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**Addressing Participation with Early Inflammatory Arthritis  
Insights into the Lived Experience and  
Exploring a Clinical Model to Address Participation Restrictions**

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

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**Discipline of Occupational Therapy**



## **Declaration**

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## Summary

The focus of this multiphase study is exploring the impact of inflammatory arthritis on participation and exploring how these issues may be addressed as part of clinical care. Inflammatory arthritis is an autoimmune condition with an average age of onset between 35 and 45 years of age, and whose symptoms impact on body structures, function in everyday activities, and on wider participation in life roles across the disease trajectory. Occupational therapy recognises that participation in meaningful occupations is positively linked to health and well-being and rheumatology standards of care recommend early input from multidisciplinary teams to address the medical, symptom, and broader life, impact of arthritis. Examining the types of impact on participation experienced by those with inflammatory arthritis early in the disease trajectory has received little attention in the research to date. Moreover, there is limited knowledge about how clinical services identify and address clients' participation-based restrictions. Therefore, the aims of the three phases of this study are to explore the impact of inflammatory arthritis on participation and engagement in life roles, and to gather an overview of how clinical services address client-identified participation restrictions associated with inflammatory arthritis.

A sequential mixed methods study design with a qualitative priority was used to address the study aims. Phase one utilised online descriptive survey methods to explore service providers' perspectives on the delivery of work-based support in rheumatology services for inflammatory arthritis. Phase two employed one-off focus groups with service providers, to explore the multidisciplinary-led early arthritis model to address participation in newly diagnosed inflammatory arthritis. The final phase of the study comprised individual interviews with service users attending multidisciplinary-led early arthritis services to explore the impact of newly diagnosed inflammatory arthritis on participation, and how client-identified participation and engagement restrictions were addressed in these services. Phase one online survey findings were analysed descriptively, and qualitative data gathered from the open-ended questions were analysed using basic content analysis. A qualitative description framework was used in the qualitative phases of the study to provide a rich description of the experiences under study. Qualitative data from phases two and three were analysed using thematic analysis methodologies.

Study findings confirm and emphasise the significant and pervasive early impact of inflammatory arthritis on participation across all areas of life and across all life stages for this client group. Participation-based restrictions were identified as present from the onset of the disease and were described in the areas of paid employment, valued life roles, partnerships, parenting, social and leisure roles. Changes in physical and psychosocial capacity were emphasised as resulting in adjustments to the type, and extent of engagement people with inflammatory arthritis can enjoy, which was identified as directly impacting on self-identity, well-being, and quality of life. Role switch was identified as a significant consequence of early inflammatory arthritis which was unequivocally emphasised as negatively impacting on occupation-based participation across all roles, with resultant negative consequences on well-being and self-identity. Findings highlight the importance of addressing the impact on occupation-based participation associated with early inflammatory arthritis and emphasise the value of healthcare providers' being cognisant of extent and type of impact on participation early in the disease so that these can be incorporated into routine healthcare services.

Study findings highlight the extensive impact of inflammatory arthritis on work, and the clear need for work-related supports for this population, however there are differences in how these identified work-based difficulties are being managed. Findings confirm that addressing employment retention is within the scope of rheumatology services and consequently should be included in healthcare services. Survey findings identify a lack of clarity in traditional approaches regarding management of work-based issues and highlight service providers' uncertainty as to the optimal time for referral for work support. This lack of certainty on timing was emphasised as having a negative consequence on rates of work referral and provision of work support services. Furthermore, findings highlighted that a lack of clarity as to how best address work issues strongly contributed to service providers' dissatisfaction with the level of work-based supports in traditional clinical rheumatology services. By contrast, the multidisciplinary-led early arthritis clinic model, was identified as providing a coordinated approach to effectively manage work-based problems. Findings emphasised that the explicit focus on work participation within the multidisciplinary-led service provided clarity and a clear process to identify and manage work-based issues which significantly contributed to both service providers' and service users' satisfaction with how work issues were addressed. Findings highlighted that in traditional approaches clinicians are not directive in addressing work ability and this lack of implicit consideration of paid employment in the traditional approach can cause inequities in access to services and onward referral. Conversely the multidisciplinary-led early arthritis model scope has an explicit emphasis on impact on participation including work.

The multidisciplinary-led early arthritis model is identified as a clinical management approach to address participation and engagement, beyond symptom management, in service users with newly diagnosed inflammatory arthritis. This model provides automatic and immediate access to support for service users to identify and manage occupation-based participation restrictions associated with early inflammatory arthritis. It utilises a flexible approach to support service users in their first year post-diagnosis to improve disease management, support occupational adaptation, and increase quality of life by addressing participation-based restrictions as part of routine care. Mechanisms of delivery within the structure of the model to address these occupation-based participation difficulties include, the centrality of the client, social prescribing and self-management, and a full team working in an interdisciplinary way. An explicit emphasis on participation, combined with a 'right advice, in the right way and at the right time' approach, was recognised as being the most influential features of the delivery of this multidisciplinary-led early arthritis model in supporting positive health outcomes. Study findings identify the multidisciplinary-led early arthritis model as a credible approach to address participation-based restrictions and deliver on the rheumatology guidelines as part of routine healthcare in an approach that is positively regarded by both service users and service providers.

The domain of occupational therapy in addressing client-identified participation-based restrictions within the rheumatology team has been clearly identified in this study. Service users emphasised their positive experiences of occupational therapy in supporting life-role participation. Furthermore, the role of occupational therapy in addressing occupation-based participation was extensively highlighted by the service providers in this study. The multidisciplinary-led early arthritis model maps onto the Irish rheumatology model of care (HSE, 2018), 'right place, right time' approach but importantly includes a 'right way' approach which is identified as influential in the effective delivery of client-focussed and client-centred care.

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## Table of Contents

Declaration	iii
Summary	iv
Acknowledgements	vi
Table of Contents	vii
List of Figures	xiii
List of Tables	xiv
List of Appendices	xv
List of Abbreviations	xvi
CHAPTER ONE: INTRODUCTION AND BACKGROUND	1
1.1 Introduction	1
1.2 Overview of Inflammatory Arthritis	1
1.3 Participation	1
1.4 International Guidelines and Research	2
1.5 Context of Current Rheumatology Services in Ireland	3
1.5.1 Multidisciplinary-Led Early Arthritis Model in Rheumatology Services in Ireland	4
1.5.2 Multidisciplinary-Led Early Arthritis Clinic Model Process and Structure	5
1.6 Researcher's Personal Statement	6
1.7 Research Aims	7
1.8 Objectives and Rationale	7
1.9 Thesis Structure	8
CHAPTER TWO: LITERATURE REVIEW	9
2.1 Structure of Literature Review	9
2.1.1 Search Strategy	9
2.2 Incidence, Prevalence and Aetiology of Inflammatory Arthritis	10
2.3 Participation and Engagement and Influence on Health and Well-being	11
2.3.1 Impact of Inflammatory Arthritis on Occupation-based Participation and Engagement across the Lifespan	12
2.3.1.1 Early Versus Established Disease Impact on Occupation-based Participation	12
2.3.1.2 Gender Differences Impact on Occupation-based Participation	14
2.3.2 Measurement of Participation	15
2.4 Service Delivery Structures for Early Disease Management	16
2.4.1 Multidisciplinary Team Management of Inflammatory Arthritis	17
2.4.2 Standards and Models of Service Delivery	18
2.4.3 Participation-based Interventions	20
2.4.3.1 Work Participation Interventions	20
2.4.3.2 Symptom-based Participation Interventions	23
2.4.4 Self-Management and Lifestyle Participation	24
2.4.5 Including the Clients' Perspectives in their Care	25

2.5	Summary	27
CHAPTER THREE: METHODOLOGY		28
3.1	Introduction	28
3.2	Research Aims and Objectives	28
3.2.1	Study Objectives	29
3.3	Overall Study Methodology	29
3.3.1	Study Design: Mixed Methods	30
3.3.2	Mixed Methods Design Typology: Sequential Mixed Methods Design	31
3.3.3	Embedded Methods Design	33
3.3.4	Structure and Design of the Study	34
3.4	Phase 1 Online Survey	34
3.4.1	Background to Phase 1	34
3.4.2	Objectives of Phase One	35
3.4.3	Phase One Research Survey Design	35
3.4.3.1	Survey Design and Piloting	36
3.4.3.1.1	Section A - Addressing Work in Your Service	36
3.4.3.1.2	Section B - Work and Occupational Therapy	37
3.4.3.1.3	Section C - Service Demographics	37
3.4.3.2	Inclusion Criteria	38
3.4.3.3	Exclusion Criteria	38
3.4.4	Sampling Strategy and Sample Size	38
3.4.5	Recruitment Method	38
3.4.6	Ethical Approval & Data Collection	39
3.4.7	Survey Data Analysis	39
3.5	Theoretical Framework Guiding the Qualitative Design in Phases 2 and 3	40
3.6	Phase 2 - Focus Groups with Service Providers	43
3.6.1	Objectives of Phase 2	44
3.6.2	Phase 2 Research Design	44
3.6.2.1	Inclusion Criteria	45
3.6.2.2	Exclusion Criteria	46
3.6.3	Sampling Strategy and Sample Size	46
3.6.4	Recruitment Method	46
3.6.5	Focus Group Guide	47
3.6.6	Focus Groups	48
3.6.6.1	Stage 1 – Introductions	49
3.6.6.2	Stage 2 - Describing the Multidisciplinary-Led Early Arthritis Model	50
3.6.6.3	Stage 3 - Early Impact on Clients' Participation and Engagement	50
3.6.6.4	Stage 4 - If and How Clients' Participation is Addressed by the Multidisciplinary-Led Early Arthritis Model	50
3.6.6.5	Stage 5 - Appraising the Multidisciplinary-Led Early Arthritis Model	50
3.6.7	Focus Group Data Collection Process	51

3.6.8	Focus Group Data Analysis	51
3.6.9	Ethical Approval & Data Collection	53
3.7	Phase 3 - Semi-Structured Interviews with Service Users	53
3.7.1	Objectives of Phase 3	53
3.7.2	Phase 3 Research Design	53
3.7.3	Sampling Strategy and Sample Size	55
3.7.3.1	Inclusion Criteria	55
3.7.3.2	Exclusion Criteria	55
3.7.4	Recruitment Method	55
3.7.5	Interview Guide	56
3.7.6	Interviews	57
3.7.6.1	Stage 1 - Settling In	58
3.7.6.2	Stage 2 - Impact on Participation and Engagement	58
3.7.6.3	Stage 3 - Multidisciplinary-Led Early Arthritis Clinic Addressing Participation and Engagement	59
3.7.6.4	Stage 4 - Evaluation of Multidisciplinary-Led Early Arthritis Model	59
3.7.7	Interview Data Collection Process	60
3.7.8	Interview Data Analysis	60
3.7.9	Ethical Approval & Data Collection	62
3.8	Strategies for Increasing Rigour in the Qualitative Analysis of Phases 2 and 3	62
3.8.1	Trustworthiness and Credibility	63
3.8.1.1	Freedom to Speak	63
3.8.1.2	Participant Selection	63
3.8.1.3	Participant Driven Data Collection	64
3.8.2	Ensuring Participants' Voices are Heard	65
3.8.2.1	Focus Groups to Facilitate Discussion	65
3.8.2.2	Probing for Clarification and Depth	65
3.8.2.3	Member Checking	66
3.8.3	Ensuring Participants' Perceptions are Accurately Represented	67
3.8.3.1	Ensuring Accurate Transcription	67
3.8.3.2	Thematic Analysis and Coding	67
3.8.3.3	Attention to Context	70
3.8.4	Transferability	70
3.8.5	Integrity and Reflexivity of the Researcher	71
3.8.5.1	Researcher's Personal Influencers	71
3.8.5.2	Reflecting on Researcher Bias	72
3.8.6	Peer Review	72
3.9	Summary	73
CHAPTER FOUR: RESULTS FROM ONLINE SURVEY		74
4.1	Introduction	74
4.2	Overview of Chapter	74

4.3	Sample	75
4.4	Demographics of Typical Clinical Caseload	76
4.4.1	Age	76
4.4.2	Profile of Worker Role Categories	76
4.4.3	Work Needs	77
4.5	Current Rheumatology Practice in Addressing Work	78
4.5.1	Evaluating Rheumatology Work-Based Participation Support	78
4.5.2	Evaluating Rheumatology Work Support - Asking the Work Question	79
4.5.3	Influencers in Addressing Work-Based Issues	80
4.5.4	Barriers to Addressing Work	81
4.5.5	Work Support Outside of Rheumatology Services	82
4.6	Rheumatology Occupational Therapy and Work	82
4.6.1	Referrals to Occupational Therapy for Work Support	82
4.6.2	Barriers to Referral to Occupational Therapy for Work Support	83
4.7	Potential Strategies to Improve Rheumatology Work Related Services	84
4.8	Summary	85
CHAPTER FIVE: FINDINGS FROM FOCUS GROUPS		87
5.1	Introduction	87
5.2	Sample	87
5.3	Qualitative Analysis and Findings	88
5.4	THEME ONE: Early Arthritis Impact on Participation	88
5.4.1	Role Impact	89
5.4.2	Impact on Balance of Roles and Levels of Engagement	91
5.5	THEME TWO: How Multidisciplinary-Led Clinics Address Impact on Participation	93
5.5.1	Emphasis on Participation	93
5.5.2	Mechanisms of Model to Address Participation	95
5.5.2.1	Ease of Early Access to Deliver Participation-based Interventions	95
5.5.2.2	Coordinated Multidisciplinary Team Approach with Inter-team Working	99
5.5.2.3	Supporting Readiness and Change	100
5.5.2.4	Organisational Aspects	101
5.6	THEME THREE: Appraisal of the Multidisciplinary-Led Early Arthritis Model	103
5.6.1	Early Access	104
5.6.2	Prolonged Contact	105
5.6.3	Full Team with Members' Understanding of Each Other's' Roles	107
5.6.4	Challenges and Opportunities of the Model	109
5.7	Summary	110
CHAPTER SIX: FINDINGS FROM INITIAL INTERVIEWS		111
6.1	Introduction	111
6.2	Objectives of Phase 3	111
6.3	Sample	111

6.3.1	Age of Participants	114
6.3.2	Aetiology	114
6.4	Qualitative Analysis	115
6.5	THEME ONE: Pervasive Impact on Participation and Self-Identity Theme	116
6.5.1	Altered Capacity	118
6.5.1.1	Paid Employment and Student Roles	118
6.5.1.1.1	Physical Impact on Work Participation	119
6.5.1.1.2	Capacity for Work	119
6.5.1.1.3	Psychosocial Impact on Work Participation	120
6.5.1.1.4	Influence of Disclosing on Altered Employment Capacity	121
6.5.1.2	Relationships	122
6.5.1.2.1	Life-Partner Relationships	122
6.5.1.2.2	Parent-Child Relationships and Roles	124
6.5.1.2.3	Role Switch	125
6.5.1.3	Home and Other Valued Life Roles	126
6.5.1.3.1	Personal Care and Domestic Roles	127
6.5.1.3.2	Leisure Role	127
6.5.1.3.3	Driving Role	127
6.5.2	Well-being and Emotional Implications	128
6.5.3	Disruption in Normal Occupational Balance	129
6.5.4	Reconstructed Future	130
6.6	THEME TWO: Learning to Live Well with Inflammatory Arthritis	131
6.6.1	Right Advice, in the Right Way, at the Right Time	132
6.6.1.1	Function of Multidisciplinary-Led Early Arthritis Clinic	132
6.6.1.2	Early Access to Multidisciplinary Intervention	134
6.6.2	'The Right Way' Concept	136
6.6.2.1	Therapeutic Relationship	136
6.6.2.2	Prolonged Support	138
6.6.2.3	Individualised Approach	138
6.6.3	Adaptations for Participation	140
6.6.3.1	Adjustments in Life Roles	141
6.6.3.1.1	Employment Adjustments	141
6.6.3.1.2	Adjustments for Home-Based and Other Valued Life Roles	144
6.6.3.2	Self-Management & the Active Participant	145
6.6.3.3	Re-identifying View of Self	147
6.7	Areas for Future Development	148
6.7.1	Psychological Supports	148
6.7.2	Peer Support	148
6.7.3	Work Friendly Appointments	150
6.8	Summary	150

CHAPTER SEVEN: DISCUSSION	151
7.1 Introduction	151
7.2 Participation Restrictions Early in the Inflammatory Arthritis Trajectory	152
7.2.1 Impact of Inflammatory Arthritis on Daily Living Activities Early in the Disease	152
7.2.2 Impact on Life Roles Early in the Disease	153
7.2.2.1 Impact on Work Roles Early in the Disease	154
7.2.2.1.1 Premature Work Cessation	154
7.2.2.1.2 Changes to Occupational Balance to Retain Employment	154
7.2.2.1.3 Influence of Diagnosis Disclosure	155
7.2.2.2 Impact on Participation in Valued Life Roles Outside of Work Early in the Disease	156
7.2.2.2.1 Impact on Partnership Roles Early in the Disease	156
7.2.2.2.2 Impact on Parenting Roles Early in the Disease	157
7.2.2.2.3 Impact on Social and Leisure Roles Early in the Disease	158
7.2.3 Impact on Well-being	160
7.3 Addressing Work-based Participation in Current Clinical Practice	161
7.4 Multidisciplinary-led Early Arthritis Clinics as a Model to Address Participation and Engagement	163
7.4.1 Structure of the Model	163
7.4.2 The Centrality of the Client	164
7.4.3 Emphasis on Participation	164
7.4.4 Self-Management and Social Prescribing	165
7.4.5 Full Multidisciplinary Team Working in an Interdisciplinary Way	166
7.4.6 'A Right Place, Right Time and in the Right Way Approach	166
7.5 The Contribution and Scope of Occupational Therapy in Addressing Occupation-based Participation Difficulties within the Multidisciplinary-led Early Arthritis Clinic Model	167
7.6 Strengths and Limitations of the Study	169
7.7 Implications for Practice	173
7.8 Implications for Research	174
7.9 Conclusion	175

## List of Figures

Figure 1.1	Model Structure	5
Figure 3.1	Overall Study Methodology	33
Figure 3.2	Sections of the Survey	36
Figure 3.3	Stages of Focus Group	49
Figure 3.4	Stages of Semi-Structured Individual Interviews	58
Figure 4.1	Visual Descriptor for Presentation of Findings	75
Figure 4.2	Breakdown of Respondents by Profession	75
Figure 4.3	Age Demographic of Rheumatology Service Users	76
Figure 4.4	Proportion of Clients with Work Needs	78
Figure 4.5	Evaluation of How Well Work Needs are Currently Supported in Rheumatology Services	78
Figure 4.6	Perspectives on How Well Work Needs are Supported in Current Services per Discipline	79
Figure 4.7	Factors Which Influence Team Members to Address Work Issues	80
Figure 4.8	Potential Strategies to Improve Organisation of Work-Related Services	84
Figure 5.1	Visual Descriptor of Overarching Themes Identified	88
Figure 5.2	Early Arthritis Impact on Participation Overarching Theme with Subthemes	89
Figure 5.3	Multidisciplinary-Led Clinics Addressing Impact on Participation Overarching Theme with Subthemes	93
Figure 5.4	Mechanism of Model to Address Participation Subtheme with Expansions	95
Figure 5.5	Appraisal of the Model Overarching Theme with Subthemes	104
Figure 6.1	Diagnosis	114
Figure 6.2	Overarching Themes Identified	115
Figure 6.3	Pervasive Impact on Participation Overarching Theme with Subthemes	117
Figure 6.4	Altered Capacity Theme with Expansions	118
Figure 6.5	Altered Capacity within Relationships	122
Figure 6.6	Altered Capacity within Home and Other Valued Life Roles	126
Figure 6.7	Learning to Live Well with Inflammatory Arthritis Overarching Theme with Subthemes	132
Figure 6.8	Right Advice, in the Right Way, at the Right Time Subtheme	132
Figure 6.9	'The Right Way' Concept Subtheme	136
Figure 6.10	Adaptation for Participation Subtheme	141

## List of Tables

Table 1.1	Length of Time Multidisciplinary-Led Early Arthritis Clinics Operational	4
Table 2.1	Structure of the Literature Review	9
Table 3.1	Qualitative Description Criteria Neergaard et al. (2009) & Sandelowski (2000)	43
Table 3.2	Criteria for Thematic Analysis (Braun & Clarke, 2006, p. 87)	69
Table 4.1	Profile of Rheumatology Population Using the ISCO-08	77
Table 4.2	Asking the Client About Work at Appointments	79
Table 4.3	Factors Which Made Work Issues Least Likely to be Addressed	81
Table 4.4	Barriers to Addressing Work	81
Table 4.5	Barriers to Routinely Referring to Occupational Therapy for Work Support	83
Table 5.1	Demographics	87
Table 5.2	Breakdown of Sample per Focus Group	88
Table 6.1	Breakdown of Sample per Recruitment Site	112
Table 6.2	Demographics	113
Table 6.3	Age of Participants	114
Table 6.4	Length since Diagnosis	114
Table 6.5	Overarching Themes and Themes	116

## List of Appendices

- A.1. Phase One Ethics Approval
- A.2. Phase One Online Survey
- A.3. Phase Two TCD Ethics Approval
- A.4. Phase Two Focus Group Participant Information Letter and Consent
- A.5. Phase Two Focus Group Question Guide
- A.6. Phase Two Focus Group Follow Up Letter with Themes
- A.7. Phase Three Ethics Approvals
- A.8. Phase Three Individual Interview Participant Information Letter and Consent
- A.9. Phase Three Recruitment Poster Displayed in Clinical Areas
- A.10. Phase Three Individual Interview Question Guide
- A.11. Phase Three Individual Interview Follow Up Letter with Themes
- A.12. Dissemination Outputs

## List of Abbreviations

ACR	American College of Rheumatology
AOTA	American Occupational Therapy Association
AOTI	Association of Occupational Therapists of Ireland
BCG	British Columbia Guidelines for Clinical Practice
BSR	British Society for Rheumatology
CAOT	Canadian Association of Occupational Therapists
DOH	Department of Health
DMARD	Disease Modifying Anti-Rheumatic Drug
EULAR	European League Against Rheumatism
EUMUSC.net	European Musculoskeletal Conditions Surveillance and Information Network
HSE	Health Service Executive
ICF	International Classification Framework
ISCO-08	International Standard of Occupations Classification
NICE	National Institute of Clinical Excellence
n	Number/quantity
RA	Rheumatoid Arthritis
RCT	Randomised Controlled Trial
VLR	Valued Life Roles
WHO	World Health Organisation

## **CHAPTER ONE: INTRODUCTION AND BACKGROUND**

### **1.1 Introduction**

This multiphase study is concerned with exploring participation with inflammatory arthritis. The overall aims of the three phases of this study are to explore the impact of inflammatory arthritis on participation and engagement in life roles, and to gather data to inform how clinical services address client-identified participation restrictions associated with inflammatory arthritis. Phase one utilised anonymous online descriptive survey methods to explore service providers' perspectives on the delivery of work-based participation support in rheumatology services for inflammatory arthritis. Phase two of this study employed one-off focus groups with service providers to describe and explore multidisciplinary-led early arthritis clinics as a model for addressing participation in newly diagnosed inflammatory arthritis. The final phase of the study comprised individual interviews with service users attending multidisciplinary-led early arthritis clinics to explore the impact of newly diagnosed inflammatory arthritis on participation, and how the client-identified impact on participation and engagement were addressed in the multidisciplinary-led early arthritis clinics.

### **1.2 Overview of Inflammatory Arthritis**

Inflammatory arthritis is a complex progressive disease with 2,250 cases diagnosed annually in Ireland (Kane & Kavanagh, 2011) and with an average age of onset between 35 and 45 years of age (HSE, 2018). Inflammatory arthritis is an umbrella term describing conditions which present with inflammatory synovitis as well as other systemic symptoms and includes rheumatoid arthritis (RA), undifferentiated inflammatory arthritis, and psoriatic arthritis (ACR, 2010). It is a life-long condition which requires the person to make behaviour changes and adjustments in order to manage the impact of the diagnosis on their lives, and to support continued participation and engagement in age-appropriate life roles. Challenges associated with the diagnosis include managing fluctuating symptoms of pain, stiffness, and fatigue as well as managing impact on functional ability, self-identity, psychosocial consequences, and ability to retain valued life roles. It is recognised that inflammatory arthritis can negatively impact quality of life with associated implications for the person's emotional well-being and body image, as well decreased social participation, and social well-being (Backman, 2006).

### **1.3 Participation**

Symptoms of inflammatory arthritis impact on all levels of human functioning classified by the World Health Organisation (WHO) (2001) International Classification Framework (ICF). Symptoms have consequences for body structures, with associated influences on function and completion of everyday activities, as well as impacting on wider participation in life roles and life situations across the disease trajectory. Within this study participation is being considered under the ICF definition which emphasises the right to engage, and participate fully, in life situations, and recognises the dynamic relationship between meaningful life roles and health (Hemmingsson & Jonsson, 2005). Participation is understood to include involvement in any life occupations and roles that may be self-initiated, family-based, or socio-politically originated (Wilcock & Hocking, 2015). Participation is

recognised as being broader than self-care and work, and includes leisure, social roles, and relationships. Furthermore, participation requires integration of social roles, habits, and routines, as well as a variety of physical and psychological performance abilities. Occupational therapy theory supports the view that participating in meaningful occupations is positively linked to health and well-being (Wilcock & Hocking, 2015). Disability due to established arthritis leads to participation that is less diverse, more located in the home, involves fewer social relationships and less active recreation (Ahlstrand et al., 2015a, 2015b). Kristiansen, Primdahl, Antoft, & Horslev-Petersen (2012a, 2012b) report that RA has a considerable impact on occupational performance with most significant impact on self-identity, social relationships, employment, and interactions with healthcare systems. These authors highlight the importance of continuing participation in home, leisure, and work roles for these clients in order to maintain their perception of normality in everyday life which is inherently linked to perceived quality of life. Adequately addressing participation restrictions and supporting engagement is important to empower clients to make choices about their occupations and engage in meaningful fulfilling life activities (Squire, 2012).

Previous research highlights the impact of established and chronic arthritis on participation in meaningful life activities including employment, parenting, leisure, and social engagement (Backman et al., 2007; Connolly, Fitzpatrick, O'Toole, Doran, & O'Shea, 2015; Gignac et al., 2014; McCormack, O'Shea, Doran, & Connolly, 2018; Reinseth et al., 2010; Squire, 2012; Vooijs, Leensen, Hoving, Wind, & Frings-Dressen, 2017). While there is an acknowledgement that inflammatory arthritis may have a negative impact on participation in the early stages of the disease, there is less research published examining the impact on participation early in the disease trajectory. Literature on the early disease impact on participation tend to focus on specific elements of participation, and interventions which support specific participation-restrictions. Benka et al. (2016a, 2016b) highlight participation restrictions in social roles and social engagement due to early inflammatory disease which require interventions to support quality of life. Research on paid employment in early arthritis highlights a growing recognition of the value and importance of providing meaningful interventions to support work participation (Codd, Stapleton, Veale, FitzGerald, & Bresnihan, 2010; Hammond et al., 2017; Sverker et al., 2014; Walker-Bone & Black, 2016). Studies report that the quality of interactions between clients and service providers have a strong impact on addressing client-identified needs, and on the value of the interventions in supporting adaptation in life situations and self-management (Dures et al., 2017; Kristiansen et al., 2012b). These authors highlight that positive client experiences are directly linked to supports provided by healthcare professionals and are subject to continuity of care, a personal and trusting relationship with the service providers, and support clients to actively self-manage.

#### **1.4 International Guidelines and Research**

Within all of the national and international standards for the clinical management of inflammatory arthritis there is a consistent recommendation that a multidisciplinary approach is the optimum method to maximise long-term health-related quality of life outcomes (BSR, 2006; EULAR, 2016; EUMUSC.net, 2013a; HSE, 2018 NICE, 2009, 2018). These guidelines state that best outcomes for inflammatory arthritis are subject to early referral to specialist multidisciplinary teams with the skills

to implement standards of care for this population. Alongside addressing medical and symptom management such as pain, swelling, and fatigue, these guidelines recommend early input from multidisciplinary teams to address the broader life impact of arthritis. These broader life impacts outlined include psychosocial health, everyday activities, mobility, vocational issues and financial stability, relationships and social connectedness, leisure activities, and sleep disturbance. In order to effectively address these medical and broader life impacts early multidisciplinary team involvement is recommended within all of the guidelines. Additionally, the guidelines report that in order to adequately address the broader life impact, early intervention by the multidisciplinary team should focus on client-centred approaches to empower self-management. This is in agreement with Chou, Brigg, and Wluka (2017) who recognise the importance of the broader life impact and recommend that these broader health needs should be addressed in clinical rheumatology services early in the disease trajectory.

However, despite these standards of care, there is widespread recognition that there is considerable variability in levels of multidisciplinary team involvement, and delivery of multidisciplinary interventions, often because of suboptimal staffing levels, and also recognition that available resources are conditional on geographical location (EUMUSC.net, 2013b; HSE, 2018; NAO, 2009; The Kings Fund, 2009). Segan et al. (2017) suggest that alternative models of care should be considered to improve delivery of services to address client-perceived needs. A possible opportunity to remediate service inequalities, and improve quality of outcomes, for this population could be through specialist medical intervention and early diagnosis in conjunction with specialist multidisciplinary team interventions to facilitate client self-management and maintain client-perceived quality participation.

### **1.5 Context of Current Rheumatology Services in Ireland**

Similar to the international standards of care, the Irish model of care for rheumatology recommends timely access to appropriate healthcare comprising an actively managed client pathway to improve outcomes for people with rheumatic and musculoskeletal disorders (HSE, 2018). Rapid access to early arthritis clinics for diagnosis and commencement of drug management is recommended by the Irish Society for Rheumatology in Ireland (Kane & Kavanagh, 2011). However, these early arthritis clinics are typically staffed by a rheumatologist and a nurse and are primarily focussed on diagnosis, and early medical and symptom management. Usually, there is no allied health involvement in these early arthritis clinics, instead the physician and nurse act in a gate-keeping role with involvement of the multidisciplinary team in client care dependent on a gatekeeper referral system. In this model the client does not get automatic access to the full multidisciplinary team. This delay in accessing the wider multidisciplinary team is a common issue internationally and was highlighted by Segan et al. (2017) who reports that low rates of referral to the multidisciplinary team by physicians persist despite the known benefits of allied health professional involvement in the management of inflammatory arthritis. The delay in referral to the multidisciplinary team and subsequent negative impact on clients' health management and health outcomes has also been emphasised (Segan et al., 2017). Multidisciplinary teams in Irish rheumatology services typically include nursing, occupational therapy and physiotherapy service providers who work in collaboration with the medical teams. However, a

lack of adequate staffing resources across all disciplines in current Irish rheumatology services poses a challenge in addressing health needs for this population and is likely to influence rates of referral (HSE, 2018).

### 1.5.1 Multidisciplinary-Led Early Arthritis Model in Rheumatology Services in Ireland

In recent years there has been an emergence of a small number of multidisciplinary-led early arthritis clinics in Ireland which provide assessment and management to clients with newly diagnosed inflammatory arthritis along a model of care within four to six weeks of diagnosis (Lee & Kane, 2012). Operating in parallel to the traditional medical clinics, these multidisciplinary-led early arthritis clinics were originally designed on a Treat to Target (2010) approach for managing this population from diagnosis. Treat to Target (2010) is an established protocol for drug management and escalation of doses to achieve optimum disease remission as quickly as possible and is typically managed by the nurse. The multidisciplinary-led early arthritis model, initially developed in one service in 2009, was based on the desire to provide a more coordinated and comprehensive management for the treatment of clients with inflammatory arthritis by allowing early and automatic access to wider health professional input beyond the standard medical and nursing input of the typical Irish early arthritis clinics. The pilot model was presented at the Irish Society for Rheumatology conference in 2012 (Lee & Kane, 2012). Although the pilot predated the publication of the HSE model of care for rheumatology in 2018, it maps onto this rheumatology model of care which advocates a “*right person, right place, first time approach*” (p. 2) to clients with inflammatory arthritis. Subsequent to the pilot, three other rheumatology sites adopted the multidisciplinary-led early arthritis model for managing clients with newly diagnosed inflammatory arthritis. A small clinical service evaluation from one of the three sites, presented at the Irish Society for Rheumatology conference in 2015, profiled the symptom range and severity, and associated functional impairment typically seen at these clinics, and emphasised the early impact of inflammatory arthritis and identified the role of multidisciplinary-led early arthritis clinics in providing interdisciplinary intervention from diagnosis to support positive outcomes (Codd, Burke, Naramore, Kane, & Mullan, 2015a). While there has been some expansion of this model over time, national uptake in other rheumatology sites has been slow, and at the time of this study there are four rheumatology services in Ireland providing multidisciplinary-led early arthritis services based on the initial pilot. At the time of phase two of the study (2016) these four sites were operational for a range of two to nine years (Table 1.1).

Table 1.1: Length of Time Multidisciplinary-Led Early Arthritis Clinics Operational

Site Number	Years Clinic Operating
Site 1	9
Site 2	2
Site 3	2
Site 4	4

### 1.5.2 Multidisciplinary-Led Early Arthritis Clinic Model Process and Structure

The model structure is such that, following a medical appointment to confirm a diagnosis of inflammatory arthritis, clients are automatically streamed into the multidisciplinary-led early arthritis clinic service which delivers early intervention comprising nursing, occupational therapy, and physiotherapy services. A visual descriptor of the process of the model from point of diagnosis at the medical clinic and through the first year is presented in Figure 1.1.

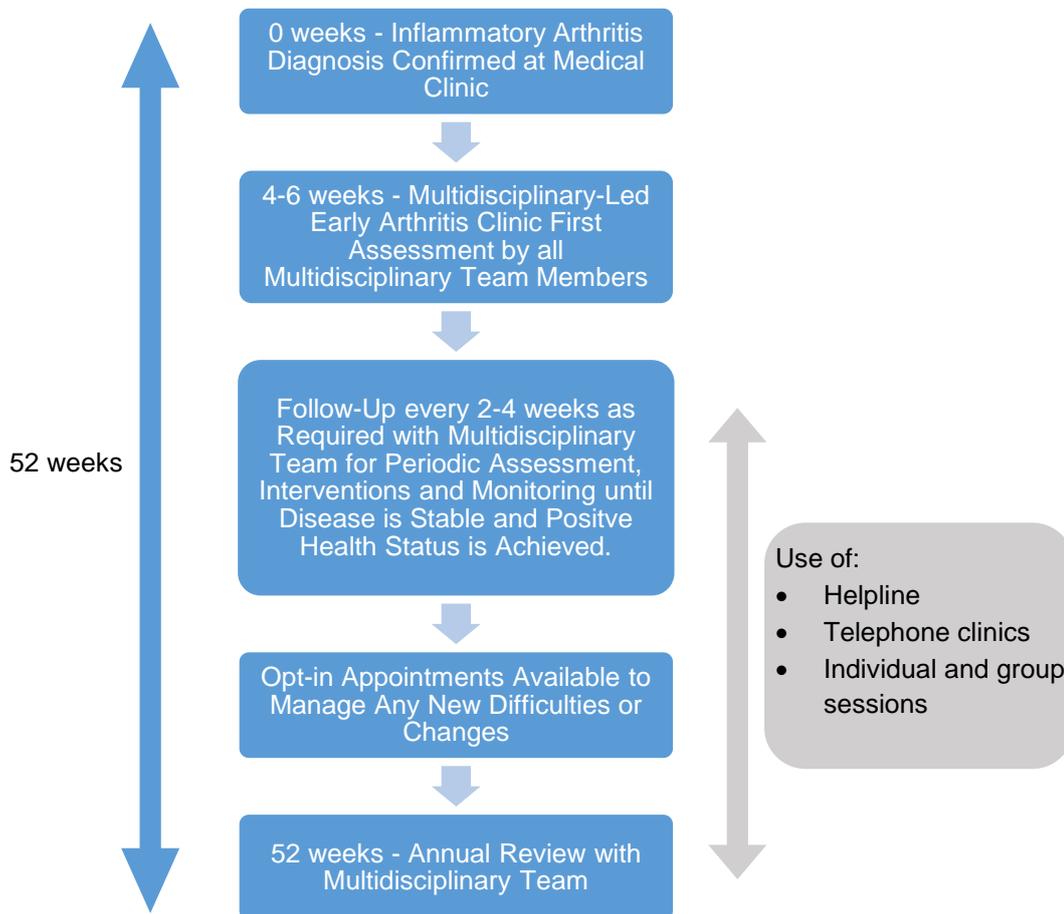


Figure 1.1: Model Structure

The process begins with a first appointment with the three professions which typically ranges from 90 to 150 minutes. Subsequent intervention-focused appointments are managed slightly differently in each site; however, the intention is that subsequent multidisciplinary-led early arthritis appointments comprise at least two disciplines consecutively, with each discipline offering a 30 to 60-minute slot subject to client need. Clients are closely linked with the multidisciplinary-led early arthritic clinic service for their first year post-diagnosis. When clients have completed an episode of care and are mutually (client and team) viewed to be doing well, further appointments will not be scheduled, however, the client can, and is actively encouraged to 'opt-in' as required, should needs or concerns arise. Twelve months following their first appointment all clients are offered an annual review to monitor status and to identify and manage any new issues. After the annual review appointment, the majority of clients are typically discharged to the general rheumatology service.

However, if prolonged involvement with the multidisciplinary team is indicated at the annual review stage there is the option to do so.

The model has expanded in scope since inception and currently attempts to incorporate early management of participation-related disease difficulties in order to maximise health status and engagement early in the disease trajectory. However, as there has been limited national uptake of this model and it has not been evaluated in a structured way, a review of this model to examine the impact of this multidisciplinary approach on managing client-identified participation restrictions early in the disease would be indicated. Research reports that there can often be a variation between service providers' and service users' perspectives and priorities of clinical practice (Blondeau, Valois, Keyserlingk, Hebert, & Lavoie, 1998). Service providers may advocate established strategies to manage symptoms based on evidence-based practice (Henriksen & Rosenqvist, 2003) and based on their own resources, and not always incorporate the service user and their personal experience and priorities at the core of interventions (Yen et al., 2011). Therefore, it is considered essential that any review, of the multidisciplinary-led early arthritis model, include the perspectives of both the service providers and the service users, to inform, whether the model addresses clients' early disease-related participation needs, and what interventions are delivered to ameliorate participation-based restrictions.

## **1.6 Researcher's Personal Statement**

The researcher is an occupational therapist with twenty years' experience in the clinical area of rheumatology occupational therapy. Her clinical experience has included working in traditional rheumatology service models across all rheumatology conditions and at all stages across disease trajectories. She has also had the opportunity to practice in one of the four multidisciplinary-led early arthritis clinics. While acknowledging that an understanding of the underlying disease and disease process is important, as an occupational therapist, the researcher is particularly interested in the occupational implications of the disease, rather than the disease itself. Through clinical exposure with this client group, the researcher recognises the occupational and participation-based implications of inflammatory arthritis. She has first-hand clinical experience of how inflammatory arthritis can interrupt balance of occupational performance areas and decrease participation and engagement in valued life roles. In her clinical practice, the researcher has found that when asked, clients disclose diverse participation and engagement restrictions which result from their inflammatory arthritis. Based on her clinical experience of rheumatology services, the researcher suggests that the impact on participation is often sub-optimally managed in traditional service models due to delays in detection of participation-based problems and appropriate onward referral. Furthermore, she recognises the clinical practice challenges to prioritise participation and engagement needs within limited health resources.

The researcher has previously undertaken qualitative research at MSc. level exploring the impact of a new diagnosis of RA on paid employment participation, and she has also been involved in some small clinical rheumatology practice studies. Findings of the MSc. study have laid the foundations for this current PhD study. While the MSc. study was principally focussed on paid employment among

people with RA, this current PhD study is aimed at exploring inflammatory arthritis impact on wider participation, inclusive of but not limited to paid employment, and also, how these participation issues are addressed in clinical practice. Throughout the five years that she has been working in a multidisciplinary-led early arthritis clinic service, she has seen first-hand the personal impact of inflammatory arthritis on clients' participation and engagement in valued life roles early in the disease trajectory. The researcher is mindful that the multidisciplinary-led early arthritis clinic model originated from an operational desire to provide a more coordinated and comprehensive management for clients with inflammatory arthritis. However, she sees how the move from traditional rheumatology service configuration to a multidisciplinary-led early arthritis clinic model potentially affords the opportunity to address the impact on participation and engagement restrictions. She believes that a structured review of the multidisciplinary-led early arthritis clinic model would provide important information on if, and how, this model addresses client-identified participation restrictions and needs.

### **1.7 Research Aims**

The overall aims of this study are to explore the impact of inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level.

### **1.8 Objectives and Rationale**

There are three objectives for this study:

1. To explore service providers' perspectives on the delivery of work-based participation support in current rheumatology services for inflammatory arthritis and identify factors which help or hinder provision.
2. To describe and explore multidisciplinary-led early arthritis clinics as a model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives.
3. To explore the impact of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement among a cohort of service users attending multidisciplinary-led early arthritis clinics in Ireland.

The rationale for objective one is that previous studies have informed on work participation, but there is limited research examining rheumatology teams' perspectives on addressing and providing services on work participation in the Irish context of practice. Further knowledge on these perspectives would inform clinical practice on managing this condition. This objective is addressed in phase one of this study and includes a target population of medical doctors, nurses and physiotherapists currently working in all clinical rheumatology services in Ireland. The reasoning for objective two is explore a new service model (the multidisciplinary-led early arthritis clinics) and to explore the opportunity offered by this model in moving beyond the limited traditional service approach, to address client-identified participation issues early in the disease trajectory through the lens of the service providers' perspectives. This objective is also concerned with service providers' perspectives on how clients' participation and engagement is addressed within the model. Phase two of the study addresses this objective and employs a target population of service providers

(nurses, occupational therapists, and physiotherapists) currently working in multidisciplinary-led early arthritis clinics. A comprehensive consideration of both the service providers' and the service users' perspectives would inform current clinical practice and add to the merit and the meaning of service delivery. The final study objective is addressed in phase three which includes a target population of service users who are currently attending a multidisciplinary-led early arthritis clinic service within Ireland or have attended a multidisciplinary-led early arthritis clinic service in Ireland within the last two years.

## **1.9 Thesis Structure**

The thesis comprises seven chapters. This chapter (chapter one) has outlined the rationale for undertaking the study, the context of current rheumatology services, the aims, and objectives of the study. Additionally, the challenges in adequately addressing participation in early and established inflammatory arthritis management in line with national and international guidelines has been highlighted. This chapter has also placed the researcher in context.

Chapter two outlines the literature available on this clinical practice area. The chapter provides a review of the literature on the incidence and prevalence of inflammatory arthritis. Literature on participation and engagement and the influence of these on health and well-being will be outlined, including the impact of inflammatory arthritis on occupation-based participation and engagement across the lifespan. Literature on rheumatology service delivery structures and models of care for early inflammatory disease management will be presented including multidisciplinary team management, participation-based interventions and self-management and lifestyle participation. The final section of the literature review will review the inclusion of the clients' perspectives in their own care.

Chapter three describes the framework and the methods used in the study to address the study objectives. The chapter provides a detailed account of the steps taken by the researcher at all stages of the research so that findings can be compared against other studies on the topic.

The study findings are presented over the course of three chapters (chapters four, five, six). Chapter four reports on phase one of the study and presents the service providers' perspectives on the delivery of work-based participation support in current rheumatology services for inflammatory arthritis. Chapter five outlines the service providers' perspectives on the multidisciplinary-led early arthritis clinics as a model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis. Chapter six presents the service users' perspectives on the impact of newly diagnosed inflammatory arthritis on their meaningful participation and how the multidisciplinary-led early arthritis clinics had supported them to address these self-directed participation and engagement difficulties.

Chapter seven discusses and integrates the research findings from the three phases. This final chapter also situates the findings within the research and proposes recommendations for clinical practice.

## CHAPTER TWO: LITERATURE REVIEW

### 2.1 Structure of Literature Review

The literature review will be presented under four main headings (see Table 2.1). The first section will briefly outline the incidence, prevalence, and aetiology of inflammatory arthritis in Ireland. This will be followed by a description of participation and engagement, and the influence of these on health and well-being with inflammatory arthritis as well as the challenges of measuring participation in practice. Literature on the impact of arthritis on occupation-based participation engagement across the lifespan will also be presented. The final section will describe rheumatology service delivery structures for inflammatory disease management and will review the literature on multidisciplinary team management, standards of care and models for management, and participation-based interventions. This final section will also consider the inclusion of clients' perspectives in their own care.

Table 2.1: Structure of the Literature Review

Section	Topic
Section 2.2	<ul style="list-style-type: none"><li>• Incidence, prevalence, and aetiology of inflammatory arthritis</li></ul>
Section 2.3	<ul style="list-style-type: none"><li>• Participation and engagement and their influence on health and well-being</li><li>• Impact of inflammatory arthritis on occupation-based participation and engagement across the lifespan<ul style="list-style-type: none"><li>○ Early versus established disease impact on occupation-based participation</li><li>○ Gender differences in impact on occupation-based participation</li></ul></li><li>• Measurement of participation</li></ul>
Section 2.4	<ul style="list-style-type: none"><li>• Service delivery structures for early disease management</li><li>• Multidisciplinary team management of inflammatory arthritis</li><li>• Standards and models of care of service delivery</li><li>• Participation-based interventions<ul style="list-style-type: none"><li>○ Work Participation-based Interventions</li><li>○ Symptom-based Participation Interventions</li></ul></li><li>• Self-management and lifestyle participation</li><li>• Including the clients' perspectives in their care</li></ul>
Section 2.5	<ul style="list-style-type: none"><li>• Summary</li></ul>

#### 2.1.1 Search Strategy

The overall focus of this study is the exploration of the impact of inflammatory arthritis on participation and engagement in life roles, therefore the search strategy focussed on published research on the early impact on participation and engagement in life roles specific to inflammatory arthritis. Research

on multidisciplinary and early management of inflammatory arthritis was also included. Published articles on specific aspects of role participation such as employment, parenting and social roles were also included. The background of the researcher is in occupational therapy and the study was conducted as an occupational therapy study, therefore, occupational therapy literature and research on participation and engagement in life roles was included. However, the search was not restricted to occupational therapy literature, but emphasis is placed on relevant occupational therapy literature in the review.

Literature was searched using the following databases: PubMed, AMED (Allied and Complementary Medicine), CINAHL, PsycINFO, Web of Science, Academia, and Google Scholar. Search terms included inflammatory arthritis, rheumatoid arthritis, psoriatic arthritis, early onset disease, impact, participation, engagement, occupations, valued life roles, work, employment, leisure, social participation, parenting, everyday activities, multidisciplinary, management, occupational therapy. In addition to online searches, hand-searching through the reference lists of relevant articles was used to further identify appropriate literature. No time period restriction was used when searching and only articles published in English were included. Published literature that was current up to the time of commencement of each phase of the study was influential in the design of each individual study phase. More recent literature and publications (up to and including 2020) are also included in the discussion chapter and referred to in the literature review as appropriate.

## **2.2 Incidence, Prevalence and Aetiology of Inflammatory Arthritis**

Inflammatory arthritis is recognised as a complex autoimmune disease with 2,250 cases diagnosed annually in Ireland (Kane & Kavanagh, 2011). Inflammatory arthritis is an established umbrella term used to describe conditions which present with inflammatory synovitis alongside other systemic symptoms and includes RA, undifferentiated inflammatory arthritis, and psoriatic arthritis (ACR, 2010). The disease affects women more than men at a ratio of 3 to 1, and can occur at any age, with the peak age of onset being between 35 and 45 years of age (HSE, 2018). The HSE (2018) model of care for rheumatology reports that approximately 40,000 Irish people have a diagnosis of RA and approximately 10,000 have a diagnosis of psoriatic arthritis. Undifferentiated inflammatory arthritis is the term used to describe early inflammatory arthritis symptoms which cannot yet be clearly diagnosed or differentiated from other conditions and accounts for approximately one third of new cases seen in early rheumatology medical clinics (Hazes & Luime, 2011). Irish data on the incidence of undifferentiated inflammatory arthritis is lacking but a Dutch multicentre epidemiological review of fourteen international studies of early arthritis report the incidence of inflammatory arthritis in these studies ranges from 115 to 271 per 100,000 adults (Hazes & Luime, 2011). In some instances, a diagnosis of undifferentiated inflammatory arthritis is later classified as a psoriatic arthritis or RA diagnosis, for others they continue to be treated and managed under the diagnostic label of undifferentiated inflammatory arthritis.

The aetiology of inflammatory arthritis is not clear; however, it is understood that initiation of the disease can be triggered by genetic or environmental factors. Inflammatory arthritis is characterised by an inflammatory process in the synovium of the joint, that if untreated leads to the destruction of

both the cartilage and bony structures of the joint, with resulting multi-joint pain, swelling, restriction in motion and function of joints, early morning joint stiffness, and disability (Hammond & Dziedzic, 2010). Systemic inflammation associated with the disease results in symptoms of fatigue and malaise, and is also associated with extra-articular comorbidities, including cardiovascular disease, which can result in increased mortality in patients (Malm et al., 2016; Singh et al., 2015). Inflammatory arthritis has a significant impact on ability to carry out everyday activities, including home, work, and leisure tasks, and negatively impact health-related quality of life (Singh et al., 2015). Irish data reports that approximately seventy percent of those with inflammatory arthritis are unable to work outside the home as a result of their disease (Bevan, McGee, & Quadrello, 2009). As such, inflammatory arthritis and its associated impact causes a substantial burden on the person, healthcare systems and on society (Woolf & Pfleger, 2003). It is agreed that suboptimal, or delayed treatment of inflammatory arthritis, will result in permanent joint damage, disability, long-term morbidity, and premature mortality (Kane & Kavanagh, 2011; Malm et al., 2016; Singh et al., 2015). Drug therapy options have improved significantly over recent years, as has the evidence for early aggressive immunosuppressive drug therapy intervention approaches which have decreased disease activity, decreased joint destruction, and improved rates of remission (Kane & Kavanagh, 2011). However, the significant impact of the disease on everyday activities and participation persists, such as in employment and social occupations (Ahlstrand et al., 2015a; Verstappen, 2013; ter Wee et al., 2011). Inflammatory arthritis remains a lifelong condition which requires close monitoring of disease activity and ongoing and complex drug therapy as well as healthcare interventions, to support improved quality outcomes in all aspects of health and well-being.

### **2.3 Participation and Engagement and Influence on Health and Well-being**

The WHO (1948) constitution considers health as *'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity'*. A broadening of the assumptions of health by Huber et al. (2011) includes recognition of the subjective experience of health, and the ability to adapt to ones' own circumstances, and to self-manage, as part of retaining health status. Health and well-being are widely viewed as positive concepts which are determined by a combination of many factors including physical capacity, social, and personal resources (Law, Steinwender, & LeClair, 1998; Gallagher, Muldoon, & Pettigrew, 2015). The WHO (2001) ICF considers disease under the areas of body functions and body structures, everyday activities, and participation in life situations. These ICF areas are interconnected, and interactions can be influenced by personal and environmental factors (Verstappen, 2013). The ICF consider participation as the right to engage and participate fully in life situations and recognises the dynamic relationship between meaningful life roles and health (Hemmingsson & Jonsson, 2005). However, many occupational therapy authors argue that the ICF definition is too narrow and should be broadened to include the social and emotional aspects of the experience of engaging in life roles (Hemmingsson & Jonsson, 2005; Fisher, 2013; Piskur et al., 2014; Sverker et al., 2019; Thyberg, Arvidsson, Thyberg, & Nordenfelt, 2015; Whalley Hammell, 2016). These authors assert that these socio-emotional elements of participation are key to capturing the subjective experience of participation and reflect the concept of the individual as an active agent in his/her lived experience.

Participation includes involvement in life occupations and roles that may be self-initiated, family-based, or socio-politically originated (Wilcock & Hocking, 2015). Participation in everyday occupations, including self-care tasks, paid employment, leisure, social roles, and relationships, is considered fundamental to quality of life, and is associated with well-being (Law, 2002). Studies report that there is strong evidence to support the influence of valued occupation on health and well-being in chronic disease (Curtin, Galvin, & Robinson, 2019; Eklund, Hermansson, & Hakansson, 2012; Katz et al., 2009; Wilcock & Hocking, 2015). A dynamic two-way process exists between occupation and self-identity, whereby identity is shaped by the occupations we engage in as individuals, but also, self-identity determines our patterns and choice of occupations (Christiansen, 2000; Sverker et al., 2019). Furthermore, it is recognised that participating in occupations provides a pattern to life routines across the lifespan, and inform context, self-identity, and life-satisfaction (Curtin et al, 2019; Hasselkus, 2006).

### **2.3.1 Impact of Inflammatory Arthritis on Occupation-based Participation and Engagement across the Lifespan**

Studies investigating the impact of inflammatory arthritis on participation tend to consider this topic in three ways. Firstly, many studies focus on specific elements of participation, for example, the impact of inflammatory arthritis on home role engagement, employment participation, parenting, leisure and social roles has been explored (Ahlstrand et al., 2012, 2015; Backman et al., 2007; Benka et al., 2016a, 2016b; Codd et al., 2010, 2015b; Hoving et al., 2013; Lacaille, White, Backman, & Gignac, 2007; Mussen et al., 2013; Reinseth et al., 2010; Sverker et al., 2014, 2015; Zekowitz, Looper, Mustafa, Purden, & Baron, 2013). Secondly, the impact of inflammatory arthritis on participation has been considered under the context of symptom impact (such as fatigue, pain, and psychological impact) on participation in life roles (Ahlstrand et al., 2015b; Backman, 2006; da Silva, Philips, & Buttgerit, 2011; Connolly et al., 2015, Hodkinson et al., 2012). Finally, this topic has been considered in terms of gender differences in participation with inflammatory arthritis (Flurey et al., 2017; Gignac et al., 2014; Ostlund et al., 2016; Ostlund et al., 2018).

#### **2.3.1.1 Early Versus Established Disease Impact on Occupation-based Participation**

The area of participation has been more widely considered among populations with established and chronic inflammatory arthritis with fewer published papers considering the impact of early arthritis. Additionally, there is no clear definition available as to what constitutes 'early' disease. In the literature reviewed for this thesis, the parameters of 'early arthritis' varies across studies with a range of three months to six years post diagnosis being reported as early inflammatory arthritis. The Swedish TIRA Study have examined interventions for early inflammatory arthritis (less than three years post diagnosis) and have more recently published papers considering the participation-based impact in this population in the areas of home and work impact, strategies to handle participation restrictions, and gender differences in strategies utilised, as well as exploring the influence of significant others' on participation (Bergstrom et al., 2019; Ostlund et al., 2016, 2018; Sverker et al., 2014, 2015).

The ability to continue to live a normal life and maintaining engagement in everyday home, work, and leisure roles in conjunction with the diagnosis of inflammatory arthritis is the primary goal of this population (Squire, 2012; Kristiansen et al., 2012a, 2012b). However, functional ability and health-related quality of life are known to be compromised in RA. A European-wide study (11 countries) which included people with early (n=237) and established (n=513) RA, (average length since diagnosis 9.1 years) reported the significant impact of early morning stiffness on function and quality of life with RA from both the patients' (82%, n=615) and rheumatologists' (n=497, 96%) perspective regardless of the stage in the disease trajectory (da Silva et al., 2011). Approximately two-thirds of patient participants reported modifications to their typical morning and home routines and associated emotional impact due to compromised normal function as a result of early morning stiffness. Although this study included early and established RA, the findings were not stratified per time since diagnosis (da Silva et al., 2011). Hodkinson et al. (2012) examined health outcomes in clients with early RA of less than two years duration (n=134) who were treated with disease-modifying anti rheumatic drugs (DMARDS) for twelve months. This study reported that despite twelve months of DMARD therapy, a large majority (69%, n=92) still had substantial functional disability (HAQ > 0.5) and the majority (66%, n=89) had suboptimal mental health [SF-36 mental composite score < 66.6]. Benka et al. (2016a, 2016b) examined the influence of social participation and health-related quality of life among people with RA across the disease trajectory. Findings reported that participation restrictions correlated with increased pain, fatigue, anxiety, and depression regardless of time since diagnosis. Perceived social participation restrictions were associated with the mental health aspect of quality of life among those in the early stages of the disease, whereas negative physical health implications were more influential among those with established RA.

Qualitative studies have identified that early RA (<3 years duration) impacts on all aspects of occupational performance and self-identity and highlight the need for early interventions to support those with early RA to better manage symptoms, manage the social, emotional and psychological consequences of the disease, and address participation issues including adaptation in participation (Ahlstrand, et al., 2015a; Bergstrom et al., 2019; Kristiansen et al., 2012a, 2012b, Sverker et al., 2015; Ostlund et al., 2014). Squire (2012) reported on the negative impact of established RA on participation in previously enjoyed life roles, interests, physical and emotional health, and quality of life. The empowerment of clients to take control over their occupations and to retain normalcy, or a reframed view of normalcy was identified as hugely important for those with established disease. This empowerment requires an approach that moves beyond symptom management and needs to include environmental and social elements and influencers of participation. Reframing of client priorities in established arthritis, particularly after disease flares, to decrease the negative impact on participation and enable occupational balance is recognised (Squire 2012).

Inflammatory arthritis is a lifelong condition and, as such, has ramifications for role participation across the lifespan. Studies examining parenting roles with inflammatory arthritis report gender neutral physical limitations associated with the disease which impact on the person's ability to carry out their parenting role in both early (<18 months) and established disease (Backman et al., 2007; Zerkowitz et al., 2013). Furthermore, Zerkowitz et al. (2013) highlighted that parents with early

inflammatory arthritis (females, n=20, 69%), report increased parenting stress and negative emotional aspects of parenting which are linked to the physical limitations of the disease and result in increased parenting disability and parent and child distress.

Paid employment is an area of participation that has received a lot of attention in the RA literature and research, perhaps this may be due to the age profile of RA and the more tangible aspect of work compared to other areas of life participation. Work instability and work disability are common consequences of inflammatory arthritis which frequently occur very early in the disease trajectory (Codd et al., 2015b; Gilworth, 2001). Despite drug therapy advances, retaining work ability remains a challenge. A systematic review examining the effects of biological agents on work participation for RA reported that fifty percent of the studies demonstrated a positive influence on employment retention (Ter Wee et al., 2011). However, although medical and drug therapy advances for treating inflammatory arthritis have significantly decreased disease activity and work absenteeism, work loss among employees with RA remains high. It is apparent therefore, that pharmacological management alone is not effective in addressing work ability, absenteeism, and employment retention.

In his review of research pertaining to employment with inflammatory arthritis, Jetha (2015) identifies that employment rates among young adults (aged 16 to 40 years) vary widely, with between 11% to 71% of this cohort currently employed. Work participation and role retention are influenced by disease severity, educational attainment, and gender, with less females engaging in, and retaining employment (Jetha, 2015). Subsequent qualitative research by Jetha et al. (2018) reported on employment impacts across the lifespan. This study found that younger adults, those earlier in their disease trajectory, and those recently appointed to their work role, reported the greatest difficulties at work. This younger age category was identified as being the least likely to access or utilise workplace resources, when compared with middle-aged and older adults, and those with more established disease. Security of tenure and length of service in worker role were identified as influential in accessing, and utilising workplace accommodations, regardless of age. Both this study and others have highlighted the use of work-specific and outside-work adjustments to support employment retention and sustainability (Codd et al., 2010; Jetha et al., 2018). Furthermore, research has shown that participation in outside of work activities is deprioritised to support work ability, with the utilisation of external lifestyle alterations to manage the impact of early RA (<2 years) on both work participation and normal lifestyle (Codd et al., 2010). In early and established disease, the meaning and value that a person with inflammatory arthritis attributes to their work, has been recognised as influential in determining their motivation for work retention (Codd et al., 2010; Gignac et al., 2014).

