survey (SPUNS) • Childhood Cancer Survivor Study (CCSS)
Wrong outcome/concept (n=7)	• Memorial Symptom Assessment Scale Short Form (MSAS-SF) • Posttraumatic Growth Inventory (PTGI) • Posttraumatic Stress Disorder Checklist - Civilian Version (PCL-C) • Charlson Comorbidity Index (CCI) • Profile of Mood States (POMS) • The Princess Margaret Hospital Satisfaction with Doctor Questionnaire (PMH-PSQ-MD) • Body Uneasiness Test (BUT)
Too specific (*n*=9)	• Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-F) • Functional Assessment of Cancer Therapy – Bone Marrow Transplant (FACT-BMT) • Functional Assessment of Cancer Therapy - Anaemia (FACT-An) • European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Information Module (EORTC QLQ - INFO25) • Hospital Anxiety and Depression Survey (HADS) • Depression, Anxiety and Stress Scale (DASS-21) • Medical Outcomes Study Social Support Survey (MOS-SSS) • Hamilton Anxiety Rating Scale (HAM-A) • Appraisal and Life Threat and Treatment Intensity Questionnaire (ALTTIQ)
Not validated (*n*=1)	• Houts et al Service Need Items (not validated)

Beaumont Hospital
Ethics (Medical Research) Committee

Chairperson: [redacted] Administrator [redacted]
Convenor:

9th April 2021

REC reference: 20/89

Vanessa Boland
PhD Candidate
School of Nursing,
Trinity College Dublin,
24 D'Olier Street, D02 T283.

To: vboland@tcd.ie
cc: [redacted]

Dear Ms. Boland

REC REF: 20/89
Principal Investigator: Ms. Vanessa Boland, PhD student (TCD)
Study Title: Living beyond a cancer diagnosis: a mixed-method investigation of the unmet needs of lymphoma cancer survivors in Ireland.
Consultant co-investigators: [redacted] Consultant Haematologists, Beaumont Hosp.

I confirm research ethics committee approval is now in place for this research study which seeks to proceed in Beaumont Hospital. (This study was reviewed at a full meeting of the committee held on the 11th December 2020)

HSE North East Area Research Ethics Committee
HSE Dublin North East, Bective Street, Kells, Co. Meath

List of site/s with favourable opinion/approval

Research Identification

Title of Research:
"Living beyond lymphoma: a mixed method investigation of the unmet needs of cancer survivors in Ireland"

Approval to commence the study was given on 17/8/2021.

The study approval is extended to each of the site/s listed below.

Applicant	Site
Vanessa Boland	Our Lady of Lourdes Hospital, Drogheda, Co. Louth

Signed: [redacted] .....
Chair of Committee

Date: **17/8/2021**

SJH/TUH Research Ethics Committee Secretariat
email: researchethics@tuh.ie
JREC Ref.: 2021-09 Chairman's Action (05)

Tallaght University Hospital | Ospidéal Ollscoile Thamhlachta
An Academic Partner of Trinity College Dublin

Prof. Anne-Marie Brady,
Trinity College Dublin,
College Green,
Dublin 2

29th September 2021

REF: Living Beyond a Cancer Diagnosis: A Mixed Methods Investigation of the Unmet Needs of Lymphoma Cancer Survivors in Ireland

REC: 2021-09 Chairman's Action (05)
(Please quote reference on all correspondence)

Date of Valid Submission to REC: 19.02.2021
Date of Ethical Review: 29.09.2021

Dear Prof. Brady,

The Chairperson, [redacted], on behalf of the St. James's Hospital/Tallaght University Hospital Joint Research Ethics Committee (SJH/TUH JREC), has reviewed correspondence which you submitted, including responses to review comments, and has given **FULL APPROVAL** for this study to proceed.

The following documents were reviewed:

- Cover Letter
- Response-to-Comments Letter
- Standard Application Form
- Study Poster

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 online amendment form and the changes must be tracked/highlighted clearly. Approval from the JREC is required before implementation of the changes.*

Yours sincerely,

[redacted]

REC Officer – [redacted]
SJH/TUH 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.

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Connolly Hospital
Blanchardstown
Dublin 15
D15 X40D
Tel: (01) 8213844

Vanessa Boland
Trinity Centre for Practice for Healthcare & Innovation
School of Nursing & Midwifery
24 D'Olier Street
Dublin 2

28th October 2021

CHB004/21

Re: **Study: Living beyond a Cancer diagnosis: a mixed method investigation of the unmet needs of Lymphoma Cancer survivors in Ireland.**

Dear Ms. Boland,

Thank you for your submission to Connolly Hospital Research Ethics Committee and your subsequent revisions as we requested. These revisions have now been reviewed and I would like to confirm that your study has been approved.

Apologies for the delay in this communication.

If you require any further information, please do not hesitate to contact me or paula.hatt@hse.ie

Yours sincerely,

[redacted]

Clinical Director
Chairperson, Research Ethics Committee

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Vanessa Boland
School of Nursing & Midwifery,
Trinity College Dublin,
24 D'Olier Street,
Dublin 2

16th July 2021

Ref: 210605

Title of Study: Living beyond lymphoma: a mixed methods investigation of the unmet needs and quality of life outcomes of lymphoma cancer survivors in Ireland.

Dear Vanessa,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in July 2021. 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,

[redacted]

[redacted]
Chairperson
Faculty Research Ethics Committee

Appendix 6 Approval for Use of Phase One Instruments

Date: Tue, 27 Oct 2020 at 22:18
Subject: SF-SUNS
To: vboland@tcd.ie <vboland@tcd.ie>
[redacted]

Dear Vanessa,

Thank you for your interest in the SF-SUNS.

Please find attached a copy of the following documents:

- SF-SUNS
- Paper describing the development of the SF-SUNS
- SF-SUNS user guide

The SF-SUNS can be used free of charge, we just ask that all relevant ethics and institutional approvals are sought before implementing their use. We also ask that the appropriate acknowledgment is made to the development papers and manuals of the SF-SUNS in any publications, reports or presentation that you make using data collected from this measure.

Please do not hesitate to contact me if you have any further questions or concerns.

Kindest regards,
[redacted]

PROVIDING A VOICE FOR PATIENTS WORLDWIDE

FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY (FACIT)
LICENSING AGREEMENT

The Functional Assessment of Chronic Illness Therapy System of Quality of Life questionnaires and all related subscales, translations, and adaptations ("FACIT System") are owned and copyrighted by David Cella, Ph.D. The ownership and copyright of the FACIT System resides strictly with Dr. Cella. Dr. Cella has granted FACIT.org ("Licensor") the right to license usage of the FACIT System to other parties. Licensor represents and warrants that it has the right to grant the License contemplated by this agreement to the party listed below ("Licensee") for use of the measure and languages listed below in the study listed below ("Study"). This license is applicable for individual and/or academic researchers working on a not-for-profit research project.

Name ("Licensee"): Vanessa Boland

Measurement: FACT-Lym

Language(s): English

Study Title ("Study"): Living Beyond Lymphoma Study

This current license is only extended to Licensee's Study subject to the following terms:

1) Licensee agrees to provide Licensor with copies of any publications resulting from this study or produced as a result of collecting data with any FACIT questionnaire.

2) Due to the ongoing and evolving nature of questionnaire development, treatment modalities and cross-cultural linguistic research, Licensor reserves the right to make adaptations or revisions to wording in the FACIT, and/or related translations as necessary. If such changes occur, Licensee will have the option of using either previous or updated versions according to their own research objectives.

3) Licensee may not change the wording or phrasing of any FACIT document without previous permission from Licensor. If any changes are made to the wording or phrasing of any FACIT item without permission, the document cannot be considered the FACIT, and subsequent analyses and/or comparisons to other FACIT data will not be considered appropriate. Permission to use the name "FACIT" will not be granted for any unauthorized translations of the FACIT items. Any analyses or publications of unauthorized changes or translated versions may not use the FACIT name. Any unauthorized translation will be considered a violation of copyright protection.

4) In all publications and on every page of the FACIT used in data collection, Licensor requires the copyright information be listed precisely as it is listed on the questionnaire itself.

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PROVIDING A VOICE FOR PATIENTS WORLDWIDE

and FACIT.org

6) In no case may any FACIT questionnaire be placed on the internet without password protection. To do so is considered a violation of copyright.

7) Licensor reserves the right to withdraw this license if Licensee engages in scientific or copyright misuse of the FACIT system of questionnaires.

8) There are no fees associated with this license.

9) This license is effective for two years upon the date of signature. If Licensee requires an extension beyond this 2-year period, Licensee must contact Licensor and obtain an extension.

Signature: *Vanessa Boland*

Email: vboland@tcd.ie

From [redacted]
Date: Tue, 13 Jul 2021 at 15:46
Subject: Registration ID 42273_TOU
To: vboland@tcd.ie <vboland@tcd.ie>

Dear Ms. Vanessa Boland,

Thank you for your request.

Please be informed that the attached Terms Of Use apply to the use of the Qualtrics and the Paper versions. Please confirm that Trinity College Dublin can accept the attached Terms Of Use and thereafter we will be able to send you the versions.

Please note that the following is **not allowed** according to the Terms Of Use:

- Provide the **Paper version in any other way than on paper** to be filled out with pencil, by example implement the EQ-5D Paper into an online survey, app or electronic device.
- Use of EQ-5D versions **in a new study/project without a new registration**.
- Use the requested version when the study/project is **funded by a profit-making stakeholder**.
- Use the requested version without separate permission when the intention is **to charge a fee for third party access** to the collected data in the project.
- **Distribute the versions to third parties** -other than clinical sites- without prior approval of Euroqol.
- **Modify, alter, amend** the provided EQ-5D Paper version and or EQ-5D Digital version.
- **Develop any new language** of the provided versions without permission of Euroqol.
- **Reproduce the EQ-5D** Paper or Digital module version **in a publication or on the internet** without permission.

You also requested for the English (Ireland) Qualtrics version, which is not available at the moment. Instead I have added the English (UK) version for Qualtrics which can also be used in Ireland.

Kind regards,

[redacted]
Legal Counsel
EuroQol Research Foundation

Appendix 7 Participant Information Leaflet

Patient Information Leaflet

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Study title: Living beyond lymphoma: a mixed-method investigation of the unmet needs and quality of life outcomes of cancer survivors in Ireland.

Principal investigator's name/title: **Principal investigator's title:**	Ms Vanessa Boland PhD Candidate, School of Nursing & Midwifery, Trinity College Dublin, Dublin 2.
Telephone number of principal investigator:	[redacted]
Email of principal investigator:	vboland@tcd.ie
Co-investigators name: **Consultant co-investigator's title:**	[redacted]
Data Controller's Identity	Trinity College Dublin
Data Protection Officer's Identity	Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2.

You are invited to take part in a research study that is being done by **Trinity College Dublin** at [redacted] Before you decide whether you wish to take part, please read this information sheet carefully. Ask any questions you may have. Don't feel rushed or under pressure to make a quick decision. You should 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 may wish to discuss it with your family, friend, or healthcare professional.

You don't have to take part in this study. You can change your mind about taking part in the study. You don't have to give us a reason. If you opt out, rest assured it won't affect your cancer care in the future.

Why is this study being done?

We are doing this study **to understand the needs of lymphoma cancer patients and survivors.** The results of this study will help to inform the development of healthcare and support services that will respond to lymphoma survivor's needs.

Who is organising and funding this study? Will the results be used for commercial purposes?

The research is being conducted as part of an academic qualification [Vanessa Boland is a student on the Doctor of Philosophy programme with Trinity College Dublin, under the supervision of Professor Anne-Marie Brady and Dr Amanda Drury]. This research is funded by the School of Nursing & Midwifery PhD Scholarship, Trinity College Dublin. This study is not being conducted for commercial purposes.

Why am I being asked to take part?

You have been invited to take part because you are aged 18 years or older, were diagnosed with lymphoma cancer between one and five years ago and are attending for treatment or follow up care in participating hospitals.

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. The survey is about your experiences and needs as a lymphoma cancer patient or survivor. The survey will ask questions about your health, well-being, and your needs. You are invited to answer the questions based on your personal experience. Your survey answers will be **confidential.**

If you give your permission, you may be contacted to participate in an optional follow-up interview. You will be invited to answer interview questions based on your personal experience of a lymphoma cancer diagnosis and how this has affected your quality of life. The interview will last one hour or less. The interview discussion will be audio recorded. The purpose of the recording is to allow the researcher to capture all the information discussed during the interview, which is important for later analysis. Should you wish to review and edit your interview transcript, this can be arranged.

Has this study been approved by a research ethics committee?

This study has been approved by [redacted] Research Ethics Committee.

What are the benefits?

Taking part in this study will not directly benefit you. However, your participation may help us to understand better the needs and quality of life of lymphoma cancer survivors in Ireland. This may

result in new knowledge which can inform the development of services which can respond to the needs of lymphoma cancer survivors.

What are the risks?

