# Enhancing People-Centred Arthritis Care: A Design Thinking and Empathy-Driven Approach through Interdisciplinary Research

**Yaohan Xing**

A thesis submitted in partial fulfilment of the requirements of
Birmingham City University
for the degree of Doctor of Philosophy
May 2025

The Faculty of Art, Design and Media, Birmingham City University

# Declaration

I declare that no material contained in this thesis has been submitted for any other academic award.

I confirm that this thesis is entirely my own work and is based on my original research. All sources of information have been properly acknowledged, and any direct quotations from the work of others are clearly indicated using quotation marks.

# Acknowledgements

As I write these words, I find myself at the end of a long and unforgettable journey.

Many thanks to my supervisor, Associate Professor Mersha Aftab, for your thoughtful guidance and unwavering support throughout my doctoral journey. I still remember that, at the very beginning of my PhD, you said to me, “I’m proud of you.” Those words stayed with me and carried me through the entire process. Thank you for your consistent trust and encouragement. Although I started this journey with uncertainty, under your guidance I gradually became more confident and determined, and eventually reached this important milestone. Along the way, I learned not only how to conduct research, but also how to think critically, express myself clearly, and respond to external doubts and challenges. Through you, I came to understand the strength and resilience women can embody. You are not only an outstanding scholar and educator, but also a guiding presence in my life.

Many thanks to my second supervisor, Professor Joanne Brooke, for your professionalism and consistent support throughout my PhD. You always approached my work with care and patience, and your thoughtful feedback helped me move forward whenever I felt stuck. Your guidance not only improved the quality of my research, but also showed me what it means to be truly dedicated. I’m especially grateful for your timely responses and the support you offered whenever I needed it. Your calm strength and steady presence reassured me during difficult times and reminded me that I was never alone on this journey. More than once, I’ve thought how fortunate I’ve been to have you by my side.

I would also like to thank all the participants who reached out and took part in this study. Thank you for your trust, kindness, and willingness to be involved. Your honest and thoughtful contributions brought depth and authenticity to this research. Special thanks to Arthritis Action for supporting the recruitment process by helping to share information about the project and enabling more potential participants to engage.

I am also grateful to all the staff at the Faculty of Art, Design and Media. Thank you for your ongoing support, patience, and assistance throughout my doctoral studies. Whether it was administrative matters, access to learning resources, and your warm and efficient help provided a solid foundation for my research and learning.

A special thank you to my friend Isabelle Uner, for your invaluable advice and constant encouragement throughout the writing of this thesis. Thank you for always being there when I needed support, always offering your help and companionship without hesitation. Your presence made this journey less overwhelming and filled it with warmth and reassurance.

I am deeply grateful to my family for your unwavering understanding and support. You have given me the chance to see a bigger world, to pursue greater dreams, and to make more meaningful choices in life. And to my friends, thank you as well. During the years I spent studying abroad, it was your presence that reminded me how true friendship can transcend distance and time.

Finally, I would like to dedicate this part to myself. During my PhD, there were moments of joy and gratitude, but also periods of struggle and helplessness. I cried more times than I could count, yet after every low point, I somehow found the strength to rise again. This journey has been a profound transformation. It has not only sharpened my academic abilities, but has also made me more resilient, more self-assured, and more thoughtful. Most importantly, it has changed the way I see the world and understand humanity. I still remember the day I first walked onto a university campus. I never imagined that one day I would come this far. And now, as I prepare to leave, I find myself wondering: who will I become next?

Life is like a book and every sentence we write carries meaning and value. I hope that in the chapters yet to come, I will continue to love the process of writing my own story.

# Abstract

As populations age, arthritis has become an increasingly urgent global health concern, highlighting the need for more responsive and people-centred healthcare services. This study explores how people-centred care can be improved in arthritis healthcare by integrating design thinking with qualitative research methods.

The research was conducted in two phases. A systematic review examined how people-centred care is defined and applied in existing studies on arthritis, providing a theoretical foundation. Building on this, the study adopted an interpretative phenomenological approach, incorporating the empathy stage of design thinking to explore the lived experiences of people with arthritis. Semi-structured interviews were used to collect data, which were analysed using thematic and framework analysis, supported by user journey mapping.

The findings reveal key areas where people with arthritis encounter challenges, gaps, and unmet needs in their interactions with healthcare services. The research demonstrates the potential of design thinking, supported by interdisciplinary collaboration and user-focused analysis, to contribute to the development of more empathetic, adaptive, and inclusive arthritis care.

A major outcome of this study is the proposal of a novel circular framework for people-centred arthritis care. This model moves beyond traditional linear service delivery by emphasising continuity, responsiveness, and experience-based design. The research also introduces an interdisciplinary methodology combining design thinking, phenomenology, and user journey mapping.

By centring the experiences of people with arthritis, this study provides practical insights and tools for healthcare providers seeking to improve service quality and contributes to advancing people-centred approaches within arthritis care.

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# Chapter 1: Introduction

## 1.1 Overview

The introduction chapter sets the background and rationale for the study, situating the research within the context of arthritis as a growing health challenge and exploring the significance of people-centred care in addressing the complex needs of individuals living with long-term conditions. The introduction chapter outlines the limitations of current healthcare systems in delivering responsive, coordinated, and holistic care, and considers the role of self-management and design thinking in improving patient experience and outcomes. The chapter introduces the research questions and objectives, and explains the methodological approach adopted to explore people-centred care from both theoretical and user-defined perspectives. By integrating a systematic review, qualitative research, and design thinking, the study provides the foundation for examining how arthritis services can be improved through a people-centred approach to better reflect the lived realities of those they aim to support.

This thesis adopts an interpretive phenomenological orientation to examine people-centred arthritis healthcare as lived service experience within a complex and fragmented system. Rather than developing or testing solutions, it seeks to understand how individuals living with arthritis experience and make sense of healthcare services. Design thinking is employed as a methodological approach to support holistic sense-making of multi-layered service experiences, not as an epistemological position or design-led paradigm. Relevant literature contributes to the research context and informs the articulation of research aims, providing an evidence-informed backdrop for exploring participants’ experiences.

## 1.2 Research Questions, Aims and Objectives

The purpose of this research is to explore people-centred care in arthritis healthcare services, integrating insights from a systematic review, user perspectives, and a design thinking approach. This study aims to bridge the gap between existing theoretical frameworks and real-world user experiences, and further investigate how design thinking, through interdisciplinary collaboration, can contribute to the development of people-centred care in arthritis healthcare services.

### 1.2.1 Research Questions

To achieve this, the study is guided by the following research questions:

*What are the people-centred care elements in arthritis healthcare service?*

This question was addressed through the development and completion of a systematic review of the literature, which synthesised existing knowledge on people-centred care in arthritis healthcare services. By identifying the core elements from previous research, this study establishes a foundational understanding of the key characteristics and principles of people-centred care in this context.

*What are the people-centred care elements in arthritis healthcare services from the users' perspective?*

While the systematic review provides an academic and theoretical foundation, this question focuses on the perspectives of individuals living with arthritis. Using a design thinking approach within a qualitative research framework, this study aims to uncover how users define, experience, and evaluate people-centred care in arthritis healthcare services. The findings will offer a bottom-up, user-driven perspective to complement the systematic review's theoretical insights.

*How can design thinking, through interdisciplinary collaboration, enhance the development of people-centred care in arthritis healthcare services?*

Building on the insights from the previous questions, this question investigates the role of design thinking in fostering interdisciplinary collaboration to improve people-centred care. It explores how empathy-driven approaches and iterative problem-solving can enhance healthcare services for people with arthritis. By addressing this question, the study aims to demonstrate the practical implications of design thinking in shaping more inclusive and responsive healthcare solutions.

### 1.2.2 Research Objectives

To address the above questions, this study sets out the following objectives:

To systematically identify and synthesise the key elements of people-centred care in arthritis healthcare services based on existing literature.

To explore and define the user perspective of people-centred care in arthritis healthcare services through qualitative research and a design thinking approach.

To examine how design thinking, through interdisciplinary collaboration, can facilitate the development and enhancement of people-centred care in arthritis healthcare services.

By integrating systematic review findings, user insights, and interdisciplinary methodologies, this research aims to offer both theoretical contributions and practical guidance for improving arthritis healthcare services with a stronger emphasis on people-centred care.

## 1.3 Research Context and Background

### 1.3.1 Defining Arthritis: Classification, Disease Burden, and Key Types

The World Health Organisation (WHO) International Classification of Diseases-11 (IDC-11) classification of arthritis is a group of diseases primarily affecting one or more joints, characterised by common features such as pain, swelling, and stiffness (World

Health Organisation, 2022). ICD-11 places these conditions under the broader category of *chronic secondary musculoskeletal pain*, which is further subdivided into categories such as *musculoskeletal pain related to persistent inflammation* (such as rheumatoid arthritis) and *musculoskeletal pain associated with structural changes* (such as osteoarthritis) (Perrot et al., 2019).

There are multiple types of arthritis. For example, osteoarthritis is defined as a group of distinct but overlapping diseases, which may have different aetiologies yet share similar biological, morphological, and clinical outcomes (World Health Organisation, 2025). Osteoarthritis primarily affects the articular cartilage, subchondral bone, ligaments, joint capsule, synovium, and periarticular muscles (WHO, 2025). Although the exact aetiology is not completely understood, identified risk factors include female sex, genetic predisposition, metabolic influences, and excessive mechanical loading (WHO, 2025). Rheumatoid arthritis (RA), by contrast, is a chronic joint condition characterised by persistence and/or erosion (WHO, 2025). According to the ICD-11 definition, a diagnosis of RA requires confirmed synovitis in at least one joint, with no alternative diagnosis that more plausibly explains the synovitis (WHO, 2025). Other forms of arthritis include juvenile idiopathic arthritis, gout, and psoriatic arthritis, among others (WHO, 2025).

The global prevalence of osteoarthritis is expected to rise in tandem with the ageing population (World Health Organisation, 2023a). In 2019, an estimated 528 million people worldwide were living with osteoarthritis - an increase of 113% compared to 1990 (National Institute for Health and Care Excellence, 2023). Osteoarthritis primarily affects older adults, with approximately 70% of individuals diagnosed from the age of 55 years and above, and 60% are women (NICE, 2023). Due to the ongoing demographic shift towards an older population, alongside rising rates of obesity and injury, the global burden of osteoarthritis is projected to increase further (WHO, 2023a).

In 2019, an estimated 18 million people worldwide were living with rheumatoid arthritis (World Health Organisation, 2023b). Approximately 70% of those affected are women, and 55% are aged over 55 (WHO, 2023b). Of those living with arthritis, 13 million people are estimated to be living with moderate to severe rheumatoid arthritis, which could benefit from rehabilitation interventions (WHO, 2023b). Juvenile idiopathic arthritis (JIA) encompasses all forms of arthritis of unknown cause with onset before the age of 16 and a duration of at least six weeks. In the UK, approximately 1,000 children are diagnosed with JIA each year, with an estimated 10,000 children living with the condition. JIA can persist into adulthood, with around one third or more of affected children continuing to require treatment into their adult years (NICE, 2015).

### 1.3.2 Comprehensive Management to Arthritis Treatment

The management of arthritis in the UK follows a comprehensive evidence-based approach, primarily guided by the National Institute for Health and Care Excellence (NICE). Treatment strategies are tailored according to the type of arthritis, the severity of symptoms, the presence of comorbidities, and individual patient preferences. For osteoarthritis, NICE guidelines recommend a core set of non-pharmacological interventions, including structured exercise programmes, weight management for individuals who are overweight or obese, and patient education regarding the condition and its progression (NICE, 2022). Pharmacological options include the use of topical and oral non-steroidal anti-inflammatory drugs (NSAIDs) (NICE, 2022). When conservative management proves insufficient, surgical options such as joint replacement may be considered (NICE, 2022).

NICE guidelines for the management of rheumatoid arthritis emphasise the importance of early diagnosis and the prompt initiation of disease-modifying anti-rheumatic drugs (DMARDs), ideally within three months of symptom onset (NICE, 2018). Regular monitoring, coordinated multidisciplinary care, and timely treatment escalation are key components of the recommended care pathway (NICE, 2018). Where appropriate, patients may also receive support through self-management programmes, psychological interventions, and occupational therapy, contributing to a holistic model of care aimed at improving function and quality of life (NICE, 2018).

These national recommendations reflect broader international guidelines, which advocate for the integration of pharmacological and non-pharmacological care (Wasserman, 2011). Non-pharmacological approaches, such as physical therapy, hydrotherapy, therapeutic fasting, symptom diaries, and dietary interventions including essential fatty acid supplementation, have been associated with short-term benefits in managing arthritis symptoms (Rindfleisch and Muller, 2005). Patient education, in particular, is critical for enhancing self-management, allowing individuals to minimise the impact of arthritis on their daily life (Damgaard et al., 2023). Multidisciplinary care models that combine education with ongoing physical and psychological support are increasingly recognised as best practice in improving patient outcomes (Damgaard et al., 2023).

### 1.3.3 The Significance of Self-Management in the Context of Arthritis Care

Over the past 25 years, evidence has demonstrated the effectiveness of self-management in alleviating arthritis-related pain and disability (Lorig et al., 1985; Lorig et al., 1999; Lorig et al., 1993; Lorig et al., 2005; Kruger et al., 1998; Wong et al., 2004). The concept of self-management has been defined in various ways within the literature. Barlow (2002b, P178) proposed the definition: "*Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with chronic condition.*" This definition underscores that the management of arthritis, which extends beyond adherence to treatment guidelines and necessitates a comprehensive approach that integrates the physiological, psychological, and social dimensions of chronic disease management (Barlow et al., 2002a; Damgaard et al., 2023). Enhancing patients' belief in their ability to manage symptoms and maintain functional capacity is a key objective of self-management education programmes in arthritis care (Brand et al., 2013). To effectively cope with chronic illness, individuals must learn to identify bodily signals, emotional triggers, and personal response patterns, and align their decisions with their own desired quality of life, rather than passively adhering to healthcare system-defined standards of living (Thorne, 1999; Marques et al., 2021).

Self-management can be understood as a process. In interactions with patients, health professionals help to build arthritis-related knowledge, develop relevant skills, and foster the confidence needed to apply them (Dwarswaard et al., 2016). Such professional support enables individuals to promote their health, manage their condition, and know when and where to seek appropriate support (Dwarswaard et al., 2016). People with arthritis are encouraged to engage in shared responsibility and decision-making in the management of their condition, in order to enhance their confidence and self-management skills (Nikiphorou et al., 2021; Dures and Hewlett, 2012). Key components of self-management include targeted disease education, problem-solving strategies, cognitive behavioural therapy, goal setting, coping skills training, and general patient education, which have been shown to produce positive outcomes in people living with arthritis (Marques et al., 2021).

Supporting people with arthritis to develop effective self-management approaches requires meaningful interaction between the healthcare team and patient (Olsson et al., 2020). Through these interactions, healthcare professionals can provide guidance, encouragement, and personalised strategies that enable patients to take a more active role in managing their condition (Olsson et al., 2020). Active patient involvement is essential, healthcare professionals and patients are expected to share expertise, work collaboratively towards the patient's personal goals, and jointly assume responsibility for addressing problems raised by the patient (Olsson et al., 2020).

People with arthritis seek to understand the benefits and risks of antirheumatic therapies, the long-term side effects, treatment regimens, and therapeutic principles to enhance their self-management skills (Barlow et al., 2002a; Beauvais et al., 2019; Kristiansen et al., 2012; Radford et al., 2008; Zuidema et al., 2015). Various initiatives have been developed to support self-management systems, including therapeutic writing (self-expression) programmes, pain management programmes, stress management programmes, depression management programmes, and self-help (self-management programme) (Parker and Hart, 2009). Patient education programmes are designed to equip individuals with rheumatoid arthritis with the knowledge and strategies necessary to adjust and improve essential daily activities, thereby preventing functional limitations associated with disease progression (Parker and Hart, 2009).

The current literature identifies positive outcomes associated with self-management programmes for individuals with arthritis, including improved symptom control, enhanced self-efficacy, and better quality of life (Uritani et al., 2021). For people with arthritis, it is crucial to create a healthcare system and broader social environment that support symptom management and the capacity to effectively manage a long-term condition (Fairley et al., 2021). Unfortunately, rheumatologists and/or physicians caring for patients with arthritis often lack the time to provide comprehensive psychological support and self-management education, as noted by Oh et al. (2024). While such care may be delivered by nurses or allied health professionals, this study highlights time constraints specifically among doctors. Healthcare professionals play a vital role in motivating people with arthritis to adopt and maintain healthy lifestyles (Drake et al., 2024).

### 1.3.4 The Current Arthritis Services in England

In the England, General Practitioners (GPs) have been the initial point of contact for patients within the National Health Service (NHS) for over a century, assuming the dual role of referrer and ‘gatekeeper’ to specialist services (Dando et al., 2020). The establishment of the GP referral mechanism was catalysed by the emergence of medical specialisation in the late nineteenth century (Townson, 2014). In its early stages, this shift gave rise to an informal arrangement whereby GPs could refer patients to specialist colleagues while maintaining ongoing responsibility for their care (Weisz, 2003; Townson, 2014). The shift in system was later formally endorsed in the Dawson Report, which helped institutionalise the practice of referral via GP letters to specialist services, ultimately embedding it within routine healthcare delivery (Dando et al., 2020).

Within the contemporary healthcare system, patients continue to rely on GPs to facilitate access to appropriate clinical professionals at the right time and in the right setting, in order to obtain advice and/or treatment for their health concerns (Dando et al., 2020). However, prior to consulting a GP, patients may seek support from a range of other services, such as allied health professionals, pharmacists, and telephone or online platforms (Stack et al., 2019).

Existing evidence suggests care coordination remains a challenge in primary care for individuals with a range of long-term conditions, including arthritis (Stumm et al., 2019; Smith et al., 2021). In the UK, GPs serve as expert medical generalists and are often the first point of contact for medical advice and treatment for their registered NHS patients (House of Commons Library, 2025). The majority of general practices in England are part of a primary care network (PCN), collaborating with other local health and social care providers to deliver coordinated care and an extended range of services (House of Commons Library, 2025). For over two decades, personalised care has been a central theme in England health policy. Key strategies have included shared decision-making, the promotion of self-management, and active patient involvement - each aimed at improving the quality and safety of care (McCann et al., 2024). England healthcare has consistently aimed to support patients' individual preferences, dignity, and autonomy across all stages of care planning, treatment, and decision-making (NHS Health Education England, 2017).

People-centred needs have also been explored within the broader matrix of patients' home, social, cultural, and religious contexts, with the aim of supporting their relationships and lived realities (Coulter and Oldham, 2016; Entwistle and Watt, 2013). Although person-centred care (PCC) has been actively promoted and efforts have been made to integrate it across NHS England, significant implementation gaps remain. These are largely attributable to chronic underfunding and workforce shortages (Fang et al., 2024), resulting in low levels of service standardisation and inequitable distribution of treatment models across different populations (Gabriel et al., 2019).

Gaps in care pathways - such as limited continuity between healthcare providers and long waiting times - have been linked to patient distress, reduced trust, and negative care experiences (Bala et al., 2017). Many people with arthritis describe inconsistent rehabilitation journeys, often shaped by the complexity of the healthcare system and their multiple health and social care needs (Feddersen et al., 2022). These issues contrast with the principles of person-centred care, which stress the need for joined-up support and smooth transitions between services (Feddersen et al., 2022). These structural challenges have hindered the realisation of PCC, lengthened waiting times, and increased reliance on self-management or private healthcare options (Fang et al., 2024). Meanwhile, healthcare professionals have highlighted the importance of prioritising team-based, patient-centred approaches to lifestyle management (Drake et al., 2023). In addition, people with arthritis have reported that their concerns are not always taken seriously, and that poor understanding of the information they receive limits the effectiveness of person-centred care (Segan et al., 2018).

Regional disparities, inequalities, and discriminatory factors, such as racism, ageism, and gender and cultural bias, further hinder the system's ability to respond to the multidimensional needs of patients (Fang et al., 2024). The COVID-19 pandemic has intensified these existing challenges in delivering people-centred care across the UK (Moynihan et al., 2021). This unprecedented crisis severely strained already overstretched public health resources, amplifying long-standing issues such as staff shortages, barriers to data sharing, poor inter-organisational coordination, and widening inequalities (Bambra et al., 2021). In response to these pressures, healthcare delivery models rapidly shifted, with a particular emphasis on the expansion of remote consultations in primary care (Joy et al., 2020). The expansion of remote consultations helped maintain access during national restrictions due to the pandemic, but also raised concerns about its long-term implications for continuity and equity of care (Joy et al., 2020). As remote care approaches continue to be used in primary care, concerns have been raised about their potential negative impact on continuity of care, particularly for patients with long-term or complex conditions (McCann et al., 2024).

Recent NHS plans indicate an intention to embed remote consultations as a core modality within general practice in the UK (McCann et al., 2024).

### 1.3.5 People-Centred: What This Means

The term user-centred is commonly used in service design and design thinking to highlight a focus on the user throughout the design process. According to Norman (2013), user-centred design is a philosophy that places the needs, abilities and experiences of users at the heart of every stage of the design process, aiming to make systems usable, useful and meaningful. Similarly, Cautela et al. (2009) argue that user-centred design is a precise design method whose application conducts designers to develop usable design solutions for end users.

People are often referred to as “users”, but this can diminish their contribution to research, as they are positioned merely as respondents to designer-defined questions and predetermined processes (Gheerawo, 2018). This removes the human perspective, which often leads to hidden insights, innovation, and design opportunities (Gheerawo, 2018). While user-centred is widely used in service design and design thinking, terms such as patient-centred, person-centred, and people-centred are more common in healthcare research. As this study focuses on healthcare service contexts, it is relevant to consider how these terms have evolved and are used across different fields.

In the field of healthcare, the term patient-centred is commonly used to emphasise a focus on the individual within care processes. Patient-centred care has been described as seeing the patient as a unique person (Redman, 2004). It is regarded as a standard of practice that reflects respect for the patient as a person in their own right (Binnie and Titchen, 1999; Shaller, 2007). Patient-centred care further stresses the importance of taking the patient’s perspectives and circumstances into account in decision-making, rather than merely focusing on collaborative goal setting (Ponte et al., 2003). As Coulter (2002) defines it, patient-centred care involves providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.

Person-centred care has long been closely associated with the discipline of nursing, with a focus on viewing individuals as unique persons, respecting their rights, fostering mutual trust and understanding, and developing therapeutic relationships (McCormack and McCance, 2016). Ekman et al. (2011) distinguish person-centred care from patient-centred care, arguing that person-centred care avoids the tendency to reduce individuals to their symptoms or medical conditions. Emphasising the concept of the person is seen as essential, requiring a more comprehensive approach to care that incorporates various aspects of wellbeing, including an individual's background, expressions, preferences and beliefs (Ekman et al., 2011).Person-centred care is not limited to those receiving treatment, but also involves families and caregivers, people who are not currently unwell, and activities related to health promotion and disease prevention (Santana et al., 2018).

People-centred care refers to an approach that deliberately adopts the perspectives of individuals, carers, families and communities, recognising them as active participants in and beneficiaries of trusted health systems (World Health Organization, 2016). People-centred care is organised around the comprehensive needs of people rather than individual diseases and are guided by respect for social preferences (WHO, 2016). People-centred care emphasises the active role of individuals in clinical contexts and requires that patients are provided with the education and support needed to make informed decisions and participate in their own care, which also highlights the importance of enabling carers to function effectively within supportive working environments (WHO, 2016). In contrast to patient-centred care or person-centred care in clinical encounters, people-centred care offers a broader perspective that not only addresses individual health but also extends to the health of communities and the vital role that people play in shaping health policies and services (WHO, 2016). As noted by Sanz et al. (2021), people-centred care involves recognising service users as unique individuals (Redman, 2004), acknowledging their status as persons (Binnie and Titchen, 1999), and incorporating their views into decision-making processes (Shaller, 2007). This approach seeks to empower individuals by strengthening their role in managing their own health, offering information, support, comfort, acceptance, legitimacy and confidence (Fulford et al., 1995).

Although this study draws on a wide range of existing literature related to person-centred care, patient-centred care, and people-centred care to trace their meanings and evolution, the term people-centred is adopted throughout. The choice of people-centred reflects the study's focus on broader, system-level practices of people-centredness in healthcare services. The term people-centred encompasses not only individual perspectives within clinical care, but also the involvement of families, carers, communities, and policy actors, making it particularly well-suited to the study's emphasis on service integration and systemic coherence.

### 1.3.6 People-Centred Arthritis Healthcare Service

Person-centred care (PCC) has demonstrated positive outcomes in disease management (Kogan et al., 2016) and is recognised as a high-quality care model that contributes to improved health service outcomes (Harding et al., 2015). The World Health Organisation has called for a transformation of healthcare systems towards integrated, person-centred health services (WHO, 2015). PCC represents a shift from the traditional biomedical model, in which patients are passive recipients of medical interventions, towards a more humanistic approach that empowers patients to actively engage in their care and decision-making processes (McCormack et al., 2015).

The traditional healthcare system has primarily focused on disease treatment (Allen, 2019), with its emphasis often placed on the illness rather than the holistic needs of the patient. However, people-centred healthcare necessitates consideration of multiple dimensions, including patients' emotional, cognitive, and social contexts (WHO, 2009). Miles (2012) argued disease constitutes only one aspect of the patient's overall experience and that patients should not be regarded merely as carriers of their medical conditions (Lee, 2010; Fairley et al., 2021; van Slingerland et al., 2022).

People-centred health services aim to place individuals and communities at the centre of healthcare systems, empowering patients to take an active role in managing their own health rather than merely receiving care passively (Patrício et al., 2020). People-centred characteristics are diverse, reflecting a range of attitudes and behaviours that may be understood as part of "treating people as persons," or, at a minimum, as avoiding the neglect or disregard of important aspects of their humanity (Entwistle et al., 2018; Mitchell et al., 2022).

Supporting individuals with long-term health conditions typically requires, among other things, attention to personal autonomy and overall wellbeing, recognising that patients themselves undertake the majority of day-to-day and long-term management of these conditions (McCann et al., 2024). Supporting individuals with long-term health conditions also requires caution to ensure that the healthcare system's emphasis on biomedical indicators of health does not overshadow or displace attention to people's broader needs and personal priorities (Entwistle et al., 2018; Mitchell et al., 2022).

PPC enhances the satisfaction of people with arthritis regarding health services and positively influences job satisfaction of healthcare professionals (World Health Organization, 2015). This person-centred approach to care also aligns with broader healthcare reforms. Specifically, the transition towards an integrated, person-centred model of care addresses challenges associated with population ageing, the rising prevalence of chronic diseases, low adoption of healthy lifestyles, and the decentralisation of healthcare systems (Maurits et al., 2018). Moreover, healthcare services represent an expensive, complex, and essential public service, exerting a profound impact on the global economy and individuals' quality of daily life (Berry and Bendapudi, 2007). The growing ageing population and escalating healthcare costs place substantial strain on healthcare systems (Patrício et al., 2020). In many developed countries, an increasing number of older adults receiving long-term care are opting for home-based support, while hospital stays have become shorter than in previous decades

(OECD, 2015). When individuals are equipped to manage their health effectively, hospital admission rates can be reduced, thereby alleviating pressure on existing healthcare systems. This shift highlights the importance of PPC in enabling individuals to manage their health more effectively and receive appropriate support in community settings, thereby contributing to more sustainable and responsive healthcare systems.

PPC contributes to the establishment of a healthcare provider-patient relationship founded on mutual respect and understanding, recognising individuals' rights, values, and beliefs (McCormack et al., 2008). The World Health Organization (2015) has outlined five interdependent strategic directions that need to be adopted in order for health service delivery to become more people-centred and integrated (see Figure 1.1):

- Empowering and engaging people: Empowering and engaging people aims to enhance the capacity of individuals and communities in health decision-making and service co-production.

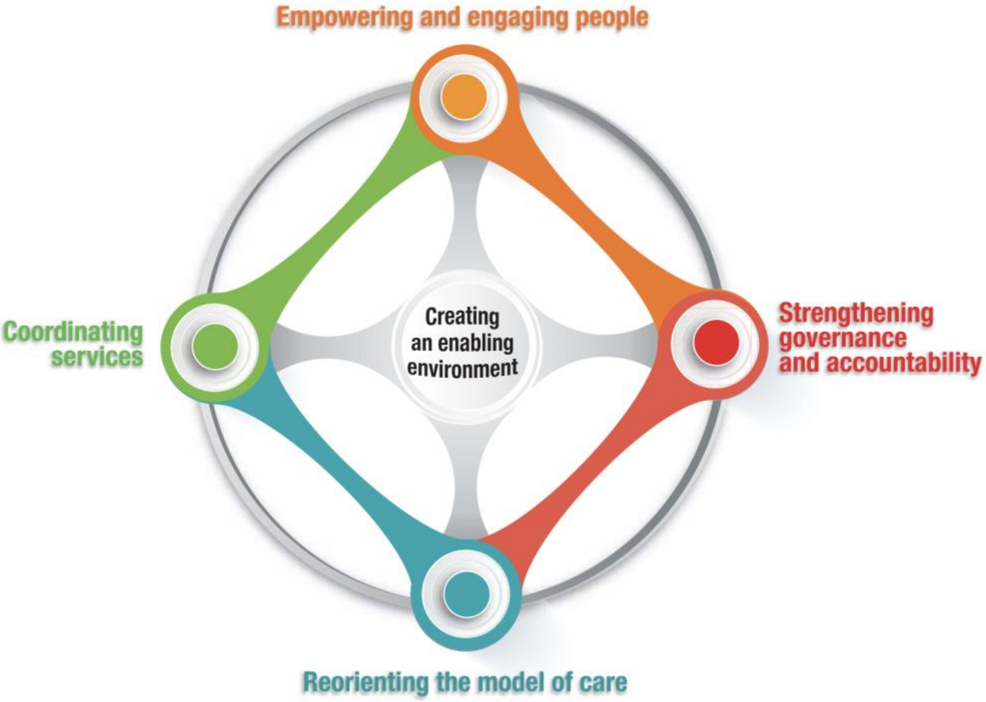
- Strengthening governance and accountability: Strengthening governance and accountability means promoting transparent decision-making and ensuring shared responsibility among providers and service managers.

- Reorienting the model of care: Reorienting the model of care aims to strengthen primary and community care and promote cross-sector collaboration to deliver holistic services focused on health promotion and efficient use of resources.

- Coordinating services: Coordinating services aims to integrate care across all levels and sectors to address fragmentation and improve quality, continuity, and emergency response capacity.

- Creating an enabling environment: To put the previous four strategies into practice, creating an enabling environment aims to drive systemic changes in legislation, financing, policy, and workforce development to support people-centred reform.

*Figure 1.1 The five strategic directions for People-Centred Care (WHO, 2015)*



Despite global efforts to implement PCC, significant barriers persist. Sinaiko et al. (2019) identified several potential obstacles, including a lack of respectful and reliable information exchange, organisational culture within healthcare institutions, inadequate training for clinical experts, and inconsistencies in external incentive mechanisms. Poor communication can hinder shared decision-making and weaken trust (Segan et al., 2018; Battista et al., 2022). In many healthcare institutions, rigid structures and efficiency-driven routines reduce opportunities for meaningful patient interaction (Segan et al., 2018). Additionally, healthcare professionals may lack training in the relational aspects of care, and funding or policy frameworks often fail to reward person-centred approaches (Moore et al., 2017).

In line with person-centred care principles, a reformed healthcare system should aim to improve the care experience of individuals with arthritis, alongside fostering collaborative relationships between service users and healthcare providers (Segan et al., 2018). A core strategy of person-centred care involves recognising and responding to people’s perspectives, needs, values, expectations, and capabilities within their social contexts (Ekman et al., 2011). Concurrently, healthcare professionals must establish relationships with patients based on the principles of respect and equity (Wigzell, 2017). For example, the Nursing and Midwifery Council (NMC, 2018) highlights the importance of prioritising people, practising effectively, and preserving safety, all of which align closely with person-centred approaches. These regulatory frameworks reinforce the ethical and practical foundations of person-centred care in everyday clinical practice. Thus, a person-centred healthcare system must also address the issue of information asymmetry between healthcare professionals and patients, particularly the gap between medical expertise and patients' personal health experiences (Black and Gallan, 2015).

In advancing the principles of person-centred care, it is essential to consider how broader systemic, technological, and research developments shape both the delivery of care and the opportunities for reform. Emerging technologies present significant opportunities for the implementation of integrated, person-centred care (Li and Huang, 2022). For instance, patient-centred technologies such as health applications, wearable devices, and online community support facilitate more efficient healthcare delivery and, in some cases, can partially replace traditional medical interactions (Patrício et al., 2020). Furthermore, new technologies can enhance collaboration among stakeholders within the healthcare system, including hospitals, insurance providers, pharmacies, and patients' families (Pinho et al., 2014).

In recent years, healthcare services have become a critical component of emergency response systems and a domain where academia can generate substantial research contributions and societal impact (Berry, 2019). This trend has, to some extent, incentivised more scholars and practitioners to engage in healthcare service research. However, existing literature remains predominantly focused on biomedical phenomena, clinical outcomes, and methodological advancement (Greenhalgh et al., 2019). While such studies are indispensable, they often overlook the nuanced, lived experiences of patients navigating complex healthcare systems. As a result, the relational, emotional, and contextual dimensions of care remain under-explored. In response to these gaps, this research will centre on the lived experiences of individuals with arthritis, with a particular focus on the everyday realities of engaging with healthcare services. By examining the practical applications of person-centred care (PCC), this study aims to foreground patient voices, contextual needs, and experiential knowledge as essential components in the redesign of healthcare services.

### 1.3.7 People-Centred Arthritis Healthcare Service in Design

The concept of people-centred arthritis healthcare service in this study draws on the World Health Organization's definition of people-centred care, which emphasises care that is organised around the needs, values, and preferences of individuals, families, and communities (WHO, 2016). In this context, people with arthritis are positioned as active users of healthcare, and user-centredness is framed in terms of designing services that reflect their lived experiences and priorities. The concept of people-centred service in this study is grounded in the lived experiences of individuals with arthritis as they interact with healthcare services. Guided by the design thinking concept, this project aims to inform the development of more person-centred services for people with arthritis, which may contribute to improved user experience.

User-centredness is a key principle in design thinking, emphasising empathy and a deep understanding of users' needs (Brown, 2010). As Brown (2010) notes, meaningful solutions emerge when people are placed at the centre of the design process. Service design is an effective method to solve problems (Kimbell, 2011) and applies to public services (Stickdorn et al., 2018), including healthcare (Spacey, 2019). User-centred design is embedded within service design as a foundational approach, ensuring that services are shaped by the experiences, needs, and priorities of those who use them.

Service design focuses on improving existing services through co-creation with users (Stickdorn et al., 2018), while design thinking begins with redefining the problem through early user involvement (Brown, 2010) - both emphasise active participation from the outset. Value is not embedded in a tangible product but emerges through the experience of using the service. In healthcare, the participation of patients in shaping their care experience is fundamental to generating meaningful value. However, as Polaine et al. (2013) and Luther (2025) observe, traditional models of healthcare delivery have often prioritised operational efficiency and cost reduction, frequently at the expense of user experience. This reflects a misalignment between current system objectives and the principles of value creation in design thinking, where user experience should be considered a core outcome rather than a secondary concern. In design thinking, user experience functions as both an indicator and an enabler of value. Design thinking aims to improve or reinvent services by making them more effective and meaningful for both users and organisations through iterative, user-centred and co-creative processes (Stickdorn and Schneider, 2011). As emphasised by Brown and Katz (2019), better outcomes are achieved when users are treated as active participants rather than passive recipients. Consequently, understanding the user is not merely a preliminary step but a foundational principle in design thinking. Accurately capturing users' needs, habits, cultural backgrounds, and motivations enables the creation of solutions that are not only functional, but also emotionally resonant and contextually appropriate.

While design thinking and service design have distinct theoretical origins, their integration through interdisciplinary collaboration offers innovative research pathways for tackling complex healthcare challenges. In the context of this study, design thinking contributes creative problem-solving and user-centred exploration, while healthcare brings methodological rigour and clinical insight. This combined approach forms the basis for exploring how arthritis services might be reimagined to better reflect the needs and experiences of those who use them.

## 1.4 Research Methods

The research methods adopted in this study are guided by an interpretive phenomenological orientation, which prioritises understanding lived experiences as contextual, relational, and meaning-laden. Methodological decisions were therefore shaped by the need to remain open to participants' sense-making processes rather than to impose predefined theoretical or analytical structures. Within this orientation, design thinking is employed as a methodological approach that supports the exploration and organisation of multi-layered service experiences and facilitates holistic sense-making across service contexts. This section outlines how the systematic review, qualitative data collection, and analytical approaches were combined in alignment with the study's theoretical positioning and research aims.

In selecting an appropriate methodological approach, a range of qualitative approaches commonly used in healthcare research were considered, including interpretive qualitative inquiry and service-oriented analytical methods. The research aims required an approach capable of engaging with lived experiences across multiple service touchpoints and system levels. Design thinking supports integrative sense-making across these dimensions by enabling holistic framing and empathetic interpretation of interconnected service experiences. This alignment with the study's focus on understanding how people-centred care is experienced within complex arthritis healthcare services makes design thinking well suited to addressing the research aims.

This qualitative study explores people-centred care in arthritis healthcare services through a combination of a systematic review, qualitative data collection, and the application of multiple interpretative analytical approaches. The study is structured to develop a comprehensive understanding of existing knowledge and user perspectives, and to examine how design thinking contributes to sense-making within complex healthcare service environments.

### *Systematic Review*

A systematic review was conducted to identify and synthesise people-centred care elements in existing arthritis healthcare literature. Unlike a traditional literature review, a systematic review allows for a transparent, reproducible, and methodologically rigorous synthesis of peer-reviewed evidence (Moher et al., 2009). This approach was particularly important given the interdisciplinary nature of this research, which draws from health services, design studies, and social science. The systematic review synthesises how people-centred care has been conceptualised and operationalised within existing arthritis healthcare literature, contributing to a comprehensive understanding of the field. The insights generated through the review inform the research context and support the articulation of research aims, offering an evidence-informed backdrop against which participants' experiences are explored. The peer-reviewed paper has been published outlining the findings and significance of the systematic review (see Appendix H).

### *Qualitative Data Collection*

To capture first-hand experiences and perspectives of people with arthritis, semi-structured interviews were conducted. Participants were recruited through LinkedIn, Twitter, Facebook arthritis support groups, and the Arthritis Action website. An open-ended, empathy-led interview guide was used to encourage participants to share their lived experiences, needs, and reflections in their own words. This approach enabled the generation of rich, in-depth accounts aligned with the people-centred focus of the study.

### *Data Analysis*

Data analysis included an interpretative phenomenological approach during the thematic analysis phase to explore how participants make sense of their lived experiences in arthritis healthcare services. Thematic analysis allowed for in-depth insights into the subjective and emotional dimensions of these experiences. In parallel, framework analysis was employed to develop a user experience framework, providing a structured synthesis of key patterns across the data. To support interpretation, a user journey map was developed to visually represent individuals' experiences across the care continuum, and to identify the challenges and needs encountered throughout their healthcare journeys.

By combining systematic review, qualitative inquiry, and structured analytical methods, this study provides a robust methodological framework for investigating people-centred care in arthritis healthcare services.

## 1.5 Research Significance and Contributions

This research seeks to contribute to the growing field of people-centred care in arthritis healthcare by bridging gaps between existing knowledge, patient experiences, and innovative approaches to service design. In view of the increasing recognition of the importance of aligning healthcare delivery with the lived realities of individuals, this study positions itself to offer meaningful insights into how arthritis care can become more responsive, inclusive, and user focused.

By drawing on both systematic review and qualitative inquiry, the study is situated to provide a multi-layered understanding of the experiences, needs, and interactions of people with arthritis within arthritis care. The findings from this study will inform theoretical discussions concerning user experience in arthritis management, while also addressing practical considerations related to healthcare design and service development.

Moreover, this study explores the potential of visual and design-led methodologies, such as user journey mapping and design thinking, to deepen understanding of healthcare delivery from the perspectives of people with arthritis. In doing so, the study aspires to contribute to interdisciplinary dialogue at the intersection of health research, service innovation, and design practice.

This research, which centres on the perspectives of people with arthritis and collaborative approaches to problem-solving, is expected to inform not only academic discourse but also the work of healthcare practitioners, policymakers, hospitals, and community-based organisations dedicated to improving arthritis care. In this way, the study anticipates making a broader contribution to the advancement of people-centred approaches within the context of arthritis and long-term care.

## 1.6 Target Audience

This research is intended to engage a diverse yet interconnected audience spanning academic, professional, and policy domains. At its core, the study speaks to scholars and researchers in the fields of health services research, medical sociology, and design studies, particularly those interested in people-centred approaches to healthcare, qualitative methodologies, and lived experience.

Beyond the academic community, this research is directed towards healthcare practitioners and service designers who are actively involved in shaping and delivering arthritis care. By offering insights into the experiences of people with arthritis and exploring the use of user journey mapping and design thinking, the study aims to inform practice-oriented innovation and support more empathetic and responsive service models across clinical, hospital, and community-based settings.

Policymakers and health system leaders constitute another key audience. The study's findings have the potential to inform the development of policies that promote user engagement, shared decision-making, and inclusive service delivery. By grounding these insights in lived experience, the research aspires to support ongoing efforts to make health systems more adaptable to the complex needs of people living with arthritis.

Finally, this research is of relevance to advocacy groups and third-sector organisations that support people with arthritis. By foregrounding the voices of people with lived experience and illuminating barriers within the healthcare journey, the study contributes to broader advocacy for equitable, people-centred care.

In bringing together these varied perspectives, the research aims to foster dialogue and collaboration across disciplines and sectors, thereby supporting the development of more humane and effective healthcare systems.

## 1.7 Ethical Considerations

Ethical approval for this research was obtained from Birmingham City University's Ethics Committee (see Appendix A). All participants provided informed consent, and procedures were followed to ensure confidentiality, voluntary participation, and the right to withdraw. The study was conducted in line with ethical standards for research involving human participants (World Medical Association, 2013).

## 1.8 Thesis Structure

This thesis is structured to systematically explore people-centred care in arthritis healthcare services, integrating a systematic review, qualitative research, and design thinking approaches. The chapters are organised as follows:

*Chapter 1: Introduction*

This chapter introduces the background and rationale for the research, outlining the importance of people-centred care in arthritis healthcare services. Introduction chapter defines the research questions, objectives, and methodological approach of the study.

*Chapter 2: Systematic Review*

This chapter presents a systematic review of existing literature on people-centred care in arthritis healthcare services. Systematic review chapter identifies key elements, challenges, and gaps in current healthcare models, serving as the foundation for the qualitative study. The findings from this review inform the research design and help contextualise user perspectives.

### *Chapter 3: Methodology*

This chapter outlines the research design, data collection methods, and analytical strategies used in the study. Methodology chapter describes the integration of semi-structured interviews, thematic analysis guided by an interpretative phenomenological approach, framework analysis, and user journey mapping. The chapter also discusses the philosophical foundations that underpin the methodological choices. In addition, the chapter details ethical considerations, participant recruitment procedures, and the strategies employed to ensure the rigour and credibility of the qualitative data.

### *Chapter 4: Data Analysis*

This chapter presents the process of qualitative data analysis, exploring participants' experiences, perceptions, and interactions with arthritis healthcare services. The data analysis chapter applies framework analysis in combination with user journey mapping and thematic analysis to categorise key insights and to illustrate care pathways and service interactions.

### *Chapter 5: Findings*

This chapter introduces the people-centred care framework and presents the key people-centred elements in arthritis healthcare services from the user perspective. The framework, derived from the framework analysis, provides a structured representation of how people with arthritis experience and engage with healthcare services across different stages of their care journey. In parallel, the thematic analysis identified core people-centred elements as defined by participants themselves, offering insight into the values, expectations, and relational dimensions that shape their experiences. This chapter focuses on capturing user-defined aspects of people-centred care.

### *Chapter 6: Discussions*

This chapter critically examines the findings in relation to existing literature, research objectives, and theoretical frameworks. The discussion chapter discusses the alignment and divergence between systematic review findings and user perspectives, explores how design thinking and interdisciplinary collaboration contribute to people-centred care, and reflects on the practical and theoretical implications of the developed framework.

*Chapter 7: Conclusion*

The final chapter summarises the key contributions of the study, discusses theoretical and practical implications, and provides recommendations for future research and practice. Conclusion chapter also acknowledges the limitations of the study and suggests potential directions for further exploration in people-centred healthcare and service innovation.

This structured approach ensures a logical flow from theoretical foundations to empirical findings, leading to a comprehensive discussion and practical recommendations.

## 1.9 Summary

This chapter has outlined the context, aims, and methodological direction of the study, highlighting the growing relevance of people-centred care in arthritis services. The chapter outlined the significance and limitations of current healthcare systems in delivering responsive, coordinated, and holistic care, and considers the role of self-management. Focusing on the relevance of interdisciplinary approaches which combines systematic review, qualitative data, interpretative data analysis approaches from life sciences and design thinking, the chapter provides the foundation for a people-centered arthritis healthcare service. The introduction chapter ends with the thesis structure. To establish a foundation for the empirical enquiry, the next chapter presents a systematic review of existing literature on people-centred care in arthritis healthcare.

# Chapter 2: Systematic Review

## 2.1 Introduction

This chapter presents a systematic review that examines the core elements of people-centred care within arthritis services. In the context of continued concern for the quality of chronic illness care, an increasing number of studies call for evidence-based approaches to promoting people-centred models of arthritis services. While people-centredness has been increasingly promoted in chronic disease management, there remains limited clarity regarding how this concept is operationalised in the context of arthritis care, particularly in terms of specific service features, interactions, and delivery models.

The systematic review is a key method for synthesising the state of knowledge within a specific field (Page et al., 2021). The systematic review is characterised by the use of explicit, systematic, and replicable procedures to identify primary studies that meet predefined criteria, followed by critical appraisal and integration of their findings (Pollock and Berge, 2018). Compared with traditional literature reviews, systematic reviews are guided by clearly formulated research questions and follow a standardised process to collect and synthesise relevant evidence as comprehensively as possible (Aromataris and Pearson, 2014). Systematic review minimises bias, enhances the reliability of conclusions, and improves the transparency of research (Aromataris and Pearson, 2014). In health research, systematic reviews provide a robust foundation for decision-making grounded in the best available evidence. They not only enable the synthesis of data across multiple studies to produce new, overarching conclusions, but also facilitate the integration of diverse forms of evidence to explore the underlying meaning of complex phenomena (Pollock and Berge, 2018). Therefore, systematic reviews are applicable not only to questions concerning the effectiveness of interventions, but also serve as a credible knowledge base for theory building and practical improvement in the design of complex health services and policies

(Aromataris and Pearson, 2014).

The aim of this review is to identify and synthesise the key components that constitute people-centred care from the perspectives of both service users and providers. By focusing on qualitative evidence, the review brings lived experiences and user-defined priorities to the foregrounds, offering a conceptual foundation for the empirical design and analysis in later chapters. The main objective is to identify the key elements and current status of health services centred around people with arthritis. The aim of this chapter is to answer the following research question: *What are the critical people-centred factors of the healthcare service for people with arthritis?*

This review adopts a qualitative systematic review approach, specifically employing synthesis (Dixon-Woods et al., 2005), to explore the people-centred elements within arthritis services. This method was chosen to enable a deeper understanding of the subjective and contextual dimensions of people-centred care. Qualitative synthesis is particularly well suited to research in service design, where meaning, experience, and implementation are central concerns (Thomas and Harden, 2008). The reporting of this review followed the PRISMA 2020 guidelines (Page et al., 2021) to enhance transparency and clarity, as PRISMA was applied solely as a reporting framework. The actual conduct of the review was guided by principles of qualitative evidence synthesis and theoretical aggregation methods (Thomas and Harden, 2008), ensuring a rigorous and conceptually driven process.

The chapter proceeds by outlining the review methodology, presenting the main findings, and discussing the implications of these findings for people-centred service innovation and research.

## 2.2 Method

This chapter reports a systematic review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Framework. Systematically searching relevant databases aims to identify relevant research on people-centred healthcare services. Subsequently, further selection, analysis, and literature summary are conducted to summarise the current research status of people-centred healthcare services comprehensively.

### 2.2.1 Search Strategy

The keywords related to people-centred services for people with arthritis were informed by the key literature and models of people-centred care in arthritis. Three searches were conducted using key search terms (see Table 2.1, Table 2.2, and Table 2.3). The first row of Table 2.1 (below) covers the central idea of the research. The second and third rows contain relevant keywords used to identify the fields of arthritis and healthcare services. The fourth and fifth rows determine the specific coverage directions that must be studied. In the other two searches, Table 2.2 (below) and Table 2.3 (below), the first row also proposes people-centred research. The second row restricts the type of arthritis in healthcare services, and the third row is about determining the specific scope of research and practice. The results of all three searches were pooled, and all eligible studies identified from these combined searches were included for screening and full-text review. As this is an interdisciplinary research, the above search strings were entered and retrieved in the following databases: Scopus, Web of Science, Medline, PubMed, Psych info, and Cinahl. Although no design-specific databases were searched independently, Scopus and Web of Science were purposefully selected as they index a wide range of interdisciplinary journals, including those in design studies, service design, and design thinking. As this is a paper published in English, the inclusion criteria included service for the management of arthritis, written in English and published between 2011 and 2025.

*Table 2.1 First Search Terms and the Search String*

| Search Lines | Search Terms | Filtered by |
|---|---|---|
| 1 | "People-centred" OR "patient-centred" OR "human-centred" OR "person-centred" OR "humanity-centred" | Title/Abstract/Keywords |
| 2 | "arthritis" OR "Osteoarthritis" OR "Rheumatoid Arthritis" | Title/Abstract/Keywords |
| 3 | "arthritis service" OR "arthritis care service" OR "NHS" OR "National Health Service" | Title/Abstract/Keywords |
| 4 | "product" OR "process" OR "care" OR "support" | Title/Abstract/Keywords |
| 5 | "feedback" OR "improvement" OR "levels of service" OR "service levels" | Title/Abstract/Keywords |

*Table 2.2 Second Search Terms and the Search String*

| Search Lines | Search Terms | Filtered by |
|---|---|---|
| 1 | "people-centred" OR "human-centred" OR "person-centred" | Title/Abstract/Keywords |
| 2 | "arthritis care" OR "arthritis" | Title/Abstract/Keywords |
| 3 | "healthcare" OR "self-care" | Title/Abstract/Keywords |

*Table 2.3 Third Search Terms and the Search String*

| Search Lines | Search Terms | Filtered by |
|---|---|---|
| 1 | "people-centred" OR "patient-centred" OR "person-centred" OR "patient preference" OR "client identified" | Title/Abstract/Keywords |
| 2 | "arthritis" OR "arthritis care" | Title/Abstract/Keywords |
| 3 | "service" OR "development" OR "value" | Title/Abstract/Keywords |

### 2.2.2 Inclusion and Exclusion Criteria

This systematic review focuses on providing people-centred services for people with arthritis. Therefore, it was essential to determine whether each study explicitly focused on people with arthritis as the primary population of interest, and whether the study included a clear discussion, evaluation, or development of people-centred service models or approaches relevant to their care.

The researcher developed selection criteria based on expert knowledge and with reference to key papers in the relevant topic area. This review has three inclusion criteria and two exclusion criteria (see Table 2.4). The inclusion criteria were defined as follows: studies must (1) focus on people-centred services; (2) specifically target individuals with arthritis; and (3) be published in English. Studies were excluded if they (1) focused on chronic diseases in general, including arthritis, without specifically targeting arthritis as the primary condition; or (2) addressed treatment techniques or medical interventions rather than healthcare services or care delivery. There are no geographical restrictions for this review.

***Table 2.4 Studies Selection Criteria for Systematic Review***

| Selection Types | Selection Criteria |
|---|---|
| **Inclusion** | (1) focus on people-centred services;<br>(2) specifically target individuals with arthritis;<br>(3) be published in English. |
| **Exclusion** | (1) focused on chronic diseases in general, including arthritis, without specifically targeting arthritis as the primary condition;<br>(2) addressed treatment techniques or medical interventions rather than healthcare services or care delivery. |

### 2.2.3 Study Selection

For each study, results related to key factors of people-centred services, delivery platform and service delivery were extracted. Numerous studies focus on the statistics and analysis of nursing issues or clinic treatments for arthritis patients. The main focus of this research is to analyse existing nursing services or to identify directions for future development. Nevertheless, all studies are based on how they define people-centred services and, in addition, analyse whether services or care conform to the characteristics of people-centredness. Therefore, the study will encode the critical points of the people-centred factors they specifically analysed. In addition, it encodes the study's delivery methods and results of care and services. This data will specifically analyse the form in which people-centred services are delivered, as well as the effectiveness and main obstacles of transmission.

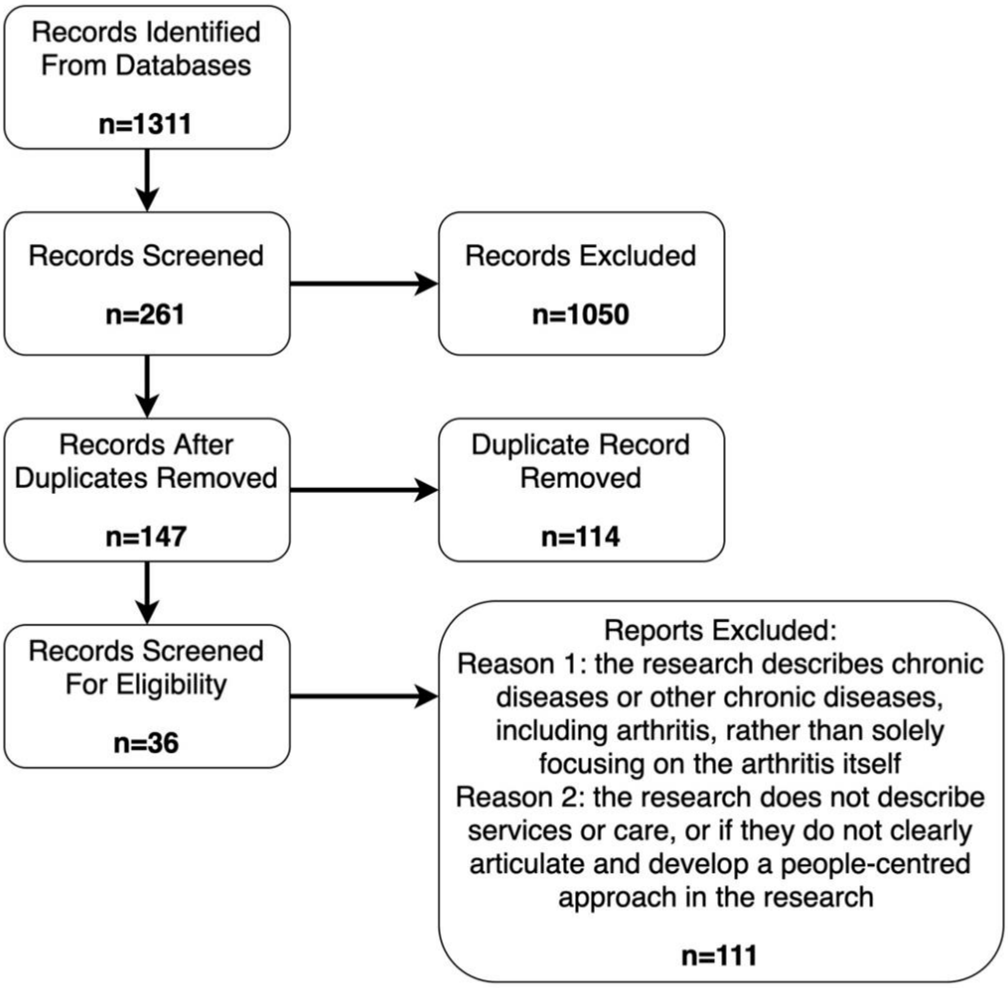
### 2.2.4 Analytic Strategy

This review adopts the research method of theoretical synthesis. Following Thomas and Harden's (2008) method for thematic synthesis, a line-by-line coding of the results sections of included studies was conducted. Initial codes were generated inductively based on recurring patterns related to people-centred care features. These codes were then grouped into descriptive themes through constant comparison. Finally, three overarching analytical themes emerged, representing key domains within people-centred healthcare services: (1) core elements of service design, (2) service delivery platforms, and (3) perceived outcomes of care. These themes were not predetermined but developed iteratively through the coding process, guided by both the review aim and recurring patterns in the data.

## 2.3 Result

A total of 1311 records were retrieved across all databases. After removing duplicates (n = 1050), 261 unique records remained for title and abstract screening. Based on the inclusion and exclusion criteria, 147 articles were selected for full-text review. Following full-text screening, 36 articles met all criteria and were included in the final synthesis (see Figure 2.1). All screening and selection decisions were conducted independently by the lead author. To ensure consistency and transparency, a predefined set of inclusion and exclusion criteria was strictly applied at each stage of the screening process. Ambiguous cases were carefully reviewed against the criteria, and decisions were documented to maintain a clear audit trail.

*Figure 2.1 Flowchart of the Review Process*



### 2.3.1 Introduction to Included Studies

A total of 36 studies met the inclusion criteria and were included in this review. The studies spanned a range of countries, with the majority conducted in UK, Europe, Australia, Canada. Most studies adopted qualitative methodologies, including interviews, focus groups, and ethnographic observations, while a smaller number employed mixed methods designs. The participant groups primarily consisted of individuals living with arthritis and healthcare professionals involved in their care.

### 2.3.2 Data Extraction Table

To systematically identify and synthesise the core elements and findings related to people-centred care in the included studies, a data extraction table was developed (see Table 2.5). This table summarises key information from each study, including basic study characteristics, research design, data sources, study aims, and key findings related to people-centred care. The data extraction table serves to highlight the main concerns and principal conclusions of different studies in relation to people-centred care practice, thereby providing a foundation for subsequent comparative analysis and synthesis.

*Table 2.5 Data Extraction Table for Studies on People-Centred Care*

| Author (Year) | Country | Study Type | Study Design | Data Source(s) | People- Centred Focus / Aim | Key Findings Related to People-Centred Care |
|---|---|---|---|---|---|---|
| **Bergsten et al. (2011)** | Sweden | Empirical | Qualitative (Grounded Theory) | Interviews with 18 healthcare providers | To explore healthcare providers' experiences of their interaction with patients in managing RA | Patient education and rehabilitation; Patient Involvement; Medical staff failed to communicate with patients, and there were difficulties in dialogue and interaction, which patients described as a failure. |
| **Gagliardi et al. (2011)** | Canada | Protocol | Realist Review | Literature review (1995–2010), stakeholder consultations in arthritis | To develop a conceptual framework for patient-mediated knowledge translation interventions to enhance patient-centred care | Evidence suggests that informing, educating, and supporting patients to engage in their own healthcare leads to improved utilization and outcomes. |
| **Betteridge et al. (2016)** | Europe | Expert Opinion | Multidisciplinary consensus | Expert panel discussions, literature review | To identify barriers to optimal care in psoriatic arthritis (PsA) and propose patient-centred strategies to improve management | individualized according to their symptoms and predominant pattern of disease; Improving a patient's knowledge; patient using shared decision-making tools. |
| **Blome et al. (2016)** | Multi-country | Empirical | Mixed Methods | Qualitative interviews with 120 patients; Pilot testing (n=55); Validation survey (n=203) | Develop and validate a patient-centred questionnaire capturing treatment goals and needs of patients with nail psoriasis | Doctors and patients work together to meet the needs of patients; |
| **Chou et al. (2017)** | Australia | Conceptual | Narrative Review / Commentary | Literature synthesis informed by a systematic scoping review | Exploring patient-centered management in inflammatory arthritis emphasizing the need to go beyond disease control, respond to the broad health and lifestyle needs of patients, and propose a more humane service improvement path. | patient participation in decision-making; hope to receive education about my own illness and potential therapies; Shared decision-making, digital health tools, peer support, flexible service models (such as telemedicine) |

| Author (Year) | Country | Study Type | Study Design | Data Source(s) | People- Centred Focus / Aim | Key Findings Related to People-Centred Care |
|---|---|---|---|---|---|---|
| **Ammerlaan et al. (2017)** | Netherlands | Empirical | Qualitative + Concept Mapping | Online focus groups, consensus meetings, card sorting, hierarchical cluster analysis | To investigate patient preferences and needs regarding the structure and content of a person-centred online self-management support program for people with rheumatic diseases | patients with RA have informational, emotional, social and practical support needs; an individualised approach; |
| **Ammerlaan et al. (2017)** | Netherlands | Empirical | Reflective Practice / Case-Based | Patient stories, stakeholder collaboration, reflective narrative, implementation experiences | Explore young adults' needs in transitional care for JIA and reflect on health professionals' roles in supporting patient-centred care and self-management | Lack of communication and coordination |
| **de Souza et al. (2017)** | UK | Case Study | Qualitative | Patient feedback, educational program participation, mobile app usage data | To develop patient-centred strategies to enhance rheumatology outpatient services through active patient involvement | involve patients; Education can empower patients to self-manage their condition; Mobile applications can enhance self-care and improve patient treatment outcomes |
| **Geenen et al. (2018)** | Europe | Review | Systematic Review of Reviews | 186 included systematic reviews and meta-analyses | To develop evidence-based recommendations for pain management in IA and OA with a patient-centred, biopsychosocial perspective | take account of their expectations and preferences for treatment; individuals differ widely in terms of management needs. |
| **Bala et al. (2018)** | Sweden | Empirical | Cross-sectional measurement study | Questionnaire survey among 343 RA patients at 6 nurse-led outpatient rheumatology clinics (part of BARFOT study) | Develop and validate the metrological characteristics of PCCoc/rheum tools to evaluate patients' perceived level of patient-centered care, based on the PCC conceptual framework centered on outpatient meetings between nurses and RA patients | personalise care; Social environment, personalization, shared decision-making, empowerment, and communication |

| Author (Year) | Country | Study Type | Study Design | Data Source(s) | People- Centred Focus / Aim | Key Findings Related to People-Centred Care |
|---|---|---|---|---|---|---|
| **Bala et al. (2018)** | Sweden | Instrument development study | Mixed Methods | Secondary analysis of existing interview data with RA patients;item testing and evaluation interviews with 50 patients attending nurse-led rheumatology clinics | To conceptualize and operationalize person-centred care (PCC) in nurse-led outpatient rheumatology clinics and to develop and preliminarily validate a patient-reported measurement instrument (PCCoc/rheum) | Patients actively participate in their care and decision-making processes; Personalisation, Coordination; Social environment, personalisation, shared decision-making, empowerment, and communication |
| **Hall et al. (2018)** | Canada | Review | Narrative Review | Literature from the past 5 years reporting on patient satisfaction and/or health economic outcomes in multidisciplinary care models involving allied health professionals | To evaluate patient satisfaction and economic outcomes associated with multidisciplinary care models in rheumatology, particularly those involving nurses and pharmacists | patient education; patient satisfaction; psychosocial support; Coordinated nursing |
| **Segan et al. (2018)** | Multi-country | Review | Scoping review | Peer-reviewed publications from MEDLINE, EMBASE, CINAHL, PsycINFO (1990–2016) | To identify and synthesise existing literature on patient-perceived needs related to non-pharmacologic health services in inflammatory arthritis, with emphasis on communication, follow-up care, healthcare access, and use of allied health and complementary/alternative medicine (CAM) | Patients valued positive interactions and relationships with their healthcare providers; follow-up care included adequate consultation time, proximity of care, continuity of care and timely referral to specialists; Patients may require education around changes to models of care |

| Author (Year) | Country | Study Type | Study Design | Data Source(s) | People- Centred Focus / Aim | Key Findings Related to People-Centred Care |
|---|---|---|---|---|---|---|
| **Vodopivec and Vrijhoef (2019)** | Multi-country | Review | Descriptive Analysis | 50 peer-reviewed articles (2013–2018) from Cochrane, PubMed, and EMBASE databases | To provide an overview of integrated care models for patients with rheumatoid arthritis, focusing on strategies and interventions used in designing and implementing these models, and their outcomes | Patient empowerment, engagement and experience of care; social support; empowering and engaging people, strengthening governance and accountability, reorienting the model of care, coordinating services, creating an enabling environment. |
| **Lopatina et al. (2019)** | Canada | Empirical | Case Study | Document review, focus groups, interviews, stakeholder meetings | Explore how patient voices were incorporated into the redesign of a centralized intake system for RA referrals from primary care | Long term and continuous follow-up |
| **Lange et al. (2019)** | Sweden | Empirical | Qualitative Study | Participants from the intervention arm of a randomized controlled trial conducted in 2015–2016 | Explore aspects of participation in moderate- to high-intensity exercise with person-centred guidance influencing the transition to independent exercise among older adults with RA | shared decision making; |
| **Gabriel et al. (2019)** | UK | Empirical | Comparative cohort (retrospective analysis) | Patient-reported outcomes and cost data across two surgical care pathways (n=50) | To assess whether redesigning hip OA surgical pathways using value-based healthcare (VBHC) principles can improve value | Better communication and teamwork among doctors |
| **Hammer et al. (2020)** | Denmark | Empirical | Cross-Sectional Survey | Online questionnaire (n=664 patients with RA, PsA, axial SpA) | To explore preferences for self-management and support services in patients with inflammatory joint disease (IJD), and whether preferences differ by age, sex, diagnosis, and disease duration | Self-management interventions and patient education that involve patient participation in disease management, improvement of mental health, coping abilities, and health promoting behaviors; personalisaiton. |

| **Author (Year)** | **Country** | **Study Type** | **Study Design** | **Data Source(s)** | **People- Centred Focus / Aim** | **Key Findings Related to People-Centred Care** |
|---|---|---|---|---|---|---|
| **Brkic et al. (2021)** | Norway | Conceptual | Mini review / Conceptual Model | Literature review, healthcare system data, conceptual modeling | To propose a decentralized, patient-centered lifelong treatment model for RA outpatient management in Norway | Remote healthcare strategy can reduce the number of traditional face-to-face visits |
| **Sweeney et al. (2021)** | Multi-country | Review | Thematic Synthesis | 8 qualitative studies (2010–2019), 133 early RA patients | Explore patient perspectives on nurse-led care in early rheumatoid arthritis | good communication skills and friendly environment; having patients as individuals with unique needs, concerns |
| **Fairley et al. (2021)** | Multi-country | Review | Scoping Review | 31 included studies; sourced from MEDLINE, EMBASE, CINAHL, PsycINFO (1990–2020) | Identify and synthesize non-healthcare needs perceived by people with osteoarthritis (OA) and inflammatory arthritis (IA) to inform person-centred care | social support and social needs |
| **Doumen et al. (2021)** | Belgium | Empirical | Qualitative | 5 focus groups (2 with nurses, 2 with patients, 1 with rheumatologists; total n = 42) | Explore stakeholders' perceptions of the advantages, disadvantages, and conditions for implementing nurse-led clinics (NLCs) in RA care, with a focus on their person-centred potential. | Provide education to patients on their condition, medication adherence, and adverse reactions |
| **Tvedten et al. (2021)** | Australia | Empirical | Qualitative | interviews with 29 patients; participatory research with a team including patients, clinician, nurse, researcher | Explore the implicit patient-centred intentions of providing personalised written consultation summaries in rheumatology care | Personalized written information; Maintain health education; patient participation; Continuity of Information and Security of Continuous Management |
| **Cozad et al. (2022)** | USA | Review | Systematic Review | 28 mobile health apps available in the U.S. app stores | Evaluate the extent to which mobile health apps for rheumatoid arthritis support patient-centered care through engagement and activation features | Patients and healthcare providers jointly participate in decision-making at the point of care; |

| Author (Year) | Country | Study Type | Study Design | Data Source(s) | People- Centred Focus / Aim | Key Findings Related to People-Centred Care |
|---|---|---|---|---|---|---|
| **van Slingerland et al. (2022)** | Netherlands | Empirical | Cross-sectional survey | PCCoc/rheum instrument, Self-Management Web questionnaire | To explore patient-perceived levels of and needs for person-centered care (PCC) in inflammatory arthritis patients visiting nurse practitioners (NPs) | Communication, social environment, personalization, shared decision-making, and empowerment; improve communication; |
| **Feddersen et al. (2022)** | Denmark | Empirical | Qualitative (Longitudinal Semi-structured Interviews) | Interviews conducted at three time points | To explore perceived barriers and facilitators to coherent rehabilitation pathways for individuals with inflammatory arthritis, emphasizing the role of person-centred care in enhancing coherence | focusing on the individual's needs, preferences and values; Coordination and communication between professionals; consultation time; Personalised care; patient satisfaction; patient education |
| **Andev et al. (2023)** | UK | Empirical | Quantitative Survey | Online anonymised survey of 316 adults with RA or AJIA (July 2021) | To understand the experiences of people with RA and AJIA regarding healthcare access and delivery changes during COVID-19 | education and supported self-management; Patient education; Virtual medicine is likely to lead to some degree of inaccuracy; Increase consultation time; More advanced technology |
| **Abenoja et al. (2023)** | USA | Review | Rapid Review | 11 empirical studies (quantitative and mixed methods), 2010–2021 | Identify updated strategies (post-2010) to support equitable, person-centred early OA diagnosis and management for disadvantaged groups, including women | shared decision-making; A method to meet the needs and preferences of different groups |
| **Van Slingerland et al. (2023)** | Netherlands | Empirical | Mixed Methods | Quantitative: Online patient-reported outcome measures; Qualitative: Open-ended responses on goal-setting experiences | Evaluate the effect of a goal-setting strategy with integrated feedback on goal attainment and health-related quality of life (HRQoL) in patients with inflammatory arthritis | Nursing that focuses on individual patient needs; The preferences, needs, and values of patients should guide clinical decision-making. |

| Author (Year) | Country | Study Type | Study Design | Data Source(s) | People- Centred Focus / Aim | Key Findings Related to People-Centred Care |
|---|---|---|---|---|---|---|
| **Gagliardi et al. (2023)** | Canada | Empirical | Qualitative | Interviews with 27 diverse women with osteoarthritis and 31 healthcare professionals | Explore strategies to overcome barriers to equitable, timely, person-centred osteoarthritis care for diverse women | Establishing a healing relationship; Shared decision-making; Responding to or managing emotional reactions |
| **Abuwa et al. (2023)** | Canada | Review | Content Analysis | 36 osteoarthritis (OA) clinical guidelines published between 2003 and 2021 | Examine the extent to which OA guidelines provide guidance on equitable, person-centred care for disadvantaged groups, including women | Develop a multi-pronged action plan based on patient needs; Continuous monitoring and follow-up to evaluate the status and goals of osteoarthritis; OA information and support must be tailored to individual needs. |
| **Sweeney et al. (2023)** | UK | Empirical | Qualitative | Semi-structured interviews with 16 rheumatology nurse specialists in England | To develop an understanding of what comprises nurse-led care in early rheumatoid arthritis from the perspective of rheumatology nurse specialists in England. | Education and support; Satisfy social and psychological needs; Coordinated nursing; importance of carefully listening to the patient's voice. |
| **Codd et al. (2023)** | Australia | Empirical | Mixed Methods | Patient-reported outcome measures and semi-structured interviews | Explore how a multidisciplinary-led early arthritis service addresses client-identified participation needs | Personalised approach; long-term support; Emphasise participation; |
| **Drake af Hagelsrum et al. (2023)** | Sweden | Empirical | Qualitative | Semi-structured interviews with 20 RA patients | Explore patients' perceptions of lifestyle discussions in early rheumatology care | Educate patients; Personalised lifestyle information; 50-60% of patients not only need more information, but also hope that this information can be personalised and customised |

| Author (Year) | Country | Study Type | Study Design | Data Source(s) | People- Centred Focus / Aim | Key Findings Related to People-Centred Care |
|---|---|---|---|---|---|---|
| **Blum et al. (2024)** | Denmark | Empirical | Qualitative | Semi-structured interviews with 15 patients who participated in the INSELMA intervention | Explore patients' experiences of participating in the INSELMA nurse-coordinated multidisciplinary self-management intervention for inflammatory arthritis | Personalised exercise plan; Continuous care; The initial consultation should be conducted face-to-face to establish a confidential relationship. For participants with diverse symptoms, long schedules, or busy work schedules, they prefer telephone follow-up. |
| **Landgren et al. (2024)** | Sweden | Empirical | Qualitative (Phenomenographic approach) | Semi-structured interviews with 31 patients (22 women, 9 men; aged 38–80) diagnosed with early RA (<1 year) and treated with DMARDs for 3–7 months | Describe patients' understanding of health in early RA to inform person-centred care | shared decision-making; Empower patients and approach from their perspective |

### 2.3.3 Overview of Results to be Presented

The findings of the included studies were synthesised thematically and are presented across three overarching themes: (1) core elements of person-centred service design, (2) service delivery platforms, and (3) perceived outcomes of care. These themes reflect recurring patterns and concepts related to how people-centred care was conceptualised and implemented across different contexts. Each element is described in detail in the following sections, with illustrative data and interpretations.

