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A Comparative Evaluation of Two Delivery
Methods for a Work Focused Fatigue
Management Intervention for Individuals with
Inflammatory Arthritis

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Philosophy

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Declaration

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Summary

Background

Inflammatory Arthritis (IA) often leads to early work disability, significantly impacting individuals' employment and causing socioeconomic challenges. Fatigue, a major symptom of IA, adversely affects productivity and increases absenteeism. Individuals with IA in Ireland prefer peer-supported, group-based rehabilitation interventions. To address this, the Fatigue Management Education for Work (FAME-W) intervention was developed as an in-person, group-based programme. Due to the COVID-19 pandemic, it was adapted to an online format, and a self-guided workbook was introduced.

Methodology

The development of the FAME-W intervention followed the Medical Research Council (MRC) framework for complex interventions, ensuring it was theoretically grounded and tailored to the needs of individuals with IA. The overall aim of this research was to test the feasibility and compare two different delivery methods of the same intervention: an online group-based format and a self-guided workbook. Therefore, three separate studies were undertaken as part of this research. First, a feasibility study assessed the feasibility and acceptability of delivering the FAME-W intervention online and as a self-guided workbook through a comparative randomised controlled trial incorporating qualitative components. Second, a multisite comparative randomised control trial was conducted across multiple sites to evaluate and compare both delivery methods in improving work performance among individuals with inflammatory arthritis. Third, a mixed-methods process evaluation was performed to assess the implementation and impact of the intervention for both delivery methods, focusing on factors such as fidelity, reach, dose, mechanisms of impact, and contextual influences.

Results

Feasibility study concluded that both the online and self-guided workbook formats were feasible and acceptable. Improvements in symptom management and work ability suggest these formats can effectively support individuals with inflammatory arthritis, supporting progression to a larger, powered comparative trial. In the randomized control trial, neither the online nor the workbook formats showed statistically significant differences between groups in improving work performance, fatigue, pain, or quality of life. However, slight within-group improvements were observed. In the process evaluation, although recruitment challenges were present, participants represented diverse demographics and IA conditions. The online format was valued for its interactivity and peer support, fostering a sense of community. The self-guided workbook was valued for its flexibility and ease of use, allowing self-paced learning. Both delivery methods, along with their goal-setting components, were seen as important mechanisms of change, helping participants improve self-management of IA-related fatigue and stress. Barriers such as poor internet connectivity and limited time hindered engagement, while supportive work environments and high motivation facilitated better outcomes.

Conclusion

The research demonstrated that both the online group-based and self-guided workbook formats offer comparable support in managing inflammatory arthritis symptoms and enhancing work performance. The findings support the need for larger-scale studies to further evaluate the effectiveness of these interventions and to refine strategies for their implementation, considering the contextual factors that influence participant engagement and outcomes.

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- Karkon, S., Connolly, D., McCormack, R., Irudayaraj, B., Fitzgerald, P. et al Perceptions of goal setting from participants of online and self-guided workbook of FAME-W
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- Karkon, S. & Connolly, D. (2021) “Feasibility of an Online “Fatigue and Activity Management Education in Work (FAME-W) Intervention for Individuals with Inflammatory Arthritis” *Presentation made to the Association of Occupational Therapists of Ireland (AOTI)*, virtual Conference, October 8, 2021.
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List of Abbreviations

ACR	(American College of Rheumatology)
AHI	(The Arthritis Helplessness Index)
AIMS2	(The Arthritis Impact Measurement Scales II)
AxSp	(Ankylosing Spondylitis)
BOCF	(Baseline Observation Carried Forward)
BRAF	(Bristol Rheumatoid Arthritis Fatigue questionnaire)
CARD	(The Centre for Arthritis and Rheumatic Diseases)
CCA	(Complete Case Analysis)
COPM	(Canadian Occupational Performance Measure)
DAS28	(Disease Activity Score in 28 joints)
DMARDs	(Disease-modifying anti-rheumatic drugs)
EULAR	(European League Against Rheumatism)
EQ-5D	(The EuroQol Index)
FAME-W	(FATigue Management Education for Work)
HAQ	(Health Assessment Questionnaire)
HSE	(Health Services Executive)
IA	(Inflammatory Arthritis)
ITT	(Intention to Treat)
JAK	(Janus Kinase Inhibitors)
LOCF	(Last Observation Carried Forward)
MCAR	(Missing Completely at Random)
MI	(Multiple Imputation)
MRC	(Medical Research Council)
NHS	(National Health Service)
NSAIDs	(Nonsteroidal Anti-Inflammatory Drugs)
OA	(Osteoarthritis)
OT	(Occupational Therapy/Therapist)
PsA	(Psoriatic Arthritis)
RA	(Rheumatoid Arthritis)
RADAI	(Rheumatoid Arthritis Disease Activity)
RA-WIS	(Rheumatoid Arthritis Work Instability Scale)
SLE	(Systemic Lupus Erythematosus)
SSc	(Systemic Sclerosis)

TNF	(Tumor Necrosis Factor)
UC	(Usual Outpatient Care)
UK	(United Kingdom)
US	(United States)
VR	(Vocational Rehabilitation)
VRC	(Vocational Rehabilitation Counsellor)
WAI	(Work Ability Index)
WES-RC	(Work Experience Survey for Rheumatic Conditions)
WLQ	(Work Limitations Questionnaire)
WPAI	(Work Productivity and Activity Impairment Questionnaire)

CHAPTER 1: INTRODUCTION

1.1 Background and need

Work disability is considered a serious consequence of Inflammatory Arthritis (IA) and begins soon after diagnosis, posing significant challenges for the individual and society (Bevan, 2015). Up to 50% of people with IA report workplace difficulties resulting in sick leave, absenteeism, and reduced productivity with many individuals taking early retirement (Connolly et al., 2015; Dadoun et al., 2014; Gignac et al., 2013; Hammond et al., 2017). Due to the impact of IA on work performance, IA is considered to have one of the greatest socioeconomic costs of any disease group (Bevan et al., 2009; Rezaee et al., 2022).

Fatigue is reported as one of the most demanding symptoms of IA (Dures et al., 2020; Pilgaard et al., 2019). It is a multidimensional symptom affecting physical, cognitive, emotional, and social functioning of individuals with IA (Geenen & Dures, 2019; Murphy et al., 2021). Fatigue can exacerbate other IA symptoms such as pain, inflammation, and sleep disturbances (Irwin, et al., 2012; Katz, 2017; Madsen et al., 2015) and can have a substantial effect on employment by causing loss of productivity at work (Druce et al., 2018; Sterling et al., 2014). Work-related difficulties attributed to fatigue include decreased ability to complete jobs, reduced performance capacity and decreased concentration and memory in work (Druce et al., 2018; Lacaille et al., 2008; Verstappen et al., 2015). Studies examining the impact of fatigue on work performance have found that individuals with IA often leave the workforce prematurely due to fatigue-related barriers (Codd et al., 2018; Hammond et al., 2017; Helme et al., 2019). A study in Ireland examined the impact of fatigue on work performance and reported a significant impact of fatigue on work activities and identified pain and stress as significant factors that exacerbate fatigue in work (Connolly et al., 2015, 2016). Participants of this study identified a need for support to manage their fatigue in order to improve their work ability.

Previous research has identified the need for work-based rehabilitation interventions to support individuals in managing the demands of their work (Codd et al., 2018; Cooper, 2000; Hammond et al., 2017; Verstappen, 2015). Interventions that focus on prevention and reduction of work disability are considered particularly important for enabling individuals with IA to remain in employment (Prior et al., 2015, Madsen et al., 2021;

Feddersen et al., 2019). To date, research has demonstrated that once people with IA stop working, returning to work is unlikely for this cohort; therefore, it is suggested that interventions focusing on job retention might be more effective than interventions to regain employment (Prior et al., 2015; Prior & Hammond, 2014).

Individual work-based rehabilitation interventions focussing on reducing presenteeism and withdrawal from work have shown significant results (Hammond et al., 2017; Keysor et al., 2018). A job retention program in the UK reduced presenteeism and absenteeism, while a web-based program in Canada, *Making It Work*, improved presenteeism and prevented short-term work cessation (Hammond et al., 2017; Luquini et al., 2020). *Work-It* intervention in United States showed reduction in work loss while a job retention programme in the Netherlands improved fatigue and emotional status, but did not reduce job loss risk (Keysor et al., 2018; De Buck et al., 2005). However, participants in the Irish study expressed a preference for group-based interventions to connect with others facing similar challenges (Connolly et al., 2015, 2016). Although many existing interventions include group elements, none are entirely group-based. Group-based interventions have been shown to enhance peer support in acquiring effective symptom management strategies for individuals with Systemic Lupus Erythematosus (SLE) (O’Riordan et al., 2017). Therefore, group-based work interventions may provide similar peer support for individuals with IA. Additionally, if group-based interventions for supporting return to work are effective, they may be more cost effective than individually delivered interventions (Biggs et al., 2020).

In response to preferences expressed by people with IA in Ireland, and to address a gap in group-based work management interventions, an occupational-therapy led, self-management intervention, **F**atigue **M**anagement **E**ducation for **W**ork (FAME-W) was developed for individuals with IA to manage fatigue, and symptoms exacerbated by fatigue, in the workplace. FAME-W was developed using the Medical Research Council (MRC) framework for development and evaluation of complex interventions (Skivington et al., 2021). Complex multi-component interventions in healthcare settings refer to interventions that involve multiple interconnected components or elements aimed at addressing multifaceted health issues or for achieving complex health outcomes (Campbell et al., 2000). As FAME-W is a complex self-management intervention, following the MRC framework ensured that the development and evaluation of FAME-W was evidence-based, theoretically grounded, and tailored to the needs of individuals with IA.

The MRC framework was originally developed by Campbell and colleagues in 2000 and characterised the development of complex interventions as a linear process. However, Craig and colleagues (2008) revised the framework introducing a four-phased non-linear development and evaluation process that is suitable for non-pharmacological interventions (Figure 1.1).

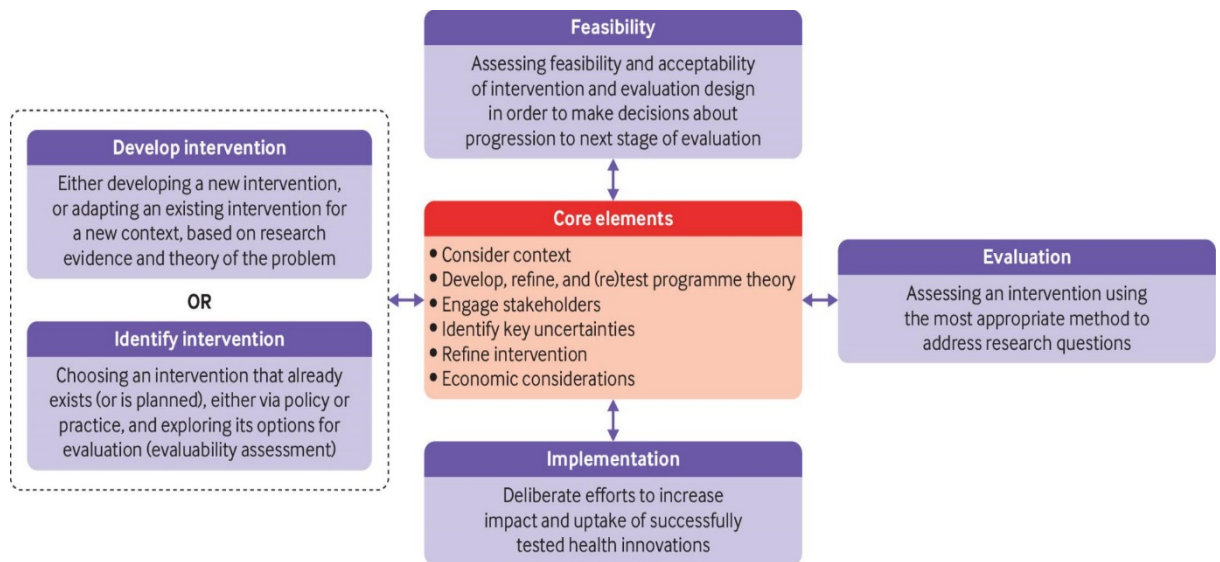


Figure 1.1 MRC Development and Evaluation phases (Skivington et al., 2021)

The four phases are as follows:

Phase 1: Development/Identification: based on existing evidence, theory, and stakeholder input, this phase involves defining the intervention components, understanding the target population, and refining the intervention through iterative processes.

Phase 2: Feasibility: the intervention is tested for feasibility, acceptability, and potential effectiveness. This involves conducting small-scale pilot studies to assess the intervention's practicality, refine study procedures, and identify any potential challenges.

Phase 3: Evaluation: the intervention is tested in a larger-scale study to assess its effectiveness, cost-effectiveness, and impact on relevant outcomes. This phase typically involves an RCT or another rigorous study design to determine the intervention's efficacy.

Phase 4: Implementation: focuses on implementing the intervention in real-world settings. This involves scaling up the intervention, integrating it into routine practice, and monitoring its implementation to ensure fidelity and sustainability (Skivington et al., 2021).

In 2021, Skivington and colleagues updated the MRC framework by adding core elements that influences the four development phases: context, program theory, stakeholders, uncertainties, refinement, and economic considerations. Context involves circumstances related to the intervention. Program theory explains how the intervention works. Stakeholders include anyone affected by or involved in the intervention. Uncertainties identify unknowns that can shape the research questions. Refinement improves the intervention, and economic considerations evaluate resource impacts (Skivington et al., 2021).

1.2 The MRC framework as applied to the development and evaluation of FAME-W

A brief overview of how the MRC framework was applied to the development of FAME-W is outlined in this section. Figure 1.2 outlines the stages of the framework along with the key components and activities associated with development of FAME-W. The arrows indicate the main interactions between these phases.

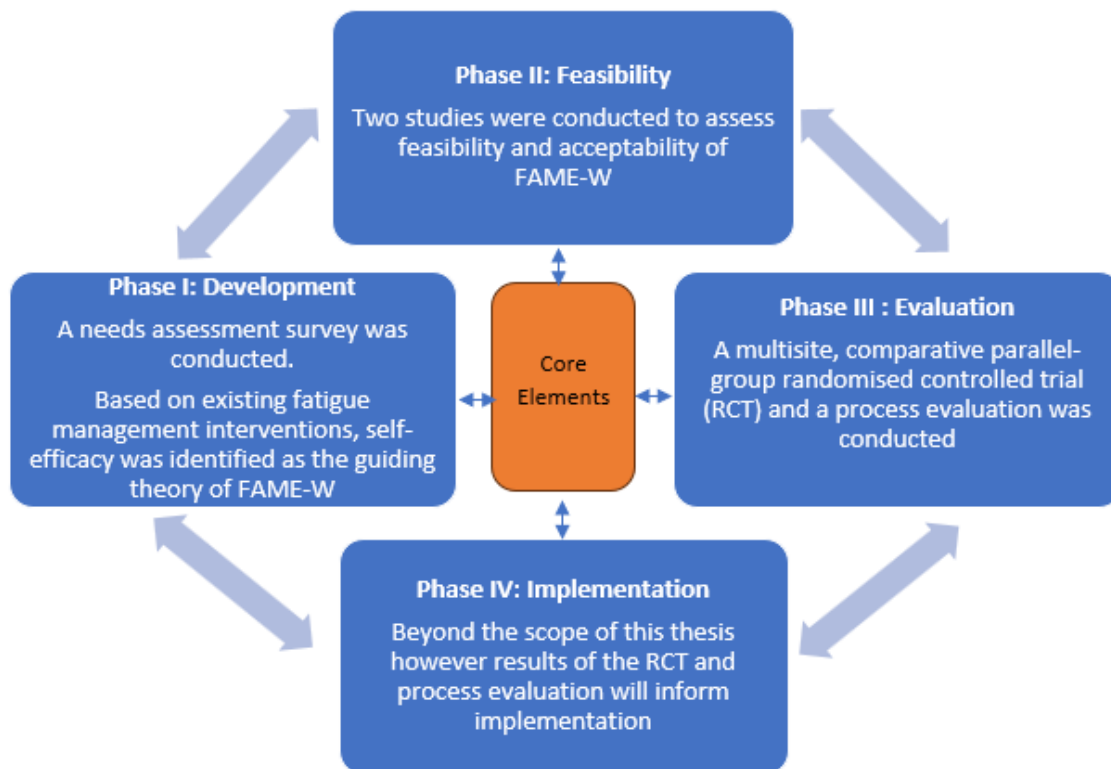


Figure 1.2 MRC framework for development and evaluation of complex interventions as it applies to FAME-W (adapted from MRC, 2021).

Phase 1: Development

Based on the MRC framework, evidence for the need of a complex intervention must be clearly established prior to designing and testing of interventions. As previously identified, a needs assessment was conducted in Ireland with individuals with IA in

employment to investigate the impact of fatigue on work and to identify support requirements for managing fatigue in the workplace (Connolly et al., 2015, 2016). Although there is considerable research internationally on the impact of fatigue on work (Dadoun et al., 2014; de Hooge et al., 2016; Druce et al., 2018; Dures et al., 2020; Guymer et al., 2015; Hammond et al., 2017; Helme et al., 2019), there was no similar research in Ireland. Therefore, to identify the impact of fatigue on work performance and factors that exacerbated fatigue in work, an observational study was carried out with 247 people with IA (Connolly et al., 2015, 2016). The findings demonstrated that employed individuals with IA experienced significant fatigue that impacted their ability to meet physical, mental and output demands of their work. Study participants identified pain and stress as significant contributors to their fatigue and described severe, unpredictable fatigue during their working day.

The study revealed a need for individuals with IA to understand fatigue and to develop strategies to manage their fatigue. As previously discussed, the study participants suggested a group-based intervention which would provide them with opportunities to meet others with IA. Therefore, the content and delivery format of FAME-W was designed to reflect the findings of this needs assessment study (Connolly et al., 2015, 2016).

FAtigue Management Education for Work (FAME-W)

FAME-W is a four-week, occupational therapy-led, group-based, self-management intervention. It is designed to equip individuals with IA with knowledge and skills to manage fatigue and address factors that exacerbate it, including pain and stress, as identified in the needs assessment study (Connolly et al., 2015, 2016). The guiding theory of FAME-W is self-efficacy, a key concept in self-management interventions that focuses on enhancing individuals' confidence in their ability to perform specific tasks and behaviours that facilitate self-management (Bandura, 1986). FAME-W incorporates strategies to increase self-efficacy, including goal setting, peer discussions, interaction, brainstorming, coaching, feedback, encouragement, and information provision. Additionally, coaching and feedback from an experienced occupational therapist in fatigue management offers personalized support and guidance, reinforcing individuals' belief in their ability to manage their fatigue in the workplace (Grant, 2013).

Each weekly session of FAME-W consists of two parts: education and goal setting. Figure 1.3 outlines the weekly content of FAME-W.

Week 1 Fatigue and Energy Management	•Understanding IA and fatigue •Factors that increase fatigue •Fatigue management strategies •Goal setting
Week 2 Managing Pain, Joint protection and Ergonomics	•Understanding pain in IA •Causes and management of pain •Joint protection and ergonomics in IA •Goal setting and goal review
Week 3 Maintaining Mental Wellbeing	•Understanding impact of stress on fatigue •Impact of stress on mental wellbeing •Stress management and relaxation techniques •Goal setting and goal review
Week 4 Effective Communications with Employers and Employment Legislation	•Strategies for effectively communicating with employers and colleagues •Employment legislation •Goal review

Figure 1.3 *Weekly content of FAME-W*

Educational topics presented each week focuses on different aspects of fatigue and factors that exacerbate fatigue as identified by Connolly et al., (2015 and 2016) for individuals with IA in Ireland. Participants in this study identified pain and stress as factors that most exacerbate fatigue in work. Therefore, this is included in weeks 1-3 in FAME-W. These individuals also expressed lack of knowledge of employment legislation and workplace accommodations that employers are obliged to provide individuals with disabilities. Therefore, Week 4 provides this information to participants. In order to facilitate group discussion and peer learning participants are encouraged to discuss their experiences of fatigue and share their experiences of fatigue with each other during the education component. Interactive sessions and brainstorming exercises encourage active participation and problem-solving, enabling participants to explore different approaches to fatigue management and build confidence in their capacity to implement effective strategies (Stajkovic & Luthans, 1998).

The provision of relevant information delivered during the educational component of each week of FAME-W equips participants with knowledge and skills essential for managing fatigue, further enhancing their sense of self-efficacy by expanding their understanding of effective coping mechanisms (Bandura, 1977; Lorig & Holman, 2003). Additionally, ongoing encouragement throughout the intervention reinforces individuals' confidence in their ability to make meaningful changes and persist in their efforts to manage fatigue

effectively (Ryan & Deci, 2000). By incorporating these elements, FAME-W not only aims to address fatigue but also promotes self-management skills as well as developing a stronger sense of self-efficacy among individuals with IA. Through active participation in the intervention and the utilization of provided resources, participants are equipped with the knowledge, skills, and confidence needed to effectively manage their condition and improve their overall wellbeing.

In the second half of each session, participants are asked to identify and set goals based on educational material covered each week. Goal setting is recommended to facilitate sustainability of self-management strategies (Lorig & Holman, 2003). The intention of goal setting is for participants to set SMART goals to apply self-management strategies discussed in the weekly sessions. SMART goal setting uses a structured format to facilitate individuals to set realistic and achievable goals (Bovend'Eerd et al., 2009). SMART goals ensure that goals are specific to the individual, measurable, attainable/achievable, relevant to the issue presented and time specific. Therefore, with the help of these goals, participants can plan for the future which increases motivation, generates a sense of hope and creates a need for persistence towards the attainment of healthy habits (Parkinson & Brooks, 2020). The aim of goal setting in the FAME-W intervention is to encourage participants to apply the learning gained from each session into practice over the coming week. Each week participants review and discuss the outcomes of their goals with their group and group facilitator. See Appendix A for structured goal setting and review worksheets.

All FAME-W participants receive a FAME-W handbook containing four chapters that align with each of the weekly educational topics. The handbook includes slides from the education sessions (see Appendix B for Week 1 slides), weekly goal setting sheets, additional resources such as pain and fatigue diaries (Appendix C) and relevant contact information. Participants are encouraged to use the handbook during their attendance at FAME-W and to keep it as a resource for future reference.

Phase II: Feasibility testing of FAME-W

As per stage II of the MRC framework, a mixed-methods feasibility study was conducted to explore the feasibility and acceptability of FAME-W. A secondary aim of the study was to examine the impact of FAME-W on (i) participants' ability to meet the demands of their work activities, (ii) fatigue, (iii) mood, and (iv) quality of life (McCormack et al., 2018).

In this study, FAME-W was delivered five times to a total of 27 individuals with different types of IA (McCormack et al., 2018). The recruitment rate for the study was 36% with 27 individuals agreeing to participate out of 75 eligible individuals. Reasons for not participating included not being available, clash with work and family commitments and difficulty travelling to the centre where the FAME-W was delivered. There was high attendance of participants at FAME-W with 78% (n=21) attending three or more of the weekly sessions indicating strong high acceptability of the intervention. Retention in the study was also high with all 27 participants completing the study outcome measures at the three-month follow-up time point. On examining work and health-related outcomes significant improvements were observed in meeting work demands, fatigue, mood and self-efficacy at three months follow-up.

Acceptability of FAME-W was also reflected in the qualitative data with participants identifying relevance of the content for managing their fatigue and identified specific strategies they acquired from FAME-W that they were applying in their workplace. On examining the handbook, participants reported the handbook's usefulness in managing their fatigue and applying strategies recommended during the programme and noted their intention to use the handbook for future reference.

As part of Phase 2 of the MRC framework for developing complex interventions, this study found that FAME-W was both feasible and acceptable for individuals with IA. These findings support moving forward to Phase 3, the evaluation phase, which involves conducting a definitive randomized controlled trial (RCT) to compare the two delivery methods of FAME-W (Figure 1.2).

1.3 Current study

The original aim of this PhD study was to proceed to a definitive RCT of FAME-W as per Phase 3 of the MRC framework. However, during the planning stages, the COVID-19 pandemic emerged, leading to government-imposed public health restrictions. These restrictions significantly limited the delivery of in-person health services to only essential services, with the majority of rehabilitation services being transitioned to online platforms. Therefore, in order to proceed with comparing the two delivery methods of FAME-W it was necessary to change the delivery format of FAME-W from in-person to online delivery. This, therefore, required a second feasibility study prior to progressing to a definitive intervention study of FAME-W. The need to undertake a further feasibility study in development of complex interventions is supported by Skivington and colleagues

(2021), who reported that progression from one phase of the MRC framework to another is not always a linear process.

Due to the need to carry out a second feasibility study on FAME-W, and based on qualitative feedback on the usefulness of the FAME-W handbook (McCormack et al., 2018), it was decided to take this opportunity to examine the feasibility of a self-guided workbook of FAME-W in comparison to the online delivery of FAME-W which is facilitated in real-time by an occupational therapist. Self-guided workbooks have proven acceptable in mental health and cancer survivorship self-management interventions however, further research is needed to compare the effectiveness of self-guided handbooks with professional-led interventions (Cuijpers et al., 2016; Takano et al., 2021). Therefore, a further aim of this second feasibility study was the test the acceptability and usefulness of a self-guided FAME-W self-management workbook through a comparative RCT design.

Therefore, overall, this PhD study involved three components:

Study 1: A feasibility comparative RCT of online delivery of FAME-W with a self-guided FAME-W workbook.

Study 2: A comparison of the two delivery methods of FAME-W intervention, online and self-guided workbook.

Study 3: A mixed-methods process evaluation of FAME-W

Study 1: Feasibility study of online and self-guided d delivery of FAME-W:

The objectives of this study were to:

- Establish the feasibility of an online delivery format of FAME-W
- Explore the transferability of FAME-W content from in-person to online delivery
- Examine the feasibility of a self-guided workbook of FAME-W
- Determine the feasibility of a comparative RCT intervention study

Study 2: Comparison of the two delivery methods of FAME-W intervention

Phase III of the MRC framework is the Evaluation phase which involves assessment of the intervention using the most appropriate method (Shahsavari et al., 2020). Based on the findings of the feasibility study (Karkon et al., 2023), and the development of the self-guided FAME-W workbook, this study was a comparative RCT study design to test the compare the two delivery methods of FAME-W for individuals with IA. The overall aim

of this study, therefore, was to evaluate and compare the occupational therapy led online FAME-W with a self-guided workbook of FAME-W.

The objectives of this study were to:

- Test and compare the impact of two delivery formats on ability to manage the demands of work,
- Test and compare the outcomes of two delivery methods in reducing the impact of fatigue, pain, and stress on work performance of individuals with IA.

Study 3: A mixed-methods process evaluation of implementation of FAME-W

The MRC framework also recommends a process evaluation which is a crucial element of intervention development (Skivington et al., 2021). Process evaluations focus on understanding the relationship between intervention and context to explain how and why interventions work or fail and whether they can be transferred to other settings and populations (Moore et al., 2015). As per recommendations of the MRC framework, a mixed -methods process evaluation was carried out to examine implementation process of online and the self-guided workbook of FAME-W. Therefore, the aim of this study was to explore the benefits participants gained from both delivery methods and to understand how these methods supported participants in managing work and health-related challenges.

The objectives of this study were to explore the three main areas of a process evaluation:

- Implementation:
 - Assess fidelity, reach, dose, and adaptations of both delivery methods
 - Evaluate participant engagement and satisfaction across both formats.
- Mechanisms of Action:
 - Explore interactions between intervention components and their contribution to outcomes.
- Context:
 - Examine external factors influencing implementation and outcomes.

1.4 Overview of Thesis

Chapter One presents a brief background and need for this research, a description of the MRC framework for complex interventions, an overview of study designs and

objectives, and reflexivity statement. Chapter Two will outline current literature in signs, symptoms and effects of IA on the individual and on work. Chapter Three will present the methods, findings and discussion of Study 1. Chapter Four and Five will outline the methods, findings and discussion of the RCT and process evaluation components of Study 2 respectively.

1.5 Conclusion

Individuals with IA experience significant fatigue that impact on daily activities including work. This results in many individuals leaving the workforce early which has considerable financial and psychological implications for the individual and results in high societal costs to support individuals on long-term disability allowances. Research on how to support individuals with IA to remain in work have recommended that interventions should be delivered early in the disease trajectory while people are still at work. Many interventions have been developed and tested for their impact on reducing absenteeism and presenteeism with some indications of effectiveness. However, the majority of these interventions are delivered individually. A study conducted in Ireland identified a preference by individuals with IA for a group-based intervention. Based on this study, a four-week, group-based intervention was developed and tested for feasibility. The findings indicated further testing of FAME-W is warranted which is the focus of this current study. If the findings of this current study demonstrate a positive effect of FAME-W on work performance, this intervention could support people with IA to remain in the workforce for longer thus supporting social, psychological and physical wellbeing.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter reviews existing literature on Inflammatory Arthritis (IA) and work/employment. The chapter is divided into two parts. Part 1 describes IA, prevalence and presentation of IA, and impact on daily activities. Following this, in Part 2, research on the impact of IA on work and interventions that have been developed to address work difficulties for individuals with IA is discussed.

Part 1: Inflammatory Arthritis

2.2 Rheumatic Diseases

Rheumatology is a branch of medicine that focuses on the diagnosis, treatment, and prevention of rheumatic diseases (da Silva & Woolf, 2010). This discipline encompasses not only the active management of these conditions, but also preventative and rehabilitative strategies that are aimed at improving outcomes and quality of life of individuals with IA (Al-Sukaini et al., 2014). Rheumatic diseases are conditions that affect the joints, muscles, bones, and sometimes other organs, leading to symptoms such as pain, swelling, stiffness, and decreased joint function (Firestein & Kelley, 2020). The term rheumatic disease is extensive, encompassing over 200 different diseases (Rome & Steward, 2020). Arthritis, falling under the broad category of rheumatic diseases, entails painful inflammation and stiffness in the joints (Adebajo & Dunkley, 2018; Goodacre & McArthur, 2013). The most prevalent types of arthritis are Osteoarthritis (OA), Rheumatoid Arthritis (RA), Psoriatic Arthritis (PsA), Ankylosing Spondylitis (AxSp), and Systemic Lupus Erythematosus (SLE) (Sangha, 2000). Arthritis affects the lives of millions of people worldwide, causing significant physical and psychological difficulties for individuals, their family members and society (Imboden et al., 2020).

Arthritis can be broadly classified into two categories, inflammatory and non-inflammatory (Liu, 2018; Slobodin, 2020). Differentiating whether arthritis is

inflammatory or non-inflammatory is the crucial first step towards further diagnosing and managing the disease (Adebajo & Dunkley, 2018; Berman et al., 2018).

Non-inflammatory arthritis, most commonly represented by OA, is characterized by the degeneration of cartilage and bones without significant inflammation (Brower & Flemming 2012; Loeser et al., 2012). This form of arthritis typically results from wear and tear of the joints over time, leading to pain and stiffness, particularly in the hips, knees, and hands (Adebajo & Dunkley, 2018; Dieppe & Lohmander, 2005).

In contrast, IA encompasses several autoimmune diseases such as RA, PsA, and AxSp (Scott et al., 2020). American College of Rheumatology (ACR) states that these conditions are marked by an immune system attack on joint tissues, causing chronic inflammation, pain, and potential joint damage (ACR, 2010). As this study focuses exclusively on inflammatory arthritis, the remainder of the chapter concentrates on understanding and managing this condition.

2.3 Inflammatory Arthritis

IA is an autoimmune disease; the result of immune system malfunctioning that causes an autoimmune reaction (ACR, 2010). This results in the body's immune system mistakenly attacking its own tissues, particularly the synovium, which lines the joints. This autoimmune response triggers chronic inflammation within the joints, leading to damage of cartilage, bone and soft tissue (van Delft et al., 2020). As a systemic condition, IA can affect various parts of the body beyond just the joints (Kim & Suh, 2020). The presence or absence of systemic characteristics related to the root cause of this condition can vary. Despite extensive research, the exact cause of IA remains unclear. However, factors such as genetic predisposition, familial history and environmental influences like exposure to tobacco smoke, are recognized as potential triggers for its onset (Deane et al., 2017). Various types of IAs exist, each with distinct characteristics and manifestations. Understanding these common types and their features is essential for effective diagnosis and management (Scott et al., 2020). Most common types of IA are RA, PsA and AxSp (Scott et al., 2020).

In addition to these forms of IA, connective tissue diseases such as Systemic Scleroderma (SSc) share similar inflammatory characteristics. Scleroderma is characterized by the hardening and tightening of the skin and connective tissues and can affect internal organs

leading to complications in the lungs, heart, kidneys, and digestive tract. It is believed to result from an overproduction of collagen, causing the skin and connective tissues to become thick and stiff (Denton & Khanna, 2017).

2.4 Prevalence of Inflammatory Arthritis

IA affects up to 2% of the world population (Chang & Nigrovic, 2019). A global report on the prevalence of arthritis reported that among those diagnosed with IA, the prevalence rates are estimated to be between 1% and 6% for RA, 0.1% to 0.5% for AxSp, and 0.1% to 0.5% for autoimmune conditions such as SLE, systemic sclerosis (SSc), and Sjögren's syndrome (Wong et al., 2010).

In the United States, arthritis—including both inflammatory and non-inflammatory types—affects approximately 53.2 million adults with RA affecting up to 1% of the adult population and AxSp impacting up to 0.5% (Fallon et al., 2023; Alamanos et al., 2006; Helmick et al., 2008; Slobodin & Eshed, 2015; Ward et al., 2016), PsA affects approximately 0.1% to 0.3% of the US population (Gladman et al., 2005; Ogdie et al., 2017).

In Europe, the prevalence rates for IA vary, with RA affecting between 1% and 6% of the population (Wong et al., 2010). In the United Kingdom, about 450,000 adults have RA, and 190,000 have PsA (Versus Arthritis, 2023).

In Ireland, arthritis affects up to 15% of the population, with inflammatory arthritis impacting approximately 2% and nearly 2,250 new cases diagnosed annually (Kane & Kavanagh, 2011). It is estimated that 40-50,000 people have RA, approximately 10,000 have PsA, and 8,000 have AS (Arthritis Ireland, 2008; HSE, 2018). Despite these estimates, The Centre for Arthritis and Rheumatic Diseases (CARD) reports that comprehensive data on the prevalence rates of different types of IA in Ireland are sparse, indicating a need for further research to provide more accurate figures (CARD, 2023).

Although prevalence rates may vary based on factors such as demographics, geographic location, and diagnostic criteria used in different studies, these prevalence rates highlight that IA is a significant health concern globally and in Ireland, affecting millions of individuals and posing challenges to both individuals and healthcare systems. Further research is needed to better understand the prevalence and impact of IA in different populations, allowing for more effective allocation of resources and development of tailored interventions to support those affected by this condition (Nikiphorou et al., 2019)

2.5 Impact of Inflammatory Arthritis on Physical and Psychological Health

In the following sections, the comprehensive impact of IA on physical and psychological health will be examined. The discussion will cover the wide range of clinical manifestations associated with IA, such as joint pain and stiffness, and systemic symptoms including fatigue. The psychological implications will also be explored, highlighting the prevalence of depression, anxiety, and stress among individuals with IA. Furthermore, effects of physical and psychological symptoms on daily activities will be outlined.

2.5.1 Clinical Manifestations of Inflammatory Arthritis

IA is a complex and multifaceted condition that significantly impacts an individual's physical and psychological health. The symptoms of IA can vary widely among individuals and may fluctuate over time, making the disease unpredictable and challenging to manage (Adebajo & Dunkley, 2018; Goodacre & McArthur, 2013). This variability has led to a shift in clinical focus from addressing specific individual symptoms to managing multiple-related symptoms, known as symptom clusters, simultaneously (Xiao, 2010). Symptom clusters, such as pain-fatigue, fatigue-depression, and pain-fatigue-depression, significantly affect the quality of life of individuals with IA (Oh, Park & Seo, 2019). Given that fatigue, pain, stress, depression, and anxiety are the most reported symptoms of IA, the next section will discuss these clinical manifestations in more detail.

Clinical Manifestations

2.5.1.1 Physical signs, symptoms and their impact on daily activities

Signs of IA include joint swelling, erythema (redness), warmth, reduced mobility, fever, and cardiovascular complications (Adebajo & Dunkley, 2018; Dijkshoorn et al., 2022; Evers et al., 2014; Maisel et al., 2021; Polinski et al., 2021; Sturgeon et al., 2016; Zielinski et al., 2019). Swelling and erythema are visible indications of inflammation within the joints, while warmth is associated with the inflammatory process (Scott et al., 2020). Reduced mobility often results from pain and stiffness, which can significantly impact daily activities (Da Silva & Woolf, 2010; Dogu et al., 2013).

Symptoms of IA encompass joint pain, stiffness, fatigue, weight loss, stress, and loss of function (Evers et al., 2014; Goodacre & McArthur, 2013; Polinski et al., 2021; Sturgeon et al., 2016). Joint pain and stiffness, particularly in the morning, are common and can be debilitating, leading to significant functional impairments (Biddle & Sofat, 2020). Weight loss may occur due to chronic inflammation, and stress can result from the chronic nature

of the disease and its symptoms (Dijkshoorn et al., 2022). The loss of function is due to the combination of pain, stiffness, and fatigue, making it difficult for individuals to perform daily tasks and maintain an active lifestyle (Da Silva & Woolf, 2010; Dogu et al., 2013).

Fatigue is considered a debilitating symptom of IA, often described as extreme and persistent tiredness, weakness, or exhaustion that can be both mental and physical (Dures et al., 2020; Hernandez-Ronquillo et al., 2011). Qualitative explorations of fatigue describe it as a frustrating and overwhelming experience, often frequent, unpredictable, and resolving (Feldthusen et al., 2013; Hewlett et al., 2005; Nikolaus et al., 2009; Repping-Wuts et al., 2008). It is frequently reported as the most problematic symptom of IA, with prevalence rates ranging from 40% to 90% (Arends et al., 2017; Dures et al., 2020; Overman et al., 2016; Pilgaard et al., 2019; Pollard et al., 2006; Repping-Wuts et al., 2007). The multifactorial causes of fatigue in IA include inflammation, pain, anemia, poor sleep, and psychosocial and personal influences (Dures et al., 2020; Repping-Wuts et al., 2009). Multiple studies highlight a correlation between high disease activity and increased fatigue levels, emphasizing the interplay between disease severity and fatigue intensity (Morlà et al., 2022; Nikolaus et al., 2013; Rongen-van Dartel et al., 2014). High levels of fatigue are negatively associated with self-efficacy, physical function, swelling, and early morning stiffness (Zielinski et al., 2019). Fatigue is a subjective experience, and it often extends beyond physical symptoms, causing distress and disrupting daily lives, influencing the ability to engage in activities individuals enjoy and maintain usual routines (Cramp, 2019). Fatigue can make it difficult for individuals to engage in physical activities, maintain employment, and participate in social activities (Cramp, 2019). Persistent and unpredictable nature of fatigue also affects concentration, memory, and decision-making abilities, thereby impeding individuals' ability to perform tasks effectively and maintain usual routines (Dar et al., 2022; Dures et al., 2020). The unpredictability of fatigue can lead to frequent cancellations of plans and a sense of isolation, further exacerbating the psychological impact of the disease (Feldthusen et al., 2013; Repping-Wuts et al., 2007).

Pain is another prevalent symptom of IA that varies in intensity and duration (Firestein & Kelley, 2020). It is caused by inflammation within the joints, leading to discomfort, tenderness, and swelling (Biddle & Sofat, 2020). The persistence and severity of pain experienced by individuals with IA have been widely documented (Lee et al., 2018). This chronic pain is primarily attributed to persistent inflammation and joint damage (Smolen

et al., 2017). Approximately 40% of individuals with IA experience persistent pain (Rutter-Locher et al., 2023). Unlike the intermittent or fleeting nature of pain in some other conditions, pain in IA tends to be chronic and can vary in intensity (Salaffi et al., 2018). Pain in IA is often described as deep, aching, and persistent, affecting an individual's ability to perform everyday activities (Biddle & Sofat, 2020; Di Carlo et al., 2021; Louati & Berenbaum, 2015; Rutter-Locher et al., 2023; Salaffi et al., 2018). Understanding the multifactorial nature of pain in IA is fundamental to comprehending the complexity of this debilitating symptom (Biddle & Sofat, 2020). Whilst pain in IA is notably linked to inflammation, it's essential to acknowledge that pain can stem from various factors beyond inflammation alone. Pain in IA is a critical symptom with wide biopsychosocial implications (Salaffi et al., 2018), often arising from cognitive and emotional processes such as mood, attention, and cognitive factors (Biddle & Sofat, 2020; Li et al., 2012; Lopes et al., 2021; Overman et al., 2016). It is frequently associated with comorbidities including depression, anxiety, and fatigue, which exacerbate the burden on affected individuals (Matcham et al., 2013). Pain, in combination with fatigue, is an exhausting symptom of inflammatory arthritis, and together they increase the level of stress in the individual (Louati & Berenbaum, 2015; Oh et al., 2019). Persistent pain can limit mobility, impair sleep quality, and hinder daily activities, thereby diminishing overall well-being and productivity (Andersen et al., 2014; Fitzcharles et al., 2010; Salaffi et al., 2018). Pain in IA also significantly impacts quality of life, contributing to physical disability, functional impairment, and psychological distress (Lee & Weinblatt, 2001; Gossec et al., 2019). Therefore, it is important to accurately measure and assess pain for effective care (Gebke et al., 2023). Understanding the multifaceted dimensions of pain is pivotal for developing more effective interventions and improved management strategies (Busch et al., 2011; Crofford, 2015; Lee & Weinblatt, 2001).

2.5.1.2 Psychological signs and symptoms

The psychological impact of IA is significant, affecting individuals' mental well-being. Individuals with IA often experience not only physical challenges but also significant psychological issues including stress, negative mood, poor self-efficacy, maladaptive coping mechanisms, depression, and anxiety (Lwin et al., 2020; Matcham et al., 2013; Nagy et al., 2023). The burden of managing pain, functional limitations, and unpredictable disease symptoms exacerbates mental health issues, leading to increased rates of anxiety and depression and reducing overall quality of life (Covic et al., 2012; Lee et al., 2018; Margaretten et al., 2011). Psychological distress can stem from navigating ever-changing symptoms, social limitations, and the emotional toll of managing a chronic condition

(Dures et al., 2014). Research consistently shows that individuals with IA are at a higher risk of anxiety, depression, and cognitive impairment compared to the general population (Lwin, 2020).

Depression and Anxiety

Individuals with IA often experience depression and anxiety, with 20-40% of those with IA meeting the criteria for major depressive disorder, and 25-70% experiencing anxiety disorders (Covic et al., 2012; Kim et al., 2020; Matcham et al., 2013). Pain and fatigue exacerbate these conditions, creating a vicious cycle (Covic et al., 2012; Matcham et al., 2013). Pain in IA can cause feelings of hopelessness and helplessness, impacting mental well-being. Combined with fatigue, pain increases stress levels, necessitating simultaneous management of both symptoms (Louati & Berenbaum, 2015; Oh, Park & Seo, 2019). The correlation of fatigue with anxiety is influenced by disease duration and health status (Bernstein et al., 2019). This cyclical relationship between mental and physical health leads to increased psychological distress and reduced quality of life (Lee et al., 2018; Margaretten et al., 2011). This underscores the importance of considering both the cognitive and emotional dimensions of fatigue in IA (Dures et al., 2020).

Furthermore, social isolation is a significant issue for individuals with IA, as the physical and psychological symptoms can limit social interactions and activities (Bay et al., 2020). The chronic nature of IA often leads to social withdrawal, as individuals may feel unable to participate in social events or maintain relationships (Smith et al., 2019). This isolation can exacerbate feelings of loneliness and depression, further impacting mental health (Lwin et al., 2020).

Studies have also shown that negative perceptions of health and ability to function can lead to depression in individuals with IA (Rezaei et al., 2014; Sturgeon et al., 2016). IA patients with depression often have impaired coping strategies, reducing physical activity and social engagement (Katz & Yelin, 2001; Sturgeon et al., 2016). This decline escalates emotional distress and frustration, increasing the negative impact of symptoms of IA (Lwin et al., 2020). Untreated depression leads to heightened pain and fatigue, decreased physical capabilities, and social withdrawal (DiMatteo et al., 2000; Hider et al., 2009; Matcham et al., 2013). Addressing depression is crucial to improving IA outcomes and treatment effectiveness (Lwin et al., 2020).

Stress

Inflammation caused by IA disrupts the body's response to stress, impacting effective coping behaviours (Evers et al., 2014; Harth & Nielson, 2019; Matcham et al., 2018). Research indicates a bidirectional relationship between stress and IA: stress can trigger disease flares, while IA symptoms can elevate stress levels (Evers et al., 2014; Harth & Nielson, 2019). Consequently, stress management strategies have become integral components of comprehensive arthritis care, emphasizing the need to address psychological well-being alongside medical interventions (Evers et al., 2014; Matcham et al., 2018).

Despite substantial evidence for the impact of IA on mood, routine assessment of emotional well-being in clinical practice remains inadequate (Zhao et al., 2024). Physicians and patients often report anxiety and depression differently, leading to underdiagnosis and insufficient psychological support (Peterson et al., 2019). A national survey in England found that psychological support offered by rheumatology units was inadequate, citing a lack of clinic time and insufficient training for clinicians in identifying psychological distress (Dures et al., 2014). This gap emphasizes the need to integrate psychological health assessment and support into routine rheumatology care.

In conclusion, the interplay between the physical and psychological impact of IA may indicate the need for comprehensive management strategies (Husni et al., 2017). Addressing both the clinical and psychological manifestations of IA is crucial for improving quality of life and daily functioning for individuals living with IA (Hansen et al., 2022). Tailored interventions and supportive environments are therefore essential to help individuals with IA manage their symptoms, maintain participation in daily activities, and continue to engage in meaningful work (Ferwerda et al., 2017). Recognizing the multifaceted nature of IA and its far-reaching effects is the first step in providing holistic care necessary for individuals with IA to lead fulfilling lives (Rausch Osthoff et al., 2018). By understanding and addressing the complex interplay between physical symptoms and psychological distress, healthcare providers can develop more effective and comprehensive treatment plans for individuals with IA (Nichol & Zhang, 2005).

2.6 Comprehensive Management of Inflammatory Arthritis

The management and treatment of IA involve a comprehensive strategy that combines pharmacological and non-pharmacological approaches (Turk et al., 2023). Recent advancements in pharmacological treatments have significantly improved outcomes for individuals with various types of IA. Key pharmacological treatments include biologics,

disease-modifying anti-rheumatic drugs (DMARDs), nonsteroidal anti-inflammatory drugs (NSAIDs), and Janus Kinase (JAK) inhibitors. These therapies play a crucial role in alleviating symptoms and potentially modifying disease progression (Smolen et al., 2023).

Non-pharmacological treatments are equally vital in managing IA (Majnik et al., 2022). These interventions include but are not limited to physical and occupational therapy to strengthen muscles and optimize joint function, weight management to reduce strain on affected joints, and joint protection techniques to minimize stress during daily activities (Baker et al., 2023). Education on joint protection methods and the use of assistive devices further empower individuals to manage their condition effectively (Firestein et al., 2020). By combining pharmacological treatments with non-pharmacological approaches, individuals with IA can better control symptoms and enhance their overall well-being (Rausch Osthoff et al., 2018). This section will cover the spectrum of treatments, ranging from conventional DMARDs to biologic agents, NSAIDs, and newer JAK inhibitors, while emphasizing the importance of non-pharmacological interventions in managing IA.

2.6.1 Pharmacological Interventions

The management of IA has witnessed a paradigm shift with the advent of pharmacological interventions, which have revolutionized the treatment landscape (Jung & Kim, 2012). Over time, the progression of pharmacological treatments in IA has evolved significantly, offering diverse options to manage these conditions effectively. Initially, NSAIDs and corticosteroids provided primary symptom relief in IA however, presently, NSAIDs and corticosteroids remain recommended for short-term pain relief in early stages of IA (Adebajo & Dunkley, 2018). In long term, the introduction of DMARDs marked a pivotal shift by targeting the underlying disease process, reducing inflammation, and halting joint damage (Emery et al., 2018). Benefits of these drugs are seen at all stages of the disease, yet optimal results are achieved when they are used shortly after the onset of symptoms. (Wilsdon & Hill, 2017). Classified as conventional or biologic, DMARDs such as methotrexate and tumour necrosis factor (TNF) inhibitors have significantly improved disease-related and health outcomes (Burmester & Pope, 2017). Conventional DMARDs are usually the first course of treatment after diagnosis and biologic DMARDs are usually prescribed after the failure of conventional DMARD therapy where there is ongoing disease activity or clinical or radiographic disease progression. Biologic agents have advanced treatment goals, promoting disease remission and joint preservation (Nagy et

al., 2021). Additionally, the emergence of JAK inhibitors such as tofacitinib and baricitinib further diversifies therapeutic options, showing promise in moderate to severe cases (Smolen et al., 2020). These pharmacotherapies aim not only to alleviate symptoms but also to halt disease progression, marking significant progress in managing IA (Fraenkel et al., 2021; Singh et al., 2012; Smith et al., 2019).

2.6.2 Nonpharmacological Interventions for Inflammatory Arthritis

IA presents a complex challenge, requiring a comprehensive approach that extends beyond pharmacological interventions (Goodacre & McArthur, 2013). Living with IA impacts on all functional domains in an individual's life. While pharmaceutical therapies have significantly improved disease-related outcomes, many individuals with IA do not reach treatment goals. Healthcare professionals assist individuals in developing coping mechanisms to reduce the impact of IA on both their physical and mental health (Goodacre & McArthur, 2013). Consequently, best-practice clinical guidelines from the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR) now recommend non-pharmacological therapies along with pharmacological therapies (Dures et al., 2023; Fraenkel et al., 2021; Parodis et al., 2023; Smolen et al., 2023). Non-pharmacological therapies, including physical exercise, occupational therapy, and lifestyle modifications, have gained prominence in complementing conventional treatments, significantly contributing to the management of symptoms and overall well-being of individuals affected by IA (Kohara et al., 2004; Özdemir et al., 2013; Santos et al., 2019; Turk et al., 2023; Wang et al., 2008).

This holistic approach, moving from a disease-focused model of care to a biopsychosocial model, acknowledges the effects of illness on physical, psychological, and social functions, providing a more extensive spectrum of therapeutic interventions (Da Silva & Woolf, 2010; Keefe et al., 2002; Stanos, 2012; Nagy et al., 2023).

2.6.2.1 Interventions for Physical Symptoms

Physical activity and exercise regimens are crucial for improving joint function and reducing pain among arthritis patients (Gwinnutt et al., 2022; Kavuncu & Evcik, 2004). Strategies such as splints and joint protection techniques improve symptoms and overall well-being (Steultjens et al., 2004). Education on joint protection and use of assistive

devices aid in management of IA (Firestein et al., 2020). Dietary interventions can play a role in reducing inflammation and weight management to reduce strain on affected joints (Baker et al., 2023).

2.6.2.2 *Psychosocial Interventions*

Psychosocial interventions address complex symptoms such as fatigue, which are often not alleviated by pharmacological treatments alone (Almeida et al., 2016). Self-management programmes, cognitive-behavioural approaches, and lifestyle interventions are beneficial in managing these symptoms (Cramp et al., 2013; Hewlett et al., 2011). Mindfulness-based stress reduction techniques also empower individuals to manage their condition effectively (Druce et al., 2016).

2.6.2.3 *Self- Management*

Self-management of IA is a vital aspect of empowering individuals to take an active role in managing their condition and improving their quality of life (Nikiphorou et al., 2021). Effective self-management strategies allow individuals to address various aspects of their condition, reducing reliance on healthcare providers and enhancing long-term outcomes (Dineen-Griffin et al., 2019; Entwistle et al., 2018; Grady & Gough, 2014). These interventions include joint protection advice to minimize strain and prevent further joint damage, the use of assistive devices to aid in daily activities, and specific hand exercises to maintain dexterity and strength (Dziedzic & Hammond, 2010). Furthermore, fatigue management is essential, as it addresses the persistent exhaustion that often accompanies IA by teaching energy conservation techniques and pacing strategies. Pain and mood management are also crucial components, incorporating stress reduction and relaxation techniques, which are effective in alleviating discomfort and improving mental well-being (Baker et al., 2023; NICE, 2009; Tuntland et al., 2009).

By integrating pharmacological treatments with these non-pharmacological approaches, individuals with IA can achieve better control of symptoms and enhance their overall well-being, leading to improved outcomes and a more holistic management of their condition.

2.6.3 Effect of pharmacological interventions on non-pharmacological interventions

The interaction between pharmacological and non-pharmacological treatments in IA is well-documented, often working synergistically to manage symptoms and improve overall health (Dures et al., 2023; Fanouriakis et al., 2024; Parodis et al., 2023; Radu & Bungau, 2021; Smolen et al., 2023). Studies suggest that effective disease control through medications can enhance the benefits of non-pharmacological treatments such as physical therapy and exercise, improving overall disease management and quality of life (Smith et al., 2020; Cramp et al., 2019; Nadia et al., 2021).

However, pharmacological treatments often have limited effects on fatigue and employment, which requires addressing cognitive, behavioral, and personal factors for substantial relief (Almeida et al., 2016; Druce et al., 2016; Kirkeskov & Bray, 2023). Therefore, a multidimensional approach that combines both pharmacological and non-pharmacological treatments is recommended. This integrated strategy leads to better outcomes and holistic management of the condition, improving physical and mental health as well as personal impact such as employment (Kirkeskov & Bray, 2023).

Part 2: Effects of IA on employment

Living with IA affects all aspects of an individual's life, exerting a significant impact on physical, psychological, and occupational functioning (Hoving et al., 2014; Lacaille et al., 2008). Individuals with IA often leave paid employment prematurely due to a combination of factors stemming from the complexities of their disease and its impact on ability to work. Several studies identified key reasons contributing to early departure from the workforce among individuals dealing with IA. These include disease activity and symptom severity, functional impairments, psychosocial factors, workplace challenges and lack of work-specific accommodations (Bolu & Balta, 2015; Callhoff 2015; Katz et al., 2011; Madsen et al., 2021; Olofsson et al., 2014; Ropponen et al., 2014; Sokka et al., 2010; van Vilsteren et al., 2015; Verstappen et al. 2005; Wolfe et al., 2014). Workplace challenges, including the need for frequent breaks, inability to perform certain physical tasks, and the necessity for a flexible schedule, can exacerbate the psychological impact of the disease, leading to financial strain and feelings of inadequacy and frustration (Katz et al., 2020; Nordmark et al., 2006; Primdhal et al., 2019; Vergne-Salle et al., 2020).

2.7 Impact of Inflammatory Arthritis on work

Individuals with IA face unique demands and challenges in the workplace. Work demands and repetitive tasks can be particularly difficult due to functional limitations, fatigue, pain, and stress (Nordmark et al., 2006; Primdhal et al., 2019). Disease activity and symptom severity are crucial factors affecting an individual's work ability. Additionally, high disease activity and severe symptoms, such as pain, fatigue, joint stiffness, and functional limitations, also significantly impact workability (Berner et al., 2018; Nikiphorou et al., 2012). Research by Verstappen et al. (2005) demonstrated a strong association between disease severity and leaving paid employment among individuals with RA. This is consistent with other research findings indicating that higher disease activity is a significant predictor of early work cessation (Galloway et al., 2020). Functional limitations imposed by IA, such as reduced mobility and dexterity, can hinder job performance and limit individuals from fulfilling the demands of their roles effectively (Dogu et al., 2013; Fifulato et al., 2021). Individuals with IA report functional impairments such as muscle weakness and poor grip strength, which affect quality of life and are major factors influencing early exit from employment (Berner et al., 2018).

Fatigue is a debilitating and pervasive symptom that presents a substantial challenge at work for those with IA (Druce et al., 2018; Pope, 2020). Its multifaceted nature leads to decreased work productivity, increased absenteeism, and difficulties in maintaining focus and concentration during work hours (Chmielewski, 2023). An Irish study reported that individuals with arthritis described fatigue as the symptom that most significantly impacted their work (Connolly et al., 2015). This impact is evident across various work responsibilities, such as reviewing documents, attending meetings, lifting or carrying objects, and remembering passwords (Connolly et al., 2015; Connolly et al., 2016). Overman and colleagues (2016) demonstrated a significant association between fatigue severity and impaired work ability among individuals with RA, highlighting its negative effects on occupational functioning. De Croon et al. (2004) reported that individuals with fatigue were 24 times more likely to report low levels of workability compared to non-fatigued individuals. The unpredictable nature of fatigue further complicates work planning and performance, as individuals may experience fluctuations in energy levels throughout the day, hindering consistent engagement in job-related tasks (Feldthusen et al., 2013). Strategies such as pacing activities, incorporating rest breaks, and implementing workplace accommodations for flexible schedules play a crucial role in mitigating the impact of fatigue on work outcomes for individuals managing IA (Katz et al., 2020).

Pain associated with IA has also been consistently linked to decreased work productivity, with individuals reporting lower levels of productivity compared to those without IA (Gossec et al., 2019; Salaffi et al., 2018). It interferes with various work tasks, affecting individuals' ability to lift and carry objects, attend meetings, and maintain focus during work hours (Biddle & Sofat, 2020). This impact on workforce participation results in a significant proportion of individuals with IA experiencing challenges in sustaining employment (Bevan et al., 2009; Sokka, 2003). Pain-related absenteeism and presenteeism are prevalent among individuals with IA, contributing to work disability and increased rates of time away from work (Lee et al., 2018; Louati & Berenbaum, 2015; Vergne-Salle et al., 2020). Pain, in combination with fatigue, is an exhausting symptom of IA, and together they increase the level of stress in the individual (Louati & Berenbaum, 2015; Oh et al., 2019).

The cognitive impairments associated with IA, often resulting from fatigue and pain, include memory lapses and difficulties in maintaining focus during workplace discussions (Feldthusen et al., 2013). Psychological stressors—including frustration, anxiety, fear,

irritability, and depressive symptoms—are prevalent among this demographic and also impact their occupational experiences (Connolly et al., 2015; Connolly et al., 2016; Feldthusen et al., 2013; Goodacre & McArthur, 2013). Depression and anxiety are particularly common and play a significant role in the decision to leave paid employment for individuals with IA (Dures et al., 2017; Katz et al., 2011; Lwin et al., 2020). The unpredictable nature of IA, coupled with symptoms of pain, fatigue, and stiffness, often leads to emotional difficulties (Goodacre & McArthur, 2013). Chronic pain exacerbates stress, anxiety, and depression, further impairing cognitive skills crucial for job performance (Vergne-Salle et al., 2020). Psychological factors also heighten pain perception and reduce functional abilities in individuals with IA (Covic et al., 2012). These challenges contribute to uncertainties regarding future work capabilities and emotional distress caused by the limitations imposed by arthritis symptoms (Hoving et al., 2014). Research has also shown a strong correlation between self-esteem and perceived work capacity. Negative self-appraisals, diminished self-assurance, and feelings of professional inadequacy often predispose individuals to leave the workforce (Lacaille et al., 2007). To address these challenges, workplace accommodations tailored to mitigate pain-related difficulties—such as ergonomic adjustments, flexible work schedules, and access to assistive devices—are crucial for promoting optimal employment outcomes for individuals with IA (Busch et al., 2011; Crofford, 2015).