Your well-being takes precedence over this study. Given the nature of reporting your experience of a lymphoma cancer diagnosis, there is potential for you to become distressed or upset. You are advised that you are entitled to seek the opinion of people you trust regarding your decision to participate in this study (this might include family, friends, or healthcare professionals).

What if something goes wrong when I'm taking part in this study?

It is unlikely that you will be harmed in any way by participating in the study. In the event of psychological distress caused by your participation in this study, the nurse research team will support you and provide you with details of support services available to you, including:

- Irish Cancer Society Daffodil Centre.
- Irish Cancer Society Nurse Line.

Will it cost me anything to take part?

No, we are not paying participants to take part in the study. However, you will be reimbursed for travel expenses if required.

Is the study confidential?

Your information will be kept private and strictly confidential. We will use your name, email address or postal address or phone number to contact you about the research study and to support data collection procedures. We will not keep your name and contact information once the study is complete. The audio-recorded interviews will be destroyed when the analysis is complete. Only the research lead [Vanessa Boland, TCD] will be able to see the information you provide. We take many steps to protect your confidentiality and keep your data safe; we will secure, encrypt, and handle your survey data so that it can no longer be attributed to you without the use of additional information, which is kept separately. When data analysis is complete, all identifying information will be destroyed by the Principal Investigator. Interview audio recordings will be destroyed when transcription accuracy is confirmed, and analysis is complete. The results of the study will be reported in international publications and presentations. No information which reveals your identity will be disclosed.

Data Protection

We will be using your personal information in our research to study the needs and quality of life of lymphoma cancer survivors in Ireland. The legal basis under which we are processing your data is for scientific research purposes – see Articles 6 and 9 of the General Data Protection Regulation 2016. We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations. The research lead [Vanessa Boland, TCD] will be the only individual to have access to and use your personal data as part of this study.

In line with the Trinity College Dublin Good Research Practice Policy, data (that can no longer be attributed to you without additional information, which is kept separately, also referred to as 'pseudonymised data') will be stored for seven years after completion of the study.

There is a potential risk that might arise for you due to data processing, such as a data breach of your personal data. Every effort will be made to reduce this risk, including the personal data collected will be the minimum required to conduct this research, data will be pseudonymised and technological and organisational security strategies (e.g., encryption, password-protection, locked storage) will be used.

By law, you can exercise the following rights in relation to your personal data unless the request would make it impossible or exceedingly difficult to conduct the research, including the right to request access to your data and a copy of it, to restrict or object to processing, to have any inaccurate information about you corrected or deleted. You have the right to withdraw your consent to your personal data being used in this research project. You will be able to do this by contacting emailing Vanessa Boland at vboland@tcd.ie. However, data that has been collected/analysed will be retained in an anonymised format to ensure the information re-source is valid, reliable, and accurate. You have the right to lodge a complaint with the Data Protection Commissioner if you are not satisfied with our response to your concerns or believe we are processing your data in a way that is not lawful.

This study will not use automated decision-making or profiling. We do not intend to further process your data other than for the purpose disclosed. Your data will not be transferred or stored outside of Trinity College Dublin, Ireland.

Consent to Future Uses

The consent form for this study also asks for your consent to 'agree to receive information about participating in future studies relating to this research for which you may be eligible'. Such consent would not go beyond cancer or to any other unrelated areas.

Where can I get further information?

If you have any further questions about this study, please contact:

Name Vanessa Boland
Address Trinity College Dublin, School of Nursing & Midwifery, 24 D'Olier Street, D02 T283
Email vboland@tcd.ie

- If you would like to take part in this study, you are asked to **sign the Consent Form provided.**
- If you consent to be contacted about taking part in a follow-up interview, you are asked to provide your contact details via the consent form provided so that we may contact you to arrange this.

Appendix 8 Study Consent Form

CONSENT FORM

PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX

I have read and understood the Participant Information Leaflet; I have received enough information about this study.	Yes☐	No☐
I understand that I am free to withdraw from the study. I understand that this is not possible when my data has been anonymised.	Yes☐	No☐
I consent to take part in this research study having been fully informed of the risks, benefits, and purpose of the study.	Yes☐	No☐
I agree to participate in an interview about this study, if required.	Yes☐	No☐
I agree to receive information about participating in future studies relating to this research for which I may be eligible.	Yes☐	No☐
I understand that there are no direct benefits to me from participating in this study.	Yes☐	No☐
I understand that results from analysis of my personal information will not be given to me.	Yes☐	No☐
I give my explicit consent to have my data processed as part of this research study.	Yes☐	No☐

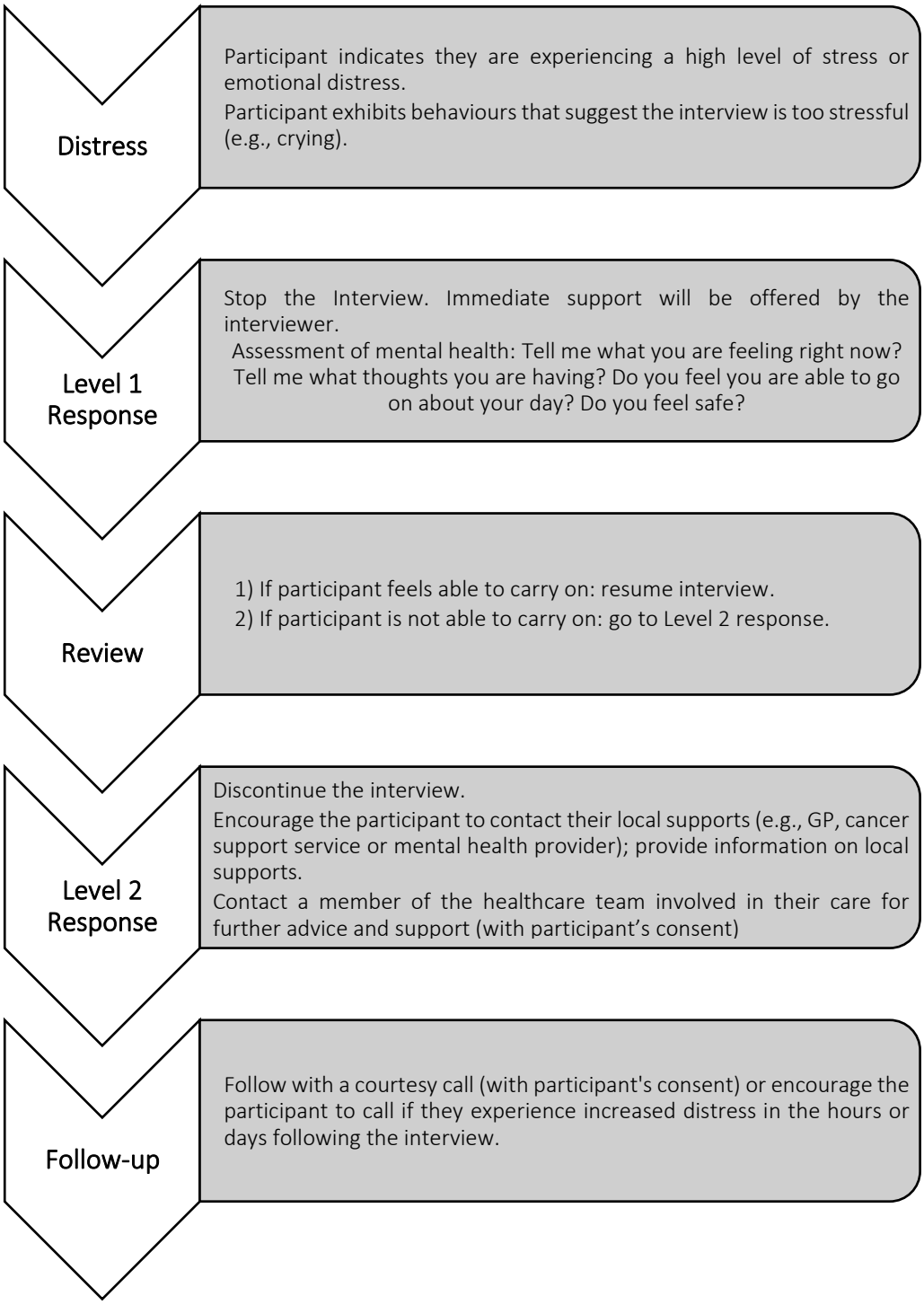
PLEASE SIGN BELOW

_____ _____ _____

Participant Name (Block Capitals) Participant Signature Date

I understand that I may be contacted in the future to participate in an interview relating to this study, I understand I have the right to decline such correspondence.	
Participant Name	
Email Address	
Phone Number	

Appendix 9 Research Interview and Distress Protocol, Adapted (Draucker et al., 2009)



Appendix 10 Online Study Recruitment Posters

Lymphoma Research Study

Researchers at Trinity College Dublin invite you to take part in an **online survey** about your **lymphoma cancer experience.**

Participants Required

- Were you diagnosed with **lymphoma cancer** between **one and five years ago**?
- Are you **18 years of age or older**?
- Have you received your **cancer care** within an **Irish hospital**?

Why is this study being done?

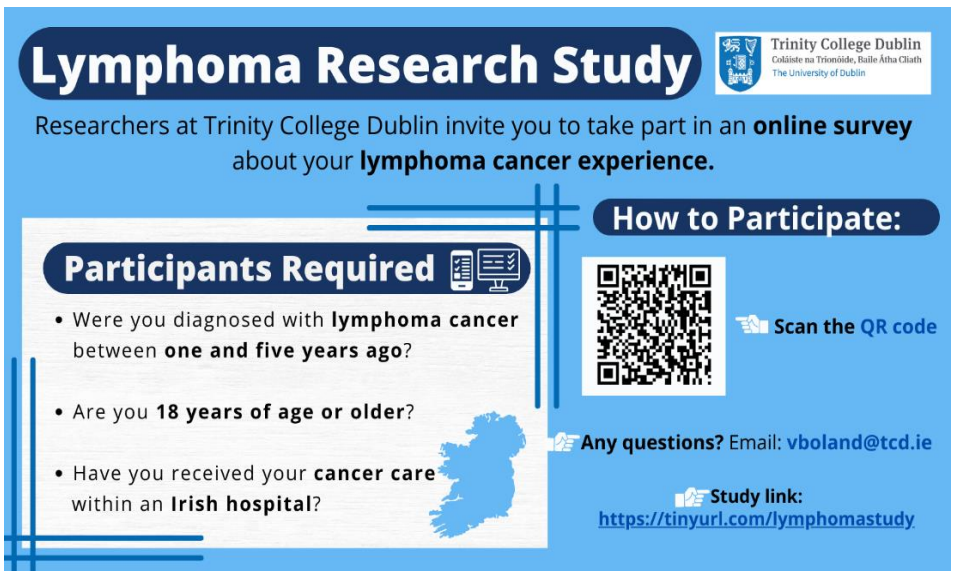
This study will help in understanding the needs of lymphoma cancer patients and survivors. The results of this study will help to inform the development of healthcare and support services that are responsive to lymphoma survivors' needs.

How to Participate:

- Scan the **QR code**
- Study link: https://tinyurl.com/lymphomastudy

Any questions?
Email: **vboland@tcd.ie**

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



Appendix 11 Hierarchical Multiple Regression Steps

Hierarchical Multiple Regression Steps
1. Fit a regression model using all the potential predictor variables.
2. Calculate the adjusted R^2 for this initial model.
3. Evaluate the adjusted R^2 value. A higher adjusted R^2 value indicates a better fit of the model, suggesting that the selected variables explain a greater proportion of the variation in the dependent variable.
4. Assess the significance and magnitude of the individual predictor variables. Consider variables with higher significance and larger coefficients, potentially more important in explaining the outcome.
5. Iterate the process by removing one predictor variable at a time from the model and re-estimating the adjusted R^2. Compare the adjusted R^2 values to assess the impact of each variable on the overall model fit.
6. Include variables that contribute to a higher adjusted R^2 value and have theoretical relevance or empirical support as potential final predictors in the model.

Appendix 12 Phase One Questionnaire

Office use only

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Living Beyond Lymphoma Survey

This study is being done to understand the needs and quality of life of individuals living with or beyond a diagnosis of lymphoma cancer. You have been asked to take part in this research survey because you have recently attended an appointment for lymphoma cancer follow-up or treatment.

The study is being carried out by nurse researchers at Trinity College Dublin. Your answers are **confidential**. Once you have filled in the survey, please return it in the freepost and addressed envelope provided – there is no need for a stamp.

We would like to thank you for taking the time to complete this survey.

The survey will take approximately 15 minutes to complete.

I have been given information about this research study and its risks and benefits. I freely give my consent to participate in this survey.

☐ **Please tick if you agree with the statement above**

If you have any questions, please contact:

Vanessa Boland,
School of Nursing and Midwifery,
Trinity College Dublin.
vboland@tcd.ie

Under each heading, please tick the ONE box that best describes your health TODAY.