### 2.3.4 Key People-Centred Elements of Arthritis Healthcare Services

Within the papers under review, multiple themes emerged, including patient participation in decision-making, patient education, increased consultation time, use of better technology, patient classification, communication skills, social environment, personalisation, emotional needs, long-term continuous care, and strengthening coordination and accountability (see Table 2.6).

***Table 2.6 Critical Elements of People-Centred Healthcare Services***

| Key Elements | Number of Papers |
|---|---|
| **Patient Participation in Decision-Making** | 19 |
| **Patient Education** | 13 |
| **Increased Consultation Time** | 3 |
| **Use of Better Technology** | 3 |
| **Patient Classification** | 2 |
| **Communication Skills** | 6 |
| **Social Environment** | 6 |
| **Personalisation** | 15 |
| **Emotional Needs** | 4 |
| **Strengthening Coordination and Accountability** | 7 |
| **Long-Term Continuous Care** | 7 |

The results of this systematic review broadly align with the five strategic directions outlined by WHO for advancing people-centred and integrated health services (WHO, 2015). For example:

Empowering and engaging people refers to enabling individuals to take an active role in their health and care (WHO, 2015). This principle is reflected in several key elements: patient participation in decision-making, commonly referred to as shared decision-making, which denotes a collaborative process whereby patients and clinicians jointly develop a treatment plan that integrates evidence-based information, clinical expertise, and the patient's preferences, values, and goals (Morrison et al., 2022); patient education, encompassing all educational activities provided to patients, including therapeutic education, health education, and health promotion (Zangi et al., 2015); and personalisation, which involves tailored care planning by healthcare professionals to address the specific needs of individual patients (Coulter et al., 2015).

Strengthening governance and accountability refers to promoting transparent decision-making processes and ensuring shared responsibility among service managers and providers (WHO, 2015). Coordinating services aims to integrate care across all levels and sectors to address fragmentation and improve quality, continuity, and emergency response capacity (WHO, 2015). These two principles are reflected in several key elements: strengthened coordination and accountability, which entails the provision of services by multiple care providers in a timely and complementary manner to achieve connected and cohesive care for patients (Langberg et al., 2019); and long-term continuous care, which should commence from the initial point of contact between people with arthritis and the healthcare system, continue through the first consultation with health professionals, be sustained through ongoing follow-up with the health professionals team (Lopatina et al., 2019).

Reorienting the model of care focuses on strengthening community-based services and cross-sector collaboration (WHO, 2015). This principle is reflected in the following key elements: use of better technology, which facilitates improved access to services and online peer support platforms for people with arthritis (Saraux et al., 2024); patient classification, defined as the extent to which patients perceive their needs to be met (Hall et al., 2018); and increased consultation time, which reflects a frequently expressed need among people living with arthritis (Segan, 2018).

Creating an enabling environment aims to drive systemic reform through changes in legislation, financing, policy, and workforce development (WHO, 2015). This principle is reflected in following key elements: social environment, which plays a critical role in fostering healthcare and broader social conditions that support symptom management and the capacity for effective self-management of long-term conditions (Fairley et al., 2021); and communication skills, as poor communication can hinder mutual understanding and trust (Fusam et al., 2024), while open and explicit two-way dialogue is regarded as essential for establishing meaningful engagement (van Eijk-Hustings et al., 2013).

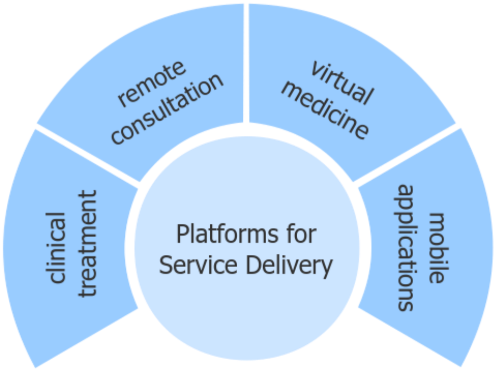
In addition, emotional needs represent a further key element, as addressing these needs can help alleviate the fear and anxiety that often arise from overwhelming emotional distress during treatment (Langberg et al., 2019).

This alignment demonstrates how practical, ground-level service elements reflect broader strategic aims, providing an evidence base for operationalising these directions in arthritis care.

### 2.3.5 Platforms for Service Delivery

Optimising how healthcare systems meet the needs of people with arthritis is a fundamental goal and one of the key principles of people-centred comprehensive care (Vodopivec and Vrijhoef, 2019). The survey results indicate that using the “right place, right time” approach can solve customer engagement-based issues and improve customer health and satisfaction outcomes (Codd, 2023). The defined functions of this service include “right place, right time” access to provide people-centred interventions to manage participatory issues and improve the health and satisfaction outcomes of service users (Codd, 2023). The survey results indicate that this is a reliable method to address the health, and broader lifestyle impacts of arthritis in clinical service provision (Codd, 2023). The people-centred nursing approach is now considered a fundamental component of nursing models, clinical guidelines, and medical safety and quality guidelines (Segan et al., 2018). One-third of people-centred services are delivered in clinical treatment. Three studies discussed remote consultation, virtual medicine, and mobile applications (see Figure 2.2). According to the National Health Service regulations, transformative outpatient care, including virtual consultation, will continue (Andev, 2023). In the study proposed by De Souza (2017), they simultaneously provided services to their patients through clinics, websites, and apps. Patients are interested in helping shape the services they receive during this process. They have played an essential and positive role in promoting changes in outpatient services and improving patient education/self-management (De Souza, 2017). A people-centred conceptual outpatient framework may also influence education and policy formulation by conveying more engaging, humanistic, and ethical perspectives that promote active and healthy living and reduce reliance on expert care (Segan et al., 2018).

***Figure 2.2 Platforms for Service Delivery***



### 2.3.6 Results of service delivery

In various studies, patients reported negative reputations for general healthcare and social support and unpleasant experiences with professionals (Feddersen et al., 2022).

The time and professional knowledge required for people-centred health services to function, the belief of clinical doctors and managers that patients are unable to make influential contributions, and the reputation threat to the organisation caused by sharing the organisation's shortcomings and difficulties with service users (De Souza, 2017). The treatment plan may demonstrate positive effects in the limited context of evaluating its research. However, it must provide a wide range of positive outcomes to benefit patients on a larger scale (Vodopivec and Vrijhoef, 2019). A key aspect of arthritis patient care is recognising joint inflammation, especially detecting low-grade synovitis, usually identified through expert examinations. Telephone and video appointments exclude hands-on medical examinations and may lead to decisions being made without all the necessary information (Andev, 2023). Virtual medicine may lead to some degree of inaccuracy - imperfect information can lead to imperfect treatment decisions. Therefore, it is necessary to develop strategies that provide services to patients with inflammatory arthritis based on safe, patient-centered care (Andev, 2023). In an era of longer appointment intervals, a mix of remote and face-to-face appointments, and the introduction of patient-initiated follow-up pathways, it is more important for patients to understand their disease and their clinical condition than ever before (Andev, 2023).

## 2.4 Discussion

### 2.4.1 Overview of People-Centred Care Insights

People-centred comprehensive care is a modern approach to addressing healthcare issues related to population change, the rising prevalence of chronic diseases, and limited resources (Vodopivec and Vrijhoef, 2019). To achieve people-centred comprehensive care, it is necessary to develop a systematic thinking perspective, which requires keeping the entire healthcare system in mind when developing, implementing, and evaluating innovations aimed at improving healthcare. People-centred comprehensive care should not be seen as the ultimate goal but as an ongoing process to optimise the healthcare system to meet the needs of arthritis patients, all other relevant stakeholders, and society (Vodopivec and Vrijhoef, 2019). Providing people-centred care is an increasingly urgent priority in the entire healthcare field. The core component of people-centred care is the collaborative creation of care through partnerships between patients, their families, caregivers, and healthcare professionals (Vodopivec and Vrijhoef, 2019). There is a primary theme, the importance of a people-centred approach, which clarifies the importance of professionals who respect the preferences of healthcare users (Feddersen et al., 2022).

Based on the above results, early healthcare services typically achieve the value of putting people first through clinics. In the past two years, there has been a trend towards combining remote and clinical medicine. Similarly, most research mentions involving arthritis users in their care and decision-making processes. Personalisation and patient education are also mentioned more frequently. Personalisation refers to customising one’s treatment plan for patients. The primary purpose of patient education is to help patients understand their situation and services and to help patients better participate in services. The primary purpose of other elements is also to help users better participate in healthcare services. The service delivery results are sometimes unsatisfactory, but these elements help achieve a more people-centred service (Vodopivec and Vrijhoef, 2019).

People with arthritis, as healthcare service users, require long-term services (Feddersen et al., 2022). The management of arthritis is limited, and treatment focuses on controlling symptoms and maintaining function (Fairley et al., 2021). For people with arthritis, creating a healthcare and broader social environment that supports symptom management and effective self-management of long-term illness is crucial (Fairley et al., 2021). Especially for osteoarthritis, there is currently no cure, and the primary purpose of treatment is to reduce joint pain and maintain mobility and quality of life (Nicolson and Holden, 2023). Although people-centred care has made significant progress in areas such as elderly care and primary healthcare, it has not met the demand in arthritis clinics (Bala et al., 2018a). The services required by people with arthritis involve different professional groups across departments (Feddersen et al., 2022). People with arthritis need care that meets their lifelong needs and expectations (Bala et al., 2018a).

The ageing population and the increasing prevalence of long-term diseases such as arthritis require healthcare to shift from acute to more sustainable care (Olsson et al., 2020). Supporting chronic disease patients in self-management and lifestyle change to achieve the best possible health and quality of life has become increasingly important (Olsson et al., 2020). Self-management is a way for people with arthritis to regulate themselves by developing strategies to adapt to their disease symptoms and treatments, enabling them to interact well with chronic diseases (Gyurcsik et al., 2013). Successful chronic disease management, including arthritis, depends on positive health behaviours (Wilcox et al., 2014; Arab et al., 2021). Enhancing self-efficacy has become a fundamental feature of many arthritis management interventions, as it has a strong relationship with healthy behaviour and health status (Brady, 2011). Self-efficacy is a person's confidence in performing specific tasks or exhibiting specific behaviours (Somers et al., 2010; Brady, 2011; Wilcox et al., 2014; Arab et al., 2021; Uritani et al., 2023).

Interventions such as health education and cognitive-behavioral therapy to improve self-efficacy are now widely recognised as effective treatment methods for improving the quality of life of arthritis patients (Gao et al., 2017). Over the past 15 years, arthritis self-efficacy has become one of the most essential psychosocial variables for understanding pain and disability in arthritis patients (Somers et al., 2010). The focus of many arthritis management interventions is to improve self-efficacy, as it has an impact on health status and treatment outcomes, and can be altered (Arab et al., 2021). In people-centred services for people with arthritis, improving self-efficacy is also the ultimate result of the following elements that must be achieved. Arthritis patients can improve their self-efficacy, pain, and function through interventions such as self-management or coping skills training (Somers et al., 2010). In short, to optimise the treatment outcomes of patients, attention should be paid to reducing the severity of the disease and improving the self-efficacy level of arthritis patients (Somers et al., 2010).

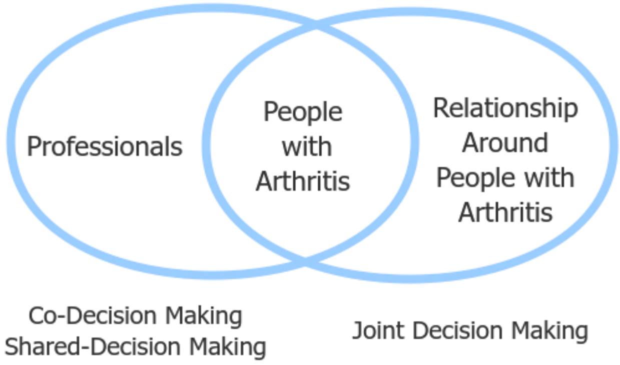
### 2.4.2 Patient Participation

It is crucial to involve patients in nursing (Drake et al., 2023). According to a people-centred care mindset, healthcare users are considered positive and self-determined individuals (Feddersen et al., 2022). Patient participation in decision-making and patient education are closely related to providing healthcare services for people with arthritis, which suggests that informing, educating, and supporting patients with arthritis to participate in their healthcare can improve utilisation and outcomes (Gagliardi et al., 2011). Among the selected studies, about 70% discussed patient participation in decision-making. In the comprehensive care approach designed for people with arthritis, patient empowerment, participation, and nursing experience prioritised (Vodopivec and Vrijhoef, 2019). Some participants reported experiencing an overarching sense of control and the ability to influence their own recovery, which lies at the heart of the concept of empowerment (Feddersen et al., 2022). Patient participation in healthcare is a means to achieve a healthcare system that responds to patient needs and values (Gagliardi et al., 2011). A helpful strategy is to motivate and empower patients to manage their lifestyle habits (Drake et al., 2023). Patient participation provides potential for targeted research and system design based on patient needs, thereby improving the patient’s nursing experience and quality (Lopatina et al., 2019).

However, many healthcare users with arthritis lack consistency in their rehabilitation pathways. This can be attributed to highly specialized and complex healthcare systems and complex health and social care needs, providing services across different professional groups and departments (Feddersen et al., 2022). In service, the core position of users in this multidisciplinary-led service seems to have the most significant impact on how users perceive it and how this understanding promotes the resolution of difficulties and priorities identified by users (Codd et al., 2023). Multidisciplinary-led services emphasise participation, which is the core of service delivery (Codd et al., 2023). Patient participation and activation are initially crucial (Betteridge et al., 2016). Patients seek out possibilities themselves or have prior knowledge of their choices in the healthcare system. They have the right to adjust the intervention measures provided to meet their own needs (Feddersen et al., 2022). Professionals sometimes believe that participation by patients with arthritis threatens their knowledge and expertise. However, patients have an independent complementary role that can provide a new perspective on existing problems (De Souza et al., 2017).

Teamwork is essential, and mutual respect is the key. The future direction is strengthening cooperation between service providers and people with arthritis (De Souza et al., 2017). A common and widely accepted viewpoint in bioethics is that capable adults can decide whether to seek healthcare, receive healthcare interventions, or participate in clinical research (Osamor and Grady, 2018). Joint decision-making, on the other hand, is the process by which most people define themselves and make decisions influenced by complex social networks, which may involve understanding and respecting the relationships that are important to them and incorporating the inherent values of these relationships into their decision-making process. (Osamore and Grady, 2018). Joint decision-making requires interaction and participation between users and experts, mutual respect and trust, and effective exchange of knowledge and professional knowledge (Coulter et al., 2015). Co-decision-making represents a collaborative, interpersonal, and interdependent process in which healthcare professionals communicate with patients about potential care choices and support their decisions (Bala et al., 2018b). Shared decision-making refers to good cooperation between patients with arthritis and professionals, understanding the individual's situation, reaching consensus on nursing needs and plans, coordinating care and follow-up, sharing nursing information with other healthcare professionals, family involvement, and clarifying the individual's responsibilities and opportunities to influence their care (Bala et al., 2018b). The conceptual relationship among the three types of decision-making is depicted in the following Figure 2.3.

*Figure 2.3 Different types of decision making*



Co-decision-making and shared decision-making are usually not fundamentally different. Both types of decision-making express the importance of individual participation in health service decisions (Li et al., 2023; Zhou et al., 2024). Co-decision-making includes interactions between patients and clinical doctors (Munhe, 2012). Shared decision-making is a process that enables patients to make fully informed and preference-concordant decisions (Katz et al., 2011). Li et al. (2023) proposed that shared decision-making can reduce conflicts, increase patient satisfaction, and improve health outcomes. Shared decision making is a method in which clinicians and patients share the best available evidence when facing decision-making tasks and support patients in considering various choices to achieve informed preferences (Elwyn et al., 2012; Bullock et al., 2024). Therefore, the core of shared decision making is the collaboration between professionals and patients (Munhe et al., 2012; Bullock et al., 2024), which is one of the core activities of person-centred care (Nota et al., 2017).

The commitment and active participation of people with arthritis are critical to achieving behaviour change in person-centred lifestyle management (Drake et al., 2023). Empowerment has been identified as a key factor in enabling such participation and is considered central to the process of shared decision-making (Drake et al., 2023). At the core of empowerment is the ability of people with arthritis to exert control over, and actively influence, their own rehabilitation process (Feddersen et al., 2022). Empowerment has been shown to support more effective self-management of the condition (Voshaar et al., 2015), and its enhancement is associated with improved quality of life and greater potential for maintaining health (Tengland, 2016). People with arthritis actively seek empowerment and express a clear desire to be involved in their own care processes (Battista et al., 2022). When healthcare professionals provide people with arthritis with adequate information and opportunities to participate in decision-making, it reflects a respect for their autonomy (Langberg et al., 2019). Improvements in patient empowerment have the potential to influence communication and treatment decisions between healthcare professionals and service users, ultimately contributing to more appropriate therapeutic goals and improved outcomes (Verbinnen et al., 2024).

### 2.4.3 Patient Education

Patient education is defined as a structured and interactive learning process aimed at supporting and enabling individuals to manage life with arthritis and to optimise their health and well-being (Jones et al., 2022). In supporting patient self-management, European Alliance of Associations for Rheumatology (EULAR) recommends that patient education should serve as the starting point and foundation throughout the entire course of the disease (Drake et al., 2024). Disease information is crucial during the first consultation with professionals during the diagnosis. Over time, providing a small amount of relevant information, goal setting and action plans will help patients with arthritis receive the diagnosis, maintain self-management motivation, and adhere to management plans (Betteridge et al., 2016). Patient education includes all educational activities, including treatment education, health education, and health promotion (Zangi et al., 2015). The importance of patients' understanding of essential information in healthcare can improve communication between patients and clinical doctors, highlighting the importance of patient education (Andev et al., 2023). To achieve reasonable control, patients need to understand their condition and access self-management resources related to education, advice, and support for their disease (National Institute for Health and Care Excellence, 2020). Improving communication and education on arthritis and its impact on social function is crucial for promoting patient-centred care (Chou, 2017).

Patient education aims to change knowledge, skills, and attitudes and improve patient treatment outcomes through behavior-al changes (Hewlett et al., 2008). Interventions for self-efficacy in arthritis patients, including patient education and self-management courses, have been developed and widely used in countries with highly developed healthcare systems to improve patient health outcomes (Arab et al., 2021). Patient education content is influenced by a range of factors, including individual needs, clinical condition, age, and expectations of professional support (Graham et al., 2012). Although guidelines and recommendations are crucial for informing good practices, patients' needs should always be at the forefront of clinical decision-making. It is essential to explain the characteristics of the disease after timely referral and diagnosis (Betteridge et al., 2016). Counselling should include information on emotions, lifestyle, disability level, and treatment goals (Betteridge et al., 2016). In the self-management of arthritis, the team and patients should share their professional knowledge, work together to achieve the individual goals of the patients, and be jointly responsible for solving the problems discovered by the patients (Olsson et al., 2020).

The characteristics and evaluation of strategies to involve patients in healthcare may benefit from knowledge translation methods. This knowledge synthesis aims to develop a conceptual framework for patient-mediated knowledge translation interventions (Gagliardi et al., 2011). Patients' preferences and expectations should be considered, and their current knowledge about the condition and what they hope to receive from services and experts should be established (Betteridge et al., 2016). Furthermore, the use of high-quality educational materials has the potential to enhance patient empowerment and facilitate more meaningful engagement in care (Verbinnen et al., 2024). High-quality educational materials typically include up-to-date information, are openly accessible, incorporate patient perspectives, use visual elements, are available in multiple formats and in patients' native languages, employ accessible language, and are endorsed by recognised scientific organisations (Verbinnen et al., 2024).

The staff emphasise the importance of giving users a ‘just right’ amount of information and not overloading them (Codd et al., 2023). Patients with arthritis should have the right to request information about arthritis or treatments they are unaware of, care standards, referral pathways, and any key points of cooperation between professionals from different disciplines (Betteridge et al., 2016). Patients often believe that the information they receive is not ideal. Healthcare professionals are key to the provision of high-quality care (Verbinnen et al., 2024). However, due to time constraints during consultations, the internet and patient organisations have been identified as valuable sources of information (Verbinnen et al., 2024). People with arthritis hope to receive education on arthritis and potential therapies to control their health, learn strategies for managing their condition, and plan for the future (Chou et al., 2017). The current research lacks information on providing patient-mediated interventions through translation alone (Gagliardi et al., 2011).

At present, a considerable proportion of patients report that they have not received any education on disease management (Pile et al., 2020). While education is recognised as essential for the self-management of chronic conditions, its effectiveness relies on being combined with the development of action plans and implemented over the long term (Fields et al., 2017). For people with arthritis, educational support should be flexible, timely, and patient-centred (Graham et al., 2012). Patient education enhances individuals’ capacity and willingness to take an active role in managing their health, and it provides the knowledge necessary to make informed choices about their condition (Jones et al., 2022). Therefore, educational provision should be current, delivered in a timely manner, and supported by appropriately trained healthcare professionals (Drake et al., 2024).

### 2.4.4 Personalisation

In addition, personalisation is another keyword that has been mentioned multiple in the systematic review findings. More than one-third of studies believe personalisation is crucial in people-centred services for people with arthritis. People-centred care emphasises that when meeting healthcare users, professionals must welcome personalised, respectful, and comprehensive approaches (Feddersen et al., 2022). At the same time, people with arthritis also expressed the need to use personal experiences and personalised methods as a starting point (Ammerlaan et al., 2017). Although many self-management plans emphasise patients' personal goals, structure, and content at the beginning of the plan, they are mostly predetermined, agreed upon, and based on group preferences (Ammerlaan et al., 2017). Therefore, healthcare services must focus on individual needs, preferences, and values rather than favouring healthcare systems and professional preferences (Feddersen et al., 2022). People-centred lifestyle management should consider everyone's needs and resources, and effective interventions should be tailored to the needs of patients with arthritis (Drake et al., 2023). The current research emphasizes the importance of customising program structure and content based on personal preferences and needs (Ammerlaan et al., 2017). Personalisation represents recognising unique human needs and concerns, preferences and values, as well as abilities and abilities (Bala et al., 2018b).

ersonalisation sometimes requires using shared decision-making tools and techniques with patients, which can help patients decide on a clear and straight-forward management plan (Betteridge et al., 2016). Personalisation based on the symptoms and main disease patterns of people with arthritis allows people with arthritis and experts to determine treatment goals, initiation, adaptation, and follow-up (Betteridge et al., 2016). The healthcare services guided by people-centred multidisciplinary team members adopt personalisation to achieve people-centeredness (Codd et al., 2023). The impact of arthritis on each patient is personal, and all interventions should be carried out within the context of the user's unique life roles and circumstances (Codd et al., 2023).

Since the twentieth century, medicine has increasingly shifted from a disease-centred to a patient-centred model by integrating patients' perspectives into care delivery (Blome et al., 2016). However, in everyday practice, outpatient consultations tend to focus on medical topics (Van Slingerland et al., 2023). People-centred care, by contrast, should be oriented towards care that addresses the individual needs of each patient (Van Slingerland et al., 2023). Existing evidence suggests that acknowledging patients as individuals with distinct needs, concerns, and preferences has measurable implications for the safety and efficacy of treatment outcomes (Voshaar et al., 2015). People-centred care recognises patients as autonomous individuals with their own preferences and intentions, irrespective of physical or cognitive limitations (Dellenborg et al., 2019). Moreover, a patient-centred approach to care enables individuals to assume personal responsibility for their treatment (Voshaar et al., 2015). The provision of personalised information, tailored to patients' existing knowledge, can also enhance their motivation to pursue healthier lives (Drake et al., 2024). Patient-centred healthcare requires that clinical decisions be made jointly by physicians and patients, based on individual needs (Blome et al., 2016). For some individuals, rapid improvement may be the highest priority, while others may place greater emphasis on the safety of the intervention (Blome et al., 2016). It can be expected that providers adopting a patient-centred orientation will continually revise their strategies through ongoing reflection, thereby enabling more personalised care (Tvedten et al., 2022).

### 2.4.5 Continuity and Coordination

In addition, long-term continuous care and treatment is also a focus of over one-third of research considerations. Continuity of care is regarded by patients as a fundamental prerequisite for the effectiveness of any care model (Doumen et al., 2021). Long-term support is a carefully considered feature of this service (Codd et al., 2023). Initial and continuous access to care are the two challenges that participants are most concerned about (Lopatina et al., 2019). Other priorities related to follow-up care include sufficient consultation time, proximity of care, continuity of care, and timely referral to experts

(Segan et al., 2018). Many patients emphasise the continuity of care (Segan et al., 2018). The research results indicate that patient-centred care for arthritis patients should be considered a continuum (Lopatina et al., 2019). This continuity starts from the first point of contact between patients and the healthcare system, through their first appointment with experts, and continues through their long-term follow-up with the rheumatology care team (Lopatina et al., 2019). Meeting individuals' needs beyond their patient experience level is crucial for improving the sustainability of healthcare systems (Vodopivec and Vrijhoef, 2019). Coordinated care refers to the provision of services by different care providers in a timely and complementary manner to ensure connected and cohesive patient care (Haggerty et al., 2008). Such coordination is expected to offer patients a more continuous, restorative, and seamless care experience (Langberg et al., 2019).

Due to administrative and financial infrastructure barriers between different institutions, the initiation of services may be delayed (De Souza et al., 2017). A lack of continuity between physicians has been identified as a factor that prolongs suffering within healthcare services and undermines trust (Bala et al., 2017). Research by Feddersen et al. (2022) further highlights insufficient communication and coordination of treatment- and care-related information among healthcare professionals. Experiences of poor coordination and communication across hospitals, departments, and physicians were prevalent, leading to a lack of consistency in the recovery journeys of healthcare users. To experience a sense of continuity during rehabilitation, people with arthritis need to encounter professionals who are empathetic and familiar with their care trajectories (Feddersen et al., 2022).

### 2.4.6 Communication, Environment, Time, Emotion and Technology in Care Delivery

Healthcare services aim to maintain or increase healthcare users' biopsychosocial functions, and increase participation in society (Feddersen et al., 2022). People with arthritis hope to be treated as individuals rather than a series of problems being solved

(Codd et al., 2023; Feddersen et al., 2022). People with arthritis need to help develop skills and confidence to manage their ‘changed selves better’ and acknowledge how multidisciplinary-led services can promote accepting and changing arthritis life (Codd et al., 2023).

In addition, patients emphasise that good communication skills and a friendly environment from rheumatology nurses are crucial for them to experience being taken care of (Bala et al., 2018, cited in Sweeney et al., 2021). Open and transparent two-way communication is crucial for patients, as they want to feel welcomed and cared for (Sweeney et al., 2021). People with arthritis engage in a dialogue with compassionate experts, who can familiarise and acknowledge patients’ perspectives and treatment plans rather than focus on other policy-driven external factors (Feddersen et al., 2022). This people-centered communication can make patients feel comfortable. The social environment represents how people with arthritis are identified, received, contacted, and communicated, as well as the conditions for good relationships and the establishment of a warm, calm, and friendly atmosphere (Bala et al., 2018b). The physical environment of a clinic to ensure integrity and comfort is an essential component of the social environment (Bala et al., 2018b). Increasing the duration of counselling can also be a factor in effectively improving patient satisfaction (Hall et al. 2018). The proposal to use better technologies for remote healthcare is also an essential manifestation of a patient-centred approach (Andev et al., 2023). It is necessary to classify patients in both outpatient and virtual settings, which is an effective measure to help patients quickly obtain information and receive treatment. Finally, strengthening the governance and accountability of the clinic system has also been proposed.

People with arthritis are the most important source of information (Coulter et al., 2015). Therefore, personalisation depends on communication between people with arthritis and professionals, which helps establish partnerships and creates conditions for planning tailored care. Personalisation is promoted when people with arthritis feel confirmed and can tell their stories, take their problems seriously, respect their experiences, use their self-knowledge, and record their personal information (Bala et al., 2018b). Through listening, encouraging, and engaging individuals in conversations with arthritis, their narratives emerge and reach consensus. Communication is considered a prerequisite for personalisation, shared decision-making, care planning, and empowerment processes and has received considerable attention in the context of people-centred care (Bala et al., 2018b). People-centred care provides personalised support, and patients typically perceive their voices as valued in medical consultations and make decisions based on personal preferences (Brkic et al., 2021). Establishing the patient's functional and valuable life goals is considered necessary, meaning they cannot do as well as they wish. Research has shown that individuals have significant differences in management needs (Geenen et al., 2018). A basic assumption for initiating self-management interventions is that when the intervention measures are customised according to individual needs and preferences, they will be more motivated, persistent, and benefit more over a more extended period (Ammerlaan et al., 2017).

## 2.5 Positioning the Systematic Review within the Overall Study

The systematic review offers a broad understanding of how people-centred care is conceptualised within arthritis and chronic care literature, outlining key elements such as continuity, coordination, information access and emotional support. In this study, its purpose is to contextualise the wider service environment in which individuals navigate their care.

While it did not inform the analytic process, the systematic review plays an important role in later stages of interpretation. Its insights help situate the empirical findings within established people-centred care frameworks and illuminate where participants' experiences align with, extend or challenge existing knowledge. This positioning maintains methodological integrity while ensuring that the review meaningfully supports the study's final interpretive framework.

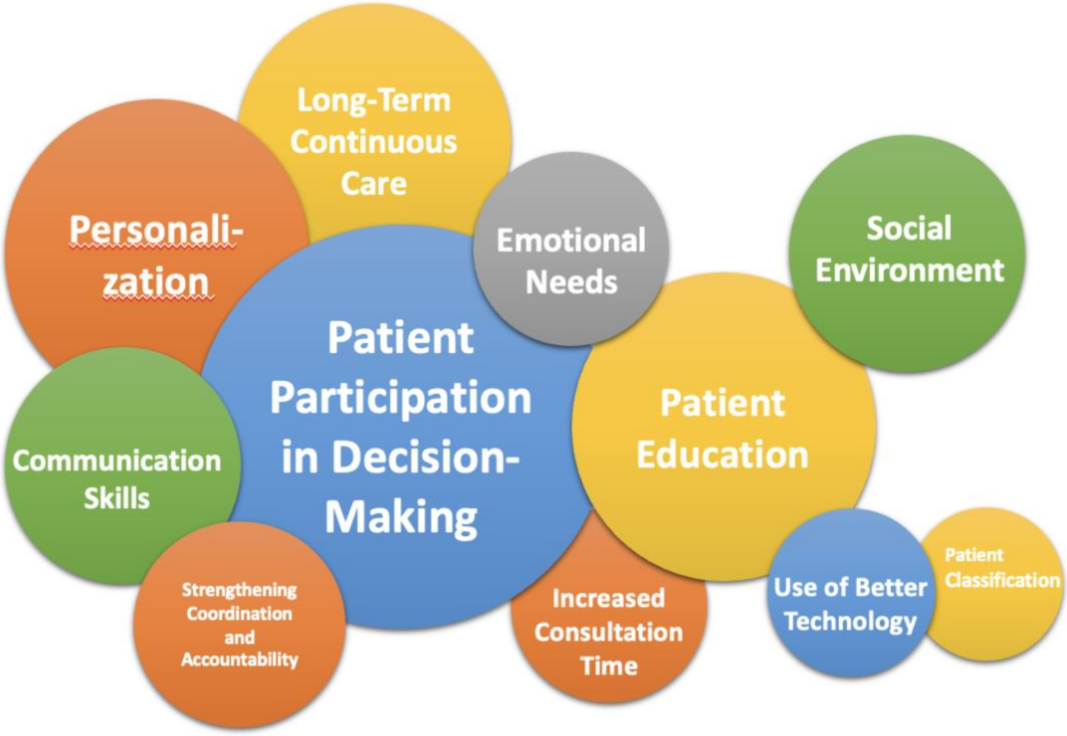
## 2.6 Summary

Based on the synthesis of included studies and supported by prior conceptual work (Bala et al., 2018a; De Silva, 2014), five key and partially overlapping pillars of people-centred care were identified in the context of arthritis services: shared decision-making, empowerment, personalisation, communication and social environment. These elements are interdependent, with communication acting as a foundational component that enables the others.

Based on the synthesis of reviewed studies, this review identifies eleven key elements that constitute people-centred care within arthritis services (see Figure 2.4):

Patient Participation in Decision-Making, Patient Education, Increased Consultation Time, Use of Better Technology, Patient Classification, Communication Skills, Social Environment, Personalisation, Emotional Needs, Strengthening Coordination and Accountability, and Long-Term Continuous Care.

***Figure 2.4 Key Elements of People-Centred Services for People with Arthritis***



This review synthesises key insights from the reviewed literature on people-centred arthritis care. It confirms the increasing urgency of shifting from system- to people-oriented service delivery, especially in response to chronic and long-term conditions like arthritis. A core prerequisite for achieving this people-centred outcome is understanding what is truly important to patients in nursing (De Silva, 2014). Although the importance and potential benefits of patient participation in health planning, research, and system design have been discussed for decades, patient participation in designing and redesigning healthcare systems has often been limited to passive participation (Lopatina et al., 2019). The concept of people-centeredness has existed for a long time, but existing organisations still have not systematically used it. If we cannot practice it ourselves, we cannot discuss people-centred care (Vodopivec and Vrijhoef, 2019). Although there are many difficulties in achieving people-centred care for people with arthritis, professionals must work alongside patients to look for a better future.

# Chapter 3: Methodology

## 3.1 Introduction

This chapter explores the research methodology, detailing the approach adopted to investigate the healthcare experiences of people with arthritis. The study adopts an interdisciplinary framework that integrates design thinking and healthcare principles to comprehensively understand user needs. The chapter presents the rationale for selecting qualitative methods, which include both thematic analysis and framework analysis. The user journey map is incorporated within the framework analysis to aid in structuring and interpreting the data. Additionally, the study draws on interpretative phenomenological insights to deeply explore the lived experiences of participants, emphasising their subjective perspectives and interactions with healthcare services. This methodological approach ensures the analysis remains user-centred and empathetic, effectively capturing the complexity of healthcare experiences while supporting the design of people-centred healthcare services.

## 3.2 Interdisciplinary Collaboration in Design and Healthcare Innovation

### 3.2.1 The Background and Challenges of Interdisciplinary Collaboration

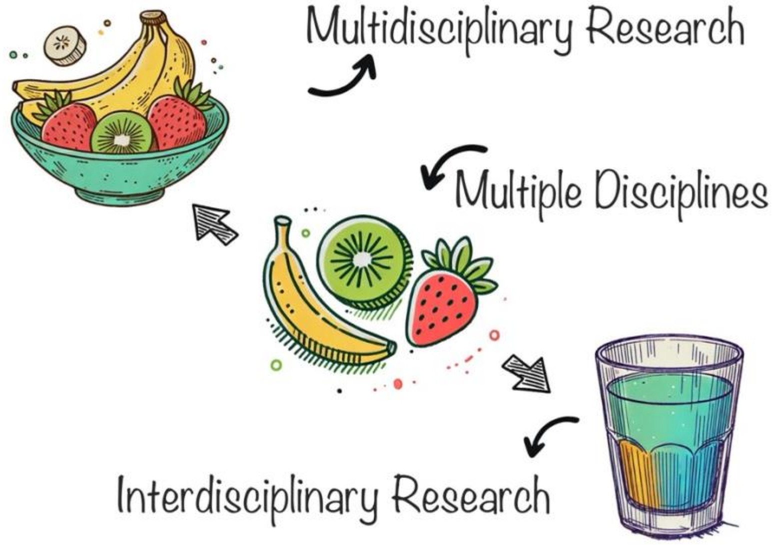
There is a broad definition of interdisciplinarity:

> "…interdisciplinarity literally means between disciplines suggesting the basic elements of at least two collaborators, at least two disciplines, and a commitment to work together in some fashion in some domain" (Stember, 1991, P14).

More specifically, interdisciplinarity involves the integration of knowledge and methods from multiple disciplines, facilitating cognitive advancements such as explaining a phenomenon, solving a problem, developing a product, or formulating a new question, in ways that would be difficult to accomplish within a single discipline (Mansilla, 2005). Interdisciplinarity can be likened to a "meeting of minds" among experts from diverse fields, where the fusion of their knowledge and methods sparks new insights or solutions. Multidisciplinarity typically refers to the straightforward juxtaposition of two or more disciplines (Moran, 2010). Multidisciplinarity is akin to placing experts from different fields within a single team, where each contributes their own knowledge but does not necessarily engage in deep collaboration, maintaining their distinct methods and perspectives. In other words, they are not jointly creating new knowledge but rather offering individual viewpoints to address the same problem.

There is a vivid metaphor regarding interdisciplinary and multidisciplinary research. Multidisciplinary research is like a bowl of fruit, where different fruits represent different disciplines, sitting closely together but remaining distinct (see Figure 3.1). In contrast, interdisciplinary research is more like a smoothie, where the fruits are blended together, creating a unified experience that belongs to the smoothie (Repko et al., 2016). The intellectual rationale for interdisciplinary work is that ideas in any field are enriched by the theories, concepts, and methods of other disciplines (Repko et al., 2016).

***Figure 3.1 An Illustrative Example of the Relationship Between Interdisciplinary and Multidisciplinary Research***



In the context of research and innovation, fostering interdisciplinary cooperation is essential to achieving mutual understanding and collaboration. Interdisciplinary collaboration allows for the integration of strengths from different disciplines to achieve outcomes that cannot be achieved by any single discipline alone (Thompson et al., 2017). Interdisciplinarity can lead to new scientific discoveries and solutions to real world problems (D'Este and Robinson-García, 2023). The integration of knowledge across diverse specialties is a key feature of interdisciplinary collaboration within research and innovation (Gonera and Pabst, 2019). The concept of interdisciplinarity aims to facilitate meaningful co-production of knowledge through integrative and participatory processes that bring together various participants, disciplines, and knowledge bases (Thompson et al., 2017).

### 3.2.2 Interdisciplinarity in Design

The inherent characteristic of design research is its proximity to, and even close collaboration with, other disciplines (Joost et al., 2016). In other words, design research is not conducted in isolation; it often requires drawing on the theories, methods, and knowledge of other disciplines. The ways in which design researchers work and practice may be of particular interest to organisations, as design has traditionally addressed open and complex problems (Cross, 2008). Design research typically maintains proximity to other disciplines, and this interdisciplinary collaboration reflects an openness that enables work alongside fields such as healthcare to address more complex real-world issues (Bazzano et al., 2017).

Through such collaboration, design research can more comprehensively address real-world challenges, fostering the application and practice of innovative solutions (Roberts et al., 2016). The interdisciplinary exchange of design thinking and health services brings significant advantages, relevance, and profound implications for healthcare innovation and service delivery (Abookire et al., 2020). Many challenges in the healthcare domain can be classified as "wicked problems", which are complex, dynamic, multi-stakeholder issues without clear solutions (Rittel and Webber, 1973).

Healthcare problems, as urgent and complex wicked problems, hold critical significance for societal progress and the improvement of well-being (Bayrak, 2022). For instance, balancing high-quality care with equity under constrained resources, or managing the pressures on health services in ageing societies, are challenges that traditional linear solutions often fail to resolve. In recent years, design researchers have shown considerable interest in projects aimed at enhancing, expanding, and supporting health and well-being services (Bayrak, 2022). Typical approaches to applying design research in healthcare include people-centred design (Melles et al., 2021) and service design (Romm and Vink, 2019).

At the core of design thinking lies an innovation process that prioritises a profound understanding of the desires, needs, and challenges of end users, emphasising deep empathy to develop holistic and effective solutions (Buchanan, 1992). This approach makes design thinking particularly well-suited to addressing wicked problems (Buchanan, 1992; Roberts et al., 2016). Therefore, combining design with healthcare services helps to provide a more comprehensive approach to addressing complex challenges.

### 3.2.3 The Interdisciplinary Role of Design Thinking in Healthcare Innovation

A robust and sustainable healthcare system must be people centred (Searl et al., 2010). Compared to traditional problem-solving approaches within healthcare and other public health-related fields, design thinking results in more successful and sustainable interventions (Abookire et al., 2020). Consequently, interdisciplinary theorisation represents a more comprehensive approach that begins with the problem and seeks to integrate knowledge from disciplines that contribute to solutions or resolutions into a new, coherent, and comprehensive theoretical understanding (Gustafsson et al., 2016). This understanding is applicable across relevant disciplines, in interdisciplinary contexts, and beyond related fields (Gustafsson et al., 2016). Design thinking enhances the satisfaction of patients, providers, and communities (Abookire et al., 2020). This is achieved by merging the creativity and people-centred methodology of design thinking with health services (D'Este, 2023).

The integration of people-centred approaches, such as design thinking, with people-led healthcare services highlights the potential of interdisciplinary methodologies in addressing complex challenges (Brown, 2009; Abookire et al., 2020). Design thinking prioritises a deep understanding of users' aspirations, needs, and challenges (Brown, 2009), while healthcare services inherently aim to improve the well-being of individuals and communities (World Health Organization, 2016). By merging these perspectives, interdisciplinary methodologies can foster innovative solutions that are both practical and empathetic (Roberts et al., 2016). For instance, applying design thinking in healthcare delivery can involve multiple stakeholders, including patients, healthcare providers, and policymakers, to co-create customised solutions (Abookire et al., 2020; Roberts et al., 2016). This approach bridges gaps between disciplines, ensuring that solutions are both user-centred and operationally feasible. Consequently, the integration of these approaches demonstrates how interdisciplinary frameworks can enhance both the processes and outcomes of healthcare innovation (Brown, 2009; Abookire et al., 2020).

In this research, an interdisciplinary framework has been adopted, integrating theories and practices from both design thinking and healthcare. Design thinking, as an innovative approach, emphasises people-centredness, collaboration, and the process of solving complex problems (Brown, 2008; Liedtka, 2018). Healthcare, on the other hand, focuses on patient needs and the delivery of medical services (World Health Organization, 2016; Abookire et al., 2020). While these two fields have distinct theoretical foundations and practical approaches, their integration through interdisciplinary collaboration can create new, more innovative research pathways for addressing complex healthcare challenges. By combining the creative problem-solving capabilities of design thinking with the scientific rigour of healthcare, this research specifically explores the provision of health services for people with arthritis.

A systematic review of the literature, presented in Chapter 2, highlighted current people-centred definitions of healthcare services provided for individuals with arthritis. Within this context, the research focuses on an in-depth exploration of the experiences of users of arthritis healthcare services.

Specifically, the design thinking approach will be employed to thoroughly analyse the needs, expectations, and experiences of users of arthritis services. Design thinking facilitates an understanding of the nature and effectiveness of arthritis services from the users' perspective while also identifying potential issues and areas for improvement within these services. Through this comprehensive investigation, the aim is to support the provision of more effective healthcare services that align with the needs of people with arthritis, ultimately enhancing their quality of life and satisfaction.

## 3.3 The Understanding and Application of Design Thinking

### 3.3.1 Conceptualising Design Thinking

Historically, design has been one of the final steps in the innovation or product development process, serving as a downstream activity focused on enhancing appeal before the product's launch (Connell, 2013). However, organisations are moving design thinking upstream, seeking to leverage designers' skills and processes to address complex problems or to construct processes and systems that optimise outcomes, improve conditions, and even enhance lives (Connell, 2013). Design thinking has emerged as a prominent concept in the field of innovation (Kleinsmann et al., 2017). Practitioners and scholars from various non-design fields have shown interest in the concept of design thinking and wish to utilise designers' problem-solving strategies (Stewart, 2011). Over the past decades, researchers have continuously explored design methods and how designers think. David Kelly of IDEO notes, "We have shifted from seeing ourselves as designers to seeing ourselves as design thinkers" (Connell, 2013). Although the term "design" has traditionally been associated with arts and crafts, design thinking, which was originally rooted in engineering, refers to the deliberate development of products and services based on people's needs (Crişan and Căldăruşa, 2017).

The vast majority of descriptions of the design thinking process highlight the people-centred nature and the core value of being end user (Brown, 2009; Martin, 2011; Crişan and Căldăruşa, 2017). Specifically, this means that within the framework of design thinking, users' needs, expectations, and experiences must be prioritised to ensure the solutions designed genuinely align with the users' actual needs and contexts. The success of design thinking lies in understanding the user rather than relying solely on technology or the subjective judgment of the designer. Therefore, this user-centred mindset is considered one of the fundamental principles of design thinking (Brown, 2009).

Design thinking starts from human needs and leverages appropriate technologies to create product value through the creation of user value (Brenner and Uebernickel, 2016). Specifically, this can be explained in three parts. First, starting from human needs, design thinking emphasises understanding the genuine needs and pain points of users. Pain points refer to specific problems, challenges, or frustrations experienced by users during their interaction with a product, service, or process (Liedtka and Ogilvie, 2011). This ensures that the design process consistently focuses on the users' perspectives and experiences. Second, leveraging appropriate technologies, suitable technologies or tools are selected throughout the process of meeting users' needs in order to support the design and implementation of solutions. These technologies may include digital tools, materials, processes, and related resources. Lastly, product value is created through user value. When a designed solution successfully addresses users' needs and delivers value, the value of the product or service itself is consequently enhanced. The distinctive characteristics of design thinking, which are collaborative, creative, and people-centred, hold significant potential for organisational development by enabling organisations to address challenges and generate intrinsic value that strengthens organisational vitality (Connell, 2013). The focus of design thinking on human experience also makes it a natural tool for service innovation (Gobble, 2014).

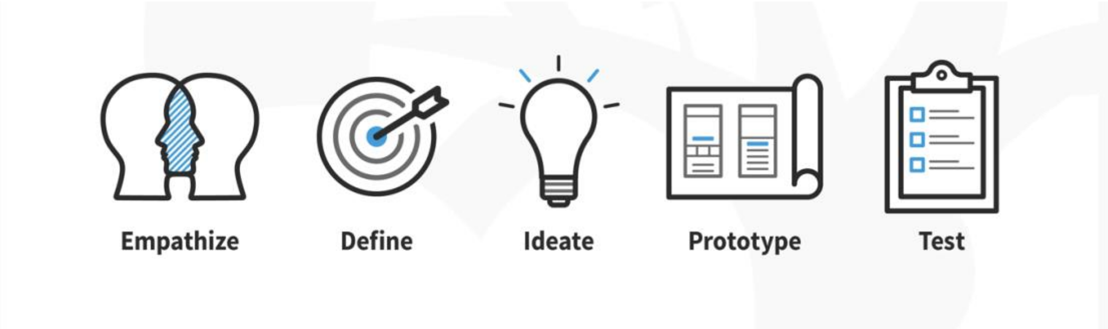
Design thinking is an approach to innovation and problem-solving (Balaram, 2011; Johansson Sköldberg et al., 2013). Design thinking is beneficial for addressing ill-defined or unknown complex problems and understanding target users' needs (Dam and Siang, 2020). Design thinking reconstructs problems and generates ideas to solve them in a people-centred manner. Both the design process for service innovation and the creative problem-solving approach requires a clear understanding of the needs and motivations of the target audience (Thomas, 2013). On the other hand, the design process is described as iterative, characterised by the continual redefinition of problems and solutions based on feedback from end-users until a final solution is achieved (Crisan and Căldăruşa, 2017). Design thinking has demonstrated its value as a methodology for generating innovative ideas (Balaram, 2011).

Design thinking is a way of creating meaning, as it challenges and expands fixed mindsets that are typically shaped by day-to-day work (Crişan and Căldăruşa, 2017). Design thinking's openness to diversity in terms of cross-structural knowledge sharing fosters and enhances participation, trust, and creativity, thereby strengthening an organisation's capacity for innovation (Efeoglu et al., 2013). The advantage of adopting design thinking lies in an organisation's ability to view the external environment from the perspective of the end user, transforming their needs into opportunities (Schifferstein et al., 2012). Applying design thinking to organisations, whether from the private or public sector, means using the user/customer journey as the reference framework in designing products or services rather than following a process workflow (Crişan and Căldăruşa, 2017). For instance, the focus is placed on the user experience, their behaviours, and their journey, from identifying potential needs to satisfying them through acquiring or using products or services, rather than starting with the design of sales or distribution strategies (Crişan and Căldăruşa, 2017). Design thinking can only be practical when the tools and methods are aligned with this new way of thinking (Brenner and Uebernickel, 2016).

Design thinking is an iterative and non-linear process primarily divided into five stages:

Empathy, Define, Ideate, Prototype, and Test (Dam and Siang, 2020) (see Figure 3.2). Design thinking is an iterative process through which one seeks to understanding users, challenge assumptions, and redefine problems (Dam and Siang, 2024).

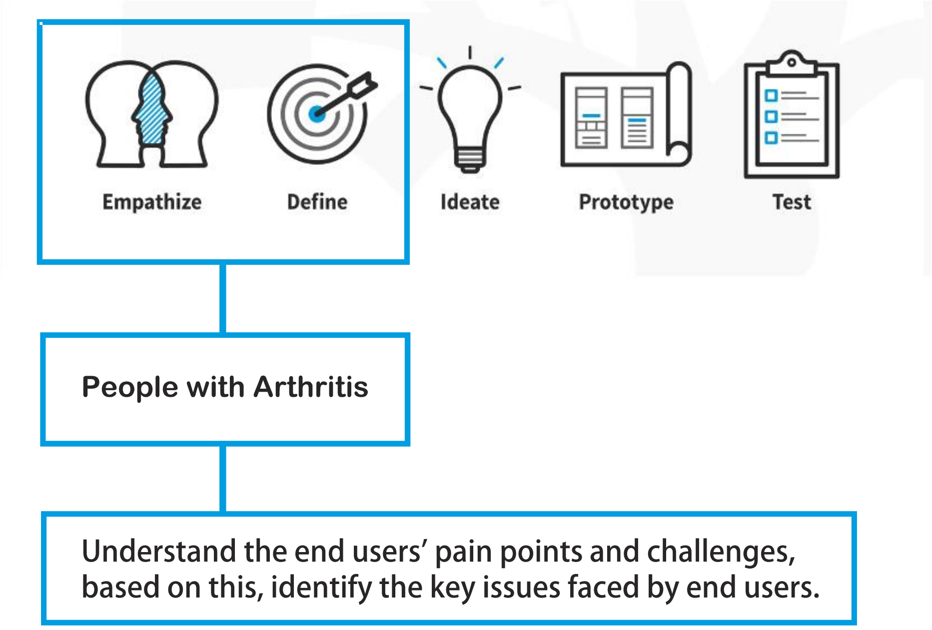
***Figure 3.2 Design Thinking Stages (Dam and Siang,2024)***



The empathise stage fosters a profound resonance with end users through active listening and observation of user behaviour (Brown, 2008). One of the defining characteristics of design thinking is its integration of empathy, creativity, and rationality to meet user needs and drive success (Gobble, 2014). People-centred design, or design thinking, which centres on empathy, context, creativity, and iteration, appears particularly well-suited to address public health issues. Over the past decade, design thinking has increasingly been employed to tackle global health challenges (Bazzano et al., 2017). Numerous acknowledged experts in the fields of design and health have advocated for a stronger intersection between the two domains, describing the potential role of social innovation in improving public health outcomes (Bazzano et al., 2017).

This research focuses on analysing people-centred perspectives of health services provided to people with arthritis through the lens of user experience. The aim is to uncover whether service delivery genuinely meets the needs and expectations of patients. Therefore, understanding user experience and integrating empathy into the data collection and analysis processes becomes essential to ensure that the research remains centred on the authentic feelings and needs of people with arthritis. The research will adopt the first two steps of the design thinking process, namely empathy and defining the problem, to gain an in-depth understanding of users' pain points and challenges. Building on this understanding, the research will identify the key issues faced by users, thereby facilitating the design of more effective health services (see Figure 3.3).

*Figure 3.3 The Application of Design Thinking in This Research*



Understand the end users' pain points and challenges, based on this, identify the key issues faced by end users.

### 3.3.2 The Application of Empathy in the Research

In 1909, psychologist Edward Titchener first introduced the term "empathy" as the English translation of the German word "Einfuhlung" (Howe, 2013, P9). The term "empathy" is derived from the Greek word "empatheia", meaning "to feel into", or to be with a person's feelings, passions, or suffering. To understand people and their situations, rather than merely explaining them, one must begin to interpret and seek meaning.

Empathy has been described as stepping into another person's shoes (or lying on their stretcher) (Brown, 2019). Design thinking guides the early stages of innovation through an empathy for users and a clear understanding of the challenges they face (Abookire et al., 2020). At the core of design thinking lies a systematic innovation process that prioritises a profound empathy for needs, and challenges of the end user, aiming to develop more holistic and effective solutions (Roberts et al., 2016). Design thinking is inherently people-centred, as design thinking is grounded in empathy for real users, understanding their needs, and formulating problem statements that align with these insights (Abookire et al., 2020). Establishing a connection with the target group, often referred to as empathy, is a crucial distinction between academic thinking and design thinking (Balaram, 2011).

The first step in design thinking, which is empathy, is typically an analytical phase aimed at understanding the user's needs and challenges (Schweitzer et al., 2024). Here, the focus is on building an empathetic understanding by setting aside personal assumptions to gain genuine and factual insights into diverse requirements (Doorley et al., 2018). Empathy goes beyond merely recognising the subjectivity inherent in the design domain; almost all contemporary descriptions of the process emphasise design thinking's core values of being people-centred and end user driven (Liedtka, 2018). This insight has attracted social scientists, who have begun to recognise empathy's potential in helping them understand human experiences from the perspective of participants (Howe, 2013). Empathy serves to inform and inspire designers to create products that meet user needs (Kouprie and Visser, 2009).

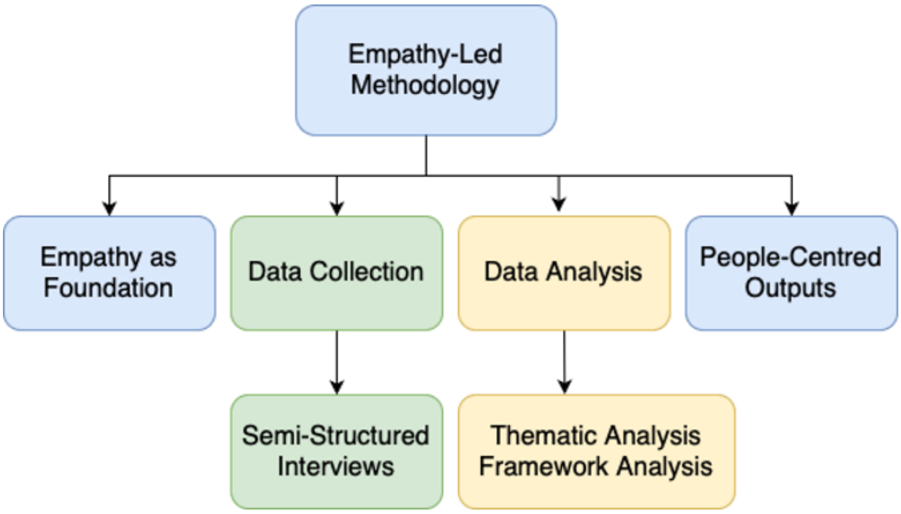
Empathy requires researchers to see the world through the eyes of end users, understand it through their experiences, and feel it through their emotions (Balaram, 2011; Connell and Tenkasi, 2015). Unlike sympathy, which involves feeling pity or compassion for others (Decety and Lamm, 2006), empathy focuses on deeply understanding and sharing the perspective of the end user. For instance, user journey maps are particularly useful tools to identify and understand the emotional fluctuations and key moments users experience when interacting with a service. Through these tools, specific stages where users may experience anxiety, confusion, or discomfort can be accurately identified, enabling targeted improvements to enhance the overall user experience (Gray et al., 2020; Stickdorn and Schneider., 2011). The boundary between researchers and users should gradually become blurred. Design thinkers need to engage with users, not oppose them or act on their behalf (Balaram, 2011). Design thinkers help people articulate latent needs which users may not even be aware of (Brown and Katz, 2019). Latent needs are often those that users have not yet been consciously recognised. In other words, while users may know the issues they face when interacting with a product or service, they might struggle to articulate or identify the root causes or deeper needs behind these challenges. Through empathy, observation, and interaction with users, design thinking is able to reveal these hidden needs, providing the foundation for more targeted design solutions.

In this research, empathy is used not just to understand user needs for service improvement, as in traditional design fields, but to engage with the personal experiences, emotions, and challenges of people living with arthritis. This approach enables a deeper discovery of user experience, facilitating insight into the emotional fluctuations and evolving needs that characterise the day-to-day realities of health management. Empathy provides a richer perspective for the research and ensures that the insights gained can support theoretical answers to complex issues. Empathy is a mindset that enables researchers to move beyond viewing individuals as mere experimental subjects or statistical outliers (Brown, 2019). In this study, empathy is understood as a means of engaging with and gaining insight into the lived experiences and perspectives of individuals living with arthritis. For researchers to "borrow" the lives of others in generating new ideas, they must first acknowledge that what may seem like difficult-to-understand behaviour represents different strategies that users employ in seeking solutions to problems in a complex and contradictory world (Brown, 2019). In the research, the researcher uses empathy to gain a deeper understanding of the needs, emotions, and challenges of end-users, particularly people with arthritis. Empathy enables the researcher to establish a human connection with users, thereby gaining insights that can facilitate the improvement of more people-centred health services.

The researcher begins by empathising with those most affected, as well as those who possess the deepest understanding of the necessary changes in products, services, or experiences (Roberts et al., 2016). Empathy is essential because what people say they do may differ significantly from what they do (Roberts et al., 2016). Through empathy, researchers bridge these gaps in understanding by striving to see the world from the users' perspectives, comprehend it through their experiences, and sense it through their emotions (Brown, 2019). Empathy enables researchers to connect with the emotions, pain, and feelings of others; only through empathy can one truly understand what others are experiencing (Smith, 2017).

In this research, empathy will permeate the entire methodology and research process. Specifically, empathy will be employed in various stages of the research, from problem definition to data collection, and from analysis to interpretation of results, to gain a profound understanding of participants' needs, perspectives, and experiences. This will be research guided by an empathy-led methodology (see Figure 3.4). The empathy-driven approach aligns closely with phenomenology, a qualitative research framework that emphasises understanding individuals' lived experiences from their own perspectives. This alignment provides a theoretical foundation for exploring participants' subjective realities and experiences in-depth, which will be elaborated upon in the following section.