2.8 Impact of Workplace Challenges

Work participation holds paramount importance for individuals with IA, as it is often integral to their sense of identity and overall well-being (Madsen et al., 2021). For individuals with IA, limitations in carrying out work tasks can lead to various adverse outcomes, including decreased social activities, isolation, financial strain, emotional distress, and diminished self-esteem (Hoving et al., 2014). This is due to the fact that engaging in work has the capacity to enhance self-esteem, foster a sense of normalcy, and improve the overall quality of life (Kristiansen et al., 2012; Verstappen et al., 2015). Studies have shown that work loss and disability can result in lower mood, self-esteem, and a sense of identity loss (Barlow et al., 2001). Despite these challenges, many individuals with IA are willing to exert considerable effort to retain their jobs (Madsen et al., 2023).

Personal factors, such as coping styles, along with external factors, including working conditions, work accommodations, and the social insurance system, as well as disease-

related factors, such as disease and symptom severity, all significantly influence the decision to stop working (Hoving et al., 2014). Insufficient workplace accommodations, lack of understanding or support from employers, and challenges in adapting job roles to accommodate the needs of individuals with IA contribute to early exits from the workforce (Ching et al., 2022; Codd et al., 2023; Gignac et al., 2015; Wilkie et al., 2020). Studies have identified that many individuals with different types of arthritis, including IA, face a lack of support in the workplace (Hoving et al., 2014; De Croon et al., 2004). A Dutch study reported that a lack of co-worker support and insufficient understanding of the disease by colleagues were cited five times more often by individuals with RA who no longer worked (De Croon et al., 2004). Moreover, a systematic review by Hoving and colleagues (2014) investigating work participation in individuals with different types of arthritis including IA identified that co-workers understanding, and disclosure of arthritis were the two most important factors required to increase workability. They reported that the absence of understanding, and disclosure led to misconceptions and difficult interactions with colleagues highlighting the importance of effective communication between co-workers to provide insight into how colleagues can assist and understand the symptoms of IA. Effective communication and understanding among co-workers are essential for addressing these challenges and fostering a supportive work environment (Hoving et al., 2014).

2.9 Financial impact of Inflammatory Arthritis on work and healthcare

Reduced productivity and increased absenteeism in the workplace caused by IA lead to substantial financial challenges for society (Bechman et al., 2023; Burton et al., 2006; Filipovic et al., 2011; Madsen et al., 2021; Safiri et al., 2019; Verstappen, 2015). The primary reason for these financial challenges is that work disability in individuals with IA is a multidimensional concept encompassing reduced employment hours, loss of promotion prospects, increased sick leave, changes in employment type, and early retirement (Allaire et al., 2003; Barrett et al., 2000; Connolly et al., 2015).

In Ireland, the Health Services Executive (HSE) has reported rheumatic diseases such as IA as the single greatest socioeconomic cost of any disease group (HSE, 2018). Due to symptoms of IA absenteeism and work disability has been shown to cause a loss of seven million working days in Ireland (Bevan, 2015). Therefore, this has resulted in a 750-million-euro cost to the Irish economy (Bevan et al., 2009). It is anticipated that the

number of individuals effected by IAs will increase dramatically due to an increase in the aging population costing the Irish health care system an estimated amount of €13.6 million annually (Doherty & O'Neill, 2013). It is estimated that for individuals with RA alone, the cost of productive time lost is €1.6 billion in Ireland (Arthritis Ireland, 2008).

Although the current academic landscape lacks substantial literature addressing cost related to all IAs in Ireland, literature on RA shows an estimated governmental expenditure of €19,596 per person per year to the government, causing an overall economic cost of approximately €544 million (Priyadarshini & Kenny, 2023). In terms of personal cost, Priyadarshini & Kenny (2023) identified that in Ireland, newly diagnosed individuals and individuals with advanced RA spend more time with health care practitioners. This costs the individual more financial burden in terms of taking time off from work, travelling to and from the clinics and increased medical expenses (Priyadarshini & Kenny, 2023). The most significant impact on the total costs among individuals with RA was determined by whether the patient was on a csDMARD or bDMARD (Priyadarshini & Kenny, 2023). Individuals with IA incur additional expenses associated with comorbidities involving both physical and mental health issues (An et al., 2019; Priyadarshini & Kenny, 2023).

The economic ramifications of IA extend across both workplace productivity and healthcare systems. This is evident in heightened absenteeism and diminished productivity in the workplace, alongside substantial healthcare expenditures (Bechman et al., 2023; Safiri et al., 2019). Conversely, a holistic management approach integrates pharmacological interventions, such as biologics, with non-pharmacological strategies such as physical therapy and joint protection methods (Turk et al., 2023). These combined efforts aim to alleviate symptoms, enhance mobility, and reduce the economic burden of IA on individuals and society.

Addressing the challenges associated with navigating the professional landscape for individuals with IA requires comprehensive workplace accommodations (Bech et al., 2020). These may include ergonomic adjustments, flexible scheduling, and personalized strategies to balance work demands and manage symptoms effectively (Hammond et al., 2017; Katz et al., 2018; van Slingerland et al., 2022). Achieving optimal work performance necessitates a holistic approach that integrates medical support, workplace accommodations, and understanding from both peers and employers (Summers et al., 2014; Tompa et al., 2015). Studies have highlighted the critical role of employer

awareness and support in creating an inclusive work environment for individuals with arthritis (Arthritis Foundation, 2020). Lack of support in the workplace, particularly from co-workers, can exacerbate challenges for individuals with IA. Findings of a survey conducted by the Arthritis Foundation (2020) emphasized the need for enhanced communication between employees and employers to address specific job-related challenges. Work-based interventions, therefore, that focus on preventing and reducing work disability are crucial for supporting continued employment for individuals with IA (Prior et al., 2015).

2.10 Work based interventions for individuals with IA

Work-based rehabilitation interventions focussing on reducing presenteeism, and work cessation have shown significant results suggesting that some strategies such as job accommodations, ergonomic and vocational counselling may help individuals to stay in work (Hammond et al., 2017; Keysor et al., 2018). However, vocational rehabilitation is often complex and can encompass a variety of components (Madsen et al., 2021). For example, fatigue management is a vital component of a work-based rehabilitation intervention because work demands and repetitive tasks are often challenging for people with IA due to physical limitations resulting from pain and fatigue (Connolly et al., 2016; Druce et al., 2018). However, many interventions do not address fatigue specifically and therefore may not include work-specific fatigue management strategies. Furthermore, the majority of these interventions are mainly individually delivered but some individuals with IA reported a preference for group-based interventions to support ability to manage demands of work (Connolly et al., 2015 and 2016).

A Cochrane review conducted by Hoving, and colleagues (2014) and a systematic review conducted by Madsen and colleagues (2021) assessed the effectiveness of non-pharmacological interventions to prevent job loss, work absenteeism or improve work functioning for employees with IA. The results indicated although further good-quality RCTs are required, job loss prevention interventions may have an effect on work ability, absenteeism and in particular job loss among persons with IA. These interventions focus on the person and the work setting while teaching alternate ways of accomplishing work tasks and possible adaptations to work settings (Désiron et al., 2011). Studies indicated that these strategies may increase work ability and improve participation in work for

people living with IA (Holland & Collins, 2018; Kristiansen et al., 2012; Nordmark et al., 2006).

A number of vocational rehabilitation (VR) interventions have been developed and tested over the past 20 years (Table 2.1). These interventions collectively contribute to a growing body of knowledge on effective management strategies for working individuals with IA, emphasizing the importance of tailored approaches, multidisciplinary collaboration, and ongoing research to refine and enhance interventions. The literature on work-focused interventions for individuals with IA encompasses a broad range of approaches, including VR programmes, occupational therapy interventions, and more comprehensive, multi-component programmes that integrate online and in-person elements (Table 2.1). These interventions, primarily assessed through RCTs, target various aspects of work retention, job performance, and overall well-being showing varying degrees of effectiveness. VR interventions, as highlighted in studies by Allaire et al. (2003) and Hammond et al. (2017), show promise in delaying job loss and enhancing work outcomes by providing tailored support such as job accommodations, vocational counselling, and self-advocacy training. Similarly, Macedo et al. (2009) demonstrated that individualized occupational therapy-led interventions significantly improve functional and work outcomes, emphasizing the importance of personalized care. However, multidisciplinary approaches, such as those explored by De Buck et al. (2005) and van Vilsteren et al. (2017), although comprehensive, yielded mixed results with some benefits in fatigue and emotional status but limited impact on job retention and productivity. Feasibility studies, such as those conducted by Hammond et al. (2017, 2020) and Madsen et al. (2023), underscore the importance of practical implementation, noting challenges in maintaining participant engagement and the complexities of personalized intervention plans. Additionally, multi-component programmes such as the “*Making it Work*” intervention (Luquini et al., 2020) suggest that integrated approaches, combining online and in-person elements, can effectively improve work participation, though these interventions are often labour-intensive and require significant participant commitment. Overall, while work-focused interventions for IA can be effective, particularly when they are personalized and multidisciplinary, their success depends on factors such as the intensity and duration of the intervention, coordination among healthcare professionals, and the specific needs of the individuals. Further research is needed to refine these interventions, ensure their scalability, and assess their long-term impact across diverse IA populations.

Detailed explanations of each intervention are presented and provided in the two sections below. The first section discusses individual work-focused interventions, which are delivered on a one-on-one basis. The second section covers mixed work-based interventions, which combine group and individual components.

2.10.1 Individual work focused interventions for individuals with IA

1. A United States based vocational rehabilitation intervention focusing on reducing both temporary and permanent job loss was evaluated by Allaire and colleagues (2003). Participants (n=152) recruited were employed individuals with different types of arthritis including IA and aged between 18 and 65 years. The study employed an RCT design with a follow-up period of 48 months. Recruited participants were randomly assigned to either the experimental group or the control group wherein the experimental group received two, 1.5-hour individual sessions of vocational rehabilitation. The intervention consisted of three components: (i) job accommodations, (ii) vocational counselling and guidance, (iii) education and self-advocacy. The control group received leaflets regarding disability employment issues and resources through mail. For Allaire and colleagues (2003) the primary outcome under investigation was the time of first job loss following recruitment to the study, defined as permanent disability, premature retirement, or a period of unemployment. The findings of the study indicated that vocational rehabilitation, when provided to individuals who were still employed, experienced a statistically significant delay in job loss compared to the control group. Participants in the intervention group exhibited a statistically significant lower risk of job loss than the control group. Therefore, it was concluded that the intervention was successful in reducing the incidence of permanent and temporary job losses. However, the study had several limitations. The intervention was brief, consisting of only two 1.5-hour sessions, which may have limited its long-term effectiveness. The study's generalizability is also constrained by its focus on a single geographic region. Additionally, the study did not account for the potential impact of varying economic conditions on job loss and retention outcomes.

Table 2-1 Work related interventions for individuals with IA and other arthritis types

Study	Country	Study Design	Participants and Type of IA	Outcome Measures	Intervention	Findings
1 Allaire et al. (2003)	USA	RCT	Employed with mixed arthritis (n=152)	Time to First Job Loss, Time to Permanent Job Loss, Count of Job Loss Events	Intervention group: two 1.5-hour individual sessions of VR: job accommodation, vocational counselling and guidance, education, and self-advocacy. Control group: received employment-related informational leaflets.	Statistical analysis showed that VR significantly delayed job loss compared to the control group. Participants in VR group had a lower risk of job loss.
2 De Buck et al. (2005)	Netherlands	RCT	Employed with mixed arthritis (n=140)	* ¹ Job satisfaction VAS, Hospital Anxiety and Depression Scale (HADS), Health Assessment Questionnaire (HAQ), RAND 36	Intervention group: job-retention VR programme: assessment and guidance from a multidisciplinary Control group: received usual care	VR improved fatigue and emotional status but did not reduce job loss risk compared to usual care.
3 Macedo et al. (2009)	UK	RCT	Employed with RA (n=32)	COPM, HAQ, RA WIS, AHI, AIMS2, DAS28, * ² Modified Health Economics Questionnaire, EQ-5D * ³ work satisfaction, work	Individualized vocational intervention: 6-8 sessions over 6 months based on the COPM. Comprehensive OT intervention. Control group: received usual care.	OT group showed significant improvements in functional and work outcomes, performance and satisfaction compared to usual care.

					performance (VAS), * ⁴ fatigue		
4	van Vilsteren et al. (2017)	Netherlands	RCT	Employed with RA (n=150)	WLQ, RAND 36, * ⁵ pain and fatigue VAS, RA WIS	Intervention group: received <i>Care for Work</i> intervention, integrated care and participatory workplace intervention delivered by a multidisciplinary team Control group: received usual care.	No significant effects observed; future research suggested for groups with severe limitations and unstable work situations.
5	Hammond et al. (2017)	UK	Feasibility RCT	Employed with IA (n=55)	RA WIS, WALS, WLQ, * ⁶ Work self-efficacy, SF- 12v2, HAQ, EQ5D, * ⁷ Hand/ wrist pain, * ⁸ health economic outcomes, * ⁹ Time to temporary or permanent job loss (days) and absenteeism	Intervention group: received the <i>WORK-IA</i> intervention plus work self-help information. Includes up to 4.5 hours of 1:1 VR meetings, work site visits, self-management strategies, job accommodations, and employment rights information. Control group: Work self-help information and usual care.	VR was credible, acceptable, and deliverable, with potential benefits including reduced job loss risk and improved work outcomes.
6	Keysor et al. (2018)	USA	RCT	Employed with mixed arthritis (n=287)	WLQ, * ¹⁰ HPQ	Intervention group: received the <i>Work-It</i> intervention, 1.5-hour meeting with a trained rehabilitation therapist, two follow-	Reduced work loss, but no significant impact on work limitations.

					up telephone calls at 3 weeks and 3 months, use of the WES-RC to assess and address work barriers, provision of written resource materials.	
					Control group: received written resource materials on employment retention.	
7	Hammond et al. 2020	UK	RCT	Employed with IA (n=240)	WLQ-25, WALS, work instability, additional presenteeism measures, work status, absenteeism and work self-efficacy, health outcomes Intervention group: received <i>WORKWELL</i> intervention; up to four 1-hour face-to-face meetings and a 30-minute telephone review after six weeks to monitor progress Control group: self-help written work advice pack	No results published
8	Luquini et al. (2021)	Canada	RCT	Employed with IA (n=564)	Number of sick days, work interruptions and the combined outcome of both, RADAI, HAQ Intervention group: received <i>Making it Work</i> intervention; 3 components: 5 self-directed web-based modules, online group sessions with trained facilitator, online consultations with OT and vocational counsellor. Control group: received written information on work and arthritis.	Effective in improving presenteeism and preventing short-term work cessation.

9						
Madsen et al. (2023)	Denmark	Feasibility Study	Employed with RA, axSpA, or PsA (n=20)	WPAI, WAI, OBQ, EQ-5D-5L, BRAF, WHO-5	Intervention group: received <i>WORK-ON</i> intervention; 6 months with 9-18 meetings depending on needs. 3 group sessions, 2.5 hours each, 2-hour individual counselling initial assessment and goal-setting by OT.	Feasibility study ongoing, no results published.

*¹Horizontal 10-cm visual analog scale (VAS)

*²A self-developed Modified Health Economics Questionnaire combined measures of presenteeism and absenteeism.

*³ 100-mm work performance and work satisfaction VAS score in the past week,

*⁴ fatigue measured on an ordinal scale (where 0 = none, 1 = mild, 2 = moderate, and 3 = severe)

*⁵ VAS scales ranged from 0 to 10, with 0 meaning no pain/fatigue at all, and 10 meaning a lot of pain/very tired.

*⁶ confidence in ability to continue working with arthritis; and ability to manage arthritis at work (0–10 numeric rating scales

*⁷ pain in the last week during moderate activity (100 mm VAS)

*⁸ A self-report measure was resource use questionnaire (use of health resources, health-related transport costs, personal and domestic care support, work support and adaptations).

*⁹ Monthly tear-off calendar, to record their work status each day (i.e. performed paid work, unable to perform paid work due to arthritis, unable to perform paid work due to other reasons, day off).

*¹⁰ World Health Organization Health and Work Performance Questionnaire, Presenteeism subscale (HPQ)

2. In another randomized controlled trial, De Buck and colleagues (2005) compared a multidisciplinary job-retention VR programme with usual outpatient care (UC) in individuals with different types of arthritis including IA at risk of job loss. Participants (n=140) were from outpatient rheumatology departments in the Netherlands. Eligible participants were in employment and aged between 18 and 63 years. Random allocation placed participants into either the VR group or the UC group. The VR programme involved a tailored assessment, education, vocational counselling, guidance, and medical or non-medical treatment from a multidisciplinary team comprising a rheumatologist, social worker, physical therapist, occupational therapist, and psychologist. The assessment addressed disease activity, limitations on functional abilities prognosis, education, and systematic registration of work-related challenges. The intervention's duration varied between 4 and 12 weeks. Patients in the UC group received care initiated by their rheumatologist, supplemented with written information. Outcome measures encompassed job loss, job satisfaction, pain, functional status, emotional status, and quality of life. The trial found no significant difference in job loss between the VR and UC groups over 24 months, however individuals in the VR group exhibited significantly greater improvements in fatigue and emotional status compared to the UC group. The results of the study led to the conclusion that while the job-retention VR programme did not reduce the risk of job loss, it effectively improved fatigue and mental health in patients with chronic rheumatic diseases at risk of job loss. However, the primary outcome of job loss prevention showed no significant difference between the intervention and control groups, limiting the programme's effectiveness. A high dropout rate reduced the study's statistical power and may have led to the loss of important data. Additionally, potential bias may have arose because the control group participants' rheumatologists were aware of their work-related issues and treatment allocation, which could have influenced the care provided and diluted the effects of the intervention. The study also included many individuals already on long-term sick leave, possibly reducing the programme's impact as these individuals were already at high risk of job loss.

3. Macedo and colleagues (2009) developed an individualized occupational therapy-led vocational intervention for individuals with RA in the United Kingdom. In this study, employed participants (n=32) were invited to participate if their scores on RA Work Instability Scale (RA WIS) were ≥ 10 , indicating medium to high work disability risk. These individuals were randomly allocated in equal numbers into two groups: one receiving comprehensive occupational therapy alongside usual care, and the other

receiving usual care alone. The intervention group received a 6-month comprehensive occupational therapy-led vocational intervention that incorporated a biopsychosocial model based on the Canadian Occupational Performance Measure (COPM) (Law et al., 1990). This involved individualized assessments of the individual's medical history, work, function, and psychosocial aspects, leading to the formulation of a personalized treatment plan spanning six to eight sessions. Sessions, conducted in various settings including rheumatology or occupational therapy departments, the home, or the workplace of the individual, ranged from 30 minutes to 2 hours, with work visits requiring the most time. Interventions covered a wide array of topics, such as education on RA, medication management, self-advocacy, workplace rights, ergonomics, discussions with employers, posture advice, pacing, stress management, assertiveness, sleep hygiene, exercises, footwear, splinting, and assertive communication. Referrals to multidisciplinary team members and community services were made as necessary. In contrast, the control group received the usual care group and routine reviews by their rheumatologists.

The study measured four main outcomes: functional status, work productivity, coping, and disease activity. Outcomes were measured at recruitment and six months after the completion of intervention. The intervention group exhibited significantly greater improvements in functional and work outcomes, including COPM, Health Assessment Questionnaire, and RA WIS, compared to the usual care group at the 6-month follow-up. In the intervention group, significant improvements were also reported in coping with RA and RA disease activity. Despite the positive results, the study's small sample size ($n=32$) limits its generalizability. Furthermore, this intervention is specifically designed for RA, and generalizing it to other types of IA poses several challenges. RA and different types of IA encompass different disease manifestations, pathologies, and patient experiences, making a one-size-fits-all approach ineffective. Furthermore, the small sample size, with only 32 participants, restricts the generalizability of the results and reduces the statistical power to detect significant differences between the intervention and control groups. Additionally, the study was conducted at a single centre, limiting the applicability of the findings to other settings or populations with different healthcare systems or demographic characteristics. These limitations suggest that while the study offers valuable insights into the benefits of occupational therapy for patients with RA, further research with larger sample sizes and in multiple centres is needed to validate these findings.

4. The “*Care for Work*” study adopted an RCT design to test the effectiveness of integrated care and participatory workplace intervention on work productivity, pain,

fatigue, and quality of life in workers with RA compared to usual care (van Vilsteren et al., 2017). One hundred and fifty employed individuals with RA were recruited and randomized into either the intervention group or the control group. The intervention group received the *Care for Work* intervention which consisted of two components: integrated care delivered by a multidisciplinary team, (an occupational physician, an occupational therapist, and rheumatologists), and a workplace intervention. Integrated care consisted of identifying functional limitations, and related barriers, at work for which the care manager proposed a treatment plan to the multidisciplinary team. At six and 12 weeks, the care manager and participant evaluated possible adjustment needed to the proposed plan. The participatory workplace intervention involved an active collaboration between the occupational therapist, the participant, and the work-based supervisor to identify and agree on workplace adaptations to overcome functional work-related barriers. The control group received usual care. Outcome measures included work, pain, fatigue, and quality of life and were collected at baseline, six and 12 months. No significant effects were observed on at-work productivity loss or secondary outcomes at six or 12 months follow up. The study suggested that future research should focus on investigating the intervention in individuals with severe limitations in work functioning and an unstable work situation. Additionally, van Vilsteren and colleagues (2017) reported that ongoing research is crucial to determine the most accurate method for measuring at-work productivity loss to enhance comparability between interventions. The study supports the need for continued efforts in understanding and improving interventions for employed individuals with RA. The findings suggest that the intervention may not be sufficient for broader implementation without further modifications. Furthermore, *Care for Work* intervention is tailored specifically for RA, presenting similar challenges for generalization as those noted for the intervention developed by Macedo et al. (2009).

5. “*WORK-IA*” is an individualized VR intervention provided by occupational therapists for individuals with RA, PsA or undifferentiated IA (Hammond et al., 2017). This feasibility RCT assessed the acceptability of job retention VR compared to written advice on work-related issues. Participants were randomly assigned to either the intervention group, which received the VR programme, or the control group, which received work-focused self-help information and usual care from their rheumatologists. The VR program involved comprehensive assessments, including a structured work interview, job discussion, and a detailed assessment of work barriers. Based on these assessments, a personalized treatment plan was developed including self-management strategies, job accommodations, and employment rights information. Discussions with employers, role-

playing in requesting accommodations, and optional work site visits were also included. The VR sessions were delivered to participants over two to four months, with each session lasting 30 minutes to two hours, totalling up to six hours of contact time. Outcome measures were collected at baseline, six months, and nine months, focusing on function, work productivity, coping, and disease activity. The findings indicated that job retention VR was credible, acceptable, and deliverable, showing potential benefits such as reduced risk of job loss, improved productivity, confidence in managing arthritis at work, physical ability, pain, and perceived health. VR group showed statistically significant improvements compared to written advice group in reducing presenteeism, absenteeism, and perceived risk of job loss, while also enhancing pain, fatigue and mental health status. However, as a feasibility study, the findings are preliminary and require validation through studies that are larger. The intervention's delivery remains as an area for further investigation. Additionally, the written advice on work-related issues lacks clarity and specificity regarding its content, raising questions about its feasibility. The study faced several limitations that may have influenced its outcomes. Variability in intervention delivery, due to the individualized nature of the VR, made it challenging to standardize the approach, potentially affecting consistency across participants. Some participants were reluctant to disclose their condition to employers, limiting the effectiveness of certain intervention components like workplace visits. Additionally, the study encountered challenges related to limited time and resources, including delays in research approvals and inconsistent facilitator availability, which reduced the recruitment period. Recruitment and retention were also significant obstacles, with low enrolment and difficulties in maintaining participant engagement, potentially impacting the study's generalizability and statistical power.

7. Following the feasibility study, Hammond and colleagues (2020) developed the "*WORKWELL*" intervention, building on the promising results of the *WORK-IA* programme, which showed potential in reducing presenteeism and job loss while improving confidence in managing IA at work. *WORKWELL* was designed to be more robust and scalable within the National Health Service (NHS), incorporating comprehensive assessments, personalized treatment plans, and a structured framework for job accommodations and self-management. The programme includes up to four face-to-face meetings, a follow-up call, and additional time for complex cases or workplace visits, totalling up to 6.5 hours per participant. The primary endpoint is presenteeism, with secondary outcomes assessed at 6 and 12 months. The intervention's complexity, including extensive assessments and individualized plans, presents logistical challenges,

especially during the COVID-19 pandemic, which required adaptations such as remote delivery. Results from the WORKWELL study have not yet been published

6. The "*Work It Study*" was conducted in Massachusetts, United States (Keysor et al., 2018). This study aimed to assess whether physiotherapists could effectively reduce work limitations and work loss among people with rheumatic and musculoskeletal conditions aged 21-65 years. The primary objective was to compare work limitations over two years between those receiving the intervention and those receiving printed employment resources. Participants were randomly assigned to either the intervention or control group. The intervention group received a 1.5-hour meeting with a trained rehabilitation therapist, followed by two telephone calls at three and 12 weeks after the initial meeting. The therapists used the Work Experience Survey for Rheumatic Conditions (WES-RC) to assess work barriers and suggest solutions, providing participants with written resource materials, including information about employment retention organizations, disability and employment legal resources, local vocational rehabilitation programs, and chronic disease management websites. The control group received the same written resource materials by mail.

The primary outcome measure was the Work Limitations Questionnaire (WLQ). Secondary outcomes included employment status and absenteeism. Participants were also interviewed at baseline, 6 months, 12 months, and 24 months. No significant difference in work limitations was observed between the groups over the 24-month study period. However, the intervention did result in a statistically significant reduction in work loss. The findings suggest that while the intervention did not significantly improve work limitations, it effectively reduced work loss, indicating its potential effectiveness in preventing job loss among at-risk populations. However, because the intervention was not tailored to IA specifically but addressed a range of rheumatic and musculoskeletal conditions, it raises concerns about its applicability to more targeted populations, potentially limiting its effectiveness. Additionally, the generic and unclear written advice, resembling pamphlets without actionable strategies, and the limited contact time with therapists might reduce the intervention's practical impact and effectiveness in addressing specific work-related challenges faced by individuals with IA. Therefore, these aspects need to be considered when applying or designing future interventions.

2.10.2 Multiple component work-base interventions for individuals with IA

A Canadian "*Making it Work*" intervention was developed to prevent work disability and help individuals with IA with work difficulties (Luquini et al., 2020). Participants were

recruited (n=564) across three Canadian provinces. Eligible participants, diagnosed with IA, employed, aged 18-59, and concerned about ability to work were randomized into intervention group or the usual care. The intervention group received the *Making it Work* programme, which consisted of three components: (i) five web-based e-learning modules on topics related to work and arthritis. These modules included a combination of text, artwork, audio recordings, video clips, self-learning activities, and animations to provide knowledge and demonstrate skills and techniques for work-related issues. (ii) participants engaged in five bi-weekly online video group sessions conducted as real-time meetings with a trained facilitator. During these sessions, they share work and day to day life related experiences, discuss problems and strategies, report progress, and practice techniques shown in the modules. (iii) participants meet individually with an occupational therapist and a vocational rehabilitation counsellor (VRC) to determine necessary changes that should be made to their work and develop an individualized plan to implement these changes. Individuals allocated to the usual care group received written information on work and arthritis. Participants in both groups were required to complete a set of questionnaires every six months for five years. The questionnaires included the RA-WIS, demographics and work cessation 2 months or more. The results of this RCT revealed that the *Making-it-Work* programme was effective in improving presenteeism and preventing short term work cessation over a two-year period (Luquini et al., 2020). However, the "*Making-it-Work*" intervention may have encountered potential challenges related to participants' ability to balance the demands of the study with their existing work responsibilities. Given that the participants were employed and already concerned about retaining their jobs, managing the added demands of a long, multi-component intervention may have posed significant challenges. This dual burden could have hindered their full engagement, potentially limiting the intervention's overall effectiveness. Furthermore, the complexity and duration of the intervention may have been overwhelming for some participants, contributing to variability in how effectively they were able to apply the strategies and benefit from the programme. These challenges might have led to inconsistencies in participants' engagement, which could, in turn, have influenced the study's outcomes.

To the author's knowledge, *Making-it-Work* intervention is the only intervention with a group component that has been tested for effectiveness.

9. In Denmark, Madsen and colleagues (2023) have developed another intervention with a group component called the *WORK-ON* intervention. The intervention consists of four components:

1. An individual two-hour assessment and goal-setting component with an occupational therapist experienced in rheumatology
2. Ongoing support for six months, helping with healthcare navigation, professional coordination, and work-related issues, including consultations and employer meetings as needed.
3. Three two-hour peer support group sessions delivered over two months. The sessions include:
 - Session 1: Legislative initiatives related to compensatory schemes and flexible job opportunities, presented by a social worker.
 - Session 2: Acceptance of the disease in relation to work, led by an experienced rheumatology nurse, focusing on dealing with lack of understanding in the workplace and sharing experiences.
 - Session 3: Coping strategies for energy management and balancing work with everyday life, led by an occupational therapist.
4. Individually tailored consultations with healthcare professionals such as physiotherapists, nurses, or social workers.

A feasibility study for *WORK-ON* is underway however, no results have been published as yet (Madsen et al., 2023).

2.11 Conclusion

Despite the known challenges as outlined throughout this chapter, there is a lack of evidence-based intervention to support individuals with IA and fatigue to remain at work. Furthermore, although research has stressed the importance of promoting self-management strategies for maintaining work employment for individuals with IAs, no evidence-based work focused self-management education interventions were identified in Ireland. As discussed above, IA has a significant economic toll on the Irish health system and considering that approximately 2% of the Irish population is affected by IA, the importance of such interventions within the Irish healthcare are evident.

Interventions discussed in Section 2.10 aimed at retaining employment and preventing work loss for people with IA. However, these interventions face several challenges. Allaire et al. (2003) showed vocational rehabilitation delayed job loss but relied on self-reported measures and a short intervention period. De Buck et al. (2005) improved fatigue and emotional status but had no significant job loss reduction and potential biases. Macedo et al. (2009) showed improvements but had a small sample size and was RA-specific. Van Vilsteren et al. (2016) found no significant productivity loss effects and faced variability and RA-specific challenges. Hammond et al. (2017, 2020) showed potential but required validation and faced logistical challenges. Keysor et al. (2018) reduced work loss but had non-specific focus, unclear advice, lack of peer support, and widely spaced follow-up calls. Luquini et al. (2021) showed effectiveness but required significant time management, impacting follow-up and participation rates. Developing streamlined strategies is crucial for improving engagement and sustainability. However, replicating these interventions in the Irish system poses further challenges due to differing social security and health systems. It is crucial to develop culturally relevant programmes tailored to the Irish context for successful implementation (Madsen et al., 2023). In addition, research has shown the importance of group-based interventions and the most of the current vocational rehabilitation interventions lack the group component (Connolly et al., 2015; Ezhumalai et al., 2018; Madsen et al., 2023; Salmon et al., 2019.). Therefore, to address an important and costly problem for Irish health system FAME-W intervention was developed. The following chapter outlines the feasibility study of FAME-W's need, methodology, findings and discussion.

CHAPTER 3: FEASIBILITY AND ACCEPTABILITY OF ONLINE DELIVERY AND SELF- GUIDED WORKBOOK OF FAME-W

3.1 Introduction

FAME-W was originally designed for in-person delivery to support work-focused self-management for individuals with Inflammatory Arthritis (IA). However, the COVID-19 pandemic necessitated a shift to online delivery for the majority of healthcare and rehabilitation services in order to adhere to public health safety measures. While the literature supports the effectiveness of online delivery in similar contexts (Du et al., 2020; Knudsen et al., 2024), it was uncertain whether this would hold true for FAME-W, making it necessary to conduct a second feasibility study to evaluate its acceptability in this new format.

According to MRC framework, developing and evaluating a complex health intervention is not a linear process (Skivington et al., 2021). A research programme could commence at any stage, contingent upon the uncertainties surrounding the core elements of the intervention. Opting for repeating phases is preferred over automatic progression if uncertainties remain unresolved (Skivington et al., 2021).

Previous qualitative findings from a feasibility study of in-person delivery of FAME-W identified the utility of the accompanying handbook in helping participants manage fatigue and effectively apply fatigue management strategies (McCormack et al., 2018). Participants suggested an option for a self-directed handbook that they could use independently. Building on this finding, a self-guided FAME-W workbook was developed to mirror the intervention's core content and support weekly goal setting.

Therefore, the purpose of this study was to test the feasibility and acceptability of online delivery and the self-guided workbook of FAME-W as a work-focused self-management intervention.

The study objectives were:

1. Establish the feasibility of an online delivery format of FAME-W
2. Explore the transferability of FAME-W content from in-person to online delivery
3. Examine the feasibility of a self-guided workbook of FAME-W
4. Determine the feasibility of a comparative RCT intervention study

Therefore, this chapter details the modifications made to the FAME-W intervention and the methods used in the feasibility study. It includes an overview of the study design, recruitment and randomization processes, as well as data collection and analysis methods. The findings, both qualitative and quantitative, are then presented, followed by a discussion that interprets and analyses these results.

Methods

3.2 Modes of Delivery

FAME-W is delivered through two distinct methods: an online platform and a self-guided workbook. Details of both delivery methods are discussed in this section.

3.2.1 Online Delivery of FAME-W

In response to the COVID-19 pandemic, the FAME-W intervention—originally designed for face-to-face delivery—has been adapted to an online group format, supplemented by a comprehensive programme handbook. This adaptation involved reducing the content delivered during each weekly session, with the omitted material incorporated into the handbook to ensure a complete learning experience. Table 3.1 summarizes the online delivery as evaluated in this study.

Table 3-1 Finalised FAME-W intervention for both delivery methods

	Online FAME-W	Self-guided FAME-W
Theory	Self-efficacy theory	
Format	Group-based	Self-guided
Mode of Delivery	Online via Zoom	Physical workbook
Content	Educational and goal setting components	
Facilitators	Occupational Therapists	Self-guided
Educational Component	Week 1: Fatigue management Week 2: Pain management, joint protection and ergonomics Week 3: Mental wellbeing Week 4: Effective communication and employment legislation	
Goal Setting Component	Weekly goal setting and review	
Resources	Participant handbook	Self-guided workbook

The online format maintains the group-based structure of the original FAME-W intervention, consisting of four weekly sessions conducted via the Zoom video conferencing platform. Sessions are scheduled at times convenient for the majority of participants, typically in the evening or late afternoon to accommodate work schedules, with multiple time slots offered to enhance accessibility.

Each session is structured as follows:

Part One: Weekly Topics (45 minutes)

The first half of each session is dedicated to educational content on symptom management and information sharing related to the weekly topics.

Comfort Break (5 minutes)

A brief intermission allows participants to rest before continuing with the session.

Part Two: Goal Setting and Review (40 minutes)

The second half focuses on individual goal setting and progress review, engaging participants in discussions and activities that promote self-management skills.

Part one: Weekly Topics

The educational component takes place during the first half of each session. The facilitator discusses the weekly educational topic and uses visual aids such as slide show presentations (copy of the slides is presented in Appendix B) alongside the programme handbook to facilitate learning. Content of the online delivery of FAME-W is presented in Table 3.2.

Modifications

Adapting FAME-W to an online format necessitated several modifications to the original in-person intervention. The duration of the weekly sessions was reduced from 2.5 hours to 1.5 hours, aligning with literature suggesting that telehealth programmes ranging from 50 to 90 minutes effectively balance comprehensive content delivery with participant engagement without causing fatigue (Corona et al., 2021; Michaelchuk et al., 2022). Research indicates that a 90-minute session is optimal for facilitating learning and interaction while minimizing the risk of participant disengagement (Cady et al., 2024; Moore et al., 2024).

This duration allows sufficient time for delivering key information and engaging participants in interactive activities, thereby enhancing the success of online interventions (Andersson et al., 2005; Warmerdam et al., 2010). Additionally, shorter sessions accommodate participants' attention spans and schedules, making it feasible for them to participate without significant disruption to their daily routines (Lynch et al., 2021). To achieve the reduced session duration, content previously presented in person—such as detailed education and examples of specific types of IA—was transferred to the programme handbook. The comfort break was also shortened from 30 minutes to 5 minutes. These modifications are detailed in Table 3.2.

Table 3-1 Online FAME-W programme content and facilitation outline

Week	Title	Online Content	In-Person Content	Facilitator	Format	Length	Setting
Week 1	Fatigue and Energy Management	Outline of programme Introductions Types of fatigue Causes of fatigue Energy management techniques SMART goal setting	Outline of programme Introductions Understanding fatigue Types of fatigue Causes of fatigue Energy management techniques SMART goal setting	Occupational Therapist	Group	Online: 90 minutes In Person: 150 minutes	Online: via Zoom In Person: allocated room in a hospital
Week 2	Managing Pain, Joint Protection and Ergonomics	Causes of pain Pain management Joint protection techniques Applying ergonomics in workplace SMART goal setting and review	Understanding pain Causes of pain Pain management Joint protection techniques Understanding Ergonomics Applying ergonomics in workplace SMART goal setting and review				
Week 3	Maintaining Mental Wellbeing	Maintaining mental wellbeing Stress management techniques Overview of relaxation techniques Relaxation exercise as a group SMART goal setting and review	Understanding mental wellbeing Maintaining mental wellbeing Overview of stress Stress management techniques Overview of relaxation techniques Relaxation exercise as a group SMART goal setting and review				
Week 4	Effective Communication and Employment Legislation	Communicating with employers Disclosing information to employers Employment rights SMART goal setting review	Communicating with employers Disclosing information to employers Employment rights Entitlements and grants SMART goal setting review				

Part two: Goal setting

As discussed in Chapter 1, during the second part of each session, participants are asked to identify and set goals based on the learnings from the educational material covered each week. The aim of goal setting in the FAME-W is to encourage participants to put the learning gained from each session into practice over the coming week (Appendix A demonstrates the goal setting worksheet utilised with examples). Each week participants review and discuss the outcomes of their goals with their online group and group facilitator.

Materials:

Online FAME-W includes a provision of a programme handbook containing information that is delivered during online FAME-W. This handbook is designed as a long-term resource, containing detailed information on fatigue management strategies for work, which complements the weekly sessions. The handbook includes a copy of the presentation slides used in each session, pain and fatigue diaries for participant use, and useful contact information, such as contacts for Non-Governmental Organisations and government services. The handbook is structured into four chapters, aligning with the weekly content of the online FAME-W programme, and participants are encouraged to use it as a supplementary resource for understanding the content and for taking notes.

3.2.2 Self-guided workbook of FAME-W

Self-guided workbook interventions have shown promise in managing symptoms and increasing quality of life (Beatty et al., 2010; Hunt et al., 2020; Redpath et al., 2023; Takano et al., 2021). Research suggests that self-guided interventions can effectively reduce pain, fatigue, and psychological distress, while also improving self-management skills and overall well-being (Corp et al., 2023; Ndosi et al., 2016). Additionally, self-guided interventions offer the flexibility for individuals to work at their own pace and convenience, which may enhance adherence and engagement (Ndosi et al., 2016). However, it's essential to consider individual preferences, needs, and readiness to engage in self-guided interventions, as well as potential barriers such as low health literacy or limited access to resources (Apolinário-Hagen et al., 2018; Gulliver et al., 2020; Ndosi et al., 2016;). Further research is needed to explore the long-term acceptability and feasibility of self-guided workbook interventions in diverse populations with IA.

A self-guided FAME-W workbook was designed as self-directed, self-management programme for individuals with IA to manage their fatigue in work and to successfully

manage the demands of their work. It consists of the four chapters corresponding to the four weeks of the FAME-W intervention as outlined in Table 3.2. For the self-guided programme, participants were expected to complete all four chapters over four weeks (one chapter per week), with at least one goal to be set and achieved each week. The self-guided workbook differs from the handbook provided with the online delivery of FAME-W. The self-guided workbook is designed to replicate the FAME-W intervention, allowing participants to work through the content independently rather than attending the sessions. It includes additional resources such as an introduction on how to effectively use the workbook, chapter summaries, guided questions to help participants engage with each chapter, and more detailed information about IA and self-management techniques compared to the materials provided in the online FAME-W programme.

3.3 Intervention Training

The principal investigator of the study, an occupational therapist experienced in rheumatology field, delivered an hour-long training workshop for occupational therapists delivering the online FAME-W programme. The training included content review for each session, weekly goal setting, and guidance on group and programme expectations. Occupational therapists facilitating the programme received the training online via Zoom. Additionally, due to changes in the programme format, the facilitator was trained on using the Zoom platform. This training covered, how to allow participants to ask questions, share presentation slides, videos, and utilize the chat option.

3.4 Study Design

This study used a pilot comparative RCT to test the feasibility of the two delivery methods of FAME-W and included qualitative methods guided by a qualitative descriptive design as outlined by Sandelowski (2010) to examine the acceptability of the two interventions i.e. online FAME-W and self-guided FAME-W workbook.

The study employed a parallel pilot comparative randomized control trial (RCT) to compare the two delivery methods of the FAME-W intervention in improving work performance. In clinical research studies, RCTs are accepted as the gold standard to study the safety and efficacy of new treatments and interventions (Kabisch et al., 2011; Hariton & Locascio, 2018). RCTs offer numerous methodological advantages. Random allocation of participants into different groups is fundamental to an RCT as it helps mitigate selection bias, ensuring comparability between groups at baseline (Schulz et al., 2010). By reducing the risk of confounding variables influencing study outcomes, randomization strengthens

the internal validity of the findings (Schulz et al., 2010). The inclusion of different groups receiving alternative treatments, such as the self-guided workbook and the online FAME-W, allows researchers to isolate the specific effects of the group intervention, distinguishing them from other factors (Gitlin et al., 2016). This comparative approach is crucial for establishing causal relationships between the intervention and observed outcomes. Unlike placebo-controlled RCTs, comparative RCTs directly compare active therapies in a head-to-head design (Henry et al., 2022). This design yields high-quality data on the relative efficacy and safety of two or more medical interventions, making them particularly valuable for guiding clinical practice. However, comparative efficacy RCTs require large sample sizes to achieve adequate power. As a result, placebo-controlled trials are more commonly conducted, both in general medicine and in rheumatology (Bourgeois et al., 2012). The extent to which pragmatic RCTs have influenced rheumatology practice guidelines or impacted clinical practice remains unclear (Henry et al., 2022). Overall, RCTs serve as indispensable methodological tools in assessing the efficacy of interventions, offering rigorous standards for generating reliable evidence to inform clinical practice and policy decisions (Núñez-Núñez et al., 2023).

Qualitative descriptive (QD) design as outlined by Sandelowski, (2010) was used to understand the acceptability of the online FAME-W programme. QD was utilised due to its suitability for providing a comprehensive and in-depth exploration of participants' experiences and perspectives without extensive interpretation or theory development (Sandelowski, 2010). It offers a direct and accessible means of presenting findings, making it valuable for informing practice, policy, and further research (Sandelowski, 2000; Kim et al., 2017). Qualitative descriptive design has been recognised as an important method for assessing, developing, and refining interventions (Sullivan-Bolyai et al., 2005). It allows researchers to explore the richness and complexity of real-life situations, capturing the nuances and intricacies that quantitative approaches may overlook (Sandelowski, 2000; Neergaard et al., 2009). Qualitative descriptive design is flexible and adaptable to various research contexts and populations (Kim et al., 2017). This flexibility enables researchers to explore research questions from multiple angles and perspectives, enhancing the depth and breadth of understanding (Neergaard et al., 2009).

3.5 Ethical approval

Ethical approval was granted by St. James's Hospital/Tallaght University Hospital Research (Appendix D).

3.6 Sample

FAME-W is for adults with IA who are currently working and are experiencing difficulty with fatigue that interferes with work performance. Therefore, the eligibility criteria for this study included:

- 1) individuals with a confirmed diagnosis of IA by a rheumatology consultant
- 2) age 18–65 years and in paid employment (full or part-time)
- 3) able to participate in a group-based self-management intervention and
- 4) able to have access to a digital device and reliable Internet service.
- 5) excluded if the individual has a co-morbid disease that will affect the symptoms of IA.

3.7 Sample Size

Small samples are recommended for feasibility studies as significance testing is not an objective of feasibility studies (Lewis et al., 2021). A sample size of 10 to conduct this study aligns with the typical sample sizes used in feasibility and acceptability studies (Scheutzow et al., 2022).

3.8 Recruitment

Participants were recruited from a Rheumatology Department of a tertiary care hospital over a one-month period. Eligible participants were identified through a two-stage process carried out by staff of the Rheumatology Department. The first stage involved screening of medical charts to identify individuals who met age and disease related eligibility criteria. The second stage involved establishing employment status of individuals meeting age and disease status criteria when they attended their out-patient appointments. Screening for eligibility was carried out by rheumatology clinic staff. Those who met all eligibility criteria were provided with a participant information leaflet (PIL) (Appendix D) during their clinic appointments and those who were interested in participating in the study were asked to contact the PhD candidate. Individuals who agreed to participate were then provided with an informed consent form and invited to complete baseline study measures either via email or mail if requested.

3.9 Randomization

Following completion of baseline study measures, participants were randomly allocated to the online FAME-W group or to the self-guided workbook group using a computer-generated randomisation list (Kim & Shin, 2014). Individuals allocated to the online group received the four-week online FAME-W programme. Those allocated to the self-guided workbook group received a copy of the self-guided FAME-W workbook via mail.

3.10 Data collection

Baseline data were collected before participants were randomised. Participants were provided with the option of completing their questionnaires online, on hard copy or when requested, with over the phone assistance. Questionnaires were sent to the participants via Qualtrics survey platform or via mail depending on their preference immediately after their agreement to take part in the study. Participants were required to complete the questionnaires in the study package at their earliest convenience.

Participants completed a demographic questionnaire and participant reported outcome measures prior to the intervention (Time 1) and at three months follow up (Time 2) (Figure 3.1).

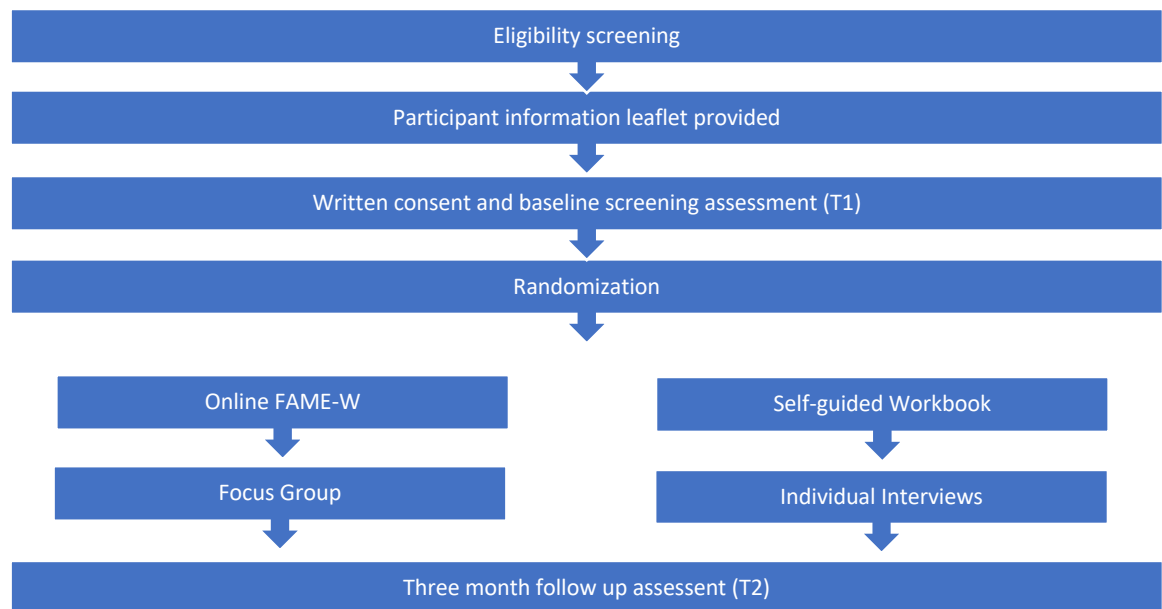


Figure 3.1 Participant recruitment, pre and post intervention steps

3.10.1 Quantitative Data

Demographic questions

All participants completed a demographic questionnaire (Appendix E). This included questions on gender, age, relationship status, living situation, diagnosis type and year, comorbidities, education, and their work. Work demographics included employment hours (full time or part time), job type (non-manual, mixed, non-manual and manual or manual) and their job title.

Outcome measures:

The primary and secondary outcome measures for this current study were the same measures used for the feasibility study of the in-person FAME-W (McCormack et al., 2018).

Primary outcome measure:

Work Role Functioning questionnaire

Work Role Functioning (WRF) (Amick et al., 2000) questionnaire consists of 27 items, and it is a self-report questionnaire. It contains five subscales related to various work demands: scheduling demands (5 items), output demands (7 items), psychical demands (6 items), mental demands (6 items), and social demands (3 items). WRF measures perceived difficulties in meeting work demands among employees. It has been widely used as an assessment of health-related work functioning in variety of settings and with different job types and individuals with mixed clinical conditions (Abma et al., 2019). Participants respond on a five-point scale where 0 = difficult all the time, 1 = difficult most of the time, 2 = difficult half of the time, 3 = difficult some of the time, 4 = difficult none of the time. In addition, participants select 'Does not apply to my job', and this is recorded as a missing value for the purposes of scoring. Each subscale is scored separately, and scores are converted into percentages where summed scores are divided by the number of non-missing items and multiplied by 25 to obtain a percentage varying from 0% (always have problems meeting the demands of the job) to 100% (have no problems meeting demands of the job). Higher percentages indicate greater ability to manage work demands (Ramada et al., 2013). Summated percentage scores are calculated if a person is not missing 20% of the items. WRF has been proven to be valid and reliable for measuring work ability in people with IA (Roy et al., 2011). WRF questionnaire was selected as the primary outcome measure as FAME-W is a work focused intervention. WRF was also used as the primary outcome measure for the face-to-face FAME-W pilot study (McCormack et al., 2018).

Secondary outcome measures

Multidimensional Fatigue Inventory (MFI) (Smets et al., 1995)

MFI is a 20-item self-reported questionnaire measuring different aspects of fatigue over a seven-day period. MFI-20 consists of five domains: general fatigue, physical fatigue, reduced motivation, reduced activity, and mental fatigue. Scores range from 1= yes, that is true to 5= no, that is not true. MFI is scored per domain where scores range from a minimum of four to a maximum of 20 for each domain. For MFI, higher scores indicate greater levels of fatigue. Scores greater or equal to 13 indicate severe fatigue levels. The MFI is a valid and reliable measure for individuals with IA (Thombs et al., 2008; Hewlett et al., 2005; Repping-Wuts et al., 2008; Goodchild et al., 2008; d'Elia et al., 2008).

Arthritis Work Spillover (AWS) (Gignac et al., 2006)

Arthritis Work Spillover was designed to assess the extent to which the demands of arthritis interfere with work performance and the extent to which work interferes with managing arthritis. AWS is a six-item self-report scale scored on a five-point Likert system starting from 1 (strongly disagree) to 5 (strongly agree) (Gignac et al., 2006). Total scores range from six to 30 where higher scores indicate a greater interference with work; higher spill-over, or that arthritis is negatively affecting the person's work (Gignac et al., 2006; Gignac et al., 2007). AWS demonstrates a high degree of internal consistency and evidence of convergent and discriminant validity (Gignac et al., 2006). AWS has been used to explore the impact of rheumatic diseases such as IA on workability (Connolly et al., 2016).

Hospital Anxiety and Depression scale (HADS) (Zigmond & Snaith, 1983)

HADS is a self-report measure with two subscales: anxiety and depression. Each of the two subscales consist of seven-item scales. Participants are asked to select the statement that is closest to their mood in the past week. These statements are scored from 0 to 3. Total scores range from 0 to 21 for each scale; 0 to 7 indicating normal levels, 8 to 10 mild, 11 to 15 moderate and 16 to 21 indicating severe anxiety or depression. HADS was originally developed for use in non-psychiatric outpatient settings, but it is also valid and reliable in the general population (Gale et al., 2010). Studies have confirmed the validity and reliability of the HADS for people with IA (Smarr & Keefer, 2011).

The Stanford Arthritis Self-Efficacy Scale Short Form (ASES-8) (Lorig et al., 1989)

ASES-8 is the short form of the Arthritis Self-Efficacy Scale with 20 questions divided into three subscales: physical function (9 questions), other symptoms (6 questions) and

pain (5 questions). The 8-item version includes questions from each of these areas. ASES-8 is a self-administered, disease-specific questionnaire suitable for all types of arthritis (Lorig et al., 1989). Groups tested with this measure include those with chronic arthritis and fibromyalgia (Lorig et al., 1989). It consists of three subscales: managing physical function, pain, and other symptoms. Participants are asked to choose the number that corresponds with their certainty of carrying out the tasks in the questions at the present time. Each question is ranked from 1= very uncertain to 10= very certain. One indicates low self-efficacy and low levels of ability to manage symptoms of arthritis. Ten indicates high levels of certainty in ability to manage symptoms of arthritis and higher self-efficacy. The scale is not scored if two or more items are missing. ASES-8 was chosen over ASES-20 as it is much less burdensome for participants than the original 3 scales with 20 total items. ASES has been proven to be valid and reliable tool for testing self-efficacy for individuals with arthritis (Brady, 2011; Wilcox et al., 2014).

The Arthritis Impact Measurement Scale Short Form (AIMS2-SF) (Guillemin et al., 1997)

AIMS2-SF is the short form of the 78-item The Arthritis Impact Measurement Scale Version 2. AIMS2-SF was created to reduce the completion time and the burden imposed on the participants caused by the 78-item AIMS. AIMS2-SF measures physical, mental, and emotional well-being of individuals with arthritis. It consists of five domains: physical functioning, symptoms, mood/affect, social interaction, and work-role components (Carr, 2003; Guillemin et al., 1997). AIMS2-SF is scored on a 5-point scale with 1 = all days and 5 = no days of arthritis impacting the five domains. Scores are calculated by summing each of the five domains where each domain ranges from 0 (perfect health status) to 10 (worst health status) and total score ranges from 0 to 60 (Carr, 2003). AIMS2-SF is a valid and reliable tool (Gignac et al., 2011) with all scales having high item-discriminant validity and Cronbach's alpha reliability above the 0.70 criterion (Ren et al., 1999).

The Short Form McGill Pain Questionnaire (SF-MPQ) (Melzack, 1987)

(SF-MPQ) measures pain in adults with chronic pain, including individuals with arthritis (Hawker et al., 2011). SF-MPQ includes a Pain Rating index (PRI), Present Pain Intensity (PPI) scale and a visual analogue scale (VAS). The three dimensions of pain experience brought together to rank sensory qualities of pain, affective qualities and subjective experiences of pain. The PRI consists of 15 pain-related words and has 2 subscales: sensory subscale with 11 words and affective subscale with 4 words. The participants are

required to rank the words on an intensity scale as 0 = none, 1 = mild, 2 = moderate and 3 = severe. The sensory subscale consists of words that describe the sensory qualities of the pain experience in terms of temporal, spatial, pressure, thermal, and other properties. The affective subscale consists of words that describe affective qualities in terms of tension, fear, and autonomic properties that are part of the pain experience. The PPI is a one item question testing the overall intensity of the present pain and VAS is used for marking average pain (Hawker et al., 2011; Melzack, 1987). The SF-MPQ scores are derived by summing the intensity rank values of the words chosen for sensory, affective, and total descriptors of PPI and VAS. SF-MPQ has been used extensively to measure pain for chronic and rheumatic conditions and has been proven to be a valid and reliable scale for pain (Tam et al., 2019).

EQ-5D-5L questionnaire (EuroQol Research Foundation, 2019)

EQ-5D-5L evaluates health-related quality of life. It comprises of two components: a health states component and a visual analog scale (VAS) (EuroQol Research Foundation, 2019). Health states consist of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (Hobbins et al., 2018). Each dimension has five levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. Participants respond to each dimension by ticking the box corresponding to the most appropriate statement. This then corresponds to a one-digit number that expresses the level selected for that dimension. This results in five, one-digit numbers that can be combined into a five-digit number that describes the patient's health state.

The EQ VAS is a vertical visual analogue scale where participants mark their self-rated health from 0= "the worst health you can imagine" to 100= "the best health you can imagine". The VAS is helpful to reflect self-judgement of health-related quality of life. EQ-5D-5L has been found to be a valid and reliable instrument for assessing health-related quality of life among patients with IA and it has been used in previous arthritis related research (Haridoss et al., 2021; Seng et al., 2020).

3.10.2 Qualitative Data

Qualitative data were collected to explore participants' acceptance of their assigned delivery method—either the online FAME-W or the self-guided FAME-W workbook—and to examine their perceptions of how these methods influenced symptom management and their capacity to meet work demands. Data were gathered through focus groups and semi-structured interviews.

Focus groups were conducted with participants from the online FAME-W group immediately after the programme to assess the acceptability of the content and delivery. Semi-structured interviews were held with participants from the self-guided FAME-W workbook group to gather their opinions, experiences, and usage of the workbook, including feedback on the content, format, ease of understanding, and its impact on their symptom management and work demands.

Focus Group

Focus groups are extensively employed in health research to explore the experiences and perspectives of patients and other stakeholders within the healthcare system (Carr, 2003; Côté-Arsenault & Morrison-Beedy, 2005; Coenen et al., 2012; Doumen et al., 2021; Kitzinger et al., 2006; Walter et al., 2017). They facilitate the collection of rich, nuanced data through group interactions and discussions, allowing participants to express their views in a dynamic setting (Kitzinger, 1995). This method leverages group dynamics to elicit deeper insights that might not emerge in individual interviews.

In this study, a focus group was conducted immediately following the completion of the online FAME-W programme with participants from the online FAME-W group. The purpose was to delve into participants' perceptions of the online FAME-W, including its design, content, key intervention components, delivery, and impact. Additionally, the focus group aimed to assess the feasibility and acceptability of the online delivery format, capturing participants' views and recommendations.

The questions guiding the focus group were based on the feasibility study of the in-person FAME-W intervention (McCormack et al., 2018) but were modified to align with the online delivery format. Specific inquiries addressed the online delivery method used and its effects on participants' learning and engagement with the programme (Appendix E). By employing a focus group, the study sought to obtain comprehensive feedback on the online adaptation of the FAME-W programme to inform future refinements.

Individual Interviews

One-to-one interviews were preferred over focus groups for the FAME-W workbook participants to allow a deeper exploration of the experiences of this intervention (Silverman, 2016). Semi-structured interviews use a set of open-ended questions but allow flexibility to ask more detailed questions (Taylor, 2023).