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 ❑

SELF-CARE

I have no problems washing or dressing myself ❑

I have slight problems washing or dressing myself ❑

I have moderate problems washing or dressing myself ❑

I have severe problems washing or dressing myself ❑

I am unable to wash or dress myself ❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑

I have slight problems doing my usual activities ❑

I have moderate problems doing my usual activities ❑

I have severe problems doing my usual activities ❑

I am unable to do my usual activities ❑

PAIN / DISCOMFORT

I have no pain or discomfort ❑

I have slight pain or discomfort ❑

I have moderate pain or discomfort ❑

I have severe pain or discomfort ❑

I have extreme pain or discomfort ❑

ANXIETY / DEPRESSION

I am not anxious or depressed ❑

I am slightly anxious or depressed ❑

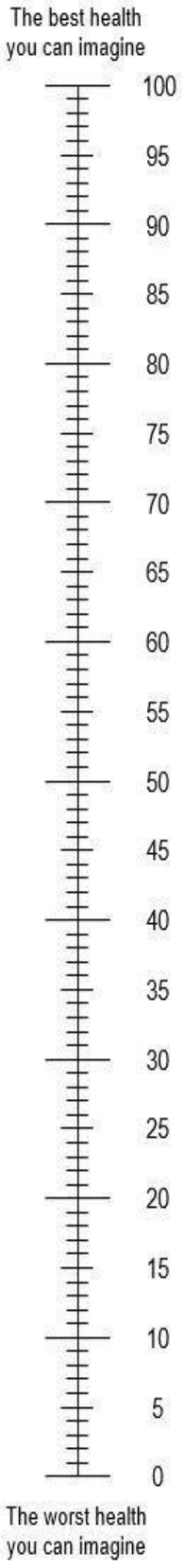
I am moderately anxious or depressed ❑

I am severely anxious or depressed ❑

I am extremely anxious or depressed ❑

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	ADDITIONAL CONCERNS	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
P2	I have certain parts of my body where I experience pain...	0	1	2	3	4
LEU1	I am bothered by lumps or swelling in certain parts of my body (e.g., neck, armpits, or groin)	0	1	2	3	4
BRM3	I am bothered by fevers (episodes of high body temperature).....	0	1	2	3	4
ES3	I have night sweats	0	1	2	3	4
LYM1	I am bothered by itching.....	0	1	2	3	4
LYM2	I have trouble sleeping at night	0	1	2	3	4
BMT6	I get tired easily	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
Ga1	I have a loss of appetite	0	1	2	3	4
HI8	I have trouble concentrating	0	1	2	3	4
N3	I worry about getting infections	0	1	2	3	4
LEU6	I worry that I might get new symptoms of my illness.....	0	1	2	3	4
LEU7	I feel isolated from others because of my illness or treatment.....	0	1	2	3	4
BRM9	I have emotional ups and downs	0	1	2	3	4
LEU4	Because of my illness, I have difficulty planning for the future.....	0	1	2	3	4

INSTRUCTIONS for Section Three

We would like to know what unmet needs you have had IN THE LAST MONTH as a result of having cancer now or in the past. An **unmet need** is a need that you have not been able to satisfy.

For each question, place a circle around the number that best describes your level of unmet need IN THE LAST MONTH. Please answer each question, even if you feel there is no way to solve the problem, or you do not have any unmet needs.

0	**No unmet need** – This was not a problem for me as a result of having cancer now or in the past.
1	**Low unmet need** – I needed a small amount of help with this problem but was not able to get it.
2	**Moderate unmet need** – I needed a moderate amount of help with this problem but was not able to get it.
3	**High unmet need** – I needed a high amount of help with this problem but was not able to get it.
4	**Very high unmet need** – I needed a very high amount of help with this problem but was not able to get it.

EXAMPLE

For each statement, circle the choice that best describes your level of unmet need.

	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need
Finding information about complementary or alternative therapies	0	1	(2)	3	4

If you circled #2, it means that IN THE LAST MONTH, you had a moderate need to know about complementary or alternative therapies but you were not able to get that information or help with your concerns.

Circle the choice that best describes your level of unmet need.

Knowing how much time I would need away from work	(0)	1	2	3	4

If you circled **0**, it means that, IN THE LAST MONTH, knowing how much time you needed away from work was not a problem for you.

We know that your unmet needs may change over time. In this survey, we want to know only about the unmet needs you have had IN THE LAST MONTH.

Please go to the next page to begin section three.

Section Three – Your Unmet Needs IN THE LAST MONTH

A. Unmet Information Needs: *This part of the survey is about unmet needs that relate to finding information IN THE LAST MONTH*

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
1.	Finding information about complementary or alternative therapies	0	1	2	3	4
2.	Dealing with fears about cancer spreading	0	1	2	3	4
3.	Dealing with worry about whether the treatment has worked	0	1	2	3	4

B. Unmet Work and Financial Needs: *This part of the survey is about unmet needs you may have had about your job and finances IN THE LAST MONTH*

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
4.	Worry about earning money	0	1	2	3	4
5.	Having to take a pension or disability allowance	0	1	2	3	4
6.	Paying household bills or other payments	0	1	2	3	4
7.	Finding what type of financial assistance is available and how to obtain it	0	1	2	3	4
8.	Finding car parking that I can afford at the hospital or clinic	0	1	2	3	4
9.	Understanding what is covered by my medical insurance or benefits	0	1	2	3	4
10.	Knowing how much time I would need away from work	0	1	2	3	4
11.	Doing work around the house (cooking, cleaning, home repairs, etc.)	0	1	2	3	4

Section Three – Your Unmet Needs IN THE LAST MONTH

*C. **Unmet Needs for Access and Continuity of Care**: This part of the survey is about unmet needs that relate to medical care IN THE LAST MONTH*

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
12.	Having access to cancer services close to my home	0	1	2	3	4
13.	Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	0	1	2	3	4
14.	Getting test results quickly enough	0	1	2	3	4
15.	Having access to care from other health specialists (dieticians, physiotherapists, occupational therapists)	0	1	2	3	4
16.	Making sure I had enough time to ask my doctor or nurse questions	0	1	2	3	4
17.	Getting the health care team to attend promptly to my physical needs	0	1	2	3	4

*D. **Unmet Coping, Sharing and Emotional Needs**: This part of the survey is about unmet needs that relate to your relationships with others and your emotional health IN THE LAST MONTH*

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
18.	Telling others how I was feeling emotionally	0	1	2	3	4
19.	Finding someone to talk to who understands and has been through a similar experience	0	1	2	3	4
20.	Dealing with people who expect me to be "back to normal"	0	1	2	3	4
21.	Dealing with people accepting that having cancer has changed me as a person	0	1	2	3	4

Section Three – Your Unmet Needs IN THE LAST MONTH

For each statement, circle the choice that best describes your level of unmet need.		*No Unmet Need*	*Low Unmet Need*	*Moderate Unmet Need*	*High Unmet Need*	*Very High Unmet Need*
22.	Dealing with reduced support from others when treatment has ended	0	1	2	3	4
23.	Dealing with feeling depressed	0	1	2	3	4
24.	Dealing with feeling tired	0	1	2	3	4
25.	Dealing with feeling stressed	0	1	2	3	4
26.	Dealing with feeling lonely	0	1	2	3	4
27.	Dealing with not being able to feel 'normal'	0	1	2	3	4
28.	Trying to stay positive	0	1	2	3	4
29.	Coping with having a bad memory or lack of focus	0	1	2	3	4
30.	Dealing with changes in how my body appears	0	1	2	3	4

Final Section 4 – About You

If you are helping someone to complete this questionnaire, please make sure this information is the patients and not your own.

4a) What is your age in years?

☐ Prefer not to say (tick box)

4b) What gender do you identify with? (select one)

☐ Female
☐ Male
☐ Prefer to self-describe (please specify)

4c) Do you live in an urban or rural area? (select one)

☐ Urban
☐ Rural

4d) What statement best describes your living arrangements?

☐ I live with my partner / spouse / family / friends
☐ I live alone
☐ I live in a nursing home or other long-term care home
☐ Other (please specify)

4e) What is your ethnic / cultural background? (select one)

White Irish
☐ Irish
☐ Irish Traveller
☐ Any other White background

African Irish
☐ African
☐ Any other Black background

Asian Irish
☐ Chinese
☐ Any other Asian background

☐ Other, including mixed background (please describe)

4f) Do you have: (select all that apply)

☐ Medical card
☐ Private health insurance
☐ Other health benefit (please specify)
☐ None of the above

4g) What is your employment status?

☐ Full time
☐ Part time
☐ Homemaker
☐ Retired
☐ Student
☐ Unemployed

4h) If you are currently employed, are you: (select one)

☐ Working less hours than you did before your cancer diagnosis
☐ Working your usual hours
☐ Working more hours than before your cancer diagnosis
☐ Not working (due to illness or other reasons)
☐ This question does not apply to me

4i) Have you been diagnosed with?

- ☐ Hodgkin Lymphoma cancer
- ☐ Non-Hodgkin Lymphoma cancer
- ☐ Other (please specify)

- ☐ I don't know / I can't remember

4j) How long ago did you receive your diagnosis of lymphoma cancer? (select one)

I was diagnosed with lymphoma cancer:

- ☐ 1 to 2 years ago
- ☐ 2 to 3 years ago
- ☐ 3 to 4 years ago
- ☐ 4 to 5 years ago
- ☐ I don't know / I can't remember

4k) What treatments have you received for your lymphoma cancer? (select all that apply)

- ☐ Chemotherapy
- ☐ Immunotherapy (e.g., Rituximab)
- ☐ Radiotherapy
- ☐ Surgery
- ☐ Other cellular therapy (e.g., CAR T therapy)
- ☐ None
- ☐ Other (please specify)

4l) Which if any of the following conditions do you have? (select all that apply)

- ☐ Alzheimer disease or dementia
- ☐ Angina
- ☐ Arthritis
- ☐ Asthma or other chronic chest problem
- ☐ Blindness or visual impairment
- ☐ Deafness or hearing impairment
- ☐ Diabetes
- ☐ Epilepsy
- ☐ Heart condition
- ☐ High blood pressure
- ☐ Kidney disease
- ☐ Liver disease
- ☐ Long term back problems
- ☐ Long-standing mental health problem
- ☐ Long-standing neurological problem
- ☐ Another long-standing condition
- ☐ I do not have any of these conditions

Thank you for participating in this study.
Your time and support for this research is greatly appreciated!

4m) Is there anything further you would like to tell us about living with or beyond a lymphoma cancer diagnosis? (Please do so in the box below)

End of Survey

Appendix 13 Content Validity Evaluation Procedure for Expert Panel

The experts were asked to score each item's clarity, relevance, and representativeness, as outlined below using the rating scale provided.
Please rate the level of **clarity** for each item on a scale of 1-4, with 4 being the clearest. 1 = item is not clear 2 = item needs major revisions to be clear 3 = item needs minor revisions to be clear 4 = item is clear
Please rate the **relevance** of each item in measuring the overarching section on a scale of 1-4, with 4 being the most essential. 1 = item is not necessary 2 = item provides some information but is not essential 3 = item is not useful but is essential 4 = item is essential
Please rate the level of **representativeness** of the item in measuring the overarching section on a scale of 1-4, 4 being the most representative. 1 = item is not representative 2 = item needs major revisions to be representative 3 = item needs minor revisions to be representative 4 = item is representative
In addition, an optional comment box was provided for each section of the questionnaire to capture suggestions from experts, such as adding or deleting items.