### **2.3.1.2 Gender Differences Impact on Occupation-based Participation**

The influence of gender on how a person's participation is impacted by the disease has been explored, although there is no clear consensus within the literature. Many studies suggest that the experience of the disease symptoms is broadly the same, however, how these disease symptoms are managed, and the associated impact on participation and priorities appear to differ. Some researchers found no gender differences in managing the impact on participation and report that men

and women use the same situation specific strategies of adjustment, avoidance, interaction, and acceptance to manage participation restrictions in early and established RA (Ostlund et al., 2016, 2018). However, other researchers report differences in how men and women manage the impact on participation associated with inflammatory arthritis. A systematic review to explore the impact, and self-management of established RA in men found similar lifestyle participation restrictions to women, however, gender differences were identified in the management of this impact relating to quality of life, work distress, self-management, coping and support (Flurey et al., 2016). According to the findings from this study and others, men are more inclined to prioritise their work role and work activity and tended to make changes to typical life patterns in order to support work ability, which was to the detriment of engagement in other outside of work roles (Flurey et al., 2016; Osterholm, Bjork, & Hakansson, 2013). Men have an increased perception that work and personal demands caused job disruptions and require support with occupational balance to manage the impact of their disease in participation in their daily life roles and situations (Gignac et al., 2014; Osterholm et al., 2013). Conversely, women report greater benefits from working and typically continue working even with higher disease activity scores and functional impact scores than their male counterparts (Gignac et al., 2014; Sokka et al., 2010). The impact of children, varying work hours, degree of job control and workplace activity limitations, as well as symptoms, have been identified as inter-role factors which impact on employment retention in both men and women. Similarly, hours of work, commuting, work demands, extent of role autonomy, and having to supervise others are equally reported by men and women with arthritis as influencing perceived ability to retain work participation (Geuskens et al., 2008; Gignac et al., 2014, 2015). All of these studies recommend including wider evaluation of work-related variables in health care assessments in order to understand the individual, and to identify and deliver meaningful work support strategies to that individual.

This section has outlined the literature with regard to participation and its influence on health, with particular emphasis on inflammatory arthritis as a health condition, and its impact on participation across the lifespan. It is clear that those with inflammatory arthritis experience a negative impact on all areas of participation and occupation, with varying levels of knowledge on specific elements of participation across early and established inflammatory disease. Regardless of disease duration, all literature on the impact of participation associated with inflammatory arthritis report this disease as negatively associated with quality of life and well-being. The negative impact on participation persists despite advances and improvement in drug management advances and subsequent reduction in disease activity. However, it appears that despite the welcome decrease in disease activity associated with improved medical management the symptoms associated with inflammatory arthritis persist and continue to have a significant negative impact on everyday activity and participation.

### **2.3.2 Measurement of Participation**

The comprehensive measurement of participation to establish need, identify treatment goals, and to evaluate outcomes is important, however, this remains a challenge both in clinical practice and in research. Many authors have sought to design measures of participation which adequately capture participation restrictions associated with inflammatory arthritis, but these have not been without difficulty in terms of ease of use, time to complete, and the requisite sensitivity to capture the

individualised participation restrictions (Wilkie, et al., 2011). Some measures examine broad domains of participation (Bjork, Thyberg, Valtersson & Katz, 2016; Katz et al., 2017), while others focus on specific domains, such as social role participation (van Genderen et al., 2016) which may be impacted by inflammatory arthritis. Alternatively, measures have adopted a more generic approach to assessing participation which are not specific to inflammatory arthritis (Cardol et al., 2001; Van der Zee et al., 2010). A recent literature review of measures for participation has identified the most widely used outcomes for participation in persons with musculoskeletal conditions (Bjork, Bergstrom, Sverker & Brodin, 2020). These authors have appraised these measures in terms of practical application and psychometric properties. Although the value and importance of measuring participation is agreed, there remains a recognition that the usability of measures of participation can be hampered by the format and application, question structure and scoring, and length of time to complete. Similarly, despite revision and adjustments as well as continued research on these outcome measures to improve the psychometric properties, a number of issues pertaining to sensitivity, validity, and responsiveness were identified which warrant consideration during selection (Bjork, Bergstrom, Sverker & Brodin, 2020). Participation is recognised as both complex and subjective, and these authors identify the practice difficulties associated with measures of participation and recommend the careful selection of the appropriate outcome measure to identify participation restrictions and to evaluate the efficacy of interventions (Bjork, Bergstrom, Sverker & Brodin, 2020). However, as inflammatory arthritis can occur at any age and because participation is so broad and dependent on life role stage, interests, and values, it remains a challenge to adequately capture this individualised information using standardised measures alone.

## **2.4 Service Delivery Structures for Early Disease Management**

The Irish model of care for rheumatology (HSE, 2018) advocates for the early diagnosis and access to services for ongoing management of inflammatory arthritis, with equality of access to high quality, timely, evidence-based care at the cornerstone its recommendations. People with rheumatology conditions frequently experience symptoms, disability, reduced societal participation and altered quality of life, and the model states that access to multidisciplinary team rheumatology services is crucial to minimising these impacts (HSE, 2018). Furthermore, the Irish model asserts that both timely access to appropriate health care, and an actively managed patient pathway will improve client outcomes (HSE, 2018). The Irish Society for Rheumatology report that Irish rheumatology standards of care recommend rapid access to early arthritis clinics for diagnosis and commencement of drug management (Kane & Kavanagh, 2011). However, these traditional early arthritis clinics are typically staffed by a rheumatologist and a rheumatology nurse and are primarily focussed on early medical and symptom management. In addition, the physician and nurse act in a gatekeeping role and further involvement of the wider multidisciplinary team in client care is dependent on whether there is a multidisciplinary team available within the service, and on a referral being made by the physician or nurse. In these traditional early arthritis clinics, the client does not get automatic access to the full multidisciplinary team. The Kings Fund (2009) criticise this gatekeeping approach and argue that this operational management of services is too dependent on consultants' individual knowledge, availability of a multidisciplinary team, and/or client assertiveness. The Kings Fund (2009) patient survey of people with a diagnosis of RA for three or more years (n=599), reported that only 50% were

ever offered an appointment with a physiotherapist, occupational therapist, or podiatrist. Similar findings were reported by Gilworth et al. (2001) who identified that work issues were not being addressed by hospital-based teams. Consequently, The Kings Fund (2009) recommend that people with RA should have access to a full multidisciplinary team which is not gatekeeper controlled, to address the complex biopsychosocial impact of the disease more effectively.

#### **2.4.1 Multidisciplinary Team Management of Inflammatory Arthritis**

It has been reported that many people with arthritis have healthcare needs that are not adequately met by medical treatment alone and the effectiveness of multidisciplinary team interventions is widely recognised in addressing these additional health needs (Vliet Vieland, Li, MacKay & Badley, 2006b). Wagner (2000) highlights that medical doctors may not have the training and time to address client issues beyond diagnosis and medical management and therefore, multidisciplinary team interventions to deliver evidence-based self-management and clinical support are an important part of chronic disease management. A cross-sectional study by Esselens, Westhovens, & Verschueren (2009) compared the effectiveness of an integrated care programme (multidisciplinary team) (n=89) with rheumatologist only care (n=102) over a one-year period with clients with early RA of less than five years duration. The integrated care strand included usual medical care and was coordinated by a rheumatology nurse specialist who measured disease activity, pain fatigue (VAS), function (HAQ) and health status (SF-36) at regular intervals and was able to refer to occupational therapy, physiotherapy, and social work. Results from the one-year measures showed the integrated care cohort had improved function and health status scores compared to the rheumatologist only care (lower mean HAQ of 0.52 versus 0.80). Although coping styles did not significantly differ between the groups, the integrated care cohort had higher implementation of active coping strategies and improved perception of therapeutic and personal control, and long-term consequences. This study reported that the immediate access to the wider multidisciplinary team members, albeit via a nurse gatekeeper, was valuable in effecting positive changes and emphasised the importance of a coordinated team working together to provide appropriate client care.

A systematic review by Speerin et al. (2014) concluded that inpatient multidisciplinary care for management of inflammatory arthritis is effective for improving disease activity and functional ability, and a key feature that contributed to the success of the multidisciplinary team was having team members working in close proximity which facilitates communication and collaboration. Few studies have focussed explicitly on evaluation of early arthritis clinics with access to multidisciplinary involvement and no studies were identified which explored multidisciplinary-led early arthritis clinics and how they address participation. Klareskog, Nordmark and Lindblad (2001) reiterate the early diagnostic and drug therapy benefits of an early arthritis clinic, but they also identify clinical practice and service gaps associated with this purely medical approach. These authors highlight opportunities for a day-care multidisciplinary approach in the initial encounter with specialist rheumatology services to firstly, promote clients to actively understand the disease and its impact, and, to develop their potential and empower them for self-management. Furthermore, it is suggested that early team-based diagnosis and management would result in increased compliance with drug and therapy

recommendations, and would increase self-confidence, work ability and social understanding of the disease (Klareskog et al., 2001).

Hehir et al. (2008) reported unmet needs among individuals with newly diagnosed RA including the need for support with the emotional consequences of the disease, treatment and medication, multidisciplinary team referrals, and self-management. Their findings highlight a gap in nurse-led clinic approaches and identify the need for early multidisciplinary involvement to better address self-management and support with the emotional impact of the disease in early arthritis. Findings from a recent systematic review examining impact of early arthritis clinics on outcomes strongly supported the efficacy of these clinics in reducing referral lag times, increasing timely diagnosis and rapid commencement of drug therapy (Govoni, et al., 2013). However, it was clear in this review that the early arthritis clinics referred to tended to be the traditional medical model which emphasised early diagnosis and early medical management, and do not include early arthritis clinics which have multidisciplinary team involvement. Furthermore, this review highlights a lack of research focussed on the longer term functional and participation-based impact of inflammatory arthritis, and whether an early arthritis model has any impact on these longer-term aspects. The impact of an early arthritis model of care which includes multidisciplinary involvement has not been researched extensively, nor has the potential of early clinics to incorporate a remit beyond early medical management to include broader function, and participation and engagement in valued life roles been explored. This is an identified gap in both rheumatology and occupational therapy literature which warrants exploration as part of the current research study.

#### **2.4.2 Standards and Models of Service Delivery**

International guidelines recommend multidisciplinary team assessment of arthritis that includes assessment of pain, fatigue, everyday activity, engagement in social, family or leisure activities, and also the ability to engage in work or paid employment (BCG, 2012; EULAR, 2016; EUMUSC.net, 2013a; NICE, 2018). A common thread across all of the guidelines is that one of the primary goals of treating the client with inflammatory arthritis should be to maximise long-term health-related quality of life which includes the maintenance of work ability and valued life roles (BCG, 2012; EULAR, 2016; Hennell & Luqmani, 2008; NICE, 2018; Treat to Target, 2010). Additionally, there is explicit recognition within these guidelines that the client should be part of the treatment team and should play an active role in decision-making regarding their care interventions. These international guidelines are important as they detail the standards to which all rheumatology services should aspire, and furthermore, they agree that if these standards were implemented consistently across all rheumatology services, then current variations in practice and inequities in access may be reduced.

Rapid access to care is recognised as extremely important to ensure prompt and early diagnosis, and commencement of medical and drug therapy management to slow disease progression, and to manage symptoms. However, quality of care is also strongly highlighted as extremely important and requiring improvement to incorporate individualised client care (The Kings Fund, 2009). Many authors advocate for a change to the pattern of care in routine rheumatology services and recommend that in addition to the important focus on early symptom and medical management,

services should expand to explicitly incorporate a client-centred approach that supports clients' occupational needs and emphasises disease self-management and engagement in life and work roles (Coole, Drummond, Watson, Worthington, & Hammond, 2013; Hoving et al., 2013; NAO, 2009; The Kings Fund, 2009). Studies have highlighted the opportunities to address meaningful life activities as part of routine rheumatology care, and to identify and support engagement, rather than traditional models of targeting the disease process only (Van der Meer et al., 2011; Sverker et al., 2014). However, current practice delivery tends to remain primarily focussed on medical and symptom management and perhaps less so on the broader participation focus as recommended.

Walker (2012) emphasises the importance of early multidisciplinary involvement in RA to treat disease activity, functional ability, and clients' goals, and states that service models should include ongoing interventions across the disease trajectory, and include flexible timing of delivery, to better support client priorities. Similarly, a need for comprehensive multidisciplinary care for clients with early arthritis across the disease trajectory which includes active client involvement and collaboration is advocated (Connelly et al., 2019; NAO, 2009; Vliet Vlieland, Li, MacKay, Bombardier & Badley, 2006a). Although the value of multidisciplinary team contributions in providing timely, quality care in early inflammatory arthritis is widely recognised, many clinical practice gaps persist. A lack of multidisciplinary team care is common in many countries due to staffing and financial resourcing issues (HSE, 2018; NAO, 2009). Although multidisciplinary team involvement early in the disease is consistently recommended, there appears to be a clinical practice shortfall in the implementation of these recommendations in service provision, and also a research gap with limited research evidence on patient experience of this type of multidisciplinary approach.

A national audit for the management of early RA and early inflammatory arthritis commissioned by Healthcare Quality Improvement Partnership described the composition of multidisciplinary teams working within UK rheumatology departments (Ndosi et al., 2017). This survey was completed by 98% (n=164) of UK rheumatology departments and findings reported that all departments included a rheumatologist and almost all included a nurse specialist. Of note, only 28 (17%) departments reported a full multidisciplinary team with a high degree of regional variation in the availability of occupational therapists, physiotherapists, and podiatrists within rheumatology services (Ndosi et al., 2017). This study highlights that although multidisciplinary care is recommended for the management of inflammatory arthritis, few UK rheumatology departments have a full complement of healthcare professionals within their team. In the Irish context, published data reports that there are 33 WTE consultant rheumatologists employed in the Republic of Ireland (HSE, 2018) and 12.7 WTE occupational therapy posts (AOTI, 2018) in public rheumatology services. The Irish model of care for rheumatology recommends a remediation in current manpower with the provision of 1 WTE rheumatologist, nurse specialist, senior occupational therapist, and senior physiotherapist per 100,000 of a population, and emphasises the challenges of addressing health needs for this population with the current suboptimal staffing (HSE, 2018).

### **2.4.3 Participation-based Interventions**

There is some evidence reporting which areas of participation are impacted by inflammatory arthritis, and therefore by extension, what participation-based restrictions should be addressed in clinical practice. Although all of the international rheumatology guidelines emphasise the importance of addressing participation in service delivery, there is limited research exploring how widely and how well this evidence and these guidelines have been translated into everyday clinical practice. A review of the literature for this thesis found that when it comes to participation-based interventions the predominant participation focus is on work. Additionally, some research has explored symptom-based participation interventions. Moreover, there is a focus on the role of self-management which has evolved from medical and symptom management and demonstrates some potential with a move into self-management programmes focussed on participation and occupation outcomes, albeit the focus tends to be predominantly on management of work impact rather than managing the wider impact on participation. Although the negative impact of inflammatory arthritis on social role participation and leisure roles has been documented, there is significantly less attention to these and other role specific participation-based interventions in the research. The issue of parenting participation-based interventions is poorly reported in the literature. A qualitative study by Grant (2001) used interviews of mothers (n=4) and occupational therapists (n=2), observation and field notes to explore occupational therapy interventions in supporting parenting with inflammatory arthritis. Findings reported positive benefits in addressing the physical limitations and support with the emotional impact which caused identified parenting restrictions; however, the findings were from a very small group of participants. This study by Grant (2001) reiterated the importance of facilitating a mother's own problem-solving strategies and balancing the physical and psychosocial aspects of intervention according to individual needs. No research on interventions that specifically addressed other broader participation roles was identified.

#### **2.4.3.1 Work Participation Interventions**

Research examining work participation interventions typically focus on external or internal modifications to the work role, or symptom management in work, to support work participation and work retention. Many participation interventions are concerned with addressing the impact of inflammatory arthritis on physical work performance as well as addressing the wider psychosocial impact on work performance both in-work role and outside-of-work (Blas, Beltran, Martinez, & Yao, 2017; Hammond et al., 2017; Keysor et al., 2018). The area of work participation interventions has been more widely considered in established and chronic inflammatory arthritis, although there has been increasing interest in interventions specifically targeting early arthritis impact on work participation in recent years. No research was identified which considered how work participation is addressed in clinical services and how clinical services identify the impact on work participation and deliver work support interventions for those with early inflammatory arthritis.

A Cochrane review of randomised controlled trials (RCTs) (Hoving et al., 2014) searched available literature up to 30<sup>th</sup> April 2014 and included three RCTs (Allaire, Li, & La Valley, 2003; de Buck et al., 2005; Macedo, Oakley, Panayi, & Kirkham, 2009) that used outcomes examining job loss, work absenteeism and work functioning to evaluate employment-related interventions for people with

inflammatory arthritis. The findings across all three studies appeared positive reporting a reduction in work instability, increased work satisfaction, reduced pain, and improved self-perceived ability to manage work. These findings were a result of interventions which included evaluation of work challenges; person-directed supports such as empowerment in work role, self-management, and job-coaching; work environment changes including work adaptations, ergonomic measures, and interventions with employer and work colleagues. Interventions were delivered either in a uni-disciplinary manner, comprised of rehabilitation counsellors (Allaire et al., 2003) or occupational therapy (Macedo et al., 2009), or multidisciplinary (comprising a rheumatologist, social work, physiotherapy, occupational therapy, occupational physician, and psychology) (de Buck et al., 2005). Positive long-term results were reported in one RCT (Allaire et al., 2003), with follow up at two years demonstrating a statistically significant reduction in job loss, and benefits persisting at 3.5 year follow up. Moreover, this study, of which 60% (n=145) had inflammatory arthritis, showed potential efficacy for work retention interventions for those with inflammatory arthritis (Allaire et al., 2003). It was not possible to infer if the method of intervention (uni-disciplinary or multidisciplinary) determined the degrees of successful outcomes as different outcome measures were used across the three studies, and an equivalent job loss outcome measure, used in both the Allaire et al. (2003) and de Buck et al. (2005) studies demonstrated comparable results. These three studies were conducted with individuals with established arthritis and did not include those with early inflammatory disease. However, the findings reiterate the benefits of this approach in supporting sustained work participation and work retention among people with inflammatory arthritis. Although the findings were positive across all three outcomes, with a reduction in work instability and increased work satisfaction, and self-perceived ability to manage work at six months, one of the RCT's (Macedo et al., 2009) was deemed to have low quality of evidence and have a high risk of performance bias.

Two recent studies have expanded on the study by Allaire et al. (2003) by implementing a similar longitudinal RCT study protocol and intervention content for work retention (WORK-IA) in the UK (Hammond et al., 2017), and (Work It Study) in the United States (Keysor et al., 2018). Both of these RCT studies examined job retention vocational rehabilitation for employed people, with inflammatory arthritis (n=55) (Hammond et al., 2017), and rheumatic and musculoskeletal conditions (n=287, of which inflammatory arthritis 28%, n=80) (Keysor et al., 2018). Presenteeism was the primary outcome in both studies and the same measure (Work Experience Survey-Rheumatic Conditions) was used in initial interview to determine work-based problems and priorities for work intervention (Hammond et al., 2017; Keysor et al., 2018). Intervention content which was replicated from the Allaire et al. (2003) study was equivalent in the two studies but was delivered differently. The UK study interventions comprised of directed one to one sessions of vocational rehabilitation with an occupational therapist, optional worksite visits and follow-up telephone review, whereas the USA study, was delivered by occupational therapists and physiotherapists, and after the initial face to face assessment in a convenient location, follow up sessions were all completed by telephone, and the USA study did not include any work site visit. Findings from both studies reported a reduction in permanent premature work loss, with the USA study reporting a statistically significant reduction in premature job loss at two-year follow-up (Hammond et al., 2017; Keysor et al., 2018). Secondary outcome measures included in the UK study demonstrated decreased rates of absenteeism, a

reduction in perceived risk of job loss, decreased pain, and improved health status (Hammond et al., 2017). Findings from the USA study reported that although difficulties at work remained after interventions (work limitations questionnaire scores were not improved), rates of work loss were reduced after the work interventions were delivered (Keysor et al., 2018). The key defining features of the intervention approach used in both of these studies was that the sessions were all individual, tailored to mutually agreed priority work problems, and flexible in their timing (time of the day, duration of session and length of prolonged contact over a 9-month period), location, and length of time between sessions, all of which facilitated scope for behaviour change. Both studies provide evidence to support specialised and individualised intervention approaches as effective in promoting advocacy and facilitating behavioural change and maintaining work retention.

A large research study from the USA completed multivariate logistic regression analysis to investigate the predictors of competitive employment in chronic arthritis (n=4281) (Mamboleo et al., 2015), and reported that vocational rehabilitation services have a significant positive influence of supporting employment status for this population. This study highlighted that those with chronic arthritis who receive vocational rehabilitation comprising workplace adjustments are 4.32 times more likely to find employment, and retain employment, than those who did not receive these interventions (Mamboleo et al., 2015). Importantly, this study emphasises that providing vocational rehabilitation has a significant impact on work retention, and healthcare staff should be aware of these resources to guide necessary work adjustments (Mamboleo et al., 2015).

Qualitative studies have also explored the impact of interventions to support work participation. A recent UK meta-ethnography analysis examined sixteen qualitative studies (five inflammatory arthritis studies), which explored employment retention with musculoskeletal disorders, from the perspectives of those who live with the conditions (Holland & Clayton, 2019). Findings highlighted that balancing work demands to the person's altered abilities, and psychosocial factors in the work environment such as an understanding of the diagnosis among employer and work colleagues were influential in supporting work retention. (Holland & Clayton, 2019). The quality of employee-employer relationships, and the level of employee autonomy to negotiate and implement workplace adjustments necessary to support work participation were identified as influencing the success of employment retention.

Similarly, encounters with health professionals in supporting work retention was noted to influence the efficacy of interventions, although many of the papers included in this meta-ethnography analysis had negative accounts of health professional interventions for work retention and highlighted participants' accounts of poor quality and ineffective healthcare support in this area. Conversely, vocational rehabilitation including condition management skills, advocacy, and advice with entitlements, provided by healthcare professionals were positively reported by the participants as influential in helping retain employment and remain confident about future working (Prior, Amanna, Bodell & Hammond, 2014a). These interventions described by Prior et al. (2014a) are widely recognised as within the scope of occupational therapy clinical practice, however, the translation into practice can be fragmented. Coole et al. (2013) report significant variations in service delivery,

assessment, and interventions regarding addressing employment issues in the UK. Frequently, interventions targeted on work-based needs are not included in service level agreements as they are not considered to be an essential service need, which means that employment issues are often not considered in service planning or addressed in practice when prioritisation of needs dictates how of limited resources are deployed (Coole, McBean & Drummond, 2015).

#### **2.4.3.2 Symptom-based Participation Interventions**

Research has also explored participation-based interventions which focus on symptom management to support role participation. The most common focus in these symptom-based participation interventions is on fatigue which is recognised as a significant symptom of inflammatory arthritis and is known to impact on engagement and participation. The negative impact of fatigue on participation and engagement in daily activities secondary to ankylosing spondylitis has been reported where fatigue was associated with lower occupational participation, quality of life and well-being, and those with higher levels of fatigue having significantly worse quality of life, and occupational participation (Connolly, Fitzpatrick, & O'Shea, 2019).

Fatigue management approaches emphasising conscious self-care strategies such as eating and sleeping well, cognitive strategies, planning, organising and prioritising strategies have been reported (Feldthusen et al., 2013). These fatigue management strategies were emphasised as positively supporting work role participation from the lived experience perspective. Fatigue-based group interventions with inflammatory arthritis to support participation have been shown to be effective in using multidisciplinary (occupational therapy and nursing), cognitive-behavioural approaches (Hewlett et al., 2019), and occupational therapy self-management approaches (McCormack et al., 2018). The findings from both studies highlighted statistically significant changes in outcome measures with reductions in symptoms, improvements in self-efficacy and mood, and improved function. Furthermore, the positive changes reported following these fatigue-based interventions to support engagement and participation persisted after the group interventions ceased with benefits at 12-week follow-up (McCormack et al., 2018), and at long-term two year follow up (Hewlett et al., 2019) and therefore demonstrate the value of this intervention approach in minimising participation restrictions.

Pain with inflammatory arthritis is recognised as a symptom which impacts on function and role participation and consequentially, pain, as a primary outcome measure, is established as a key baseline measure in all health management. This is evidenced by a recent systematic review of patient reported outcome measures (PROMS) used in rheumatology in 15 countries which identified pain measurement using a visual analogue scale as the most commonly collected outcome measure in routine clinical practice (Hiligsmann, Rademacher, Kaal, Bansback, & Harrison, 2018). Decreasing symptoms of pain and improving pain management are widely held goals in participation-based interventions although pain is usually included as a secondary outcome measure when evaluating participation-based interventions. In a review of the literature for this thesis, only one participation-based intervention study was identified which included pain as a primary outcome measure for work-based participation interventions. This study by Nordmark et al. (2006) used a pain visual analogue

scale to measure the efficacy of a multidisciplinary vocational support intervention and reported statistically significant improvements ( $p < 0.0001$ ). Studies which used pain as a secondary outcome measure to evaluate work-based participation interventions have also reported statistically significant reduction in pain scores (Hammond et al., 2017; Macedo et al., 2009), while other work-based participation interventions studies achieved pain reduction scores although these findings were not statistically significant (De Buck et al., 2005; McCormack et al., 2018). Similarly, many studies include improved pain management in outcome measures, although there was great variation in the measures used and included the Health Assessment Questionnaire, EQ5-D, the DAS-28 global assessment of disease assessment, and the Arthritis Impact Measurement Scales (Allaire et al., 2003; Hammond et al., 2017; Macedo, et al., 2009; McCormack et al., 2018; Nordmark et al., 2006). These studies all reported statistical improvements in these measures which the authors attributed to improved pain management. These measures all include pain as an element of their construction, however the pain component itself was not separated out in the analysis, therefore it is not possible to infer a delineation between pain reduction and pain management in the findings. Qualitative findings from the study by Hammond et al (2017) emphasised the benefits of this vocational rehabilitation intervention in improving pain management and the composite findings of both qualitative and quantitative measures enforce the value of these participation-based interventions in improving pain management.

Pain has also been included as an outcome measure in studies which addressed participation as part of self-management. Studies have reported the efficacy of these treatment approaches in reducing pain with some achieving statistically significant improvement (Tonga, Duger, & Karatas, 2016), with others reporting significant improvement in pain scores (Hammond & Freeman, 2004; Hammond et al., 2008). Although, pain is rarely included as a primary outcome measure in evaluating participation-based interventions, there is clear evidence in the literature that these types of interventions reduce pain symptoms and increase pain management whilst also addressing the primary goal of reducing participation restrictions.

#### **2.4.4 Self-Management and Lifestyle Participation**

Much of the participation-based interventions for managing lifestyle restrictions associated with inflammatory arthritis to in the literature tend to fall under the umbrella of self-management. Self-management programmes are established in rheumatology practice to manage patient-perceived problems with symptom management and breaking the symptom cycle (Lorig, 2015). High quality rigorous studies on self-management programmes across different arthritis conditions have demonstrated significant benefits in this type of intervention using a variety of self-management approaches including education programmes (Hammond, & Freeman, 2004; Hammond, Young, & Kidao, 2004; Kroon et al., 2014), cognitive-behavioural programmes (Dures & Hewlett, 2012; Hammond et al., 2008; Hewlett et al., 2019), goal-setting interventions (Arends, Bode, Taal, & van de Laar, 2018) and occupation-based self-management (O'Toole, Connolly & Smith, 2013, Tonga, Duger, & Karatas, 2016). However, some authors argue that benefits of self-management found in the research are being sub-optimally translated into European clinical practice with underutilisation of meaningful self-management strategies employed in clinical practice to support patients' health

and social outcomes (Elissen, et al., 2013; Stern, 2018). The findings from a thirteen-country European study of self-management approaches using mixed methodologies of questionnaire, case-study and interviews, report that European practitioners continue to focus on medical and behavioural based self-management interventions with limited attention for the emotional consequences of illness (Elissen et al., 2013). These authors highlight the need for better collaboration between clients and healthcare providers to engage in productive interactions to address individualised self-management needs in daily participation across life roles which can improve health and social outcomes.

Self-management has shown itself to be an approach which can be adapted to address broader participation-based issues such as engagement in everyday living. Self-management approaches that incorporate a client-healthcare provider partnership, which coaches and empowers active self-managers, and supports adjustments to daily life with a focus on participation in valued roles, appears to be emerging as the preferred approach in chronic diseases including arthritis (Been-Dahmen et al., 2017; O'Toole et al., 2013; Stern, 2018; Zuidema, Repping-Wuts, Evers, van Gaal, & van Achterberg, 2015). Most studies published in this area have explored self-management among people with established arthritis and there is less information on self-management with early inflammatory arthritis available. A small qualitative study (n=5) used interviews to explore the experiences of individuals with early inflammatory arthritis (<2 years) who attended a standardised self-management programme (as per Hammond et al., 2008). Study findings which captured the personal perspectives of those with early arthritis who attended the self-management programme, emphasised the positive support received within the programme with adjusting to, and occupational adaptation to live with, arthritis and towards becoming self-managers (Brownlee, Gorman, & Jackson, 2015). While this study demonstrates the potential of early lifestyle-based interventions to support self-management with inflammatory arthritis, further research is needed to explore how clinical practice can support participation and engagement in life roles early in the disease trajectory.

It is important that rheumatology service providers properly understand the type and extent of participation restrictions that service users may be experiencing because of inflammatory arthritis in order to address them. A complete understanding of the impact on participation that service users' experience should facilitate service providers to address participation and engagement and empower clients to make choices about their occupations and to support their engagement and participation in meaningful life activities (Gallagher et al., 2015; Squire, 2012). There is scope to improve understanding of the impact on participation in early disease which would positively influence the planning and delivery of rheumatology interventions to support participation across the lifespan. Although there is a variance in the focus of the types of participation-based self-management interventions evidenced in the literature, findings suggest benefits in the provision of these types of interventions in supporting participation in life roles and quality of life.

#### **2.4.5 Including the Clients' Perspectives in their Care**

Within the literature there is an emphasis on the importance of including the client in their care. Evidence from the client's perspective on inflammatory arthritis highlight service gaps in providing

them with an understanding of the impact of arthritis, lack of supports to assist them in managing the impact on everyday life and participation and adjusting to life with a diagnosis (Dures et al., 2017; Erwin, Edwards, Woolf, Whitcombe & Kilty, 2018). It is agreed that when designing and evaluating services that the client's lived experience, and the client reported impact on their quality of life and participation are important factors to be considered to ensure appropriateness and relevance of the service (Connelly et al., 2019; Montori, Britto & Murad, 2013; Rand, Dunn, Slade, Upadhyaya, & Sheehan, 2019; Sverker et al., 2019; Voshaar et al., 2015). Occupational therapy research asserts that embedding the individual's experience and perspective within service delivery is central to the effectiveness of any therapy assessment and intervention, and furthermore, that flexibility in interactions is key to the success of outcomes (Hand, Law, & McColl 2011; Nielson et al., 2019). Understanding clients' attitudes towards treatment interventions may inform shared clinical decision-making and promote adherence (Griffith & Carr, 2001). There is significant opportunity to implement these recommendations in clinical practice and incorporate clients' values and priorities in assessment, treatment decisions and intervention delivery, and thus promote high quality, client relevant care.

A systematic review of clients' perceived health information needs in established inflammatory arthritis reported high levels of unmet needs relating to gaining ownership of their condition in their lived experience (Connelly et al., 2019). Furthermore, it is recognised that a lack of goal concordance between clients and their clinicians can significantly hamper care (Barton et al., 2018). Therefore, involving the client in their own care is important to ensure client values and preferences are included and that client-centred goals are prioritised in intervention planning and delivery (Barton et al., 2018; Connelly et al., 2019; De Vries-Bouwstra et al., 2004; Dures et al., 2016b; Sverker et al., 2019; Voshaar, Nota, van der Laar, & van den Bemt, 2015). Client priorities are influenced by their health beliefs and by their life goals, and therefore inclusion of client priorities may improve engagement in treatment, improve satisfaction and improve health outcomes (Van der Elst, Meyfroidt, De Cock, De Groef, & Binnard, 2016). These authors emphasise the importance of including the client's perspective in the early management of RA and advocate that health professionals should include clients' normality construct and its meaning in treatment goals, and as a result that treatment should be dynamic and time flexible to respond to the changing normality of life for the person with arthritis (Van der Elst, et al., 2016). A recent systematic review examining client goals in established RA care reported that the significant advances in medical and drug management of RA has resulted in a widening of client goals and expectations of healthcare interventions (Hulen et al., 2017). As disease activity can now be better controlled by drug management, clients' goals of intervention have widened to include more participatory and self-management type goals such as, more information on how to better manage symptoms, how to maintain normalcy in their participation in life roles, maintaining wellness and social connectedness. In order to meet these evolving client expectations healthcare providers should adopt an approach that places greater emphasis on client-centred care. Such an approach requires effective communication between healthcare providers and their clients, with a focus on setting meaningful and relevant goals for each individual client. Although this systematic review did not include early arthritis studies, the findings reiterated the importance of

participation and engagement in life roles from the client-perspective and highlight the importance of client-valued goals in improving health outcomes.

Issues of unmet needs in client-centred care in early inflammatory arthritis are coming into focus as evidenced by a recently published protocol for a qualitative, explorative, longitudinal study exploring patient-preferred outcomes in early RA across three European countries (Van der Elst et al., 2019). Previous qualitative research by the same authors explored preferred health and treatment outcomes of RA clients in their first year of diagnosis and found that current rheumatology services do not fully appreciate client priorities in the first year post diagnosis, and as a result, these client priorities are not sufficiently met in service provision (Van der Elst, et al., 2016). Therefore, an individualised approach to early inflammatory arthritis management which incorporates clients' priorities and encapsulates broader participation issues in conjunction with service providers' knowledge, is required to ensure relevant provision of client-centred self-management supports and high-quality care early in the disease process.

## **2.5 Summary**

In this chapter the symptoms of inflammatory arthritis and their impact on participation across the lifespan of an individual have been outlined. Most research has focused on specific aspects of participation-based impact and addressing participation in specific life roles or specific disease symptoms in the established and chronic stages of this disease. There was less published research examining impact on participation early in the disease trajectory or the broader impact on participation across an individual's lifespan. Standards of care recommend that the wider impact on participation associated with inflammatory arthritis should be addressed but there this limited translation of this recommendation in current rheumatology service provision. Early and easy access to a multidisciplinary team to address the broader impact on participation and engagement is widely recommended, therefore the aims of this current study are to examine how participation is addressed in current clinical practice and in particular how the multidisciplinary-led early arthritis service model is identifying and addressing the impact of inflammatory arthritis on participation and engagement early in the disease trajectory.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Introduction**

As outlined in previous chapters, the overall focus of this study is the exploration of the impact of inflammatory arthritis on participation and engagement in life roles. Furthermore, this study seeks to explore how current services including a novel clinical service approach, namely the multidisciplinary-led early arthritis clinics, promote, and support positive outcomes to address participation and occupational engagement by exploring service providers' and service users' perspectives on this topic.

International practice guidelines (EUMUSC.net, 2013a; NICE, 2018) and literature to date in the field (Sverker et al., 2014; Verstappen et al., 2005a, 2005b), emphasise the importance of including work participation in rheumatology services for individuals who have inflammatory arthritis. Previous research (Hammond et al., 2008; Hammond & Freeman, 2004; Macedo et al., 2009; Steultjens et al., 2002) and traditional practice (Hammond & Dziedzic, 2010) in this area tends to focus primarily on symptom management and function, however there is a dearth of knowledge as to how participation is addressed in clinical practice with inflammatory arthritis. Recognition of work participation difficulties with early inflammatory arthritis is emerging, but knowledge gaps persist in understanding if, and how, clinical practice identify and address these work-based issues. This current study firstly seeks to further inform the clinical picture on supporting work participation with individuals with inflammatory arthritis by examining rheumatology teams' perspectives on addressing and providing services on work participation in the Irish context.

Secondly, this study seeks to explore the early impact of the disease on participation and occupational engagement including, but wider than, work participation. Participation is being considered under the WHO classification framework which identifies the right to engage, and participate fully, in life situations, and highlights the powerful relationship between engaging in valued life roles and health (Hemmingsson & Jonsson, 2005). In order to capture the early impact on participation, a novel service approach has been accessed. Therefore, there becomes a dual aim within phases two and three of the study to explore the early impact of inflammatory arthritis on participation, but also, to explore how these recently formed multidisciplinary-led early arthritis clinics identify and address wider participation issues among people with inflammatory arthritis in their current practice, and potential service improvements to manage client-identified participation and engagement restrictions.

### **3.2 Research Aims and Objectives**

The overall aims of this study are to explore the impact of inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level.

### **3.2.1 Study Objectives**

- To explore service providers' perspectives on the delivery of work-based participation support in current rheumatology services for inflammatory arthritis and identify factors which help or hinder provision.
- To describe and explore multidisciplinary-led early arthritis clinics as a model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives.
- To explore the impact of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement among a cohort of service users attending multidisciplinary-led early arthritis clinics in Ireland.

In this chapter the chosen methodology of the current study will be outlined. The methodology chapter will be structured following the sequential order of the data collection phases of the study as follows:

#### **Phase 1: Quantitative Research Survey**

The focus of phase one of the study was to explore service providers' perspectives on the delivery of work-based participation support in current rheumatology services for people with inflammatory arthritis

#### **Phase 2: Qualitative Focus Groups with Service Providers**

The focus of phase two of the study was to describe and explore multidisciplinary-led early arthritis clinics as a model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives.

#### **Phase 3: Qualitative Semi- Structured Interviews with Service Users**

The focus of phase three of the study was to explore the impact of newly diagnosed inflammatory arthritis on participation from the perspectives of the person with arthritis. Additionally, to explore from the service user's perspective, how the multidisciplinary-led early arthritis clinic addressed their self-identified participation and engagement needs.

### **3.3 Overall Study Methodology**

A mixed methods research approach was chosen to address the overall objectives of this study. In this chapter, an overview of mixed methods research will be presented and will include consideration as to how this methodology is suited to the current study. Sequential mixed methods design typology and embedded design model used in the current study will then be presented. An overview of the structure and design of the current study will be outlined followed by detailed description of each of the phases of the study.

### 3.3.1 Study Design: Mixed Methods

The research approach in any given study includes the study design, data collection, data analysis procedures, and interpretations of findings for the research study (Creswell & Creswell, 2018). Research approaches comprise quantitative, qualitative, and mixed methods. Quantitative methods are typically viewed as utilising deductive reasoning, objectivity, and positivism whereas qualitative methods are viewed as linked with inductive reasoning, subjectivity, and constructivism (Mortenson & Oliffe, 2009). Plano Clark and Ivankova (2016) define mixed methods research as *“a process of research when researchers integrate quantitative methods of data collection and analysis and qualitative methods of data collection and analysis to understand a research problem”* (p. 59). This definition recognises the combining and integrating of procedures to answer and add knowledge to a research question. Mixed methods research allows a combination of qualitative and quantitative methods to be used to explore and address complex practice-based problems and is increasingly popular in clinical research (Carpenter & Suto, 2008; Corcoran, 2006; Mortenson & Oliffe, 2009). As the current study is primarily a clinical based study, a mixed methods approach was considered the most appropriate method to address the study questions.

Teddlie and Tashakkori (2003) and Feilzer (2009) support the use of mixed methods design as a pragmatic approach in research studies, and they suggest that it is the research question that is of most importance, not the method used, or the underlying paradigm. The rationale for using mixed methods research in this current study is that it allows the researcher to combine quantitative and qualitative methods to address *“from multiple perspectives to facilitate understanding about multifaceted phenomena such as health, illness and occupation”* (Mortenson & Oliffe 2009, p.14). This pragmatic approach to research allows the researcher freedom to choose methods and techniques which best meet the purpose of the study and to explore and understand the research questions (Creswell & Creswell, 2018).

Mixed methods research is recognised as a pragmatic worldview approach to clinical research and appropriate to the exploratory nature of the current study. Creswell and Plano Clark (2011) report that the pragmatic approach of mixed methods is suited to ‘real world’ and ‘practice oriented’ research as opposed to positivist (quantitative) or constructivist (qualitative) research views. Within a pragmatic approach to research, the researcher recognises that there are multiple possible realities to the question under study (Feilzer, 2009). This stance echoes Teddlie and Tashakkori (2010) who contend that mixed methods emphasise the human conceptualisation of this research approach whereby ‘human problem solvers’ use multiple approaches to solve everyday problems either concurrently or in sequence in a ‘what works’ way. In mixed methods research, the researcher recognises both biased and unbiased perspectives in data collection and analysis (Creswell & Plano Clark, 2011).

Teddlie and Tashakkori (2009) support the rationale for mixed methods research when the purpose of the study is to address confirmatory and exploratory questions and to provide opportunity for greater assortment of divergent views. The current study is concerned with exploring participation with inflammatory arthritis and quantitative and qualitative methods were combined to gather a broad

range of data to inform on this clinical practice question. Health services focused research increasingly use mixed methods which include and combine qualitative research methods such as in-depth interviews and focus group interviews alongside quantitative methods such as questionnaires (Donovan & Saunders, 2005). According to Rauscher and Greenfield (2009) mixed methods design is a suitable approach for clinical research as it supports depth of understanding of illness and injury and can contribute to the development of new and innovative interventions for people with complex clinical intervention needs. The researcher recognises that combining mixed methods can provide a holistic understanding of the clinical practice question and support better informed recommendations for practice context.

Mixed methods design is suited to research which explores the impact of illness or disability on health, and the influences of context on recovery (Rauscher & Greenfield, 2009). The pragmatic paradigm recognises that research occurs in and is shaped by context. As they are still in their infancy, there has been a scarcity of research exploring the multidisciplinary-led early arthritis clinics to date. Lee and Kane (2012) described the pathway for this clinic model but there has been no research exploring how this model addresses participation and engagement on an occupational level. Previous qualitative research (Codd et al., 2010) and quantitative research (Hammond et al., 2017) on paid employment has highlighted a growing recognition of the importance of providing meaningful interventions to support work participation among people with arthritis. Additionally, research conducted on non-work based participation, such as participation in meaningful life activities including parenting, leisure and social engagement have highlighted the negative impact of the disease on participation (Backman et al., 2007; Gignac et al., 2014; Reinseth et al., 2010; Squire, 2012). However, these studies have focussed on individuals with established and chronic arthritis and not on those in the early stages of their disease. These studies simultaneously identify knowledge and knowledge gaps in this area and support the need to explore alternative models of care such as the multidisciplinary-led early arthritis model. The potential findings from this study will describe to what extent the multidisciplinary-led early arthritis clinics address and support participation in early inflammatory arthritis.

### **3.3.2 Mixed Methods Design Typology: Sequential Mixed Methods Design**

This study employed a fixed, mixed methods design whereby the researcher had planned the phases of the study during study conceptualisation and design at the start of the study (Plano Clark & Ivankova, 2016). There are a broad number of mixed methods design typologies identified within the literature and these typologies offer an important framework for the structure of a mixed methods study. It is suggested within the literature that when using a typology-based approach, researchers can choose a mixed methods design from a set of options and then modify it to the specific purposes of their study (Plano Clark & Ivankova, 2016). The overall design typology utilised in this study is best represented by a sequential exploratory mixed methods design described by Rauscher and Greenfield (2009), as this typology is suited to clinical research focused on exploration of a topic (such as participation within inflammatory arthritis) and explanation and exploration of access to health care models (such as the multidisciplinary-led early arthritis clinics). Sequential exploratory design structure has data collection and analysis which occur in distinct phases which follow each

other, and the data integration occurring at the interpretation and results stage (Creswell & Plano Clark, 2007; Rauscher & Greenfield, 2009).

Typically, the overall aims of a research study guide the emphasis placed on the data collected. In this study the overall aims were focussed on the exploration and discovery of experience and meaning of a clinical practice issue, and therefore the qualitative component of the study takes priority. The sequential exploratory mixed method approach employed has a qualitative priority, utilising a quantitative→QUALITATIVE sequence (Bryman, 2012; Corcoran, 2006; Creswell, Fetters, & Ivankova, 2004; Rauscher & Greenfield, 2009). In this study there is a subsidiary role with the quantitative component in phase one and the main priority is to the qualitative data collection methods in phases two and three. In phases two and three, the focus is on in-depth exploration and insight into lived experiences of the impact of inflammatory arthritis on occupation-based participation and engagement and exploring the impact of context (the multidisciplinary-led early arthritis clinics) in addressing this impact on participation, and on shaping health and recovery (Carpenter & Suto, 2008; Borkan, 2004).

Quantitative measures in the form of a survey are utilised in phase one to inform the clinical picture on supporting work participation with any individual with inflammatory arthritis by examining rheumatology teams' perspectives on addressing and providing services on work participation. Qualitative research methods were recognised as suitable for phases two and three as they have ability to address lived experiences, understandings, and associated meaning across contexts (Camfield, 2018; Rauscher & Greenfield, 2009). Phases two and three of the study are to explore the early impact of the disease on participation and occupational engagement including, but wider than work participation. Phases were used sequentially so that each phase could answer different research questions within the study, inform and clarify the next phase whilst informing the overall research question. The overall design fits well with the sequential exploratory mixed methods design framework (Rauscher & Greenfield, 2009) and more specifically complies with the structure of the embedded methods design (Plano Clark & Ivankova, 2016) as will be outlined below.

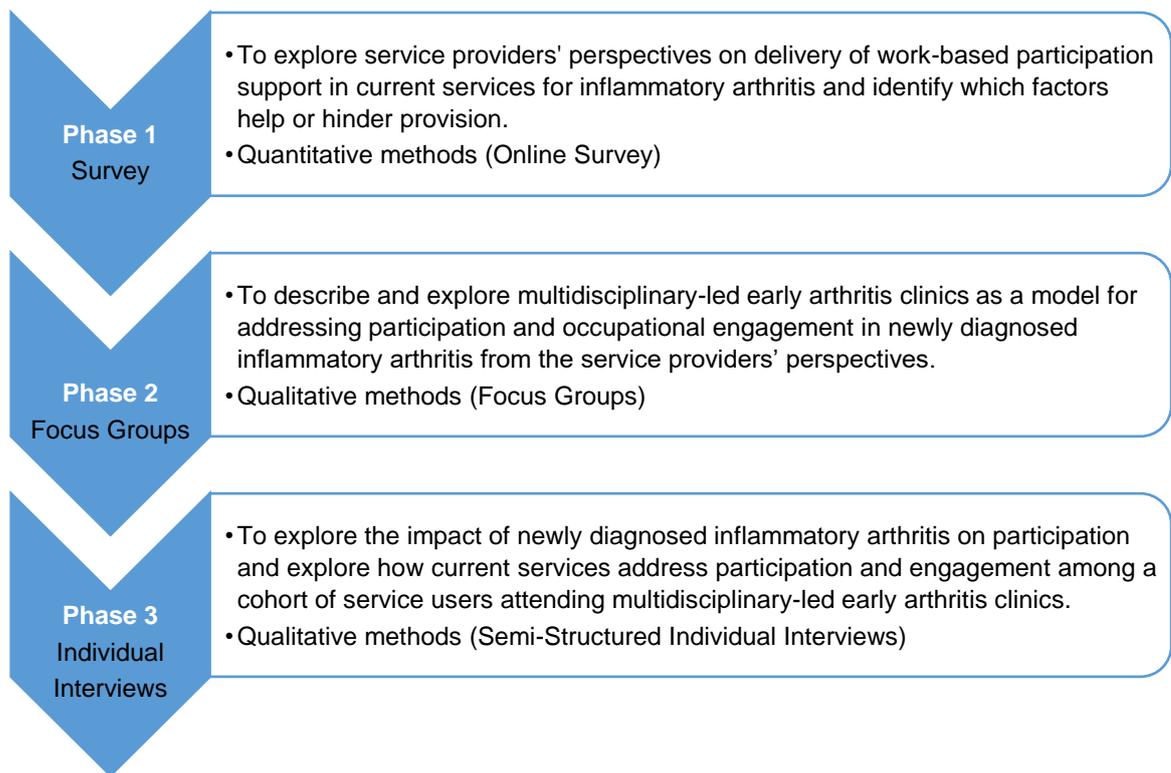


Figure 3.1: Overall Study Methodology

### 3.3.3 Embedded Methods Design

It is recognised within mixed methods research that methods can be intersected with other approaches in order to answer the research question (Plano Clark & Ivankova, 2016). One such example of intersecting with another approach is known as 'embedding.' Embedding involves *"incorporating a secondary method (quantitative or qualitative) within a research design traditionally associated with the other approach (qualitative or quantitative)"* (Plano Clark & Ivankova, 2016, p. 137). Embedding can be utilised with either concurrent or sequential designs (Creswell & Plano Clark, 2011).

In this study the quantitative strand (phase one) was embedded within the mainly qualitative exploratory study (phases two and three). The purpose of the embedded data strand is to enhance the interpretation of the larger design. In this study, as is typical of quantitative methods embedded in qualitative design, there was a convenience sample limited to service providers who can inform on the topic. Embedded designs are recognised as having unequal priority, hence the quantitative→QUALITATIVE sequence outlined earlier. In this study the embedded/subsidiary component, phase one, was designed to close the knowledge gap and to inform the clinical picture on supporting work participation with inflammatory arthritis by examining rheumatology teams' perspectives on how work participation is currently addressed within their services. In expanding knowledge on this strand, there was opportunity for findings to include greater understanding around how the early impact of inflammatory arthritis on occupation-based participation, and the impact of context (a current service approach and service providers' perspectives) to address these.

### **3.3.4 Structure and Design of the Study**

The design and execution of both phases of the study will now be presented. For clarity of explanation each phase will be outlined individually as follows:

Phase 1: Research Survey Design

Phase 2: Focus Groups with Service Providers

Phase 3: Semi-Structured Interviews with Service Users

## **3.4 Phase 1 Online Survey**

### **3.4.1 Background to Phase 1**

This phase of the research was concerned with service providers' perspectives of current rheumatology work-based support services in Ireland. It was intended to capture a broad range of influences relating to practice barriers and expectations. Work is a core component of participation and supporting work retention is recognised in the Healthy Ireland National Framework (DOH, 2013) as important to support the health and wellbeing of the Irish population. Over recent years there has been an increase in interest on the impact of inflammatory arthritis on work as a specific component of participation (Codd et al., 2010; Sverker et al., 2014; Verstappen et al., 2004). Despite this, there remains a service practice gap between the increasing understanding that work participation and engagement are impacted by inflammatory arthritis and how, and how well, this clinical practice gap is, or could be, addressed. Therefore, as a starting point in exploring participation, in line with published research, this study started with work under the umbrella of participation. This phase of the research study is an extension of the researcher's MSc. work exploring the impact of inflammatory arthritis on paid employment participation as a tangible element of participation. Subsequent phases extend and widen the focus on participation, looking first to employment participation and then broader to consider other life role participation which may be impacted by a diagnosis of inflammatory arthritis.

Recent research has examined the perspectives of rheumatology occupational therapists on the provision of work support in their clinical practice in the UK (Prior & Hammond, 2014b) and in Ireland (Corcoran et al., 2015). These studies have explored the roles and contributions of rheumatology occupational therapists in the area of work-based support. Findings from these studies highlight rheumatology occupational therapy as holding unique vocational rehabilitation skills and roles with work support in rheumatology services. These studies report that vocational rehabilitation is being addressed within current rheumatology occupational therapy services but that services are inequitable due to insufficient staffing levels, in-patient demand, waiting list pressure, limited resources, and time. The perspectives of Irish occupational therapists on work-based needs and supports in rheumatology services was recently examined by Corcoran et al. (2015) and therefore occupational therapists were not included in the study sample in phase one. Furthermore, this first phase was intended to further inform on those recent studies and explore service providers' views on work-based needs and supports for their complete caseload for inflammatory arthritis and not specifically to newly diagnosed services.

### 3.4.2 Objectives of Phase One

- To explore factors that influence or hinder rheumatology service providers referring for work support for people with inflammatory arthritis in their current clinical services.
- To examine service providers perspectives on the extent and type of work support currently available for people with inflammatory arthritis.
- To explore service providers perspectives on how occupational therapy addresses work with this population.

### 3.4.3 Phase One Research Survey Design

According to Bryman (2012) “questionnaires that are completed by respondents themselves are one of the main instruments for gathering data using a social survey design” (p. 232). Surveys are an established method of collecting data from a sample of the intended population, in this instance medical and health professionals working in clinical rheumatology (Bowen & Bowling, 2005). Surveys are recognised as a suitable tool to gather data on associations among trends, attitudes and opinions of a sample, or test associations between variables of a population (Creswell & Creswell, 2018). Surveys are frequently used in rheumatology research to gather data on clinical practice issues. In a UK study by Dures et al. (2014) a postal survey was undertaken to gather rheumatology nurses’ perspectives of psychological support provision for people with inflammatory arthritis in secondary care. Similarly, a study by Verstappen et al. (2005a) used a questionnaire on work status to assess work disability and variables associated with work disability including working conditions among clients with RA in The Netherlands. In addition, an online survey was used by Kennedy et al. (2018) to describe rheumatology health professionals’ knowledge and confidence in using physical activity measures with their clients with inflammatory joint disease, and to identify service providers’ educational needs across four countries in Europe.

Typically, surveys are predominantly quantitative in design but can also be structured to gather qualitative information using open-ended questions. It is recognised that as surveys are self-completed, it is important that the design is easy to follow and questions are salient and easily understood in order to maximise full completion and decrease risk of questions being omitted or partially answered. In the current study a survey design was deemed an attractive option to gather respondents’ views as they can be completed at a time of convenience for the respondent, and they are relatively quick to complete, and the online version of a survey supports a rapid turnaround in data collection (Forsyth & Kviz, 2006). The cost effectiveness of an online survey was also advantageous in this study bearing in mind that the sample entailed a national remit, and a wide response pool was being sought.

Therefore, in phase one of the study data was gathered using a semi-structured anonymous online descriptive survey to medical and health professionals working in clinical rheumatology through their professional bodies. The primary purpose of the survey was to address the objectives of this phase outlined above. A descriptive survey was selected as it is suited to research addressing clinical practice issues to describe knowledge, attitudes, and behaviours on a topic (Bowen & Bowling,

2005). The survey was designed specifically for the purposes of this study and was designed and structured with the knowledge and recognition that an attractive layout is likely to enhance response rates (Dillman, Smith, & Christian, 2009). The format of the survey includes mostly quantitative type questions, rating scales, ranking, and fixed choice answers but also allows for some basic elements of qualitative data through incorporation of open-ended questions and seeking commentary from respondents.

### 3.4.3.1 Survey Design and Piloting

A survey was designed specifically for the purposes of this current study. The survey content was designed by the researcher, an occupational therapist with twenty years' experience in the area of rheumatology occupational therapy. The survey underwent extensive collaborative design and review with the academic supervisor. The survey was designed to reflect the objectives of phase one of the study and gather data from the service providers' perspectives on:

- Factors that determine their referral for work support for people with inflammatory arthritis in their current clinical services.
- The extent and type of work support currently available for people with inflammatory arthritis.
- The role of occupational therapy in addressing work-based participation with this population.

Furthermore, the survey was designed to match the service provision context in Ireland. The survey which consisted of three sections, presented in Figure 3.2 below, will now be outlined.

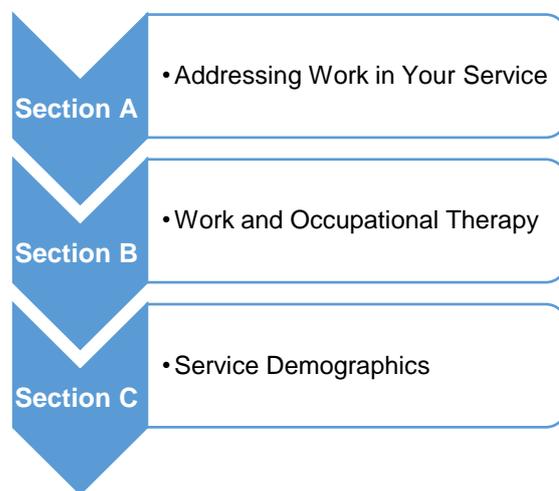


Figure 3.2: Sections of the Survey

#### 3.4.3.1.1 Section A – Addressing Work in Your Service

This section of the survey explored if, when, how, and how well, work-based participation was addressed in participants' current rheumatology service. Participants were asked to indicate percentage of their caseload with work-based needs, factors which determined work being addressed and work referrals being generated. Participants were asked to record which team members delivered work-based interventions in their current rheumatology service.

#### **3.4.3.1.2 Section B – Work and Occupational Therapy**

This section of the survey examined participants' access to, and experience of occupational therapy as part of the rheumatology team, and in particular with regard to addressing work-based participation with clients. The scope of occupational therapy in supporting work participation was examined in terms of actual and potential level of service provision. Barriers to occupational therapy were explored within this section. Furthermore, suggestions were sought as to how work-related services could be reconfigured and improved in current rheumatology services.

#### **3.4.3.1.3 Section C – Service Demographics**

The final section of the survey gathered demographic data on participants' profession and composition of their rheumatology team. Data was also collected on the age and work profile of service users.

According to Creswell and Plano Clark (2011) validity “*serves the purpose of checking on the quality of the data, the results and the interpretation*” (p. 210). In this study, content validity of the survey was established as the survey was informed by literature on best practice for supporting employment, and by previous studies from occupational therapists' perspectives (Coole et al., 2013; Corcoran et al., 2015; EUMUSC.net, 2013b; Hammond et al., 2017; NICE, 2018; Prior & Hammond, 2014b), and through pilot testing. Pilot testing a survey is an important stage of the research process in order to establish validity (face and content), to ensure that the content of the survey is valid and representative of the topic under study, and to inform an initial evaluation of the internal consistency of the questions on the survey (Creswell & Creswell, 2018). In this study piloting was an important part of the survey design process, as it second checked and helped ensure that the questions included in the survey reflected the content of the topic under study (face validity) (Bryman, 2012). Piloting provides an invaluable platform to ‘road test’ the survey in advance and highlight any potential changes or improvements to questions, sequences of questions, or to improve clarity of instructions to the respondents. In addition, piloting provides a helpful insight into how long it will take to complete the survey.

Initial piloting was completed in a hard copy format of the questionnaire and the participant information leaflet, provided to the rheumatology physiotherapist and rheumatology nurse in the researcher's place of employment. Following feedback received, a number of changes were made to the questionnaire, including adding space for additional comments after some questions. This revised draft of the questionnaire was then transferred onto an online format using the Google Docs platform. As occupational therapists were not included in the study, the online version of the questionnaire was further piloted among the rheumatology occupational therapy membership of the Association of Occupational Therapists of Ireland Musculoskeletal Advisory Group (seventeen members). This step in the process of piloting further served to ensure content validity as these professionals have significant expertise in the field of rheumatology. Feedback from piloting was used to inform the clarity, and appropriateness, of questions as well as length of time to complete. The final version of the questionnaire (see Appendix A3) was completed primarily online, using the

Google Docs platform, however a hard copy of the questionnaire was available on request and six hard copies were returned for inclusion in the data analysis.

#### **3.4.3.2 Inclusion Criteria**

- Any medical doctor, nurse or physiotherapist currently working in clinical rheumatology services.

#### **3.4.3.3 Exclusion Criteria**

- Any medical doctor, nurse or physiotherapist not currently working in clinical rheumatology services.
- Occupational therapists were excluded as their perspectives on this topic have previously been explored in studies in both Ireland and the United Kingdom.

#### **3.4.4 Sampling Strategy and Sample Size**

Convenience sampling was used as is typical for this type of research. Convenience sampling (Bowen & Bowling, 2005) is a non-probability simple sampling technique where research participants are selected based on their ease of availability. Participants were invited to be involved in this study if they were a medical or health professional working in clinical rheumatology. Every effort was made to capitalise participation by targeting participants through their professional bodies. Snowball sampling was allowed where participants were invited to forward the survey hyperlink to other relevant practising healthcare professionals that may not be registered with their professional bodies as appropriate.

In order to infer sample size and threshold for responses there was liaison with the three professional bodies whose membership were accessed for this survey namely: Irish Society for Rheumatology, Irish Society for Chartered Physiotherapists, Irish Rheumatology Nursing Forum. Based on the information received relating to membership numbers a total sample of 338 participants would be expected if a response rate of 100% were achieved. Literature on response rates in online surveys suggest that a 30-40% response rate is deemed to be acceptable for this type of methodology (Dykema et al., 2013; Kaplowitz, Hadlock, & Levine, 2004). Flanigan et al. (2008) reported that physicians and health care professionals have a 10% lower response rate to surveys than the general population. Dykema et al. (2013) examined the realities of surveying clinicians by web and reported substantial variability in the range of response rates reported in internet surveys of health professionals. This research suggests that rates of under 20%, particularly for physician surveys, are not uncommon (Dykema et al., 2013). A total sample of seventy-three was achieved and included nurses, medical doctors and physiotherapists which represented a response rate of 21.6%.