***Figure 3.4 Empathy-Led Methodology Framework***



## 3.4 The Role of Phenomenology in Research Applications

### 3.4.1 Introduction to Phenomenological Theory

Phenomenology enables researchers to gain deeper insights into how individuals experience life, perceive illness and treatment processes, endure suffering, make moral decisions, and interpret the world and communicate their thoughts (Desjarlais and Jason Throop, 2011). Phenomenology is not intended as a therapeutic approach but rather as an in-depth exploration of the essence and meaning of human experience (Van Manen, 2016). Within phenomenology, the "natural attitude" is understood as the way each person engages with the lifeworld (Husserl, 1970). The lifeworld is described as an awareness of the world, encompassing its objects and experiences, and is always juxtaposed with the horizon that provides its context (Husserl, 1970). The aim of phenomenological research is to explore our experiences of the lifeworld in this natural state (Giorgi, 1997). Put simply, it focuses on "how individuals perceive the world" rather than "what theories tell us the world is like."

Phenomenologists argue that even in the most harmonious, empathetic, and intimate interactions between people, an inherent asymmetry and instability in perspectives and experiences remain (Desjarlais, 2011; Heidegger, 1996; Husserl, 1962; Jackson, 1998). In other words, even when interactions between two individuals exhibit a high degree of harmony, empathy, and intimacy, their perspectives and experiences can never be entirely identical (Desjarlais and Jason Throop, 2011). A key concept related to the natural attitude is that phenomena present themselves differently to everyone individually (Bevan, 2014). The persistence of asymmetry and instability arises from the fact that each individual's feelings and understanding are profoundly shaped by their unique experiences and viewpoints (Desjarlais and Jason Throop, 2011). Consequently, no matter how much effort is made to understand another person's emotions, it is impossible to fully adopt their perspective and experience the world as they do (Desjarlais and Jason Throop, 2011). In analysing user perspectives, this asymmetry and variability of experience are particularly significant, as they remind researchers that even in empathy-driven design processes, it is not possible to entirely replicate or encompass users' emotions and needs.

In conducting phenomenological research, it is essential to focus directly on the phenomena themselves (Van Manen and Van Manen, 2021). This involves reawakening fundamental experiences of the world and providing a "direct description" of it (Merleau-Ponty, 1962). In other words, it requires approaching the world without preconceived notions, offering a description of how we perceive and experience it (Van Manen and Van Manen, 2021). Even carefully selected facts or experiential material can serve as examples within phenomenology, but only after being subjected to a process of application or phenomenological reduction, which renders them as "fictionalised" (Husserl, 1983). While these examples might be grounded in facts or experiences, they can only serve the purposes of phenomenological inquiry if they undergo a "fictionalisation" process. Such reduction is not merely a factual recounting but an effort to uncover deeper meanings beneath the surface.

"Life experience" remains a significant methodological concept (Van Manen, 2016). Phenomenology's aim is to delve into the specific meanings underlying phenomena by studying individuals' everyday lives (Van Manen, 2016). Phenomenology focuses on how people perceive and experience the world within diverse social and cultural contexts, and how these contexts influence their feelings and experiences (Desjarlais and Jason Throop, 2011). "Direct description" of experience is not merely storytelling or recounting events but rather uncovering the deeper elements that lie beneath the surface (Van Manen and Van Manen, 2021). Phenomenology requires researchers to observe phenomena with an open mindset, free from preconceived theories or concepts (Van Manen and Van Manen, 2021). Human experience is inherently complex, arising from interpersonal interactions and imbued with meaning (Mason, 2017). The focus is on the raw essence of life, directly perceiving phenomena and events as they manifest in consciousness, rather than altering them through analysis or interpretation (Van

Manen and Van Manen, 2021). To study human life experience, it is essential to begin with the description of these immediate perceptions. This description avoids theoretical abstraction, instead returning to the experience itself to capture its uniqueness and deeper significance (Van Manen, 2016).

The principles of phenomenology facilitate the exploration of the complex experiences of people with arthritis when interacting with healthcare systems. Phenomenological methods enable the capture of participants' everyday experiences within their natural attitudes, from identifying pain points to receiving support. Phenomenology not only uncovers the asymmetries and diversities inherent in participants' perspectives but also underscores the necessity of respecting individualised experiences when designing people-centred healthcare services. Such insights provide a more targeted foundation for optimising participants experiences and offer valuable contributions to user-driven innovation in healthcare.

### 3.4.2 The Intersection of Phenomenology and Empathy

Phenomenology and empathy-led methodology converge in their shared emphasis on understanding individuals' lived experiences and perspectives. Both approaches reject superficial observations, prioritising the subjective and often nuanced realities of participants to uncover deeper insights (Smith et al., 2009; Stein, 1989).

Phenomenology relies on in-depth interviews and participant observation, aiming to allow participants to freely express their experiences and emotions (Moustakas, 1994). Phenomenology aligns closely with empathy-driven interview designs, such as encouraging participants to share their innermost feelings through open-ended questions. The interpretive focus of phenomenology reflects the emphasis of empathy-led methodology on understanding participants' emotions and lived realities.

The theoretical underpinnings of phenomenology are closely related to the principles of empathy-led methodology, such as focus on experiencing the world through others' perspectives (Husserl, 1983) and emphasis on contextual understanding (Heidegger, 1962). Both advocate for a deeper and more holistic engagement with participants' lived realities.

Within empathy-led methodology, phenomenological methods are closely intertwined with empathy, serving as both a theoretical foundation and a practical tool for understanding participants' needs and emotions. Phenomenology emphasizes understanding participants' lived experiences from their perspectives, aligning with empathy's requirement that researchers perceive and engage with others' emotional worlds. This integration enables the exploration of complex experiences, avoids surface-level observations, and provides people-centred insights and deeper understanding for research.

### 3.4.3 Phenomenology and Its Application in Qualitative Research

In qualitative research, phenomenology guides research design by focusing on participants' subjective experiences (Moustakas, 1994). Phenomenology ensures that data collection captures the nuanced details of lived experiences, providing a solid foundation for analysis. Phenomenology facilitates a deeper exploration of participants' subjective realities, uncovering meanings that go beyond surface-level observations and enhancing qualitative inquiry. For instance, in this research, phenomenology played a pivotal role in revealing the subjective realities of individuals with arthritis, offering profound insights into their interactions with healthcare services. In summary, phenomenology serves as a cornerstone of qualitative research, offering valuable tools for exploring the depth and complexity of human experiences (Moustakas, 1994).

### 3.4.4 Phenomenological and Interpretative Foundations of the Study

In this study, a phenomenological orientation places participants' lived experiences at the centre of understanding and knowledge generation. Phenomenology calls for a "return to the experience itself," attending to how individuals perceive, experience, and ascribe meaning to their lives within the lifeworld (Husserl, 1970; Merleau-Ponty, 1962; Van Manen, 2016). At the same time, an interpretative phenomenological stance highlights the researcher's active role in meaning-making. Phenomenology is concerned not only with the content of experience but also with how it is understood. This interpretative process involves a double hermeneutic: participants interpret and give meaning to their own experiences through language and reflection, while the researcher, in turn, interprets those accounts to understand how meaning is constructed in context. Such interpretation is undertaken reflexively, recognising the researcher's pre-understandings but intentionally bracketing them to avoid imposing prior assumptions on participants' meanings.

Thus, research is understood not as a passive reproduction of participants' experiences but as an active interpretative engagement with them, a position that is central to interpretative phenomenology. Grounded in Heidegger's (1962) concept of being-in-the-world, Gadamer's (1975) philosophical hermeneutics, and Van Manen's (2016) interpretative phenomenological methodology, this approach explicitly acknowledges that meaning is not simply discovered but co-constituted through interpretation. Experience is always already interpreted, situated, and historically and socially embedded, and understanding therefore arises through an ongoing interpretative process rather than through detached description.

This interpretative phenomenological stance enables a deeper exploration of how people living with arthritis make sense of their circumstances, respond to illness, and construct meanings of self and health in continuous interaction with healthcare systems. In this sense, interpretative phenomenology is particularly well aligned with the people-centred ethos underpinning this study, as it prioritises participants' lived meanings while recognising the researcher's active role in interpreting those meanings. The phenomenological notion of empathic understanding (Stein, 1989) provides a crucial philosophical foundation for this orientation, supporting an empathy-driven and human-centred approach that seeks to enter participants' experiential worlds and attend to their subjective feelings, concerns, and structures of meaning (Howe, 2013).

Accordingly, interpretative phenomenology is not adopted merely as a philosophical position but as a clear epistemological commitment that shapes how knowledge is produced in this study. This epistemological stance explicitly acknowledges that understanding emerges through an interpretative dialogue between participants and researcher, mediated by empathy, reflexivity, and openness to participants' voices. This commitment is ensured through sustained reflexive engagement, careful interpretative analysis, and attention to the contextual, emotional, and relational dimensions of participants' accounts. As a result, the study moves beyond surface-level description to illuminate, from participants' own perspectives, the subjective and contextual dimensions of healthcare experience, thereby providing a richer and more theoretically grounded understanding of people-centred care (Van Manen and Van Manen, 2021).

## 3.5 Qualitative Research in Exploring User Perspectives

Qualitative research provides a methodological framework for exploring the subjective dimensions of human experience, particularly how individuals make sense of their lives within specific social and cultural contexts (Fossey et al., 2002; Merriam and Tisdell, 2015). Qualitative inquiry, grounded in an interpretivist epistemology, is based on the premise that meaning is not fixed or objectively measurable, but rather co-constructed through social interaction and embedded within the context of lived experience. This paradigm is especially relevant to health research where personal narratives, emotional responses, and contextual variability cannot be meaningfully reduced to numerical abstraction (Sparkes and Smith, 2014).

In the context of this study, qualitative research is not merely a tool for describing service use, but a means to access the interpretative processes through which people with arthritis experience, reflect upon, and assign meaning to their interactions with healthcare systems. The emphasis is placed on capturing the depth, richness, and diversity of these experiences, rather than identifying general trends or testing predefined hypotheses. Such an approach makes it possible to illuminate the lived realities of individuals navigating arthritis and its associated care pathways. These insights are indispensable for informing the design and delivery of responsive, people-centred services.

This research adopts a phenomenological approach to qualitative inquiry, with a specific emphasis on interpretative phenomenological analysis as the primary analytic method. Phenomenology, as a philosophical tradition, seeks to uncover the essence of experience by attending to how phenomena appear to consciousness (Smith et al., 2021a). Interpretative phenomenological analysis builds on this foundation by integrating a double hermeneutic: the researcher interprets how participants themselves make sense of their experiences (Smith et al., 2021a). This approach is particularly suited to exploring health-related phenomena where subjective meaning, emotional nuance, and contextual understanding are central. In this way, qualitative research grounded in interpretative phenomenology offers a rigorous means of uncovering the often-overlooked complexities of living with arthritis and generating insights to inform service improvement.

## 3.6 Empathy-Led Data Collection

### 3.6.1 The Application of Semi-Structured Interview

Interviews remain the most prominent data collection method in phenomenological research to date (Bevan, 2014). Semi-structured interviews aim to elicit participants' perceptions of their lives, as described through their stories, thereby capturing their experiences, emotions, and social worlds (Fossey et al., 2002), include observation, semi-structured interviews, and focus groups (Adeoye-Olatunde and Olenik, 2021). semi-structured interviews facilitate a more focused exploration of specific topics (Fossey et al., 2002). Interview guides typically consist of questions and prompts designed to steer the interview in a focused, flexible, and conversational manner

(Fossey et al., 2002). This research seeks to gather participants’ behaviours, opinions, and feelings regarding their use of healthcare services. Semi-structured interviews provide an opportunity for focused discussions while maintaining flexibility in interaction with participants, making them particularly suitable for exploring the unique needs and challenges of arthritis patients in their healthcare service experiences.

In empathy-led methodologies, the advantages of semi-structured interviews are particularly pronounced. One of the main benefits is that semi-structured interviews have successfully fostered reciprocity between interviewer and participant, allowing the interviewer to improvise follow-up questions based on participants’ responses and providing space for participants to express themselves in their language (Kallio et al., 2016). Researchers can adapt their questions spontaneously in response to participants’ answers, delving deeper into their true feelings. This flexibility is crucial for empathy research, as it enables the researcher to capture the complex emotions and experiences of the participants. At the same time, semi-structured interviews allow participants to articulate their thoughts in their own words, helping researchers understand their underlying needs and pain points.

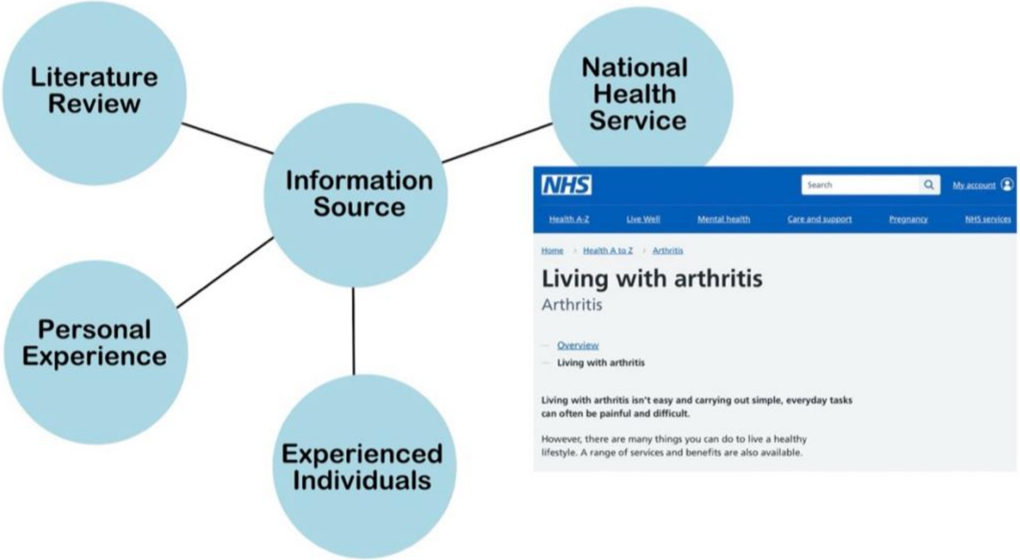
This approach enhances the understanding of people’s experiences by reducing psychological distance, bringing the research closer to participants’ authentic feelings (Finlay, 2005). Additionally, semi-structured interviews create an open communication environment that encourages participants to share more nuanced emotions and experiences, revealing deeper insights that traditional quantitative methods may fail to capture (Kvale, 2009). This flexible conversational style allows researchers to understand participants' needs multi-dimensional, ensuring that the research outcomes are more empathetic and practically valuable (Patton, 2015). The phenomenological approach commonly employs semi-structured interviews as a method that accommodates participants’ individual expressions while maintaining analytic depth (Smith et al., 2021a). Designing interview questions with empathy facilitates the elicitation of detailed and reflective accounts of lived experience (van Manen, 2023).

In the context of empathy-led research, such depth of insight provides a robust foundation for informing people-centred service design and interventions (Dewar and Nolan, 2013).

The development of a semi-structured interview guide involves five stages: (1) identifying the prerequisites for using semi-structured interviews; (2) retrieving and utilising previous knowledge; (3) formulating a preliminary semi-structured interview guide; (4) conducting a pilot test of the guide; and (5) presenting the final semi-structured interview guide (Kallio et al., 2016).

First, based on the previous section, this research confirms the adoption of semi-structured interviews. Second, a critical assessment of prior knowledge can be achieved through an extensive literature review (Barriball and While 1994; Krauss et al., 2009). Accordingly, prior knowledge establishes the conceptual foundation for the interviews (Åstedt-Kurki and Heikkinen, 1994). Literature review not only helps identify knowledge gaps in existing research but also provides theoretical support for the design and methodology of this study. Existing research findings lay a solid conceptual foundation for this interview, enabling more targeted design of the interview questions and framework. In cases where knowledge in the literature is sparse or fragmented, experiential knowledge can be used to supplement and deepen the theoretical background (Kallio et al., 2016). The design of this interview study gathers basic information on the UK healthcare system through a review of the National Health Service website, consultation with experienced individuals, and personal experience and literature reveiw (see Figure 3.5).

***Figure 3.5 The Preliminary Information Sources for Formulating Interview Questions***



Living with arthritis

Arthritis

Living with arthritis

Living with arthritis isn't easy and carrying out simple, everyday tasks can often be painful and difficult.

However, there are many things you can do to live a healthy lifestyle. A range of services and benefits are also available.

The third stage of development involves formulating the preliminary semi-structured interview guide. The objective at this stage is to utilise prior knowledge of structure, logic, and coherence to develop an interview guide that will serve as a tool for data collection. Empathy-led interviews require the use of open-ended questions, with a series of follow-up "why" questions to explore deeper and uncover underlying needs (Pradhan, 2017). This approach aligns with the philosophy of phenomenology, which emphasises understanding individuals' lived experiences and the meanings they ascribe to those experiences. By combining empathy and phenomenology, these interviews enable researchers to delve beyond surface-level responses and uncover the subjective realities of participants. Empathy can be divided into two forms. The first is experience sharing, which describes the observer's tendency to mirror the sensory, motor, visceral, and emotional states experienced by the target (Zaki, 2014). The second is mentalising, which refers to the observer's ability to make explicit inferences about the target's intentions, beliefs, and emotions (Zaki, 2014). These are two sides of the same coin, inseparable yet in competition (Zaki, 2014). These two modes of empathy complement each other during the interview process, creating a comprehensive framework for understanding. On the one hand, experience sharing allows the researcher to understand the emotional responses of people with arthritis empathically. On the other hand, mentalising enables the researcher to delve deeper into the psychological motivations and needs of people with arthritis. This dual empathy perspective plays a key role in the semi-structured interviews conducted in this research, helping the researcher not only capture the external behaviours and emotions of the patients but also gain insight into their internal psychological states related to their healthcare service experiences.

Therefore, the formulation of the preliminary interview guide not only requires careful consideration of the structure and coherence of the interview but must also integrate the core principles of empathy research. This ensures that the study can comprehensively uncover the complex experiences and needs of arthritis patients within healthcare services. Such an approach will lay a solid foundation for subsequent analysis and the design of healthcare services.

In this research, the pilot testing and final revision of the semi-structured interview guide were critical steps in its development. The purpose of conducting a pilot test on the preliminary interview guide is to assess the effectiveness of the interview questions and the smoothness of the interview process. Through pilot testing, potential issues can be identified, such as whether the questions are sufficiently open-ended and whether they effectively guide participants to express their true feelings and needs, particularly in empathy-driven research involving people with arthritis.

Based on the results of the pilot test, further revisions and refinements are made to the interview guide to ensure its logic, coherence, and flexibility. At this stage, the interview guide should have sufficient stability to maintain consistency across different interviews, while still allowing space for participants to freely express their unique responses. The final interview guide will include core open-ended questions along with appropriate follow-up prompts, ensuring that the researcher can capture participants' emotional responses, actual needs, and underlying motivations when exploring people with arthritis' healthcare experiences.

For this research, developing a comprehensive semi-structured interview guide is particularly important, as it serves not only as a tool for data collection but also as a bridge to deeply understand participants' needs through empathy-led interviews. By ensuring that the interview questions are closely aligned with the goals of empathy research, the final guide will enable researchers to gather richer and more nuanced data. This, in turn, provides a solid foundation for the design of people-centred healthcare services. This process establishes a crucial basis for exploring the real-life experiences, emotional states, and personalised needs of people with arthritis, ensuring the success of the research.

The process of adapting interview questions based on feedback from pilot interviews demonstrates the application of empathy in qualitative research. By reflecting on the insights provided by pilot participants, the questions are refined to ensure they are clear, relevant, and considerate of the participants' potential experiences and emotions. This empathetic approach ensures that the interview framework is both people-centred and effective in capturing meaningful data, aligning with the principles of empathy-led research. For example:

**Original Question:** What is the most troubling thing about arthritis? How do you usually deal with this trouble?

**Revised Question:** Does arthritis affect your life? Can you take care of yourself? If not, who is the first person you will ask for help?

**Reason:** Avoid overly abstract questions. The original question was overly broad, making it difficult for participants to provide clear responses, as the phrase "most troubling thing" encompasses a wide range of possibilities, leaving participants uncertain about how to select or articulate specific issues. In contrast, the revised question is more specific, directly inquiring about how arthritis affects daily life and whether participants can manage self-care. This approach encourages participants to reflect on concrete scenarios from their everyday experiences, resulting in clearer and more detailed responses. Furthermore, the revised question's structure and phrasing are more fluid and natural, avoiding the discomfort of abruptly introducing complex topics. By gradually guiding participants to discuss the specific impact of arthritis on their lives, this progressive design facilitates easier engagement with the interview topic and enhances the coherence and depth of the conversation.

The Final interview questions provide the necessary framework for this investigation.

### 3.6.2 Interview Implementation

In this research, data were collected via Microsoft Teams. In recent years, the diversity of digital communication technologies and advancements in technology have provided new and exciting opportunities for participant recruitment, conducting fieldwork, and disseminating research findings (Murthy, 2008; Weller, 2017; Deakin and Wakefield, 2014; Mirick and Wladkowski, 2019). Similarly, these technologies have also become a crucial part of many researchers' toolkits (Mann and Stewart, 2000; Seitz, 2016). Online interviews are often regarded as the new "methodological frontier" (Deakin and Wakefield, 2014). Within academia, online technologies have become increasingly prevalent as research aids, and the internet is now a powerful tool for future research (Illingworth, 2001).

The pandemic further normalised the use of online communication tools within research practices. Due to health and safety concerns for both participants and researchers, these tools became indispensable for maintaining research continuity during periods of restricted physical interaction (Lupton, 2021; Archibald et al., 2019). Online platforms not only ensured the feasibility of conducting interviews remotely but also highlighted their efficiency and adaptability in accommodating diverse participant needs. This shift has reinforced the integral role of digital tools in contemporary research methodologies, setting a precedent for their continued use in post-pandemic research contexts (Lupton, 2021; Gray et al., 2020).

Firstly, online interviews encourage participation from respondents who may be constrained by time and location in face-to-face interviews (Johnsone et al., 2021). As a result, the interviews are conducted under conditions that are more convenient for the participants. The use of webcams allows for interactions that are comparable to in-person settings, with the presence of non-verbal and social cues (Janghorban et al., 2014). This means that through webcams, researchers and participants can capture more body language and facial expressions, which are valuable in understanding participants' emotions and reactions during traditional in-person interviews. Thus, this form of online interaction can, to some extent, achieve effects similar to those of face-to-face interviews. The use of webcams enables online interviews to go beyond audio communication, incorporating visual elements that enhance the richness of interaction and the naturalness of communication.

Secondly, for many participants, online communication reduces the intrusion into their physical, personal space, which helps them feel more comfortable during the interaction (Weller, 2017). Both researchers and participants can remain in safe locations without encroaching on each other's personal space (Seitz, 2016). Through online interviews, researchers and participants can communicate while staying in environments where they feel safe and comfortable. Participants being in their own environments means that they may have access to various artefacts and objects that might emerge during the interview, which they may find useful to share with the researcher (Lo Iacono et al., 2016).

Thirdly, since the pandemic, it has become particularly important to minimise the risks faced by individuals with immunosuppressive conditions, such as arthritis (Nicol et al., 2020). Therefore, to ensure the safety of participants, adopting online research methods has become a necessary measure.

Microsoft Teams, as a widely used online collaboration platform, offers convenient audio and video communication features, enabling real-time interaction during remote interviews (Ilag and Sabale, 2022). For the people with arthritis group, conducting interviews through Microsoft Teams avoids the need for frequent travel and overcomes mobility challenges, offering a more flexible and comfortable way to participate (Schougaard et al., 2023). The convenience and flexibility of this platform are particularly well-suited to the interviewees in this research, allowing them to engage in interviews from familiar surroundings, which may enable them to express their feelings and needs more openly and naturally (Lo lacono et al., 2016). However, online interviews can be subject to technical issues, such as unstable network connections or device malfunctions, which could impact the interview's smoothness and the participants' willingness to communicate (Lo lacono et al., 2016). Therefore, researchers using this method must pay particular attention to preparing technical support to ensure that the interviews proceed smoothly.

Overall, Microsoft Teams provided an efficient and convenient interview tool for this research, with its flexibility and convenience meeting the needs of arthritis patients while ensuring the effectiveness of data collection.

### 3.6.3 Participants Recruitment

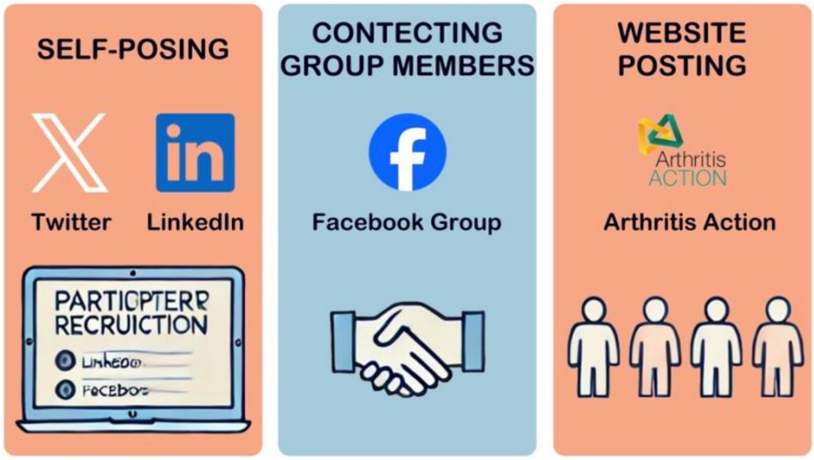
A purposive sample is defined by its characteristics that align with the objectives of the research (Andrade, 2021). Purposive sampling is often favoured by researchers who aim to explore a particular process through interviews with a pre-defined and significant group of individuals (Mikecz, 2012; Tansey, 2009). This method is particularly suitable for researchers seeking to gain a deep understanding of a specific process or phenomenon through interviews with certain groups. Purposive sampling is often used to engage participants who have a central role or in-depth experiential knowledge relevant to the research topic, including domain experts, policymakers, and people with arthritis. Purposive sampling requires researchers to actively seek out and engage with these specific respondents, rather than relying on random selection.

The advantage of purposive sampling lies in its strategic focus, as researchers select participants based on their relevance to the research aims and their potential to provide rich, meaningful data closely aligned with the study objectives (Nyimbili and Nyimbili, 2024). Additionally, this approach tends to yield high-quality data, since participants are familiar with the research context and have relevant experience, making them more likely to provide reliable and in-depth perspectives (Nyimbili and Nyimbili, 2024).

Purposive sampling specifies clear inclusion and exclusion criteria, making the selection of participants for this research inherently non-probabilistic and deliberately targeted (Campbell et al., 2020). This approach aligns with criterion sampling, where participants are chosen based on predefined criteria to ensure the relevance and quality of the data collected (Nyimbili and Nyimbili, 2024).

Participants were recruited through multiple channels (see Figure 3.6). Specifically, recruitment information was shared on social media platforms such as LinkedIn and X (formerly known as Twitter) to broaden the reach of the announcement. Additionally, the researcher actively engaged with arthritis groups on Facebook, establishing connections with potential participants who might be interested in the research. A recruitment notice was also posted on the Arthritis Action website, a UK charity dedicated to improving the quality of life for people with arthritis through self-management support and resources, to ensure that the information reached a wider target audience. The selection of these platforms aimed to attract a larger pool of participants with relevant backgrounds. Interested potential participants were able to contact the researcher via email to learn more about the research and confirm their willingness to participate.

*Figure 3.6 Participant Recruitment Platforms*



The inclusion criteria ensured that the study targeted a specific group of participants whose experiences would be most relevant to the research objectives. By requiring participants to be over 18 years of age and to have lived with arthritis for more than three years, the research aimed to include individuals who had a mature understanding of their condition and its impact on their daily lives. Fluency in English was necessary to facilitate effective communication during interviews conducted in English, ensuring that participants could express their experiences and insights without language barriers. The requirement for participants to be willing to engage through MS Teams reflected the study’s need for remote data collection, making it possible to interview participants from various locations while maintaining consistency in the method of communication. Conversely, excluding individuals who did not use UK services helped focus the study on those who had direct experience with the UK’s healthcare system, thus providing insights specific to the context of this study. The inclusion and exclusion criteria are outlined in the Table 3.1 below.

*Table 3.1 Inclusion and Exclusion Criteria for Participants*

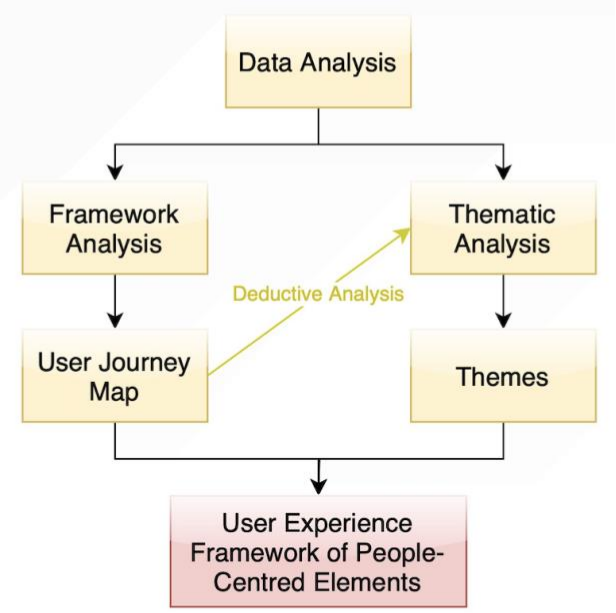
| Criteria Tpye | Details |
|---|---|
| **Inclusion Criteria** | a person over the age of 18, who has had arthritis for over 3 years, who speaks English and is willing to discuss their experiences over MS Teams. |
| **Exclusion Criteria** | Do not use UK services. |

Finally, a total of 7 participants were included in the research.

## 3.7 Data Analysis

In this study, the data analysis approach integrates framework analysis, combining user journey mapping and thematic analysis to systematically explore the healthcare experiences of people with arthritis (see Figure 3.7). These methods complement each other in capturing and interpreting the richness and complexity of participants' lived experiences.

*Figure 3.7 User Experience Framework of People-Centred Care Elements*



In this study, the user journey map served as the framework for analysis, enabling the researcher to visually map participants' experiences along their healthcare journey. The user journey map facilitated a more detailed and contextually informed understanding of how specific stages in the healthcare process influence participants' perceptions and experiences (Stickdorn and Schneider, 2012).

Building on this foundation, thematic analysis is employed to identify people-centred care elements by systematically detecting themes and patterns within the interview data, facilitating a deeper understanding of both shared experiences and individual differences. This approach is particularly well-suited to exploring how individuals with arthritis interact with healthcare services and perceive their experiences (Braun and Clarke, 2022).

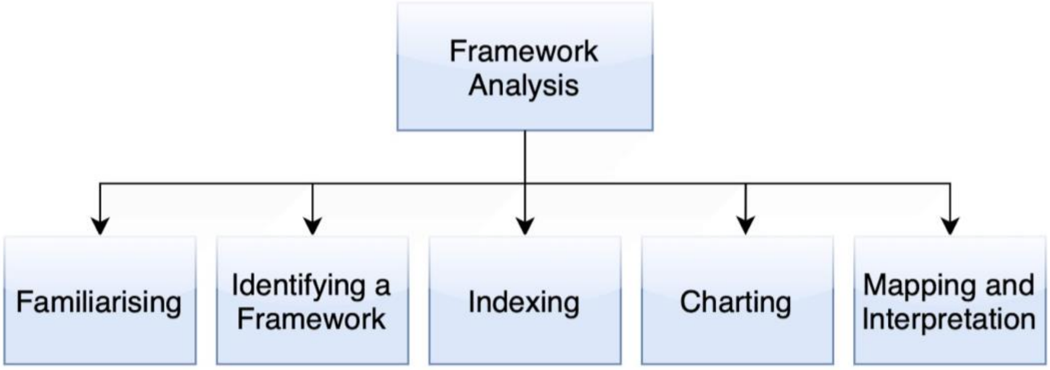
Framework Analysis offered a more structured approach by systematically organizing and interpreting data through predefined categories (Ritchie and Spencer, 2002). By integrating the results of the framework analysis, user journey mapping, and thematic analysis, this research further develops a people-centred user experience framework, offering a structured analytical basis for enhancing arthritis healthcare services.

The analytical methods chosen by the researcher, including the use of the user journey map to analyse data and a focus on people-centred understanding, align well with the principles of interpretive phenomenology (Larkin et al., 2021; Van Manen, 2016). This approach underscores the importance of understanding how individuals' experiences and meanings are shaped within specific social and cultural contexts (Heidegger, 1962). As such, the researcher integrated phenomenological perspectives, particularly in its emphasis on deeply interpreting and understanding human experience, emotions, and interactions during the data analysis phase. This fusion of phenomenological thinking will provide valuable insights into how arthritis patients navigate and interpret their healthcare experiences, ultimately contributing to the design of more responsive and empathetic services (Larkin et al., 2021; Stickdorn and Schneider, 2012).

### 3.7.1 Framework Analysis

Framework analysis was developed in the 1980s by applied qualitative researchers working at the independent Social and Community Planning Research Institute, which allows the identification of existing forms and attributes (Ritchie and Spencer, 2002). The framework approach has been developed and successfully applied for decades and has become a popular method of analysis in qualitative health research (Gale et al., 2013). This research explores the experiences of people with arthritis within existing healthcare services. By analysing user experiences, this research can determine whether current health and medical services meet the needs of service users. The data were collected through semi-structured interviews. Framework analysis is most commonly used to analyse records of semi-structured interviews (Gale et al., 2013). Therefore, the use of framework analysis to analyse the research data is highly suitable given the nature of the data and the aims of the analysis.

***Figure 3.8 The Application of Framework Analysis in the Research***



In this research, framework analysis is particularly well-suited for examining the experiential data of people with arthritis, as it enables researchers to organise and analyse large volumes of complex data in a systematic manner. Framework analysis consists of five key stages: familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation (Ritchie and Spencer, 2002; Thórarinsdóttir and Kristjánsson, 2014), providing a clear analytical pathway for researchers (see Figure 3.8). The familiarisation stage aims to achieve a comprehensive understanding of the data (Parkinson et al., 2016), which is a characteristic of almost all qualitative methods (Ritchie and Spencer, 2002). Through in-depth reading and comprehension during the familiarisation stage, researchers can grasp the detailed feelings and experiences expressed by patients in the interviews. This step is particularly useful for understanding the specific needs and pain points of people with arthritis in different healthcare service contexts, aligning with this research's focus on user experience.

Identifying and developing a framework aims to organise the data in a meaningful and manageable manner (Parkinson et al., 2016; Gale et al., 2013). This organisation aims to support subsequent analytical steps, specifically mapping and interpretation, enabling researchers retrieve, explore, and examine the data more easily. Identifying and developing the framework allows researchers to extract themes that display commonalities and differences within the data, categorising them in a meaningful way. This categorisation aids researchers in understanding the diversity of patient experiences and identifying strengths and weaknesses within healthcare services, thereby assessing whether current health services truly meet the needs of people with arthritis. Through these steps, researchers organize the data systematically and facilitate the subsequent processes of mapping and interpretation.

The purpose of mapping and interpretation goes beyond managing the data; it aims to understand it, which can be described as bringing together the key characteristics of the data to map and interpret the entire dataset (Ritchie and Spencer, 2002; Gale et al., 2013). Mapping and interpretation involve identifying patterns and articulating the researcher's insights into the data, guided by the research questions. Depending on the nature of these questions (see above), this stage may take different forms and result in either visual or narrative presentation of the findings (Ritchie and Spencer, 2002).

During data analysis, the researcher needs to move beyond mechanical, procedural approaches, focusing instead on the deeper meanings within the data, using intuition and creativity in their analysis (Ritchie and Spencer, 2002). This means that researchers should not merely follow fixed steps or technical procedures. A mechanical examination of the data risks focusing solely on surface-level characteristics and apparent content, potentially overlooking deeper, more nuanced meanings. Researchers must apply interpretative sensitivity and reflexivity to engage with the latent meanings and complexities within the data. When faced with ambiguity, they draw on theoretical sensitivity and contextual understanding to explore plausible explanations and deepen their insight into the phenomena under study (Finlay, 2005).

In this research, such flexibility is particularly crucial, as the individual experiences of people with arthritis vary widely and often encompass subjective feelings and emotions. Through the use of interpretative sensitivity and reflexive engagement, researchers can attend to the emotional complexity and nuanced experiences embedded in participants' accounts (Finlay, 2005; Smith et al., 2021). This allows for the identification of deeper meanings within the data that are not immediately observable but are central to understanding user perspectives (Finlay, 2005; Smith et al., 2021a). This approach supports the aim of this study: to explore the lived experiences of people with arthritis in healthcare services and generate insights to inform people-centred service design.

In summary, framework analysis in this research provides a structured approach to organising data and enables the researcher to delve deeply into the experiences of people with arthritis, offering a scientific basis for improving healthcare services. The framework analysis method is highly compatible with the needs of this research, as it ensures a systematic approach to analysis while allowing the researcher to use their insights to fully understand the complexity of user experiences.

### 3.7.2 User Journey Mapping: A Framework for Understanding Arthritis Healthcare Experiences

In the data analysis process of this research, the framework analysis method was selected as the primary analytical tool. Framework analysis is suitable for handling complex qualitative data due to its systematic nature and flexibility, allowing researchers to organise the data into logically structured outcomes. In this analysis, the user journey map served as the foundation of the analytical framework. By breaking down the user journey map, the researcher could generate smaller charts for various themes or stages, which detailed the experiences and feedback of people with arthritis at different service stages. This analytical approach not only helps to identify the key needs of patients but also provides valuable insights for optimising people-centred healthcare services.

A user journey map is a method for designing and evaluating user experiences in service design (Bucolo and Matthews, 2011; Johnston and Kong, 2011). It provides an intuitive depiction of the sequence of events through which users might interact with a service organisation throughout their service experience (Rosenbaum et al., 2017). User journey maps focus on understanding relevant user processes to identify areas requiring further user research (Endmann and Keßner, 2016).

A user journey map is primarily described as a visual representation of the sequence of events users experience throughout their service journey (Alvarez et al., 2020). A user journey map is an effective tool for identifying issues within existing services or uncovering opportunities for improvement (Holmlid and Evenson, 2008). A user journey map also captures users' attitudes and feelings at each touchpoint, taking into account their journey's physical and emotional aspects (Samsel, 2013; Zomerdijk and Voss, 2011). This focus on emotional and physical experiences is particularly crucial for research involving people with arthritis, as their healthcare experiences are often shaped by physical pain and emotional fluctuations. A user journey map enables a more comprehensive capture of these nuanced experiences, providing a foundation for enhancing people-centred healthcare services.

A user journey map analyses and understands user experiences from the user's perspective (Mangiaracina et al., 2009). The user journey experience involves the user's subjective assessment of the effectiveness of a product or service, the convenience of the usage process, and their overall perception: effectiveness (whether users can achieve their intended goals), efficiency (how long it takes them to do so), and satisfaction (their feelings and attitudes towards the product) (Alvarez et al., 2020). These characteristics of user journey maps can assist researchers in analysing the experiences of people with arthritis, focusing on whether users can effectively access healthcare services, whether they feel comfortable during the process, and their overall perceptions of the service. Through a detailed analysis of these aspects, researchers can provide more targeted recommendations for improving service design.

When constructing one aspect of the user journey map, several factors need to be considered: (a) the steps and actions taken by users, (b) users' expectations, (c) users' perceptions, and (d) users' satisfaction (Alvarez et al., 2020). These factors can influence their overall experience with a product or service and their relationship with the organisation (Canfield and Basso, 2017). By analysing these elements, researchers can understand the psychological and emotional dynamics of people with arthritis during their use of healthcare services, thereby identifying specific entry points for improving service design.

User journey maps are widely applied in the healthcare sector as analytical tools for examining client pathways and identifying pain points within service delivery processes (Samson et al., 2017). In this research, the suitability of the user journey map is particularly evident. The user journey map provides a systematic approach to analysing complex user experiences and visualises users' emotions and feelings throughout their interactions with services. This is crucial for understanding the real experiences of people with arthritis at different touchpoints within healthcare services. The structured approach of the user journey map enables researchers to identify the challenges that people with arthritis face while using health services and to uncover potential opportunities for service improvement by focusing on their individual needs and perceptions. This method is especially well-suited for the in-depth analysis of user needs and experiences in doctoral research, as it allows the researcher to capture specific pain points experienced by users in healthcare settings and translate these insights into the basis for data analysis and service optimisation.

In this research, the user journey map is the core framework for framework analysis. It offers a structured perspective that aids researchers in systematically organising and analysing the experiential data of people with arthritis. By mapping users' experiences at various service touchpoints onto the different stages of the user journey map, researchers can identify the key challenges and needs they encounter throughout their healthcare journey. This framework helps researchers understand users' emotions and behaviours at touchpoint and reveals overarching patterns and trends across the entire service experience, thereby supporting a more comprehensive analysis and evidence-based service improvements. Using the user journey map as a framework analysis tool ensures that the research is both systematic and organised while also allowing for a deep exploration of the individualised experiences of users within healthcare services.

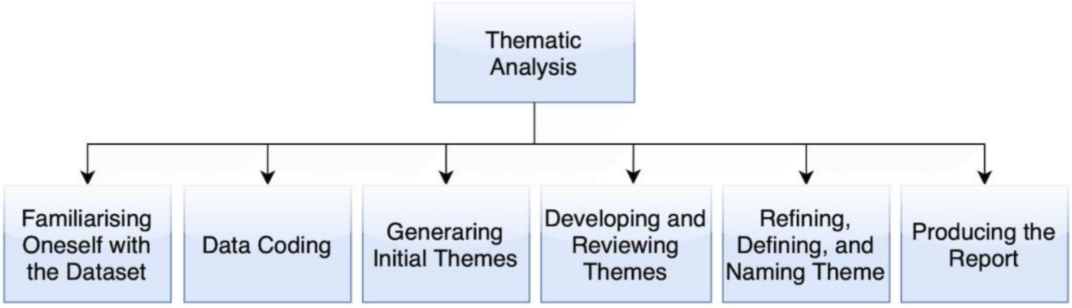
### 3.7.3 Thematic Analysis

Thematic analysis is a method for identifying, analysing, and interpreting patterns of meaning ("themes") within qualitative data (Braun and Clarke, 2022; Clarke and Braun, 2017; Saunders et al., 2023). Thematic analysis can identify patterns within and across data that relate to participants' life experiences, perspectives, viewpoints, and behavious and practices (Clarke and Braun, 2017). At a fundamental level, thematic analysis is an inductive process of developing, analysing, and interpreting patterns within qualitative datasets. It involves coding the data and constructing themes that reflect significant meanings derived directly from participants' accounts (Braun and Clarke, 2022; Nowell, 2017; Ozuem et al., 2022). Thematic analysis is one of the most common and flexible methods for examining qualitative data collected in health services research (Saunders et al., 2023). Thematic analysis is well-suited to this study's aim of exploring the healthcare experiences of people with arthritis, as it facilitates the identification of key patterns and themes within participants' accounts.

This research focuses on the healthcare service experiences of people with arthritis, a type of research that often involves a deep understanding of participants' personal feelings, experiences, and needs. Thematic analysis is particularly well-suited for uncovering these complex emotions and experiences, as it identifies recurring patterns and themes within qualitative data, leading to a more comprehensive understanding of participants' experiences. Thematic analysis helps to identify key themes within participants' narratives, thereby revealing their genuine feelings and challenges during the healthcare process. This understanding is crucial for providing more people-centred healthcare services.

The analytical process typically involves six stages: (1) familiarising oneself with the dataset; (2) data coding; (3) generating initial themes; (4) developing and reviewing themes; (5) refining, defining, and naming themes; and (6) producing the report (Braun and Clarke, 2022). In this research, the process will be applied up to the theme-naming stage to ensure a systematic handling and comprehensive understanding of the data. Additionally, the generated codes and themes will form the basis for framework analysis, further supporting the structured analysis and interpretation of the data.

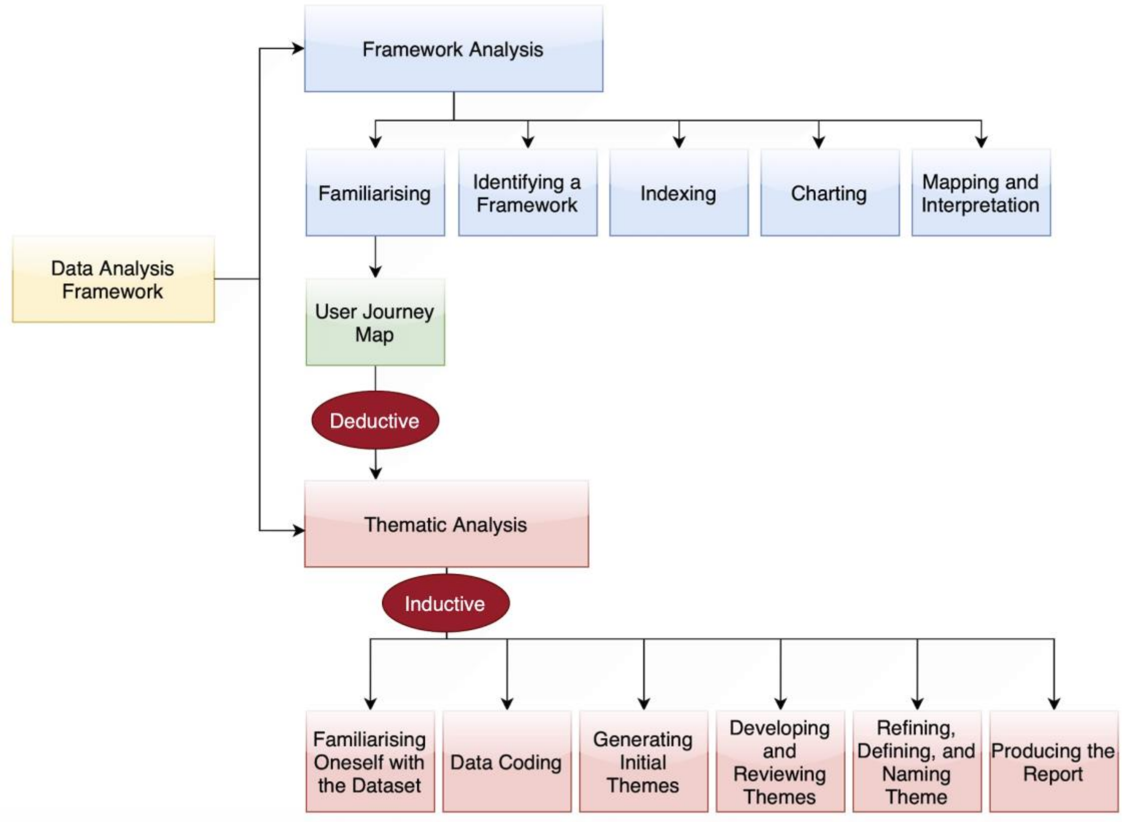
***Figure 3.9 The Application of Thematic Analysis in the Research***



### 3.7.4 A Framework-Based Approach to Data Analysis: User Journey Mapping and Thematic Analysis

This research employed both framework analysis and thematic analysis (see Figure 3.10). Framework analysis was first used to generate user journey maps, which then informed the deductive phase of the thematic analysis. Although the approaches were applied separately, they contributed complementary insights to the overall analysis. This integration enables a comprehensive understanding of the experiences of individuals with arthritis by combining the depth of thematic analysis with the structure framework analysis approach. Specifically, user journey mapping serves as the initial analytical framework, providing a structured visualisation of healthcare experiences and identifying key stages within user interactions. Thematic analysis is then applied to extract people-centred care elements, offering more profound insights into key themes and patterns within the data. This combined approach aligns closely with the research objectives, ensuring a structured yet nuanced interpretation of qualitative data and facilitating the development of the people-centred user experience framework.

***Figure 3.10 Data Analysis Framework***



Within this research, the user journey map serves as the analytical framework, providing a visual and sequential structure to represent participants' interactions within the healthcare system. The linear structure of the user journey map offers a systematic approach to organising data, enabling the categorisation of participants' experiences into distinct healthcare stages. However, while the journey map provides an overarching framework, individual experiences often deviate due to variations in service accessibility, treatment pathways, and personal circumstances. To capture these complexities, this research employs thematic analysis to identify the underlying patterns and themes embedded within participants' narratives.

Thematic analysis uses an inductive approach, allowing patterns and themes to emerge directly from the data. Subsequently, the transition from thematic analysis to framework analysis follows a deductive approach, ensuring that the analytical process remains data-driven in its exploratory phase and structured in its theoretical development. During the thematic analysis phase, the inductive approach is primarily employed to identify new, participant-driven themes, ensuring that the analysis remains closely aligned with the lived experiences of individuals with arthritis.

Building on the thematic analysis, this research employs both deductive and inductive reasoning to identify and refine key themes in participants' experiences of arthritis care. Deductive reasoning was used to organise data based on the user journey map, while inductive reasoning allowed new, unanticipated themes to emerge directly from the data. In addition, abductive reasoning enriched the analysis by enabling a reflective interpretation of findings that did not fit neatly into initial categories. By integrating these modes of reasoning, the study offers a nuanced and people-centred understanding of arthritis care that captures both expected patterns and individual variations in service experiences.

## 3.8 Ethic Consideration

The research received ethical approval (see Appendix A) from Birmingham City University's Ethics Committee prior to data collection, ensuring that all research activities adhered to the university's ethical standards and guidelines. Informed consent was obtained from all participants before data collection commenced. Participants were provided with detailed information about the research objectives, procedures, and their rights, including the right to withdraw at any time (see Appendix B). Consent was documented through signed consent forms electronically through e-mail (see Appendix C).

After data collection, all interviews conducted via Microsoft Teams were securely stored on OneDrive, an encrypted cloud storage platform approved by the university. Each recorded interview was transcribed into a text format to facilitate analysis, and the transcriptions were also stored in the same secure OneDrive environment. Data storage was managed in strict accordance with the university's data protection policies, ensuring that only authorised personnel had access to the files. To maintain confidentiality, all participant identifiers were removed from the transcripts, and each participant was assigned a unique code. This anonymisation process ensured that individual identities remained protected throughout the research process. The storage of both audio recordings and transcriptions on OneDrive provided an additional layer of security, including encryption and regular backups, thereby minimising the risk of data loss or unauthorised access.

## 3.9 Credibility, Transferability, Dependability, and Confirmability

Credibility refers to the accurate representation of the phenomenon being studied (Shenton, 2004). In this research, the credibility of the findings was established through the application of appropriate data collection and analysis methods, ensuring that the results accurately reflect the lived experiences of individuals with arthritis (Jensen, 2008). Semi-structured interviews were employed as the primary data collection method, designed with in-depth, open-ended questions and facilitated through multiple interactions with participants to capture their rich narratives and authentic experiences. During the interviews, the researcher verified the accuracy of the data and paid close attention to subtle variations within participants' accounts, thereby minimising potential errors arising from misunderstandings or biases.

In this research, transferability was supported through the provision of rich contextual information and detailed descriptions (Lincoln and Guba, 1985). Data collected from participants via semi-structured interviews, alongside an in-depth analysis of the specific experiences of individuals with arthritis within healthcare services, provided a robust foundation for readers to assess the applicability of the findings to other contexts. Additionally, purposive sampling ensured that the research focused on a specific population, offering profound insights into the healthcare experiences of individuals with arthritis (Lincoln and Guba, 1985). The applicability of the findings depends on the degree of similarity between the context of this study and the target context, making the ultimate judgement of transferability the responsibility of the reader (Lincoln and Guba, 1985).

In this research, dependability was ensured through a rigorous study design and robust data analysis methods. The combination of thematic analysis and framework analysis demonstrated the principle of triangulation, validating the consistency of the data through multi-perspective analytical approaches (Lincoln and Guba, 1985). Furthermore, a detailed audit trail was maintained throughout the research process, documenting every decision from data collection to analysis, thereby ensuring transparency and replicability. Through these measures, the study maximised dependability within the framework of a naturalistic approach (Lincoln and Guba, 1985).

Confirmability refers to the extent to which the findings of a study are shaped by the participants' experiences rather than the researcher's biases (Lincoln and Guba, 1985). In this research, semi-structured interviews and open-ended questions were employed to ensure that participants could freely articulate their authentic experiences, minimising the influence of bias on data recording (Shenton, 2004). The integration of thematic analysis and framework analysis provided a structured analytical framework, enhancing the consistency of interpretations (Braun and Clarke, 2022; Ritchie and Spencer, 2002). Furthermore, the researcher maintained a reflexive journal throughout the study, continuously monitoring and addressing personal assumptions and biases to ensure that the analysis remained participant-centred (Berger, 2015). These measures collectively ensured the confirmability of the research findings, authentically reflecting participants' experiences and the realities of healthcare services.

## 3.10 Methodological Challenges and Reflections

The concept of interdisciplinarity is not easily achieved, as communication between disciplines can pose significant challenges (Benard and De Cock-Buning, 2014). Different disciplines often operate with distinct theoretical frameworks, research methodologies, and terminologies, which may result in misunderstandings or asymmetries of information during collaborative processes (Klein, 1990). This issue is particularly pronounced in the context of complex healthcare service design, where different disciplines' theoretical frameworks, methodologies, and terminologies frequently differ considerably (Repko et al., 2017). Such differences may lead to misunderstandings or conflicts within research teams when defining problems, analysing data, or developing solutions. Consequently, establishing a shared understanding and communication mechanism to overcome these barriers and achieve genuine knowledge integration emerges as a critical challenge in interdisciplinary practice (Stokols et al., 2008). Despite the challenges associated with interdisciplinary research, precise communication mechanisms and shared research frameworks can effectively foster collaboration across disciplines, providing more comprehensive solutions to complex healthcare issues (Benard and Mooney, 2014; Repko et al., 2017).

Additionally, Microsoft Teams provided an efficient and convenient tool for conducting interviews in this research. Its flexibility and accessibility enabled the researcher to overcome geographical and temporal constraints and better accommodated the specific needs of individuals with arthritis, such as reducing physical discomfort and time pressures associated with travelling. This online interview approach effectively facilitated the smooth progression of data collection. However, it is crucial to acknowledge the potential limitations of virtual interviews, particularly the absence of non-verbal communication cues such as facial expressions and body language, which may affect the depth of understanding of participants' emotions and behaviours (Lo Iacono et al., 2016). As such, researchers must account for this as a potential source of bias during the analysis process and mitigate the information gap by adapting questioning techniques, paying closer attention to vocal tone and inflexion, and incorporating more open-ended questions (Lo Iacono et al., 2016).

Furthermore, the applicability and value of semi-structured interviews may be somewhat constrained when they cannot be conducted in a face-to-face format (Kakilla, 2021). The use of technological tools in particular poses challenges to the quality of interviews, as it may hinder the capture of participants' behaviours and reactions in their natural state, raising concerns about the authenticity and completeness of the data (Marshall and While, 1994). Therefore, researchers must carefully consider these factors in interview design and data analysis to ensure the credibility and validity of the research findings.

## 3.11 Summary

In conclusion, the methodological framework outlined in this chapter demonstrates a rigorous and systematic approach to understanding the experiences of people with arthritis in healthcare settings. The analytical process in this research begins with a structured analysis based on the user journey map, which serves as an organising framework to capture the key stages, interactions, and contextual factors shaping participants' arthritis care experiences. This structure provided a foundation for the subsequent thematic analysis, which employed both inductive and deductive reasoning. Inductive reasoning allowed for the emergence of participant-driven themes grounded in real-world experiences, while deductive reasoning supported the categorisation of these themes in relation to pre-identified concepts derived from the journey structure. Furthermore, abductive reasoning facilitates an iterative dialogue between empirical data and theoretical insights, allowing for deeper interpretation of deviations from expected healthcare pathways and a more nuanced understanding of patient experiences.

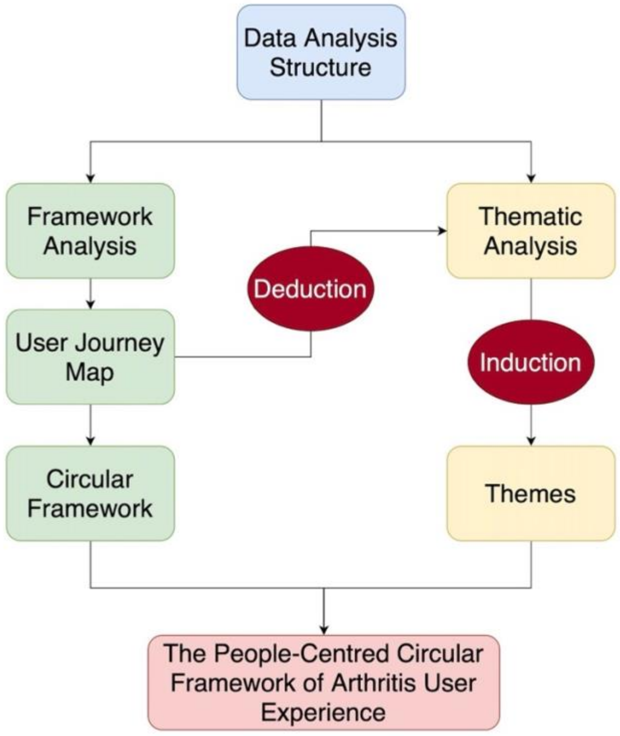
Aligned with interpretative phenomenology, this approach underscores the importance of exploring how individuals construct meaning within the healthcare context, acknowledging the interplay between personal experiences and broader systemic factors. The integration of user journey mapping, thematic analysis, and framework analysis, underpinned by multiple reasoning approaches, ensures that the research captures both the structured and subjective dimensions of participants' experiences. This methodological approach not only provides a comprehensive and people-centred interpretation of arthritis healthcare experiences but also offers actionable insights for designing more responsive and empathetic healthcare services. By prioritising people-centred analysis, the research establishes a robust foundation for deriving meaningful conclusions and practical recommendations for improving healthcare services for people with arthritis.

# Chapter 4: Data Analysis

## 4.1 Introduction

In this chapter the researcher describes how data analysis has been completed to address the question: *How are the people-centred elements within healthcare services experienced from the perspective of people with arthritis?* This chapter aims to present the application of two qualitative analytical methods adopted in this research, framework analysis and thematic analysis, in processing the data and understanding participants' experiences of healthcare services. Through an analysis of interview data from seven participants living with arthritis, the chapter not only reconstructs the behavioural trajectories within the service journey but also provides in-depth insights into how participants understood, experienced, and responded to the healthcare system at different stages, with particular attention to how they perceived people-centred elements within their care (see Figure 4.1).

***Figure 4.1 Data Analysis Structure and Stages***



## 4.2 Framework Analysis Stage 1: Data Familiarisation and User Journey Mapping

In the first stage of framework analysis, the researcher undertook an in-depth reading of the interview transcripts and re-listened to the audio recordings to gain a comprehensive understanding of the scope and diversity of the data (Ritchie and Spencer, 2002). Following the completion of data collection, the researcher entered the familiarisation phase through repeated reading, careful organisation, and initial annotation of interview content from seven individuals living with arthritis. All interviews were conducted via the Microsoft Teams platform and manually transcribed verbatim. The resulting textual data encompassed participants' narratives of their arthritis journey, experiences of service use, self-management practices, and emotional responses.

During familiarisation phase, the researcher attended not only to the explicit content of the interviews, such as symptoms and care pathways, but also to more implicit aspects, including emotional shifts embedded in participants' language and recurring points of tension. The emphasis was placed on developing an understanding of the lived experience of individuals with arthritis from a first-person perspective, with a strong focus on a people-centred analytical lens. In doing so, the researcher began to note early indications of cyclical patterns in how participants moved between phases of seeking care, adapting, and re-engaging with services.

To enhance the understanding of participants' overall experiences, this research incorporated the conceptual framing of the user journey map during the familiarisation stage to support the preliminary organisation of interview content. The user journey map highlights the phased pathways, behaviours, and emotional experiences that individuals encounter throughout their engagement with services. The familiarisation enables the researcher to develop a holistic understanding of the care experience from the participants' perspective. The familiarisation process also supported the identification of differences between participants paths, including variations in how and when individuals' healthcare returned to services

Based on the literature in chapter 1 and data, the user journey map is divided into two components: medical treatment and self-management. The medical treatment component illustrates the participants' experiences within the formal healthcare system, including prescribed interventions, medication use, and their perceived effects (Wasserman, 2011). In contrast, the self-management component traces the efforts made by participants outside the formal healthcare context to manage their condition, such as engagement in exercise routines, dietary modifications, and the use of assistive devices (Barlow, 2002b). The journey maps were organised in a linear structure, however, due to the nature of the progress of arthritis it became apparent the two components of medical treatment and self-management were often revisited, which was noted for further examination in later analytical phases.

Based on the initial reading and organisation of the interview data, this research identified several key stages within the user journey, including symptom recognition, entry into services, initial treatment, and long-term management (see Table 4.1).

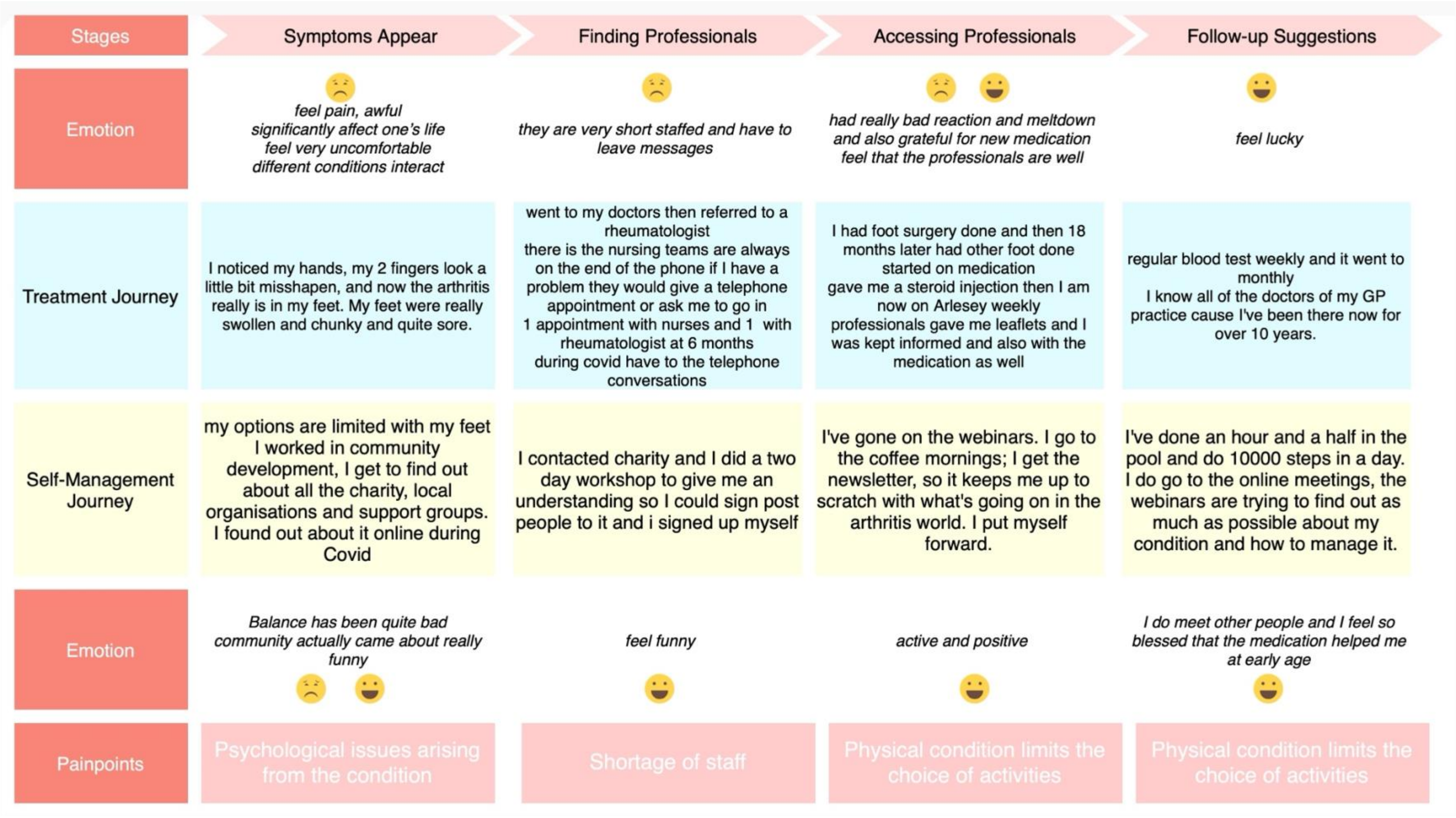
***Table 4.1 Preliminary Framework of the Arthritis User Journey***

| Stages | Medical Treatment | Self-Management |
|---|---|---|
| **Symptoms Appear** | Participants became aware of their symptoms and began to consider the need for medical consultation. | Participants recognised the need for self-management and sought information through online resources or by consulting non-profit organisations. |
| **finding professionals** | Participants sought assistance from healthcare professionals, underwent initial examinations, and received either a preliminary diagnosis or a suspected | Participants sought to further understand the suspected condition and its prognosis, turning to non-profit organisations for support or |

| | | |
|---|---|---|
| | condition. They subsequently went through the referral process and scheduled appointments with rheumatology or other relevant specialists for more detailed diagnostic assessments. | consulting online resources for information. |
| **accessing professionals** | Following a confirmed diagnosis, participants began to engage with the initial treatment plan recommended by healthcare professionals, which included medical interventions such as pharmacological treatment, physiotherapy, or surgery. | Participants gradually developed self-management strategies for their condition and began to experiment with different approaches to managing their health. |
| **Follow-up suggestions** | Participants engaged in long-term medical monitoring and follow-up consultations, continuously adjusting and optimising their treatment plans. | a long-term and consistent self-management approach |

Based on the above information, the researcher generated seven linear user journey maps, one for each participant (see Figure 4.2). Through the identification and illustration of these journey stages, the researcher was able to develop an overarching understanding of participants' experiences of healthcare services during the familiarisation phase. Particular attention was paid to the interplay between formal medical care and self-management, and how interaction shaped participants's overall experiences.