Appendix 14 Content Validity Index Scoring Manual

Adapted (Polit & Beck, 2006; Polit et al., 2007)

Basic scoring		
Rating of 3 or 4 on a scale = 1 Rating of 1 or 2 on a scale = 0		
Experts in Agreement	**Universal Agreement (UA)**	**Item-level Content Validity Index (I-CVI)**
sum up the relevant rating provided by all the experts for each item (1 + 1 + 0 + 1 + 1 + 1 + 1 + 1 + 1) = 7	Assign score '1' to the item that achieved 100% expert agreement Assign score '0' if the item did not achieve 100% agreement	The experts in agreement are divided by the number of experts. 7 of 8 experts in agreement (7/8 = 0.875)

Pc (probability of chance occurrence) is computed using the formula:

Pc = [N!/A!(N–A)!]$*. 5^n$

Where N = number of experts and A = number agreeing on good

κ^* (kappa designating agreement on relevance, clarity or representativeness):

$$\kappa^* = \text{(I-CVI} - \text{pc)/(1} - \text{pc)}$$

The relationship between I-CVI and κ^*
•••• Excellent Validity = I-CVI ≥ 0.78 and κ^* > .74
••• Good Validity = I-CVI < 0.78 and ≥ 0.60 and κ^* ≤ .74
•• Fair validity = I-CVI < 0.60 and ≥ 0.40 and κ^* ≤ .59
• Poor validity = I-CVI < 0.40 and κ^* < .40

Appendix 15 Phase Two Interview Guide

Introduction & Welcome	• Provided and explained information leaflet • Any questions? • Confirm consent • Test recording device • Participant's dignity and comfort
Main interview question	• **Could you tell me about your experiences with lymphoma cancer?** A. Please tell me more about it. B. What does that mean to you? C. Could you please give me an example. D. Could you describe what that was like for you?
Prompt A: Needs	**Since being diagnosed what have been the top three things that you needed help with?** [PROMPT: needs can relate to many areas such as, health concerns i.e., diet and nutrition, emotional i.e., worry about the future, practical concerns i.e., assistance with housework, information concerns i.e., details on how to address any side-effects you may experience).
Prompt B: Specific features of cancer care	**What types of information should be provided during cancer care?** [PROMPTS: diagnosis, life expectancy, side effects, what to do after treatment] **What things should hospitals do to provide quality treatment during cancer care?** [PROMPTS: short waiting times, provide correct treatment, provide consistent information, eliminate unnecessary tests or treatments] **What type of support services should be offered during cancer care?** [PROMPTS: emotional, spiritual, address changes in relationships, practical help with finances, childcare, transport, housework etc] **What things do you think are needed for cancer care to be coordinated?** [PROMPTS: co-ordination when discharged from hospital to home; co-ordination when moving between different hospitals or other health services; co-ordination when moving from the treatment phase to follow up care] **What type of care should cancer patients to be able to access?** [PROMPTS: quality care that is affordable, quality care close to where they live]
Thank you and finish	Thank you for taking the time to speak with me today. The time and information you have provided is greatly appreciated. Just before we end this interview, I would like to offer you the phone number for Irish Cancer Society that specialise in providing cancer support and information as sometimes speaking about your cancer experience can raise new questions or cause distress [Irish Cancer Society Cancer Nurse through the Freephone Support Line on 1800 200 700]. Thank you again.

Appendix 16 Description of Study Variables

Ordinal data

Variable Name	Description
SF-SUNS items	30-item Likert survey with five levels for each question
FACT-LYM items	42-item Likert survey with five levels for each question
EQ-5D-5L items	5-item Likert survey with five levels for each question

Nominal data

Sociodemographic characteristics

Variable Name	Description (Variable Groups)
Age groups	18 – 39, 40 – 69, 70+ years
Gender	Female, male
Residence	Urban or rural
Living arrangement	Living with others, living alone
Ethnicity	Irish, non-Irish
Employment status	Full-time/part-time, retired/homemaker, unemployed, student
Employment hours	Fewer hours, usual hours, more hours, not working
Health insurance status	Private health insurance, medical card
Sites	Cancer centre, regional hospital

Clinical characteristics

Variable Name	Variable Groups
Lymphoma diagnosis	Hodgkin Lymphoma (HL), Non-Hodgkin Lymphoma (NHL)
Time since diagnosis	1 to 3 years, 3 to 5 years
Treatment received	Chemotherapy, immunotherapy, radiotherapy, surgery, stem cell transplant
Comorbidities (conditions other than lymphoma)	Arthritis, cardiac conditions, cognitive conditions, diabetes, epilepsy, hearing or visual impairments, kidney disease, liver disease, respiratory conditions, other chronic conditions or no conditions

Continuous data

Description	Subscale name(s)
SF-SUNS: Four subscale totals with continuous scores; the total is not considered.	1. Information needs (INF) 2. Work and financial needs (FIN) 3. Access and continuity of care needs (ACC) 4. Coping, sharing and emotional needs (COP)
FACT-LYM: Five subscale totals, the total is considered, all with continuous scores	1. Physical Well-being (PWB) 2. Social and family well-being (SWB) 3. Emotional well-being (EWB) 4. Functional wellbeing (FWB) 5. Lymphoma Subscale (LYMs) o FACT-Lymphoma Trial Outcome Index (FACT-TOI) (PWB, FWB, Fact-Lym combined, range 0-116) o FACT-General (FACT-G) (PWB, FWB, SWB, EWB, range 0-108) o FACT-LYM Total Score (FACT-Total) (all subscales combined, range 0-168)
EQ-5D-5L: One visual analogue scale; the value on the scale is considered	1. Visual Analogue Scale (VAS), continuous score (range 0 – 100)

Appendix 17 Univariate analysis of Associations Between Lymphoma Survivors' QOL Outcomes and Sociodemographic Characteristics

	Physical Well-being			Social Well-being		Emotional Well-being		Functional Well-being	
	N	Mean Rank	*p*	Mean Rank	*p*	Mean Rank	*p*	Mean Rank	*p*
Gender [a]			**.001***		.581		**.046***		.070
Female	103	88.43		103.72		92.01		93.76	
Male	99	115.10		99.19		108.23		108.61	
Age [b]			.242		.394		.091		.663
18 - 39	50	97.13		89.08		82.28		95.73	
40 - 69	100	104.28		101.86		101.31		96.14	
70 or older	46	87.43		101.43		103.97		104.67	
Residence [a]			.519		.564		.603		.238
Rural	66	97.70		98.11		97.00		94.09	
Urban	136	103.34		103.15		101.49		104.38	
Living arrangement			.090		.114		.073		.198
Living with others	161	105.00		104.77		103.66		103.67	
Living alone	41	87.74		88.66		85.45		90.59	
Ethnicity [a]			.391		.999		.701		.742
Irish	177	100.18		101.50		99.41		100.49	
Other	25	110.86		101.48		104.12		104.58	
Medical card [a]			.173		.275		.751		.357
No	109	106.20		96.89		100.67		97.06	

Yes	92	94.84		105.86		98.07		104.62	
Private health insurance [a]			**.002***		.052		.054		**.047***
No	90	86.84		92.16		90.75		91.45	
Yes	111	112.48		108.17		106.50		107.76	
Employment status [b]			**.008***		**.008***		.114		.079
Full-time/Part-time	108	112.27		110.61		101.22		106.17	
Retired/Homemaker	76	92.96		98.25		104.01		99.35	
Student	10	91.40		57.85		95.60		97.25	
Unemployed	8	49.81		63.94		52.50		51.38	
Employment hours [b]			.105		.694		.270		.191
Working less hours	35	48.26		56.07		48.51		49.60	
Working usual hours	61	58.32		54.12		58.20		57.89	
Working more hours	6	63.92		53.75		57.92		59.67	
Not working	5	29.60		38.30		36.50		30.50	

Appendix 18 Univariate analysis of Associations Between Lymphoma Survivors' QOL Outcomes and Clinical Characteristics

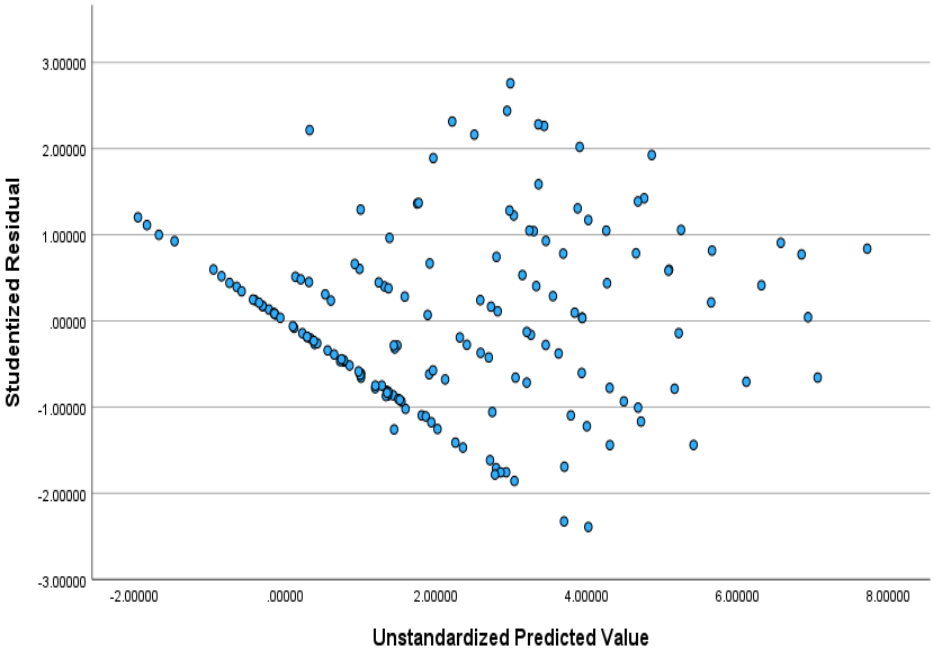
	Physical Well-being			Social Well-being		Emotional Well-being		Functional Well-being	
	N	Mean Rank	*p*	Mean Rank	*p*	Mean Rank	*p*	Mean Rank	*p*
Lymphoma type [a]			.300		.940		.966		.101
HL	51	105.01		97.49		96.78		108.54	
NHL	144	95.52		98.18		96.40		93.56	
Time since diagnosis [a]			.520		.561		**.013***		.484
1 to 3 years	116	98.75		103.03		90.86		98.07	

3 to 5 years	85	104.07		98.22		111.23	103.86	
Chemotherapy [a]			.540		1.000	.294		.602
No	17	109.79		101.50		86.03	93.97	
Yes	185	100.74		101.50		101.30	101.65	
Immunotherapy [a]			.129		.833	.805		.094
No	145	105.40		100.96		100.64	105.31	
Yes	57	91.58		102.88		98.41	90.11	
Radiotherapy [a]			**.013***		.116	.591		**.008***
No	149	95.40		97.65		98.68	94.48	
Yes	53	118.64		112.31		103.63	119.21	
Surgery [a]			.450		.391	.168		.356
No	163	99.51		99.30		96.82	98.67	
Yes	38	107.39		108.28		111.18	108.29	
No conditions [a]			**.026***		.286	.541		.180
No	114	93.48		97.65		97.78	96.15	
Yes	88	111.89		106.48		102.80	107.22	

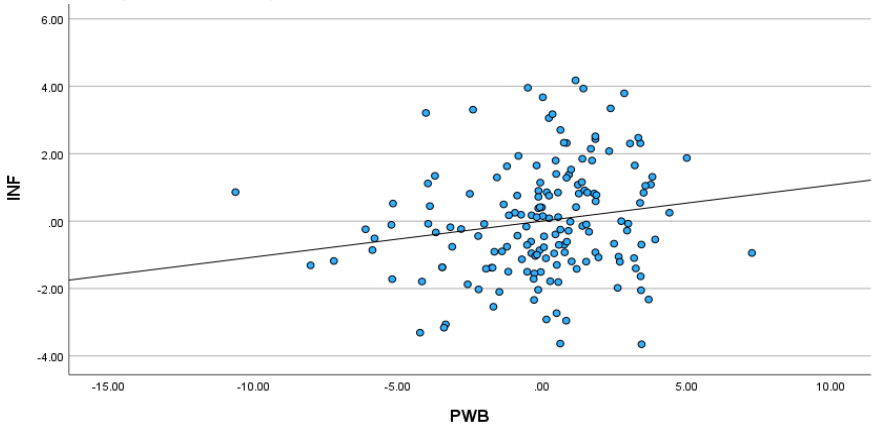
***p*=<.05**

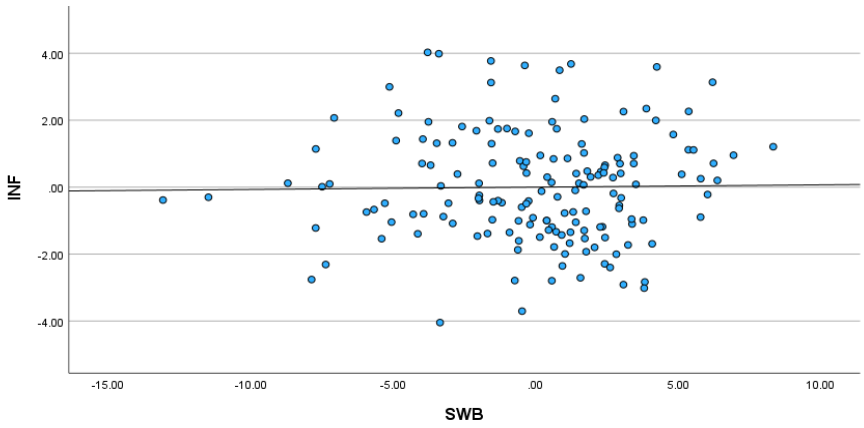
Appendix 19 Meeting the Assumptions of Inferential Statistical Tests

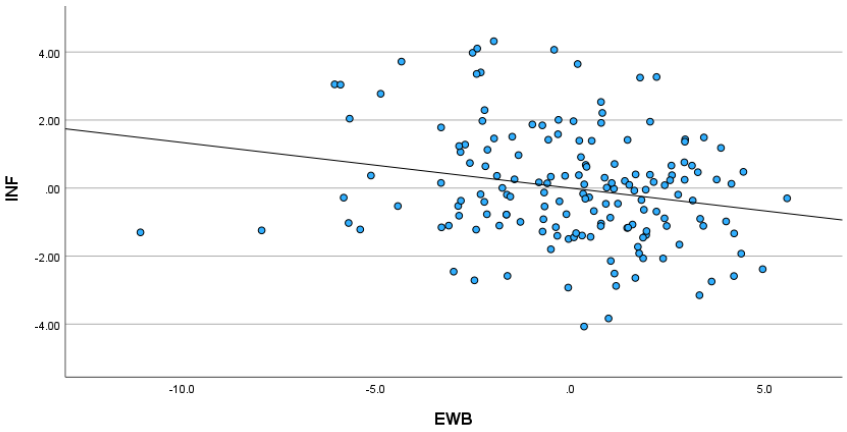
19.1 *Studentised Residuals Scatterplot for INF*