Semi structured interviews were conducted over the phone to facilitate an open exchange between the researcher and participant, allowing collection of detailed information on participants' experiences, thoughts and attitudes while encouraging an in-depth conversation regarding the topic being discussed (Hinton & Ryan, 2020) Participants of the self-guided FAME-W workbook were invited to share their thoughts and experiences regarding the self-guided workbook. The aim was to gather feedback on the workbook's acceptability and usefulness (Appendix E).

Fidelity

The success of an intervention is influenced, to some extent, by the degree of fidelity in the online delivery of FAME-W (Swindle et al., 2018). Fidelity is described as the “*degree to which an intervention was implemented as described in the original protocol or as it was intended by the program developers*” (Proctor et al., 2011, p. 69). Fidelity encompasses programme adherence by the facilitator, clear identification and reporting of changes made during delivery, participant engagement, and attendance (Dane & Schneider, 1998). To ensure fidelity in the online delivery of FAME-W, as discussed previously, the principal investigator, conducted an hour-long training workshop for the facilitators. This training, delivered via Zoom, covered essential aspects such as content review, goal setting, and effective use of the Zoom platform, including participant interaction, presentation sharing, and chat utilization.

Furthermore, fidelity assessment is crucial as the inability of interventions to achieve the intended changes in targeted outcomes may stem from inadequate implementation and delivery of the intervention rather than deficiencies in the programme's design (Durlak & DuPre, 2008; Horner et al., 2006). Therefore, to systematically document and track the delivery process, the occupational therapist delivering the online FAME-W programme completed a facilitator log after each session (Appendix F). This log served as a comprehensive tool to ensure that the programme was delivered as planned and to monitor any deviations or challenges encountered (Vanacore et al., 2024). The facilitator log included detailed session information such as the date, time, and duration of each session,

the number of participants, and any technical issues that arose. It also captured adherence to the protocol, including whether the session content was delivered as intended and any deviations from the planned structure. Furthermore, the log documented participant engagement, noting their involvement, interaction with the content, and any feedback provided.

In addition, the log allowed the facilitator to reflect on the impact of the session, note any modifications made in response to participant needs or technical challenges, and provide suggestions for future sessions. By capturing these details, the facilitator log offered crucial data for assessing fidelity, enabling a more precise attribution of any absence of intended changes in targeted outcomes to the intervention's design or delivery (Ginsburg et al., 2021). Therefore, the log played a crucial role in maintaining fidelity throughout the online delivery of FAME-W.

3.11 Data Analysis

3.11.1 Quantitative Data

All quantitative data collected through demographic and outcome measures were prepared for analysis and entered into SPSS 23.0 (SPSS Statistics for Windows, version 23.0). Descriptive analysis explored participants' clinical and demographic characteristics such as type of IA, comorbidities, education levels, living and marital status, age, gender, diagnosis year and other characteristics (Appendix G). Change scores for outcome measures were calculated for both delivery methods at baseline and at the 3-month follow-up to compare the changes between the two groups.

3.11.2 Qualitative Data

All interviews and focus groups were audio-recorded and transcribed verbatim. The transcripts were checked against the audio files for accuracy and corrections were made as identified (Clark et al., 2017).

All qualitative data including the focus group and interview transcripts were guided by Braun and Clarke's (2022) six stage thematic analysis of qualitative data. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) across a dataset in relation to a research question (Braun & Clarke, 2006; Clarke & Braun, 2013). The systemic process of analysis recommended by Clarke & Braun (2022) for rigorous thematic analysis was used. The six-stage analysis are as follows:

1. Familiarising with data: data familiarisation occurred by reading and re-reading the data. This step aids in identifying prominent patterns and significant features within the data. Any initial analytic observations were noted.
2. Generating initial codes: Coding is a term that refers to systematically segmenting the data into meaningful units, typically referred to as "chunks" or segments (Braun & Clarke, 2013; Clarke & Braun, 2013). Each segment is then assigned a label or code representing its content, facilitating subsequent analysis. Each transcript was inputted into Nvivo and coded using Nvivo by progressing systematically through each transcript creating codes. All codes and relevant data extracts were then collated.
3. Searching for themes: A theme refers to a recurring pattern or topic identified within the data that captures some aspect of the research question or objective (Clarke & Braun, 2022). Researcher searched for overarching concepts that emerge from the coded data and reflect commonalities, similarities, or shared meanings across different segments of the dataset. This enabled researcher to cluster related codes, allowing researcher to discern underlying trends or concepts within the dataset. Researcher then scrutinized the coded segments to identify recurring patterns or themes. All coded data relevant to each theme was collated.
4. Reviewing themes: Researcher critically assessed the identified themes, evaluating their coherence, relevance, and alignment with the dataset (Byrne, 2022). Themes were compared to each other, overlapping themes were combined, sub-themes were identified, and some themes were discarded if they significantly overlapped with other themes or did not sufficiently represent the data, while other themes were re-developed again (Clarke & Braun, 2017). This iterative process involves examining the relationships between themes and ensuring comprehensive coverage of the data.
5. Defining and naming themes: Themes were further refined and finalized. Researcher articulated clear definitions for each theme, elucidating their conceptual underpinnings and significance within the context of the research (Joffe, 2011). Additionally, researcher assigned descriptive and meaningful names to the themes to accurately convey their essence.

6. Reporting: The final stage entailed synthesizing the thematic analysis findings into a coherent and structured narrative (Clarke & Braun, 2017). Identified themes were presented alongside supporting evidence from the dataset, including illustrative quotes or excerpts. Furthermore, the implications of the themes for the research questions are discussed, enriching the scholarly discourse.

3.11.3 Data Analysis of Facilitator Logs

The data collected through the facilitator logs were systematically analysed using a combination of quantitative and qualitative approaches. Quantitative data from the logs, such as session duration, participant numbers, and adherence to the protocol, were aggregated and statistically analysed to identify patterns and assess overall fidelity across sessions. Qualitative data, including facilitator reflections, participant engagement observations, and notes on session modifications, were analysed using thematic analysis, following the same rigorous six-stage process outlined above. This involved coding the qualitative data to identify recurring themes and insights related to the challenges and successes of the online delivery of FAME-W.

3.11.4 Rigor

Various strategies were employed during the qualitative analysis to enhance the trustworthiness of the research findings. Rigor pertains to the confidence level in qualitative data, interpretations, and methods (Lincoln & Guba, 1985). For this study, rigour was guided by four aspects of rigour identified by Lincoln and Guba (1985): credibility, conformability, dependability, and transferability. These components of rigor served as a framework to validate the research process for the qualitative aspects of this study.

Credibility

Credibility is the confidence in the authenticity, legitimacy, and reliability of the findings (Carpenter & Suto, 2008). Strategies used in this study to ensure credibility included triangulation, member checking and encouraging honesty. Triangulation refers to the use of multiple sources or methods of data collection and analysis to enhance the credibility and reliability of finding (Noble & Heale, 2019). Triangulation was used by incorporating various data collection methods from participants such as focus group and individual interviews, ensuring a comprehensive understanding of participants' experiences of the two delivery methods of FAME-W intervention.

Member checking is a validation technique where researchers present their findings or interpretations to participants to verify the accuracy and credibility of the data collected (Birt et al., 2016). It is a common strategy adopted by researchers to address potential researcher bias (Doyle, 2007; Lincoln & Guba, 1985). Member checking was adopted to ensure accuracy on transcripts. Each participant was given the opportunity to review their focus group or interview transcripts with a brief summary of findings from their transcripts. Participants were invited to offer feedback by phone or email within two weeks of receiving the transcripts. These rigorous efforts served to enhance the credibility of the qualitative analysis, ensuring that the findings accurately reflected the participants' perspectives and experiences with the FAME-W intervention.

Encouraging honesty is a strategy in qualitative research that involves creating an environment where participants feel safe and comfortable to express their true thoughts and feelings without fear of judgment or repercussions (Shenton, 2004). This approach helps to obtain more accurate and authentic data, which contributes to the credibility of the research findings. In this study, honesty was encouraged by establishing rapport with participants, assuring them of the confidentiality of their responses, and emphasizing that there were no right or wrong answers. Additionally, participants were informed that their feedback would be used to improve the intervention, which often motivates them to provide sincere and thoughtful responses (Given, 2008).

Confirmability

Confirmability refers to the objectivity of the data and ensures that interpretations are not influenced by researcher bias (Lincoln & Guba, 1985). Confirmability was achieved through peer review of the transcripts and the generated themes by the researcher and the principal investigator. An audit trail refers to a systematic and detailed documentation of the research process, including the decisions made, methods employed, and steps taken during data collection, analysis, and interpretation (Carcary, 2020). The purpose of an audit trail is to enhance the transparency, credibility, and trustworthiness of the research by allowing other researchers or reviewers to follow the researcher's thought process and verify the integrity of the study (Rodgers & Cowles, 1993). An audit trail demonstrated each step of data analysis hoping to demonstrate confirmability. The audit trail for this study encompassed several components. Detailed documentation of research procedures was maintained throughout the study. This documentation covered various aspects, such as data collection methods, sampling strategies, and data analysis techniques. Additionally, comprehensive records of all research activities were maintained. These

records included transcripts of data, coding decisions, and memos documenting reflections and insights. Furthermore, version control of data files and analysis documents was upheld to track changes made during the research process and ensure transparency. Decision logs recorded the rationale behind key decisions made during the research process such as including inclusion/exclusion criteria for participants, selection of analytical methods, and interpretations of findings. Reflections on methodological choices, challenges encountered during data collection or analysis, and potential biases or limitations of the study were also documented.

Dependability

Dependability refers to the consistency and reliability of the study results (Ahmed, 2024; Lincoln & Guba, 1985). It involves demonstrating that the research methods are reliable and that the findings are consistent and replicable. An in-depth description of the methodology was outlined in this chapter. An audit trail was completed to ensure that the study can be repeated in the future.

Transferability

Transferability refers to the extent of which the study results are applicable within other contexts, circumstances, and settings (Merriam, 1998). This is ensured through providing adequate details about the participants, recruitment and intervention methods, and data collection strategies in sections 3.8, 3.9, 3.10 of this chapter. By diversifying recruitment methods, standardizing intervention procedures, and using multiple data collection techniques, applicability of the findings to different contexts and populations was enhanced. These strategies allow for broader representation and validation of results, making them more useful beyond the specific study setting.

3.12 Results

Recruitment

Two-hundred and sixteen patient charts were reviewed with 124 individuals meeting the age and disease status eligibility (Figure 3.2). Of these, 52 patients were approached by the clinic staff to check their employment status. The remaining 72 people either did not attend their clinic appointments or were not approached by the staff to check employment status. Of the 52 individuals approached, 19 were not working, and 13 declined the study invitation. The remaining 20 people agreed to receive the participant information leaflet and contacted the PhD candidate. After discussing the study further, five people were no longer interested in participating in the study, and five had time/scheduling conflicts. The remaining ten participants completed baseline assessments and were randomly assigned to the online FAME-W ($n = 5$) or self-guided FAME-W ($n = 5$) group. This resulted in 30.3% recruitment rate. Three individuals dropped out of the study prior to the intervention start date (two from online group and one from the self-guided group) due to acquiring COVID-19. Therefore, the final number of participants was three individuals in the online group and four in the self-guided group.

Adherence and retention

All online group participants attended all four sessions, demonstrating 100% adherence as documented in the facilitation logs. Session durations varied slightly; the first session was the longest at 100 minutes, while the subsequent sessions were relatively consistent, lasting 95 minutes, 95 minutes, and 90 minutes, respectively. The longer duration of the first session was attributed to participant introductions. All self-guided group participants reported during the individual interviews that they completed the workbook over the course of four weeks as suggested, also reflecting a 100% adherence rate. Similarly, retention was 100%, with all participants completing the study, including the follow-up assessments at three months.

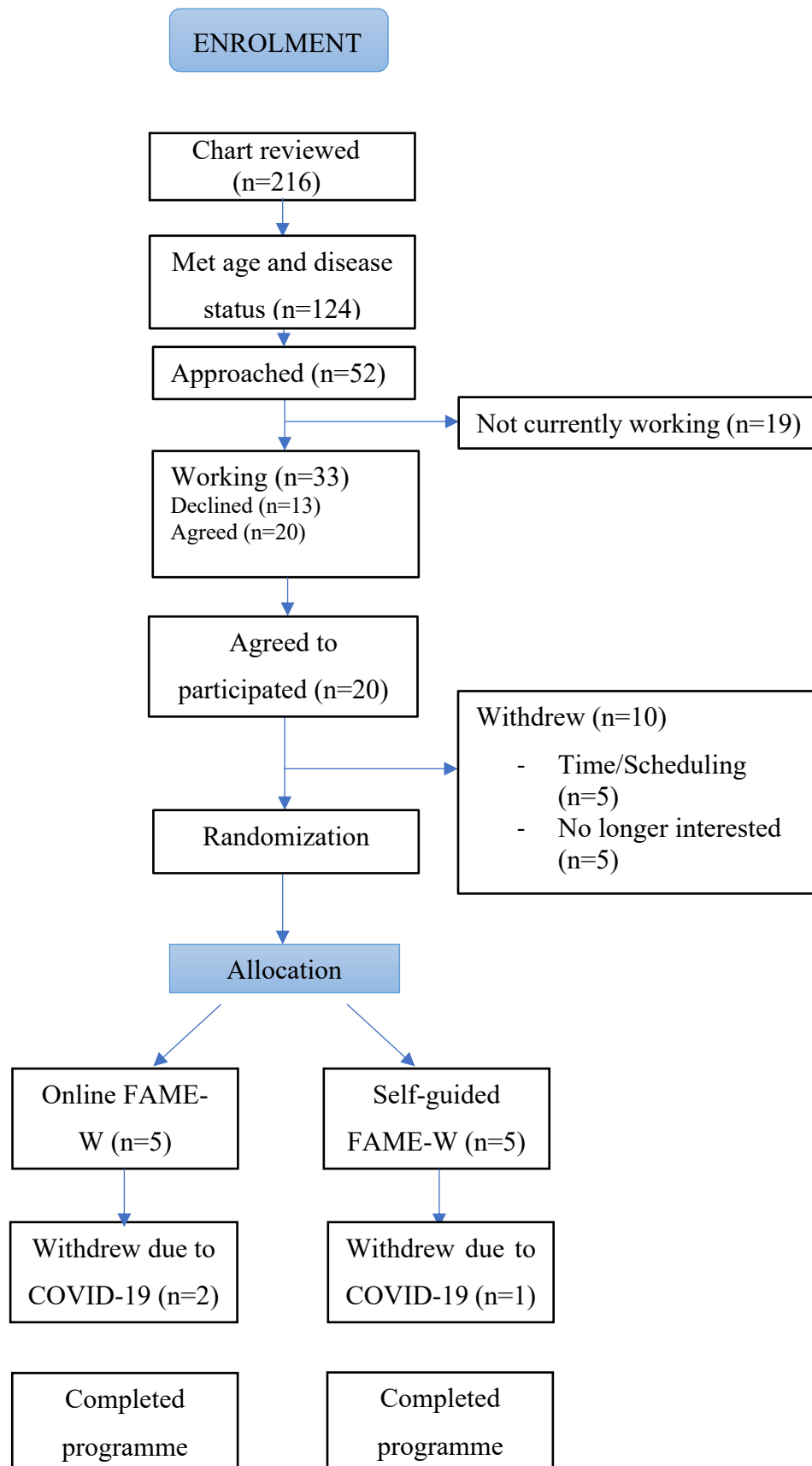


Figure 3.2 Consort Diagram

Demographics

The majority of participants in both groups had RA and were working full-time in non-manual jobs (Table 3.3). The mean age of the online group participants was 53 ± 10.4 and 56.5 ± 3.7 for the self-guided group. Most of the online group were males and the majority of the self-guided group participants were female. Table 3.3 presents demographic and clinical characteristics of all participants.

Table 3-2 Participant characteristics at baseline

Characteristics	Online Group (n=3)	Self-Guided Group (n=4)
Mean age (SD)	53 (10.4)	56.6 (3.3)
Age Range (years)	46-65	41-61
Gender		
Female (%)	1 (33.3)	3 (75)
Male (%)	2 (66.7)	1 (25)
Type of Arthritis		
RA (%)	2 (66.7)	3 (75)
Other (%)	1 (33.3)	1 (25)
Years since Diagnosis (SD)	3.3(3.2)	11 (4.1)
Marital Status		
Single (%)	1 (33.3)	2 (50)
Married (%)	2 (66.7)	1 (25)
Separated (%)		1 (25)
Living Situation		
Alone (%)	0	3 (75)
With Others (%)	3 (100)	1 (25)
Level of Education		
Secondary Level (%)	1 (33.3)	1 (25)
College/University (%)	2 (66.7)	3 (75)
Chronic Condition (Self-Reported)		
Yes	2 (66.7)	3
No	1 (33.3)	0
Employment Status		
Full Time	3	4 (100)
Part Time	0	0
Type of Work		
Non-Manual	1 (33.3)	3 (75)
Mixed	2 (66.7)	1 (25)

Outcome measures

All seven participants completed outcome measures at baseline and 3-month follow up. All measures were completed in full. Change scores between online and self-guided group were calculated for baseline and 3-month follow up. Significance testing was not carried out as this is not the function of a feasibility study (Whitehead et al., 2014). On examining

change scores, the online FAME-W group showed greater improvements in fatigue, depression quality of life and pain (Table 3.4). The self-guided FAME-W participants showed greater improvements in WRF and anxiety than the online group. However, baseline scores for WRF were considerably lower in the self-guided workbook group than the online intervention group which may explain the greater improvement in this group. Additionally, anxiety levels for the self-guided workbook participants were higher than the online participants at baseline and again at follow up. However, one participant scored at the higher end of moderate level anxiety (anxiety levels between 11 and 14) at baseline and follow-up which impacted on the median scores for this group. As the main emphasis of FAME-W is for participants to acquire fatigue management strategies, and it is encouraging to observe that fatigue has decreased for both groups with the online FAME-W group showing greater improvements.

Table 3-3 Median and change scores of outcome measures at baseline and follow up

Measure	Online FAME-W (n=3) Median (min-max)			Self-Guided FAME-W (n=4) Median (min-max)		
	T1	T2	Change Scores	T1	T2	Change Scores
Work Role Function	84.2 (81.9-92.1)	85.7 (83.4-97.3)	+1.5	74.2 (53.2-93.9)	78.9 (40.2-94.5)	+4.7
Fatigue	13.0 (8.0-14.0)	10.0 (10.0-14.0)	-3	14.0 (12.0-17.0)	12.5 (12.0-17.0)	-1.5
HADS-A	5.0 (3.0-6.0)	5.0 (3.0-6.0)	0	10.0 (7.0-14.0)	8.0 (6.0-12.0)	-2
HADS-D	5.0 (3.0-5.0)	3.0 (2.0-4.00)	-3	5.0(3.0-11.0)	6.0 (3.0-9.0)	+1
EQ-5D-5L VAS	68.0 (47.0-90.0)	75.0 (65.0-90.0)	+7	70.0 (50.0-95.0)	66.5 (50.0-95.0)	-3.5
Pain Level	4.0 (1.0-5.0)	2.0 (2.0-4.0)	-2	1.5 (1.0-4.0)	4.5 (2.0-10.0)	+3
Pain Intensity	1.0 (1.0-2.0)	1.0 (1.0-2.0)	0	0.5 (0.0-1.0)	1.5 (0.0-2.0)	+1

Qualitative Findings

The focus group with online group participants was in duration of 45.22 minutes, while the interviews with self-guided group participants varied between 16 and 141 minutes, with an average of 56 minutes. The data from both the focus group and interviews were integrated during analysis to gain a comprehensive understanding of participant experiences. Additionally, feedback and reflections from the occupational therapists, documented in detailed logbooks after each session, were meticulously analysed. This data provided valuable insights into the therapists' experiences, challenges, and observations, which were then combined with participant data to identify key themes and differences between the online and self-guided groups, enhancing the overall analysis of the study.

The qualitative exploration, which included data from focus groups, interviews, and therapist logbooks, revealed positive feedback regarding the programme's impact. Participants reported that the online format did not hinder information delivery, retention, goal setting, or group discussions. Moreover, both the online and self-guided FAME-W programme participants, as well as the occupational therapists, noted an increased understanding of symptoms and improved symptom management. These findings suggest that both versions of the FAME-W programme—online and self-guided—are feasible and effective in achieving the intended outcomes.

Three themes were identified from qualitative data analysis of both the focus groups and interviews: (a) impact of FAME-W; participants showed increased awareness and understanding of how arthritis effects work and daily life (b) disease management; programme provided participants with strategies to manage their arthritis (c) programme acceptability; overall, participants were positive about the online and self-guided workbook of FAME-W. Figure 3.3 outlines themes and subthemes.

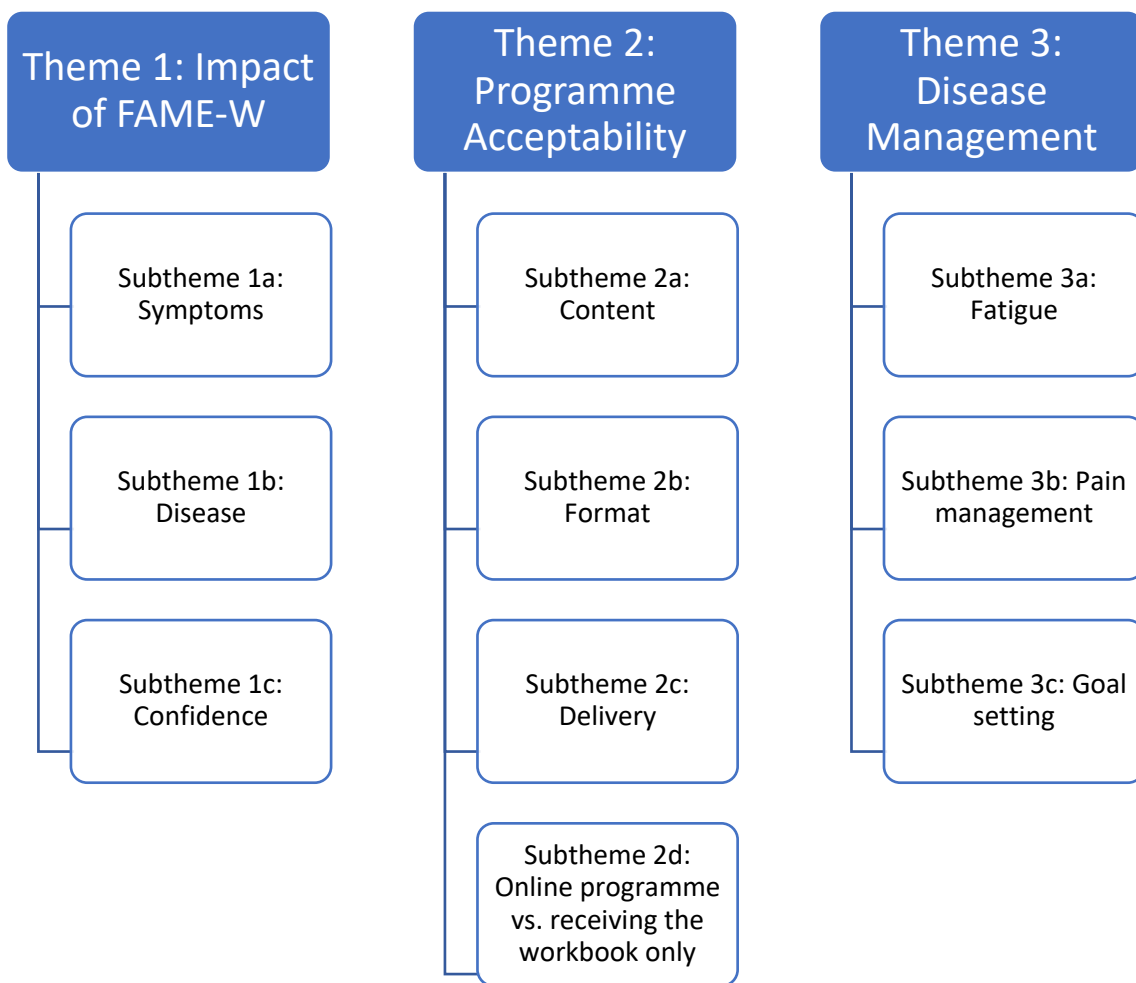


Figure 3.3 Key themes and subthemes relating to the feasibility of online and self-guided FAME-W

In Theme 1, it is reported that both the online and the self-guided workbook of FAME-W increased participants' understanding around their symptoms and symptom management. Participants shared that they had a new-found confidence in their symptom management skills. In Theme 2, participants in both groups reported that the content was relevant and beneficial. Format of the online sessions and the workbook was reported to be accessible and user-friendly. Participants indicated a preference for the online delivery of FAME-W over the workbook, citing the value of personal interactions available through the online format. Theme 3 identified specific self-management strategies gained and used by FAME-W participants. Participants reported the positive effects of the self-management strategies gained from the online intervention or the workbook. Table 3.5, 3.6 and 3.7 present participants' and the occupational therapists' experiences of the online programme.

Theme 1: Impact of FAME-W

The analysis of the qualitative data revealed that both delivery formats of FAME-W increased participants' awareness and understanding of various aspects of their disease. This included enhanced comprehension of symptoms, a deeper understanding of the disease's effects, and increased confidence in managing the condition.

Table 3-4 Focus Group and Individual Interview Analysis for Theme 1

Sub-theme	Quotes
Symptoms	<i>“At the start of the workbook, I had a lot of aches and pains in my legs in the evening. By the time I got through the workbook, I had a lot less...” (INT01)</i> <i>“It is really better to know the information before... if the symptoms are really bad you’re not going to be trying to learn new ways of thinking; it is better to be forearmed...” (FG04)</i> <i>“It offered a good insight into the problems associated with the symptoms” (INT06)</i>
Disease	<i>“For understanding the effect of pain on the body and pain in different parts of the body... it has been very helpful.” (FG03)</i> <i>“The workbook made me think about the illness, about the limitations, about the things that worked for me, and what makes my quality of life better” (INT06)</i>
Confidence	<i>“The workbook gave me reassurance and comfort to know that I’m not just imagining these symptoms and that there are ways to control them. Seeing it in writing made me feel like it is okay to have symptoms” (INT01)</i> <i>“You become more aware of arthritis and how to manage it every day” (FG02)</i>

Theme 2: Programme Acceptability

Various elements of the online and self-guided deliveries were discussed to highlight the strengths and shortcomings of the different modalities. Participants generally found both modalities of FAME-W to be acceptable, highlighting both strengths and areas for improvement. The content, format, and delivery were well-received, with positive feedback on the both methods' structure and accessibility, particularly its online format.

Table 3-5 Focus Group and Individual Interview Analysis for Theme 2

Sub-theme	Quotes
Content	<i>“Every session there are points that you wouldn't have known before” (FG02)</i> <i>“I got positives from every part of the programme...” (FG03)</i> <i>“I found the workbook really good, I found it really helpful” (INT05)</i> <i>“I found it easy to read, quite informative, and thought-provoking” (INT06)</i> FAME-W Facilitator: <i>“Positive feedback gained around relaxation activity in week three”</i>
Format	<i>“It was engaging; the online format was more accessible” (FG02)</i> <i>“I wouldn't change anything. I thought the format was excellent. It was really helpful and gave me great guidance.” (INT05)</i> FAME-W Facilitator: <i>“Participants were generally willing to participate in discussion when prompted”</i>
Delivery	<i>“As opposed to the rheumatology nurse or whatever coming at it from nursing and medicating... I think it's a good idea to have somebody that can see things from a different perspective... plus she presented it very well” (FG04)</i> <i>“I couldn't attend if it was in person” (FG02)</i> FAME-W Facilitator: <i>“No technical difficulties arose over the 4 weeks. 1.5 hours per session was long enough to cover everything”</i>

Theme 3: Disease Management

The interactive components of the FAME-W, such as group discussions for the online group and the reflective prompts for the self-guided group, facilitated a deeper understanding of disease management strategies among participants. Key areas of improvement for participants included managing fatigue, pain, and effective goal setting, which were crucial in enhancing participants' daily lives.

Table 3-6 Focus Group and Individual Interview Analysis for Theme 3

Sub-theme	Quotes
Fatigue	<i>“I’m realizing that you have to balance out resting and working.” (INT01)</i> <i>“Breaking things into parts and not trying to accomplish everything at the one time” (FG02)</i> <i>“It contained things that I could incorporate into my day into work. The emphasis on managing and reducing your fatigue was very helpful. I found I applied it to myself by making sure I took a short rest every day. And just got off my feet for fifteen twenty minutes. And it helped a lot” (INT07)</i>
Pain management	<i>“Taking time to get up off the chair and walk around even just for a few minutes. Working from home, walk up and down the stairs, get a glass of water. It reduced my pain” (INT06)</i> <i>“For me, it's dealing with pain. Fatigue in and of itself is awful, but I still think when pain is mixed in with that... that is the most overriding thing in your mind—trying to reduce that pain. So, the strategies given during sessions were very helpful, and I think pain management is a vital part of it” (FG04)</i>
Goal Setting	<i>“I had to start planning things around being mentally and physically able for my paid work—thinking about planning, thinking about setting actions. Goal setting made me think about limitations; it enhanced my life.” (INT06)</i> <i>“The goals were well defined, and I wrote them down. It’s a good exercise; I thought that was very good actually” (FG03)</i> FAME-W Facilitator: <i>“Goal setting was generally well received; participants reported positive feedback around goal setting and accountability”</i>

3.13 Discussion

The aim of this study was to test the feasibility and acceptability of an online delivery of FAME-W and a self-guided FAME-W workbook as a work-focussed self-management intervention.

Thirty-three individuals met all eligibility criteria for the study and of these, ten agreed to participate. This recruitment rate is similar to recruitment rates in other telehealth studies and is considered acceptable (Brennan et al., 2022; Carandang et al., 2022). Seven out of 10 participants who consented to take part, completed the study giving a 70% retention rate. This is considered to be highly acceptable for a pilot RCT (Brennan et al., 2022; Jacques et al., 2022). However, one of the primary limitations of this feasibility study was the small sample size, which affects the ability to fully evaluate key feasibility outcomes, including recruitment, adherence, retention, and acceptability (Eldridge et al., 2016). While feasibility studies do not aim to establish effectiveness, the final sample of only seven participants limits the ability to assess whether recruitment strategies were viable on a larger scale. Although retention and adherence were 100% among this small sample, this may not be reflective of a broader population where additional barriers to participation could emerge. Furthermore, the acceptability of the intervention was explored through qualitative feedback, but given the small number of participants, the findings may not capture the full range of participant experiences, preferences, and potential challenges. For example, individuals who enrolled may have been particularly motivated or comfortable with digital and self-guided formats, whereas those who faced barriers to participation were not captured in this study. Additionally, while all participants completed their assigned intervention, the feasibility of delivering FAME-W to a larger and more diverse group remains uncertain, particularly in terms of engagement and long-term adherence. Future feasibility research should focus on refining recruitment strategies to improve participation rates and exploring whether factors influencing retention and acceptability remain consistent across a larger sample.

Due to the COVID-19 pandemic, the research team made changes to the originally planned face-to-face delivery of FAME-W intervention. In order to adapt the original FAME-W intervention to an online delivery format, the two-hour sessions were shortened to 90 min focussing on the core elements of the programme, such as self-management strategies, participant discussion, and goal setting and by moving other elements of the programme to the handbook. Qualitative findings indicated that 90-minute FAME-W

sessions provided sufficient time for the occupational therapist to deliver the weekly topics, dedicate an appropriate amount of time to goal setting and review, and allowed participants to engage with each other. This session length is consistent with other fatigue and self-management programmes, which often range from 45 to 120 minutes per session (Alizadeh et al., 2023). The 90-minute sessions in this study offer a balanced approach, allowing for thorough coverage of material without overwhelming participants, which is comparable to other successful fatigue management interventions. Additionally, the weekly attendance of FAME-W involves commitment from participants who are in paid employment and are required to complete weekly goals to apply self-management strategies discussed during the weekly sessions. Therefore, high levels of adherence to the intervention and positive feedback from the qualitative exploration indicated that this time commitment was considered beneficial by the participants. This indicates that FAME-W is an acceptable online programme.

Virtual delivery methods have shown benefits for those working full time or living in rural and remote communities (Butzner & Cuffee, 2021). In previous research of an in-person fatigue management intervention, over half of participants who expressed interest did not attend the in-person programme due to problems commuting to programme venue (O’Riordan et al., 2017). It is hoped that by changing the delivery format of FAME-W geographical distance will no longer be a barrier for those who live in rural and remote areas. Findings of this study suggests that the online nature of the programme is more convenient and can enable participants who do not have transportation, childcare, or the ability to take time off from work. Other telehealth studies have shown similar findings (Gajarawala & Pelkowski, 2021; Oluyede et al., 2022; Reed et al., 2019; Reed et al., 2020).

Self-guided workbooks have demonstrated numerous benefits across various settings, particularly for individuals who prefer self-paced learning or have limited access to in-person resources (Greenwell et al., 2016; Gwynne et al., 2024; Rask et al., 2024). Research indicates that self-guided workbooks provide structured guidance and allow users to engage with material at their convenience, enhancing flexibility and personal control over the learning process (Beatty et al., 2010; Dineen-Griffin et al., 2019). In a study on self-management interventions, participants reported that the self-guided format of workbooks provided helpful strategies and valuable opportunities to increase their understanding and literacy on their condition (Redpath et al., 2023). This finding aligns with the results of this current study where the detailed content and structure of the self-guided FAME-W

workbook were appreciated, and participants reported increased confidence in managing their symptoms independently. Furthermore, workbooks offer a long-term resource that individuals can revisit to reinforce their understanding and skills, contributing to sustained improvements in self-efficacy and symptom management (O'Toole et al., 2021). This adaptability makes self-guided workbooks particularly valuable for those with varying schedules and commitments, as they do not require real-time participation or technological access (Takano et al., 2021). Additionally, the interactive elements and goal-setting components in workbooks promoted active learning and self-reflection for participants, which are reported as crucial for effective self-management (Schumacher et al., 2017).

FAME- W focuses on supporting individuals to develop fatigue management strategies that can be applied to their work activities (McCormack et al., 2018). Although it was not the purpose of the current study, it is worth noting that improvements in ability to manage work activities and fatigue were observed for both groups (Table 3.4). The online FAME-W participants showed greater improvements in fatigue, quality of life, depression, and pain levels than those in the self-guided group. In contrast, the self-guided group participants demonstrated greater improvements in work role functioning and anxiety levels. Paired with the qualitative data, these improvements in both groups may suggest that the strategies and the knowledge gained from online programme helped participants acquire fatigue management strategies and improve their ability to complete work activities.

3.14 Conclusion

This study demonstrated that the content of the FAME-W intervention, originally delivered in-person, could be successfully adapted for both an online format and a self-guided workbook format, with both delivery methods being acceptable to participants. Despite the small sample size, improvements were observed in fatigue management and work ability across participants in both the online and self-guided groups. The online format of the intervention enabled participation from individuals who might not have been able to attend an in-person programme due to logistical barriers such as geographic distance or scheduling conflicts.

Furthermore, the self-guided FAME-W workbook provided a flexible, self-paced alternative that was highly valued by participants for its detailed content and structure. Participants in the self-guided group reported increased confidence in managing their

symptoms independently, highlighting the workbook's impact on fostering self-efficacy and symptom management. These findings suggest that both the online and self-guided formats of FAME-W are feasible and acceptable, supporting the progression to a powered randomized control trial that includes both delivery methods.

The following chapter will discuss the randomized control trial of FAME-W, which will further explore the impact of these delivery formats on participants' outcomes.

CHAPTER 4: FAME-W RANDOMIZED CONTROL TRIAL

4.1 Introduction

This chapter outlines the aims, methods, results, and discussion of the RCT comparing the two delivery methods i.e. online and self-guided workbook. It begins by presenting the study's aims and objectives, as well as the application of the MRC framework to FAME-W. Subsequently, the chapter details the study design, recruitment process, data collection, and analysis procedures. The chapter concludes with a presentation of the study results and a discussion of the findings.

As highlighted in Chapter 1, the development and evaluation of FAME-W were guided by the MRC framework for complex interventions (Skivington et al., 2021). Table 4.1 illustrates how the various stages of the MRC framework were applied in the development, feasibility, implementation, and evaluation of FAME-W.

Table 4-1 Application of the MRC framework to the FAME-W

MRC Phase	Element	Application to FAME-W
Phase I: Development	Completing a needs assessment	Investigate the impact of fatigue on work and to identify the support requirements for managing fatigue in the workplace (Connolly et al., 2016)
	Identifying and developing appropriate theory	Literature review identified self-efficacy has been used to guide other self-management programmes. FAME-W is guided by self-efficacy theory.
	Intervention development	Need for interventions tailored to manage fatigue in work identified and developed using results

		identified in the needs assessment.
Phase II: Feasibility and acceptability	Testing procedures for acceptability, compliance, and intervention delivery	FAME-W was developed and tested as a in person intervention for feasibility and acceptability as a mixed methods RCT (McCormack et al., 2018)
	Estimating recruitment and retention	Data from pilot RCT informed strategies for recruitment and retention in Phase III.
	Determining sample size	Data from pilot RCT used to calculate sample size.
*Phase III: Evaluation	Repeated phase due to change in context	FAME-W is adapted to online delivery and self-guided workbook. These were tested and found feasible and acceptable (Karkon et al., 2023)
	Assessing effectiveness	Parallel comparative RCT
	Understanding change process	Concurrent mixed method process evaluation
	Cost-effectiveness	Beyond the scope of this study being carried out.
Phase IV: Implementation	Dissemination	Publications and engagement with key stakeholders.
	Surveillance, monitoring and long-term follow-up	If the online and/or self-guided workbook are found effective, process and outcome data could inform national implementation study

**Note Phase III: Evaluation is the focus of the PhD thesis*

Therefore, the overall aim of this study is to evaluate and compare the occupational therapy led online FAME-W with a self-guided workbook of FAME-W, as per Stage III of the Medical Research Council (MRC) framework (Medical Research Council, 2008).

The study objectives are to:

- test and compare online FAME-W with the self-guided FAME-W workbook in reducing the impact of fatigue, pain, and stress on work performance of individuals with IA,

- test and compare the online FAME-W with the self-guided FAME in improving quality of life of individuals with IA

4.2 Study Design

UK Medical Research Council (MRC) framework for evaluating complex interventions was followed for this study (Skivington et al., 2021). This study employed a parallel comparative multisite RCT to compare both delivery methods of FAME-W in improving work performance. This was discussed in detail in Chapter 3, Section 3.4

4.3 Ethical approval

Ethical approval was granted by St. James's Hospital/Tallaght University Hospital Research Ethics Committee, St. Vincent's Hospital Ethics Committee, HSE Southeast Research Ethics Committee and Sligo Research Ethics Committee (Appendix D).

4.4 Study sample

Sample Calculations

The number of participants for the study was calculated based on the Work Role Functioning Questionnaire (WRFQ) scores from the pilot study conducted by McCormack et al. (2018). In the previous study, the effect sizes for individual WRFQ scores ranged from 0.4 to 0.7. To detect an effect size of 0.4 with a significance level of 5% and a power of 80%, 99 participants per group (99 for the online group and 99 for the self-guided workbook group) were required.

However, due to recruitment difficulties caused by the COVID-19 pandemic, the sample size calculations were adjusted to detect a 0.7 effect size. For a 0.7 effect size, a sample size of 80 participants was needed. To account for a 20% attrition rate, the final sample size was calculated at 100 participants, allowing for 50 participants in each group.

Eligibility

Inclusion and exclusion criteria of the participants were discussed in Chapter 3, Section 3.6.

4.5 Recruitment

Participants were recruited through seven sites, including: (i) outpatient rheumatology clinics, (ii) occupational therapy clinics, (iii) voluntary arthritis organizations and (iv) social media. A number of recruitment strategies were employed at each site as outlined in Figure 4.1.

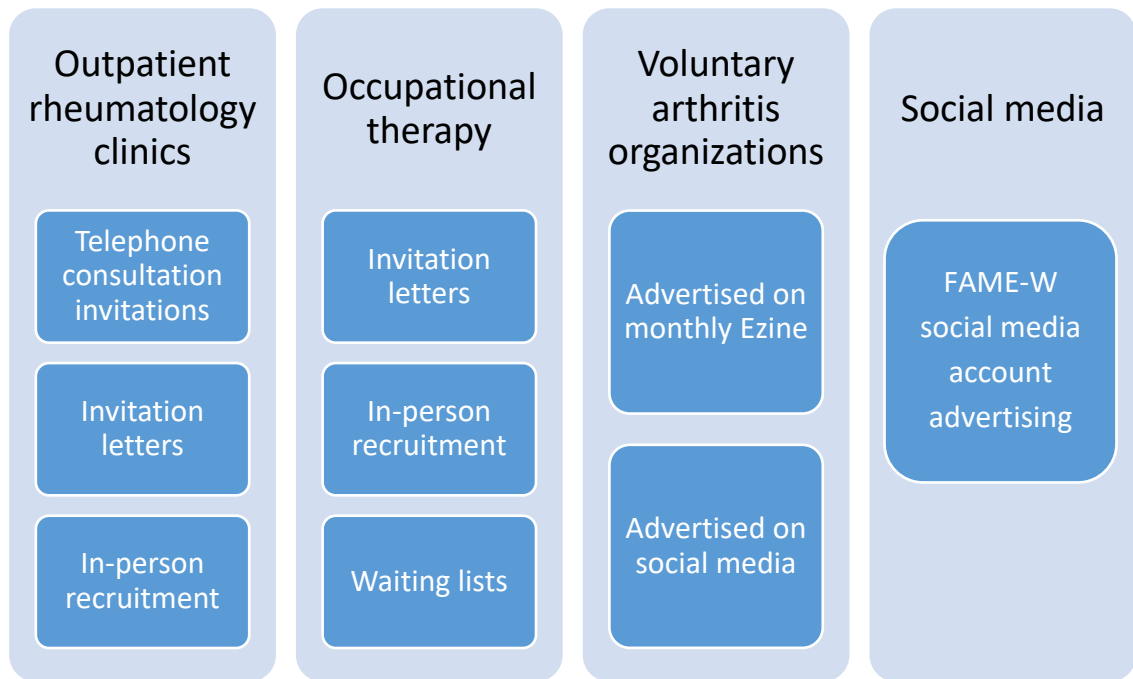


Figure 4.1 Recruitment strategies

(i) Recruitment through Outpatient Rheumatology Clinics

Individuals attending outpatient rheumatology clinics at four study sites were recruited using three different sequential approaches, in accordance with evolving COVID-19 public health guidelines. After the clinic staff identified the individuals who met the eligibility criteria through chart review, participants were recruited through: (a) invitation to participate by the rheumatology consultant during telephone consultations (b) sending invitation letters followed by a phone call and (c) in-person recruitment during out-patient clinics.

(a) invitation to participate by the rheumatology physician during telephone consultations

Clinic staff identified individuals based on their age and disease criteria prior to each clinic. A list of identified individuals was provided to each consultant the day of the clinics to check employment status during telephone consultations. If participants met the full eligibility criteria, the consultants, with the individual's consent, provided their contact

details to the PhD researcher, who then reached out to the individuals to explain the study. If the individual was interested in taking part, they were sent a PIL (Appendix D) via email or mail if requested. These individuals were given at least seven days prior to a follow up phone call.

(b) sending invitation letters followed by a phone call

Consultants reported that the telephone recruitment was time consuming and slow. This strategy was replaced with identifying patients that met the age and disease criteria through screening the weekly clinic lists for each consultant. Clinic staff sent invitation letters to identified individuals. Follow up calls were made by the clinic staff to each potential participant that did not respond to the invitation letters.

(c) in-person recruitment during out-patient clinics

Following the lifting of COVID-19-related public health restrictions, in-person recruitment resumed in all outpatient clinics of rheumatology consultants who had agreed to participate in the recruitment process. This followed the same strategy discussed in Chapter 3, Section 3.8.

ii) Occupational Therapy Clinics and Waiting Lists

Participants were recruited through five occupational therapy clinics. In these sites, occupational therapists kept a data base of all patients they have seen in the past. Participating occupational therapists examined the data bases and the waiting lists to identify individuals who met the disease, age and work-related eligibility criteria. Invitation letters were sent to all eligible individuals. In clinics, occupational therapists gave PILs to patients that fit all eligibility criteria. All patients who received the PILs were asked to contact the researcher if they were interested in taking part in the study. Individuals were given at least seven days prior to being contacted by phone for a follow up. If these individuals agreed to take part, they were invited to complete the consent form and study measures via email and, if requested, a hard copy of the consent form and questionnaires was mailed to the potential participants.

iii) Volunteer Arthritis Organizations

A voluntary organization, Arthritis Ireland, included a section dedicated to FAME-W intervention on their monthly ezine for five months explaining the intervention and eligibility criteria. This section also included the contact information of the PhD candidate

for individuals to make contact if they were interested in taking part in the study. Individuals who expressed an interest in participating were sent PILs and were invited to complete the consent form and study measures sent via email and, if requested, a hard copy of the PIL, consent form and questionnaires was mailed to the participants.

iv) Social Media

Recruitment was also carried out through social media advertising. An X account was created for the study with the handle @ArthritisandWork. Information on the study and eligibility criteria were disseminated through the X account. Participants who expressed an interest in participating were sent PILs and were invited to complete the consent form and study measures via email. Additionally, if requested by the participant, a hard copy of the questionnaires was mailed to the participants.

4.6 Randomization

Following the completion of the study measures, participants were randomly allocated to the online group or self-guided group using a computer-generated randomisation list. Individuals allocated to the online group received the 4-week online FAME-W programme. Those allocated to the self-guided group received a self-guided workbook of FAME-W.

4.7 Data Collection Methods

Questionnaires were sent to participants via Qualtricks survey platform or via mail depending on their preference. Participants were provided with the option of completing their questionnaires online, on hard copy, or over the phone with assistance.

4.7.1 Quantitative Data

Participants were asked to complete all study measures prior to the programme (T1), immediately post programme (T2), and at 3 months follow up (T3). Figure 4.2. outlines all the data collection points of this study.

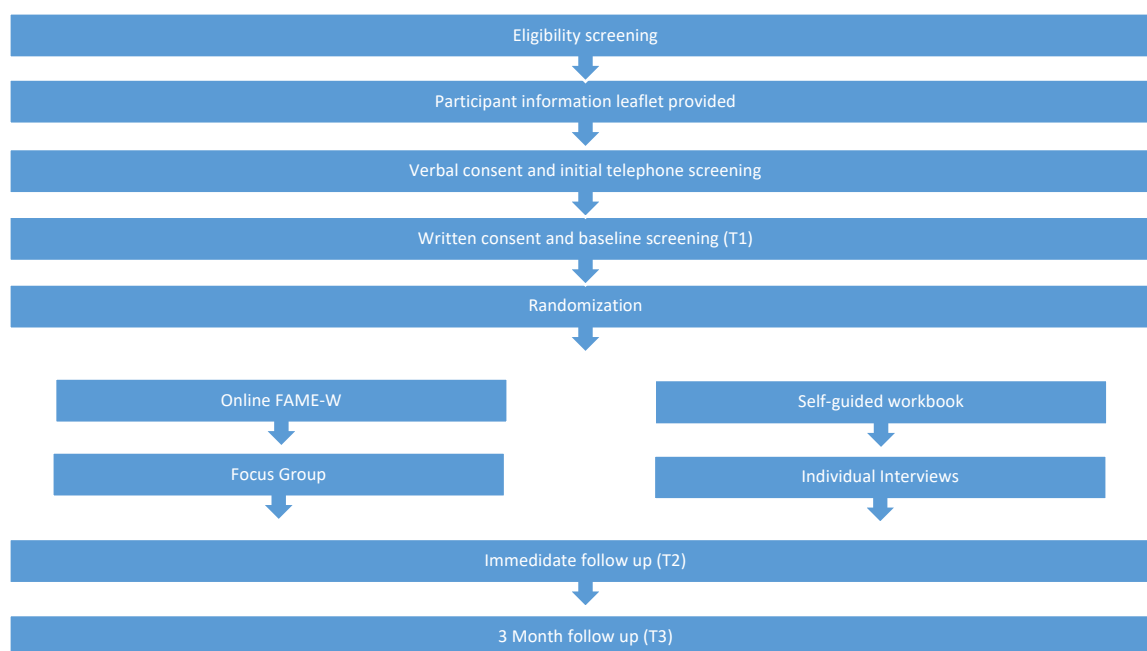


Figure 4.2 Participant recruitment, pre and post intervention steps

Demographic questions

All participants completed a demographic questionnaire (Appendix G). These included questions on gender, age, relationship status, living situation, diagnosis type and year, comorbidities, education, and their work. Work demographics included employment hours (full time or part time), job type (non-manual, mixed, non-manual and manual or manual) and their job title.

Outcome measures:

A list of outcome measures is given below. Each of the outcome measures were described in detail in Chapter 3, Section 3.10.1.

Primary outcome measure:

- Work Role Functioning questionnaire (WRF) (Amick, 2000)

Secondary outcome measures

- Multidimensional Fatigue Inventory (MFI) (Smets et al., 1995)
- Arthritis Work Spillover (AWS) (Gignac et al., 2006)
- Hospital Anxiety and Depression scale (HADS) (Zigmond & Snaith, 1983)
- The Stanford Arthritis Self-Efficacy Scale Short Form (ASES-8) (Lorig et al., 1989)

- The Arthritis Impact Measurement Scale Short Form (AIMS2-SF) (Guillemin et al., 1997)
- The Short Form McGill Pain Questionnaire (SF-MPQ) (Melzack, 1987)
- EQ-5D-5L questionnaire (EuroQol Research Foundation, 2019)

Logbook of work attendance

Participants were asked to keep a log of absenteeism periods from work over a three-month period from the start of the online programme or receiving the self-guided workbook. The participants were asked to log dates, reasons, and time period of absenteeism from work (Table 4.2) related to their arthritis. This included medical appointments, arthritis-related work difficulties and any appointments related to managing their IA. Previous research has suggested that measuring work outcomes such as absenteeism and return-to-work should be a part of the routine management of rheumatic conditions in working-age adults (Wilkie et al., 2020).

Table 4-2 Absenteeism log template

Week-beginning Date	In how many occasions did you take time off work related to your arthritis? Please record the date of absence.	For each occasion, please record the number of hours and/or days you were absent.	Please record reason for absence from work. E.g. medical appointment, sick leave/absence etc.
<i>10.04.2021</i>	<i>1</i>	<i>2 hours</i>	<i>Medical appointment</i>
<i>26.04.2021</i>	<i>3</i>	<i>1-hour x3</i>	<i>Fatigue</i>

4.8 Data Analysis

Data were inputted and analysed using IBM SPSS Statistics version 27 (StataCorp, 2017). Data analysis and reporting was in accordance with CONSORT guidelines for RCTs. An intention to treat (ITT) analysis was applied. ITT analysis ensures the inclusion of all randomized individuals in the analysis, irrespective of factors such as

noncompliance, protocol deviations, withdrawal or anything that happens after randomisation (Gupta, 2011).

Descriptive statistics were used to present data on the characteristics of the participants including age, gender, employment status (fulltime or part time), employment type (manual, non-manual, mixed), marital status, living situation (alone or with others), and clinical characteristics including IA type, year of diagnosis, and comorbidities.

Baseline, immediate and three months follow-up of primary and secondary outcome measure scores, between and within the online and the self-guided groups, were compared. Data were assessed to determine a normal or non-normal distribution.

Change scores for the online and self-guided groups were calculated between baseline, immediately after intervention and at 3 months follow up and tested for statistical significance. Statistical significance at $p < 0.05$ was assumed throughout. To determine any difference in the impact of the different modes of delivery of FAME-W, changes in primary and secondary outcome measures were computed for the self-guided and online groups.

Handling missing data in an ITT analysis, commonly used in clinical trials and experimental studies, is essential for preserving the validity of the results (White et al., 2012). Several methods are typically employed to address missing data. One such method is Last Observation Carried Forward (LOCF), which replaces missing values with the last observed value (Lydersen et al., 2019). While LOCF is simple to implement and preserves the sample size, it can introduce bias if the data are not missing completely at random (MCAR) and assumes no change in the outcome, which may not be a realistic assumption. Another method is Baseline Observation Carried Forward (BOCF), which replaces missing values with the baseline value. Although BOCF is straightforward, it may underestimate treatment effects, particularly when the treatment is effective (Twisk et al., 2020).

Complete Case Analysis (CCA) involves analysing only participants with no missing data (Dziura et al., 2013). While this method is simple and unbiased when data is missing completely at random (MCAR), it can significantly reduce the sample size and introduce bias if the data is not missing at random. Mixed-Effects Models offer another approach by modelling the observed data and incorporating random effects to account for within-subject correlation (Gabrio et al., 2022). This method is flexible and particularly suitable

for longitudinal data, as it can handle various types of missing data patterns, though it requires statistical expertise and correct model specification to be effective.

Mean imputation, where missing values are replaced with the mean of the observed data, is straightforward to implement but can reduce variability and introduce bias into the analysis (White et al., 2012). In contrast, Multiple Imputation (MI) offers a more sophisticated approach by creating multiple sets of imputations and combining the results. Though more complex and computationally intensive, this method addresses the uncertainty associated with missing data, resulting in more accurate and less biased outcomes (Jakobsen et al., 2017).

The choice of method depends on several factors, including the nature and mechanism of missing data (whether it is missing completely at random, at random, or not at random), the study design and data structure (cross-sectional vs. longitudinal data), and the available statistical expertise and resources. Generally, multiple imputation and Mixed-Effects Models are recommended for their robustness and ability to handle complex missing data patterns (Paul et al., 2022). By carefully considering the missing data mechanism and choosing an appropriate method, bias can be minimized, maintaining the integrity of the ITT analysis (Bell et al., 2014; White et al., 2012). As recommended by Austin et al., (2021), researchers are encouraged to consider multiple imputation as a valuable tool for addressing the challenges associated with missing data in clinical research. In this study, given that there was only missing outcome data and no evidence of a pattern to the missing data, multiple imputation was used for ITT analysis, based on the above-mentioned recommendations.

4.9 Results

4.9.1 Recruitment and attrition

Nine FAME-W interventions were delivered between August 2021 and May 2023. A total of 3,032 medical records were screened and 1,171 individuals met the age and disease criteria for the study. Of these, 321 individuals could not be contacted, and 36 were not interested in participating, leaving 814 individuals. Among the remaining, 604 were ineligible: 325 were unemployed, 105 had flare-ups, and 95 had contracted COVID-19. Of the 210 eligible participants invited, 132 accepted. During the process, 10 were unable to be contacted, resulting in 122 individuals who were successfully randomized into the study. Of the 122, 61 were assigned to the online and 61 to the self-guided group. In the online group, 6 participants did not attend any sessions and 9 were lost to follow up and

1 withdrew from the study, leaving 45 participants for immediate follow-up. Of these, 11 were unable to be contacted for the 3-month follow-up, resulting in 34 participants completing the 3-month follow-up. Of those who completed the 3-month follow up, 4 participants did not complete the immediate follow up questionnaires. In the self-guided group, five participants contracted COVID-19 and five withdrew from the study leaving 51 participants. Of these, 16 participants were lost to follow-up, 3 contracted COVID-19, 5 withdrew, leaving 27 participants for immediate follow-up. Of these, 3 were unable to be contacted for the 3-month follow-up. Twenty- six participants completed the 3-month follow-up whilst 6 of these participants did not complete the immediate follow up questionnaires. Participant recruitment and progression is summarised in Figure 4.1 below. Detailed information regarding attendance is described in detail as part of the process evaluation results in Chapter 5.

Therefore, the recruitment rate for this study was calculated with the number of individuals who met the full eligibility criteria. As noted previously, 604 individuals were excluded due to unemployment, as they didn't meet the full eligibility criteria for participation. This left 567 eligible individuals. Therefore, the recruitment rate was calculated based on how many of these 567 eligible individuals agreed to participate and were ultimately randomized ($n=122$). Therefore, the recruitment rate for this study was calculated to be 21.52%. Of the 122 randomized, 60 completed the three-month follow-up, resulting in a retention rate of 49.18%. Specifically, the online group had a retention rate of 55.7%, whereas the self-guided workbook group reported a lower retention rate of 39.3%.

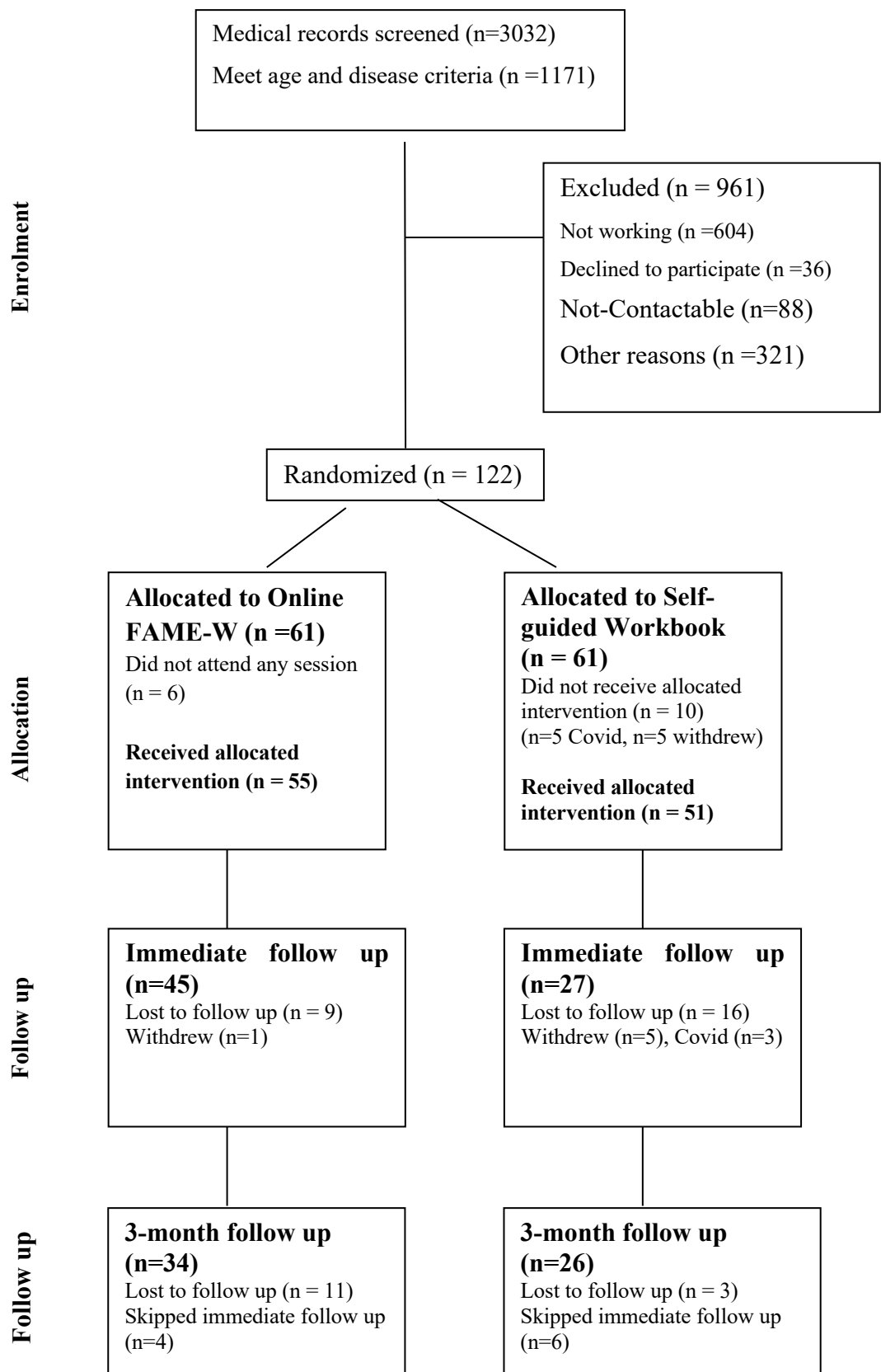


Figure 4.3 CONSORT diagram

4.9.2 Baseline demographic characteristics

The CONSORT guidelines recommend reporting baseline data for participants but advise against performing significance testing of baseline differences in RCTs (Moher et al., 2010). The characteristics of participants at baseline are summarized in Table 4.3.