*Figure 4.2 An Example of User Journey Map - Susan's User Journey Map*



| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | ☹<br>*feel pain, awful*<br>*significantly affect one's life*<br>*feel very uncomfortable*<br>*different conditions interact* | ☹<br>*they are very short staffed and have to leave messages* | ☹ ☺<br>*had really bad reaction and meltdown*<br>*and also grateful for new medication*<br>*feel that the professionals are well* | ☺<br>*feel lucky* |
| Treatment Journey | I noticed my hands, my 2 fingers look a little bit misshapen, and now the arthritis really is in my feet. My feet were really swollen and chunky and quite sore. | went to my doctors then referred to a rheumatologist<br>there is the nursing teams are always on the end of the phone if I have a problem they would give a telephone appointment or ask me to go in<br>1 appointment with nurses and 1 with rheumatologist at 6 months<br>during covid have to the telephone conversations | I had foot surgery done and then 18 months later had other foot done<br>started on medication<br>gave me a steroid injection then I am now on Arlesey weekly<br>professionals gave me leaflets and I was kept informed and also with the medication as well | regular blood test weekly and it went to monthly<br>I know all of the doctors of my GP practice cause I've been there now for over 10 years. |
| Self-Management Journey | my options are limited with my feet<br>I worked in community development, I get to find out about all the charity, local organisations and support groups.<br>I found out about it online during Covid | I contacted charity and I did a two day workshop to give me an understanding so I could sign post people to it and i signed up myself | I've gone on the webinars. I go to the coffee mornings; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world. I put myself forward. | I've done an hour and a half in the pool and do 10000 steps in a day.<br>I do go to the online meetings, the webinars are trying to find out as much as possible about my condition and how to manage it. |
| Emotion | *Balance has been quite bad*<br>*community actually came about really funny*<br>☹ ☺ | *feel funny*<br>☺ | *active and positive*<br>☺ | *I do meet other people and I feel so blessed that the medication helped me at early age*<br>☺ |
| Painpoints | Psychological issues arising from the condition | Shortage of staff | Physical condition limits the choice of activities | Physical condition limits the choice of activities |

This holistic understanding enabled the researcher to capture both commonalities and variations across individual journeys, thereby identifying key areas of focus for the preliminary analysis. In addition, during the repeated reading of the interview data, the researcher refined each participant’s user journey map by incorporating key statements expressed throughout the journey, typical events experienced, and notable emotional responses. These maps not only captured significant touchpoints across the different stages of the user journey but also reflected the nuances of individual experiences.

The key expressions, events, and emotional responses were subsequently organised within the structure of the four core stages of the user journey: symptom recognition, entry into services, initial treatment, and long-term management. This process helped ensure that the evolving understanding remained closely aligned with participants’ lived realities and provided a clear foundation for the subsequent phases of the Framework Analysis process.

In this way, the familiarisation and journey mapping stages jointly established both the empirical and conceptual groundwork for subsequent analysis. Empirically, these stages organised participants’ accounts into a structured representation of key events, service touchpoints, and emotional responses across different phases of the arthritis care journey, enabling comparison of commonalities and variations across individual experiences. Conceptually, this process supported the development of an initial analytical orientation towards how people-centredness was experienced and enacted across the care trajectory.

The journey maps also revealed the non-linear and often circular nature of arthritis care experiences, in which participants moved repeatedly between symptom recognition, service entry, treatment adjustment, and long-term management. By foregrounding this iterative pattern, the mapping process ensured that subsequent Framework Analysis remained grounded in the dynamic realities of chronic illness care rather than assuming a linear progression. Together, these stages provided a coherent foundation for interpreting how people-centred care was shaped across diverse arthritis care contexts.

## 4.3 Framework Analysis Stage 2: Identifying Framework

The development of the framework within the framework analysis was informed by repeated reading and organisation of the interview data, supported by the key service-related stages identified in the user journey maps as structural reference points. Rather than summarising participants' accounts, this stage involved making deliberate analytical decisions about what counted as a meaningful pattern and why certain service encounters, or emotional responses appeared repeatedly across different narratives. Through immersive and iterative engagement with the transcripts of the seven participants, typical situations, significant events, and notable emotional shifts encountered throughout their service experiences were carefully identified and annotated (Smith et al., 2009). This process enabled the researcher to progressively clarify the core stages of participants' engagement with services and to construct a structured understanding of the overall content of the data.

Subsequently, the researcher further refined and clarified four main analytical stages by drawing on key moments, service touchpoints, and emotional fluctuations repeatedly referenced by participants during the interviews. These stages did not impose a priori but emerged through the identification of patterns that persisted across narratives, which recognised how participants reflected on broader systemic challenges. These four stages, needs identification, information acquisition, service utilisation, continuity and coordination of care, reflect the core issues and experiential dimensions commonly encountered by users throughout the healthcare journey. The four stages represent not only the abstraction of the interview data but also a staged synthesis ground in participants' lived experience.

In constructing the framework, the researcher further incorporated commonly occurring and representative service stages from the user journey maps, such as symptom recognition, entry into services, initial treatment, and long-term management. By positioning each interview excerpt within the journey map, the researcher engaged with the data to trace where along the care trajectory particular challenges intensified or altered. This process supported the identification of cyclical patterns in participants' experiences (Ritchie and Spencer, 1994). These concrete service stages were analysed across the broader four-stage analytical structure outlined above, allowing for a perspective that is both detailed and holistic. This integrated structure ensured that the analysis could comprehensively reflect the multidimensional needs and experiences articulated by participants, while also reinforcing the people-centred orientation of the research. The integrated structure provided a robust and coherent foundation for the subsequent stages of indexing and in-depth analysis.

***Table 4.2 Preliminary People-Centred Framework Structure: An Illustrative Case from Susan's Journey***

| Domains of User Experience | Thematic Framework Stage | User Journey Map Stage | Description or Illustrative Quote |
|---|---|---|---|
| Medical Treatment | Needs Identification | Symptoms Appear | My finger looks a little bit misshapen. I think no one need to do something about that, so I went to my doctors. |
| | Needs Identification | Symptoms Appear | Now, the arthritis really is in my feet |
| | Needs Identification | Symptoms Appear | I didn't really wear normal shoes cause I couldn't get normal shoes on, my feet were really swollen |
| | Needs Identification | Accessing Professionals | I had foot surgery done and bunions and wires and things. I had one foot done first and then 18 months later I had other foot done |
| | Needs Identification | Symptoms Appear | A few years later, I've noticed that my toes have really swollen…and chunky and quite sore. So, I went to my doctors. |
| | Service Utilisation | Finding Professionals | He referred me to a rheumatologist |
| | Needs Identification | Accessing Professionals | I started on medication, which was *NAME*…but I had a really bad |

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|---|---|---|---|
| | | | reaction…I was sick, I had headaches, and it never went away. |
| | Needs Identification | Accessing Professionals | I went back and anyway they then put me on a drug called *NAME*. So, I was on that, but then I started to get hives on my skin, rashes, and things like that. |
| | Needs Identification | Accessing Professionals | My feet were really swollen…I had a real meltdown, and I think that's what did it, for third drug that I'm now on |
| | Needs Identification | Follow-Up Suggestions | I'd gone from a regular blood test cause I've been at. I was having weekly blood tests, and it went to monthly |
| | Needs Identification | Follow-Up Suggestions | I got a steroid injection but then…they must have had a case conference to put me on what I'm on now, which is the *Name* which is the injection that I have weekly |
| | Needs Identification | Follow-Up Suggestions | I had to go for the blood test weekly |
| | Service Utilisation | Finding Professionals | I cannot fault the rheumatology whatsoever I can ring go up |
| | Information Acquisition | Accessing Professionals | When I first got diagnosed…they gave me leaflets. I was kept informed and with the medication as well. |
| | Service Utilisation | Finding Professionals | There are the nursing teams are always on the end of the phone, although they're very short staffed and you do have to leave messages sometimes because there's so busy. But where they can, they do get back to you if there's any issues. And I think that if I did have a problem about my manager, my conditions, I think they would automatically |

|  |  |  |  |
|---|---|---|---|
|  |  |  | either give me a telephone appointment or ask me to go in because I am seeing face to face twice a year. |
|  | Service Utilisation | Finding Professionals | I have one appointment with the nurses at 6 months later and one appointment with my rheumatologist six…so I see twice a year I actually go to the hospital, but obviously during covid we have the telephone conversations, but they do like to see you because you’ve got to have the blood tests. |
|  | Continuity and Coordination of Care | Follow-Up Suggestions | If you don’t see the same doctor twice or you’ve got a locum doctor then there, that’s where the issues arise because you’ve no continuity of care |
|  | Continuity and Coordination of Care | Follow-Up Suggestions | I think that’s where a lot of the problems lie. It’s the continuity of care. I’m lucky because I know all of the doctors of my GP practice cause I’ve been there now for over 10 years. |
| Self-Management | Needs Identification | Symptoms Appear | I’ve been a walker, but my options are limited with my feet |
|  | Needs Identification | Follow-Up Suggestions | I’ve done an hour and a half in the pool this morning. And I do swim in the fast lane, so I am a pretty proficient swimmer, and I do try and do my 10000 steps in a day. |
|  | Information Acquisition | Follow-Up Suggestions | I do go to the online meetings. The webinars are trying to find out as much as possible about my condition and how to manage it. |
|  | Service Utilisation | Finding Professionals | I worked in community development…when I came back to this country, I thought I want to |

| | | | |
|---|---|---|---|
| | | | work in community development…so I get to find out about all the charity, all the local organisations and support groups… then I found out about it online during covid I'd say. I contacted them to find out about when meetings were and I did a two day workshop in *NAME* to give me an understanding so I could sign post people to it…I signed up myself |
| | Information Acquisition<br>Service Utilisation | Follow-Up Suggestions | I've gone on the webinars. I go to the coffee morning; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world. |

The development of the framework reflects a data-driven and logically coherent analytical approach, integrating a design thinking methodology centred on the user journey map. Each stage of framework was grounded not only in how participants expressed their experiences, but how their experiences connected to specific moments on the journey map, enabling deeper interpretive insights into their motivations, frustrations, and coping strategies.

During this stage, the researcher also considered alternative ways of structuring participants' service experiences, such as treating emotional responses as a separate analytical stage. However, this interpretation lacked consistency across cases and offered limited additional explanatory value. The four-stage structure was therefore retained as the most coherent representation of recurring experiential patterns.

By using the user journey map as a guiding structure and placing user experience at the core, the framework establishes a systematic and robust foundation for the subsequent stages of indexing and charting within the framework analysis process.

## 4.4 Framework Analysis Stage 3: Indexing

Following the establishment of the thematic framework, the researcher proceeded to the indexing stage. The aim of this stage was to systematically categorise all interview data according to the four core stages identified in the previous phase, needs identification, information acquisition, service utilisation, and continuity and coordination of care. These stages, derived from participants' lived experiences, represent key points within the user journey and reflect the inherent structural features of the care process. Importantly, the use of these stages provided an interpretive scaffold that allowed the researcher to consider the significance of each data segment within the broader service trajectory experienced by each participant, rather than treating the data as isolated statements. This ensured that the analysis remained closely aligned with users' real-life experiences while maintaining a clear and coherent analytical logic.

During the indexing process, the researcher focused on mapping segments of the interview data to the appropriate stage within the framework, while also examining the deeper interpretive meanings that underpinned each narrative moment. The intention was not to sort the data but to trace how particular statements revealed shifting needs, emotional responses, and decision-making processes across different points in the journey.

The researcher carefully reviewed the interview transcripts of all seven participants, assessing each passage in relation to the relevant service touchpoint, specific user behaviour, emotional response, and position within the broader service pathway. This analytical judgement involved reading the data in two ways: the surface description, which refers to what the participant explicitly said, and the deeper interpretive layer, which reflects what the moment might represent in relation to the journey map or the emerging circular framework. Each segment was then indexed according to its alignment with one of the guiding analytical stages.

For example, when participants described their early awareness of symptoms, initial uncertainty, or personal explanatory models, these passages were indexed under needs identification. Beyond the literal statement of symptoms, the indexing recognised how these early narratives often revealed feelings of doubt or frustration, signalling the early emotional undercurrents of each participant's journey. Content relating to the active search for information about the condition, evaluation of treatment options, or attempts to access additional resources was categorised as information acquisition. Detailed accounts concerning treatment decisions, experiences with healthcare professionals, resource selection, and navigation of health systems were assigned to the service utilisation stage. Finally, data reflecting long-term support, monitoring, ongoing treatment adjustments, and perceptions of coordination were categorised under continuity and coordination of care. In many cases, these passages also included reflections that hinted at challenges in maintaining consistency, building trust, or navigating fragmented care, which were noted during indexing as recurring patterns across participants.

Throughout the indexing process, the researcher adhered to the principles of consistency and inclusivity, ensuring that key data and significant perspectives were comprehensively captured within the indexing framework. At the same time, care was taken to preserve the narrative context of each excerpt, especially where a participant's tone, emotion, or implicit meaning contributed to understanding their journey within the health system. This avoided excessive abstraction or decontextualisation (Ritchie and Spencer, 2002). By grounding indexing in both the explicit content and the researcher's interpretative insights into participants' accounts, this stage provided a reliable and analytically rich foundation for deeper interpretive synthesis in the following stages.

## 4.5 Framework Analysis Stage 4: Charting

The objective of the charting stage is to extract the indexed content from the original transcripts and reorganise it into a structured framework that facilitates analysis and comparison. This structured approach effectively avoided the risk of over-fragmenting or excessively segmenting the interview data. The structured approach emphasised the temporal flow of experiences across different stages of the journey and highlighted the inherent continuity and coherence between behaviours and emotional responses at various points in time. In reorganising the data, the researcher made interpretive decisions about which narrative elements captured key shifts in experience, ensuring the charted summaries reflected not only what participants said but also what these expressions indicated in terms of emotional transitions, decision-making processes, or systemic pressures (World Health Organisation, 2015). This method closely aligns with the core principles of the people-centred approach, which prioritises attention to the evolving nature of user experiences and their interactive dimensions, enabling a holistic understanding of the contexts in which participants engage with healthcare services.

Table 4.3 provides a structural illustration of the charting matrix, with selected excerpts presented for illustrative purposes only. For this illustration, data from two participants have been included to demonstrate how experiences were summarised across the four analytical stages.

***Table 4.3 Structural Illustration of the Charting Matrix***

| Participants | Susan | David |
|---|---|---|
| **Needs Identification** | My fingers look a little bit misshapen;<br>Now the arthritis really is in my feet;<br>A few years later, I've noticed that my toes were really swollen;<br>My options are limited with my feet. | One of the things with arthritis is you don't get a definitive diagnosis;<br>You go and somebody looks at your shoulder or your knee or your hip and say you've got arthritis there. |
| **Information Acquisition** | I do go to the online meetings. The webinars are trying to find out as much as possible about my condition and how to | There was a sort of advice line they had, which I was part of. If I needed to. |

| | | |
|---|---|---|
| | manage it;<br>I’ve gone on the webinars;<br>When I first got diagnosed, they gave me leaflets, I was kept informed and also with the medication as well. | |
| **Service Utilisation** | I signed up myself…I join the group;<br>I go to the coffee mornings;<br>I cannot fault the rheumatology department whatsoever I can ring go up.there is the nursing teams are always on the end of the phone. | If I’ve had a kind of long connection with a consultant, they will give me their telephone number and I can arrange a direct appointment;<br>I’m happy talking to a GP on the phone, that’s easier to do than seeing them;<br>It is only 10 minutes appointments, so you have to say whatever you want to say and get an answer and get a prescription if you need one. |
| **Continuity and Coordination of care** | I’m lucky because I know all of the doctors of my GP practice casue I’ve been there now for over 10 years. | |

Through this chart, the researcher was able to clearly present each participant’s individual trajectory and overall experience across the four analytical stages, providing a rich and well-structured foundation for the subsequent mapping and development of an integrated experience framework. Importantly, the charting process also identified the cyclical nature of participants’ journeys, as similar emotional or practical challenges resurfaced at different stages, thereby informing the refinement of the circular framework and demonstrating how individual journey maps supported its conceptual development.

## 4.6 Framework Analysis Stage 5: Mapping and Interpretation

In the final stage of framework analysis, the researcher focused on the charted data from the previous phase, advancing the analysis through cross-stage and cross-participant structural linkage and pattern recognition. The aim was to construct an analytical framework that could effectively represent the full scope of participants' service experiences. The mapping process revealed a cyclical pattern within participants' service journeys. This led to the construction of a circular framework of user experience, centred on the four core analytical stages.

The development of this framework was not based on priori assumptions but was instead gradually constructed through the following three stages of analysis.

Firstly, building on the charting phase, the researcher examined the logical relationships between the four analytical stages: needs identification, information acquisition, service utilisation, and continuity and coordination of care. Through longitudinal tracking of individual journeys, it became evident that most participants did not complete the service pathway in a single, linear sequence. Rather, following a period of care or self-management, they often returned to the stage of recognising new or unmet needs. This pattern was particularly pronounced at the stage of needs identification, where participants articulated different needs at different points in time. This observation suggested the service journey of individuals living with arthritis is characterised by a circular nature. However, it is important to note that not all participants demonstrated this cyclical pattern in the same way or to the same extent, and this variation required careful interpretive engagement rather than assuming uniformity across cases. For example, some participants showed only partial return to needs identification stage, whereas others moved rapidly back and forth between stages depending on fluctuations in symptoms, availability of services, or personal readiness. This observation suggested the service journey of individuals living with arthritis is characterised by a circular nature.

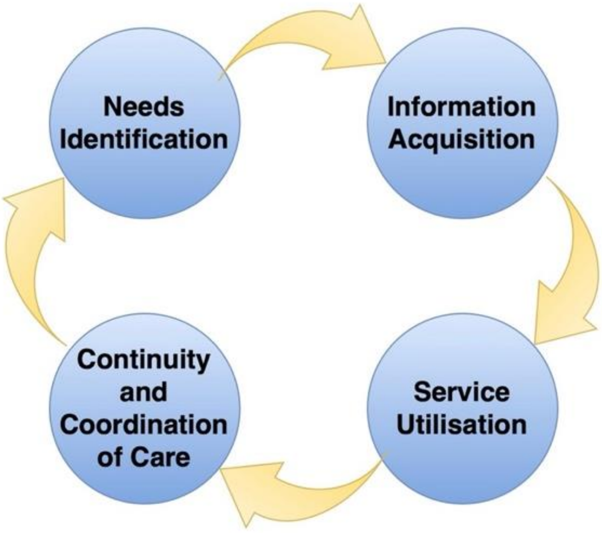
Secondly, the researcher further analysed participants’ narratives around transitions between stages, with a focus on identifying the key touchpoints and mechanisms of transition from one stage to the next stage. For example, participants’ return to the stage of needs identification was often triggered by changes in symptoms; progression from information acquisition to service utilisation frequently occurred when acquired information was processed into actionable decisions. These transitions were influenced by factors such as time, service accessibility, available resources, and psychological readiness. In analysing these transitions, the researcher deliberately moved beyond surface-level descriptions of participants' verbal accounts to interpret underlying mechanisms, such as the emotional labour involved in reframing new information, the uncertainty inherent in decision-making, or the implicit expectations participants held about service responsiveness. These interpretive steps enabled a deeper understanding of how transitions were experienced, not merely reported. This analysis of participants’ transitional narratives enabled the researcher to understand not only the connections between stages, but also how these transitions collectively formed a dynamic and circular system of engagement with services, rather than a strictly linear process.

While shared patterns, including the interweaving of family support and interactions with community resources, were consistently observed, some participants articulated other concerns. These differences offered critical analytical insights, highlighting that although the cyclical structure provides an overarching pattern, the lived experience within each loop may differ substantially depending on personal, contextual, or systemic factors.

Thirdly, once the structural relationships and mechanisms of transition had been identified, the researcher developed a visual representation of the stage-to-stage dynamics, gradually constructing a people-centred model of service experience structured around the four analytical stages as interconnected components within a circular framework. Here, the journey maps played a foundational role: each individual map provided micro-level temporal and emotional cues, while the circular model abstracted these into a macro-level structural pattern. This dual perspective ensured that the final framework was grounded in individual lived experiences while representing a synthesised pattern across cases.

The final circular framework comprises four interconnected stages, “Needs Identification”, “Information Acquisition”, “Service Utilisation”, and “Continuity and Coordination of Care”, each systematically derived from the user journey map and participants’ lived experiences through framework analysis (see Figure 4.3). This framework captures the cyclical nature of arthritis care, recognising that patients do not follow a linear healthcare pathway but rather move through these stages repeatedly as their condition evolves. Importantly, the circular model does not assume participants must always begin at the same point or follow the sequence in a fixed order. Instead, movement between stages can occur in multiple directions, at varying speeds, and triggered by different symptoms. For example, some participants returned directly from service utilisation to needs identification without passing through extended periods of continuity and coordination. The flexible sequencing reflects both the non-linearity of chronic illness trajectories and the personalised nature of people-centred care.

***Figure 4.3 Circular Framework of User Experience***



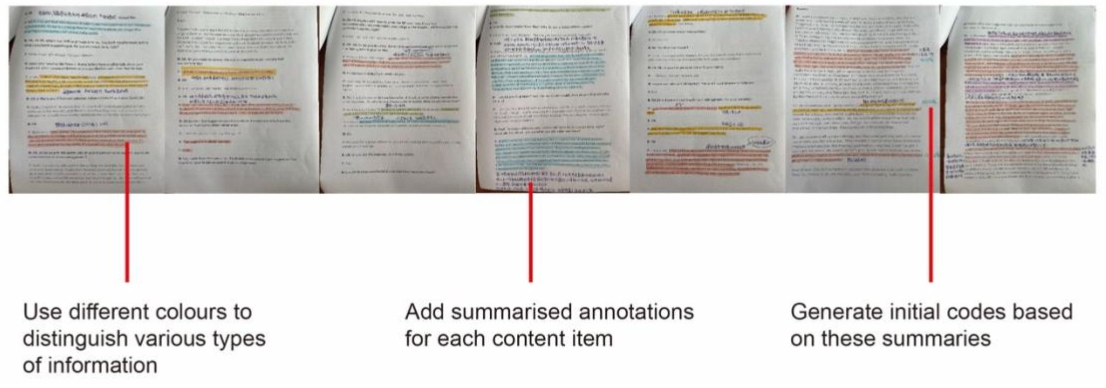
The resulting circular framework of service experience emerged as a structural outcome through continuous comparison, longitudinal tracking, and iterative synthesis. This circular model enables a comprehensive representation of the service pathways and experiential logic of people with arthritis. By integrating variation, commonality, and interpretive depth, the framework identifies not only the cyclical rhythm present across most participants but also the differentiated ways in which individuals navigate these cycles.

## 4.7 Thematic Analysis Stage 1: Familiarising with the Dataset

In the framework analysis stage, the researcher achieved familiarisation with the dataset. However, during the subsequent thematic analysis, the researcher further immersed in the data, specifically focusing on the people-centred approach of healthcare services. This deeper engagement allowed for the exploration and identification of nuanced patterns and insights that explicitly align with people-centred elements within participants' experiences.

The first stage of thematic analysis is crucial to develop an in-depth understanding of the dataset through an immersive approach. This process centres on a further familiarisation of the data to ensure a comprehensive understanding of the underlying structures, themes, and subtle variations (Green and Guinery, 2004). In practice, familiarising with the dataset involves not only reading the data word by word but also recording any initial analytical thoughts, emerging themes, or patterns for systematic analysis later (Braun and Clarke, 2022) (see Figure 4.4). These brief notes should capture each data item's unique information and its position within the overall dataset, aiming to identify interconnections and potential associations among data points (Braun and Clarke, 2022). This approach provides a holistic insight into the dataset, laying the groundwork for more detailed analysis to follow.

***Figure 4.4 Familiarising with the Dataset***



During the thematic analysis process, the researcher utilised both digital and physical formats of the data (Braun and Clarke, 2022). The transition between these mediums prompted new reflections, insights, and interpretations. The researcher observed digital data facilitated swift retrieval and systematic organisation around specific themes, while physical data fostered a heightened emotional connection through tactile engagement (Ellis and Tucker, 2020). The switching process highlighted the multifaceted relationship between the researcher and the data, underscoring how different mediums can draw attention to varying details within the data (Kehrer and Hauser, 2012). Furthermore, changes in physical environments, such as working at a desk, in a library, or at a café, influenced the researcher’s emotional state and energy levels, thereby shaping their sensitivity to the data and interpretative responses (Braun and Clarke, 2022).

In this stage, the researcher began to pay attention not only to the explicit content of participants’ accounts but also to the implicit emotional tone, hesitations, and contradictions in their narratives, which provided interpretative depth beyond descriptive summarisation.

The researcher, drawing on participants’ interview data, generated codes and themes to uncover new insights and patterns rather than to validate pre-established hypotheses. The data revealed numerous accounts concerning the limitations of health service resources, accompanied by diverse and intense emotional reactions. The narratives shared by participants resonated with their lived experiences, while also complementing and challenging preconceived notions and misunderstandings about the current state of healthcare services for people with arthritis.

In the process of familiarising the data, the researcher was prompted to consider the influence of subjectivity on data interpretation carefully. For instance, the researcher initially held a more critical view of the efficiency of the NHS system. However, during the familiarisation process, positive evaluations of the NHS by certain participants were noted. This recognition prompted the researcher to acknowledge and bracket their biases, ensuring that the diversity and complexity of participants' perspectives were interpreted objectively and aligned with the principles of interpretative phenomenological analysis. Therefore, during the familiarisation process, the researcher was mindful of the influence of subjectivity on the interpretation of the data, recognising the importance of critically reflecting on how personal perspectives might shape the analysis.

## 4.8 Thematic Analysis Stage 2: Data Coding

The element of data coding within thematic analysis, is a systematic and meticulous approach to processing the data, which is essential. Coding involves identifying data segments that are relevant to the research question and possess potential significance or analytical value, assigning each with concise yet analytically rich description (coding labels) (Braun and Clarke, 2022). The core of this process involves focusing on specific and detailed content, capturing distinct meanings or concepts within each data segment through coding. Coding is not merely a summary or simplification of data content; it also reflects an analytical perspective of the data (Braun and Clarke, 2022). Once coding across the dataset is complete, all coding labels should be systematically organised, compiling relevant data segments under each label to facilitate further in-depth analysis. However, during coding, the researcher made explicit analytical decisions to identify meaningful segments, by distinguishing between surface-level descriptions and deeper interpretative cues within participants' accounts. This process ensured the avoidance of a purely descriptive coding.

The researcher employed line-by-line semantic coding, allowing semantic codes to capture the explicitly expressed meanings from participants (Braun and Clarke, 2022), thereby gaining a deeper understanding of the attitudes and experiences of people with arthritis regarding healthcare services. However, the researcher observed that focusing solely on the semantic level might overlook deeper, underlying meanings. This prompted a deliberate methodological decision to document initial latent reflections alongside semantic codes, ensuring that potential alternative interpretations remained visible throughout later stages of analysis. To address this, the researcher reflected on how to capture the latent dimensions during subsequent analyses while documenting the semantic codes. Extracting the most significant and frequently occurring initial codes aids in understanding people with arthritis' perceptions of the elements within people-centred healthcare services while preserving their language and original intent.

In the process of thematic extraction, line-by-line coding was initially employed to identify the specific needs and experiences of people with arthritis, refining these into multiple preliminary codes. At this stage, the researcher began comparing emerging codes with points highlighted in the journey maps, including emotional peaks, disruptions, and transitions, so coding remained anchored within participants' lived service trajectories rather than in isolated statements.

Here are two examples of how codes were extracted and developed from participants' statements.

For example, the participant said, "*I had a real meltdown and I think that's what did it, for the third drug that I…that I'm now on*", illustrates how their treatment plan evolved in response to personal experiences and needs. The mention of transitioning to a third drug highlighted a deliberate, targeted adjustment in their treatment plan to address challenges they faced with previous medications. This reflects the code of a targeted treatment plan, where adjustments are made based on the individual's specific circumstances and responses to prior interventions. Beyond the semantic meaning, the researcher noted the emotional breakdown ("meltdown") as an inflection point in the participant's journey map, signalling not only medication failure but a crisis in self-management capacity.

Through reflexivity, a process that involves the researcher's critical self-awareness and examination of how their background, assumptions, and positionality may shape the research process and interpretations (Braun & Clarke, 2022), the researcher critically reflected on their initial interpretations. This ensured that the code was firmly grounded in the participant's lived experiences rather than influenced by pre-existing assumptions about standardised treatment plans. Reflexivity is a key component of qualitative research, promoting transparency and rigour while ensuring that the analysis remains aligned with the participants' perspectives.

Another example is, the participant also highlighted the emotional perspective, stating, "…some of these people literally can't move and can't do anything, so in that aspect I…I feel OK." This illustrates how their interaction with others in a community setting not only provides perspective but also supports their psychological well-being. This aligns with the code of receiving psychological support through non-profit organisations, where shared experiences can foster resilience and emotional balance. The researcher recognised that this interpretation required careful attention to the interplay between the participant's emotional expression and the broader context of community support. By reflecting on the potential influence of their own expectations about community groups, the researcher ensured that the analysis accurately captured the participant's sense of gratitude and emotional connection, rather than imposing an external framework on their experience.

An example of the initial coding for one participant is shown below.

*Table 4.4 Exmaple of Initial Coding - Using One Participant as an Illustration*

| Prticipant 1 - Susan | Initial Coding |
|---|---|
| had foot surgery done 1st and then 18 months later I had the other foot done | **Targeted Treatment Plan** |
| …so I started on medication, which was methotrexate.. | **Targeted Treatment Plan** |
| I'd gone from a regular blood test cause I've been at…I was having weekly blood tests and it went to monthly… | **Targeted Treatment Plan** |
| …I had a real meltdown and I think that's what did it, for the third drug tha I…that I'm now on. | **Targeted Treatment Plan** |
| I'm on now, which is the (*hosipital name*) which is the injection that I have weekly. | **Targeted Treatment Plan** |
| I had the first operation in October…And the other foot is due to be done in mid-March… | **Targeted Treatment Plan** |
| I've done a..an hour and a half in the pool this moring. And I do swim in the fast lane, so I am a …a pretty proficients swimmer and I do try and do my 10000 steps in a day. | **Targeted Self-Management Plan** |
| we got a newsletter from you with your research attached | **Access Information from Non-profit Organisations** |
| I do go to the online meeting | **Access Information from Non-profit Organisations** |
| the webniars are trying to find out as much as possible about my condition and how to manage it. | **Access Information from Non-Profit Organisations** |
| ..and I do meet other people and I 'm thinking, I feel so blessed that the | **Engage with the Community through** |

| | |
|---|---|
| medication I've got helped me at an early age, cause some of these people literatly can't move and can't do anything, so in that aspect I … I feel OK. | **Non-Profit Organisations**<br>**Access Psychological Support** |
| I've gone on the webinars. I go to the coffee mornings; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world | **Access Information from Non-Profit Organisations**<br>**Engage with the Community through Non-Profit Organisations** |
| whatsover, I can ring go up. | **Appointment and Communication Channels** |
| if I've got issues with my medication because it comes from a third party which has been a bit of an issue. The drugs cause it's not issued from the hospital. | **Third-Party Service Integration** |
| when I first got diagnosed, I got-they gave me leaflets. I was kept informed and also with the medication as well. | **Access Information from Professionals** |
| there is the nursing teams are always on the end of the phone, although they're very short staffed and you do have to leave messages sometimes because there's so, so busy. | **Resource Shortage** |
| I think that if I did have a problem about my manager, my conditions, I think they would automatically either give a telephone appointment or ask me to go in because I am seeing face to face twice a year. | **Appointment and Communication Channels** |
| they've consulted me and they're like, you know when I did they…they asked me if I wanted to do my injection weekly or two weekly or you know they consulted me through the plan, because obviously there's a plan there for me and without that, withou that first point of call | **Targeted Treatment Plan** |

| | |
|---|---|
| from...from the GP practices | |
| and the problem is though, our NHS as you know is overwhelmed and it's the doctors are just to just overload it, and if you don't see the same doctor twice or you've got a locum doctor then there, that's where the issues arise because you've no continuity of care. | **Resource Shortage**<br>**Continuity of Care** |

Following the above process, the following codes were derived from the coding of interview data from seven participants.

***Table 4.5 Codes Generated from the Data***

| Number | Code Label |
|---|---|
| 1 | Targeted Treatment Plan |
| 2 | Targeted Self-Management Plan |
| 3 | Continuity of Care |
| 4 | Economic Factors Influence Self-Management Approaches |
| 5 | Economic Factors Influence the Choice of Services |
| 6 | Access Information from Non-Profit Organisations |
| 7 | Access Information from Professionals |
| 8 | Engage with the Community through NHS |
| 9 | Engage with the Community through Non-Profit Organisations |
| 10 | Access Psychological Support |
| 11 | Appointment and Communication Channels |

| | |
|---|---|
| 12 | Resource Shortage |
| 13 | Long Waiting Time |

During the coding process, the researcher recognised the importance of capturing both the emotional dimensions within participants' semantic expressions and the hidden features underlying their discourse. For instance, the code "continuity of care" semantically refers to the need for seamless healthcare services. However, the emotions embedded within participants' narratives, such as frustration over fragmented services, were equally critical to interpreting this code. The researcher reflected that such emotional characteristics might directly influence participants' overall attitudes towards healthcare services, thereby shaping the direction of the coding process. In the initial stages of coding, the interplay between discourse and emotion emerged as central to understanding participants' experiences. This reflection highlighted the importance of decoding not only explicit information but also exploring how participants articulate their deeper needs and experiences through language and emotion (Lindquist et al., 2015).

## 4.9 Thematic Analysis Stage 3: Generating and Defining Themes

A theme captures shared meaning, unified by a central organising concept within reflexive thematic analysis. Themes are defined through the coherence of meaning and conceptual consistency, with each theme having its distinct core organising concept (Braun, Clarke, & Rance, 2014). The analytical task involves exploring shared or similar ideas or meanings expressed in different contexts. Sometimes, this unifying pattern may be more apparent at the semantic or explicit level; at other times, it may be more conceptual or latent (Braun and Clarke, 2022).

In this study, thematic analysis is not merely a tool for identifying shared meaning but also a means of deeply exploring the core concerns and needs of people with arthritis in their experiences of healthcare services. These themes often manifest as explicit statements at the semantic level or as implicit, underlying emotions and attitudes.

### 4.9.1 Developing Initial Themes from Codes

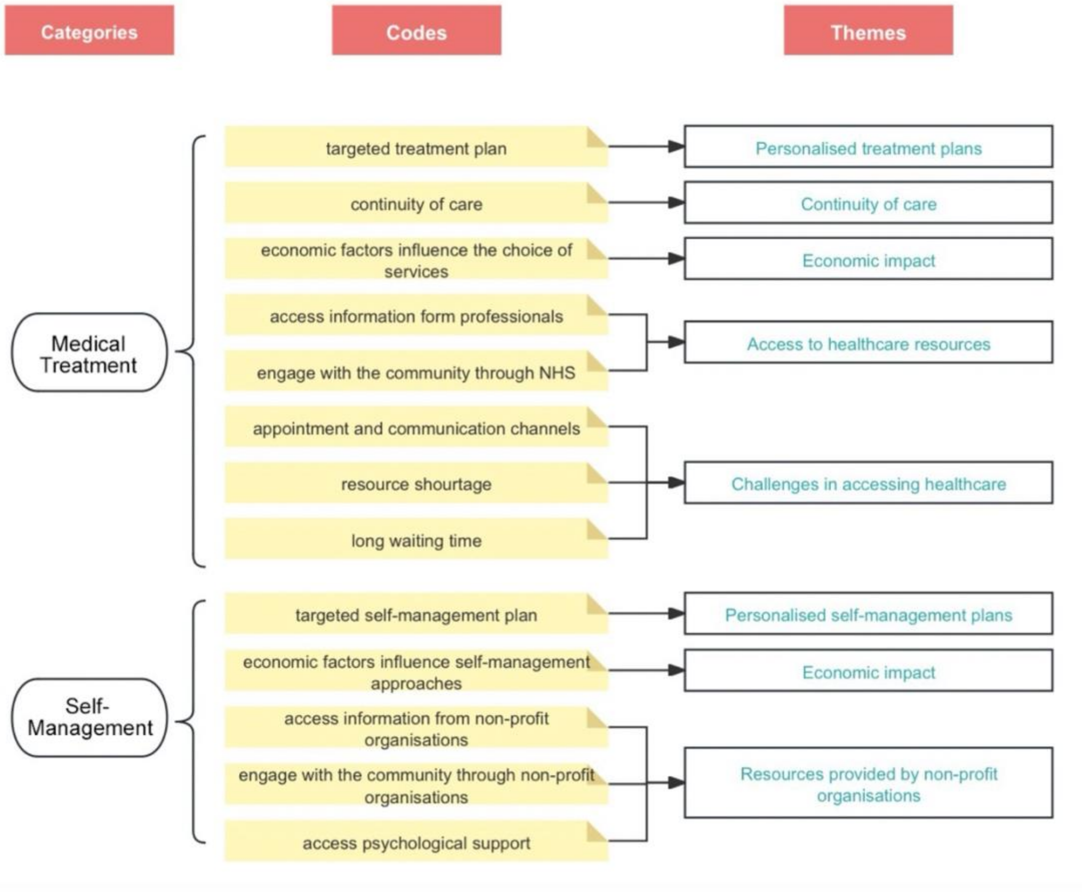
The process of generating initial themes involves a series of interactions with the data coding to explore areas of similar meaning (Braun and Clarke, 2022). Subsequently, potentially relevant codes are grouped together to form candidate themes, and these preliminary patterns of meaning are further examined (Braun and Clarke, 2022). This exploration requires consideration from multiple perspectives: the internal coherence of each grouping, its relevance to the research question, and its role as part of the broader analysis. The researcher also made explicit analytical decisions at each step. For example, determining whether codes shared only descriptive similarity or represented deeper conceptual resonance. Such distinctions were guided by iterative comparison of participants' narratives and theoretical constructs from the literature. The researcher noted that this iterative process required not only analytical focus but also critical reflection on how personal biases and assumptions influenced the grouping of codes. For example, an initial tendency to prioritise codes that reflected systemic barriers was later balanced by deliberately revisiting and integrating codes related to individuals' access to information and educational support.

Themes must capture multiple facets of an idea or concept, which collectively contribute to a shared core idea or central organising concept (Braun and Clarke, 2022). This implies that codes are aggregated into broader patterns that are conceptually coherent and provide significant, relevant insights addressing the research question. During this phase, the researcher critically questioned whether certain codes truly shared a conceptual connection or whether they were grouped due to surface-level similarities. For instance, the inclusion of "resource shortage" under challenges in accessing healthcare was re-evaluated to ensure it reflected participants' nuanced descriptions of both physical and human resource constraints.

The nature of research is inherently interpretative, shaped by the researcher's beliefs and perceptions of the world, as well as their assumptions about how the world should be understood and studied (Lincoln, 2005). These beliefs may often be implicit, intangible, or even subconsciously held. This implies that researchers may not always be fully aware of how their own values and biases influence the research process, necessitating vigilance and reflexivity throughout the research. In this research, reflexivity was maintained by regularly documenting analytical decisions, critically reflecting on potential biases through reflective journaling, and engaging in peer debriefing sessions with supervisors to enhance awareness of any underlying assumptions and ensure transparency and rigour.

The researcher identified several key potential concerns expressed by participants regarding their use of healthcare services. Initially, based on findings from the literature review, two broad categories were established: "access to professionals" and "self-management". These categories reflected the primary behaviours identified among arthritis patients, focusing on treatment and self-management strategies. Subsequently, themes were developed within each of these patterns, focusing on participants' experiences in engaging with healthcare services. These themes were primarily centred on the core experiences described by users during their interactions with healthcare systems. In this process, the researcher initially divided the codes into two categories: medical treatment and self-management (see Figure 4.5), which are derived from the User Journey Map developed in Framework Analysis Stage 1.

*Figure 4.5 Developing Initial Themes from Codes*



The detailed explanation of how codes were systematically developed into themes is provided in Section 4.9.1.1.

#### 4.9.1.1 Process of Developing Initial Themes

The process of refining codes involved analysing patterns and relationships to consolidate codes into coherent themes, ensuring they captured participants' experiences while staying grounded in the data.

*1. Personalised Treatment Plans*

The code Treatment plan evolved into the theme Personalised treatment plans by capturing participants' diverse experiences with tailored care. Some expressed frustration with standardised approaches, while others shared positive experiences with individualised solutions. These contrasting emotions underscored the importance of personalisation in shaping their satisfaction. The researcher interpreted these accounts as illustrating how participants valued being listened to and having their needs considered in treatment decisions.

### 2. *Continuity of Care*

The code Continuity of Care was developed into the theme of the same name to reflect participants' consistent emphasis on seamless, ongoing support in their healthcare journeys. Participants described both the reassurance provided by consistent care relationships and the challenges arising from disruptions, such as staff changes. The researcher noted that these accounts described participants' experiences of maintaining continuity of care and accessing consistent support across services.

### 3. *Economic Impact (Access to Professionals)*

The code "Economic factors influence the choice of services" formed the theme "Economic Impact (Access to Professionals)" as participants subtly indicated that financial considerations guided them towards more affordable options. Their indirect references highlighted how economic factors influenced their decisions, often shaping the accessibility and type of care they pursued.

### 4. *Access to Healthcare Resources*

Codes such as "access information from professionals" and "engage with the community through NHS" were grouped under this theme, as both reflect resources obtained from professionals within healthcare systems. Additionally, the researcher critically considered the contexts in which these resources were accessed. For instance, participants often framed accessing information through professionals in terms of both the quality of the information and the ease or difficulty of obtaining it. This reflection led to an exploration of how structural factors, such as appointment availability or professional attitudes, influenced participants' ability to access these resources.

### *5. Challenges in Accessing Healthcare*

Codes including “appointment and communication channels”, “resource shortage”, and “long waiting time” were grouped together as they collectively highlight the obstacles and difficulties participants faced when navigating healthcare services. Furthermore, the grouping process highlighted the interplay between these challenges. For instance, resource shortages were often linked to long waiting times, while ineffective communication channels exacerbated participants’ frustration when trying to navigate these shortages. The researcher recognised that these connections underscored the systemic nature of these challenges.

### *6. Personalised Self-Management Plans*

The code “Targeted self-management plan” developed into the theme “Personalised Self-Management Plans” as participants often received self-management advice tailored to their individual needs. They also described actively seeking strategies that suited their preferences and felt manageable for them to adopt.

### *7. Economic Impact (Self-Management)*

The code “Economic factors influence self-management approaches” developed into the theme “Economic Impact (Self-Management)” as participants described abandoning certain self-management methods due to financial constraints. They also showed a preference for free or more affordable options when choosing self-management strategies.

### *8. Resources Provided by Non-Profit Organisations*

Within the domain of self-management, the codes “access information from non-profit organisations”, “engage with the community through non-profit organisations” and “access psychological support” were combined into a single theme, reflecting resources participants accessed via non-profit organisations. During this process, the researcher reflected on potential overlaps between non-profit and professional resources and questioned whether participants' reliance on non-profits stemmed from unmet needs within the professional system.

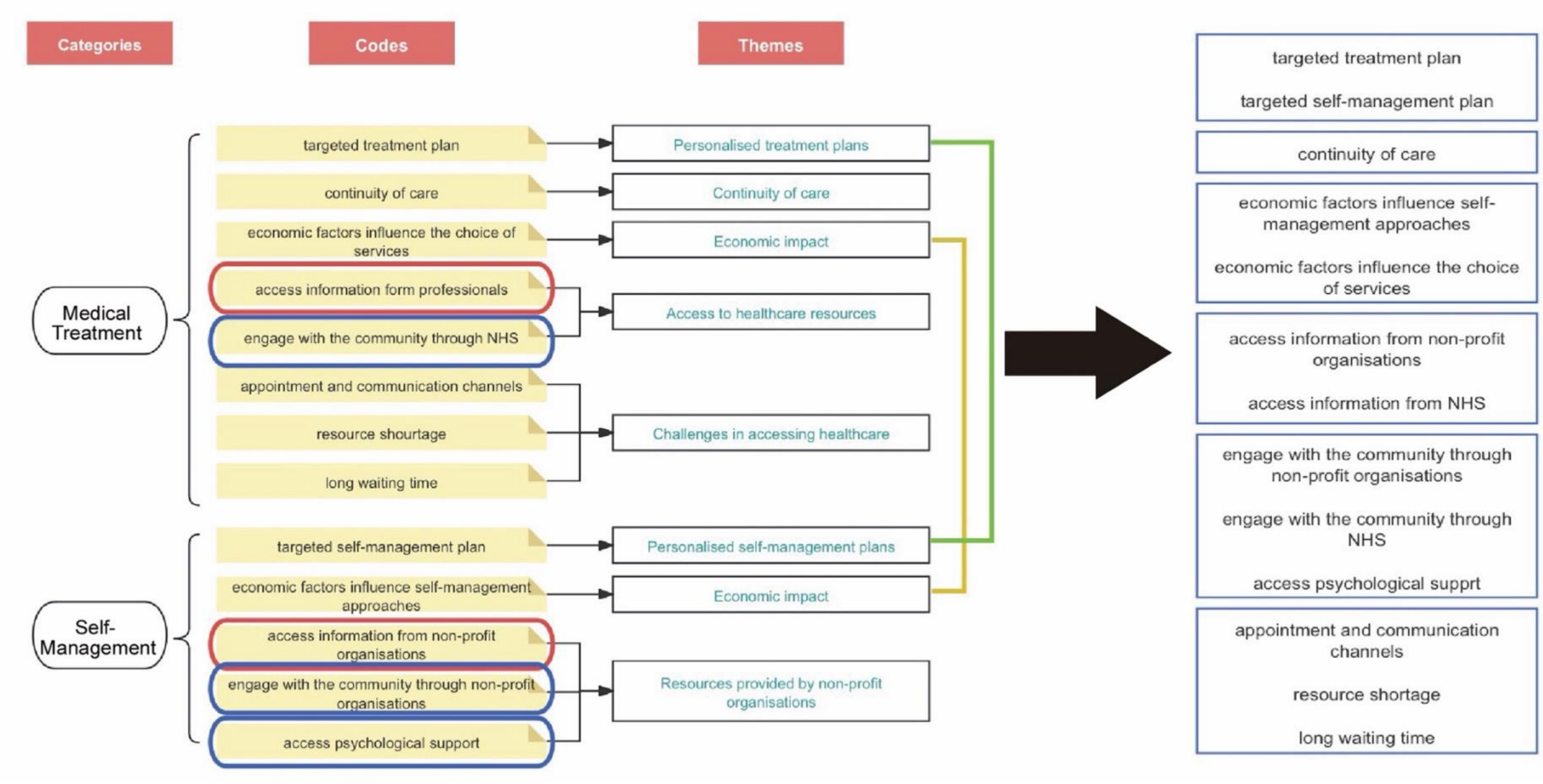
The purpose of these initial themes is to illustrate both the supportive and challenging aspects of participants' experiences with healthcare services, structured into two primary dimensions: "access to professionals" and "self-management". Together, these themes captured the key dimensions of participants' experiences, providing an initial analytic foundation for exploring how people with arthritis navigate healthcare and self-management in practice.

### 4.9.2 Developing and Reviewing Themes

Following the first round of categorising and summarising themes, the researcher identified overlapping and broad thematic content within the categories of "access to professionals" and "self-management". The initial themes generated were found to be repetitive and lacked specificity. At this stage, the researcher revisited earlier coding decisions to determine whether such repetition resulted from genuine conceptual overlap or from insufficient distinction during the first round of analysis. The researcher reflected that this breadth might indicate an overemphasis on the semantic level during the initial coding phase, potentially overlooking the latent meanings embedded in participants' narratives. For instance, certain codes might ostensibly fall under "accessing professionals" while simultaneously reflecting patients' reliance on self-management resources. This overlapping categorisation prompted the researcher to critically examine the underlying logic of the coding process. By evaluating the significance and relevance of these themes in addressing the research question, the researcher refined and further developed the themes based on the initial results (see Figure 4.6). This refinement involved checking each theme was internally coherent and meaningfully distinct from others, ensuring that no major aspects of participants' accounts were lost through condensation or merging. The researcher ensured that each theme fully reflects the content of the data. Each refined theme was compared again with the coded data extracts to confirm that its scope and interpretation remained grounded in participants' accounts.

During theme development, the researcher also reviewed codes that did not progress into final themes. For example, isolated references to family involvement appeared only in a small number of accounts and did not demonstrate the conceptual depth needed to form a coherent theme. These decisions were made by returning to the narrative context and assessing the analytical value of each code, ensuring that the final themes reflected clear and well-defined patterns within the dataset.

*Figure 4.6 Diagram Illustrating the Reclassification of Codes*

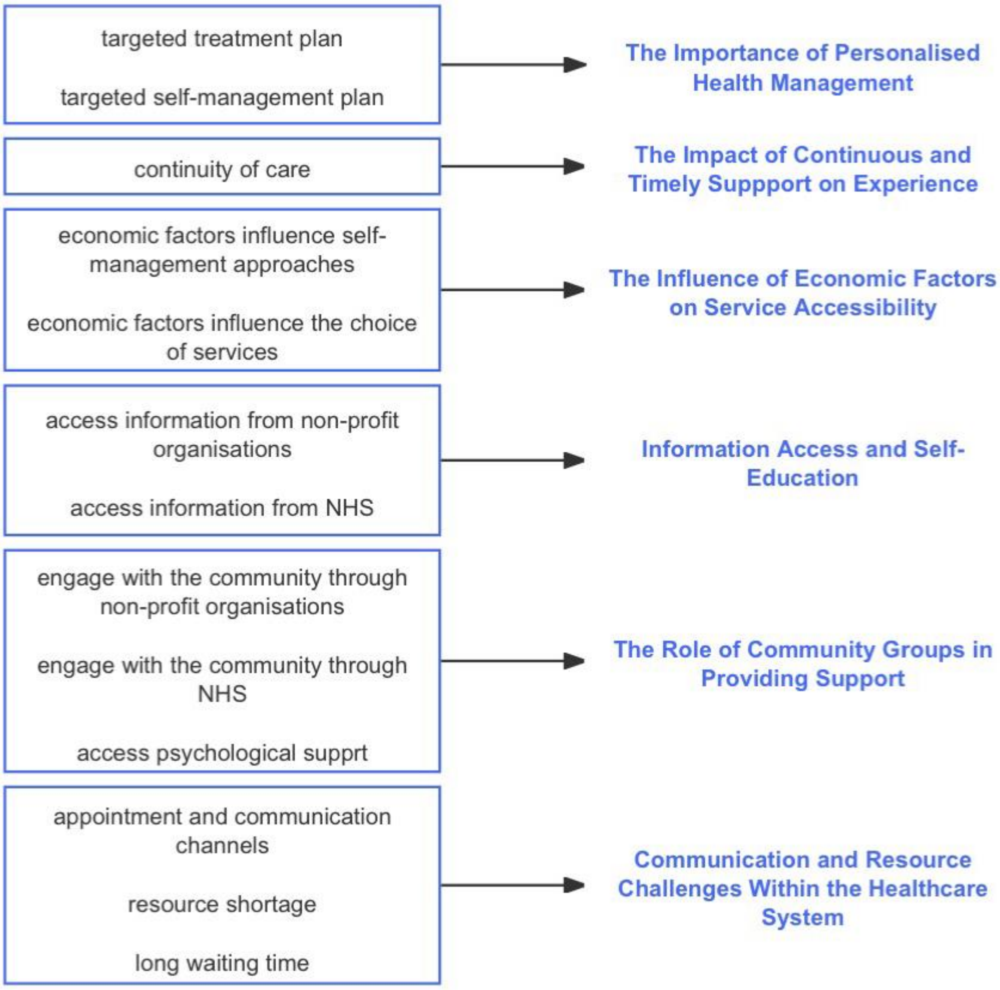


### 4.9.3 Development of Final Themes

The final themes were developed through an integrative analytical approach, combining deductive insights from the linear user journey maps with inductive thematic analysis. Initially, the predefined journey stages, symptom recognition, entry into services, initial treatment, and long-term management, provided a structured deductive framework, explicitly categorised into two domains: medical treatment and self-management. This structured approach allowed the researcher to systematically identify key touchpoints, experiences, and recurring challenges within each domain, serving as a foundational guide to organising the data. Subsequently, an inductive thematic analysis was conducted, enabling an open exploration and deeper interpretation of emerging patterns specifically centred around the people-centred concept. During this phase, codes were reviewed for conceptual coherence, ensuring that each inductively generated theme represented a distinct aspect of participants' lived experiences rather than a repetition of descriptive categories. Through iterative synthesis and refinement, the deductively derived stages from the user journey maps informed and shaped the inductively generated themes, resulting in comprehensive, nuanced themes that authentically represent participants' lived experiences within the context of arthritis health services.

Through this process of coding categorisation and thematic elevation, the researcher ensured that each theme fully reflects the content of the data, with the relationship between codes and themes illustrated in the accompanying figure 4.7. Each theme was then reviewed against raw data excerpts to confirm that it captured the dominant meaning expressed by participants without overextending interpretation.

***Figure 4.7 The Relationship Between Code Labels and Themes***



### *a. The Importance of Personalised Health Management*

The codes “targeted treatment plan” and “targeted self-management plan” appeared frequently, reflecting participants’ consistent emphasis on the need for personalised support and management. These codes underscored the importance of tailoring healthcare services to individual circumstances, addressing the unique challenges and needs faced by each participant. Consequently, these codes were consolidated into the theme “the importance of personalised health management” to highlight the central role of personalised care in healthcare services. This elevation was based on participants’ explicit contrasts between standardised and individualised care, showing that personalisation was a recurring evaluative lens rather than a single preference.

### *b. The Impact of Continuous and Timely Support on Experience*

The code "continuity of care" was elevated to the theme "the impact of continuous and timely support on experiences", summarising participants' expressed need for consistency and responsiveness in improving healthcare experiences. This theme captures participants' expectations for healthcare services to be long-term, stable, and promptly responsive, while also highlighting the critical role of sustained support in patients' health management.

### *c. The Influence of Economic Factors on Service Accessibility*

In the last section, the influence of economic factors was evident across codes within both "access to professionals" and "self-management", emphasising the profound impact of financial circumstances on health management decisions. Consequently, the two codes, "economic factors influence the choice of services" and "economic factors influence self-management approaches", were elevated to the theme "the influence of economic factors on service accessibility". This theme encapsulates how economic factors act as both constraints and determinants in participants' choices regarding healthcare services and self-management strategies. Under the theme "the influence of economic factors on service accessibility", these codes systematically illuminate the dual influence of financial conditions on participants' health-related decisions: encompassing both the limitations in accessing healthcare services and the barriers to implementing effective self-management practices.

### *d. Information Access and Self-Education*

Additionally, codes related to "information access" appeared frequently, further highlighting participants' reliance on reliable health information, which was particularly critical in the self-management process. The codes "access information from non-profit organisations" and "access information from NHS" were consolidated into the theme "information access and autonomous self-education". The theme "information access and autonomous self-education" demonstrates that information serves not only as the foundation for patient education but also as a core resource for enhancing participants' autonomy in managing their health. The diversity of information sources, from the NHS to non-profit organisations, was repeatedly emphasised. Participants noted that accessing a range of information sources enabled them to gain a more comprehensive understanding of their condition and management options, allowing them to develop tailored action plans based on insights from different sources. The theme "information access and autonomous self-education" summarises how participants utilised various sources of information to strengthen their self-management capabilities, while also underscoring the critical importance of reliable information in patient education and disease management. By integrating these codes, this theme highlights the empowering potential of information, particularly in enhancing individuals' capacity to navigate complex health challenges.

### *e. The Role of Community Groups in Providing Support*

The codes "engage with the community through NHS", "engage with the community through non-profit organisations", and "access psychological support" were consolidated into the theme "the role of community groups in providing support". This theme aims to comprehensively explore how community support shapes participants' health experiences and its significance in enhancing their health management abilities and psychological resilience.

By merging these codes under the theme "the role of community groups in providing support", the analysis captures the multifaceted impact of community support, including practical resource provision, emotional comfort, and psychological reinforcement. This theme not only highlights the diverse ways in which community resources meet participant needs but also emphasises the empowerment and mutual support that patients gain through engagement with community groups. The grouping decision here was guided by the recurring emphasis on collective support and shared understanding rather than the institutional setting of these interactions.

*f. Communication and Resource Challenges Within the Healthcare System*

Numerous codes highlighted the multifaceted challenges faced by people with arthritis within the healthcare system, such as “appointment and communication channels”, “resource shortages”, and “long waiting times”. These codes clearly reflect the barriers people with arthritis encounter in accessing healthcare services, particularly in terms of communication efficiency and the equitable distribution of resources. These codes were consolidated into the theme “communication and resource challenges within the healthcare system” to emphasise systemic issues in healthcare delivery. This theme not only summarises the common difficulties patients experience in accessing care but also reveals the far-reaching impact of these challenges on their overall healthcare experience.

### 4.9.4 Defining and Naming Key Themes

To provide greater clarity and depth, this section outlines the definitions of each theme, offering a detailed explanation of their meanings and the underlying concepts they encompass. Each definition was developed through iterative comparison between coded data and interpretive summaries to ensure that the wording of the themes accurately reflected participants’ own expressions and the conceptual focus of analysis.

**The Importance of Personalised Health Management:** This theme refers to the development of tailored treatment and health management plans based on an individual’s specific health status, preferences, and lifestyle. Personalised health management aims to address the unique needs of each person, enhancing the effectiveness of self-management and fostering active engagement in treatment to support long-term health outcomes.

**The Impact of Continuous and Timely Support on Experience:** This theme highlights the influence of ongoing and timely support on the overall experience of people with arthritis in their care journey. Such support includes regular follow-ups and daily monitoring, providing essential assistance in the management of arthritis.

**The Influence of Economic Factors on Service Accessibility:** This theme explores the impact of financial circumstances on the ability of people with arthritis to access certain services, self-management programmes, and treatment options. Economic factors may limit their options and influence their choices regarding healthcare.

**Information Access and Self-Education:** This theme focuses on the ability of individuals to access information related to health management and engage in self-education. Access to information and opportunities for self-learning can empower individuals living with arthritis to better understand their condition, explore available treatment options, and develop effective management strategies, thereby strengthening their awareness and capacity for self-management.

**The Role of Community Groups in Providing Support:** This theme refers to the emotional support, knowledge sharing, and practical guidance that individuals receive from community groups. Community groups play a vital role in the social interaction and psychological support of people with arthritis, helping them feel understood and supported, which enhances the overall rehabilitation experience.

**Communication and Resource Challenges within the Healthcare System:** This theme captures the communication difficulties and resource limitations that patients encounter within the healthcare system. These challenges may include long waiting times for appointments, limited communication channels, and resource shortages, which restrict people with arthritis from accessing consistent and effective care and shape their healthcare experiences.

These themes are closely interconnected, collectively reflecting various aspects of people-centred healthcare services. For instance, the theme of “Personalised Health Management” not only encompasses people with arthritis’ control over and adaptation to their own health management, but also positively influences their psychological well-being through emotional support. Similarly, the impact of economic factors on service choices and self-management strategies is significant, forming the theme "The Influence of Economic Factors on Service Accessibility". Together, these themes illustrate the complex needs of people with arthritis within personalised services, offering a structured perspective for understanding and optimising people-centred healthcare services.

This synthesis highlights how the analytic process moved from descriptive grouping to conceptual clarity, ensuring that each theme contributes a distinct yet connected insight into people-centred care. At this stage, previously established descriptive groupings were reviewed, compared, and integrated to refine the analytical focus of each theme. This process supported the consolidation of themes that were conceptually distinct while remaining analytically connected within the overarching interpretation of people-centred care.

## 4.10 Mapping Thematic Findings onto the Circular Framework

This research employed two qualitative analytical methods, framework analysis and thematic analysis, to generate an in-depth interpretation of interview data collected from seven participants living with arthritis. During the analytical process, framework analysis was first used to establish a structured understanding of user experience, followed by an independent thematic analysis to explore the deeper meanings underpinning those experiences. To ensure analytical rigour and transparency, this chapter presents the implementation of both methods and the logic underpinning their integration, while clearly delineating their respective roles and outputs.

Within the framework analysis, a structured examination of the interview data led to the development of a user experience framework centred on four core stages: needs identification, information acquisition, service utilisation, and continuity and coordination of care. These stages do not follow a linear sequence but instead form a circular structure, reflecting participants' repeated progression through a cyclical journey of recognition, exploration, utilisation, and adjustment while managing their condition (see Figure 4.3). This framework emerged from the processes of data indexing and charting and was progressively shaped through the analysis of inter-stage relationships during the mapping and interpretation phase.

Following the construction of the structural circular framework, an independent thematic analysis was conducted to further examine how participants understood people-centred elements within healthcare services from their own perspectives. Thematic analysis led to the identification of six representative themes: The Importance of Personalised Health Management; The Impact of Continuous and Timely Support on Experience; The Influence of Economic Factors on Service Accessibility; Information Access and Self-Education; The Role of Community Groups in Providing Support; Communication and Resource Challenges within the Healthcare System.

These themes were derived from cross-participant and cross-stage content synthesis, with a particular focus on uncovering the core concerns, cognitive challenges, and adaptive strategies expressed by individuals living with arthritis in their service experiences. In contrast to the stage-based trajectory presented through framework analysis, thematic analysis places greater emphasis on the horizontal aggregation of meanings and the interpretive understanding of underlying contextual mechanisms.

To enable the effective integration of findings from the two analytical approaches, this stage of the research used the four stages identified through framework analysis as the structural scaffold (codes), and the six themes developed through thematic analysis as expressions of interpretive meaning (themes). These two layers were systematically matched and combined. The integration process involved returning to original coded excerpts to confirm that each theme’s dominant meaning corresponded to the experiential focus of the relevant stage, ensuring alignment without forcing connections.

The matching process was guided by three key principles:

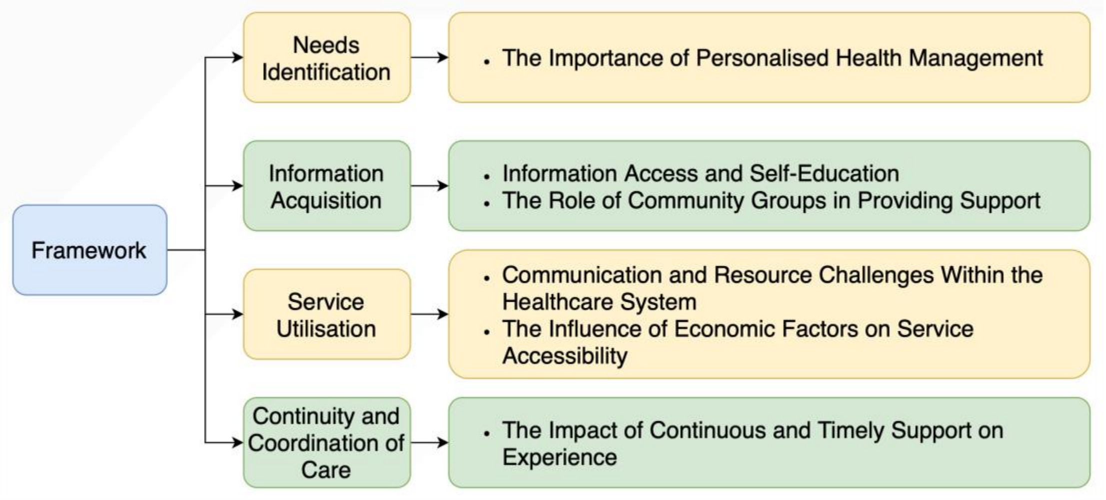
- The position within the user experience that each theme primarily addressed;

- The stage-specific context of the original quotations supporting each theme;
- The extent to which the theme and the stage were logically aligned or offered mutual insight.

These principles supported the maintenance of clear boundaries between stages while acknowledging that some participant accounts spanned more than one phase; in such cases, the primary experiential emphasis was used to determine placement.

The following paragraphs will explain how the themes and coding labels were allocated to these four stages, along with the analytical rationale underpinning these assignments (see Figure 4.8).

***Figure 4.8 Framework Stages and Themes Allocation***



In the “Needs Identification” stage, the theme “The Importance of Personalised Health Management” highlights participants’ desire and efforts to identify solutions tailored to their specific circumstances when they first became aware of their health needs. Participants needed to define their health needs and seek suitable solutions as they recognised their symptoms. This theme was assigned to this stage as participants often described their initial recognition of needs together with the search for approaches that matched their individual situations, indicating that personalisation shaped their earliest interpretations and decisions.

In the “Information Acquisition” stage of the circular framework, the themes “Information Access and Autonomous Self-Education” and “The Role of Community Groups in Providing Support” explicitly align with this phase. This stage highlights participants’ proactive efforts to seek, filter, and apply health information, often as a response to newly recognised needs. While the first theme reflects individual strategies for learning and decision-making, the second emphasises the value of community groups as trusted sources of peer-shared knowledge and emotional support. The data indicated that information seeking, whether individually or through communities, was a central activity at this stage, guiding the placement of both themes here. Together, these themes underscore the central role of information-seeking at both individual and collective levels in participants’ ongoing health management.

In the “Service Utilisation” stage of the circular framework, two key themes are aligned with this critical phase, highlighting the challenges participants encountered when engaging with healthcare services. The theme “Communication and Resource Challenges within the Healthcare System” reflects the barriers participants faced in terms of communication and resource availability. The theme “The Influence of Economic Factors on Service Accessibility” illustrates the profound impact of financial considerations on participants’ ability to select and utilise services. Together, these themes capture the difficulties participants experienced in navigating healthcare systems, where communication breakdowns, limited resources, and economic constraints emerged as major barriers to effective service utilisation.