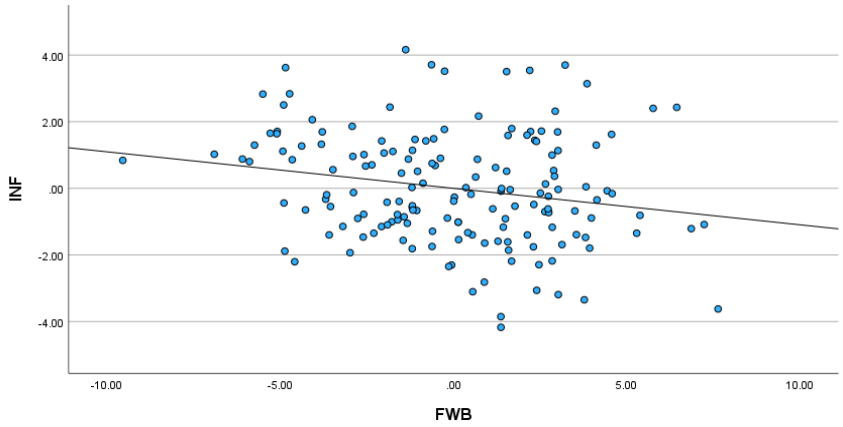


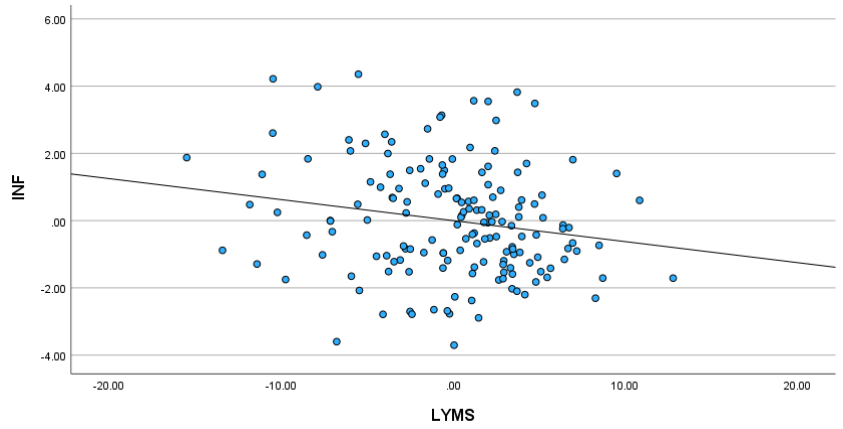
19.2 *Partial Regression Plots for INF*

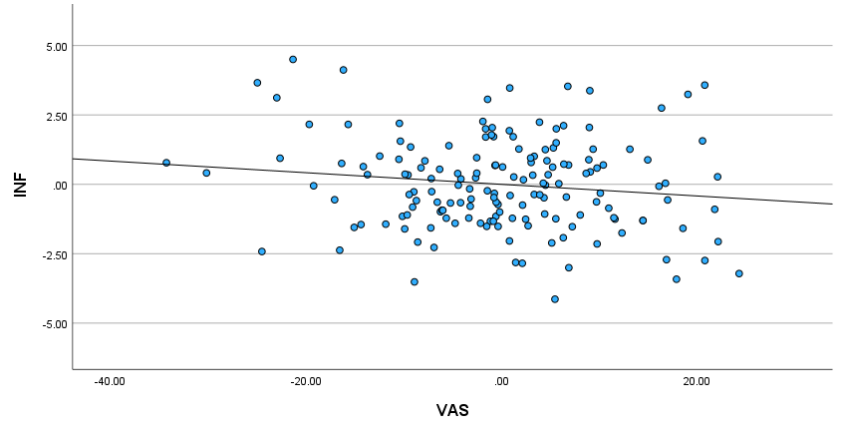




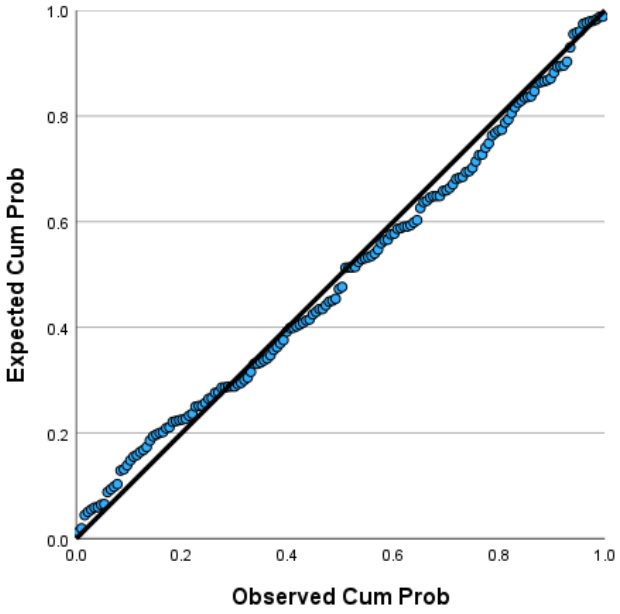

INF
4.00
2.00
.00
-2.00
-4.00
-10.0
-5.0
.0
5.0
EWB


INF
4.00
2.00
.00
-2.00
-4.00
-10.00
-5.00
.00
5.00
10.00
FWB


INF
6.00
4.00
2.00
.00
-2.00
-4.00
-20.00
-10.00
.00
10.00
20.00
LYMS


INF
5.00
2.50
.00
-2.50
-5.00
-40.00
-20.00
.00
20.00
VAS

19.3 *Normal P-plot for INF*



19.4 *Residual Statistics for INF*

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	-1.9482	7.7206	2.2407	1.95718	162
Std. Predicted Value	-2.140	2.800	.000	1.000	162
Standard Error of Predicted Value	.480	1.369	.744	.134	162
Adjusted Predicted Value	-2.3711	7.2995	2.2424	1.98704	162
Residual	-4.02336	4.05344	.00000	1.62453	162
Std. Residual	-2.251	2.268	.000	.909	162
Stud. Residual	-2.391	2.758	.000	1.008	162
Deleted Residual	-4.67506	6.06026	-.00168	2.00684	162
Stud. Deleted Residual	-2.435	2.830	.001	1.015	162
Mahal. Distance	10.600	93.419	27.827	11.028	162
Cook's Distance	.000	.134	.008	.015	162
Centered Leverage Value	.066	.580	.173	.068	162

a. Dependent Variable: INF

19.5 ***Correlations Table (Multicollinearity) for INF***

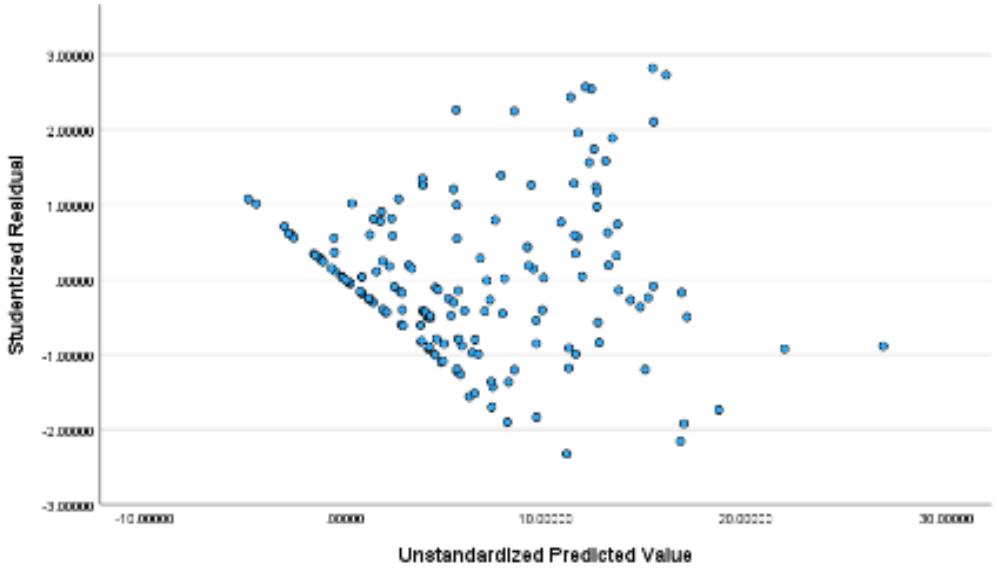
Table 1. Correlations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. INF	--																						
2. Gender	-.235	--																					
3.Age Groups	-.129	-.029	--																				
4.Residence	-.001	-.098	.042	--																			
5. Employment status	-.032	.042	.156	-.011	--																		
6. Medical card	-.018	-.066	.211	.004	.295	–																	
7. Private health insurance	-.080	.027	.011	-.012	-.246	-.418	--																
8. Lymphoma type	-.029	.009	.328	-.099	-.079	-.067	.086	--															
9. Time since diagnosis	-.190	-.017	.210	.062	.088	.181	-.056	-.084	–														
10. Sites	-.028	.168	.114	-.110	.074	.061	-.142	.070	-.024	--													
11. Chemotherapy	-.040	.048	-.035	-.059	.073	.028	-.058	-.008	.115	.096	--												
12. Immunotherapy	.015	-.065	.131	.085	-.041	-.068	.145	.229	.020	-.073	-.048	--											
13. Radiotherapy	-.051	.113	.051	.080	-.022	.017	.017	-.248	-.009	-.036	-.103	-.124	--										
14. Surgery	-.135	.063	-.063	-.046	.072	-.012	-.002	-.157	-.004	-.032	.010	-.163	.092	--									
15. Cardiac conditions	-.079	.023	.441	.016	.130	.164	-.107	.205	.113	-.042	.012	.091	-.036	-.136	--								
16. Hearing/visual impairments	-.149	.110	.262	-.041	.098	.062	.002	.069	.049	.180	-.030	.036	-.068	-.018	.138	--							
17. None of these conditions	.140	.017	-.445	.037	-.266	-.147	.048	-.176	-.167	-.070	.015	-.107	.021	-.037	-.488	-.275	--						
18. PWB	-.269	.172	-.060	.039	-.249	-.083	.202	-.065	.061	-.160	-.037	-.079	.151	.067	-.078	-.130	.172	--					
19. SWB	-.215	-.038	.050	.062	-.189	.067	.150	.003	-.047	-.075	.081	.005	.094	.086	-.114	-.005	.074	.343	--				
20. EWB	-.507	.102	.127	.053	-.148	-.053	.141	.036	.153	-.101	.072	.012	.026	.067	.056	.032	.066	.538	.283	–			
21. FWB	-.435	.119	.044	.089	-.135	.064	.135	-.134	.064	-.139	.054	-.125	.190	.080	-.095	-.051	.091	.598	.597	.542	--		
22. LYMS	-.438	.139	.075	.038	-.199	-.075	.248	-.023	.053	-.176	-.016	-.106	.097	.065	-.038	-.033	.112	.739	.372	.687	.624	--	
23. VAS	-.388	.012	.031	-.011	-.149	.040	.118	-.087	.030	-.009	-.170	-.111	.093	.078	-.100	.015	.052	.570	.319	.478	.654	.543	–

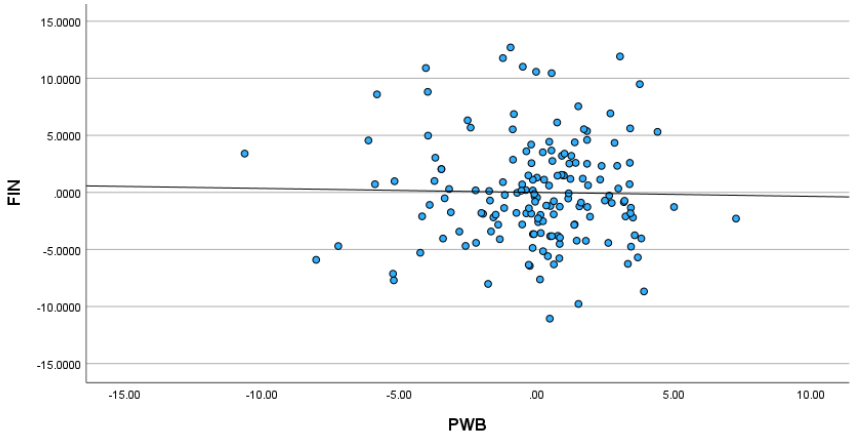
19.6 ***Collinearity statistics table for INF***