#### **3.4.5 Recruitment Method**

Applications were made to the three relevant professional bodies listed above, to seek permissions to access their membership in order to distribute the questionnaire. Consent was obtained from the three professional bodies and each professional body acted as a gatekeeper for their members.

Gatekeepers within the professional bodies circulated the email invitation to participate in this study through organisationally agreed structures. The email invitation to participate included the participant information leaflet and the hyperlink to the online survey (see Appendix A2). The researcher did not liaise directly with any participants. In keeping with agreed structures within the three professional bodies a maximum of two polite email reminders were circulated as follow-up (after two weeks and after three weeks) to maximise participation. Follow-up reminders to encourage responses is typical in survey type data collection and recognised as extremely important to maximise response rate (Forsyth & Kviz, 2006). As previously stated, snowball sampling was allowed, and participants were invited to forward the survey hyperlink to other relevant healthcare professionals as appropriate. The survey was live over a three-month period from January to March 2016.

#### **3.4.6 Ethical Approval & Data Collection**

Ethical approval for this phase of the study was obtained from the Trinity College Dublin, School of Medicine Research Ethics Committee prior to the commencement of the study (see Appendix A1). Data collection was completed between January and March 2016.

#### **3.4.7 Survey Data Analysis**

The returned surveys were analysed descriptively by responses and by profession under the three objectives outlined above. This is in line with typical analysis of surveys which can use the unit of analysis as either individual or groups (Bowen & Bowling, 2005). Descriptive analysis allows large amounts of returned data to be condensed and summarised into smaller meaningful units which can be easily understood without sacrificing important findings (DePoy & Gitlin, 2011). Descriptive analysis is considered appropriate for the type of data gathered in phase one of this study as it allows total sum of responses, frequency distribution (including percentages), and measures of central tendency (median, mean) to be calculated. Frequency distribution was used to determine how often variables reoccurred in response to set questions and were used to identify the pattern of variables, as well as the most common variables in response to the set questions (DePoy & Gitlin, 2011). Measures of central tendency were completed to provide numerical values to the findings, by identifying which is the midpoint point score on the rating scales (median) and the average scores recorded (mean) on the set questions (DePoy & Gitlin, 2011). The Google Docs platform allowed for some basic analysis of the findings however the majority of the descriptive analysis was completed using Microsoft Excel. Microsoft Excel was used to calculate the total sum of responses, frequency distribution, and measures of central tendency.

Any additional comments included by participants were recorded qualitatively. These qualitative comments were then analysed using basic content analysis methodologies (Julien, 2008). Basic content analysis involved a process of firstly reading through all of the qualitative comments recorded per question to become familiar with the data. This was completed using a paper copy of the qualitative comments per question printed from the Google Docs platform. As advocated by Saldana (2009) the next step in basic content analysis involved the researcher immersing herself in the data and repeatedly reviewing the responses (involving making notes in the margins and highlighting correlated text). This process of repeatedly reviewing the data helped highlight similarities in the

qualitative comments and these similarities were then grouped together into units of code. The coding strategy, and emerging codes were next reviewed and debated with the academic supervisor to add to the rigour of the analysis. Subsequently, these units of code were counted to gather information on their frequency and to determine trends in the qualitative comments. Findings at this stage in the analysis were further reviewed, challenged, and agreed with the academic supervisor. In this way, basic content analysis was used to transform initially qualitative findings into quantitative data.

### **3.5 Theoretical Framework Guiding the Qualitative Design in Phases 2 and 3**

Phases two and three of this study form the primary qualitative component of the research. While phase one was the smaller quantitative component specifically exploring work participation in inflammatory arthritis, phases two and three explore the expanded impact of early inflammatory arthritis on wider participation in everyday occupations including and beyond paid employment.

Phase two seeks to describe and explore the multidisciplinary-led early arthritis model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives. This phase of the study encompasses the views of service providers on how multidisciplinary-led early arthritis clinics address wider participation issues currently and explore the benefits and challenges of this model of service provision in addressing occupation-based participation and engagement issues. Phase three is focussed on in-depth exploration and insight into lived experiences of the early impact of inflammatory arthritis on occupation-based participation and engagement from the perspective of the service user. In phases one and two the focus was on service providers' perspectives of how work and broader participation was impacted in early inflammatory arthritis and how current services were addressing these participation issues. Phase three allows for the views of the service users of the multidisciplinary-led early arthritis clinics on how early inflammatory arthritis impacts on their occupation-based participation and engagement levels, but also on how they felt these issues were, or could be addressed within the service they received in the multidisciplinary-led early arthritis clinics.

Phases two and three of this study were designed to explore participation restrictions in early arthritis, and healthcare service inputs provided that specifically addressed this impact on participation. It was considered important that the perspectives of both service providers and service users be sought to gain a more comprehensive overview of the associated issues, as previous research has highlighted variances between service providers' and service users' views on clinical services provided and clinical services received (Blondeau et al., 1998). Service providers may advocate established intervention strategies focussed on the management of symptoms based on evidence-based practice (Henriksen & Rosenqvist, 2003), however, this approach may not always facilitate the incorporation of the service users' personal experience and priorities at the core of interventions (Yen et al., 2011). By designing the study to take both service providers and service users perspectives into account a more comprehensive overview may be achieved, and the findings of the study may be better able to inform future practice. Gaining an understanding of these issues through the lens of both sets of stakeholders would be the first step in establishing any variance in their perspectives as highlighted

by Blondeau et al. (1998). Gaining the perspectives of both sets of stakeholders may highlight areas for future practice development and refinement of the newly established multidisciplinary-led early arthritis clinics and analysis of the findings may be used to unite the focus of service providers and service users in addressing relevant occupational engagement and participation-based restrictions of early inflammatory arthritis as reported by service users. This supports the study by Dures et al. (2017) who reported that clinical team interactions with clients which validate the impact of inflammatory arthritis on participation in life roles could reduce psychological distress and support adaptation and self-management.

Qualitative research aims to provide understanding to a situation through the lens of those experiencing it (Bradshaw, Atkinson, & Doody, 2017; Vaismoradi et al., 2013). As the qualitative phases of this study are concerned with providing insight into lived experiences of the impact of inflammatory arthritis on occupation-based participation and engagement and exploring a current service approach to address this impact, qualitative approaches are deemed most appropriate. Sullivan-Bolyai, Bova, and Harper (2005) contend that clinical research is central to improving health related outcomes and reducing inequality in service provision.

Qualitative description and phenomenology are both qualitative research approaches which are concerned with describing the lived experience of individuals in the topic under study. Both of these approaches are suited to research which explores health and illness (Willis, Sullivan-Bolyai, Knafel & Cohen, 2016) and therefore both warranted careful consideration during the study design stage. There are many similarities between the two approaches, both use purposive sampling techniques to identify a sample with experience of the topic under exploration, both employ interview and focus groups as data collection methods, both utilise similar data analysis strategies such as thematic analysis. However, there are a number of important differences between the two approaches which ultimately informed the decision to select qualitative description as the preferred approach for this study.

Phenomenology is concerned with detailed descriptions of the lifeworld and the essence of the lived experience by the person who has had the first-hand experience (Willis et al., 2016). Similar to qualitative description, it develops perspectives defined by experience, and the benefit of both of these research approaches is a deeper understanding of these perspectives. However, in phenomenology a central and defining feature is that of 'epoché', whereby the researcher relinquishes all previous knowledge of the topic under study through a process of bracketing (Munhall, 2007; Willis et al, 2016). Bracketing is a central tenet of phenomenological reduction which allows a topic to be explored by the researcher as new, without any pre-conceived ideas. By contrast, in qualitative description the researcher is not required suspend her perspectives of the topic under exploration although strategies for increasing rigour (outlined in section 3.8) are extremely important to ensure the veracity and validity of the findings.

Additionally, there are important differences in the data collection design process of the two approaches. Phenomenology employs broad questions closely aligned to the study aim to explore

the essence of the topic as subjectively lived. The broad questions relate to the experience of the phenomenon and the specific context which has influenced the experience (Creswell & Creswell, 2018). Conversely, qualitative description design typically includes use of frameworks, which in this study are the focus group guide (section 3.6.5) and interview guide (section 3.7.5). The framework is informed by the literature, to provide a broad structure and direction to the topics to be discussed (Willis et al., 2016). Fundamentally though, the difference in the two approaches relates to the research question. Phenomenology approaches seek to understand the essence of the lived experience by seeking study participants' reflections on the meaning of the experience and detached or bracketed from the researcher's beliefs. In contrast, qualitative description approaches seek to describe the lived experience in everyday language, and in the broad and pragmatic context of life (Sandelowski, 2000; Willis et al., 2016). In this way qualitative description findings reflect a rich account of the topic that remains data near and incorporates both the lived experience of the impact of illness or disability on health, and the influences of context on shaping this experience (Rauscher & Greenfield, 2009; Willis et al., 2016). While findings from phenomenology approaches inform understanding of the complexities of the topic, qualitative description findings are suited to clinical practice studies, as findings can translated into targeting pragmatic interventions to improve healthcare provision and decrease health barriers (Bradshaw, Atkinson, & Doody, 2017; Rauscher & Greenfield, 2009; Sullivan-Bolyai et al., 2005).

Therefore, the theoretical framework that was used in the design of the qualitative component of this study is Qualitative Description (QD) as described by Sandelowski (2000), and Neergaard et al. (2009). Qualitative description aims to provide a rich description of experiences, events, or processes in everyday language although, it does not purport to provide theory development, or interpretative meaning of experiences (Sullivan-Bolyai et al., 2005). Accordingly, qualitative description is recognised as an appropriate approach to research addressing clinical practice issues, as results can translate directly into targeted improved access to and use of clinical practice and decrease health barriers (Kim, Sefcik & Bradway, 2017; Sandelowski, 2000; Sullivan-Bolyai et al., 2005). Qualitative description is recognised as suited to mixed method research where the aim of the research is to get first-hand knowledge of clients', relatives', or professionals' experiences (Neergaard et al., 2009). In this study the first-hand knowledge includes the service providers' experience in phase two, and the service users' experience in phase three. Qualitative description methodologies are established in occupational therapy research concerned with evaluating and developing new clinical services. A qualitative study by Stapleton, Connolly, and O'Neill (2015) employed qualitative description methods to explore the factors which influence the clinical pre-selection screening process for a stroke patient's suitability for driving which are typically conducted by clinicians practicing at a generalist level. Furthermore, Irish rheumatology occupational therapy research has utilised qualitative description methods to explore the lived experience of arthritis, as evidenced by a study by Connolly et al. (2015) which used a qualitative descriptive design to explore the perspectives of people with rheumatic diseases and their experiences with fatigue in work.

Neergaard et al. (2009) and Sandelowski (2000) have compiled a number of criteria relating to study design, data collection, and data analysis for the qualitative description framework. These criteria

include that: the research question is founded in existing knowledge and that the study design includes a mix of recognised qualitative methods, purposive sampling is utilised, open-ended questions are used within semi-structured interviews for data collection, data is analysed qualitatively using content analysis and that analysis and interpretation of results are reported descriptively and remain data near. In this study the design of the qualitative components in phases two and three of the study meet all of the five criteria of qualitative description as outlined by Neergaard et al. (2009), and Sandelowski (2000) (see Table 3.1).

Table 3.1: Qualitative Description Criteria Neergaard et al. (2009) & Sandelowski (2000)

Criteria of Qualitative Description	Used in the Current Study
1. Founded in existing knowledge and design of studies include a mixture of components of established qualitative methodological frameworks.	✓ The research aims and objectives were based on literature searches, knowledge of international standards for rheumatology best practice and clinical expertise.
2. Purposive sampling is most appropriate in QD studies.	✓ Phases 2 and 3 utilised purposive sampling
3. Usually semi-structured interviews with open ended questions are used.	✓ Phase 2 used Focus Groups (service providers) with Interview Guide including open questions. Phase 3 used Semi-Structured Interviews (service users) including open questions.
4. Data are typically analysed using qualitative content analysis	✓ Thematic analysis was employed in this study which is recognised as a form of qualitative content analysis as described by Sandelowski (2000).
5. Analysis and results are reported descriptively staying close to the data.	✓ A data near approach was utilised in analysis and presenting of the findings in both phases two and three of the study.

### 3.6 Phase 2 – Focus Groups with Service Providers

This phase of the research project was concerned with describing and exploring multidisciplinary-led early arthritis clinics as a model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives.

Traditional early arthritis clinics in Ireland provide an early appointment to be assessed by a rheumatologist to confirm a diagnosis of inflammatory arthritis and to commence drug therapy. They are typically a one-time early access appointment and thereafter clients are streamed into return visit appointments in the general rheumatology service and are referred to therapy services individually

as identified, at time points in the treatment trajectory by the physician. A newer model of early assessment and intervention for inflammatory arthritis which includes the multidisciplinary team from diagnosis has been emerging in Ireland. These newly established multidisciplinary-led early arthritis clinics, first reported in 2012, provide allied health and nursing interventions as a quality initiative in parallel to the traditional medical clinics to manage client needs in a timely fashion within four to six weeks of diagnosis (Lee & Kane, 2012). In contrast to the traditional early arthritis clinic model, which are staffed by a rheumatologist and rheumatology nurse, and focussed on medical management of symptoms with onward referral for multidisciplinary inputs at a later point at the discretion of the referrer, the multidisciplinary-led early arthritis clinic focusses on early symptom management from a multidisciplinary perspective. Additionally, the multidisciplinary-led early arthritis clinics offer a comprehensive management approach for the treatment of clients with inflammatory arthritis by allowing early and automatic access to wider health professional input beyond the standard medical and nursing input of the typical early arthritis clinics. The multidisciplinary input has potential to focus beyond symptom management and look at interventions to address the impact of symptoms on function, occupation-based participation, and engagement, and to support self-management.

The medical component of client care within rheumatology services with multidisciplinary-led early arthritis clinics remains as per the international standard, with medical focus on diagnosis and drug therapy and therefore, medical doctors were not included in the focus groups for this study. It is the early and automatic access to intervention by other members of the multidisciplinary team (occupational therapy, physiotherapy, and nursing) that is the key distinguishing feature of the multidisciplinary-led early arthritis clinics, therefore the focus of phase two of this study was on the allied health and nursing team members and not the medical doctors.

### **3.6.1 Objectives of Phase 2**

- To explore the multidisciplinary-led early arthritis clinic service providers' perspectives of the impact of newly diagnosed inflammatory arthritis on service users' participation and occupational needs.
- To examine service providers perspectives of the effectiveness of this model of service provision in addressing the occupation-based impact on participation and engagement.
- To explore the benefits and challenges of this model of service provision in addressing occupation-based participation and engagement issues.

### **3.6.2 Phase 2 Research Design**

To address the objectives of this phase a qualitative descriptive methodology using focus groups was chosen. Qualitative description (Neergaard et al., 2009; Sandelowski, 2000) was selected as it is best suited to research addressing clinical practice issues. Focus groups are recognised as an established qualitative data collection method to explore experiences, and perspectives of participants on a specific topic (Carpenter & Suto, 2008). Identified strengths of focus groups include their potential to gather in-depth information on a topic and to generate more detailed information which arises from the interactions of the group participants. It was considered that a focus group

platform would facilitate discussion and generate multiple perspectives to explore breadth of ideas and learning on the positives and challenges of this model. In the present study, focus groups were identified as the most suitable method to gather the data in phase two as they provide a platform to gather data on the operations of the multidisciplinary-led early arthritis clinics in line with international standards of care, as well as capture professional insights into the impact on participation and engagement associated with inflammatory arthritis and service configuration to support these difficulties.

Use of focus groups, for qualitative data collection to gather the healthcare provider perspective, is established in rheumatology research, Dures, Rooke, Hammond, & Hewlett (2019a) conducted focus groups alongside interviews to understand the experiences of rheumatology nurse and occupational therapist tutors who delivered a novel fatigue intervention in a trial setting, and their views on requirements for clinical implementation. Similarly, Yen et al. (2011) employed focus groups comprising health professionals to explore their responses to patients' experiences and perceptions of health issues with chronic illness. Additionally, a study by Pollard et al. (2011) utilised a combination of focus groups and face-to-face interviews to gather the views and experiences of service recipients (clients and carers) and service providers (rheumatologists and general practitioners) regarding rheumatology care services in a UK inner-city setting and to explore how quality of care and seamless integrated care in RA currently is, or could be, implemented from these perspectives.

Focus groups were favoured over semi-structured interviews for phase two data collection, as they were deemed to facilitate a more rounded evaluation of the clinic approach as a whole and avoid the risk of the discussion narrowing to specific issues for one discipline. Additionally, focus groups were considered preferable to semi-structured interviews as they provide opportunity to capture data on how the whole multidisciplinary team service influences outcomes and the impact of a coordinated team approach on supporting service delivery. Focus groups were selected to ensure the whole multidisciplinary team model's influence was captured in data collection rather than one discipline's perspective. Typically focus groups include a sample of four to six people and comprise a homogeneous group selected because of their knowledge on the specific topic (Lysack, Luborsky, & Dillaway, 2006). In this study the decision was made to facilitate focus groups specific to each rheumatology site in order to facilitate greater discussion of the topics and to capture context: how each service operates, how each service addressed the study objectives, and explore any variances in how the original pathway (Lee & Kane, 2012) for the multidisciplinary-led early arthritis clinics was being implemented.

### **3.6.2.1 Inclusion Criteria**

- Nurses, occupational therapists, and physiotherapists currently working in multidisciplinary-led early arthritis clinics in Ireland.

### 3.6.2.2 Exclusion Criteria

- Any medical professionals not currently working in multidisciplinary-led early arthritis clinics in Ireland.

### 3.6.3 Sampling Strategy and Sample Size

At the time of this study, these multidisciplinary-led early arthritis clinics were being implemented in four sites in Ireland. The researcher attempted to achieve 100% coverage of this emerging area by purposively recruiting allied health professionals and nurses currently working in all four multidisciplinary-led early arthritis clinics. Data collection involved three focus groups comprising this purposive sample of fifteen healthcare professionals currently working in multidisciplinary-led early arthritis clinics across the four service areas and included nurses, occupational therapists, and physiotherapists.

Purposive sampling is typical for this type of qualitative research and is one in which *“respondents, subjects or settings are deliberately chosen to reflect some features or characteristics of interest.”* (Carter & Henderson, 2005, p. 226). The characteristics of interest of the participants recruited for this phase of the study was that they were all currently working in, and therefore had experience in delivering, multidisciplinary-led early arthritis clinics. Both Creswell and Plano Clarke (2011) and Lysack et al. (2006) recommend the intentional selection of participants with experience in a specific area of practice as a preferred method of purposive sampling. Therefore, in this study the researcher intentionally selected healthcare professionals currently working in multidisciplinary-led early arthritis clinics to provide the necessary information based on their experience and expertise in the area under exploration in this phase of the study.

### 3.6.4 Recruitment Method

Irish rheumatology services which provide multidisciplinary-led early arthritis clinics were identified through national rheumatology interest groups namely the Irish Rheumatology Nursing Forum and the Association of Occupational Therapists of Ireland Musculoskeletal Advisory Group. Service providers of these clinics (rheumatology nurses, senior occupational therapists, and senior physiotherapists) received a written invitation pack to participate in the research. Invitation packs comprised the participant information leaflet and the informed consent form and a stamped addressed envelope (see Appendix A5). Invitation packs were forwarded by post by a gatekeeper. Upon receipt of signed consent forms, the researcher forwarded a copy of the topic guide (see Appendix A6) to the participants in advance of meeting to inform on the types of topics and questions to be discussed at the focus group and to allow time to prepare. Lysack et al. (2006) propose that supplying research participants with an interview guide in advance of the focus group is advantageous because it allows participants time to consider the topics and their responses in advance, and therefore they come to the focus group better prepared. The researcher then contacted the participants by telephone to coordinate a place and time of convenience for the focus group.

### **3.6.5 Focus Group Guide**

The topic guide questions for the focus groups were designed to specifically answer the objectives of phase two. The guide questions were constructed by the researcher, who has extensive experience in inflammatory arthritis care both with established disease and with recently diagnosed disease. The researcher has clinical experience spanning both the traditional and the newly established multidisciplinary-led early arthritis clinic models of care. Focus group questions were also informed through collaboration with the academic supervisor. There was extensive review of all standards of care for this clinical population. The Irish rheumatology model of care (HSE, 2018) and standards of care for Europe (EULAR, 2016; EUMUSC.net, 2013a, 2013b; NICE, 2018), the UK (BSR, 2006), America (AOTA, 2014; ACR, 2010) and Canada (BCG, 2012; CAOT, 2009) were all reviewed and considered as part of the focus group question design. These standards of care recommend early access to a specialised team (including doctors, nurses, occupational therapists, and physiotherapists) to receive appropriate information and education about their condition and its management in their everyday lives, including home, work, social roles, and the emotional and psychological impact. According to these standards, access to specialised services should be rapid, flexible in content and delivery, (in order to cater to clients' needs) and prolonged, (to ensure the right type of support is delivered) and should include regular review. These standards propose that the client is an equal member of their health care team and is an active partner in the decision-making regarding interventions. The standards advocate that interventions should be evidence-based and focused on promoting health and wellness but relevant to the specifics of the individual client. The focus group topic guide incorporated a synthesis of these international guidelines to explore how the multidisciplinary-led early arthritis clinics compared.

Consideration was given to two substantial reports which had previously explored the quality and accessibility of traditional rheumatology multidisciplinary team services in the UK (NAO, 2009; The Kings Fund, 2009). These reports detail the poorer health and socioeconomic outcomes associated with suboptimal inflammatory arthritis management. Whilst recognising the potential rheumatology services have for positive health outcomes, these reports highlight the inequity in access to, and provision of, traditional rheumatology multidisciplinary team services and variances within the composition of teams across the UK. These reports recommend early access to a client-centred coordinated rheumatology multidisciplinary team to provide a holistic assessment of health status and well-being of the client, in order to identify their health and engagement needs, so that that interventions provided are relevant and timely and support self-management. The Kings Fund (2009) report details the need for wider access to health professionals' rheumatology interventions which are less dependent on the consultant referrer, or the knowledge and assertiveness of the patient. This report suggests that there is opportunity to improve rheumatology services for newly diagnosed patients and recommends changes in traditional patterns of care to deliver improved, quality, specialised services. The recommendations from these two reports were included in the focus group topic guide to explore if and how the multidisciplinary-led early arthritis model supports timely access to deliver on client-centred health and engagement needs. Furthermore, as phase two of the study is concerned with early impact of symptoms on occupation-based participation and engagement, the WHO (2001) ICF and journal articles which considered the implications of early inflammatory arthritis

and participation in work and in non-work based participation under the ICF were included in the design and content of focus group topic guide questions (Benka et al., 2016a, 2016b; Sverker et al., 2014; Verstappen, 2013).

From an occupational therapy perspective, a review paper which examined the influence of meaningful social and occupation-based activities on health and wellbeing by Gallagher et al. (2015) was considered during focus group question content design. This theoretical review paper discussed the significance of participation and occupation on health and well-being from an occupational therapy and a social psychology perspective and informed the focus group question content in phase two and the semi-structured individual interviews in phase three, to explore whether the multidisciplinary-led early arthritis model design addresses participation. Equally, consideration was given to works by Segan et al. (2017) which explored the impact of meaningful client-centred care on developing therapeutic relationships, supporting self-management, and delivering improved health outcomes. These papers combined with the rheumatology international standards of care discussed above have shaped the focus group question content to explore if occupation-based participation and engagement were addressed within the multidisciplinary-led early arthritis model. In this way, the topic guide was designed in line with the qualitative description framework employed in this study, whereby use of the expert knowledge of the researcher and the academic supervisor, as well as research and international guidelines, was used to gather information on a unique service area that has potential for intervention development (Sullivan-Bolyai et al., 2005).

The focus group topic guide was designed to reflect the objectives of phase two of the study and gather data from the service providers' perspectives on:

- A description of the multidisciplinary-led early arthritis model.
- The early impact of inflammatory arthritis on clients' participation and occupational engagement including, but not limited to work participation.
- A description of how multidisciplinary-led early arthritis model interventions are utilised to address client-identified participation restrictions and support occupation-based participation and engagement.
- An appraisal of the multidisciplinary-led early arthritis model.

The topic guide was used to structure the stages of the focus groups which is outlined below in the focus group section.

### **3.6.6 Focus Groups**

Allied health and nursing professionals from all four multidisciplinary-led early arthritis clinics agreed to participate in the study. Given the geographical dispersion of the clinic sites, three focus groups were conducted. Two sites were combined into one focus group as they were the original pathway site and its' satellite service and were deemed to be closely aligned as they had the same medical consultants and medical management processes, and they were also geographically close to each other. This combination also enabled the researcher, who was a staff member of the satellite service, to partake in the focus group. It must be acknowledged that the researcher's involvement in the data

generation in one of the focus groups could have had implications on the type of data generated in that focus group and could have impacted on the other focus group participants' perceived freedom to speak. This risk of influencing peers in the focus groups through conscious bias was recognised in the study design. However, this multidisciplinary-led early arthritis model is an emerging approach to treatment and 100% coverage of all the staff who worked in these services was keenly sought to add to the knowledge base on the topic. The researcher is an occupational therapist in one of the services and were she not to have been involved in the focus group one of the services would not have been represented. Given that the research study is concerned with the impact of the diagnosis on life role participation and how these services address these participation restrictions it was considered that her non-involvement would result in important information from one site being omitted. Based on this, the decision was made for the researcher to be involved in the focus group and this combined site focus group was facilitated by the academic supervisor. This risk of bias associated with the researcher's involvement was actively considered and managed through the strategies to increase rigour employed in the study design. The other two focus groups were facilitated by the researcher.

The focus groups typically comprised five stages and were guided by the semi-structured framework of the topic guide. The stages of the focus groups will now be outlined (Figure 3.3).

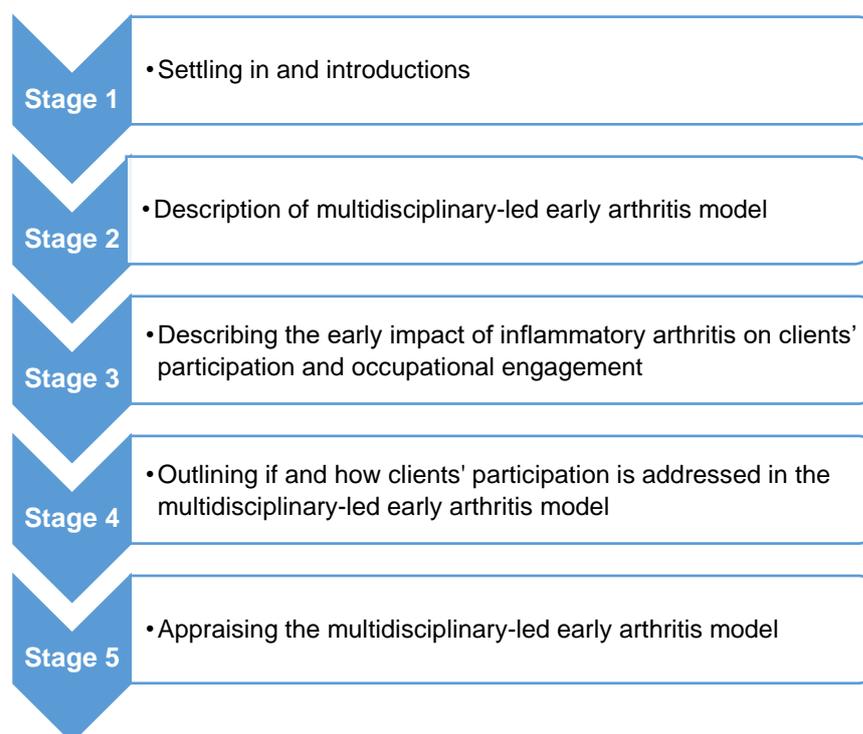


Figure 3.3: Stages of Focus Group

#### 3.6.6.1 Stage 1 – Introductions

The first stage of the focus group was a settling-in piece and involved outlining the format of the focus group, namely, what to expect, and encouraging participants to share as much of their views and experiences as they wished, asking the participants about themselves, (name, role, length of time in

clinical rheumatology) and the client pathway into their service (wait times for initial diagnosis and medical management in their service).

#### **3.6.6.2 Stage 2 – Describing the Multidisciplinary-Led Early Arthritis Model**

In the next stage of the focus group, participants were asked to illustrate the structure and delivery of the multidisciplinary-led early arthritis model in their site. Participants were each asked to describe how the model operates in their site, namely, which health professionals make up the team, the type of clients they see, and logistical and time factors. Participants were asked to recount their focus for client assessment and interventions attending the multidisciplinary-led early arthritis clinics. Participants were asked to describe if, how, and when, the team members overlap or work jointly and how the team communicates. Participants were asked to discuss if or how their service has evolved since implementing this model.

#### **3.6.6.3 Stage 3 - Early Impact on Clients' Participation and Engagement**

In the third stage participants were asked to describe what they see as the impact of inflammatory arthritis on their service users' everyday life and engagement in daily occupations and roles in this early stage of their disease. Participants were asked to recount the impact on occupational performance and participation their service users were identifying and also, who (service user or staff) raises the issue of impact on participation.

#### **3.6.6.4 Stage 4 – If and How Clients' Participation is Addressed by the Multidisciplinary-Led Early Arthritis Model**

In this section of the focus group discussion participants were asked if and how they assess for and deliver interventions to address the impact of inflammatory arthritis on their service users' daily life, occupations and life roles including paid employment, family roles, social and leisure participation, and relationships. This stage of the focus group also explored interventions focussed specifically on addressing occupational needs and participation and which team member typically takes responsibility for interventions.

#### **3.6.6.5 Stage 5 - Appraising the Multidisciplinary-Led Early Arthritis Model**

The fifth stage of the focus group was concerned with appraising the multidisciplinary-led early arthritis model. Participants were asked to share their views on the role that this model has in addressing the impact on participation and lifestyle management needs of service users. Furthermore, participants' views were sought regarding any identified unmet needs and any factors which may help or hinder supporting participation with this population. Participants were asked to appraise the model in terms of timing, perceived benefits, and challenges of managing this population under this model and how well this model positively supports health outcomes for service users.

The focus groups were conducted employing an informal, relaxed style of conversation and interaction. This was cognisant of and influenced by recommendations by Carpenter and Suto (2008) who advocate use of 'purposeful conversation' as an approach to maintain flexibility and adaptability

during qualitative interviewing. During each focus group the interviewer was careful to utilise strategies of 'probing and exploration' to fully examine and uncover participants' views and reflections on the topics under discussion as advocated by Patton (2002). Member checking was embedded within the process of conducting each focus group interview. Mays and Pope (2000), and Milne and Oberle (2005) both recommend employing member checking techniques within focus groups between the stages, to aid summarising and reflection and to add to the quality and relevance of the information-rich data collected. During the transition points occurring between the stages of the focus groups, the interviewer summarised participants' views and also clarified the main points raised. The interviewer used these transition points between the stages to mirror back to the participants what was heard and therefore allowing the participants to further explain or expand on their views before transitioning on to the next stage of the interview. It also was an opportunity for other participants within the focus groups to concur, disagree or further add to the discussion. Focus groups were audio recorded on an Olympus DS-55 digital recorder and were a maximum of two hours duration.

### **3.6.7 Focus Group Data Collection Process**

The researcher listened back to each focus group audio within 24 hours of completion of the focus group to check the recording. Within the 24-hour period after the focus group, the researcher inputted into a reflexive log, which recorded her thoughts and reflections arising from the focus group. The log also recorded a written summary of the main issues arising from the focus group content which was used to inform subsequent focus groups and was also used in the preliminary coding stage as advocated by Braun and Clarke (2006). This ongoing reflection and summarising of emerging topics assisted in ensuring that the focus group content remained aligned with the study objectives. The data collection was completed in an iterative cycle whereby the stages of listening back to the audio and writing a reflective summary into the log was completed in advance of the subsequent focus group. This iterative cycle for data collection allowed the researcher to identify gaps within the data and to identify new lines of enquiry prior to the next focus group which added to the depth and quality of data collected (Vaismoradi et al., 2013). This concept of an active researcher who immerses him/herself in the data in order to gain an in-depth understanding of the topic is advocated by Braun and Clarke (2006) to add strength to quality of the data collected and subsequent data analysis.

### **3.6.8 Focus Group Data Analysis**

The audio recordings were transcribed verbatim by a professional transcriber for analysis. The researcher then cleaned the typed transcripts of personal identifying information: names were replaced with professional title and locations were replaced with 'rheumatology service'. Transcripts were read and re-read multiple times whilst concurrently listening to the audio recordings to ensure no information was omitted and to confirm accuracy.

Initial analysis employed elemental coding by hand, which involved familiarisation with the data: listening to the audio recordings alongside actively reading the paper transcripts, writing notes in the margins, and highlighting issues of interest and relevance (Braun & Clarke, 2006; Saldana, 2009). Second round of initial analysis employed structural coding, a method of elemental coding which employs simple codes and themes beside the text and then grouped in a Microsoft Word document

to frame the transcript content. Structural coding was used as a foundation coding framework to help to begin the process of organising data into meaningful groups (Braun & Clarke, 2006; Saldana, 2009). Structural coding acts as a labelling method allowing the researcher to categorise the data and usually results in the identification of large segments of text under broad topics, these broad topics form the basis for further analysis (Saldana, 2009). This method of first cycle coding is considered appropriate for exploratory investigation and when semi-structured data gathering protocols have been used (Braun & Clarke, 2006; Saldana, 2009). Elemental coding of themes was based around the five stages of the focus group topic guide and phase two study objectives which is keeping with the theoretical approach for thematic analysis. Coding of the full data corpus was systematic with equal attention given to each data item and notable meanings identified so that repeated patterns were highlighted in the data.

Following peer review with the academic supervisor of the hand-coded transcripts, coding strategy, conceptualised themes and progress, the three focus group transcripts were imported into the NVivo9 software computer package. The framework of codes (referred to as 'nodes' in NVivo9) were established in the NVivo9 programme according to the original themes identified during the hand coding. The researcher then coded all of the transcripts again using the NVivo9 package, with new 'nodes' being added as identified. This re-coding of all of the focus group transcripts 'as new' a second time by the researcher added to intra-coder reliability and added to the strength of the codes identified (Creswell & Creswell, 2018). At regular intervals throughout the coding process the researcher read through the sections of already coded text within each node to check for similarities and consistency within the coding. This process of reading, checking, and comparing is called constant comparison and is a recognised strategy to increase rigour in analysis (Barbour, 2001). This is congruent with the recommended methodology for thematic analysis which recommends a cycle of naming, reviewing, and searching for themes (Vaismoradi et al., 2013). On completion of the coding, each node was printed out and the sections of text contributing to each theme was re-read by the researcher to check for consistency within the content of each node (Braun & Clarke, 2006).

The next stage of the thematic analysis involved listing all codes and themes under consideration in a grouping process in the form of a table. This use of tabling the codes and themes was a practical strategy to view and consider the different themes and how they could be combined into larger overarching themes. Progression of this analysis involved transforming the table into thematic maps. Thematic analysis uses thematic mapping to visually present the generated codes and themes and their relationships. Thematic maps are an effective way to visually perceive the themes under consideration but are also a practical way of reviewing and refining codes and themes as part of the data analysis process (Braun & Clarke, 2006). The visual thematic maps were particularly helpful in structuring the overarching themes, subthemes, and their relationships. These maps and the earlier table supported the subsequent reviewing and refining of themes as part of the level two theme review. Initially there were 53 codes and five overarching themes identified. Through a process of debate, constant comparison, and consideration in the context of their validity and integrity in relation to the data corpus (Braun & Clarke, 2006), these nodes and themes were merged and collapsed down to a total of eight nodes and three overarching themes. An earlier theme outlining the structure

of the model was collapsed into an overarching theme with a greater focus on the mechanisms of how the clinics addressed participation. The first overarching theme was 'Early Arthritis Impact on Participation' which included two nodes which described both the role impact, and the impact on balance of roles and the level of engagement. The second overarching theme 'How Multidisciplinary-Led Clinics Address Impact on Participation' outlines the perception of the multidisciplinary team that the scope of this model has expanded to include participation-based problems and that the multidisciplinary team members are aware of, and alert to the impact on participation as a result of early inflammatory arthritis, as well as describing the mechanisms that the model uses to address participation restrictions. The final overarching theme 'Appraisal of the Model' includes nodes which reflect how, and how well, the model addresses participation restrictions.

### **3.6.9 Ethical Approval & Data Collection**

Ethical approval for this study phase was obtained from the Trinity College Dublin, School of Medicine Research Ethics Committee prior to the commencement of the study (see Appendix A4). Data collection for phase two was completed between September and December 2016.

### **3.7 Phase 3 – Semi-Structured Interviews with Service Users**

Phase three employed qualitative descriptive methods to explore the impact of newly diagnosed inflammatory arthritis on the person's participation and explore how current services address client-identified occupation-based participation and engagement restrictions among a cohort of service users attending multidisciplinary-led early arthritis clinics in Ireland. Qualitative description is recognised as an appropriate design methodology in clinical research to explore and gather insights into the lived experiences of the topic under study (Borkan, 2004). It is recognised that inclusion of clients' experience, and meaning of experiences, is important when evaluating and developing service design (Coole et al., 2015; Mancuso et al., 2001).

#### **3.7.1 Objectives of Phase 3**

Phase three of the study involved participants with early diagnosed inflammatory arthritis who were currently attending or had recently attended the multidisciplinary-led early arthritis clinics. Semi-structured interviews were carried out with participants who were attending/had attended these clinics with the specific purpose of exploring:

- Their perception of how newly diagnosed inflammatory arthritis impacted on their everyday occupations and participation.
- Their perceptions on how their self-identified occupation-based participation and engagement needs were addressed by the multidisciplinary-led early arthritis clinics, and any suggested potential service improvements to manage client-identified participation and engagement restrictions.

#### **3.7.2 Phase 3 Research Design**

While phase two explored the service providers' perspectives, phase three focussed on an exploration of the service users' perspectives on the impact of newly diagnosed inflammatory arthritis

on occupation-based participation, and on how multidisciplinary-led early arthritis clinics address participation and engagement on an occupational level. As previously outlined, similar to phase two of the study, a qualitative approach was taken in phase three, and qualitative description was the chosen methodology guiding the design and execution of this phase. The research objectives for phase three are concerned with exploring first-hand the client experience of living with, and experiencing the participation-based restrictions associated with, their inflammatory disease, and equally the first-hand client experience of accessing the multidisciplinary-led early arthritis clinics. Qualitative description methodology is used when the study aims to obtain rich descriptions of personal client experiences which can be analysed and results translated directly into improving clinical practice, (Neergaard et al., 2009; Sandelowski, 2000). This qualitative descriptive design is similar to that of work by Connolly et al. (2015), mentioned earlier in the theoretical framework section, which also used one-to-one semi-structured interviews, in their study to explore the perspectives of with people with rheumatic diseases and their experiences with fatigue in work.

In the current study, semi-structured interviews were used in phase three data collection to provide insight into lived experiences of the impact of inflammatory arthritis on occupation-based participation and engagement and to explore a current service approach to address these restrictions. In phase three, the service users' perspective could have been gathered using focus groups or individual interview. Use of both semi-structured interviews and focus groups, for qualitative data collection to gather the client perspective, is established in rheumatology occupational therapy research. Prior et al. (2016) used semi-structured interviews with clients to evaluate an occupational therapy-led work rehabilitation programme for people with inflammatory arthritis. Backman et al. (2007) used purposive sampling and in-depth individual interviews to describe the impact of chronic, inflammatory arthritis on parenting and to develop a conceptual framework for subsequent study of mothering. Additionally, other rheumatology researchers have favoured semi-structured interviews for qualitative data collection of the client perspective of clinical practice, Hale et al. (2006) conducted semi-structured interviews to examine perceptions of clients with systemic lupus erythematosus about their health care provision. Also, Dures et al. (2019b) used individual semi-structured interviews to gather insights into the experience of getting a diagnosis of psoriatic arthritis and how this impacted clients' engagement with treatment and care.

Semi-structured individual interviews were deemed the most suitable method to gather the data in phase three of this study as they provided a platform to gather personal insights into daily lived experiences with inflammatory arthritis and the client-identified impact on participation in life roles. Individual interviews are an established qualitative data collection method and are frequently used in clinical research to explore and add understanding to the topic under consideration (Carpenter & Suto, 2008). Through interview, a range of topics could be discussed and explored more deeply in a way that could not have been achieved with a survey design. Equally, it was considered that a focus group methodology could limit the degree of sharing of the personal experience of living with inflammatory arthritis and the meaning of impact on personal participation. Additionally, on a practical level semi-structured individual interviews were favoured as sampling was across the four service sites, and service users were geographically spread out. The researcher recognised that potential

participants each had individual personal commitments (work, home, social) that needed to be facilitated in order to identify a convenient time to meet for interview and which could have prohibited participation in a focus group format. During data collection the interviewer travelled to a convenient location to meet with service users for interview.

### **3.7.3 Sampling Strategy and Sample Size**

Purposive sampling was used as is typical for this type of qualitative research whereby participants meeting the inclusion criteria are intentionally selected to inform on the topic under research (Creswell & Plano Clark, 2007; Lysack et al., 2006). The researcher intentionally selected participants from the four Irish rheumatology services which operate the multidisciplinary-led early arthritis clinic model of service. Based on the figures received from the combined four databases, a total of 225 participants would be expected if a response rate of 100% were achieved. The researcher also intentionally selected participants who were at different stages in their disease trajectory within the two-year post diagnosis criteria. Additionally, representation of participants from all four sites was considered an important part of recruitment. A flexible sampling strategy was employed whereby sampling was concurrent to the data analysis and recruitment continued until a level of saturation was achieved. Sampling sought to ensure a spread of participants from each site and also a spread of age groups. Saturation was considered to be achieved when the data gathered informed findings and no new findings were identified (Milne & Oberle, 2005). A total purposive sample of forty-three participants was achieved indicating a response rate of 20%.

#### **3.7.3.1 Inclusion Criteria**

Individuals who met the following criteria were included in the study:

- Aged 18 years and older.
- Have a diagnosis of inflammatory arthritis, which may include RA, psoriatic arthritis or undifferentiated inflammatory arthritis confirmed by a rheumatologist.
- Up to two years post diagnosis.
- Currently attending one of the four multidisciplinary-led early arthritis clinic services within Ireland or have attended multidisciplinary-led early arthritis clinic service in Ireland.
- Able to give informed consent to participate in the study.

#### **3.7.3.2 Exclusion Criteria**

- Any individual who has a diagnosis of inflammatory arthritis of greater than two years post diagnosis
- Any individual with a diagnosis of inflammatory arthritis who has not attended a multidisciplinary-led early arthritis clinic service.

### **3.7.4 Recruitment Method**

At each site, a nominated senior staff member accessed the multidisciplinary-led early arthritis clinic database to identify potential participants who met the inclusion criteria. Clients who attended these

services within the two-year time frame received a written invitation pack to participate in the research. Invitation packs were forwarded by post by a gatekeeper. The invitation pack comprised the participant information leaflet and interview guide (see Appendix A9). Posters (see Appendix A10) were also displayed in the clinic areas advertising the research. Potential participants contacted the researcher (or the independent interviewer) if interested in participating in the research study. These contact points were used to answer any questions and provide any clarifications on what was involved in participating in the study. A place and time of convenience for the semi-structured interview was coordinated and informed consent forms and a stamped addressed envelope were forwarded by post. Consent forms were signed prior to interview (see Appendix A9).

### **3.7.5 Interview Guide**

As this phase of the study is concerned with impact of symptoms on occupation-based participation and engagement in early disease from the service users' perspective, question content was again guided by the WHO (2001) ICF and publications which had reported on the implications of early inflammatory arthritis and participation in work (Codd et al., 2010; Geuskens et al., 2008; Sverker et al., 2014; Verstappen, 2013; Walker-Bone & Black, 2016). Publications which considered participation in valued life roles with established inflammatory arthritis (Backman et al., 2007; Kristiansen et al., 2012a, 2012b; Reinseth et al., 2010) and social participation with early and established inflammatory (Benka et al., 2016a, 2016b) were examined as part of the interview content design to gather recommendations from those with established disease which could be applicable in early management.

Phase three is also focussed on service users' perceptions on how the multidisciplinary-led early arthritis clinics address their self-identified occupation-based participation and engagement restrictions. Additionally, this phase is concerned with service users' views on potential service improvements to manage client-identified participation and engagement restrictions in life roles. Therefore, published reports which explored the quality and accessibility of traditional rheumatology multidisciplinary team services in the UK (NAO, 2009; The Kings Fund, 2009) were again reviewed and integrated into guide question content for this phase of this study. These reports identified the gaps and also the opportunities for improvement in service coordination and delivery of meaningful client-centred care. These reports, which incorporate the patient perspective, provided a helpful yardstick to inform the content of interview questions to gather the service users' perspectives on the quality and suitability of the newly established multidisciplinary-led early arthritis model to address occupation-based participation and engagement. An occupational therapy publication which also incorporated the service user perspective by Coole, et al. (2013) by examining client and employer perspectives on how UK occupational therapy services delivered work-based supports to clients with musculoskeletal conditions further influenced the interview guide content. Equally, recommendations from standards of care for this clinical population, discussed previously, influenced interview content design as questions were included to explore whether multidisciplinary-led early arthritis clinics were flexible, timely and client-centred in their assessments and interventions to support meaningful participation everyday lives (AOTA, 2014; ACR, 2010; BCG, 2012; BSR, 2006; EULAR, 2016; EUMUSC.net, 2013a, 2013b; HSE, 2018; NICE, 2018). Additionally, recommendations by Segan et

al. (2017) to consider models of care other than the traditional models, to meet client-perceived needs and improve health and participation-based outcomes were reflected in the question design.

The semi-structured individual interview guide was designed to reflect the objectives of phase three of the study and gather data from the service users' perspectives on:

- The impact of newly diagnosed inflammatory arthritis on their ability to participate in everyday occupations, life roles, including home, work, leisure, social roles and relationships and lifestyle in general.
- Whether these life-based difficulties in occupation-based participation and engagement were addressed within the multidisciplinary-led early arthritis clinics.
- An appraisal of the multidisciplinary-led early arthritis model, how current services could be organised and delivered to maximise participation and engagement in life roles among people with newly diagnosed inflammatory arthritis.

The interview guide questions (see Appendix A11) for the semi-structured interview were designed in keeping with a qualitative description framework whereby the expert knowledge of the researcher was used to gather information on a clinical service area that has potential for development and improvement (Sullivan-Bolyai et al., 2005). The interview guide was informed by the researcher's clinical experience to date in the traditional model of care, as well as in the more recently established multidisciplinary-led early arthritis clinics. Interview guide questions were also informed through collaboration with the academic supervisor. As advised by Donovan and Sanders (2005) the interview guide was sequenced to support a natural flow, facilitating topics to smoothly transition into related areas. The interview guide was provided to potential participants, to supply information on the types of topics and questions which would be discussed during the semi-structured interview. Sending the interview guide out in advance allowed participants' time to prepare and consider the issues for discussion and thus ensure 'information rich' interviews. It also allowed potential participants to consider if they wanted to be involved in the study and enabled them to give informed consent to participate as they had greater awareness of the content and focus of the interviews. The interview guide was used to structure the stages of the semi-structured individual interviews which is outlined below in the interview section.

### **3.7.6 Interviews**

Service users across the four rheumatology sites who consented to participate in this research met with the interviewer at a time and location of their convenience, for a once off semi-structured interview. The purpose of the interview was to gather data on their lived experience on the early impact of the disease on their participation and occupational engagement in both work and non-work activities. The interview was also used to explore the service users' perspectives on how the multidisciplinary-led early arthritis clinics addressed their issues or concerns regarding the impact of inflammatory arthritis on occupation-based participation and engagement.

As recommended by Carpenter and Suto (2008) a conversational style was employed for the interviews to encourage a comfortable dialogue to develop. While the interview guide was used as a reference to ensure that key topics were covered, the order of the interview did not necessarily rigidly follow the guide. Instead, participants were given freedom to speak and encouraged to recount their personal narrative of the topics discussed, to share their perspectives, and to develop their points and thinking. This meant that participants were permitted to expand on and follow a conversation point to its' natural end before returning to the next question and in this way added to the richness of the data. This strategy of flexibility and adaptability in interviews is typical of qualitative interviewing and recognises the potential for overlap and natural deviation within an interview experience in order for the participant to tell their story (Carpenter & Suto, 2008).

The individual interviews typically comprised four stages and were guided by the semi-structured framework of the interview guide. The stages of the individual interviews which are presented in Figure 3.4 below will now be outlined.

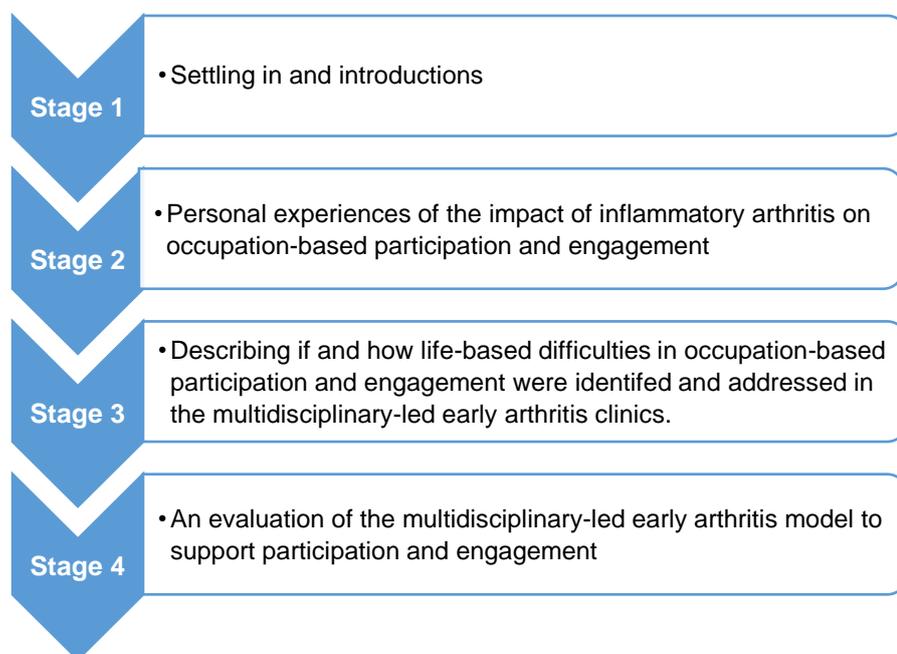


Figure 3.4: Stages of Semi-Structured Individual Interviews

### 3.7.6.1 Stage 1 – Settling In

The initial stage was a settling-in piece and involved outlining the format of the interview and what to expect, explaining to the participant that they were welcome to share as much of their views and experiences as they wished, asking the participant about themselves, (age, diagnosis, time since diagnosis), path to diagnosis and current health.

### 3.7.6.2 Stage 2 – Impact on Participation and Engagement

The interview then moved on and participants were asked to describe their experiences and perspectives of how inflammatory arthritis had impacted on their everyday participation and engagement in work and non-work activities. This stage of the interview explored the participants'

personal experiences of how arthritis symptoms impacted on ability to engage and participate in life roles and daily occupations (home, employment, hobbies, social roles, relationships) and routines (lifestyle and life in general).

### **3.7.6.3 Stage 3 – Multidisciplinary-Led Early Arthritis Clinic Addressing Participation and Engagement**

Subsequently, participants were asked to describe if these impacts on participation and engagement were identified and addressed by the multidisciplinary-led early arthritis clinics. Participants were asked what types of advice or intervention was provided to address these impacts, who gave the advice and also to evaluate the participation-based intervention (was it helpful, what else should be included, was any participation-based concern not addressed).

### **3.7.6.4 Stage 4 – Evaluation of Multidisciplinary-Led Early Arthritis Model**

The final stage of the interview explored the participants' views on the multidisciplinary-led early arthritis model. Participants were asked to discuss if they felt that they were included as a team member in their own treatment plans, if so in what ways, and how well. Participants were asked to evaluate the timing of the model, and the timing and types of lifestyle management type interventions. Participants' views were sought regarding what is most important and valuable to include in rheumatology services for people with a new diagnosis and which approaches are successful and which should be amended to improve to positively support quality health and participation outcomes.

Similar to the methods used in conducting the focus groups, throughout the interviews the interviewer employed strategies of 'probing and exploration' (Patton, 2002) to develop participants' answers on the topics, and again, member checking (Mays & Pope, 2000; Milne & Oberle 2005) was embedded within the process and completion of each interview. At the natural end of answers and also at the transition points between the stages of the interview, the interviewer utilised the opportunity to summarise participants' views and clarify the main points raised. This allowed the participants to clarify, or further explain or expand on their views before transitioning forward to the next stage of the interview. This summarising and mirroring of the participants' perspectives was found to be a practical strategy to support deepened discussion of the topics and fit well within a natural, comfortable conversation-style dialogue.

Interviews were facilitated by either the researcher or an independent interviewer. As previously outlined, the researcher was also a staff member at one of the research sites. In order to minimise potential bias, the researcher did not facilitate any of the data collection at the site that was her place of work, and an independent interviewer was used for all steps in this strand of data collection. The independent interviewer completed a total of eight interviews in the phase three data collection. She is a senior occupational therapist with more than twenty years clinical experience in the area of cognition and memory impairment. She is highly competent at measuring and managing the impact of this on daily life roles and occupations. Furthermore, she has expertise in supporting clients with a diagnosis of memory impairment and supporting adjustments associated with this diagnosis. The independent interviewer has postgraduate research experience at MSc. level, and she has also been

involved in a number of small clinical practice evaluations and quality initiative audits. She does not work in the clinical area and was not known at all to any of the potential participants from this site. Interviews were audio recorded on an Olympus DS-55 digital recorder and were a maximum of ninety-seven minutes duration.

### **3.7.7 Interview Data Collection Process**

Research processes employed in phase two data collection, were replicated in phase three. The researcher listened back to the audio from each individual interview within 24 hours of completion to check the accuracy of the recording. A reflexive log was further employed in this phase of the study and, within 24 hours of each interview, the researcher completed a written log record which summarised her thoughts and ideas arising from the interview, as well as a synopsis of the main issues emerging from the interview content. This reflexive log was a useful practical tool which served to highlight both similarities and gaps in the data collected and was used to guide subsequent interviews to ensure adequate exploration of topics and saturation of issues raised. The reflexive log was later used in the preliminary coding stage (Braun & Clarke, 2006).

Additionally, the independent interviewer and the researcher had a debriefing session after each interview completed by the independent interviewer. A summary of each debriefing session (including synopsis, gaps, and future directions) was also written into the reflexive log and equally included in the consideration and planning of subsequent interviews. Furthermore, the researcher had debriefing sessions with the academic supervisor at time points throughout the schedule of interviews which were used to update on interview progress, check interview content and topics arising, and identify gaps. This strategy is advocated by Braun and Clarke (2006) who advise immersion in the data in order to gain an in-depth understanding of the topic and ensure that the interview content remains focussed on the study objectives which also adds strength to the analysis of the data.

### **3.7.8 Interview Data Analysis**

The audio recordings were transcribed verbatim by a professional transcriber for analysis. The researcher then cleaned the typed transcripts of personal identifying information: family members' names were replaced with their role 'husband', 'mother', 'daughter', names of places of work or school were omitted and replaced with 'work' or 'school', names of team members were replaced with professional title and service locations were replaced with 'rheumatology service'. Transcripts were read, and re-read multiple times whilst concurrently listening to the audio recordings to confirm the veracity of the written record and to provide certainty that there were no omissions

In phase three data analysis the interview transcripts were analysed in an iterative cycle, whereby the analysis was carried out concurrently with the data collection. This iterative process was purposely included in phase three study design, as the back and forth between the stages of data gathering and analysis is agreed to facilitate opportunity for new lines of enquiry to be followed in subsequent interviews and thus add to the depth and quality of data analysis (Braun & Clarke, 2006;

Vaismoradi et al., 2013). Furthermore, this process ensured a thorough exploration of the issues by ensuring all components of the phase three objectives were addressed across the interviews.

Qualitative analysis of the interview data followed a number of stages. The initial stage employed elemental hand-coding of ten of the paper transcripts. This stage of coding helped the researcher to become immersed in the data. She listened to the audio recordings whilst concurrently actively reading the paper transcripts, and hand-writing notes in the margins, and highlighting points of interest and relevance (Braun & Clarke, 2006; Saldana, 2009). After the initial paper exercise piece, a second round of preliminary analysis was completed to frame the transcript content. This stage of analysis employed structural coding to group the identified simple codes and themes in a Microsoft Word document. This structural coding was used to generate a classification system to group the data in the initial analysis and identify broad topics for the next stage of analysis. Saldana (2009), and Braun and Clarke (2006) both recommend this method of initial analysis in exploratory studies using semi-structured data gathering protocols. In line with the theoretical approach for thematic analysis, the researcher used the structure of the interview guide and study objectives to provide the initial framework to guide the initial structural coding of themes. The full data corpus was included in the coding process and equal attention given to each data item and all notable meanings. This was completed carefully and methodically to ensure that all repeated patterns were identified.

The hand coded transcripts, coding strategy, and conceptualised themes were next reviewed, debated and agreed as a part of a 'check mechanism', with the academic supervisor. Following this agreement, the forty-three interview transcripts were imported into the NVivo9 software computer package. As described in phase two analysis previously, in phase three data analysis, the framework of codes/nodes used in the NVivo9 programme was originally organised using the clusters/categories identified during the hand coding analysis. Using the NVivo9 package the researcher then coded all forty-three interview transcripts, including re-coding the ten transcripts already coded by hand. Re-coding of the ten transcripts was a purposeful strategy employed by the researcher to support intra-coder agreement and add to the rigour of the qualitative analysis. During this stage of coding the researcher systematically implemented the recommendations of Vaismoradi et al. (2013) by employing a cyclical strategy of naming, reviewing, and searching for codes and themes, with new 'nodes' being added to the document as identified. This strategy also incorporated a method of inter-code checking to ensure similarities and consistency within the coding (Barbour, 2001). This inter-code checking was valuable to affirm the veracity of the early findings and it also provided the researcher with a greater understanding of the patterns of codes and themes in the early analysis (Anney, 2014). When this stage of thematic analysis was completed, all of the nodes were printed out and a further cycle of checking and re-reading, using constant comparison, was undertaken by the researcher as the paper copy of each category was reviewed for node/theme content consistency (Braun & Clarke, 2006).

The next stage of thematic analysis involved listing all nodes/codes under consideration in a grouping exercise using a matrix. This practical strategy was found to be extremely helpful in the analysis of phase two data and was therefore repeated in phase three thematic analysis. Listing the

nodes/codes into clusters or categories to form themes in a matrix provided a powerful visual basis to look at the data and to reflect on, and consider, the different codes and categories and how they could be combined into larger overarching themes. The matrix served to visually represent the codes and the code clusters which formed themes identified, and to check for similarities between the content of the themes and to examine the relationships between the themes. At this point in the analysis 70 nodes/codes and four major themes were tabulated into the matrix. The next stage of the thematic analysis in this study involved reconfiguring the content of the matrix into a more visual platform in the form of thematic maps. According to Braun & Clarke (2006) thematic maps are a powerful way to visually identify the conceptualised themes and their relationships. Furthermore, thematic maps are accepted as a practical way to review and hone codes, code clusters (themes) and overarching themes as part of the process of data analysis.

In this study, the researcher found the process of mapping and charting data into visual thematic maps particularly helpful in structuring the overarching themes, themes, and their relationships. Both during the development of the matrix, and subsequently during the construction of the thematic maps, content was debated with the academic supervisor and considered in the context of validity and integrity in relation to the data corpus (Braun & Clarke, 2006). This debate and further consideration and analysis of the thematic map content supported deepened conceptualisation of the themes, and supported amalgamation of codes into broad themes and overarching themes. Through this process of debate and review, the importance of themes relating to the study aims were challenged. An initial overarching theme of 'symptomology' was largely discarded with only relevant elements incorporated into a theme around the impact of symptoms on participation. Overlapping themes were combined and overarching themes were teased out and made clearer. This resulted in refinement of codes and themes to conclude with eight subthemes and two overarching themes. The two overarching themes identified were 'Pervasive Impact on Participation and Self-Identity', (four subthemes) which described the impact of inflammatory arthritis on participants' ability to engage in meaningful self-directed occupations and 'Learning to Live Well with Inflammatory Arthritis' (four subthemes) which describes the participants' view and experiences on how the multidisciplinary-led early arthritis clinic model had supported them to live well with inflammatory arthritis.