In the “Continuity and Coordination of Care” stage of the circular framework, the theme “The Impact of Continuous and Timely Support on Experience” is explicitly aligns with this critical phase. This theme reflects participants’ high expectations for consistency and responsiveness in medical and support services, as well as the profound impact these factors have on their health management experiences. The theme highlights participants’ significant need for coordination within healthcare services. “The Impact of Continuous and Timely Support on Experience” captures the core characteristics of the “Continuity and Coordination of Care” stage, emphasising how sustained support, timely interventions, and coordinated care collectively shape participants’ health management journeys.

While mapping themes onto the circular framework, the researcher noted a small number of experiential elements that did not fully align with the cyclical pattern, such as partial or incomplete returns to earlier stages. These instances were acknowledged during analysis, but they did not provide sufficient analytic direction to warrant modification of the overall framework.

## 4.11 Summary

Through the framework analysis and thematic analysis, this chapter has developed a multidimensional understanding of the service experiences of individuals living with arthritis. Framework analysis provided a four-stage structure grounded in the user journey, clearly delineating the key components and sequential characteristics of participants’ engagement with healthcare services. Building upon this, thematic analysis identified key experiential themes embedded in participants’ narratives, highlighting core people-centred elements within the service process.

This integration of structure (framework) and meaning (themes) not only broadened and deepened the analytical scope, but also enhanced the coherence and rigour of data interpretation. The following chapter will further explore the practical and theoretical implications of the circular analytical framework and the six core themes identified in this study.

# Chapter 5: Findings

## 5.1 Introduction

Findings chapter builds upon the chapter 4, data analysis, which through the application of framework analysis in conjunction with the user journey map, developed a circular framework comprising four stages: needs identification, information acquisition, service utilisation, and continuity and coordination of care. The circular framework was designed to present the lived experiences of individuals with arthritis within healthcare service process. Simultaneously, thematic analysis identified key people-centred elements from the perspective of individuals living with arthritis, reflecting their concerns across various dimensions including medical support, information access and emotional needs. Due to the interpretive phenomenological orientation of this study, findings from the systematic review were kept separate from the thematic analysis as the themes were developed directly from participants' lived experiences.

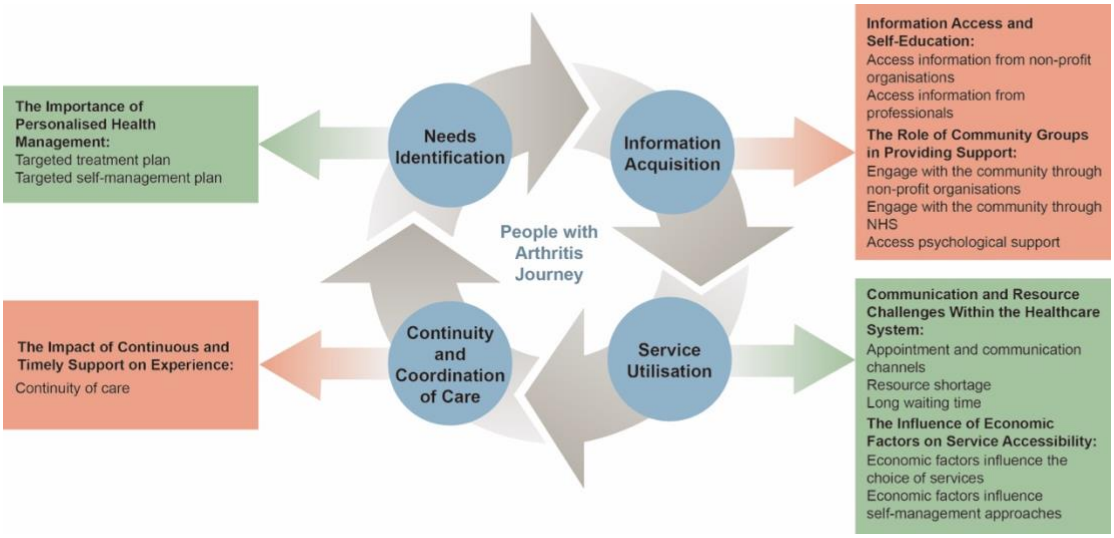
As outlined in Chapter 1, people-centred healthcare requires attention to the emotional, cognitive and social dimensions of the patient experience (World Health Organisation, 2009). The core of people-centred health services lies in placing the individual at the centre of the system, with an emphasis on enhancing individuals' sense of control over their health, rather than treating them as passive recipients of care (Patrício et al., 2020). These foundational perspectives frame the analysis in this chapter.

The findings chapter presents participants' narratives and corresponding thematic content in accordance with the four stages of the circular framework. This structure is used to organise and contextualise the themes generated through thematic analysis, allowing for a clear alignment between participants' experiences and key stages in the health journey. The chapter explores how individuals living with arthritis identify their needs, acquire information, utilise services, and develop trust and continuity within ongoing care, with a focus on how the principles of people-centred care are manifested throughout these stages. The findings indicate the simultaneous presence of people-centred practices and unmet needs in participants' experiences of arthritis care. These coexisting experiences are presented according to the stages of the circular framework and the corresponding thematic content.

## 5.2 The Circular Framework as a Lens for People-Centred Findings

This research employs a combined approach of framework analysis and thematic analysis to explore people-centred elements of healthcare services from the perspective of individuals living with arthritis. Through iterative reading, coding and organization of the interview data, a circular framework was developed to represent the key stages and interrelated themes characterising user's engagement with arthritis services. The final circular framework (see Figure 5.1) comprises four stages: needs identification, information acquisition, service utilisation, and continuity and coordination of care. The circular framework reflects the complex and ongoing experiences associated with the long-term management of arthritis.

***Figure 5.1 Circular Framework of Arthritis User Experience Incorporating People-Centred Elements***



During the first stage of framework analysis, the researcher utilised data mapping to generate a linear user journey map, developing a map for each participant. The linear journey maps were based on a chronological sequence, structured as “symptoms appear”, “finding professionals”, “accessing professionals” and “follow-up suggestions”. Linear maps provided a clear representation of participants’ key actions and experiences, effectively organising the core stages of their journeys and establishing a preliminary framework for analysis.

The linear user journey maps developed during the first stage of the framework analysis did not adequately capture the experiences of some participants who, in practice, returned to earlier stages of their journey. Among a significant proportion of participants, the progression was not unidirectional but instead characterised by cyclical and iterative patterns. For example, Susan mentioned: *“I initially noticed my hands on my 2 fingers...my fingers look a little bit misshapen. I think I need to do something about that…so I went to my doctors.”* However, this was not the first occasion on which she sought medical assistance for joint-related issues. She had experienced similar circumstances previously: *“I’ve noticed that my toes were really, really swollen. And there were really chunky and quite sore. And so, I went to my doctors with my toes and obviously it have been before my finger.”* Susan’s experience demonstrates that individuals with arthritis frequently return for medical assistance in response to evolving health needs arising at different stages or affecting different parts of the body.

Susan’s experience indicate that participants’ health management journeys are not fixed linear processes but are characterised by recurring patterns, revealing a more intricate and dynamic nature. The complexity necessitates a more flexible and comprehensive approach to effectively reflect the authenticity of participants lived experience.

The circular framework reveals the dynamic nature of participants’ experiences through its cyclical structure. As arthritis is a chronic condition with no definitive cure, real-life experiences rarely follow a single linear process but instead involve ongoing cycles of follow-up consultations and the emergence of new issues. For people with arthritis health management is a long-term process encompassing multiple healthcare interactions and lifestyle adjustments. The circular framework reflects the continuity and repetitiveness of participants' journey, illustrating their experiences are not confined to a linear trajectory with a definitive endpoint, but rather represents an ongoing and iterative process.

## 5.3 Needs Identification Stages

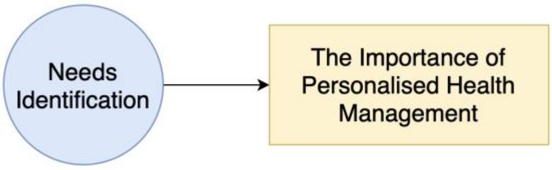
### 5.3.1 introduction

The first stage of the circular framework, Needs Identification, corresponds to the initial phase of the user journey, where individuals begin to recognise changes in their health and the need for medical support. This stage is characterised by participants' reflections on physical symptoms, disruptions to daily routines, and moments of realisation that prompted them to seek help or re-evaluate their self-management strategies.

Needs identification involves identifying key factors or events prompting users to acknowledge their need for medical assistance, such as visible changes, increased pain, functional limitations, or disruptions to daily life. For example, June sought medical help due to swollen toes, which caused discomfort when wearing shoes. While Alex experienced persistent joint discomfort in various parts of his body, repeatedly leading him to consult professionals.

During the needs identification stage, people with arthritis faced one key challenge in addressing their health needs: the importance of personalised health management (see Figure 5.2). The findings underscore the significance of adopting a people-centred approach, in which individual experiences, preferences, and socio-economic contexts are prioritised to ensure timely and effective identification of health needs.

*Figure 5.2 Framework of Findings for the Needs Identification Stage*



The following section presents participants' accounts of early experiences, highlighting how personalisation, as a key element of people-centred care, is reflected during the critical first phase.

### 5.3.2 The Importance of Personalised Health Management

The finding highlights the central role of personalised health management in addressing the diverse needs of individuals living with arthritis. A core principle of people-centred healthcare lies in the provision of tailored support, grounded in a nuanced understanding of each person's preferences, lifestyle, and health condition (Feddersen et al., 2022). Personalised health management within this data has been defined as tailoring of health-related plans, advice or services to accommodate individual preferences, daily routines, symptom patterns, or social contexts, as described by participants.

In the context of arthritis, individuals' experiences often vary significantly, rendering a 'one-size-fits-all' approach to healthcare insufficient in meeting the practical needs of all service users. The narratives of several participants illustrate the real-life significance of personalised health management in specific contexts.

In identifying his needs, John explored symptom relief strategies that could offer short-term improvement while aligning with his broader health goals. John discussed how his treatment plan was shaped around his current condition and future health considerations. He recalled: *"the long term, it's gonna be knee replacements, but the specialist suggested that I'm a little bit too young to go into getting knee replacements because they only last for a 10, 12, 13 years before you have to get it done again. So*

*I'm holding out with the steroid injections for the time being. And then once I've got a bit older then it'll go to new replacement."*

In John's experience, the healthcare specialist considered factors beyond immediate symptoms, such as life stage and long-term care planning, when discussing potential options. John's narrative reveals treatment decisions were made not solely based on clinical assessment, but through a broader evaluation that included his age, the projected longevity of the surgical outcome, and his individual preferences. The process of evaluating and balancing options due to individual circumstances underscore the significance of personalised health management, where treatment strategies are adapted to the person and evolve over time.

Moreover, John's experience reflects the characteristics of people-centred care. Rather than imposing a unilateral decision, healthcare professionals engaged with him in a collaborative dialogue to determine the most appropriate course of action. John's life pace and long-term health goals were explored and respected. A dynamic and context-sensitive approach, focused on individuals' long-term wellbeing and grounded in their personal backgrounds, embodies the core principles of people-centred healthcare.

As part of identifying his needs, Alex engaged in a self-directed and co-created health management plan, selecting strategies based on personal preferences and perceived effectiveness. For example, Alex stated: *"I'm usually like things that are cold, like cold therapy instead of hot. So I do have like some spray, some gel I can rub in, and that can kind of help."* Such self-directed selection of suitable approaches exemplifies a key feature of personalised health management.

The development of exercise plans in response to individual physical needs marked an important step in identifying suitable support. Helen described receiving an exercise plan during the pandemic, provided by a non-profit organisation. *"I actually had exercises during the pandemic prescribed to me by *non-profit organisation 1*, so I could still try and keep my joints moving properly. So that was the biggest benefit from* *them, that someone who looked at the syndrome and tailored them to fit me."* In this experience, Helen highlighted that the exercises were adapted to her condition and her individual needs were considered.

Helen's experience reflected personalisation of exercise plans, as the support was aligned with her specific symptoms and physical requirements. Helen's description indicates she recognised and valued this form of individual attention. Helen also described a long-standing exercise routine prescribed by a physiotherapist: *"I do one where I stretch my back...I have a scoliosis, so I exercise my back and then I do it all with foam weights in the water... it's all prescribed by the physiotherapist, like 14 15 years ago."* The exercises Helen mentioned were linked to different physical concerns, such as scoliosis and arthritis, and were maintained over time. According to Helen, the plan addressed multiple areas of her body and was developed in response to her individual conditions.

Susan described experiencing adverse reactions to multiple medications during her treatment. She stated: *"I got it really bad in my feet and so I started on medication, which was methotrexate. I think I took it, but I had a really bad reaction. I was sick, I had headaches, and it never went away."* After this, her medication was changed: *"I went back and anyway they then put me on a drug called leflunomide. So, I was on that, but then I started to get hives on my skin, rashes, and things like that."* Following these repeated side effects, a new plan was introduced: *"I had a real meltdown and I think that's what did it, for the third drug that I'm now on."* Susan described how she was involved in decisions regarding the third medication: *"They must have had a case conference to put me on what I'm on now…and they've consulted me…they asked me if I wanted to do my injection weekly or two weeklies…they consulted me through the plan, because obviously there's a plan for me."*

Susan's narrative indicates that she was given the opportunity to express her preferences regarding how medication would be administered. The option to choose the frequency of injections, and her repeated reference to being consulted, reflect the element of participation in decision-making. The involvement of the individual in planning, and the attention to how treatment would be delivered in practice, suggest that Susan experienced this stage of care as responsive to her needs.

During the need's identification stage, the importance of personalised health management was demonstrated through individuals' interactions with professionals. The experiences of Alex, Susan, Helen and John identified service recommendations were often informed by their specific health conditions, daily routines, and personal preferences. In these cases, professionals sought to tailor their advice to individual circumstances, such as symptom presentation, responses to medication, the feasibility of physical activity, and the person's decision-making preferences.

The service interactions described in these cases demonstrate key elements of people-centred care, with a particular emphasis on personalisation and participation in decision-making. The emphasis on personalisation and participation in decision-making also aligns with the findings of the systematic review, which identified these as central components of people-centred care across existing literature.

Participants were not simply passive recipients of standardised advice. In certain contexts, they were able to express their preferences, and these preferences were acknowledged and incorporated into the care process. Service interactions that prioritised individual needs enabled treatment pathways to become more closely aligned with personal circumstances. Health management approaches were also adjusted in response to different life situations. These accounts show personalised health management was an early mechanism through which individuals begin to shape their care, highlighting its foundational role in people-centred practice

### 5.3.3 Summary of Healthcare Needs Identification

During the need's identification stage, participants described the process through which they recognise symptoms, sought help, and attempted initial self-management. In some narratives, elements of people-centred care were evident, particularly in situations where individual experiences were acknowledged and addressed. Several participants reported the advice they received corresponded with their health conditions, daily routines, and functional capacities. This alignment indicated certain characteristics of personalised health management.

In parallel, some participants demonstrated a tendency to make active choices and to adapt their management strategies. The individual efforts to initiate and adjust self-management approaches reflected a sense of agency in health management and represent a key aspect of people-centred care, which emphasises the evolving role of the patient.

In summary, the expression of personalised health management at this stage encompassed both the alignment of service recommendations with individual circumstances and the incorporation of participants' specific contexts and preferences into the management process. This indicates needs identification is not merely a clinical step but an early people-centred process in which individuals start to define what matters to them.

## 5.4 Information Acquisition

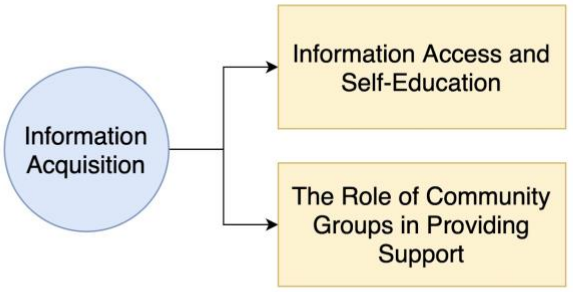
### 5.4.1 Introduction

The second stage of the circular framework, information acquisition, corresponds to the process in the user journey whereby individuals, following the recognition of health needs, actively or passively seek relevant information. This stage is characterised by participants' efforts to explore areas such as disease diagnosis, treatment options, and day-to-day management advice. The stage also reflects their actual experiences in accessing, understanding, and evaluating information.

Information acquisition involved the use of multiple sources, including advice from healthcare professionals, resources provided by non-profit organisations, online information platforms, and social channels. At this stage, participants sought not only authoritative information to understand their condition, but also guidance on how to translate such information into practical and actionable management strategies.

During the information acquisition stage, participants' narratives highlighted "Information Access and Self-Education" and "The Role of Community Groups in Providing Support" as key aspects of their experiences (see Figure 5.3). Participants experienced varied conditions in acquiring health-related knowledge, particularly in accessing informational support that was timely, comprehensible, and relevant to their personal circumstances. Community groups were also described as important sources of informal support, offering opportunities for knowledge exchange, emotional reassurance, and shared experience among peers. The manifestation of people-centred care at this stage lies in the extent to which information provision responds to individual contexts, differences in capabilities, and specific needs, thereby enabling more effective participation in health management.

***Figure 5.3 Framework of Findings for the Information Acquisition Stage***



The following section presents participants' specific experiences during the process of information acquisition, with a particular focus on how the key elements of information accessibility and personalisation, which are central to people-centred care, were manifested at this stage.

### 5.4.2 Information Access and Self-Education

A variety of pathways and approaches to information access and self-education emerged from the research. Participants engaged with diverse sources of information over the course of managing their condition, using information to develop understanding, evaluate potential interventions, or support everyday management practices. The main sources of information included healthcare professionals, non-profit organisations, and online platforms.

Information access and self-education comprises three interrelated aspects. First, healthcare professionals served as trusted sources of information. Second, non-profit organisations offered supplementary support for information dissemination through materials, events, and dedicated websites. Third, participants also described obtaining information via search engines, social media, or video-sharing platforms, highlighting the diversity of information channels and the flexibility of content formats. Engagement with these sources of information also contributed to a heightened sense of agency and participation among individuals, as they became more equipped to understand and navigate their own care.

The availability of information, the modes through which it was communicated, and the degree to which content was aligned with individual needs collectively shaped the process of information acquisition. These aspects are closely linked to key principles of people-centred care, including respect for individual differences, support for information accessibility, and the promotion of self-management capabilities. The following cases illustrate the varied practices and experiences associated with information acquisition and examine how these reflect the core elements of people-centred care.

Healthcare professionals played a central role in the provision of trustworthy and timely information, particularly at the point of diagnosis, where individuals often required clear and accessible explanations to navigate their condition. Susan described receiving extensive informational support from healthcare professionals during the initial stage following her diagnosis. She noted: *"When I first got diagnosed, they gave me leaflets. I was kept informed and also with the medication as well."* In addition, she highlighted her communication experiences with the rheumatology specialist: *"My experience is from day one with my rheumatologist, you know from the explain everything to you know it's all been explained to me."*

Susan's narrative indicated that information was delivered in multiple formats across different points of care, including written materials and face-to-face explanations. Susan referred to "being continually informed" and noted that "everything was explained clearly", suggesting that the service process responded to her needs for understanding both the condition and the available treatment options. Susan's experience illustrated key aspects of people-centred care, specifically information accessibility and clarity of communication.

Susan's perception of being "informed" and having information "explained" reflects her view that the communication approach adopted by the service was attentive to her capacity to comprehend information and to her specific informational needs. Susan's experience suggests people-centred care involved more than the provision of information. People-centred care requires information to be communicated clearly, at an appropriate time and in a suitable format, enabling service users to engage with condition management with greater clarity and preparedness.

Non-profit organisations also emerged as important and trusted sources of health-related information, particularly in supporting individuals with condition-specific knowledge and self-management strategies. David described receiving practical and applicable health advice through a non-profit organisation. He stated: *"I like the approach of...here are some things you could do and including in the things you can get for free or for reduce cost. Try those rather than just sitting there feeling sorry for yourself."*

The information described by David encompassed a range of options, including both free services and low-cost resources. The inclusion of these varied options reflected a consideration by the provider of the practical circumstances and varying needs that users might encounter. David's experience illustrated an emphasis within people-centred care on the relevance of information and the flexibility of its delivery. David noted the phrase "you could do", indicating that the information was presented as a suggestion rather than a fixed instruction. Presenting information in the form of suggestions rather than fixed instructions provided David with a degree of choice. David's positive response to the way the information was delivered suggests he regarded the content as flexible and responsive to his personal circumstances.

Susan described regularly accessing arthritis-related informational resources through a non-profit organisation over an extended period. She stated: *"I do go to online meetings with *non-profit organisation*...the webinars are trying to find out as much as possible about my condition and how to manage it."*Susan also described her participation in in-person activities: *"I contacted them to find out about when meetings were and I did a two-day workshop in *city 1* to give me an understanding so I could signpost people to it... I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world."* Susan's description indicated that the informational resources she accessed provided ongoing content related to arthritis, which she regarded as helpful in enhancing her understanding of the condition and its management.

Susan's experience illustrated how the accessibility and relevance of information supported the delivery of people-centred care. The content Susan engaged with addressed topics she considered important and was delivered in a manner she found practical. Susan's positive appraisal of these resources suggests the information aligned with her actual needs.

Susan's experience illustrates that people-centred informational support is most effective when the content aligns with an individual's specific circumstances. Responsiveness to ongoing informational needs further forms a critical foundation for enabling self-education. People-centred care emphasises not only the provision of information, but how the information can support individuals in maintaining an ongoing understanding of their condition and in making informed decisions over time.

Information access and self-education highlights two key elements of people-centred care: the accessibility of information and the relevance of content to individual needs. Participants felt supported when the information they received was tailored to their needs and addressed their specific concerns. These experiences demonstrate that people-centred care involves not just providing information but enabling individuals to understand and apply it within the context of their own lives. The emphasis on individual understanding and the application of health-related information is consistent with the earlier systematic review, which identified patient education as a fundamental component of people-centred care. In the present study, participants' descriptions of seeking, interpreting, and using information reflect how effective patient education supports autonomy, fosters confidence, and enables informed engagement with health management. Together, these accounts illustrate information access functions as an early mechanism through which individuals build understanding and confidence, highlighting the foundational role of information access in enabling people-centred engagement in care.

### 5.4.3 The Role of Community Groups in Providing Support

Alex's experience illustrates how people-centred care can be reflected in both informational and relational aspects of support. Alex's engagement with a range of non-profit resources and NHS-led group activities provides insight into how individuals access knowledge and connection to navigate health-related challenges.

The ability to access information through a variety of channels played an important role in supporting individual self-management and enhancing informational accessibility. Alex stated: *"I'm actually a member of *non-profit organisation 2*, the national ankylosing spondylitis society… I did find it helpful because it does give you quite a lot* *of useful information, like tips on how to maybe do things or not overdo things… I get the magazine a s well… there's a lot of information booklets… there's a helpline as well… if you've got any questions or if you need any help…"* He also referred to another source of information: *"I've actually looked on *non-profit organisation 1* as well, and I do find that quite an interesting website because it gives you different types of arthritis, or maybe the medications, because sometimes I'm not sure what medications do for my condition… it's interesting to read."*

Alex described accessing a wide range of arthritis-related informational resources through a non-profit organisation, including magazines, information booklets, website content, and telephone support. Alex regarded the information as "helpful" and "readable" and addressed specific issues of concern to him, such as coping strategies and the effects of medication. Alex's experience reflected two key elements of people-centred care, namely information accessibility and content relevance. The information was delivered through multiple channels, enabling Alex to access useful content at different times and in various contexts. The materials focused on specific issues and were presented in a format he could understand and apply.

Alex's positive evaluation of these resources suggests the concerns he considered important were effectively addressed. Alex perceived the information to be accessible and aligned with his personal needs, which provided practical value. Alex's experience highlights the combined role of channel diversity and content specificity in people-centred informational support. When information is delivered in ways that match both the user's context and capacity for understanding, it becomes more meaningful and usable. This underscores the principle within people-centred care that effective support involves not only the provision of information but also ensuring that the content can be meaningfully accessed, understood, and applied.

In addition to formal information sources, opportunities for peer connection also played a meaningful role in the information acquisition process. Alex mentioned that he established connections through an NHS group course and continued to stay in touch with some of the people on the course after the course had ended. He stated: *"I've actually done it within the NHS. And then obviously these people that are in these groups, they've ended up becoming friends. And obviously I've not done these classes for a while, but I have actually kept in touch with a few of them, so it is nice that I can still comment of keeping talks and you know I'm not the only person."* Alex described the group activity not only provided condition-related information but also created opportunities for sustained social interaction.

Alex emphasised that communication with other people with arthritis continued beyond the course and contributed to a sense of connection. Alex's references to "making friends", "staying in touch", and "not being the only one" reflect the emotional support gained through peer contact. Alex's experience demonstrates the importance of social connection and emotional support as integral components of people-centred care. Within the process of information acquisition, the interactive environment facilitated by the service enabled Alex to develop both an understanding of his condition and a feeling of being recognised by others. The emotional and relational aspects of this process indicate that people-centred care can address social support needs by fostering shared understanding and empathetic engagement during learning.

The key people-centred elements evident in Alex's experience are information accessibility, content relevance, and social connection. Alex felt supported when the information he received was tailored to his needs and when he was able to maintain meaningful relationships beyond formal services. Alex's experience highlights that people-centred care goes beyond the delivery of accurate information. People-centred care also involves creating conditions that enable individuals to feel informed, understood, and socially connected throughout the process of learning to manage their condition.

### 5.4.4 Summary of Information Acquisition

During the information acquisition stage, service users' experiences indicated information accessibility, content relevance, and social interaction accompanying the process of obtaining information collectively constituted the main characteristics of informational support. The extent to which services were able to provide information that was relevant to individual circumstances and communicated in a clear and comprehensible manner emerged as a recurring focus at this stage.

The information-seeking pathways described by participants demonstrated considerable diversity, encompassing formal healthcare services, non-profit organisations, and online channels. Information was perceived as more practical and relevant when it addressed issues of personal concern and offered a degree of choice in how to engage with or act upon the content.

In addition, some information-seeking behaviours were accompanied by interpersonal interaction, which enabled individuals to recognise that they were not alone and fostered a sense of emotional resonance throughout the learning process. Within the context of information acquisition, people-centred care involves not only the manner in which content is delivered but also the extent to which informational support responds to individuals' needs for understanding and social connection.

The findings at information acquisition stage indicate that people-centred care places emphasis on the extent to which information aligns with individual circumstances and supports the process of understanding, assimilating, and applying relevant knowledge at a pace that reflects each person's own context. Overall, these patterns identify information acquisition is not merely about receiving knowledge but represents a people-centred process in which individuals develop the capacity to interpret, apply, and situate information within their own lives.

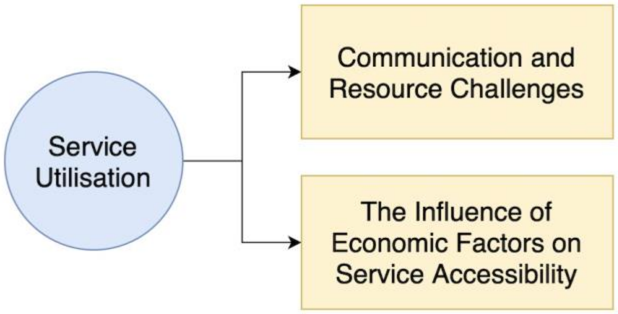
## 5.5 Service Utilisation Stage

### 5.5.1 Introduction

The third stage of the circular framework, service utilisation, corresponds to the phase in the user journey in which individuals move from recognising health needs and acquiring information to actively engaging with and making use of health services. During this stage, participants begin to establish concrete connections with the healthcare system, participating in processes such as diagnosis, treatment, follow-up, or other forms of supportive intervention. The related experiences typically involve the process of accessing services, modes of communication with professionals, and the influence of external factors on service utilisation.

The findings indicate that experiences during the service utilisation stage primarily centred around two themes: communication and resource challenges within the healthcare system, and the influence of economic factors on service accessibility (see Figure 5.4). The first theme, communication and resource challenges, encompassed issues such as difficulties in making appointments, long waiting times, and ineffective communication of information. The second theme, the influence of economic factors on service accessibility, was reflected in the ways in which financial circumstances influenced decisions regarding the use and continuity of services. Economic considerations were reported as a significant factor when deciding whether to access certain forms of care or determining how to organise self-management practices.

*Figure 5.4 Framework of Findings for the Service Utilisation Stage*



At Service Utilisation stage, elements of people-centred care may be reflected in the extent to which services are appropriately adjusted to meet individual needs, the clarity and comprehensibility of communication, and the degree to which personal background and living circumstances are considered in the design and delivery of care. The overall perception of whether care is people-centred may be influenced by the effectiveness of communication, the coordination of resources, and the accessibility of services during the process of service utilisation.

The following section presents specific cases that illustrate key experiences during the service utilisation stage and explores how these experiences reflect and give meaning to the principles of people-centred care.

### 5.5.2 Communication and Resource Challenges Within the Healthcare System

During the service utilisation stage, modes of communication and resource conditions had a significant impact on individuals' experiences of care. Participants' narratives referred to several aspects closely related to people-centred care, particularly the adequacy of consultation time, the availability and configuration of staff, and the clarity and coherence of service processes. These factors were closely linked to the extent to which services were able to understand and respond to individual needs.

During the service utilisation stage, participants described a range of experiences related to communication and the availability of healthcare resources. Participants' narratives reflected varying degrees of responsiveness in how services addressed individual needs, supported understanding, and facilitated communication. Modes of information exchange, the accessibility of staff, and the complexity of service arrangements were all identified as key factors influencing the quality of interaction within healthcare services.

This section presents specific narratives to illustrate how modes of communication and resource allocation influenced participants' experiences of service utilisation. The following content outlines how participants' descriptions reflected key elements of people-centred care, and explains why, within contexts, such aspects were perceived as an indicative of a people-centred approach.

Participants' experience highlighted how limitations in staffing and service capacity influenced their experiences of communication and support during the service utilisation stage. When describing his experience of service utilisation, Alex noted that NHS appointments could feel overly time pressured. He stated: *"I think I feel NHS appointments can be rushed. And I don't feel like I'm getting my point across enough. So, it can be a little bit frustrating."*

Alex explained that the limited time available during face-to-face consultations made it difficult for him to fully express his thoughts. The sense of "not getting my point across" contributed to a feeling of frustration. The difficulties Alex encountered in expressing himself relate to the people-centred care elements concerning the opportunity for patients to be heard and to communicate their perspectives. Alex's emphasis on the inability to convey his views suggests a desire for more time to articulate his situation, which was not accommodated within the current mode of interaction. The challenges Alex described highlight that, in assessing whether care is people-centred, it is important to consider whether communication processes provide individuals with sufficient opportunity to share their experiences and concerns. Such opportunities are central to ensuring that care is responsive to personal needs.

When discussing her contact with the nursing team, Susan noted that responses were often delayed due to staff shortages. She stated: *"There is the nursing teams are always on the end of the phone, although they're very short staffed and you do have to leave messages sometimes because there's so busy."* Susan described how delays in communication occurred when staff were unavailable, requiring her to leave messages and wait for further response. Susan's experience relates to the people-centred care principle of timely responsiveness to individual needs. Susan's reference to the lack of immediate replies due to staffing constraints suggests that the service did not always meet her expectations regarding response times. The situation Susan described highlights the ability of services to respond promptly to users' requests is a key aspect of how people-centred care is perceived in practice as being responsive to individual circumstances.

Long waiting times for specialist appointments or surgical procedures emerged as a significant concern in participants' descriptions of service utilisation, directly influencing how the responsiveness of care was perceived. Alex referred to a prolonged delay in accessing specialist care during his description of service utilisation. He stated: *"I think obviously within the NHS it's quite a bit of a problem at the moment, and there's a lot of backlogs and I am actually on the waiting list for 13 months to see a neurologist. Because I don't know if it's related to my arthritis."*

Alex description revealed that, due to service backlogs, he experienced a prolonged wait while seeking an explanation for his symptoms. The delay in accessing specialist care relates to the people-centred care elements of timely responsiveness to health concerns. Alex sought to understand whether his symptoms were connected to his existing condition, yet the extended waiting time prevented him from receiving professional input in a timely manner. The delay contributed to a sense that the service was insufficiently responsive to his individual concerns. Alex's experience of delayed access contributes to an understanding that people-centred care is not solely about the availability of services, but also about whether those services can respond when needed to support individuals in making sense of their health and circumstances.

June explained although she had been placed on the waiting list for surgery, a considerable delay was expected before receiving treatment. She stated: *"I decided I had to put my name down for the operation and I'm now on the list and in this part of the world it's a wait for about 8 months. That's very good for the health service. Some people you probably know this, if you've read the newspapers, I believe that some people wait more than two years."* June described a substantial waiting period between the initial request for care and the actual scheduling of surgery, and she compared her experience with reported waiting times in other regions.

June's situation reflects the element of timeliness in responding to requests for health services, as emphasised in people-centred care. June mentioned an eight-month waiting period, indicating the service did not respond to her needs through immediate arrangement, but rather placed her in a prolonged queue for access. The delay June experienced highlights the significance of waiting times as a factor shaping individuals' perceptions of whether care is people-centred. The ability of services to respond within a reasonable timeframe is a key consideration in understanding how people-centred care is experienced during the stage of service utilisation.

Participants' reflections revealed that system-level procedures, including referral pathways and standardised communication formats, shaped how easily they were able to access services and express their personal circumstances. Susan referred to the way in which the structure of service pathways and referral mechanisms could affect her access to specialist care. She stated: *"It's got to start at the GP, that's the initial point. When you go to the GP because that's the starting point to get the referral to see a rheumatologist and there can be gatekeepers. If you've got a doctor that's not listening or you know, just a stopping you off, you're not gonna get past the first hurdle to see a rheumatologist."* Susan pointed identified at the primary care stage, a lack of listening or proactive engagement from the doctor could create barriers to accessing further specialist services.

Susan’s experience reflects the people-centred care principle concerning the clarity and supportiveness of service pathways. Susan emphasised access to specialist care is contingent on the actions and attitudes of primary care professionals. The initial stage of accessing care could be constrained by the clinician’s willingness to listen and to initiate a referral, which in turn shaped Susan’s opportunity to access specialist support. Susan’s experience highlights people-centred care involves more than ensuring the existence of services. The principle of people-centredness also relates to the accessibility and navigability of service pathways. A process that lacks transparency or is perceived to be controlled by gatekeepers may limit an individual’s ability to progress through the system and to feel heard. Structural and relational barriers of this kind influence how the responsiveness of care and the extent to which it is experienced as people-centred are perceived in practice.

June described changes in her interactions with primary care services, noting that since the onset of the pandemic, communication with general practitioners had shifted in ways that made it more difficult for her to convey her personal circumstances. She stated: *“I have to say that contact with GP has got very difficult since the pandemic. I don’t mind doing it a talking on the telephone or doing video interviews at all, but I do want to do things where I can communicate. I don’t want to have tick boxes which you choose questions that somebody else has chosen for you. I dislike to tick boxes a lot because they don’t allow for somebody who’s a dislike to tick boxes like me, who has got lots to say. It was only asking questions about the things that they don’t give you the answers for frequently asked questions.”* June noted that communication based on predetermined questions limited her ability to describe her personal circumstances. She expressed a preference for having the opportunity to speak more freely, rather than being restricted to options defined by the system.

June’s experience relates to the people-centred care principle of flexibility in modes of expression. June highlighted that her need to communicate in a more individualised way was not fully supported by the existing procedures, particularly when faced with standardised questioning formats. The situation described by June underscores the importance of allowing individuals to articulate their health concerns in ways that reflect their own perspectives. The extent to which services support personalised forms of expression is a key factor in understanding how people-centred care is perceived in communication practices.

During the service utilisation stage, participants described a range of experiences related to key elements of people-centred care, including the organisation of consultation time, the availability of staff responses, and the structure of service pathways. Participants' experience reflected varying degrees of flexibility and adaptability in how services supported individual expression, responded to health concerns, and facilitated entry into the system.

Specifically, some participants noted that the brevity of consultation appointments made it difficult to fully express their personal circumstances, which in turn affected their sense of participation in the communication process. The reported difficulty in articulating individual concerns during short consultations corresponds to the emphasis identified in the systematic review on the importance of increased consultation time and communication skills within people-centred care. The extent to which services provide adequate space for dialogue directly influences whether individuals feel their health experiences are understood and valued.

In addition, participants' descriptions of delayed responses, extended waiting times, and staffing shortages revealed the time-related pressures that affected the ability of services to respond to individual requests. The capacity of a service to offer timely responses after a need has been expressed represents a core aspect of responsiveness within people-centred care. The importance of timely responsiveness aligns with the emphasis placed in the systematic review on elements such as increased consultation time, which support more responsive and attentive care delivery.

Some participants also noted that structural features within current procedures - such as referral pathways or the use of predetermined questions - introduced limitations in communication. Participants' descriptions relate to two key aspects of people-centred care: flexibility in modes of expression and the clarity of service processes. The systematic review identified the use of better technology as a supportive condition for enabling more effective communication within healthcare settings.

Overall, participants' descriptions highlighted how consultation time, staffing arrangements, and procedural structures shaped their experiences of service utilisation. The implementation of people-centred care at this stage depended on whether services supported individual expression, understanding, and timely response. Participants' reflections on communication and system design offer further insight into how people-centred care is encountered through direct interactions with the healthcare system. These accounts illustrate communication and resource arrangements operate as key mechanisms shaping whether individuals feel understood, supported, and able to participate meaningfully in their care.

### 5.5.3 The Influence of Economic Factors on Service Accessibility

During the stage of service utilisation, some participants indicated that economic factors had a tangible influence on decisions regarding their approaches to health management and the selection of services. The theme, the influence of economic factors on service accessibility, focuses on two interrelated aspects: first, the ways in which financial circumstances shaped self-management approaches, and second, how economic considerations formed part of the decision-making process when choosing between available services.

Participants' experiences suggest in such context; the manifestation of people-centred care depends not only on the availability of services but also on whether those services are appropriate and affordable in relation to individuals' everyday circumstances. The following paragraphs presents specific narratives to explore how economic factors influenced participants' perceptions of, and engagement with, people-centred care during service utilisation.

When describing their experiences of service utilisation, Susan and John referred to the influence of economic factors on their choice of services. Susan stated: *"My twin sister was living in the UK and she got her feet done on the NHS because obviously, it's free here."* John also stated: *"I don't really think they could offer me any different than what the NHS could do."* The descriptions provided by both participants indicated that cost and financial feasibility were important factors influencing their decisions when faced with different service options.

Both Susan and John emphasised the acceptability of NHS services, partly due to the absence of direct costs. Susan and John's experiences relate to the people-centred care principles of service accessibility and financial affordability. When services are perceived as financially acceptable, individuals are more likely to incorporate them into their personal health management strategies. The participants' accounts suggest that, for a service to be experienced as people-centred, its economic characteristics must align with users' practical circumstances, forming a critical component of the service selection process.

When discussing potential self-management strategies, Ann expressed concern about the financial burden associated with certain activities. She stated: "It's a thing is because I'm not working, I'm finding them a little bit expensive." Ann explained she was not currently in employment and therefore some self-management activities were financially difficult to sustain, which influenced whether she could incorporate them into her daily routines. Ann's experience relates to the people-centred care principle of aligning support with individual life circumstances. Ann's description illustrates that, within the context of self-management, the extent to which services or recommendations take account of a person's financial situation is a key factor in determining the feasibility of participation. Ann's account highlights that people-centred care, in relation to self-management, involves more than simply offering advice. People-centred care concerns whether such advice is practically achievable and appropriately aligned with the user's social and economic context.

In summary, participants' narratives demonstrated that economic considerations played a significant role in shaping both the uptake of formal services and the feasibility of self-management strategies. The perceived affordability and contextual appropriateness of available options directly influenced how services were evaluated and whether they were integrated into everyday health practices. Participants' experiences underscore the importance of recognising financial realities as an integral part of people-centred care, particularly in ensuring that services are not only available, but also accessible, sustainable, and responsive to individuals' circumstances. This highlights economic considerations are not external constraints but fundamental conditions that shape how people-centred care can be enacted in everyday life.

### 5.5.4 Summary of Service Utilisation

During the stage of service utilisation, participants described a range of experiences concerning communication practices, resource conditions, and economic factors, which shaped how they accessed and engaged with healthcare services. Participants' experiences reflected several core elements of people-centred care, particularly the provision of opportunities for expression, the timeliness of responses to individual health needs, and the financial feasibility of services.

In relation to communication and resource availability, some participants reported that limited consultation time, staffing shortages, or complex procedures affected their ability to convey personal concerns and receive timely responses. When individuals lacked sufficient time or support to express themselves, it became more difficult to perceive services as attentive to their needs. Participants' accounts highlighted the importance of extended consultation time, improved communication strategies, and accessible service processes as key features of people-centred care. The experiences suggest that the extent to which services allow individuals to be heard and understood under real-world conditions forms a critical foundation for the perception of people-centredness in communication.

At the same time, participants' reflections on economic constraints indicated that the affordability of services had a direct impact on both the selection and uptake of care. In decisions regarding formal services or self-management approaches, some participants explicitly considered cost as a determining factor. The descriptions of cost-related decision-making demonstrate that people-centred care is not solely concerned with the availability of services, but also with their alignment, in both form and cost, with users' living circumstances. Within this context, financial accessibility emerges as an essential dimension in assessing whether care is experienced as people-centred.

Viewed collectively, participants' experiences illustrate how people-centred care was perceived and enacted during the stage of service utilisation. The notion of people-centredness was not confined to whether services were offered but extended to whether they were capable of supporting individual expression, facilitating understanding, and enabling sustainable participation. The reported experiences related to communication, resource conditions, and economic considerations deepen the understanding of how people-centred care is experienced in routine healthcare interactions. Taken together, these findings highlight service utilisation is shaped by interacting relational, structural, and economic factors, reinforcing that people-centred care depends on how well services align with the realities individuals face when trying to access and engage with care.

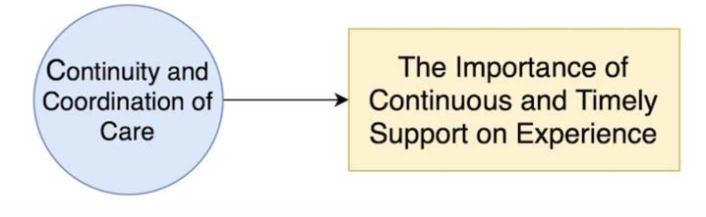
## 5.6 Continuity and Coordination of Care

### 5.6.1 Introduction

The user journey progresses into the stage of continuity and coordination of care, which reflects the ongoing relationship and support arrangements established between individuals and the healthcare system following initial consultations. At continuity and coordination of care stage, service interactions are no longer limited to one-off appointments, but include follow-up care, continuity of information, and sustained responses to changes in health status. The provision of follow-up, the maintenance of information across encounters, and the responsiveness to evolving health needs are particularly critical in the context of chronic condition management, as they concern the extent to which care can maintain consistency over time while demonstrating an ongoing understanding of and respect for individual circumstances.

This section focuses on the theme of the importance of continuous and timely support on experience (see Figure 5.5). The following content presents relevant narratives to illustrate how key elements of people-centred care were manifested during this stage, and how these experiences contribute to a deeper understanding of what constitutes people-centred care and why it matters.

***Figure 5.5 Framework of Findings for the Continuity and Coordination of Care Stage***



### 5.6.2 The Importance of Continuous and Timely Support on Experience

The importance of continuity and proactive follow-up as core elements of people-centred care is illustrated in the following example. Ann noted the absence of follow-up contact had affected her perception of the service. She stated: *"They don't check back, and I think they should. I think they should ask me how it's going. Because if they leave it. If they don't ask again, how are they going to know if things are going well?"* Ann explained that following the initial contact, service providers did not take the initiative to check on her progress. She expressed a desire for some form of continued follow-up to ensure that her health was developing as expected.

Ann's experience relates to the people-centred care elements of continuity of support and mechanisms for feedback. Ann’s emphasis on “they should ask me how it’s going” reflects an expectation that services should maintain an ongoing interest in her health over time, rather than limiting attention to the initial point of contact. The situation described by Ann highlights that, within people-centred care, the ability of services to maintain contact and express ongoing concern in later stages is a significant factor influencing user experience. Continuous support rather than one-off can help to build trust in the service and demonstrates attentiveness to changes in individual circumstances.

The importance of maintaining stable care relationships as part of people-centred care is evident in concerns about consistency across healthcare encounters. When sharing her views on the service, Susan pointed out the lack of consistent contact with the same doctor could lead to problems. She stated: *“If you don’t see the same doctor twice or you’ve got a locum doctor then there, that’s where the issues arise because you’ve no continuity of care.”* Susan believed that frequent changes in doctors could disrupt the continuity of care, potentially undermining the consistency and coordination of the service provided.

The concern Susan raised regarding changes in care providers relates to the people-centred care principle of continuity of care. She emphasised consistent contact with the same healthcare professional supports the development of a long-term understanding of the individual’s health, thereby strengthening the coherence of service provision. Susan’s reflection contributes to a deeper understanding of people-centred care by highlighting that the ability of services to maintain continuity in care relationships is a key factor in determining whether individuals feel consistently supported and understood over time.

The importance of continuous and timely support is reflected in John’s experience of disengagement from care during and after the pandemic. He stated: *“It’s not very often I go to a GP now because the GP that I did have is actually retired now, but I’ve not really been to a GP for well really since the pandemic.”* John’s account illustrates how the retirement of a familiar GP, combined with service disruptions during the pandemic, led to a prolonged period without contact or follow-up. The absence of a clear pathway back into care contributed to his reduced engagement.

John's experience highlights a lack of continuity and proactive support, both of which are central to people-centred care. John's experience suggests that when services do not maintain contact or respond to changes in provider relationships, individuals may feel overlooked or disconnected. John's account deepens the understanding of people-centred care by showing that timely, ongoing engagement, particularly during periods of transition, is key to helping individuals feel supported and remembered by the system. Taken together, these experiences identify continuity and timely follow-up function as core mechanisms through which individuals sustain trust, feel recognised, and remain meaningfully connected to their care.

### 5.6.3 Summary of Continuity and Coordination

Participants' statements indicated that the continuity and responsiveness of care were central to how people-centred care was experienced during the stage of ongoing service engagement. Ann raised concerns about the lack of follow-up contact, which led her to question whether the service genuinely cared about her health progress. Susan expressed frustration regarding frequent changes in doctors, suggesting that such inconsistency undermined the coherence of care. John described a prolonged period of disengagement from services following the retirement of his regular GP and the disruption of care during the pandemic, highlighting the absence of timely follow-up or re-engagement. These views highlighted two key elements of people-centred care, namely long-term continuous care and the strengthening of coordination and accountability, both of which were identified in the systematic review conducted as part of this research.

Ann's emphasis on "they should ask me how it's going" reflected her expectation of continued engagement and a structured feedback mechanism. This suggested she regarded continuity and ongoing concern as integral to the quality of care. Susan's reference to the absence of "continuity of care" in the context of rotating doctors underscored the importance she placed on stable care relationships and the ongoing development of professional understanding. Similarly, John's experience pointed to a breakdown in continuity and coordination, where the lack of a clear pathway back into care left him feeling disconnected from services over an extended period.

Participants' perspectives contribute to a deeper understanding of people-centred care by illustrating how, from the user's point of view, the ability of services to ensure continuity and uphold coordinated responsibility forms a critical foundation of perceived quality. John's account reinforced the idea that consistent engagement over time, particularly in response to known changes such as provider retirement, is essential for sustaining trust and maintaining access. This understanding aligns closely with the two elements identified in the systematic review, emphasising the need for consistency over time and the organisational capacity to ensure coherent communication and clearly defined responsibilities across the care pathway. The interpretation of continuity and coordinated responsibility as fundamental to people-centred care aligns closely with the two elements identified in the systematic review. The connection between participants' experiences and the two elements identified in the systematic review emphasises the need for consistency over time and the organisational capacity to ensure coherent communication and clearly defined responsibilities across the care pathway. Overall, these accounts highlight continuity and coordination are not simply structural features of the system but relational processes that enable individuals to experience care as coherent, dependable, and genuinely people-centred.

## 5.7 Conclusion

The findings chapter draws on the results of both framework analysis and thematic analysis to construct a circular framework grounded in the user journey, designed to present the lived experiences of individuals with arthritis within the context of healthcare service use. The circular structure reflects the reality faced by individuals with chronic conditions, who often revisit earlier stages, seek ongoing support, and continually adjust their management strategies. This structural arrangement, in itself, embodies a key characteristic of people-centred care, namely the recognition of evolving and cyclical needs over time, rather than assuming a linear care pathway with a single point of entry and conclusion. The circular framework places emphasis on the individual perspective, acknowledging the dynamic nature of users' roles in long-term health management and underscoring the need for service systems to respond and adapt to personal continuity and change. Through this structure, the research is able to systematically capture which aspects of care are perceived as people-centred, and why they are experienced in this way.

During the stage of needs identification, personalised health management emerged as a central concern. The extent to which service providers were able to recognise and respond to individuals' symptom patterns, daily routines, and health-related goals represented a direct manifestation of the people-centred care principles of personalisation and participatory decision-making.

In the stage of information acquisition, the accessibility and relevance of information, as well as the space available for individuals to articulate their concerns, were identified as critical factors influencing users' understanding of their condition and their capacity for self-management. These findings highlighted the practical dimensions of patient education and social support within people-centred care.

During the stage of service utilisation, communication practices, resource conditions, and financial feasibility were found to significantly shape the experience of care. Participants' narratives suggested that people-centred care is not only defined by the availability of time and appropriate modes of communication, but also by the ability of services to respond in a timely manner and align with individuals' socio-economic contexts.

In the stage of continuity and coordination of care, ongoing contact and consistency in care relationships served as key reference points by which participants assessed whether services were experienced as people-centred. These experiences further reinforced the importance of long-term continuous care and coordinated accountability as essential components of people-centred care.

Overall, the findings suggest that the manifestation of people-centred care is not confined to a single service context or specific behaviour but is interwoven throughout different stages of the user journey in multiple forms. The extent to which individuals feel listened to, receive appropriate explanations, and are involved in management decisions under conditions of respect forms the core foundation upon which care is perceived as people-centred. When compared with the people-centred care components identified in the systematic review, the findings presented in this chapter not only confirm key principles from the literature, such as participation in decision-making, communication, care coordination, and continuity of care, but also extend the understanding of these principles by illustrating how they are enacted and experienced in specific service encounters from the users' perspective.

The cases and themes explored in this chapter reveal both the existing people-centred practices within arthritis services and the areas within current systems and processes that remain insufficiently addressed. These findings will be examined in greater depth in the following discussion chapter, where they will be situated in relation to the theoretical framework and existing research. This will allow for a more comprehensive reflection on the value, limitations, and future directions of people-centred care in practice.

# Chapter 6: Discussion

## 6.1 Introduction

This Chapter discusses the findings of the study in relation to the core research questions and existing literature. The aim of this chapter is to synthesise the empirical data, conceptual developments, and methodological innovations presented in previous chapters, with the objective of critically interpreting how these findings contribute to the development of people-centred arthritis care.

In this chapter, primary attention is given to address the following two research questions:

- How can design thinking, through interdisciplinary collaboration, enhance the development of people-centred care in arthritis healthcare services?

- What are the people-centred care elements in arthritis healthcare services from the users' perspective?

To address one of the key research questions of this study, namely how design thinking facilitated through interdisciplinary collaboration can advance the development of people-centred care within arthritis healthcare services, Section 6.2 delineates the study's contributions to knowledge. These contributions include the formulation of a people-centred circular framework, the methodological integration of design thinking into qualitative research, and the interdisciplinary application of user journey mapping. Such developments demonstrate the methodological and conceptual value of design thinking in fostering more responsive and collaborative models of care.

In response to another key research question of the study, namely what the people-centred care elements in arthritis healthcare services are from the users' perspective, Section 6.3 provides an in-depth analysis of the care elements identified through their lived experiences. This section examines how these elements are constructed, negotiated, or challenged within everyday service interactions. By foregrounding the voices and perspectives of people with arthritis, the analysis deepens understanding of what people-centred care entails in practice, particularly within the context of arthritis services.

In addition, section 6.4 explores the broader implications of the study for theory, practice, and policy, particularly by linking empirical findings to structural and systemic challenges. This section offers an integrative reflection on both core concerns addressed by the study.

Finally, section 6.5 puts forward a set of practice-oriented and research-informed recommendations aimed at guiding the future design, delivery, and evaluation of arthritis care services. These recommendations are grounded in the study's holistic engagement with both research questions.

Through this structure, the chapter builds a critical narrative that connects empirical findings with theoretical frameworks and repositions service users as active agents in shaping the future of arthritis care.

## 6.2 Contribution to Knowledge

The aim of this section is to articulate to the contributions of this study to the existing body of knowledge. Focusing on the core theme of service experience among individuals living with arthritis, this research advances new perspectives and methodological pathways across three dimensions: theoretical construction, methodological integration, and interdisciplinary application.

Firstly, in relation to theoretical construction, by deductively and inductively analysing the lived experiences of people with arthritis, the study proposes a people-centred, circular framework of user experience. This framework addresses the limitations of traditional linear patient journey models and offers a more dynamic understanding of service experiences in the context of arthritis care.

Secondly, regarding methodological integration, the study incorporates design thinking principles into the process of qualitative data analysis. This integration extends the application of design thinking within the field of arthritis research and demonstrates how experience-driven approaches can support service improvement in arthritis management.

Thirdly, in terms of interdisciplinary application, the study employs user journey mapping both as an analytical tool and as a means of theoretical construction. This dual function enhances the organisation and interpretation of qualitative data and contributes a novel approach to interdisciplinary research in people-centred arthritis care.

Building on the three dimensions outlined above, namely theoretical construction, methodological integration, and interdisciplinary application, this study shows how combining design thinking with framework and thematic analysis supports interdisciplinary collaboration in arthritis care. Design thinking acts as a bridge, enabling the development of people-centred service models grounded in the lived experiences of individuals with arthritis.

These contributions directly address the central research question: *How can design thinking, through interdisciplinary collaboration, enhance the development of people-centred care in arthritis healthcare services?* This study strengthens the theoretical and methodological foundations of people-centred arthritis care and offers new directions for future service improvement.

### 6.2.1 Reconceptualising the Patient Journey: A People-Centred Circular Framework for Understanding Arthritis Care Experiences

The findings from this study contribute to the theoretical development of people-centred arthritis care services by proposing a circular framework of arthritis user experience, comprising four interrelated phases: needs identification, information acquisition, service utilisation, and continuity and coordination of care. The circular framework did not stem from preconceived theoretical assumptions but was instead developed inductively through the analysis of data exploring the experiences of people living with arthritis.

The circular framework of arthritis user experiences incorporating people-centred elements, developed in this study, underscores the dynamic and cyclical nature of care needs as experienced by participants, reflecting how these needs evolve in response to changing health conditions and life circumstances. People with arthritis do not move through distinct stages in a linear manner. Instead, they often shift back and forth between identifying needs, seeking information, using services, and navigating continuity and coordination of care, in response to changing life circumstances and fluctuations in their health. The repeated revisiting of care stages and the ongoing adjustments made by people with arthritis gives rise to an iterative and interdependent process that more accurately reflects the lived realities of managing arthritis.

In existing research, patient journey mapping has emerged as an increasingly prominent methodological approach for capturing and analysing patient experiences (Davies et al., 2023). To represent the patient journey, researchers have employed a range of visual formats, including linear diagrams and mind maps (Davies et al., 2023). Additionally, tools such as customer journey maps, experience maps, and service blueprints commonly adopt a linear or chronological structure to illustrate patients' continuous interactions with the healthcare system across different time points (Joseph et al., 2020; Joseph et al., 2022). These linear approaches are particularly useful in identifying key touchpoints and potential "bottlenecks" within the care pathway (Joseph et al., 2020).

For instance, Haldeman et al. (2018) proposed an evidence-based, person-centred patient care pathway applicable to a range of spine-related conditions. The pathway adopts a linear progression, beginning with the patient's initial awareness of a health issue, followed by preliminary screening, clinical assessment, therapeutic intervention, and culminating in treatment outcomes. Similarly, in their study with people with arthritis, May et al. (2025) developed a linear journey map, which delineates the experience of people with arthritis into distinct stages: “before the diagnosis”, “diagnosis”, “after the diagnosis”, and “current treatment”. While the study by May et al. (2025) effectively captures the sequential progression of patient experiences and associated emotional responses, its analysis remains primarily situated within a linear narrative, falling short of uncovering the dynamic mechanisms underpinning interactions between patients and the healthcare system.

As discussed above, prior research tends to represent the patient journey as a linear process. However, currently, there is limited evidence of journey mapping focused on the service experiences of people with arthritis. In practice, people with arthritis often navigate across multiple service systems, encountering multidimensional challenges such as iterative decision-making, resource uncertainty, and shifting roles. In response to these realities, the present study proposes a new people-centred framework, adopting a circular structure and comprising four distinct phases, to more accurately represent the interactions between people with arthritis and healthcare services.

The key innovation of the people-centred circular framework of arthritis user experience lies in the reconceptualisation of people with arthritis as active “agents” and “co-creators”, rather than passive “recipients” of care. People with arthritis are no longer viewed as individuals who merely progress along a predetermined care pathway. Instead, they are recognised as central actors who continually assess their needs, seek information and support, and access relevant health and community services, such as appointments, treatments, and self-management support, across different domains throughout the service journey.

The circular framework of arthritis user experience incorporating people-centred elements expands the conceptualisation of the patient’s role, but also places new demands on service design, requiring providers to develop more flexible and responsive support systems that acknowledge and strengthen patients’ active engagement in their health journeys. The circular framework developed in this study highlights the active and ongoing role of people with arthritis in navigating care. The circular framework illustrates how individuals continuously engage in identifying needs and accessing services. While linear models of care journeys have been useful in structuring service delivery by outlining typical stages (May et al., 2025; Haldeman et al., 2018), they may not fully capture the fluid, adaptive nature of care experiences in conditions such as arthritis. By contrast, the circular structure proposed here offers a more flexible and iterative understanding of the care process.

This study contributes new knowledge, through addressing a gap in current literature, by introducing a circular framework that maps the service experiences of people with arthritis, a perspective largely absent from existing journey mapping approaches. The circular form of the framework serves as a structural enhancement to conventional linear models, better reflecting the cyclical and evolving nature of arthritis care. In addition, the framework offers a new theoretical starting point for examining patient agency, transitional support mechanisms, and the responsiveness of healthcare systems.

While healthcare transformation frameworks often conceptualise patient journeys at a structural or organisational level, this study provides a micro-level, experience-based account of how care pathways unfold in practice, responding to critiques that integrated care frameworks tend to privilege system design over patients' lived and experiential perspectives (Hughes et al., 2020).

### 6.2.2 Extending the Boundaries of Knowledge: An Interdisciplinary Analytical Framework for Understanding Arthritis Service Experiences

Historically, research has often been confined within strict disciplinary boundaries, with limited exchange of ideas and methodologies across fields (Singh and Virk, 2023). Although approaches grounded in a single discipline are typically characterised by a high degree of focus, they are sometimes insufficient to fully capture the complexity and interconnectedness of the issues at hand (Singh and Virk, 2023). The limitation inherent in single-disciplinary approaches is particularly evident in research on people-centred healthcare services for patients with arthritis, whose complex needs often span multiple domains, including medical care, psychological wellbeing, and social support. Moreover, the absence of perspectives from other disciplines constrains the breadth of inquiry, thereby missing opportunities for breakthroughs that interdisciplinary collaboration might afford (Smye and Frangi, 2021).

Concurrently, healthcare systems are facing increasingly complex challenges and must respond rapidly to the evolving health needs of patients and society at large (Flood et al., 2021). The medical field is fraught with significant challenges, and it may be argued that addressing these issues necessitates researchers moving beyond the limitations of single-discipline frameworks (Smye and Frangi, 2021). In response to the increasing complexity of healthcare systems and the evolving health needs of patients and society, the healthcare sector has begun to explore capabilities and models that transcend traditional disciplinary boundaries, integrating design practices to foster innovation and transformation (Palazzo et al., 2024).

In the existing research, the majority of scholars have primarily applied design thinking methodologies to the enhancement of existing services or the development of new products within the healthcare sector, typically following the five-step process associated with design thinking (Chatpun et al., 2022; Hsieh et al., 2023; Ouyang et al., 2023; Koppel and Sullivan, 2022; Kennedy et al., 2024; Kim et al., 2022; Almaghaslah et al., 2021; Wang et al., 2025). In addition, several studies have employed design thinking in the structural innovation of existing frameworks, generating new operational guidance processes (Lorusso et al., 2021; Teo et al., 2023).

However, recent discussions concerning the nature of design thinking have emphasised that it should not be understood merely as a linear set of procedural steps, but rather as an evolving body of practices, methodological systems, and modes of working rooted in design education and professional practice (Matthews et al., 2023). Within this understanding, human-centred research, analytical inquiry, and the critical reconstruction of existing practices remain central to the operation of design thinking (Matthews et al., 2023). Consequently, the integration of design thinking elements into data analysis processes aligns with its fundamental characteristics and offers a novel methodological pathway for healthcare service research grounded in user experience. Building upon this context, this study proposes a new interdisciplinary data analysis approach that integrates framework analysis, thematic analysis, and design thinking principles.

This study initially employed Framework Analysis as the preliminary method of data analysis. Originating from the applied research tradition proposed by Ritchie and Spencer (1994), framework analysis is particularly well-suited to policy and service-related research that requires a structured and staged handling of data. By organising and coding interview content related to participants' experiences of service encounters, a service journey framework was constructed, grounded in the actual sequence of user actions. At this stage, the analysis focused on identifying the key touchpoints and pathways through which individuals living with arthritis interacted with the service system across the care continuum.

This study also employed the thematic analysis approach outlined by Braun and Clarke (2022) to examine participants' narratives concerning their service experiences. By coding and categorising recurring expressions of service needs, personal perceptions, and emotional responses within the interview data, the analysis identified a range of representative person-centred service elements. Thematic analysis in this study was employed to foreground the perspectives of people with arthritis, shaping an understanding of their experiences with healthcare services and enabling the identification of key themes that influence the perceived quality of care. These themes provided both a value-oriented and content-informed foundation for the development of the service model.

Following the completion of both the framework and thematic analyses, the study proceeded to combine the outcomes of these two approaches, incorporating key principles from design thinking, particularly the ‘empathise’ and ‘define’ phases (Wolniak, 2017), to deepen the understanding of service experiences. Design thinking emphasises the importance of approaching problems from the perspective of service users, enabling a re-identification and redefinition of their needs, challenges, and opportunities for transformation along the service journey (Brown, 2009).

Guided by design thinking, the study aligned the people with arthritis action pathways generated through framework analysis with the people-centred service elements derived from thematic analysis, thereby establishing a systematic connection between service structures and user needs. Through this integrative process, the study developed a composite model, a circular framework of arthritis user experiences incorporating people-centred elements, that brings together structural and value-based dimensions. This circular framework not only reveals the dynamic and non-linear nature of service engagement among people living with arthritis, but also highlights the cyclical nature of service encounters and the interrelations between different stages.

The interdisciplinary analytical approach proposed in this study, integrating framework analysis, thematic analysis, and principles of design thinking, constitutes a methodological innovation in the study of arthritis service experiences. The interdisciplinary analytical approach employed in this research represents the first application of such an approach within healthcare and design field. In contrast to previous studies that primarily introduced design thinking at the stage of intervention design (Lorusso et al., 2021; Hsieh et al., 2023; Teo et al., 2023), this research positions design thinking as a theoretical lens within the qualitative data analysis process. This approach contributes to the theoretical refinement of design thinking and broadens its applicability within the domain of health sciences. Importantly, this interdisciplinary analytical approach addressed the recognised limitation in healthcare transformation literature, which has tended to prioritise structural integration and system redesign while paying comparatively limited attention to how transformation is enacted and experienced in everyday care (Greenhalgh et al., 2018). By foregrounding lived experience, service navigation, and patient sense-making, this study bridges macro-level reform agendas with micro-level service realities. This integrative methodology not only enhances the depth and applied value of understanding user experiences but also offers a novel theoretical foundation for future exploration of service users' active roles, their support needs during transitions between care stages, and the ways in which service systems might more effectively respond to these evolving needs.

Both framework analysis and thematic analysis have been widely applied in health service research, and design thinking is increasingly employed in the development of health interventions, systematic integration of these three approaches within a single study remains exceedingly rare and is scarcely documented in the existing literature. Most studies regard design thinking primarily as a tool for the later stages of solution development (Chatpun et al., 2022; Fortune et al., 2022; Ouyang et al., 2023; Koppel and Sullivan, 2022; Kennedy Oehlert et al., 2024; Kim et al., 2022; Almaghaslah et al., 2021; Wang et al., 2025), rather than as a theoretical lens guiding the process of qualitative data analysis. Addressing this gap, the present study innovatively embeds key principles of design thinking within the qualitative analytic process, emphasising the dual integration of structural and interpretive dimensions through empathy and problem redefinition. This methodological innovation advances qualitative health research by providing a coherent and theory-informed framework for analysing the complexity and dynamism inherent in-service user experiences.

### 6.2.3 Bridging Design and Health Research: A People-Centred Model Informed by User Journey Mapping

The researcher proposes a new pathway for transforming user experience data into a visual format - by constructing a user journey map to illustrate the interactions and experiences of individuals with arthritis across different stages. In this study, user journey maps were incorporated into the data analysis phase of the qualitative research as a key tool for identifying the structural patterns and experiential characteristics within user experiences. The user journey map not only supported the analysis of stage-specific experiences across individuals within the service process but also provided a foundation for subsequent theoretical development.