Table 4-3 Baseline characteristics of randomized participants

	Online Group (n=61)	Self-Guided Group (n=61)
Mean age (SD)	48.7 (10.08)	49.64 (10.01)
Age Range in years	25-65	24-65
Gender		
Female (%)	46 (75.4)	51 (83.6)
Male (%)	15 (24.6)	10 (16.4)
Type of Arthritis		
RA (%)	25 (41)	20 (32.8)
PA (%)	14 (23)	15 (24.6)
FM (%)	7 (11.5)	6 (9.8)
AS (%)	5 (8.2)	5 (8.2)
SLE (%)	1 (1.6)	3 (4.9)
GOUT (%)	0 (0)	1 (1.6)
Other (%)	9 (14.8)	11 (18)
Years since Diagnosis (SD)	9 (6.60)	10 (8.06)
Marital Status		
Married (%)	44 (72.13)	37 (60.7)
Single (%)	15 (24.59)	17 (29.9)
Separated (%)	2 (3.28)	6 (9.8)
Widowed (%)	0	1 (1.6)
Living Situation		
With Others (%)	57 (93.4)	49 (80.3)
Alone (%)	4 (6.6)	12 (19.7)
Level of Education		
College/University (%)	51 (83.6)	45 (75.8)
Leaving Certificate (%)	5 (8.2)	9 (14.8)
Junior Certificate (%)	5 (8.2)	6 (9.8)
Primary Level (%)	0 (0)	1 (1.6)
Chronic Condition (Self-Reported)		
Yes (%)	36 (59.0)	37 (60.7)
No (%)	25 (41.0)	24 (39.3)
Employment Status		
Full Time (%)	41 (67.2)	48 (78.7)
Part Time (%)	20 (32.8)	13 (21.3)
Type of Work		
Non-Manual (%)	38 (62.3)	41 (67.2)
Mixed (%)	20 (32.8)	16 (26.2)
Manual (%)	3 (4.9)	4 (6.6)

Participants in the online FAME-W group (n=61) had a mean age of 48.7 years (SD = 10.08), with an age range of 25-65 years. In the self-guided FAME-W group (n=61), the mean age was 49.64 years (SD = 10.01), with an age range of 24-65 years. The majority of participants in both groups were female, comprising 75.4% of the online FAME-W group and 83.6% of the self-guided group.

The distribution of IA types was similar in both groups, with RA and PsA being the most common. In the online FAME-W group, 41% had RA and 23% had PsA, while the self-guided group had 32.8% with RA and 24.6% with PsA, indicating both groups were primarily affected by these types of IA. The mean number of years since diagnosis was 9 years (SD = 6.60) for the online FAME-W group and 10 years (SD = 6.08) for the self-guided group.

Marital status distribution indicated that most participants were married: 72.13% in the online FAME-W group and 60.7% in the self-guided group. The proportion of single, separated, or widowed participants was lower. In terms of living situation, majority of participants reported to be living with others.

Education levels varied, with the majority of participants holding a college or university degree: 83.6% in the online FAME-W group and 75.8% in the self-guided workbook FAME-W group. The remaining participants had educational attainment ranging from primary to leaving certificate levels.

A significant proportion of participants reported having a chronic condition other than IA: 59% in the online FAME-W group and 60.7% in the self-guided group. Regarding employment status, 67.2% of participants in the online FAME-W group were employed full-time, compared to 78.7% in the self-guided group. Part-time employment was reported by 32.8% of participants in the online FAME-W group and 21.3% in the self-guided workbook FAME-W group.

The type of work participants were engaged in showed that 62.3% of participants in the online FAME-W group and 67.2% in the self-guided group were involved in non-manual work. Mixed work types were reported by 32.8% in the online group and 26.2% in the self-guided group. Manual work was reported by 4.9% in the online group and 6.6% in the self-guided group.

4.9.3 Normality Testing

Data from all outcome measures were analysed to assess normality, however, as the data in this study did not meet the requirements for parametric testing, non-parametric tests were conducted for all outcome measures. For between group testing Mann-Whitney U tests and within group testing Friedman's Two-Way Analysis were used.

4.9.4 Multiple Imputation

In order to ensure that the randomness of multiple imputation did not affect the results of the analysis, ten imputations were performed. However, because the results were consistent across all imputations, only the first imputation will be reported throughout the chapter.

4.9.5 Work Role Functioning (WRF) questionnaire

The primary outcome measure for this study was Work Role Functioning (WRF) questionnaire (Amick, 2000). WRF consists of five subcategories: work scheduling demands, output demands, physical demands, mental demands and social demands. Table 4.4 presents median scores over time for both delivery methods at three time points; baseline (T1), immediate follow-up (T2) and 3-months follow up (T3).

Comparison of changes in the sub-categories of WRF are presented in Table 4.4. Each category was tested between the online FAME-W and the self-guided workbook. Change scores were calculated between T1 and T2, T1 and T3, and T2 and T3. However, Mann-Whitney U tests showed no statistically significant differences between the two groups at any of the time points, as indicated by the p-values (Table 4.4).

Overall, scores for the online group decreased between T1 and T2 but largely returned to baseline by T3, with the exception of physical demands and social demands, which showed reduced variability, and mental demands, which saw a slight improvement. For the self-guided group, all domain scores returned to baseline by T3. While output demands exhibited a slight increase in the median to 80.00. Overall, the medians remained relatively close to their baseline values, with slight changes across the categories

Table 4-4 Scores of Sub-Categories of WRF at three time points and the significance testing findings

Sub-Categories of WRF	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Work Scheduling Demands	70.00 (5-100) 35.00	69.4 (5-95) 12.50	70.8 (20-100) 7.90	75.00 (30-100) 30.00	69.00 (30-100) 10.40	71.2 (25-95) 10.00	0.901	0.265	0.223
Output Demands	79.00 (7-100) 22.00	76.00 (0-100) 9.00	79.00 (46-100) 9.00	79.00 (0-100) 23.50	78.00 (39-100) 7.00	80.00 (64-100) 9.00	0.775	0.808	0.680
Physical Demands	65.00 (4.2-100) 37.50	60.9 (4.2-95.80) 9.00	62.3 (4.2-100) 13.35	62.50 (4.2-100) 33.30	58.35 (12.5-79.2) 8.40	62.10 (87-12.5) 8.10	0.262	0.947	0.418
Mental Demands	75.00 (20.80-100) 16.60	75.00 (25-100) 10.30	77.45 (8.30-100) 5.70	79.20 (20.80-100) 20.90	75.55 (41.7-100) 8.30	79.20 (50-100) 6.90	0.078	0.146	0.305
Social Demands	91.70 (25-100) 25.00	83.6 (33.3-100) 14.80	88.95 (33.3-100) 6.25	91.70 (8.30-100) 16.70	85.1 (25-100) 7.10	91.1 (66.7-100) 5.60	0.488	0.758	0.831

Table 4-5 Median for Work Role Functioning Subscales and Pairwise Comparisons (p-values) for Online FAME-W Participants

Sub-Categories of WRF	Online FAME-W Median			Online FAME-W Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Work Scheduling Demands	70.00	69.4	70.8	.853	.546	.430
Output Demands	79.00	76.00	79.00	.698	.207	.099
Physical Demands	65.00	60.9	62.3	.843	.921	.921
Mental Demands	75.00	75.00	77.45	.745	.227	.378
Social Demands	91.70	83.6	88.95	.265	.676	.126

Table 4.5 presents the within-group differences in WRF subcategories for the online group. Friedman analysis incorporated Bonferroni adjustments to p-values to account for the multiple comparisons effect. This adjustment method rigorously controls the family-wise error rate, thereby mitigating the risk of Type I errors, which are prevalent when multiple hypotheses are tested concurrently (Sauro & Lewis, 2012). For the online FAME-W group, work scheduling demands remained stable, with no significant changes between time points. Output demands showed a small fluctuation, but the changes were not statistically significant. Physical demands and mental demands had minimal variations in medians, and none of the comparisons were significant. social demands fluctuated slightly but again, without significant differences.

Table 4-6 Median for Work Role Functioning Subscales and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

Sub-Categories of WRF	Self-guided Workbook Median			Self-guided Workbook Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Work Scheduling Demands	75.00	69.00	71.2	.642	.816	.816
Output Demands	79.00	78.00	80.00	1.0	0.66	.092
Physical Demands	62.50	58.35	62.10	0.016[.048]*	.878	0.016[.048]*
Mental Demands	79.20	75.55	79.20	.001[.004]*	.482	.011[.034]*
Social Demands	91.70	85.1	91.1	.035[.105]*	.574	.008[.023]*

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

For the self-guided group, within group analysis showed that in the physical demands, significant decrease were observed from T1 to T2 and improvements from T2 to T3 returning close to baseline levels (Table 4.6). Mental demands also showed significant decrease, from T1 to T2 and improvements from T2 to T3 returning close to baseline levels. Social demands showed significant decrease between T1 to T2 and T2 to T3. Significant decrease at T1 to T2 was adjusted to be non-significant after the Bonferroni corrections. Conversely, the work scheduling and physical demands subscales did not reach statistical significance.

4.9.6 Secondary Outcome Measures

4.9.6.1 Multidimensional Fatigue Inventory (MFI)

MFI consists of five sub-categories. These are general fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue. Table 4.7 presents the median, minimum, maximum, IQR scores and the p values of MFI in all three time points for both delivery methods. Analysis from the Mann-Whitney U test presented in Table 4.7, showed no significant differences between the two delivery methods at any time points.

In the online FAME-W group, there were no statistically significant differences between the three time points. Most categories, such as general fatigue, remained below baseline scores by T3, indicating some improvement over time. However, these changes were not substantial.

In the self-guided group, the physical fatigue category increased in median scores from T1 to T3. Other categories showed slight fluctuations, but no other significant changes were observed.

Table 4-7 Scores of Sub-Categories of MFI at three time points and the significance testing findings

Sub-Categories of MFI	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
General Fatigue	12.00 (4-20) 6.0	11.36 (4-20) 4.23	11.00 (5-19) 3.0	12.00 (5-20) 7.0	11.9 (4-19) 4.0	12.00 (4-20) 4.11	.607	.734	.608
Physical Fatigue	12.00 (6-20) 4.0	12.00 (4-20) 4.00	12.00 (7-19) 2.60	12.00 (6-20) 5.0	11 (4-20) 3.81	12.49 (4-20) 4.0	.068	.962	.133
Reduced Activity	11.00 (4-20) 5.0	11.68 (4-18) 5.06	12.66 (6-19) 3.0	12.00 (6-20) 4.0	12.29 (4-19) 3.00	13.00 (4-19) 3.20	.615	.702	.979
Reduced Motivation	12.00 (4-20) 3.0	11.82 (4-20) 3.00	11.43 (7-18) 3.56	12.00 (6-20) 4.0	11.75 (4-19) 3.03	12.00 (4-20) 3.51	.998	.768	.744
Mental Fatigue	13.00 (4-20) 4.0	11.92 (4-20) 4.18	12.00 (4-15) 4.68	11.00 (4-20) 5.0	12.03 (4-19) 3.51	12.03 (4-20) 3.19	.493	.688	.479

The Friedman analysis across three time points for the online group showed no significant differences in any of the sub-categories across the three time points (Table 4.8).

Table 4-8 Median for Fatigue Sub-Category Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

Sub-Categories of MFI	Online FAME-W Median			Online FAME-W Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
General Fatigue	12.00	11.36	11.00	.319	.365	.928
Physical Fatigue	12.00	12.00	12.00	.964	.651	.619
Reduced Activity	11.00	11.68	12.66	.786	.174	.227
Reduced Motivation	12.00	11.82	11.43	.587	.786	.786
Mental Fatigue	13.00	11.92	12.00	.619	.964	.651

The self-guided group demonstrated variability in the sub-categories (Table 4.9). Although most comparisons remained statistically non-significant, physical fatigue showed a notable decrease, non-significant after the Bonferroni correction, from T1 to T2 ($p = 0.033[.098]^*$), indicating an improvement immediately following the completion of the workbook that was not sustained at the 3-month follow-up (T3). Other fatigue dimensions such as general fatigue and mental fatigue did not exhibit significant changes, echoing the findings of the online FAME-W.

Table 4-9 Median Fatigue Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

Sub-Categories of MFI	Self-guided Workbook Median			Self-guided Workbook Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
General Fatigue	12.00	11.9	12.00	.676	.781	.486
Physical Fatigue	12.00	11.00	12.49	.033[.098]*	.610	.104
Reduced Activity	12.00	12.29	13.00	.781	.330	.210
Reduced Motivation	12.00	11.75	12.00	.642	.227	.458
Mental Fatigue	11.00	12.03	12.03	.745	.286	.458

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

This differential impact between the two delivery modalities suggests that while immediate improvements can be seen in physical aspects of fatigue with more hands-on, workbook-based approach, sustaining these benefits poses a challenge. Moreover, the lack

of significant changes in other fatigue categories highlights the complexity of addressing multifaceted fatigue dimensions in therapeutic settings.

4.9.6.2 Hospital Anxiety and Depression scale (HADS)

Depression and anxiety categories of HADS were analysed and the medians and p values are presented in the Table 4.10. Analysis comparing the online FAME-W and self-guided groups for anxiety and depression, Mann-Whitney U analyses did not show any significant differences between the groups at any time points (T1, T2, or T3). Both groups showed similar patterns in terms of symptom severity according to the standard cut-off scores for the HADS.

For anxiety, the online FAME-W group reported a median score of 8.0 at T1, and the self-guided group reported a median score at 8.5, both falling within the mild range. By T2, the online group showed improvements, with the median score dropping to 5, placing it within the normal range, and the self-guided group's score decreasing to 7, also in the normal range. At T3, the online group experienced a slight increase to 6.40, still in the normal range, while the self-guided group remained stable at 7, continuing in the normal range. For depression, at T1, the online group reported a median score of 6 and the self-guided group at 7, both in the normal range. Over time, both groups showed minor decreases in their depression scores. At T2, the online group's median score fell to 5.38, and the self-guided group showed a similar reduction to 5.55, both remaining in the normal range. At T3, the online group's score rose slightly within normal limits, and the self-guided group remained stable at 5.53.

Table 4-10 Scores of Sub-Categories of HADS at three time points and the significance testing findings

Sub-Categories of HADS	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Anxiety	8.00 (0-19) 6.00	5.00 (0-15) 6.00	6.40 (0-20) 4.69	8.5 (0-20) 8.00	7.00 (0-20) 4.26	7.00 (0 -20) 4.00	.542	.422	.983
Depression	6.00 (1-19) 7.00	5.38 (0-17) 5.00	6.18 (0-14) 4.00	7.00 (0-18) 5.00	5.55 (0-17) 4.38	5.53 (0-16) 3.73	.739	.871	.947

Despite these reductions in anxiety and depression scores, the statistical analysis shows p-values greater than 0.05 across all time-point comparisons for both delivery methods, indicating that these changes were not statistically significant. This suggests that, while there was a trend toward improvement in both anxiety and depression levels, the changes were not substantial enough to achieve statistical significance within the scope and duration of the study. However, greater improvements were observed in anxiety scores from baseline to T2 and T3 for the online group compared to the self-guided group, though these differences were still not statistically significant. Overall, both programmes appear similarly successful in maintaining anxiety and depression within normal or mild levels over time.

The Friedman tests of the online group showed statistically significant changes between T1 and T2 however, with Bonferroni-adjusted results no statistical significance was found. Depression scores did not exhibit significant changes at any of the tested intervals (Table 4.11).

Table 4-11 Median Anxiety and Depression Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

Sub-Categories of HADS	Online FAME-W Median			Online FAME-W Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Anxiety	8.00	5.00	6.40	.024 [.071]*	.161	.390
Depression	6.00	5.38	6.18	.085	.469	.319

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

Conversely, for the self-guided workbook group, statistically significant improvements in both anxiety and depression scores were observed (Table 4.12). Specifically, a significant reduction in anxiety scores was evident from T1 to T2 ($p = 0.007$ adjusted $p=.021$), and for depression, a significant reduction was observed from T1 to T2 ($p = 0.011$ adjusted $p=.032$).

Table 4-12 Median Anxiety and Depression Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

Sub-Categories of HADS	Self-guided Workbook Mean Rank			Self-guided Workbook Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Anxiety	8.5	7.00	7.00	.007[.021]*	.104	.286
Depression	7.00	5.55	5.53	.011[.032]*	.029[.087]*	.710

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

These results illustrate that while both delivery methods were effective in reducing symptoms of anxiety and depression, neither group exhibited clinical levels of anxiety and depression at baseline, which may explain the stable scores over time. The application of the Bonferroni correction further enhances the robustness of these results by addressing potential issues with multiple comparisons, ensuring that the findings are reliable and not due to chance.

4.9.6.3 The Short Form McGill Pain Questionnaire (SF-MPQ)

SF-MPQ includes a Pain Rating index with two subcategories (sensory and affective), a visual analogue scale (VAS) and Present Pain Intensity scale (Table 4.13). Mann-Whitney U test showed that there were no statistically significant differences between the online and self-guided groups in reducing pain symptoms across the sensory, affective, VAS, and pain intensity subcategories of the SF-MPQ.

For sensory pain, median scores remained consistent across time points. By T3, both groups exhibited slight increases in median scores, but the differences between the two groups were negligible, with p-values indicating no statistically significant differences. For affective pain, both groups started with similar median scores and remained stable over time. Once again, no significant differences between the two groups were found.

In terms of VAS scores, both groups exhibited similar trends. At T1, both the online and self-guided groups had median scores of 5, with minor decreases over time that were not statistically significant. The pain intensity scores followed a similar pattern, with both groups showing consistent median scores of 2 across all time points and no significant group differences.

Table 4-13 Scores of Sub-Categories of SF-MPQ at three time points and the significance testing findings

Sub- Categories of SF-MPQ	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Sensory	10 (0-33) 11	9 (0-24) 10	12 (0-30) 5	12 (0-29) 10	9.07 (0-23) 4.37	11.66 (0-22) 4.20	.506	.710	.951
Affective	4 (0-12) 4	3 (0-10) 3.00	3.56 (0-11) 2.98	3.5 (0-11) 3	2.9 (0-10) 2.79	3.10 (0-8) 2.42	.869	.721	.634
VAS	5 (1-10) 3	4.9 (1-9) 2.71	4.47 (1-9) 2.54	5 (0-10) 3	5 (1-8) 2.32	5 (1-9) 2.02	.865	.703	.488
Present Pain Intensity	2 (0-5) 2	2 (0-5) 1.29	2 (0-5) 1.50	2 (0-5) 1	2 (0-4) 1.52	2 (0-5) 1.36	.814	.418	.354

Pain Rating Index (PRI)

For the Friedman tests a significant change was observed in the online FAME-W, with a significant decrease in affective category from T1 to T2 ($p = .016$ adjusted $p = 0.046$) suggesting an initial decrease of affective pain components, which, did not show significant changes at the 3-month follow-up (Table 4.14).

Table 4-14 Median Sensory and Affective Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

Sub-Categories of SF-MPQ PRI	Online FAME-W Median			Online FAME-W Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Sensory	10.00	9.00	12.00	.147	.037[.112]*	.526
Affective	4.00	3.00	3.56	.016[.046]*	.319	.161

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

The self-guided group displayed no significant changes in the sensory or affective pain ratings across the three time points, as all Bonferroni-adjusted p-values remained above the 0.05 threshold. The only exception was a marginal increase from T2 to T3 in the sensory subcategory ($p = .023$ adjusted $p = 0.069$), which did not reach conventional levels of statistical significance after Bonferroni adjustments (Table 4.15).

Table 4-15 Median Sensory and Affective Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

Sub-Categories of PRI	Self-guided Workbook Median			Self-guided Workbook Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Sensory	12.00	9.07	11.66	.178	.353	.023[.069]*
Affective	3.5	2.9	3.10	.051	.577	.164

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

These findings underscore the differential impact of the delivery methods on sensory versus affective pain components. While the online FAME-W appears to offer temporary relief, particularly in affective aspects of pain, the self-guided workbook of FAME-W does not demonstrate a significant impact on altering pain perceptions within the timeframe of the study. The application of the Bonferroni correction across analyses

ensures a conservative interpretation of these results, strengthening confidence in the observed effects being unlikely due to chance.

Visual Analog Scale (VAS)

The Friedman test analysis revealed no significant changes over the course of the study for any group. The online group exhibited minimal fluctuations in VAS, however, pairwise comparisons of the time intervals yielded no statistically significant differences indicating stability in pain perception as measured by VAS throughout the programme period (Table 4.16).

Table 4-16 Median VAS Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

Category	Online FAME-W			Online FAME-W		
	Median			Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
VAS	5.00	4.9	4.47	.821	.964	.856

Similarly, for the self-guided group the pairwise comparisons between the three time points showed no significant differences. These results suggest that neither delivery method significantly altered participants' self-reported pain levels as measured by the VAS throughout the study duration (Table 4.17).

Table 4-17 Median VAS Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

Category	Self-guided Workbook			Self-guided Workbook		
	Median			Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
VAS	5.00	5.00	5.00	.889	.676	.577

The consistency in VAS scores across both groups and across all three time points underscore the challenge of achieving significant changes in pain. This stability in pain assessment reflects the persistent nature of pain as captured through the VAS, highlighting the need for possibly more intensive or alternative therapeutic approaches to achieve notable improvements in pain management.

Present Pain Intensity (PPI)

In the online group, analysed by the Friedman test, the pairwise comparisons did not reveal any statistically significant differences indicating no substantial change in participants' pain intensity (Table 4.18).

Table 4-18 Median PPI Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

Sub-Categories of SF-MPQ	Online FAME-W			Online FAME-W		
	Median			Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T-T3	T3-T2
PPI	2.00	2.00	2.00	.892	.479	.415

Similarly, the self-guided group also yielded no statistically significant results. These outcomes suggest that neither delivery method significantly influenced the reported pain intensity levels over the study duration (Table 4.19).

Table 4-19 Median PPI Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

Sub-Categories of SF-MPQ	Self-guided Workbook			Self-guided Workbook		
	Median			Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
PPI	2.00	2.00	2.00	.676	.676	.403

These results underscore a consistent pattern of stability in pain intensity ratings across both delivery methods. This stability points to the resilience of pain perceptions to moderate intervention strategies within the timeframe analysed, highlighting potential gaps in the success of the current interventions to elicit significant changes in pain intensity as assessed by this specific metric.

4.9.6.4 Arthritis Work Spillover (AWS)

Arthritis Work Spillover total scores are calculated and presented in Table 4.21. The analysis revealed no statistical changes between two groups.

For the online group, Friedman analysis showed no statistically significant changes. Furthermore, the medians remained the same throughout the study period (Table 4.20).

Table 4-20 Median AWS Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

Sub- Categories of AWS	Online FAME-W Medians			Online FAME-W Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Total	19.98	19.98	19.98	.258	.619

Table 4-21 Scores of Sub-Categories of AWS at three time points and the significance testing findings

Sub-Categories of AWS	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Total	19.98 (7.98-30) 7.98	19.98 (7.98-30) 7.56	19.98 (12-30) 7.08	19.98 (12-30) 6.96	19.02 (6-28.92) 4.46	18.66 (12-28.98) 5.64	.418	.604	.184

In the self-guided group, a significant reduction was observed between T1 and T2 ($p = 0.02$, adjusted $p = 0.061$), however after Bonferroni adjustments this was not significant. This may be indicating a meaningful decrease in overall arthritis-related work spillover. This improvement was maintained through the end of the study, as shown by a further significant reduction between T3 and T1 ($p = 0.016$, adjusted $p = 0.047$), suggesting a sustained reduction in the interference of arthritis with work. These findings highlight both an initial improvement in managing the impact of work on arthritis and a long-term reduction in overall work-related interference from arthritis (Table 4.22).

Table 4-22 Median AWS Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

Sub-Categories of AWS	Self-guided Workbook Median			Self-guided Workbook Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Total	19.98	19.02	18.66	.020[.061]*	.016[.047]*	.426

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

These findings suggest that the self-guided workbook was effective in reducing overall negative outcomes related to arthritis at work. In contrast, the online group appeared to maintain baseline levels without significant improvement or deterioration across the measurement intervals.

4.9.6.5 EQ-5D-5L Questionnaire

EQ-5D-5L comprises of two components: a health states component with an index score and a visual analogue scale (VAS). Health states consists of five dimensions: mobility (MO), self-care (SC), usual activities (UA), pain/discomfort (PD), and anxiety/depression (AD). Score for each subgroup are presented in Appendix H.

The results of the comparison using Mann Whitney U test between the online FAME-W and self-guided workbook groups for the EQ-5D-5L Index Scores and VAS scores across three time points (T1, T2, and T3) showed no statistically significant differences between the two groups. For index scores, both groups remained stable over time. The online group had a median score of 0.72 at both T1 and T3, with a slight decrease to 0.71 at T2. The self-guided group similarly maintained a stable median score of 0.7 at T1, and 0.71 at both T2 and T3. The IQRs for both groups fluctuated slightly but did not indicate substantial variation in the index scores.

For VAS Scores, which reflect the participants' self-assessed health on a scale from 0 (worst health imaginable) to 100 (best health imaginable), the online group maintained a median score of 60.00 at T1, increased slightly to 63.00 at T2, and then decreased to 58.95 at T3. The self-guided group also showed consistent median scores, with 60.00 at T1, increasing to 62.38 at T2, and slightly decreasing to 57.11 at T3. Again, the IQR for both groups varied slightly over time, but there were no substantial differences between them. The p-values for VAS score comparisons between the groups indicated no statistically significant differences in self-reported health perceptions across time points between the two groups.

In summary, neither the index scores nor the VAS Scores showed statistically significant differences between the online and self-guided groups over the course of the study, suggesting comparable health outcomes between the two delivery methods.

Table 4-23 Scores of Sub-Categories of AWS at three time points and the significance testing findings

Sub-Categories of EQ-5D-5L	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Index Scores	.72 (-.13-0.95) 0.31	.71 (-.24-.93) 0.39	.72 (-.17-1) 0.63	.70 (-.41-1) 0.26	.71 (-.24-.93) 0.46	.71 (-.17-1) 0.39	.334	.928	.220
VAS	60.00 (20-90) 30.00	63.00 (40-90) 11.73	58.95 (2-90) 15.62	60.00 (10-95) 23.11	62.38 (40-85) 8.59	57.11 (30-90) 6.84	.560	.562	.517

The analysis of EQ-5D-5L index scores, using the Friedman test across three time points showed that within the online FAME-W, there were no statistically significant changes over time. This suggests a stable but unimproved state across the assessed dimensions. Notably, the overall health perception as measured by the VAS showed a significant decline from T2 to T3 ($p=.006$ adjusted $p = .018$), reflecting a decrement in perceived health quality despite the stability in individual health dimensions (Table 4.24).

Table 4-24 Median Index Scores, VAS Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

Sub-Categories of EQ-5D-5L	Online FAME-W Median			Online FAME-W Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Index Score	.72	.71	.72	.856	.526	.651
VAS	60.00	63.00	58.95	.246	.114	.006[.018]*

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

Similarly, the self-guided group exhibited no significant changes in index scores. Similar to the online group, the VAS scores indicated a significant reduction in overall health perception from T2 to T3 ($p=.011$ adjusted $p = .034$). These outcomes underscore a complex relationship between the stability or minor improvements in specific health state dimensions and the declining overall health perception (Table 4.25).

Table 4-25 Median Index Scores, VAS Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook of FAME-W

Sub-Categories of EQ-5D-5L	Self-guided Workbook Median			Self-guided Workbook Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Index Score	.70	.71	.71	.610	.430	.194
VAS	60.00	62.38	57.11	.205	.205	.011[.034]*

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

4.9.6.6 The Stanford Arthritis Self-Efficacy Scale Short Form (ASES-8)

Participant confidence in managing arthritis symptoms was assessed at three time points: T1, T2, and T3 (Table 4.26). The comparison of ASES-8 total scores between the online FAME-W and self-guided workbook groups revealed a significant difference from T1 to T2, with a p-value of 0.005, indicating an improvement in self-efficacy during this period in both groups, particularly for the self-guided workbook group.

However, no significant differences were found between the groups for the T1 to T3 comparison ($p = 0.16$) or the T2 to T3 comparison ($p = 0.65$). This suggests that while both groups improved from T1 to T2, these gains were largely maintained but not significantly different between the two groups by T3.

At T1, the online group had a higher median score compared to the self-guided group. By T2, both groups improved. The statistically significant p-value of 0.005 between T1 and T2 highlights that both delivery methods had a notable positive effect on self-efficacy during this period and that there were differences in the amount of change between the two groups.

At T3, the median scores for both groups slightly decreased, but these changes were not statistically significant, as reflected by the p-values for the T1-T3 ($p = 0.16$) and T2-T3 ($p = 0.65$) comparisons.

In conclusion, while there was a significant improvement in self-efficacy between T1 and T2, particularly in the self-guided group, no significant differences were observed between the groups over the longer term (T3).

Table 4-26 Scores of Sub-Categories of AWS at three time points and the significance testing findings

ASES-8	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Total	5.38 (1-9.12) 2.62	5.86 (2.25-9.62) 2.00	5.58 (2.25-7.9) 1.71	4.56 (1-9.76) 2.74	5.73 (2-8.50) 2.09	5.17 (1.62-8.5) 1.70	.005	.168	.654

Friedman test for the online group, did not show any statistically significant changes as indicated by the pairwise comparisons (Table 4.27) This suggested that the online FAME-W maintained a stable influence on participants' self-efficacy over the period studied.

Table 4-27 Median ASES-8 Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

ASES-8	Online FAME-W			Online FAME-W		
	Median			Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Total	5.38	5.86	5.58	.205	.298	.821

Conversely, the self-guided group demonstrated a significant fluctuation in median scores. From an initial score of 4.56 at T1, there was an increase to 5.73 at T2. The increase from T1 to T2 was statistically significant ($p = .001$; Bonferroni-adjusted $p = .004$), pointing to a substantial improvement in self-efficacy shortly after the completion of the workbook. However, this improvement was not sustained by T3. Still, the overall change from T1 to T3 was in a positive direction, although not statistically significant (Table 4.28).

Table 4-28 Median ASES-8 Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

ASES-8	Self-guided Workbook			Self-guided Workbook		
	Median			Pairwise Comparisons p-value		
	T1	T2	T3	T1-T2	T3-T1	T3-T2
Total	4.56	5.73	5.17	.001[.004]*	.095	.126

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

These findings underscore the impact of the self-guided workbook on improving self-efficacy among participants in the short term, with some regression noted over a longer period. In contrast, the online FAME-W seemed to provide a stable but non-improving effect on participants' self-efficacy related to managing arthritis.

4.9.6.7 The Arthritis Impact Measurement Scale Short Form (AIMS2-SF)

AIMS2-SF consists of five sub-categories: physical functioning, symptoms, mood/affect, social interaction, and work-role components. Each of these components and the total score were calculated between three time points.

AIMS2-SF sub-category scores and total scores were tested using Mann-Whitney U for significant difference between T1-T2, T1-T3 and T2-T3 (Table 4.29). The analysis of the between the online FAME-W and self-guided workbook groups revealed no statistically significant differences across any of the sub-categories or total scores at any of the time intervals indicating that both delivery methods had a comparable impact on participants' arthritis-related outcomes. In the online group, there was a slight improvement in physical functioning, as indicated by the decrease in the median physical functioning score from T1 (2.50) to T3 (2.08). Additionally, the total median score decreased from T1 (21.21) to T3 (20.35), suggesting an overall modest reduction in the impact of arthritis over time.

In contrast, the self-guided group experienced a slight worsening in certain areas. The median physical functioning score increased from T1 (2.50) to T3 (2.70), indicating a minor decline in physical functioning. Similarly, the median scores for symptoms subcategory rose from T1 (5.00) to T3 (5.47), suggesting a small increase in symptom severity. Social interaction also showed a worsening trend, with the scores increasing from T1 (4.38) to T3 (5.17). Despite these increases, the total median score slightly decreased from T1 (22.79) to T3 (21.42), indicating some overall improvement, although less consistent compared to the online FAME-W group.

Table 4-29 Scores of Sub-Categories of AIMS2-SF at three time points and the significance testing findings

Sub-Categories of AIMS2-SF	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Physical Functioning	2.50 (.21-5.62) 1.45	2.33 (0-5.62) 1.66	2.08 (.62-8.3) 1.53	2.50 (.21-6.25) 1.66	2.50 (0-2.5) 1.63	2.70 (.62-5.43) 1.66	.458	.875	.932
Symptoms	5.00 (.83-10) 4.17	5.00 (.83-10.0) 4.17	5.00 (.83-10.0) 3.34	5.00 (.83-10) 2.53	5 (2.5-9.17) 2.53	5.47 (3.03-9.17) 2.04	.116	.377	.675
Mood/Affect	4.50 (2.5-7) 2.00	5.00 (2.5-7.00) 2.00	5.00 (2.5-7.00) 2.00	5.00 (1.5-8.5) 1.50	4.8 (1.5-8.00) 1.5	4.5 (2.00-8.00) 1.50	.525	.161	.204
Social Interaction	5.00 (.62-10) 2.50	5.00 (1.25-10.00) 1.87	5.00 (1.25-10.00) 2.50	4.38 (1.25-7.50) 1.87	4.69 (1.25-8.12) 1.87	5.17 (1.5-8.75) 1.47	.417	.998	.782
Work-Role	4.38 (1-8.12) 2.50	4.38 (0-7.5) 1.88	4.07 (1.25-7.50) 2.00	4.38 (1.25-8.75) 1.5	4.38 (1.25-8.75) 1.88	3.75 (0-6.88) 1.88	.512	.922	.202
Total	21.21 (10.01-36.91) 6.41	21.23 (12.95-33.21) 7.06	20.35 (11.34-31.05) 6.51	22.79 (9.83 - 34.96) 5.91	22.4 (8.07-30.32) 5.5	21.42 (11.49-31.12) 7.52	.559	.631	.138

Friedman test for the online group, showed a statistically significant difference between T1 and T3 ($p = 0.012$ [0.036]* after Bonferroni correction) in the total scores (Table 4.30). However, when examining the individual sub-categories, no statistically significant changes were detected over time. Although there were slight trends toward improvement or stability—such as a decrease in the median for physical functioning suggesting better physical functioning, and a minor improvement in work-role—these changes were not statistically significant. The other sub-categories remained stable, with only minor fluctuations.

Table 4-30 Median AIMS2-SF Sub-Category Scores and Pairwise Comparisons (p-values) for Online FAME-W Participants

AIMS2-SF	Online FAME-W Median			Online FAME-W Pairwise Comparisons p value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Physical Functioning	2.50	2.33	2.08	.390	.147	.556
Symptoms	5.00	5.00	5.00	.619	.556	.928
Mood/Affect	4.50	5.00	5.00	.821	.821	.651
Social Interaction	5.00	5.00	5.00	.497	.587	.892
Work-Role	4.38	4.38	4.07	.338	.273	.891
Total	21.21	21.23	20.35	.361	.012 [0.036]*	.110

* Bracketed [] p-values have been adjusted by the Bonferroni correction for multiple tests

Results from the Friedman tests on the self-guided group is presented in Table 4.31. The findings indicate that the self-guided workbook did not lead to statistically significant changes in the sub-categories or the total score over the three time points.

Table 4-31 Median AIMS2-SF Sub-Category Scores and Pairwise Comparisons (p-values) for Self-Guided Workbook Participants

AIMS2-SF	Self-Guided Median			Self-Guided Pairwise Comparisons p value		
	T1	T2	T3	T1-T2	T1-T3	T2-T3
Physical Functioning	2.50	2.50	2.70	.246	.816	.353
Symptoms	5.00	5.00	5.47	.330	.486	.781
Mood/Affect	5.00	4.8	4.5	.486	.164	.486
Social Interaction	4.38	4.69	5.17	.816	.745	.926
Work-Role	4.38	4.38	3.75	.640	.281	.543
Total	22.79	22.4	21.42	.111	.101	.963

4.9.6.8 Log book of work attendance

Absenteeism related to IA management and IA related health problems, was tracked through absenteeism logs. Participants from both the online FAME-W and self-guided workbook groups were asked to log any arthritis-related work absences. Six participants from the online FAME-W group and two participants from the self-guided group submitted their logs. The reasons for absences included medical appointments, pain treatments, and emergency hospital visits. The total hours missed due to these absences varied significantly among participants. Participants from the online FAME-W group missed an average of 5.29 hours (SD = 10.70 hours) over three months, while participants from the self-guided workbook group missed an average of 9.33 hours (SD = 6.80 hours).

4.9.7 Conclusion

The findings from the study indicate that no statistically significant differences were observed between the online FAME-W and self-guided workbook groups across the majority of the measured outcomes. In the context of the Work Role Functioning Questionnaire, although both groups demonstrated slight improvements at T2, these changes were not statistically significant, and by T3, any gains in work role functioning had largely returned to baseline levels. This suggests that while both delivery methods may have had a short-term impact on work role functioning, these effects were not statistically significant or sustained over time.

Similarly, results from the Multidimensional Fatigue Inventory revealed no statistically significant differences in fatigue levels between the two groups. Both groups showed stability or minor fluctuations across the five subcategories of fatigue (general fatigue,

physical fatigue, reduced activity, reduced motivation, and mental fatigue), with no statistically significant changes over time, further supporting the conclusion that neither intervention offered a statistically significant advantage in managing fatigue-related symptoms.

Regarding mental health outcomes, the Hospital Anxiety and Depression Scale results did not reveal statistically significant differences between the groups. While the self-guided workbook group showed a slightly larger reduction in anxiety and depression scores between T1 and T2, these improvements were not statistically significant, and by T3, these changes were not maintained. This pattern suggests that both interventions may have contributed to mild improvements in anxiety and depression in the short term, but neither had a statistically significant long-term impact.

The Short Form McGill Pain Questionnaire findings reveal that there were no statistically significant differences between the online FAME-W and self-guided workbook groups in reducing pain symptoms across various subcategories. Both groups displayed consistent median scores over time in sensory and affective pain, indicating no substantial change in pain perceptions. Although the online FAME-W group showed a temporary significant decrease in affective pain between T1 and T2, this change was not sustained by T3. The VAS and Present Pain Intensity measures also demonstrated stability, with both groups maintaining similar pain levels throughout the study period. This lack of significant variation across the measured outcomes suggests that neither the online nor self-guided workbook interventions led to meaningful improvements in pain symptoms over time. The stability in pain assessment highlights the potential need for more intensive or alternative approaches to achieve substantial changes in pain management for participants. The Arthritis Work Spillover scores indicated no statistically significant differences between the groups. However, the self-guided workbook group exhibited a statistically significant improvement between T1 and T3.

The EQ-5D-5L results, both in terms of index scores and the VAS, showed no statistically significant differences between the groups over time. However, the VAS scores reflected a decline in self-reported health, in both groups. Both groups initially showed an improvement in VAS scores at T2, by T3 there was a clear decline, indicating a worsening in perceived health status, though between the two groups these changes were not statistically significant. However, in within group analysis statistically significant worsening in VAS scores were reported from T2 to T3 for both groups. This suggests that

while the both groups experienced an initial positive change, the gains were not sustained, with some indication of worsening by the study's conclusion.

Regarding self-efficacy, as measured by the Stanford Arthritis Self-Efficacy Scale, both groups showed a improvements between T1 and T2, with the self-guided workbook group showing a slightly larger increase resulting in a statistically significant difference in group comparisons. However, by T3, these improvements were not sustained, suggesting that the initial positive impact on self-efficacy was not maintained over time.

Finally, in terms of arthritis-specific outcomes, the Arthritis Impact Measurement Scale Short Form results similarly showed no statistically significant differences between the groups across the study period. Both groups displayed minor improvements in physical function, symptoms, and social interaction subscales, but these changes were not statistically significant. However, the online group showed a statistically significant improvement in total scores from T1 to T3. The results suggest that while there may have been small gains in certain areas, they were not sufficient to demonstrate a clear, sustained impact of either intervention on arthritis-related health outcomes.

In conclusion, the results suggest that both the online FAME-W and self-guided workbook interventions have limited long-term impact. While both the online FAME-W and self-guided workbook group demonstrated initial positive effects on specific outcomes, such as self-efficacy and anxiety, these improvements were generally not statistically significant or sustained. The lack of statistically significant differences between the two groups across most measures suggests that both delivery methods offer similar levels of support for managing the challenges associated with arthritis in the workplace, with neither intervention demonstrating a clear statistically significant advantage across the majority of outcomes. Furthermore, the decline in VAS scores for the self-guided workbook and online group highlight the potential for worsening perceived health over time, underscoring the need for ongoing or enhanced intervention strategies to maintain long-term benefits.

4.10 Discussion

The present study aimed to evaluate two different delivery methods of FAME-W in reducing work-related fatigue and improving quality of life among individuals with IA delivered either online or through a self-guided workbook. The study adhered to the MRC framework for evaluating complex interventions, ensuring a methodologically robust approach to both the design and execution of the trial (Skivington et al., 2021).

Recruitment

Recruitment is a critical component of a successful clinical trial, particularly in studies involving chronic conditions such as IA (AlHeresh et al., 2021; Kennedy et al., 2022). The initial sample size for the study was calculated based on the WRF questionnaire scores from the pilot study by McCormack et al. (2018). The WRF questionnaire measures the degree to which health problems impact an individual's ability to meet work demands. In this study, to detect an effect size of 0.4 with a significance level of 5% and a power of 80%, 99 participants per group were required. However, due to recruitment difficulties exacerbated by the COVID-19 pandemic, the sample size calculations were adjusted to detect a 0.7 effect size as per McCormack et al. (2018). This adjustment had several implications for recruitment efforts. By reducing the required sample size, the study aimed to alleviate some of the recruitment difficulties. A smaller sample size meant that the study could proceed with fewer participants while still achieving sufficient statistical power to detect meaningful differences between the online and self-guided workbook groups. This was particularly important given the context of the pandemic, which posed additional barriers to recruitment, such as limited access to potential participants and increased health concerns. However, targeting a higher effect size also increased the importance of minimizing attrition to preserve the study's statistical power. With a smaller sample size, the impact of each participant dropping out is more pronounced, potentially affecting the study's ability to detect significant effects. Therefore, retention strategies became crucial to ensure that the study maintained enough participants to meet its statistical goals.

The recruitment required careful planning due to the pandemic, however, the final recruitment rate of 21.5%, aligns with typical rates observed in similar self-management intervention studies, which often report rates between 10% and 30% (Hiemstra et al., 2024). For example, a study examining self-management interventions in people with chronic conditions reported recruitment rates within this range, especially when interventions were delivered remotely or during challenging times such as the COVID-19

pandemic (Jacques et al., 2022). The impact of remote recruitment strategies and challenges related to participant engagement during the pandemic has been widely noted across various health interventions (Harris et al., 2021).

Although the recruitment rate was comparable to that of similar studies, the process was not without its challenges. Several factors likely contributed to the difficulties encountered. First, the demands of participating in a study, including time commitments and the requirement to engage with interventions regularly, can deter potential participants, particularly those already managing a chronic condition that impacts daily life (Konstantinou et al., 2020). Second, some individuals may not have fully recognized the potential benefits of participating in the study, or they may have held misconceptions about the effectiveness or relevance of the interventions for their specific circumstances. For instance, some participants might have believed that they were managing well enough at work and therefore did not perceive the need for additional support. However, they may not have considered that participating in the intervention could have helped them optimize their work performance or better manage their condition (Getz, 2007; Miller, 1998). This lack of awareness or misperception likely contributed to the lower recruitment and engagement rates observed in the study. Third, the ongoing COVID-19 pandemic may have heightened health concerns and logistical challenges, discouraging participation due to increased stress levels, and shifting priorities in health management. Studies in multiple health fields have faced similar challenges during Covid (Abdulhussein et al., 2022; Nomali et al., 2023). Furthermore, the pandemic significantly disrupted traditional recruitment methods, such as in-person clinic visits, and necessitated a shift to remote recruitment strategies, including social media and telephone consultations. While these methods allowed the study to continue, they may not have been as effective in reaching all eligible participants, particularly those less comfortable with technology or those experiencing pandemic-related stress.

These challenges underscore the need for strategies that enhance participant engagement and support from the outset. Effective recruitment strategies could include targeted outreach efforts, partnerships with healthcare providers and patient advocacy groups, and clear communication about the potential benefits and support available during the study (Young et al., 2015). By addressing these issues proactively, future studies can improve participant recruitment and retention, ultimately leading to more robust and generalizable findings.

Demographics

The participants were predominantly female, which aligns with epidemiological data indicating that IA is more prevalent among women than men (Kvien et al., 2006). This gender distribution reflects the gendered nature of IA and highlights the need for self-management interventions to address the unique challenges faced by women in managing their condition. Furthermore, the higher proportion of female participants is consistent with self-management intervention studies, which tend to have higher female participation rates (Sharkey et al., 2020). This raises concerns about the generalizability of the findings to male participants, who may experience different arthritis-related issues or treatment outcomes.

Most participants were employed full-time. Rates of individuals in full-time workforce are similar to those of other studies (McCormick et al., 2018; Tanski et al., 2022). Full-time employment could imply higher work demands and potentially greater stress, which might exacerbate IA symptoms and reduce the effectiveness of interventions aimed at mitigating work-related fatigue (Madsen et al., 2021; Paterson et al., 2021). On the other hand, participants engaged in non-manual work were predominant in both groups, which might have influenced the relevance and applicability of certain aspects of the interventions, particularly those targeting physical demands.

A majority of participants held college or university degrees. This high level of educational attainment may influence the impact of self-management interventions, as individuals with higher education levels might be more adept at understanding and implementing complex management strategies. Research has shown a correlation between higher education and improved health outcomes, which reinforces this possibility (Raghupathi et al., 2020). This would be particularly important for a self-guided workbook programme because success in managing health relies heavily on a person's ability to independently interpret and apply the information provided, which requires a solid understanding of the material that higher education might facilitate. The findings suggest that the interventions were well-suited to a highly educated population, but they also raise questions about their applicability and accessibility to individuals with lower educational backgrounds, who might require different approaches or additional support. Therefore, future research should also attempt to include a more diverse demographic range to enhance the generalizability of the findings (Shea et al., 2022). This includes targeting male participants, those with lower educational attainment, and younger individuals who might be at different stages of their arthritis journey (Burchett et al., 2020).

The study included a diverse range of IA types, with RA and PsA being the most common. The diversity of IA among participants suggests that the intervention was versatile enough to address varied symptoms and challenges associated with different forms of the disease. Participants had a mean age of approximately 49 years, with an age range spanning from the mid-20s to mid-60s. This age range captures a critical working-age population likely to face significant work role challenges due to IA. This age range is consistent with other studies conducted in Ireland and internationally on the impact of IA on work (Connolly et al., 2016; Madsen et al., 2021).

Moreover, the duration of IA among participants varied, with an average of 9 to 10 years since diagnosis, indicating that most participants may have been managing their IA with established patterns of coping and work adaptation. These factors might have limited the potential impact of the intervention, as individuals with long-standing IA may have already developed personal strategies for managing their symptoms, potentially reducing the perceived effectiveness of either delivery method of FAME-W.

The majority of participants lived with others (93.4% in the online group and 80.3% in the self-guided group) and were married (72.13% and 60.7%, respectively). Living with others may provide social support that is beneficial in managing a chronic condition such as IA. The marital status and living situation could potentially influence the outcomes of self-management interventions, as individuals with strong support networks may have better adherence to treatment plans and more favourable outcomes. A longitudinal study looking at the role of significant others in disease related factors and sickness absence from work found that although individuals with IA often report receiving substantial support from their significant others, this does not always result in improved work outcomes (Bergström et al., 2021). Thus, it is important to examine other aspects of support that may impact work outcomes, such as the type and quality of support provided. Future research should explore these different forms of support and identify when it is most beneficial for significant others to participate in the rehabilitation and self-management processes to improve the likelihood of individuals with IA achieving a well-functioning and sustainable work life.

Retention, Attrition and Adherence

The overall retention rate, based on the number of participants who completed the 3-month follow-up, was 49.18%. Specifically, the online intervention group had a retention rate of 55.7%, whereas the self-guided workbook group reported a lower retention rate of 39.3%.

These findings suggest that the online format may have been more effective at maintaining participant engagement, possibly due to the interactive elements of the digital intervention. This disparity in retention between the two groups highlights how intervention format can directly impact participant engagement and adherence over time. Retention rates in self-management intervention studies can vary significantly, particularly when interventions are delivered remotely or under challenging conditions such as the COVID-19 pandemic. Typically, retention rates for self-management programmes range from 50% to 90%, with higher rates often associated with more structured or in-person interventions (Harris et al., 2021). However, during the pandemic, studies utilizing remote or digital platforms have reported retention rates as low as 40-60% due to challenges in maintaining participant motivation and perceived benefits (Cadilhac et al., 2020; Harris et al., 2021). In this context, the retention rates observed in this study align with the lower end of the typical range, particularly in the self-guided workbook group. While these retention figures are lower than ideal, they are consistent with the challenges observed in similar studies, especially those conducted in remote formats during the pandemic. Attrition rates in similar interventions have shown wide variability, which is common in studies involving remote or self-guided formats (Doumen et al., 2022). High attrition rates pose significant challenges in clinical trials, as they reduce the statistical power of the study and can limit the generalizability of the findings (Siddiqi et al., 2008). In the self-guided workbook group, the dropout rate may have been exacerbated by the self-directed nature of the intervention, which can be difficult to sustain without external motivation or direct support (Banerjee et al., 2017; Mohr et al., 2011). For both groups, it is possible that maintaining engagement with the programmes was challenging, particularly if participants did not perceive immediate or significant benefits.

Adherence to the intervention is a critical factor in understanding the overall effectiveness of the study. In the online group, adherence was likely influenced by the interactive nature of the digital format, which may have facilitated higher participant engagement. Studies have shown that online interventions, when well-structured and interactive, tend to promote better adherence compared to self-guided or less interactive formats (Hanano et al., 2022; Titov, 2013). However, in the self-guided workbook group, the self-directed nature of the programme may have required a higher degree of motivation and discipline, which can be difficult to sustain over time. Research on self-directed interventions frequently highlight challenges in maintaining engagement, as these types of interventions rely heavily on participants' internal motivation to consistently follow through with the

programme (Banerjee et al., 2017; Mohr et al., 2011). In this study, adherence to the interventions was likely a major factor in the observed retention rates.

Other internet-based programmes have shown similar patterns of low adherence and high attrition, often attributed to the lack of engaging content or the absence of immediate, tangible results, which diminishes motivation (Ali et al., 2022). This further emphasizes the need for strategies to increase participant engagement and support throughout the study. Additionally, the COVID-19 pandemic had a substantial impact on clinical trials worldwide, with a global decline in participant recruitment and retention. Studies reported a roughly 30% decrease in participant enrolment during the pandemic, reflecting increased health concerns and logistical challenges (Medidata, 2020). Participants in this study may have faced additional health-related challenges or changes in their condition, further complicating their ability to remain engaged in the study. Addressing these issues through targeted strategies, such as enhanced participant engagement methods and flexible intervention designs, can improve the success of future research efforts and enhance the effectiveness of interventions designed to support individuals with arthritis. By learning from these challenges, future studies can be better equipped to sustain participant involvement and ultimately generate more robust and generalizable findings. The challenges in recruitment and attrition faced by this study underscore the complexities of conducting research in chronic conditions such as IA.

Impact on Managing Work Demands

Individuals' ability to meet the demands of their work is a critical aspect of quality of life for those with IA, as the condition often impacts physical capabilities, cognitive focus, and emotional well-being, all of which are essential for maintaining productivity at work (Connolly et al., 2016; Tanski et al., 2022). To assess work role functioning, the WRF Questionnaire (Amick, 2000) was used to evaluate the effects of both the online FAME-W programme and the self-guided workbook.

The findings suggest that neither delivery method produced statistically significant changes in work role functioning when comparing the two methods directly. Both the online programme and the self-guided workbook showed limited impact overall, with some modest improvements in specific sub-categories, but none reaching statistical significance across the groups over time. These findings can be interpreted positively, however, as they indicate that both delivery methods—online and self-guided—are

equally helpful in maintaining work role functioning, suggesting potential flexibility in programme choices.

The use of a self-guided workbook in this particular cohort is a novel approach, and there is a lack of literature specifically addressing its impact in this context. From a cost-efficiency perspective, the self-guided workbook offers a scalable solution, with lower operational expenses compared to the online format, which typically involves higher ongoing costs due to facilitation (Campbell et al., 2023). While online interventions provide more structure and guidance (Huang et al., 2024), the self-guided workbook may encounter lower engagement levels, as noted in the literature on self-guided formats (Bakarat & Maguire, 2022; Levin et al., 2020; Strauss et al., 2023). This potential for lower engagement in self-guided formats highlights the need for further research into its effectiveness within this specific population.

Within-group comparisons revealed significant findings, particularly regarding the self-guided workbook. The self-guided workbook showed significant within-group decrease in mental, and social demands, suggesting that its self-paced and reflective nature may be less effective in enhancing these aspects of work role functioning over time. However, the absence of significant differences between the two groups overall suggests that, while less beneficial, the self-guided workbook was not substantially less effective than the online intervention. The variability in participant responses, as indicated by wide interquartile ranges at baseline, suggests that individual differences such as personal motivation, and external support systems may have played a role in participant outcomes, potentially diluting the observed effects.

For the online FAME-W programme, slight improvements were observed in work-related mental and output demands over time, though these did not lead to significant changes. This is consistent with findings from the broader literature, such as systematic reviews on workplace interventions for musculoskeletal disorders, which have shown limited significant effects on work role improvements (Lenzen et al., 2016). The online format likely helped participants maintain or slightly improve functioning, but without generating statistically significant results.

Given these findings, future research should explore the impact of the self-guided workbook against a control group and assess whether additional support mechanisms, such as one-on-one coaching or interactive elements, could enhance the observed effects. Incorporating long-term follow-up would also help determine whether these modest gains

can be sustained. Such research could refine these interventions to serve as accessible tools for improving work role functioning in individuals managing chronic conditions.

In addition to the impact of the delivery, it is crucial to consider the role of support systems. Self-management strategies, while beneficial, might require supplementary mechanisms such as workplace accommodations, occupational therapy, or cognitive-behavioural therapy to address psychological barriers to work performance. A scoping review emphasized the importance of addressing not only the physical but also the psychological and social aspects of chronic conditions, as exemplified by FAME-W's in-person format, which includes therapist and peer support (Damgaard et al., 2023).

Furthermore, individualized interventions tailored to specific work demands may be more effective in the long run. Evidence from Macedo et al. (2009) demonstrated that personalized occupational therapy interventions significantly improved work-related outcomes for individuals with RA. Similarly, studies such as "*Care for Work*" by van Vilsteren et al. (2017) highlight the need for integrated care and workplace interventions, though they also underscore the necessity for further refinement to optimize effectiveness. Employers and policymakers also play a critical role in supporting these interventions. Studies by Hammond et al. (2017, 2020) highlight the value of workplace accommodations such as flexible work arrangements and ergonomic adjustments, which can complement self-management interventions and lead to improved outcomes for employees with arthritis.

More research is needed to explore the long-term effects of these interventions on work role functioning. While short-term improvements have been observed, such as in the *WORK-IA* and *WORKWELL* programmes (Hammond et al., 2017, 2020), the sustainability of these benefits remains uncertain. By integrating healthcare providers, employers, and support networks into future interventions, a more comprehensive approach could be developed, addressing both the medical and psychological aspects of chronic conditions while ensuring that workplace accommodations are effectively implemented for long-term success.

Impact of Delivery Methods on Fatigue

Fatigue in IA is one of the most common and debilitating symptoms (Chmielewski et al., 2023). The goal of the FAME-W intervention was not to eliminate fatigue, but rather to decrease its impact on participants' work performance. The findings reveal both the

potential and limitations of the two delivery methods—online and self-guided—of the FAME-W intervention in managing this complex symptom.

Fatigue in IA is influenced by multiple factors, including pain, sleep disturbances, psychological stress, and physical inactivity. This multifaceted nature makes fatigue particularly challenging to address through a single intervention (Connolly et al., 2016). While other fatigue management interventions, such as those conducted by Durcan et al. (2014), Feldthusen et al. (2016), and Hewlett et al. (2019), have demonstrated statistically significant reductions in fatigue through structured physical activity and cognitive-behavioural therapy, no studies to date have directly compared different delivery modalities of the same intervention specifically for reducing fatigue in individuals with IA in a work-related context (Damgaard et al., 2023). This gap in the literature underscores the need for future research to explore how different delivery methods might impact the effectiveness of fatigue management interventions.

In this study, the online FAME-W and the self-guided workbook showed some positive trends, though neither delivery method achieved statistically significant improvements across all fatigue measures. When comparing the two methods, the online group showed slight improvements in general fatigue, whereas the self-guided workbook demonstrated initial reductions in physical fatigue. However, neither group saw sustained or widespread improvements, highlighting the challenges of addressing fatigue with these particular delivery formats.

The online FAME-W group showed some improving trends, particularly in the reduction of general fatigue, with a narrowing IQR, suggesting that some participants experienced more consistent management of their fatigue. However, these improvements were not statistically significant and were not consistent across the entire group. Studies have found that online programmes may provide some relief from symptoms such as fatigue however, they often fail to produce significant improvements across all participants (Beatty et al., 2016). Therefore, findings point to a potential of relief from fatigue that may be provided by the online FAME-W, but also emphasizes its limitations in producing significant and lasting effects across all participants.

The self-guided workbook initially showed a reduction in physical fatigue, suggesting that participants may have benefited from strategies aimed at managing the physical aspects of fatigue. However, these improvements did not continue in long term and returned back to baseline, indicating that additional support might be necessary to sustain the benefits

over time. Other studies have found similar results (Grunfeld et al., 2019). The workbook's self-paced nature may provide immediate relief, but its ability to address long-term fatigue management remains limited. Moreover, the persistence of mental fatigue in this group suggests that cognitive and emotional aspects of fatigue may require more than self-management interventions alone as this has been also reported in other studies (Alizadeh et al., 2023; Brown et al., 2023; Shawli et al., 2019).