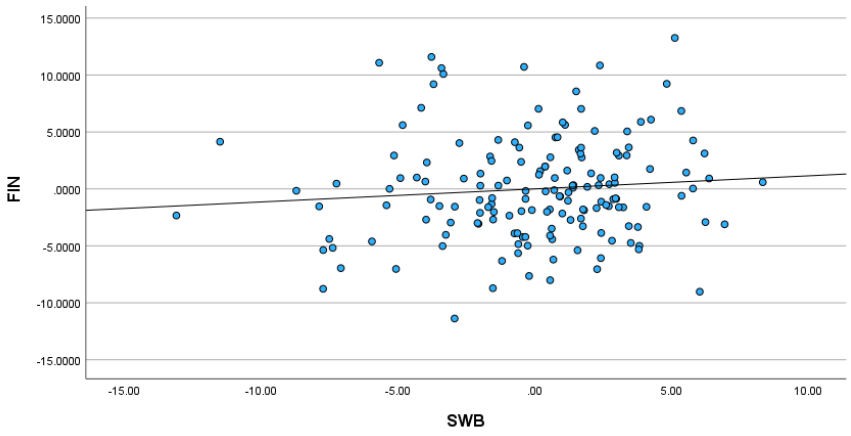
	Collinearity Statistics	
	Tolerance	VIF
(Constant)		
Gender	0.690	1.449
Age_3_groups=40 - 69	0.176	5.679
Age_3_groups=70 or older	0.119	8.391
Medical card	0.628	1.593
Private health insurance	0.609	1.642
Residence	0.877	1.140
Employment status=Retired and Homemaker	0.363	2.753
Employment status=Student	0.672	1.488
Employment status=Unemployed	0.767	1.303
Sites	0.740	1.352
Time since diagnosis	0.740	1.351
Lymphoma type	0.263	3.802
Chemotherapy	0.852	1.174
Immunotherapy	0.729	1.371
Radiotherapy	0.770	1.299
Surgery	0.842	1.188
None of these conditions	0.610	1.640
PWB	0.339	2.952
SWB	0.544	1.839
EWB	0.375	2.664
FWB	0.262	3.810
LYMS	0.244	4.102
VAS	0.402	2.488
Interaction_PWB_EWB	0.687	1.456
Interaction_LYM_Age2	0.120	8.311
Interaction_LYM_Age3	0.116	8.603

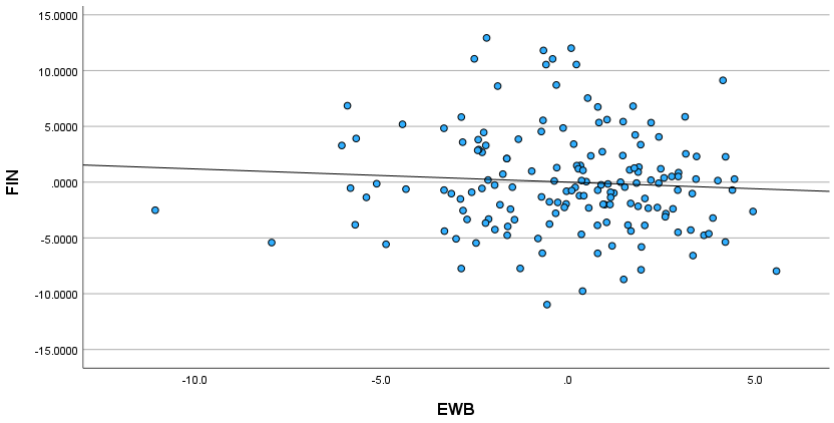
19.7 ***Studentised Residuals Scatterplot for FIN***

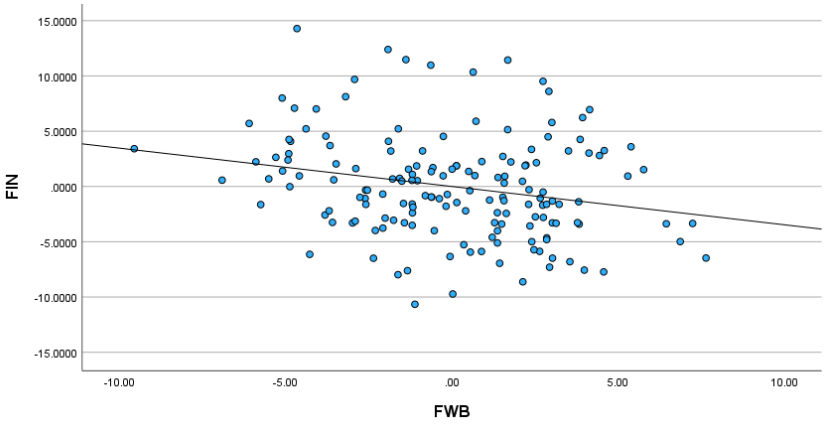


19.8 ***Patrial Regression Plots for FIN***






15.0000
10.0000
5.0000
.0000
-5.0000
-10.0000
-15.0000
FIN
-10.0
-5.0
.0
5.0
EWB


15.0000
10.0000
5.0000
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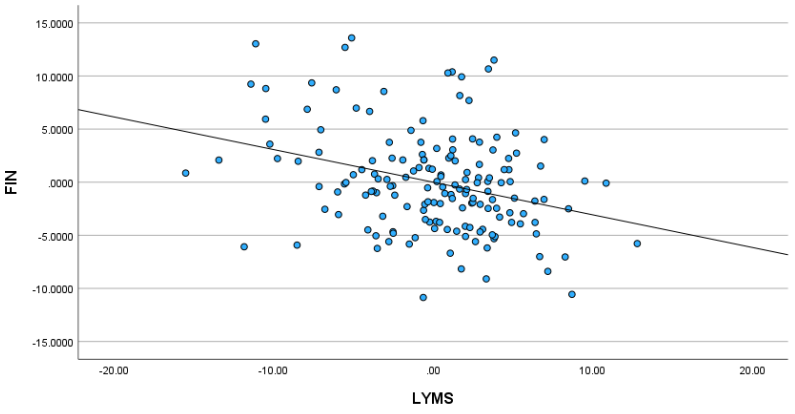
-10.0000
-15.0000
FIN
-10.00
-5.00
.00
5.00
10.00
FWB


15.0000
10.0000
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FIN
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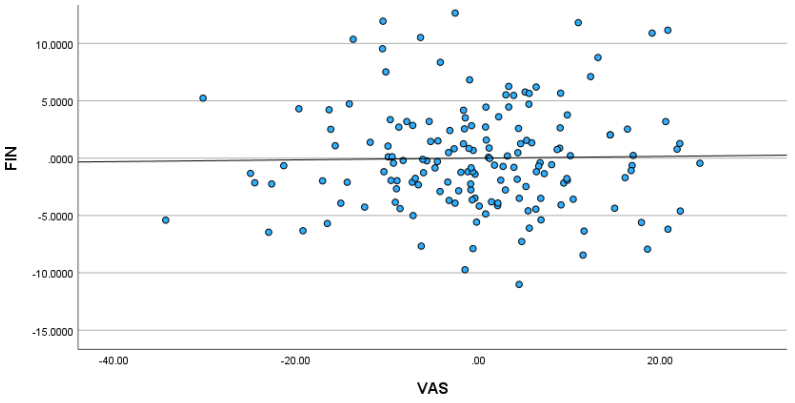
-10.00
.00
10.00
20.00
LYMS


10.0000
5.0000
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FIN
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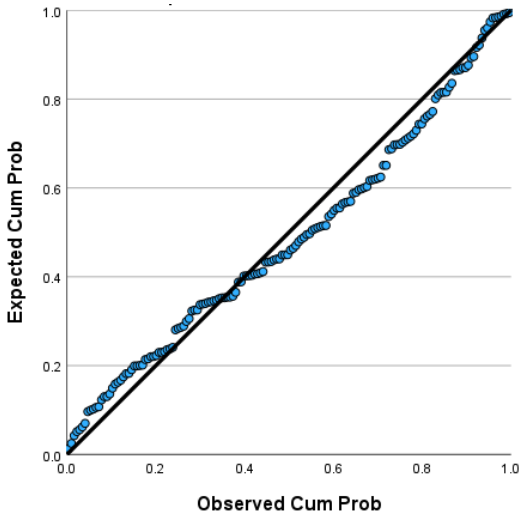
-20.00
.00
20.00
VAS

19.9 ***Normal P-plot for FIN***



19.10 ***Residuals Statistics table for FIN***

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	-4.835221	26.830635	6.403292	5.6152311	162
Std. Predicted Value	-2.001	3.638	.000	1.000	162
Standard Error of Predicted Value	1.329	3.791	2.062	.372	162
Adjusted Predicted Value	-5.852222	30.844175	6.437562	5.8524406	162
Residual	-11.0454454	12.6690569	.0000000	4.5000350	162
Std. Residual	-2.231	2.559	.000	.909	162
Stud. Residual	-2.329	2.821	-.003	1.009	162
Deleted Residual	-12.0332651	16.6172409	-.0342697	5.5757313	162
Stud. Deleted Residual	-2.369	2.899	-.001	1.019	162
Mahal. Distance	10.600	93.419	27.827	11.028	162
Cook's Distance	.000	.131	.009	.015	162
Centered Leverage Value	.066	.580	.173	.068	162

a. Dependent Variable: FIN

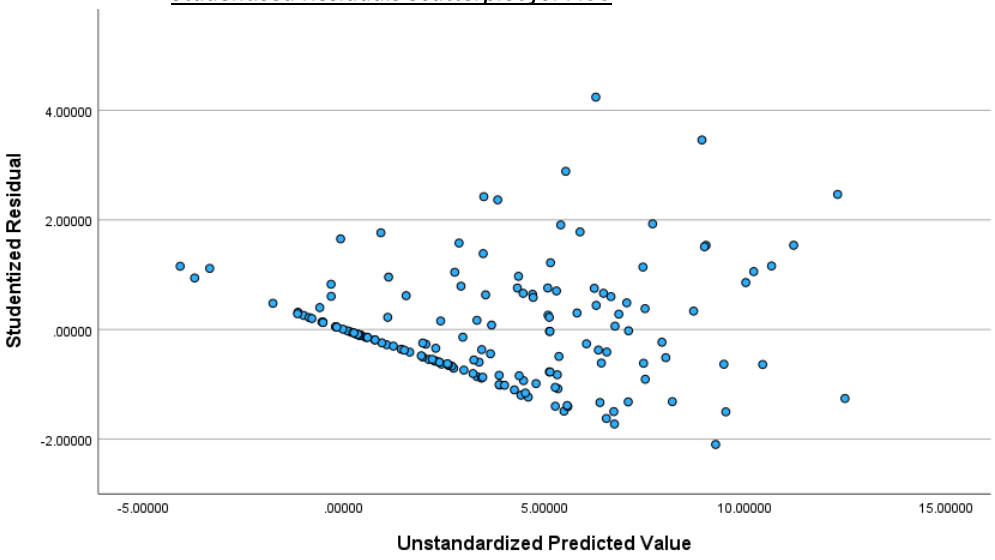
19.11 *Correlation Tables (Multicollinearity) for FIN*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. FIN	--																						
2. Gender	-.121	–																					
3 Age Groups	-.269	-.029	--																				
4.Residence	-.018	-.098	.042	--																			
5. Employment status	-.017	.042	.156	-.011	--																		
6. Medical card	-.089	-.066	.211	.004	.295	--																	
7. Private health insurance	-.124	.027	.011	-.012	-.246	-.418	–																
8. Lymphoma type	-.058	.009	.328	-.099	-.079	-.067	.086	--															
9. Time since diagnosis	-.138	-.017	.210	.062	.088	.181	-.056	-.084	--														
10. Sites	.010	.168	.114	-.110	.074	.061	-.142	.070	-.024	--													
11. Chemotherapy	-.069	.048	-.035	-.059	.073	.028	-.058	-.008	.115	.096	–												
12. Immunotherapy	.072	-.065	.131	.085	-.041	-.068	.145	.229	.020	-.073	-.048	--											
13. Radiotherapy	-.124	.113	.051	.080	-.022	.017	.017	-.248	-.009	-.036	-.103	-.124	--										
14. Surgery	.001	.063	-.063	-.046	.072	-.012	-.002	-.157	-.004	-.032	.010	-.163	.092	--									
15. Cardiac conditions	-.151*	.023	.441	.016	.130	.164	-.107	.205	.113	-.042	.012	.091	-.036	-.136	--								
16. Hearing/visual impairments	-.129	.110	.262	-.041	.098	.062	.002	.069	.049	.180	-.030	.036	-.068	-.018	.138	--							
17. None of these conditions	.071	.017	-.445	.037	-.266	-.147	.048	-.176	-.167	-.070	.015	-.107	.021	-.037	-.488	-.275	--						
18. PWB	-.460	.172	-.060	.039	-.249	-.083	.202	-.065	.061	-.160	-.037	-.079	.151	.067	-.078	-.130	.172	--					
19. SWB	-.383	-.038	.050	.062	-.189	.067	.150	.003	-.047	-.075	.081	.005	.094	.086	-.114	-.005	.074	.343	--				
20. EWB	-.528	.102	.127	.053	-.148	-.053	.141	.036	.153	-.101	.072	.012	.026	.067	.056	.032	.066	.538	.283	--			
21. FWB	-.512	.119	.044	.089	-.135	.064	.135	-.134	.064	-.139	.054	-.125	.190	.080	-.095	-.051	.091	.598	.597	.542	--		
22. LYMS	-.611	.139	.075	.038	-.199	-.075	.248	-.023	.053	-.176	-.016	-.106	.097	.065	-.038	-.033	.112	.739	.372	.687	.624	–	
23. VAS	-.460	.012	.031	-.011	-.149	.040	.118	-.087	.030	-.009	-.170	-.111	.093	.078	-.100	.015	.052	.570	.319	.478	.654	.543	–