### **3.7.9 Ethical Approval & Data Collection**

Ethical approval for this study was obtained from Tallaght University Hospital Research Ethics Committee, Naas General Hospital Research Ethics Committee, Waterford University Hospital Research Ethics Committee and Sligo University Hospital Research Ethics Committee prior to the commencement of data collection (see Appendix A8). Data collection was completed November 2017 to June 2018.

### **3.8 Strategies for Increasing Rigour in the Qualitative Analysis of Phases 2 and 3**

Qualitative description was the guiding methodology for phases two and three in this study. Rigour in qualitative research is ensured via the use of various strategies with the data collection and data analysis stages of the study. In this study the qualitative analysis of phases two and three was guided by strategies to increase rigour including trustworthiness and credibility, integrity and reflexivity of

the researcher, member checking, and peer review which will now be considered (Krefting, 1991; Milne & Oberle, 2005).

### **3.8.1 Trustworthiness and Credibility**

Credibility relates to how authentic, legitimate, and reliable the findings are in a research study (Carpenter & Suto, 2008). Principally, the credibility of qualitative description-based research is subject to *“the researcher’s ability to capture an insider (emic) perspective and to represent that perspective accurately”* (Milne & Oberle, 2005, p. 413). The ability of the researcher to capture and present the participants' perspective in the data gathering of phases two (the focus groups) and three (the individual semi-structured interviews) of the study, and subsequent data analysis was central to the authenticity and credibility of the study. Milne and Oberle (2005) contend that trustworthiness and credibility of the qualitative data is achieved by a number of factors, namely ensuring; participants have freedom to speak, participants' voices are heard and finally participants' voices are veraciously represented. Strategies to achieve trustworthiness and credibility employed in the present study will now be outlined.

#### **3.8.1.1 Freedom to Speak**

Adequately ensuring freedom to speak is agreed as an important part of ensuring rigour in qualitative description analysis. Milne and Oberle (2005) report that adequately ensuring participants' freedom to speak is subject to a number of study design-based issues including participant selection, and participant-driven data collection. The current study employed steps in both the data collection and data analysis stages of phases two and three to support freedom to speak and these will now be considered in turn.

#### **3.8.1.2 Participant Selection**

A purposive sampling strategy was employed for both the focus groups (phase two) and for the individual interviews (phase three). The rationale for this sampling approach was based on the knowledge that this would ensure that 'key participants' were targeted for inclusion who could provide in-depth information on the topics at hand and have the personal experience to inform on the topic. Key participants are specifically selected for inclusion in qualitative description studies based on their experience and expertise in the area under exploration in the study (Creswell & Plano Clark, 2007; Lysack et al., 2006). With regard to phase two sampling, there are a limited number of multidisciplinary-led early arthritis clinics available in Ireland, therefore there was directed purposive selection of the nurses, occupational therapists, and physiotherapists who currently work in these clinics, inviting them to participate in the focus groups. It was considered that nurses and allied health professionals currently working in these multidisciplinary-led early arthritis clinics would have an informed opinion as to how these clinics address occupation-based participation and occupational engagement in those individuals with newly diagnosed inflammatory arthritis, based on their clinical practice. Participant selection in phase three of this study sought to purposively include participants who had been diagnosed with inflammatory arthritis within the last two years and had attended one of the four multidisciplinary-led early arthritis clinic sites. In this way participants in phase three of the

study had an informed opinion due to their lived experience of both their recent diagnosis and also their service users' experience of these clinics.

In phase two the researcher attempted to achieve 100% coverage of this emerging area by purposively recruiting allied health professionals and nurses currently working in all four multidisciplinary-led early arthritis clinics. Phase three employed a flexible sampling strategy whereby sampling was concurrent to the data analysis and sampling purposely comprised adequate representation of participants from each site. Saturation was viewed as achieved when there was both a reasonable range of ages and spread of participants from each of the four rheumatology sites interviewed, and when the data gathered informed findings and no new findings were identified (Milne & Oberle, 2005).

In this study, data collection for the focus groups (phase two) continued over a four-month period and data collection for the semi-structured interviews (phase three) over an eight-month period. This allowed for development and refinement of the data gathering approaches in each phase based on emerging findings and review of reflexive log. This ongoing refinement fits within the qualitative description framework which allows for modification and transformation within the data collection as patterns begin to emerge (Neergaard et al., 2009). Furthermore, this process of development and refinement of data collection approaches, over subsequent focus groups (phase two) and interviews (phase three), to ensure all study objectives are met and no information is missed, sits within thematic analysis methodologies to add rigour to the study findings (Vaismoradi et al., 2013). Data collection for phases two and three extended over a period of four and eight months for each phase respectively thus allowing for prolonged contact. This prolonged contact with the study allowed the researcher to immerse in the topic and develop an in-depth understanding of the phenomenon under study and adds to the credibility of the findings (Creswell, 2009; Teddlie & Tashakkori, 2009). Prolonged engagement was not with the participants in the study, as the participant contact related to a one-off attendance at a focus group (phase two) or an individual semi-structured interview (phase three).

#### **3.8.1.3 Participant Driven Data Collection**

Use of a flexible topic guide such as the semi-structured topic guide for the focus groups (phase two) and the semi-structured interview guide for the interviews (phase three) is recognised as an important strategy to ensure participant driven data. This flexible topic guide provided in advance allows participants time to reflect on the topics and types of questions under consideration, and to prepare in advance of meeting. The topic guide highlighted that the questions and topics were not exhaustive. It also advised participants that they could raise other related issues if they felt these were important. Furthermore, the topic guide also facilitates freedom to speak in the data collection stages as it enables participants to share their own narrative and perspectives (Milne & Oberle, 2005).

Data collection methods for phases two and three were based on the topic guide and utilised a conversational style to encourage a free-flowing and flexible dialogue rich in detail and allowed for the participants' narrative, and therefore included expansion and diversion into related issues (Patton, 2002). This conversational style helped to ensure the emic perspective of the participants

and also facilitated a researcher-participant relationship which adds to the rigour of the study design and subsequent findings (Milnes & Oberle, 2005).

### **3.8.2 Ensuring Participants' Voices are Heard**

Milne and Oberle (2005) report that an important feature of qualitative description studies is adequately ensuring that participants' voices are heard. Within this study three of the methods recommended by Milne and Oberle (2005) were employed in effort to explore the topics in detail, and to allow participants to opportunity to contribute and ensure their voices were heard. These data gathering-based methods include use of focus groups to facilitate discussion (phase two), probing for clarification and depth (phases two and three), and member checking (phases two and three). These three strategies will be outlined now.

#### **3.8.2.1 Focus Groups to Facilitate Discussion**

Focus group data is noted to be participant driven because this platform allows a safe, shared environment to recount narrative related to the topic and to facilitate sharing and discussing of the topic (Milne & Oberle, 2005). The environment of a focus group enables participants to hear each other's perspectives, and this can prompt sharing and discussion of viewpoints. Focus groups were an appropriate method for phase two data collection as all participants were healthcare professionals and the focus of the discussion was on non-personal topics relating specifically to professional practice issues. Phase two focus groups generated dynamic and active discussion of the topic. Participants were eager to share their views and also listened to each other and debated differing perspectives. This forward and backward discussion and debate of the topic helped to explore in detail service providers' perspectives of the impact of newly diagnosed inflammatory arthritis on service users' participation and service users' occupational needs. It also helped to tease out some of the issues and challenges relating to managing this population using this service model, and the barriers and facilitators to implementing international standards of care for this population. Therefore, in the focus groups the researcher's role was one of facilitator outlining the purpose of the focus group and supporting full group participation (Milne & Oberle, 2005).

#### **3.8.2.2 Probing for Clarification and Depth**

During both the focus groups and the individual interviews, the researcher employed the strategy of probing for clarification and depth. Frequently used in qualitative description studies, this approach is recognised as a useful tool to provide increased understanding about the study topics (Milne & Oberle, 2005). This strategy requires the researcher be attentive to cues that suggest participants have more to say on a topic or issue. Within the focus groups and the individual interviews, participants were facilitated to expand on personal points and perspectives relevant to the research topic by active listening, asking follow-up and related questions, and encouraging expansion of the discussion. During both the focus groups and the individual interviews, the researcher used natural breaks within dialogue to paraphrase and summarise content discussed, before transitioning to the next stage. This helped to check authenticity of data gathered and to facilitate a natural opportunity for the participants to add in, clarify or further develop their narrative. A final summing up was

conducted by the researcher at the end of each focus group and at the end of each interview and participants were invited to make any clarifications or further additions.

### **3.8.2.3 Member Checking**

As discussed earlier in this chapter, a key strategy in qualitative description data analysis known as member checking (Mays & Pope, 2000; Milne & Oberle, 2005), was employed in phases two and three data gathering. Member checking is an established method to enhance the credibility of findings and add rigour to the study processes. It is undertaken in qualitative description studies in order to support active involvement of research participants to help validate data gathered and confirm the accuracy of findings (Birt, Scott, Cavers, Campbell, & Walter, 2016). The process of member checking facilitates a natural opportunity for the participants to add in, clarify or further develop their narrative. In this study member checking was completed by the researcher in the dialogue of the focus groups and the interviews at the natural end of participants' answers, and at transition stages in the data gathering, to mirror what was heard and to paraphrase and summarise content shared. A final summing up was conducted by the researcher at the end of each interview and participants were invited to make any clarification or additions. These member checking strategies are in keeping with the recommendations of qualitative description authors who recommend that member checking should be an ongoing process of clarifying and probing and cross-checking findings during the interview and summarising main points at the end of each interview (Barbour, 2001; Mays & Pope, 2001; Milne & Oberle, 2005).

During data collection, the process of reading and re-reading of the transcripts while listening to the audio to ensure that no information was omitted, and to confirm accuracy, is also a recognised part of the member checking process (Mays & Pope, 2000). Each participant of the phase two focus groups was offered a copy of their group transcript for member checking, and in phase three participants were offered a copy of their own interview transcript for member checking. Additionally, as part of the process of member checking and validating the findings, participants from both phases two and three were forwarded a summary (see Appendix A7 & A12) of preliminary emerging issues and themes collectively representing all of the data from their focus group or interview to check for accuracy and representedness (Creswell, 2009; Krefting, 1991; Milne & Oberle, 2005). These member checking strategies were important in the data analysis as both phases sought to collect data on the lived experience and therefore this check mechanism helped ensure participant representedness on the topics (Birt et al., 2008). In this way qualitative data collected was member checked by study participants to ensure respondent validity and reduce possible researcher bias.

In this study in phases two and three there was a high level of engagement, debate, and discussion by participants in the in-dialogue member-checking and this strategy was found to be effective in clarifying and confirming perspectives on the topics discussed. None of the participants engaged in the member checking process following data analysis and receipt of synthesised findings with emerging issues. This may be due to the time lapse between engaging in the research data collection and receipt of the summary of findings, which is typical in qualitative research. In addition, it may reflect proposals by Estroff (1995) who suggests that participants may decide to broadly accept all

interpretations presented by the researcher without further question. Neither levels of engagement in the member checking processes were surprising to the researcher, there was dynamic engagement in-dialogue and participants gave of their time and opinions, and it is likely that they were not motivated to engage in the final member checking of the synthesised findings as they had already engaged.

### **3.8.3 Ensuring Participants' Perceptions are Accurately Represented**

Milne and Oberle (2005) report that in qualitative description research the trustworthiness of a research study is a significant element of the study design. These authors propose that trustworthiness is subject to a number of data gathering and data analysis-based methods which were incorporated into this study design and include ensuring accurate transcription, coding, and continuous attention to context. These data gathering and data analysis-based study methods will be outlined now.

#### **3.8.3.1 Ensuring Accurate Transcription**

This important strategy to support the rigour of this qualitative study has been outlined earlier in this chapter. Audio from both the focus groups and the individual interviews were audio recorded on an Olympus DS-55 digital recorder. The researcher listened back to each audio within 24 hours of completion to check the recording. All of the audio recordings were transcribed verbatim by a professional transcriber for analysis. The researcher maintained a reflexive log for phase two and three data collection and used this log to retain a written record of a synopsis of the completed focus groups and interviews, and also to summarise emerging topics and to signpost subsequent data gathering. Use of a field journal is recognised as an important strategy to add to the credibility and rigour of a study (Anney, 2014). Transcripts were read and re-read many times while listening to the audio to ensure no information was omitted and to confirm it as an accurate reflection of the content of the interview (Creswell, 2009).

#### **3.8.3.2 Thematic Analysis and Coding**

Qualitative data was analysed using thematic analysis and methodologies which are congruent with qualitative description as it is *“a method for identifying, analysing, and reporting patterns (themes) within data”* (Braun & Clarke, 2006, p. 79). Thematic analysis is appropriate in studies which to aim to explore meaning and the narrative of experiences as well as describe the emerging findings within context (Vaismoradi et al., 2013). The theoretical framework of qualitative description guiding the qualitative study design and the thematic analysis methodologies employed in the data analysis endeavour to provide rich description of the experience rather than high level interpretation and thus minimise researcher bias in the analysis. Thematic analysis is viewed as a flexible approach to examining narrative text from focus groups and/or interviews for common patterns (themes) and describing in rich detail the qualitative findings.

From a philosophical perspective it is considered that thematic analysis is based on a factist perspective which seeks to inform on the perceptions and behaviours of participants, and it assumes that the data gathered is authentic (Braun & Clarke, 2006; Vaismoradi et al., 2013). Thematic analysis

requires searching across the data corpus to find repeated patterns of meaning which form the themes. It employs methodologies in the data analysis which endeavour to provide rich description of the experience rather than high level interpretation (Braun & Clarke, 2006). These methodologies, outlined in Table 3.2 below, provide clarity on how the qualitative data was analysed in this study and are important in adding to the rigour and credibility of the study. This form of analysis recognises the active role of the researcher in the research process, identifying themes and further exploring areas of interest within the data. Furthermore, implementation of this framework of thematic analysis allows this study to be compared to other studies on the topic (Braun & Clarke, 2006). Braun and Clarke (2006) recommend a checklist of criteria for thematic analysis which was employed in the qualitative data analysis.

Table 3.2: Criteria for Thematic Analysis (Braun & Clarke, 2006, p. 87)

Criteria	Description	Used In Current Study
1. Familiarisation with Data	Data is transcribed verbatim, and transcripts are checked against audio for accuracy. Reading and re-reading noting initial ideas	✓
2. Generating Initial Code	Coding interesting features of the data systematically across the data corpus, collating data relevant to each code.	✓
3. Searching for Themes	Collating codes into potential themes, gathering all data relevant to each potential theme.	✓
4. Reviewing Themes	Checking if themes work in relation to coded abstracts (Level 1) and the data corpus (Level 2), generating a thematic map	✓
5. Defining and Naming Themes	Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme.	✓
6. Producing the Report	The final opportunity for analysis. Selection of vivid, compelling abstract examples, final analysis of selected abstracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis	✓
7. Active Researcher	Researcher is active in the research process.	✓

According to Braun and Clarke (2006) a theme “captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set” (p. 82). The active involvement of the researcher in the research process combined with the debate and discussion with the academic supervisor are important steps in thematic analysis to identify and refine themes. Of note in thematic analysis methods the ‘keyness’ of a theme is dependent on what significance it encapsulates towards the study objectives. Frequency and prevalence of themes is less relevant in thematic analysis than importance and meaning with regard to the exploration of the study objectives. This differs from content analysis methodologies which

include quantifiable measures counting the frequency of codes and transforming these initially qualitative findings into quantitative data (Braun & Clarke, 2006; Vaismoradi et al., 2013).

In this study 'theoretical' thematic analysis methods were employed which were guided by the researcher's theoretical and clinical interest in the research topic and supported the researcher's engagement in the literature prior to analysis. This approach allowed a rich and detailed description of the data as well as more detailed analysis of the health services implications (Braun & Clarke, 2006). The step by step of thematic analysis employed in this study was discussed earlier in the analysis sections of this chapter (focus group data analysis (3.6.8) and interview data analysis (3.7.8)).

Steps to add rigour to the coding process in the data analysis of phases two and three have been outlined previously in this chapter. Phases two and three both employed strategies of intra-coder agreement (Creswell & Creswell, 2018) (re-coding 'as new' the three focus group transcripts and the ten individual interview transcripts) to add to the rigour of the analysis. Furthermore, both phases utilised inter-coder checking (Barbour, 2001) during analysis by cyclically naming, reviewing, and searching for themes and then checking to ensure similarities and consistency within the coding (Vaismoradi et al., 2013).

### **3.8.3.3 Attention to Context**

It is considered that an understanding of the context of the qualitative data gathering, both focus group and individual interview adds to the trustworthiness and authenticity of a study (Milnes & Oberle, 2005). Use of notetaking during the qualitative data gathering, as well as maintenance of a reflexive log were strategies employed by the researcher to add understanding and meaning to the data. These strategies helped to gather nuanced data within the interviews themselves, by identifying points to tease out further, as well as informing subsequent data gathering within both phases two (focus groups) and three (individual interviews). This attention to context informed the iterative cycle of data gathering and data analysis which allowed for new lines of enquiry to be followed in subsequent data gathering and added to the depth and quality of data analysis (Vaismoradi et al., 2013). This is in keeping with recommendations of Braun and Clarke (2006) who advise a looping process with movement back and forth between the phases of data gathering and analysis.

The researcher's own experience would have also influenced context in data collection. The researcher has clinical experience in both traditional and the newly established multidisciplinary-led early arthritis clinics as models of service delivery and this clinical experience in both service models would have influenced, and added to, attention to context.

### **3.8.4 Transferability**

The ability to transfer or generalise findings in qualitative studies is an important part of adding to the veracity and relevance of a study. Transferability is predicated on two main factors, namely the use of purposive sampling, and the use of thick description in the reporting of findings (Anney, 2014). Purposive sampling in this study has been outlined previously in this chapter, but it is important to

reiterate the value of focusing on key participants or informants to provide in-depth findings. Thick description in reporting of each of the steps within the research methodology is important to ensure that this study could be replicated by other researchers. Every effort has been made in this chapter to provide thick description of the methodologies used and rationale and context for same in keeping with the COREQ guidelines for reporting the qualitative data (Tong, Sainsbury, & Craig, 2007).

### **3.8.5 Integrity and Reflexivity of the Researcher**

It is recommended that in order to ensure integrity in a qualitative study it is necessary to consider potential sources of bias in the study namely the researcher personal influencers, researcher bias, and peer review (Milnes & Oberle, 2005).

#### **3.8.5.1 Researcher's Personal Influencers**

The researcher was not an experienced researcher prior to conducting the research. She had undertaken qualitative postgraduate research at MSc. level exploring the impact of a new diagnosis of RA on paid employment and had also been involved in some modest clinical practice studies, but her main experience was in the clinical field of rheumatology occupational therapy. This clinical experience and novice researcher experience are recognised as potential for researcher bias and have been considered in the proceeding sections, as have strategies employed to minimise this bias.

The researcher was responsible for developing the research question and this was generated in the context of her clinical rheumatology experience. Her understanding of the current rheumatology service context in Ireland for management of participation in rheumatology services and reading of the international literature on this topic informed the overall study design and the individual study phases. The researcher facilitated two of the focus groups with her academic supervisor and she also completed many though not all of the individual interviews. This prolonged engagement in the data gathering, in phase two and three over a four- and eight-month period respectively, supported her immersion in the topic and deepened her appreciation of the study context (Anney, 2014). This prolonged contact and engagement is recognised as a positive, as her ability to deeply understand the topic and ability to probe and clarify depth when necessary added to the integrity of the findings (Anney, 2014; Milnes & Oberle, 2005). However, the potential for bias is also recognised and was minimised by use of reflexive strategies outlined previously.

As a reflexive researcher, it is recognised that the participants' experiences captured in the focus groups and in the individual interviews would have been viewed through the lens of the researcher's own experiences and interpretations as a rheumatology occupational therapist. Also, it must be acknowledged that she would have come to the analysis stage with preceding knowledge of the data and also some early analytic thoughts. However, strategies to increase rigour and trustworthiness were employed in this study in response to these known intrinsic design issues and to strengthen the quality of the study design, analysis, and study findings.

### **3.8.5.2 Reflecting on Researcher Bias**

In qualitative description studies the analysis and results are reported descriptively staying close to the data but a low level of interpretation is recognised (Neergaard et al., 2009). Similarly, thematic analysis is viewed as a flexible approach to examining narrative text from focus groups and/or interviews for common patterns (themes) and describing in rich detail the qualitative findings. It does not purport to provide a high level of interpretation to the findings (Braun & Clarke, 2006).

Conneeley (2002) asserts that in qualitative research, the researcher's own place in society has an impact on the research, and the role of a practitioner-researcher has opportunity for bias which must be considered. This recognition of the impact of the researcher's background and experience is important when considering bias in data collection and analysis (Kuczynski & Daly, 2003). In this study the researcher held a dual role of clinician and researcher/interviewer. As an occupational therapist with twenty years' experience in the clinical area of rheumatology, the researcher's input in facilitating the focus groups and conducting individual interviews was grounded with consideration of the context and enabled an understanding and ability to probe and clarify depth when necessary (Milnes & Oberle, 2005). Also, as the researcher was also involved in the data gathering, it must be acknowledged that she would have come to the analysis stage with preceding knowledge of the data and also some early thoughts on analysis. This potential for bias, due to early interaction with the data, was minimised by full immersion in the audio and the transcripts for familiarisation with the full extent of the data (Braun & Clarke, 2006). Furthermore, the academic supervisor facilitating a focus group and the independent interviewer undertaking some of the individual interviews were additional strategies to minimise bias.

Allowing participants to share their own narrative and perspectives in the data gathering was an important tool to ensure client driven data and to minimise researcher bias. Use of member checking in-dialogue and during data analysis were important steps utilised to minimise researcher bias and ensure that the participant voices were heard. Also, the use of notetaking during the qualitative data gathering and the maintenance of a reflexive log were strategies employed by the researcher to minimise bias and to add to the integrity of this study (Vaismoradi et al., 2013).

### **3.8.6 Peer Review**

The qualitative description framework recommends peer review as a method to increase veracity and validity of findings and to test growing concepts and findings in order to remain close to the meaning identified (Anney, 2014; Creswell, 2009; Lysack et al., 2006; Milne & Oberle, 2005).

There was extensive liaison with the academic supervisor through all of the overall study and with the design of the qualitative phases (phase two and three) the focus group question guide, facilitating a focus group, the semi-structured interview design and in the peer review of the analysis. Peer review of all emerging themes (phase two and three) was completed by the academic supervisor, second-checking a random selection of transcripts to examine if issues identified are accurate and to ensure that no issues were missed (Barbour, 2001; Richards & Morse, 2007). Conceptualised themes were debated at length and challenged at data analysis discussions with the academic

supervisor. This was in keeping with recommendations by Braun and Clarke (2006) who advocate an ongoing reflexive dialogue between the researchers (in this case the researcher and the academic supervisor), to discuss themes and judgements, and choices around themes, and meaning in the data set. This process of debate and challenging themes supported honest consideration of the data and deeper understanding and reflexive analysis of the resulting findings (Anney, 2014). Use of direct quotes in the results chapters (chapters 5 and 6) support the emerging themes and add to the trustworthiness of the findings (Milnes & Oberle, 2005).

### **3.9 Summary**

In this chapter, this sequential mixed methods design typology and the embedded design model used in this research study has been outlined. An overview of the structure of the study has been presented and a detailed description of each of the phases of the study has been described. Phase one (quantitative research survey), phase two (qualitative focus groups with service providers), and phase three (qualitative semi-structured individual interviews with service users) processes have been presented.

The findings from each phase of the study will be presented in the following three chapters (Chapters Four, Five, and Six). Chapter Four reports on phase one of the study and presents the service providers' perspectives on the delivery of work-based participation support in current rheumatology services for inflammatory arthritis. Chapter Five outlines the service providers' perspectives on the multidisciplinary-led early arthritis clinics as a model for addressing occupation-based participation and engagement in newly diagnosed inflammatory arthritis. Chapter Six presents the service users' perspectives on the impact of newly diagnosed inflammatory arthritis on participation and how current services address client-identified occupation-based participation and engagement needs.

## CHAPTER FOUR: RESULTS FROM ONLINE SURVEY

### 4.1 Introduction

Phase one of this study was focussed on an exploration of service providers' perspectives on the delivery of work-based participation support in current rheumatology services for inflammatory arthritis. This phase of the study aimed to scope patterns of work referral within current service provision, and types of work support currently available in Irish rheumatology services for people with inflammatory arthritis. Respondents were asked to identify factors which help or hinder work-based service provision including current practices and challenges. Furthermore, this phase of the study was concerned with exploring the role of occupational therapy in addressing work from the rheumatology teams' perspectives.

Data was gathered using a semi-structured anonymous online descriptive survey which was designed specifically for the purposes of this current study. The online survey was completed by medical and health professionals working in clinical rheumatology. In this chapter the findings will be presented which will address the objectives of this phase of the study as outlined below:

- To explore factors that influence or hinder referring for work support for people with inflammatory arthritis in their current clinical services.
- To examine service providers perspectives on the extent and type of work support currently available for people with inflammatory arthritis.
- To explore service providers perspectives on how occupational therapy addresses work with this population.

Qualitative findings using participant quotes are used throughout to support the description of the findings and the source of each quote is given after the quote. Abbreviations will be used as follows; (Dr) will be used for quotes taken from a medical doctor participant; (N) will indicate quotes taken from a nurse participant, and (PT) will be used to indicate a quote taken from a physiotherapist.

### 4.2 Overview of Chapter

The structure of the online survey was used to group and present the findings from this phase of the study:

- Firstly, a basic description of the respondents will be outlined.
- Then, a profile of the characteristics of the typical rheumatology population treated by the respondents will be outlined.
- Findings on current rheumatology practice in addressing work in Ireland will be presented.
- Data on occupational therapy input in addressing work-based participation issues from the perspective of the other rheumatology team members will be presented.
- and finally, potential strategies recommended by the respondents to improve rheumatology work-based participation support services will be discussed.

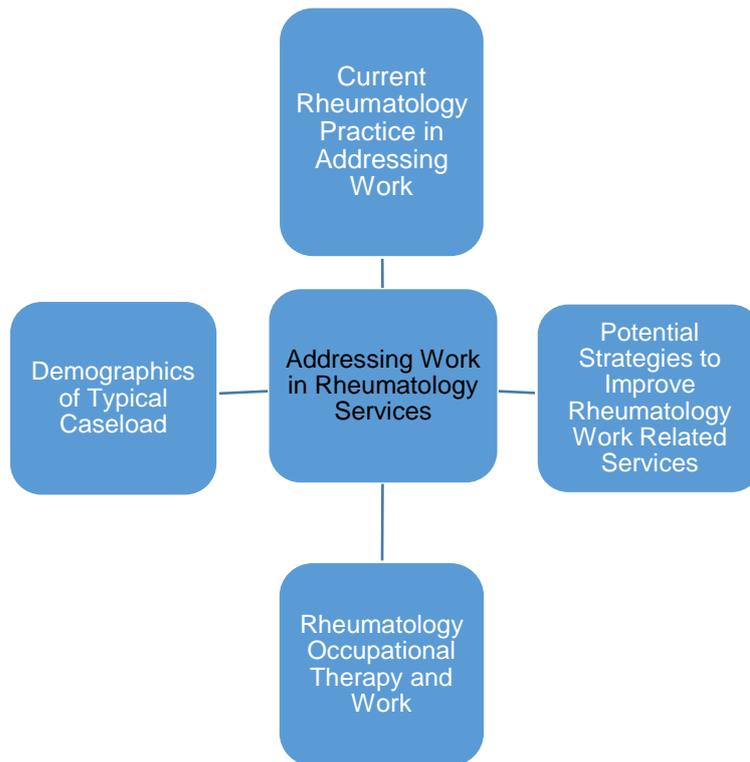


Figure 4.1: Visual Descriptor for Presentation of Findings

### 4.3 Sample

An email invitation including the participant information leaflet and the hyperlink to the online survey was sent out to 338 rheumatology team members, and 73 completed questionnaires were returned and included in the analysis, representing a response rate of 21.6%. Of the 73 returned questionnaires, 30 (41%) were returned by physiotherapists, 25 (34%) were returned by nurses, and 18 (25%) were returned by medical doctors.

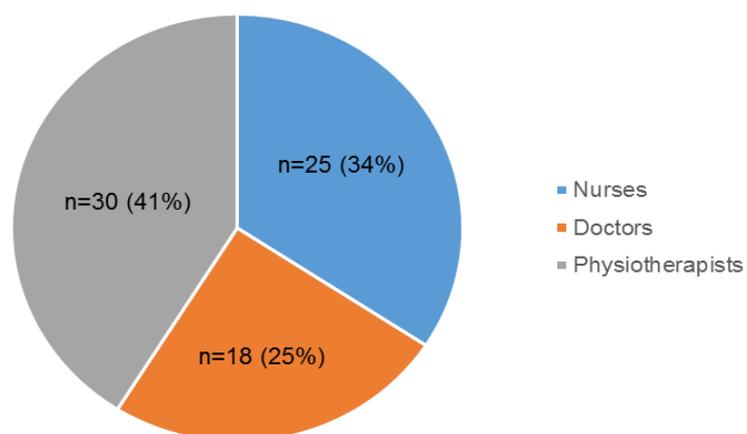


Figure 4.2: Breakdown of Respondents by Profession

## 4.4 Demographics of Typical Clinical Caseload

### 4.4.1 Age

Respondents indicated that 71% of service users were of working age, namely between 18 and 65 years of age. A full breakdown of participants' responses regarding the age profile of their caseload is presented in Figure 4.3 below.

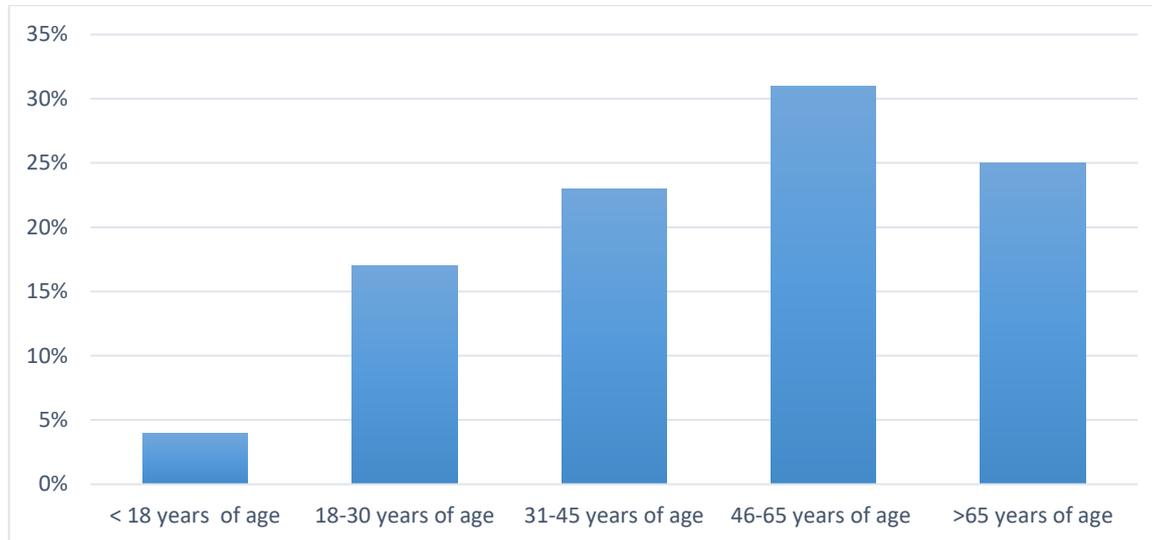


Figure 4.3: Age Demographic of Rheumatology Service Users

### 4.4.2 Profile of Worker Role Categories

Participants were asked to profile their current caseload using the International Standard of Occupations Classification (ISCO-08) in order to gather information on the types of worker roles presenting to current rheumatology services. Participants were asked to divide their current caseload into percentages per worker role under the classification framework. This task proved to be a difficult one for respondents with 52 of the 73 completing this question. Qualitative comments added by respondents reflect the challenge associated with it and the lack of awareness of the rheumatology team members regarding caseload worker role status.

*'I haven't thought about this before and cannot make a fair comment on this.'* (PT)

*'I don't know as we have no data to answer your question.'* (Dr)

The 52 responses to this question were analysed and are presented in Table 4.1 below. The ranges for each of the worker categories reported by those who completed this question are presented.

Table 4.1: Profile of Rheumatology Population Using the ISCO-08

Occupation	Range
<b>Managers</b> (Managing directors, chief executives, business services, sales, marketing and development managers, hospitality, or retail managers)	0-20%
<b>Professionals</b> (engineers, architects, doctors, health professionals, nurses, teachers, IT, and legal professionals)	3-50%
<b>Technicians and Associate Professionals</b> (electricians, healthcare assistants, sports instructors, legal associates, bank officials, telecommunication, and broadcasting technicians)	3-50%
<b>Clerical Support Workers</b> (secretaries, data entry positions, bank tellers, administration roles)	3-50%
<b>Service and Sales Workers</b> (travel attendants, waiters, bar staff, hairdressers, beauticians, childcare workers, shop sales staff)	5-50%
<b>Skilled Agricultural, Forestry and Fishery Workers</b> (farmers, forestry fishery workers)	0-50%
<b>Craft and Related Trade Workers</b> (builders, plumbers, plasterers, painters, mechanics, handicraft workers, cabinet makers, garment, and food producers)	5-40%
<b>Plant and Machine Operators and Assemblers</b> (stationary plant and machine operators, mobile plant operators, drivers)	0-20%
<b>Elementary Occupations</b> (cleaners, labourers, street vendors, refuse workers)	2-60%
<b>Armed Forces Occupations</b> (commissioned and non-commissioned officers and other ranks)	0-10%

#### 4.4.3 Work Needs

Work needs were recognised as an important issue for rheumatology service users. Of the total sample, the highest number of respondents (n=40, 55%) estimated that between 25-49% of their caseload had work needs requiring assessment or intervention. In addition, 23% (n=17) of respondents identified that 50-75% of rheumatology clients in their services have work needs necessitating evaluation and intervention (see Figure 4.4).

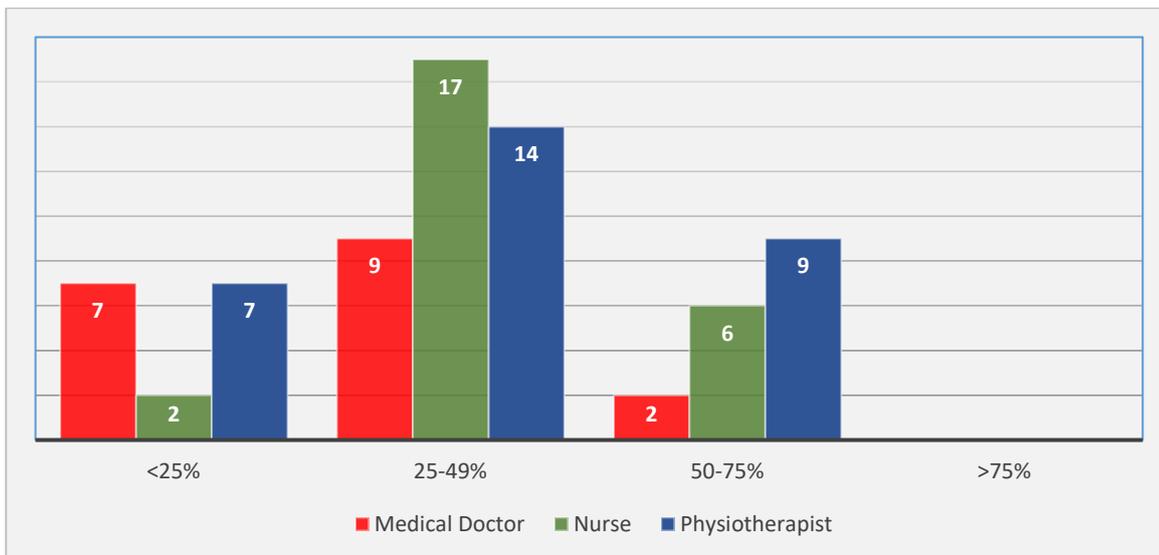


Figure 4.4: Proportion of Clients with Work Needs

#### 4.5 Current Rheumatology Practice in Addressing Work

The majority of respondents across the three professions of nursing, physiotherapy, and medical doctors (n=69, 95%) agreed that addressing employment retention was within the remit of clinical rheumatology services. Of the total number of respondents 48 (66%) reported that clients' work needs are currently supported within their rheumatology services.

##### 4.5.1 Evaluating Rheumatology Work-Based Participation Support

Respondents were asked to evaluate how well current services in which they work support work needs for clients. A numeric rating scale was used to capture this information whereby 0 indicated not at all well, through to 10 which indicated extremely well. Results from this rating scale are presented in Figure 4.5 below.

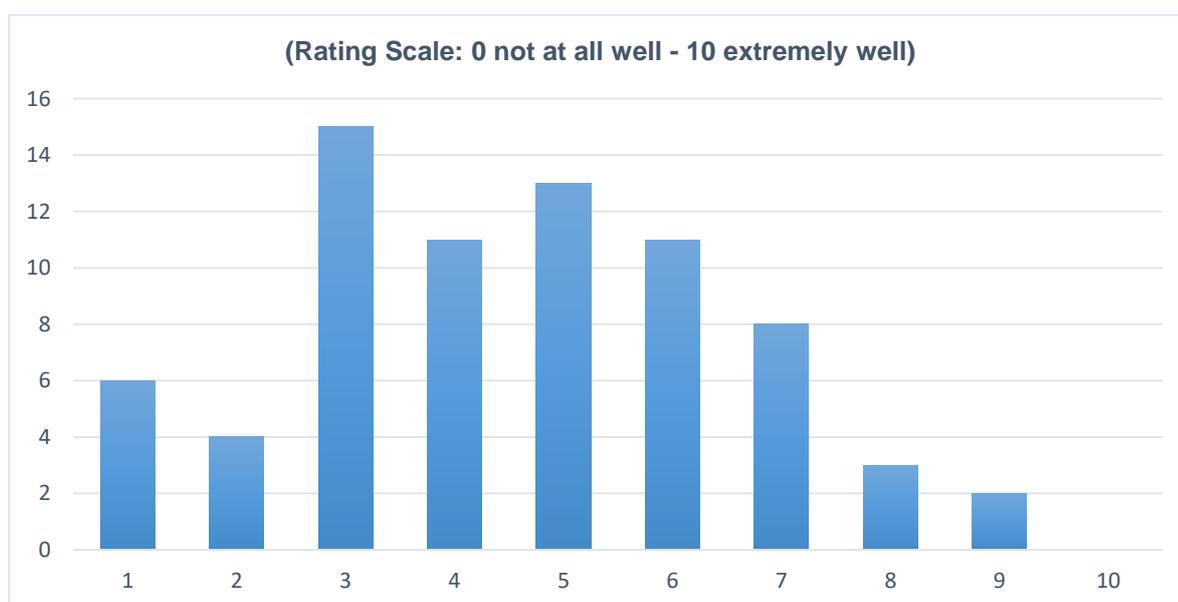


Figure 4.5: Evaluation of How Well Work Needs are Currently Supported in Rheumatology Services

The greatest number of respondents (n=49, 67%) scored 5 or less indicating these respondents were less than satisfied with the level of support provided for work needs in current clinical rheumatology services. Overall, there was broad consistency of scores across the three disciplines with no major variance noted in responses received per discipline (see Figure 4.6 below).

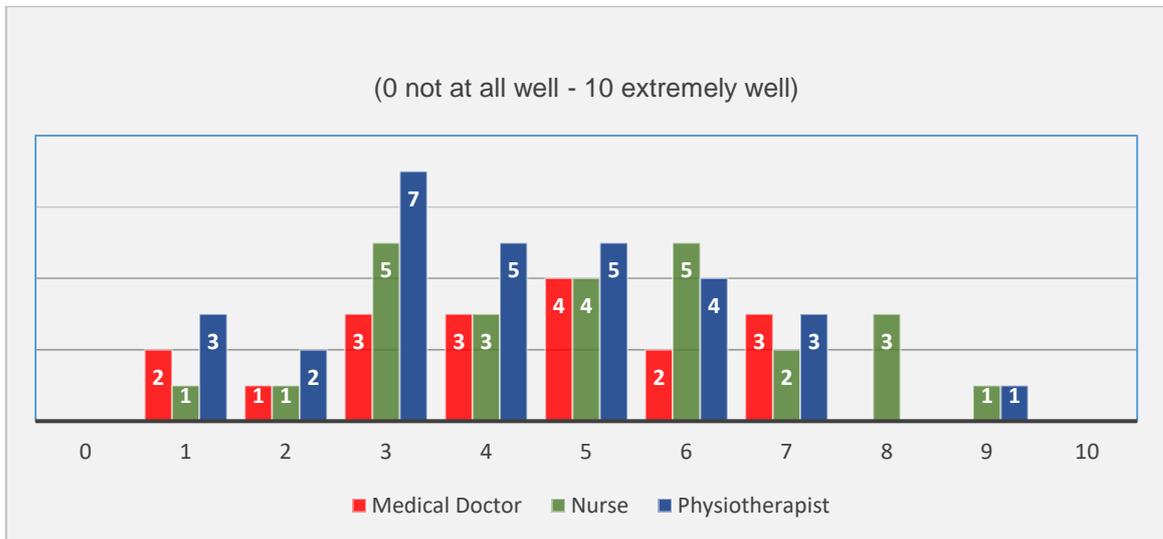


Figure 4.6: Perspectives on How Well Work Needs are Supported in Current Services per Discipline

#### 4.5.2 Evaluating Rheumatology Work Support – Asking the Work Question

A majority of respondents (n=59, 81%) reported that they routinely ask clients at their first appointment about their work status and work ability, with the highest proportion of the medical respondents (n=17, 95%) reporting that they routinely ask about work at a first appointment. However, results indicate that work-based issues were less frequently addressed at subsequent appointments with a reduction in responses across all disciplines (n=41, 56%). Table 4.2 presents the overall and breakdown of responses below.

Table 4.2: Asking the Client About Work at Appointments

		Yes		No	
At First Appointment	Medical Doctor	17		1	
	Nurse	16		9	
	Physiotherapist	26		4	
	<b>Total</b>		<b>59</b>		<b>14</b>
At Subsequent Appointments	Medical Doctor	7		11	
	Nurse	12		13	
	Physiotherapist	22		8	
	<b>Total</b>		<b>41</b>		<b>32</b>

In the qualitative comments many respondents differentiated between asking about work versus providing assessment and intervention on work retention and work support. Although work appears to be routinely addressed in the initial interview process, it was not consistently included in subsequent appointments and interventions, or there were limited work-based interventions offered.

*'I often address work as in ask how it's going, that might impact on change to meds etc, but I don't treat or advise about work accommodations or getting back to work or the legal stuff that's not my role.'* (N)

*'Patients may be asked about their work issues regularly but addressing the issue is not as routine.'* (PT)

### 4.5.3 Influencers in Addressing Work-Based Issues

Respondents were asked about a number of factors which influenced their likelihood to address work issues with clients. Factors which positively influenced rheumatology team members to address work-based issues are presented in Figure 4.7 below. Respondents indicated that work issues were most likely to be addressed when the client themselves initiates the conversation about work concerns (n=68, 94%). Of interest, one rheumatology team member participant reported that addressing work was the role of the client within rheumatology services. Other influencing factors which prompted work to be addressed included when the client reports work absenteeism (n=61, 83%), when the client's work involved a physical component (n=55, 75%) and when the client is under 65 years of age (n=52, 71%).



Figure 4.7: Factors Which Influence Team Members to Address Work Issues

Factors which had the least influence in prompting rheumatology team members to address work-based issues with clients are presented in Table 4.3 below. Clients with a diagnosis of inflammatory arthritis for more than five years were least likely to be asked about work status and work issues (n=41, 56%). Furthermore, even if the rheumatology team member perceived the client to be work vulnerable or work unstable, they did not necessarily address work issues with the client, with 25

(34%) respondents indicating that even when they perceived the client to be work vulnerable this still did not prompt them to ask about work.

Table 4.3: Factors Which Made Work Issues Least Likely to be Addressed

Factors	Number (n)
Client has inflammatory arthritis for more than five years	n=41, (56%)
Client has mechanical joint changes evident on presentation	n=29, (40%)
Client is early in their disease trajectory	n=28, (38%)
Client is perceived to be work vulnerable / work unstable	n=25, (34%)

#### 4.5.4 Barriers to Addressing Work

A number of barriers to addressing work were identified with the majority of respondents (n=67, 92%) highlighted that the two main barriers to addressing work were: limited time in clinical setting to address work, and unfamiliarity with best practice for work support. Table 4.4 below outlines participants' responses to work barriers in current rheumatology services.

Table 4.4: Barriers to Addressing Work

Barriers	Number (n)
Time is too limited in clinic sessions to deal with work	n= 67, 92%
I am not familiar with best practice and legislation for work support	n=67, 92%
I do not feel I have capacity to effectively address work issues in a clinic session	n= 63, 86%
Work is too complex, and I do not have the competencies to address it effectively	n=60, 82%
My role does not include addressing work	n=27, 38%
I am not confident in my skills and ability to assess and address work issues	n=16, 22%

Qualitative comments received from the open-ended data highlight the challenges experienced by rheumatology team members to effectively manage work support. These qualitative comments identify a number of factors which influence addressing work support and help to qualify the findings presented in Table 4.2 which present the factors which make work-based issues least likely to be addressed as well as the current barriers to addressing work (Table 4.3). These include:

- Time pressure at appointments  
*'It is opportunistic. In the context of a busy service, it really is more when patients bring it up'*  
(Dr)
- Uncertainty regarding optimal timing of addressing work in the disease management pathway.  
*'The timing piece is unclear to me. When should we refer about work?'* (PT)
- Lack of knowledge of best practice in managing work-related issues.  
*'I don't know where to sign post them to if there is a problem, so I don't tend to raise it myself.'*  
(N)
- Work disability has already occurred.  
*'When patient refers to one or other social welfare benefits or asks for a letter supporting being unable to work.'* (Dr)

#### **4.5.5 Work Support Outside of Rheumatology Services**

Participants were asked if work was not addressed in clinical practice where do their service users typically access work support. Of the 30 responses to this question, n=10 (33%) reported that they did not know where clients could access work support. Some respondents (n=7, 23%) viewed the GP as the point of contact for work issues, and some (n=6, 18%) identified the role of occupational health. A very small number of respondents suggested referral to other service providers for work support included Arthritis Ireland (n=3, 10%), Citizen's Advice (n=1, 3.5%), Social Work (n=1, 3.5%), Human Resources in the Client's Workplace (n=1, 3.5%) and Social Welfare (n=1, 3.5%).

#### **4.6 Rheumatology Occupational Therapy and Work**

Responses from participants on occupational therapy input in addressing work-based participation issues from the perspective of the other rheumatology team members indicated that participants consider work as a domain for occupational therapy. Responses also highlighted limitations in participants' occupational therapy service provision which acted as a barrier to effective addressing of work issues in their current clinical rheumatology services. These findings are presented below.

##### **4.6.1 Referrals to Occupational Therapy for Work Support**

The main reasons for referral to occupational therapy were influenced by traditional occupational therapy roles in rheumatology namely: splinting (n=72, 98%), activities of daily living assessment/intervention (n=69, 94%), and joint protection education (n=64, 87%). A majority of respondents (n= 57, 78%) identified occupational therapy as the most appropriate profession to address work-based participation support. Work-related issues accounted for 55% (n=40) of rheumatology team members' referrals to rheumatology occupational therapy in this study.

Rheumatology multidisciplinary team members reported that occupational therapy in their services currently provide work-based participation interventions including:

- Provision of solutions for work-based problems (n=46, 63%)
- Applying lifestyle balance skills including coping and self-management to support work retention (n=45, 61%)
- Advice on retraining and/or return to work (n=40, 55%)
- Customise condition management skills to specifically match the work tasks of client (n=38, 52%)

Respondents reported that there was potential for the future development of the occupational therapy role in current clinical rheumatology services to contribute to work-based participation and employment retention through:

- Provision of work-related legislation (n=54, 73%)
- Liaison with co-workers/employers (n=55, 75%)
- Applying self-advocacy skills such as negotiation and communication skills (n=48, 66%)
- Advice on social benefits (n=48, 66%)

#### 4.6.2 Barriers to Referral to Occupational Therapy for Work Support

Although many respondents reported regular referral to occupational therapy for work issues, 51% (n=37) respondents reported that they did not routinely refer to occupational therapy for work-based participation support due to a range of factors as indicated in Table 4.5 below. Some respondents indicated more than one reason as a barrier to their routinely referring to occupational therapy for work-based intervention. Of the 37 respondents who do not routinely refer to occupational therapy for work-based support, 26 (70%) reported that this was due to a lack of a referral pathway for occupational therapy work-based support in current clinical rheumatology services. In addition, almost half of respondents to this question (n=17, 46%) disclosed that they did not know that occupational therapy addressed work issues.

Table 4.5: Barriers to Routinely Referring to Occupational Therapy for Work Support

Barriers	Number (n)
Lack of referral pathway for work in current rheumatology service	n=26
Lack of knowledge that occupational therapy addressed work issues	n=17
Limited availability of occupational therapy in current rheumatology service	n=9
Occupational therapy does not address work issues in current rheumatology service	n=4

Qualitative comments received on the role of occupational therapy in work support from the open-ended data highlight the lack of clarity in clinical practice around routinely referring to occupational therapy for work support and the influence of:

- Lack of knowledge of the rheumatology team of the role of occupational therapy in worker-role support.
- Limited occupational therapy service which resulted in them vetting referrals and prioritising referral for basic occupational therapy.
- View that work support is desirable or specialist rather than core occupational therapy practice in rheumatology.

*'We need early access to OTs specialising in supporting patients to return to the workforce and to remain in the workforce by re-skilling or retraining. Currently when we refer them to OT often the basic needs take priority e.g., splinting or aids to support in daily activities and there is little focus in long term follow up of work-related issues.'* (PT)

*'These would all be of benefit but access to OT services is very limited'* (N)

#### 4.7 Potential Strategies to Improve Rheumatology Work Related Services

Participants' views were sought regarding potential changes which could be made to current clinical rheumatology services to improve referral to and provision of work support services for clients. Participants were asked to consider a series of suggestions regarding the organisation and provision of work-related services and indicate which suggestions they consider may improve their existing rheumatology service. Figure 4.8 below outlines participants' responses to these potential strategies to improve current rheumatology work-related services.

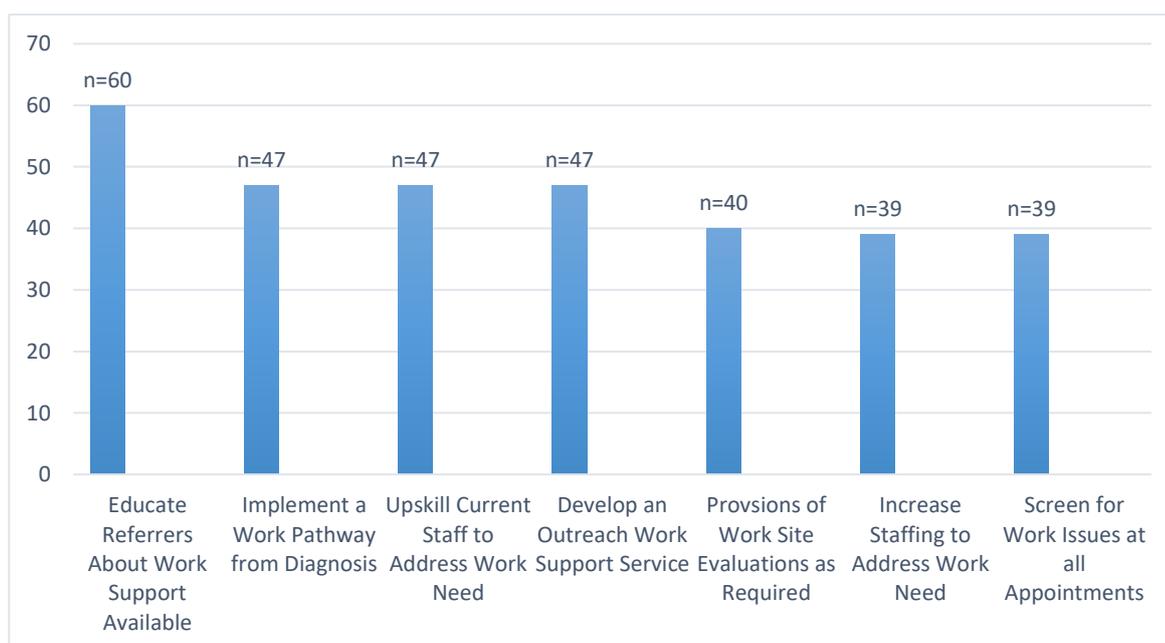


Figure 4.8: Potential Strategies to Improve Organisation of Work-Related Services

The main strategies to improve current rheumatology work support services identified by respondents related to scope for changes within existing structures. Education for rheumatology team members as to what work support is available within current service (n=60, 82%) was viewed as the most important change which could be made to existing clinical rheumatology services to improve work-based supports. Reconfiguration of current rheumatology services to include an inflammatory pathway that includes work as a core component to be addressed from time of initial diagnosis (n=47, 64%) and upskilling current staffing to address work need (n=47, 64%) were viewed as significant potential opportunities to improve current clinical rheumatology services. Additionally, development of an outreach work support service (n=47, 64%) was viewed as a strategy which could improve work-based services.

Qualitative comments also highlighted the views of some respondents that the acute hospital setting may not be the most suitable location for work-based participation support and employment retention services. Additionally, the qualitative comments identified the views that the acute setting is operating within limited resources and under significant pressure which was described as restricting the scope and type of work-support services that current rheumatology services could offer service users.

*'Work-related services might have a better chance of success if they were located in community services as part of a formal 'step-down' pathway from current hospital rheumatology service to community-based service.'* (PT)

*'The service is under a lot of pressure as it is and adding things like talking to employers or workplace assessment would work better as an outreach service.'* (Dr)

*'There is a huge gap in the service and despite detecting issues with patients' ability to work there is not enough support for patients wishing to remain in the workforce, or at least I am not aware of it.'* (N)

#### **4.8 Summary**

Findings from phase one examining employment participation support in Irish rheumatology services reinforce the evidence that current service provision is inequitable and varied. Work needs tend to be addressed within current clinical rheumatology services primarily when the client initiates the issue. Although work is routinely addressed at clients' first appointment across all disciplines, work-based issues are less frequently addressed at subsequent appointments indicating that work is not necessarily a focus of intervention. The majority of survey respondents viewed employment support as within the remit of rheumatology but perceived a lack of current service resources in relation to time, staffing, expertise. Occupational therapy was identified as the most appropriate profession within rheumatology services to address work-based participation support. However, limited access to rheumatology occupational therapy and uncertainty as to referral pathways for employment support, as well as the optimum timing for work intervention, all hamper current delivery of work support services. Despite some rheumatology services providing employment support overall current provision was deemed suboptimal and dependent on subjective variables. These results suggest that service improvements could be achieved by improving timing and quality of services to address employment needs early in the disease in line with international standards including through

educating the multidisciplinary team members as to what work-based participation support are available within services, when, and how to access them, and through the implementation of a clinical pathway for employment retention.

## CHAPTER FIVE: FINDINGS FROM FOCUS GROUPS

### 5.1 Introduction

Phase two of this study was concerned with describing and exploring multidisciplinary-led early arthritis clinics as a model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives. Data was gathered using one-off focus groups with staff working in the multidisciplinary-led early arthritis clinics with the specific purpose of addressing the objectives for this phase of the study as outlined below:

- To explore the multidisciplinary-led early arthritis clinic service providers' perspectives of the impact of newly diagnosed inflammatory arthritis on service users' participation and occupational needs.
- To examine service providers perspectives of the effectiveness of this model of service provision in addressing the occupation-based impact on participation and engagement.
- To explore the benefits and challenges of this model of service provision in addressing occupation-based participation and engagement issues.

In this chapter the findings emerging from focus groups undertaken with service providers will be presented. Qualitative description research principles were followed in the analysis as described in the methodology chapter (chapter three). Findings have been presented based on thematic analysis of the focus group data using straightforward description. Participant quotes are used throughout to support the description of the findings and the source of each quote is given after the quote. Abbreviations will be used as follows; (N) will indicate quotes taken from a nurse participant, (OT) will be used for quotes taken from an occupational therapy participant and (PT) will be used to indicate a quote taken from a physiotherapist. Each abbreviated source will be followed by a participant number, for example (OT #1), (PT #2).

### 5.2 Sample

Purposive sampling was employed to recruit allied health professionals and nurses currently working in all four sites providing multidisciplinary-led early arthritis clinic rheumatology services. The sample comprised the full complement of all of the current configuration of staff in these multidisciplinary-led early arthritis services and therefore, 100% coverage of multidisciplinary-led early arthritis team staff members working in all four clinics was achieved. Data was gathered over three focus groups comprising fifteen healthcare professionals and included nurses, occupational therapists, and physiotherapists (see Table 5.1). Focus groups were completed over a three-month period between October and December 2016. Duration of focus groups was between 53 minutes and 92 minutes and the average duration of the interviews was 73 minutes.

Table 5.1: Demographics

Discipline	Nursing	Occupational Therapy	Physiotherapy
Number	n=4	n=7	n=4

Table 5.2 below presents the distribution and numbers of disciplines in each of the focus groups.

Table 5.2: Breakdown of Sample per Focus Group

Focus Group Number	Sample Breakdown	Number (n)
Focus Group 1 (2 sites combined)	Nursing	n=2
	Occupational Therapy	n=3
	Physiotherapy	n=2
Focus Group 2	Nursing	n=1
	Occupational Therapy	n=2
	Physiotherapy	n=1
Focus Group 3	Nursing	n=1
	Occupational Therapy	n=2
	Physiotherapy	n=1

### 5.3 Qualitative Analysis and Findings

Following analysis of the phase two data, three overarching themes and within them a total of eight subthemes were identified which reflect the narrative and will now be presented.

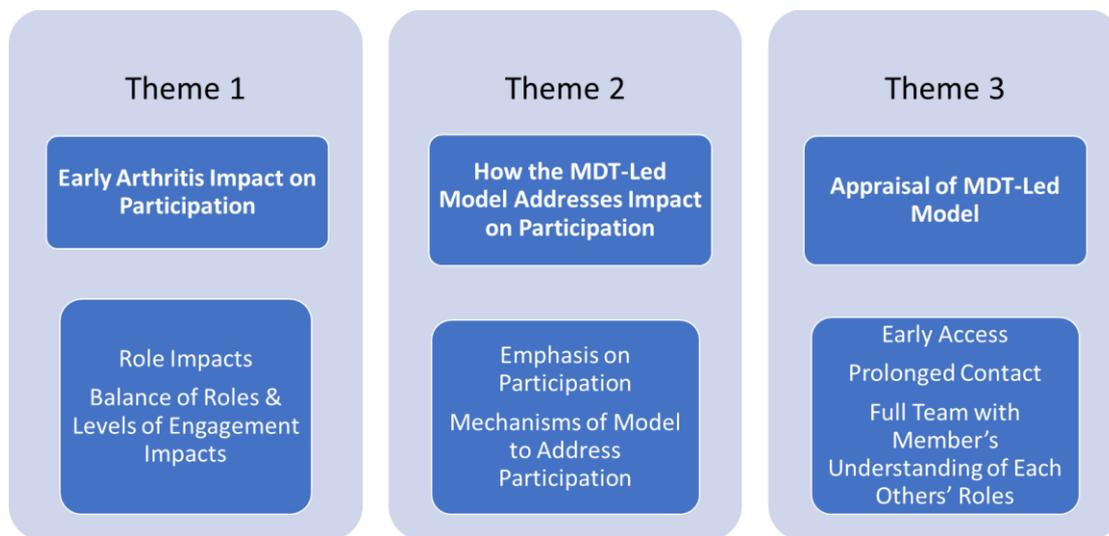


Figure 5.1: Visual Descriptor of Overarching Themes Identified

### 5.4 THEME ONE: Early Arthritis Impact on Participation

The overarching theme of 'Early Arthritis Impact on Participation' encompasses two subthemes which are: role impact; and impact on balance of roles and levels of engagement (see Figure 5.2).