Overall, the lack of statistically significant changes across most sub-categories of the MFI reflects the limitations of both the online and self-guided delivery methods of FAME-W in their current forms. The decrease in general fatigue scores and the contraction of the IQR in the online group suggest that some participants were able to manage their fatigue more consistently, but the interventions did not yield substantial or long-lasting results. Similarly, while the short-term reduction in physical fatigue in the self-guided group was promising, the absence of sustained improvements points to the need for more comprehensive and continued support. This is supported by other studies such as Brown et al. (2023), who found that while online programmes tend to show improvements in general fatigue, and interventions or reference materials resembling the self-guided workbook of FAME-W help with physical fatigue, neither format consistently delivers long-term, widespread benefits.

These findings highlight the importance of focusing not only on the absolute reduction of fatigue but also on how participants perceive and manage its impact on their work and daily lives (Feldthusen et al., 2013; Power et al., 2021). Although the interventions did not completely eliminate fatigue, enabling participants to reach a level where fatigue becomes more manageable represents a valuable and meaningful outcome as seen in other studies (Barakou et al., 2024).

In conclusion, the mixed results underscore the need for more comprehensive and sustained interventions that include regular follow-ups and additional support mechanisms. Incorporating personalized fatigue management plans or combining self-management strategies with professional support could enhance the long-term effectiveness of these interventions. Periodic reassessments and follow-up sessions may also help maintain the initial benefits observed immediately post-intervention.

Impact on Mental Anxiety and Depression

The FAME-W's holistic approach, which addresses various aspects of fatigue management, stress reduction, and work performance, appears to have contributed to the

observed reductions in anxiety and depression. The inclusion of stress management techniques, pain and cognitive engagement through strategies such as goal setting likely played a role in improving participants' mental health. Additionally, the intervention's emphasis on enhancing self-efficacy may have strengthened participants' confidence in managing their condition, thereby reducing psychological distress. Previous studies have identified a statistically significant association between anxiety and depression and low self-management behaviour in individuals with IA, highlighting the importance of addressing mental health issues as part of a comprehensive self-management intervention (Vestergaard et al., 2024).

The FAME-W intervention demonstrated potential in reducing anxiety and depression in both feasibility studies (Karkon et al., 2023, McCormack et al., 2018). Both delivery methods led to reductions in anxiety from mild to normal levels and maintained depression within the normal range in accordance with the HADS questionnaire scoring guidelines (Zigmond & Snaith, 1983). However, these reductions were not statistically significant. The lack of statistically significant findings, along with the shift from mild to normal anxiety levels and low baseline depression scores, suggests that both interventions could positively impact anxiety and depression. However, larger studies or targeting participants with greater initial severity may yield clearer results. Similar challenges have been noted in other research. For instance, Würtzen et al. (2013) found that mindfulness interventions for anxiety and depression led to improvements, though these were not always statistically significant, suggesting the need for larger trials to assess true effectiveness. Firth et al. (2017) reported comparable outcomes in a meta-analysis of smartphone-based interventions, where small improvements were observed but were not statistically significant. Likewise, Välimäki et al. (2017) highlighted that web-based interventions for adolescents showed reductions in anxiety, though the statistical significance of these findings were limited. Fodor et al. (2018) also emphasized that while virtual reality interventions for anxiety had moderate effects, they did not always achieve statistical significance, indicating that interventions may be more impactful for individuals with higher baseline severity. These findings underscore the need for further research to determine whether these interventions can produce sustained, long-term improvements, especially for individuals starting with more severe symptoms of anxiety or depression. The online format of the current study also showed reduction in anxiety from baseline to immediate follow-up, likely due to the structured support, peer interactions, facilitated through the online sessions. These social and emotional connections can help reduce

feelings of isolation and provide psychological relief, which are particularly beneficial in managing anxiety (Franqueiro et al., 2023). Research has shown that online peer support interventions, especially those that foster frequent interaction and engagement, can improve mental health outcomes by providing emotional support and creating a sense of belonging for participants (Merchant et al., 2022; Simmons et al., 2023). These benefits are often cited as reasons for reduced anxiety and depression in similar online interventions.

Conversely, the self-guided workbook group displayed more consistent improvements in both anxiety and depression over time. This aligns with findings from studies on self-help interventions (Lewis et al., 2012). The self-directed nature of this modality likely encouraged participants to engage with the material at their own pace, fostering deeper reflection and a more personalized application of strategies. The responsibility placed on participants to implement these strategies independently may have enhanced their self-efficacy, contributing to sustained improvements in mental health.

Impact on Pain Management

The management of pain in IA remains a significant challenge (Sarzi-Puttini et al., 2024). The consistent pain intensity observed across both groups, as reflected by the VAS and Present Pain Intensity scales, highlights the resilience of pain to moderate interventions. External factors, such as the COVID-19 pandemic, may have further exacerbated pain experiences through increased anxiety, social isolation, and reduced access to healthcare (El-Tallawy et al., 2021). Despite some reductions in pain in both groups, the analysis of the two delivery methods did not reveal any statistically significant reductions. These changes, although present, were not substantial enough to be considered statistically significant, which mirrors findings from other studies comparing self-guided and online interventions. In those studies, improvements were observed but did not reach statistical significance without more professional guidance or tailored support (Ruehlman et al., 2012; Moman et al., 2019).

In the online FAME-W group, initial reductions in sensory and affective pain scores were noted, but these improvements were not maintained at the three-month follow-up. The slight increase in sensory pain scores over time suggests that the initial relief provided by the online format may have been temporary, potentially due to the initial novelty or heightened engagement at the start of the intervention. The lack of sustained improvement underscores the difficulty of achieving long-term pain relief through online interventions

alone, especially when ongoing reinforcement and support are lacking. Other web based self-management interventions for IA have reported no significant differences in pain level pre and post intervention suggesting a need for more professional support and more tailored approaches to the individual needs of participants (Zuidema et al., 2019).

The self-guided workbook group demonstrated stable pain scores across all time points, with minor fluctuations that did not reach statistical significance. This stability might indicate that the workbook approach helped prevent worsening of pain, even though it did not lead to significant improvements. The self-guided modality, while offering flexibility, may lack the necessary interactive components and real-time feedback that could enhance pain management outcomes that were seen in the online FAME-W programme. Other structured programmes, such as the Arthritis Self-Management Programme developed at Stanford University, with guided sessions and personalized support, have shown more effective pain management outcomes. The intervention group in this programme had statistically significant less pain compared to the control group, highlighting the importance of engagement, customization, and follow-up in interventions aiming to reduce and manage pain intensity (Leung et al., 2016).

Quality of Health

The findings from this study provide insights into the impact of the FAME-W intervention on participants' health-related quality of life (HRQoL). The stability of EQ-5D-5L index scores suggests that both delivery formats effectively maintained participants' overall HRQoL throughout the study period. Given that individuals with IA typically report lower HRQoL across all dimensions (Salaffi et al., 2019; Villalobos-Sánchez et al., 2024), this stability is important, indicating the intervention helped prevent further deterioration in HRQoL, a crucial factor in managing the long-term effects of IA.

However, the significant decline in VAS scores from T2 to T3, despite stable EQ-5D-5L index scores, raises concerns about participants' overall health perceptions. The VAS scores, which reflect participants' general health perceptions, provide a summary measure of overall well-being that integrates physical, psychological, and social factors (EuroQol, 2019). VAS scores, which capture broader self-assessed health perceptions, often reflect variations in subjective well-being that may not always align with functional stability. This is well-documented in the literature. It has been reported that VAS scores frequently reflect changes in subjective well-being that diverge from stable functional measures (Busija et al., 2020). Similarly, Mason et al. (2022) observed that while functional health remained stable, self-assessed health declined, emphasizing the need for interventions to

address not only functional outcomes but also broader health perceptions. Furthermore, the significant drop in these scores suggests that participants felt a deterioration in their overall health, which may have been influenced by the cumulative effects of the COVID-19 pandemic. Studies have found that the VAS scores for EQ-5D-5L decreased during the pandemic in comparison to pre-pandemic data (Sun et al., 2023). The pandemic introduced numerous stressors, including social isolation, economic uncertainty, and disruptions to routine healthcare, all of which could have contributed to this decline in perceived health (Jeffers et al., 2022). For individuals with IA, the pandemic may have exacerbated existing symptoms and introduced new psychological challenges, such as increased stress, which could have negatively impacted their overall sense of well-being.

These findings suggest that while the intervention effectively maintained functional outcomes, it may not have fully captured or addressed participants' overall subjective health perceptions. This underscores the importance of future interventions focusing on both maintaining functional well-being and addressing participants' broader health perceptions to improve overall quality of life.

Self-Efficacy in Managing Inflammatory Arthritis

The findings highlight the differing impacts of the online FAME-W programme and the self-guided workbook on self-efficacy in managing arthritis, a critical concept in self-management interventions (Damgaard et al., 2023). Although there was a statistically significant difference between the two delivery methods, the self-guided group showed greater improvements. As a result, the self-guided workbook provided a statistically significant short-term improvement in self-efficacy. This increase may be attributed to the workbook's requirement for active personal engagement, which likely encouraged participants to internalize and apply the strategies more effectively, as emphasized by the theory of self-efficacy in self-management (Gallagher, 2021). Findings are consistent with studies such as App-based Education and GOal setting in RA (AEGORA) which is a multicentre, pragmatic randomised controlled trial investigating the effectiveness and feasibility of a mobile health (mHealth) self-management intervention aimed at improving self-efficacy in patients with RA (Doumen et al., 2023).

The effects of the workbook were temporary, as by T3, the benefits had diminished, though self-efficacy scores remained elevated compared to baseline. This suggests that while the workbook was effective in improving self-efficacy in the short term, maintaining these improvements over time without ongoing support proved challenging, reflecting the

mixed effects of self-management interventions in long-term effectiveness observed in other self-management interventions (Uritani et al., 2021). In contrast, the online FAME-W programme offered more stable, albeit modest, improvements. These findings highlight the need for interventions that can both rapidly enhance and sustain self-efficacy over time, possibly by combining the immediate impact of self-guided approaches with the ongoing support of online programmes.

Optimizing Interventions Based on Impact of Arthritis

In comparing both the online and self-guided delivery methods, the study demonstrated that both delivery methods had a modest impact on reducing the overall burden of arthritis, particularly through structured support that helped participants manage the complex physical and emotional challenges of IA as reported by the results of AIMS2-SF.

The incremental overall improvements observed in the FAME-W programme highlight the potential of structured, interactive interventions to reduce the burden of arthritis. Similar findings have been reported by Stellefson et al. (2013), who reviewed structured self-management interventions and emphasized that these types of interventions are likely to result in novel approaches. Yet, these programmes often show limited effectiveness in addressing specific areas such as physical functioning and symptom management. The marginal improvements in this study also reveal the limitations of such programmes in achieving meaningful, sustained changes in specific areas such as physical functioning and symptom management. Likewise, Allam et al. (2015) found that while web-based interventions for rheumatoid arthritis provided substantial social support and engagement, they often failed to produce meaningful changes in physical functioning, underlining the need for more targeted interventions.

One important takeaway from these findings is that chronic conditions such as arthritis require ongoing, multifaceted interventions (HSE, 2018). While the online FAME-W programme showed some benefit in reducing the overall impact of arthritis, the lack of significant improvements in specific sub-categories suggests that focusing on holistic and tailored strategies might be more effective. Research supports this approach, indicating that behaviour change interventions in chronic illness management should be tailored to individual needs to produce sustained improvements in areas such as physical functioning and symptom management (Araújo-Soares et al., 2018).

Furthermore, participants managing IA likely need support that goes beyond short-term interventions or general strategies—they may benefit from programmes that address their

unique challenges in physical functioning, emotional health, and social well-being in a more personalized way. Similarly, a meta-analysis demonstrated that while self-management programmes provide overall benefits, they often fail to deliver significant improvements in specific outcomes such as pain relief and physical function (Du et al., 2011). This highlights the need for more comprehensive and personalized interventions to fully address the multidimensional challenges faced by individuals with arthritis.

The findings also point to the importance of engagement and support in self-management interventions. The self-guided workbook, which allowed for more flexibility but less interaction and support, led to less consistent improvements. This implies that self-directed interventions, while offering autonomy, may need to be supplemented with periodic follow-ups, coaching, or booster sessions to maintain their effectiveness over time. This aligns with other research findings where supportive self-management, combined with regular follow-ups, has been found to be crucial in preventing declines in areas such as physical and social functioning, which otherwise tend to suffer in the absence of structured engagement (Campanini et al., 2022; Taylor et al., 2019). Without these supports, participants may struggle to sustain the benefits, leading to declines in key areas such as physical and social functioning. For future interventions, combining self-directed approaches with regular check-ins or professional guidance may help improve participant engagement and support sustained long-term improvements. Moreover, these results highlight the importance of considering individual variability in responses to interventions. The wide variation in participant outcomes, underscores the fact that people with IA do not all experience their condition in the same way. Interventions should thus be designed to be flexible enough to accommodate different levels of severity, comorbidities, and personal circumstances. The study by Vermaak et al. (2015) further reinforces this, as it showed that sustained improvements often require interventions that are adaptable and responsive to the evolving needs of participants.

FAME-W and Minimally Clinical Important outcomes

Minimal Clinically Important Change refers to the smallest difference in an outcome measure that is perceived as meaningful by individuals and has practical implications for clinical or self-management interventions (Draak et al., 2019). In this study, established MCID thresholds were 1.5–2.0 points for the HADS (Puhan et al., 2008; Snaith, 2003), 2–3 points for the SF-MPQ (Salaffi et al., 2004), 0.03–0.07 for the EQ-5D-5L index score (Coretti et al., 2014), and 1.5–2.0 points per subscale for the MFI (Smets et al., 1995). Across all outcome measures, neither the online nor self-guided intervention groups

achieved minimal clinically important changes, except for anxiety scores in HADS, where reductions met the lower bound of the threshold (1.5 points) in both groups. The absence of clinically meaningful changes across most measures, highlights the potential limitations of the intervention in addressing work-related fatigue and associated psychological and physical health concerns in IA. These findings underscore the importance of refining the intervention to enhance its capacity to yield clinically meaningful improvements. Future iterations could consider more stringent participant selection criteria, such as screening for individuals with greater baseline fatigue or work-related difficulties to target those most likely to benefit from the intervention. Additionally, the use of alternative outcome measures with greater sensitivity to detect change related to the intervention may more accurately capture meaningful improvements in fatigue, pain, and work ability. Given the progressive and fluctuating nature of IA, a more sustained or multimodal intervention that incorporates booster sessions, tailored behavioural strategies, or workplace accommodations may be necessary to facilitate long-term improvements in work-related fatigue and overall well-being.

Absenteeism

Although the limited absenteeism data offers insights into work disruptions faced by some participants, the low response rate—only six out of 60 participants that completed and returned their three-month follow-up delivered their logs—greatly limits the generalizability of these findings. This low response rate may be attributable to several factors. The process of maintaining an absenteeism log may have been viewed as burdensome for participants, particularly those already managing a chronic condition. Furthermore, participants who were more engaged in the intervention or experienced more significant health-related work absences may have been more motivated to return their logs. Conversely, those who missed little to no time may have felt that returning their logs was unnecessary or that their contribution was minimal, resulting in a selection bias in the data. As the majority of the interventions took place during the COVID-19 pandemic, those who were working from home may not have had many absences from work, as medical appointments were also conducted virtually (Gottlieb et al., 2022; Saraux et al., 2024). Additionally, being at home may have reduced the need to formally take time off for other arthritis-related issues, such as fatigue and pain (Tengilimoğlu et al., 2022). It is possible that the flexibility of working from home allowed participants to manage their symptoms more easily without having to report absences, as they could attend to their health needs without interrupting their workday. For example, Zhang et al. (2022) found that remote work during the pandemic reduced absenteeism and presenteeism for

individuals with chronic conditions such as IA, allowing them to balance work and health responsibilities more effectively without interruption. Furthermore, given that most healthcare interactions were conducted via telephone or virtual consultations during this period, individuals may have been less likely to have taken time off work for physician visits, potentially reducing the need to formally track work absences. Beyond contextual factors, aspects of the study's methodology may also have influenced engagement with employment log completion. Participants were provided with paper-based employment logs and received weekly reminders via text during the intervention period, followed by monthly reminders via text and email during the three-month follow-up period, but response rates varied. While these reminders were intended to encourage engagement, it is possible that their timing, frequency, or delivery method did not fully align with participants' preferences or routines, potentially limiting their impact. Additionally, the level of detail requested in the logs may have been perceived as burdensome, particularly for individuals experiencing fatigue or fluctuating symptoms, which could have made regular documentation challenging.

To enhance response rates in future research, several methodological refinements could be considered. Simplifying the format of employment logs, incorporating digital tracking tools or mobile applications for easier data entry, and adjusting the frequency and timing of reminders based on participant preferences could improve engagement (Munzert et al., 2021; Wang et al., 2021). Research suggests that integrating employment logs into an already structured data collection process, such as embedding them within questionnaires administered immediately after either delivery method and at three months post-intervention, may reduce participant burden (Jäckle et al., 2019; Harari et al., 2017). Furthermore, providing briefer logs with only essential data fields and offering small incentives for completion has been shown to enhance adherence and retention in digital data collection studies (Oakley-Girvan et al., 2022; Twis et al., 2020).

Offering small incentives, such as payments or gift vouchers for completing and returning all questionnaires and logbooks, could also increase participant motivation and engagement. Ensuring that participants understand the importance of their contributions, regardless of the amount of work missed, could reduce selection bias and improve completion rates. Lastly, regular follow-up reminders from the research team could encourage timely completion and submission of logs, especially if paired with incentives and digital tools to ease the burden of participation.

Implications of Missing Data and Multiple Imputation

In this study, multiple imputation was employed to address missing data, given the substantial loss of participants at the three-month follow-up. As discussed previously (Section 4.8), multiple imputation is a widely accepted method that reduces bias and maximizes available data under the intention-to-treat (ITT) principle (Lee & Stuart, 2019). However, the decision to use multiple imputation warrants critical reflection, particularly given that up to 50% of the data were imputed.

The imputation of such a large proportion of missing data has important implications for the interpretability of findings. Multiple imputation assumes data are missing at random, but this assumption cannot be definitively confirmed. If data were not missing at random, the imputation process could introduce bias, potentially distorting true effect sizes and either diluting real effects or obscuring subtle trends (Lloydwin et al., 2025; Santer et al., 2024).

Additionally, while multiple imputation artificially retains sample size and statistical power, it does not fully account for the uncertainty inherent in missing data. This may result in confidence intervals that appear narrower than they would be in a complete case analysis, potentially giving a misleading impression of precision (Austin et al., 2021; Salbach et al., 2024).

In acknowledging these limitations, it is important to consider that multiple imputation was chosen based on its methodological strengths and recommendations in the literature for handling missing data in clinical trials (Li et al., 2024; Lobo et al., 2024). Nonetheless, the findings from this RCT should be interpreted with caution, taking into account the potential influence of imputed data on the results. Future studies might benefit from strategies to minimize missing data during data collection, such as improving participant retention strategies, using real-time monitoring to address missing responses early, and designing studies with lower participant burden to reduce dropout rates.

Impact of COVID-19 Pandemic

The role of the COVID-19 pandemic must be considered in interpreting these findings. The pandemic created a unique and challenging environment that likely influenced participants' experiences and the effectiveness of the FAME-W. Social isolation, disrupted routines, and the anxiety surrounding health and economic stability could have amplified participants' perceptions and experiences (Gustavsson & Beckman, 2020; van Zanten et al., 2020). For many, the shift to remote healthcare and the reliance on self-guided

interventions may have led to feelings of being inadequately supported, which in turn may have contributed to the deterioration in perceived health (Jeon et al., 2024). Additionally, the pandemic likely exacerbated feelings of uncertainty and helplessness, which could have intensified symptoms of anxiety and depression, further influencing participants' overall health perceptions (Manchina et al., 2022). The increase in variability observed in pain/discomfort and anxiety/depression scores highlights how the pandemic affected participants differently, with some managing to cope with the stressors better than others. This variability suggests that while the FAME-W intervention provided a foundational level of support, it may not have been fully equipped to address the intensified and diverse needs that arose during the pandemic.

4.11 Conclusion

The findings emphasized that recruitment and retention was affected by the COVID-19 pandemic, with the online group showing higher retention than the self-guided workbook group and that neither delivery method significantly improved work role functioning, fatigue, or pain, though the self-guided workbook showed short-term gains in mental and social demands.

The self-guided workbook was a novel approach, as there are no previous IA interventions using a self-guided workbook as a standalone method. While cost-effective, it may require additional support mechanisms, such as personalized follow-ups, to sustain improvements. The study emphasized the need for future research on more tailored, professionally supported interventions, as pandemic-related stress likely impacted the outcomes.

CHAPTER 5: PROCESS EVALUATION

5.1 Introduction

This chapter presents the methodology, results and discussion of a process evaluation of the two delivery methods of the FAME-W intervention: online sessions and self-guided workbook. The chapter begins by highlighting the importance and necessity of process evaluation, outlines the aims and objectives, and presents the study design. Detailed descriptions of data collection and analysis methods follow, leading into the presentation of the findings.

The Medical Research Council (MRC) framework recommends process evaluation to gain a deeper understanding of how complex interventions work in practice (Skivington et al., 2021). Process evaluations are systematic assessments of the implementation and delivery of an intervention (Moore et al., 2015). They are integral to the development and assessment of complex interventions, helping to assess implementation fidelity, delivery, and receipt of the intervention, as well as the context in which it operates (Moore et al., 2015). This evaluation provides insights into success factors and barriers to implementation, offering understanding into how interventions function in real-world settings beyond theoretical constructs. It also informs opportunities for refinement and enhancement in design and evaluation strategies (Moore et al., 2015).

The Medical Research Council identified three core elements of a process evaluation (Figure 5.1) i) implementation (what was implemented and how), ii) mechanisms of impact (how and why the intervention works) and iii) context (contextual factors that may influence the implementation and effectiveness of the intervention) (Moore et al., 2015).

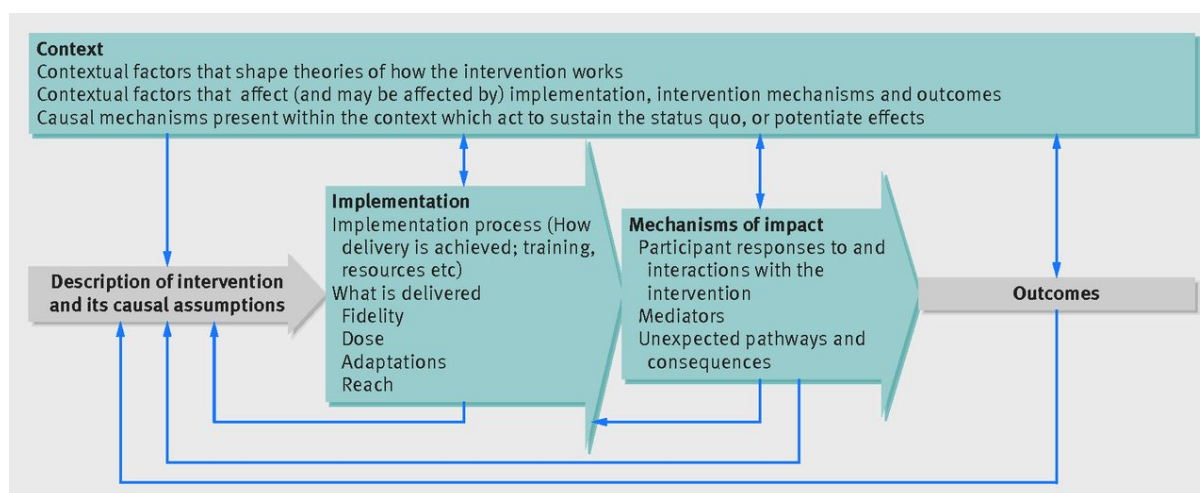


Figure 5.1 Key functions of process evaluation and relations among them according to the MRC framework on process evaluations (adapted from Moore et al., 2015)

i. Implementation

Implementation involves examining the fidelity, reach and dose of the intervention and identifying adaptations made to the intervention delivery.

Fidelity:

Fidelity refers to the extent to which an intervention is implemented as it was originally designed or intended (Moore et al., 2015). It assesses whether the intervention was implemented according to the established protocol, including the content, format, duration, and techniques used in the intervention. High fidelity means that the intervention is delivered consistently and accurately across all participants.

In the online FAME-W, fidelity involved ensuring that the online sessions were delivered exactly as planned, following the intended curriculum and structure. This included verifying that the key components, such as self-management strategies and goal-setting activities, were consistently presented during each session. For the self-guided group, fidelity was assessed by ensuring that participants engaged with the workbook content as instructed, covering all necessary material to maintain consistency with the original programme design.

Reach:

Reach refers to the extent to which the intervention reaches its intended target population (Moore et al., 2015). It involves assessing how many individuals within the eligible population actually participated in the intervention and whether the participants represent the broader target group in terms of demographics or other relevant characteristics.

For this study, reach was evaluated by measuring how many of the eligible individuals with IA participated in the online or the self-guided delivery methods. This also involved analysing the demographics of the participants (e.g., age, gender, employment status) to determine if they were representative of the broader target population, ensuring that the intervention had broad applicability.

Dose:

Dose refers to the amount or intensity of the intervention that participants receive (Moore et al., 2015). This can include the number of sessions attended, the duration of each session, and the extent of participant engagement with the intervention materials. The concept of dose also covers both the intended dose (what was planned) and the received dose (what participants actually experienced).

In the online FAME-W, dose was assessed by tracking the number of sessions the participants attended, the length of those sessions, and the level of engagement during each session. For the self-guided group, dose was measured by evaluating how thoroughly participants engaged with the workbook material, such as whether they completed all the exercises or only partially engaged with the content. This helped determine if participants received enough exposure to the intervention to expect meaningful outcomes.

Adaptations:

Adaptations are any changes made to the original intervention design or delivery during the course of implementation (Moore et al., 2015). These can include modifications to the content, format, delivery method, or other aspects of the intervention to better fit the context, address challenges, or meet participants' needs.

For the online programme, adaptations were necessary due to the shift from an in-person to an online delivery format caused by the COVID-19 pandemic. These changes included shortening the duration of the sessions from 2.5 hours to 1.5 hours and incorporating more content into the self-guided workbook that was originally intended to be delivered in person. Documenting these adaptations was crucial for understanding how the delivery changes might have influenced the outcomes and for guiding future implementations of the programme.

ii. Mechanisms of impact

Mechanisms of impact explore how participants respond to and interact with FAME-W. The analysis of these mechanisms focused on understanding how FAME-W did or did not

produce change in how individuals with IA managed their fatigue in order to help them manage the demands of their work. This is important to understand how the effects of the intervention occurred and how these effects might be replicated (Moore et al., 2015).

iii. Context:

Exploring the intervention context involves understanding external factors surrounding the implementation of FAME-W. This includes any circumstances, conditions, or environmental influences that may act as barriers or facilitators to the intervention's implementation or its effects (Moore et al., 2015). Key contextual elements include geographical location and internet connectivity, where participants in remote areas may struggle with poor internet access, leading to inconsistent participation and potentially reducing the programme's effectiveness (Freeman et al., 2020). Cultural attitudes toward online learning also play a significant role, as participants from cultures that prioritize face-to-face interaction may be less engaged in an online format, diminishing the impact of the intervention (Zeng et al., 2022). Additionally, workplace flexibility is a crucial factor; participants with supportive and flexible work environments are more likely to attend and fully engage in the sessions, enhancing the intervention's success, while those with rigid work schedules may find it difficult to participate, thereby affecting their outcomes (Carolan et al., 2018; Kossek et al., 2014). Understanding these factors helps identify how the intervention interacts with its surroundings, providing insights into why certain strategies may work in one setting but not in another, and aids in generalizing findings beyond a specific evaluation (Moore et al., 2015).

By focusing on these areas, process evaluation informs opportunities for refinement and enhancement in intervention design and evaluation strategies. Furthermore, by systematically assessing implementation, mechanisms of action, and context, researchers can gain a deeper understanding of how interventions work, identify areas for improvement, and ensure their effectiveness across diverse settings (Pfadenhauer et al., 2017). This approach not only enhances the interpretation of outcome data but also informs strategies for refining and improving FAME-W for future implementation.

5.2 Process evaluation aims and objectives

The overall aim of this process evaluation was to understand how the two delivery methods of FAME-W—(i) an online and (ii) a self-guided workbook—were implemented in practice and how they functioned within their intended contexts. To achieve this aim, the objectives were framed around the three key elements of process evaluation: implementation, mechanisms of action, and context:

Implementation:

- Assess how the online FAME-W and the self-guided workbook FAME-W were implemented in practice, including the fidelity, reach, dose and adaptations
- Identify barriers and enablers to the implementation of both the online and self-guided FAME-W.

Mechanisms of Action:

- Examine interactions between different components of the interventions to understand how they contribute to achieving the intended outcomes.
- Evaluate participant engagement and satisfaction with both the online and self-guided FAME-W to gauge how these factors influence the impact of both delivery methods.

Context:

- Explore the contextual factors that influenced the implementation and impact of both the online and self-guided FAME-W, identifying how these external factors impacted the outcomes.

5.3 Methodology

5.3.1 Study design

A parallel mixed methods study design was used for the process evaluation (Schoonenboom & Johnson, 2017). As per the MRC recommendation, qualitative and quantitative data were utilized to assess how the intervention was implemented in practice and how it functioned within its intended context (Skivington et al., 2021).

Mixed methods research combines quantitative and qualitative approaches to provide a comprehensive understanding of a research question. It leverages the strengths of both methods: quantitative research offers standardized, generalizable data, while qualitative research provides rich, subjective insights into complex realities (Creswell & Creswell, 2017; Wasti et al., 2022; Morse, 2016). This combination allows researchers to explore

different dimensions of a topic, making it particularly useful in fields such as health care, where it is considered a more holistic approach (Kettles, 2011; Fàbregues & Paré, 2018). By integrating diverse data types, mixed methods research offers a fuller picture and deeper understanding, making it a “gold standard” in many disciplines (Creswell & Creswell, 2017; Wasti et al., 2022).

The parallel mixed methods design, also known as convergent parallel or convergent design, is a specific approach within mixed methods research. It involves collecting quantitative and qualitative data simultaneously or with minimal time lag, analysing them separately, and then merging or integrating the results, with each component operating independently to address different aspects of the research question (Schoonenboom & Johnson et al., 2017). This design allows researchers to compare and contrast different types of data to validate and enrich their findings. Integration occurs at one or more “points of interface,” where the results from both methods are combined to provide a comprehensive understanding of the research topic (Morse, 2016; Guest, 2013). The below diagram visually describes parallel mixed methods design (Figure 5.2).

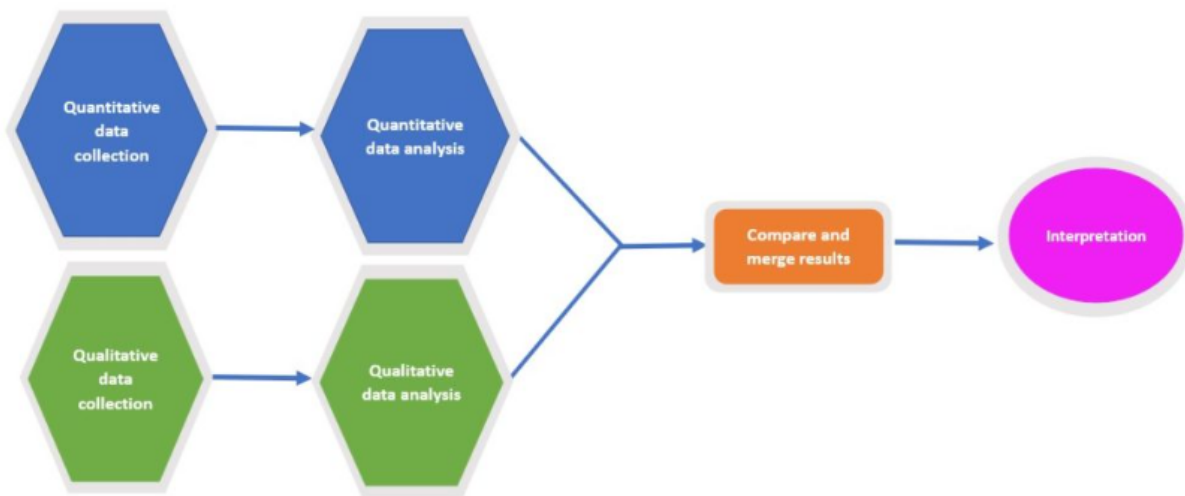


Figure 5.2 Parallel mixed methods design (adapted from Alele & Malau-Aduli, 2023)

Therefore, this process evaluation, a parallel mixed methods design was employed to evaluate the implementation of the FAME-W interventions. Qualitative methods captured participants' experiences and perceptions, offering insights into the programme's impact on their lives. Simultaneously, quantitative data provided statistical trends of attendance. This integration of data sources allowed for a holistic understanding of the implementation of the programmes (Creswell & Clark, 2018; Tashakkori & Creswell, 2007).

5.3.2 Study Population

The sample for this study consists of three groups:

- Individuals with IA who completed either the online FAME-W intervention or the self-guided workbook of FAME-W,
- Occupational therapists who recruited study participants and delivered the online FAME-W,
- Rheumatologists who recruited participants for the study.

This study population was selected to comprehensively understand the implementation and functioning of the interventions. Individuals with IA who participated in either in the online FAME-W or the self-guided FAME-W provided insights into how the intervention was integrated into their daily lives, helping to evaluate participant engagement and satisfaction. Occupational therapists offered perspectives on the fidelity of implementation, and identify barriers and enablers, thereby contributing to an understanding of how the interventions operated within their intended contexts and highlighting interactions between different components. Rheumatologists offered insights on reach. These insights are essential for refining the interventions and ensuring they are effectively tailored to meet the needs of the target population (Moore et al., 2015).

5.3.3 Recruitment methods

Recruitment methods for the participants taking part in online and self-guided FAME-W are described in detail in Chapter 4, section 4.5.

Occupational therapists and rheumatology consultants were invited by the PhD candidate through direct contact at each site to participate in the study. They were provided with a detailed project description, an overview of the study methods, and a presentation of the FAME-W intervention, including the different methods of delivery and content. This information was presented by the PhD candidate and the principal investigator of the study. Those interested in contributing, either to the process evaluation or to assist in recruiting participants for RCT, contacted the PhD candidate to express their interest

5.3.4 Data collection methods

Data were collected through qualitative and quantitative methods. Data collection methods and rationale for the data collected, as identified by MRC guidance for process evaluations, is outlined in Table 5.1.

Table 5-1 Process evaluation data collection framework (Moore et al., 2015)

Dimensions of Process Evaluation	Reason for data collection	Data source
Implementation of the intervention	- To whom was the intervention delivered? (Reach) - How was delivery of FAME-W achieved (training, resources)? - What was delivered (fidelity, dose, adaptations, and reach)?	- Participant questionnaires and demographic information from baseline - Therapist log/Fidelity tool - Interviews with health professionals involved in programme delivery and recruitment - Focus groups with online group participants - Semi structured interviews with self-guided group participants - Attendance by the online group participants
Mechanisms of impact	- Participant responses to, and interactions with, online FAME-W and the self-guided FAME-W - Unanticipated pathways and consequences	- Focus groups with the online FAME-W participants - Semi-structured individual interviews with the self-guided FAME-W workbook participants - Interviews with healthcare professionals to explore potential causal mechanisms. - Quantitative data collected including demographic information and outcome measures from intervention participants
Context	- Contextual factors which shaped theories of how FAME-W intervention works - Contextual factors which affected implementation, intervention mechanisms, and intervention outcomes - Causal mechanisms that may have been present within the context which sustain the status quo, or enhance effects	- Logs maintained regarding context of delivery - Focus groups with online FAME-W participants and individual interviews with self-guided workbook participants and occupational therapists were conducted to explore contextual variations—including technological literacy and access, motivation and self-efficacy, health literacy, personal circumstances, psychosocial factors, cultural and socioeconomic factors, and health status—in uptake and outcomes

Quantitative Data Collection

Quantitative data on implementation, specifically fidelity and dose, were collected through facilitators' logs (Appendix F). These logs tracked participant engagement with the online platform, including the session attendance, session duration, and completion rates for programme sessions (Moore et al., 2015; Abildgaard et al., 2016). The reach of the intervention was examined through demographic data and patient-reported outcome measures gathered from baseline questionnaires as discussed in Chapter 4, Section 4.9.

Qualitative Data Collection

Qualitative data were collected through focus groups and individual interviews.

Focus groups

All participants who attended the online FAME-W were invited to participate in a focus group on the final programme session. This is common practice in group interventions to minimise participant burden and maximise the number of participants who would participate (McCormack et al., 2018; O'Toole et al., 2021).

In this study, focus groups were conducted to explore participants' perceptions of the online FAME-W, concentrating on its design, content, key components, and delivery. The focus groups also aimed to assess participants' views on the programme's impact, implementation, and recommendations for improvement. Focus groups are an effective method in process evaluations because they allow for the collection of diverse perspectives and insights from participants in a relatively short period (Liamputtong, 2011). They facilitate interaction among participants, encouraging the exchange of ideas and experiences related to the intervention being evaluated (Henderson & Carter, 2009; Ritchie et al., 2013).

Focus groups are efficient, allowing the collection of qualitative data from both an individual and collective perspective (Liamputtong, 2011). Group interactions tend to focus on the most salient issues, enabling researchers to identify relatively consistent views among participants (Lysack et al., 2017). This approach helps identify common themes, barriers, and facilitators to implementation, generating rich qualitative data that complement quantitative findings (Hamilton & Finley, 2024). The use of focus groups in this study was particularly appropriate because participants were part of a pre-existing group, having attended the online FAME-W sessions. These shared experiences can make participants feel more comfortable with one another, fostering open discussions and enabling them to challenge each other. This setting is invaluable for exploring group

dynamics, reaching consensus, and understanding divergent opinions on various aspects of the intervention implementation process (Farnsworth & Boon, 2010).

Semi-structured individual Interviews

Participants in the self-guided workbook group were invited to participate in semi-structured interviews. To ensure the data remains manageable for researchers, it is recommended that no more than 50 individuals are interviewed. Therefore, a minimum of 50% of participants recruited from each site who completed the self-guided workbook were invited to take part in semi-structured individual interviews (Vasileiou et al., 2017). Therefore, four weeks after the designated start date, participants were contacted via telephone by the researcher to verify completion of the workbook. Interviews were conducted during this follow up call to minimise participant burden and maximise the numbers who would participate.

All occupational therapists and rheumatology consultants involved in delivery and recruitment were also invited to take part in individual semi-structured interviews after the recruitment and delivery were completed in their sites.

Individual interviews are valuable tools for process evaluations (Schuster et al., 2023). Interviews are described as purposeful conversations used to generate narrative accounts or descriptions and interpretations of phenomena (Sarantakos, 2012; Yeo et al., 2013). In particular, semi-structured individual interviews use a predetermined set of open-ended questions, providing the flexibility to adjust questions and prompts to gather more comprehensive and reliable information (Taylor & Kielhofner, 2006). Semi-structured interviews provide an intimate and confidential setting for participants to express their thoughts, experiences, and perceptions without the influence of group dynamics (Henderson & Carter, 2009). This method enabled the researcher to delve deeper into participants' perspectives, probing specific issues or concerns related to the self-guided programme. Individual interviews are particularly useful for exploring sensitive topics or when participants have diverse experiences that may not be fully captured in a group setting (Hinton & Ryan, 2020).

5.3.5 Data analysis

Quantitative Data Analysis

Quantitative process evaluation data were collected through demographic forms, recruitment, and fidelity logs. Data were inputted to IBM SPSS Statistics version 27 (StataCorp, 2017) and summarised using descriptive statistics to examine the reach and dose of the intervention.

Qualitative Data Analysis

Analysis of all qualitative data including focus groups and interviews were guided by Braun and Clarke's (2022) six stage thematic analysis of qualitative data as described in the feasibility study (Chapter 3 Section 3.11.)

5.3.6 Rigor

Various strategies were employed during the qualitative analysis to enhance the trustworthiness of the research findings. Rigor, pertains to the confidence level in qualitative data, interpretations, and methods (Lincoln & Guba, 1985). For this study, rigour was guided by four aspects of rigour identified by Lincoln and Guba (1985): credibility, conformability, dependability, and transferability. These strategies used to ensure rigour of the process evaluation are the same as those described in detail for the feasibility study (see Chapter 3, section 3.9.1).

5.4 Results

This section delineates the findings from the process evaluation of the online and self-guided FAME-W delivery. The section commences with a discussion of the duration of the focus groups and semi-structured interviews conducted with participants and healthcare professionals, providing context for the qualitative data collection process. Subsequently, the qualitative and quantitative results will be systematically presented in accordance with the key components of process evaluation as outlined in the MRC framework: implementation, mechanisms of impact, and contextual factors.

5.4a Summary of Focus Groups with Online FAME-W and Interviews with Self-Guided Workbook Participants and Healthcare Professionals

Participants focus groups

As discussed in detail in Chapter 3, focus groups were conducted with the online FAME-W participants immediately after the last session of the programme. Nine focus groups were conducted, one per programme. The number of participants in the focus groups ranged from three to 10. The average focus group duration was 32.7 minutes.

Participant interviews

Thirty-six individual interviews were conducted over the phone with self-guided workbook participants. Interview lengths ranged from 16 minutes to 60 minutes. The average interview length was 33.24 minutes.

Interviews with the healthcare professionals

Healthcare professionals' interviews were conducted with two rheumatology consultants and 6 occupational therapists. Interview duration ranged between seven and 32 minutes with a mean of 21.8 minutes.

5.4b Implementation, Mechanism of Impact and Context of Online and Self-Guided FAME-W

This section presents the findings focusing on the three key components outlined by the MRC framework: the implementation of online and self-guided delivery methods, mechanisms of impact, and contextual factors.

The analysis offers insights into various aspects of the FAME-W intervention, including the training and resources provided, fidelity and quality of delivery, recruitment and reach strategies, participant experiences, behavioural and psychological outcomes, and external influences on implementation. These findings highlight the strengths and challenges of the interventions while providing guidance for optimizing and scaling the intervention in broader contexts and populations.

Table 5-2 Themes according to MRC process evaluation functions

Process Evaluation Key Components	Sub- Components	Factors
Implementation	Reach	Participant Characteristics Recruitment Strategies
	Dose	Attendance Rates for Online FAME-W Chapter and Weekly Session Lengths Availability of Resources
	Fidelity and Adaptations	Adequacy of Training Adherence to Online FAME-W Content Content Relevance Format Suitability Engagement and Interaction Suggestions for Programme Improvement
Mechanisms of Impact	Improvement in Self- Management Skills	Understanding and Managing Fatigue Impact of Goal-Setting Techniques Integration of Practical Strategies
	Empowerment and Wellbeing	Self-Efficacy, Confidence and Awareness Improvement in Overall Well-being Sustainability of Behavioural Changes
	Influential Factors on Outcomes	Positive Influences Challenges and Barriers
Context	External Factors Influencing Implementation	Environmental and Organizational Factors Social and Cultural Influences on Intervention Engagement Cultural attitudes towards self-management and IA
	Contextual Enablers and Barriers to Implementation	External Enablers to implementation External Barriers to implementation

5.4.1 Implementation of FAME-W

This section presents the qualitative and quantitative findings related to implementation of online and self-guided workbook of FAME-W. As discussed previously, implementation examines how delivery is achieved and what is delivered in terms of reach, dose, fidelity, and adaptations. There is no consensus on how best to divide the study of implementation into key subcomponents (such as fidelity, dose, and reach) (Moore et al., 2015) however, this section will systematically present the findings by organizing the analysis around these specific subcomponents. Each subcomponent will be examined in detail, allowing for a structured and comprehensive assessment of the implementation process.

5.4.1.1 Reach

This section focuses on the concept of reach, which examines who and who did not receive the either delivery method of FAME-W.

Participant Characteristics

The findings presented here will explore the characteristics of those who were recruited, including sources of recruitment, the types of IA they had, the duration of their IA, and the types of employment the participants came from (Table 5.3). By analysing these factors, we can gain a clearer understanding of the demographic and occupational reach of the intervention.

Table 5-3 Participant characteristics for both delivery methods

	Online Group (n=61)	Self-Guided Group (n=61)
Mean age (SD)	48.7 (10.08)	49.64 (10.01)
Age Range in years	25-65	24-65
Gender		
Female (%)	46 (75.4)	51 (83.6)
Male (%)	15 (24.6)	10 (16.4)
Type of Arthritis		
RA (%)	25 (41)	20 (32.8)
PA (%)	14 (23)	15 (24.6)
FM (%)	7 (11.5)	6 (9.8)
AS (%)	5 (8.2)	5 (8.2)
SLE (%)	1 (1.6)	3 (4.9)
GOUT (%)	0 (0)	1 (1.6)
Other (%)	9 (14.8)	11 (18)
Years since Diagnosis (SD)	9 (6.60)	10 (8.06)
Marital Status		

Married (%)	44 (72.13)	37 (60.7)
Single (%)	15 (24.59)	17 (29.9)
Separated (%)	2 (3.28)	6 (9.8)
Widowed (%)	0	1 (1.6)
Living Situation		
With Others (%)	57 (93.4)	49 (80.3)
Alone (%)	4 (6.6)	12 (19.7)
Level of Education		
College/University (%)	51 (83.6)	45 (75.8)
Leaving Certificate (%)	5 (8.2)	9 (14.8)
Junior Certificate (%)	5 (8.2)	6 (9.8)
Primary Level (%)	0 (0)	1 (1.6)
Chronic Condition (Self-Reported)		
Yes (%)	36 (59.0)	37 (60.7)
No (%)	25 (41.0)	24 (39.3)
Employment Status		
Full Time (%)	41 (67.2)	48 (78.7)
Part Time (%)	20 (32.8)	13 (21.3)
Type of Work		
Non-Manual (%)	38 (62.3)	41 (67.2)
Mixed (%)	20 (32.8)	16 (26.2)
Manual (%)	3 (4.9)	4 (6.6)

The participants had a mean age of approximately 49 years, with a higher proportion of females in both groups (75.4% in the online group and 83.6% in the self-guided group). Rheumatoid arthritis (RA) was more prevalent in the online group (41%), while the distribution of Psoriatic Arthritis (PsA) was more evenly spread across both groups. Fewer participants reported having rarer forms of IA, such as lupus, gout, and fibromyalgia. On average, participants had been living with their condition for approximately nine to ten years. Socioeconomically, the majority were married and lived with others, with a significant portion holding a college or university degree (83.6% in the online group and 75.8% in the self-guided group). Full-time employment was more common in the self-guided group (78.7%), with most participants in both groups engaged in non-manual work.

Table 5.4 highlights the feedback on the diversity within the participant sample, showcasing a wide range of backgrounds. Facilitators reported on how well the participant group mirrors the broader population of individuals with IA.

Table 5-4 Representativeness of the online group sample

Summary of findings	Facilitator Quotes (OT)	Online Participant Quotes (FG)
Both programmes featured a diverse participant sample, encompassing different employment types, job demands, and diagnoses. Facilitators noted that addressing the diverse needs and conditions presented challenges but also added significant value to the delivery of the programmes.	<i>“Everyone had different needs. Some people were self-employed so you had to tend to their needs and others were employed by companies. Some were manual workers and some weren’t so it was a mix of people” (OT3)</i> <i>“I had a good mix. Some people in my group had very sedentary jobs and some were very physical.” (OT1)</i> <i>“I think everyone in my group had a different diagnosis which made it challenging and interesting” (OT4)</i>	<i>“It was interesting to me the other people with different types of inflammatory processes, and how they all manage, to learn from it. And that was very good and interesting” (FG12)</i> <i>“I felt like none of us had anything in common except IA. It seemed like everyone was coming from a different direction, everyone had a different experience.” (FG17)</i>

Recruitment Strategies

This section reports the findings on the recruitment process, emphasizing the strategies that were successful and identifying areas where improvements are needed for further development.

Facilitators and barriers to recruitment

Various strategies were employed to recruit participants. Recruitment took place across seven sites, including outpatient rheumatology and occupational therapy clinics, voluntary arthritis organisations, and social media. As detailed in Chapters 3 and 4, recruitment efforts faced significant challenges due to disruptions caused by COVID-19 and limited resources, necessitating adaptations to improve participation.

As a result, recruitment progressed more slowly than expected due to the pandemic's impact and associated challenges. Recruitment was delayed due to redeployment of healthcare practitioners, delays in ethical approvals causing challenges in committing to the study. Table 5.5 summarises the challenges each site faced.

Table 5-5 Challenges faced in recruitment for each delivery site

<i>Site ID</i>	<i>Delays in Ethics</i>	<i>Redeployment of healthcare practitioners</i>	<i>Challenges in commitment to the study</i>	<i>Delays in months</i>
1		X	X	7
2		X	X	16
3	X		X	5
4	X		X	2
5	X		X	24
6	X		X	24
7		X		12

Due to recruitment challenges, all programmes experienced delays ranging from two months to two years. Specifically, the prolonged delays at sites 5 and 6 necessitated merging participants from these two sites for programme delivery.

Insights from healthcare professionals on the effectiveness of the recruitment methods, along with the challenges faced, offer a thorough evaluation of the strategies' success and the obstacles encountered. These insights highlight areas for potential improvement in future recruitment efforts and are detailed in Table 5.6.

Table 5-6 Qualitative findings on barriers and facilitators to recruitment

Categories	Summary of Findings	Health Care Professionals' Quotes
Effectiveness of recruitment methods	Healthcare professionals reported that identifying individuals from waiting lists and maintaining a physical presence in clinics were considered key strategies that facilitated recruitment. The preliminary identification of eligible participants streamlined the process. These methods enhanced visibility of the study in clinics and provided immediate support, serving as effective reminders and prompts for both staff and potential participants.	<i>"I think the way that we recruited, including people who were on a waiting list was helpful. I don't know if that had any impact on the level of participation in the group, in that they had been waiting a long period. I don't know what the best way to recruit is" (OT1)</i> <i>"when you came into the clinics there was a faster recruitment rate. You were there, it's automatically a prompt, even for the clinic staff to go "oh yes, FAME-W recruitment". You were a physical reminder to recruit and if we had questions we were able to solve it there with you" (RHM1)</i> <i>"I don't think we could have come up with a better way of recruiting especially during COVID. I think the way we did it, from my point of view worked well. And it was very helpful to have some preliminary identification [age and diagnosis, work status]. And you being in the clinic was also helpful as a reminder" (RHM2)</i> <i>"We have the patient information on age, diagnosis and employment on file. I was able to identify individuals easily from my data base and invite them to the study" (OT2)</i>
Barriers to recruitment	Numerous barriers were identified in the interviews that impeded recruitment efforts. COVID-19 led to staff shortages and disrupted regular clinic operations, significantly affecting recruitment. Many	<i>"We couldn't recruit any participants from my clinics. I suppose mainly because I am the only one in rheumatology right now and COVID was also a factor. I didn't have time for recruitment" (OT1)</i>

	healthcare practitioners reported that they were overwhelmed by the shift to phone clinics, which reduced their focus on recruitment. The recruitment process faced significant challenges due to the unpredictable nature of IA and the complex personal circumstances of potential participants, such as financial instability and family responsibilities. Healthcare professionals noted that the fluctuating symptoms of IA left many individuals unable to work, which, combined with financial pressures and caregiving duties, further reduced participation rates. The situation was exacerbated by the cancellation of in-person clinics and the shift to online consultations, which limited healthcare professionals' ability to focus on recruitment. Additionally, the absence of dedicated arthritis clinics and inadequate resources further impeded effective recruitment efforts.	<i>"I've had patients who've come in and said, this is just not the time for me to work. I have my kids, they are small and financially I am on illness benefit. Or they were let go during COVID." (OT3)</i> <i>"We used to have an arthritis clinic, but because of resources at the minute that's not running. We normally would have had a rapport and a relationship with those patients, and not just for the study. So, if we had more resources that definitely would have made a difference in recruitment." (OT5)</i> <i>When we discussed recruitment before COVID, I was confident that our patient profile fit with the eligibility criteria. But when we tried to recruit, I realized they are either in and out of work or not working at all or their condition isn't stable" (OT6)</i> <i>"it was hard. Phone clinics were new to us. It was new and unprecedented times with COVID. The focus of attention was just checking in with these patients, seeing how they are, trying to answer their queries, and their concerns. So, I would say recruitments, during that initial period was very, very slow. Very difficult, because of COVID and everything else going on. The project just didn't seem like a priority. So that was a big challenge" (RHMI)</i>

5.4.1.2 Dose

Dose refers to the amount of intervention content received by participants (Saunders, 2015). For this study dose was measured through the attendance rates and the duration of intervention delivery.

Attendance Rates for the Online FAME-W

Weekly attendance data were collected from all sites. The total number of participants varied per site and per programme (Table 5.7). Overall, forty-one participants attended all four sessions. The first week demonstrated a high attendance rate, with 90% of participants attending the sessions. In the second week, a total of 52 (85.25%) participants attended the programme, resulting in a slight decrease in the attendance rate. In the third week, attendance dropped to 43 (70.49%), and in the final week, a total of 46 (75.4%) participants was present. Overall, sites 3, and 7 had the highest rates of attendance with site 5 and 6 having the lowest attendance rate with 4 participants not attending any programmes.

Table 5-7 Online FAME-W Weekly attendance rates per site

Site ID	Programmes Delivered (n= number of participants)	Weekly Attendance			
		Week 1	Week 2	Week 3	Week 4
		(attending participants/ number of participants)			
1	1 (n=12)	11 (92%)	8 (66%)	6 (50%)	10 (83%)
	2 (n=7)	6 (86%)	6 (86%)	5 (71%)	4 (57%)
	3 (n=7)	6 (86%)	6 (86%)	3 (43%)	5 (71%)
2	1 (n=5)	5 (100%)	4 (80%)	4 (80%)	3 (60%)
3	1 (n=5)	5 (100%)	5 (100%)	5 (100%)	4 (80%)
4	1 (n=5)	4 (80%)	5 (100%)	3 (60%)	3 (60%)
5&6	1 (n=8)	6 (75%)	6 (75%)	5 (62 %)	5 (62%)
7	1 (n=7)	7 (100%)	7 (100%)	7 (100%)	7 (100%)
	2 (n=5)	5 (100%)	5 (100%)	5 (100%)	5 (100%)

Completion Rates for the Self-Guided Workbook

For the self-guided group, participants were expected to complete all four chapters over four weeks (one chapter per week), with at least one goal to be set and achieved each week. Dose was assessed by having participants self-report the amount of time they spent on each chapter, which was discussed and documented during individual interviews. Overall, 72% of participants reported that they completed all chapters and activities in the workbook. Table 5.8 below presents the self-guided workbook completion rates.

Table 5-8 Self-guided workbook completion rates.

Site ID	Programme number (number of workbooks sent)	Participants who completed the self-guided programme
1	1 (n=12)	11 (92%)
	2 (n=6)	4 (67%)
	3 (n=6)	4 (80%)
2	1 (n=4)	3 (75%)
3	1 (n=5)	3 (60%)
4	1 (n=5)	2 (40%)
5&6	1 (n=9)	6 (67%)
7	1 (n=8)	6 (75%)
	2 (n=6)	4 (67%)
Total numbers	61	43 (72%)

Chapter and Weekly Session Lengths

Reporting the length of the online sessions and chapters of the self-guided workbook involves examining the amount of content delivered in each session, which helps to evaluate if the intended quantity of the intervention (or "dose") was provided to participants (Rowbotham et al., 2019; Saunders, 2015). This helps to determine if participants received an adequate amount of the programme to achieve the expected outcomes. (Saunders, 2015). Table 5.9 presents participants' experiences and feedback regarding the length of chapters in the self-guided workbook and the duration of online sessions of the FAME-W. These insights are vital for optimizing the intervention's design to better accommodate the needs and preferences of participants.

Table 5-9 Chapter and session lengths for online and self-guided workbooks

Category	Summary of Findings	Online Participant Quotes (FG)	Workbook Participant Quotes (Int)	Facilitator Quotes (OT)
Length of programme	Four-week duration-was reported as maintaining interest and was seen as manageable. Length of the workbook was reported to be suitable to complete in four weeks. Both the online programme and the self-guided workbook were well-received in terms of length, structure, and effectively engaging participants.	<i>"It flew by actually. We couldn't believe it was four weeks already." (FG7)</i> <i>"I think the length was perfect. Because you grab people's attention. I think when you make a programme longer people lose interest." (FG21)</i> <i>"Initially I thought "oh God four weeks is a long time" but when we were taking part in it, it didn't seem as long." (FG45)</i> <i>"I don't think I would have committed to anything longer than this." (FG12)</i>	<i>"The length was just right. Initially looking at it you're going "oh god, loads in this", but then once you got into it, you realize, "oh, that's a chapter. Okay, I have to read that chapter and get into that". And then you see that you easily went through so it's about an hour and 15 minutes a chapter" (Int44)</i> <i>"I thought it was going to be very thick. When I got it, I was pleasantly surprised at the size of it and the information it contains compared to its size." (Int 27)</i> <i>"Four chapters, four weeks is doable. Chapters weren't lengthy</i>	<i>"I think four weeks was good. If it was longer we would have covered more individual, personalized strategies but I think for a group-based programme four weeks is enough. If they need more help they can come see us" (OT3)</i>

			<i>and they were simple, an hour a chapter” (Int 1)</i>	
Length suggestions	Some participants suggested an additional week might improve interactions and experience sharing. This adjustment could enhance the programme. Suggestions for length adjustment are noted for future refinement.	<i>“We didn't get to know one another. If we had the first week to talk to each other maybe that would have been more comfortable to share personal things. Maybe an extra week is needed.” (FG3)</i> <i>“I say it was a wee bit short I could have done with a couple extra of weeks to make it more relatable for me.” (FG27)</i> <i>“Good to have five sessions, we can talk more with each other.” (FG15)</i>	<i>“I think it could be longer, it wouldn't have bothered me if there was more information” (Int15)</i> <i>“I think I would have delayed starting it if it was thicker, it would've scared me off”(Int31)</i>	<i>“I was initially thinking 90 minutes might not be enough to cover everything but we went through it and I think for an online programme it is adequate” (OT4)</i>

Availability of Resources

Occupational therapists and participants evaluated the availability of resources, such as handbooks for the online programme and for occupational therapists. They also assessed the workbook for the self-guided programme, offering insights into the accessibility, quality, and usefulness of these resources. Their perspectives highlighted key aspects of resource provision that influence the intervention's implementation. The following Table 5.10 reports the findings related to the feedback on the adequacy and impact of the resources used throughout both delivery methods.