The user journey map, developed through framework analysis, provided the structural foundation for the people-centred circular framework of arthritis user experience. Thematic analysis was subsequently applied to identify key people-centred elements across different stages of the journey, which were then integrated into the structural map to produce the final circular model. The user journey maps, developed through framework analysis, provided a logical basis for dividing the care process into stages and a visual structure for illustrating the cyclical relationships between them. This mapping process reflected an interpretative organisation of user narratives, allowing for the segmentation of experiences in a way that was informed by both empirical data and relevant theoretical perspectives. In parallel, thematic analysis was conducted to inductively identify people-centred elements embedded within and across these stages. These themes were then integrated into the mapped structure, enabling the construction of a circular framework that combined both structural progression and user-centred meaning.

Therefore, the user journey map functioned not only as a mediating tool within the analytical process, but also as a critical component in the construction of core theoretical insights specific to arthritis services. The integration of the user journey map into the process of qualitative analysis represents, to the best of current knowledge, a novel application within research on service experiences in arthritis care, marking a substantive extension of people-centred analytical approaches in this field.

In health research, patient journey mapping has been used to explore patient experiences across a range of healthcare contexts and settings (Davies, 2015), which is also referred to as “patient journeys”, “patient pathways” for example (Barton et al., 2019). Patient journey mapping is a relatively recent research approach that emphasises the use of qualitative data to generate deeper insights into lived experiences of patients (Holt et al., 2025). Patient Journey mapping has been applied in a limited but growing number of healthcare studies as a means of capturing patient experience within increasingly complex healthcare systems (Bearnot and Mitton, 2020). Projects employing patient journey mapping almost invariably place the individual at the centre of inquiry, aiming to understand and improve both the personal experience and the systems being navigated (Kelly et al., 2016; Kushniruk et al., 2020; Richardson et al., 2007; Bulto et al., 2024). As the journey is mapped, barriers, enablers, and gaps in service delivery are identified and reported from a patient-centred perspective (Davies et al., 2023).

In existing research, patient journey mapping projects are understood as patient-centred initiatives aimed at better understanding the barriers, enablers, experiences, service interactions and/or outcomes encountered by individuals and/or their carers and family members when entering, navigating, experiencing, and exiting one or more services within the healthcare system (Curry, 2007). Patient journey mapping, in this context, involves the creation of visual or descriptive maps by documenting elements of the journey (Davies et al., 2023). Patient journey mapping provides evidence from the patient's perspective and highlights experiences through the lens of patients and consumers (Bulto et al., 2024). Patient journey mapping offered detailed insights into patient experiences, service gaps, and the barriers and facilitators within healthcare delivery (Bulto et al., 2024). Patient journey mapping holds promising potential to contribute to the design of people-centred health services (Holt et al., 2025).

In comparison to the existing applications of patient journey mapping in health research, this study represents a substantive extension at both methodological and theoretical levels. Previous research has primarily emphasised the use of patient journey mapping as a qualitative data-driven tool to represent patients' pathways and experiences within healthcare systems (Davies et al., 2023; Bulto et al., 2024), with most studies focusing on the patient-centred identification of barriers, enablers, and emotional responses within service processes (Kelly et al., 2016; Richardson et al., 2007). For instance, May et al. (2025) divided the patient journey into several stages to describe the care experiences of individuals with axial spondyloarthritis and their relatives, and the resulting stage-based trajectory closely mirrors the structure of user journey mapping. However, May et al. (2025) did not elevate the approach to a tool for theoretical construction. Instead, the analysis remained at the level of experiential summary and narrative presentation.

In contrast to previous studies, this research not only utilised the user journey map as a visualisation tool but also embedded it within the analytical structure as part of the framework analysis, where it served to organise the user experience into a sequence of action-based stages. Separately, thematic analysis was conducted to identify people-centred elements across these stages. These two strands of analysis were later integrated during the development of the circular user experience model. Specifically, the journey structure derived from framework analysis was combined with the thematic insights to construct a model that captures both the procedural and experiential dimensions of arthritis care.

Methodologically, this study is the first within the field of arthritis care research to employ user journey mapping as a theoretical construct, rather than solely as a visual or descriptive tool. Distinct from conventional “patient journey mapping” approaches grounded in clinical pathways (May et al., 2025; Davies et al., 2023; Cherif et al., 2020), this study draws on the concept of the “user journey map” from design theory, placing greater emphasis on the interrelations between different stages of service and their cyclical nature. Accordingly, the user journey map in this study functions not only as a tool for organising user experiences, but also as a foundational methodological approach for constructing a model of arthritis service experience.

While design thinking in healthcare research is most often applied as a tool for intervention development or service innovation (Bate and Robert, 2023). This study advances the contribution by positioning design thinking as an analytical lens within qualitative data analysis. By embedding principles such as empathy, problem reframing, and iterative sense-making into the analytic process, the study extends design thinking beyond solution generation to support deeper understanding of lived care experiences.

## 6.3 Discussion on the people-centred service

This section consolidates the theoretical definition and practical elements of people-centred care as conceptualised in this study through the lens of arthritis service experiences. Drawing from existing literature and empirical findings, the study develops a refined definition of people-centred arthritis care, one that centres on lived experience, adapts to multidimensional needs, and unfolds as a dynamic, cyclical process rather than a linear progression. This conceptualisation is grounded in the circular framework of arthritis user experience developed through the integration of design thinking and qualitative analysis. This section's discussion does not serve as a repetition of the empirical findings presented earlier. Instead, through conceptual integration and theoretical reflection, it aims to elevate and reconfigure the significance of these experiential elements within the broader framework of people-centred healthcare systems.

The subsequent subsections detail six key elements that collectively operationalise this model: personalised health management, information access and self-education, the role of community groups, communication and resource challenges, economic factors, and continuity and timely support. Each theme reflects how people with arthritis actively navigate, interpret, and shape their care journeys, revealing both facilitators and barriers to the realisation of people-centred care in practice. Rather than presenting a static checklist, these elements are interdependent and fluid, corresponding to different phases of the circular framework. Together, they offer a situated, experience-based account of how people-centred care can be more meaningfully implemented in arthritis services, emphasising flexibility, responsiveness, and shared agency across time and settings.

### 6.3.1 People-Centred Care for Arthritis Service: Definition

For decades, healthcare systems have predominantly been organised from a biomedical perspective, whereby the needs of clinicians and the system have taken precedence in the delivery of care to patients (Voshaar et al., 2015). A widely accepted definition of people-centred care is respectful of and responsive to individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions (Weinberg et al., 2011). The fundamental principle of people-centred care lies in the comprehensive respect for patients as unique individuals embedded within their specific social contexts. This approach emphasises the importance of involving patients as co-creators of their care in collaboration with the multidisciplinary team, in order to ensure that their needs, preferences, and values are genuinely understood and considered throughout the care process (Voshaar et al., 2015). People-centred care places each patient at the core of the healthcare system and acknowledges them as whole persons with physical, psychological, and social needs (Voshaar et al., 2015). A critical step towards delivering effective, people-centred care is an understanding of the individual's lived experience (Fairley et al., 2021). People-centred care seeks to provide patients with comprehensive and impartial information, grounded in the best available evidence, whilst taking into consideration their cultural traditions, personal preferences and values, family circumstances, social context, and lifestyle (Voshaar et al., 2015). However, the definitions outlined above are largely predicated on single or relatively stable clinical encounters. As a result, they offer limited insight into how patients with chronic conditions continually navigate between multiple service touchpoints, repeatedly recalibrate their understandings and expectations, and sustain long-term care experiences under structural constraints. Particularly in the context of long-term condition management, such as arthritis care, these definitions remain insufficient to account for empirical realities including service fragmentation, information asymmetries, and deficits in care continuity (Coulter et al., 2015; Nolte and McKee, 2008; Singer et al., 2011).

Analysis of service experiences of participants with arthritis in this study indicates existing definitions of people-centred care continue to exhibit conceptual blind spots in explaining patients' long-term care experiences. The findings suggest service experiences do not unfold along clear or linear trajectories; instead, they are characterised by high levels of dynamism, iterative adjustment, and movement across contexts, particularly in relation to needs recognition, information access, service coordination, and the provision of sustained long-term support. Based on the analysis of service experiences among people living with arthritis, this study proposes a definition of people-centred arthritis care as:

*"a holistic model of service delivery centred on patients' lived experiences, dynamically responsive to their multidimensional needs, and encompassing the continuum from needs identification, information access, and service utilisation to ongoing support and service coordination, emphasing active patient participation, continuity of care pathways, and personalised care delivered through interdisciplinary collaboration."*

This definition is derived from the circular framework of arthritis user experience incorporating people-centred elements developed in this study. The framework conceptualises care not as a static or linear process, but rather as a continuously evolving cycle that responds to the changing needs of people with arthritis. In comparison to conventional definitions of people-centred care, the formulation proposed in this study offers a more integrated and dynamic perspective. The circular framework places particular emphasis on the continuity of care, recognising that care does not end with the conclusion of treatment but extends to include ongoing follow-up and long-term support.

The circular framework of arthritis user experiences incorporating people-centred elements also foregrounds equity in access to information and resources, treating informational accessibility and interpretive support as essential components of care rather than peripheral additions. Furthermore, the circular framework highlights the active involvement of people with arthritis as co-participants, challenging the notion of patients as passive recipients and instead positioning them as engaged partners throughout the care journey. Finally, the framework underscores the importance of coordinated collaboration across professional boundaries, advocating for a shift from isolated clinical encounters to more systemic, cross-disciplinary, and synergistic approaches to care delivery. Taken together, these elements not only reflect the inherent complexity of managing long-term conditions such as arthritis, but also provide a conceptual foundation for designing more responsive, inclusive, and integrated arthritis services in the future.

### 6.3.2 Elements of People-Centred Arthritis Care

This section outlines six key elements of people-centred care, as identified in this study through the lived experiences of people with arthritis. These elements represent interrelated domains that collectively shape how individuals engage with, interpret, and navigate healthcare services. First, personalised health management refers to the need for care strategies to be tailored to the individual's unique clinical, psychological, and social context. Second, information access and self-education highlights the active role of individuals in acquiring and making sense of health information across both formal and informal sources. Third, the role of community groups is explored as a vital, though often under-recognised, source of emotional, informational, and practical support. Fourth, communication and resource challenges are identified as major difficulties that limit people's ability to get the care they need, often due to wider system pressures. Fifth, the influence of economic factors is considered as part of the reasoning individuals apply when making care decisions. Finally, the need for continuity and timely support is highlighted as central to building trust and maintaining meaningful care over time. These elements collectively offer a practical understanding of how people-centred care is experienced and point towards directions for improving services in line with what matters most to people living with arthritis.

#### 6.3.2.1 The Importance of Personalised Health Management

In this study, personalised health management is defined as the capacity of healthcare services to adapt care strategies flexibly in accordance with the individual's specific clinical condition, lifestyle, psychological state, and social context, rather than adhering to a standardised, one-size-fits-all protocol. Based on the findings of this study, personalisation within people-centred care extends beyond differentiated treatment and instead highlights a deeper tension between standardised service protocols and the need to respond to the singularity of individuals' lived experiences.

In the context of arthritis, personalisation is particularly critical due to the considerable variability observed in symptom fluctuations, treatment responses, self-management capacities, and individual life priorities among people with arthritis, as evidenced in this study. These variations indicate that personalisation in arthritis care is not simply a matter of preference matching but reflects fundamentally different orientations towards what individuals value in their care trajectories. A truly people-centred service must be capable of identifying and responding to these individual differences, rather than applying a generic, standardised pathway to all.

In the systematic review presented in chapter 2, over one-third of the included studies identified personalisation as a critical component in delivering people-centred care for individuals with arthritis. Personalisation signifies the recognition of everyone's unique needs and concerns, preferences and values, as well as their capacities (Bala et al., 2018b). The impact of arthritis is inherently individualised; therefore, all interventions should be framed within the context of the person's specific life roles and environmental circumstances (Codd et al., 2023). People-centred care highlights the importance of healthcare professionals adopting a personalised, respectful, and holistic approach in their interactions with patients (Feddersen et al., 2022). Similarly, people living with arthritis have expressed a preference for care that is informed by personal experience and tailored to their individual situations (Ammerlaan et al., 2017).

Although personalised health management is an established concept within health services literature, this study illustrates how its enactment is shaped by specific stages and conditions within arthritis care trajectories. Contrary to the critique that chronic illness care is overly standardised and neglects individual variation (Ammerlaan et al., 2017), participant accounts revealed examples of flexible, person-responsive care practices. These findings suggest that people-centred care is not merely aspirational but is already being enacted within specific service encounters.

Importantly, this study identifies the needs-identification stage of the user journey as a critical point at which personalisation can have the greatest impact. This early phase, when individuals are beginning to make sense of symptoms and shape expectations, exhibits the widest diversity in concerns. The data suggest that timely recognition of these differences can provide the basis for more responsive and meaningful care. Rather than offering a new definition, the study contributes a situated understanding of how personalised health management may be operationalised in arthritis services. This emphasis on contextual application serves to complement and expand the theoretical and practical foundations of people-centred care.

#### 6.3.2.2 Information Access and Self-Education

Based on findings from this study, information access and self-education constitute a core component of people-centred care, referring to the ability of people with arthritis to proactively obtain, comprehend, and apply relevant health information when faced with health-related concerns. This process enhances their understanding of the condition and supports informed decision-making and more effective self-management.

In arthritis care, information access and self-education extend beyond the acquisition of medical facts. These practices of seeking, interpreting, and applying health-related information illustrate how individuals actively engage in interpretive and adaptive work that extends care beyond formal clinical encounters. Moreover, the multiplicity of information sources highlights how knowledge seeking in arthritis care is distributed across professional and informal domains. These findings suggest that variation in individuals' ability to access and use diverse sources of information may indicate whether arthritis services truly support patient empowerment or continue to reinforce passive roles.

Patient education aims to improve treatment outcomes by promoting behavioural change through the enhancement of knowledge, skills, and attitudes (Hewlett et al., 2008). Following timely referral and post-referral processes, it is essential to provide patients with clear explanations regarding their condition (Betteridge et al., 2016). Healthcare professionals should incorporate information concerning emotional wellbeing, lifestyle factors, and treatment goals (Betteridge et al., 2016). Clinicians have emphasised the importance of delivering information in a manner that is "just right", sufficient to empower without overwhelming the patient (Codd et al., 2023). At the same time, patients have expressed a desire to receive education on arthritis and potential treatment options, to gain greater control over their health, learn strategies for disease management, and engage in future planning (Chou et al., 2017). In the context of arthritis self-management, healthcare teams and patients should share professional and experiential knowledge, working collaboratively to achieve the individual's personal goals (Olsson et al., 2020).

Taking together, these findings extend existing understandings of patient education in arthritis care by illustrating how information acquisition is not limited to professional instruction but also involves active and multidimensional engagement with various informal sources. While previous studies have highlighted the importance of structured patient education and clear communication from healthcare professionals (Betteridge et al., 2016; Codd et al., 2023), this study reveals how individuals independently navigate diverse information environments to make sense of their symptoms and treatment options. This indicates a shift away from the traditional model of one-way information provision towards a more dynamic approach, characterised by self-directed learning and the development of personal understanding.

Importantly, within the circular framework developed in this study, information access and self-education emerge as a foundational phase, marking the point at which individuals begin to transform uncertainty into action. This early-stage engagement not only initiates their care journey but also reflects their agency, priorities, and level of health literacy. As such, the quality of this phase influences the entire care experience that follows. By foregrounding the patient's active role in knowledge seeking, the circular model challenges linear assumptions regarding care as something initiated solely by professionals and repositions information access as a shared and negotiated process. This reconceptualisation provides a more realistic account of how people with arthritis begin to engage with care systems in complex and iterative ways.

#### 6.3.2.3 The Role of Community Groups in Providing Support

While previous research acknowledged the relevance of emotional and social support for individuals with arthritis (Fairley et al., 2021; Feddersen et al., 2022), the findings of this study indicate involvement in community groups, including mutual aid activities, online networks, and local initiatives both within and beyond NHS affiliated services, plays a more central and multifaceted role than has previously been emphasised. Notably, this role did not emerge from a pre-imposed framework but surfaced organically through participants' narratives, highlighting community spaces as vital for navigating psychological adjustment, making treatment decisions, and managing the everyday complexities of illness. These forms of peer-based support may offer a more relatable and empathetic context than formal settings alone, echoing literature that calls for integrating lived experience into care design (Tsekleves & Darby, 2021; Codd et al., 2023).

However, engagement with such groups is inherently individualised and should be regarded as an important but optional component of people-centred care, rather than a universal requirement (Coulter et al., 2015). Within the circular framework developed in this study, community support aligns most clearly with the continuity and coordination of care phase, reinforcing the notion that care is not limited to institutional encounters but is instead distributed across various social and experiential spaces. By foregrounding the significance of community relationships, on the terms of the individuals themselves, this study contributes a situated, experience-driven perspective to ongoing discussions around integrated and relational models of arthritis care.

Community groups also play a critical supportive role in the information acquisition stage of the user experience. Existing research has widely emphasised that individuals living with arthritis rely on diverse networks of social support in the course of self-management, with the very concept of self-management inherently involving collaboration with community resources (Richard and Shea, 2011). This study extends existing perspectives by illustrating how community groups function not only as sources of emotional support and information, but also as platforms for meaning making and the development of practical coping strategies. Consistent with previous studies highlighting the value of peer-led groups (Neville et al., 1999; Fairley et al., 2021), peer interaction within community settings can be understood as contributing to condition understanding, identity reconstruction, and the exploration of more personalised coping approaches. These forms of social engagement provided a type of support that was often more resonant and contextually attuned than that available within formal healthcare environments.

In addition, existing research has highlighted that community groups facilitate the formation of new social relationships among people with arthritis (Hamnes et al., 2011; Radford et al., 2008). People living with arthritis have expressed a strong desire for opportunities to share their experiences of illness and treatment with others, a form of exchange that is widely recognised for its emotional and psychological support potential (Primdahl et al., 2011; Dickerson, 2006; Avis et al., 2008; Sinclair and Blackburn, 2008; Lempp et al., 2006; Ussher et al., 2006). As Dwarswaard et al. (2016) emphasise, people with arthritis often require multilayered support from a range of sources. This study extends these insights by demonstrating that such newly formed relationships serve not only as vehicles for emotional connection, but also as mediators in the co-construction of health knowledge. Through the exchange of lived experiences and treatment strategies, community interactions can be seen to transform traditionally professional-led knowledge acquisition into a more agentic and collaborative practice of information negotiation. While some scholars have cautioned that the role of informal networks is not uniformly beneficial (Vassilev et al., 2014), their functional value in the everyday management of arthritis is increasingly acknowledged (Dwarswaard et al., 2016). The present study further substantiates this trend, highlighting the indispensable role that community groups play in facilitating information sharing, collective sense-making, and emotional adjustment.

Building on this foundation, the study proposes a reconsideration of the role of information acquisition within people-centred care. This stage is not merely a process through which patients receive biomedical knowledge, but also one in which health information is collectively interpreted and transformed through social relationships and experiential interaction. Within the circular framework of arthritis user experience incorporating people-centred elements developed in this study, community groups occupy a central position in the information acquisition stage. Through the sharing of lived experiences and reciprocal peer support, these groups enable patients to translate information into meaningful understanding and practical health-related actions, thereby serving as a vital anchor for the realisation of people-centred care.

#### 6.3.2.4 Communication and Resource Challenges

This study identifies communication and resource challenges as significant factors shaping the service use experiences of people with arthritis. Participants reported difficulties such as unclear or rushed communication with professionals, limited access to information, and inconsistent or fragmented service processes. These issues influenced their ability to understand treatment options, navigate care pathways, and feel supported during service interactions.

The study identified people living with arthritis frequently encounter communication and information-related challenges during their engagement with healthcare services. These issues are particularly pronounced in contexts where consultation time with specialists is limited and waiting times for appointments are prolonged, leading to service experiences that are widely perceived as inefficient and unhelpful. This observation aligns with existing literature suggesting reduced physician availability constrains patients' opportunities to articulate their circumstances and feel understood, thereby undermining trust and the personalisation of clinical recommendations (Bala et al., 2017). The compressed pace of communication and limited depth of interaction not only restrict the ability of people with arthritis to actively express themselves, but also diminish their trust in, and satisfaction with, the outcomes of care.

Although contemporary healthcare systems increasingly adopt modalities such as telemedicine to enhance service efficiency (Andev et al., 2023), the study indicates remote care formats were not perceived as inherently problematic. Instead, their concerns primarily related to the quality and depth of communication during such interactions. Therefore, the acceptance of remote consultations is contingent on the preservation of meaningful and dialogic communication with specialists. This finding diverges from concerns in existing literature regarding the potential informational incompleteness of virtual care (Andev et al., 2023), and points to the need to resist equating "face-to-face" with "effective communication". Therefore, it is essential to consider whether people with arthritis are provided with adequate opportunities for self-expression and meaningful understanding across varying formats of care provision.

While previous studies have identified 'listening' as a fundamental component of people-centred care (Brkic et al., 2021; Blum et al., 2024), the present study demonstrates that, under current institutional arrangements, the practice of listening is subject to structural limitations. Appointment systems and time-pressured clinical workflows were shown to offer limited opportunities for meaningful dialogue and shared decision-making. Advancing people-centred communication therefore necessitates systemic reform, including more appropriately allocated consultation times, improved specialist accessibility, and enhanced responsiveness within service delivery. Prior research has further indicated effective triage can facilitate access to the most appropriate care resources, which is essential for fostering communicative space and supporting more personalised care trajectories (Andev et al., 2023).

In summary, this study not only reinforces existing findings concerning the influence of communication quality on service experience, but also extends current understanding by highlighting how, during the service use phase, the direct interactions between people with arthritis and the healthcare system are shaped by a range of structural factors. A key challenge identified is how to ensure sufficient time and opportunity for meaningful communication between people with arthritis and healthcare professionals, communication that not only allows individuals to express their concerns but also supports mutual understanding, particularly in service environments constrained by limited resources. Within the circular framework of arthritis experience developed in this study, the service use phase is conceptualised not solely in terms of accessibility, but also about the quality of communication, the clarity of information provided, and the extent to which people with arthritis are given opportunities to articulate their needs and receive appropriate responses. These findings call for a reconsideration of priorities: the enhancement of service experience lies not in the selection of specific technological solutions, but in the extent to which different models of care are able to safeguard the voice, understanding, and participation of people with arthritis.

#### 6.3.2.5 The Influence of Economic Factors on Service Accessibility

Economic considerations function not only as barriers to access but also as part of the practical reasoning shaping how people with arthritis navigate healthcare services. Decisions around service use were shaped not only by the availability of care but by how well different options aligned with their financial circumstances, daily routines, and personal priorities. In this context, people-centred care should acknowledge that services must be not only accessible but also workable within the lived realities of people with arthritis.

At the same time, it is important to recognise that healthcare services must remain sustainable at the system level. While care models should aim to accommodate individual economic capacities, they must also operate within resource constraints. A realistic approach to people-centred care therefore requires balancing responsiveness to individual needs with the broader requirement of service viability.

The World Health Organisation (2016) highlights economic barriers can limit healthcare access, especially for low-income populations. While such discussions often focus on structural access issues, financial considerations such as the affordability of private therapy and self-management strategies also shaped how care options were evaluated. Although economic concerns were not a primary theme in the analysis, these examples suggest that cost-related reasoning may still influence service use, even within a publicly funded system like the NHS.

#### 6.3.2.6 The Importance of Continuous and Timely Support on Experience

The importance of continuity and timely support on experience constitutes a core component of people-centred care, reflecting the service system's capacity for sustained attentiveness over time and its ability to respond proactively at critical moments. Continuity and timely support on experience primarily concerns whether care relationships can maintain stable, ongoing professional understanding and communication. The importance of continuity and timely support on experience underscores that people-centred care is not defined by a single instance of positive experience, but rather by a sustained care process grounded in stable relationships and reliable support mechanisms. Existing literature has widely emphasised the critical role of continuity of care in enhancing patient experience and promoting the sustainability of healthcare systems (Vodopivec and Vrijhoef, 2019; Segan et al., 2018), continuity remains unevenly realised in everyday arthritis care. In practice, care processes often lack sustained support mechanisms following initial service encounters, particularly in the absence of systematic feedback channels or proactive follow-up arrangements. As Lopatina et al. (2019) argue, people-centred arthritis care should be conceptualised as a continuous process, beginning with first contact and extending through specialist treatment to long-term follow-up. In practice, arthritis care is more often characterised by episodic contact than by ongoing continuity, revealing a persistent gap between idealised care trajectories and current service configurations.

Furthermore, previous research has noted people with arthritis commonly regard continuity as a fundamental precondition of any care model (Doumen et al., 2021), and that ongoing contact with the same healthcare professional contributes to a sense of security and the development of trust (Sjö and Bergsten, 2018). In this study, some participants described feelings of uncertainty and communication breakdown arising from the lack of a stable point of contact during their care journeys. This finding, viewed from the perspective of people with arthritis, extends the existing literature by not only reinforcing the importance of continuity in fostering trust, but also illustrating the specific ways in which service experiences may be compromised in its absence.

A lack of continuity in care may not only influence how people with arthritis subjectively evaluate their service experiences but may also point to underlying limitations in the ability of current care models to respond to longer-term support needs. Prior research has emphasised attending to individuals' needs beyond immediate clinical concerns is a central component of people-centred care (Vodopivec and Vrijhoef, 2019). Findings from this study suggest in the absence of continuity, some people with arthritis face greater challenges in developing trust or accessing stable support throughout the care process, factors which may, in turn, shape their overall perception of care and influence the sustainability of their engagement.

Within the circular framework of arthritis user experience developed in this study, "continuity and coordination of care" is conceptualised as a phase that does not occur automatically, but instead requires active and deliberate maintenance. Existing literature highlights the importance of service continuity in the delivery of people-centred care (Segan et al., 2018; Vodopivec and Vrijhoef, 2019), continuity remains difficult to sustain within existing service arrangements. This phase is critical within the framework not only because it reflects whether care is maintained across multiple points of contact, but also because it signals whether individuals continue to receive responsive and sustained support throughout the care process. The observed absence of structured feedback mechanisms or follow-up arrangements raises important questions about how current systems might be better configured, at a structural level, to support a truly people-centred approach to ongoing care.

## 6.4 Implications and Recommendations

This section outlines the broader implications of the study's findings and offers targeted recommendations for arthritis service providers, policymakers, and researchers. These insights, while grounded in the lived experiences of people with arthritis, may also offer transferable perspectives for related care contexts involving long-term conditions. However, given the qualitative and condition-specific nature of this study, all recommendations should be interpreted with consideration for contextual relevance.

### 6.4.1 Re-conceptualising Arthritis Care Experience: A Circular Framework

The findings challenge and extend existing conceptualisations of patient experience in chronic illness care, specifically in the context of arthritis. By proposing a circular rather than linear framework, the study contributes to a shift in understanding service experiences not as fixed sequences, but as dynamic, iterative processes shaped by personal agency and contextual change. This reframing has important implications for future health research. Scholars are encouraged to view people-centred care frameworks not only as practical instruments for service delivery, but also as conceptual tools for critically analysing and reconfiguring care systems. Adopting this perspective supports a deeper integration of people-centred principles into the conceptual understanding of healthcare.

### 6.4.2 Design Thinking as a Methodological Innovation in Health Research

This research integrates design thinking not merely as a service development tool but as a methodological lens within qualitative data analysis. This interdisciplinary approach centres the agency of service users in knowledge production and offers a new paradigm for analysing and redesigning care systems. By positioning design thinking as both method and theory, this approach invites researchers to treat people-centred care frameworks not just as delivery mechanisms, but as theoretical foundations for healthcare analysis and transformation.

In existing healthcare literature, design thinking is primarily mobilised at the stage of intervention design or service improvement (Bate and Robert, 2023). This study demonstrates an alternative methodological contribution by integrating design thinking principles directly into the qualitative analytic process. In doing so, design thinking functions not only as an innovation tool but as a methodological orientation that supports empathy-driven interpretation, problem reframing, and iterative sense-making within health research.

### 6.4.3 Practical Implications for Service Providers: Flexibility, Informality, and Inclusion

The circular framework offers practical guidance for redesigning arthritis care pathways to reflect lived realities. Service providers are encouraged to:

- Move away from rigid, standardised models.
- Embrace re-entry points, cyclical planning, and responsiveness to changing life contexts.
- Recognise and integrate informal resources like peer networks and community-led initiatives, rather than treating them as peripheral.

These elements must be woven into patient education, follow-up systems, and ongoing support structures.

### 6.4.4 Policy-Level Recommendations for Health System Transformation

At the policy level, this study supports WHO’s call for integrated, people-centred services and offers a concrete framework for operationalising these principles. The findings highlight the importance of:

- Recognising patient agency.
- Promoting informational equity.
- Prioritising experiential coherence and user participation over service outputs.

Key policy actions include:

- Prioritising flexible care pathways with multiple entry points.
- Allocating resources to sustain long-term, community-integrated support.
- Institutionalising participatory design processes through journey mapping and co-creation workshops.

Contemporary healthcare transformation agendas frequently emphasise structural integration, efficiency, and system-level redesign (WHO, 2016). While these priorities are essential, the findings of this study indicate that reforms which overlook patients’ lived experiences of service navigation and information access risk reproducing fragmentation at the experiential level. This study therefore contributes an experience-based perspective to healthcare transformation discourse, grounding policy reform in the realities of everyday service use and highlighting the importance of patient agency, informational equity, and experiential coherence in long-term care contexts such as arthritis.

### 6.4.5 Implications for Service Delivery Reform

To implement the circular model, service delivery structures may be reorganised to:

- Develop re-entry mechanisms and feedback loops.
- Enable iterative planning that adapts to changing patient needs.
- Create navigable, co-constructed information systems through interactive platforms, peer-led networks, or embedded informational roles within clinics.

These changes support patient autonomy and engagement in care planning.

### 6.4.6 Expanding the Research Agenda: Applying and Testing the Circular Model

Future research could:

- Extend the people-centred circular framework to other chronic illnesses (e.g. diabetes, cardiovascular disease, mental health).
- Investigate how patient agency functions within structurally constrained care environments.
- Explore how systems can better support agency through co-produced care planning.

### 6.4.7 Potential Limitations and Unintended Consequences of Implementing the Circular Framework

- While the circular framework proposed in this study offers a people-centred and experience-informed approach to understanding arthritis care, its implementation in practice may also give rise to potential limitations and unintended consequences that warrant careful consideration.
- One potential risk concerns the emphasis on active patient participation. Although

the framework foregrounds patient agency and co-participation, not all individuals living with arthritis may have equal capacity, resources, or health literacy to engage at the same level. Without appropriate professional support, there is a risk that responsibility for navigating care pathways may be unevenly transferred to patients, potentially exacerbating existing inequalities.

- A further consideration relates to system-level capacity. The flexible and iterative nature of the circular framework may be difficult to operationalise within healthcare settings constrained by limited time, workforce pressures, and rigid organisational structures. In such contexts, implementation may become inconsistent, leading to variability in care experience across services or regions.

- In addition, while community-based and peer support can play a valuable role in sustaining long-term care, over-reliance on informal resources may unintentionally obscure gaps in formal service provision. Finally, tensions may arise between the framework's emphasis on experiential coherence and performance-driven evaluation metrics commonly used in healthcare systems, risking symbolic rather than substantive adoption.

Taken together, these considerations highlight that the circular framework should be applied as a guiding and reflective tool rather than a prescriptive model, with careful attention to context, equity, and system constraints to avoid unintended consequences.

### 6.4.8 Advancing Interdisciplinary Approaches: Design Thinking in Comparative Perspective

There is a need for comparative studies that evaluate the role of design thinking in health research. Future work could:

- Examine how different disciplines implement design-led methods.

- Assess the effectiveness of design thinking versus traditional qualitative approaches.

- Explore how interdisciplinary research can translate patient insights into structural innovations across various health contexts.

- From a comparative interdisciplinary perspective, design thinking offers a distinct contribution by mediating between clinical knowledge, service structures, and lived experience. Unlike discipline-bound analytical frameworks, design thinking enables the integration of experiential insight into system-level reflection, making it particularly valuable for healthcare contexts characterised by complexity and fragmentation (Greenhalgh et al., 2018).

## 6.5 Summary

This chapter has addressed the research questions by examining the constituent elements of people-centred arthritis care experience and exploring how design thinking, through interdisciplinary collaboration, can inform innovative service models. Through in-depth analysis of the study's findings, the chapter introduces a circular user experience framework that is both theoretically original and practically relevant. This framework moves beyond the limitations of conventional linear care pathways by emphasising the agency, continuity, and adaptability of individuals navigating complex care journeys.

First, in terms of knowledge contribution, the study develops an interdisciplinary methodological framework that integrates principles of design thinking with qualitative analysis. This not only extends the theoretical application of design thinking within health research but also offers a novel pathway for investigating service user experiences. Second, through the visual analysis of user journeys, the study proposes a structural tool that captures the dynamic nature of service use, thereby providing a theoretically grounded and methodologically actionable foundation for future people-centred service design. The chapter then turns to a discussion of key people-centred service elements, identifying six interrelated dimensions: personalised health management; information acquisition and self-education; the role of community support; communication and resource-related challenges; the impact of financial factors; and the need for continuity and timely support. These elements are deeply embedded in the lived realities of people with arthritis, reflecting the complexity, multiplicity, and cyclical nature of service needs. They also correspond to the dynamic interrelations between different stages of the circular framework. Finally, the chapter outlines a series of theoretical, practical, and policy-related implications. At the theoretical level, it calls for a reconceptualisation of people-centred care as a critical analytical lens and a tool for reconfiguring care systems. At the practical level, it highlights the need for service providers to enhance flexibility and integrate informal resources. At the policy level, it advocates for structural mechanisms that ensure user participation, equitable access to information, and sustained support.

In summary, this chapter deepens our understanding of people-centred arthritis care experience and offers a robust theoretical and methodological foundation for service improvement, system reform, and future research. The following chapter will conclude the thesis by reflecting on the overall contributions of the study, acknowledging its limitations, and proposing directions for further inquiry.

# Chapter 7: Conclusion

## 7.1 Introduction

his chapter provides a summary of the main content, key findings and key contribution of the study, and this chapter also identifies several limitations and proposes directions for future research. As a qualitative study focused on the service experiences of people with arthritis, this research begins from the daily practices of people with arthritis and proposes a circular framework of experience of people with arthritis. This research aims to illuminate how people with arthritis perceive, navigate, and reshape their interactions with the healthcare system over time, by systematically identifying key elements of people-centred care, exploring user perspectives through qualitative and design thinking methods, and examining how interdisciplinary collaboration can inform and enhance the development of more responsive arthritis healthcare services.

This chapter begins by summarising the study's contributions to knowledge, followed by a critical review of the research aims and how they were addressed throughout the study. This chapter then reflects on the methodological framework employed and proceeds to synthesise the key findings in relation to the research objectives. This chapter also identifies the potential beneficiaries and target audiences of the research. Based on theoretical insights and empirical observations, a set of practical and policy-oriented recommendations is presented. The chapter also provides a reflective account of the study's limitations, particularly concerning sample characteristics, methodological scope, and the generalisability of findings. Finally, this chapter outlines directions for future research, drawing on both the gaps encountered, and opportunities revealed during the research process. Through this structure, the chapter offers a comprehensive conclusion and critical reflection on the overall study.

## 7.2 Summary of Contribution to Knowledge

This study makes a distinctive contribution to the growing body of knowledge on people-centred care in the context of long-term condition management, with a specific focus on arthritis. Through an in-depth exploration of the service experiences of individuals living with arthritis, this research offers original insights that extend beyond conventional care journey models. By integrating qualitative methods, design thinking, and interdisciplinary perspectives, the study introduces novel theoretical and methodological frameworks that advance both academic understanding and practical approaches to people-centred service design. The contributions can be articulated across three interrelated dimensions: theoretical construction, methodological integration, and interdisciplinary application.

Concretely, the research develops a people-centred circular framework comprising four interrelated phases, needs identification, information acquisition, service utilisation, and continuity and coordination of care. This circular framework, grounded in empirical data, captures the cyclical and adaptive nature of service engagement and offers a theoretical alternative to the dominant linear care pathways. The circular framework reflects how people with arthritis actively re-engage with healthcare systems across changing life contexts and health conditions.

At the methodological level, the study presents an interdisciplinary analytical framework, which represents a methodological innovation rarely documented in current health services research and showcases how design thinking can be repositioned not only as a tool for solution development but also as a theoretical lens for data interpretation.

Furthermore, the study repositions user journey mapping, a concept traditionally used for descriptive or visual purposes, as a core analytic and theory-building device. By aligning mapped service stages with inductively derived people-centred elements, the study constructs a circular model that both structurally and interpretatively represents user experience in arthritis care. This methodological reconfiguration bridges the gap between descriptive mapping and theoretical modelling, providing new avenues for interdisciplinary inquiry.

These contributions directly address the central research question of how design thinking, through interdisciplinary collaboration, can enhance the development of people-centred care in arthritis healthcare services and respond to a critical gap in the existing literature. The findings not only advance the theoretical and methodological foundations of people-centred arthritis care but also offer practical insights for rethinking service delivery, system responsiveness, and user engagement in chronic condition management.

Beyond its individual contributions to theory, methodology, and interdisciplinary practice, this study offers an integrative model that connects these domains in a mutually reinforcing way. The research demonstrates how qualitative and design-based methods can serve not only as tools for data collection and interpretation but also as foundational mechanisms for theoretical construction. In turn, the conceptual framework developed through these methods, namely the circular model of arthritis user experience, feeds back into practical service and policy considerations, offering a theory-informed basis for system redesign.

This integrative approach forms a coherent loop in which empirical insights derived from user narratives inform the construction of a theoretical model, and this model, built using design-informed qualitative methods, subsequently provides practical direction for service innovation. By embedding design thinking within the analytical process, the study reconfigures the traditional separation between research and application, demonstrating that methodological choices are not merely technical decisions but epistemological commitments that shape what kinds of knowledge are produced and how they can be used.

Such a synthesis contributes to a growing call for more holistic, reflexive approaches in health and social care research, particularly in the context of long-term conditions. By demonstrating how theory, method, and practice can be integrated around a shared commitment to user experience, this study proposes a transferable model for future research that aims to be not only explanatory, but transformative.

## 7.3 Review of the Study and Research Aim

This study set out to explore people-centred care in arthritis healthcare services by integrating evidence from a systematic literature review, qualitative data grounded in user experiences, and design thinking as an interdisciplinary methodological approach. The central purpose was to bridge the gap between existing theoretical frameworks and the lived realities of people with arthritis, and to examine how design thinking can contribute to more inclusive and responsive healthcare practices.

The research was guided by three core questions:

**What are the people-centred care elements in arthritis healthcare services?**

This study conducted a systematic review of existing literature to identify the core elements of people-centred care in arthritis healthcare services, including key dimensions such as patient participation in decision-making, patient education, personalisation, communication and coordination, emotional support, continuity of care and so on. These findings provided a solid theoretical foundation and conceptual reference for the subsequent empirical investigation.

**What are the people-centred care elements in arthritis healthcare services from the users' perspective?**

This question was addressed through qualitative interviews with people living with arthritis, using a design thinking method. The analysis uncovered how individuals define, interpret, and evaluate care experiences. Unlike the structured and abstract concepts found in the literature, the user insights emphasised lived complexity, including evolving care needs, shifting personal responsibilities, and the strain associated with navigating discontinuous and uncoordinated care pathways, which informed the development of a dynamic and circular user experience framework.

**How can design thinking, through interdisciplinary collaboration, enhance the development of people-centred care in arthritis healthcare services?**

Drawing on the principles of empathy, iteration, and co-creation, this study used design thinking not just as a solution tool, but as a logic for qualitative analysis and theoretical synthesis. The integration of framework analysis, thematic analysis, and user journey mapping offered a new interdisciplinary pathway for interpreting service experiences and constructing practical service models. This fulfilled the third research aim by demonstrating how design-led approaches can bridge disciplinary silos and enrich the development of people-centred care.

Each of the research objectives was explicitly addressed through a layered research design. The systematic review provided a top-down theoretical lens, the qualitative study generated bottom-up user insights, and the integration of design thinking created a methodological bridge between the two. This triangulated approach strengthened the internal coherence of the study and reinforced its contribution to the development of people-centred care in arthritis services.

## 7.4 Methodological Framework

This study embraces an interdisciplinary approach to advance the understanding and development of people-centred care in arthritis services. Recognising that the complexities of long-term condition management extend beyond the boundaries of any single discipline, the research integrates perspectives and methods from health services research, design studies, and qualitative inquiry. This interdisciplinary grounding enhances the depth, flexibility, and relevance of the study’s findings, and contributes to the development of more holistic, user-responsive care models.

A key innovation of this research lies in its integration of design thinking not merely as a tool for idea generation or service innovation, but as a core analytical method embedded within the qualitative research process. While design thinking is often associated with solution-oriented activities such as prototyping, this study demonstrates how its principles, especially empathising, defining, and mapping, can inform the interpretation of complex service experiences. By doing so, the study positions design thinking as a methodological logic for organising and synthesising data grounded in lived experience.

To operationalise this integration, the research employed a multi-layered qualitative data analysis approach combining framework analysis, thematic analysis, and user journey mapping. Framework analysis (Ritchie and Spencer, 1994), drawn from applied policy research traditions, was used to structure participants' service experiences into distinct stages of action and decision-making. Thematic analysis, as developed by Braun and Clarke (2022), was then applied to explore the meanings, expectations, and emotional responses embedded in these experiences.

The analytical process was further enhanced by incorporating elements of design thinking, particularly through the creation of user journey maps. These maps served not only as visual aids but also as analytical scaffolds that supported the synthesis of structural and interpretive insights. By aligning the framework stages with inductively derived user themes, the study constructed a people-centred and circular model of arthritis service experience. This model illustrates the cyclical and non-linear nature of care engagement, highlighting how users repeatedly navigate and reconfigure their relationships with healthcare services in response to changing needs.

The interdisciplinary nature of this analysis allows for a richer understanding of user experience, capturing both the operational structures of service delivery and the subjective realities of those living with chronic illness, particularly arthritis. The interdisciplinary methodology bridges methodological traditions by applying design logic within qualitative analysis and thereby expands the role of design thinking within health research. This integration offers not only a theoretical advancement but also practical tools for developing responsive and people-centred care pathways grounded in users' real-world contexts.

## 7.5 Summary of Key Findings

This study provides an in-depth account of how individuals living with arthritis manage their condition in the context of daily life, with particular attention to how they engage with, interpret, and respond to the healthcare system over time. The findings reveal that service use is not a linear trajectory but a complex and cyclical process, shaped by evolving needs, fluctuating health conditions, and shifting roles within both personal and clinical contexts.

A key outcome of the study is the development of a circular framework of arthritis user experience, which reflects the iterative and dynamic nature of living with a long-term condition. The circular framework offers a reconfiguration of patient experience, conceptualising it not as a fixed sequence of stages but as an ongoing process of negotiation between health-related needs, available resources, and the structural realities of the care system. This framework captures how people with arthritis continuously reassess their priorities, adapt their self-management strategies, and re-enter the system at different points, often revisiting earlier phases such as need identification or service engagement in response to changes in their condition or life circumstances.

Crucially, the circular model foregrounds people-centred elements derived directly from user narratives. These include the importance of relational continuity, emotional validation, clarity of information, and accessible coordination of care. The study highlights how people with arthritis themselves define what makes care meaningful, supportive, or fragmented, challenging professional or institutional definitions of quality that may otherwise be imposed. These insights challenge assumptions embedded in many existing care models and point toward service configurations that are more aligned with the lived experiences of those they intend to support.

Overall, the study's findings contribute to a more grounded and relational understanding of service experience in arthritis care. By positioning people with arthritis as active agents who engage with and shape their care environments, the research reframes user experience as a site of continuous interaction and adaptation. This conceptual shift holds important implications for how healthcare services are designed, evaluated, and improved, moving from static service delivery models to approaches that can respond flexibly to the evolving and cyclical nature of chronic illness, particularly arthritis.

## 7.6 Beneficiaries or Audience

The findings and contributions of this research hold relevance for multiple audiences across healthcare, policy, academia, and service design. By centring the lived experiences of people with arthritis and proposing a people-centred, circular framework of service experience, the study offers conceptual and practical insights that may inform efforts to improve long-term condition care more broadly.

### 7.6.1 People living with arthritis and other chronic conditions

This research validates and foregrounds the voices of individuals managing arthritis in everyday life. By articulating common challenges, unmet needs, and meaningful aspects of care from the user's perspective, the study provides a framework through which people with arthritis may better understand and reflect on their own experiences. The findings also offer a shared language for articulating needs in communication with healthcare providers.

### 7.6.2 Healthcare professionals and service providers

Clinicians, including nurses, doctors, allied health professionals, and service coordinators, may benefit from the study's insights into how care is experienced on the ground. The identified people-centred elements, such as emotional support, relational continuity, information accessibility, and responsiveness, can guide service planning and improve the quality of interactions with patients. The circular framework invites professionals to reconsider standardised pathways and attend more closely to the non-linear and adaptive realities of living with chronic illness, particularly arthritis.

### 7.6.3 Health system planners and policymakers

For policymakers and health system leaders working to design more integrated and responsive care models, the study provides a user-informed framework that highlights structural gaps and opportunities for improvement. The circular model can be used as a diagnostic tool to evaluate where fragmentation or discontinuity occurs in service provision, and to support the development of people-centred policies grounded in lived experience.

### 7.6.4 Researchers in health, design, and social care

The interdisciplinary methodology employed in this research, combining framework analysis, thematic analysis, and design thinking, offers a replicable model for future studies exploring complex service experiences. It demonstrates how design thinking can be embedded within qualitative research as a way of organising and interpreting data. Researchers across health services, people-centred design, and qualitative inquiry may draw on this study to inform their own analytical practices.

### 7.6.5 Service designers and innovation teams

This research contributes directly to the practice of people-centred service design in health and social care contexts. By generating a detailed understanding of how individuals navigate services, the study provides foundational material for co-design workshops, persona development, or journey mapping exercises. It also reinforces the importance of grounding design in rich, contextualised narratives rather than abstract user profiles.

In summary, the value of this study lies not only in what it reveals about arthritis care, but also in how it models a people-centred, interdisciplinary approach to health research and service innovation. Its insights are applicable to a range of stakeholders committed to creating more responsive, equitable, and meaningful care experiences.

## 7.7 Recommendations

This study offers several key recommendations for enhancing the development of people-centred arthritis care, with targeted guidance for doctoral researchers, service providers, and educators in both design and the life sciences. Grounded in the lived experiences of people with arthritis and informed by the circular user experience framework developed in this research, these recommendations highlight the importance of integrating flexibility, interdisciplinarity, and user perspective into care models and research approaches.

### 7.7.1 For Doctoral Researchers Conducting Interdisciplinary Research in Design and Life Sciences

This study demonstrates the value of embedding design thinking not merely as a tool for innovation, but as a theoretical and analytical lens within qualitative research. Doctoral researchers working across disciplines are encouraged to move beyond viewing design thinking as an “add-on” to applied research and instead treat it as a critical methodology for framing research questions, interpreting user experience, and constructing theoretical models. Incorporating design principles such as empathy, iteration, and visual mapping within data analysis can deepen user engagement and support the generation of knowledge that is both contextually grounded and analytically robust. Researchers should also engage critically with the epistemological tensions between disciplines, and work to build shared vocabularies and frameworks that support genuine methodological integration.

### 7.7.2 For Service Providers in Arthritis and Long-Term Condition Care

Service delivery teams should embrace care models that reflect the cyclical, adaptive nature of patients' lived experiences. The circular framework developed in this study illustrates the need to shift from linear, standardised care pathways to approaches that allow for flexible re-engagement based on changes in health status and life context. Providers are encouraged to co-design care plans with patients, support the integration of informal and community-based resources, and develop follow-up systems that are responsive, not prescriptive. Greater attention should be paid to emotional continuity, communication clarity, and navigability across services. Incorporating these people-centred elements can enhance care satisfaction, self-management, and long-term outcomes.

### 7.7.3 For Educators in Design and Life Sciences

This study calls for stronger integration of design-led thinking and people-centred methodologies into the education of both designers and healthcare professionals. Educators in design programmes should expose students to complex, real-world problems in healthcare, encouraging them to apply empathy-driven, iterative approaches not only to product or service design, but also to research, policy, and system-level thinking. Conversely, life science and health professional education should include foundational training in qualitative methods, collaborative design-oriented approaches, and frameworks for engaging people with lived experience. Facilitating cross-disciplinary learning environments in which students of medicine, nursing, public health, and design can collaborate will help foster the next generation of professionals who are capable of working at the intersection of user experience, clinical evidence, and system innovation.

In summary, this study's contributions extend beyond the context of arthritis care. They offer concrete pathways for bridging disciplines, reshaping services, and reforming professional training. By centring user experience not only as a subject of study but as a driver of innovation, these recommendations aim to support more equitable, responsive, and meaningful health systems.

## 7.8 Limitation

While this study makes contributions on theory and methodology, several limitations remain, which warrant further refinement and exploration in future research.

Firstly, in terms of sample composition and data sources, the study is primarily based on interviews with people with arthritis from a specific geographic region. Participants shared similar cultural contexts, access to services, and social resources, as they were largely situated within a particular healthcare system. This relative homogeneity may limit the external validity of the findings, particularly in contexts characterised by greater ethnic diversity, more fragmented service infrastructures, or significant resource constraints. The applicability of the framework in such settings remains to be tested.

Secondly, although the study foregrounds the subjective experiences of people with arthritis, the data collection was largely limited to single interviews. The absence of longitudinal follow-up or participatory observation restricts the study's capacity to capture temporal shifts in user experience, changes in care relationships, and evolving coping strategies. While the circular nature of experience has been theorised, its unfolding over time within real-life trajectories would benefit from future longitudinal research.

Thirdly, the people-centred elements identified in this study are derived from patients' lived experiences but have not yet been empirically tested in practice-based interventions. The proposed framework remains, at present, a theoretical construct. Future studies should consider how this framework might be translated into an actionable tool for service improvement, particularly in the domains of policy development and institutional design.

Lastly, this research primarily adopts the perspective of service users and does not systematically incorporate the views of other key stakeholders, such as healthcare providers, policymakers, or informal caregivers. As a result, the processes through which multiple actors collaborate, negotiate, and co-create service experiences remain underexplored and represent an important area for future investigation.

## 7.9 Future Research

The circular user experience framework and the people-centred elements proposed in this study offer a novel theoretical tool and practical approach for understanding and improving service experiences in chronic illness care. However, as an exploratory study, the findings remain open to further development and expansion. Future research may advance this work in several directions.

Firstly, it is recommended that the applicability and transferability of the framework be examined in the context of other chronic conditions. Arthritis is characterised by a long disease course, fluctuating symptoms, and high dependence on health services, features that are shared with other chronic illnesses such as diabetes, heart failure, and chronic obstructive pulmonary disease. Comparative studies across different conditions may help to assess how the circular framework performs in varying contexts and to refine it towards a more generalisable model of people-centred service design.

Secondly, future research should deepen the application of co-creative approaches involving multiple stakeholders. While this study adopts a people-centred perspective, the improvement of service experiences ultimately requires collaboration among service users, healthcare professionals, administrators, and policymakers. Further studies could employ action research or experience-based co-design (EBCD) to support meaningful engagement between users and providers, and to explore the mechanisms through which co-creation influences organisational change and service innovation.

Thirdly, there is a need to translate the study’s findings into policy-level and system-level interventions, and to evaluate their effectiveness. The people-centred elements identified in this research offer a theoretical basis for the development of service evaluation tools, policy indicators, and system performance measures. Future work could pilot experience-informed service redesign initiatives at local or national levels, assessing their impacts on patient satisfaction, service integration, and health outcomes.

Finally, from a methodological perspective, future research would benefit from incorporating longitudinal designs or mixed methods approaches in order to better capture the temporal evolution of service experiences and their interactions with institutional contexts. This would offer a more dynamic understanding of how experiences shift across disease progression, service transitions, and different stages of life, thereby informing more responsive and sustainable models of chronic care delivery.

## 7.10 Conclusion

In conclusion, people-centred care should not remain a rhetorical ideal in health service reform, but rather serve as the starting point for understanding, designing, and evaluating healthcare systems. It is only by listening to patients' stories, respecting their lived experiences, and responding to the realities of their everyday lives that we can begin to grasp both the potential and the limitations of healthcare services as they are experienced in practice.

Through the development of a user experience framework grounded in the perspectives of people with arthritis, this study has revealed the dynamic, evolving nature of service experience. It also underscores a critical insight: the value of care lies not only in the clinical effectiveness of interventions, but also in whether individuals feel understood, supported, and empowered throughout their care journeys.

To realise truly people-centred healthcare in the future, systems must move away from institution-centred logics and towards life-centred approaches, shifting from the delivery of services to the co-construction of meaning. This, ultimately, is the direction in which ongoing inquiry and practice must evolve.

### 7.10.1 Reflections as a Researcher

In existing healthcare literature, design thinking is primarily mobilised at the stage of intervention design or service improvement (Bate and Robert, 2023). This study demonstrates an alternative methodological contribution by integrating design thinking principles directly into the qualitative analytic process. In doing so, design thinking functions not only as an innovation tool but as a methodological orientation that supports empathy-driven interpretation, problem reframing, and iterative sense-making within health research.

Throughout this journey, I have shifted from being a distant observer to becoming a listener, a facilitator, and a co-learner. Engaging deeply with the narratives of people with arthritis required me to hold space for uncertainty, contradiction, and vulnerability. It also required navigating the tension between the analytic clarity demanded by research and the messy, nonlinear realities of lived experience.

Integrating design thinking into a qualitative research framework was both methodologically enriching and intellectually demanding. At times, I questioned how far these distinct traditions could truly speak to each other. Yet it was precisely in the struggle to make these conversations possible, across disciplines, methodologies, and modes of knowing, that I found new clarity about what it means to do health research in a more people-centred and integrative way.

Looking ahead, I hope to continue building research that bridges disciplinary silos, amplifies marginalised voices, and contributes to the design of systems that not only function better, but feel more just, compassionate, and responsive to those who use them.

Genuinely people-centred care begins by listening to the stories people have to tell.

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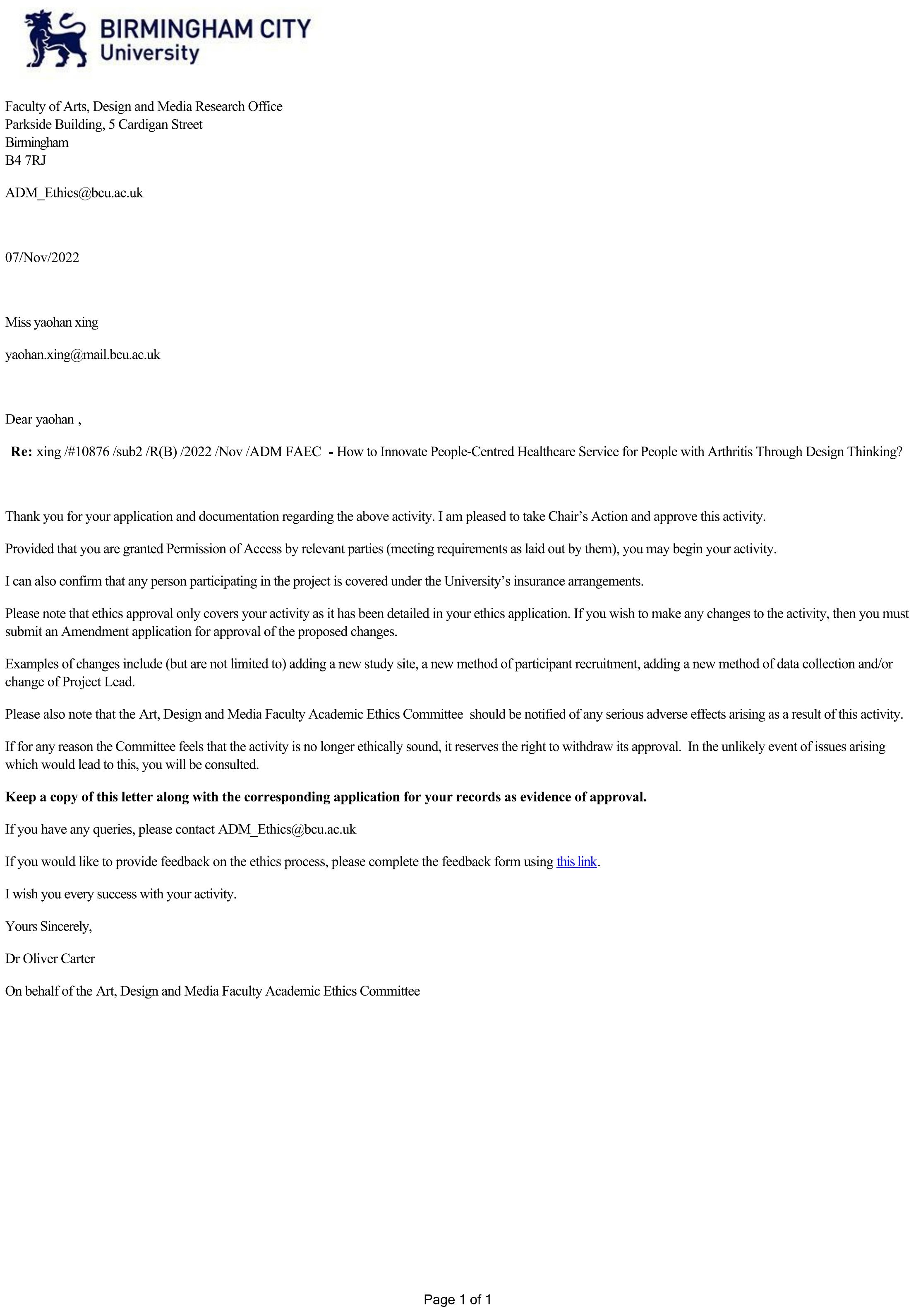
# Appendix A: Confirmation of ethics approval



BIRMINGHAM CITY
University

Faculty of Arts, Design and Media Research Office
Parkside Building, 5 Cardigan Street
Birmingham
B4 7RJ

ADM_Ethics@bcu.ac.uk

07/Nov/2022

Miss yaohan xing

yaohan.xing@mail.bcu.ac.uk

Dear yaohan ,

**Re:** xing /#10876 /sub2 /R(B) /2022 /Nov /ADM FAEC **-** How to Innovate People-Centred Healthcare Service for People with Arthritis Through Design Thinking?

Thank you for your application and documentation regarding the above activity. I am pleased to take Chair’s Action and approve this activity.

Provided that you are granted Permission of Access by relevant parties (meeting requirements as laid out by them), you may begin your activity.

I can also confirm that any person participating in the project is covered under the University’s insurance arrangements.

Please note that ethics approval only covers your activity as it has been detailed in your ethics application. If you wish to make any changes to the activity, then you must submit an Amendment application for approval of the proposed changes.

Examples of changes include (but are not limited to) adding a new study site, a new method of participant recruitment, adding a new method of data collection and/or change of Project Lead.

Please also note that the Art, Design and Media Faculty Academic Ethics Committee should be notified of any serious adverse effects arising as a result of this activity.

If for any reason the Committee feels that the activity is no longer ethically sound, it reserves the right to withdraw its approval. In the unlikely event of issues arising which would lead to this, you will be consulted.

**Keep a copy of this letter along with the corresponding application for your records as evidence of approval.**

If you have any queries, please contact ADM_Ethics@bcu.ac.uk

If you would like to provide feedback on the ethics process, please complete the feedback form using this link.

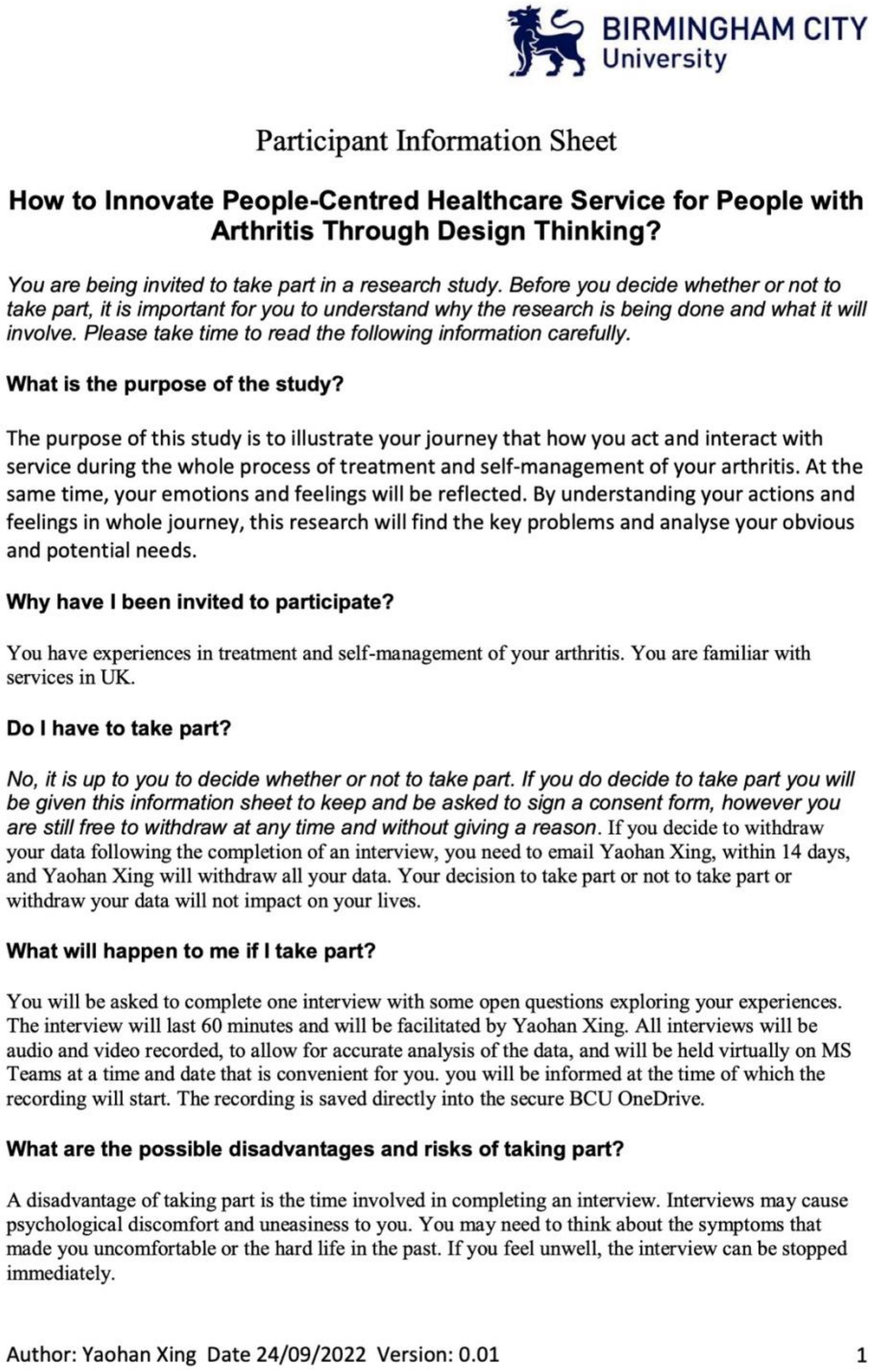
I wish you every success with your activity.

Yours Sincerely,

Dr Oliver Carter

On behalf of the Art, Design and Media Faculty Academic Ethics Committee

# Appendix B: Participant Information Sheet



BIRMINGHAM CITY
University

## Participant Information Sheet

### How to Innovate People-Centred Healthcare Service for People with Arthritis Through Design Thinking?

*You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.*

**What is the purpose of the study?**

The purpose of this study is to illustrate your journey that how you act and interact with service during the whole process of treatment and self-management of your arthritis. At the same time, your emotions and feelings will be reflected. By understanding your actions and feelings in whole journey, this research will find the key problems and analyse your obvious and potential needs.

**Why have I been invited to participate?**

You have experiences in treatment and self-management of your arthritis. You are familiar with services in UK.