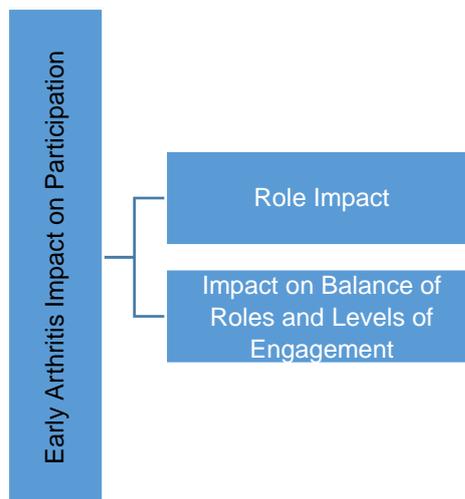


Figure 5.2: Early Arthritis Impact on Participation Overarching Theme with Subthemes

### 5.4.1 Role Impact

Participants described the age profile of clients attending the multidisciplinary-led early arthritis services ranged from young adults at the beginning of their adult journey, through to middle-aged and older adults. They reported extensive symptoms and symptom management needs, with associated limitations in personal and domestic activities of daily life, in the early stages of inflammatory arthritis which required multidisciplinary intervention. Service providers described how the diverse life stages seen in the client profile of their typical caseload result in diverse life roles and demands and therefore, types of impact on participation for each individual client varied accordingly. Participants identified a significant impact on participation in this client group across all valued life roles and situations.

*'We see parents, young parents, who are pregnancy induced diagnosis that would be something we would see. And then, middle-aged people, grandparents, that type of role. They mightn't be in paid work but that is the role that they do, minding or caring for grandchildren, and they very much want to retain this role, and often their families rely on their fulfilling this role. And sometimes the focus could be with people with the very heavy traditional labouring jobs, driving big trucks, mechanics, those kinds of jobs as well. So very varied.'* (OT #3)

Participants reported that their clients frequently reported participation restrictions in home, leisure, driving, social and work roles as a result of symptoms.

*'Some people arrive, and they haven't been able to pull down their trousers to go to the toilet or pull them back up again. They can't feed themselves, they can't open jars, can't open the fridge. They can't play with their kids.'* (OT #2)

Participants widely reported that early impact on employment-related participation due to symptoms were commonly identified by their clients who were in paid employment. These impacts were further compounded by the fluctuating nature of symptom presentation, and the participants agreed that work impact was an area that was of great concern to their clients and therefore required assessment and intervention.

*'There'd be a lot of looking at where they are at now and what they are finding difficult to do in work. Giving them a space to identify the problems and concerns that they have around any work issues, or work instability worries that are there, and also ways to manage working with arthritis on-going. They tend to be quite stressed about work and they can be really overwhelmed with the thoughts of managing arthritis and how they'll keep going in work and keep the money coming in.'* (OT #6)

Furthermore, while the direct work impact was identified as an area that needed to be addressed, participants were also cognisant of the wider indirect work impact, such as on household finances and with relationships, which were important drivers in supporting clients to maintain the worker role.

*'Not being able to work, the impact that, that has financially on peoples' incomes and the strain then that puts on partner, marital relations, you know they are really, really stressed and I think that stress doesn't help the condition.'* (OT #2)

Participants consistently reported that clients attending this multidisciplinary-led early arthritis service were concerned about difficulties they were experiencing with their parenting roles as a result of their early arthritis. Diverse restrictions associated with parenting participation were reportedly disclosed to service providers in these clinics, including restrictions in physical care of their children, as well as wider parenting impacts such as social engagement and the role reversal which occurs due to their disease.

*'Especially young mums, they are having to ask their children to do things and that's really impacting on the children as well'* (OT #2)

*'They are finding it challenging to spend quality time with their children. It's the biggest parent thing actually'* (OT #7)

*'It changes the whole dynamic of the parent-child relationship and growing up with a parent like that, you know, changes a whole child's perspective on their whole life. And they don't get to be a kid because they are busy caring for somebody else'* (N #1)

Some participants reported that impact on driving was disclosed by clients at these clinics, and that driving restrictions were a barrier to participation for many of these clients which required early intervention.

*'Probably the driving is one that is a big thing for many of our patients, like the practicalities of driving difficulties. ... driving can be a very difficult limitation for them.'* (OT #5)

Participants described the impact of early inflammatory arthritis on self-identity and the value of one's own contribution and self-worth. This less tangible impact was recognised as a powerful influence on participation which is reportedly seen in the multidisciplinary-led early arthritis clinics.

*'I think it is a huge relief to share something as personal as like 'I can't put on my bra myself' or 'I can't open the mascara and I define myself by my shoes or my style and that's how people know me and that is gone, it's like a piece of me is gone' ... Because something as trivial as that is actually really big, because it's the impact on somebody's identity.'* (OT #2)

*'I think loss of role, loss of employment, be it working in or outside the home, I think this feeling of being dependent on others to do menial day to day things has a massive impact on participation' (OT #1)*

It is important to consider that these issues, described by healthcare providers working in the multidisciplinary-led early arthritis service, were reported as common problems and areas of concern by their clients. The clients seen in these multidisciplinary-led early arthritis service were early in their disease trajectory (in their first-year post-diagnosis), and so these reports from the healthcare providers highlight the negative impact of the disease on activities and participation in life roles from the outset of the disease.

#### **5.4.2 Impact on Balance of Roles and Levels of Engagement**

In addition to the extensive impact on participation typically disclosed by clients at these early clinics, service providers also described the client-identified impact of early disease on occupational balance and reduced engagement in previously held roles. Participants described how their clients disclosed reductions in participation across all occupational performance areas. Furthermore, participants described typical patterns among their clients whereby maintenance of the work role was frequently prioritised and often to the detriment of other important life roles including family, social and leisure roles. Participants emphasised that this client-based prioritisation appeared to be to the detriment of clients' perceived quality of life and satisfaction of life experience.

*'Life balance is one of the first things that goes. If they (clients) are trying to cope with staying at work, then they will exhaust themselves with their days work, and their roles at home or their leisure things will all go out the window.'* (OT #4)

*'It seems that the fun stuff goes, and then the basic, you know, keep the money coming in, keep working, is all the focus. So, they say 'work and self-care is about as much as I can manage, I can't do anymore'. And that's really depressing to think that all 'I can do is work and rest, work and rest' (OT #2)*

*'so that 20-40 catchment group who are maybe working, maybe have a family, or you know expect to be having a life, want to keep up with their peer in terms of the social life or leisure and hobbies, and then they just get flooded. And if they get to work, they get home and go straight to bed. ... So, they find they have to just cut that other life stuff out just to survive.'* (OT #1)

Participants emphasised their awareness of the presence of loss which occurs for clients with newly diagnosed inflammatory arthritis, which is caused by a disruption in clients' previously valued roles and occupational balance. Participants described the importance of being sensitive to this loss when engaging with their clients, and the role of the multidisciplinary team in supporting a reconstructed pattern of engagement in valued occupations.

*'A lot of the time they (clients) are coming to you feeling quite defeated or deflated that they have lost so much. I mean there is a fear that this is the way it is going to be forever more, and it's trying to enlighten them as to other ways of doing things. Maybe you know they used to enjoy exercise and running was important and they can't do that, or they used to enjoy*

*playing at concert pianist level and they have had to drop out of the orchestra. But it is like, well maybe you can't do it to that level, but let's look at what you enjoyed and how we might get you doing that again in a different way. Because I think they come feeling you know, they have just been given life changing news. And it is life changing, absolutely.'* (OT #2)

*'It's 'feeling like yourself' isn't that the thing people (clients) would say to you, 'I want to feel like myself, I want my style back, or the girlfriend, wife, mother, friend that I used to be or see myself as', those impacts are very important to these patients. And I think, we in this role get to hear those needs in a way that the medical clinic don't. And I think when the patients get the chance to say those concerns, that this is the appropriate platform to name them. And for the patient there is even a bit of relief in a way, that they have been named and there is something they can do to manage them.'* (OT #3)

Participants reported that the model's original remit was disease control and symptom management of affected body structures and activity limitations. However, participants described how their role has evolved, and although it has continued to include symptom management, it has also transitioned to include participation in life roles as they were being exposed to clients expressing this participation-based impact to them. Through this expansion in scope, they report that they now have the opportunity to explore and address the wider impact on participation early in the disease. Service provider participants reported that they routinely explore status in, and any identified issues with, work, sleep, leisure, and home roles, as well as disease symptoms as part of both their assessments and their follow-ups with this client group.

The key defining features of this model which differs from typical clinical practice relates to the service model structure. The structure of this model uniquely supports the automatic early access to the multidisciplinary team to ensure timely identification of problems and the life impact of inflammatory arthritis. Participants emphasised that the early automatic access to the multidisciplinary team, coupled with the flexible and prolonged support over the first-year post-diagnosis facilitates a platform and an opportunity ask about participation-based status and impact, and also to appropriately address any identified difficulties. Furthermore, service providers recognised and described how the structure of the model, the interworking style of multidisciplinary team members, and the process of interaction between team members and the client enable disclosure of participation issues and subsequent interventions to remediate these participation issues. Early access to interventions was considered by participants to improve participation-based outcomes because important and meaningful issues are quickly identified and remediated. Additionally, they reported that the model facilitates the client to work collaboratively with the multidisciplinary team to address these life impacts and support occupational adaptation and self-management. In this way, participants reiterate that they are well placed for early detection of any emerging impact on participation and furthermore, they are contextualising the role of the service for service users in terms of addressing these participation and engagement issues.

## 5.5 THEME TWO: How Multidisciplinary-Led Clinics Address Impact on Participation

*'Really, it's about listening to their own story, what's important to them? What has changed for the bad because of arthritis? And where their priorities are in terms of interventions and figuring a plan from those perspectives.'* (OT #3)

This overarching theme encompasses two subthemes (see Figure 5.3), firstly, is the perception of the multidisciplinary team that the scope of this model has expanded to include participation-based problems, and that multidisciplinary team members are aware of, and alert to, the impact on participation as a result of early inflammatory arthritis. The second subtheme examines the mechanisms that the model uses to address participation-based and engagement issues with service users.

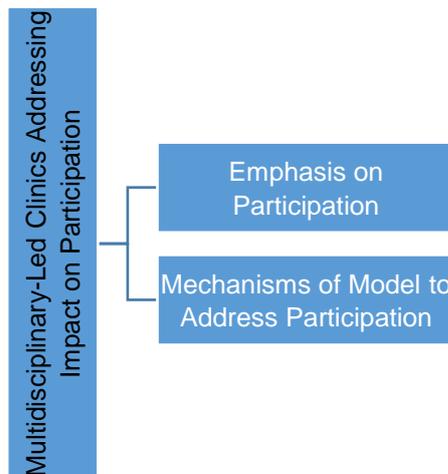


Figure 5.3: Multidisciplinary-Led Clinics Addressing Impact on Participation Overarching Theme with Subthemes

Participants described in the focus groups, how the multidisciplinary-led early arthritis clinics, comprise a reconfiguration of existing resources in order to streamline services and to ensure consistent early access to the multidisciplinary team of nursing, occupational therapy, and physiotherapy disciplines. These multidisciplinary-led early arthritis clinics provide early access to assessment and management for clients with inflammatory arthritis along a model of care in their first year of diagnosis.

*'We really want to get to these patients as fast as possible and treat them to prevent problems and damage and keep them in work. Because, for a lot of them, their impact on work is huge. They may have been in and out of work and maybe have had to give up a job because of their condition.'* (N #2)

### 5.5.1 Emphasis on Participation

*'It's more holistic now; it's about their quality of life and managing their condition much more now.'* (OT #7)

Participants all described an explicit awareness of the potential impact on participation-based and engagement that can, and frequently do, occur as a result of early inflammatory arthritis. Participants emphasised that they deliberately consider how their clients participate in life roles and life situations

with a new diagnosis of inflammatory arthritis. Additionally, they reported that they viewed addressing client-identified participation restrictions due to early arthritis as within the scope of the multidisciplinary-led early arthritis service. As the impact on participation and engagement in life roles were now viewed as within the remit of the model, service providers stated that they explicitly and consciously include these within assessment and treatment, and therefore, it has become a unique aspect of the service. Participants described how they saw the model as having the potential to deliver meaningful interventions to support and ameliorate the impact on participation.

*'I suppose the first part of the assessment was and still is about the symptoms, what are the symptoms in terms of pain, fatigue, joints involved heat and swelling, and the impact on mood and on everyday tasks. But now, it's also how the symptoms have changed their lives. What's changed in their work, in their home roles, what's changed in their leisure? And what's their reacting to symptoms, or how proactive can we make them from a self-management point of view. How can we support them so that they feel confident from the education, that they can feel empowered, so that from an engagement point of view ... it is a personal choice, rather than firefighting, that's dictating how active they are in their life roles?'* (OT #3)

The importance of asking participation-based questions was repeatedly described by participants. These questions were described as an integral part of evaluating the disease impact and in informing relevant interventions to address difficulties in engagement and participation in meaningful roles. Participants placed emphasis on specifically asking participation-based questions *'around their roles and their routines and how that is being impacted'* (OT #6), so that the skill of the multidisciplinary team members and the team approach can be employed to address the identified issues. In addition to asking participation-based questions, participants described the importance of being attentive to subtle cues and employing active listening strategies in order to hear and, identify what issues are meaningful to their service users and what is the personal impact on self-identity experienced due to inflammatory arthritis. One participant highlighted the importance of asking the right questions, namely, specifically asking about impact on roles and routines. She emphasised that the types of questions asked will determine whether impact on participation on life roles will be disclosed.

*'if you just put one question, 'what are your main functions?' initially they (clients) say what symptoms they have and they talk about pain, stiffness, fatigue and not able to sleep. That is the normal, usual thing that they always say ... when you ask them 'what are your main difficulties, how it is affecting you in your everyday?' when you put the question that way, they give you a list of their main problems, what are their difficulties at home, with work, with hobbies'* (OT #7)

Participants described asking participation-based questions to discover the broader impact on employment, relationships and leisure which are subject to clients' priorities and interests. They reported that in this model, clients are asked specifically about the impact of inflammatory arthritis on their life roles, and they are also advised that addressing these life impacts sit within the scope of the multidisciplinary-led early arthritis service. Therefore, a unique element of this service is asking about and addressing the impact on participation early in the diagnosis, and also, in asking these participation-based questions, service users' awareness of their life impact is heightened and what

the multidisciplinary-led early arthritis service can offer is contextualised. Service providers emphasised that participation is inherently linked to personal meaning and value, and a sensitive understanding of clients' unique circumstances, values and motivations is required in order to succeed in delivering appropriate valued interventions. Participants reported that this expansion of the original remit of the multidisciplinary-led early arthritis service to include participation in life roles happened organically in response to client needs.

### 5.5.2 Mechanisms of Model to Address Participation

*'It's actually looking at how the symptoms are impacting on their roles, as a parent or caregiver, or worker. It's looking at their roles and their routines and how are they being impacted and looking at what the issues are and how we can help them.'* (OT #6)

Participants described mechanisms of the multidisciplinary-led early arthritis model which facilitate addressing service users' participation and engagement restrictions due to early inflammatory arthritis such as, ease of early access to deliver participation-based interventions, a coordinated multidisciplinary team approach with an interdisciplinary way of working, supporting readiness to change and change management, and organisational aspects of the model (outlined in Figure 5.4).

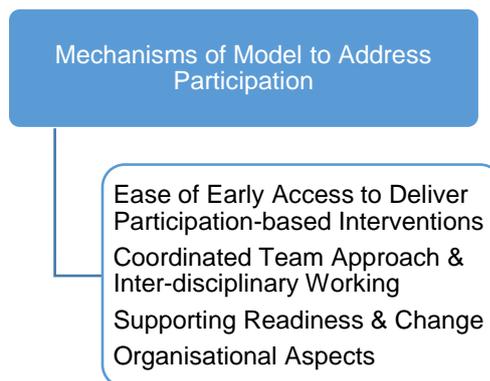


Figure 5.4: Mechanism of Model to Address Participation Subtheme with Expansions

#### 5.5.2.1 Ease of Early Access to Deliver Participation-based Interventions

*'With the early recognition of problems, we are fostering self-management from the word go, in the knowledge that the first year is key to their outcome'* (PT #4)

Participants described how the automatic earlier access to this cohort of clients afforded opportunities to identify and address restrictions in meaningful occupations including paid employment, voluntary work, parenting, hobbies, and social roles, and driving. Participants emphasised that this automatic early access to the wider multidisciplinary team ensured that clients were educated by the service providers as to what the service can offer and were asked about symptom and participation-based restrictions early in their diagnosis with a view to delivering relevant interventions to address these difficulties.

*'The biggest shift in evolvment and change has been around work and asking the work question. Definitely that's become a massive part of service need with this group'* (OT #6)

*'I always check in with them about work and sleep and pain and fatigue, and those things so in terms of their expectations of the service, they will have an understanding that any difficulties in those different areas are appropriate to be raised here.'* (OT #4)

Focus group participants reported that clients received early education about condition and symptom management, but importantly, the structure of the multidisciplinary-led early arthritis model supported the delivery of self-management strategies early in the disease trajectory and enabled the early delivery of interventions to treat client-identified participation difficulties. An important feature of this early access was the ease in which clients could access supports with consecutive appointments, individual and group interventions, out of hours appointments, helpline, and telephone clinics all part of the suite of resources.

At the core of all participation-based interventions described was the service providers' understanding that the impact of arthritis was individual to each client, and all interventions should be delivered in the context of the clients' life roles and situation. Participation-based interventions delivered by the multidisciplinary-led early arthritis team are described as varied and dependent on client need. There was an established view across the three focus groups that wider participation roles and engagement issues sits within the scope of occupational therapy *'any problems with things like driving or social roles and I send them to OT'* (N #3). Frequently reported participation-based interventions included addressing employment issues, supporting parenting-based restrictions, ameliorating driving issues, and self-management and lifestyle management with lifestyle redesign to support occupational balance.

Early detection of work vulnerability and delivery of early interventions to support work retention, change work structures or roles to improve overall quality of life was identified as an important role of the multidisciplinary-led early arthritis service. Occupational therapy was identified by team members as the discipline to deliver work-based supports. Participants described the early work participation support strategies which were delivered in the multidisciplinary-led early arthritis service. These strategies included analysis of the work role, work environment (physical and psychosocial), and external to work demands (life outside of work and the impact that has on in-work management). Interventions outlined included collaboratively remediating identified issues by educating the client about condition management skills and teaching communication and advocacy strategies to support negotiation and discussion of work needs and entitlements with employers.

*'Looking at work. I suppose if people are struggling with long shifts, looking at different ways of working, looking at ergonomics, education around legislation. A lot of people are afraid to say that they have a condition. Fear in maintaining employment is significant too. So just educating the patient about their rights as an employee and also giving them information to advise their employers as to what their responsibilities are, you know, within reasonable accommodations, to give them certain, not breaks, but certain concessions if you like, on how they work, and the way they work, and how they manage their workload.'* (OT #2)

*'You need to be involved and go out to the work and do a work assessment or an ergonomic assessment'* (OT #5)

Participants described intervention strategies they delivered to manage parent role restrictions which were dependent on the clients' unique circumstances but incorporated 'in-role' changes to the environment setup, role specific joint protection and posture, as well as 'out of role' changes to support capacity for parenting engagement such as prioritising, planning and delegating other roles and tasks.

*'aids and adaptations for functional difficulties that they might be having, looking at compensatory techniques for those ADLS (activities of daily living) they do for their child, or specific parenting tasks, finding acceptable different ways of doing things.'* (OT #2)

*'I would look at how they are planning their day, how they are organising their routines. And sometimes the biggest problem for them is they cannot say no to others, so they are getting less time for what they feel is most important, their children. So, my interventions would focus on managing these aspects, to broaden the parent space for the quality time.'* (OT #7)

Participants described how driving participation is addressed within the service model and how advice and interventions '*around positioning, posture, joint protection*' (OT #6) are delivered to improve driving capacity and endurance. Participants reported providing guidance on external and internal changes to ameliorate driving difficulties. Participants recounted that remediating restrictions to driving participation was frequently reported as a valued goal by service users. Occupational therapy participants described the barrier to independence that resulted from impaired driving ability due to symptoms and they described internal and external driving strategies that they delivered as appropriate to ameliorate driving difficulties.

*'We do advise on mirrors and posture advice regularly and there is adaptive equipment that we would recommend at times.'* (OT #5)

*'the extra grip that goes on the steering wheel. We speak about the centre mirror that helps them actually. Sometimes if they are planning to buy a car we'd advise about in-car features to consider or maybe an automatic depending'* (OT #7)

Participants all reiterated the role of the model in supporting social and leisure role participation. They emphasised how the model structure afforded an avenue to encourage and support return to previously enjoyed interests, to deliver guidance around engaging in new social and leisure interests, and in particular, the importance of social and leisure activities to promote and influence health and well-being. This strand with supporting engagement in social and leisure roles was viewed as a positive and important element of supporting healthy lifestyle engagement and satisfaction.

*'leisure and social engagement is one we would do a lot around, particularly if they aren't of working age, encouraging voluntary roles, and promoting getting more involved in volunteering. I would do a lot with that, what are their interests, what opportunities are there locally for them. It's a good opportunity for adding structure in routine and they value the social outlets with something they enjoy. Or also tapping into local retirement groups sometimes, depending on what they are doing and what might appeal and be the hook to get them more engaged.'* (OT#6)

The negative influences of inflammatory arthritis on normal occupational balance and the associated impact on emotional well-being were widely recognised by all of the focus group participants. There was clear understanding of the distressing fallout for clients associated with a disrupted occupational balance and decreased engagement due to active disease, which is often perceived by clients as outside their locus of control. Addressing these disrupted balance issues and the emotional fallout linked with this imbalance, using a person-centred approach, was detailed as a focus of interventions. Interventions described to improve occupational balance were subject to the clients' own situation and priorities and included education about the health benefits of balance in normal occupation, and strategies to support change in current status by increasing or decreasing activity within occupational performance areas depending on client priorities. Interventions to promote and support health, and inclusion of health promoting behaviours were emphasised across all three focus groups.

*'It's trying to strike that balance and encouraging them of the importance of getting balance with them all is where we like to target our interventions. But financial pressures I suppose, means that work is always going to be the driver, so that is often our early focus.'* (OT #4)

*'and more than just what they had lapsed and what they have stopped doing. We are trying to promote them to actually get involved, and they may previously not have been involved in physical activity, but really promoting it as part of their management.'* (PT #3)

*'Sometimes our role might be with somebody who used to be very active and then with arthritis did nothing, but now through our involvement has taken up yoga or taken up Pilates, or the parent who was finding it all really hard who has now engaged in a local mother and toddler group. So, you're putting local health promoting options on their radar, opportunities that feel attainable and relevant to them and that has helped them take the step forward to do something with it. And it has made a difference to that person. A difference in their perceived health and social connectedness.'* (OT #3)

Participants emphasised that, although clinical interventions described were established health interventions for this population, the unique aspect in this model, is the early delivery of interventions in an individualised way, tailored to the client themselves, and to their life demands and situations.

*'Activity management and pacing is huge, it's enormous and then obviously fatigue management. But there's no one specific approach, it's person-led.'* (OT #6)

*'I would give specific recommendations on physical activity. But individual to the patient. There is no protocol followed. It would be giving them advice from my knowledge and from what they are telling me they want to do or what they would be interested in doing.'* (PT #3)

Knowledge of local community supports and services in the geographical area were emphasised as a cornerstone to ensuring relevant supports particularly with regard to promoting active and social leisure engagement, employment rights and entitlements, and retraining options. Signposting included recognition of the importance of providing clear, accurate information regarding entitlements and employment rights. This information was described as valuable in developing an active self-managing client who is armed and informed to make decisions around supporting work engagement and develop leisure and social enhancement in a sustainable way. Some of the sites in the study

were particularly closely aligned to their local employment services and described this as a strength and a support with work-related issues. Local services used to promote positive health behaviours and engagement outlined, included, registered charity groups, education and training boards, local library services, local fitness and social groups and the Citizen's Information service.

*'Directing them to what is out there for them support-wise and group-wise or getting in touch with Arthritis Ireland and getting in touch with what is available to them locally.'* (PT #3)

*'I think when you are trying to work with somebody, knowing the geographical area that they live or work in makes such a difference in terms of what you are directing them to. You know when you get the odd patient from a different county altogether it is very hard to know what the services are there locally, and I think that can be a barrier if you are linking with retraining or if you are trying to link with the training boards. It's good to have local links because I think that it makes the whole thing more likely to be a success.'* (OT #3)

### **5.5.2.2 Coordinated Multidisciplinary Team Approach with Inter-team Working**

There was strong recognition across all focus groups that a coordinated multidisciplinary team approach which is working in an interdisciplinary way, and the includes the client as an active team member, was fundamental to the effectiveness of the multidisciplinary-led early arthritis model in addressing participation-based issues among their client group.

*'We know what we are good at doing and we will ask the question 'are you sleeping?' 'How is your mood?' We are much better at doing that, I think, than the medics are, and that's evidence proven. And I think we deal with it (issues) well within the team, either individually or together, you know I can say to the others 'this patient is not coping, or can you see them for stress management' or whatever it is.'* (N #1)

The value and importance of making a connection with the client and of building a therapeutic relationship in order to support meaningful assessment and intervention was reported as key. Participants reiterated that the service model was about ameliorating the symptom impairment but also on supporting clients' perspectives on health and illness and on maximising meaningful participation. Cultivating a therapeutic relationship with the client was emphasised as important to support client disclosure of concerns, ensure relevant meaningful timely interventions, and also to support clients to feel able to follow up or 'opt-in' along the trajectory of care if disease or health status changed.

*'You need to build that therapeutic relationship as it is so important in dictating how well you are going to work with the person.'* (OT #5)

*'On the first day I suppose it's making contact with the patient is the big thing. Seeing their perception of what they have been told they have been diagnosed with and kind of getting that out initially. It's so important I think to get clear messages across. I kind of try and focus on where they think they are at, what they are struggling with, where they want to be, what's their perception of what they have been diagnosed with'* (PT #4)

*'It's an opportunity for the patients to share like, so if they say, 'I feel like I am always letting people down' and you can say 'well why?' 'Because I am always making arrangements to meet X and I never get there, I'm too tired, I'm too sore' you know and then the tears come, so it's reassurance, it's discussion, it's opportunity really to address these participation difficulties.'* (N #1)

The requirement for and benefits of good interdisciplinary communication was repeatedly emphasised by all participants. Participants emphasised that service users are directly benefiting from the model as they have early and timely assessment and intervention. Additional and perhaps subtle indirect client benefits described were associated with inter-team support and coordinated care afforded with this model (*'shared responsibility'* N#4) and the associated capacity for improved care.

*'Or sometimes you can bounce ideas off each other, do you know, and just opinions which is just huge.'* (OT #5)

The benefits of the team approach as support for team members (*'it's the backup'* N #3) to scaffold service delivery was appreciated by participants when working with this client cohort. Central to the workings of this model is an awareness and respect for each discipline's role and a recognition of and commitment to collaborative working in order to better support person-centred care.

*'I suppose we pick up from each other what they (patient) are struggling with, like if (nurse) has already assessed them she might give me the heads up say that he's struggling with a full day on his feet, or the hands are the big trouble there etc'* (PT #3)

There was widespread recognition of the complexities of this client cohort and the requirement for adequate clinical experience across each of the disciplines and within the team in order to function appropriately to address service users' needs. The model was considered to require a significant degree of clinical experience across all of the disciplines and this clinical and specialism experience was strongly associated with the model's ability to reach and deliver on disease management through medication escalation, and on addressing participation and engagement-based issues.

*'Experience is the key thing. I would be saying senior grade you know, because I think, just the complexities of this patient group to be able to ensure to meet their needs. You do need to have a couple of years under your belt.'* (PT #4)

### **5.5.2.3 Supporting Readiness and Change**

*'It's about accepting (the diagnosis) and empowering the patient to be able to manage it'* (N #4)

Participants highlighted the value of the multidisciplinary-led early team approach in being attentive towards, and sensitive to, the client in terms of their journey in adjustment to their diagnosis. Participants reiterated the importance of empathy and compassion when sensitively and respectfully evaluating clients' readiness to hear new information, and readiness to change lifestyle routines to support and include disease management. All participants emphasised the importance of the 'just right' amount of information for clients and the significance of *'not to overload them too much'* (PT

#4). This balance was described as a mix of clinical reasoning and evaluating the service user as an individual and understanding the value of *'how they are and how you approach them'* (PT #4). There was a recognition that this model provided a platform to clients as they came to terms with the impact of their diagnosis and its symptoms on their participation in everyday life role and as they were supported towards self-management. This evaluation of clients' well-being status was described as influential in ensuring that the right type of meaningful support and intervention in the right format can be delivered in a timely manner as advocated in the model of care for rheumatology (HSE, 2018).

*'You have to gauge very much where the person is at and that will decide what you can do that day, and what needs to be the focus of the sessions for that person.'* (OT #5)

*'Sometimes I feel that they are totally bombarded, they are not hearing it all. So if I feel that the person is being bombarded too much on that first appointment, you know sometimes there's only so much they can take on, then I would say, I will talk more on the next occasion.'* (OT #4)

*'They have to go on their own journey and we just have to go with them, be the support for them until they are ready to engage.'* (PT #4)

Participants described how their early assessment incorporates an exploration of clients' current and previous patterns of participation and engagement in life interests and life situations. They emphasised that by understanding these patterns of participation in life situations and understanding how readiness for change will dictate the pace of adaptation and self-management, appropriate supports can be identified. The right type of help at the right time is central to this perspective and assists in the process of client-identified participation-based priorities for interventions. Participants highlighted that by being attuned to clients' broader participation and life situation it is possible to set meaningful goals against the backdrop of clients' lived experience which have an increased chance of sustainable change over time. The importance of noticing change in life patterns as well as the positive influence of making changes to support self-management were recognised.

*'and for us (MDT) it's trying to get that balance and looking at, you know in terms of income what do you need to survive, what can you change? Can you work less hours at the moment? You know, try to divvy out jobs at home to your partner, the ones that traditionally you would have done. Because that way, you might actually have capacity to go out for a drink on a Thursday or Friday night, or whatever, to spend quality time with your partner. Because the notion of it just being work and rest is not very appealing to a lot of people'* (OT #2)

*'that's an opportunity to discuss patient goals with them and see what do they want to do, do they want to get back playing golf or do they want to be able to work for a full day and not feel exhausted. So, whatever it is for the patient. We would work together to identify what goals the patient wanted to achieve, and we'd work towards them'* (OT #5)

#### **5.5.2.4 Organisational Aspects**

Practical operational team strategies were described by all participants as being influential in supporting the multidisciplinary-led early arthritis service in addressing participation restrictions. Elements such as use of shared notes were agreed as supporting team communication and increase

inter-team awareness and coordinated care of clients across all disciplines. Similarly, the practicality of being located geographically close together within the building was described as influential in supporting ease of communication and teamwork.

*'We have our electronic record which facilitates a lot of the communication, everybody feeds into that record, so if we are doing outcome measures, all of the team can see it.'* (N #2)

*'I suppose the medical team can see what you have been doing and I suppose that's the point of the electronic record, that it's transparent what the MDT team do. It is more transparent what the OT does, what the physio ... can do with the person.'* (OT #1)

All participants highlighted that preparing the clients for the service was an important part of providing timely service and also in getting valued and meaningful issues addressed. As part of this, two sites described how they had evolved their pathway processes to develop an information leaflet about the multidisciplinary-led early arthritis service and team, which is forwarded to clients in advance of the first appointment. These information leaflets were reported as a practical, helpful tool to set the scene in terms of clients' expectations of the service and in preparing them for their appointment.

*'we put together a simple pamphlet that goes out with the MDT appointment (letter) to say, you are going to meet three services, this is what these three services are going to be asking you about, this is what you can expect in terms of interventions from them. So, managing expectations and helping them be prepared made our time work much better.'* (OT #3)

*'We have a separate little book, a guide which gives them the brief of what the inflammatory arthritis clinic is like and how it is going to operate'* (N #4)

As alluded to earlier, some organisational strategies at some of the sites which supported the ease of early access to the service included out of hours appointments for working clients or those with life commitments which caused time constraints. Participants reported that these were intended to support clients to engage with the service without incurring additional job or life stress or any requirement to take annual leave. Out of hours appointments were at 7.30am, or 8am or evening appointments up to 6pm. Furthermore, helpline and telephone clinics, described as a cornerstone of service delivery across all sites, were reportedly not explicitly incorporated into the original model, but have evolved into a key component of the multidisciplinary-led early arthritis service approach. All participants reported that they felt the telephone helpline was an influential support to service users in their first year of their diagnosis. The helpline was described as a practical way for clients to access the service and it encouraged them to be proactive in their disease management by opting-in with queries and concerns which could then be managed early and avoid time delays to remediating difficulties.

*'The helpline is an integral part of the inflammatory arthritis clinic. So, from the word go, at zero when they start their treatment the helpline is introduced to them and the role of the helpline, so the whole gap between zero and six weeks is all gone now. So if they don't tolerate the methotrexate, they don't wait 'til the next appointment, they ring, and they say I can't do this or I can't take that and you make a change to their treatment. It gets them in the habit of making contact and gets them going with self-management. It has made a huge difference I would say.'* (N #4)

In addition to the helpline, focus group participants described developing a scheduled telephone review clinic, predominantly for nursing issues although some occupational therapy and physiotherapy participants reported running review clinics by telephone in response to client need. Participants who run these telephone clinics emphasised that they are a time efficient and effective way to manage some of the clients' needs and also, they reported that clients were satisfied with the service as a way of managing needs in a timely and time-saving way.

*'I have introduced a telephone clinic now. So, I can book them into a telephone clinic and telephone them and do the assessment over the phone. That works well for blood monitoring and status review. It saves them coming in here, taking time off, all that kind of stuff.'* (N #1)

*'I would use a telephone clinic as well sometimes to follow up, if it's appropriate, depending on what's happening, it can take a lot of pressure off patients from a geographical perspective, getting in and out of appointments.'* (OT #3)

## **5.6 THEME THREE: Appraisal of the Multidisciplinary-Led Early Arthritis Model**

In appraising this multidisciplinary-led early arthritis model there was widespread agreement across all of the focus groups that the clinic model has established itself as providing an early access and early intervention service which provides *'holistic multidisciplinary team management of these patients'* (N #3). Overall strengths of the model identified comprised: opportunity for early access to multidisciplinary intervention, prolonged support with a coordinated team to effect change and support self-management and, composition of a full core team with team members who have a clear understanding of each other's' role. Challenges and opportunities associated with this service model approach were also explored and presented within this section.

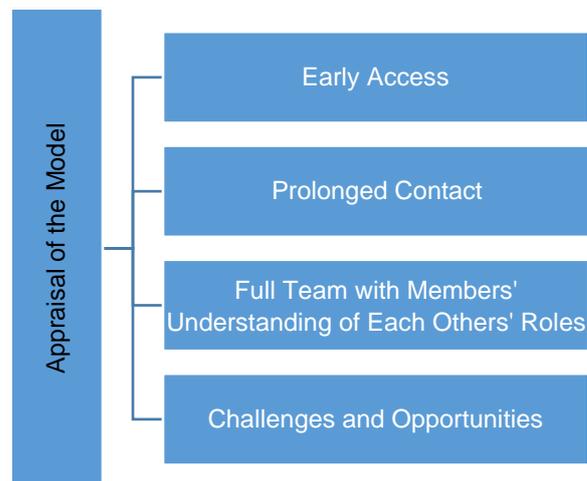


Figure 5.5: Appraisal of the Model Overarching Theme with Subthemes

### 5.6.1 Early Access

A key feature of the multidisciplinary-led early arthritis model is the automatic early access to the full multidisciplinary team, and the opportunity that creates to ask about, and deliver supports to address the client-identified impact on participation. Early access was considered a positive factor that facilitated asking participation-based questions, however, there was recognition of the clinical skills (both in terms of understanding of the disease, its' occupational implications and its' management, and the interpersonal skills of the healthcare providers) required to support clients' readiness for change within this early approach. There was implicit agreement across all of the focus groups that this early multidisciplinary-led model was effective in addressing the broader life issues for patients because there was early identification of the difficulties and problems, and that this early detection was strongly associated with improved management and amelioration.

*'I suppose the fact that we have the clinic, and those people get to us sooner, then we are able to address their issues much sooner' (OT #1)*

*'You're picking them up earlier, you're discussing them earlier and you're able then to manage them better.' (N #1)*

All participants emphasised the opportunity for early coordinated intervention as a unique service benefit which would not have previously been available under the traditional rheumatology management model.

*'The early access. We (OT) wouldn't have seen them as early on. Or they mightn't have even come through OT at all if it wasn't for this (MDT clinic) service. We mightn't have seen them until later on when the damage was done.'* (OT #4)

*'So, I think by capturing them early, I suppose, at least we can give that extra bit of time to those patients what are really struggling.'* (PT #1)

Early access to intervention was viewed as key to improving disease status, and health and engagement which facilitated a preventative approach to management of the condition. Additionally, the early access supported wider interventions beyond symptom management to include interventions to address changes caused in life roles (home, work, and leisure). The early access to

this population was described as central to timely management of issues and minimising negative health changes and reduction in engagement in life activities. The early access was also emphasised as a platform to focus on promoting proactive self-management strategies and increasing confidence and empowerment to be able to continue with engagement roles.

### **5.6.2 Prolonged Contact**

The prolonged contact over the first year was identified as a key strength of the model which promoted self-management and garnered clients' confidence in this self-management, *'to foster an active approach to their disease, to get them on board'* (PT #4). Additionally, the participants described how the prolonged support afforded by the model during clients' first year post diagnosis provided a powerful platform to build therapeutic relationships which they can use as a mechanism to effect change. Participants described how prolonged support provides a scaffold to adjust to the diagnosis, and the implications of that diagnosis on participation and engagement roles over time. Furthermore, they highlighted that the model facilitates service providers to respond to client needs in a flexible and prolonged way as required through this period of adjustment and towards self-management. Participants described how frequently clients have a heightened concern about the implications of their diagnosis on a particular aspect of their own lives which needs to be addressed first so that subsequent needs and impacts can also be adequately supported. Prolonged support *'seeing them again and again over the stages'* (OT #4) was agreed as hugely important in order to properly address meaningful impacts and to promote meaningful participation in living well with the diagnosis.

*'They may be fixated on one thing at that time, maybe the work issue, or getting the family and work balance right, and what's the best thing I should be doing? So they might be fixated on one issue in that early time so you need to bring them back to address other things then'* (OT #4)

*'So you have all of your follow ups to allow you to focus on the symptoms and as you are dealing with the splints or the equipment or whatever, then you have that time with them, an hour every week or two weeks or month or whatever is feasible to give a chance to look at and address those wider issues'* (OT #1)

There was recognition of the importance of prolonged support to build and develop a relationship between the service user and the multidisciplinary team and the potential for positive effect that this therapeutic relationship has on supporting meaningful interventions to support change and self-management.

*'And for some people they aren't going to bare their soul in the first clinic (visit), it will take much longer. But I suppose it gives you and them that opportunity that they realise that once they are in with you, then you are there with them until their issues are resolved. At least they have that space, that they can use the team, and that they team is there for them and they will be supported through this'* (OT #1)

*'We try and them see until they are really independent, even if it takes long, we will prolong their appointments. To be frank I personally think that is what has the biggest impact.'* (OT #7)

*'Sometimes patients, the minute they have the diagnosis of arthritis, they can crumble and fall right down, and there's a lot of handholding and therefore the therapeutic relationship that they develop with the three of us (nurse, OT, PT) is vital. I think that's really, really, important'* (PT #4)

An additional identified strength of the multidisciplinary-led early arthritis model associated with prolonged contact was the time that it afforded clients and the associated benefits of this additional time in supporting key messages and relevant interventions.

*'we have a bit more time and we can spend that time on education and probably between the three disciplines, we are hopefully saying a lot of the same type of things to the patients so it's the same message going to them'* (N #2)

Inherently linked with the concept of having time to deliver interventions is the recognition of the appropriate timing of interventions. Participants reported how their understanding of the psychological impact of the diagnosis on a client, greatly influences how they gauge and support their clients' ability to cope, readiness to hear and readiness to engage in change. Participants described how the model facilitates this client-centred adjustment through the team approach and through the timing of interventions over the first year. Participants described being attuned to clients' stress associated with their new diagnosis (*'can get so overwhelmed'* OT #6) and the need to tread softly to support them. The focus group data identified a confidence and strength within the power and scope of the multidisciplinary-led team approach to support emotional well-being and adjustment to a new diagnosis. Participants emphasised the capacity of the shared team to work together with the service user to deal with emotional implications and support a transition towards acceptance. Implicit in all of the participants' discussions on the strengths of the model was the coordinated interventions delivered which were always described as tailored to individual client's needs.

A further emphasised strength of this model was the education opportunity to advise service users of what services are available and within that, interventions to support their health in order to encourage a more proactive approach to their health management. This concept of educating the clients about the service, and what to expect, was viewed as important to promote self-management, whereby clients have a clear point of contact to the service through the helpline and they know when and how to opt-in.

*'From the patient's perspective, their familiarity of what's available to them. They previously would have had very little contact with physio or OT prior to diagnosis before they became affected with their symptoms. I think it's really good for them to be aware of what is here, because they're going to be managed here more than likely for the course of their disease.'* (PT #3)

*'It is about empowering the patients to know what they can get from the service.'* (OT #1)

Additionally, participants highlighted that the prolonged support has a role to encourage appropriate 'opt-in' appointments if disease or health status change and the client requires a further episode of care. Participants suggested that the likelihood of appropriate 'opt-ins' is directly linked to the quality and strength of the therapeutic relationship that has been cultivated and also on the service users' understanding of active self-management. Additionally, the annual review was broadly agreed as an important piece in the prolonged contact in order to monitor status and deliver timely interventions as required.

*'They (clients) have built up relationships with us and so they will go back to the people they know when they have a worry.'* (N #1)

*'The annual review is really important because people can slip through the net. They have been lost because they haven't gone back to their clinical appointments either through DNA's or work pressures, and we have brought them back and we have got to reel them right back in again. So, the annual review is definitely invaluable and worth keeping.'* (N #4)

### **5.6.3 Full Team with Members' Understanding of Each Other's' Roles**

In appraising the multidisciplinary-led early arthritis model, service provider participants emphasised that an essential element of the models' success was that it included a full core multidisciplinary team of nursing, occupational therapy, and physiotherapy professionals. Additionally, they emphasised that this full core team working collaboratively together, and not simply in parallel, was a defining strength of the model. Participants discussed the difference between essential and useful elements of the multidisciplinary team composition. Some participants described challenges associated with a lack of psychology supports when clients' needs are greater than the skill set of the multidisciplinary team and clients are struggling. Conversely the site who did have access to psychology support reported that this was a desirable option but not a core option, whereas nursing, occupational therapy, and physiotherapy were viewed as key team members. Other useful disciplines reported were dermatology, dietetics, and cognitive behavioural therapy.

*'You need to have a team. And there's no point in having a nurse and a physio or a nurse and an OT. You need to have the whole team. Psychological intervention is a nice add on, but it can still function extremely well.'* (N #4)

*'We don't have psychology. We don't do any CBT, like there is only so much we can do. We are limited professionally to deal with some of the emotional impacts.'* (PT # 3)

*'I think there is a certain amount, you know with everyone's input that does help them, the support to reinforce that things are going to get better and that ye can manage and there is ways to overcome. But you would need the extra for people who continue to struggle, and we haven't got cognitive behavioural support or anything like that which is a huge loss.'* (N #3)

Participants recognised and emphasised the importance that the sum of the model is greater than the sum of its parts and it is the collaborative impact of the team assessing for and treating body function, activity limitations and impact on participation that was emphasised as the strong indicator

of change success. Central to the participants' perceived success of the multidisciplinary team approach was the close working relationships and the awareness of team members' roles and skills.

*'I am very aware of the other lifestyle issues and the physical therapy but then I would be depending on the girls (OT and PT) to fill in a lot of that. So, I am very much depending on the OT's and physios then, even though I touch on it.'* (N #3)

*'There's no point in a CNS trying to think that she is the OT/PT for everybody. While we are extremely harmonious, we all know, without even thinking about it, what our roles and what our expertise is.'* (N #4)

*'Also, if your team know your role, like that is so important, because as a team member, in knowing what to expect from the team, you can help people an awful lot that way.'* (OT #3)

The positives of the team approach for the service users was also reiterated ('we work as a holistic team' OT #7). Participants described how the service delivery was more rounded and cohesive as a result of this coordinated team approach.

*'I think the positive from working together and using this type of approach is that it has filtered out into our management and we are all giving the same messages. We are much more streamlined in our approach whereas it is less physio, OT, nursing, that would be my perception'* (PT #4)

The expertise of the team was highlighted by participants as influential in addressing and delivering interventions to support client-identified participation difficulties. Although team member composition was matched across the four sites, variation in team members' specialist clinical skills in some areas were identified by the participants as barriers and opportunities for future improvements. There was a range in skill specialism identified by participants which was person-centred rather than profession-centred and was identified across sites, with some sites reporting proficiency whereas other sites detected less depth in some specialist skill areas. Range in skill specialism was described in the participation areas of vocational rehabilitation, entitlements, and driving. Participants across all disciplines from one site had undertaken further specialist Motivational Interviewing and Acceptance Commitment Therapy training to strengthen their skills to support clients' change management. Further specialist training in this area was strongly recommended by these participants as a powerful skill set to facilitate and promote health behaviour change.

*'I think as a team here our experience in MI (Motivational Interviewing) and ACT (Acceptance Commitment Therapy) has helped us no end in changing our whole approach to this cohort of patients. It has moved us from a very medical focussed way of care where the essence of a therapeutic relationship could get lost. I would say strongly that MI and probably our cognitive approach to patients through ACT has influenced things significantly.'* (N #4)

One site described a service gap with regard to vocational rehabilitation whereby previously there had been an occupational therapist recruited for a time to deliver work-site interventions and this had been viewed as very successful though since ceased due to geographical demands and inadequate resources.

*'and patients went back to work; I found that actually one girl that was working in manual labour went back to college, do you know what I mean, which is great. And she is very happy that she is back retraining. You know I do feel that patients can need more intensive OT. You know I miss that extra bit of OT support.'* (N #3)

This direct work support had ceased, however this site described how although they could no longer offer onsite work-based assessments and interventions they continued to deliver work support interventions which included communication, advocacy and negotiation with employers, and condition management and activity modification advice.

#### **5.6.4 Challenges and Opportunities of the Model**

Participants' views were sought on the challenges of the model in its current form and any areas for improvement. While participants were reportedly confident in the services' strength in addressing participation-based needs, there was recognition that availability of the right types of assessments and outcome measures to capture the impact on participation were lacking.

*'I just think that there is so much that you are missing (in outcomes). You can see the journey the person has gone through from when you started with them to when you finish up with them, but it is not measured adequately. I don't think that it is being measured effectively. So, you are losing it.'* (OT #1)

*'The measures that we use are very much around the disease and the symptoms and it can be harder to capture the measures that go with the participation piece. ... capturing the social engagements, their physical activity, their quiet leisure, their parenting roles, their mood, the things we do provide interventions on, it is very hard to capture the right evidence for all of that work. ... that's a challenge for me, findings the right tools to capture the wider impacts. I feel I am addressing them in my practice but capturing evidence of change beyond client report or client satisfaction is hard.'* (OT #3)

In reflecting on the model as it is currently being implemented and scope for improvements, participants highlighted that scheduled multidisciplinary team case review-type meetings would be a beneficial development. The opportunity for an established platform to review and discuss aspects of cases which might be of concern and identify next steps was a gap in all services involved in this study. One site described sometimes having impromptu meetings pre-clinic to update and/or raise concerns about clients attending the multidisciplinary-led early arthritis service and quickly plan next steps or confirm progress. The face-to-face piece of this meeting was central to its perceived success, but this case review style meeting was not a standard part of operations and was inconsistent subject to time restrictions.

*'I think the face-to-face part of that is what really works, because we do email each other about things, and use (electronic records) but I think the pow-wow is definitely an efficient way and just it's the chance to re-frame what is happening for this patient, what is important for that person at the moment and agree who is going to move ahead with it I suppose.'* (OT #3)

The other sites did not have this mechanism within their services although there was widespread recognition of the potential value.

*'I would say a more formal meeting of ourselves would help with discussion. I think the sitting down doing this (focus group) has probably triggered that a little bit. We meet on the corridor informally and we discuss a patient with each other, but we don't have a structure and maybe that's one thing we really should.'* (OT #4)

Similarly, there was recognition that a case conference style structure would be a positive addition to the model to support staff learning, strengthen communication and support decision-making with client needs.

There was recognition amongst participants that there was potential for this model to extend into primary care, and that this would be in line with the model of care for rheumatology (HSE, 2018). Primary care services were agreed to be an appropriate platform to deliver services for these types of chronic diseases however some participants reported a dearth of expertise in primary care service providers which would hamper transitioning of these clients to be managed in tertiary care services.

*'it (primary care) seems to be quite lacking in terms of specialities'* (PT #2)

Participants reported that there is further scope to develop group programmes to implement lifestyle redesign and work-based group interventions. The timing associated with these lifestyle and participation groups were discussed by some participants, particularly groups targeting employed clients and the associated need for out of hour's options to support attendance. One participant discussed how she had previously successfully run a number of employment retention style groups in the evenings and that while this mapped well for service users it was difficult to sustain for the service provider due to personal commitments.

*'There's a definite need, but basically, because I suppose my personal life just got very busy in the evenings it was harder for me. Yet in the evening is a good time to run this type of education and support group for people who are working, but who need some support to continue to engage and manage in work.'* (OT #6)

## **5.7 Summary**

The multidisciplinary-led early arthritis model originated from a motivation to streamline service delivery processes for both service providers and clients. Facilitated by the early opportunity for intervention, service providers described how this service has organically, broadened its' scope to address the wider impact on participation. Service providers emphasised the extensive early impact of symptoms with this client group, which result in limitations in everyday activities and diverse impact on participation in life roles. Service providers described that through the early involvement of multidisciplinary team, there were better opportunities for life impacts to be addressed. Service providers identified mechanisms which support addressing the client-identified impact on participation included: a view that the scope of the model includes participation, ease of early access to deliver participation-based interventions, a coordinated multidisciplinary team approach which operates in an interdisciplinary way, support with readiness for change and supporting change, and some organisational aspects. In appraising how well the model addresses client-identified participation issues, aspects such as: early access; prolonged contact; and a full team were noted as influential in determining success.

## **CHAPTER SIX: FINDINGS FROM INITIAL INTERVIEWS**

### **6.1 Introduction**

The focus of this phase of the study is on the exploration of the impact of early inflammatory arthritis on participation and engagement in life roles from the perspective of service users attending multidisciplinary-led early arthritis clinics. A further focus this phase of the study was to seek service users' perspectives on how they perceived the newly established clinical service approach (multidisciplinary-led early arthritis clinics) addressed their occupation-based participation and engagement in the early stage of the disease trajectory. In this chapter the findings emerging from the qualitative interviews of service users attending multidisciplinary-led early arthritis clinics will be presented.

### **6.2 Objectives of Phase 3**

Phase three of the study involved participants with newly diagnosed inflammatory arthritis who were currently or had recently been service users at the multidisciplinary-led early arthritis clinics. One-off semi-structured individual interviews were carried out with participants with the specific purpose of exploring:

- Their perception of how newly diagnosed inflammatory arthritis impacted on their everyday occupations and participation.
- Their perceptions on how their self-identified occupation-based participation and engagement needs were addressed by the multidisciplinary-led early arthritis clinics, and any suggested potential service improvements to manage client-identified participation and engagement restrictions.

Principles guiding qualitative description research outlined in the methodology chapter (chapter three) were followed in the data collection and analysis. Findings have been presented based on thematic analysis of the interview data using straightforward description. Participant quotes are used throughout to support the description of the findings and the source of each quote is given after the quote.

### **6.3 Sample**

Participants were recruited from four sites currently providing multidisciplinary-led early arthritis clinic rheumatology services. Participants were recruited at different stages along their pathway of care and all of the participants were within the two-year post-diagnosis criteria. Purposive sampling was employed for this qualitative description research and a total of forty-three individuals participated in this phase of the research study. Efforts were made to include participant representation from across all four sites. A total of 225 invitation packs were forwarded to service users who met the inclusion criteria across the four sites inviting them to participate in this phase of the study. The total sample number achieved was n=43 (males n=12 [28%], females n=31 [72%]), and the time since diagnosis ranged from 5 to 24 months. The breakdown of numbers recruited from each site is outlined in Table 6.1 below.

Table 6.1: Breakdown of Sample per Recruitment Site

Site Number	Sample Number
Site 1	20
Site 2	8
Site 3	6
Site 4	9

Basic demographics are summarised in Table 6.2.

Table 6.2: Demographics

Participant	Gender	Age (Years)	Diagnosis	Time Diagnosed (Months)
1	Female	46	Rheumatoid Arthritis	24
2	Male	62	Rheumatoid Arthritis	17
3	Male	69	Rheumatoid Arthritis	17
4	Female	39	Psoriatic Arthritis	11
5	Male	73	Psoriatic Arthritis	23
6	Male	53	Psoriatic Arthritis	24
7	Female	41	Inflammatory Arthritis	19
8	Female	73	Rheumatoid Arthritis	11
9	Female	45	Rheumatoid Arthritis	24
10	Female	18	Inflammatory Arthritis	12
11	Female	35	Rheumatoid Arthritis	24
12	Female	46	Rheumatoid Arthritis	22
13	Female	32	Rheumatoid Arthritis	20
14	Male	41	Rheumatoid Arthritis	10
15	Female	42	Rheumatoid Arthritis	11
16	Female	54	Rheumatoid Arthritis	13
17	Male	47	Psoriatic Arthritis	17
18	Female	26	Psoriatic Arthritis	20
19	Female	54	Rheumatoid Arthritis	23
20	Female	79	Rheumatoid Arthritis	6
21	Female	73	Rheumatoid Arthritis	19
22	Female	18	Inflammatory Arthritis	10
23	Female	54	Rheumatoid Arthritis	24
24	Female	40	Psoriatic Arthritis	6
25	Female	49	Rheumatoid Arthritis	24
26	Female	69	Psoriatic Arthritis	11
27	Female	40	Inflammatory Arthritis	24
28	Female	58	Rheumatoid Arthritis	22
29	Female	59	Rheumatoid Arthritis	12
30	Female	33	Rheumatoid Arthritis	5
31	Male	51	Rheumatoid Arthritis	17
32	Female	32	Rheumatoid Arthritis	20
33	Male	77	Rheumatoid Arthritis	12
34	Female	52	Rheumatoid Arthritis	18
35	Female	52	Rheumatoid Arthritis	20
36	Male	79	Rheumatoid Arthritis	23
37	Female	48	Rheumatoid Arthritis	6
38	Female	57	Rheumatoid Arthritis	19
39	Male	77	Rheumatoid Arthritis	24
40	Male	67	Rheumatoid Arthritis	18
41	Male	63	Rheumatoid Arthritis	17
42	Female	68	Rheumatoid Arthritis	22
43	Female	43	Rheumatoid Arthritis	14

### 6.3.1 Age of Participants

All participants were aged between 18 years and 79 years and had a mean age of 51.95 years. The median age was 52 years.

Table 6.3: Age of Participants

	Number (n)	Minimum	Maximum
Age (Years)	43	18	79

Three participants were under thirty years of age and the majority were over thirty years of age with a spread over the decades as follows: 31-40 years n=7; 41-50 years n=10; 51-60 years n= 10; 61-70 years n=6; 71-80 years n=7.

### 6.3.2 Aetiology

All participants had an established diagnosis of an inflammatory arthritis confirmed by a consultant rheumatologist. The majority of participants has a diagnosis of rheumatoid arthritis (n=32, 75%).

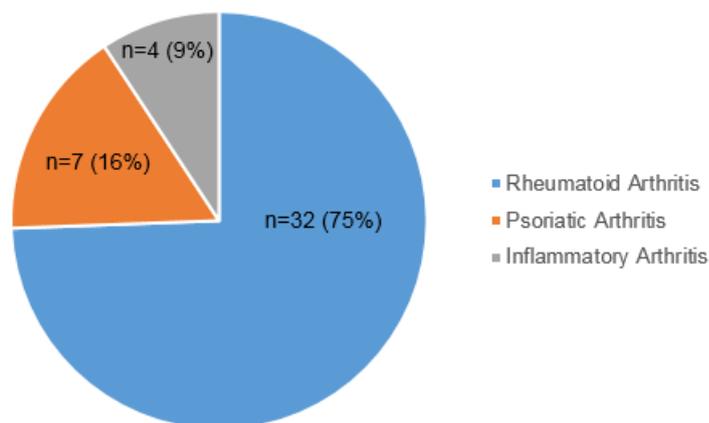


Figure 6.1: Diagnosis

All participants were within the two-year post-diagnosis criteria and had a mean length since diagnosis of 17.09 months.

Table 6.4: Length since Diagnosis

	Number (n)	Minimum	Maximum	Median	Mean
Time since diagnosis (months)	43	5	24	18	17.09

One-off interviews were completed over an eight-month period between November 2017 and June 2018. Interviews were conducted in a place and time of convenience for the participants. Interviews were conducted by the researcher except for the interviews of participants who attended the

rheumatology service where the researcher was employed. These participants were interviewed by a senior occupational therapist who had postgraduate research experience and was provided with training and guidance prior to interviewing. The duration of the interviews was between 23 minutes and 97 minutes and the average duration of the interviews was 55 minutes.

#### 6.4 Qualitative Analysis

Qualitative description principles were followed in the data collection and analysis, and findings have been presented using a thematic analysis approach as outlined in the methodology chapter. Following the analysis of the interview transcripts of the 43 participants, two overarching and interlinked themes were identified: the 'Pervasive Impact on Participation and Self-Identity', and 'Learning to Live Well with Inflammatory Arthritis'.

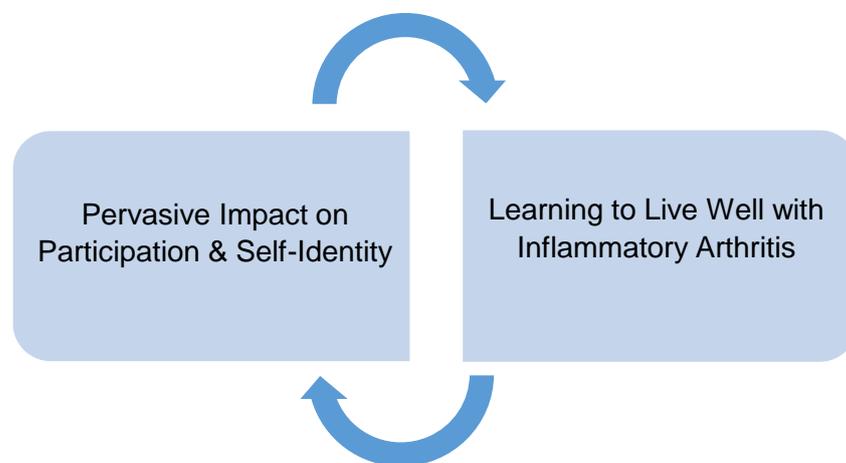


Figure 6.2: Overarching Themes Identified

Transcript content was further analysed into descriptive subthemes within these two overarching themes. Four subthemes were identified within the 'Pervasive Impact on Participation and Self-Identity' that principally explained the impact of inflammatory arthritis on participants' ability to engage in meaningful self-directed occupations. The 'Learning to Live Well with Inflammatory Arthritis' overarching theme comprised four themes which described the participant's views and experiences on how the multidisciplinary-led early arthritis clinics had supported them to live well with inflammatory arthritis and potential elements of service improvement (see Table 6.5).