Table 5-10 Availability of Resources

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)	Facilitator Quotes (OT)
Accessibility and quality of materials provided	The handbook received by online group and the facilitators and, workbook received by the self-guided group were reported to be highly accessible and comprehensive, appreciated for their ease of use and effective integration into training sessions.	<i>"I like the fact that the OT went online and actually showed us where to find the resources while sharing the screen. She didn't just skip over that and it is good to know these resources actually exists"</i> (FG42)	<i>"I thought the workbook was good, the paper quality wasn't cheap, and it wasn't heavy. It was easy to hold, no pressure on my wrists or fingers"</i> (Int19)	<i>"The handbook was brilliant, and it was just sent to me and I got it on PDF as well. It had every information they [participants] needed."</i> (OT2) <i>"The workbook was a very good resource for participants and myself. The information in it was very good"</i> (OT4)
Feedback on the usefulness of resources	Both facilitators and participants evaluated the resources for their practical utility and comprehensive coverage. This assessment helped enhance understanding	<i>"Without the resources like the handbook and the links at the back, you've just been labouring the point without directions."</i> (FG10)	<i>"The resources at the back were very good. If I need more help I can go to the other resources the book showed, like a golden page"</i> (Int33)	<i>"It was also a good guidance for me. I read through the chapters before the sessions. I could add info from or to the book when I was explaining"</i> (OT2)

	and application of the content.	<i>“Going through the handbook just reinforces the information like looking at the notes after you've committed to the meeting and it sets the knowledge.” (FG30)</i>		<i>“The handbook was very useful to refer the participants back to and to reminding them to keep that and have it as a resource” (OT3)</i>

5.4.1.3 Fidelity and Adaptations

Fidelity of the intervention was measured through self-reported fidelity log book completed by the facilitators at the end of each session for four weeks (See Appendix F).

Adequacy of Training

As detailed in Chapter 3, the occupational therapists responsible for delivering the online FAME-W received training on delivery of the FAME-W and were asked to provide feedback on the content and format of the training session, as well as any necessary changes to the delivery concerning missing information (Table 5.11). Additionally, facilitators shared their perspectives on the effectiveness of the training.

Table 5-11 Feedback on training and resources

Categories	Summary of Findings	Facilitator Quotes (OT)
Content and format of training sessions for facilitators	Facilitators reported that the training was effective and well-organized, covering all necessary content. Training delivered in an online format facilitated familiarity with the programme's structure.	<i>“As was everything, this was online as well. I don’t think it would’ve made a difference if it was in person actually. But we covered all the chapters and the goal setting.” (OT1)</i> <i>“As OTs we would be doing this on daily bases. None of the information was new but it was good in terms of getting to know the slides and the flow.” (OT3)</i> <i>“I thought the training was organized and focused to what is expected of me as the facilitator” (OT4)</i>

Facilitator feedback on training effectiveness	Training enhanced facilitators' confidence and clarity in their roles, particularly for those new to leading programmes. The structured and comprehensive training was essential for preparing facilitators to effectively deliver the programme.	<i>"I have been part of other programmes but I never delivered a whole programme by myself. It was good to go over everything and know what is expected of me as I have never done an online group before" (OT1)</i> <i>"I think it is good that we have training and not just left with the slides and the handbook. It gave me a sense of relief to go over it to know what I need to do" (OT4)</i>

Adherence to online FAME-W content

Table 5.12 presents the results from the fidelity log book per online programme for each session of the programme. All sites successfully delivered the planned four weekly sessions. Although facilitators reported that all content was delivered as intended, there was considerable variation in session duration across different sites. This variation suggests that some content may have required more time to deliver, additional content may have been included, or extended time was needed for goal setting, as illustrated in Table 5.12.

Table 5-12 Adherence of occupational therapists to intervention content and length

Site ID	Programmes delivered	Week 1		Week 2		Week 3		Week 4	
		Components Delivered	Duration (minutes)	Components Delivered	Duration (minutes)	Components Delivered	Duration (minutes)	Components Delivered	Duration (minutes)
1	1	100% (14/14)	*130	100 % (8/8)	**75	100 % (9/9)	85	100% (11/11)	**75
	2	93% (13/14)	85	100% (9/8)	90	100 % (9/9)	**80	100% (11/11)	**60
	3	100 (14/14)	95	100 % (8/8)	**80	100 % (9/9)	90	100% (11/11)	90
2	1	100% (14/14)	95	100 % (8/8)	90	100 % (9/9)	90	100% (11/11)	85
3	1	93% (13/14)	*105	100% (9/8)	90	100 % (9/9)	*120	100% (11/11)	90
4	1	100 (14/14)	90	100 % (8/8)	**80	100 % (9/9)	*105	100% (11/11)	85
5&6	1	100 (14/14)	*100	100 % (8/8)	85	100 % (9/9)	90	100% (11/11)	85
7	1	100 (14/14)	*100	100 % (8/8)	**80	100 % (9/9)	90	100% (11/11)	90
	2	100 (14/14)	90	100 % (8/8)	90	100 % (9/9)	95	100% (11/11)	85

Note: Considerable deviations from intervention content are highlighted in bold,

*Denotes overtime

** Denotes undertime

The longest delivery time recorded was 130 minutes for Week 1, and the shortest was 60 minutes in the last session, demonstrating considerable variation across different weeks. The mean delivery time across all weeks and sites was 95 minutes, with Site 3 having the longest overall duration and Site 1 (programme 2) having the shortest. Week 1, that includes introduction to the programme and to the group was the longest session for most sites, with a mean duration of 98 minutes, while Week 3 which focuses on mental health was the second longest with a mean of 94 minutes. Occupational therapists attributed the longer sessions in the first week to participant introductions and programme orientation, and the longer sessions in the third week to relaxation practice (Table 5.14). The mean and median values for each week are presented in Table 5.13.

Table 5-13 Mean and median values of each week

	Week 1	Week 2	Week 3	Week 4
Mean (minutes)	98	84	94	83
Median (minutes)	95	85	90	85

Facilitators provided weekly feedback on the fidelity logs for any session that went over or under five minutes. Facilitator in Site 1 delivering the first FAME-W programme reported that the reason for long session was due to large number of participants and their introduction to the group. The facilitators at Site 3 reported that in Week 3, a participant became extremely emotional discussing the impact of stress on their work and daily life. Consequently, the facilitator had to extend the comfort break beyond the suggested duration. There was no change of facilitators in any programme.

Facilitator adherence to the programme's content delivery guidelines was rated high, with only two facilitators deviating from the guidelines during the first week. Site 1 in the second programme and site 3 did not include sleep hygiene lecturette in their first session. They shifted this to week 2 due to going overtime in their first sessions.

Table 5-14 Adherence to Program Content

Categories	Summary of Findings	Facilitator Quotes (OT)
Consistency in delivering programme components as designed	Facilitators adhered to the FAME-W programme guidelines, ensuring all key components were delivered as designed. However, they identified the need for flexibility in delivery of content.	<i>"I went over important bits with you [PhD candidate] before each session and we had the training so I delivered everything in the order it was" (OT3)</i> <i>"every person needs something different and if I were to run it again I think each session would be different again. Overall I delivered everything that was on the fidelity sheet" (OT2)</i> <i>"I tried to give people a coffee break but they wouldn't take it" (OT4)</i>
Variations in delivery across different sites/programmes	Variations were made to better suit session group dynamics and participants' needs. For example, sleep hygiene content was rescheduled in two programmes for better timing, and emotional responses extended a session in Site 3.	<i>"I had to move sleep hygiene to the following week because the first week ran over. But I think it was okay, it fit well with the second week as well and I think participants were happier to not prolong the session" (OT1)</i> <i>"This time I had to move sleep hygiene to the following week because the first session was running too long" (OT4)</i> <i>"Someone got overly emotional during a session so that session ran really long because I had to give a longer comfort break and phoned the participant to make sure they were okay" (OT2)</i>

Content Relevance

As discussed in Chapter 3, while the content of the online and self-guided workbook of FAME-W is the same, it was delivered in different formats. Both content and format are crucial to maintaining fidelity in programme implementation, ensuring consistent and effective delivery (Carroll et al., 2007). Therefore, delivering content that is relevant to the participants ensures the intervention aligns with its objectives and goals, thereby enhancing the programme's efficacy and integrity.

Table 5-15 Content Relevance for both interventions

Category	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Appropriateness and comprehensiveness of content	Participants appreciated the content's depth and relevance of the content, noting its thorough coverage of important topics and structured presentation.	<i>"I found it all very good. I was really shocked to see how much we didn't know." (FG6)</i> <i>"I think it was really comprehensive and it was well structured. I liked the content." (FG1)</i> <i>"The topics were excellent and they cover everything that you need and that you don't necessarily think about when you live with this [inflammatory arthritis]. I was really amazed" (FG32)</i>	<i>"It covered the main four issues affecting me day to day." (Int12)</i> <i>"All chapters were relevant. I can't say that one was more relevant than the other" (Int36)</i> <i>"Every chapter hit the nail on the head" (Int7)</i> <i>"I wouldn't have done a better job explaining my problems" (Int25)</i> <i>"I found it very informative and very relatable to where I'm at right now." (Int30)</i>
	Participants highlighted chapters on fatigue, mental health, legislation, and ergonomics as particularly useful, noting their practical benefits in daily life	<i>"Fatigue doesn't really just affect the work it happens every day and everywhere. So, I just got more out of that fatigue management personally." (FG24)</i> <i>"I found the mental health and mental well-being session very helpful as well because mental health</i>	<i>"The last chapter was the most beneficial chapter for me. It breaks things down into the tips for telling people at work and it's a sensitive one. It also covers your rights the things you want to tell people at work." (Int4)</i>

Useful and beneficial chapters	and work environments.	<i>is something we probably forget about because you just get on with it." (FG5)</i> <i>"I thought the legislation session was good because this is something that I wouldn't have known." (FG43)</i> <i>"For me ergonomics section was the most useful. After this session (employment) I am going to ask my manager to get me an ergonomic chair and other things." (FG16)</i>	<i>"The fatigue section was very relevant and helped me manage my fatigue more" (Int17)</i> <i>"The ergonomics section was particularly good for work." (Int9)</i> <i>"The most beneficial chapter would be the stress one. You have lots of techniques like the meditation the yoga the Pilates because of other symptoms I get anxious at work. So, the stress one was most helpful" (Int35)</i> <i>"Chapters were linked. How can I say one was better for me than the other? They went hand in hand." (Int24)</i>

Format Suitability

The format of the two delivery models of FAME-W significantly influenced participants' experiences, particularly in terms of their engagement, understanding, and satisfaction with the intervention. Participants reflected overall structure of both modalities, as highlighted in the Table 5.16 below. Their feedback underscores the impact of these elements on their engagement, understanding, and satisfaction. Analysing these factors offers insights into the programme's effectiveness and identifies areas for potential improvement to enhance participant experience and efficacy.

Table 5-16 Feedback on the format of both delivery methods

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Accessibility and clarity of presentation	The structured and clear layout of both delivery methods were highly valued. Participants particularly found the self-guided workbook beneficial for its user-friendly, colourful, and detailed design, which enhanced engagement. A participant found the smiley face rating system, which featured three options—a big smile, a neutral smile, and a sad face—more personalized and less burdensome than common numerical rating systems. They appreciated the system's simplicity, noting that it allowed them to quickly and intuitively select an option without the	<i>"Every week seems to have a defined subject. It was well laid out nicely divided yet connected."</i> (FG28) <i>"It was easy to follow it was all connected."</i> (FG2) <i>"Each week was divided into two and each week was clear as to what we would expect. It was also in the workbook. Very clear"</i> (FG16)	<i>"I think it was very user friendly. And well laid out and colourful. Nicely spaced out and quite detailed. Very easy to use. I enjoyed reading this."</i> (Int15) <i>"It was very practical very easy to understand. So as someone who is coming from a completely different non-medical background it definitely made a lot of sense."</i> (Int5) <i>"I thought it was done very well. I liked the way it gave you your information and then made you put it in use."</i> (Int13) <i>"Smiley faces rating system was good. I am tired of seeing numbers everywhere. It was simple and I didn't have to think. I saw and circled the face that looks like me at that</i>

	cognitive effort typically required by numerical scales.		<i>time. It made it more personal."</i> (Int28)
Language used	The language used in both delivery formats was straightforward and free from medical jargon, making it accessible to all participants. This simplicity enhanced overall engagement and understanding.	<i>"She (the OT) didn't use complicated words when describing things"</i> (FG28) <i>"The facilitator simplified everything, I didn't feel patronized"</i> (FG2)	<i>"The language used was, it was simple enough to understand, it wasn't too technical, which I appreciated."</i> (Int31) <i>"There wasn't any medical jargon in it, it was in layman's terms"</i> (Int20)

Engagement and Interaction

The feedback presented in Table 5.17 specifically applies to the online FAME-W programme. Participants' reflections focused on the nature of interactions between facilitators and participants, as well as their overall engagement during the sessions. This included facilitator-participant interactions and the degree to which participants actively engaged with the programme content. The feedback from both the occupational therapists and participants aided in understanding the strengths of the intervention and areas for improvement in the delivery of the online delivery of the FAME-W programme.

Table 5-17 Interactions between online participants and the facilitators

Categories	Summary of Findings	Online Participant Quotes (FG)
Facilitator-participant interactions	Facilitator's expertise, approachability, and interactive style was highly valued. Participants appreciated facilitator's ability to address questions effectively, facilitate discussions, and normalize their experiences related to stress and sleep issues.	<i>"The facilitator was knowledgeable, she was able to answer all our questions and point us to the right direction"</i> (FG18) <i>"We could talk about things with the facilitator and normalise our stresses and feelings and failures of not being able to sleep or relax."</i> (FG45) <i>"I thought the facilitator was very good at facilitating the discussion between people as well. It wasn't all just her talking at us for an hour and a half or so."</i> (FG39)

The engagement with the intervention for participants in the self-guided workbook group differed from that of the online group. While the online participants actively interacted

with both the facilitator and each other, creating a dynamic environment characterized by varying levels of talkativeness and engagement, the self-guided group adopted different strategies to stay connected to the intervention (Table 5.18). These strategies included engaging with reflective prompts, and sharing the learned information from the workbook with peers.

Table 5-18 Engagement of participants with the workbook

Categories	Summary of Findings	Workbook Participant Quotes (Int)
Participant engagement in chapters	Participants actively engaged with the workbook, noting that its simplicity encouraged interaction. Some took detailed notes and revisited the content to reinforce learning. One participant shared the workbook's insights with friends, who also found it useful.	<i>"I made sure to read it carefully and take notes. I underlined and went back again" (Int6)</i> <i>"I think the simplicity of it made me engage with the content." (Int16)</i> <i>"I showed it to friends of mine some of the things in the workbook. They found it very useful as well." (Int32)</i>

Feedback from both online participants and facilitators underscores the importance of active participation and shared discussions in fostering a supportive environment. These findings demonstrate FAME-W 's flexibility and adaptability in meeting diverse participant needs across different formats, enhancing the overall effectiveness of the interventions (Table 5.19).

Table 5-19 Engagement of participants with the online programme

Categories	Summary of Findings	Online participant quotes	Facilitator Quotes
Participant engagement in sessions	Participants showed different levels of engagement, with some being more talkative and others needing prompting. Overall, discussions were positive, and participants valued the opportunity to connect with others. Facilitators noted that prior familiarity with participants helped sessions run effortlessly.	<i>“Some of us was more talkative than others. Sometimes I wonder if I am oversharing but this is what it is for isn’t it?” (FG46)</i> <i>“It was very good to hear other people, and it was good to talk to those that understand” (FG25)</i> <i>“Everyone had something to say when we shared goals, it was a good discussion” (FG8)</i>	<i>“I knew the people, I’ve seen them in clinics before. They were all attentive in sessions, they talked and participated so it ran smooth” (OT2)</i> <i>“I had couple talkative people and some that wouldn’t talk unless I prompted but I guess that is the reality with any group” (OT3)</i>

Suggestions for Programme Improvement

In this section, suggestions were made by participants for improving their allocated programme are presented. These suggestions reflect the participants’ preference for more personal interaction, better group dynamics, and enhanced digital resources. The findings in Table 5.20 highlight areas where the programme could be refined to better meet the needs of participants.

Table 5-20 Participant suggestions for improving both delivery models

Category	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Suggestions for Intervention Improvement	Participants suggested several improvements, including more personal interaction, better group dynamics, digital resources, and practical tools such as apps and colour-coded cards. These suggestions aimed to enhance the overall impact and accessibility of both the online and the self-guided delivery formats of FAME-W.	<i>"In person would be more personal and we would make more connections. You could get to know them personally and explain your concerns and listen to their concerns." (FG31)</i> <i>"You'd have to find a way of building the group dynamic and building the group, trusting each other before we could really get into it and talk a bit more about it because it was just important information rather than a sense of meaning really an ownership of that information." (FG40)</i> <i>"I think that the discussion piece could be addressed with breakout sessions. If people get to know each other a bit better people will feel more comfortable with the whole zoom thing. Potentially 20-minute breakout sessions would be useful. Get to know each other. And understand each other's differences I suppose with all of this because it affects everybody differently." (FG44)</i>	<i>"Maybe if there is an index card version like a colour-coded one so I can just go pick up a card and give it to my employer to read it or a family member and maybe make it kid-friendly as well?" (Int26)</i> <i>"Something like an app will be much easier. Because when you have a spare second, you'd have the time to read. And you might have a reminder pop up on your phone to kind of record your pain and your fatigue." (Int34)</i> <i>"If the workbook was digital and you can have links for more information or links that take you to more examples like when it talks about yoga you can click a link and go to a yoga video." (Int2)</i>

5.4.2 Mechanism of Impact

This section presents the findings related to mechanism of impact of the two delivery methods of FAME-W. Mechanism of impact focuses on understanding how and why an intervention produces its effects (Moore et al., 2015). This involves examining the processes and interactions that occur during the implementation of the intervention, which contribute to the observed outcomes.

In the following sections, the evaluation of the mechanisms of impact of FAME-W will be structured into two primary categories: outcomes and factors that impact outcomes. The outcomes section presents the changes and improvements that participants experienced as a result of the intervention, focusing on both behavioural and psychological changes as well as improvements in self-management skills. The factors that impact outcomes section delves into the elements that either facilitated or hindered these changes, examining both the positive influences that supported participants and the challenges that presented barriers. Each of these categories are further divided into subgroups to provide a clearer understanding of what aspects of the intervention were successful and what areas may require adjustment or improvement, thereby offering a comprehensive view of the mechanism of impact within this process evaluation.

5.4.2.1 Outcomes

Improvement in Self-Management Skills

This section reports the improvement in self-management skills among participants and it refers to the changes or results that occur as a consequence of the FAME-W intervention. Participants reported significant improvements in their ability to manage their condition through enhanced understanding of fatigue, adoption of goal-setting techniques, and integration of practical strategies into their daily routines. The findings suggest that both online and self-guided participants were able to apply these skills effectively, leading to better management of their symptoms and overall well-being.

Understanding and Managing Fatigue

This section addresses participants' understanding and management of fatigue, a key aspect of their condition. The findings highlight significant improvements in managing fatigue, with participants reporting increased empowerment and energy. The

intervention's emphasis on goal-setting, structured activities, and self-compassion proved effective in enhancing participants' daily lives and overall well-being (Table 5.21).

Table 5-21 Feedback on understanding and managing fatigue

Category	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Understanding and Managing Fatigue	Participants highlighted increased awareness and understanding of fatigue as a significant part of their condition. They reported significant improvements in managing fatigue, noting feelings of empowerment and increased energy, particularly through goal-setting and structured activities. Both online and self-guided participants found that taking breaks, goal-setting, and self-compassion were effective strategies. The programme effectively combined theoretical insights with practical applications, helping participants enhance their daily lives and overall well-being.	<i>"This gave me a total insight that fatigue was such a big part of the disease that I'm dealing with that I didn't rate it as important before or recognise that it was such a part of it."</i> (FG33) <i>"I think we understand fatigue better now and it's through the mix of both things like goal setting and the OT explaining it. It is like you get the lecture and then you do the practice."</i> (FG4) <i>"Taking breaks was for work and relaxing was for me. I wouldn't have put a specific time aside to relax. It was motivating. I feel more energetic."</i> (FG35) <i>"I just found that on your good days you can do the goals but you need a contingency plan for your bad days and I think we have a lot of those bad days."</i> (FG23)	<i>"The book helped me understand you're not imagining it is part of this. You have to work on it and work on yourself and I see it as self-care. You have to give yourself the time and space."</i> (Int22) <i>"One goal was to walk more since I sit most of the day. I now walk for half an hour every lunchtime which helps me both mentally and physically."</i> (Int19) <i>"It made me realize it's okay... It's okay to be kind to yourself."</i> (Int12)

Impact of Goal-Setting Techniques

This section explores the adoption of goal-setting techniques by participants in the FAME-W intervention. Both online and self-guided participants found these techniques to be highly beneficial, reporting better management of fatigue, increased energy, and enhanced confidence (Table 5.22). Goal-setting not only helped participants differentiate between fatigue and laziness but also increased their motivation and communication skills.

Table 5-22 Feedback on using goal setting as part of the intervention

Category	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Adoption of Goal-Setting Techniques	Participants from both the online and self-guided groups found goal-setting techniques in the FAME-W program highly beneficial. They reported better management of fatigue, increased energy, and greater confidence. Goal-setting helped them distinguish between fatigue and laziness and improved their motivation and communication. Both groups expressed intentions to continue using these strategies, seeing them as effective tools for managing their condition and enhancing overall well-being.	<i>"Because of goal setting I manage better now. I am fatigued. It's not laziness. I found that because I have these goals in my life. I'm a lot more energetic." (FG19)</i> <i>"I think we'd all like to carry on with setting goals. It will definitely be used because we picked up things that we would like to continue with not just at work either." (FG31)</i>	<i>"One of my goals was to go to bed early and wake up early giving me time for myself before work and some days go for a walk before work to exercise and rest well." (Int21)</i> <i>"The goals I had were resting more and walking every day. I also tried cycling a couple of times a week for 20 to 30 minutes. Sometimes I couldn't because of pain and fatigue. But I was still going I set goals every week because they made me feel better." (Int29)</i> <i>"It gave me confidence and goal setting helped with that. It boosted my confidence to say no, to talk to colleagues and my manager." (Int8)</i> <i>"I certainly do find that</i>

			<i>setting of a goal idea helpful and certainly will be taking them forward the way it was shown with the steps and the sheet because it makes it easier and more real." (Int34)</i>

Integration of Practical Strategies

The integration of practical strategies learned in both delivery methods played a crucial role in improving symptom management both at home and in the workplace. Participants applied techniques such as pacing, taking breaks, and setting boundaries to manage their conditions more effectively. For those in the online group, these strategies were further reinforced by guidance from facilitator and personalized adjustments, leading to significant improvements in their daily functioning and overall well-being (Table 5.23).

Table 5-23 Feedback on utilizing the strategies learned from the intervention

Category	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Integration of Practical Strategies	Participants learned and applied practical strategies such as pacing, taking breaks, and setting boundaries, which led to improved symptom management both at home and at work. For the online group, these strategies were supported by guidance from occupational therapists and personalized adjustments.	<i>"The OT was really strict with saying no; we don't always have to agree to extra tasks. I didn't want to let anyone down but the OT made me realize the importance of self-care." (FG11)</i> <i>"Simple things like sitting down preparing vegetables. Changing the mindset that we don't have to stand up all the time. My default would be to stand up but I sit now." (FG9)</i> <i>"Just to say I'm not able to, I'm in pain or I'm not able to Hoover. And just to pace myself and if I can only Hoover half the house today then let that be it. If I can do it at home, I can carry that mentality to work." (FG14)</i> <i>"The prioritising and planning side of things giving myself just time to feel sore or tired giving myself a few minutes to relax. You don't want people to think you don't work but what is the point</i>	<i>"Fatigue and pain diaries were a bit of a chore initially. But when I got into them they were helpful because you could track the activities that caused the most fatigue and pain especially at work." (Int20)</i> <i>"I focused on managing fatigue and pain at work by scheduling breaks, walking to the cooler or talking to someone instead of calling or emailing. These small breaks helped a lot." (Int28)</i> <i>"I liked the way it addressed the stress and the tips that it gives you to manage stress like the scenery exercise and mindfulness. I did those during my lunch." (Int1)</i> <i>"I get up every 30 minutes from my chair. It became a habit now. I set a timer on my phone and I've seen the benefit of it." (Int9)</i>

		<i>of doing so much today if I can't come in tomorrow?" (FG26)</i> <i>"Some of us can't take frequent breaks but as she [facilitator] was saying you can even take a 30-second break. And that the toilet is there there's always an out nobody can tell you that you can't go to the bathroom." (FG4)</i>	<i>"I filled out the pain diary and I actually figured out the days I am most in pain and the reason for it. I showed it to work and talked to them about it." (Int12)</i>

Empowerment and Wellbeing

This section presents findings on the positive changes participants experienced in self-efficacy, confidence, and overall well-being. The results highlight growth in these areas, along with the sustainability of the behavioural changes made. Participants reported a stronger sense of control over their symptoms and adopted strategies that improved both their mental and physical health.

Self-Efficacy, Confidence, and Increased Awareness

Participants reported that the FAME-W intervention influenced their beliefs in their ability to manage their symptoms and challenges they experience due to their IA. Table 5.24 below presents data on how participants reported increased self-efficacy and confidence reflecting increased ability to handle daily tasks and manage their health more effectively.

Table 5-24 Impact of FAME-W on wellbeing and confidence

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Growth in Self-Efficacy and Confidence	Participants gained significant confidence in managing their symptoms, adopting a proactive approach, and acceptance of personal responsibility for their health.	<i>"It has given us the encouragement to not be afraid of the symptoms." (FG17)</i> <i>" It makes you feel a bit that you're empowered that you can make a difference in controlling the symptoms." (FG41)</i> <i>"Just a lightbulb moment to say great this is not my fault because you can blame yourself for all the symptoms." (FG22)</i> <i>"It actually made me stop and think and actually re-evaluate how I was doing things." (FG1)</i>	<i>"It's all about self-empowerment. It is also about putting the emphasis back on oneself to say thanks for your help I can manage or say can't manage. Knowing how to handle it" (Int11)</i> <i>"It made me believe that I can actually manage this. I can do things to manage it." (Int22)</i> <i>"It helped me accept this diagnosis." (Int15)</i> <i>"It gave reassurance. There were one or two things in there that I kind of had thought I</i>

			<i>was imagining. And to see it and reading it made me feel like well actually it is okay to feel that way. I feel informed and also it is reassuring." (Int3)</i>

Improvement in Overall Well-being

This section highlights the improvements in overall well-being experienced by participants. The participants reported significant positive changes, including increased energy, better management of fatigue, and a deeper awareness of their condition. These improvements were largely attributed to practical strategies such as mindfulness and better body mechanics, which were integral to sustaining these benefits over time (Table 5.25).

Table 5-25 Feedback on Improvement in Overall Well-being

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Improvement in Overall Well-being	Participants experienced improvements in their overall well-being, including increased energy, better fatigue management, and greater awareness of their condition. Practical advice, such as mindfulness and body mechanics, contributed to these positive changes.	<i>"The focus on the breaks was good for me and the meditation during lunch was a very good suggestion." (FG38)</i> <i>"I think in a roundabout way for me I feel like I have more energy and less fatigue because I'm doing one more thing every day. And that makes me feel better." (FG36)</i> <i>"It did make me more conscious. It has made me take stock about how I am actually feeling and it made me realize that my tiredness is because of my condition." (FG37)</i>	<i>"Minding yourself in a sense of not abusing your body really got me thinking. And since I've stopped using my hands as tools my hands have improved greatly." (Int14)</i> <i>"I wouldn't have thought to use larger joints to do things. And moving breaks is something I'll definitely be using in work because I sit for a couple of hours at my desk and not get up. The whole book showed me things I've been doing wrong." (Int35)</i>

Sustainability of Changes Achieved Through the Intervention

This section examines the sustainability of behavioural changes among participants, focusing on the mechanisms that supported the long-term adoption of these changes. The findings underscore the importance regular self-assessments, goal-setting exercises, and methodical strategies, in facilitating the maintenance of behavioural improvements (Table 5.26).

Table 5-26 Feedback on the sustainability of changes achieved

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Sustainability of changes	Sustaining behavioural changes was supported through regular check-ins, goal setting, and practical strategies. Participants reported ongoing commitment to these practices, which helped in managing symptoms more effectively.	<i>"Regular check-ins with yourself keep you going. I learned great techniques like writing a diary at night and listing worries beside my bed to help sleep better." (FG13)</i> <i>"I take breaks in the afternoon as suggested by the programme. I don't get that pace of exhaustion that I used to get a couple of weeks ago in the afternoons. The fatigue diary helped to notice this. Now when I'm in work I use the strategies that we talked about with the OT and all that has happened helped." (FG15)</i>	<i>"I certainly do find that setting of a goal idea helpful and certainly will be taking them forward the way it was shown with the steps and the sheet because it makes it easier and more real." (Int34)</i> <i>"You just have to think about how to keep going. Like the book said go for a walk with a friend. I found a walking group in my area it helps me to actually do it." (Int26)</i>

5.4.2.2 Factors That Influence Outcomes

Influential Factors on Outcomes

In this section, the influential factors that impacted the outcomes of the intervention are presented. These include both positive influences that facilitated the successful implementation of strategies and challenges or barriers that participants encountered. The findings reveal a complex interplay of factors that either supported or hindered participants in achieving their goals.

Positive Influences

This section explores how positive influences, particularly the application of learned strategies in daily life, contributed to the successful outcomes of the intervention. Participants highlighted the crucial role of occupational therapists and the practical advice provided, which were instrumental in integrating symptom management strategies into their routines. These influences not only improved daily productivity but also played a significant role in enhancing the overall impact of both delivery methods (Table 5.27)

Table 5-27 Applying and sustaining learned changes

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Positive Influences	Both delivery methods effectively encouraged participants to integrate practical strategies into daily routines, significantly improving symptom management and daily productivity. The guidance from occupational therapists and practical advice were key positive influences on participants' ability to implement and sustain changes. These influences were highly valued by participants.	<i>"The OT was really strict with saying no; we don't always have to agree to extra tasks. I didn't want to let anyone down but the OT made me realize the importance of self-care." (FG11)</i> <i>"Some of us can't take frequent breaks but as she [facilitator] was saying you can even take a 30-second break. And that the toilet is there there's always an out nobody can tell you that you can't go to the bathroom." (FG4)</i> <i>"Right now, I try to do the goals because I have to come here and tell everyone about it but when this is done that will be a challenge." (FG29)</i>	<i>"I take breaks in the afternoon as suggested by the programme. I don't get that pace of exhaustion that I used to get a couple of weeks ago in the afternoons." (Int15)</i> <i>"Fatigue and pain diaries were a bit of a chore initially. But when I got into them they were helpful because you could track the activities that caused the most fatigue and pain especially at work" (Int20)</i> <i>"I liked the way it addressed the stress and the tips that it gives you to manage stress like the scenery exercise and mindfulness. I did those during my lunch" (Int1)</i> <i>"I get up every 30 minutes from my chair.</i>

			<i>It's became a habit now. I set a timer on my phone and I've seen the benefit for it" (Int9)</i>

Challenges and Barriers in Achieving Desired Outcomes from the Intervention

This section addresses the challenges and barriers participants faced while trying to implement the strategies from the intervention. Key obstacles included work demands, unpredictable fatigue, and difficulties with the practicality of the advice provided. Both online and self-guided participants expressed concerns about managing their goals during fluctuating energy levels and daily work pressures, which often hindered the overall effectiveness of the both delivery methods (Table 5.28).

Table 5-28 Feedback on challenges and barriers in achieving desired outcomes from the intervention

Subtheme	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Challenges and Barriers	Participants faced significant challenges in implementing strategies, particularly due to work demands, unpredictable fatigue, and the practicality of advice. These barriers sometimes hindered the effectiveness of both delivery methods.	<i>"Just with fatigue and work it is hard to find time to do anything." (FG9)</i> <i>"I just found that on your good days you can do the goals but you need a contingency plan for your bad days and I think we have a lot of those bad days" (FG23)</i> <i>"When this is done, goal setting will be a challenge. I am going to have to push myself through pain, fatigue and work to continue with the goals" (FG29)</i>	<i>"Some of the suggestions are great in theory but hard to put into practice especially when you're dealing with unpredictable fatigue." (Int11)</i> <i>"It's not always easy to implement what we learn especially when you're already dealing with pain and fatigue on daily basis." (Int14)</i> <i>"It tells you to do certain things but I can't. If I were to tell my boss I can't do something I'll be told that it is time to leave; you're not really able to</i>

			<i>do the job anymore."</i> <i>(Int10)</i> <i>"The tips are helpful but I struggle to stick to them consistently because my energy levels vary so much." (Int23)</i>

5.4.3 Context

Context refers to any external factors that may act as barriers or facilitators to the implementation of the intervention or its effects (Moore et al., 2015). Understanding the context involves examining the environmental, organizational, social, and cultural factors that interact with the intervention, contributing to the observed outcomes. In this study, two distinct delivery contexts were examined: the online and self-guided formats. Each context presents unique challenges and advantages that influence how participants engage with the either delivery method of the intervention, impacting the outcomes observed. This section presents findings related to how these contexts influenced the implementation of the FAME-W intervention.

External Factors Influencing Implementation

This section presents findings on how environmental and organizational factors influenced the implementation of both delivery methods of FAME-W. External factors play a crucial role in shaping how participants engage with and benefit from FAME-W. The implementation and impact of interventions are significantly influenced by factors such as workplace accommodations, organizational support, and environmental conditions, all of which have been further impacted by the COVID-19 pandemic, altering work environments, social interactions, and access to healthcare. Understanding the context in which the intervention is delivered—whether online or self-guided—is essential for identifying the barriers and facilitators that affect participant engagement and outcomes.

Environmental and Organizational Factors

Participants emphasized the importance of workplace accommodations, such as ergonomic adjustments, flexible work hours, and emotional support from colleagues and supervisors. These accommodations can significantly affect individuals' ability to manage

their conditions and maintain productivity. The results presented in Table 5.29 provided insights into how participants applied the knowledge on accommodations in their real-world work settings, demonstrating both the practical impact of the intervention and the challenges encountered, such as the need for self-advocacy and the role of supportive managers. Moreover, these experiences were influenced by different contexts, such as remote work during the COVID-19 pandemic, which shaped how participants engaged with and benefited from the intervention.

Table 5-29 New knowledge on workplace support and accommodation

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Workplace support and accommodations	Feedback from participants highlighted the benefits of ergonomic adjustments and clear communication about employment rights, which were key elements in the FAME-W intervention. Participants appreciated the knowledge gained about workplace accommodations and legal rights in order to seek better support from employers.	<i>"For me ergonomics section was the most useful. After this session I am going to ask my manager to get me an ergonomic chair and other things. (FG40)</i> <i>"This week (Employment rights and legislation session) was probably very insightful for me because I didn't know that you are entitled to certain things after disclosure." (FG28)</i> <i>"My line manager actually read the booklet. I had it with me at work for the ergonomics of my table and she saw it. She asked me if she could read it. She read it and it has helped her understand things about me. She</i>	<i>"I work from home now because of COVID and I sent the ergonomics section to work and they got me a chair and that helped with pain because I was suffering with pain around my neck and shoulders and I found after the chair I have no issues. And that tied in with, you know, prioritizing stuff like that. And conserving energy." (Int13)</i> <i>"Knowing that it is my legal right to ask for accommodations is good. I am going to go ahead and speak to my manager about it." (Int2)</i> <i>"In fairness my work is good at supporting me, but knowing all this, knowing that there are</i>

		<i>is willing to sort things out at work with me about the breaks and bad days.” (FG1)</i>	<i>grants that can help, I feel more comfortable asking for accommodations or time off” (Int33)</i>

Social and Cultural Influences on Intervention Engagement

Social support networks provide essential emotional, informational, and practical help, enhancing participants' ability to manage their conditions and engage with self-management practices. Cultural beliefs and norms influence how individuals perceive and adopt self-management strategies. Understanding these attitudes is crucial for creating culturally sensitive and effective interventions. By examining these factors, valuable insights are gained regarding how social and cultural contexts shape the success of the intervention. Table 5.30 presents how social and cultural factors impacted on the implementation and outcomes of both delivery methods.

Table 5-30 Impact of social and cultural factors

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Social support networks	The findings highlight clear differences between the online and self-guided groups in terms of social support. Participants in the online group benefited significantly from peer interactions, which provided emotional support and reduced feelings of isolation. In contrast, self-guided participants expressed a need for more social connection, noting the absence of peer support as a gap in their experience. These differences emphasize the importance of	<i>"When you have disabilities like we have it's hard to get to know people who have a similar experience in life. Nobody can really relate to the fact that I look normal yet want to fall asleep in the middle of the day. It's nice to talk to people that have a similar experience and frustrations. Because sometimes you'll feel quite alone. I feel like the odd one out." (FG25)</i> <i>"Interacting with other people who are having</i>	<i>"No one really understands. When your leg is broken they can see it but with this its invisible." (Int8)</i> <i>"I find I always tell my kids I am tired and they don't understand that. The fact that it might be hard to get off the chair unless I do it a certain way. I don't think they understand" (Int32)</i> <i>"A support group would be very beneficial. If I were talking to people that have the same experiences that would really help" (Int3)</i>

	social context in intervention delivery, suggesting that incorporating more opportunities for peer interaction could enhance the impact of self-guided interventions.	<i>the same experiences really helped. It brought a few things home to me." (FG37)</i> <i>"A core part of the benefits people got from this was just a support because they have realised that it's a community and people are people there." (FG17)</i> <i>"It is really helpful to see that you're not the only person struggling that it can get better, I can feel better, I can manage it better." (FG42)</i>	<i>"I looked at the resources at the back of the book and found that there are some groups that meet up, I will be trying to go to those. It will be nice to talk to people that know how it is to live with IA" (Int6)</i>

Cultural Attitudes Towards Self-Management and IA

Cultural attitudes towards self-management and IA, as reported by both online and self-guided workbook participants, reflect beliefs and practices that shape individuals' approaches to managing their conditions. These attitudes play a key role in influencing how participants initially engage with, and ultimately benefit from, the intervention strategies (Table 5.31).

Table 5-31 Cultural Attitudes Toward Self-Management

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)
Cultural attitudes towards self-management and IA	Cultural attitudes significantly shaped participants' initial resistance to some FAME-W intervention strategies, such as viewing help-seeking as weakness or relying solely on medication. However, as they	<i>"I wouldn't ask for help. That is not how I was raised. I was pushing myself and it was making it worse. I feel better about asking for help now." (FG5)</i>	<i>"Medication was the only thing I was using. You don't think about managing it without medication, that's just not what we were told" (Int2)</i> <i>"I think here in the west we are so focused on</i>

	engaged with the program, many began to challenge these beliefs, recognizing the value of rest, seeking help, and exploring non-medical options. These shifts highlight the importance of addressing cultural factors within the intervention to enhance its impact and participant outcomes.	<i>“I was raised in a house of hard workers. So, taking rest breaks or feeling fatigue was like laziness. But now I know if I don’t listen to my fatigue it will keep me away from work” (FG26)</i>	<i>medication and drug therapies we forget that there are other ways or we are seen as hippies” (Int33)</i> <i>“We are just not the asking for help kind of people. You help others but you don’t ask for help, it is seen as weakness” (Int8)</i>

Contextual Enablers and Barriers to Implementation

While the majority of enablers and barriers to the intervention’s impact have been addressed throughout this chapter, certain contextual factors related to implementation warrant further examination. Specifically, the accessibility and convenience of the program's delivery methods, the provision of technical support for online participants, and the assistance offered to self-guided participants in completing the workbook are critical contextual elements that influence participant engagement and programme outcomes. Additionally, contextual barriers such as technical challenges and the lack of timely feedback, which can impede the effective implementation of the programme, have not been discussed in sufficient detail. This section will therefore provide a more comprehensive analysis of these contextual enablers and barriers within the framework of process evaluation.

External Enablers to implementation

The successful implementation of the two delivery methods of FAME-W intervention is significantly influenced by various factors including convenience. The convenience of the delivery methods plays a crucial role in shaping participants' and facilitators' engagement with the delivery of the intervention. The context in which the intervention is delivered—whether online or through a self-guided workbook—directly influences how easily participants can access and interact with the materials. For many, the flexibility of the online format or the self-paced nature of the workbook significantly enhances their ability to participate effectively. Additionally, external factors such as the COVID-19 pandemic further underscore the importance of convenience, as avoiding in-person meetings became essential. Table 5.32 reports the feedback on external enablers to both delivery methods.

Table 5-32 External enablers to implementation

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)	Facilitator Quotes (OT)
Convenience	Participants highly valued the online and self-guided formats for their flexibility, reducing logistical burdens and enabling easier engagement with the material. This was particularly appreciated by those managing chronic conditions, where energy conservation and accommodating fluctuating symptoms are crucial.	<i>"When it is online it doesn't matter what time, I finish work. It's just so easy to log on. There is no time to get here or time to allocate for travelling." (FG13)</i> <i>"I would not have taken part if it wasn't online because of the commute." (FG6)</i> <i>"Sometimes with classes that are in person the journey to get there is tiring. But online takes less away from the overall day." (FG2)</i> <i>"Just able to log on and be here in your home in your own space and be comfortable" (FG33)</i>	<i>"You can read it at your own pace and take it in however you want to and go back to it whenever you want to. You don't have to be somewhere at a certain time for it" (Int32)</i> <i>"I think courses are problematic. You might be having problems at work or problems at home and you just have to be here. And it's an inconvenience as well. If I had a choice I would choose the workbook" (Int5)</i> <i>"Honestly, I think in person would just be inconvenient especially if you like outside of the city or have bad internet" (Int27)</i>	<i>"Online was quite convenient during COVID. We didn't have to focus on public health measures or think about it" (OT1)</i> <i>"Although I think in person would be better, online was good. It was easier in a sense that we didn't have to worry about finding a room or refreshments" (OT4)</i>

Support provided during the intervention

The level and type of support provided to participants are critical contextual factors that influence their engagement and success. Support, whether in the form of group interactions in the online setting or individualized assistance in the self-guided workbook format, plays a key role in how participants experience the intervention. The online group benefited from a sense of community and shared understanding, which helped normalize their experiences and fostered a supportive environment. Conversely, workbook participants valued the ability to reach out for help when needed, ensuring they could still access guidance and resolve any issues despite working independently (Table 5.33).

Table 5-33 Feedback on the support provided

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)	Facilitator Quotes (OT)
Support	The intervention's success was partly due to effective support mechanisms. Online settings fostered community and motivation, while the workbook format provided structured guidance and easy access to help. This support was essential for maintaining engagement and enhancing the learning experience.	<i>"It's always accepting, it is a positive group setting it makes you say I'm just going to try to make it as best as we can."</i> (FG8) <i>"Everyone understood. Everyone knew. We talked about bad days and everyone had them. You could see people nodding and saying me too or it is okay"</i> (FG15)	<i>"The check ins to see if I had finished the workbook was a good reminder to get it done. It was also a good reminder that I could reach out if I had questions"</i> (Int19) <i>"Well, I mean the workbook is a standalone, do it by yourself thing but it was a constant reminder that I could reach out to you or the OT if I needed help."</i> (Int21)	<i>"Workbook was good but you were also there for any questions or if I needed help so you were a resource as well. So I think for running this the first time I was happy to know I could reach you anytime"</i> (OT1) <i>"It was good to know that if I had any technical issues, you were available to help"</i> (OT3)

External Barriers to implementation

Facilitators of the online group and the participants of both groups faced barriers in implementing the needs of the both delivery formats. These challenges included technical issues and the absence of social interaction and engagement. Table 5.34 below highlights these primary challenges, and barriers encountered. Insights range from technical issues such as connectivity problems to the need for more personal interaction and engagement to foster better relationships and effective communication within the programme.

Table 5-34 External barriers to implementation

Categories	Summary of Findings	Online Participant Quotes (FG)	Self-Guided Participant Quotes (Int)	Facilitator Quotes (OT)
Technical challenges	For the online format, external technological factors such as connectivity issues disrupted participants' ability to fully engage with the programme. For self-guided participants, delays in receiving the workbook materials posed a similar challenge. These external factors hindering participants' ability to follow the intervention's timeline.	<i>"Zoom has crapped out on more than one occasion just completely crapped out on me." (FG24)</i> <i>"Sometimes internet wouldn't connect or go slow and I'd miss things" (FG6)</i>	<i>"My workbook got lost in mail. You did send a new one but it arrived much later than anticipated" (Int36)</i> <i>"Compared to the time you sent it, it arrived so much later" (Int4)</i>	Facilitators did not report any technical challenges during their facilitation
Lack of contact and social aspects	The absence of in-person contacts limited relationship building and motivation, with participants and facilitators noting that face-to-face interactions would likely	<i>"You would get a lot more out of it when you do it face to face, because you build those relationships" (FG38)</i> <i>"Face to face is a bit more social, and we could have got</i>	<i>"I would have appreciated a weekly check in to remind me to get read the book" (Int18)</i> <i>"Maybe if you rang to see how I got on with the goals, that would have helped me</i>	<i>"I think it would be better in person to create that rapport with participants." (OT4)</i>

	enhance programme outcomes and participant engagement.	<i>to know each other a little bit better, could have made friendships out of it. Because I find with long term illnesses it can be isolating at times.” (FG20)</i> <i>“I say it is something that's better done in person. It is easier if you're in a room and the interaction is a little more personal.” (FG4)</i> <i>“Online doesn't affect ability to take information on board but the interaction suffers” (FG12)</i>	<i>actually get them done” (Int12)</i> <i>“Can you not make a group of the people that get the workbook and we can help each other or get to know people that have IA?” (Int3)</i> <i>“If you rang every week or texted to say, “hey it is week 2, read chapter 2 and do this”, that would have eased things a bit” (Int10)</i>	<i>“I think in person would foster more conversations between participants. It would make it easier to deliver the programme” (OT1)</i>

5.4.4 Conclusion

In alignment with the three key components of process evaluation, implementation, mechanisms of impact, and context, the FAME-W intervention demonstrated effective delivery through both online and self-guided formats. The intervention's success was influenced by high levels of participant engagement, improvements in symptom management, and the ability to tailor strategies to individual needs. However, challenges such as fluctuating fatigue levels and external barriers like COVID-19 impacted recruitment and participation rates. The process evaluation emphasizes the critical role of context, including social and cultural factors, in shaping the overall outcomes and highlights areas for improvement in future implementations, particularly in enhancing support and addressing barriers to sustained participation.

5.5 Discussion

The overall aim of this process evaluation was to understand how the online and self-guided workbook of FAME-W were implemented in practice, to examine mechanisms of action of the intervention and understand the impact of the context on intervention delivery and outcomes.

In process evaluation, the concepts "implementation," "mechanism of impact," and "context" are key components that provide insights into how a program or intervention functions and achieves its intended outcomes (Moore et al., 2015). Accordingly, this section will be presented around these three components of the process evaluation framework, and the discussion will follow the same structure.

Implementation

Recruitment Strategies and Reach

Demographics

The demographic data revealed that the majority of participants were middle-aged women living with IA, with a high proportion diagnosed with

RA or PsA. This demographic profile is consistent with those observed in other self-management studies (Greenhalgh, 2009; Horrell & Kneipp, 2017). The average age across both the online and self-guided workbook groups was approximately 49 years, and over 75% of participants were female. Most participants were married, employed in non-manual jobs, and had high levels of educational attainment, with over 75% holding a college or university degree. These characteristics are significant in understanding the context of the participants, as they likely influenced both their engagement with the intervention and their ability to apply the self-management strategies discussed (Damgaard et al., 2023; Vestergaard et al., 2024). Participants in both the online and self-guided workbook groups shared similar characteristics, which strengthens the results' validity by ensuring that the characteristics that might affect outcomes were balanced across groups (Flecha et al., 2016; Leroy et al., 2022).

Given the demographic profile, the intervention may have been more accessible to individuals with higher educational backgrounds and those in non-manual occupations. People in these roles typically benefit from better working conditions and health protections (Siegrist & Marmot, 2004; Tausig, 2013) potentially making these individuals more receptive to participating in self-management interventions. Additionally, individuals with higher education levels tend to have greater health literacy (Beauchamp et al., 2015; Jansen et al., 2018), which may contribute to a heightened awareness of the importance of self-management and a greater likelihood of active engagement in the intervention. However, while non-manual jobs may offer better physical working conditions (Siegrist & Marmot, 2004; Tausig, 2013), recent trends suggest that these occupations are associated with increased stress due to factors such as higher job demands, work-family conflicts, and the pressures of managing resources (Damaske et al., 2016; Koltai & Schieman, 2015; Schieman, 2013; Schieman & Glavin, 2016; Schieman & Reid, 2009; Schieman et al., 2006). This 'stress of higher status', a term coined by Pérez-Zapata, et al., 2016, may lead non-manual workers to seek

out interventions that address not only physical health but also mental well-being. Data from the European Labour Force Surveys support this, with 85% of workers reporting that work intensity, —characterized by time pressures and overload—poses a significant risk to mental health (Eurostat: European Commission, 2012).

In contrast, manual jobs, which are more prevalent in lower-income occupations, often present physical challenges that differ from the mental and emotional demands faced by non-manual workers (Ahn et al., 2019). The higher representation of non-manual workers in the intervention may therefore reflect increased awareness of mental strain and motivation to address work-life balance conflicts through self-management interventions. Moreover, the heightened health literacy of individuals in non-manual occupations likely contributed to their willingness to participate in the intervention. Future recruitment efforts should aim to include a more diverse population, particularly those in manual jobs or those with lower educational attainment, as these groups may face unique challenges in managing IA and could benefit from tailored support. Expanding recruitment in this way would provide a more inclusive understanding of how different occupational and educational backgrounds impact engagement with self-management strategies (Ackerman & Busija, 2012; O'Toole et al., 2013).

The appropriateness of the recruited participants was a critical factor in the success of both online and self-guided modalities. Healthcare professionals and participants agreed that the individuals selected were suitable for the intervention, considering participants' levels of functional independence and the impact of possible comorbidities. The most suitable participants were those with a certain level of functional independence and motivation to make changes. Previous research supports this approach, showing that individuals with higher physical function are twice as likely to attend a chronic disease self-management intervention compared to those with lower physical function (Dattalo et al., 2012). Participants with higher levels of function and motivation may have engaged more with the

intervention, as they faced fewer physical and emotional barriers. This initial selection process was crucial to ensure that those recruited could benefit from the FAME-W intervention, similar to strategies used in other Irish self-management programmes to ensure the best possible outcomes (O'Toole et al., 2021).

The initial selection process was vital in ensuring that participants were appropriate for the FAME-W intervention, regardless of whether they were randomly assigned to the online or self-guided group. For online FAME-W, participants needed functional independence and motivation to engage with the content, set and review goals, participate in discussions, and undertake activities independently. Similarly, the self-guided format required participants to rely on intrinsic motivation and independence to take initiative, set goals, and review their progress without direct oversight. Prior research supports this approach, indicating that the motivation and functional independence of participants play a key role in the success of self-management programmes (Lally et al., 2020; Ugalde et al., 2017; Palermo et al., 2018). For example, Lally et al. (2020) emphasise that intrinsic motivation is crucial for the effectiveness of unguided self-management interventions. Additionally, Ugalde et al. (2017) highlight how self-guided interventions are most successful when participants possess both motivation and independence, allowing them to engage fully with the programme. Palermo et al. (2018) further reinforce the importance of selecting participants who have the functional skills and motivation to use mobile-based self-management interventions effectively. Healthcare practitioners involved in recruitment thus prioritised individuals with higher levels of function and motivation, aligning with these findings and ensuring that participants could effectively engage in self-management activities.

The success of both delivery methods of FAME-W depends not only on selecting participants with the necessary functional independence and motivation but also on including those with lower functional ability and motivation. Addressing this wider spectrum of needs is crucial, as individuals with lower function or motivation may face unique challenges

that impact their ability to stay in work (Valaas et al., 2023). By incorporating these individuals, the intervention can develop more tailored support strategies that are relevant to those who may benefit most from intervention. This inclusive approach ensures a more representative participant pool and provides insights into the diverse factors influencing engagement and self-management. By strategically selecting participants across varying levels of function and motivation, the intervention maximises benefits, fosters meaningful discussions, and highlights the importance of targeted support for successful intervention outcomes. This approach is supported by digital self-management interventions that have demonstrated increased engagement and positive outcomes through inclusive and person-centred design (Doyle et al., 2021).

The recruitment phase of the study encountered several challenges that necessitated significant adjustments to its implementation, as detailed in Chapter 3 and 4. Primary among these was the impact of the COVID-19 pandemic, causing disruptions in clinic operations and staff shortages, which impacted recruitment efficiency. A narrative review of clinical research during the COVID-19 pandemic highlighted that such difficulties were common, suggesting that these challenges were widespread during this period (Nomali et al., 2023). Furthermore, the pandemic led to the need for revised recruitment strategies and a corresponding adjustment in the power calculation to accommodate a reduced sample size. Delays in obtaining necessary ethical approvals due to the redeployment of healthcare professionals to COVID-19 duties and the suspension of non-COVID research activities, further delayed the initiation and progress of the study. Such delays not only postponed the study start but also compressed the data collection timelines, potentially diminishing recruitment rates and affecting participant engagement. Other clinical research trials have faced similar issues in terms of delaying efficiency (Trøseid et al., 2022).

Additionally, frequent adjustments in recruitment methods due to ongoing changes in public health measures and the redeployment of key personnel,

such as rheumatology physicians and occupational therapists, disrupted traditional recruitment channels. This disruption significantly reduced the number of eligible participants being approached and likely diminished engagement from healthcare professionals, who are crucial for recruiting and retaining participants. Non-in-person recruitment strategies, such as telephone outreach, proved to be less effective than anticipated, resulting in reduced efficiency and hampering efforts to meet recruitment targets (Wright et al., 2021). Despite these challenges, studies found that strategies such as leveraging waiting lists and maintaining a physical presence in clinics helped mitigate recruitment issues (Pullyblank & Atav, 2022). Similar strategies were adopted by other studies during and post-pandemic, including virtual recruitment, telephone calls, email, flyers, and word-of-mouth, to ensure a diverse participant sample and address challenges in participant engagement (Simmons et al., 2022). These alternative methods enriched the intervention outcomes by reflecting a broad range of experiences and needs. The pandemic necessitated an adjustment in recruitment power from detecting a 0.4 effect size to a 0.7 effect size while maintaining a power of 80%, resulting in a recalculated requirement of 80 participants. To account for a 20% attrition rate, the final sample size was set at 100 participants, with 50 in each group. As the pandemic prolonged and caused further dropouts, it became appropriate to increase recruitment numbers to account for potential increased attrition rates.

These recruitment strategies proved useful, as evidenced by the observed attrition rates. The combined attrition rate for immediate follow-up was approximately 30.3%, and for the 3-month follow-up, it was 39.3%. These figures are within the range reported in a systematic review on engagement and attrition of e-health tools (Doumen et al., 2022). Although recruitment faced difficulties, the number of participants recruited for each delivery was sufficient, ranging from 5 to 12. Feedback from facilitators after the first session suggested that in order to ensure better delivery, the number of participants should be kept at ten or fewer for the remaining programmes. This adjustment aligns with findings from

other self-management intervention studies, which suggest that optimal group sizes typically range from 4 to 15 participants, balancing discussion opportunities and intervention effectiveness (Bourgault et al., 2015; Jaglal et al., 2013; Jonkman et al., 2016; Peterson et al., 2022).

Despite these challenges, recruitment was more successful when occupational therapists recruited participants they knew from their clinics. In these cases, full attendance and consistent follow-up were observed, likely due to the relationship established between the facilitators and participants. Studies indicate that strong relationships, communication, and trust between facilitators and participants can significantly enhance engagement and programme adherence (Martin et al., 2023). This rapport fosters a supportive environment, leading to higher attendance and improved follow-up outcomes (Kwame & Petrucka, 2021). However, the disruptions and barriers faced during the recruitment process may have skewed the demographic and health status representation of the study sample, potentially affecting the external validity and generalizability of the findings. These cumulative challenges necessitated strategic responses as discussed previously. The implications of these adjustments must be transparently discussed when interpreting the findings, as they could significantly affect the reliability and validity of the research conclusions (Moreels, et al., 2023). In summary, the COVID-19 pandemic necessitated flexible and adaptive recruitment strategies for FAME-W programmes. Despite challenges, effective recruitment methods ensured a diverse participant sample, contributing to the richness of intervention outcomes. Adjustments in recruitment power and sample size maintained the study's integrity. The observed attrition rates were within expected ranges, underscoring the success of the adapted recruitment strategies.

The qualitative component of this evaluation was limited to individuals who completed the intervention. The decision not to include the perspectives of those who withdrew from the study and/or lost to follow-up, was informed by methodological, ethical, and practical considerations.

This process evaluation aimed to assess implementation fidelity, participant engagement, and perceived benefits, consistent with the MRC framework (Moore et al., 2015). The focus on those who completed the intervention enabled a detailed exploration of how the intervention was delivered and experienced, facilitating a robust assessment of its mechanisms of impact. However, excluding individuals who did not complete their assigned programme represents a limitation, as their perspectives could have provided valuable insights into barriers to participation, reasons for disengagement, and potential accessibility challenges. The absence of these data constrains the ability to capture the full spectrum of participant experiences thereby limiting the generalizability of findings and modifications to the intervention (Tindall et al., 2020).

Fidelity and Quality of Delivery

Training and Resources

The training provided to occupational therapists for delivering the online FAME-W was well-received, with facilitators appreciating the clarity and comprehensiveness of the content. This is a significant finding because insufficient training has previously been identified as a barrier to the successful delivery of self-management interventions (Jordan & Osborne, 2007). The facilitators found the training effective in familiarizing them with the programme's slides and flow, even though the content was not new to their daily occupational therapy practice. The online format did not diminish the training's effectiveness, as noted by the facilitators suggesting that that online training can be an effective method for delivering interventions, providing an opportunity to innovate and expand the reach of educational programs. Studies have shown that online training can be as effective as a face to face training session (Bahasoan et al., 2020; Peterson & McCleery, 2014).

The availability and quality of resources, particularly the handbook and workbook, were positively evaluated by both facilitators and participants.

The high usability and relevance of these materials were seen as critical to the successful delivery of the interventions. Facilitators noted that the resources were not only accessible and easy to use but also comprehensive, providing all necessary information to effectively support participants. This comprehensive coverage facilitated full engagement with the content, enhancing the learning experience and intervention outcomes. Investing in high-quality, relevant materials is crucial for the success of similar programmes, as they significantly contribute to effectiveness by promoting better understanding and application of the content, a view supported by Frieden (2014). Research by Margolis et al. (2001) further supports this, emphasising that quality materials enhance the effectiveness of interventions.

Research indicates that certain self-management interventions require intensive training periods for facilitators, which can reduce clinical time and increase costs (Lawn & Schoo, 2010). However, the FAME-W programme benefitted from its facilitators being occupational therapists already practicing in rheumatology field, which aligned well with their existing knowledge and skills, thus minimising the need for additional training resources. The strength of this approach lies in utilising practising rheumatology occupational therapists rather than those from other specialties, which research has shown leads to more effective programme delivery (Leenen et al., 2017; Sinclair et al., 2020). The facilitators' expertise and practice in rheumatology likely contributed to the high fidelity of the programme. Moreover, participant engagement was enhanced by the interactive and supportive nature of the sessions, led by knowledgeable and responsive occupational therapists. Feedback from participants highlighted the facilitators' ability to foster meaningful discussions, normalise experiences, and create a supportive environment conducive to learning and self-management.