**Do I have to take part?**

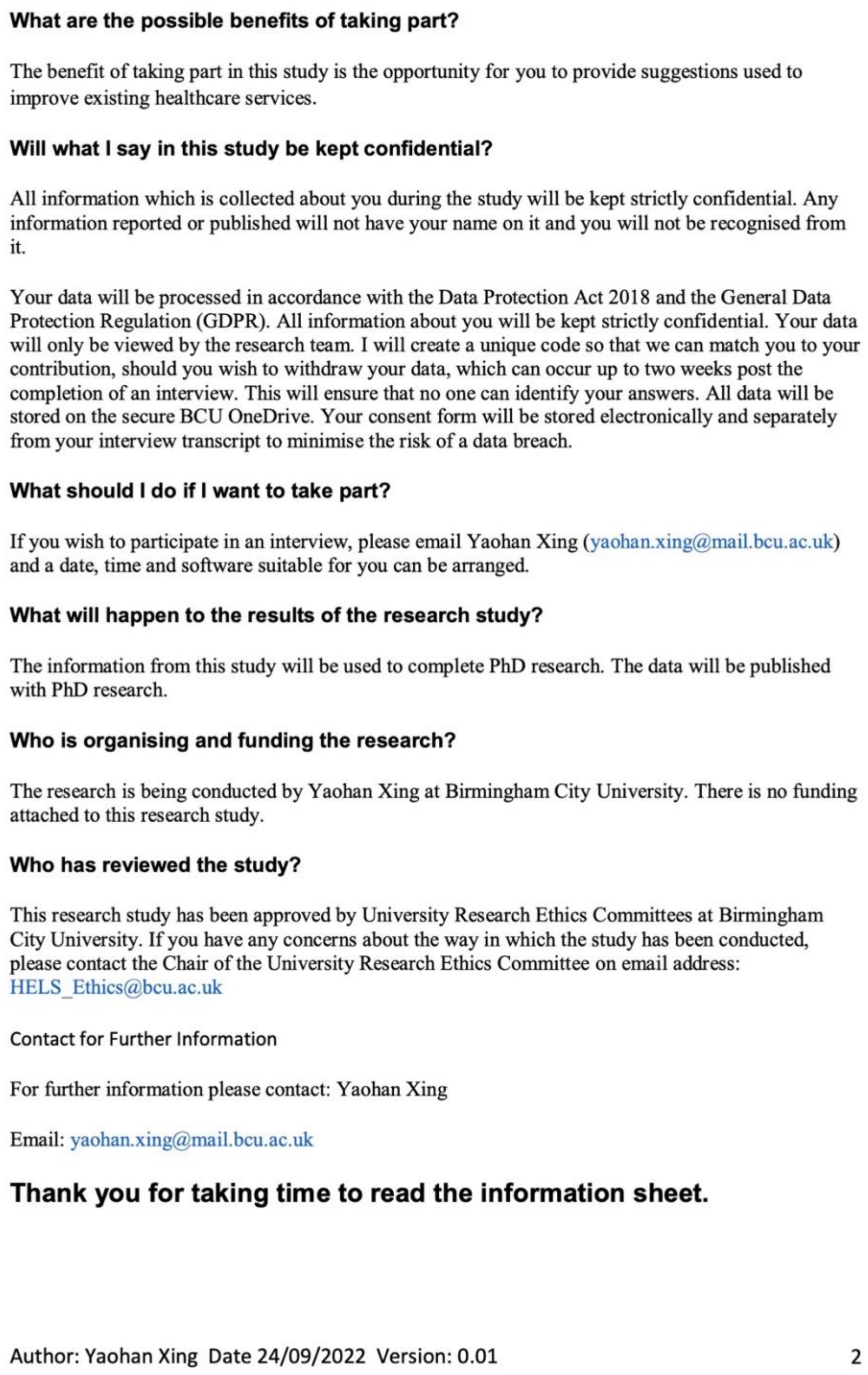
*No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, however you are still free to withdraw at any time and without giving a reason*. If you decide to withdraw your data following the completion of an interview, you need to email Yaohan Xing, within 14 days, and Yaohan Xing will withdraw all your data. Your decision to take part or not to take part or withdraw your data will not impact on your lives.

**What will happen to me if I take part?**

You will be asked to complete one interview with some open questions exploring your experiences. The interview will last 60 minutes and will be facilitated by Yaohan Xing. All interviews will be audio and video recorded, to allow for accurate analysis of the data, and will be held virtually on MS Teams at a time and date that is convenient for you. you will be informed at the time of which the recording will start. The recording is saved directly into the secure BCU OneDrive.

**What are the possible disadvantages and risks of taking part?**

A disadvantage of taking part is the time involved in completing an interview. Interviews may cause psychological discomfort and uneasiness to you. You may need to think about the symptoms that made you uncomfortable or the hard life in the past. If you feel unwell, the interview can be stopped immediately.



### What are the possible benefits of taking part?

The benefit of taking part in this study is the opportunity for you to provide suggestions used to improve existing healthcare services.

### Will what I say in this study be kept confidential?

All information which is collected about you during the study will be kept strictly confidential. Any information reported or published will not have your name on it and you will not be recognised from it.

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation (GDPR). All information about you will be kept strictly confidential. Your data will only be viewed by the research team. I will create a unique code so that we can match you to your contribution, should you wish to withdraw your data, which can occur up to two weeks post the completion of an interview. This will ensure that no one can identify your answers. All data will be stored on the secure BCU OneDrive. Your consent form will be stored electronically and separately from your interview transcript to minimise the risk of a data breach.

### What should I do if I want to take part?

If you wish to participate in an interview, please email Yaohan Xing (yaohan.xing@mail.bcu.ac.uk) and a date, time and software suitable for you can be arranged.

### What will happen to the results of the research study?

The information from this study will be used to complete PhD research. The data will be published with PhD research.

### Who is organising and funding the research?

The research is being conducted by Yaohan Xing at Birmingham City University. There is no funding attached to this research study.

### Who has reviewed the study?

This research study has been approved by University Research Ethics Committees at Birmingham City University. If you have any concerns about the way in which the study has been conducted, please contact the Chair of the University Research Ethics Committee on email address: HELS_Ethics@bcu.ac.uk

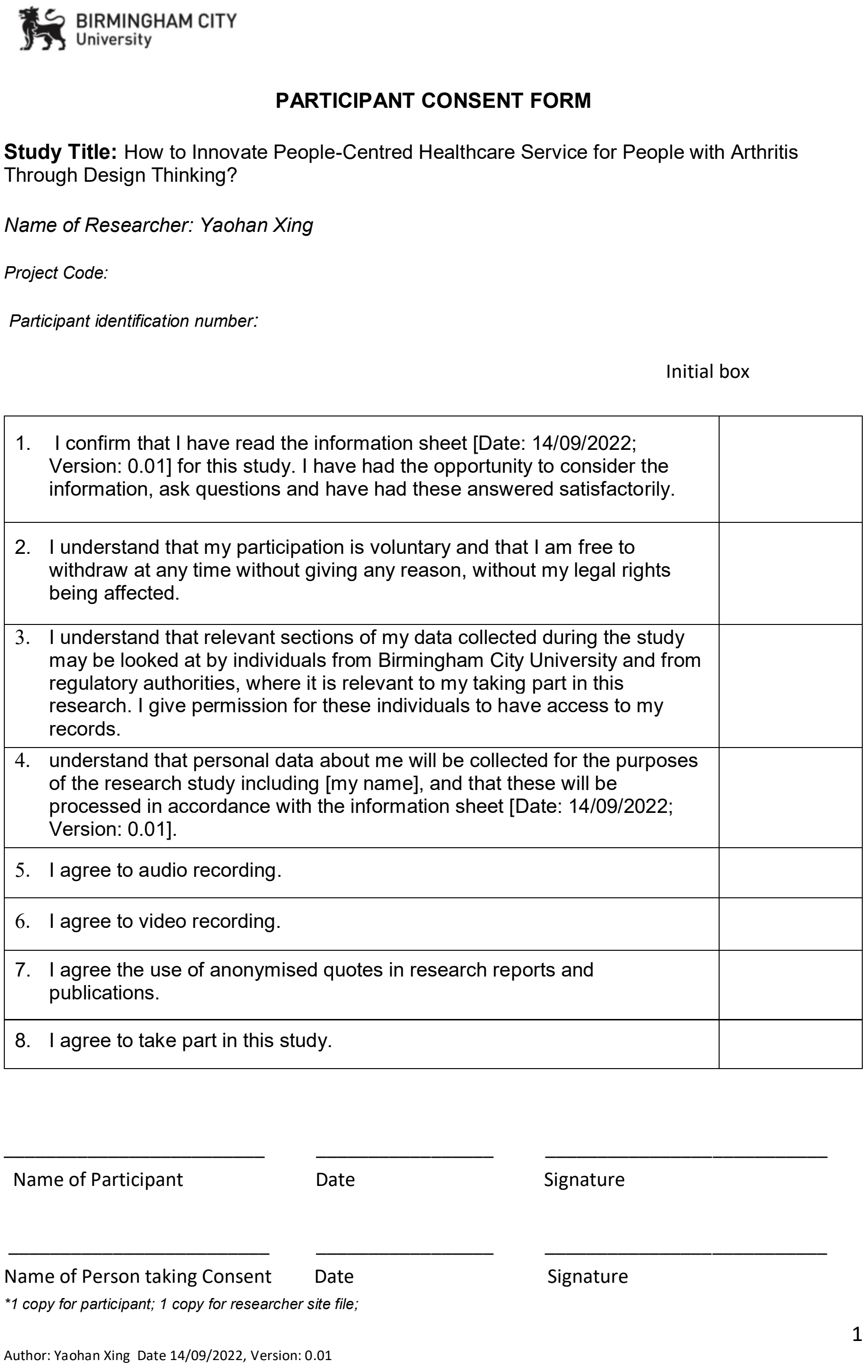
Contact for Further Information

For further information please contact: Yaohan Xing

Email: yaohan.xing@mail.bcu.ac.uk

## Thank you for taking time to read the information sheet.

# Appendix C: Participant Consent Form



BIRMINGHAM CITY
University

## PARTICIPANT CONSENT FORM

**Study Title:** How to Innovate People-Centred Healthcare Service for People with Arthritis Through Design Thinking?

*Name of Researcher: Yaohan Xing*

*Project Code:*

*Participant identification number:*

Initial box

| | |
|---|---|
| 1. I confirm that I have read the information sheet [Date: 14/09/2022; Version: 0.01] for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. | |
| 3. I understand that relevant sections of my data collected during the study may be looked at by individuals from Birmingham City University and from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. | |
| 4. understand that personal data about me will be collected for the purposes of the research study including [my name], and that these will be processed in accordance with the information sheet [Date: 14/09/2022; Version: 0.01]. | |
| 5. I agree to audio recording. | |
| 6. I agree to video recording. | |
| 7. I agree the use of anonymised quotes in research reports and publications. | |
| 8. I agree to take part in this study. | |

____________________ ______________ ____________________

Name of Participant Date Signature

____________________ ______________ ____________________

Name of Person taking Consent Date Signature

**1 copy for participant; 1 copy for researcher site file;*

1

Author: Yaohan Xing Date 14/09/2022, Version: 0.01

# Appendix D: Interview Questions

Hello, I'm Yaohan. I'm really glad that you're willing to share your experiences with me. I'm a PhD student, and my research focuses on healthcare services in the UK. I understand that this is an important topic for many people here. Arthritis is quite common - not just in the UK, but around the world. I'd like to hear about what it has been like for you.

Would you mind sharing your experience?

What is the part of your experience that you want to share most or that impresses you most?

Could you still remember when you just diagnosed arthritis?

How were/are you feeling? Symptoms

How do you usually deal with it?

Would you mind sharing how do you come into the professionals/charity? Is it positive experiences?

When was the last time you went to the clinic? How is it going? When will be the next time? Next week?

If you go there so frequently, it must be something really bothering you? What do you think is the most satisfying thing in this process? What's the thing that bothers you most? so if you go there so frequently, it must be something really bothering you?

How do you think about suggestions from professionals?

Will someone accompany you to do this? Does this process need the help of family members or nursing staff?

What is the most troubling thing about arthritis?

Do you feel uncomfortable when you want to go outside?

Do you participate in any activities to manage arthritis? I heard in UK they have a lot of charities to help some people, like arthritis action, do you hear about it? Access? Helpful? Or you have other recommendations? Would you mind sharing how you find them and why you choose them?

What kind of activities will help you?

Is there anything that impresses you most?

Do these activities meet all your needs?

Will you present your needs to professionals? Did they respond to your needs?

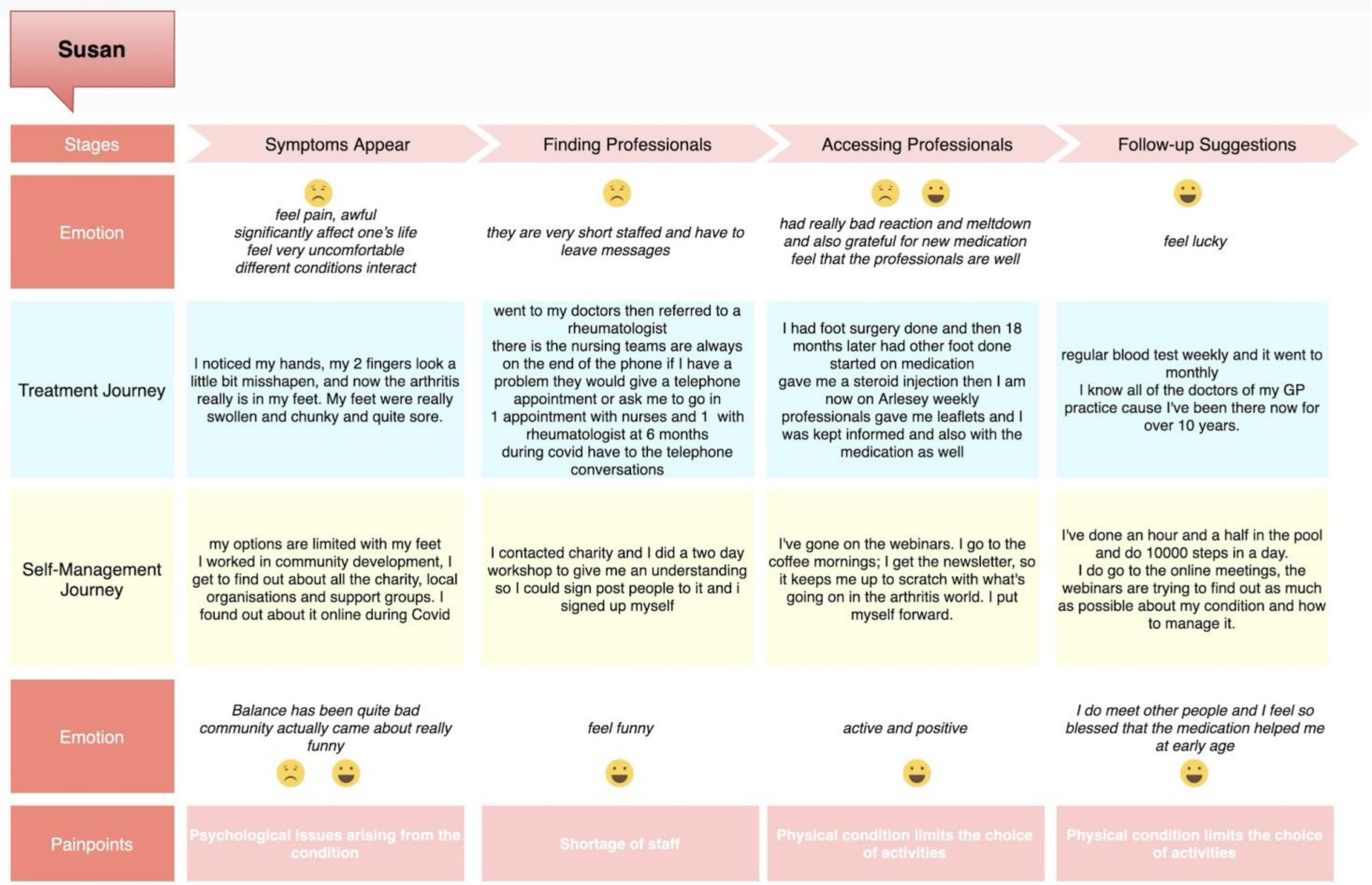
# Appendix E: User journey maps illustrating each participant’s experience of living with arthritis

This appendix presents the individual user journey maps developed for each participant in the study. These visual representations were constructed based on interview data and reflect participants’ lived experiences navigating arthritis-related services.

Each journey map captures stages actions, emotional responses throughout their care experience.

All personal identifiers have been removed to ensure confidentiality. Participants are referred to using anonymised codes (e.g., Susan, John).

## a. Susan’s User Journey Map



**Susan**

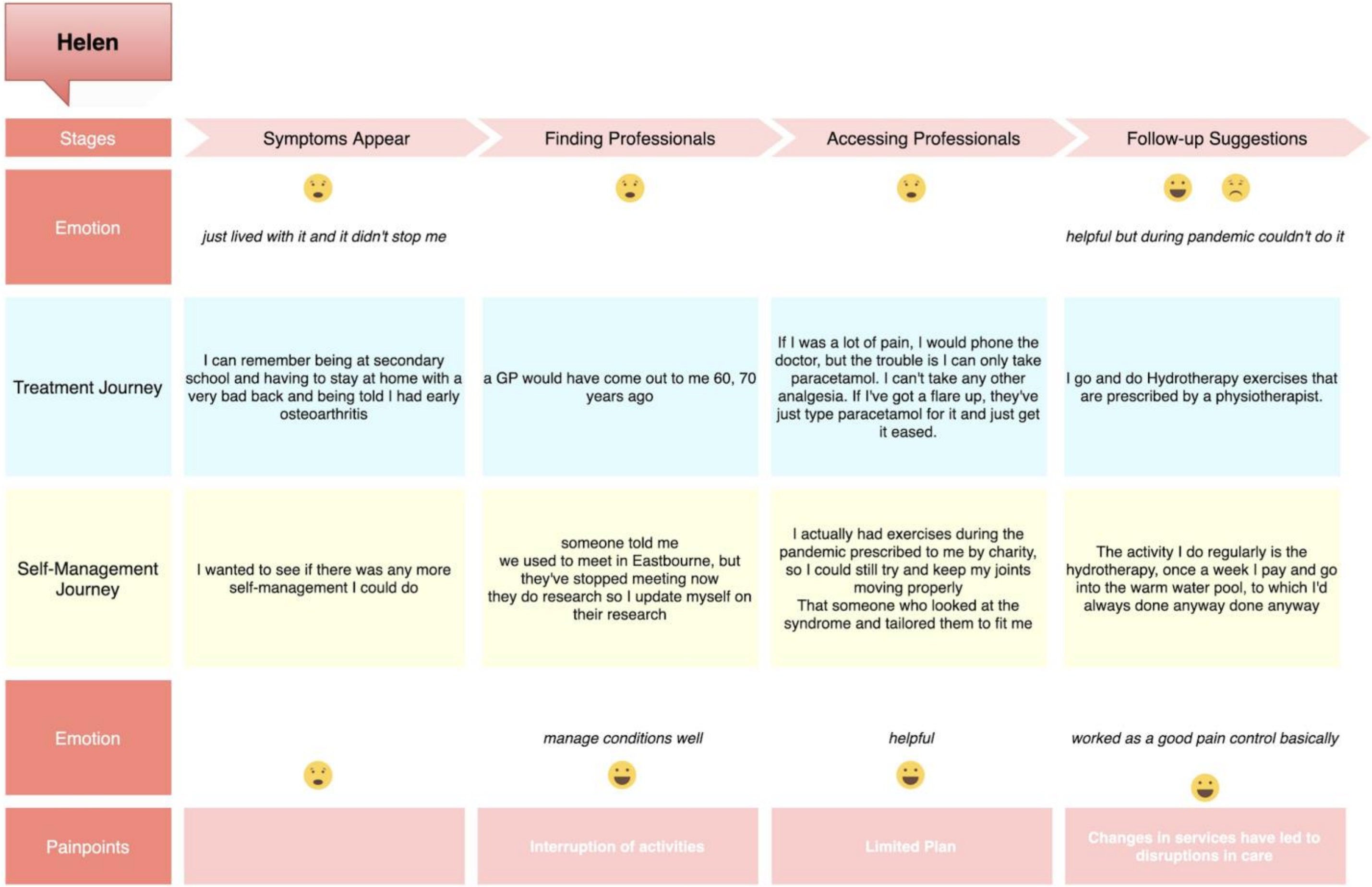
| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | ☹<br>*feel pain, awful*<br>*significantly affect one’s life*<br>*feel very uncomfortable*<br>*different conditions interact* | ☹<br>*they are very short staffed and have to leave messages* | ☹ ☺<br>*had really bad reaction and meltdown*<br>*and also grateful for new medication*<br>*feel that the professionals are well* | ☺<br>*feel lucky* |
| Treatment Journey | I noticed my hands, my 2 fingers look a little bit misshapen, and now the arthritis really is in my feet. My feet were really swollen and chunky and quite sore. | went to my doctors then referred to a rheumatologist<br>there is the nursing teams are always on the end of the phone if I have a problem they would give a telephone appointment or ask me to go in<br>1 appointment with nurses and 1 with rheumatologist at 6 months<br>during covid have to the telephone conversations | I had foot surgery done and then 18 months later had other foot done<br>started on medication<br>gave me a steroid injection then I am now on Arlesey weekly<br>professionals gave me leaflets and I was kept informed and also with the medication as well | regular blood test weekly and it went to monthly<br>I know all of the doctors of my GP practice cause I've been there now for over 10 years. |
| Self-Management Journey | my options are limited with my feet<br>I worked in community development, I get to find out about all the charity, local organisations and support groups. I found out about it online during Covid | I contacted charity and I did a two day workshop to give me an understanding so I could sign post people to it and i signed up myself | I've gone on the webinars. I go to the coffee mornings; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world. I put myself forward. | I've done an hour and a half in the pool and do 10000 steps in a day.<br>I do go to the online meetings, the webinars are trying to find out as much as possible about my condition and how to manage it. |
| Emotion | *Balance has been quite bad*<br>*community actually came about really funny*<br>☹ ☺ | *feel funny*<br>☺ | *active and positive*<br>☺ | *I do meet other people and I feel so blessed that the medication helped me at early age*<br>☺ |
| Painpoints | Psychological issues arising from the condition | Shortage of staff | Physical condition limits the choice of activities | Physical condition limits the choice of activities |

## b. John’s User Journey Map

**John**

| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | 😮<br>*It wasn't really a shock* | ☹<br>*the pandemic does have an impact on service use* | ☹<br>*had really bad reaction and meltdown and also grateful for new medication feel that the professionals are well* | 😮 |
| Treatment Journey | I was like getting really bad pain with my knees | I went to GP and it was him that suggested I go to see as a specialist it's not very often I go to a GP because the GP that I have did have is actually retired now. I've not really been to a GP for well really since the pandemic. | I have steroid injections in both knees, but that's only three times a year. and that does alleviate the pain, but only for 5 like 6 weeks, and then it starts kicking in again, you know | I have been advised that the long term, it's gonna be knee replacements. but the specialist the suggested that I'm a little bit too young to go into getting knee replacement because they only last for a 10, 12, 13 years before you have to get it done again. I'm holding out with the steroid injections for the time being. |
| Self-Management Journey | I get quite a bit of pain, I don't really move as much, especially at home. I don't tend to move as much as what I really should do. | I'm doing on online chat tomorrow with the group but it was only for a couple of weeks ago. I did a web thing like a exercise<br>really should be moving, even just walking up an down it tends to ease it. I was moving quite a bit. | I've gone on the webinars. I go to the coffee mornings; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world. I put myself forward. | on their website, they've actually got a list of like local physiotherapist, who mainly deal with knee issues and things |
| Emotion | *it;s really made things worse*<br>☹ | *the web thing was really quite interesting moving did actually help things a little bit. the pain wasn't so bad.*<br>😀 | *active and positive*<br>😀 | *not really been in touch and gonna investigate in a little while*<br>😮 |
| Painpoints | Psychological issues arising from the condition | The pain has persisted despite ongoing treatment. | Changes in services and personnel have led to disruptions in care. | |

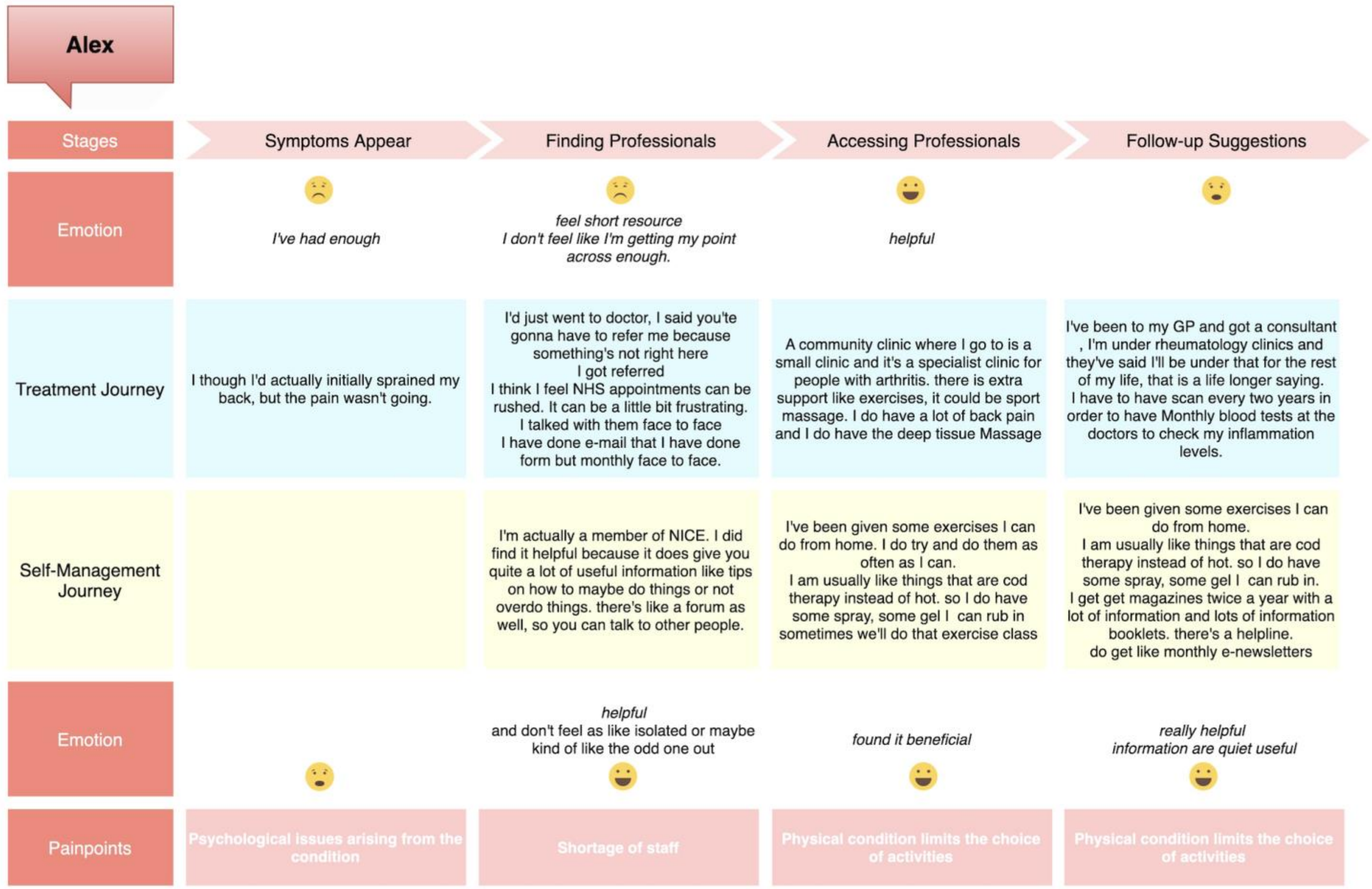
## c. Helen’s User Journey Map



**Helen**

| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | 😯<br>*just lived with it and it didn't stop me* | 😯 | 😯 | 😀 ☹<br>*helpful but during pandemic couldn't do it* |
| Treatment Journey | I can remember being at secondary school and having to stay at home with a very bad back and being told I had early osteoarthritis | a GP would have come out to me 60, 70 years ago | If I was a lot of pain, I would phone the doctor, but the trouble is I can only take paracetamol. I can't take any other analgesia. If I've got a flare up, they've just type paracetamol for it and just get it eased. | I go and do Hydrotherapy exercises that are prescribed by a physiotherapist. |
| Self-Management Journey | I wanted to see if there was any more self-management I could do | someone told me<br>we used to meet in Eastbourne, but they've stopped meeting now<br>they do research so I update myself on their research | I actually had exercises during the pandemic prescribed to me by charity, so I could still try and keep my joints moving properly<br>That someone who looked at the syndrome and tailored them to fit me | The activity I do regularly is the hydrotherapy, once a week I pay and go into the warm water pool, to which I'd always done anyway done anyway |
| Emotion | 😯 | *manage conditions well*<br>😀 | *helpful*<br>😀 | *worked as a good pain control basically*<br>😀 |
| Painpoints |  | Interruption of activities | Limited Plan | Changes in services have led to disruptions in care |

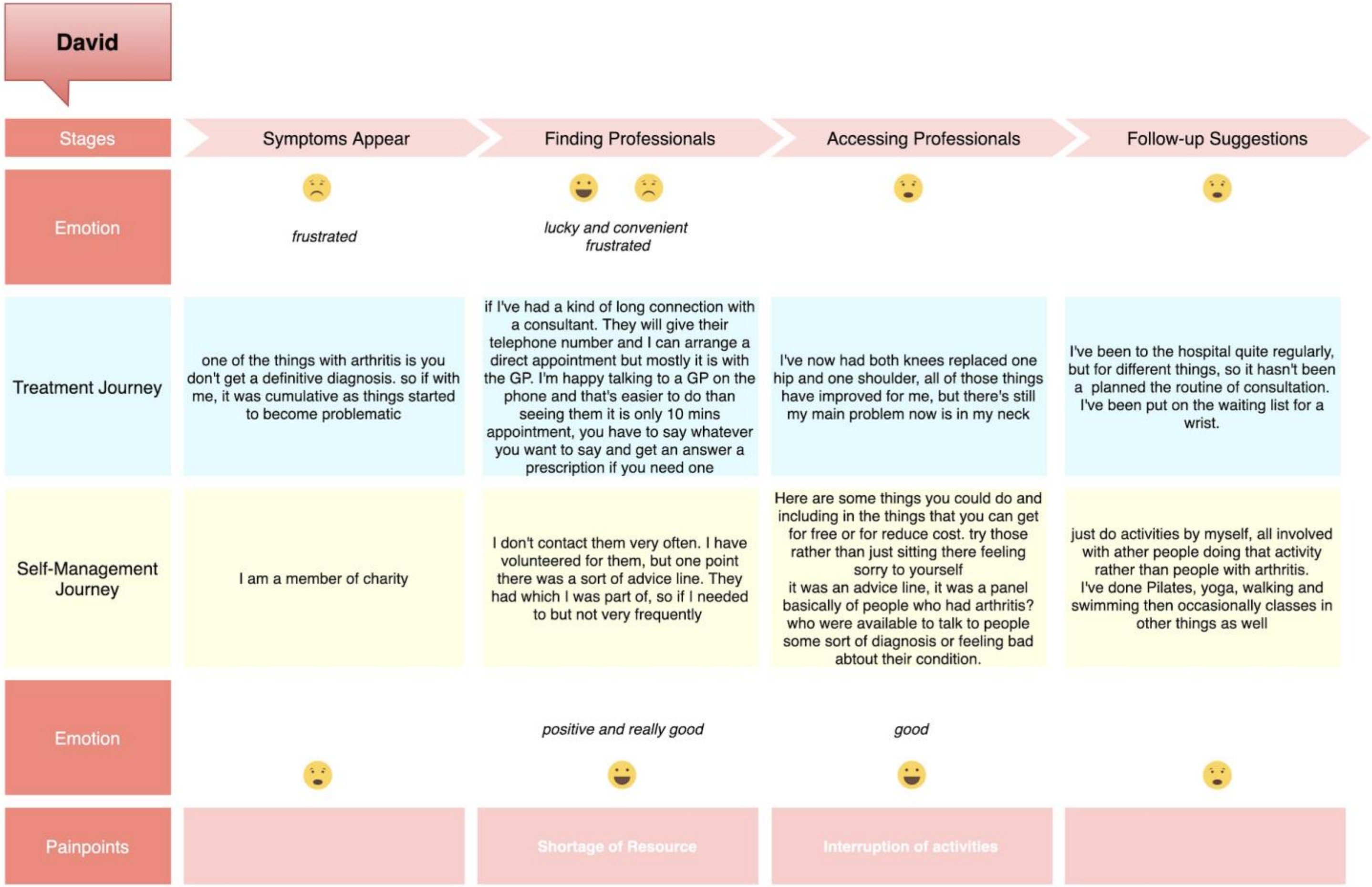
## d. Alex’s User Journey Map



**Alex**

| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | 🙁<br>*I've had enough* | 🙁<br>*feel short resource*<br>*I don't feel like I'm getting my point across enough.* | 😀<br>*helpful* | 😮 |
| Treatment Journey | I though I'd actually initially sprained my back, but the pain wasn't going. | I'd just went to doctor, I said you'te gonna have to refer me because something's not right here<br>I got referred<br>I think I feel NHS appointments can be rushed. It can be a little bit frustrating.<br>I talked with them face to face<br>I have done e-mail that I have done form but monthly face to face. | A community clinic where I go to is a small clinic and it's a specialist clinic for people with arthritis. there is extra support like exercises, it could be sport massage. I do have a lot of back pain and I do have the deep tissue Massage | I've been to my GP and got a consultant , I'm under rheumatology clinics and they've said I'll be under that for the rest of my life, that is a life longer saying.<br>I have to have scan every two years in order to have Monthly blood tests at the doctors to check my inflammation levels. |
| Self-Management Journey | | I'm actually a member of NICE. I did find it helpful because it does give you quite a lot of useful information like tips on how to maybe do things or not overdo things. there's like a forum as well, so you can talk to other people. | I've been given some exercises I can do from home. I do try and do them as often as I can.<br>I am usually like things that are cod therapy instead of hot. so I do have some spray, some gel I can rub in<br>sometimes we'll do that exercise class | I've been given some exercises I can do from home.<br>I am usually like things that are cod therapy instead of hot. so I do have some spray, some gel I can rub in.<br>I get get magazines twice a year with a lot of information and lots of information booklets. there's a helpline.<br>do get like monthly e-newsletters |
| Emotion | 😮 | *helpful*<br>and don't feel as like isolated or maybe kind of like the odd one out<br>😀 | *found it beneficial*<br>😀 | *really helpful*<br>*information are quiet useful*<br>😀 |
| Painpoints | Psychological issues arising from the condition | Shortage of staff | Physical condition limits the choice of activities | Physical condition limits the choice of activities |

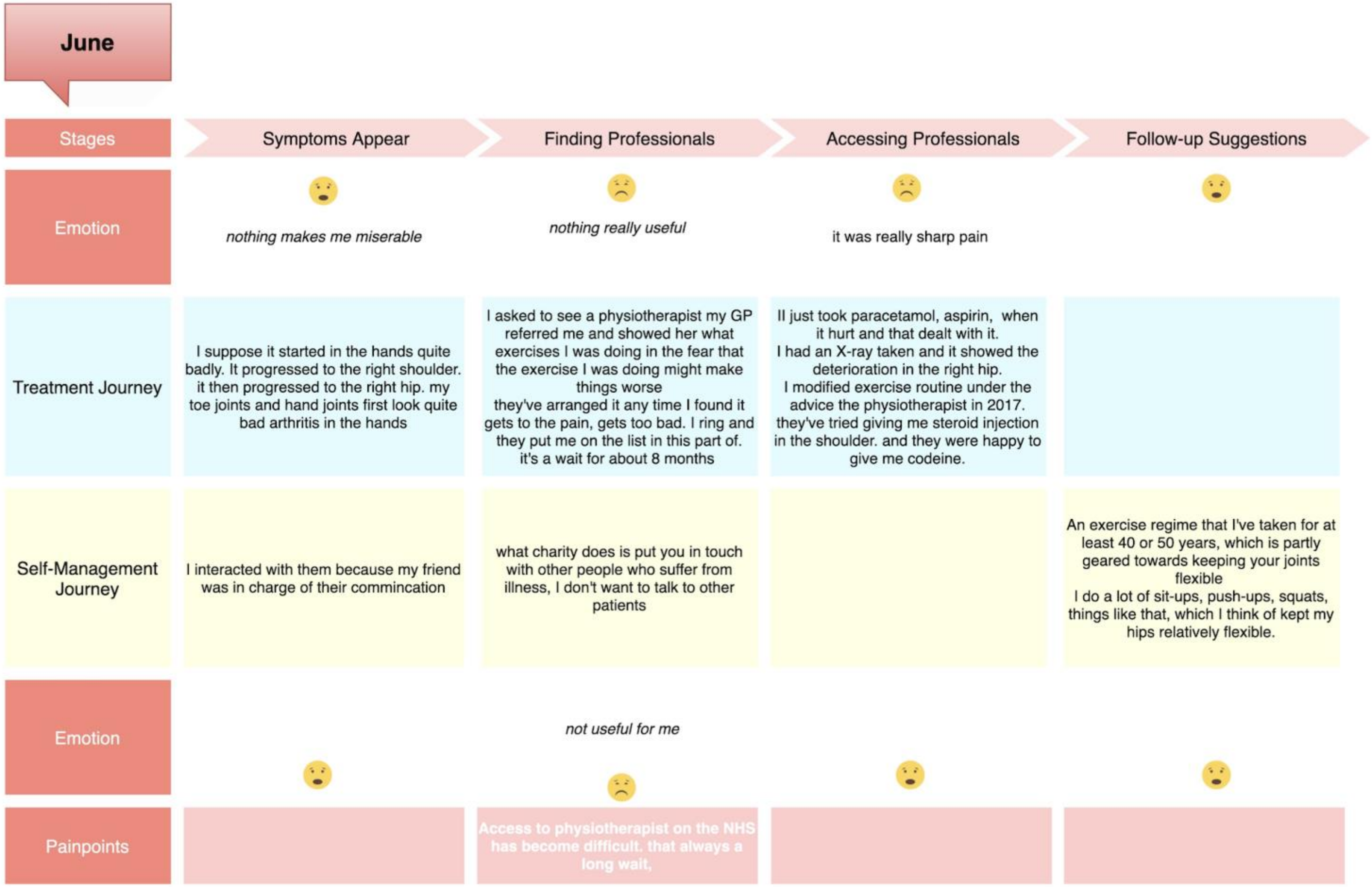
## e. David’s User Journey Map



**David**

| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | ☹<br>*frustrated* | 😀 ☹<br>*lucky and convenient*<br>*frustrated* | 😮 | 😮 |
| Treatment Journey | one of the things with arthritis is you don't get a definitive diagnosis. so if with me, it was cumulative as things started to become problematic | if I've had a kind of long connection with a consultant. They will give their telephone number and I can arrange a direct appointment but mostly it is with the GP. I'm happy talking to a GP on the phone and that's easier to do than seeing them it is only 10 mins appointment, you have to say whatever you want to say and get an answer a prescription if you need one | I've now had both knees replaced one hip and one shoulder, all of those things have improved for me, but there's still my main problem now is in my neck | I've been to the hospital quite regularly, but for different things, so it hasn't been a planned the routine of consultation. I've been put on the waiting list for a wrist. |
| Self-Management Journey | I am a member of charity | I don't contact them very often. I have volunteered for them, but one point there was a sort of advice line. They had which I was part of, so if I needed to but not very frequently | Here are some things you could do and including in the things that you can get for free or for reduce cost. try those rather than just sitting there feeling sorry to yourself<br>it was an advice line, it was a panel basically of people who had arthritis? who were available to talk to people some sort of diagnosis or feeling bad abtout their condition. | just do activities by myself, all involved with ather people doing that activity rather than people with arthritis.<br>I've done Pilates, yoga, walking and swimming then occasionally classes in other things as well |
| Emotion | 😮 | *positive and really good*<br>😀 | *good*<br>😀 | 😮 |
| Painpoints |  | Shortage of Resource | Interruption of activities |  |

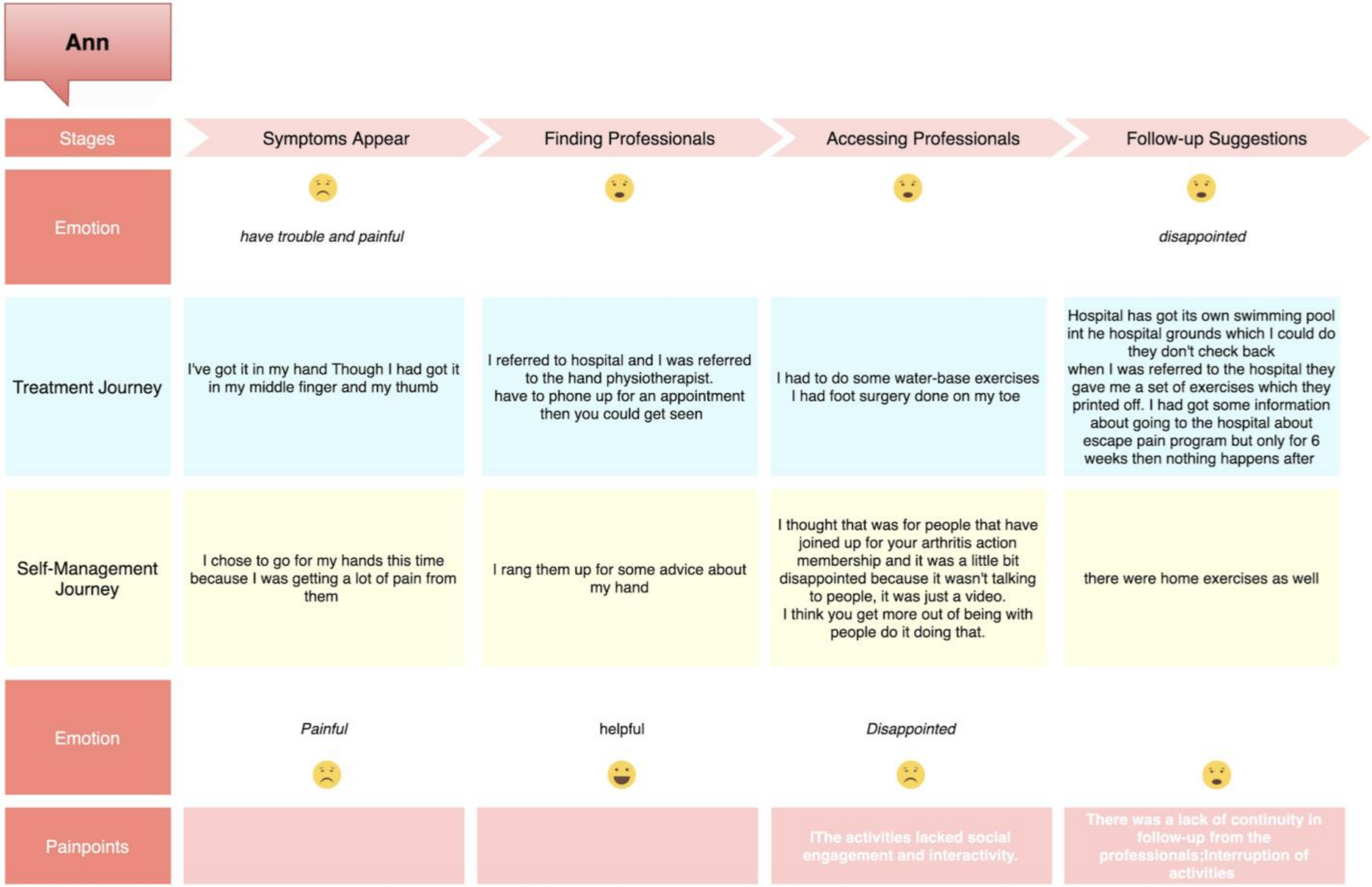
## f. June’s User Journey Map



**June**

| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | 😮<br>*nothing makes me miserable* | ☹<br>*nothing really useful* | ☹<br>it was really sharp pain | 😮 |
| Treatment Journey | I suppose it started in the hands quite badly. It progressed to the right shoulder. it then progressed to the right hip. my toe joints and hand joints first look quite bad arthritis in the hands | I asked to see a physiotherapist my GP referred me and showed her what exercises I was doing in the fear that the exercise I was doing might make things worse they've arranged it any time I found it gets to the pain, gets too bad. I ring and they put me on the list in this part of. it's a wait for about 8 months | II just took paracetamol, aspirin, when it hurt and that dealt with it.<br>I had an X-ray taken and it showed the deterioration in the right hip.<br>I modified exercise routine under the advice the physiotherapist in 2017.<br>they've tried giving me steroid injection in the shoulder. and they were happy to give me codeine. | |
| Self-Management Journey | I interacted with them because my friend was in charge of their commincation | what charity does is put you in touch with other people who suffer from illness, I don't want to talk to other patients | | An exercise regime that I've taken for at least 40 or 50 years, which is partly geared towards keeping your joints flexible<br>I do a lot of sit-ups, push-ups, squats, things like that, which I think of kept my hips relatively flexible. |
| Emotion | 😮 | *not useful for me*<br>☹ | 😮 | 😮 |
| Painpoints | | Access to physiotherapist on the NHS has become difficult. that always a long wait, | | |

## g. Ann’s User Journey Map



**Ann**

| Stages | Symptoms Appear | Finding Professionals | Accessing Professionals | Follow-up Suggestions |
|---|---|---|---|---|
| Emotion | ☹<br>*have trouble and painful* | 😮 | 😮 | 😮<br>*disappointed* |
| Treatment Journey | I've got it in my hand Though I had got it in my middle finger and my thumb | I referred to hospital and I was referred to the hand physiotherapist.<br>have to phone up for an appointment then you could get seen | I had to do some water-base exercises<br>I had foot surgery done on my toe | Hospital has got its own swimming pool int he hospital grounds which I could do they don't check back<br>when I was referred to the hospital they gave me a set of exercises which they printed off. I had got some information about going to the hospital about escape pain program but only for 6 weeks then nothing happens after |
| Self-Management Journey | I chose to go for my hands this time because I was getting a lot of pain from them | I rang them up for some advice about my hand | I thought that was for people that have joined up for your arthritis action membership and it was a little bit disappointed because it wasn't talking to people, it was just a video.<br>I think you get more out of being with people do it doing that. | there were home exercises as well |
| Emotion | *Painful*<br>☹ | helpful<br>😀 | *Disappointed*<br>☹ | 😮 |
| Painpoints | | | IThe activities lacked social engagement and interactivity. | There was a lack of continuity in follow-up from the professionals;Interruption of activities |

# Appendix F: Preliminary People-Centred Framework Structure

## a. Susan’s Journey Through the Preliminary Framework

| **Domains of User Experience** | **Framework Stage** | **User Journey Map Stage** | **Description or Illustrative Quote** |
|---|---|---|---|
| Medical Treatment | Needs Identification | Symptoms Appear | My finger looks a little bit misshapen.I think no one need to do something about that, so I went to my docotors |
| | Needs Identification | Symptoms Appear | Now, the arthritis really is in my feet |
| | Needs Identification | Symptoms Appear | I didn’t really wear normal shoes cause I couldn’t get normal shoes on, my feet were really swollen |
| | Needs Identification | Accessing Professionals | I had foot surgery done and bunions and wires and things. I had one foot done first and then 18 months later I had other foot done |
| | Needs Identification | Symptoms Appear | A few years later, I’ve noticed that my toes have really swollen…and chunky and quite sore. So, I went to my doctors. |
| | Service Utilisation | Finding Professionals | He referred me to a rheumatologist |
| | Needs Identification | Accessing Professionals | I started on medication, which was *NAME*…but I had a really bad reaction…I was sick, I had headaches and it never went away. |
| | Needs Identification | Accessing Professionals | I went back and anyway they then put me on a drug called *NAME*. so I was on that, but then I started to get hives on my skin, rashes, and things like that. |

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|  | Needs Identification | Accessing Professionals | My feet were really swollen…I had a real meltdown and I think that's what did it, for third drug that I'm now on |
|  | Needs Identification | Follow-Up Suggestions | I'd gone from a regular blood test cause I've been at. I was having weekly blood tests and it went to monthly |
|  | Needs Identification | Follow-Up Suggestions | I got a steroid injection but then…they must have had a case conference to put me on what I'm on now, which is the *Name* which is the injection that I have weekly |
|  | Needs Identification | Follow-Up Suggestions | I had to go for the blood test weekly |
|  | Service Utilisation | Finding Professionals | I cannot fault the rheumatology whatsoever I can ring go up |
|  | Information Acquisition | Accessing Professionals | When I first got diagnosed…they gave me leaflets. I was kept informed and also with the medication as well. |
|  | Service Utilisation | Finding Professionals | There is the nursing teams are always on the end of the phone, although they're very short staffed and you do have to leave messages sometimes because there's so busy. But where they can, they do get back to you if there's any issues. And I think that if I did have a problem about my manager, my conditions, I think they would automatically either give me a telephone appointment or ask me to go in because I am seeing face to face twice a year. |
|  | Service Utilisation | Finding Professionals | I have one appointment with the nurses at 6 months later and one appointment with my rheumatologist |

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| | | | six…so I see twice a year I actually go to the hospital, but obviously during covid we have the telephone conversations, but they do like to see you because you’ve got to have the blood tests. |
| | Continuity and Coordination of Care | Follow-Up Suggestions | If you don’t see the same doctor twice or you’ve got a locum doctor then there, that’s where the issues arise because you’ve no continuity of care |
| | Continuity and Coordination of Care | Follow-Up Suggestions | I think that’s where a lot of the problems lie. It’s the continuity of care. I’m lucky because I know all of the doctors of my GP practice cause I’ve been there now for over 10 years. |
| Self-Management | Needs Identification | Symptoms Appear | I’ve been a walker, but my options are limited with my feet |
| | Needs Identification | Follow-Up Suggestions | I’ve done an hour and a half in the pool this morning. And I do swim in the fast lane, so I am a pretty proficient swimmer, and I do try and do my 10000 steps in a day. |
| | Information Acquisition | Follow-Up Suggestions | I do go to the online meetings. The webinars are trying to find out as much as possible about my condition and how to manage it. |
| | Service Utilisation | Finding Professionals | I worked in community development…when I came back to this country, I thought I want to work in community development…so I get to find out about all the charity, all the local organisations and support groups…then I found out about it online during covid I’d say. I contacted them to find out about when |

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|  |  |  | meetings were and I did a two day workshop in *NAME* to give me an understanding so I could sign post people to it…I signed up myself |
|  | Information Acquisition Service Utilisation | Follow-Up Suggestions | I've gone on the webinars. I go to the coffee morning; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world. |

## b. John's Journey Through the Preliminary Framework

| **Domains of User Experience** | **Framework Stage** | **User Journey Map Stage** | **Description or Illustrative Quote** |
|---|---|---|---|
| Medical Treatment | Service Utilisation | Finding Professionals | So I went to the GP and it was him that died that suggested I go to see as a specialist at *City Name* |
|  | Service Utilisation | Finding Professionals | It's not very often I go to the GP now because the GP that I did have is actually retired now. but I've not really been to a GP for well really since the pandemic |
|  | Needs Identification | Accessing Professionals | I have steroid injections in both knees, but that's only three times a year. And that does alleviate the pain, but only for like 5 or 6 weeks, and then it starts kicking in again |
|  | Needs Identification | Follow-Up Suggestions | I have been advised that, the long term, it's gonna be knee replacements. But the specialist the suggested that I'm a little bit too young to go into getting knee replacements because they only last for a 10, 12, 13 years before you have to get it done again. |

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|---|---|---|---|
| | Needs Identification | Follow-Up Suggestions | I'm holding out with the steroid injections for the time long being. And then once I've got a bit older then it'll go to new replacements. |
| Self-Management | Needs Identification | Finding Professionals | When I actually saw an advert in the street. Yeah yeah, so tha's how I like going to them. |
| | Information Acquisition | Follow-Up Suggestions | They're on their website on our thoughts, action website. They've actually got a list of like local physiotherapist, who mainly deal with as you know, knee issues and things |
| | Information Acquisition | Accessing Professionals | At the moment it's I've only done. I'm doing once I'm doing an online chat tomorrow with the group but it was only for a couple of weeks ago that I did a web thing with for a like exercise, which was really quite interesting |
| | Needs Identification | Symptoms Appear | Since I get quite a bit of pain, I don't really move as much, especially at home. That I don't tend to move as much as what I really should do |
| | Needs Identification<br>Information Acquisition | Accessing Professionals | If you just, you know, really should be moving, even if it's just walking up and down and things like that, it tends to ease it. But I was doing some work in the house yesterday. Actually, I was like moving quiet, moving about quite a bit. And it did actually help things a little bit, that's the suggested |
| | Needs Identification | Follow-Up Suggestions | Just walking, because I do struggle with stairs. It's like the jarring impact we like when I'm going up and downstairs, it's or especially downstairs. It's like the jarring on |

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|  |  |  | the knees, that’s what worst thing. But generally walking on flat service is OK for me. |
|  | Information Acquisition | Accessing Professionals | I’ll probably gonna be listening more than anything to see what other people have got any suggestions or hints and tips and things. It’ will be interesting to see what they say tomorrow. |

## c. Helen’s Journey Through the Preliminary Framework

| **Domains of User Experience** | **Framework Stage** | **User Journey Map Stage** | **Description or Illustrative Quote** |
|---|---|---|---|
| Medical Treatment | Needs Identification<br>Service Utilisation | Accessing Professionals | If I was in a lot of pain, yes, I would phone the doctor, but the trouble is I can only take paracetamol. I can't take any other analgesia. |
|  | Service Utilisation | Follow-Up Suggestions | the other treatment is that I go and do Hydrotherapy exercises that are prescribed by a physiotherapist |
|  | Needs Identification<br>Service Utilisation | Accessing Professionals | I've had lots of surgery and I'm doing the exercise just to keep the hip going. No, but I do it for the whole body is so it's all prescribed by the physiotherapist, like 14, 15 years ago. |
|  | Service Utilisation | Finding Professionals | for joint problems, you have to go to the doctor and then you get referred to something called especially orthopedic things or anybody with any bone problems you get with referred to these and then they decide whether you get referred to the orthopedic surgeon. So you can |

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| | | | go to a GP, but where's you would have years ago been referred straight to the hospital. It doesn't happen like that locally. |
| Self-Management | Needs Identification | Symptoms Appear | Someone told me about it and obviously I wanted to see if there was any more self-management I could do |
| | Information Acquisition<br>Service Utilisation | Finding Professionals | we used to meet in *City Name*, but they've stopped meeting now. But you know they do research. So I update myself on their research. |
| | Needs Identification<br>Service Utilisation | Accessing Professionals | But the but because I had this syndrome, which means that I can dislocate joints. They…I actually had exercises during the pandemic prescribed to me by arthritis action, so I could still try and keep my joints moving properly. So that was the biggest benefit from them. That someone who looked at the syndrome and tailored them to fit me. |
| | Service Utilisation | Follow-Up Suggestions | The activity I do regularly is the hydrotherapy, which I will do this afternoon. I am not allowed, Obviously, to work out in a gym or anything like that. So once a week I pay and go into the warm water pool. To which I'd always done anyway, before the pandemic, which worked as a good pain control basically. Yeah. |

## d. Alex’s Journey Through the Preliminary Framework

| Domains of User Experience | Framework Stage | User Journey Map Stage | Description or Illustrative Quote |
|---|---|---|---|
| Medical Treatment | Needs Identification<br>Service Utilisation | Symptoms Appear<br>Finding Professionals<br>Accessing Professionals | I thought I'd actually initially sprained my back. But, the pain wasn't going. It was just. It just wasn't easing and after 18 months I've had enough. I'd just went to doctor. I said you're gonna have to refer me because something's not right here. I got referred and I had my MRI scan, I think about six or seven weeks after and then I got diagnosed with ankylosing spondylitis. So and that was in 2015 when I got diagnosed. So yeah, I kind of went nearly two years of not knowing what's going on. So it wasn't. It was pretty dreadful. |
| | Service Utilisation | Follow-Up Suggestions | I've been to my GP and I have got a consultant as well. I'm under. I'm under rheumatology, I'm under rheumatology clinics or and they've said I'll be under that for life. No, for the rest of my life. |
| | Service Utilisation | Follow-Up Suggestions | I have to have scans every two years in order to check that my spines not Getting damaged. So yeah, I need to have like scans, and I have to have Monthly blood tests at the doctors to check my inflammation levels. |
| | Service Utilisation | Finding Professional | I feel NHS appointments can be rushed. And I don't feel like I'm getting my point across enough. so, it can be a little bit frustrating. |
| | Service | Accessing | A community clinic where I go to |

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| | Utilisation | Professionals | it's like. It's a small clinic and it's- it's for it's a specialist clinic for people with arthritis. |
| | Service Utilisation | Finding Professionals | I talked with them face to face. Also, sometimes I have emailed and like last like, oh, I'm a bit concerned about this. Can you kind of give me your A bit of information, so yeah, I have done e-mail that I have done form but it's mostly face to face. |
| Self-Management | Needs Identification<br>Information Acquisition | Accessing Professionals | I've been given some exercises I can do from home. I do try and do them as often as I can, but sometimes it is difficult and if I feel quite ill I can't… I can't do one, but I will maybe have a sore called, maybe use like. I'm usually like things that are cold. like cold therapy instead of hot. |
| | Information Acquisition | Accessing Professionals | my sometimes it's within the private and NHS they can Recommend certain things I can do, exercises or maybe sleep nights and sleep hygiene to try and help me get like a decent sleep. So yeah, I've had quite a lot of Different things, but mostly from my…my private physical. He's kind of give me like an…an exercise plan. |
| | Information Acquisition | Finding Professionals | And I'm actually a member of Nice. Yeah, the In national and ankylosing spondylitis society, I've been a member of them ever since I got diagnosed in because I got diagnosed in 2015. And I did find it helpful because it does give you quite a lot of Useful information like |

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| | | | tips on how to maybe do things or not overdo things. |
| | Information Acquisition | Accessing Professionals | There's like a forum as well, so you can talk to other people. |
| | Information Acquisition Service Utilisation | Follow-Up Suggestions | I get Centre magazine as well, which is like twice a year, so that has like a lot of information and there's a lot of like information booklets. You can read and there's like a helpline as well. You can ring. You know like if you've got any answers or if you need any help with anything. So yeah, it's been pretty useful. |
| | Information Acquisition | Follow-Up Suggestions | I've actually I've looked on for arthritis action As well, and I do find that quite a an interesting website because it gives you like Different types of arthritis, or maybe the medications, because sometimes I'm not sure what medications do for my condition. I'm not sure how they work or it's it's interesting to read. |
| | Information Acquisition | Accessing Professionals | It's actually part of my I've actually done it within the NHS. And then obviously these people that are in these groups, these- I‘ve actually ended up becom- they’ve ended up becoming friends. And obviously I've not done these classes for a while, but I have actually kept in touch with a few of them, so it is nice that I can still Comment of keeping talks and you know I'm not the only person. |
| | Information Acquisition | Follow-Up Suggestions | they sometimes send emails and.Yeah, I do get that information Booklets attached. I do have more interaction with the *Charity |

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| | | | Name*. To be fair, I think they've been more active, so I do get like monthly e-newsletters which are quite useful. |

## e. David's Journey Through the Preliminary Framework

| Domains of User Experience | Thematic Framework Stage | User Journey Map Stage | Description or Illustrative Quote |
|---|---|---|---|
| Medical Treatment | Needs Identification Continuity and Coordination of Care | Symptoms Appear | You've got arthritis. You go and somebody looks at your shoulder or your knee or your hip and say you've got arthritis there. So if with me, therefore, it was cumulative, as…as things started to become problematic. Uh. The…there was there was a diagnosis, but one of the frustrations with having arthritis, is there is nobody who takes an overall view of the whole of you. It's people who are interested in shoulders or knees or hips or ankles or…or something like that. So it's all very kind of…Uh…desperate. You know what I mean? They it's very confused. So the answer to your question is that I…It was more that somebody said you this. I think it was my hip. That was my knee, was my knee. Said this knee is too badly damaged to carry on, you need a replacement. |
| | Service Utilisation | Accessing Professionals | I've now had both knees replaced one hip and one shoulder. And all of those things have improved things |

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|---|---|---|---|
| | | | for me, but there's still…my main problem now is in my neck. |
| | Service Utilisation | Finding Professionals | I've been to the hospital quite regularly, but for different things, so it hasn't been a planned the routine of consultations. But things like. Uh. I've been put on the waiting list for a wrist replacement. |
| | Service Utilisation | Finding Professionals | if I've had a kind of long connection with a consultant. They will give me their telephone number and I can arrange a direct appointment. |
| | Service Utilisation | Finding Professionals | But mostly it is with the GP. |
| | Service Utilisation | Finding Professionals | And as I said, the that that surgery works really well. I think the frustration is that it is only 10 minute appointments. So you know, you have to say whatever you want to say and get an answer and get a prescription if you need one. |
| Self-Management | Needs Identification | Symptoms Appear | if I need it. I mean, I'm a member of arthritis action |
| | Information Acquisition<br>Service Utilisation | Finding Professionals | I don't contact them very often. I have…I have volunteered for them, but one point there was a sort of advice line. They had, which I was part of. Uh. So yeah, I would. I would. I would if I needed to. But not, but you know, not very frequently. |
| | Information Acquisition<br>Service Utilisation | Accessing Professionals | Here are some things you could do and including in the things that you can get for free or for reduce cost. Try those. Rather than just sitting there feeling sorry for yourself. |
| | Information | Accessing | It was an advice line or something |

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| | Acquisition<br>Service Utilisation | Professionals | like an advice line. It…it was a panel basically of people. Uh. Who had arthritis? Who were available to talk to people who were…We would have some sort of diagnosis or feeling Bad about the…About their condition. Just to talk to them about, you know what it's like and what's available |
| | Service Utilisation | Accessing Professional | I think I only ever got one call actually. The one call was arranged and then cancelled and another one, but that that was it. So, I don't know what's happened to the scheme now, but. I thought it was quite a good idea. |

## f. June's Journey Through the Preliminary Framework

| **Domains of User Experience** | **Framework Stage** | **User Journey Map Stage** | **Description or Illustrative Quote** |
|---|---|---|---|
| Medical Treatment | Needs Identification | Accessing Professionals | It was really sharp pain, they started me on paracetamol, aspirin, something like that when it hurt, and that dealt with it |
| | Needs Identification<br>Service Utilisation | Accessing Professionals | In 2017, six years ago, I had really acute pain. So for the first time, I had an X-ray taken and it showed the deterioration in the right hip |
| | Needs Identification<br>Service Utilisation | Finding Professionals<br>Accessing Professionals | I had the sharp in the hip, I asked to see a physiotherapist my GP referred me. And showed her what exercise I was doing in the fear that the exercise I was doing might make things worse |

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| | Needs Identification<br>Service Utilisation | Finding Professionals | I modified exercise routine under the advice of the physiotherapist in 2017, I had no problem in reaching a physiotherapist |
| | Needs Identification | Symptoms Appear | I have seen several physiotherapists. I saw the first physiotherapist to see if there were any extra exercises I could do to increase and this is for the shoulder to begin with for the shoulder because it's more disabling than the pain in the hip |
| | Information Acquisition | Accessing Professionals | Quite frankly, they didn't add anything to what I already know about this exercise |
| | Information Acquisition | Accessing Professionals | As a medical aid, not as a beauty aid or as a sporting aid, I've never been very sporty. So I don't feel that what I've seen or physiotherapist has been very helpful |
| | Service Utilisation | Accessing Professionals | It has got steadily more difficult getting help as I've got older as opposed to becoming easier because I'm older and more and more disabled. So access to physiotherapy on the national health has become difficult. That always a long wait, but it's always been very good. |
| | Needs Identification | Accessing Professionals | When the aspirin and paracetamol didn't seem to be enough, they were happy to give me codeine, so, I now occasionally take codeine |
| | Needs Identification<br>Service Utilisation | Finding Professionals<br>Accessing Professionals | Last year, when the second of X-rays were taken, and damage to the right hip was so pronounced. he said you should have your name put down for replacement straight away, and only because you say you're not suffering severe pain do I say put it |

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|---|---|---|---|
| | | | off. So they’ve arranged it anytime I found it gets to the pain, gets too bad. I ring and they put me on the list in this part of |
| | Service Utilisation | Finding Professionals | I’m now on the list and in this part of the world it’s a wait for about 8 months. That’s very good for the health service. Some people you probably know this. If you’ve read the newspapers, I believe that some people wait for it counts as an elective operation hip replacement. |
| | Service Utilisation | Finding Professionals | I have to say that contact with the GP has got very difficult since the pandemic. I don’t mind doing it a talking on the telephone or doing video interviews as all, but I do want to do things where I can communicate. I don’t want to have tick boxes which you choose questions that somebody else has chosen for you. I dislike to tick boxes a lot because they don’t allow for somebody who’s a chatter box like me, who has got lots to say. It was only asking questions about the things that they don’t give you the answers for frequently asked questions |
| | Service Utilisation | Finding Professionals | I have always contacted physiotherapist, so the only ones I’ve seen, physiotherapists, so I’ve seen. I’ve contacted through the GP service |
| Self-Management | Needs Identification | Follow-Up Suggestions | An exercise regime that I’ve taken for at least 40 or 50 years, which is partly geared towards keeping your joints flexible |

| | | | |
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| | Information Acquisition | Finding Professionals | I was medicating myself and just checking on the internet with the sites that I rely on Med and the Mayo Clinic one |
| | Information Acquisition | Finding Professionals | What *Charity Name* does is put you in touch with other people who suffer from illness |
| | Service Utilisation | Finding Professionals | |
| | Information Acquisition<br>Service Utilisation | Follow-Up Suggestions | I've gone on the webinars. I go to the coffee morning; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world. |

## g. Ann's Journey Through the Preliminary Framework

| **Domains of User Experience** | **Framework Stage** | **User Journey Map Stage** | **Description or Illustrative Quote** |
|---|---|---|---|
| Medical Treatment | Service Utilisation | Finding Professionals | And also asked me a lot of questions. And then I… I had been referred To Umm, hospital. |
| | Service Utilisation | Accessing Professionals | And I had to do some exercises there water-based exercises. |
| | Service Utilisation | Symptoms Appear | Though I I had got it in my middle finger. And I was referred to the hand physiotherapist. |
| | Service Utilisation | Finding Professionals | it's- have to phone up for an appointment. And then you could get seen. |
| | Service Utilisation | Follow-Up Suggestions | Hospital has got its own swimming pool it in the in the hospital grounds, which I do go to sometimes. |
| | Service Utilisation | Accessing Professionals | yesterday I did talk to the doctor about my because I had foot surgery |