Table 6.5: Overarching Themes and Themes

Overarching Themes	Themes
Pervasive Impact on Participation and Self-Identity	<p><b>Altered Capacity</b></p> <ul style="list-style-type: none"> <li>• Paid Employment</li> <li>• Relationships</li> <li>• Home &amp; Other Valued Life Role</li> <li>• Role Switch</li> </ul> <p><b>Well-being and Emotional Implications</b></p> <p><b>Disruption in Normal Occupational Balance</b></p> <p><b>Reconstructed Future</b></p>
Learning to Live Well with Inflammatory Arthritis	<p><b>Right Advice, in the Right Way, at the Right Time</b></p> <ul style="list-style-type: none"> <li>• Function of MDT Early Arthritis Clinic</li> <li>• Early Access for MDT Intervention</li> </ul> <p><b>'The Right Way' Concept</b></p> <ul style="list-style-type: none"> <li>• Therapeutic Relationship</li> <li>• Prolonged Support</li> <li>• Individualised Approach</li> </ul> <p><b>Adaptations for Participation</b></p> <ul style="list-style-type: none"> <li>• Adjustments in Life Roles</li> <li>• Self-Management &amp; the Active Participant</li> <li>• Re-identifying View of Self</li> </ul> <p><b>Areas for Future Development</b></p>

## 6.5 THEME ONE: Pervasive Impact on Participation and Self-Identity Theme

*'It (arthritis) has affected my relationship with my kids, with my family, with my husband. It has affected my job. And it's one word. And it's one disease. Like you want to try and box it off and just go, 'we will put that in a corner, and we won't let it affect anything else'. But it does.'* #30

The overarching theme of 'Pervasive Impact on Participation and Self-Identity' encompasses four subthemes which are: altered capacity; well-being and emotional implications; disruption in normal occupational balance; and reconstructed future (see Figure 6.3).

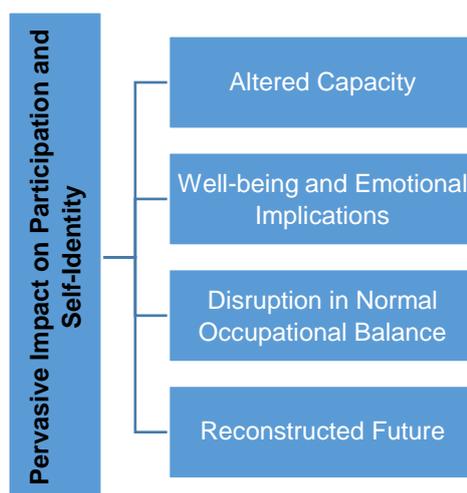


Figure 6.3: Pervasive Impact on Participation Overarching Theme with Subthemes

This overarching theme relates to the impact of the diagnosis on occupation and participation from the lived experience of the person with arthritis. Participants described the impact on life roles including paid employment, home-based roles, parenting, and relationships that were present from the onset of the disease. Diverse life impacts were identified by the participants which were subject to factors such as age and stage in life, and life interests. Participants described how the diagnosis and the early impact of arthritis forced them to reconsider their roles. Similarly, relationships required re-formation subject to adjusting to the diagnosis and its impact. Participants described the impact on occupational balance and engagement. Additionally, participants described how the diagnosis had forced them to consider a reconstructed future. Moreover, participants describe how self-identity is shaped by the impact on occupation-based participation and engagement resulting from the diagnosis.

Permeating into all subthemes within the overarching theme of 'Pervasive Impact on Participation and Self-Identity' was the person's lived experience versus the lack of awareness of the diagnosis and its impact by family, friends, and work colleagues. Participants described how their social networks would typically understand that pain is a feature of the disease but would be unaware of the complex multi-layer impact of symptoms on participation and how these pervasive impacts challenge self-identity. This perception of a lack of understanding was repeatedly emphasised within the data and was a source of stress and frustration, as well as a barrier to participation and social engagement.

*'People don't understand, like with arthritis there is not only pain but there are load of different thing included in it...I have stopped working, stopped being in college, I am doing less with my friends and my family.'* #22

*'I half think people don't believe me. They think I'm putting it on. I am young, and like, if a 60-year-old woman came in and said 'I have arthritis' everyone would be jumping up and letting them sit down. Like I am saying it and it's like 'sure you are only 39, get over yourself.'* #4

While participants emphasised that their social networks did not adequately understand the complexities of the disease, there was also frequent reporting of participants' own reluctance and avoidance to discuss their diagnosis with friends and family. This reflects the intricacies of receiving and adjusting to a diagnosis of inflammatory arthritis and highlights the challenges for both the person themselves and their support systems.

*'There are loads of people who don't know I have rheumatoid arthritis and I have no intention of ever telling them, because I never wanted to talk about it too much to anybody, or have it be a thing you know. A thing that we can discuss openly because it would just upset me too much with other people.'* #1

### 6.5.1 Altered Capacity

Participants described how inflammatory arthritis altered their capacity to engage in previously held life roles such as paid employment, relationships and home and other valued life roles (VLR) (Figure 6.4).

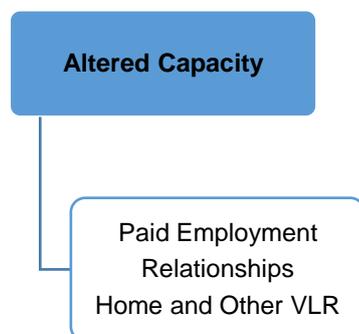


Figure 6.4: Altered Capacity Theme with Expansions

#### 6.5.1.1 Paid Employment and Student Roles

*'It (arthritis) has changed the way I live my life. If I wanted to work fulltime, I physically could not. And even in the job I'm doing, I feel guilty that I can't do more for them. There is no expectation, this is all me, all here in my own head. I am a young woman, I should be able to do more, but I can't. And then I have to say, cop on, you're fine, you know, it could be worse. And sometimes it's good if I have a meeting to go to because then I am out of my own head, whereas if I don't have that I am feeling sorry for myself.'* #12

The impact of arthritis on altered capacity in paid employment was widely reported by participants. While paid employment was reported by participants to be a meaningful life role (*'I love work, I love having a purpose'* #24), it was also described as a burden by some as they reported a pressure to maintain paid work regardless of health status. This self-perceived importance on maintaining work ability also had significance for participants' emotional well-being.

*'I said I am going to go into work, because like you know it's one of these things, you don't want to be seen as a burden either, you know, you have an important role to play but I went in, but I couldn't work.'* #14

Participants described the need to remain in work for financial reasons particularly if they were the main earner in their family. Work strain was frequently described and reflects the pressures that

accompany being the main provider in a family, and the additional burden of managing work demands whilst concurrently managing inflammatory arthritis.

*'I'm a busy person. I have got a job that I don't particularly like, it's highly pressured but I am supporting four people here. You know I do feel the financial burden in doing that.'* #6

*'But I never missed a day, once again, not because I was being loyal or anything, it's because I didn't have a choice. If I didn't go to work, I didn't have any money. So, I had to.'* #9

Participants discussed their altered capacity for employment with regard to the; physical impact on their work participation, capacity for work, psychosocial impact on work participation, and influence of disclosing on altered employment capacity. Repeatedly the impact of altered capacity for employment were reported by participants as having negative implications for self-esteem and mood.

#### **6.5.1.1.1 Physical Impact on Work Participation**

The physical demands of being in work as well as the physical demands associated with the specific work role were frequently highlighted by participants. Participants described how the symptoms of arthritis impacted negatively on their capacity to perform some physical aspects of their work roles such as reduced mobility within the work environment; reduced endurance and capacity for the working day; prolonged postures; moving and lifting self and resources within the work environment. This impact on physical capacity were a source of frustration to all as they reflected an enforced restriction and changes to pace and technique in order to continue to manage in work role.

*'I found sitting at a computer wasn't great for me, bending over, my neck was killing me. I would be very meticulous about my work, I would be going over everything to make sure it was perfect, and I knew it was the bending over that was killing my neck, so it's affected my life.'* #19

*'I had to stop hairdressing. I couldn't hold the hairdryer up, it's just too heavy. It's just too much on the arms, blow drying and all that. I just couldn't manage.'* #15

*'I was studying so any prolonged use on the laptop or the writing or anything like that, taking notes in class, things like that they were difficult.'* #28

#### **6.5.1.1.2 Capacity for Work**

Aside from work demands, participants described the impact of their diagnosis on their capacity to manage work-supporting tasks such as morning routines, commute to work, and sleep, as a result of their arthritis. These work supporting tasks were recognised as a vital part of maintaining work participation.

*'It was gone to the stage where the likes of getting dressed in the morning, getting out of bed, doing the simple things to get ready for work, whatever the case may be, I was finding myself getting up 15-20 minutes earlier. And actually, facing putting on my socks and getting dressed, all of that was becoming a nightmare.'* #17

*'I would have walked about 20 minutes to get to the train station and then I would have sat on a train for half an hour, and of course by the time I had sat down on that train I had seized up completely, and then it was another 20 minute walk the other side. So, by the time I got to work I was exhausted, and it was only 7 o'clock.'* #18

Many participants discussed how arthritis negatively impacted their work ability leading to a discrepancy between their work capacity and the demands of the job. This discrepancy forced modifications to their physical work demands, commute demands, giving themselves more time in morning preparation for work, changing or reducing their work hours and/or work role, and in extreme cases giving up work and resulting work disability. Participants reported needing additional time to complete work demands and described an associated stress from constantly trying to keep up.

*'It (work) took me four hours even though I am only getting paid for two hours. But still I never missed it (work)'* #9

*'Well, I used to do night duty before (arthritis) but there you see you're lifting patients and I just couldn't do it.'* #34

Participant #7 described ceasing her paid work role pre-diagnosis due to difficulties with managing and understanding her symptoms and their intrusion on her work role. She reflected on the loss of self, associated with the loss of work role:

*'I am not really going anywhere now. I barely leave the house. And that's really kind of hard. I know for my brain it would be good if I didn't stay at home all the time all the day, because I am kind of isolating myself, I know it.'* #7

The impact of sleep disturbance on work performance and employment capacity was described by participants. The ability to enjoy typical, restorative sleep was identified as diminished due to their diagnosis. The negative implications of suboptimal sleep on next day capacity for work participation and engagement were emphasised.

*'Trying to get comfortable in bed and waking five, six, seven times at night. Never really getting a good night's sleep and then trying to do a day's work. Nightmare. And then I'd have been really irritable at home here too. Just everything then would drive me demented'* #6

*'And then that broken sleep at night-time, it really affects your day. It's a killer, you know.'* #3

### **6.5.1.1.3 Psychosocial Impact on Work Participation**

The pervasive nature of symptoms associated with arthritis was frequently reported by participants as having significant psychosocial impact on work ability and perceived quality of work participation. Many participants reported that although altered capacity in physical work demands was very challenging, it was the psychosocial impact, such as expectations of others and self-expectations, that has the greatest impact on sustaining work ability at this early stage in their disease trajectory. Participants emphasised the cognitive demands of simultaneously living with symptoms whilst completing the intellectual demands of their work. Participants widely reported stress and guilt associated with work expectations from both self and others which they described as difficult to

reconcile. Similarly working participants widely emphasised how their perception of self as a worker was impacted by the condition.

*'The invisible bit of it is the hardest thing about all of it, like I can deal with the injections. I can deal with the tablets. I can deal with the methotrexate making you feel the way it does. But when you are at a staff meeting and they are looking for volunteers and they always look to the younger ones, and you are like 'I can't'.' #18*

The majority of participants described an unwillingness to recognise the impact of their diagnosis on their work and a persistence to continue on regardless for as long as possible in normal work engagement until either they could not sustain work or until they reconciled their delayed recognition of the impact on work. This unwillingness or denial around work impact is linked strongly to self-identity and view of self as a worker.

*'I didn't recognise it (work impact) until I would say I got a belt in the middle of the forehead to recognise it. It took me a bit of time to cop on to that. Now I suppose I did recognise it in some ways but not in its totality, and I suppose the issue for me, like when you get to my stage, are you on the scrap heap or are you finished one chapter? That was very hard because I have so much to offer. And you know it's just changing that mind-set as well, that you can be done without.' #41*

#### **6.5.1.1.4 Influence of Disclosing on Altered Employment Capacity**

Diagnosis disclosure to employers and work colleagues was described as an issue for many participants. The majority of participants appeared to have preconceived idea of negative results of disclosing, including fear of being made redundant.

*'I didn't want to tell people I had rheumatoid arthritis. I tried to keep it hidden from my job because I didn't want them to get rid of me. So I didn't tell them at all. But because I kept it hidden it became an extra burden that ultimately, I couldn't manage. So I left that job myself in the end, because managing the work with symptoms and hiding the symptoms was just too much to cope with' #1*

Findings highlighted a definite variance on altered capacity for paid employment between those who disclosed their diagnosis to their employer and work-based social network and those who did not. Typically, participants who had disclosed their arthritis were more likely to describe fewer psychosocial and emotional implications on work, even when the physical demands of the work role remained challenging.

*'My friends in work and all, all know. I wouldn't be the type of person to hide it. I don't feel like that, like, I wouldn't be embarrassed about it. It is what it is, do you know? I have it and that's it. I have no issues with people knowing, my friends would definitely know, and my boss, he has been great for appointments, very supportive and everything.' #27*

At the initial stage of their diagnosis many participants did not have the correct knowledge to guide disclosure or to understand the implications of disclosing in supporting their work ability. Participants highlighted the role that the multidisciplinary team can play in assisting and guiding them in making this work-related disclosure.

*'At that point I didn't realise that I had rights to kind of talk to people about adapting things for myself in work. That came later when I saw (OT).'* #18

### 6.5.1.2 Relationships

Participants described how the diagnosis had negatively impacted on their capacity to engage in relationships and how the nature of their relationships were changed as a result of arthritis and its pervasive fluctuating symptoms. Negatively impacted relationships reported by participants included close familial relationships with life partners and children, as well as friendships.

*'I have probably stopped a lot of interaction with people. Yeah literally because it's kind of like up/down/up/down/up/down. So, do I ring people when I am up? Do I ring them when I am down? Do I meet them when I am up? Do I meet them when I am down? When you are down, you don't want to bring anyone else down. And when you're up, you don't want to give a false impression that this is where you're at.'* #1

Participants widely described the impact of arthritis on their sense of self, how they view themselves, and how they present to, or are thought to be perceived by, others. Participants shared how early arthritis impacted on their typical behaviour and personality and the implications of this on their relationships, and how relationships were changed or strained as a result.

*'I am so cranky; I am so cranky sometimes. And it's hard on my family. And I am under pressure to be the same person I always was'* #7

Participants described a compilation of different relationships impacted by arthritis: life-partner, parent-child relationships, and a forced role switch (outlined in Figure 6.5 below) which will now be presented.

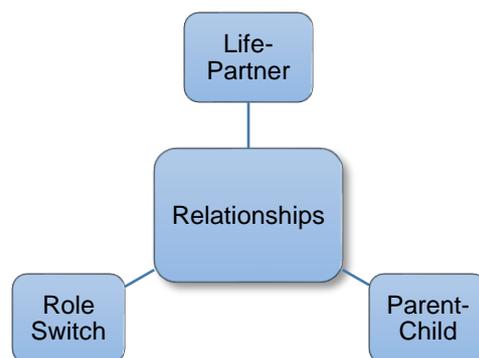


Figure 6.5: Altered Capacity within Relationships

#### 6.5.1.2.1 Life-Partner Relationships

The emotional impact and stress on life-partner relationships were widely reported by participants and the sense of partnership and togetherness was tested in many cases. Many participants reported guilt associated with relationships; guilt for an unexpected diagnosis, as well as for the far-reaching implications of this diagnosis on their relationship with their life-partner. Participants emphasised a

non-gender specific protectionist approach towards family members where they internalised their own thoughts and worries in order to spare their family members from being worried about them. This protectionist approach was strongly associated with an internalising of diagnosis-based worries efforts which added to relationship strain.

*'I would do my best not to let my children or anyone see I was in a lot of pain, or my wife for that matter. I kept it from her and them as much as I could.'* #17

*'It (arthritis) does affect relationships. I mean there is a frustration and tension that happens because of it. I think it's not only me, but the situation is unfair and it's unfair on my husband. He didn't expect this. Neither of us did. Neither of us asked for this. It's just one of these things. And it's not just me, he has it as a problem as well, and our daughter.'* #23

Furthermore, many participants described how their life-partner relationships had been strained by the partner's lack of understanding and knowledge, both of the clinical presentation of early arthritis and also how to help.

*'It (arthritis symptoms) would nearly have started arguments between us because he (husband) thought I was just kind of being lazy.'* #32

*'I was hiding my pain from (wife). I was doing my best to hide my pain from her, but she knew I was suffering. Everybody around me knew I was suffering but I wouldn't give in. I suppose sometimes I could be grouchy or whatever the case may be when I would come home, she would know. It didn't put stress on our relationship, but it obviously didn't help, but I suppose I was lucky. She is a good girl and she looked after me so as best she could, as much as I would let her.'* #17

Participants discussed the impact of their arthritis on their shared activities with partners and family members and how this insidious impact resulted in a shrinking of social outlets for more than just themselves which resulted in further guilt and regret.

*'Before, if myself and (husband) go out, he likes a pint with all his friends and he would drive out to the pub, it's about four mile out the road where our pub is, and I would always drive home. But even that, I can't drive now so I can't do that with him. So he can't even go out.'* #42

The pervasive impact of arthritis on altered capacity with physical intimacy in life-partner relationships was discussed by several participants. This topic was raised more readily by younger participants and only by female participants and was an identified concern for them in terms of current and future life expectations. Additionally, the implications of how this altered capacity affects the closeness and connectedness of being together was identified as adversely impacting self-identity, and well-being.

*'and then you can't be intimate because you can't move basically, so there's that side to it as well. So it does put a massive strain, like even now, like he's fantastic, he is great and he is supportive, but like we are still not where we were because it does take its toll. You are just like, I can't move, I can't walk, don't touch me, I don't feel like myself. I don't feel like being with anyone.'* #30

*'It does affect your relationship with your partner cause there's just no mojo there anymore. It's kind of like, look, it's not your fault and it's not my fault. It's just something we have to deal with.'* #13

#### **6.5.1.2.2 Parent-Child Relationships and Roles**

*'my role as a parent, to me, it has narrowed.'* #19

The complex multi-faceted demands and expectations that accompany parent-child relationships and roles were widely discussed by participants. Participants described how the everyday *'mammy activities'* #32 were hampered. Participants extensively discussed restrictions: caring for children, supporting their personal care, meal preparation *'lifting and carrying, opening packets of crisps or popcorn and cereal'* #32; lifting and transporting children, walking children to school or after-school activities; managing homework; supporting children's leisure and social activities.

Participants illustrated how their view of the parenting role was now compromised and challenged due to their altered capacity. There was a sense of sadness and regret that accompanied the description of altered capacity in parent roles as a result of the early impact of symptoms, particularly in play-related roles. Types of engagement in play were adjusted due to altered capacity and both parent and grandparent participants described how they could not sustain active, physical-based play due to symptoms and instead had to modify their interactions within this role to include more sedentary play.

*'All of it was so hard. I just couldn't manage, and I would be thinking 'oh we have to do something today it is a sunny day; we have to go out, we have to be at the beach. I have to bring him (son) somewhere, he should be in a play zone or in the park you know. The pressure and the mam-guilt.'* #15

*'He (son) would be a very active child. But there's a lot of things in terms of that like, as I say, that he's interested in that I can't do. Like he went through this phase recently of wrestling. So he used to like say 'oh mam pretend to be this character' and I will always be like 'oh hang on, oh no, I can't'. Like just kind of things that someone else might take for granted.'* #27

Parent participants were acutely aware of the impact their diagnosis on their ability to be the parent they thought they would be. They described how the emotional consequences of the diagnosis such as irritability, low mood, and crankiness tainted parent-child participation, and influenced their interactions with their children, as much as their other symptoms.

*'I used to get into such bad form ... I can remember my son saying to me one day, 'I know why Mammy, because GaGa told me, it's because you're in pain all that time and that's what pain does to you.' That broke my heart.'* #9

Frequently participants discussed how they had to delegate their parent roles to others, *'like my mother and my mother-in-law had to mind my kids because I couldn't pick them up'* #30. This re-allocation of duties was consistently viewed negatively. All parent participants described guilt at having to allocate their parenting roles to their children or other family (partner, sibling, grandparent). There was widespread emphasis of remorse at the impact of their symptoms on their children's

childhood, and a sadness that their children should be aware of symptoms *'my kids are suffering because of this (arthritis)'* #16. Self-perception as a parent and child's perception of parent were highlighted as hugely important. There was a strong desire to do well and to create childhoods that were happy. There was considerable self-imposed pressure to shield children from the impact of arthritis on their parents.

*'I don't want her (daughter) to think of me always sitting down and not being able to do anything. I don't talk about sickness. I think if you grow up in a house where there is sickness all the time it brings your mood down and she is only sixteen and with the help of God, it (arthritis) is going to be managed and I don't want to spoil life for her. I only have one child so I might as well make it as happy as possible for her.'* #38

*'You get to a point where you have to say 'right, I am here to care for my children and if I can't care for them, what's the purpose of doing this? .... they have their childhood once; I have their childhood once. I don't want them to look back in twenty years and go 'God mammy was in bed a lot' or 'mammy couldn't go here because she didn't feel well or couldn't do things or she was ratty' or anything like that.'* #11

### **6.5.1.2.3 Role Switch**

Participants described forced role switch repeatedly within the interviews, with the majority of participants highlighting change in roles within relationships as an early impact of their diagnosis. Types of role switch included partners, children, siblings, and parents switching into carer role for the participant and assisting the participant with their basic personal self-care tasks. All of these role switches were viewed as necessary to support the participant, but equally all were described as a negative impact of arthritis on well-being and self-identity. Some participants shared how their life-partners, family members or friends had to give up work or take time off work to care for them with resultant adverse effects on emotional well-being.

*'She (daughter) helps me a lot. Her and her brother, they help out with their little brother. But the problem is he is their brother not their child, and I feel very guilty sometimes.'* #19

Role switch around personal care tasks was described by several participants and was associated with their reliance on family members such as life partners to assist them in completing basic self-care activities. The resulting change in relationship dynamic was repeatedly emphasised.

*'I found it hard to get into bed and even undress and get out of bed. But even now today, my wife is great, she is my best friend, I would be lost without her in the sense that she still does help me today because I can't really bend. And she ties my laces and sometimes buttons my shirt. It's kind of simple things you take for granted you know?'* #39

Role switch also relates to the redistribution of participants' previously held roles, for example, their children having to assume the parent role for their own siblings, or extended family members assuming parenting roles in lieu of the participant. Reliance on other people to perform their parenting roles was negatively viewed by participants. The extent of role switch reported on both levels was an unexpected finding arising from the data and the degrees of impact of this switch on emotional well-being, mood and self-identity was extensively reported.

*'I had my seven-year-old child helping me get dressed. I had people coming to my house at eight o'clock in the morning to bring my kids to school' #13*

*'My mother-in-law had to mind my kids because I couldn't pick them up. Like from being such an independent person to having a team of people to come and help me. My husband had to take time off work because he wasn't sure in the morning if I was going to be able to move, or that I needed help out of bed. So there's the physical side of it and then the mental side. I thought, because you are used to doing your own thing and then someone to come in on top of you. I know like they are fantastic, and I can't praise them enough for all the help they gave me, but, it's just I do my own things my own way, just like everyone has their own way of doing things. And just when you're 33, to have two young kids and have someone else mind them, like that was a huge thing in my head. And I was just cross.'* #30

Despite the multitude of adverse emotions associated with sustaining relationships with arthritis there was awareness of the value of human interaction in supporting health and well-being. Participants described that having a purpose and a commitment to others provided a positive focus in encouraging and promoting daily engagement.

*'I do get frustrated, you know. I do, because I am thinking am, I ever going to feel fabulous again? But I imagine, if you didn't have children, or if you didn't have people to focus on, it'd be very difficult. I HAVE to get up in the morning and that's probably a good thing.'* #12

### 6.5.1.3 Home and Other Valued Life Roles

*'I was surprised at the simple things I couldn't do. Sometimes I couldn't turn on the tap. I couldn't paint the house. I was the carer in the house, so you know with the kids coming out from college and my wife was at home and I was trying to peel and get dinner ready and I couldn't do it. You know just actually gripping things. Even with my grandkids, the little fellow was two and I found it hard to lift him. So it was all that sort of stuff, do you know, and I was surprised, they were just normal run of the mill things.'* #2

Home and other valued life roles theme is a compilation of personal care and domestic roles, leisure roles, and driving (outlined in Figure 6.6 below) which will now be presented.

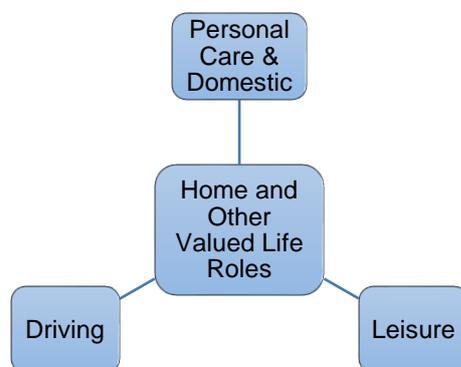


Figure 6.6: Altered Capacity within Home and Other Valued Life Roles

#### **6.5.1.3.1 Personal Care and Domestic Roles**

Altered capacity in the physical demands of personal care tasks such as washing, dressing, and shaving, and domestic-based participation such as meal preparation, ironing, cleaning was frequently described by participants. Restrictions in task completion due to symptoms and requirements to engage assistance of others were reported.

*'When I am fairly normal, I am fine in self-care. When I am pretty bad getting dressed is difficult, sometimes maybe washing my hair, those kinds of things are definitely more difficult.'* #27

*'Opening a bottle of shampoo can be quite painful, just at the tips of my fingers and I'd pass it to (husband) and say would you open that. You know even your cleanser, silly little things like that, opening bottle tops or anything like that is quite difficult.'* #20

#### **6.5.1.3.2 Leisure Role**

Many participants reported early changes to their leisure role participation resulting in a reduction and in some cases cessation of valued leisure activities (*'I don't really have any hobbies anymore'* #31) The degree to which arthritis impacted on previously enjoyed leisure was influenced by how committed to the activity participants had been, and perceived knowledge regarding the fallout of the leisure role on symptoms.

*'It was taking longer to recover from training, and after a match it could take me a day or two to recover. I was always putting it down to something else. And when you play hurling, you're regarded as this that and the other, so you don't let pain bother you.'* #17

Regardless of how extensive the changes were to leisure participation there was a consistent reporting of loss associated with reduced leisure engagement. The types of leisure engagement impacted were not limited to sport-based leisure, other social activities (meeting friends, going for a meal or drinks) were also frequently described as being impacted due to symptoms early in the disease trajectory.

*'or even things like I would have gone to the cinema a lot with my roommate, but the idea of sitting for two and a half hours in the cinema, like I used to get an aisle seat so I could move my legs around, but that put me off. I knew I would be sitting, and I knew I'd be sore.'* #18

*'I've had to give up two things: golf which I loved and going to the pub on a Saturday.'* #26

#### **6.5.1.3.3 Driving Role**

*'I miss my car wicked. Ah that's it. I just miss it so much because you lose your independence when you can't drive.'* #42

Driving was extensively described as a valuable participation-based role. Early symptoms were highlighted as restricting physical ability for driving requirements that resulted in associated constraint in independence and autonomy. Participants described mechanical and skill-based demands of driving which were impacted early in the disease.

*'My driving was impacted for a while, thank God now I'm ok, but like I couldn't change gears, I couldn't turn to check if there are cars coming, any of that.'* #30

Driving provides a medium for independence and therefore altered capacity in this domain was identified as a destructive impact of arthritis on participation and social connectedness. Loss of driving independence had clear consequences on participation in valued roles for participants.

*'I couldn't drive and I am really independent. I am just so used to being able to do everything myself and needing to do everything myself that, it just completely threw me that I couldn't drive.'* #27

Furthermore, participants emphasised the role demands which were compromised and challenged as a result of driving difficulties arising early in the disease.

*'I couldn't even drive a car and obviously I had school runs to do.'* #11

### **6.5.2 Well-being and Emotional Implications**

*'It was like your life just dropped into a bucket.'* #34

Participants described the adverse impact of arthritis on well-being and the emotional repercussions which accompany a new diagnosis, with associated altered capacity for participation and challenges to expectations of self. Low mood, stress, guilt, and blame had an extensive influence on how much participants were impacted by the diagnosis and how it affected their participation, decreased capacity, view of future and perceived ability to cope.

*'The dark place I was in would have been both physically and psychologically. Psychologically everything was doom and gloom, I was out of work, I couldn't see myself getting back to work, I was getting frustrated, I was probably getting depressed. It's not something you can subjectively say, but people looking at it objectively would say, yeah getting really down and out, and hopeless. Hopelessness was setting in.'* #41

*'When I look back on it now, I just think 'God', that's how much it impacted on my mental health and my whole thinking.'* #1

Mood and mental health status were strongly identified as influencing symptoms and perceived capacity for engagement in life roles. Similarly, the emotional and well-being impact was emphasised by participants as directly impacting perceived ability to cope and perceived ability to adjust to the diagnosis and also significantly shaped interactions with others (relationships). Participants described feelings of frustration, irritability, uselessness, and anger and shared how these emotions impacted their engagement and capacity for interactions with others. The constant worry associated with early arthritis was described by participants.

*'Mentally you are fighting. When you get up in the morning, from the time you wake up or even during the night you are fighting all the time, between pain, worrying about getting up in the morning, worrying how you are going to get through work. If you don't get to work, or if you are not able to go to work, how are you going to pay the bills? Mentally you are fighting with yourself 24 hours a day.'* #17

Participants' own perception of arthritis appeared to inherently shape the measure of impact on emotional well-being. Self-assessment of the diagnosis in terms of perceived severity and perceived reality strongly influenced wellbeing.

*'I never thought arthritis was as bad as it was until I got it. I always thought people were going 'ah it's arthritis' and now when I have it, I am going 'no, no, it's ARTHRITIS, like, you don't understand. Its losing control of your body and losing control of your mind ever so slightly as well. I think I did' #30*

### **6.5.3 Disruption in Normal Occupational Balance**

*'It's like my pilot light goes out after a certain amount of time, or it's like the car losing power. It's like you're a car and all is going well, and suddenly, it's like a car losing power and stops. That's the way I feel.' #23*

Findings consistently highlighted the consequences of the fluctuating nature of arthritis on capacity, pace and demands of previously held and enjoyed participation. Disruption in normal occupational balance was caused by decreased capacity and endurance for previously held occupations. Lack of certainty relating to capacity and endurance in occupation-based participation was identified as a definite stressor which also infiltrates well-being. Participants described varying responses to this shifting capacity and responses were influenced by personality and knowledge about condition management *'it was dictating the pace of life and the content of the things I was doing.'* #12.

Some participants described how they were prioritising work over other life roles in order to endure work ability.

*'I used to get up at six and then I'd go to work for seven and I'd be in work until six, then I'd go home, get an hour's train back. There was no one to support me either, and now I'm regretting it, but really, I blocked it all out and just powered through the pain because there was no other option. That's probably why it (arthritis) deteriorated so quickly. By the time I went back to my rheumatologist, getting out of bed was a nightmare, because my hands, my legs, I just couldn't move them. As soon as I got home from work, if I sat down, that'd be that I wouldn't be able to move at all. So, I could see that something had to give.'* #18

The impact of fatigue on participation and regulating occupational balance was frequently described by participants.

*'I would have found, say I had a kid's party, and had a shower, got dressed, went down to the shops got the kids something, went to the party. I'd be sitting there nearly falling asleep. It was just too much for me. Or if I got up in the morning and had a shower and did all that, then I couldn't go out shopping because I would be too tired. I would have to sit down at the supermarket. I was just exhausted. I can't do a load of things together.'* #15

Additionally, participants described how their typical daily routines were altered due to symptoms and that these changes in pace and routine resulted in a dysregulation of their normal occupational balance. Routines such as managing morning self-care routines and managing domestic activities such as meal preparation and laundry were all identified as impacted by symptoms of fatigue or physical restriction and manifested early in the disease. Similarly, the consequences of diminished work, leisure, and social engagement due to symptoms were reported as permeating into an overall feeling of limitation and restricted occupational engagement. These daily routines and interests were

recognised as a vital part of maintaining balance in health and engagement and the shift in typical occupational balance was recognised by participants.

Participants described having a dynamic support scaffold as a main determinant for successfully negotiating the fluctuating scales of balance in occupational performance. This support scaffold concept was frequently identified by participants as a determinant for coping and was described as a fluid, personalised support web and dependent on the individuals' own preferences, some participants identified family or friends, whilst others reported the multidisciplinary team. Regardless of the origin or make-up of the support network, having one was identified as important to navigate occupational balance restrictions associated with the increased demands associated with participating in daily routines or the decreased participation in valued occupational performance areas.

*'I was very lucky that I had a good support network, but if you didn't have that. I mean my heart would go out to anybody that didn't, because it was really, really tough.'* #11

#### **6.5.4 Reconstructed Future**

*'the future is my fear.'* #25

Fear of the future, and loss of future plans were strongly emphasised by participants and the associated impact weighed heavily on participation and engagement. Mourning for a future which had been planned was a central part of recognising the impact on current and future participation. Additionally, grief and anxiety-based fear related to what the future might now hold with a diagnosis of arthritis were described.

*'I was in mourning for my life. That's what I was. Honestly, because your life is never going to be the same again, I think anyway.'* #9

The complex multi-faceted impact of arthritis on a person's sense of self and their individual expectations and demands for participation and engagement in life roles were highlighted. Impact on future participation was identified as having physical, emotional, and psychosocial origins and were intrinsically linked with the degree of adjustment to the diagnosis. Participants reiterated that a constant mindful effort was required to facilitate acceptance of the diagnosis and the required management of the impact now and in the future.

*'I think one of the hardest parts to accept that you are not the same person. You can't do the same things the same way you use to do them before.'* #7

*'It's very hard, and mentally, it is a mental battle to keep positive and not let it consume you. Not let this movement, this pain consume you. I am just breathing in, breathing out, and I am just living in the moment. I am not going to the future.'* #12

All participants considered the impact of arthritis on future participation and potential repercussions on their engagement levels. This effort to envisage a future with arthritis caused concern around quality of life for self and for significant others.

*'I am still trying to get used to the fact do you know what will be maybe in the next 10-15 years. I won't have any more children, but how will it affect my life, me personally, how will it affect my life with (wife).'* #14

*'There's the worry for the future that am I going to be ok, what way am I going to be? Whether I am going to be able to work, or whether I am going to be dependent on my partner.'* #28

Fear of the future and ageing with arthritis were identified as motivators to change lifestyle habits and to encourage improved management of arthritis to ensure best possible quality of life into ageing.

*'I am going to try and look after myself if I can, because I definitely don't want to be, when I am in my late 50's or 60's, be crippled with arthritis.'* #37

*'You prepare yourself in some ways for life when you're in your 70's, 80's, but I am saying I am not going to be 80 when I am only 40.'* #14

Participants discussed how their diagnosis impacted on decision-making for future plans. Some participants discussed how their arthritis has prompted them to consider steps to shape their future life choices in a different way, for example undertaking different training to support change of work or choosing careers which were perceived as more manageable with the diagnosis. One of the younger participants (#10) described how looking to the future with inflammatory arthritis informed and guided her choices and decisions for future careers.

*'I wasn't necessarily picking my career based on my arthritis but the amount of physical demands in jobs were a factor.'* #10

## **6.6 THEME TWO: Learning to Live Well with Inflammatory Arthritis**

The second overarching theme 'Learning to Live Well with Inflammatory Arthritis' encompasses three subthemes and describes participants' narratives of how the mechanisms of delivery of the multidisciplinary-led early arthritis clinics impacted on their ability to manage early inflammatory arthritis and how this model influenced change and supported them to live well with arthritis by addressing participation and engagement in life roles. The subthemes associated with this overarching theme are: Right Advice, in the Right Way, at the Right Time', The Right Way' Concept, and Adaptations for Participation (outlined in Figure 6.7 below).

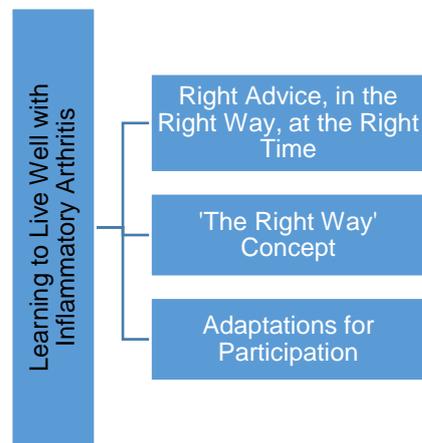


Figure 6.7: Learning to Live Well with Inflammatory Arthritis Overarching Theme with Subthemes

### 6.6.1 Right Advice, in the Right Way, at the Right Time

*'I think the early intervention is vital. That once I got here, I think within shortly afterwards I seem to have been seen by OT and Physio and their focus was all on living with arthritis, like managing the symptoms but still doing. #28*

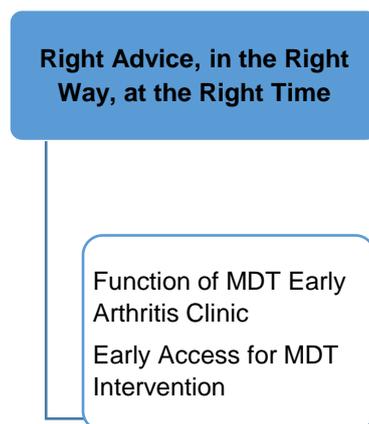


Figure 6.8: Right Advice, in the Right Way, at the Right Time Subtheme

#### 6.6.1.1 Function of Multidisciplinary-Led Early Arthritis Clinic

Participants recognised the role of the multidisciplinary-led early arthritis clinics in providing advice on managing the impact of arthritis on everyday engagement and participation. One participant described how the team in the multidisciplinary-led early arthritis clinics were able to *'take a helicopter view of the whole thing'* #6. The importance of context; right place, right time for intervention, beyond medical intervention was illustrated by participant #28 who reflected how she would have previously relied on online guidance on symptoms and medications but that online resources did not equip her to actually manage her symptoms in the way the multidisciplinary-led early arthritis interventions did at the clinic.

*'I wouldn't have known about anything with the hand rests or the gloves or anything like that. Or the impacts of how I actually moved my joints when doing something. That was all new. Any googling I did would have looked at symptoms and the medicine, but not how you would cope, or like the management of it.'* #28

Participants reported that the multidisciplinary-led early arthritis clinics provided practical, person-centred advice early in the diagnosis to improve their ability to complete everyday tasks and roles that were important to them. Additionally, participants emphasised how remediating these practical engagement difficulties promoted their perceived quality of, and satisfaction with, their participation in life roles. Participants described how the combined support of the multidisciplinary team early in the diagnosis developed their confidence in self-management and in their ability to live well with arthritis.

*'through the whole year, they (MDT) have talked with me about what I need to do with managing life stuff as well as my medication... the support over the first year since diagnosis really helped me learn how to self-manage and to live and live well with this (arthritis).'* #32

*'So for me the rheumatology service is the right place where I can name 'when I am pulling weeds and doing things in the garden, or when I am steering the car' like that feels like the right place to say, this is where I feel the problem, how can you help me sort it out?'* #8

Participants discussed their experiences of how the multidisciplinary-led early arthritis service ameliorated the pervasive impact of arthritis on participation with the 'right help, in the right way and at the right time' approach.

*'I wanted to be well. I was fortunate to get her (OT) at the right time to get the help and support I needed. Now I feel everything is just slotting nicely into place, things are going great and all I can do is hope that they continue to feel this great.'* #1

*'I think you should see them all (MDT) at the time (from diagnosis) because it's more beneficial to you. You're taking it all in then. You know what's wrong, and with the team then you know what you need to do. You know what's going to help you and how to manage it. It also gave me a confidence in knowing what helped me feel I was managing.'* #15

Participants emphasised how the multidisciplinary-led early arthritis service supported reframing of the diagnosis within their lives and they reiterated the value of this type of support. Participants reported that the message received from the multidisciplinary team was one of learning to live well with arthritis and acquisition and assimilation of skills and awareness of life choices to become an active self-manager of their condition and support meaningful engagement.

*'the whole team really did address the life impact piece. I think (OT) more than anyone addressed the life impacts, but physio did as well. I do remember sitting and talking to OT about it. And she was kind of really good and asking about this and that and also things I hadn't thought about and maybe also things that I hadn't realise had affected me, things like driving and jobs at home, opening jars even. And I was like 'oh wow I didn't know there was anything like this.'* #27

*'That whole lifestyle piece I think that's been the most confidence building thing for me moving forward. It has been like the meetings with (OT) and having chats makes me feel a bit less like I have got a disability and more a bit like, that it's just a very liveable-with condition.'* #18

Participants appreciated the role of the multidisciplinary-led early arthritis clinics in addressing the impact on participation and engagement associated with diagnosis early in the disease trajectory. Participants speculated that these occupation-based difficulties would likely not be addressed by the medical clinic where the emphasis would primarily be on symptom and medication management.

*'Well I mean I figure the actual medication is just the doctor and the other stuff, the life stuff sits with the girls (MDT).'* #28

*'The specific problems at home, in work, with my golf, with driving, that was all through OT. I got more information out of OT than I would have got from anybody. The physio was good too, but it's just that if you get to know one person and you meet them a second time and more, well it's on a personal level now and it was relevant stuff to me.'* #14

Similarly, several participants discussed their surprise at and pleasure with the holistic nature of the service model, and the open-door approach to link in to address queries, and therefore gain timely guidance supporting achievable management rather than feeling overwhelmed by a building up of queries and concerns.

*'it (MDT-led clinic) was unexpected but brilliant. I thought, if you have arthritis you go and you will probably see a doctor you know 'how are you feeling, keep taking your tablets'. But I was surprised that when I came in that OT took such an active role in this and also that the physio saw me and gave me a programme of exercises that I could do myself.'* #2

Participants emphasised that the team composition and the operational factors associated with the multidisciplinary-led early arthritis clinics, such as early access to intervention and the delivery style, facilitated the approach where occupational-based participation and engagement could be addressed.

### **6.6.1.2 Early Access to Multidisciplinary Intervention**

The aim of the multidisciplinary-led early arthritis model is to offer early appointments and interventions immediately post-medical diagnosis to support symptom management and promote living well with inflammatory arthritis. Timing of support was widely identified as being a benefit. Participants universally welcomed the opportunity for early intervention to address the impact on participation and engagement so that *'you have a chance to get ahead of it'* #14. Participants described how early access to multidisciplinary team provided a valuable platform to ask questions, have their individual concerns addressed, and receive timely and helpful emotional and practical support to assist with adjusting to the new diagnosis. This sense of being proactive in the early management of the diagnosis to support quality of life and quality of engagement was repeatedly and positively reported by participants.

*'Everything is so well planned. The appointments with the girls (MDT), I think I met them maybe the week after I'd met the consultant. It was perfect timing, for me anyway it was the right time because they could answer questions and they could give me support and they could give me extra information and they validated how I was feeling.'* #12

*'it was so helpful to be seeing the team so often in the beginning. It's just that I didn't know what was going on. It was a big thing for me, like, it felt like my whole life was changing and I was glad of the team, to explain to them how much pain I was in, and to get help through that time.'* #35

This prompt early access to multidisciplinary team services was viewed as supportive and timely to deal with health and lifestyle-based needs. There was recognition that the multidisciplinary-led early arthritis clinic was part of the rheumatology care package and 'a steppingstone to managing this (arthritis)' #15. Furthermore, participants emphasised the importance of having access to the concurrent supports - the medical review with the doctor, and then the full multidisciplinary team, nurse, occupational therapy, and physiotherapy to support best outcomes 'I think you need all of them together' #15.

*'I feel the support I got from the girls (MDT), I mean if that service wasn't there and you were just seeing a consultant and being checked in and out by a nurse, I really would be in a very bad way. So that (MDT) support has saved my life and has kept my head right.'* #12

Differences between the traditional model and the multidisciplinary-led early arthritis model were discussed by one participant who had initially attended a traditional rheumatology service in the United Kingdom before moving to Ireland where she attended a rheumatology site which had a multidisciplinary-led early arthritis clinic service. She discussed the gaps and the emotional turmoil that she felt were associated with the lack of support in the first six months of her diagnosis in the traditional model.

*'When I was in the NHS I literally only got a rheumatologist appointment, where they told me, you have got psoriatic arthritis, we're going to put you on methotrexate, there are the side effects, and you know, we will see you in three months. ... And I didn't really have any help, like there was no helpline call. There was nothing and literally I just was kind of at sea with these horrible medicines that made me feel like a zombie. I was still in pain because I didn't know that they would take up to twelve weeks to kick in. so I was just waiting, waiting and waiting to feel better, and I had no idea, and my head saying like 'come on be strong, power through' but actually by doing that I was doing far more damage to myself. I hadn't realised. It was only when I came here and met (MDT) that they saw beginnings of deformities in my hands. And I was like, how had I not known'. #18*

This participant reflected on differences between the two service models and emphasised the importance of gaining the right information at the right time.

*'even that first meeting with the NHS rheumatologist, it would have been nice to have had some sort of lifestyle discussion at that point as opposed to what happened. Because I came away and it was another three months before I saw anybody. And then I came here to (MDT clinic) and was blindsided by it, because I thought it was going to be more of the same. And then I talked to the physio and the OT and it was like 'oh, ok, so this is going to be a big lifestyle change for me. I hadn't realised.'* #18

## 6.6.2 'The Right Way' Concept

This subtheme describes the features of the delivery methods of the model and how the multidisciplinary team members work within the model to influence change to facilitate clients to live well with inflammatory arthritis.

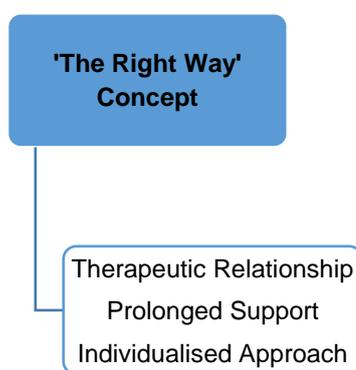


Figure 6.9: 'The Right Way' Concept Subtheme

### 6.6.2.1 Therapeutic Relationship

The quality of the therapeutic relationship between the client and the multidisciplinary team practitioners was described by participants as being fundamental to the success of the service in addressing meaningful participation. This relationship was highlighted as influencing depth of engagement and ensuring a supportive space for the delivery of individually tailored occupation-based interventions. The vast majority of participants repeatedly reported feeling understood, being listened to, being treated with respect, and being in receipt of interventions that delivered solutions to their unique circumstances which were collaboratively identified and implemented between themselves and the multidisciplinary team. Participants emphasised positive outcomes associated with feeling understood by the multidisciplinary team, and how these acted as a catalyst to support change and self-management. These elements were consistently identified by service users as underpinning success of this model in addressing occupation and participation and supporting emotional health and quality outcomes in a way that was valuable and exclusive.

A sense of connectedness with team members and a perception that the team were genuinely interested in the service user was influential in disclosure of needs, and success of meaningful interventions offered. Furthermore, participants described a recognition that the therapeutic

relationship was two-way and had parity of responsibility to influence change and promote self-management of the condition.

*'I mean I felt like I could tell them anything or ask them anything that I needed to know. Like they (MDT) were completely adjusting to my needs all the time' #10*

*'but the fact that she (OT) had her list and we had agreed that she had set things for her to do and things for me to do, and it was like, 'did you?' and you know, I was getting closer each time to doing it and because she didn't pressure me. Everything was just step by step and it wasn't rushed. And in the end, it was absolutely the right approach for me. She made me accountable for me as well. Even though in my head I know that I have to do these things but before I came to her, I felt like I wasn't brave enough to do them and I had been filled with fear. So when I knew I was going back to OT, I'd be thinking 'did I do that? And if I don't do it, how am I expecting anything to change?' And I learned from OT the only way something is going to change is if I do something, take up something, or if I alter my thinking.' #1*

The overall majority of participants reported an atmosphere of openness and genuine interest among multidisciplinary team members to support them to remediate their occupation-based participation difficulties within the demands and realities of real life. Participants emphasised that this atmosphere supported equal collaboration in interventions and ensured supports provided were both relevant and achievable.

*'They (MDT) are all so helpful, but the most important thing is do what you are told or as much as you can and to be honest with them about how you're getting on. I had to tell physio, look I can't do it three times a day and they went 'just do what you can', and that was helpful you know. Things run a lot more helpful when you go by the book with them and be honest.' #39*

Participant #15 discussed how the therapeutic relationship that she had with her multidisciplinary team was instrumental in delivering the right advice for her in the right way at the right time and that this was influential in supporting her to become an active participant in the management of her arthritis. The multidisciplinary team's local knowledge of community services and the way in which they tailored interventions to assist implementation of positive health behaviours, as well as the team's recognition of her readiness to change, and incorporate positive health strategies appears to have been influential in supporting positive changes. This participant comments on how the easy, conversational style of the team helped her to hear the recommendations, and this motivated her to try new techniques to support her self-management of her arthritis. She described how her occupational therapist effectively started her off with breathing techniques and postural advice and then progressed this to include community-based stress management and movement by using social prescribing to suggest a local course that might be of interest and would be of benefit.

*'She was telling me all about that, whereas I would have never thought about any of that before. And she said 'go, you might like it, you never know, you might surprise yourself' and I did and I love it and I go now twice a week and it's really helped my joints.' #15*

### 6.6.2.2 Prolonged Support

*'Time, time to talk made a difference.'* #1

Prolonged support described by participants included face-to-face appointments which were individual and/or group based, and telephone support as required to facilitate self-management, and an annual review. Participants consistently emphasised a strength of the service as providing space and time to identify the disease impact on occupation-based participation in their life roles and to plan and implement meaningful interventions to support their engagement. Participants described adequate time in contacts, as well as a sense of connectedness they felt from being linked to the services for a prolonged time. A majority of participants reported not feeling rushed, even when services were busy, and they described how having space to air concerns was conducive to identifying the right next steps in subsequent interventions.

*'I definitely felt with the girls (MDT) that there was the right amount of time to deal with how things are, talk it through and make plans and goals that fit with where I was at. And they gave us their numbers like if we needed to ring them at any time.'* #22

Participants described the prolonged support offered in the first year following medical diagnosis as a key benefit of the multidisciplinary-led early arthritis service. This was important for two main reasons, firstly; the prolonged support enabled the building of the therapeutic relationship which was central to supporting meaningful interventions. And, secondly, it provided a platform to respond to the varying needs and deliver associated interventions required over the first year of diagnosis.

*'You don't want to come in and huffing on a stranger and go 'well actually I don't do this, I can't do this, and I can't do this.' So I would have vaguely touched on things in the beginning. As the appointments progressed, I probably voiced it a little bit more and more. I think it's an Irish thing, just say you're grand. But over time it was easier, more comfortable to discuss the life-based problems.'* #11

The coordinated approach of the multidisciplinary team in providing prolonged support was also reported by participants as a strength of the multidisciplinary-led early arthritis model. Additionally, participants described a consistency in approach and advice given by the team members in relation to recommendations to support health and quality of engagement. This coordinated and consistent approach to supporting engagement and participation, recognised that lifestyles, not simply body structures, are impacted by inflammatory arthritis.

*'I was surprised at how much support there was because I assumed that you are going to a consultant and that's it. And then all of a sudden, you have a phone number to ring somebody if you are worried, in (Nurse)'s case and then as I say you have somebody showing you what's available to you, how to problem-solve some of the difficulty and how to keep moving forward in your life despite the condition.'* #28

### 6.6.2.3 Individualised Approach

The prolonged support described by participants was reportedly delivered through an individualised approach and was noted to be flexible and varied based on participants' needs and preferences. The personal touch in interactions, and a perception that the multidisciplinary team were genuinely interested in their personal story and their individual needs were described as important mechanisms

for supporting change and management of meaningful life impacts *'because not everybody are on the same level #7*. Participants recounted their experiences of how the team members engaged with them, and met them where they were, in order to identify within their own unique circumstances and priorities. Participants reported that they felt listened to in their interactions with the team and this contributed to their increased satisfaction with the multidisciplinary-led service, as well as having a direct impact on whether participants got what they wanted and needed from the service.

*'Feeling listened to, like being able to say, I'm not sure about this, or I'm worried about this, like you're able to name some of your worries, and like, that flexibility to talk about how you're feeling with everything, that helps you feel you've a choice, and a choice is easier to react to and follow the advice. I think talking to the girls (MDT) helps. I don't know what way they say things to you, but it just clicks.'* #15

Similarly, participants described an important feature of the multidisciplinary team interventions that they received was, that the interventions were tailored to address their unique issues. Participants reported that they appreciated that the multidisciplinary team approach that they received was focussed on meaningful interventions that were directly linked to performance and engagement in valued roles and typically included work, leisure, and parenting roles.

*'I know that everybody will be different, but for me I suppose I knew the work end of it was coming to an end, but the other things always take over. So for me focussing on my painting, the guitar, the work with the horses – these were the practical things that I was having problems with and wanted to discuss with OT.'* #3

*'so for me, OT was looking at how I was dealing with things at home and at work. How I deal with it really, the emotional stuff that goes with doing or not doing life stuff, getting back to work, or not doing stuff with my friends. That's what was important to me and that's what she helped me with.'* #22

The overall majority of participants recounted interactions with multidisciplinary team members which incorporated empathy and compassion. Participants emphasised that these characteristics of the multidisciplinary team approach were important catalysts in both determining and maximising client engagement in identifying participation restrictions, and in incorporating the multidisciplinary interventions delivered. Participants described the types of multidisciplinary interventions they received in the service which both promoted and supported them to live well with arthritis. These multidisciplinary interventions described all sit within typical care, but what appears to have made them special is that the intervention was targeted at what was meaningful to each person and was not considered by participants to be delivered in a generic way. Participants emphasised that this individualised approach was a valued feature of the service. Participants reported that they appreciated the person-centred manner in which the advice and interventions were tailored to the individual, their life roles and lifestyle. Furthermore, the quality of interaction between client and multidisciplinary team practitioners influenced the extent to which interventions were rated as beneficial.

*'when I was making the plan with OT about mapping where I was and where I wanted to go, I was working on the basis of how I was going to try and get back to work, or else get as independent as I could and what were the actions, the steps to be taken in the middle of that. Incremental steps. And a lot of it was around pacing, not bullocking at it. Not trying to do everything together.'* #41

*'So the OT would have looked at that lifestyle piece. Like she would have helped me work-wise a lot. She looked at driving and gave me a cushion for the car, you know a thing that raises me up a bit. Like that was helpful, it was. She talked with me about parenting kind of roles, like managing (son)'s demands and managing symptoms when at his football matches, and how to have some energy and interest to do stuff with him.'* #9

*'I have learned to economise my energy expenditure and yeah I choose to spend my energy on fun things. Now that was something (OT) really opened my mind to and encouraged me with. To keep the social commitments that I had always enjoyed. Like I would have always volunteered, and I do Special Olympics basketball on a Thursday so there will always be a rest before I go to that and then I will do that for the hour and I love it. So now I'm back doing something I love and I'm taking part without actually killing myself. Now I'll be exhausted after but good tired. Happy tired.'* #12

A very small number of participants (n=3) described some aspects of service delivery which they felt were not individualised and this appears to have had a detrimental impact on their interactions with the service. These participants recounted a perceived lack of personal interest from some multidisciplinary team members which they reported impacted negatively on their comfort in disclosing personal impact on participation. Furthermore, participants highlighted that this perceived lack of personal interest led to them not seeking specific guidance around managing or modifying participation restrictions in their own lives. This perceived lack of individualised approach was negatively viewed by these participants and perhaps resulted in these participants not benefiting as much as possible from the multidisciplinary-led early arthritis service.

*'very light touch, very generic, very standard issue, it was a bit cold, a bit clinical ... a conveyor belt, you are moving on now and that's it.'* #6

*'I am not looking for a friend, but I do need someone I can talk to, who will listen to me.'* #43

### **6.6.3 Adaptations for Participation**

This subtheme describes the features of interventions which participants recounted that they received in the multidisciplinary-led early arthritis service to influence change and support adaptations to improve participation. Adaptations included adjustments within life roles, supporting self-management and being an active participant in the management of their health and engagement; and finally supporting change through a process of re-identification of view of self, post-diagnosis of inflammatory arthritis. Adaptations were linked with participants' desire to retain participation in valued life roles and the interventions described were noted to map onto identified areas of need.

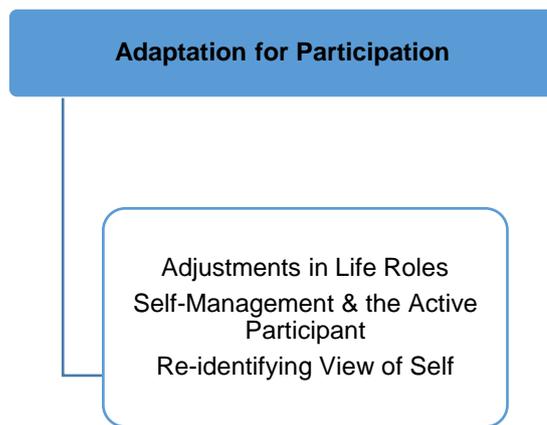


Figure 6.10: Adaptation for Participation Subtheme

### 6.6.3.1 Adjustments in Life Roles

Participants widely reported role adjustments to support participation in valued life roles such as employment, relationships, and home. These adjustments to life roles due to their arthritis were subject to variables depending on type of role and participants' perceived ability to cope with role demands. Participants described how they had tended to make 'reactive' decisions while they were experiencing symptoms prior to the diagnosis in order to manage decreased capacity. Participants reported that these reactive adjustments increased stress and decreased their sense of control over their arthritis and its management in participation in their roles and tasks. Following discussion with the multidisciplinary team participants reported that they felt empowered to make what they considered 'better' or more informed decisions. Proactive adjustments to life roles were described by participants who made changes following consultation with the multidisciplinary team. Participants emphasised the individualised and collaborative approach taken to decision-making that enabled them to engage in and retain their valued roles. Participants reported that this individualised approach matched their lifestyle and commitments. Participants highlighted adjustments which included direct interventions and advocacy-based interventions to enable self-management.

*'I remember doing exams in January (before MDT involvement) and the first night I had an exam, I put my coat which has a big hood on it as a cushion and I thought great, and I did my exam OK. Then it came to the second exam and she said, 'no coats' and I was like 'oh my God' and I was in absolute agony. I'd have loved to bring a cushion to college, but I thought I would be looked at left, right and centre. I hadn't known that those options were there for me until I met OT, she helped me link with college about simple solutions to avoid making my pain worse in college, and that was a big help, like I had an exam last night and I brought my wedge cushion, and that just made a huge difference.'* #24

#### 6.6.3.1.1 Employment Adjustments

Participants who were in paid employment or undertaking education described a wide range of direct interventions that they received from the multidisciplinary-led early arthritis team to assist them in retaining their work/student role through adjustments for their altered capacity. Participants recounted how input from the multidisciplinary team had enabled them to make accommodations

and adopt strategies that facilitated them in continuing to meet the demands of their employment/education. Participants described direct interventions delivered including use of ergonomic techniques, changes to equipment and technology used, breathing techniques, manual handling, splinting, and internal self-management strategies that enabled them to continue meeting the demands of their employment/education. Further multidisciplinary team interventions described included engaging with relevant departments and services to organise reasonable accommodations as per employment legislation and State Examinations Commission entitlements. Advice under reasonable accommodations included change from one employment role or course of study to another, changes to work hours including overtime and shift work, adjustments to work/student environment, changes to routines and patterns associated with work/student role. Participants emphasised that through multidisciplinary team interventions achievable and workable changes to their unique circumstances to support disease management and health were implemented. Participants described how in-work amendments and adjustments to work role structure support an overall feeling that work is manageable and less stressful.

*'I've learned so much from the (MDT) team about the impact of stress on my fatigue and ways to manage it better. Like this was one thing we discussed a lot. So now, because I work for myself, I pace it completely now. This way I am able to take a bit longer between clients, I can sit down and have a cup of coffee. This way keeps me going and confident that I can keep working this way.'* #24

Participants were aware that there was an opportunity for workplace assessment by the multidisciplinary-led early arthritis service. Uptake of this service was variable and dependent on participants' own circumstances and preferences. Participants who did avail of a workplace review described that it consisted of an assessment of the work environment and subsequent changes to improve workflow and accommodate symptom management in the work environment. These practical supports were positively viewed by participants not only in supporting work ability, but also reportedly improved their confidence in their ability to sustain work. Those who did avail of this work intervention emphasised the value of it. Those participants who chose not to avail of it described receiving clinic-based work interventions which empowered them to communicate and negotiate with their employer around their work needs.