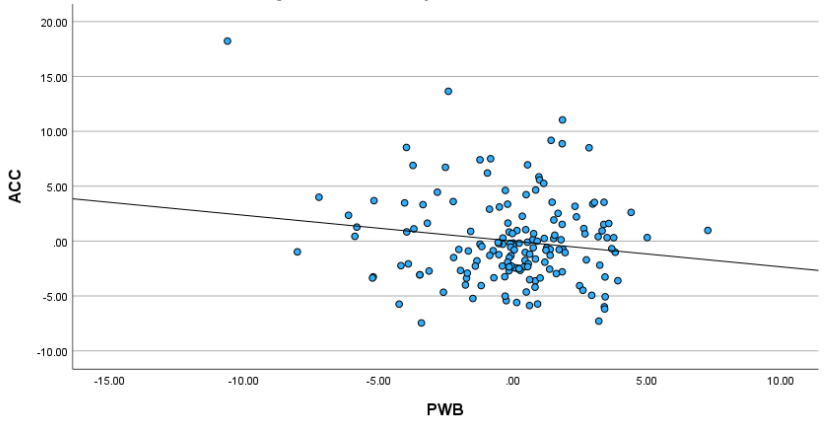
19.12 ***Collinearity Statistics Table for FIN***

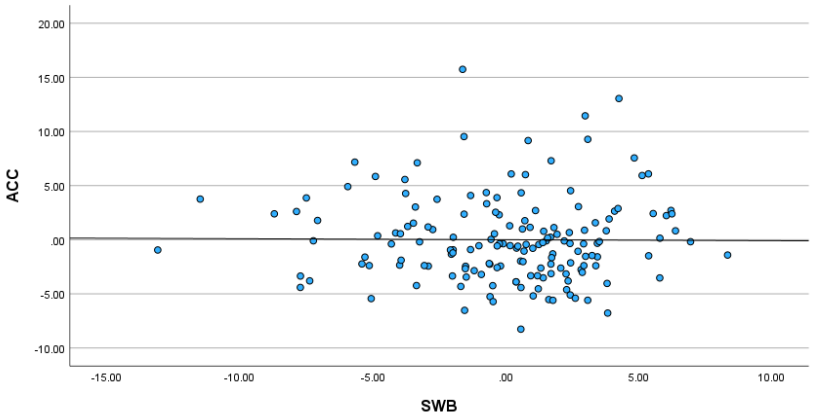
	Collinearity Statistics	
	Tolerance	VIF
(Constant)		
Gender	0.690	1.449
Age_3_groups=40 - 69	0.176	5.679
Age_3_groups=70 or older	0.119	8.391
Medical card	0.628	1.593
Private health insurance	0.609	1.642
Residence	0.877	1.140
Employment status=Retired and Homemaker	0.363	2.753
Employment status=Student	0.672	1.488
Employment status=Unemployed	0.767	1.303
Sites	0.740	1.352
Time since diagnosis	0.740	1.351
Lymphoma type	0.263	3.802
Chemotherapy	0.852	1.174
Immunotherapy	0.729	1.371
Radiotherapy	0.770	1.299
Surgery	0.842	1.188
Cardiac conditions	0.627	1.595
Hearing or visual impairments	0.750	1.334
None of these conditions	0.610	1.640
PWB	0.339	2.952
SWB	0.544	1.839
EWB	0.375	2.664
FWB	0.262	3.810
LYMS	0.244	4.102
VAS	0.402	2.488
Interaction_PWB_EWB	0.687	1.456
Interaction_LYM_Age2	0.120	8.311
Interaction_LYM_Age3	0.116	8.603

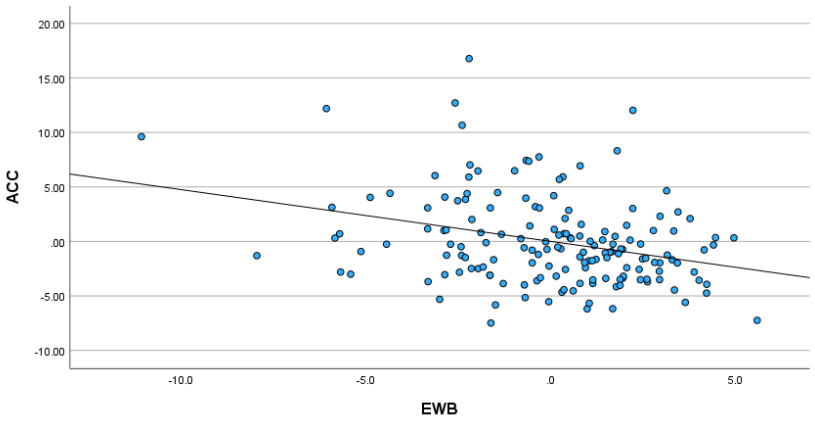
19.13 *Studentised Residuals Scatterplot for ACC*



19.14 *Partial Regression Plots for ACC*






ACC
EWB
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10.00
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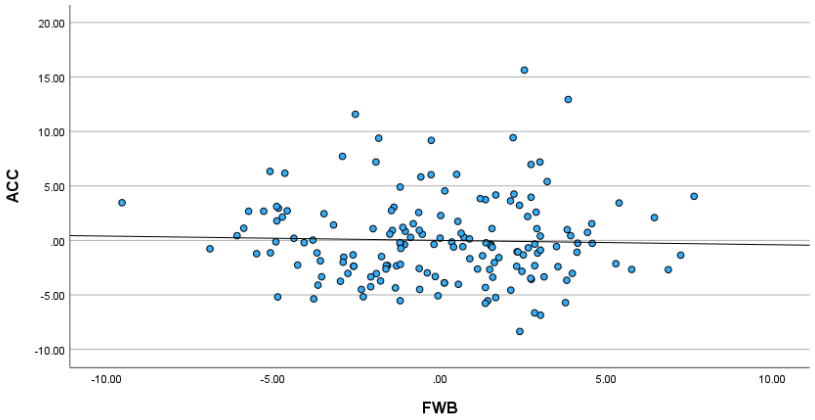
5.0


ACC
FWB
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10.00
5.00
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-10.00
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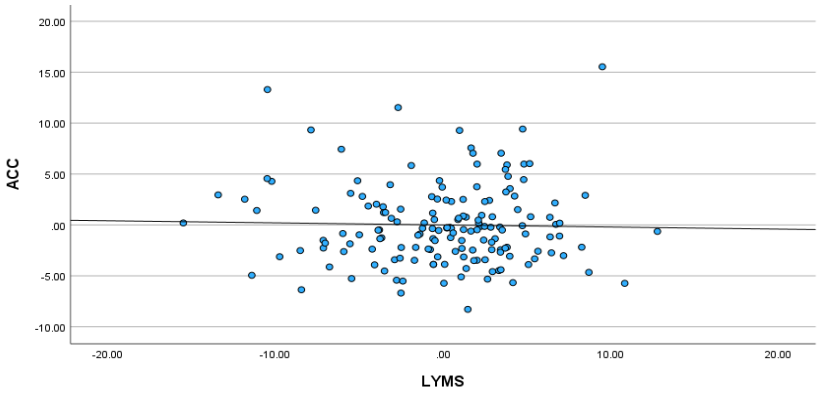
.00
5.00
10.00


ACC
LYMS
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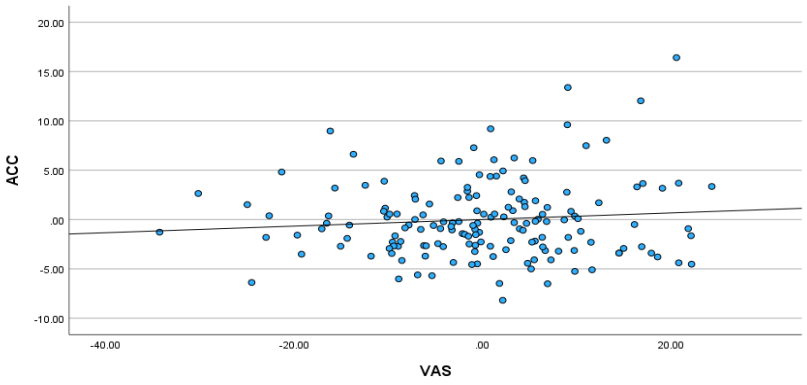
10.00
20.00


ACC
VAS
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10.00
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-10.00
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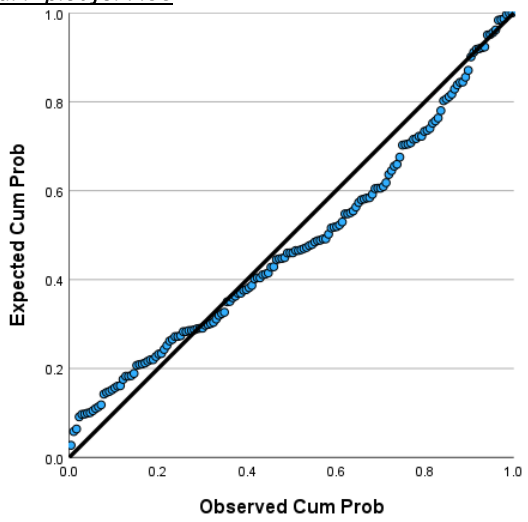
-20.00
.00
20.00

19.15 *Normal P-plot for ACC*



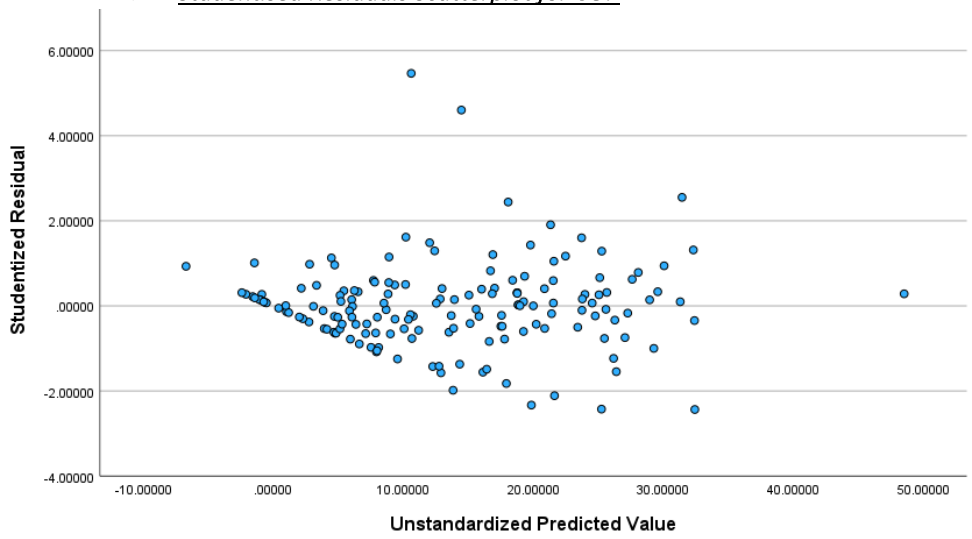
19.16 *Residuals Statistics table for ACC*

Residuals Statistics[a]