Overall, the combination of well-received training and high-quality resources contributed to the effective delivery and high fidelity of the FAME-W intervention. This underscores the importance of adequate

training and resource provision in the successful implementation of self-management interventions.

Adherence to the programme protocol

Facilitators of the online FAME-W self-reported high levels of adherence and fidelity. Adherence to the programme protocol varied slightly across sites, with facilitators making necessary adjustments to accommodate session dynamics and participant needs. Despite these variations, the core components were delivered consistently, demonstrating high fidelity. Facilitators reported some deviations, such as rescheduling sleep hygiene content to fit session timings better or extending sessions due to emotional responses from participants. These adjustments illustrate the required flexibility in delivering the programme across different contexts while maintaining core protocol fidelity. Research by Anyon et al. (2019) supports this approach, emphasizing that reconciling adaptation and fidelity is crucial for scaling up quality programmes. The study discusses the challenges of maintaining fidelity while allowing facilitators to make necessary adaptations to suit the unique dynamics of each session and participant group, ultimately ensuring that core programme components are upheld while meeting participant needs effectively. Furthermore, although there were differences in delivery time, the mean delivery time across all programmes and sessions was 94 minutes rather than the intended 90 minutes, further supporting the fidelity of the programme across all sites. The intervention content was delivered with high fidelity, with some variation between facilitators and between certain intervention categories. A multitude of self-management interventions report similar results for variations in facilitators, content, and the duration of the first session (Leenen et al., 2017; Sinclair et al., 2020; Toomey et al., 2017). These insights underscore the importance of supporting facilitators to ensure that programme fidelity is maintained while allowing for responsive adaptations to meet participants' needs.

The MRC guidance on process evaluations highlights the challenge of balancing fidelity with flexibility in implementing complex interventions

across multiple sites (Moore et al., 2015). Pragmatic evaluators must recognize that interventions will inevitably be adapted to fit different contexts, and these adaptations should be monitored to understand their impact on effectiveness (Moore et al., 2015). Toomey et al. (2017) identified three factors influencing fidelity in complex behavioural change interventions: provider, participant, and programme factors. In this study, variations in group size, dynamics, and individual participation may have led to deviations from the intervention protocol. For example, smaller group sizes and lower attendance could have resulted in shorter sessions due to limited opportunities for peer discussion and learning. Conversely, larger groups with positive dynamics facilitated more extended and enriching discussions. Participant engagement was notably enhanced by the interactive and supportive nature of the sessions, led by knowledgeable and responsive occupational therapists. The facilitators' expertise in rheumatology likely influenced programme fidelity, as their ability to foster meaningful discussions, normalize experiences, and create a supportive environment was evident in participant feedback (Bond et al., 2022). Effective self-management requires patients to be confident and committed to self-care (Asmat et al., 2023). Therefore, a patient-centred approach is crucial, as it encourages motivation and the adoption of strategies discussed in the programme (van der Eijk et al., 2013). A key advantage of the online FAME-W is its delivery by qualified professionals who can address the unique needs and emerging issues of participants, even those not explicitly covered in the training or intervention content. This adaptability was particularly evident in addressing topics such as COVID-19, which arose organically during discussions.

Participant feedback, collected through individual interviews, was used to evaluate the quality of delivery for the self-guided workbook. Participants rated the workbook 8.5/10 for clarity and usability, indicating that the materials were generally clear and user-friendly. These findings align with other studies that use materials such as handbooks, websites, or mobile apps, which emphasize the importance of clarity, usability, and comprehensiveness in educational materials (Cai et al., 2017; Floch et al.,

2020; Zheng et al., 2024). Participants highlighted the workbook's strengths in delivering content that was accessible and practical. The high scores suggest that the workbook effectively communicated its intended messages and facilitated learning and engagement. This is consistent with the findings of other studies that emphasized that the accessibility and adaptability of educational workbooks play a crucial role in learning effectiveness (Redburn & Hayes, 2024). The participants' feedback indicates that the workbook's structure and content effectively met the users' educational needs. However, the qualitative feedback pointed out specific areas where enhancements are necessary.

For example, the call for more detailed instructions suggests that while the overall content was clear, certain sections might require additional guidance to ensure comprehensive understanding. Studies have shown that technology-enhanced learning tools, including workbooks, must be designed to be flexible and adaptive to different learner needs (Chan, 2020). This may point to a need for incorporating more examples or step-by-step instructions, which could help bridge any gaps in comprehension. Additionally, feedback highlights the importance of adaptability in educational materials. While the workbook was generally well-received, its ability to accommodate diverse learning styles and needs is crucial for maximizing its impact.

This focus on adaptability is echoed in the research by Slavuj et al. (2017), which emphasizes the importance of modifying educational systems to cater to varied learner needs to improve engagement and outcomes. Understanding these can inform future content development, ensuring that educational materials are not only clear and comprehensive but also flexible enough to cater to varied participant preferences. Similarly, Anyon et al. (2019) found that balancing fidelity and flexibility in educational interventions enhances their effectiveness, suggesting that workbook content should maintain its core structure while allowing for responsive adjustments based on participant feedback.

To enhance user comprehension based on feedback regarding detailed instructions, future iterations of the workbook should include expanded explanations and illustrative examples where necessary. Such an approach aligns with the user-centred design principles, which emphasises tailoring content to enhance clarity and learning (Quintana & Haley, 2020). This will ensure that all learners can fully grasp the material. Adopting a user-centred design for future revisions can help identify specific needs and preferences through user testing and iterative feedback, enabling the creation of a more personalised learning experience that accommodates different learning styles (Shivers-McNair et al., 2018).

Aligning the workbook with other educational tools, such as apps and websites, by integrating digital elements could further increase engagement and retention. Becksford et al. (2021) demonstrate the effectiveness of incorporating user testing into learning experience design to create dynamic and engaging content. For example, adding QR codes that link to instructional videos or supplementary online resources can provide a more dynamic, multi-modal learning experience. To maintain the workbook's relevance and effectiveness, establishing a mechanism for continuous feedback maybe essential. Studies have shown that iterative testing and user feedback are crucial for adapting educational content to evolving needs (Horsky & Ramelson, 2016).

The positive feedback on the workbook's usability indicates potential for broader applications, suggesting that similar self-guided materials could be developed for various topics or demographics. A study by Drzyzga and Harder (2023) on learner dashboards further supports the idea of customising content based on iterative feedback and user needs. Customising content for different audiences could significantly expand the workbook's utility and impact.

Overall, the workbook demonstrated high fidelity and quality of delivery, as evidenced by positive participant feedback. Addressing areas for improvement while leveraging participant insights will enable future iterations to enhance learning outcomes and contribute to more effective

educational interventions. These findings are supported by existing research and suggest that self-guided workbooks can be an effective tool in healthcare interventions (Schumacher et al., 2017; Takano et al., 2021). However, further research is needed to explore the long-term effectiveness and feasibility of such interventions in diverse populations. Future iterations of the workbook should address the identified challenges and incorporate feedback to enhance clarity, usability, and overall effectiveness.

Attendance to the online programme

The overall attendance rates for the online FAME-W participants are distributed across various sites. Attendance rates were generally high at the beginning but showed a decline over time. In the first session, attendance was notably high, with 88.5% of participants attending in Week 1. This strong initial engagement slightly decreased to 85.2% in Week 2. However, a more significant decline was observed in Week 3, where attendance dropped to 67.2%. By Week 4, attendance rebounded slightly to 75.4%. Similar trends were seen in other Irish self-management interventions (O'Toole et al., 2021). Despite the overall high initial attendance, maintaining participant engagement throughout the intervention period proved challenging, particularly during Week 3. This may be attributed to the session content or the possibility that three consecutive weeks of the intervention led to participant fatigue. Donkin and Glozier (2012) discuss similar challenges, noting that maintaining engagement in online psychological interventions can be difficult, with adherence being influenced by various factors including session content, user motivation, and potential fatigue.

Site-specific dynamics contributed to these trends, with some sites such as Site 7 maintaining 100% attendance consistently, while others experienced significant drops. The variation in attendance rates are similar to other self-management programmes as discussed in a scoping review on understanding the barrier to participation in group chronic disease self-management programmes (Kessler et al., 2023). Factors such as

participant fatigue, competing commitments, and the demanding nature of the intervention were likely contributors to this decline. Similar reasons or barrier to attendance have been reported in other self-management interventions (Hudon et al., 2016). These variations underscore the need for tailored strategies to sustain participant involvement and address potential barriers that may arise as the intervention progresses. Strategies to sustain attendance, such as incorporating more engaging content and providing additional support, should be considered in future implementations (Bauermeister et al., 2018). Furthermore, site-specific logistics, such as accessibility and session timing, play a significant role in attendance (Greer et al., 2020). The effectiveness and engagement level of facilitators can also impact participant retention, with more engaging facilitators likely increasing attendance. Studies of self-management interventions suggest that demographic differences and personal circumstances, such as age and health conditions, influence how consistently participants can attend sessions (Ashtarian et al., 2012). Adaptations in programme content and delivery tailored to site-specific needs can lead to higher engagement. Additionally, community engagement, initial recruitment processes, and external factors such as local COVID-19 restrictions or transportation issues affect attendance rates. Support services like childcare or flexible scheduling, along with follow-up and reminder systems, also contribute to the variations in attendance. These factors collectively shape the distribution of attendance rates across different sites.

The overall, attendance rates were high at the beginning of the online programme but showed a decline over time. This trend was consistent across different sites, with the highest attendance observed in the first week and a noticeable drop by the third week. Factors such as participant fatigue, competing commitments, and the demanding nature of the programme were likely contributors to this decline. Despite the challenges, the overall attendance rates indicated strong initial engagement, underscoring the importance of maintaining participant interest and motivation throughout the programme. Strategies to sustain

attendance, such as incorporating more engaging content and providing additional support, should be considered in future implementations.

Participant Engagement, Content and Format

Participant engagement was a critical factor in the success of the FAME-W intervention. The interactive and supportive environment of the online sessions facilitated high levels of engagement. Participants appreciated the opportunity to share their experiences, learn from others, and receive validation for their feelings and symptoms. Other studies have found similar results (O'Toole et al., 2021). The self-guided workbook group also reported high levels of engagement, although the lack of direct interaction with facilitators and peers was noted as a limitation, as seen in other studies (Gulliver et al., 2021). Strategies to enhance engagement in the self-guided format, such as incorporating reflective prompts and opportunities for peer sharing, could further improve participant experiences.

The length and manageability of both chapters and sessions are crucial for participants managing a chronic condition such as IA. Participants generally found the four-week duration of the online programme to be engaging and manageable, maintaining their interest throughout. Some participants suggested that an additional week might improve the programme by allowing more time for personal interactions and experience sharing. This may be attributed to an increased sense of belonging to a group of individuals sharing similar experiences, as IA can often lead to social isolation (Bay et al., 2020). However, occupational therapists often face challenges due to work and caseload demands, leading to limited involvement in group-based interventions (Tinnelly & Byrne, 2016; Wood et al., 2013). Consequently, it is perhaps unsurprising that most occupational therapists were not in favour of extending the programme further. The length of the sessions was also reported to be acceptable. These lengths of sessions are similar to other online self-management interventions (Corona et al., 2021). Regarding the self-guided workbook, participants appreciated its concise and user-friendly

format, indicating that the length and structure were well-received and did not overwhelm them.

Participants expressed high satisfaction with the content's appropriateness and comprehensiveness, echoing findings by Stinson et al. (2010) that well-structured, relevant materials enhance user satisfaction in online and self-guided interventions. Both online and workbook users appreciated the content's relevance to daily IA challenges, studies have found this to significantly improve the perceived usefulness of self-management interventions (Xie et al., 2020). Chapters on fatigue management, mental well-being, legislation, and ergonomics were particularly useful, with participants applying these strategies practically, aligning with Hersche et al.'s (2022) emphasis on the importance of actionable content for enhancing self-management. Some participants indicated that the programme content primarily reinforced existing knowledge rather than introducing new concepts, focusing on helping participants implement this knowledge into their daily routines. This aligns with findings from other studies, which have shown that self-management interventions, while reinforcing existing knowledge, enable participants to translate that knowledge into practice (Barlow, et al., 2005). In terms of the most beneficial chapter, participants in both interventions gave varying responses which did not lead to a specific answer.

Mechanisms of Impact

The qualitative process evaluation found that participants and facilitators perceived the group-based nature of the online programme and the goal-setting components of both delivery methods as important mechanisms of change. One function of process evaluations is to explore how interventions bring about change, which is crucial for replicating the intervention's effects (Moore et al., 2015). The FAME-W intervention is based on the theory of self-efficacy, which theorizes that goal-setting and group processes provide opportunities for performance mastery, symptom reinterpretation, modelling, and social persuasion, all of which are key to

the intervention's effectiveness (Lorig & Holman, 2003). The evaluation findings suggest that these components were indeed mechanisms of change in the FAME-W intervention. Furthermore, a review by Allegrante and colleagues (2019) has shown that goal-setting is vital in chronic disease management – such as IA – and is frequently used in self-management interventions. Additionally, Araujo-Soares and colleagues (2019) have demonstrated that goal-setting should be incorporated when developing behaviour change interventions for self-management.

Participant Experiences and Perceptions

Both delivery methods of the FAME-W intervention had a positive impact on participants' self-management skills and work performance, with the goal-setting component being particularly effective. Goal-setting not only fostered a sense of empowerment but also improved participants' ability to manage their symptoms. Many participants reported feeling more energetic and motivated to engage in self-care activities due to goal setting. Goal-setting is one of the skills theorised to be necessary to successfully self-manage chronic diseases such as IA (Allegrante et al., 2019) and aims to address individual needs, facilitate behavioural change, and enhance self-efficacy (Lorig & Holman, 2003). Previous research on the FAME-W intervention (Karkon et al., 2023; McCormack et al., 2018) also identified weekly individual goal-setting and review as crucial components, consistent with studies on IA interventions (Damgaard et al., 2023; van Slingerland et al., 2023).

However, those who expressed a dislike for goal-setting still reported enjoying other aspects of the intervention. It's possible that even if participants did not set goals themselves, they benefited from observing others set and review goals, which can enhance self-efficacy through peer learning and modelling. It is recognized that some participants may be unable or unwilling to participate in self-management goal-setting, which may reflect their stage of readiness to change (Lenzen et al., 2016). Rehabilitation literature also indicates that not all individuals see the need for goal-setting (Plant et al., 2016).

The supportive community environment of the online programme offered significant benefits, such as peer support and shared experiences, which were less prominent in the self-guided workbook group. Participants valued the opportunity to share their experiences, learn from others, and receive validation for their feelings and symptoms. This aligns with the findings of Hughes et al. (2020), whose systematic review of qualitative literature on chronic disease self-management programmes highlighted that both facilitators and participants valued the group setting and interactions with others facing similar health challenges. Peer support within the group provides emotional and social backing from others who understand their struggles, fostering a sense of community and reducing feelings of isolation (Jackson et al., 2019). This supportive environment allows members to share practical tips, strategies, and personal experiences, offering diverse perspectives and practical advice on managing the condition (Stenberg et al., 2016). The collective encouragement and accountability found in group settings can increase motivation and adherence to self-management practices (Stødle et al., 2019). Additionally, witnessing others successfully manage their condition can increase self-efficacy, empowering participants and enhancing their confidence in their ability to manage their own health (Wu et al., 2016). The social interactions and shared understanding within the group also contribute to improved psychological well-being, reducing stress, anxiety, and depression associated with chronic illness (Jackson et al., 2019). Structured education sessions within the group provide valuable information on disease management, treatment options, and lifestyle modifications, while also offering a space for participants to develop and practice new skills, such as goal setting, problem-solving, and coping strategies. Research indicates that these group self-management programmes can lead to better physical health outcomes, including improved disease control and reduced symptoms, underscoring the comprehensive benefits of such interventions (Jackson et al., 2019; Stenberg et al., 2016).

In contrast, the self-guided workbook's lack of interactive components posed a barrier for some participants in fully engaging with the content. Studies have found that self-guided interventions, while effective in delivering content, often leave users without necessary feedback or guidance, impacting their ability to track progress (Linardon et al., 2024). Workplace and environmental factors also influenced the extent to which participants could apply the strategies learned during the intervention. Those who had supportive employers, flexible work hours, or access to ergonomic equipment reported better outcomes, as they could more easily integrate the strategies into their daily routines. Conversely, participants who worked in rigid environments or faced unsupportive employers encountered difficulties in implementing the changes, which limited their ability to fully benefit from the intervention.

Several factors influenced the outcomes of the intervention, both positively and negatively. On the positive side, the direct interaction with facilitators and peer support in the online format were significant contributors to participants' progress. The tailored feedback and emotional support provided by facilitators helped participants feel more confident in applying the strategies and allowed them to make necessary adjustments based on real-time guidance. Additionally, participants often cited the value of peer support, as interacting with others who shared similar challenges made them feel less isolated and more motivated to persist with the strategies learned.

Confidence and Empowerment

Another significant outcome of the FAME-W intervention was an increase in participants' confidence and sense of empowerment. Many reported feeling more in control of their symptoms and confident in managing their condition day-to-day. This was due to the intervention's focus on self-efficacy and practical solutions that could be readily applied. These findings align with research showing that self-management interventions enhance self-efficacy and empower patients to manage the physical, psychological, and social impacts of arthritis (Damgaard et al.,

2023). Additionally, studies indicate that such interventions effectively improve health-related behaviours, fostering greater control over health outcomes (Kerari et al., 2024; Shao et al., 2020).

The goal-setting component of the intervention was particularly effective in enhancing participants' confidence. Engagement in goal-setting activities, alongside educational components, contributed to increased self-efficacy and improved symptom management. This aligns with findings from other studies, where structured goal-setting within self-management interventions significantly enhanced participants' perceived control over their condition and their ability to manage symptoms effectively (Doumen et al., 2023; Arends et al., 2020). Furthermore, such interventions have been shown to facilitate shifts in attitudes towards fatigue, promoting the adoption of practical strategies for improved symptom management (Hansen et al., 2022). Establishing realistic, achievable goals provided participants with a sense of accomplishment, thereby reinforcing their capacity for managing inflammatory arthritis. The development of this confidence was not limited to health management alone; it often extended into other areas, with participants feeling more assertive in advocating for their needs within occupational and social contexts. For example, participants felt more empowered to seek workplace adjustments, such as ergonomic modifications, after gaining a deeper understanding of their rights and the importance of self-care. These outcomes are supported by research indicating that self-management interventions empower patients to take control of their health and advocate effectively within their professional environments (Damgaard et al., 2023).

In contrast, participants in the self-guided workbook format expressed a need for more support and interaction, suggesting that future adaptations could include increased facilitator engagement to reinforce these gains in confidence. Research indicates that self-guided web-based interventions can benefit significantly from added support, such as facilitator guidance, to enhance adherence and the overall effectiveness of self-management strategies (Xie et al., 2020).

Challenges and Barriers

Despite the positive outcomes, participants faced several challenges in implementing the strategies learned from the interventions. Time constraints, physical limitations, and the unpredictable nature of IA were significant barriers. Similar barriers have been seen in other self-management interventions (Crawford et al., 2022). Participants in the self-guided workbook group also noted that the content seemed more geared towards office settings, making it less applicable to those in physically demanding jobs. Suggestions for improvement included incorporating more interactive elements, such as breakout sessions during online meetings, and creating digital versions of the workbooks with links to additional resources and videos. Participants also recommended developing family-friendly materials to help explain fatigue to children and other family members, as well as creating an app to remind participants to record their symptoms.

Context

The process evaluation examined the critical contextual factors influencing the implementation of both delivery modalities of FAME-W, focusing on external, social, and cultural aspects. Context, as outlined previously in Chapter 1, refers to the external factors that may act as barriers or facilitators to the intervention's success (Moore et al., 2015). Understanding these factors involves exploring the environmental, organizational, social, and cultural dimensions that interact with the intervention, shaping the observed outcomes (Limbani et al., 2019). Process evaluation explored the context of the online and self-guided workbook formats of FAME-W, providing insights into the external factors influencing implementation, the social and cultural contexts of participants, and the enablers and barriers encountered during the intervention. By examining these elements, we gain a comprehensive understanding of how context impacts the impact and adaptability of FAME-W.

External Factors Influencing Implementation

The implementation of the FAME-W interventions was influenced by various environmental and organizational factors. The COVID-19 pandemic significantly impacted the availability of healthcare professionals to recruit and deliver the sessions, ethical approval processes, and the overall delivery of the interventions (Moreno-Mulet et al., 2021). The influence of the COVID-19 pandemic played a significant role in shaping the delivery and success of both formats. The online format, in particular, benefited from the pandemic context, as it allowed participants to engage from the comfort of their homes, reducing logistical burdens such as travel. Many participants appreciated the flexibility and convenience of the online sessions, particularly those balancing work or fluctuating health conditions. Henshall et al. (2022) found that web-based interventions during COVID-19 improved accessibility, flexibility, and engagement among healthcare professionals, demonstrating the benefits of online formats in the pandemic context. In contrast, the self-guided workbook format offered flexibility, which some participants found beneficial in managing their daily responsibilities. However, as discussed previously this format lacked the immediate peer support and feedback available in the online group.

Social and Cultural Influences

The social and cultural context of participants significantly influenced the implementation and outcomes of the FAME-W interventions. The diversity among participants—ranging from variations in employment types, job physicality, and cultural backgrounds—enriched the intervention experience by enabling a broader exchange of experiences and strategies. However, this same diversity also posed challenges in tailoring the content to meet the varied needs of all participants.

Social support networks emerged as critical to the success of the interventions. Participants reported significant benefits from interacting with peers who shared similar experiences, which reduced feelings of isolation and fostered a sense of community. These peer interactions not

only provided emotional, informational, and practical support but also normalized participants' struggles, making them feel less alone. This peer support was crucial in motivating participants and enhancing their engagement with the interventions. Research indicates that social support networks play a crucial role in enhancing the effectiveness of health interventions by reducing isolation, fostering community, and providing emotional, informational, and practical support to participants (Shalaby & Agyapong, 2020; Rayland & Andrews, 2023). Studies by Bjørlykhaug et al. (2022) and Webber & Fendt-Newlin (2017) highlight that these peer networks can also help address health inequalities and facilitate recovery by promoting diverse social connections and supportive engagement. Overall, the peer support within interventions improves participants' engagement, normalises shared struggles, and supports mental well-being.

In contrast, participants who followed the self-guided workbook noted the benefits of independence in the workbook format but often highlighted the absence of social interaction as a gap. This suggests that future iterations of the self-guided workbook could be improved by incorporating opportunities for peer interaction, such as virtual discussion groups or periodic check-ins. These may address the limitations of self-guided formats, providing emotional and practical support to enhance the intervention experience (Ugalde et al., 2017). Furthermore, these may increase participant engagement and effectiveness of the programme (Amanvermez et al., 2022). The value of peer support was evident across all formats, demonstrating its essential role in empowering participants to manage their conditions more effectively.

Cultural attitudes towards self-management and arthritis played a pivotal role in shaping how participants engaged with FAME-W, a self-management intervention developed in Ireland by Irish occupational therapists for individuals living in the Irish context. Initially, some participants resisted adopting strategies such as pacing and seeking assistance, viewing these behaviours as signs of weakness due to deeply rooted cultural norms (Mingo et al., 2013). Mingo and colleagues

identified that African American participants often refrained from seeking help, as independence was highly valued in their cultural framework, which hindered the uptake of self-management practices. A similar pattern emerged in a Hong Kong-based study by Leung et al. (2016), where cultural influences significantly impacted participants' perceptions of self-management interventions for chronic inflammatory arthritis. These findings align with the scoping review by Damgaard et al. (2023), which highlighted the necessity for interventions to be congruent with patients' cultural, psychosocial, and personal beliefs to enhance engagement.

However, as participants progressed through FAME-W, many began to challenge their pre-existing beliefs, recognising the importance of self-care and non-medical strategies in managing their condition. Eyles et al. (2017) similarly noted that interventions accounting for cultural attitudes resulted in enhanced self-management capabilities and more accurate assessments of outcomes. Such transformations in attitudes underscore the potential for interventions to shift cultural norms, encouraging participants to adopt a more proactive approach to managing their symptoms.

The transformative potential of culturally tailored interventions is further evidenced in the work of Williams et al. (2017), which demonstrated that peer mentoring facilitated the adoption of self-management behaviours, particularly among minority groups who valued community support. This aligns with the broader conclusion that addressing cultural attitudes within self-management frameworks can significantly influence behaviour change. Additionally, Shao et al. (2021) found that a culturally tailored self-management programme in China significantly improved participants' self-efficacy and attitudes towards exercise and joint protection, highlighting the critical role of culturally sensitive approaches in overcoming resistance.

The emphasis on cultural considerations is further supported by Williams et al. (2016), who evaluated an "a la carte" intervention for African American lupus patients. This intervention accounted for cultural

sensitivities, resulting in greater adherence to self-management practices. Likewise, Ehrlich et al. (2016) noted that culturally responsive self-management programmes led to improved health outcomes and shifts in beliefs regarding self-care, highlighting the necessity of integrating cultural beliefs early in the intervention process to help participants overcome barriers more swiftly.

Furthermore, Li et al. (2012) explored the use of digital media in delivering culturally tailored self-management interventions for rheumatologic conditions, concluding that digital approaches significantly enhanced participant engagement, especially when interventions addressed cultural nuances and provided personalised support.

The outcomes of FAME-W reflect the impact of shifting cultural norms, encouraging participants to seek assistance and adopt a proactive approach to managing their symptoms. By the end of the intervention, many participants had embraced strategies they initially resisted, underscoring the transformative potential of addressing cultural attitudes. Incorporating a more explicit focus on cultural beliefs and attitudes earlier in the process could enable participants to overcome these barriers sooner, thereby enhancing their engagement and improving outcomes.

FAME-W is an Irish study, developed by Irish occupational therapists for individuals living in Ireland. Therefore, the success of both programmes as reported by the participants could be attributed to the development of culturally relevant programmes that fit the Irish context (Madsen et al., 2023). Other interventions have found similar results by delivering the interventions by culturally concordant study staff and culturally-tailored experiential activities (Jayaprakash et al., 2016).

Workplace Support and Organizational Factors

As a work-focused intervention, participants emphasized the importance of implementing strategies in the workplace and the impact of the workplace environment on symptom management. Ergonomic adjustments, flexible work hours, and emotional support from colleagues

and supervisors were essential for enabling participants to manage their conditions effectively while maintaining productivity. The level of support and accommodations provided by employers emerged as a critical factor, significantly influencing participants' ability to engage with the interventions. Studies focusing on work experiences of individuals with IA have found similar results (Holland & Collins, 2018).

Participants' feedback highlighted the importance of understanding employment rights and advocating for necessary accommodations. The insights gained from the ergonomic and employment rights sessions empowered participants to seek support proactively, enhancing their self-efficacy and overall well-being. This finding underlines the need for comprehensive support systems within workplace environments to facilitate effective self-management of chronic conditions such as IA (Grady & Gough, 2014; Bosma et al., 2021).

5.6 Conclusion

The process evaluation of the FAME-W intervention including both of its delivery methods underscores the importance of flexible, well-structured training and resources, high fidelity in delivery, and effective recruitment strategies. The positive impact on participants' self-management skills, confidence, and overall well-being highlights the potential of these interventions to improve outcomes for individuals with inflammatory arthritis. Future implementations should consider incorporating more interactive and digital elements to enhance participant engagement and support long-term behaviour change.

CHAPTER 6:

CONCLUSION

6.1 Introduction

The overall aim of this research was to test the feasibility and compare two different delivery methods of the same intervention: online & self-guided workbook. Three separate studies were undertaken as part of this research; a feasibility study, a multisite comparative RCT and a process evaluation. This chapter provides an overall conclusion based on the findings from those studies. The feasibility of the online and self-guided workbook formats was tested through a comparative RCT incorporating qualitative components, and both formats were found to be feasible. A parallel comparative multisite RCT evaluated and compared the outcomes of both delivery methods in improving work performance for individuals with IA. Additionally, a mixed method process evaluation was conducted to assess the implementation and impact of the intervention for both delivery methods. The chapter also presents the strengths and limitations of each delivery method, outlining their implications for future research and clinical practice. Finally, it provides recommendations for refining the FAME-W intervention and highlights areas for further exploration, offering opportunities to enhance its impact and scalability in future implementations.

6.2 Comparison of Delivery Methods

The FAME-W intervention was delivered through two distinct methods: an online therapist-led format and a self-guided workbook. The online delivery provided participants with an interactive, group-based experience, guided by an occupational therapist over a structured four-week period. This format allowed for real-time collaboration, support, and immediate feedback. In contrast, the self-guided workbook enabled participants to independently work through the same content at their own

pace. Despite the differing delivery methods, no significant differences were observed in participant outcomes between the two groups.

Each group consisted of 61 participants, with similar completion rates (75.4% for the online group and 72% for the self-guided group). These minimal differences in completion rates reflect comparable levels of adherence, suggesting that both formats successfully maintained participant engagement despite their contrasting structures. The comparable rates may indicate that the self-paced nature of the workbook was as supportive in promoting motivation as the structured, therapist-led online sessions. This highlights the adaptability and accessibility of both formats, catering to varied individual needs, such as accommodating personal schedules, technological access, and different learning preferences (Bodenheimer et al., 2002; Lattie et al., 2022). However, while the process evaluation indicated that participants valued the flexibility of both formats, the RCT data suggest that this did not translate into sustained differences in outcomes, underscoring the need for a nuanced interpretation of engagement and its impact.

Further supporting this, the consistent engagement observed across both formats reflects the intrinsic appeal of the FAME-W content, which likely played a key role in participant motivation. According to Patten et al. (2022), digital self-management interventions can enhance adherence due to their flexibility and ability to meet the diverse needs of participants. However, it is important to consider that these high levels of engagement may have been more reflective of participants' intrinsic motivation rather than the delivery method itself. Other studies have also emphasized the self-selection bias in digital interventions (Crutzen et al., 2011; Hirani et al., 2017; Lorig et al., 2006; Patten et al., 2022). This raises critical questions about the generalizability of these findings to populations with varying degrees of motivation.

The comparable completion rates also underline the robust design of the FAME-W intervention. The ability to deliver a uniform, effective intervention through two distinct modalities highlights the adaptability of

the intervention, an important factor when considering scalability and applicability in diverse contexts. The intervention content, regardless of delivery method, was engaging and manageable, ensuring that participants across both formats received the same core material. The high fidelity to the content and uniformity in delivery across both methods ensured that participants experienced the same intervention, making it possible to measure the intervention's impact without introducing variability based on delivery format (Bellg et al., 2004; Carroll et al., 2007). While some participants noted minor differences in session duration and reading times, both groups agreed that the four-week timeframe was sufficient. This consistency is critical for maintaining the integrity of the intervention and ensuring that any observed differences in outcomes can be attributed to participant factors rather than content variability (Cissell, 2004; Hoffman et al., 2014; Steckler, & Linnan, 2002). However, this finding calls into question the extent to which the delivery method influences the intervention's efficacy, an area in need of further exploration, especially when considering the need for personalized treatment approaches in IA management. Additionally, the quantitative findings from the RCT suggest that while both formats were feasible and engaging, neither delivery mode led to sustained improvements, raising questions about the degree to which engagement translates into long-term behavioural change.

One of the most important findings in this study is the lack of statistically significant differences between the online and self-guided workbook groups concerning long-term outcomes. Both formats resulted in initial improvements in areas such as fatigue management, work role functioning, and mental health. However, these improvements were not sustained at the three-month follow-up, suggesting that the format of the intervention was not a decisive factor in determining long-term impact. Instead, this points to the importance of ongoing reinforcement mechanisms—rather than the mode of delivery—for maintaining improvements over time (Arnberg et al., 2014). The apparent lack of significant differences in either group points to the potential limitations of standalone interventions. It calls for a paradigm shift in IA management

where continuous, adaptive support models may be more effective than discrete, time-limited interventions (Mohr et al., 2011; Nahum-Shani et al., 2015). The process evaluation highlighted participants' appreciation for both the structured support of the online format and the autonomy of the self-guided workbook. However, the RCT data suggest that these preferences did not translate into sustained behavioural changes, emphasizing the need for caution in interpreting qualitative feedback as indicative of overall intervention impact.

From a theoretical standpoint, Bandura's (1977) self-efficacy theory offers valuable insight into the potential reasons why both delivery formats of the current study may have struggled to maintain long-term improvements. Managing chronic illness such as IA requires not only initial behaviour change but also ongoing reinforcement and feedback to maintain those changes (Araújo-Soares et al., 2019; Hood et al., 2018; Wagner et al., 2001). The absence of ongoing feedback loops and accountability structures may have caused participants' initial improvements in fatigue management and work accommodations to diminish over time. This highlights the importance of adopting more dynamic intervention models that extend beyond the limited timeframe of the FAME-W intervention. While the qualitative findings from the process evaluation provided valuable insights into participant experiences and preferences, they must be interpreted alongside the RCT data, which suggest that neither delivery format alone was sufficient to produce long-term benefits.

Comparing Online and Self-Guided to In-Person Delivery

When comparing the current study to the in-person FAME-W pilot (McCormack et al., 2018), which utilized an in-person, group-based approach, several key differences emerge. In the pilot study, participants reported significant long-term improvements in fatigue, pain, mood, and work demands at the 12-week follow-up. These sustained improvements suggest that the in-person format, which provided direct engagement, structured support, and social reinforcement, was crucial in facilitating

lasting behaviour change. In contrast, the online and self-guided formats used in this study, while effective at promoting initial engagement, failed to sustain these improvements over time. By the three-month follow-up, most outcomes had returned to baseline levels, including fatigue and pain, which had not shown significant long-term improvement.

The differing outcomes can be attributed to the delivery format. The in-person sessions in the original study likely provided participants with continuous support and real-time feedback that facilitated long-term success. In contrast, the online and self-guided formats, while offering initial flexibility and autonomy, lacked the intensive, therapist-led interaction necessary for sustained behaviour change. This aligns with previous research, which highlights the role of continuous support in maintaining improvements in chronic illness management such as IA (Simister et al., 2018). The results from (McCormack et al., 2018) also suggest that face-to-face group-based interventions may have promoted a sense of accountability and community, which could have driven more sustained engagement with fatigue management strategies. Nonetheless, while these qualitative aspects of the in-person intervention appear advantageous, it is necessary to interpret them alongside the quantitative findings from this study, which suggest that neither online nor self-guided delivery methods led to long-term differences in work ability. This underscores the complexity of intervention effectiveness, where engagement alone may not be sufficient to ensure sustained behaviour change. The findings here suggest that while autonomy is valuable, especially for participants managing complex work-life-health balances, the absence of sustained therapist interaction may compromise the intervention's ability to instil lasting behaviour change. This raises a critical question for future interventions as to how the benefits of both autonomy and structured support can be integrated to sustain long-term gains.

Evaluation of Quantitative and Qualitative Data from the RCT and Process Evaluation

A key consideration in interpreting the study findings is the discrepancy between the quantitative results from the RCT and the qualitative insights from the process evaluation. While the process evaluation provided rich contextual insights into participants' experiences, the RCT was designed to assess measurable changes in work role functioning, fatigue, and mental health. The RCT findings indicated that neither delivery method led to statistically significant long-term improvements, suggesting that while the intervention positively influenced self-management strategies and goal setting, its impact may not have been fully captured through the quantitative measures used in this study.

One possible explanation for this discrepancy is that the outcome measures used in the RCT may not have been the most appropriate tools to capture the specific benefits reported by participants. While participants highlighted goal setting and goal attainment as valuable aspects of the intervention, goal attainment was not explicitly measured in the RCT. The omission of a validated goal attainment measure may have limited the ability to detect meaningful progress in participants' self-management and work-related functioning. Future studies should consider incorporating goal attainment scaling or similar validated instruments to better align the quantitative assessment with the aspects of the intervention that participants found most valuable.

Another consideration is that while participants provided positive feedback on their experiences, the lack of sustained quantitative improvements raises questions about the intervention's capacity to produce long-term behavioural change without continued support. Existing research on self-management interventions has emphasized the need for ongoing reinforcement mechanisms to sustain benefits over time. For instance, Lorig et al. (2006) demonstrated that self-management programs incorporating follow-up reinforcement strategies led to better long-term outcomes in chronic disease management. Similarly, a

systematic review by Nolte & Osborne (2013) found that structured follow-ups and booster sessions significantly enhance adherence to self-management interventions.

Taken together, the quantitative and qualitative findings provide complementary perspectives. The quantitative findings underscore the importance of ongoing reinforcement strategies, while the qualitative feedback highlights the perceived value of self-management strategies among participants. The discrepancy between these findings suggests that while participants may have developed useful skills, they may require additional support to sustain and integrate these strategies into their daily lives. Future research should consider expanding the range of quantitative outcome measures and incorporating structured follow-up components to ensure a more comprehensive evaluation of self-management interventions over time.

6.3 Strengths and Limitations of the Study

Strengths of the Study

The study possesses several strengths that contribute to its robustness. First, the design of the study, which utilized a mixed-methods approach, enhanced the depth and richness of the findings (Wasti et al., 2022). The quantitative data offered measurable outcomes, while the qualitative feedback from participants and facilitators provided context and deeper insights into the participants' lived experiences (Moser & Korstjens, 2017; Tashakkori & Teddlie, 2010). This integration of methods allowed for a comprehensive exploration of the impact of the two delivery formats, capturing not only statistical outcomes but also personal experiences that may not be easily quantifiable (Johnson & Onwuegbuzie, 2004). The use of both online and self-guided formats allowed the research to explore the efficacy of different delivery methods, which is highly relevant in both clinical and real-world contexts. The online format's flexibility was particularly important during the COVID-19 pandemic when in-person sessions were not feasible. This highlighted the adaptability of FAME-W, showcasing its potential for remote or hybrid delivery in clinical settings.

Another key strength was the participation of individuals with different types of IA, demonstrating the adaptability and suitability of FAME-W across various IA populations. This adaptability underscores the intervention's ability to work effectively for people with different forms of IA, strengthening the claim that the FAME-W intervention is not limited to a specific type of IA but can be generalized to a broader population. Such versatility is essential in both clinical and research contexts, as it reflects the intervention's potential to address diverse patient needs and conditions. Including participants from multiple IA populations also broadens the scope of the study's findings, making them more applicable to real-world settings. If the intervention had demonstrated positive outcomes solely for one specific type of IA, the results would have been narrower in scope. However, by demonstrating that people with various types of IA benefited from the intervention, the study's outcomes suggest that FAME-W has a more robust and relevant impact, making it suitable for a wider range of patients. Moreover, the adaptability of FAME-W enhances its relevance to clinical practice. Since the intervention has been shown to work across different IA populations, healthcare providers can feel more confident in recommending it to a diverse patient base. This flexibility, especially in a clinical setting, allows the intervention to be a valuable tool for managing fatigue and work demands for individuals with various IA profiles, contributing to more effective, personalized care.

Additionally, the involvement of occupational therapists and rheumatology physicians in both the recruitment and facilitation processes strengthen the study. These healthcare professionals brought clinical expertise and credibility to the intervention, which likely enhanced participant trust and engagement, a factor known to positively influence health outcomes (Birkhäuser et al., 2017; Bombard et al., 2018). Research demonstrates that trust in healthcare professionals is closely tied to greater patient engagement and adherence to interventions, which likely contributed to participants' adherence to the FAME-W intervention and its overall effectiveness (Brennan et al., 2013). Their involvement also

ensured that the participants were carefully selected based on their clinical profiles, ensuring that they met the necessary requirements for inclusion in the programme. Additionally, the practical focus of the FAME-W on real-world strategies for managing fatigue and work demands meant that participants could apply what they learned immediately in their daily lives.

Limitations of the Study

Despite its strengths, the study had several limitations. The design of the FAME-W intervention was informed by qualitative research on work-related challenges faced by individuals with IA, including a study that explored the impact of fatigue on work ability and found that individuals often struggle with unpredictable fatigue, difficulties managing workload, and the emotional toll of balancing employment with their condition (Connolly et al., 2016). However, while these qualitative insights informed the intervention, direct patient and public involvement (PPI) during the development phase could have further strengthened the study design by ensuring that participant preferences, communication styles, and accessibility needs were more explicitly integrated. Similarly, involving individuals with IA in the interpretation of study outcomes could have provided valuable contextual insights, enhancing the relevance and applicability of the findings. Moving forward, embedding PPI from the outset can enhance future research by refining intervention design, optimizing recruitment strategies, and ensuring that outcome measures align with participant priorities. PPI is increasingly recognized as integral to patient-centred research, contributing to feasibility, impact, and engagement (Greenhalgh et al., 2019; Richards et al., 2015).

Another limitation of the study is the short-term, three-month follow-up period, which may not provide a comprehensive understanding of the intervention's long-term impact. Behavioural changes, particularly in chronic illness – such as IA – management, often diminish over time without continued reinforcement, making it difficult to assess whether the initial improvements in fatigue management and work role functioning can be sustained in the absence of ongoing support. Moreover, IA tend to

follow fluctuating patterns, where symptom relapse is common (Adebajo & Dunkley, 2018). A longer follow-up period would allow researchers to observe whether participants experience setbacks in managing fatigue or declines in work performance, which may not have emerged within the short three-month window. Additionally, given that work-related demands and stressors can vary significantly over time, a three-month follow-up may only capture a stable period in participants' lives, potentially overlooking the true impact of the intervention on their ability to manage more challenging or fluctuating work environments. Extending the follow-up period would provide more meaningful insights into the durability of the intervention's effects and how well participants can sustain these gains when faced with the inevitable shifts in work and life stressors.

Facilitator experience also varied, which may have influenced the consistency of session delivery. While occupational therapists received training for facilitating the online delivery, some variations in adherence to the online FAME-W's protocol were observed, especially in terms of session length and the depth of discussions. This variation was often due to the emotional needs of participants or facilitator discretion, which, while reflecting the flexibility needed for such interventions, also impacted consistency across groups. These differences may have affected the overall outcomes, as participants in some sessions received more personalized or extended support than others (Olmos-Ochoa et al., 2021).

The self-guided workbook format also introduced limitations for some participants. The absence of real-time feedback and peer interaction in this format may have left some participants struggling to maintain motivation and adhere to the intervention's recommendations. This has been seen in other workbook interventions (Takano et al., 2021). Future iterations of this format should consider incorporating more facilitator support or interactive elements in the self-guided format to address this limitation.

The demographic composition of the study, primarily involving middle-aged, educated women with RA, is consistent with the population most

affected by this condition. While the study achieved diversity in terms of employment status and work-related challenges, the underrepresentation of men and younger adults—especially given that certain subtypes of IA are more prevalent in males—raises concerns about the generalizability of the findings. Gender, age, and education level can significantly influence engagement and outcomes in chronic illness interventions, and the limited representation of these groups may constrain the external validity of the study (Chen et al., 2022). To address this, future iterations of FAME-W should employ stratified sampling techniques to recruit a more balanced and representative sample. This approach would ensure the findings are applicable to a broader range of individuals and could provide deeper insights into how demographic variables such as gender, age, and socioeconomic status influence the efficacy and engagement with the intervention.

6.4 Implications for practice and research

The findings of this study offer insights that may be relevant to clinical practice, particularly concerning the delivery of self-management programmes for individuals with IA. FAME-W was designed to enhance self-efficacy and symptom management through different delivery formats (Karkon et al., 2023a; Karkon et al., 2023b; McCormack et al., 2018). While the qualitative findings from the process evaluation indicate that participants valued the flexibility and accessibility of these formats, the quantitative results from the RCT did not show statistically significant differences between the online and self-guided workbook groups. Furthermore, neither delivery method resulted in clinically meaningful improvements across most outcome measures, with the exception of anxiety scores, where reductions just reached the lower bound of the minimally clinically important threshold. This limits the strength of recommendations for adopting either format in clinical practice, as the lack of measurable change suggests the intervention may not yet be ready for routine implementation without further adaptations or support. These mixed findings suggest that the observed benefits were limited, highlight

the need for further investigation before drawing firm conclusions about the role of different FAME-W delivery formats in clinical practice.

One possible approach to integrating FAME-W into clinical settings could be the use of a hybrid model that combines online and self-guided elements. For instance, an initial facilitated session that may be either in-person or online, could be followed by a self-guided phase where participants engage with a workbook or digital platform. Periodic check-ins, whether virtual or in-person, could provide opportunities for participants to discuss their progress, seek clarification, and receive guidance. Such structured support could help address the limited impact observed in this study by increasing engagement and promoting sustained behaviour change, which may in turn improve clinical outcomes. However, the feasibility, acceptability, and impact of such a hybrid approach require further evaluation, particularly in diverse clinical environments.

In clinical practice, the online format could be particularly valuable for service users with busy schedules or those living in remote areas where access to in-person care may be limited. The self-guided workbook, on the other hand, could benefit those living in rural areas as well as individuals who prefer independent learning, enabling them to engage with the material at their own pace. However, the lack of interaction with other individuals with IA and health care professionals in the self-guided format, as reported in the qualitative feedback, raises concerns about engagement, adherence and additional support. Clinics interested in offering self-guided interventions may need to explore additional support mechanisms, such as follow-up calls or virtual peer discussions, to enhance motivation and retention. Given that in this study the quantitative data showed no clinically meaningful changes, such enhancements may be essential to increase the programme's potential impact in real-world settings. Future research should examine whether such adaptations contribute to better engagement and sustained outcomes over time.

Another important consideration for clinical integration is tailoring the content to suit individual needs. This could be done during the occupational therapy consultation session or through follow-up calls or check-ins. For example, participants with physically demanding jobs might receive advice on ergonomic adjustments, while those in sedentary roles may benefit from different pacing strategies. Personalized adaptations based on participants' work environments, symptom severity, or personal circumstances would enhance the relevance and applicability of the intervention while reducing the need for more time-intensive individual therapy. However, it remains unclear whether tailored adaptations improve outcomes compared to standardized interventions, and further research is needed to explore the balance between individualization and scalability in clinical settings.

The self-guided workbook presents several clinical advantages. One of its primary strengths is resource and time efficiency. Unlike traditional group or one-on-one interventions, the workbook allows individuals to work independently, enabling clinicians to allocate their time and resources to seeing more patients. This reduces the demand for continuous clinician presence and improves overall care delivery efficiency. Additionally, the workbook minimizes recruitment challenges by eliminating the need for group session participation, making it easier for individuals to engage at their own pace. In terms of cost-effectiveness, the workbook is a financially advantageous solution. Once developed, it can be distributed to many patients with minimal recurring costs, making it a scalable and practical option for healthcare providers. However, while cost considerations suggest that a self-guided format could be more scalable, a comprehensive evaluation of its long-term sustainability and impact on healthcare utilization is necessary before widespread implementation can be recommended. While the programme offers promising cost-efficiency, the current findings indicate that this alone is not a sufficient justification for implementation; further evidence of clinically meaningful improvements is needed to support its routine use in practice. The simplicity of facilitation is another important benefit, allowing clinicians

to oversee multiple patients using the workbook without needing to be involved at every step, thus enabling support for a larger patient population.

The workbook can also be integrated into a hybrid model as well, combining self-paced learning with peer support or group settings to enhance engagement and improve patient outcomes. Structured check-ins with clinicians can further help monitor progress and address any issues that arise. These periodic follow-ups ensure that patients stay on track while maintaining the self-guided nature of the intervention. However, any such integration into clinical care should be approached cautiously and accompanied by further evaluation, particularly given the limited quantitative impact observed. Overall, the self-guided workbook is a clinically viable and scalable tool, offering flexibility, cost-effectiveness, and improved care efficiency in healthcare settings but additional refinement and testing are required to ensure it delivers meaningful improvements for people with IA.

Implications for Future Research

Interventions for individuals with IA have primarily been delivered on an individual basis, despite evidence indicating a clear patient preference for group-based interventions. However, further research is required to evaluate the long-term effectiveness of group-based interventions compared to individualized approaches, particularly in key areas such as job retention and fatigue management. The present study found no significant differences in outcomes between these two delivery modalities, underscoring the need for further investigation into these domains.

While work-specific interventions for individuals with various forms of arthritis are available, they predominantly rely on clinician-led sessions. The intervention examined in this study is distinct in that it introduces a self-guided workbook, serving as a standalone tool that allows individuals to engage with the material independently, without the need for continuous clinician oversight. The introduction of this self-guided

approach represents a significant innovation in the field of work-related arthritis interventions, providing individuals with increased flexibility and autonomy. Its potential for scalability and cost-effectiveness positions this model as a compelling option for healthcare providers aiming to optimize resource allocation while maintaining or improving patient outcomes.

Considering that this study found no significant differences in outcomes between online and self-guided workbook formats, combined with the relative cost-effectiveness of the self-guided workbook, future research should explore a three-arm randomized controlled trial. This proposed study would compare the efficacy of self-guided workbooks, in-person interventions, and a control group to determine which approach is most effective in enhancing work ability, managing fatigue, and improving overall health outcomes for individuals with IA. Such a study would provide a more comprehensive understanding of the comparative effectiveness and cost-efficiency of different intervention formats.

A key area for future investigation is the comparative evaluation of self-guided interventions, online programs, and traditional in-person delivery. While this study did not find statistically significant differences between the online and self-guided workbook formats, a randomized controlled trial with a larger sample size and additional outcome measures could provide further insight into their respective benefits and limitations. Additionally, future research should consider assessing long-term work-related outcomes, such as career progression, job satisfaction, and sustained employment, as these aspects remain sparse in the existing literature.

The economic implications of self-management interventions also warrant further examination. While self-guided workbooks may be cost-efficient from a resource allocation perspective, the lack of direct facilitation raises questions about engagement and adherence over time. Future research should investigate whether different intervention formats lead to differences in healthcare utilization, work productivity, or reliance on

medication. A formal cost-analysis comparing group-based, individual, and self-guided approaches would be valuable for informing policy decisions and clinical implementation strategies.

Additionally, there is a need to ensure that self-management interventions are accessible to a diverse range of individuals with IA. The sample in this study, while varied in some aspects, was limited in others. Future research should aim to recruit a more diverse sample, particularly men, younger adults, individuals from lower socioeconomic backgrounds, and those in varied occupational roles. Understanding how the intervention performs across different demographic and occupational groups will be essential in ensuring that it is relevant and applicable to the broader IA population.

While the findings of this study suggest that self-management programs such as FAME-W may hold promise, a cautious and measured approach is needed when interpreting their implications for practice. Further research, including long-term follow-ups, economic evaluations, and comparative effectiveness studies, will be critical in determining the most suitable and sustainable strategies for integrating self-management interventions into healthcare settings.

Dissemination and Uptake of the FAME-W Workbook

If demonstrated to be effective in future studies, the integration of the workbook into routine clinical practice could be facilitated through rheumatology and occupational therapy services, where healthcare professionals can provide it as a resource alongside routine consultation. Embedding the workbook within multidisciplinary care pathways, particularly within return-to-work and vocational rehabilitation interventions, may further strengthen its reach and impact. Additionally, the workbook could be incorporated into patient education initiatives, supported by clinicians and arthritis organizations to ensure its availability to a wider audience.

Digital adaptation and online accessibility may also enhance uptake of the workbook, allowing individuals to engage with the content in a flexible, self-paced manner. Developing complementary resources, such as short instructional videos or interactive online modules, could facilitate engagement and provide guidance on key self-management techniques. Moreover, increasing awareness through professional networks, patient advocacy groups, and social media campaigns could support its wider adoption.

6.5 Conclusion

In conclusion, the FAME-W intervention has demonstrated benefits in improving self-management skills, fatigue management, and empowering individuals with IA to take control of their condition. However, the study faced several limitations, including recruitment challenges and sample size reduction. Future research should address these limitations, exploring the long-term effects of the intervention, investigating hybrid delivery models, and focusing on cost-effectiveness.

The implications for clinical practice are clear: self-management interventions such as FAME-W should be integrated into routine care, offering individuals the tools to better manage their condition and improve their quality of life. With further research and refinement, FAME-W has the potential to become a cornerstone of care for individuals living with IA, empowering them to live more proactive, healthier lives.

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APPENDICES

Appendix A: Goal Setting Sheets

Example of Weekly Goal Setting

In writing your action plan, be sure it includes:

1. What you are going to do over the next week?
2. How much/how often are you going to do it?
3. When you are going to do it (time of day)?
4. What days of the week are you going to do it?

This week I will:

Go for a walk (what)

Three times (how much/how often)

After lunch (when: time of day)

Mon, Wed and Friday (what days)

What will support or enable me to achieve this goal?

Have suitable foot ware and rain gear

Contact Jimmy to walk together

Do light activities in the mornings that I go walking

What barriers/difficulties might stop me achieving this goal?

Fatigue

Weather

Not in the mood/Lack of motivation

Confidence in achieving my goal

This is how confident I am that I will achieve my goal this week:

(0 = not at all confident, 10 = totally confident)

0	1	2	3	4	5	6	7	8	9	10

Week 1 Goal Setting

In writing your action plan, be sure it includes:

1. What you are going to do over the next week?
2. How much/how often are you going to do it?
3. When you are going to do it (time of day)?
4. What days of the week are you going to do it?

This week I will:

_____ (what)

_____ (how

much/how often)

_____ (when: time of

day)

_____ (what days)

What will support or enable me to achieve this goal?

What barriers/difficulties might stop me achieving this goal?

Confidence in achieving my goal

This is how confident I am that I will achieve my goal this week:

(0 = not at all confident, 10 = totally confident)

0	1	2	3	4	5	6	7	8	9
					10				

Goal review

To what extent did you achieve your goal/s this week?

If you achieved your goal:

What helped you to achieve your goal/s?

How did you feel as a result of achieving your goal/s?

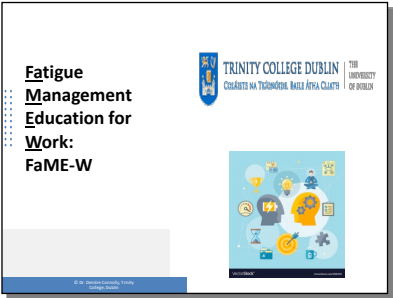
If you did not achieve your goal:

What do you think were the main reasons/barriers for not achieving your goal/s?

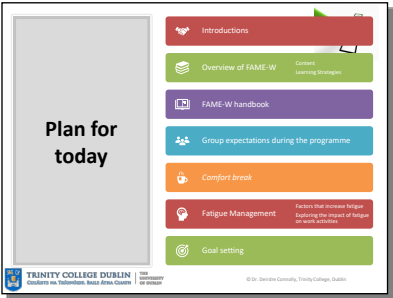
What could you do differently next time?

Appendix B: Online FAME-W Slides from Week 1

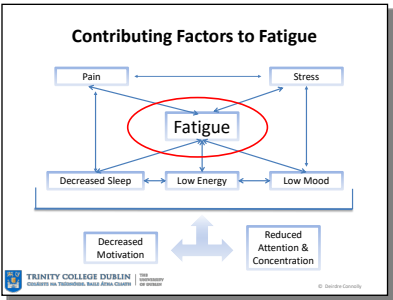
Slide 1



Slide 2



Slide 3



Slide 4

What we will cover

- Week 1: Fatigue and energy management
- Week 2: Managing pain, protecting your joints, and ergonomics
- Week 3: Maintaining Mental Wellbeing
- Week 4: Effective Communication with Employers and Employment Legislation



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Slide 5

Learning Strategies

- **Interactive**
 - Through discussion
 - Sharing experiences and strategies
 - Through activity
 - Setting and reviewing weekly goals



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Slide 6

INTRODUCTIONS



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Slide 7

Group Expectations

- Behaviours that are considered acceptable or non-acceptable within the group, in order for the group to work efficiently

Get along

Respect others

On task only

Use quiet voices

Participate

Stay in your group

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Handbook

- To complement what is covered in the programme
- Personal Resource
- Individual Goal Setting
- Bring each week

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Tea break

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Slide 10



Slide 11

What is fatigue?

- Rheumatic diseases can cause extreme fatigue which can drain you of your energy
- Research indicates that up to 90% experience fatigue (Norheim, Jonsson & Omdal, 2011)
- Described as a subjective lack of physical and/or mental energy that can interfere with usual and desired activity
- "Beyond ordinary tiredness and something rest does not always improve" (Neill, 2005)
- 3 main types of fatigue
 - Physical
 - Mental
 - Cognitive

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What causes fatigue?

- The disease itself
- Inactivity
- Poor Nutrition
- Insufficient rest
- Emotions
- Medication

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Strategies for managing fatigue

- Manage energy levels efficiently
- Sleep well
- Take a rest during the day as required
- Take regular physical activity
- Eat well
- Manage anxiety and stress



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Slide 14

The four Ps of energy efficiency

A diagram illustrating the four Ps of energy efficiency. It features a green square background with a white cross-like shape in the center. Four blue rounded squares are arranged in a 2x2 grid, each containing one of the 'Ps'. The top-left square is labeled 'Planning', the top-right is 'Pacing', the bottom-left is 'Prioritizing', and the bottom-right is 'Positioning'. The white shape in the center has four arrowheads pointing towards each of the blue squares.

Planning	Pacing
Prioritizing	Positioning

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Planning

- Think before you start!
- Look at how things are organised in your class. Plan your work so that you are motivated and organised.
- Each day, review your plan and decide if you can put things up for the activities for that day.
- If you can't, then you may have to change them to be smaller, more manageable things and spread them out.
- Be flexible. If you don't have the energy to do an activity, then don't do it.
- If you have too many urgent tasks, prioritise them.
- You may have completed others and ask for help.
- Keep a daily planner or calendar or you may lose things or forget your plan for the next day and week.