*'I got an ergonomic assessment in work there last year and she (OT) gave me all the good advice and they (employer) provided me with a special kind of lumbar support chair.'* #6

*'She (OT) helped me a lot coming up to my Leaving Cert. I had to get the disability access route for college. So I done my Leaving Cert on a laptop, because I wasn't able to write. OT helped me with the process for that, like assessments for the Dept. of Education and also practising my typing and posture all that.'* #10

Participants who were currently working described how the collaborative approach with the multidisciplinary team assisted them in gaining a better understanding of their arthritis and how it was impacting on, and was being impacted by, their work. This collaborative approach enabled the participants to better manage their condition whilst simultaneously maintain their paid employment and obtain the right fit between the condition and the work demands. Participants described a

collaborative process of engagement with the multidisciplinary team to identify what needed to change (in-work or outside of work) and mapping how these changes could occur. Advice with disclosing the diagnosis as part of the process of implementing work changes was broadly described by working participants.

*'I didn't know where to start with deciding what I wanted to do. But as a child I had always liked lorries and was always around them, and I decided now that's what I want to do. I want to drive a lorry. That's something I have been working through with OT, how to make it happen and figuring the steps of the plan. So, we've looked into it and now I got my disability sorted and next I have to pass my theory test. And with the disability you are allowed to work 15 hours. So I have set myself a goal with (OT) for five weeks and I have booked the driver theory test and gave myself that five weeks to study. Setting that deadline was really helpful for me to focus.'* #22

*'OT guided me with disclosing to them in work about my arthritis and also about talking to them about my difficulties and needs in work. She had actually suggested she'd put it in a letter to them, but I didn't want to do it like that, so we went through what I needed to say to them in HR and that really helped me. I'm due back to see her (OT) in two weeks to talk about how I got on with that.'* #37

Participants described advocacy-based interventions that they received from the multidisciplinary team which enabled self-management through adjustments to occupational balance; changes to life demands outside of the role; and inclusion of positive health behaviours in everyday life to support work ability and capacity for work or study. Reflecting on the just right amount between work and life roles and the balance that is required one participant (#1) had previously worked full-time and had given up that job due to her diagnosis. She described that with occupational therapy input through the multidisciplinary-led clinic she had re-engaged in the work environment on a two-and-a-half-day week basis with a partial capacity payment and had maintained this level of paid employment for more than six months at the time of interview. She reported being very satisfied with her return to work in what she viewed as a sustainable way. She attributed her successful return to work to the multidisciplinary team advice she received including active interventions, advocacy-based interventions and entitlement advice which guided her decision-making.

*'I want to be part of something. But I still have a mortgage to pay. And there's no way I could survive on benefit alone. If I didn't have that benefit coming in, there's no way I could work part-time. OT gave me the support to do that. OT gave me the information I needed at the right time to help me get back into the workforce ... I had to take a lot of actions to get there, like I needed the support, and I needed the guidance and I needed to want to be well.'* #1

This just right balance was also echoed by participant #18 who described how through the support she received from the multidisciplinary team she made the decision to decrease her additional work hours to improve her lifestyle balance for health. The implications of the guidance she received highlight the team approach in supporting confident self-management with the strategies and informed decision-making to maintain health and participation.

*'OT talked about how, I was coping in work and she gave me advice about my kind of vulnerable areas with work, things to watch out for and how to think about, alternatives She also gave me leaflets about 'fit to work' And I read that, and then she gave me a booklet about rights for an employee and an employer, that was good. I found it important information to know, because I think that reiterates your confidence with managing too, doesn't it? So, with all that, and from talking it through with OT I've made the decision to reduce my hours in the last couple of months because it's just not been doable. So I teach, obviously it's a school day full-time, but then there are loads of after school things, and it's great money, so I was all over it, but then it was just I couldn't do it, so I had to cut back on that. My first job is to teach, the rest of it I have to kind of prioritise, and since pulling back hours it has been much more manageable.'* #18

Participants described how, through multidisciplinary team interventions, they have learned to utilise awareness strategies outside of work/study to circumvent and minimise work impact. Simple strategies taught by the multidisciplinary team such as planning, pacing, and using alternative methods were reported as being influential in facilitating flow in working-life management.

*'I do tend to be very conscious of taking breaks now. I have learned the value of breaks from the girls (MDT)' #25*

*'I am trying to prepare everything in advance now. OT would have really emphasised the benefits of forward planning for the days I'm working. So I have my work clothes put out on time. I have all the dog's dinners prepared in advance.'* #1

Participants valued receiving work-based entitlements information early in their diagnosis from the multidisciplinary team. Participants discussed how feeling armed with accurate entitlements information negated ambiguity and anxiety associated with asking for help, and they emphasised that early access to this information supported their sense of making informed decisions in a timely manner.

*'It's easier because it's your right isn't it? And when you don't know your rights like. I have worked all my life, I am only 48, I have never been on the dole. When you are in employment you don't want to be building up something with your boss. You want to try and keep it on a level pegging, so knowing if you are coming into an awkward situation with your boss, it's always helpful to know these things. I had no idea of the options available to me until I talked to OT' #17*

#### **6.6.3.1.2 Adjustments for Home-Based and Other Valued Life Roles**

Participants described personalised advice received from the multidisciplinary team around their home and social routines and how to modify problem tasks and/or routines to improve symptom management and support function. Participants described how the multidisciplinary team delivered education and practical support around incorporating positive health behaviours into everyday routines and how they have implemented this advice in their own life circumstances to manage energy levels, stress levels and symptoms. Participants described techniques and adjustments they received from the multidisciplinary team which they have internalised, and the positive impact of these adjustments on their perceived ability and self-identity.

*'Since coming here (MDT clinic) my social activities are all very managed and very planned. I have completely embraced to do the things I love as opposed to going to ground like before. This was the advice and help from OT, we talked about this a lot. I have completely embraced it. I was a member of a book club before and we'd meet once a month, I've gone back to going to that. But I would always come home earlier now, because if I don't then I am written off for the whole week. So I do that, and I enjoy that. Myself and (husband), consciously now, we go out for an early bird on a Saturday night. About 9pm I'm home and in my jim-jams, but we have still gone out, we have made the effort.'* #12

Participants reported receiving multidisciplinary team advice on internal and external adjustments to ameliorate symptoms when driving depending on their needs. Internal adjustments refer to advice that participants described regarding intrinsic changes to their habits, posture, methods of awareness and routines. These included strategies to notice their steering wheel grip, avoid over-gripping, improving grip and posture, using cues in the natural environment to adjust (traffic lights), and mindfully including stretches during and after car journeys.

*'I've learned I shouldn't hold on so tight (to the steering wheel). I'm inclined to hold it a little bit tight. So I have found myself loosening my grip, and things like the traffic lights, I take my hands off the steering wheel and that as much as I can. Now I kind of steer like 'this' as opposed to gripping, so now it's almost like a cup as opposed to tight gripping. Things like were really good.'* #18

Multidisciplinary team advice on external adjustments described included changes to participants' driving environment, either by changing the set-up of the driving environment (seat, wheel position) with existing in-car features, or by utilising external features (seating wedge, padded steering wheel or splinting supports) to promote improved driving posture and associated enhanced driving capacity.

*'We have a knob (on the steering wheel), but even at that, without the support of this (wrist brace). It helps, and the OT also gave me a glove to wear if I hadn't this (wrist brace).'* #35

### **6.6.3.2 Self-Management & the Active Participant**

*'The client is front and centre, yeah, we talk about person-centred services, it's (MDT clinic) a true person-centred service and it is that the circle is there (MDT) and they are all supporting. I think I feel fairly active in managing it myself now.'* #41

Participants widely described a sense of being an equal team member in the management of their health and well-being *'I feel I am in this with them (MDT)'* #16. This perception of being equal in the process was appreciated by participants and appears to have had a powerful influence on ensuring participants were engaged in their own care and influenced their decision-making in conjunction with their team to support timely delivery of meaningful and appropriate supports.

*'that's important too, give me information and giving me choices, figuring with me, what would be acceptable to me.'* #23

Participants emphasised the benefits of multidisciplinary team interventions which delivered knowledge and skills to remediate the impact of arthritis on their occupation-based participation and engagement and developed their confidence as an active self-manager. Participants reported that the process itself was *'a learning curve'* #14 in order to refine strategies to best suit their individual

roles and engagement. They consistently highlighted that they have learned from the multidisciplinary team the importance and value of cultivating observation and reflection strategies for active self-management.

*'That whole process of reflection has been a very helpful health behaviour to learn here (MDT clinic) because it's letting me see, 'how am I, what have I been doing, how has that helped me, how has that taken more of my reserves.' I suppose it helps you see what's good and what's not so good, and that helps you keep doing what's good. Because good intentions slip, don't they, for all of us, for eating well, for sleeping well, exercising, managing stress, managing demands? And we know what we should do, but the theory can be very different to the habit. And for me I've learned it's trying to keep a hook or a hold on the things that are good for me and trying to let go a bit of the things that aren't.'* #6

*'There is an alternative to everything, I can see that now, and she (OT) was encouraging me to notice what I do, and how I do it, and to see if that is good for my pain or not. And then to like notice alternative ways that might work better and won't hurt.'* #10

Participants reported that multidisciplinary team provided them with the skills to implement adjustments to life patterns and coping skills which have increased their resilience and a confidence in ability to retain capacity and quality of life. Participants described specific self-management-based interventions which they received from the multidisciplinary-led early arthritis team to support life pattern changes consisted of; fatigue management, integrating symptom management into participation, changing life patterns to include positive health behaviours, and goal setting to promote life pattern changes. Participants described a growing confidence with these strategies, which they used eclectically to meet their needs. Similarly, participants highlighted the impact of their growing knowledge and confidence with modifying their environment to meet their needs and an overall recognition that these changes to environment, habits, and routines early in their disease trajectory based on the multidisciplinary team advice can have a significant influence of maintaining health.

*'It's very, very hard. Like that's the bit (pacing) I find the most frustrating. Some days I am really good at it, some days I'm not good at it. And that's what's been really difficult, and also like planning for the week. Because actually by the time you reach Wednesday and you're supposed to be going out with people and you're wrecked, and you can't do that anymore. Or you might need to reschedule and being more flexible.'* #18

*'I feel everything is just slotting nicely in place. I know its kinds of like 'yeah things are going great now and I feel great' and all I can do is hope that they continue to feel this great, rather than expecting them to plummet.'* #1

Additionally, participants described how self-management was influenced by the emotional impact of their arthritis. There was a recognition that emotional wellbeing was subject to variations in perceived ability to cope which in turn had a direct influence on participation and engagement. This perceived ability to cope and make decisions to support wellbeing strongly influenced adjustment, coping capacity, and confidence in an active participant role in disease management.

*'I decided to notice that a lifestyle change probably had to happen because it wasn't working, like I couldn't cope.'* #18

Participants identified with the multidisciplinary team message of the importance of linking symptom management into everyday engagement and participation. They reported that they had learned that by including awareness of self, their health status and task, they felt more confident managing symptoms in the moment, and avoided symptom accumulation. Participants described how these awareness strategies supported them to consciously adapt previously held patterns of movement and habits and *'experiment in which way is best'* #1. Confidence in self-management cultivated by the multidisciplinary team was identified as key to integrating symptom management into participation.

*'the best advice out of it all about coming here when I look back was really about like making plans for myself, and setting myself goals, and making plans with my friends and looking to work and what my work could be and knowing that I am making it for myself. That no one else is making the plans for me. I was building myself up with the goals and they (MDT) got me into the routine of doing things that helped me feel better and more able and feel in better form.'* #22

### **6.6.3.3 Re-identifying View of Self**

Participants described being changed as a person following a diagnosis of inflammatory arthritis and they reiterated the requirement to incorporate this change into their future management of self. Participants emphasised that accepting and managing this 'changed self' strongly impacted on their confidence and ability to self-manage. Part of adjusting to this change included a process of recognising that this condition was permanent, and internal searching, linked with grieving to re-balance and re-identify with self. They described how they received multidisciplinary supports to assist with this re-identifying of self which they valued and emphasised that this support facilitated a process of accepting and changing in order to be able to enjoy a meaningful life.

*'It's knocked my self-confidence I suppose. And then obviously the first thing was the knock on, I wanted to make sure, because I had worked very hard to get my mental health to a point where I was doing really well and I didn't want that (arthritis) to have an effect at all, but it did have an effect. It's hard to leave those lesson plans or whatever so that I am in the zone to catch up with people. It's hard to do a bit and let it go, but I've learned here (MDT clinic), that pacing and making choices kind of, is the way to go. I, I don't know, not redefine yourself, but kind of readjust to what I can do. I am getting there, but I'm a work in progress.'* #18

*'It's just a case of you want to be normal but unfortunately you can't. It's like you have a limit and the sooner you realise what your limit is, the better it is for you. So it's just changing your mind set, that's what I've learned here (MDT clinic). Changing your mind set so that you focus your energy on the important stuff and the stuff that helps you feel like yourself.'* #30

As part of re-identifying a personal view of self, some participants who were in the later years of their working life, reported actively choosing to cease paid employment in order to improve their quality of life. While this role termination had been unanticipated prior to disease onset, there were narratives of re-evaluating status and priorities and actively choosing to opt-in to an alternative chapter which was perceived as being more likely to support health and quality of life experience. Participants who

described these life changes reported that they actioned them consciously with the support of occupational therapy interventions received through the service.

*'so with OT initially the plan was work, and certainly the plan was independence and then I had to reconcile that the chapter was closing on work and opening into retirement. Now I suppose my story isn't that I have gone back to work, but the story is, I have got myself to a place, and I have decided to retire. But retire to live life, rather than to vegetate and decay. So I'm looking for a good twenty years. So in some ways that's a chapter in my life finishing up but now there are so many other chapters opening up, in the golf club, the garden club.'* #41

## **6.7 Areas for Future Development**

Participants' views were sought to identify perceived service gaps and potential service development opportunities. These findings are presented below.

### **6.7.1 Psychological Supports**

Although the majority of participants reported that the model adequately supported their needs holistically, a few participants did identify that further psychological support would have been helpful for their personal experience and that access to this should be considered in terms of service development in the future.

*'I think I got good support from the team with coping and managing the stress and anxiety that goes with arthritis, but I do think it would have been nice to have an option of a counselling referral. I remember at one of the meetings, the OT said she could give a dietitian referral no problem, and I was like it would be really nice from a mental health point of view, even just if it was one or two sessions just to kind of initially talk through the feeling of arthritis.'* #18

*'I mean it's such a shock when you get it and then like you do get depressed from it and when you are in constant pain. I think although OT dealt with everything and she (OT) addressed the emotional piece, because I really felt I could talk to her, but I didn't fully know was I bringing the emotional piece to the right person in a way. I don't know would a counsellor maybe approach it differently and would they go deeper in what way you are feeling.'* #28

### **6.7.2 Peer Support**

All participants reported receiving telephone contact details for team members and an open-door approach to accessing the multidisciplinary-led early arthritis service. This open-door policy to link in should a query or concern arise was universally viewed as a positive support. One site provided service users with a booklet detailing the multidisciplinary-led early arthritis clinic service, team composition, contact numbers and team members' scope of practice. This booklet, which was posted out with the first appointment, was positively reported by participants from that site, as they reported that it gave them a sense of what to expect from the service. Other site participants reported that their first contact with the multidisciplinary-led early arthritis clinic included verbal provision of the same information. A communication passport to log appointments, issues and support interactions

between the client and team was suggested by participants as a helpful resource development to support service users in their knowledge and engagement with rheumatology services, and as a method to support active self-management and appointment preparation. Participants emphasised that this passport concept would support seamless care and increase client confidence as an active participant in their own care.

*'I think some sort of a booklet given to you, that you can have all your appointments in it and maybe notes for me or the team to write in it to log what was discussed or what we will look at would be good. I think that'd be really helpful.'* #19

*'They had a booklet that they were working out of, with information about what were the support networks, information for at home, what each contact (with MDT) included, useful information for me.'* #41

Information accessibility was frequently raised by participants. Current multidisciplinary team platforms described were one-to-one, group education, written information, and demonstration. Most participants who attended group education reported this was a valuable adjunct to their one-to-one learning and an opportunity for peer learning and social support. Participants described being signposted to community supports, primary care services, relevant apps available, and to social media links for registered charity-based support.

*'It was very good because you hear first-hand what other people are finding hard, and you say, 'that's right that's my experience as well' and you realise you are not alone. Because you see sometimes you do feel that you are the only person with this problem.'* #23

Suggested addenda to promote accessibility of support and knowledge included signposting to suitable DVDs and YouTube links, perhaps reflective of how society interacts with information today. Caution was raised regarding written information, as although many participants found the resources provided very helpful, some found the volume overwhelming.

Participants suggested the option of a break-out room for clients attending appointments, where they would have the option and opportunity, to meet others with a shared experience, to gain and provide social support *'to make you feel you are not alone here.'* #16 This concept of an informal coffee room-type environment to facilitate a coming together, information sharing, and social link was consistently raised within the interviews as a service improvement opportunity. This links to the sense of isolation which accompanies inflammatory arthritis either because of a lack of understanding, or because participants seek a protectionist approach to shield their loved ones from the disease impacts. Participants across all ages reported a perceived value in an opportunity to gain informal social support from others with a shared experience in order to assist them to make sense' of their pre-diagnosis as well as post-diagnosis living with arthritis.

*'Even if there was a little room ... Things like that, it's amazing. It makes you feel you are not alone here. It'd be nice to have a space to talk to people who are living with the same condition, it'd be a help. I couldn't have those conversations with my husband or my daughter. I don't want to.'* #37

### 6.7.3 Work Friendly Appointments

Working participants suggested inclusion of work friendly appointments, either early morning or late evening, which they stated would significantly ease some of the burden of simultaneously managing work and arthritis. This service improvement suggestion arises from the recognition that inflammatory arthritis is a lifelong condition requiring ongoing management. Most working participants reported using annual leave days to attend appointments but *'the half days add up, don't they?'* #6. Participants who did not work full-time reported that they schedule appointments for their non-workdays in order to minimise impact on work but consequently cause impact on non-work participation.

*'The appointments I got have been around 2.30 p.m., which means I have to take a half-day holiday ... maybe offering people who work morning appointments, or say 6 or 7 o'clock in the evening, when you know I am not rushing to go to work. I am on the way home from work and I would go there.'* #6

### 6.8 Summary

There is broad consensus from participants that a diagnosis of inflammatory arthritis is synonymous with life impacts and that there is a need for support with engagement and participation in occupations early in the disease. There is recognition that medics do not have the time to address this impact on participation, nor is it a medical role. Participants emphasised that meeting occupational engagement needs and supporting participation were properly addressed and managed well within the multidisciplinary-led early arthritis model. Extensive mechanisms of delivery were identified in this study which address these client-identified participation needs and support clients to live well with inflammatory arthritis. Whilst the majority of participants reported individualised care to support meaningful participation and engagement, a very small number described some challenges in feeling able to have open discussion relating to their own circumstances which impeded a more meaningful interaction and opportunity for change. Early access to multidisciplinary team supports afforded by the multidisciplinary-led early arthritis model was identified as significantly supporting clients' opportunity for proactive self-management. The right advice, in the right way and at the right time was recognised as being the most influential features of the delivery of this multidisciplinary-led early arthritis model in supporting positive health outcomes.

## CHAPTER SEVEN: DISCUSSION

### 7.1 Introduction

This study was conducted to explore the impact of inflammatory arthritis on participation within an Irish context of service provision. It was also concerned with examining how a recently adopted new multidisciplinary-led early arthritis model may address participation and engagement among service users with newly diagnosed inflammatory arthritis. The aims of the research were to explore the impact of inflammatory arthritis on participation and engagement in life roles, and to get an overview of how clinical services can address client-identified participation restrictions associated with the disease early in the disease trajectory. The study was completed over three phases in order to address the study objectives which were:

- To explore service provider's perspectives on the delivery of work-based participation support in current rheumatology services for inflammatory arthritis and identify factors which help or hinder provision.
- To describe and explore multidisciplinary-led early arthritis clinics as a model for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives.
- To explore the impact of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement among a cohort of service users attending multidisciplinary-led early arthritis clinics in Ireland.

The study was designed as a mixed methods study, with a predominantly qualitative priority, and involved three phases of data collection to effectively address the study aims. Phase one was an online survey to gather an overview of service providers' perspectives on how work-based participation is currently delivered in clinical services. Phase two comprised focus groups with service providers who work in the recently established multidisciplinary-led early arthritis clinics, to explore their perceptions of the impact of early inflammatory arthritis on clients' participation, and how this multidisciplinary-led early arthritis model addresses this identified occupation-based impact on participation and engagement. Phase three entailed semi-structured interviews with service users of the multidisciplinary-led early arthritis clinics, to explore the impact early inflammatory arthritis on their participation and engagement in valued life roles, and to explore their perceptions of how the multidisciplinary-led early arthritis model addressed these identified participation and engagement needs. The main findings from all three phases will be discussed collectively in this chapter within the context of the three study objectives outlined above.

This study was not designed as an intervention study, rather, it was designed with the intent of providing a more naturalistic type of enquiry that was appropriate and sensitive to the context of current clinical rheumatology practice and this novel multidisciplinary-led early arthritis service provision here in Ireland. This area of practice has received little attention in the research to date, and this study is the first study of its type to be carried out in Ireland where the process of addressing participation in rheumatology clinical practice, and the potential of an alternative clinical service

model (multidisciplinary-led early arthritis clinics) to address these issues have not previously been researched. This is the first piece of comprehensive research exploring how this clinical model functions through the perspectives of the service users and service providers. However, while the findings are reflective of the Irish context of practice, they also have international implications and provide some insights and findings that up to now appear have received limited attention in the international literature.

This chapter will firstly discuss the study findings on participation restrictions early in the disease trajectory and contextualise the findings within the existing research. Managing work-based participation in current clinical practice will then be considered and study findings will be situated within the existing knowledge base. Multidisciplinary-led early arthritis clinics as a model to address participation and engagement will then be examined and the identified key features of this service approach to address occupation-based participation will be appraised with synthesis of the findings from the dual perspectives gathered. Study findings will then be considered with regard to the contribution and the role of occupational therapy in addressing occupation-based participation difficulties, and the scope of occupational therapy within this new multidisciplinary-led early arthritis clinic model. The strengths and limitations of this study will then be discussed. Finally, the study findings will be considered in terms of implications for clinical practice as well as their significance for future research.

## **7.2 Participation Restrictions Early in the Inflammatory Arthritis Trajectory**

As outlined in the introduction chapter, participation is an important component of health and well-being which impacts on quality of life. It is broadly recognised that chronic disease such as inflammatory arthritis results in participation restrictions, and subsequently, international standards of care recommend addressing participation restrictions and supporting engagement as an integral part of rheumatology care (BSR, 2006; EULAR, 2016; EUMUSC.net, 2013a; HSE, 2018; NICE, 2009, 2018). However, there is limited understanding of the types of participation restrictions experienced by those with inflammatory arthritis early in the disease trajectory. Findings across the three phases of the current study consistently highlighted the extensive impact of inflammatory arthritis on participation from the perspective of service providers (phase one and two) and the perspective of the services users with newly diagnosed arthritis (phase three). Findings, particularly those arising from phase three, highlighted the impact of early inflammatory arthritis on everyday living activities, such as personal and home tasks, impact on life roles, such as home, parenting and relationship roles, and the considerable psychosocial impact.

### **7.2.1 Impact of Inflammatory Arthritis on Daily Living Activities Early in the Disease**

In this study participants with newly diagnosed inflammatory arthritis described how the symptoms of early inflammatory arthritis resulted in them experiencing considerable difficulties and challenges in performing their everyday activities. The phase two focus groups findings also highlighted that service providers were aware of the presence of considerable difficulties which their clients were reporting in completing their personal and domestic activities of daily living in early inflammatory arthritis. Findings from both qualitative phases of this study emphasise that these daily functional

difficulties are present early in the disease trajectory as a result of the symptoms associated with early inflammatory arthritis. In fact, it is also likely that these impacts on daily activities may have been present pre-diagnosis and would have contributed to individuals' seeking medical help in the first instance. These findings further emphasise the negative impact on well-being and quality of life which is synonymous with these functional limitations and restrictions early in the disease, and echo findings by Hodkinson et al. (2012) who also identified significant functional disability associated with early RA despite use of DMARD therapy.

Findings from the current study are in line with previous research examining daily living difficulties associated with inflammatory arthritis, however, previous research has tended to highlight these issues among people with chronic and established inflammatory arthritis (Hand et al, 2011; Hammond & Dziedzic, 2010; Squire, 2012, Voshaar et al., 2015). The current study has found that this same level of activity limitations is present from the outset among people newly diagnosed with inflammatory arthritis, and that these activity limitations are present despite the recent advances in drug therapy to control the disease activity. These findings contribute to the emerging focus on the impact on participation early in the disease trajectory, and add to work by Ahlstrand et al. (2015a, 2015b) and da Silva et al. (2011) who have explored the relationship between symptoms and activity limitations in people with early RA. Exploration of the activity limitations associated with inflammatory arthritis early in the disease trajectory is only recently receiving attention in the research. Research emerging from Scandinavia (Bergstrom et al., 2019; Sverker et al., 2015) is also highlighting similar activity limitation among people early in the disease trajectory. The commonality in the findings between the current study and the emerging international research indicates that this issue may be widespread, and not a unique feature of the participants in the current study. Furthermore, the findings appear to consistently indicate that a diagnosis of inflammatory arthritis can have a major impact on people's daily functioning from the outset. While significant advances have been made in the drug therapy management of inflammatory disease, and although new rheumatology medications are proven to control the disease process more effectively (Kane & Kavanagh, 2011; Treat to Target, 2010), this study found that despite being on active drug treatments people with newly diagnosed inflammatory arthritis continue to report considerable difficulty with everyday activities. This finding emphasises the need for service providers to be cognisant of the extent and impact of these limitations early in the disease and highlights the need for these be addressed in healthcare services.

### **7.2.2 Impact on Life Roles Early in the Disease**

In addition to the activity limitations experienced early in the disease, the findings of this study also highlight the impact of inflammatory arthritis on wider life role participation and engagement. These findings were extensively emphasised across all phases of the study by service providers (phase one and two), and participants with newly diagnosed arthritis (phase three). Findings reported in this study are in line with previous research which has described the impact on participation in work, parent, social and leisure roles among people with chronic and established inflammatory arthritis (Backman, 2007; Benka 2016a, 2016b; Connolly, et al, 2015; Grant, 2001; Hoving et al., 2013; Malm, et al., 2016; Reinseth et al., 2010; Squire, 2012; Verstappen et al., 2004). Furthermore, findings are reflective of existing research which report the considerable impact of inflammatory arthritis disease

on everyday activities and participation in employment and social roles despite improved drug therapy (Ahlstrand et al., 2015a; Verstappen, 2013; ter Wee et al., 2011). This study makes an important contribution to the knowledge base by highlighting that inflammatory arthritis causes diverse negative impacts on participation, resulting in considerable participation-based restrictions early in the disease trajectory, and these negative impacts are often already established at time of diagnosis. Limitations in daily activities which occur as a direct result of the disease process, have been identified as having a follow-on consequence on life roles and engagement in valued participation. In turn, these participation-based restrictions have been emphasised as having a significant knock-on effect on quality of life and well-being. In this early disease study, participation-based restrictions were widely reported in the first two years of the disease and were pervasive in all life roles and across all life stages.

### **7.2.2.1 Impact on Work Roles Early in the Disease**

The impact of inflammatory arthritis on the person's participation in paid employment is often a focus of research studies, perhaps because paid employment is a more concrete aspect of overall participation and is more easily measured quantitatively than other areas of life participation. Findings from this study identifying early participation-based restrictions in the area of employment are in line with previous research which has detailed work participation restrictions early in the disease trajectory (Codd et al., 2010, Hoving et al., 2013; Lacaille et al., 2007; Van der Meer et al., 2011). Extensive physical and psychosocial altered capacity for work participation detailed in this study adds to the knowledge base of the early impact of inflammatory arthritis on work participation, and highlight the increased risk of work instability, as well as difficulties with work retention, early post-diagnosis.

#### **7.2.2.1.1 Premature Work Cessation**

Working participants in this study experienced significant work-based restrictions in the early stages of their disease. The extent of premature work cessation early in the disease trajectory was an important and somewhat unexpected finding of this study. Many of the people with arthritis in this study reported having to cease work as a direct result of the impact of their symptoms on their work participation and work ability. Previous research recognises the consequence of work disability associated with inflammatory arthritis, and Irish research has reported that 40% of people with RA leave the workforce in the first five years of diagnosis (Bevan et al 2009). Additionally, data from a 32-country study, has reported that one in every three people with RA becomes work disabled within two years of diagnosis (Sokka et al., 2010). The current study found that work cessation frequently occurred in the first two years post-diagnosis which supports the QUEST-RA study findings (Sokka et al., 2010) and suggests that significant work disability may be occurring earlier in the Irish context than previously realised.

#### **7.2.2.1.2 Changes to Occupational Balance to Retain Employment**

Many working participants in this study described making changes to their work role and their outside of work roles, with an associated disruption to their typical occupational balance and well-being, in order to retain employment. These reported changes were emphasised by participants as being necessary to support work retention but were also recognised as being implemented at the expense

of other life roles and relationships. This client prioritisation of work above all else was similarly reported by the service providers in phase two, who recognised how client's financial pressures and worries experienced in conjunction with early disease, often resulted in them discontinuing previously valued life roles in order to prioritise and support work retention. Across the qualitative data (phases two and three) there was widespread reporting of the impact of this 'work-first' focus and how it leads to a disruption in occupational balance, home participation, and social/leisure participation, and contributes to relationship strain. While this disruption to role balance has been previously identified in established and chronic inflammatory disease (Gignac et al., 2014), the current study has highlighted that these disruptions are present from the onset of the disease. Furthermore, existing research reports that people of working age with inflammatory arthritis frequently make changes to their typical role balance and deprioritise outside of work role participation in order to support work retention (Jetha et al., 2018). The current study adds to the knowledge base by providing information on the types of changes and disruption of normal occupational balance that participants in this study made in order to support employment retention early in the disease process. Furthermore, this study provides insights into the perceived impact of these early changes to support work retention on quality of life and well-being.

#### **7.2.2.1.3 Influence of Diagnosis Disclosure**

Disclosure of diagnosis was emphasised by both service providers and service users in this study as having a significant influence on the extent of the impact that inflammatory arthritis had on work participation. The majority of working participants in this study reported being fearful of the negative consequences of disclosing their diagnosis to their employers. Some participants in this study chose not to share their diagnosis with their employers and work colleagues. All of the participants who did not disclose reported negative experiences with perceived employment capacity, and perceived psychosocial and emotional capacity to retain work participation. Furthermore, these working participants reported negative outcomes regarding work role retention. Conversely, those who did disclose their diagnosis in work reported no negative consequences associated with this disclosure, apart from the initial apprehension and anxiety about making the disclosure. Moreover, these study participants who did disclose their diagnosis in their work setting all reported this as a positive experience with positive outcomes. The disclosure enabled them to access workplace adaptations and accommodations, as well as psychosocial supports, which improved their confidence, work ability, and assisted their work retention. Workplace adaptations are known to add to capacity for work retention (Hammond et al., 2017; Hoving et al., 2013; Keysor et al., 2018; Macedo et al., 2009; Mancuso et al., 2001), therefore diagnosis disclosure is recommended (Bevan, 2009) and the current study provides valuable insights into the perceptions and outcomes of disclosure early in the disease trajectory. These study findings recognise that disclosing is a sensitive and delicate matter that comes with high levels of associated anxiety and apprehension, with a predominant fear or expectation of negative consequences. However, for those who did make workplace disclosure the outcome was consistently positive and supported work retention. Therefore, addressing fear of disclosure, and diffusing the negative myths associated with disclosure may be an important contributing factor in reducing premature work cessation early in the disease trajectory for people with inflammatory arthritis.

### **7.2.2.2 Impact on Participation in Valued Life Roles Outside of Work Early in the Disease**

In addition to the significant early impact on work participation, this study also widely reported additional pervasive participation-based restrictions which were experienced in other valued areas of participation, and which were emphasised as being present from the onset of the disease. In particular, this study highlighted the early impact on participation on partnership roles, parenting, social and leisure roles. These types of participation restrictions have received some attention predominantly in established inflammatory arthritis to date (Backman et al., 2007; Benka et al., 2016a, 2016b; Reinseth et al., 2010). Although the findings are similar, it is an important delineation in the current study that these impacts are all described as experienced early in the disease trajectory. The majority of the research exploring the impact on participation in inflammatory arthritis in early disease has been completed in Scandinavian countries (Ahlstrand et al., 2012, 2015a, Kristiansen et al, 2012a; Sverker et al., 2015, 2019). Findings from the current study add to the knowledge base of participation-restrictions experienced early in the disease trajectory and also provide important context to the Irish experience of early inflammatory arthritis. Findings from the current study combined with recent research from Scandinavia add to the composite findings, and all contribute new insights into aspects of participation other than employment that have received less attention in the research to date. Furthermore, findings from this study are mirroring the emerging research coming from Scandinavia which has identified disease impacts on other highly valued life roles which are leading to decreased quality of life and well-being. It is important therefore, that healthcare providers working with clients who are recently diagnosed or working with clients in the first two years post diagnosis, have an explicit awareness of the major impact on participation associated with the disease. Healthcare providers should recognise the dual need for early drug management, combined with early interventions to address these client difficulties with everyday activities and role participation within service provision.

#### **7.2.2.2.1 Impact on Partnership Roles Early in the Disease**

Qualitative findings in this study strongly emphasise the pervasive impact of early inflammatory arthritis on partnerships and relationships. People with arthritis in this study highlighted how their self-identity was negatively impacted by their symptoms that manifested early in the diagnosis, and that this in turn had significant follow-on consequences for their typical behaviour and personality which caused a changed dynamic in relationships and frequently a relationship strain. This finding is supported by a recent study by Bergstrom et al. (2019) who reported on the emotional consequences of early RA on relationships, and the anxiety and fear of failing loved ones. Similar to the Scandinavian study, in the current study there was a widely reported protectionist approach whereby participants described containing their emotional stresses to insulate their loved ones and taking on an added responsibility of shielding their family from the impact of the disease. The concept of shielding identified in the current study was strongly linked with an increase in internal worry which added to relationship strain. Moreover, the protectionist strategies adopted early in the disease were reported equally by both men and women with inflammatory arthritis in this study. These findings relating to life-partner relationships are important in providing new insights into the impact of this disease on participation in relationships, and the associated roles that accompany relationships. This

emerging area of participation has received limited attention in the research to date and findings from the current study add to the knowledge base on the impact on partnerships early in the disease trajectory.

While the impact of the symptoms of arthritis on fulfilling relationship roles were described by all participants regardless of gender, the pervasive impact of early inflammatory arthritis on altered capacity with physical intimacy in life-partner relationships was discussed by some participants, but interestingly, this was only discussed by female participants in the study. These physical intimacy restrictions reported in the current study were closely aligned to the associated impact on connectedness and self-identity. This finding regarding the impact of inflammatory arthritis on physical intimacy in relationships was also identified by Bergstrom et al. (2019). However, while the Scandinavian study identified difficulties with physical contact, they did not note any gender differences, and the Scandinavian participants reported that they always found ways to make physical contact manageable (Bergstrom et al., 2019). By contrast, the young female participants in the current study who highlighted this issue, all reported difficulties managing physical contact due to early symptoms and emphasised their concerns regarding the associated negative consequences on relationship connectedness and on well-being. This aspect of relationship impacts was not discussed by the male participants in this study, neither was it specifically asked about in the interview when discussing the impact on partnerships as it is a sensitive issue. The lack of male discussion of this issue in the current study may be considered in the context of research by Flurey et al. (2017), who highlighted that men with RA report the emotional impact on their masculine identity due to their diagnosis, and that they do not discuss emotional concerns unless explicitly asked direct questions. An earlier study by Hill (2004) explored the impact of established RA on people's sexual activity and reported negative impacts of RA symptoms on engagement in intimacy. At that time, it was suggested that maintaining intimacy in relationships was important for people with established RA, and it was reported that poor communication between clients and healthcare providers was associated with suboptimal management of this participation restriction (Hill, 2004). Findings from the current study identify that this intimacy difficulty is experienced by individuals with early inflammatory arthritis, and therefore, needs to be on the agenda for discussion as part of clinical care, and should be incorporated into the design and delivery of interventions for this population. Furthermore, cognisant of the current study findings and combined with work by Flurey et al. (2017), this area of physical intimacy as part of relationships needs to be discussed using direct questions as part of clinical care.

#### **7.2.2.2.2 Impact on Parenting Roles Early in the Disease**

The negative impact of early inflammatory arthritis on all aspects of parenting roles were strongly emphasised by parent participants in phase three, and also by service providers in phase two of this study. Participants identified role disruption as a result of the altered physical and emotional capacity for activities associated with parenting roles which occurred due to disease symptoms. These findings highlighting role disruption due to physical restrictions, and difficulties meeting the physical demands of the parenting role, are supported in the literature by Backman et al. (2007) who reported on the physical challenges associated on mothering with established arthritis, and by Zelkowitz et al.

(2013) who highlighted parenting difficulties with instrumental childcare tasks with early inflammatory disease. Furthermore, findings from the current study highlight the role loss which was synonymous with the impact of early inflammatory arthritis on participants' previously held perceptions of the type of parent they would be, and the type of parent engagement and interaction they would have with their children. This role loss was deeply felt by parents with arthritis in this study and was equally reported by male and female participants. Similar to the partnership findings discussed earlier, parents with arthritis in this study highlighted a burden to protect and shield their children which impacted on their child-parent relationships, and which further contributed to emotional burden and guilt about perceived role success. Furthermore, the parenting-participation restrictions identified in this study were associated with extensive negative psychosocial impact on quality of life and well-being. These findings add to the limited existing knowledge base on the impact of inflammatory arthritis on parenting roles and are in line with current knowledge of parenting-participation restrictions associated with established (Backman et al., 2007) and early (Zelkowitz et al., 2013) disease.

The concept of role switch was an important finding arising from the phase three service user interviews and was identified as having a significant effect on occupation-based participation restrictions across all roles, and in particular parenting roles. In the context of parenting, role switch comprised children caring for parents, children assuming parenting roles for other siblings, and other family members assuming participant's parenting roles. Although role switch was highlighted as necessary to support the person with inflammatory arthritis, it was unanimously described by service users, and service providers, as a negative impact of inflammatory arthritis on well-being and self-identity. This concept of role switch adds important context to previous research with parents with early inflammatory arthritis (Zelkowitz et al., 2013) which reports that the psychosocial stress of parenting with early disease is associated with parenting disability. The importance of being cognisant of, and giving attention to, the impact of early inflammatory arthritis on role switch and the consequential negative impact on well-being, is emphasised within the qualitative findings of the current study. The study findings highlight that awareness of role switch is important for healthcare providers when working with those recently diagnosed, in order to deliver the appropriate type of meaningful practical and/or emotional support to service users to support role participation. Furthermore, the current study findings add to the research in understanding these early physical and psychosocial parenting participation-based restrictions which are an important element of participation and which have been identified as a priority of intervention and support within healthcare.

#### **7.2.2.2.3 Impact on Social and Leisure Roles Early in the Disease**

There was a significant reporting of loss associated with social and leisure role participation identified in this study by the people with arthritis, which was similarly recognised by the service providers in the focus groups. This loss of valued social and leisure roles was emphasised as negatively affecting quality of life early in the disease process. All participants in this study consistently reported modifications to, reduction in, and in some cases cessation of, the types of social and leisure engagement they had previously enjoyed which occurred as a direct result of their early inflammatory

arthritis. Engagement changes were not limited to physical and active pursuits, but equally included more sedentary and social interests such as going to the cinema or meeting friends. This loss was a consequence of altered physical capacity, prioritisation of other roles and commitments, and the psychosocial and emotional impact of the diagnosis. Moreover, loss of social and leisure participation was attributed to the fluctuating nature of symptoms, and the associated constraints that this variable status had on making social and leisure plans.

Research on social and leisure participation restrictions has not received extensive attention to date, and therefore these findings add to the existing knowledge base which recognises the impact of established and chronic arthritis on social role participation and quality of life (Benka et al., 2016a, 2016b), and leisure participation with women with RA (Reinseth et al., 2010). The Scandinavian study reported that despite the known benefits of physical activity for health, the majority of those with established RA have a significantly low level of participation in active leisure which is associated with high levels of fatigue, low self-efficacy in function, and unemployment (Reinseth et al., 2010). In the current study, although disease symptoms and fluctuation of disease presentation were similar factors in negative leisure changes, the 'work-first' focus on employment retention was identified as having a negative impact on leisure participation in the early stages of the disease. This finding suggests differences in how people with early versus established disease manage their leisure participation in conjunction with managing their condition and are important as they highlight variations in the types of interventions and supports required to address these participation difficulties across the disease trajectory.

Research by Benka et al. (2016a, 2016b) has reported that social participation restrictions in the early stages of inflammatory arthritis were more often a consequence of the mental health impact of the condition, and that physical health implications were more common among those with established RA. The current study shares some commonalities with Benka et al. (2016a, 2016b), and has also identified that social role restrictions were associated with increased psychosocial impact in early inflammatory arthritis. Phase three participants highlighted the pervasive negative impact of fluctuating symptoms on their capacity to engage in valued social roles such as friendships, and they reiterated the negative impact of the diagnosis on their self-identity, and how they present to, or are viewed by others. Participants discussed the burden of managing friendships with inflammatory arthritis as the physical symptoms and their fluctuating presentation made it difficult to commit to social engagements and resulted in them being perceived as an unreliable friend. In the current study, the physical consequences of the disease, combined with the psychosocial impact resulted in participants becoming increasingly isolated from their social networks. In this way, findings from the current study suggest that social participation-based restrictions in early inflammatory arthritis were equally due to the negative physical and psychosocial consequences of early disease. Therefore, the current study adds to the research by expanding the understanding of social role participation-based restrictions associated with early inflammatory arthritis which require healthcare interventions to support quality of life and well-being.

### **7.2.3 Impact on Well-being**

Previous research has identified the impact of inflammatory arthritis on well-being across the disease trajectory (Dures, et al., 2017). This current study adds to the body of knowledge of the emotional impact associated with the disease by expanding the understanding of the early impact of inflammatory arthritis on well-being and emotional health, and by describing the consequences of these early impacts on occupational balance, and a reconstructed future. In this study, phase three participants described the complex multi-faceted impact of early inflammatory arthritis on sense of self, and the associated impact on participation in the now, and in the future, and the resulting reconstructed future. Disruption in normal occupational balance was strongly emphasised by study participants (in phases two and three) as an early consequence of the disease which directly impact on levels of participation and engagement in valued life roles. This disruption in normal occupational balance was identified as having physical, emotional, and psychosocial origins, and was highlighted as being intrinsically linked to the degree of adjustment to the diagnosis and has important implications for perceived future participation. These findings from the current study add to findings with established RA (Malm et al., 2016), and the composite findings reiterate the requirement for attention to the early impact of inflammatory arthritis on occupational balance and for inclusion of these element in clinical practice in order to incorporate clients' needs and priorities in the present and into the future.

In the current study the early impact of inflammatory arthritis on well-being were widely described by participants across all ages and gender. Furthermore, these impacts were also supported by the service providers' accounts in phase two, who were all very cognisant of the extent of types of participation-based restrictions associated with early disease, across the lifespan, life roles, and across important relationships, and the consequential fallout that this has on client well-being. Participants described the emotional stresses and guilt experienced, from the outset as a result of their inflammatory disease. The suddenness of the onset of the disease and the unexpected emotional impact were pervasive from the outset, and contributed to additional feelings of guilt as the disease symptoms impacted negatively on their ability to fulfil their valued relationship and familial roles. These findings which describe the psychosocial and emotional impact caused by early participation-based restrictions are important, as previous authors have identified the need to understand the socio-emotional elements of participation so that the lived experience can be captured and the individualised impact can be addressed in interventions (Fisher, 2013; Piskur et al., 2014, Sverker et al., 2019; Thyberg et al., 2015).

This study has highlighted the extensive and varied impact on occupation-based participation and engagement associated with early inflammatory arthritis and contributes to the rheumatology and occupational therapy knowledge base on the subject. Service user narratives have been matched by service provider accounts of the impact of early disease on participation and engagement in life roles across the life span. In this study participants are naming and seeking support with occupation-based participation in expanded life roles across their life span which include work, leisure, social roles, and relationships. Participants consistently report that addressing the impact on participation is an important part of managing their care and health, and they identify that they require early

interventions to address these early participation restrictions. Furthermore, participants emphasised that they would like this kind of help from the clinical services that they attend. These findings are important as previous authors have highlighted a lack of client–evidence on inflammatory arthritis and a dearth of understanding of the impact of inflammatory arthritis, resulting in a shortfall of information for designing and delivering appropriate supports to manage impact on everyday life and participation (Dures et al., 2017; Erwin et al., 2018). Inclusion of interventions to address identified occupation-based participation and engagement restrictions will assist in achieving the goal of normalcy described by Van der Elst et al. (2016) and Kristiansen et al. (2012a, 2012b). By increasing our understanding of the early impact on participation associated with this condition, there is important opportunity to broaden healthcare providers' understanding of the impact on participation and ensure inclusion of interventions to address these types of participation-based difficulties in routine clinical practice.

### **7.3 Addressing Work-based Participation in Current Clinical Practice**

From a participation perspective the majority of rheumatology research to date has focussed on work, and work participation is known to be significantly impacted by inflammatory arthritis. It is acknowledged that early and lifelong work participation restrictions and work disability are associated with this disease (Barrett et al., 2000; Codd et al., 2010, Hallert et al., 2012; Tillet et al., 2012). Phase one findings reported that 71% of their service users were of working age which highlights the scale of the problem in the Irish context. Supporting work participation and employment retention is recognised within the international guidelines as an integral role and responsibility of rheumatology clinicians (Bevan, 2015, EULAR, 2016, EUMUSC.net, 2013a, NICE, 2018). This study has examined addressing work-based participation in two service approaches, namely the traditional approach in phase one, and the more recently established multidisciplinary-led early arthritis clinic model in the subsequent study phases. Across the whole study awareness of the extent of the impact of inflammatory arthritis on work has been emphasised, however there are differences in how these identified work-based difficulties are being managed. Findings from the overall study confirm that addressing employment retention is within the remit of clinical rheumatology services and should be managed as part of healthcare which is in line with the international guidelines (BSR, 2006; EULAR, 2016; EUMUSC.net, 2013a; NICE, 2009, 2018). However, phase one findings emphasise a lack of certainty in the traditional approach regarding when and how to address work-based issues and highlight some confusion on the part of service providers as to the optimal time for referral for work support. This lack of certainty on timing highlighted in this study was identified as negatively impacting on the referral for, and coordination of, appropriate work support services (Codd, Stapleton, Kane & Mullan, 2018a). In addition to this lack of clarity as to how best address work issues, findings emphasised service providers' dissatisfaction with the level of support provided for work needs in traditional clinical rheumatology services. Conversely, the newer multidisciplinary-led early arthritis model, reflected in the findings from phase two and three, was identified as being streamlined and more effective in addressing work issues. Study findings highlighted the explicit focus on work participation within the multidisciplinary-led service scope which provided clarity and structure as to how work-based issues were addressed, early management of identified work issues,

and resulted in increased satisfaction with work-based participation management on the part of both the service providers and the service users.

This study has highlighted that in traditional approaches rheumatology clinicians are not directive in addressing work ability and employment-based restrictions, and they rely predominantly on the client to raise work issues (Codd et al, 2018a). Relying on the client to raise concerns about work participation is not without difficulties, as it is dependent on the clients' knowledge and confidence to discuss work issues with the rheumatology team. Additionally, study findings have identified that client initiation of a work concern is influenced by their therapeutic relationship with the rheumatology clinician, and their perception that this is the appropriate space to name work concerns. This lack of implicit consideration of the impact on work participation in the traditional approach identified in this study can cause inequities in access to services and onward referral. This is a significant study finding as most current rheumatology services operate a traditional gatekeeper approach for referral to work support-based services, and gatekeeper approaches have been previously criticised for delaying access to coordinated multidisciplinary interventions which can result in negative employment outcomes (NAO, 2009; The Kings Fund, 2009). Conversely the multidisciplinary-led early arthritis clinic model has an explicit emphasis on the impact on participation including work, which is on the agenda right from the beginning and viewed as a core part of the specific remit of the service. The multidisciplinary-led early arthritis model provides automatic early access to interventions to remediate any impact on participation including work in a way which might be missed in the traditional approach due to lack of clarity about when and how to address work issues. The benefits of an early automatic coordinated multidisciplinary approach to address work needs highlighted in this study is in line with advice by Walker-Bone & Black (2016) and Varekamp et al. (2009) who advocate for integrated timely provision of services to explore barriers which prevent work ability and address work-based participation throughout the disease trajectory.

While the phase one findings highlighted problems with traditional approach to managing work issues, by contrast, the qualitative findings from subsequent phases described service providers' positivity and proactivity that work issues can be dealt with properly, in a timely manner, and importantly, addressing these identified work-based restrictions were viewed as within the remit of the service model. A similar vein of positivity and satisfaction emerged from the phase three interviews where service users identified that they received sound, relevant advice regarding work-based restrictions and concerns, and that these work-based interventions were reported as the right type of help, received at the right time and in a way that was deemed acceptable and helpful for them. The employment adjustments for adaptation for work participation identified in the qualitative findings are supported in the literature (Corcoran et al., 2015; Feldthusen et al., 2013; Gignac et al, 2014, 2015; Hoving et al., 2014; Holland & Clayton, 2019, McCormack et al., 2018) as is the early and individualised approach (Hammond et al., 2017; Keysor et al., 2018) utilised in the multidisciplinary-led early arthritis model to support work retention and address work-based restrictions. This study has highlighted the lack of clarity and focus on managing work-based needs in the traditional approach which can result in fragmented care. Furthermore, this study has identified service provider and service user satisfaction with a multidisciplinary-led early arthritis approach

which has an explicit emphasis on addressing participation within its scope and a clear structure that provides clarity to how work-based issues are managed as part of service provision.

#### **7.4 Multidisciplinary-led Early Arthritis Clinics as a Model to Address Participation and Engagement**

The multidisciplinary-led early arthritis model described in this study is one service approach to address participation and engagement including work in service users with newly diagnosed inflammatory arthritis. Agreement regarding the importance of early medical management of this condition is established within the literature, as is the multidisciplinary team remit (BSR, 2006; EULAR, 2016; EUMUSC.net, 2013a; HSE, 2018; NICE, 2009, 2018). While drug therapy advances could contribute to an assumption that impact on participation may no longer be an issue for this population, findings from this study confirm and emphasise the significant early impact of inflammatory arthritis on participation across all areas of life for this client group. Furthermore, this study has identified a clinical management approach provided by the multidisciplinary-led early arthritis model which focuses on the whole person and the far-reaching impact of the diagnosis on the person's participation, with subsequent management of identified occupation-based difficulties directly from point of diagnosis. While there has been limited uptake of this service model nationally to date, study findings indicate that the multidisciplinary-led early arthritis model is a clear example of the operationalisation of the international guidelines and standards of care for this population. The stated recommendations of these standards were all deeply embedded and incorporated into practice within this model. Service providers who work within this service model described being more satisfied with the model's approach which facilitates them to incorporate the guidelines and standards for this population in their delivery of routine care.

This study has identified the key features of the multidisciplinary-led early arthritis model to address these occupation-based participation difficulties as; structure of the model (ease of early access and prolonged support), the centrality of the client, emphasis on participation, social prescribing and self-management, a full multidisciplinary team who are, importantly, working in an interdisciplinary way, and 'a right place, right time and in the right way approach'. These features all map onto the stated recommendations within the rheumatology guidelines and will be discussed in turn now.

##### **7.4.1 Structure of the Model**

A fundamental defining feature of the structure of the multidisciplinary-led early arthritis model is that it does not employ a gatekeeper approach, which is typical in traditional clinical practice and which has been criticised by others for limiting service access (NAO, 2009; The Kings Fund, 2009). Instead, the multidisciplinary-led early arthritis model provides automatic, easy, and immediate access to support, for service users to manage the occupation-based participation difficulties associated with early inflammatory arthritis. Study findings emphasised that early access was influential in improving participation-based outcomes because this format supported early detection of problems and coordinated care to limit entrenchment and proactively manage needs in a timely way. Furthermore, this early and automatic access minimised the risk of issues being missed and the facilitated the platform to ameliorate these problems in a person-centred way.

Prolonged support over the first-year post-diagnosis is incorporated within the structure of the model, and this was identified as a significant feature which facilitated and nurtured the therapeutic relationship, strengthened the partnership approach, and influenced the effective management of occupation-based difficulties. This capacity within the model structure to provide prolonged and flexible support was consistently highlighted as a strength of the model which supported the client in their first-year post-diagnosis and are an implementation of recommendations by Hand et al. (2011) and Nielson et al. (2019) who advocate for flexibility in interactions in order to support successful interventions. Study findings emphasised the importance of prolonged support in order to improve disease management, support occupational adaptation and increase quality of life, by addressing client-identified participation-restrictions as part of routine care. Study findings suggest that this multidisciplinary-led early arthritis model ensures rheumatology services are well placed to target those at risk of decreased participation and engagement in life and social roles.

#### **7.4.2 The Centrality of the Client**

The centrality of the client in the service model has been identified as a defining feature of this model which highlights how the lived experience of the client is embedded in the service delivery and is reflective of occupational therapy theory (Hand et al., 2011, Nielson et al., 2019). This centrality refers to the individualised approach to assessing and managing client-identified occupation-based participation restrictions, and also the emphasis on facilitating the client to be an active participant in their own care. This partnership approach, with an active client-participant, was identified as influencing the effectiveness by which individual needs in daily engagement in various life roles were managed and was positively reported as improving health and social outcomes. The centrality identified in this study was fundamental in how client-identified difficulties and priorities were addressed and are reflective of an implementation of previous research recommendations (Barton et al., 2018; Connelly et al., 2019; Dures et al., 2016b; Sverker et al., 2019; Voshaar et al., 2015) to ensure that client values are incorporated into intervention planning. Furthermore, these findings from the current study combined with findings by Van der Elst, et al. (2016) add to the composite findings, and all contribute new insights into the importance of health professionals incorporating clients' normality construct and the meaning associated with clients' life-based priorities into interventions which are person-centred and reflective of the client's life stage and life roles. This person-centred approach was also evidenced in the use, and type, of social prescribing reported in this study and highlighted the important dynamic of including the client 'front and centre' so that the social prescribing was both meaningful and helpful to their lived experience.

#### **7.4.3 Emphasis on Participation**

Previous authors have recommended that service providers have a complete understanding of service users' experience of the impact of their inflammatory arthritis on participation so that they can effectively address them, and so that they can address participation-based restrictions and empower choice in occupational engagement (Gallagher et al., 2015; Squire, 2012). The multidisciplinary-led early arthritis model incorporates an emphasis on participation which is explicitly considered by service providers as part of the service remit, and therefore participation is routinely explored and addressed within the multidisciplinary teams' assessment and interventions. This emphasis on

participation in the multidisciplinary-led early arthritis model was clear from the data gathered from both the service providers and service users, who described that addressing participation-based restrictions sat within the scope of the clinical practice delivered and received. An emphasis on participation and deliberately asking direct questions about participation, valued life roles and participation restrictions, appears to have a fundamental impact on clients' having their participation and engagement needs addressed in the service. The importance of asking the right questions, namely explicitly asking about the impact on role engagement and participation-based restrictions to tasks and routines, was emphasised by service providers. These findings mirror findings by Flurey et al. (2017) who commented on the need to ask men with RA direct questions about their emotional issues. In addition, the current study highlighted that an emphasis on participation provides service users with valuable awareness of the life impact associated with the disease and provides important context as to the role of the multidisciplinary-led early arthritis service in addressing these needs within their service provision. The explicit emphasis on participation detailed in this study is a key defining feature of the model which is fundamental in translating the international guidelines and research findings on rheumatology best practice for this client group into clinical care.

#### **7.4.4 Self-Management and Social Prescribing**

The multidisciplinary-led early arthritis model has been identified as supporting service users to learn to live well with inflammatory arthritis through the principles of self-management which are embedded in the treatment approach. The ethos of developing self-management is present from the outset with an individualised approach which empowers service users to become confident self-managers. Developing self-management and promoting the 'active participant' is predicated on the therapeutic relationship and collaboration between service users and service providers to support and encourage the identification of meaningful priorities for interventions subject to the individual experience. Clinical practice approaches in the multidisciplinary-led early arthritis model described in the findings, are an implementation of recommendations by Elissen et al. (2013) who identified shortfalls in self-management approaches which focus on medical and behavioural interventions and recommends inclusion of a client-healthcare provider partnership approach to support self-management in participation.

The self-management approach detailed in the multidisciplinary-led early arthritis model demonstrates the value of a social prescribing approach, empowering both self-management and the 'active participant' and supports adjustments to daily life with a focus on participation in valued roles. These approaches are in line with emerging recommended approaches in chronic disease management including inflammatory arthritis (Been-Dahmen et al., 2017; Connelly et al., 2019; O'Toole et al., 2013; Zuidema et al., 2015) and are important to support clients to gain ownership of their condition, be directive in addressing their participation restrictions, and actively involved in setting priorities for interventions. Social prescribing is recognised as a mechanism for promoting health and well-being through access to local services (The Kings Fund, 2017). In this study social prescribing was described from the dual perspectives of service providers and service users as an effective method to energize and motivate the translation of knowledge into skills and behaviour that had opportunities for success, as they were anchored to local, community and exercise groups. The

social prescribing described in the current study, although not exclusively utilised by the occupational therapist on the multidisciplinary-led early arthritis team, is reflective of recommendations by Whalley Hammell (2016) who advocates for occupational therapists to facilitate empowerment in clinical practice, by giving their clients choices, and support with actions to enhance their capacity, quality of life, and sense of well-being. Study findings highlight the value and potential of social prescribing to act as a catalyst to empower and support health behaviour change, promote self-management, and support the concept of living well with a chronic condition.

#### **7.4.5 Full Multidisciplinary Team Working in an Interdisciplinary Way**

This multidisciplinary-led early arthritis model provides access to a full multidisciplinary team (nurse, occupational therapist, and physiotherapist) who are working in a collaborative, and interdisciplinary way, to provide disease management supports and interventions to assist with adjustment to a new diagnosis, and to address the early impact of inflammatory arthritis on participation and engagement. Research has highlighted the challenges of meeting the standards of care when resources of specialised health professionals is lacking and where there is a lack of multidisciplinary teams (EUMUSC.net, 2013, NAO, 2009; The Kings Fund, 2009). The multidisciplinary-led early arthritis model is a credible approach which employs team members with a full understanding of each other's roles, who work collaboratively, and who are motivated to address the health and lifestyle impact associated with inflammatory arthritis. Specialists and health professionals with specialised skills were emphasised as key to implementing some of the standards and this view was reiterated within the study findings. Moreover, as advocated in the international guidelines, the coordinated team approach in the multidisciplinary-led early arthritis service delivers seamless meaningful care whereby both the service users' needs are effectively addressed, and the multidisciplinary team members feels supported.

#### **7.4.6 'A Right Place, Right Time and in the Right Way Approach**

Findings from this study detail how the multidisciplinary-led early arthritis model supports improved health and meaningful participation by delivering adjustments for valued life roles, facilitating self-management, and delivering multidisciplinary supports to assist with a 're-identifying with self' in a way which is in line with the recommendations of The Kings Fund (2009) and NAO (2009). The actual interventions delivered and received, as recounted by service providers and service users are in line with best practice and with the evidence-base available (BSR, 2006; EULAR, 2016; EUMUSC.net, 2013a; HSE, 2018; NICE, 2009, 2018). However, it is the 'right advice in the right way and delivered at the right time' that appears to have the greatest influence in addressing clients' healthcare needs in this study, supporting the remediation of occupation-based restrictions, and assisting them to learn how to live well with inflammatory arthritis.