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| | | | done on my toe now because I had an ingrown toenail. |
| | Continuity and Coordination of Care | Follow-Up Suggestions | They don't check back. Not. And I think they should. I think they should ask me how…how it's going. Because if…if they leave it. If they don't, ask again. How are they going to know if things are going well? |
| | Information Acquisition | Accessing Professionals | I went when I was referred to the hospital. They gave me a set of exercises which they printed off. For me So like leg stretches |
| | Information Acquisition | Accessing Professionals | Then, about five years later, I had got I Got some information about going to the hospital about a program bit… Bit like the escape pain program where you it's a bit like gym based you can- you can go 3 minutes on different exercise types of equipment. And then It's not like a full gym because it's not as intense as being in the gym because you only get 3 minutes to go on each one. |
| | Continuity and Coordination of Care | Accessing Professionals | But that was only for six weeks and then Nothing happens after that. |
| | Needs Identification | Symptoms Appear | I chose to go for my hands this time because I was getting a lot of pain from them. |
| Self-Management | Needs Identification | Finding Professionals | I clicked on to the their website. I think I can't remember how I come across them. But anyway, I went on to their website and I think it was about four or five years ago. |
| | Service Utilisation | Finding Professionals | They were doing a Help for Heroes. so people that didn't have that much |

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| | | | money Could join the membership and get her treatments done for half price. |
| | Information Acquisition | Accessing Professionals | What once I rang them up for some advice about my hand. |
| | Information Acquisition | Accessing Professionals | I thought that was for people that have joined up for your arthritis action membership and it was a little bit disappointed because it wasn't talking to people. It was just a video. That was going to be shown on YouTube, so, well, a little bit disappointed about that. Although the exercises were good in themselves. Well, I think it's…it's better if people doing them in person because if you just get shown and exercise and on video. You're just left to do it yourself and…And although it might be OK, but I think you get more out of being with people do it doing that. |

# Appendix G: Charting Table for Framework Analysis

## a. Susan's Data Chart

| Participants | Susan |
|---|---|
| **Needs Identification** | My fingers look a little bit misshapen;<br>Now the arthritis really is in my feet;<br>A few years later, I've noticed that my toes were really swollen;<br>My options are limited with my feet. |
| **Information Acquisition** | I do go to the online meetings. The webinars are trying to find out as much as possible about my condition and how to manage it;<br>I've gone on the webinars;<br>When I first got diagnosed, they gave me leaflets, I was kept informed and also with the medication as well. |
| **Service Utilisation** | I signed up myself…I join the group;<br>I go to the coffee mornings;<br>I cannot fault the rheumatology department whatsoever I can ring go up.there is the nursing teams are always on the end of the phone. |
| **Continuity and Coordination of care** | I'm lucky because I know all of the doctors of my GP practice casue I've been there now for over 10 years. |

## b. John's Data Chart

| Participants | John |
|---|---|
| **Needs Identification** | I have been advised that the long term, it's gonna be knee replacements. And but the specialist the suggested that I'm a little bit too young to go into getting knee replacements because they only last for a 10, 12 ,13years before you have to get it done again. I'm holding out with the steroid injections for the time being and then once I've got a bit older then it'll go to new replacement.<br>I don't tend to move as much as what I really should do..it's actually made things worse |
| **Information** | I'm doing an online chat tomorrow with the group but it was only |

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|---|---|
| **Acquisition** | for a couple of weeks ago that I did a web thing with for a like exercise, which was really interesting<br>I'll probably gonna be listening more than anything to see what other people have any suggestions or hints and tips and things, it'll be interesting to see what they say tomorrow |
| **Service Utilisation** | I went to the GP and it was him died that suggested I go to see as a specialist at *hospital name* I did go originally start off at the GP you know |
| **Continuity and Coordination of care** | It's not very often I go to a GP now because the GP that I did have is actually retired now, but I've not really been to a GP for while really since the pandemic |

## c. Helen's Data Chart

| **Participants** | **Helen** |
|---|---|
| **Needs Identification** | I want to see if there was any more self-management I could do<br>I had this syndrome, which means that I can dislocate joint, They actually had exercises during the pandemic prescribed to me by *Charity*, so I could still try and keep my joints moving properly. So that was the biggest benefit from them, that someone who looked at the syndrome and tailored them to fit me |
| **Information Acquisition** | They (charity) do research, so I update myself on their research |
| **Service Utilisation** | If I was in a lot a pain, I would phone the doctor<br>Once a week I pay and go into the warm water pool to which I'd always done anyway, which worked as a good pain control basically |
| **Continuity and Coordination of care** | the program was only for 6 weeks then nothing happens after that they don't check back and I think they should ask me how it's going if they don't ask again, how are they going know if things are going well |

## d. Alex’s Data Chart

| **Participants** | **Alex** |
|---|---|
| **Needs Identification** | I thought I’d actually initially sprained my back, but the pain wasn’t going. It just wasn’t easing<br>I’ve been given some exercises I can do from home…I’m usually like things that are cold therapy instead of hot |
| **Information Acquisition** | They can recommend certain things I can go exercises or maybe sleep nights and sleep hygiene to try and help me get like a decent sleep<br>I did find *Charity* helpful because it does give you quite a lot of useful information like tips on how to maybe do things or not overdo things. There’s like a forum as well, so you can talk to other people.<br>I get centre magazine as well, which is like twice a year, so that has like a lot of information and there’s a lot of like information bookltes, you can read and there’s like a helpline as well…I do find that quite an interesting website because it gives you like different types of arthritis, or maybe medications, because sometimes I’m not sure what medications do for my condition, I’m not sure how they work or it’s interesting to read.<br>*Charity* sometimes send emails and I do get that information booklets attached. I do have more interaction with the them…I do like get monthly e-newsletters which are quite useful. |
| **Service Utilisation** | I’d just went to doctor, I said you’re gonna have to refer me because something’s not right here<br>I think I feel NHS appointments can be rushed. And I don’t feel like I’m getting my point across enough, so, it can be a little bit frustrating.<br>I talked with them face to face, sometimes I have e-mailed and like last time I’m a little bit concerned about this…I have done form but it’s mostly face to face |
| **Continuity and Coordination of care** | |

## e. David's Data Chart

| Participants | David |
|---|---|
| **Needs Identification** | One of the things with arthritis is you don't get a definitive diagnosis;<br>You go and somebody looks at your shoulder or your knee or your hip and say you've got arthritis there. |
| **Information Acquisition** | There was a sort of advice line they had, which I was part of. If I needed to. |
| **Service Utilisation** | If I've had a kind of long connection with a consultant, they will give me their telephone number and I can arrange a direct appointment;<br>I'm happy talking to a GP on the phone, that's easier to do than seeing them;<br>It is only 10 minutes appointments, so you have to say whatever you want to say and get an answer and get a prescription if you need one. |
| **Continuity and Coordination of care** | |

## f. June's Data Chart

| Participants | June |
|---|---|
| **Needs Identification** | An exercise regime that I've taken for at least 40 or 50 years, which is partly geared towards keeping your joints flexible<br>It was really sharp pain I couldn't do anything and they started me on paracetamol, aspirin, something like that when it hurt |
| **Information Acquisition** | Just checking on the internet with the sites that I rely on |
| **Service Utilisation** | It has got steadily more difficult getting help as I've got older as opposed to becoming easier because I'm older and more and more disabled, so access to physiotherapy on the NHS has become |

| | |
|---|---|
| | difficult, that always a long wait<br>He said you should have your name put down for replacement straight away. And only because you say you're not suffering severe pain do I say put it off. So, they've arranged it any time I found it gets to the pain, gets too bad<br>It's wait for about 8 months, that's very good for the health service, some people you probably know this, if you've read newspapers, I believe that some people wait for it more than 2 years<br>I have to say that contact with the GP has got very difficult since the pandemic, I don't mind doing it a talking on the telephone or doing video interviews at all, but I do want to do things where I can communicate. I don't want to have tick boxes a lot because they don't allow for somebody who's a chatter box like me, who has got lots to say. It was only asking questions about the things that they don't give you the answers for frequently asked questions.<br>I have always contacted physiotherapist, so the only ones physiotherapist I've seen I've contacted through the GP service |
| **Continuity and Coordination of care** | |

## g. Ann's Data Chart

| **Participants** | **Ann** |
|---|---|
| **Needs Identification** | I chose to go for my hands this time because I was getting a lot of pain from them |
| **Information Acquisition** | When I was referred to the hospital, they gave me a set of exercises which they printed off<br>I rang them up for some advice about my hand<br>It's better if people doing them in person because if you just get shown and exercise and on video, you're just left to do it yourself…I think you get more out of being with people doing that |
| **Service** | Have to phone up for an appointment. And then you could get seen |

|  |  |
|---|---|
| **Utilisation** | it’s (yoga) a thing is because I’m not working, I’m applying them a bit expensive |
| **Continuity and Coordination of care** | the program was only for 6 weeks then nothing happens after that they don’t check back and I think they should ask me how it’s going if they don’t ask again, how are they going know if things are going well |

# Appendix H: Coding Framework for Thematic Analysis

## a. Susan: Coded Transcript Excerpts

| Susan | Initial Coding |
|---|---|
| had foot surgery done 1st and then 18 months later I had the other foot done | targeted treatment plan |
| …so I started on medication, which was methotrexate.. | targeted treatment plan |
| I'd gone from a regular blood test cause I've been at…I was having weekly blood tests and it went to monthly… | targeted treatment plan |
| …I had a real meltdown and I think that's what did it, for the third drug tha I…that I'm now on. | targeted treatment plan |
| I'm on now, which is the (*hosipital name*) which is the injection that I have weekly. | targeted treatment plan |
| I had the first operation in October…And the other foot is due to be done in mid-March… | targeted treatment plan |
| I've done a..an hour and a half in the pool this moring. And I do swim in the fast lane, so I am a …a pretty proficients swimmer and I do try and do my 10000 steps in a day. | targeted self-management plan |
| we got a newsletter from you with your research attached | access information from non-profit organisations |
| I do go to the online meting | access information from non-profit organisations |
| the webniars are trying to find out as much as possible about my condition and how to manage it. | access information from non-profit organisations |
| ..and I do meet other people and I 'm thinking, I feel so blessed that the medication I've got helped me at an early age, cause some of these people literatlly can't move and can't do anything, so in that aspect I … I feel OK. | engage with the community through non-profit organisations<br>access psychological support |
| I've gone on the webinars. I go to the coffee mornings; I get the newsletter, so it keeps me up to scratch with what's going on in the arthritis world | access information from non-profit organisations<br>engage with the community through non-profit organisations |

| | |
|---|---|
| whatsover, I can ring go up. | appointment and communication channels |
| if I've got issues with my medication because it comes from a third party which has been a bit of an issue. The drugs cause it's not issued from the hospital. | third-party service integration |
| when I first got diagnosed, I got-they gave me leaflets. I was kept informed and also with the medication as well. | access information from NHS |
| there is the nursing teams are always on the end of the phone, although they're very short staffed and you do have to leave messages sometimes because there's so, so busy. | resource shortage |
| I think that if I did have a problem about my manager, my conditions, I think they would automatically either give a telephone appointment or ask me to go in because I am seeing face to face twice a year. | appointment and communication channels |
| I actually go to the hospital, but obviously during covid we have to have the….the telephone conversations, but they do like to see you because you've got to have the blood test. | appointment and communication channels |
| they've consulted me and they're like, you know when I did they…they asked me if I wanted to do my injection weekly or two weekly or you know they consulted me through the plan, because obviously there's a plan there for me and without that, withou that first point of call from...from the GP practices | targeted treatment plan |
| and the problem is though, our NHS as you know is overwhelmed and it's the doctors are just to just overload it, and if you don't see the same doctor twice or you've got a locum doctor then there, that's where the issues arise because you've no continuity of care. | resource shortage<br>continuity of care |

## b. John: Coded Transcript Excerpts

| John | Initial Coding |
|---|---|
| it's not very often I go to a GP now because the GP that I did have is actually retired now. Umm, but I I've not really been to a GP for well really since the pandemic | continuity of care |
| I get I have steroid injections in both knees, but that's only three times a year, and that does alleviate the pain, but only for like 5 or 6 weeks, and then it starts kicking in again | targeted treatment plan |
| I have been advised that, and the long term, it's gonna be knee replacements. And but the specialist the suggested that I'm a little bit too young to go into getting knee replacements because they only last for 10..12..13 years before you have to get it done again. umm so I'm...I'm holding our with the steroid injections for the time being. and then once i've got a bit older then it it'll go to new replacement. | targeted treatment plan |
| they're(Arthrtis Action) in a like an exercise plan for ummm-you know like gentle exercises for people with arthritis and that was really interesting actually. | targeted treatment plan |
| I'm doing an online chat tomorrow with…with the group but it was only for a couple of weeks ago that I did that a web thing with for a like a exercise | engage with the community through non-profit organisations<br>access information from non-profit organisations |
| it was for like people with gent work with other issues, not…not…not just knees, but maybe elbows or hips or…or hands and things like that. It was just like stretching and and … and like generally moving. So so soon as I, I tend to quite I - I Since I get quite a bit of pain, I don't really move as much, especially at hone. that I don't tend to move as much as what I really should do and...and they suggested that. it's..it's actually made things worse if you just sit in | engage with the community through non-profit organisations<br>targeted self-management plan |

| | |
|---|---|
| really should just be moving, even if it's just walking up and down and···and···and things like that it..it..it tends to ease it.......I was like, moving quite, moving about quite a bit. And it did actually help things a little bit. The pain wasn't so bad. | targeted self-management plan |
| I'll probably gonna be listening more than anything to see what other people have suggest···have···have got any suggestions or hints and tips and thins | engage with the community through non-profit organisations<br>access information from non-profit organisations |

## c. Helen: Coded Transcript Excerpts

| Helen | Initial Coding |
|---|---|
| never go regularly. I've only gone when the joints have got so painful that I know that they need replacing | targeted treatment plan |
| I would phone the doctor | appointment and communication channels |
| they've just type paracetamol for it and just get it eased | targeted treatment plan |
| I get what they call patient transport service it's an NHS that you phone up has provided you qualify for | targeted treatment plan |
| the other treatment is that I go and do Hydrotherapy exercises that are prescribed by a physiotherapist. To that's what the other way I manage it, which is exercising in warm water. | targeted treatment plan |
| obviously I wanted to see if there was any more self-management I could do | access information from non-profit organisations |
| we used to mee in (city name), but they've stopped meeting now | appointment and communication channels |
| I actually had exercises during the pandemic prescribed to me by Arthritis Action | targeted self-management plan |
| the activity I do regularly is the hydrotherapy, which I will do this afternoon | targeted self-management plan |

| | |
|---|---|
| once a week I pay and go into the warm water pool. To which I'd always done anyway, before the pandemic, which worked as a good pain control basically. | targeted self-management plan |
| I do one where I stretch my back......I do it all with foam weights in the water. So you've got resistance. Though I used to shoulder exercises, back exercises cause I have an arthritic hip. Walking and sitting on what they call a noodle to try and keep the core strong. | targeted self-management plan |
| I've had lots of surgery and I'm doing the exercise just to keep the hip going. No, but I do it for the whole body is so it's all prescribed by the physiotherapist, like 14,15 years ago. | targeted treatment plan |

## d. Alex: Coded Transcript Excerpts

| Alex | Initial Coding |
|---|---|
| I have to scan every two years in order to check that my spines not getting damaged. I need to have like scans, and I have to monthly blood tests at the doctors to check my inflammation levels. | targeted treatment plan |
| I think they're quite stretched and sometimes without like being deliberate. I think I feel NHS appointments can be rushed. And I don't feel like I'm getting my point across enough. So it can be a little bit frustrating. So yeah, with private it seems..seems to flow. you know, it seems to be more targeted to me. | short consultation time |
| what need like you know, extra…extra support and like the could be exercises. It could be like sports massage, that type thing, cause I do have a lot of back pain and I do have the deep tissue massage, which does, which is it is very helpful. | targeted treatment plan |

| | |
|---|---|
| I've been given some exercises I can do from home. I do try and do them as often as I can, but sometimes it is difficult and if I feel quite ill I can't…I can't do one, but I will maybe have a sore called, maybe use like, I'm usually like things that are cold like cold therapy instead of hot. so I do have, like, some spray, some gel I rub in, and that can kind of help. | targeted self-management plan |
| sometimes it's within the private and NHS they can recommend certain things I can do, exercises or maybe sleep nights and sleep hygiene to try and help me get like a decent sleep. So yeah, I've had quite a lot of different things, but mostly from my…my private physical, he's kind of give me like an..an exercise plan. | targeted self-management plan |
| and I did find it helpful because it does give you quite a lot of useful information like tips on how to maybe do things or not overdo things. There's like a forum as well, so you can talk to other people. | access information from non-profit organisations<br>engage with the community through non-profit organisations |
| I get centre magazine as well, which is like twice a year, so that has like a lot of information and there's a lot of like information booklets. | access information from non-profit organisations |
| there's like a helpline as well. You can ring. You know like if you've got any answers or if you need any help with anything | access information from non-profit organisations |
| because if I connect with other people that are in like a similar situation now, yeah, I don't feel as like isolated or maybe kind of like the odd one our, if you if you know what I mean, it's kind of his nice to know that I'm like ,not the only one and I can speak to people and get advice and maybe ask about certain things that I'm not sure about. so for me it is a big like a big plus. | access information from non-profit organisations<br>engage with the community through non-profit organisations<br>access psychological support |

| | |
|---|---|
| sometimes we'll do that exercise classes. I obviously it's like sometimes we do like a lot of Chur, chur based exercises. So obviously it kind of supports that bad. But we're still like moving our arms and legs and trying to do things like that. So yeah, I have done that a couple of times and I have found it beneficial. | targeted treatment plan<br>engage with the community through NHS |
| then obviously these people that are in these gourps, these-I've actually ended up becom-they've ended up becoming friends | engage with the community through NHS |
| (Arthritis Action) sometimes send emails and I do get that information booklets attached. I do have more interaction with the NAS. To be fair, I think they've been more active, so I do get like monthly e-newsletter which are quite useful | access information from non-profit organisations |
| I talked with them face to face. Sometimes I have emailed and like last like, oh, I'm a bit concerned about this. Can you kind of give me you’re a bit of information, so yeah, I have done e-mail that I have done from but it's mostly face to face. | appointment and communication channels |
| I don't know if it's related to my arthritis, but I do keep getting like problems in my legs an feet. But yeah, it's it is. I think with COVID 19, I think with the pandemic it's… it's been pretty horrendous. Yeah, it's not. It's been quite negative for me, really. it's caused a lot of problems. | long waiting time |

## e. David: Coded Transcript Excerpts

| **David** | **Initial Coding** |
|---|---|
| there was a diagnosis, but one of the frustrations with having arthritis, is there is nobody who takes an overall view of the whole of you. It's people who are interetested in shoulders or knees or hips or ankles or…or something like that. So it's all very kind of ...uh...desperate. | continuity of care |
| I've been put on the waiting list for a wrist replacement | targeted treatment plan |

| | |
|---|---|
| it's always different bits of the body, not an overall arthritis consultation. So yes, I've seen…I've seen a lot of the consultants | continuity of care |
| one occasion I was..I was forbidden from…Uh…having a hip replacement where I lived in in (*city name*). Uh, because I weighed too much. | targeted treatment plan |
| sometimes, if I've had a kind of long connection with a consultant. They will give me their phone number and I can arrange a direct appointment. But mostly it is with the GP. | appointment and communication channels<br>continuity of care |
| the other thing is for me very often I'm happy talking to a GP on the phone. And that's easier to do than…than seeing them. | appointment and communication channels |
| I think the frustration is that it is only 10 minute appointments. So you know, you have to say whatever you want to say and get an answer and get a prescription if you need one | appointment and communication channels<br>short consultation time |
| ..you as an individual mostly need help with day-to day life and…and creating the conditions which can make things more positive for you. Uh, so for quite a time I had something to do with them. …here are somethings you could do and including in the things that you can get for free or for reduce cost. try those. rather than just sitting there feeling sorry for yourself. | access information from non-profit organisations<br>Economic factors influence self-management approaches |
| it was an advice line or something like an advice line. It… it was a panel basically of people. Uh. Who had arthritis? Who were we would have some sort of diagnosis or feeling bad about the…about their condition. Just to talk to them about, you know what it's like and what's available... | access information from non-profit organisations<br>access psychological support |
| just do it by myself. Really. All involed with other people doing that activity rather than people with arthritis | targeted self-management plan |
| I've done Pilates. I've done yoga. I've done mainly what I do is walking and swimming. Uh and… and then occasionally classes in other thins as well. | targeted self-management plan |

## f. June: Coded Transcript Excerpts

| June | Initial Coding |
|---|---|
| incidentally I have a…an exercise regime that I've taken for at least 40 or 50 years, which is partly geared towards keeping your joints flexible umm, a cardiovascular exercise. | targeted self-management plan |
| my exercise…oh yes…load bearing to avoid osteoporosis. I do a lot of sit-ups, push-ups squats, things like that. Which I think of kept my hips relatively flexible. | targeted self-management plan |
| in the early 70s I had troubles with my hands and my feet. In my mid 70s I started to notice the knees getting stiff and that's when I started these flexibility exercises in space. I did a lot. I did a lot of exercise, so the knees aren't really too much of a trouble. | targeted self-management plan |
| I just took paracetamol, aspirin, something like that when it hurt. And that dealt with it. | targeted self-management plan |
| I had an X-ray taken and it showed the deterioration in the right hip. | targeted treatment plan |
| it is very severe in my shoulder, but I'm told that there is no operation to correcting arthritic shoulder, so I just put up with that. | targeted treatment plan |
| haven't been a big user of these services because I'm a medical journalist. I tend to go straight to the medical… the medical websites that work for me | access information from non-profit organisations |
| when I was 82 and I had the sharp pain in the hip, I went to the I…I asked to see a physiotherapist my GP referred me. And the and showed her what exercises I was doing in the fear that the exercise I was doing might make things worse. So that's the first time I used the health services apart from having an X-ray taken | targeted treatment plan |
| otherwise, I was medicating myself and just checking on the on the Internet with the sites that I rely on like Med, MD and Mayo Clinic one they give me much more information…… | targeted self-management plan |

| | |
|---|---|
| so the first time I saw an ..a physiotherapist in…in 2000……she said I wasn't doing anything to do any harm, but that because of the shoulder, I might find the push-ups difficult | targeted treatment plan |
| since the acute pain decaying became came worse since February 2020, I have seen several physiotherapists, I saw the first physiotherapist to see if there were any extra exercises I could do to increase and……and quite frankly, they didn't add anything to waht I already know about this exercise. | targeted treatment plan |
| access to physiotherapy on the National Health has become difficult. That always a long wait, but it's always been very good when I've got it. | long waiting time |
| and I've had no problem in talking to the GP. They've been constructive on 2 occasions. They've tried giving me steroid injections in the shoulder. Sadly, it doesn't seem to improve it. It does help some people steroids into the joint. Sadly, it doesn't help me. So it's a question of what I take for drugs. | targeted treatment plan |
| and quite frankly, I've had no problem in getting help when the aspirin and paracetamol didn't seem to be enough, they were happy to give me codeine. So, I now occasionally take codeine. | targeted treatment plan |
| what Arthritis Care does is put you in touch with other people who suffer from illness. Now, I don't find other people who suffer a great deal of help. | engage with the community through non-profit |
| (the professional) said you should have your name put down for replacement straight away. And only because you say you're not suffering severe pain do I say put it off. So, they've arranged it any time I found it gets to the pain, gets too bad. I ring and they put me on the list in this part. | targeted treatment plan<br>appointment and communication channels |
| I decied I had to put my name down for the operation and it's on that…I'm now on the list and in this part of the world it's a wait for about 8 months. That's very good for the health service | long waiting time |

| | |
|---|---|
| I believe that some people wait for it counts as an elective operation hip replacement. I think many people wait more than two years. A lot of our friends have gone privately. Nearly all my friends have done privately. They don't want to wait. | long waiting time |
| I have to say that contact with the GP has got very difficult since the pandemic. I don't mind doing it a talking on the telephone or doing video interviews at all, but I do want to do things where I can communicate. I don't want to have tick boxes which you choose questions that somebody else has chose for you. I dislike to tick boxes a lot because they don't allow for somebody who's a chatter box like me, who has got los to say it. It was only asking questions about the things that they don't give you answers for frequently asked questions. | targeted treatment plan<br>appointment and communication channels |
| they (Arthritis Action) were good at giving information | access information from non-profit organisations |
| I'm sure they(Arthritis Action) help people who know a little less medicine and who are little less good at coping on them on their own | access information from non-profit organisations |
| The Arthritis Care is there for people who don't understand, I think, to help them understand what's happening and how they can cope | access information from non-profit organisations |
| I started exercising in my 30s, and what I used was something called the Canadian XBX course | targeted self-management plan<br>access information from non-profit organisations |
| so my … my exercise regime floor exercises for cardiovascular I used to I…I first of all I did running up and down stairs. For a certain period of time, you're 10 minutes fight type quarter 20 minutes, something like that. And then I since moving I've just done the job down a steep hill and up a steep hill to get my break. | targeted self-management plan |

## g. Ann: Coded Transcript Excerpts

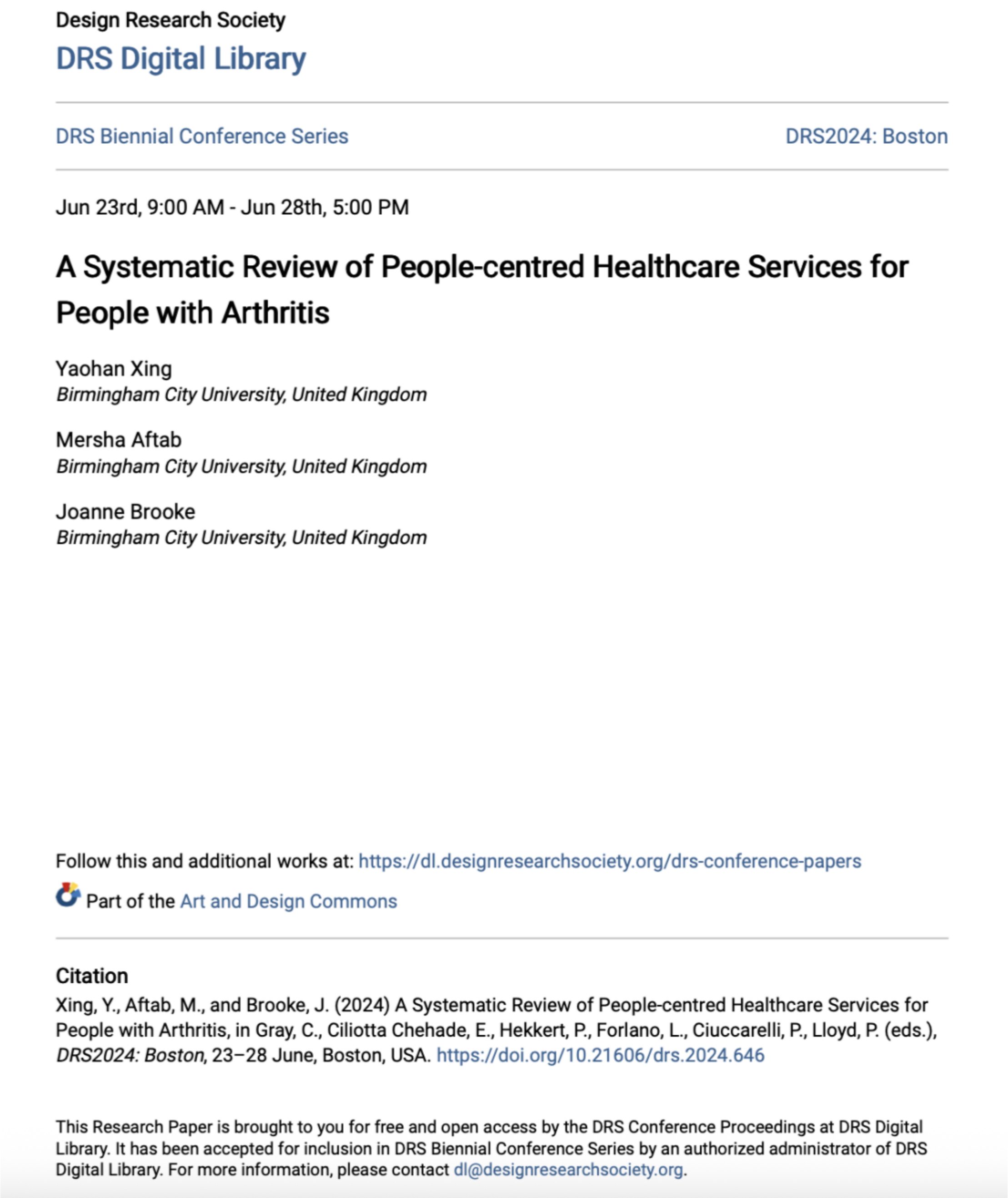
| Ann | Initial Coding |
|---|---|
| I had been referred to umm..hospital. And I had to do some exercises there water-based excercises. | targeted treatment plan |
| it's have to phone up for an appointment | appointment and communication channels |
| I can't go to the hospital anymore because they referred me a long time ago to hydrotherapy. And I…I like swimming. And I've been told that I can only do one lamp breaststroke,2…2 lamps, front crawl…... | targeted treatment plan |
| I've-I've also seen on the notice board that there's like Thai Chi, not Tai Chi but another version, different version, more gentle- qi- [attempts to say Qigong]. You might know it, [Qigong], something? It's a more gentle legs leg, more leg movement and things. | access information from NHS |
| it's a thing is because I'm not working, I'm applying them (yoga) a bit expensive | Economic factors influence self-management approaches |
| they don't check back. And I think they should. I think they should ask me how…how it's going. Because if..if they leave it. If they don't, ask again. How are they going to know if things are going well? | continuity of care |
| when I was referred to the hospital. They gave me a set of exercises which they printed off. For me so like leg stretches and umm…then, about five years later, I had got some information about going to the hosipital about a program bit…bit like the escape pain program where you it's a bit like gym based you can-you can go 3 minutes on different exercise types of equipment. and then it's not like a full gym because it's not as intense as being in the gym because you only get 3 minutes to go on each one. that was only for 6 weeks and then nothing happens after that. | targeted treatment plan<br>continuity of care |

| | |
|---|---|
| they(Arthritis Action) were doing a Help for Heroes, so people that didn't have that much money could join the membership and get her treatments done for half price. | Economic factors influence the choice of services |
| I thought that was for people that have joined up for your Arthritis Action membership and it was a little bit disappointed because it wasn't talking to people. It was just a video⋯......it's better if people doing them in person because if you just get shown and exercise and on video. You're just left to do it yourself and...and although it might be OK, but I think you get more out of being with people do it doing that. | engage with the community through non-profit organisations<br>access psychological support |
| I just I do the exercises. Well, I haven't done them for about a week now | targeted self-management plan |

# Appendix I: Published Paper Included in the Thesis

## Conference papers:

Xing, Y., Aftab, M. and Brooke, J., 2024. A systematic review of people-centred healthcare services for people with arthritis. In: Gray, C., Ciliotta Chehade, E., Hekkert, P., Forlano, L., Ciuccarelli, P. and Lloyd, P. (eds.) *DRS2024: Boston, 23–28 June*, Boston, USA.



Jun 23rd, 9:00 AM - Jun 28th, 5:00 PM

### A Systematic Review of People-centred Healthcare Services for People with Arthritis

Yaohan Xing
*Birmingham City University, United Kingdom*

Mersha Aftab
*Birmingham City University, United Kingdom*

Joanne Brooke
*Birmingham City University, United Kingdom*

**Citation**
Xing, Y., Aftab, M., and Brooke, J. (2024) A Systematic Review of People-centred Healthcare Services for People with Arthritis, in Gray, C., Ciliotta Chehade, E., Hekkert, P., Forlano, L., Ciuccarelli, P., Lloyd, P. (eds.), *DRS2024: Boston*, 23–28 June, Boston, USA. https://doi.org/10.21606/drs.2024.646

DRS BOSTON 20 DRS 24 JUNE 24 — 28

# A systematic review of people-centred healthcare services for people with arthritis

Yaohan Xing*, Mersha Aftab, Joanne Brooke

Birmingham City University, United Kingdom

*Corresponding e-mail: Yaohan.xing@mail.bcu.ac.uk

doi.org/10.21606/drs.2024.646

**Abstract**: The aim of this paper is to explore the practice of people-centred design using design thinking in healthcare for people with arthritis. People-centred design has significantly progressed in the healthcare industry, including the management of arthritis. This paper reports a systematic review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Framework. It explores the research and practice in the person-centred design of healthcare services for people with arthritis. Six databases were searched: Scopus, Web of Science, Medline, PubMed, Psych info, and Cinahl. Inclusion criteria included service for the management of arthritis, written in English and published between 2011 and 2023. A total of 27 articles were included in the review. This is part of a dual-disciplinary doctoral study illustrating healthcare services for people with arthritis and potential improvements in people-centred design guided by design thinking.

**Keywords**: people-centred; design thinking; dual disciplinary; healthcare

## 1. Introduction

Globally, populations are ageing (Cotis, 2003). More than half of the older population in the UK have more than two common long-term diseases (Age UK, 2019). Chronic diseases have replaced acute diseases as a global burden (WHO, 2015) and require management for the lifespan of the individual (Nolte and McKee, 2008). In the UK, more than 10 million people have a diagnosis of arthritis – a long-term chronic illness – and this figure is increasing daily (NHS, 2016). Healthcare is essential to public services and to support those with arthritis (Spacey, 2019).

For the past few decades, professionals in healthcare systems have focused on people-centred care (PPC) (Bala et al., 2018). PCC involves healthcare professionals applying people-centred perspectives and attributes to develop and maintain interpersonal relationships, care planning and delivery (Slater, 2006). PCC represents the transformation from the traditional biomedical model, where people who need healthcare services are the passive target of medical intervention, to a more humanised and value-based model – people who need healthcare services actively participate in decision-making and planning of their care (McCormack et al., 2015). A collaborative PCC model supports people who need healthcare services to determine better what services they need and how companies or governments provide them (Kjeken et al., 2006).

Service design supports developing innovative or improvement services to ensure they are practical, functional, ideal for customers or effective for organisations (Moritz, 2005). Services occur through the interaction between service providers and users, commonly referred to as patients, who should be at the centre of the service design process (Stickdorn and Schneider, 2011). Therefore, service design requires an accurate understanding of users (Stickdorn and Schneider, 2011). In addition, design thinking is a people-centred way of thinking (Interaction Design Foundation, 2016). The root of every innovation is human needs. Design thinking explores the needs of people and uses appropriate technology to create product value through user value (Brenner and Uebernickel, 2016). Therefore, rationalising design methods and design thinking is feasible to help a healthcare service realise people-centred innovation.

People with arthritis need to be placed at the centre of services, and care is a shared vision from both a design perspective and a health service perspective. This paper aims to systematically review the literature to confirm the key elements and descriptions of the person-centred approach in health services. An overview of people-centred services will demonstrate how services are currently defined and designed and how they are delivered. In interdisciplinary research, the systematic review results will be the foundation for people-centred innovation guided by design thinking.

## 2. Method

This paper reports a systematic review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Framework. Systematically searching relevant databases aims to identify relevant research on people-centred healthcare services. Subsequently, further selection, analysis, and literature summary are conducted to summarise the current research status of people-centred healthcare services comprehensively. The main objective of this paper is to identify the key elements and current status of health services centred around people with arthritis. The question we aim to answer is: what are the critical person-centred factors of the healthcare service for people with arthritis?

### *2.1 Search strategy*

The keywords related to people-centred services for people with arthritis are derived from previous reviews of main relevant literature. Three searches were conducted using key search terms (see Table 1, Table 2, and Table 3). The first row of Table 1 (below) covers the central idea of the research. The second and third rows contain relevant keywords used to identify the fields of arthritis and healthcare services. The fourth and fifth rows determine the specific coverage directions that must be studied. In the other two searches, Table 2 (below) and Table 3 (below), the first row also proposes people-centred research. The second row restricts the type of arthritis in healthcare services, and the third row is about determining the specific scope of research and practice. As this is an interdisciplinary research, the above search strings were entered and retrieved in the following databases: Scopus, Web of Science, Medline, PubMed, Psych info, and Cinahl. As this is a paper published in English, the inclusion criteria included service for the management of arthritis, written in English and published between 2011 and 2023.

*Table 1 First Search Terms and the Search String.*

| Search Lines | **Search Terms** | **Filtered by** |
|---|---|---|
| 1 | "people-centred" OR "patient-centred" OR "human-centred" OR "person-centred" OR "humanity-centred" | Title/Abstract/Keywords |
| 2 | arthritis" OR "Osteoarthritis" OR "Rheumatoid Arthritis" | Title/Abstract/Keywords |
| 3 | "arthritis service" OR "arthritis care service" OR "NHS" OR "National Health Service" | Title/Abstract/Keywords |
| 4 | "product" OR "process" OR "care" OR "support" | Title/Abstract/Keywords |
| 5 | "feedback" OR "improvement" OR "levels of service" OR "service levels" | Title/Abstract/Keywords |

*Table 2 Second Search Terms and the Search String.*

| Search Lines | **Search Terms** | **Filtered by** |
|---|---|---|
| 1 | "people-centred" OR " human-centred" OR " person-centred." | Title/Abstract/Keywords |
| 2 | "arthritis care" OR "arthritis" | Title/Abstract/Keywords |
| 3 | "healthcare" OR "self-care" | Title/Abstract/Keywords |

*Table 3 Third Search Terms and the Search String.*

| Search Lines | **Search Terms** | **Filtered by** |
|---|---|---|
| 1 | "people centred" OR "patient centred" OR "person centred" OR "patient preference" OR "client identified" | Title/Abstract/Keywords |
| 2 | "arthritis" OR "arthritis care" | Title/Abstract/Keywords |
| 3 | "service" OR "development" OR "value" | Title/Abstract/Keywords |

## *2.2 Inclusion and exclusion criteria*

This systematic review focuses on providing people-centred services for people with arthritis. Therefore, it is crucial to research whether there is a focus on people with arthritis and whether there is discussion or development of people-centred services. This research developed selection criteria based on expert knowledge and with reference to key papers in the relevant topic area. This review has three inclusion criteria and two exclusion criteria. If the research is about a people-centred service in English, and the target group is arthritis users, then this research can be included. If this research discusses chronic diseases, including arthritis, rather than solely focusing on arthritis itself, it is excluded. Suppose this research discusses not services or care but techniques or treatment methods; in that case, this research is excluded. There are no geographical restrictions for this review.

## *2.3 Study selection*

For each study, results related to key factors of people-centred services, delivery platform and service delivery were extracted. Numerous studies focus on the statistics and analysis of nursing issues or clinic treatments for arthritis patients. The main focus of research is to analyse existing nursing services or to identify directions for future development. Nevertheless, all studies are based on how they define people-centred services and, in addition, analyse whether services or care conform to the characteristics of people-centredness. Therefore, the study will encode the critical points of the people-centred factors they specifically analysed. In addition, it encodes the study's delivery methods and results of care and services. This data will specifically analyse the form in which people-centred services are transmitted, as well as the effectiveness and main obstacles of transmission.

## *2.4 Analytic strategy*

This review adopts the research method of theoretical synthesis. Theoretical synthesis mainly reviews a wide range of research, including qualitative research (Thomas and Harden, 2008). Information extraction and encoding will be divided into three themes in the people-centred healthcare services. The first category outlines essential elements covered by people-centred healthcare services. Regarding healthcare services, research focuses on achieving people-centred services through different elements. The second type is the platform that delivers services. The different platforms that deliver services determine the key personnel involved and the chosen technologies. It also shows which platform to choose or how to choose nursing services to achieve people-centred services. The third type displays the results of service delivery. Based on the delivery results, the feasibility of existing services for people-centred services can be analysed and evaluated. Information extraction comes from extra services that can be analysed and evaluated. Information extraction comes from extracting keywords and critical sentences matching the selected research topic. The encoding under each topic is in a parallel relationship. Consider differences in the elements of services or care. The above themes can have varying degrees of impact on service delivery outcomes.

## 3. Results

The query returned 1024 articles, and 157 articles were determined based on the selection results. After removing duplicates, 97 articles were left for full-text filtering again—the final sample identified 27 articles included in the system review (see Figure 1).

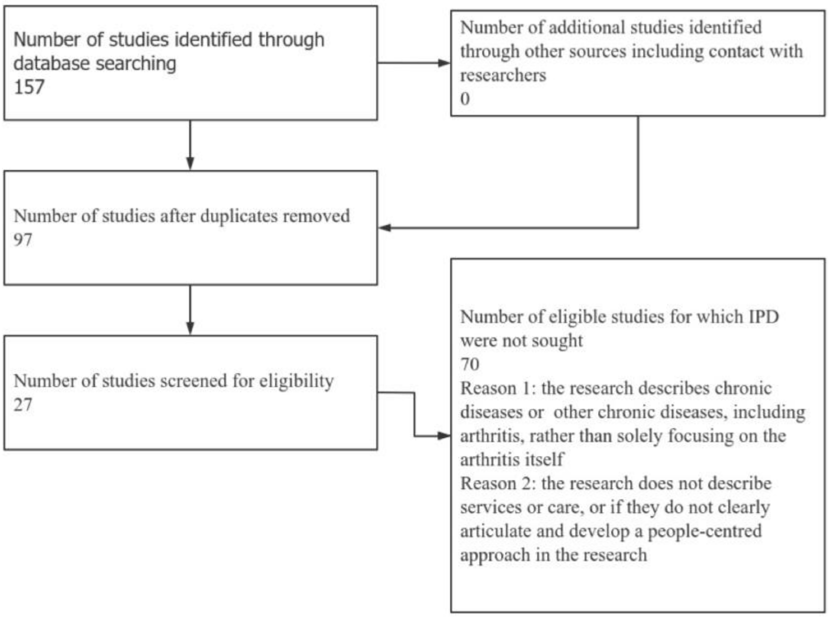


*Figure 1 Flowchart of the review process.*

### *3.1 Key elements of people-centred healthcare services for people with arthritis*

Within the papers under review, multiple themes emerged, including patient participation in decision-making, patient education, increased consultation time, use of better technology, patient classification, communication skills, social environment, personalisation, emotional needs, long-term continuous care, and strengthening coordination and accountability (see Table 4).

*Table 4 Critical Factors of People-Centred Healthcare Services*

| **Key Elements** | **Number of Papers** |
|---|---|
| Patient Participation in Decision-Making | 19 |
| Patient Education | 10 |
| Increased Consultation Time | 3 |
| Use of Better Technology | 3 |
| Patient Classification | 2 |
| Communication Skills | 6 |
| Social Environment | 6 |
| Personalization | 10 |
| Emotional Needs | 4 |
| Strengthening Coordination and Accountability | 5 |
| Long-Term Continuous Care | 7 |

Patient participation in decision-making and patient education are closely related to providing healthcare services for people with arthritis, which suggests that informing, educating, and supporting patients with arthritis to participate in their healthcare can improve utilisation and outcomes (Gagliardi et al., 2011). Among the selected studies, about 70% discussed patient participation in decision-making. In the comprehensive care approach designed for people with arthritis, patient empowerment, participation, and nursing experience prioritised (Vodopivec and Vrijhoef, 2019). Patient participation in healthcare is a means to achieve a healthcare system that responds to patient needs and values (Gagliardi et al., 2011). A helpful strategy is to motivate and empower patients to manage their lifestyle habits (Drake et al., 2023). Patient participation provides potential for targeted research and system design based on patient needs, thereby improving the patient's nursing experience and quality (Lopatina et al., 2019). Patient education is another critical point that has been repeatedly mentioned. Patient education includes all educational activities, including treatment education, health education, and health promotion (Zangi et al., 2015). The importance of patients' understanding of essential information in healthcare can improve communication between patients and clinical doctors, highlighting the importance of patient education (Andev et al., 2023). to achieve reasonable control, patients need to understand their condition and access self-management resources related to education, advice, and support for their disease (National Institute for Health and Care Excellence, 2020). Improving communication and education on arthritis and its impact on social function is crucial for promoting patient-centred care (Chou, 2017).

In addition, personalization is another keyword that has been mentioned multiple times. More than one-third of studies believe personalisation is crucial in people-centred services for people with arthritis. Personalization sometimes requires using shared decision-making tools and techniques with patients, which can help patients decide on a clear and straightforward management plan (Betteridge et al., 2016). Personalization based on the symptoms and main disease patterns of people with arthritis allows people with arthritis and experts to determine treatment goals, initiation, adaptation, and follow-up (Betteridge et al., 2016). The healthcare services guided by people-centred multidisciplinary team members adopt personalization to achieve people-centeredness (Codd et al., 2023). The impact of arthritis on each patient is personal, and all interventions should be carried out within the context of the user's unique life roles and circumstances (Codd et al., 2023)

In addition, long-term continuous care and treatment is also a focus of over one-third of research considerations. Due to administrative and financial infrastructure barriers between different institutions, the initiation of services may be delayed (De Souza et al., 2017). Many patients emphasise the continuity of care (Segan et al., 2018). The research results indicate that patient-centred care for arthritis patients should be considered a continuum (Lopatina et al., 2019). This continuity starts from the first point of contact between patients and the healthcare system, through their first appointment with experts, and continues through their long-term follow-up with the rheumatology care team (Lopatina et al., 2019). Meeting individuals' needs beyond their patient experience level is crucial for improving the sustainability of healthcare systems (Vodopivec and Vrijhoef, 2019). In addition, patients emphasise that good communication skills and a friendly environment from rheumatology nurses are crucial for them to experience being taken care of (Bala et al., 2018, cited in Sweeney et al., 2021). Open and transparent two-way communication is crucial for patients, as they want to feel welcomed and cared for (Sweeney et al., 2021). People with arthritis engage in a dialogue with compassionate experts, who can familiarise and acknowledge patients' perspectives and treatment plans rather than focus on other policy-driven external factors (Feddersen et al., 2022). This people-centered communication can make patients feel comfortable. The social environment represents how people with arthritis are identified, received, contacted, and communicated, as well as the conditions for good relationships and the establishment of a warm, calm, and friendly atmosphere (Bala et al., 2018b). The physical environment of a clinic to ensure integrity and comfort is an essential component of the social environment (Bala et al., 2018b). Increasing the duration of counselling can also be a factor in effectively improving patient satisfaction (Hall et al. 2018). The proposal to use better technologies for remote healthcare is also an essential manifestation of a patient-centred approach (Andev et al., 2023). It is necessary to classify patients in both outpatient and virtual settings, which is an effective measure to help patients quickly obtain information and receive treatment. Finally, strengthening the governance and accountability of the clinic system has also been proposed.

### *3.2 Platforms for service delivery*

Optimizing how healthcare systems meet the needs of people with arthritis is a fundamental goal and one of the key principles of people-centred comprehensive care (Vodopivec and Vrijhoef, 2019). The survey results indicate that using the "right place, right time" approach can solve customer engagement-based issues and improve customer health and satisfaction outcomes (Codd, 2023). The defined functions of this service include "right place, right time" access to provide people-centred interventions to manage participatory issues and improve the health and satisfaction outcomes of service users (Codd, 2023). The survey results indicate that this is a reliable method to address the health and broader lifestyle impacts of arthritis in clinical service provision (Codd, 2023). The people-centred nursing approach is now considered a fundamental component of nursing models, clinical guidelines, and medical safety and quality guidelines (Segan et al., 2018). One-third of people-centred services are delivered in clinical treatment. Three studies discussed remote consultation, virtual medicine, and mobile applications (see Figure 2). According to the National Health Service regulations, transformative outpatient care, including virtual consultation, will continue (Andev, 2023). In the study proposed by De Souza (2017), they simultaneously provided services to their patients through clinics, websites, and apps. Patients are interested in helping shape the services they receive during this process. They have played an essential and positive role in promoting changes in outpatient services and improving patient education/self-management (De Souza, 2017). A people-centred conceptual outpatient framework may also influence education and policy formulation by conveying more engaging, humanistic, and ethical perspectives that promote active and healthy living and reduce reliance on expert care (Segan et al., 2019).

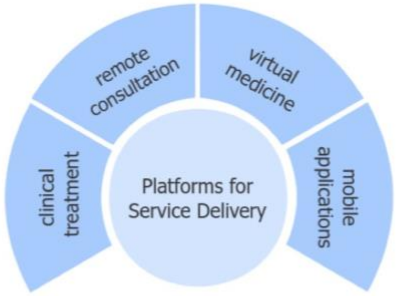


*Figure 2 Platforms for service delivery*

### 3.3 Results of service delivery

Replacing expert-led care with patient-led care can reduce the increase in adverse events. In various studies, patients reported negative reputations for general healthcare and social support and unpleasant experiences with professionals (Feddersen et al., 2022). The treatment plan may demonstrate positive effects in the limited context of evaluating its research. However, it must provide a wide range of positive outcomes to benefit patient s on a larger scale (Vodopivec and Vrijhoef, 2019). A key aspect of arthritis patient care is recognising joint inflammation, especially detecting low-grade synovitis, usually identified through expert examinations. Telephone and video appointments exclude hands-on medical examinations and may lead to decisions being made based without all the necessary information (Andev, 2023). Virtual medicine may lead to some degree of inaccurary - imperfect information can lead to imperfect treatment decisions. Therefore, it is necessary to develop strategies that provide services to patients with inflammatory arthritis based on safe, patient-centered care (Andev, 2023). In an era of longer appointment intervals, a mix of remote and face-to-face appointments, and the introduction of patient-initiated follow-up pathways, it is more important for patients to understand their disease and their clinical condition than ever before (Andev, 2023). The time and professional knowledge required for people-centred health services to function, the belief of clinical doctors and managers that patients are unable to make influential contributions, and the reputation threat to the organisation caused by sharing the organisation's shortcomings and difficulties with service users (De Souza, 2017).

## 4. Discussion

People-centred comprehensive care is a modern approach to addressing healthcare issues related to population change, the rising prevalence of chronic diseases, and limited resources (Vodopivec and Vrijhoef, 2019). To achieve this, it is necessary to develop a systematic thinking perspective, which requires keeping the entire healthcare system in mind when developing, implementing, and evaluating innovations aimed at improving healthcare. People-centred comprehensive care should not be seen as the ultimate goal but as an ongoing process to optimise the healthcare system to meet the needs of arthritis patients, all other relevant stakeholders, and society (Vodopivec and Vrijhoef, 2019). Providing people-centred care is an increasingly urgent priority in the entire healthcare field. The core component of people-centred care is the collaborative creation of care through partnerships between patients, their families, caregivers, and healthcare professionals (Vodopivec and Vrijhoef, 2019). There is a primary theme, the importance of a people-oriented approach, which clarifies the importance of professionals who respect the preferences of healthcare users (Feddersen et al., 2022).

Based on the above results, early healthcare services typically achieve the value of putting people first through clinics. In the past two years, there has been a trend towards combining remote and clinical medicine. Similarly, most research mentions involving arthritis users in their care and decision-making processes. Personalization and patient education are also mentioned more frequently. Personalization refers to customising one's treatment plan for patients. The primary purpose of patient education is to help patients understand their situation and services and to help patients better participate in services. The primary purpose of other elements is also to help users better participate in healthcare services. The service delivery results are sometimes unsatisfactory, but these elements help achieve a more people-centred service (Vodopivec and Vrijhoef, 2019). (see Figure 3)

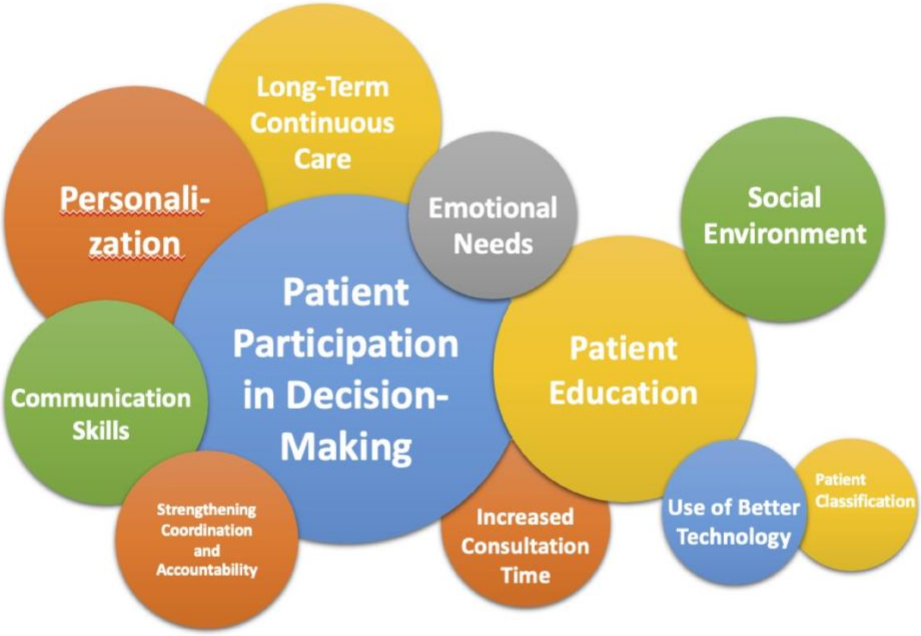


*Figure 3 Key elements of people-centred services for people with arthritis*

People with arthritis, as healthcare service users, require long-term services (Feddersen et al., 2022). The management of arthritis is limited, and treatment focuses on controlling symptoms and maintaining function (Fairley et al., 2021). For people with arthritis, creating a healthcare and broader social environment that supports symptom management and effective self-management of long-term illness is crucial (Fairley et al., 2021). Especially for osteoarthritis, there is currently no cure, and the primary purpose of treatment is to reduce joint pain and maintain mobility and quality of life (Nicolson and Holden, 2023). Although people-centred care has made significant progress in areas such as elderly care and primary healthcare, it has not met the demand in arthritis clinics (Bala et al., 2018a). The services required by people with arthritis involve different professional groups across departments (Feddersen et al., 2022). People with arthritis need care that meets their lifelong needs and expectations (Bala et al., 2018a).

The ageing population and the increasing prevalence of long-term diseases such as arthritis require healthcare to shift from acute to more sustainable care (Olsson et al., 2020). Supporting chronic disease patients in self-management and lifestyle change to achieve the best possible health and quality of life has become increasingly important (Olsson et al., 2020). Self-management is a way for people with arthritis to regulate themselves by developing strategies to adapt to their disease symptoms and treatments, enabling them to interact well with chronic diseases (Gyurcsik et al., 2013). Successful chronic disease management, including arthritis, depends on positive health behaviours (Wilcox et al., 2014; Arab et al., 2021). Enhancing self-efficacy has become a fundamental feature of many arthritis management interventions, as it has a strong relationship with healthy behaviour and health status (Brady, 2011). Self-efficacy is a person's confidence in performing specific tasks or exhibiting specific behaviours (Somers et al., 2010; Brady, 2011; Wilcox et al., 2014; Arab et al., 2021; Uritani et al., 2023).

Interventions such as health education and cognitive-behavioral therapy to improve self-efficacy are now widely recognized as effective treatment methods for improving the quality of life of arthritis patients (Gao et al., 2017). Over the past 15 years, arthritis self-efficacy has become one of the most essential psychosocial variables for understanding pain and disability in arthritis patients (Somers et al., 2010). The focus of many arthritis management interventions is to improve self-efficacy, as it has an impact on health status and treatment outcomes and can be altered (Arab et al., 2021). In people-centred services for people with arthritis, improving self-efficacy is also the ultimate result of the following elements that must be achieved. Arthritis patients can improve their self-efficacy, pain, and function through interventions such as self-management or coping skills training (Somers et al., 2010). In short, to optimize the treatment outcomes of patients, attention should be paid to reducing the severity of the disease and improving the self-efficacy level of arthritis patients (Somers et al., 2010).

## *4.1 Patient participation*

It is crucial to involve patients in nursing (Drake et al., 2023). According to a people-centred care mindset, healthcare users are considered positive and self-determined individuals (Feddersen et al., 2022). However, many healthcare users with arthritis lack consistency in their rehabilitation pathways. This can be attributed to highly specialised and complex healthcare systems and complex health and social care needs, providing services across different professional groups, departments (Feddersen et al., 2022). In service, the core position of users in this multidisciplinary-led service seems to have the most significant impact on how users perceive it and how this understanding promotes the resolution of difficulties and priorities identified by users (Codd et al., 2023). Multidisciplinary-led services emphasise participation, which is the core of service delivery (Codd et al., 2023). Patient participation and activation are initially crucial (Betteridge et al., 2016). Patients seek out possibilities themselves or have prior knowledge of their choices in the healthcare system. They have the right to adjust the intervention measures provided to meet their own needs (Feddersen et al., 2022). Professionals sometimes believe that patients with arthritis participation threatens their knowledge and expertise. However, patients have an independent complementary role that can provide a new perspective on existing problems (De Souza et al., 2017). Teamwork is essential, and mutual respect is the key. The future direction is strengthening cooperation between service providers and people with arthritis (De Souza et al., 2017). Co-decision-making represents a collaborative, interpersonal, and interdependent process in which healthcare professionals communicate with patients about potential care choices and support their decisions (Bala et al., 2018b). Joint decision-making requires interaction and participation between users and experts, mutual respect and trust, and effective exchange of knowledge and professional knowledge (Coulter et al., 2015). Shared decision-making refers to good cooperation between patients with arthritis and professionals, understanding the individual's situation, reaching consensus on nursing needs and plans, coordinating care and follow-up, sharing nursing information with other healthcare professionals, family involvement, and clarifying the individual's responsibilities and opportunities to influence their care (Bala et al., 2018b)

Co-decision-making and shared decision-making are usually not fundamentally different. They often express the importance of individual participation in health service decisions (Li et al., 2023; Zhou et al., 2024). Co-decision-making includes interactions between patients and clinical doctors (Munhe, 2012). Li et al. (2023) proposed that shared decision-making can reduce conflicts, increase patient satisfaction, and improve health outcomes. Shared Decision Making is a method in which clinicians and patients share the best available evidence when facing decision-making tasks and support patients in considering various choices to achieve informed preferences (Elwyn et al., 2012). Therefore, the core of Shared Decision making is the collaboration between professionals and patients (Munhe et al., 2012). A common and widely accepted viewpoint in bioethics is that capable adults can decide whether to seek healthcare, receive healthcare interventions, or participate in clinical research (Osamor and Grady, 2018). Joint decision-making, on the other hand, is the process by which most people define themselves and make decisions influenced by complex social networks, which may involve understanding and respecting the relationships that are important to them and incorporating the inherent values of these relationships into their decision-making process. (Osamore and Grady, 2018). (see Figure 4).

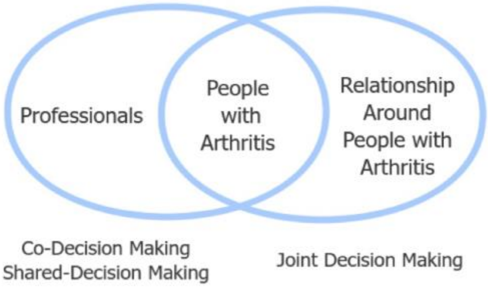


*Figure 4 Different type of decision making*

## 4.2 Patient education

Disease information is crucial during the first consultation with professionals during the diagnosis. Over time, providing a small amount of relevant information and goal setting and action plans will help patients with arthritis receive the diagnosis, maintain self-management motivation, and adhere to management plans (Betteridge et al., 2016). Interventions for self-efficacy in arthritis patients, including patient education and self-management courses, have been developed and widely used in countries with highly developed healthcare systems to improve patient health outcomes (Arab et al., 2021). Although guidelines and recommendations are crucial for informing good practices, patients' needs should always be at the forefront of clinical decision-making. It is essential to explain the characteristics of the disease after timely referral and diagnosis (Betteridge et al., 2016). Counselling should include information on emotions, lifestyle, disability level, and treatment goals (Betteridge et al., 2016). The characteristics and evaluation of strategies to involve patients in healthcare may benefit from knowledge translation methods. This knowledge synthesis aims to develop a conceptual framework for patient-mediated knowledge translation interventions (Gagliardi et al., 2011). Patients' preferences and expectations should be considered, and their current knowledge about the condition and what they hope to receive from services and experts should be established (Betteridge et al., 2016). The staff emphasised the importance of giving users a 'just right' amount of information and not overloading them (Codd et al., 2023). Patients with arthritis should have the right to request information about arthritis or treatments they are unaware of, care standards, referral pathways, and any key points of cooperation between professionals from different disciplines (Betteridge et al., 2016). Patients often believe that the information they receive is not ideal. In addition, they hope to receive education on arthritis and potential therapies to control their health, learn strategies for managing their condition, and plan for the future (Chou et al., 2017). The current research lacks information on providing patient-mediated interventions through translation alone (Gagliardi et al., 2011). Patient education aims to change knowledge, skills, and attitudes and improve patient treatment outcomes through behavioral changes (Hewlett et al., 2008). In the self-management of arthritis, the team and patients should share their professional knowledge, work together to achieve the individual goals of the patients, and be jointly responsible for solving the problems discovered by the patients (Olsson et al., 2020).

## 4.3 Personalisation

People-centred care emphasises that when meeting healthcare users, professionals must welcome personalised, respectful, and comprehensive approaches (Feddersen et al., 2022). At the same time, people with arthritis also expressed the need to use personal experiences and personalised methods as a starting point (Ammerlaan et al., 2017). Although many self-management plans emphasise patients' personal goals, structure, and content at the beginning of the plan, they are mostly predetermined, agreed upon, and based on group preferences (Ammerlaan et al., 2017). Therefore, healthcare services must focus on individual needs, preferences, and values rather than favouring healthcare systems and professional preferences (Feddersen et al., 2022). People-centred lifestyle management should consider everyone's needs and resources, and effective interventions should be tailored to the needs of patients with arthritis (Drake et al., 2023). The current research emphasizes the importance of customising program structure and content based on personal preferences and needs (Ammerlaan et al., 2017). Personalization represents recognising unique human needs and concerns, preferences and values, as well as abilities and abilities (Bala et al., 2018b).

## 4.4 Communication skills

People with arthritis are the most important source of information (Coulter et al., 2015). Therefore, personalisation depends on communication between people with arthritis and professionals, which helps establish partnerships and creates conditions for planning tailored care. Personalization is promoted when people with arthritis feel confirmed and can tell their stories, take their problems seriously, respect their experiences, use their self-knowledge, and record their personal information (Bala et al., 2018b). Through listening, encouraging, and engaging individuals in conversations with arthritis, their narratives emerge and reach consensus. Communication is considered a prerequisite for personalisation, shared decision-making, care planning, and empowerment processes and has received considerable attention in the context of people-centred care (Bala et al., 2018b). People-centred care provides personalised support, and patients typically perceive their voices as valued in medical consultations and make decisions based on personal preferences (Brkic et al., 2021). Establishing the patient's functional and valuable life goals is considered necessary, meaning they cannot do as well as they wish. Research has shown that individuals have significant differences in management needs (Geenen et al., 2018). A basic assumption for initiating self-management interventions is that when the intervention measures are customised according to individual needs and preferences, they will be more motivated, persistent, and benefit more over a more extended period (Ammerlaan et al., 2017).

## 4.5 Emotional Needs, Social Environment and Long-Term Continuous Care

Healthcare services aim to maintain or increase healthcare users' biopsychosocial functions, and increase participation in society (Feddersen et al., 2022). People with arthritis hope to be treated as individuals rather than a series of problems being solved (Codd et al., 2023; Feddersen et al., 2022). People with arthritis need to help develop skills and confidence to manage their ‘changed selves better’ and acknowledge how multidisciplinary-led services can promote accepting and changing arthritis life (Codd et al., 2023). In addition, many patients with arthritis emphasise the importance of seeing experts and facilitating access to medical consultation in arthritis care (Segan et al., 2018). There is a lack of communication and coordination among professionals in providing information about treatment and care (Feddersen et al., 2022). In addition, long-term support is a carefully considered feature of this service (Codd et al., 2023). Initial and continuous access to care are the two challenges that participants are most concerned about (Lopatina et al., 2019). Other priorities related to follow-up care include sufficient consultation time, proximity of care, continuity of care, and timely referral to experts (Segan et al., 2018). A welcoming and familiar nursing environment that allows for undisturbed conversations during meetings is considered engaging, safe, and reinforcing (Bala et al., 2018b). Investigating people-centred strategies and providing interventions tailored to different nursing environments, patient groups, economies, and healthcare systems can provide novel and practical solutions (Chou et al., 2017).

## 5. Conclusion

In summary, people-centred healthcare services are mainly represented by five related and partially overlapping fields: social environment, personalisation, shared decision-making, empowerment, and communication (Bala et al., 2018a; Bala et al., 2018b). The first four characteristics represent increasingly high-level people-centred care, while communication is considered to be mixed with the other four characteristics (Bala et al., 2018a; Bala et al., 2018b). A core prerequisite for achieving this people-centred outcome is understanding what is truly important to patients in nursing (De Silva, 2014). Although the importance and potential benefits of patient participation in health planning, research, and system design have been discussed for decades, patient participation in designing and redesigning healthcare systems has often been limited to passive participation (Lopatina et al., 2019). The concept of people-centeredness has existed for a long time, but existing organisations still have not systematically used it. If we cannot practice it ourselves, we cannot discuss people-centred care (Vodopivec and Vrijhoef, 2019). Although there are many difficulties in achieving people-centred care for people with arthritis, professionals must work alongside patients to look for a better future.

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About the Authors:

**Yaohan Xing**, PhD candidate at Birmingham City University's Faculty of Art, Design, and Media, is a proficient design researcher and interdisciplinary scholar, tackling real-world challenges in service-centred domains through innovative design methods and design thinking.

**Dr. Mersha Aftab** is Course Director for MA Design Management Course and a senior lecturer in Design Management at Birmingham City University. Her research interest is putting design as a strategic lead and proposing human-centered innovation. As the lead for a design-led transformation group, Mersha uses empathy to connect and integrate disciplines to create a valuable contribution to transformations.

**Professor Joanne Brooke** is Director of the Centre of Social Care, Health, and Related Research at Birmingham City University. Joanne is an experienced health researcher, including the development of evidence-based frameworks to support the implementation of healthcare initiatives in prison.