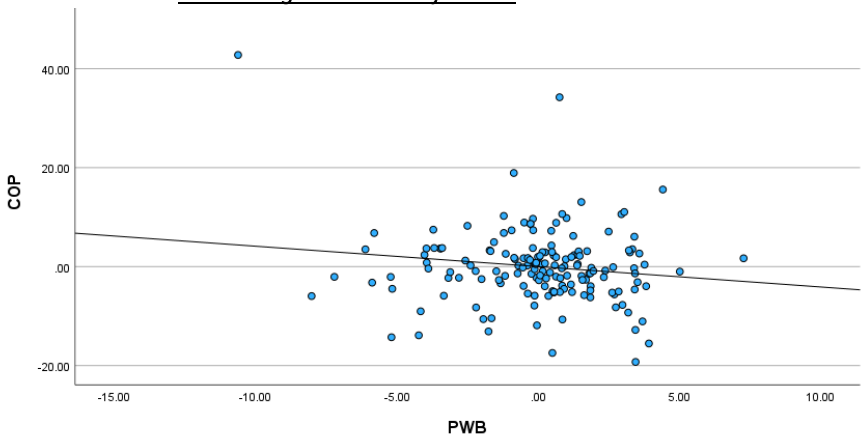
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	-4.0722	12.4797	3.7654	3.25119	162
Std. Predicted Value	-2.411	2.680	.000	1.000	162
Standard Error of Predicted Value	1.152	3.288	1.788	.322	162
Adjusted Predicted Value	-6.0247	14.5187	3.7390	3.39478	162
Residual	-8.26001	15.72369	.00000	3.90222	162
Std. Residual	-1.924	3.662	.000	.909	162
Stud. Residual	-2.098	4.240	.003	1.012	162
Deleted Residual	-9.82310	21.07273	.02642	4.85243	162
Stud. Deleted Residual	-2.126	4.542	.007	1.029	162
Mahal. Distance	10.600	93.419	27.827	11.028	162
Cook's Distance	.000	.211	.009	.021	162
Centered Leverage Value	.066	.580	.173	.068	162

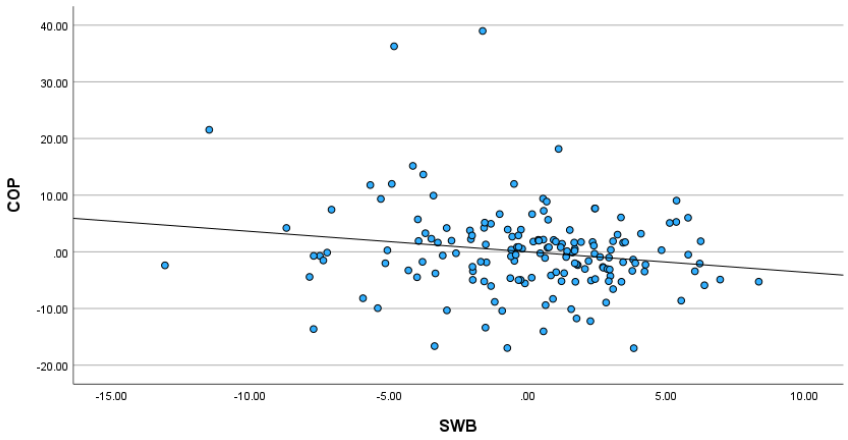
a. Dependent Variable: ACC

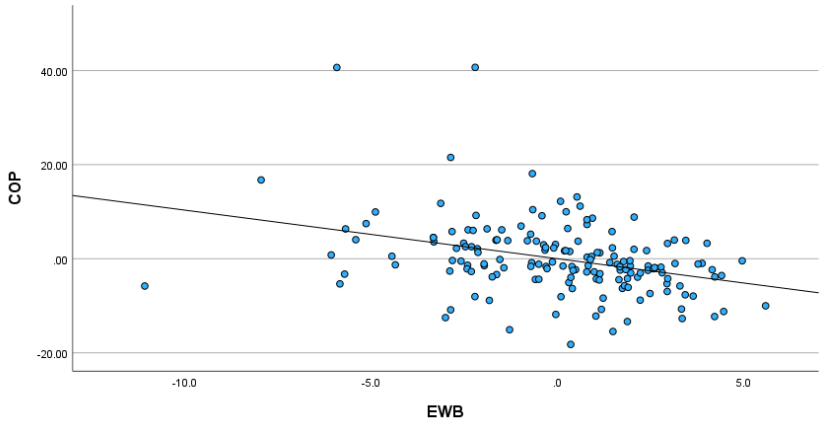
19.17 ***Studentised Residuals Scatterplot for COP***



19.18 ***Partial Regression Plots for COP***



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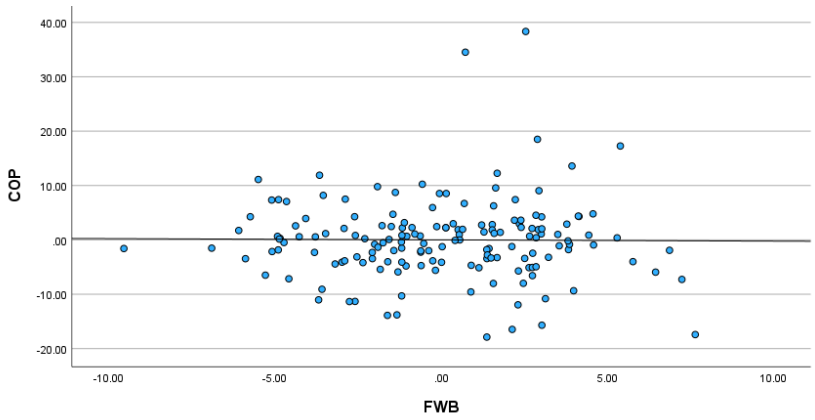
EWB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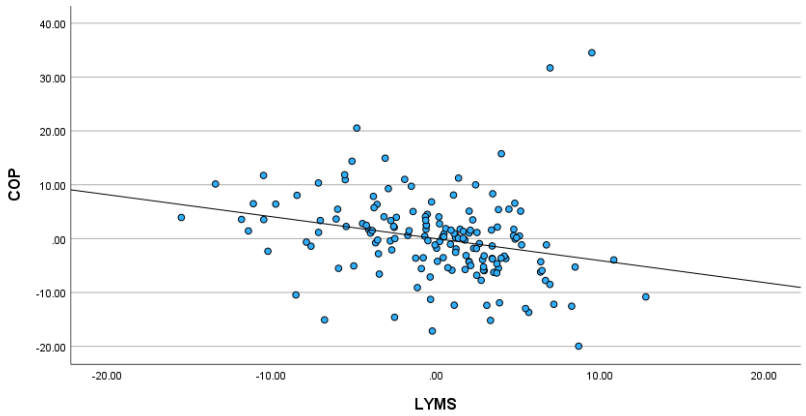
10.00
FWB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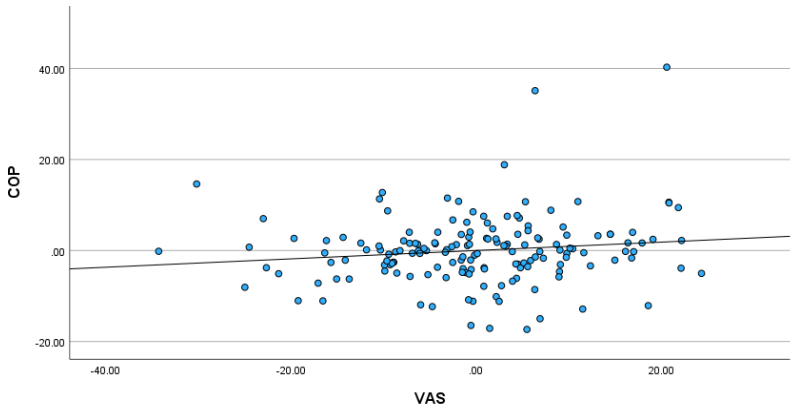
-20.00
-20.00
-10.00
.00
10.00
20.00
LYMS


COP
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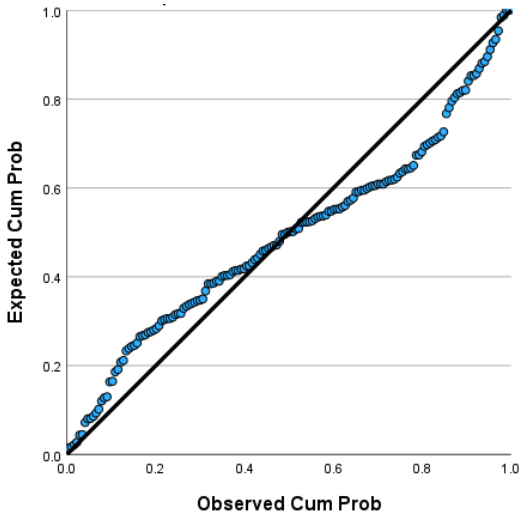
.00
-20.00
-40.00
-20.00
.00
20.00
VAS

19.19 *Normal P-plot for COP*



19.20 *Residuals Statistics Table for COP*

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	-6.7108	48.5174	13.5954	9.56392	162
Std. Predicted Value	-2.123	3.651	.000	1.000	162
Standard Error of Predicted Value	2.182	6.228	3.387	.610	162
Adjusted Predicted Value	-8.5231	46.4152	13.5855	9.78959	162
Residual	-17.84935	38.39195	.00000	7.39160	162
Std. Residual	-2.195	4.721	.000	.909	162
Stud. Residual	-2.435	5.465	.001	1.016	162
Deleted Residual	-23.89115	51.45249	.00990	9.25822	162
Stud. Deleted Residual	-2.482	6.183	.007	1.057	162
Mahal. Distance	10.600	93.419	27.827	11.028	162
Cook's Distance	.000	.350	.009	.031	162
Centered Leverage Value	.066	.580	.173	.068	162

a. Dependent Variable: COP

19.21 ***Correlations Table (Multicollinearity) for COP***

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. COP	--																						
2. Gender	-.194	--																					
3 Age Groups	-.206	-.029	–																				
4.Residence	.033	-.098	.042	--																			
5. Employment status	.087	.042	.156	-.011	--																		
6. Medical card	.042	-.066	.211	.004	.295	--																	
7. Private health insurance	-.166	.027	.011	-.012	-.246	-.418	–																
8. Lymphoma type	-.144	.009	.328	-.099	-.079	-.067	.086	--															
9. Time since diagnosis	-.100	-.017	.210	.062	.088	.181	-.056	-.084	--														
10. Sites	.050	.168	.114	-.110	.074	.061	-.142	.070	-.024	--													
11. Chemotherapy	.041	.048	-.035	-.059	.073	.028	-.058	-.008	.115	.096	--												
12. Immunotherapy	-.017	-.065	.131	.085	-.041	-.068	.145	.229	.020	-.073	-.048	–											
13. Radiotherapy	-.050	.113	.051	.080	-.022	.017	.017	-.248	-.009	-.036	-.103	-.124	--										
14. Surgery	.050	.063	-.063	-.046	.072	-.012	-.002	-.157	-.004	-.032	.010	-.163	.092	--									
15. Cardiac conditions	-.057	.023	.441	.016	.130	.164	-.107	.205	.113	-.042	.012	.091	-.036	-.136	–								
16. Hearing/visual impairments	-.124	.110	.262	-.041	.098	.062	.002	.089	.049	.180	-.030	.036	-.068	-.018	.138	--							
17. None of these conditions	-.033	.017	-.445	.037	-.266	-.147	.048	-.176	-.167	-.070	.015	-.107	.021	-.037	-.488	-.275	--						
18. PWB	-.531	.172	-.060	.039	-.249	-.083	.202	-.065	.061	-.160	-.037	-.079	.151	.067	-.078	-.130	.172	--					
19. SWB	-.338	-.038	.050	.062	-.189	.067	.150	.003	-.047	-.075	.081	.005	.094	.086	-.114	-.005	.074	.343	--				
20. EWB	-.645	.102	.127	.053	-.148	-.053	.141	.036	.153	-.101	.072	.012	.026	.067	.056	.032	.066	.538	.283	--			
21. FWB	-.472	.119	.044	.089	-.135	.064	.135	-.134	.064	-.139	.054	-.125	.190	.080	-.095	-.051	.091	.598	.597	.542	--		
22. LYMS	-.664	.139	.075	.038	-.199	-.075	.248	-.023	.053	-.176	-.016	-.106	.097	.065	-.038	-.033	.112	.739	.372	.687	.624	--	
23. VAS	-.374	.012	.031	-.011	-.149	.040	.118	-.087	.030	-.009	-.170	-.111	.093	.078	-.100	.015	.052	.570	.319	.478	.654	.543	--

19.22 ***Collinearity Statistics Table for COP***

	Collinearity Statistics	
	Tolerance	VIF
(Constant)		
Gender	0.690	1.449
Age_3_groups=40 - 69	0.176	5.679
Age_3_groups=70 or older	0.119	8.391
Medical card	0.628	1.593
Private health insurance	0.609	1.642
Residence	0.877	1.140
Employment status=Retired and Homemaker	0.363	2.753
Employment status=Student	0.672	1.488
Employment status=Unemployed	0.767	1.303
Sites	0.740	1.352
Time since diagnosis	0.740	1.351
Lymphoma type	0.263	3.802
Chemotherapy	0.852	1.174
Immunotherapy	0.729	1.371
Radiotherapy	0.770	1.299
Surgery	0.842	1.188
Cardiac conditions	0.627	1.595
Hearing or visual impairments	0.750	1.334
None of these conditions	0.610	1.640
PWB	0.339	2.952
SWB	0.544	1.839
EWB	0.375	2.664
FWB	0.262	3.810
LYMS	0.244	4.102
VAS	0.402	2.488
Interaction_PWB_EWB	0.687	1.456
Interaction_LYM_Age2	0.120	8.311
Interaction_LYM_Age3	0.116	8.603