The concept of the 'right advice, in the right way, and delivered at the right time' is recognised as a unique and key defining feature of the multidisciplinary-led early arthritis model interventions. This study finding incorporates the values of the HSE (2018) model of care for rheumatology which has a stated objective to employ a '*right help, at the right time*' (p.2) approach for individuals with inflammatory arthritis. The findings from this study expand this recommendation to incorporate the

value of the right advice at the right time and importantly, the right way was identified as fundamental to the model's success. Study findings highlight the powerful influence of the core delivery mechanisms employed in the multidisciplinary-led early arthritis model, namely, therapeutic relationship, prolonged support, and an individualised approach in supporting success. These mechanisms, which were defined in this study as part of the 'right way' concept, appear to have been significantly influential in addressing client-identified needs and participation-based restrictions and supporting change. These 'right way' mechanisms were strongly emphasised as catalysts which positively facilitate self-management and encourage clients to be active members of their own healthcare teams. There were equally important learning insights identified in the findings on the value of these 'right way' concepts, by the majority of participants who received them as part of their care, as well as from the small number of participants who reported a suboptimal tailored individual care. Lack of individualised care was linked to a diminished therapeutic relationship and perceived lack of freedom to speak and be heard, as well as perceived time pressures on the part of the team which limited participants using their time to address their own personal concerns and resulted in opportunities being missed. These important study findings provide significant insights into the power of these interpersonal aspects in influencing intervention relevance and efficacy and should be used to inform how rheumatology clinical practice is currently delivered as well as used to guide development and improvements to service delivery.

### **7.5 The Contribution and Scope of Occupational Therapy in Addressing Occupation-based Participation Difficulties within the Multidisciplinary-led Early Arthritis Clinic Model**

This study has clearly identified the domain of occupational therapy in evaluating and addressing client-identified participation-based restrictions within the rheumatology team. Service users in this study emphasised their experiences of occupational therapy interventions to support participation and highlighted the important and vital role of occupational therapy to address participation including work but also wider than work, within this service model. Furthermore, the scope of occupational therapy practice in addressing occupation-based participation restrictions was consistently highlighted by the service providers in phases one and two of this study.

With regard to supporting work participation, there was distinct view by rheumatology clinicians in phases one and two that addressing work-based issues sat within the scope of occupational therapy practice. This finding is in line with Corcoran et al. (2015) who reported that vocational rehabilitation is within the domain of occupational therapy and that work-based needs accounted for 64% of referrals to Irish rheumatology occupational therapy services. The challenge of delivering services with inadequate resources was recognised in the phase one findings with limited access to occupational therapy identified in both the quantitative and qualitative findings. This limited access to occupational therapy was emphasised as a barrier to effectively address work issues in current services and are reflective of findings from Corcoran et al. (2015) who also reported a high level of unmet need associated with insufficient occupational therapy staffing nationally, and limited resources and time. Findings from the current study combined with findings from Corcoran et al. (2015) add to the composite findings, and all contribute new insights into the workforce barriers which

both hamper and compromise the delivery of occupational therapy services to properly address employment participation and employment retention as part of routine clinical practice in Irish rheumatology services.

There was recognition within the phase one data that the rheumatology clinicians surveyed (medical doctors, nurses, and physiotherapists) do not appear to consider addressing the worker-role as within their professional scope of typical practice as evidenced by their qualitative comments and difficulties profiling work roles within their caseloads. Conversely, rheumatology occupational therapy research has focused specifically on considering work participation, in terms of; work impact and work demands to inform the design and delivery of specific work supports, and interventions to support work participation and work retention (Codd et al., 2018b; Corcoran et al., 2015; Hammond, et al., 2017; Macedo et al., 2009; McCormack et al., 2018). This finding not only reinforces the clear role of occupational therapy in addressing participation, but also adds to the debate on how best to structure services for this population and reinforces previous criticism of the traditional gatekeeper approach to work-based services (NAO, 2009; The Kings Fund, 2009). These study findings add to the knowledge base as to how clinical services should be configured and support recommendations for automatic access to the wider healthcare team, but in particular occupational therapy whose scope of practice includes paid employment, so that participation in work is properly addressed in routine clinical rheumatology care.

Furthermore, the contribution and scope of occupational therapy within the rheumatology healthcare team in addressing the broader occupation-based participation issues in areas such as home, social, parenting, driving, and leisure were all widely reported by service providers in phase two. While the service providers described a blended and cross-over approach to managing some of the participation restrictions, there was a strong sense within the findings that participation interventions ultimately rest with occupational therapy. In addition, service users in this study all strongly highlighted that their occupation-based participation concerns and restrictions were principally addressed by the occupational therapist on the multidisciplinary team. Furthermore, service users emphasised that these participation restrictions were positively and comprehensively addressed by occupational therapy and they expressed their satisfaction with how this was done. Occupational therapists consider participation as within their domain of concern (AOTA, 2014; Fisher, 2013; Law, 2002; Wilcock & Hocking, 2015). Supporting participation and engagement in valued occupations across the lifespan is the fundamental goal of occupational therapy and the focus of occupational therapy interventions (AOTA, 2014). Findings from the current study add to the existing research in chronic disease which highlight the influence of occupation and participation-based interventions on supporting health and well-being (Connolly et al., 2019; Curtin et al., 2019; Eklund et al., 2012; Katz et al., 2009). Significantly, the study findings highlight that the other rheumatology healthcare professionals share this perspective that addressing occupation-based restrictions and supporting engagement in all life roles sits within the remit of occupational therapy, and also, importantly, that service users recognised that this is an occupational therapy role.

Previous authors have emphasised the need to incorporate the client perspective when delivering and appraising clinical practice to ensure that lived perspective of the disease impact on clients' quality of participation, and quality of life, are included in the design and delivery of appropriate services (Montori et al., 2013; Rand et al., 2019). The findings from the current study provide insights into the client's lived experience of participation restrictions early post diagnosis with inflammatory arthritis, and also their views on how a service model, and in particular occupational therapy, effectively addressed their occupation and participation restrictions. These service user findings from phase three are important as previous rheumatology literature has identified a shortfall in client-evidence of experiences, and satisfaction with services which deliver interventions to address everyday life activities and participation in services for people with inflammatory arthritis (Connelly et al., 2019; Dures et al., 2017; Erwin et al., 2018; Sverker et al., 2019; Voshaar et al., 2019). These study findings further add to the debate regarding evaluating rheumatology services and the role of occupational therapy in delivering participation-based interventions as part of routine clinical practice. The commonality in the findings between the current study and the international research indicates that intervention approaches which address participation restrictions contribute to meaningful client prioritised therapy. Furthermore, the findings of this study identify a credible and feasible approach, namely the multidisciplinary-led early arthritis model, to address participation-based restrictions and deliver on the international guidelines as part of routine clinical practice in a format that is positively regarded by both service users and service providers. The current study data details expansive qualitative evidence that addressing participation-based restrictions and supporting engagement are emphasised by service users as being managed, and managed well, by occupational therapy.

## **7.6 Strengths and Limitations of the Study**

This study was conducted to explore an area of practice that has received little attention in the research to date. It is the first of its kind to be conducted in Ireland, and a qualitative descriptive approach was deemed appropriate to explore and describe this area of clinical practice. Addressing participation is an established recommendation within rheumatology guidelines and standards, but translation of this recommendation into practice has been variable and hampered by service structures and resourcing issues. The multidisciplinary-led early arthritis model is still relatively new in Ireland and an equivalent model was not identified in the international research. Previous research by Blondeau et al. (1998) has reported variation in service users and healthcare providers' perspectives of service provision. The current study is the first piece of comprehensive research looking at how this model functions through the perspectives of the service users and service providers. This study is contributing to the research by exploring service user and service provider's perspectives and adding new information and confirming other areas of understanding on the topic.

This study design was pragmatic and incorporated multiple perspectives in the different phases in order to give a rounded evaluation and presentation of the topic. The study design was informed by recommendations by Pollard et al. (2011) that a multi-perspective qualitative approach is useful to capture the experiences of all the stakeholders involved in the treatment and care.

The online survey in phase one captured data on current rheumatology work-based support services in Ireland from the perspectives of rheumatology team members. These findings are important as they provide novel evidence of the Irish experience regarding how work-based needs are currently identified and addressed for clients with inflammatory arthritis, and the findings provide insight into the clinical practice barriers which hamper delivery of work supports. Furthermore, phase one findings contribute to the knowledge base on the topic by providing both quantitative and qualitative data on the rheumatology teams' perspectives of the role of occupational therapy in addressing work. These findings add to previous work exploring occupational therapists' perspectives by Corcoran et al. (2015) and contribute to our understanding of how current Irish rheumatology services address and manage employment-based issues, gaps, and areas of improvement. They also contextualise the Irish experience and allow comparison with international evidence and practice. However, as a response rate of 21.6% was achieved in the online survey, results must be interpreted with some caution as they cannot be generalised to the full cohort of rheumatology health professionals in Ireland. Although, it must be acknowledged that the response rate achieved in this online survey was in line with typical response rates for surveys of this type, as Dykema et al. (2013) has reported that response rates of under 20% in internet surveys of health professionals are not uncommon. The risk of positive selection bias should be acknowledged when considering the online survey findings. Typically in any research, respondents who have strong feelings, either positive or negative, on the topic under exploration tend to opt-in to participate, however, this is a research issue rather than a study design issue. In phase one, all individuals who met the inclusion criteria were invited to participate and they self-selected to participate and to complete the anonymous online survey. The risk of non-response bias must also be acknowledged when considering phase one findings in the context of the response rate achieved. However, use of an anonymous survey with simple language which was piloted extensively in advance of data collection were all practical steps employed to manage the risk of this type of bias. Furthermore, when examining the findings from the online survey there was reasonable spread of responses across the disciplines surveyed with no meaningful distinction in uptake or non-participation between disciplines.

The phase one online survey was specifically concerned with paid work as a tangible component of participation. The online survey was designed to extend the knowledge base on how employment participation needs are identified and managed in current clinical practice, and thereby provide opportunity to improve the clinical management of this element of participation. Less is known about how wider participation issues in other valued life areas are understood or managed in traditional services. As evidenced by the phase three findings, broader life roles are typically less concrete, more nuanced, and subjective in nature. Broader life roles have received less attention in the research and in clinical practice to date. Inclusion of these broader participation issues in the online survey would have been worthwhile in order to add to the knowledge base of how these issues are currently identified and managed in traditional clinical practice and consequently, exclusion of these elements of participation in the online survey could be viewed as a limitation. However, it was considered that the baseline knowledge on the clinical management of these broader life participation roles is much lower as they are less concrete than work participation and therefore an online survey was not the best format to explore the wider aspects of participation. As there is some increasing

knowledge of work participation, adding to this specific area of participation in the first instance, by seeking a national rheumatology response, was viewed as an important step forward. Importantly, it was felt that inclusion of the less tangible elements of participation and how they are managed in clinical practice could have negatively impacted on response rates. Our understanding of how wider life role participation is managed in traditional rheumatology services is less developed than work, although expanding the knowledge base in this area would be beneficial given how strongly valued they were identified within the interview findings in phase three. Future research could explore the management of other life role engagement in the traditional model and perhaps compare it with how these issues are managed in the multidisciplinary-led early arthritis model.

A strength of the phase two qualitative evaluation is the 100% coverage achieved of multidisciplinary-led early arthritis team members who participated in the study. This helped ensure that a wide range of views and practical clinical experiences were captured. Furthermore, it is a strength of this study that in evaluating this model, guidance has been sought from current multidisciplinary-led early arthritis team members as to how other rheumatology services could reconfigure to deliver this model, and what team members, clinical skills, specialist skills and resources would be required. Concerted efforts in phase three sampling to intentionally sample participants who were at different stages in their disease trajectory within the two-year post-diagnosis criteria and include a spread of age groups is viewed as a strength of this study. In addition, phase three sampling strategies to ensure inclusion of participants from each site contributed to the strength of this study.

The qualitative priority of this study could be viewed as a study limitation because it is concerned with exploration of the impact of inflammatory arthritis from the perspectives of the service providers and the service users and does not include a quantitative evaluation component. However, it is important that qualitative exploration of a topic comes first, in order to get a proper sense of subject. Vaismoradi et al. (2013) suggests that the quality of qualitative research findings should be determined by whether any new insights into the subject have been provided. This study has added to the body of research in understanding the early impact of inflammatory arthritis on participation and has provided important new information on how clinical services address client-identified participation restrictions. Furthermore, this study has contributed new insights, and has added to the body of client-evidence on this subject as advocated in the literature (Dures et al., 2017; Erwin et al., 2018). The findings provide a baseline for more structured approaches to the study of this area of practice in future research in the Irish context. Future research could incorporate quantitative evaluation with an economic component and also there is scope to incorporate a longitudinal element to examine outcomes over time.

The independent interviewer in the phase three data collection did not have clinical rheumatology experience and this could be considered a limitation of this study. However, she has extensive clinical occupational therapy experience of more than twenty years duration and she also has postgraduate research experience at MSc. level. This independent interviewer is highly experienced in the area of cognition in the geriatric population and in clinical practice, she routinely assesses for, and delivers occupational therapy interventions for those with a life-changing diagnosis of memory impairment.

Therefore, she is very experienced in exploring and assessing the impact of symptoms on life role participation and being cognisant of the types of support required to adjust to a new diagnosis in that clinical area. Given her clinical expertise at being attuned to, and, navigating the psychosocial impact of a new diagnosis she was identified as a good candidate to fulfil the independent interviewer role. Moreover, she has postgraduate research experience which equipped her with awareness of research ethics and interview skills required for the role. These clinical and research skills were considered a suitable match to meet the requirements of the independent interviewer role in this study, as she has the experience to understand and explore the complexities of the impact of a diagnosis on engagement and participation in meaningful life roles. Finally, there was comprehensive pre-interview training and post interview debriefing to support the independent interviewer in this role to ensure that she was appropriately and fully exploring the topic and probing the issues raised.

The researcher's clinical experience was influential in identifying the research question and designing the study. She was involved in the data collection, analysis, and interpretation of all the data across the study. Furthermore, she was also involved in the data generation in one of the focus groups and in the analysis of data that she co-generated. As such, potential for research bias must be acknowledged as a study limitation. However, given that this model is an emerging approach to treatment it was considered desirable to achieve 100% coverage of the staff who worked in these rheumatology services in the data collection. Furthermore, non-participation of the researcher in the focus group would have resulted in one of the four services not being fully represented and this was viewed as a negative. Therefore, the decision was made for the researcher to participate in one of the three focus groups which were conducted in this phase of the study. In order to manage the potential for research bias associated with the researchers' involvement specific steps were taken in the data collection and data analysis stages, namely, the academic supervisor facilitated the focus group, during this focus group the researcher was sensitive to the potential for bias, and made efforts not to contribute excessively. Following data collection, the data from the three focus groups were amalgamated for analysis and the composite findings are reflective of all three focus groups. Moreover, there was 100% checking of all the composite data from the three focus groups by a second person. With regard to phase three data collection, the researcher did not facilitate any of the data collection at the site that was her place of work, and an independent interviewer was used for all steps in this strand. The independent interviewer completed eight of the phase three interviews. Additionally, there was 100% checking of all of the data arising from all of the interviews by a second person.

The study was purposely designed so that the model structure and pathway could be accurately described and understood before seeking the perspectives of those who attend the model. Therefore, phases two and three were sequenced to first describe and add understanding to the multidisciplinary-led early arthritis model as a concept, before exploring the service providers' and subsequently, the service users' perspectives of the model. Understanding this novel model itself through the lens of those operating within it was viewed as an important first step in the study and was considered appropriate as a starting position before exploring the service user perspective. However, this sequence could be viewed as a limitation of the study and it is possible that by seeking

the service users' perspectives of the model first and then incorporating those findings into a subsequent phase seeking the service providers' perspective there could have been an opportunity to add to the findings. It is possible that this alternative sequence could have added an opportunity to second check the service providers' perspectives of the service users' reports. However, given that this multidisciplinary-led early arthritis model is a novel service initiative, it was considered essential to describe the model and how it operates as a first step before appraising it from the perspectives of those attending these rheumatology services.

## **7.7 Implications for Practice**

This study has provided detailed descriptive data on the impact on participation experienced by people with early inflammatory arthritis. Furthermore, findings highlight that addressing client-identified participation-restrictions is viewed by service users as an important part of managing their care and health. Service users in this study have clearly identified that they require early interventions to address these early participation restrictions, and importantly, service users are clear that they would like to receive these types of participation-based interventions from the clinical services that they attend.

The subjective experience of participation and the need for individualised approaches have been documented in this study. Adequately incorporating personal context into assessment of participation is important to deliver relevant meaningful interventions in clinical practice which have a greater opportunity for success. This identified requirement for an individualised approach when measuring and addressing participation is not without challenge in clinical practice. The lack of appropriate outcome measures to capture participation restrictions in clinical practice is widely recognised. Current measures of participation can be quite generic, are frequently labourious to complete, and lack the scope to accurately assess the subjective experience of participation. Furthermore, this study has identified that assessment of participation is both sensitive and complex. Disclosure of participation restrictions in meaningful life roles was intrinsically linked to the model's emphasis on participation as well as factors incorporated in the 'right way' concept. Timing of assessment and adequate time in interventions were also fundamental to participation restrictions being disclosed and should therefore be factored into clinical practice. Similarly, the powerful influence of the partnership approach used in this model to identify and deliver individualised adaptations for participation support was highlighted. While a standardised assessment of participation is desirable to provide quantitative evidence of how the participation-based restrictions identified are being managed within this model, the role of interview to capture each person's individual wide-ranging issues in work, life-partner relationships, home, and leisure roles cannot be under-estimated. These elements of the 'right place, right time, and in the right way' were hugely influential in improving the participation-based outcomes because this format supported early detection of problems and minimised the risk of issues being missed. Interview as a mode of assessment was a fundamental part of capturing the need early and not missing subjectively meaningful participation restrictions, therefore, therapists should be confident of the role and value of a good interview in clinical practice. A full understanding of the participation-based restrictions is central to ensuring delivery of

appropriate supports by service providers and an improved clinical experience for service users in clinical practice.

This exploration and description of the multidisciplinary-led early arthritis model indicates that the model successfully operationalises the international guidelines and standards of care for this population. This study provides rich description of the potential that this model has to translate standards and guidelines into clinical practice. The study emphasises the benefits of a full multidisciplinary team with the specialist skills and established interdisciplinary working and the capacity of this team approach to deliver the right help, in the right way, and at the right time. This study provides important evidence that a multidisciplinary-led early arthritis model approach is a feasible way to deliver services to this population. Although there has been limited implementation of this model to date, findings from this qualitative study indicate a high level of service user and service provider satisfaction with this multidisciplinary-led early arthritis approach and support the rationale for continued expansion of this service approach on a national basis. From a clinical practice perspective, there is scope to reconfigure existing multidisciplinary teams in some of the rheumatology services nationally so that this multidisciplinary-led early arthritis model could be implemented and services delivered in this way. However, some rheumatology services nationally are not adequately resourced across all of the multidisciplinary team, and in particular occupational therapy staffing, therefore, increased staffing would be required in order to be able for those services to deliver this model. Dissemination of the study findings at national rheumatology conferences, through journal publications, and to the National Clinical Care Programme for Rheumatology and the Association of Occupational Therapists of Ireland would be an important next step in providing evidence to support this multidisciplinary-led early arthritis model as a feasible approach in addressing participation restrictions in people with inflammatory arthritis. Sharing the study findings in this way creates the opportunity to shape the direction of future rheumatology services in Ireland and to support the implementation of a model which integrates and delivers on both the national and international guidelines. Additionally, study findings are important to inform workforce planning nationally to ensure that rheumatology services have the adequate staffing resources to implement this 'right place, right time, and in the right way' approach which is positively regarded by both service users and service providers.

In this study the scope of occupational therapy was strongly and positively emphasised by service users and demonstrates occupational therapy clinical practice which is moving away from component-based management and into participation and engagement. Findings demonstrate how occupational therapists are practising differently and advocates the use of occupation-based and participation-based approaches with this client population.

## **7.8 Implications for Research**

This study has provided a comprehensive insight into the impact of inflammatory arthritis on participation early in the disease trajectory. It has confirmed that this impact on participation is deeply felt early in the disease and managing these participation-restrictions and supporting engagement has been clearly identified by participants as a priority for their healthcare. This study has contributed

to the knowledge base of impact on participation which includes work, but also wider than work for this population across the lifespan. This study has provided rich qualitative description of the value of the multidisciplinary-led early arthritis model in addressing client-identified participation restrictions. This study was an exploratory qualitative study, and this approach must come first before quantitative evaluation so that the topic is understood. Future research could consider a quantitative approach to examine the effectiveness of this model and could include an economic analysis of the cost-benefit of this multidisciplinary-led early arthritis model in order to explore and quantify the benefits of this approach. Moreover, bearing in mind that the multidisciplinary-led early arthritis model maps onto the Irish model of care for rheumatology (HSE, 2018), future research could examine if the model could be rolled out nationally.

Service user reports from phase three describe the suitability and value of this type of model in addressing participation and engagement. Similarly, service providers identified using qualitative measures to describe participation outcomes in their clinical practice. However, service providers highlighted a lack of suitable clinical practice tools which could effectively measure the value and efficacy of the participation-based interventions delivered and capture participation outcomes. Future research with participation as an outcome would require careful study design because of the wide-ranging issues in work, life-partner relationships, and other life role participation. It is possible that because each person's own participation needs can be so individual, that may account for why researchers tend to focus on a specific element of participation in studies. Therefore, it is speculated that a mixed methods approach would more accurately support future research on this topic.

## **7.9 Conclusion**

This multiphase study has contributed to the rheumatology and occupational therapy knowledge base by providing important qualitative description and evidence of the extensive, and diverse impact of inflammatory arthritis on participation early in the disease trajectory. In addition, the multi-perspective qualitative approach utilised has gathered data to inform how clinical services address these client-identified participation restrictions and has also qualitatively appraised how well clinical services are addressing these needs. Findings indicate that adopting a 'right advice, in the right way, and at the right time' approach can remediate participation-based engagement issues and improve health, quality of life, and satisfaction outcomes for service users. There was unanimous agreement among service users that the multidisciplinary-led early arthritis model was well placed to address participation restrictions. This multidisciplinary-led early arthritis model maps onto the Irish rheumatology model of care (HSE, 2018), 'right place, right time' approach but which also incorporates a 'right way' approach which has a powerful opportunity to deliver client-focussed and client-centred care. This approach recognises that inflammatory arthritis is an enduring, life-long condition which requires early access, parity of relationship between client and multidisciplinary team, and flexible and prolonged support to promote disease management and service users' participation and engagement needs across all life stages.

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## APPENDICES

### A.1. Phase One Ethics Approval



Coláiste na Tríonóide, Baile Átha Cliath  
Trinity College Dublin  
Ollscoil Átha Cliath | The University of Dublin

Yvonne Codd



23<sup>rd</sup> December 2015

Ref: 20151103

**Title of Study:** To examine current rates of referral for work support for those with inflammatory arthritis in Ireland and identify influencing factors

Dear Ms Codd,

Further to a meeting of the School of Medicine Research Ethics Committee held in November 2015, we are pleased to inform you that the above project has been approved.

Yours sincerely,

**Professor Thomas Rogers**  
Chairperson  
School of Medicine Research Ethics Committee

**An tOllamh Paul Browne** MB, BSc, FRCR, FRCR  
Ceann Scoil an Leighis

**Ms. Orla Bannan**  
Barrthóir na Scoile

**Scoil an Leighis**  
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**Professor Paul Browne** MB, BSc, FRCR  
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## A.2. Phase One Participant Information Letter



Trinity College Dublin  
The University of Dublin

### **A Study to examine current rates of referral for work support for those with inflammatory arthritis in Ireland and identify influencing factors.**

Dear Medical Colleague,

You are receiving this email and invited to participate in this survey as you are a healthcare professional working in clinical rheumatology. The aim of this survey is to inform knowledge and experience of the organisation and delivery of rheumatology services for inflammatory arthritis in Ireland, by examining current referral patterns for work and exploring service providers' perspectives of how work is addressed.

Clinical Guidelines on Rheumatoid Arthritis (NICE, 2009) recommend multi-disciplinary team assessment to address any effect of arthritis on ability to work. Patterns of referral for work support and associated factors in current Irish practice are not well known, and there is a lack of knowledge as to how well work is being addressed currently within Irish rheumatology services for people with inflammatory arthritis.

Participation in the study will involve the completion of a short online survey which will take no longer than 15 minutes to complete. The survey is completely anonymous and you will not be required to disclose your name or place of work.

If you would like to participate in the survey please click on the hyperlink [here](#) \* to access the online version of the survey. Alternatively, if you would prefer to complete a paper copy, both a paper copy and a stamped addressed envelope will be forwarded at your request, please contact the lead researcher, Ms Yvonne Codd, by email: [REDACTED]

Please feel free to forward this information letter and the survey hyperlink to healthcare colleagues working in inflammatory arthritis clinics. I would welcome as wide a range of responses as possible.

Ethical approval for the study has been granted by the Trinity College Dublin, School of Medicine Research Ethics Committee.

If you have any further questions related to this study please contact the lead researcher, Ms Yvonne Codd, by email: [REDACTED]

If you have already participated in this study, thank you very much for your contribution and time.

Kind regards

Yvonne Codd, BSc. Cur Occ (Hons), MSc. Cur Occ, MAOTI

\* In the event this hyperlink does not work, please copy and paste this URL into your browser:

<https://docs.google.com/forms/d/1XSj73-B4-hqioAKXiBNfiDBRagWqL7NhV6fJtZgPqzA/viewform>

### A.3. Phase One Online Survey



This questionnaire is designed gather information on current rheumatology service provision to support paid work/employment in patients with inflammatory arthritis (rheumatoid arthritis, psoriatic arthritis and inflammatory spondyloarthropathy) and your views on this.

For the purposes of this survey 'work' as a term relates to paid employment.  
Please answer the questions with inflammatory arthritis as the primary diagnosis.

#### Section A: Addressing Work In Your Service

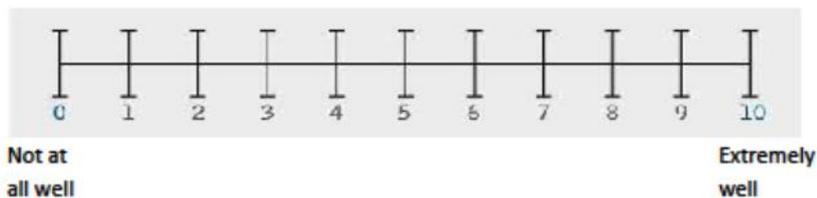
1. Do you consider that supporting employment retention falls within the remit of the rheumatology team?

Yes   
No

2. Are patients' work needs currently supported within your rheumatology service?

Yes   
No

3. Please use the continuum below to rate how well you consider patients' work needs are supported within your rheumatology service currently?



4. What proportion of patients in your rheumatology service have work needs requiring assessment or intervention?

>75%   
50-75%   
25-49%   
<25%

5. If work is addressed within your rheumatology service please indicate by whom. Please tick all that apply.

- Doctor
- Rheumatology Nurse
- Occupational Therapist
- Physiotherapist
- Other  Please specify \_\_\_\_\_

6. Do *you* routinely ask patients at their first appointment about their work status and work ability?

- Yes
- No

7. Do *you* routinely ask patients at their review appointments about their work status and work ability?

- Yes
- No

8. Which factors influence you to address work?

I WILL discuss work issues IF:	Always	Often	Some-times	Rarely	Never
Age – the person is under 65					
The person is currently in paid employment					
The person reports work absenteeism or is on sick leave					
The person is not currently in paid employment but is of working age					
The person themselves voices concerns in relation to work					
The person is the main earner in the household					
The person is working in a manual/physical type job					
I perceive the person to be work vulnerable / work unstable					
The person has active disease on presentation					
The person is early in their disease trajectory					
The person has mechanical joint changes evident on presentation					
The person is >5 years since diagnosis					

If there are any other factors which influence you in addressing work with patients, please detail them below:

9. What factors hinder *you* in addressing work issues with patients?  
Please read the statements below and indicate to what degree you agree or disagree with each statement.

I DO NOT discuss work issues BECAUSE:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Time is too limited in clinic sessions to deal with work					
Work is too complex and I do not have the competencies to address it effectively					
I am not familiar with best practice and legislation for work support					
I am not confident in my skills and ability to assess and address work issues					
I do not feel I have capacity to effectively address work issues in a clinic session					
My role does not include addressing work					

If there are any other factors which hinder you in addressing work with patients, please detail them below:

10. If you do not address work issues in your clinical practice where do your patients access work support?

If you don't know where your patient's access work supports please tick here

**Section B: Work and Occupational Therapy**

1. Do you have access to occupational therapy support as part of your rheumatology service?

Yes

No

2. What are the typical reasons you refer a person to occupational therapy?

Reason for referral to Occupational Therapy	Please Tick all that apply
ADL assessment/intervention	
Splinting	
Joint Protection Education	
Fatigue Management	
Work assessment/intervention	
Driving	
Stress management	
Posture and ergonomics	
Advice regarding lifestyle balance	
Leisure Participation	
Home Visit/Home assessment	

Other: \_\_\_\_\_

3. Do you think occupational therapy has a role in work assessment/ support?

Yes

No

4. If you have access to occupational therapy do you routinely refer to the occupational therapist for work assessment/ support?

Yes

No

5. What type of work interventions do you expect occupational therapy in your rheumatology service can offer?

Work Intervention	Occupational Therapy currently DO this	Occupational Therapy COULD contribute	This would be USEFUL for patients YES or NO
Provision of Work Assessment (in clinic or workplace)			
Provision of Solutions for Work Based Problems			
Customise Condition Management Skills to Specifically Match the Work Tasks of the Person			
Liaison with Co-workers/employers			
Provision of Work Related Legislation Advice			
Applying Self-Advocacy Skills such as Negotiating and Communication Skills			
Advice on Social Benefits			
Advice on Retraining and/or Return to Work			
Applying Lifestyle Balance Skills including Coping & Stress Management Skills			

If there are any other work interventions which you feel would be useful in supporting work with your patients, please detail them below:

--

5. If you have access to occupational therapy but do not refer for work assessment/ support, please outline your reasons below:

I do NOT refer to occupational therapy for work assessment because:	Please tick all that apply
There is limited access to occupational therapy	
Occupational therapy in my service does not address work issues	
I did not know that occupational therapy addressed work issues	
We do not have an established clinical pathway for addressing work related issues in our rheumatology service	

Any comments you would like to add?

--

6. Do you have any suggestions regarding organisation/provision of work related services which might add to your existing rheumatology service?

Improve Provision of Work Support by:	Please tick all that apply
Education for referrers as to what work support is available within current service	
Screen for work issues at all appointments	
Implement an inflammatory pathway that includes work as a core component to be addressed from time of initial diagnosis	
Upskill current staffing to address work need	
Increase staffing to address work need	
Provision of work site evaluations as required	
Develop an outreach work support service	

Any further comments you would like to add?

**Section C: Service Demographics**

- What is your profession?
  - Medical Doctor
  - Nurse
  - Physiotherapist
  - Other  Please specify \_\_\_\_\_
- Approximately how many new referrals does your service receive per year? \_\_\_\_\_

3. What is the current make-up of the Rheumatology Multi-Disciplinary Team in which you work and their Whole Time Equivalent (WTE)?

Profession	Present in Team Yes/No	Number of Positions	Whole Time Equivalent
Consultant Rheumatologist			
Specialist Registrar			
Triage Physiotherapist			
Advanced Nurse Practitioner			
Clinical Nurse Specialist			
Rheumatology Nurse			
Clinical Specialist Physiotherapist			
Physiotherapist			
Clinical Specialist Occupational Therapist			
Occupational Therapist			
Social Work			
Psychology			
Other			

4. What is the typical age demographic of patients attending your service?  
Give the approximate percentage of overall caseload within each age category below

Age Category	% of Overall Caseload
<18 years of age	
18 to 30 years of age	
31 to 45 years of age	
46-65 years of age	
>65 years of age	

5. Approximately what percentage of your patients would fit within the following worker categories?

<b>Managers</b> (Managing directors, chief executives, business services, sales, marketing and development managers, hospitality or retail managers)	
<b>Professionals</b> (engineers, architects, doctors, health professionals, nurses, teachers, IT and legal professionals)	
<b>Technicians and Associate Professionals</b> (electricians, healthcare assistants, sports instructors, legal associates, bank officials, telecommunication and broadcasting technicians)	
<b>Clerical Support Workers</b> (secretaries, data entry positions, bank tellers, administration roles)	
<b>Service and Sales Workers</b> (travel attendants, waiters, bar staff, hairdressers, beauticians, childcare workers, shop sales staff)	
<b>Skilled Agricultural, Forestry and Fishery Workers</b> (farmers, forestry fishery workers)	
<b>Craft and Related Trade Workers</b> (builders, plumbers, plasterers, painters, mechanics, handicraft workers, cabinet makers, garment and food producers)	
<b>Plant and Machine Operators And Assemblers</b> (stationary plant and machine operators, mobile plant operators, drivers)	
<b>Elementary Occupations</b> (cleaners, labourers, street vendors, refuse workers)	
<b>Armed Forces Occupations</b> (commissioned and non-commissioned officers and other ranks)	

*International Standard of Occupations Classification (ISCO-08)*

**Thank you very much for taking the time to complete this questionnaire.**

#### A.4. Phase Two TCD Ethics Approval



Coláiste na Tríonóide, Baile Átha Cliath  
Trinity College Dublin  
Ollscoil Átha Cliath | The University of Dublin

Ms Yvonne Codd



26<sup>th</sup> July 2016

Ref: 20160602

**Title of Study:** A qualitative study to explore multidisciplinary led early arthritis clinics as a model for managing occupational needs in early inflammatory arthritis.

Dear Ms Codd,

Further to a meeting of the School of Medicine Research Ethics Committee held in June 2016, we are pleased to inform you that the above project has been approved.

Yours sincerely,

Professor Thomas Rogers  
Chairperson  
School of Medicine Research Ethics Committee

An tOllamh Paul Browne MB, BSc, FRCR  
Ceann Scoil an Leighis

Ms. Orla Rannan  
Riarthóir na Scoile

Scoil an Leighis  
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## A.5. Phase Two Focus Group Participant Information Letter and Consent



17<sup>th</sup> September 2016

### **PARTICIPANT INFORMATION LEAFLET**

**Study Title: A qualitative study to explore multidisciplinary led early arthritis clinics as a model for managing occupational needs in early inflammatory arthritis.**

**Principal Investigator: Yvonne Codd, PhD researcher and Senior Occupational Therapist**

Dear

You are invited to participate in this piece of research as you are working in clinical rheumatology and are involved in the provision of a multidisciplinary led early arthritis clinic service.

International consensus and evidence-based standards for clinical management state that early multidisciplinary intervention is the optimum way to manage and ensure best long-term health outcomes for this patient group (ARMA 2004, BSR 2006, EULAR/ACR 2007, NICE 2009, BCMA 2012, EUMUSC.net 2013a). However, there is a wide variance in the delivery of multidisciplinary input for this patient group and it is recognised that there is a constant need for services to continue to develop in order to better meet the needs of the service users. One of the more recent developments in Ireland has been the establishment of a small number of multidisciplinary led early arthritis clinics providing assessment and intervention to patients with inflammatory arthritis.

This study seeks to explore the service providers' views on the multidisciplinary led early arthritis clinics as a model for addressing occupational needs among patients with early inflammatory arthritis attending these clinics. As part of this study we are also interested in exploring the current service provision within these multidisciplinary led early arthritis clinics and how these compare to international standards of care for clinical management of this patient group.

Your participation in the study will involve attending one focus group comprised of nurses, occupational therapists and physiotherapists who deliver multidisciplinary led early arthritis clinics. It is expected that the duration of the focus group will not exceed two hours. The focus group discussion will be audio-recorded to allow for analysis but no identifying information will be included in the transcripts of the focus group discussion. Your participation is entirely voluntary. If you initially decide to take part you can subsequently change your mind without difficulty. Audio-recordings from the focus group will be held securely for five years in keeping with best practice on data retention.

If you would like to participate in this research, please complete the attached informed consent form and return it to the lead researcher (Yvonne Codd) in the stamped addressed envelope provided. You will then be forwarded an interview guide outlining the topics and types of questions that will be discussed at the focus group to allow you to reflect and prepare for the focus group. Focus groups will be facilitated in a location

of convenience for participants and any travel or parking expenses incurred by participants will be refunded. You will be offered a copy of the transcript of the focus group for review if you so wish.

Ethical approval for the study has been granted by the Trinity College Dublin, School of Medicine Research Ethics Committee. If you have any further questions related to this study please contact the lead researcher, Ms Yvonne Codd, by email: [mooneyy@tcd.ie](mailto:mooneyy@tcd.ie)

Kind regards

Dr. Tadhg Stapleton

Assistant Professor in Occupational Therapy

Trinity College Dublin



## INFORMED CONSENT FORM

**Study Title: A qualitative study to explore multidisciplinary led early arthritis clinics as a model for managing occupational needs in early inflammatory arthritis.**

**Principal Investigator: Yvonne Codd, PhD researcher and Senior Occupational Therapist**

This study and this consent form have been explained to me. My Principal Investigator has answered all my questions to my satisfaction. I believe I understand what will happen if I agree to be part of this study.

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I have received a copy of this agreement.

I understand that the audio-recordings from the focus group will be held securely for five years in keeping with best practice on data retention. I understand that the transcripts of the focus group discussion will be anonymised and that no identifying information will be disclosed in any future presentation of the study findings. I understand that I will be offered a copy of the transcript of the focus group for review if I so wish.

**PARTICIPANT'S NAME:**

**PARTICIPANT'S SIGNATURE:**

**Date:**

**Date on which the participant was first furnished with this form:**

**Statement of investigator's responsibility:** I have explained the nature, purpose, procedures, benefits, risks of, or alternatives to, this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

**Principal Investigator's signature:**

**Date:**

## A.6. Phase Two Focus Group Question Guide



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

### SERVICE PROVIDERS INTERVIEW GUIDE QUESTIONS

**Study Title: A qualitative study to explore multidisciplinary led early arthritis clinics as a model for managing occupational needs in early inflammatory arthritis.**

**Principal Investigator: Yvonne Codd, PhD researcher and Senior Occupational Therapist**

Dear

Thank you for your interest in participating in this study. This guide has been collated in order to help you prepare for the focus group by outlining the broad topics we are interested in hearing your views and opinions on. We would ask you to consider these topics in advance of the focus group. This guide is not exclusive and if you have other topics you feel are important to discuss you can of course do so during the focus group.

#### 1. SERVICE DESCRIPTION

- Describe the structure, set-up and delivery of MDT early arthritis clinic in your dept.
- What is the main focus of your typical assessments and interventions with patients attending the clinic?
- How has your service evolved in implementing this model?

#### 2. SERVICE USERS' OCCUPATIONAL NEEDS

- As part of your assessment and intervention do you routinely ask patients about the impact of the diagnosis of inflammatory arthritis on their daily life, their occupations and life roles (such as impact on paid employment, family roles, and social and leisure participation)?
- What do your patients report as the major impact inflammatory arthritis has on their everyday life and engagement in daily occupations and roles in the early stages of the disease?

#### 3. EVALUATION TO MEET THE OCCUPATIONAL NEEDS

- What areas do you consider when you assess the impact of arthritis on a person's life and occupations?
- How do you document and record this type of information? Do you use standardised assessment tools? Do you have a checklist to gather this type of information?
- Do you offer any interventions focussed specifically on addressing occupational needs of these patients? If so, can you describe these, and which member of the MDT typically takes responsibility for these interventions?

#### 4. EVALUATING THE MODEL

- Do you think this model has a role to play in addressing the occupational needs of service users? Are there any unmet needs?
- What factors do you think help or hinder addressing the occupational needs of service users?
- What do you see as the benefits and challenges of managing this population under this model?

#### 5. COMPARING THE MODEL TO INTERNATIONAL STANDARDS OF CARE FOR THIS POPULATION

- How effectively does this model implement international clinical standards of care for this population?

- Do you perceive any barriers and facilitators to implementing international clinical standards of care for this population in Ireland?

Thank you for your consideration of these questions. We look forward to discussing these at the focus group.

## A.7. Phase Two Focus Group Follow Up Letter with Themes



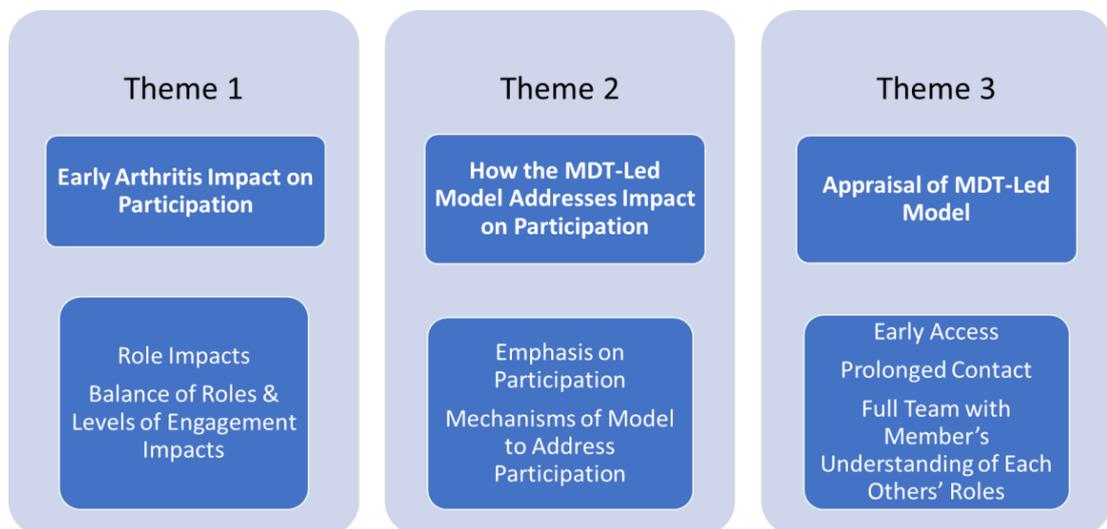
Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

**Study Title: A qualitative study to explore multidisciplinary led early arthritis clinics as a model for managing occupational needs in early inflammatory arthritis**

Dear

Thank you for participating in the above study.

This study was concerned with describing and exploring multidisciplinary-led early arthritis clinics as a pathway for addressing participation and occupational engagement in newly diagnosed inflammatory arthritis from the service providers' perspectives. The qualitative findings from the one-off focus groups have now been analysed. From the data collected three broad overarching themes and within them eight sub-themes which collectively reflect the focus groups' narrative on how multidisciplinary-led early arthritis clinics as a pathway address participation and occupational engagement in newly diagnosed inflammatory arthritis. These findings are illustrated in the graphics below:



Overarching Themes	Subthemes
Early Arthritis Impact on Participation	<b>Role Impact</b> <b>Impact on Balance of Roles and Levels of Engagement</b>
How the MDT-Led Early Arthritis Clinic Model Addresses Impact on Participation	<b>Emphasis on Participation</b> <b>Mechanisms of Model to Address Participation</b> <ul style="list-style-type: none"> <li>• Ease of Early Access to Deliver Participation-based Interventions</li> <li>• Coordinated Team Approach &amp; Inter-disciplinary Working</li> <li>• Supporting Readiness &amp; Change</li> <li>• Organisational Aspects</li> </ul>
Appraisal of the Model	<b>Early Access</b> <b>Prolonged Contact</b> <b>Full Team with Members' Understanding of Each Other's' Roles</b> <b>Challenges and Opportunities</b>

If you wish to clarify any of these themes or include additional issues, please do not hesitate to contact me on 086-3007365.

Thank you for your involvement with this study and for sharing your views and experiences.  
Yours sincerely

Yvonne Codd

PhD Researcher & Senior Occupational Therapist

## A.8. Phase Three Ethics Approvals

THE ADLAIDE & MEATH HOSPITAL  
INCORPORATING THE NATIONAL CHILDREN'S HOSPITAL



SJH/AMNCH Research Ethics Committee Secretariat  
Claire Hartin Ph: 41 42 199  
email: clairs.hartin@amnch.ie

**THE ADELAIDE & MEATH  
HOSPITAL, DUBLIN**  
INCORPORATING  
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND  
TELEPHONE: 353 1 442000

Ms. Yvonne Codd  
PhD Researcher and Senior OT



27<sup>th</sup> October 2017

**Re: To explore the impacts of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics.**

**REC Reference: 2017- 10 - Chairman's Action (16)**  
*(Please quote reference on all correspondence)*

Dear Ms. Codd,

The REC is in receipt of your recent application to SJH/AMNCH Research Ethics Committee in which you queried ethical approval for the above named study.

The Chairman, Dr. Peter Lavin, on behalf of the Research Ethics Committee, has reviewed your correspondence and granted ethical approval for this study.

Yours sincerely,

Claire Hartin  
Secretary  
SJH/AMNCH Research Ethics Committee

The SJH/AMNCH Joint Research and Ethics Committee operates in accordance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive



Naas General Hospital  
Naas, Co. Kildare

12/12/17

Ms. Yvonne Codd,  
Researcher and Senior Occupational Therapist,(Rheumatology)  
Discipline of Occupational Therapy,  
Trinity Centre for Health Sciences St. James's Hospital,  
St. James's Street,  
Dublin 8

**Title of Study:** To explore the impacts of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics.

Dear Yvonne,

I am happy to inform you that the above study has been approved by the hospital's Ethics Committee.

Publications arising from research conducted in Naas General Hospital as approved by the Ethics Committee should include an acknowledgement to NGH as a research site. The hospital supports the International Committee of Medical Journal Editors (ICMJE) criteria for authorship and contributors and expects all principle investigators to adhere to these principles.

Yours sincerely,

Alice Kinsella  
General Manager

Telephone: 045 849500  
[www.naashospital.ie](http://www.naashospital.ie)

*Naas General Hospital is an affiliated teaching hospital with the faculty of Health Sciences, Trinity College.*

Research Ethics Office Old School of Nursing  
University Hospital Waterford

Tel: 051-842026/051-842391

Ms Yvonne Codd

27<sup>th</sup> November 2017

PhD Researcher & Senior Occupational Therapist,  


**Study Title: "To explore the impacts of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics".**

**STUDY STATUS: APPROVED**

Dear Ms Codd

The Research Ethics Committee Coordinator, 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:

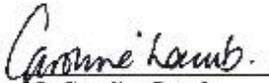
1. Ethics Submission Form.
2. Research Proposal
3. Interview Schedule
4. Participant Information Sheet
5. Participant Consent Form
6. Ethical Approval letter from SJ11 / AMNCH
7. Signed hard copy of Declaration Form

8. CV of Chief Investigator – Ms Yvonne Codd
9. Insurance/Indemnity cover letter – Willis Towers Watson

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 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.

Yvonne Codd

25<sup>th</sup> January 2018

**Re. Research Ethics Application**

Dear Ms Codd

The Research Ethics Committee (REC) at Sligo University Hospital has reviewed your revised submission for ethical review of the study *"To explore the impacts of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics"*. The REC Chairperson has granted the study favourable ethical approval.

The documents reviewed were:

- Ethics application V1
- Poster for Clinic
- TCD Proof of Registration
- CV Yvonne Codd PI
- Ethics application V2 addressing amends requested

The REC requires that approved studies submit an annual report to the REC. The annual report for the above study is due January 2019.

Yours sincerely,



Dr. Miriam O'Sullivan  
REC Chairperson

**Mission Statement**

*Sligo University Hospital is committed to the delivery of a high quality, patient centred service in a safe, equitable and efficient manner. We recognise and value the contribution of each staff member and endeavour to support them in their ongoing development.*

## A.9. Phase Three Individual Interview Participant Information Letter and Consent



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

### PARTICIPANT INFORMATION LEAFLET

**Study Title: To explore the impact of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics.**

**Principal Investigator: Yvonne Codd, PhD researcher and Senior Occupational Therapist**

Dear

You are invited to participate in this piece of research as you have been diagnosed with an inflammatory arthritis within the last two years and you are currently attending, or have within the last two years attended, the multidisciplinary-led early arthritis clinics within your rheumatology service.

The overall aim of the research is to explore the impact of inflammatory arthritis on participation in home, work and life roles and to explore how current services address participation and engagement on an occupational level.

If you agree to participate, you will be requested to meet with the principal investigator (Yvonne Codd) on one occasion to complete an interview. The aim of the interview will be to get a deeper understanding of the impact of your arthritis on your work, home, and life roles, what changes you have made to your employment and life roles since your diagnosis. I will also be interested to hear your views on how you feel current rheumatology services addressed these impacts on life roles and any ideas and suggestions that you have as to how current services could be organised and delivered to help maximise participation in home, work, social and leisure roles for people with newly diagnosed inflammatory arthritis. For your information copy of the interview guide is attached to give you an overview of the types of topics I hope to discuss.

Interviews will be facilitated in a location of convenience for yourself and any travel or parking expenses incurred will be refunded. The interview should take approximately one hour. The interviews will be audio recorded to allow for analysis, but no identifying information will be included in the transcripts, your name will not be included in the interviews nor will the hospital where you received services be disclosed. All information will be treated in the strictest confidence; you will remain completely anonymous and will not be identified in the final write up of the study. You may receive a copy of the transcript of your interview for review if you so wish. Audio-recordings from the interviews will be held securely for five years in keeping with best practice on data retention.

Your participation is entirely voluntary. If you initially decide to take part, you can subsequently change your mind without difficulty. If you would like to find out more and are interested in participating in this research please contact the principal investigator (Yvonne Codd), by email: [mooneyy@tcd.ie](mailto:mooneyy@tcd.ie) or by telephone: 045 849615. The principal investigator will be able to answer any questions you might have and if you are interested in participating, she will arrange a place and time of convenience for you for the interview. An informed consent form and stamped addressed envelope will then be forwarded to you for return to the principal investigator (Yvonne Codd). Ethical approval for the study has been granted by the Tallaght Hospital / St. James's Hospital Joint Research Ethics Committee (REC).

Kind regards

Dr. Tadhg Stapleton

Assistant Professor in Occupational Therapy



**PATIENT CONSENT FORM**

**Study Title: To explore the impact of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics.**

**Principal Investigator: Yvonne Codd, PhD researcher and Senior Occupational Therapist**

**PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX**

**Yes**

**No**

I have read and understood the Participant Information		
I have had the opportunity to ask questions and discuss the study		
I have received satisfactory answers to all my questions		
I have received enough information about this study		
I understand that I am free to withdraw from the study at any time without giving a reason and without this affecting my future medical care		
I agree to take part in the study		
I understand that all information I provide through my participation in the study will be treated with complete confidentiality and my identity will not be disclosed in any reports arising from this study		
Participant's Signature:		
Date		
Participant's Name in print:		
Investigator's Signature:		
Date		
Investigator's Name in print:		

## A.10. Phase Three Recruitment Poster Displayed in Clinical Areas

Would **you** be interested in participating in a research study exploring early impacts of inflammatory arthritis on home, work and life roles?

Would you be interested in sharing your views and suggestions as to how current rheumatology services could be organised to better address these types of impacts?

Do you have Inflammatory Arthritis?

Are you currently or have you previously attended the Multidisciplinary-led Early Arthritis Clinic?

**Why get involved?** This research project seeks to explore the early impacts of inflammatory arthritis on participation in work, home, life and leisure roles. A greater understanding of these impacts in the newly diagnosed population could help to improve current rheumatology service delivery.

**What would it involve?** Participation in this research study involves a once off interview.

**How to get involved?** If you are interested in finding out more, please contact the Principal Investigator, Yvonne Codd, by Telephone [REDACTED] or by Email [mooneyy@tcd.ie](mailto:mooneyy@tcd.ie)



## A.11. Phase Three Individual Interview Question Guide



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

### INTERVIEW GUIDE

**Study Title: To explore the impact of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics.**

**Principal Investigator: Yvonne Codd, PhD researcher and Senior Occupational Therapist**

Dear

Thank you for your interest in participating in this study. The purpose of this guide is to help you prepare for the interview by outlining the broad topics I am interested in hearing your views and opinions on. This guide is not exhaustive and if you have other topics you feel are important to discuss, you can of course do so during the interview.

In the interview I would like to find out how having arthritis might have impacted on your ability to engage in your various life roles and if the arthritis has had any impact on how well you perform your various daily living roles and routines.

1. Has having arthritis impacted in any way on how you engage in and perform your:
  - Day to day tasks at home, outside of work, in the evenings and at weekends.
  - Your employment (paid or unpaid) work.
  - Engaging in your hobbies, interests, social life and social roles.
  - Relationships with friends, family, and engagement in your family roles.
  - Your lifestyle and life in general.
  
2. At the clinics, did anybody ask if you had experienced changes or difficulties in these areas as a result of your arthritis?
  - Did you get any advice on how to address these impacts of arthritis and overcome these problems? Who gave the advice, what was it, was it helpful for you?
  - Did you feel you could ask about these issues at the clinic or that it was appropriate to ask about these issues with the team in the service?
  - Were there any concerns in these areas that you experienced that were not addressed by the service?
  
3. Had you thought about the effect of your arthritis symptoms on the different home, work, leisure, family and social aspects of your life before you attended rheumatology services?
  - Was it helpful and was it the right time for you to be asked/ think about these issues?
  - When do you think it is good to hear about these lifestyle management type interventions?
  - What do you think is important and valuable to include in rheumatology services for people with a new diagnosis?
  - Where do you feel the focus should be in intervention?
  - How do you think this type of intervention should be delivered? What would be most helpful for you?

## A.12. Phase Three Individual Interview Follow Up Letter with Themes



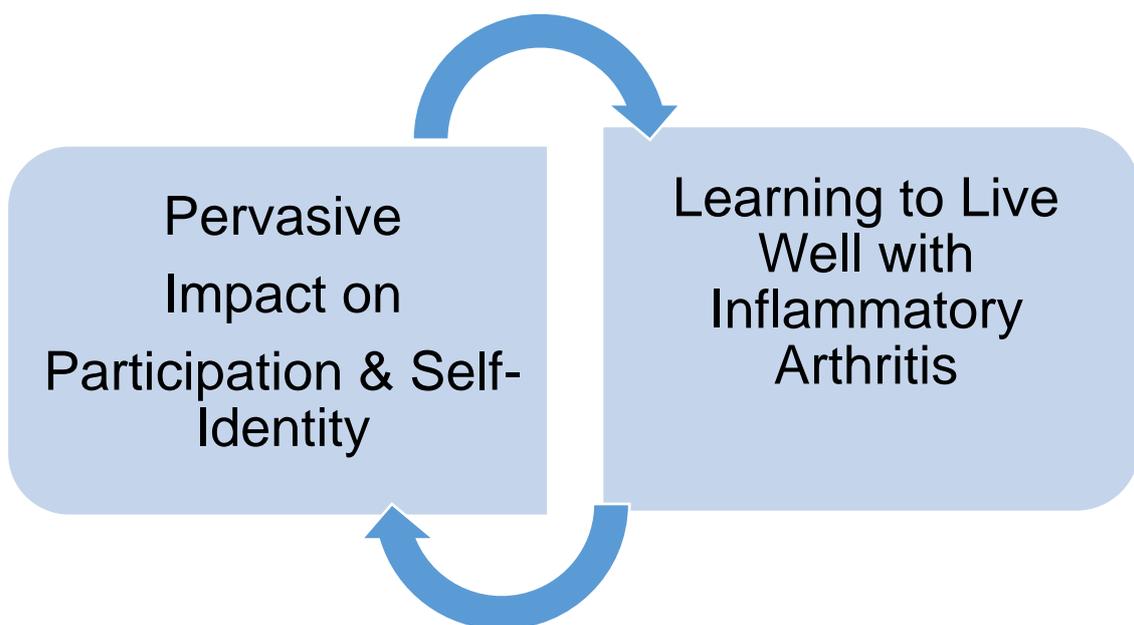
Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

**Study Title: To explore the impact of newly diagnosed inflammatory arthritis on participation and explore how current services address participation and engagement on an occupational level among service users attending multidisciplinary-led early arthritis clinics.**

Dear

Thank you for participating in the above study.

The qualitative findings from the interviews have now been analysed. From the data collected two broad overarching themes have been identified which collectively reflect the impact of a new diagnosis of inflammatory arthritis on participation and how current rheumatology services address participation and engagement 'Pervasive Impact on Participation and Self-Identity' theme principally explains the impact of inflammatory arthritis on participants' ability to engage in meaningful self-directed occupations. The 'Learning to Live Well with Inflammatory Arthritis' theme describes the participant's views and experiences on how the multidisciplinary-led early arthritis clinics had supported them to live well with inflammatory arthritis. These findings are illustrated in the graphic and table below:



Overarching Themes	Themes
Pervasive Impact on Participation and Self-Identity	<p><b>Altered Capacity</b></p> <ul style="list-style-type: none"> <li>• Paid Employment</li> <li>• Relationships</li> <li>• Home &amp; Other Valued Life Role</li> <li>• Role Switch</li> </ul> <p><b>Well-being and Emotional Implications</b></p> <p><b>Disruption in Normal Occupational Balance</b></p> <p><b>Reconstructed Future</b></p>
Learning to Live Well with Inflammatory Arthritis	<p><b>Right Advice, in the Right Way, at the Right Time</b></p> <ul style="list-style-type: none"> <li>• Function of MDT Early Arthritis Clinic</li> <li>• Early Access for MDT Intervention</li> </ul> <p><b>'The Right Way' Concept</b></p> <ul style="list-style-type: none"> <li>• Therapeutic Relationship</li> <li>• Prolonged Time for Talk and Support</li> <li>• Individualised Approach</li> </ul> <p><b>Adaptations for Participation</b></p> <ul style="list-style-type: none"> <li>• Adjustments for Employment &amp; Student Roles</li> <li>• Adjustments for Home &amp; Other VLR</li> <li>• Self-Management &amp; the Active Participant</li> <li>• Reidentifying View of Self</li> </ul> <p><b>Areas for Future Development</b></p>

If you wish to clarify any of these themes or include additional issues please do not hesitate to contact me on 086-3007365.

Thank you for your involvement with this study and for sharing your views and experiences.

Yvonne Codd

PhD Researcher & Senior Occupational Therapist

## **A.13. Dissemination Outputs**

### **Peer Reviewed Journal Publication**

Codd, Y., Stapleton, T., Kane, D., & Mullan, R. (2018). A survey to establish current practice in addressing work participation with inflammatory arthritis in the Irish clinical setting. *Musculoskeletal Care*, 16(1), 158-162. DOI: 10.1002./msc.1198

### **Peer Reviewed Conference Oral Presentation**

Codd, Y. (2020). *Exploring the Impact of Early Inflammatory Arthritis on Participation: How do Clinical Services Address Client-identified Participation Restrictions?* Oral Presentation: Association of Occupational Therapists of Ireland Annual Conference. Limerick, Ireland.

Codd Y. (2016). *Addressing Employment Participation in Inflammatory Arthritis: Irish Rheumatology Clinicians Experiences and Perspectives.* Oral Presentation: Health and Social Care Professions Research Conference, Dublin Castle: Dublin.

### **Peer Reviewed Conference Poster Presentations**

Codd, Y., Mullan, R., Kane, D., Coe, A., & Stapleton, T. (2021). 'The right advice, in the right way and at the right time': An Innovative Multidisciplinary Approach to Address Client-Identified Participation Needs in Early Inflammatory Arthritis. FORTHCOMING EVENT, Poster submitted to *EULAR Annual European Congress of Rheumatology. Paris, France.*

Codd, Y., Stapleton, T., Mullan, R., & Kane, D. (2017). A Survey to Establish Current Practice in Addressing Work Issues Among People with Inflammatory Arthritis in the Irish Clinical Setting. *EULAR Annual European Congress of Rheumatology. Madrid, Spain.*

Codd, Y., Stapleton, T., Mullan, R., & Kane, D. (2017). How is work participation for those with inflammatory arthritis currently addressed in rheumatology services? Irish rheumatology clinicians' experiences and perspectives. Conference Poster Presentation: *Association of Occupational Therapists of Ireland Annual Conference. Limerick, Ireland.*

Codd, Y., Stapleton, T., Mullan, R., & Kane, D. (2016). Addressing Work Participation in Inflammatory Arthritis: Irish Rheumatology Clinicians Experiences and Perspectives. Poster presented at the *Irish Society for Rheumatology / Irish Rheumatology Health Professional Society Autumn Conference. Naas, Ireland.*