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Slide 16

Prioritising



- Identify work activities and roles that are most important to you each day and week and prioritise these.
- What is:**
 - Urgent (must be done today)
 - Important (must be done within the next few days)
 - For later (must be done this week or month)
 - Not necessary (keep the big picture in mind)
- Learning to say 'no' is important in managing your energy levels

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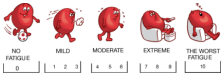
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Slide 17

Fatigue Diary

List your daily activities and rate how tired you feel following these activities
Can help you to identify and prioritize activities that cause high levels of fatigue



NO FATIGUE	MILD	MODERATE	EXTREME	THE WORST FATIGUE
0	1 2 3	4 5 6	7 8 9	10

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Pacing

-  Pace your work activities by taking frequent breaks throughout your working day
-  Take breaks when doing long or tiring tasks
 - Short rest breaks of five minutes during tasks
 - Change position
 - Stretch
-  Plan for unanticipated interruptions, mistakes or distractions
-  Do not fight fatigue or push yourself to exhaustion
 - Recognise your energy levels throughout your working day

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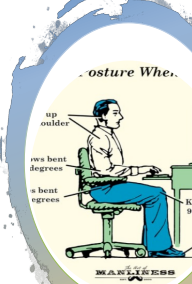
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Positioning

- Learning to position your body correctly can reduce strain on your joints and help diminish fatigue
- Avoid excessive movements such as bending and reaching
- Think about how you group and store work applications
 - Heavy items in close away to reach places
 - Light articles in high and low areas
 - Store items used in collaboration together - e.g. software
- Assemble necessary supplies and equipment prior to beginning work task
- Sit when you can
 - Sitting can take up to 25% of your energy
 - Use a chair with good back support



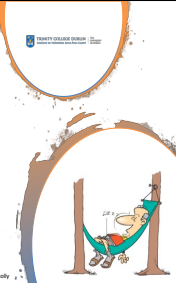
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Slide 20

Resting to manage fatigue

- important part of fatigue management
- Taking a rest is not "giving in" to fatigue
 - short and frequent rests
 - 10 to 60 minutes
- Identify a suitable place in work to rest
- Increase rest times in lead up to important work activities and events



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Slide 21

Sleep and fatigue

- Insufficient sleep = more fatigue
- Sleep allows the body to recover from, and prepare for, daily activities
- Sufficient sleep has a positive influence on physical and mental health
- Recommended to have 7-9 hours of sleep



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Slide 22

Sleep strategies

- Establish a realistic sleep routine
- Have a comfortable bed/mattress
- Comfortable room temperature and lighting
- Avoid exercising too close to usual bed time
- Avoid eating, drinking caffeine and alcohol before bed
- Don't go to bed too full or hungry
- Limit fluid intake before bed
- Write down stressors and/or 'things to do tomorrow' before bed time
- Turn off electronic devices



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Conclusion

- Fatigue is a real symptom of rheumatic diseases
- Like all other symptoms it needs to be managed
- Recognise activities and factors that increase your fatigue
- Listen to your body and acknowledge when you feel fatigue
- Trial different management strategies to find the ones that work for you

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Slide 24

Goals for the week

- What are you going to do?
 - How much?
 - When?
 - How often?
- Steps to achieve the goal
- Barriers and Enablers?
- How confident are you? (0=no confidence 10=totally confident)



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 Specific

 Measureable

 Attainable

 Relevant

 Timed

S.M.A.R.T Goals

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Slide 26

Goal-setting format

In writing your weekly goal's, be sure it includes

1. **what** you are going to do.
2. **how much** you are going to do.
3. **when** you are going to do it, and
4. **how many** days a week you are going to do it.

This week I will...	go for a walk.	(what)
	30 minutes	(how much)
	After lunch	(when)
	3 days this week	(how many)

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Goal-setting

What supports/enablers are available to help me achieve this goal?
Choose suitable days
Contact a friend to walk with me
Eat/rest before walking

What barriers may there be to me achieving this goal?
Procrastination
Fatigue

How confident are you
(0= not at all confident; 10= totally confident) _____

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Goal review

- To what extent did you achieve your goal/s this week?

If you achieved your goal:

- What helped you to achieve your goal/s?
- How did you feel as a result of achieving your goal/s?

If you did not achieve your goal:

- What do you think were the main reasons/barriers for not achieving your goal/s?
- What could you do differently next time?



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Next Week...

- You can read over today's information in your **handbook**.
- Next week we will be focusing on **pain management and joint protection strategies**
- Practice your **goals**
- Don't forget your **handbook!**





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Appendix C: Pain and Fatigue Diaries

Day	8am-1pm (morning)	Pain Scale (1-10)	1-6pm (afternoon)	Pain Scale (1-10)	6-12pm (evening)	Pain Scale (1-10)
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						

Appendix D: Ethical Approval Letters, DPIA Approval, Participant Information Leaflet and Consent Forms

SJH/TUH Research Ethics Committee Secretariat

JREC Reference: 2020-07 List 25 – Amendment (6)

email: researchethics@tuh.ie

Ms Shalaeh Karkon,
St James's Hospital,
James' Street, Dublin 8

18th August 2020

REF: Testing the Effectiveness of Fatigue and Activity Management in Work (FAMEW) Intervention for Individuals with Rheumatic Disease

REC: 2020-07 List 25 – Amendment (6)

(Please quote reference on all correspondence)

Date of Valid Submission to REC: 17.07.2020

Date of Ethical Review: 22.07.2020

Dear Ms Karkon,

The Chairman, Prof. Richard Deane, on behalf of the Research Ethics Committee, has reviewed the amendment you submitted to the SJH/TUH JREC for the above named study and has given **FULL** approval for this amendment.

The following documents were reviewed:

- Patient Information Leaflet
- Amendments
- Application Form

Please note that ethical approval for this study is only active under the following conditions:

1. *Applicants must submit an annual report for ongoing projects.*
2. *Applicants must submit an end of study declaration/end of study report upon completion of the study.*
3. *All adverse events must be reported to the JREC.*
4. *All changes (minor and substantial) to documentation/study must be submitted to the JREC using the amendment request form and the changes must be tracked/highlighted clearly. Approval from the JREC is required before implementation of the changes.*

It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection regulation (GDPR), Health Research Regulations and the Data Protection Act 2018.

Yours sincerely,



REC Officer – Dr Sadhbh O'Neill

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.

PARTICIPANT INFORMATION LEAFLET

Testing the Effectiveness of “Fatigue and Activity Management in Work” (FAME-W) Intervention for Individuals with Rheumatic Diseases

Principal Investigator: Dr. Deirdre Connolly Associate Professor

Lead Co- Investigator: Dr. Finbarr O’Shea Consultant Rheumatologist

Co-investigators: Dr. Michele Doran Consultant Rheumatologist
 Ms. Shalaleh Karkon Ph.D. Researcher
 Ms. Hazel Mc Cormac Occupational Therapist
 Ms. Aoife O’Gorman Manager

You are being invited to take part in a research study to be carried out at St. James’s Hospital and Tallaght University Hospital by Dr. Deirdre Connolly. Before you decide whether or not you wish to take part, you should read the information provided in this leaflet carefully. Take time to ask questions – 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. You may wish to discuss it with your family, friends or GP.

PART 1 – THE STUDY

Why is this study being done?

The purpose of the study is to test the effectiveness of an online **F**atigue **M**anagement **E**ducation for **W**ork (FAME-W). FAME-W is a four-week self-management programme which has been designed for people with rheumatic diseases (RDs) such as rheumatic arthritis, and lupus. This self-management program is designed to reduce the impact of fatigue, pain and stress on work performance of individuals with rheumatic diseases. Previous studies found

that RD are one of the most common causes of work disability. Studies show that up to half of people with RD have workplace difficulties resulting in sick leave and reduced productivity. As a result, this study hopes to find if FAME-W is effective in managing the physical, mental and social demands of work of individuals with Rheumatic Diseases.

Why am I being asked to take part?

- You have a definite diagnosis of a stable rheumatic disease such as arthritis, lupus and fibromyalgia
- You are between ages of 18 to 65
- You have the ability to provide informed consent
- You are currently employed (full or part time)
- Your consultant thinks that you are able to participate in online FAME-W
- You are able to attend the four-week online self-management programme

Do I have to take part? What happens if I say no? Can I withdraw?

You don't have to take part in this study. Your participation is entirely voluntary.

If you decide to take part, you will be asked to sign the consent form. You will be given a copy of this information sheet and a signed consent form for you to keep. If you decide to take part, you can subsequently change your mind without difficulty.

If you decide to take part, you can subsequently change your mind without difficulty. You can change your mind about taking part in the study and opt out at any time even if the study has started. You don't have to give a reason for not taking part or for opting out.

If you decide not to take part it won't affect your current or future medical care.

If you wish to opt out, please contact Shalaleh Karkon at karkons@tcd.ie who will be able to organize this for you.

How will the study be carried out?

This study will begin September 2020 and it will continue for 2 years. It will take place in both St. James's Hospital and Tallaght University Hospital. Approximately 200 participants will be recruited for this study.

The purpose of this study is to test the effectiveness and acceptability of FAME-W to manage the physical, mental and social demands of work of individuals with Rheumatic Diseases.

This study will take the form of a **randomised controlled trial**. A randomised controlled trial is a very high-quality form of research when participants who share a particular characteristic (i.e. rheumatic arthritis, lupus, fibromyalgia) are randomly assigned to receive two different interventions. In this way researchers can compare the outcomes between the two groups and decide if the intervention had any effect.

During this study period participants will be put into to either group intervention or handbook intervention groups. The people participating in the group intervention will take the online four-week FAME-W program to test the effectiveness of FAME-W as a work focused self-management programme to improve individuals' ability to manage their work demands. The handbook group will receive a handbook of the FAME-W programme that contains all information that those attending will get on self-management strategies on managing fatigue, pain and stress in the workplace, and information on legislation to support work participation.

All participants will be asked to participate in individual interviews and focus groups following the FAME-W program. The participants will be contacted for follow up in 3 and 6 months after the end of FAME-W intervention.

What will happen to me if I agree to take part?

As a participant, you will meet the principle investigator and co investigators mentioned on the first page.

You will be asked to answer a series of questions about your arthritis, fatigue and mental health.

If you do agree to take part, you will either asked to:

Attend the 4-week FAME-W sessions online by the St. James's Hospital or Tallaght University Hospital occupational therapists depending on which hospital you receive care from

OR

You will be given a self-guided handbook on FAME-W.

At the end of four weeks, you will also be asked to take part in individual interviews or focus groups depending on which group you were assigned to. These will be audio recorded and will be available to you if you wish to review or edit the recordings.

Additionally, you will be contacted for follow up in 3 and 6 months after the end of FAME-W intervention for a follow up interview.

Are there any benefits to me or others if I take part in the study?

You will benefit directly from taking part in this study by learning self-management strategies to reduce the impact of fatigue, pain and stress on work performance. Additionally, the information we will obtain may provide further knowledge of this condition.

Are there any risks to me or others if I take part in the study?

We do not anticipate adverse effects during the assessments or exercise sessions. You will only be invited to join the study if your consultants feel that you are well enough to participate in this programme.

What will happen if something goes wrong when I'm taking part in the study?

Your safety while taking part in the study is most important. All study assessments and intervention sessions will be carried out by researchers with expertise in this area. The Occupational Therapy departments of each hospital (St. James's Hospital or Tallaght University Hospital) where all sessions will be performed have trained medical professionals on site.

What other treatments are available to me?

Alternative treatments from outpatient occupational therapy clinics from St. James's Hospital or Tallaght University Hospital may be sought.

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

When the study is complete participants and their families will be invited to an information evening in which the overall results of the study will be presented.

It is hoped that the findings from this study will be published in relevant peer-reviewed journal articles and conference presentations (e.g. the Irish Rheumatology Society).

PART 2 – DATA PROTECTION

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Specific questionnaires will be asked to be completed to better understand your physical and mental wellbeing as well as an audio recorded individual interviews and focus groups.

Your medical records will be accessed and reviewed by the occupational therapists and the rheumatology consultants of the hospitals in order to establish whether you are eligible for the participation.

Additionally, identifiable data will be collected in order to contact the participants for the follow up period.

What will happen to my personal data?

All hard copy data will be stored in a locked filing cabinet in the Trinity Centre for Health Sciences, St. James's Hospital.

Audio recordings from the focus groups and interviews will be transferred onto a password-protected computer and it will be erased from the digital recorder.

All data will be coded meaning that when you enrol on the study you will be assigned a unique code identifier and all of your study results will be stored under this code identifier. No names of individual participants will appear on any of the data sets.

Coded data will be retained period of five years as per recommended practice. The data will be destroyed after five years – from the time the study ended – by the principle investigator Dr. Deirdre Connolly.

The personal data obtained during the study period will only be used to achieve the objective of this research project and will not be processed in a way that damage or distress will be caused to the participant.

No data will leave Trinity Centre for Health Sciences, St. James's Hospital.

The law on data protection means we have to protect your data to a very high standard (GDPR, 2018).

Who will access and use my personal data as part of this study?

Members of the FAME-W research team will access and use your personal data as part of the study. Research team members will only be granted access to your data when they have completed training in data protection. Data collected throughout the study will always be kept in Discipline of Occupational Therapy, Trinity Centre for Health Sciences, St. James's Hospital.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is very important to the research team. There will be many steps taken to make sure that your identity is protected during the study period and your data is kept safe.

- All the hardcopies of data collected will be in locked cabinets, in locked offices with restricted access.
- All the electronic files of data including identifiable information collected will be on password protect Trinity College Dublin computers.
- All research team member will go through data protection training.
- A Data Protection Impact Assessment have been completed to minimise any potential data breach risks.
- Data security procedures are regularly reviewed by data protection officers to keep your data safe.
- Your data will not be identifiable in any of the presentations or publications related to this study.

What is the lawful basis to use my personal data?

By reference to Article 6 and Article 9 of GDPR, the lawful basis for the processing of data is as follows:

Article 6(1)(a) states processing shall be lawful if the data subject has given consent to the processing of his or her personal data for one or more specific purposes.

Article 9(2)(j) states that processing is necessary for scientific research purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

What are my rights?

You have rights to:

- access your data that is being held
- restrict the use of your data that is being held
- correct inaccuracies in your data
- delete information of your data
- portability of your data
- object to profiling of your data

PART 3 – COSTS, FUNDING & APPROVAL

Will it cost me anything if I agree to take part?

It will not cost you anything to take part in this study. However, you will be asked to cover your own travel costs. The study place will be covered under Trinity College Clinical Indemnity Insurance.

Who is funding this study? Will the results study be used for commercial purposes?

There are no grants or funding in place for this study and the results will not be used for commercial purposes.

Has this study been approved by a research ethics committee?

Ethical approval has been sought from the Tallaght University Hospital/ St James's Hospital Research Ethics Committee (researchethics@tuh.ie)

PART 4 – FUTURE RESEARCH

Will my personal data and/or biological material be used in future studies?

No, your personal data will not be used for future studies.

PART 5 – FURTHER INFORMATION

Where can I get further information?

Principal Investigator(s):

Dr. Deirdre Connolly – Associate Prof. at TCD

Email: connoldm@tcd.ie

- Data controllers:

Trinity College Dublin

- Data Processor(s):

Dr. Deirdre Connolly – Associate Prof. at TCD

Email: connoldm@tcd.ie

Shalaleh Karkon – PhD researcher

Email: karkons@tcd.ie

- Data Protection Officer:

dataprotection@stjames.ie

What happens if I wish to make a complaint?

Complaints regarding this study should be directed to the Principal Investigator Dr. Connolly at connoldm@tcd.ie. Complaints regarding data protection should be directed to the Data Protection Officer at Trinity College Dublin (dataprotection@tcd.ie).

Will I be contacted again?

Yes. You will be contacted for a follow up session in 3 months after the end of FAME-W intervention.

CONSENT FORM

Testing the Effectiveness of "Fatigue and Activity Management in Work" (FAME-W) Intervention for Individuals with Rheumatic Diseases

To be completed by the **PARTICIPANT**:

I have read and understood the information leaflet.	YES ☐	NO ☐
I have had the opportunity to discuss the study, ask questions about the study and I have received satisfactory answers to all my questions.	YES ☐	NO ☐
I have received enough information about this study.	YES ☐	NO ☐
I understand that I am free to withdraw from the study at any time without giving a reason and this will not affect my future medical care.	YES ☐	NO ☐
I agree to allow the researchers use my information (personal data) as part of this study as outlined in the information leaflet.	YES ☐	NO ☐
I agree to allow the researchers access my medical records as part of this study	YES ☐	NO ☐
I agree to be contacted by researchers as part of this study	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 give my explicit consent to have my data processed as part of this research study'	YES ☐	NO ☐

Participant's Name (Block Capitals):	
Participant's Signature:	
Date:	

To be completed by the **RESEARCHER**:

I have fully explained the purpose and nature (including benefits and risks) of this study to the participant in a way that he/she could understand. I have invited him/her to ask questions on any aspect of the study.	YES ☐	NO ☐
I confirm that I have given a copy of the information leaflet and consent form to the participant.	YES ☐	NO ☐

Researcher's Name (Block Capitals):	
Researcher's Title & Qualifications:	
Researcher's Signature:	
Date:	



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

26/01/2021

Study Title: Testing the Effectiveness of “Fatigue and Activity Management in Work” (FAMEW) Intervention for Individuals with Rheumatic Diseases

DPIA Amendment: Online data collection using Qualtrics

To Whom it May Concern

I have reviewed the revised Data Protection Impact Assessment (“**DPIA**”) in relation to the above-listed study. Following a review of information regarding the proposed amendment to processing and detail regarding the nature of data processing undertaken as a consequence as described I am satisfied that the intended processing of personal data for the purposes of this study as set out within the amended DPIA is in compliance with data protection legislation, specifically the EU General Data Protection Regulation (“**GDPR**”), Data Protection Acts 1988 - 2018 and Health Research Regulations 2018.

Please note that the completion of a DPIA is not a one-time exercise, but a continual process. If at any stage there are further changes to the processing envisaged by this DPIA please contact me.

Sincerely,

A handwritten signature in black ink, appearing to be 'J. Eustace'.

John Eustace, Data Protection Officer.



Sligo Research Ethics Committee
Chairperson: Dr. Miriam O'Sullivan

Phone: +353-71-91 80305

Mail: [office@ ref-sligo.ie](mailto:office@ref-sligo.ie)

Web: www.ref-sligo.ie

Sligo, March 16th, 2022

Re. Research Ethics Application No. 894

Dear Shalaleh,

The Research Ethics Committee (REC) at Sligo University Hospital has reviewed your request for ethical approval of the study ***“Testing the Effectiveness of “Fatigue and Activity Management in Work” (FAME-W) Intervention for Individuals with Rheumatic Diseases ”***

The submission underwent review and the REC Chairperson has given a ***favourable opinion*** ***(Approved)*** for this study for Sligo University Hospital.

Documents reviewed since provisional approval:

Conditional FAME-W Manor Hamilton ConsentForm Clean Copy
Conditional FAME-W Manor Hamilton ConsentForm Track changes
Conditional FAME-W Manor Hamilton Ethics App_25_11_2021
Clean Copy
Conditional FAME-W Manor Hamilton Ethics App_25_11_2021
Track Changes
Conditional FAME-W ManorHamilton PIL Clean Copy
Conditional FAME-W ManorHamilton
PIL Track Changes Cover letter for
requested Amendments

You should note that ethical approval will lapse if you do not adhere to the following conditions: 1 Submission of an Annual Progress Report (due annually from the date of your approval letter) 2 Report unexpected events or any event that may affect ethical acceptability of the study.

3 Submit any change to study documentation (minor or major) to SUH REC for review and approval. Amendments must be submitted on an amendment application form and revised study documents must clearly highlight the changes and contain a new version number and date.



Amendments cannot be implemented without written approval from SUH REC.

- 4 Notify SUH REC of discontinuation of the study.
- 5 Submit a Final Study Report/Study Synopsis when the study has been completed.
- 6 Notify in writing when co-investigators are added to or removed from the research study. Only the named and approved PI and the co-investigator may carry out the research described in the research study.

Yours sincerely

Dr. Miriam O'Sullivan
REC Chairperson

Research & Education Foundation CLG,

Company Registration No 196307. Registered Charity No 20026189. Registered address as above.

PLEASE ENSURE THAT DATA PROCESSING COMPLIES WITH THE NEW GDPR REGULATION WHICH CAME

INTO EFFECT ON 25th May 2018. *This submission has been reviewed from an ethical perspective only. It is the responsibility of the PI/ sponsor/ data controller and relevant Data Protection Officer to ensure and monitor compliance with any relevant legislation in the country where the study is due to take place or any local policy in the site where the study is due to take place. Your attention is drawn to new EU regulations concerning Data Protection, and provisions in Irish legislation for application of these regulations in Medical Research. Guidance is available from HRB on the following links:*

<http://www.hrb.ie/funding/gdpr-guidance-for-researchers/health-research-regulations-2018-faq/> <https://www.youtube.com/watch?v=jcfSRpvxY5A>

The REC at SUH cannot interpret GDPR or approve consent waivers.

Patient Information Leaflet

Study title: Testing the Effectiveness of “Fatigue and Activity Management in Work (FAME-W)” Intervention for Individuals with Rheumatic Diseases

Principal investigator’s name: Deirdre Connolly
Principal investigator’s title: Doctor of Philosophy
Telephone number of principal investigator: +353 1 8963216
Consultant co-investigator’s name: Shalaleh Karkon
Consultant co-investigator’s title: Ms.
Data Controller’s/joint Controller’s Identity: Trinity College Dublin
Data Controller’s/joint Controller’s Contact Details: dataprotection@tcd.ie
Data Protection Officer’s Identity: Ms Evelyn Fox
Data Protection Officer’s Contact Details: evelyn.fox@tcd.ie

You are being invited to take part in a research study to be carried out at Our Lady’s Hospital ManorHamilton by Dr. Deirdre Connolly.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don’t feel rushed and don’t feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as ‘Informed Consent’.

You don't have to take part in this study. If you decide not to take part it won't affect your future medical care.

You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don't have to give us a reason. If you do opt out, rest assured it won't affect the quality of treatment you get in the future.

Why is this study being done?

The purpose of the study is to test the effectiveness of FATigue Management Education for Work (FAME-W). FAME-W is a four-week self-management programme which has been designed for people with rheumatic diseases (RD) such as rheumatic arthritis, lupus and fibromyalgia. This self-management program is designed to reduce the impact of fatigue, pain and stress on work performance of individuals with rheumatic diseases. Previous studies found that

RD are one of the most common causes of work disability. Studies show that up to half of people with RD have workplace difficulties resulting in sick leave and reduced productivity. As a result, this study hopes to find if FAME-W is effective in managing the physical, mental and social demands of work of individuals with Rheumatic Diseases.

Who is organising and funding this study?

This study is being conducted by Dr. Deirdre Connolly for the purposes of obtaining an academic qualification for Shalaleh Karkon. There is no grant or funding associated with this study. There is no payment to the principle and co-investigators (Dr. Deirdre Connolly and Shalaleh Karkon) to recruit participants for this project.

Why am I being asked to take part?

You have a definite diagnosis of a stable rheumatic disease such as arthritis, lupus and fibromyalgia

You are between ages of 18 to 65

You have the ability to provide informed consent

You are currently employed (full or part time)

You are able to attend the online four-week self-management programme

How will the study be carried out?

This study began January 2021, and it will continue for 2 years. It will take place in Our Lady's Hospital Manorhamilton, Waterford University Hospital, Our Lady's Hospice, St. James's Hospital and Tallaght University Hospital. Approximately 200 participants will be recruited for this study.

The purpose of this study is to test the effectiveness and acceptability of FAME-W to manage the physical, mental and social demands of work of individuals with Rheumatic Diseases.

This study is a mixed method randomised controlled trial. A randomised controlled trial is a very high-quality form of research when participants who share a particular characteristic (i.e. rheumatic arthritis, lupus, fibromyalgia) are randomly assigned to receive two different interventions. In this way researchers can compare the outcomes between the two groups and decide if the intervention had any effect.

During this study period participants will be allocated to either the online group intervention or self-guided intervention groups. The people participating in the group intervention will take the online four-week FAME-W program to test the effectiveness of FAME-W as a work focused self-management programme to improve individuals' ability to manage their work demands. The self-guided group will receive a self-guided handbook of the FAME-W programme that contains all information that those attending will get on self-management strategies on managing fatigue, pain and stress in the workplace, and information on legislation to support work participation.

All participants will be asked to participate in individual interviews and/or focus groups following the FAME-W program. The participants will be contacted for follow up in 3 months after the end of FAME-W intervention.

What will happen to me if I agree to take part?

As a participant, you will meet the principal investigator and co investigators mentioned on the first page.

You will be asked to answer a series of questions about your arthritis, fatigue, and mental health.

If you do agree to take part, you will either asked to:

Attend the 4-week FAME-W sessions online by the Our Lady's Hospital Manorhamilton occupational therapists

OR

You will be given a self-guided handbook on FAME-W.

At the end of four weeks, you will also be asked to take part in individual interviews or focus groups depending on which group you were assigned to. These will be audio recorded and will be available to you if you wish to review or edit the recordings.

Additionally, you will be contacted for follow up in 3 and 6 months after the end of FAME-W intervention for a follow up interview.

Video/and or Audio recordings?

The individual interviews and focus groups following the FAME-W program will be audio recorded via Trinity College Dublin professional and secure Zoom account. These will be available to you if you wish to review or edit the recordings. These recordings will help us understand the areas we need to improve.

The online FAME-W session will not be recorded by the Occupational Therapists. The online FAME-W session should not be recorded by you, and it must not be shared with anyone.

What other treatments are available to me?

Alternative treatments from outpatient occupational therapy clinics form Our Lady's Hospital Manorhamilton may be sought.

If you wish to not take part in this study, your regular treatment will not be affected.

What are the benefits?

You will benefit directly from taking part in this study by learning self-management strategies to reduce the impact of fatigue, pain, and stress on work performance.

What are the risks?

We do not anticipate adverse effects during the assessments or exercise sessions. You will only be invited to join the study if your consultants feel that you are well enough to participate in this programme.

What if something goes wrong when I'm taking part in this study?

Your safety while taking part in the study is most important. All study assessments and intervention sessions will be carried out by researchers with expertise in this area. The Occupational Therapy department where all sessions will be performed have trained medical professionals on site.

Will it cost me anything to take part?

It will not cost you anything to take part in this study.

Is the study confidential?

Your privacy is very important to the research team. There will be many steps taken to make sure that your identity is protected during the study period and your data is kept safe.

All the hardcopies of data collected will be in locked cabinets, in locked offices with restricted access.

All the electronic files of data including identifiable information collected will be on password protect Trinity College Dublin computers.

All research team member will go through data protection training.

A Data Protection Impact Assessment have been completed to minimise any potential data breach risks.

Data security procedures are regularly reviewed by data protection officers to keep your data safe.

Your data will not be identifiable in any of the presentations or publications related to this study.

Throughout the study specific questionnaires will be asked to be completed to better understand your physical and mental wellbeing as well as an audio recorded individual interviews and focus groups. However, this information will not be revealed to anyone.

Your medical records will be accessed and reviewed only by the occupational therapists and the rheumatology consultants of the hospitals in order to establish whether you are eligible for the participation.

Additionally, identifiable data will be collected in order to contact the participants for the follow up period but again, this information will not be shared with anyone and will only be known to principle and co- investigator (Dr. Deirdre Connolly and Shalaleh Karkon)

All hard copy data will be stored in a locked filing cabinet in the Trinity Centre for Health Sciences, St. James's Hospital.

Audio recordings from the focus groups and interviews will be transferred onto a password-protected computer and it will be erased from the digital recorder.

All data will be coded meaning that when you enrol on the study you will be assigned a unique code identifier and all of your study results will be stored under this code identifier. No names of individual participants will appear on any of the data sets.

Coded data will be retained period of five years as per recommended practice. The data will be destroyed after five years – from the time the study ended – by the principal investigator Dr. Deirdre Connolly.

The personal data obtained during the study period will only be used to achieve the objective of this research project and will not be processed in a way that damage or distress will be caused to the participant.

No data will leave Trinity Centre for Health Sciences, St. James's Hospital.

Internet communication is not guaranteed to be secure and confidential. Our Lady's Hospital Manorhamilton or Trinity College Dublin will not be held responsible if an outside party accesses your personal information.

Additionally, confidentiality is limited as the researchers are professionally responsible for reporting any allegations of professional misconduct.

The law on data protection means we must protect your data to a very high standard (GDPR, 2018).

When the study is complete participants, and their families will be invited to an information evening in which the overall results of the study will be presented.

It is hoped that the findings from this study will be published in relevant peer-reviewed journal articles and conference presentations (e.g., the Irish Rheumatology Society and Irish Association of Occupational Therapists).

Data Protection

The purpose for processing your personal data is to test the effectiveness and acceptability of FAME-W to manage the physical, mental and social demands of work of individuals with Rheumatic Diseases (RD).

Your data protection is important to us. By reference to Article 6 and Article 9 of GDPR, the lawful basis for the processing of your data is as follows:

Article 6(1)(a) states processing shall be lawful if the data subject has given consent to the processing of his or her personal data for one or more specific purposes.

Article 9(2)(j) states that processing is necessary for scientific research purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

For the protection of your data, members of the FAME-W research team will be the only people that can access and use your personal data as part of the study. Research team members will only be granted access to your data when they have completed training in data protection. Data collected throughout the study will always be kept in Discipline of Occupational Therapy, Trinity Centre for Health Sciences, St. James's Hospital.

As per recommended practice, coded data will be retained for a period of five years. The data will be destroyed after five years – from the time the study ended – by the principle investigator Dr. Deirdre Connolly.

Additionally, there are no risks and/or implications that might arise as a result of the data processing

Your participation is entirely voluntary. You have the right to withdraw consent. You don't have to take part in this study. Your participation is entirely voluntary. If you decide to take part, you will be asked to sign the consent form. You will be given a copy of this information sheet and a signed consent form for you to keep. If you decide to take part, you can subsequently change your mind without difficulty. If you decide to take part, you can subsequently change your mind without difficulty. You can change your mind about taking part in the study and opt out at any time even if the study has started. You don't have to give a reason for not taking part or for opting out. If you decide not to take part it won't affect your current or future medical care. If you wish to opt out, please contact Shalaleh Karkon at karkons@tcd.ie who will be able to organize this for you.

You have a right to lodge a complaint. Complaints regarding this study should be directed to the Principal Investigator Dr. Connolly at connoldm@tcd.ie. Complaints regarding data protection should be directed to the Data Protection Officer at Trinity College Dublin (dataprotection@tcd.ie).

As a participant in this study you have rights to:

access your data that is being held

restrict the use of your data that is being held

correct inaccuracies in your data
delete information of your data
portability of your data
object to profiling of your data - There will be no automated decision making,
including profiling.

It is hoped that the findings from this study will be published in relevant peer-reviewed journal articles and conference presentations (e.g. the Irish Rheumatology Society and Irish Association of Occupational Therapists).
Your data will not leave Dr. Connolly's office in Trinity Centre for Health Sciences, St. James's Hospital.

Consent to Future Uses

Your personal data will not be used for future studies.

Where can I get further information?

If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won't affect the quality of treatment you get in the future.

If you need any further information now or at any time in the future, please contact:

Dr. Deirdre Connolly – Associate Prof. at TCD

Email: connoldm@tcd.ie

Address: Trinity Centre for Health Sciences, St. James' Hospital, James Street,
Dublin D08 W9RT, Ireland

Shalaleh Karkon – PhD researcher

Email: karkons@tcd.ie

Address: Trinity Centre for Health Sciences, St. James' Hospital, James Street,
Dublin D08 W9RT, Ireland

Professor Douglas Veale
Consultant Rheumatologist
Our Lady's Hospice & Care Services
Harold's Cross
Dublin 6

16th March 2020

RS20003

Testing the Effectiveness of "Fatigue and Activity Management in Work (FAMW) Intervention for Individuals with Rheumatic Diseases

Documentation:

Application form, v1, 05.11.2019. Our Lady's Hospice Research Approval form. CIS confirmation of cover 03.12.2019 Patient Information and Consent form. Signatories page.

Dear Professor Veale,

I refer to correspondence of 7th February in response to ours of 16th January 2020. Following review of the responses and clarifications received, this study has been granted full Ethics approval.

Please note, it is the responsibility of the Principal Investigator and Sponsor to retain full file copies of all documentation submitted and received in respect of this study application.

Yours sincerely,



Dr. Ronan Killeen
Chairperson
Ethics & Medical Research Committee

**Professor Douglas Veale
Consultant Rheumatologist
Our Lady's Hospice & Care Services
Harold's Cross
Dublin 6**

04/05/2022

REF No: RS003

Testing the Effectiveness of "Fatigue and Activity Management (FAMM)" Intervention for Individuals with Rheumatic Diseases

Dear Professor Douglas Veale

The following amendments are approved by the Ethics and Medical Research Committee;

☐ Data Protection Impact Assessment (DPIA) Template – Research

Yours sincerely,



Professor Ronan Killeen
Chairperson
SVHG Ethics and Medical Research Committee

Research Ethics Office Old School of Nursing
University Hospital Waterford
Tel: 051- 842026/051-842391

29th March 2021

Dr Deirdre Connolly
Associate Professor
Occupational Therapy
Trinity College Dublin
Trinity Centre for Health Sciences
St James' Hospital
James Street
Dublin

STUDY TITLE: "Testing the Effectiveness of "Fatigue and Activity Management in Work (FAME-W)" Intervention for Individuals with Rheumatic Diseases"

STUDY STATUS: APPROVED

Dear Dr Connolly,

The Research Ethics Committee Co-ordinator, REC, HSE, South East reviewed the above study.

Expedited ethical approval has been granted for the above study and constitutes full ethical approval.

The following documents were reviewed and approved:

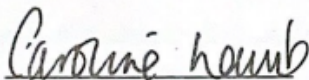
1. Research Ethics Standard Application Form
2. Project Description
3. Interview Schedule
4. Questionnaire/s
 - Demographics and Questionnaires
 - Focus Group Questions
5. Participant Information sheet
6. Participant Consent Form
7. Cover Letter
8. Letter to Department Head

9. Declaration Form
10. CV of Principal Investigator – Dr Deirdre Connolly
11. Insurance Document
 - Willis Towers Watson (TCD Indemnity)
 - State Indemnity Confirmation
 - UHW Indemnity
12. GDPR Certificate

In addition this study will be outlined at the next planned Research Ethics Committee Meeting for the HSE, South Eastern Area by the Research Ethics Committee Coordinator and any comments made at this meeting in relation to your study shall be communicated to you in writing.

It is a requirement of the REC, HSE, South East that you send copy of your study results to the Research Ethics Office on completion.

Yours sincerely,



Ms Caroline Lamb
Research Ethics Committee Coordinator
Health Service Executive, South Eastern Area

The Research Ethics Committee, HSE, South East is a recognized Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human use) Regulations 2004 and as such is authorized to undertake ethical review of clinical trials of all descriptions and classes for the Republic of Ireland.

The Research Ethics Committee, HSE, South East issues ethical approval on the basis of information provided. It is the responsibility of the researcher to notify the Research Ethics Office of any changes to a study to ensure that the approval is still relevant.

Cc: Ms Shalaleh Karkon

PATIENT CONSENT FORM

Study title: Testing the Effectiveness of “Fatigue and Activity Management in Work (FAME-W)” Intervention for Individuals with Rheumatic Diseases

I have read and understood the Information Leaflet about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	Yes ☐	No ☐
I understand that I don't have to take part in this study and that I can opt out at any time. I understand that I don't have to give a reason for opting out and I understand that opting out won't affect my future medical care.	Yes ☐	No ☐
I am aware of the potential risks, benefits and alternatives of this research study.	Yes ☐	No ☐
I give permission for researchers to look at my medical records to get information. I have been assured that information about me will be kept private and confidential.	Yes ☐	No ☐
I have been given a copy of the Information Leaflet and this completed consent form for my records.	Yes ☐	No ☐
I consent to take part in this research study having been fully informed of the risks, benefits and alternatives.	Yes ☐	No ☐
I give informed explicit consent to have my data processed as part of this research study.	Yes ☐	No ☐
I consent to be contacted by researchers as part of this research study.	Yes ☐	No ☐

FUTURE CONTACT		
OPTION 1: I consent to be re-contacted by researchers about possible future research related to the current study for which I may be eligible.	Yes ☐	No ☐

Patient Name (Block Capitals) _____ | Patient Signature _____ | Date _____
 Translator Name (Block Capitals) _____ | Translator Signature _____ | Date _____
 Legal Representative/Guardian Name _____ | Legal Representative/Guardian Signature _____
 Date _____

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

 -----Name (Block Capitals) _____ | Qualifications _____ | Signature _____ | Date _____

Appendix E: Focus Group and Interview Guides

Participant Focus Group Interview Guide

Purpose

You have been asked to participate in this focus group interview because of your participation in the group over the last four weeks. I am interested in your opinions about the group design and content and what impact if any the group had on you and on your working life.

This is just a conversation. We are interested in all your ideas, comments and suggestions. There is no right and wrong answers. We want both positive and negative feedback.

Procedure

If at anytime you want to stop please let me know. This discussion should take approximately **45 minutes**. Although we will audiotape the interview, your identity will never be revealed, or connected in any way to your comments. While we may report quotes collected during this interview, at no time will we connect those comments with any individual. No one except the researcher will listen to the tape. Let me know if you would like to skip a question because you don't know how to respond to it.

Let's discuss how the group affected you if at all over the last few weeks

Impact of the group

What did you learn about managing your condition in the group? Did it help you manage your condition on a daily basis in your working life?

Have you made any specific changes to your work or in your work place? If so how have they impacted on your work roles, routine or performance? If not, why not?

Which elements of the programme initiated these changes?

What was the most important thing that you did or learnt during the group?

In what overall ways, if any, **have you benefited** from the group?

- What kind of impact did the group have on your condition/health?
- What impact did the group have on your work roles and activities?
- Did the group have any effect on your general daily routines and activities outside of work?

Do you feel these impacts or effects that the group has had will last now that the group is ending?

Now let's consider the design and structure of the group

Group Design

What did you think of the number of sessions? Was it too much or too little?

What did you think of the length of each session? Was 2 hours too long? Could it have been longer? Was the time of day suitable - the afternoon?

What are your opinions of the topics that were covered in the group? Did you feel there were any topics that should have been included or left out?

What session did you find the most helpful or beneficial?

What was the least helpful session?

If you could change anything about the group what would it be? (Involvement of other health professionals?)

Imagine it is your job to design a group to help people with Rheumatic conditions to manage their health and decrease the effects of their condition in the workplace

How do you think you could get people to come to a group like this? What would be the best way to inform/contact people about the group?

What do you think should be included in the group?

Do you think the group would have been better if there had been an even number of men and women in the group?

Do you think a female only or all male group may have been more beneficial than a mixed group?

Let's think about the goal setting that was covered every week

Goal Setting

Did you find filling out the goal setting sheets helpful?

Did you look at the goal setting sheet during the week?

Did setting goals make you do things you wouldn't have done otherwise?

Do you think the group was enough to help achieve your goals/ difficulties you identified that you set when you first met Shalaleh?

Why/ why not? What else or what other supports if any would you have liked?

We will discuss the group booklet and other resources (relaxation music; information provided re helpful apps; Arthritis Ireland booklets) that were provided to you

Group Booklet

How often, if at all, did you look at the booklet and information provided [Probe: Which sections did you use? What made you decide to look at these sections?]

To what extent was the booklet helpful? [Probe: what makes you think this?]

Is there anything else that would be useful to help you manage your health and participate in work activities that you feel should have been included?

At the beginning of the programme individual sessions were also offered such as the workplace site visit.

Are any of you thinking about taking this offer up? If so why? If not, why? (Disclosure, moving around several different work environments, ergonomic assessments provided already to all employees in your work place, or any other reasons) [see if they say these themselves first]

Finally, what was your overall impression or opinion of the group as a whole? Good or Bad?

Thank you very much for your time and participation!

FAME-W Interview Questions

What was your overall impression of the **content** of the handbook?

- What are your opinions of the topics that were covered in each chapter? Did you feel there were any topics that should have been included or left out?
- Which chapter did you find the most helpful or beneficial?
- What was the least helpful session?
- If you could change anything about the content what would it be?

What was your overall impression of the **format** of the handbook?

- What are your opinions/experiences of reading the handbook?
- What did you think of the length of the handbook? Was it too long?
- Did you find the handbook easy to read? Was the wording easy to understand or too technical?
- Did you find the guidance probes – at the end of the chapters and throughout the chapters – helpful? Did it help you understand and engage with the content more? [*Probe: if they don't recall or understand refer to the handbook to give specific examples*]
 - If yes, how?
 - If no, why? How to can this be improved?

Goal Setting

Did you find filling out the goal setting sheets helpful?

Did you look at the goal setting sheet during the week?

If not: Do you think that you would've filled out the goal setting sheet if this was a face to face intervention?

Did setting goals make you do things you wouldn't have done otherwise?

Overall

- Did reading the handbook on your own affect your learning? Do you think you'd learn more if this information was given to you face to face delivered by a therapist or a video? [*Probe: if the information was delivered like a class*]

To what extent was the handbook helpful? Would you say that it was effective in managing your fatigue and pain? [*Probe: what makes you think this?*]

Is there anything else that would be useful to help you manage your health and participate in work activities that you feel should have been included?

Which aspects of the handbook did you find most effective to manage your symptoms (for work) and why?

Which aspects of the handbook did you find **least** effective to manage your symptoms (for work) and why?

Has the handbook helped you to **understand** your fatigue better?

If so, in what way?

If not, why do you think that it did not help?

Has the handbook helped you to **manage** your fatigue better (in work)?

If so, in what way?

If not, why do you think that it did not help?

How are you managing your fatigue now?

Are you using any specific strategies from the handbook to help you manage your fatigue?

If so, which strategies are you using and how effective are they for you?

If not, why not?

Would you have liked to have contact with the people implementing the program more than you did? If so, what kind of contact? Or did you think handbook by itself was effective enough?

Did you find it hard to be motivated to do it on your own?

If so what type incentives or probes do you think would have helped you?

Have you any recommendations for improving the handbook for future?

Ask to rate their satisfaction with the handbook on a scale of 1-10:

1 = not useful/helpful/relevant and 10= extremely useful/helpful and relevant

Appendix F: Facilitator Logs

Session One: Introduction to FAME-W and Fatigue Management

Date: _____ Time start: _____ Time end: _____ Online platform: _____

Duration of session: _____

How many people attended the session: _____ (Please remember to record individual participant attendance)

Please indicate if the following content and activities were covered in today's session

Content/Activity	Completed		Time taken	Comments (Any additional comments, success/challenges in completing content/activity)
1. Plan for the day	Yes	No		
2. Introduction to facilitators and participants: Activity	Yes	No		
3. Aims of FAME-W and programme overview: Lecturette	Yes	No		
4. Overview of FAME-W content: Lecturette	Yes	No		
5. Learning strategies of FAME-W: Lecturette	Yes	No		
6. Being in a group- what works and doesn't; Brainstorm group rules: Activity	Yes	No		
7. Weekly goal setting and goal review: Lecturette	Yes	No		
8. Overview and function of FAME-W handbook	Yes	No		
9. Comfort/Tea break	Yes	No		
10. Fatigue in RMD: Lecturette	Yes	No		
11. Contributing factors to fatigue: Lecturette				
12. Energy management – the 4 Ps: Lecturette	Yes	No		

Session Two: Pain management, joint protection and ergonomics

Date: _____ Time start: _____ Time end: _____ Online platform: _____

Duration of session: _____

How many people attended the session: _____ (Please remember to record individual participant attendance)

Please indicate if the following content and activities were covered in today's session

Content/Activity	Completed	Time taken	Comments (Any additional comments success/challenges in completing content/activity)
1. Introduction to the topic: Lecturette	Yes No		
2. Causes of pain in Rheumatic Diseases: Lecturette	Yes No		
3. Joint protection (JP) principles and JP applied to work	Yes No		
4. Principles of ergonomics: Lecturette	Yes No		
5. Application of ergonomics to work: Lecturette	Yes No		
6. Comfort/Tea break	Yes No		
7. Setting goals: Activity Did all participants set a goal for the week? Please indicate how many set goals X/X	Yes No Yes No ____/____		
8. Closing: Plan for next week	Yes No		

Did you follow and complete the programme content as per facilitator training workshops? Yes No

If no, please indicate why: _____

What went well today?

What problems, if any, arose in the group today?

Session Three: Maintaining Mental Well-Being

Date: _____ Time start: _____ Time end: _____ Online platform: _____

Duration of session: _____

How many people attended the session: _____ (Please remember to record individual participant attendance)

Please indicate if the following content and activities were covered in today's session

Content/Activity	Completed	Time taken	Comments (Any additional comments success/challenges in completing content/activity)
1. Plan for today: Lecturette	Yes No		
2. Definitions of stress and impact of prolonged stress: Lecturette	Yes No		
3. Impact of stress on work: Lecturette	Yes No		
4. Strategies for managing stress in the workplace: Lecturette			
5. Trial of relaxation strategies: Activity			
6. Tea Break	Yes No		

7. Goal Review: Activity	Yes No		
How many participants achieved their goal this week? X/X	____/____		
8. Setting goals: Activity	Yes No		
Did all participants set a goal for the week?	Yes No		
Please indicate how many set goals X/X	____/____		

9. Closing: Plan for next week	Yes	No		

Did you follow and complete the programme content as per facilitator training workshops? Yes No

If no, please indicate why: _____

What went well today?

What problems, if any, arose in the group today?

Session Four: Employment legislation and communicating effectively with employers and colleagues

Date: _____ Time start: _____ Time end: _____ Location: _____

Duration of session: _____

How many people attended the session: _____ (Please remember to record individual participant attendance)

Please indicate if the following content and activities were covered in today's session

Content/Activity	Completed	Time taken	Comments (Any additional comments success/challenges in completing content/activity)
1. Introduction: Plan for today	Yes No		
2. Employment legislation in Ireland: Lecturette	Yes No		
3. Legislation to support reasonable work accommodations: Lecturette	Yes No		
4. Financial supports and benefits: Lecturette	Yes No		
5. Disclosure obligations to employer: Lecturette	Yes No		
6. Strategies for disclosure to employer: Lecturette			
7. Strategies for effective communication: Lecturette	Yes No		
8. Programme Review: Lecturette	Yes No		
9. Tea Break	Yes No		
10 Goal Review: Activity	Yes No		
How many participants achieved their goal this week? X/X	____/____		

11 Closing: Plan for next week	Yes	No		

Did you follow and complete the programme content as per facilitator training workshops? Yes No

If no, please indicate why: _____

What went well today?

What problems, if any, arose in the group today?

Appendix G: Questionnaires

Please complete the following questionnaires after reading the information leaflet and if the following apply:

Full Name:

Demographic Questionnaire

Date of Birth	____/____/____ Day/Month/Year	
Gender	Male ☐ Female ☐	
County of Residence		
Rheumatic Condition Type and year of diagnosis	Rheumatic Condition Type Rheumatoid Arthritis ☐ Psoriatic Arthritis ☐ Systemic Lupus Erythematosus ☐ Ankylosing Spondylitis ☐ Systemic Sclerosis ☐ Gout ☐ Polymyalgia rheumatica ☐ Other (please specify) _____	Year of Diagnosis _____ _____ _____ _____ _____ _____ _____
Rheumatic Disease Activity	Please circle a number below from 0-10 to indicate your overall assessment of your disease activity during the last week 0 1 2 3 4 5 6 7 8 9 10 None severe	
Other health conditions (not rheumatic)	Yes ☐ No ☐ Please specify: _____	

Marital status (check✓ only one)	Single	☐
	Married	☐
	Separated/divorced	☐
	Widowed	☐
Living situation	Living alone	☐
	Living with other	☐
Highest level of education	Primary	☐
	Secondary as far as inter/junior certificate	☐
	Secondary to leaving certificate	☐
	College/University	☐
Please state your current employment: 		
Check the box that best describes your current or most recent employment	Non-manual (e.g. administrative, managerial, supervisory, office and other professional, such as teacher) ☐	
	Mixed, non-manual and manual (e.g. sales and service occupations such as waitress, personal care attendant, patient care nurse, nurse's aide, driver) ☐	
	Manual with no supervisory duties (e.g. carpenter roofer, loader, sales, technician) ☐	
Please indicate your employment hours	Full-time	☐
	Part-time	☐

Multidimensional Fatigue Inventory

Below is a list of statements that describe how people sometimes feel due to their fatigue. Please read each item carefully, then circle the number next to each item which best describes how true each statement has been for you in the **past 7 days**.

	Yes, that is true				No that is not true
1. I feel fit.	1	2	3	4	5
2. Physically, I feel only able to do a little.	1	2	3	4	5
3. I feel very active.	1	2	3	4	5
4. I feel like doing all sorts of nice things.	1	2	3	4	5
5. I feel tired.	1	2	3	4	5
6. I think I do a lot in a day.	1	2	3	4	5
7. When I am doing something, I can keep my thoughts on it.	1	2	3	4	5
8. Physically I can take on a lot.	1	2	3	4	5
9. I dread having to do things.	1	2	3	4	5
10. I think I do very little in a day.	1	2	3	4	5
11. I can concentrate well.	1	2	3	4	5
12. I am rested.	1	2	3	4	5
13. It takes a lot of effort to concentrate on things.	1	2	3	4	5
14. Physically I feel I am in a bad condition.	1	2	3	4	5
15. I have a lot of plans.	1	2	3	4	5
16. I tire easily.	1	2	3	4	5
17. I get little done.	1	2	3	4	5
18. I don't feel like doing anything.	1	2	3	4	5
19. My thoughts easily wander.	1	2	3	4	5
20. Physically I feel like I am in excellent condition.	1	2	3	4	5

The Work Role Functioning Questionnaire

Work Role Functioning Questionnaire		Difficult all the time	Difficult most of the time	Difficult half of the time	Difficult some of the time	Difficult none of the time	Does not apply to my job
WORK SCHEDULING DEMANDS							
1	Work the required number of hours						
2	Get going easily at the beginning of the workday						
3	Start on your job as soon as you arrived at work						
4	Do your work without stopping to take extra breaks or rests						
5	Stick to a routine or schedule						
OUTPUT DEMANDS							
6	Handle the workload						
7	Work fast enough						
8	Finish work on time						
9	Do your work without making mistakes						
10	Satisfy the people who judge your work						
11	Feel a sense of accomplishment in your work						
12	Feel you have done what you are capable of doing†						
PHYSICAL DEMANDS							
13	Walk or move around different work locations (for example, go to meetings)						
14	Lift, carry, or move objects at work weighing more than 10 pounds†						
15	Sit, stand, or stay in one position for longer than 15 minutes while working						
16	Repeat the same motions over and over again while working						
17	Bend, twist, or reach while working						
18	Use hand-held tools or equipment (for example, a phone, pen, keyboard, computer mouse, drill, hairdryer or sander)						
MENTAL DEMANDS							
19	Keep your mind on your work						
20	Think clearly when working						
21	Do work carefully						
22	Concentrate on your work						
23	Work without losing your train of thought						
24	Easily read or use your eyes when working						
SOCIAL DEMANDS							
25	Speak with people in-person, in meetings or on the phone						
26	Control your temper around people when working						
27	Help other people to get work done						

Arthritis Work-Spillover

Arthritis Work-Spillover

Please indicate to what extent you agree with the following statements regarding your **rheumatic condition** and your employment

In general,...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A
The demands of my job make it difficult for me to take good care of my rheumatic condition	☐	☐	☐	☐	☐	☐
It takes a great deal of my energy and time to manage my work demands.	☐	☐	☐	☐	☐	☐
My rheumatic condition suffers because of the demands of my work	☐	☐	☐	☐	☐	☐
The demands of my rheumatic condition make it difficult for me to do as good a job at my work as I would like	☐	☐	☐	☐	☐	☐
It takes a great deal of my energy and time to manage the demands of my rheumatic condition	☐	☐	☐	☐	☐	☐
The quality of my work suffers because of the demands of my rheumatic condition	☐	☐	☐	☐	☐	☐

EQ-5Q-5L

EQ-5Q-5L

By placing a tick in one box in each group below, please indicate which statements best describe your own health state 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 ☐

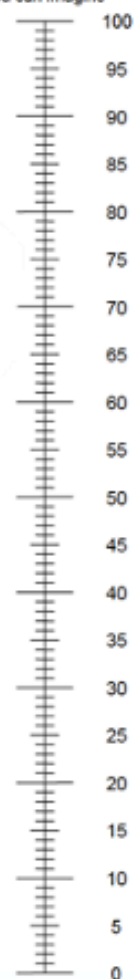
Anxiety / Depression

- 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=

The best health
you can imagine



The worst health
you can imagine

Mood Questionnaire

Tick the box beside the reply that is closest to how you have been feeling in the past week.

Don't take too long over you replies: your immediate is best.

	I feel tense or 'wound up':		I feel as if I am slowed down:
3	Most of the time	3	Nearly all the time
2	A lot of the time	2	Very often
1	From time to time, occasionally	1	Sometimes
0	Not at all	0	Not at all
	I still enjoy the things I used to enjoy:		I get a sort of frightened feeling like 'butterflies' in the stomach:
0	Definitely as much	0	Not at all
1	Not quite so much	1	Occasionally
2	Only a little	2	Quite Often
3	Hardly at all	3	Very Often
	I get a sort of frightened feeling as if something awful is about to happen:		I have lost interest in my appearance:
3	Very definitely and quite badly	3	Definitely
2	Yes, but not too badly	2	I don't take as much care as I should
1	A little, but it doesn't worry me	1	I may not take quite as much care
0	Not at all	0	I take just as much care as ever
	I can laugh and see the funny side of things:		I feel restless as I have to be on the move:
0	As much as I always could	3	Very much indeed
1	Not quite so much now	2	Quite a lot
2	Definitely not so much now	1	Not very much
3	Not at all	0	Not at all
	Worrying thoughts go through my mind:		I look forward with enjoyment to things:
3	A great deal of the time	0	As much as I ever did
2	A lot of the time	1	Rather less than I used to
1	From time to time, but not too often	2	Definitely less than I used to
0	Only occasionally	3	Hardly at all
	I feel cheerful:		I get sudden feelings of panic:
3	Not at all	3	Very often indeed
2	Not often	2	Quite often
1	Sometimes	1	Not very often
0	Most of the time	0	Not at all
	I can sit at ease and feel relaxed:		I can enjoy a good book or radio or TV program:
0	Definitely	0	Often
1	Usually	1	Sometimes
2	Not Often	2	Not often
3	Not at all	3	Very seldom

Arthritis Self-Efficacy

Arthritis Self-Efficacy

1. How certain are you that you can decrease your pain quite a bit?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

2. How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with your sleep?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

3. How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with the things you want to do?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

4. How certain are you that you can regulate your activity so as to be active without aggravating your arthritis or fibromyalgia?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

5. How certain are you that you can keep the fatigue caused by your arthritis or fibromyalgia from interfering with the things you want to do?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

6. How certain are you that you can do something to help yourself feel better if you are feeling blue?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

7. As compared with other people with arthritis or fibromyalgia like yours, how certain are you that you can manage pain during your daily activities?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

8. How certain are you that you can deal with the frustration of arthritis or fibromyalgia?

not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

Arthritis Impact Measurement Scales 2 (AIMS2-SF)

Arthritis Impact Measurement Scales 2 (AIMS2-SF)	All Days	Most Days	Some Days	Few Days	No Days
During the past four weeks.....					
1. How often were you physically able to drive a car or use public transportation?	☐	☐	☐	☐	☐
2. How often were you in a bed or chair for most of the day?	☐	☐	☐	☐	☐
3. Did you have trouble doing vigorous activities such as running, lifting heavy objects, or participating in strenuous sports?	☐	☐	☐	☐	☐
4. Did you have trouble either walking several blocks or climbing a few flights of stairs?	☐	☐	☐	☐	☐
5. Were you unable to walk unless assisted by another person or by a cane, crutches or walker?	☐	☐	☐	☐	☐
6. Could you easily write with a pen or pencil?	☐	☐	☐	☐	☐
7. Could you easily button a shirt or blouse?	☐	☐	☐	☐	☐
8. Could you easily turn a key in a lock?	☐	☐	☐	☐	☐
9. Could you easily comb or brush your hair?	☐	☐	☐	☐	☐
10. Could you easily reach shelves that were above your head?	☐	☐	☐	☐	☐
11. Did you need help to get dressed?	☐	☐	☐	☐	☐
12. Did you need help to get out of bed?	☐	☐	☐	☐	☐
13. How often did you have severe pain from your arthritis?	☐	☐	☐	☐	☐
14. How often did your morning stiffness last more than one hour from the time you woke up?	☐	☐	☐	☐	☐
15. How often did your pain make it difficult for you to sleep?	☐	☐	☐	☐	☐
16. How often have you felt tense or high strung?	☐	☐	☐	☐	☐
17. How often have you been bothered by nervousness or your nerves?	☐	☐	☐	☐	☐
18. How often have you been in low or very low spirits?	☐	☐	☐	☐	☐
19. How often have you enjoyed the things you do?	☐	☐	☐	☐	☐
20. How often did you feel like a burden to others?	☐	☐	☐	☐	☐
21. How often did you get together with friends or relatives?	☐	☐	☐	☐	☐
22. How often were you on the telephone with close friends or relatives?	☐	☐	☐	☐	☐
23. How often did you go to a meeting of a church, <u>club</u> , team, or other groups?	☐	☐	☐	☐	☐
24. Did you feel that your family or friends were sensitive to your personal needs?	☐	☐	☐	☐	☐

SHORT-FORM MCGILL PAIN QUESTIONNAIRE

Words below are used to describe pain. Tick the column that represents the severity you feel for each type of pain.

	NONE	MILD	MODERATE	SEVERE
THROBBING	_____	_____	_____	_____
SHOOTING	_____	_____	_____	_____
STABBING	_____	_____	_____	_____
SHARP	_____	_____	_____	_____
CRAMPING	_____	_____	_____	_____
GNAWING	_____	_____	_____	_____
HOT-BURNING	_____	_____	_____	_____
ACHING	_____	_____	_____	_____
HEAVY	_____	_____	_____	_____
TENDER	_____	_____	_____	_____
SPLITTING	_____	_____	_____	_____
TIRING – EXHAUSTING	_____	_____	_____	_____
SICKENING	_____	_____	_____	_____
FEARFUL	_____	_____	_____	_____
PUNISHING-CRUEL	_____	_____	_____	_____

Visual Analog

On a scale of 1 – 10 how would you rate your pain levels (1 = no pain, 10 = worst possible pain)

1 NO PAIN	Please write the number _____	10 WORST POSSIBLE

Present Pain Intensity

Please circle your present pain intensity

- 0 NO PAIN
- 1 MILD PAIN
- 2 DISCOMFORTING
- 3 DISTRESSING
- 4 HORRIBLE
- 5 EXCRUCIATING

Appendix H: Sub-Categories of EQ-5D-5L

Sub-Categories of EQ-5D-5L	Online FAME-W			Self-Guided Workbook			Comparisons		
	T1	T2	T3	T1	T2	T3	T1-T2	T1-T3	T2-T3
	Median (min-max) IQR			Median (min-max) IQR			P-Values		
Mobility	2 (1-4) 2.00	2 (1-4) 2.00	2 (1-4) 2.00	2 (1-4) 2.00	2 (1-4) 1.63	2.00 (1-4) 1.03	.930	.368	.957
Self-Care	1 (1-4) 1.00	1.03 (1-3) 1.00	1.14 (1-3) 1.00	1 (1-3) 1.00	1.03 (1-3) 1.00	1.46 (1-3) 1.00	.641	.680	.138
Usual Activities	2 (1-5) 1.00	2 (1-5) 1.02	2 (1-4) 1.12	2 (1-4) 1.00	2 (1-4.38) 1.21	2.00 (1-4) 1.19	.294	.981	.424
Pain/Discomfort	3 (1-4) 1.00	2.91 (1-5) .81	3 (1-5) 1.41	3 (1-5) 1.00	2.91 (1.18-4.56) .86	3.00 (1-5) 1.23	.814	.836	.915
Anxiety/Depression	2 (1-4) 1.00	2 (1-4) 1.13	2 (1-5) 1.61	2 (1-5) 2.00	2 (1-5) 1.32	2.00 (1-5) 1.56	.824	.202	.123