Patient Activation in Inflammatory Arthritis

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Abstract

Patient activation covers the skills, abilities and behaviour that contribute to how able and willing someone is to take an active role in managing their health. Patient activation is currently often assessed using the Patient Activation Measure (PAM). While there is growing interest in patient activation, there has been limited research about it within inflammatory arthritis (IA). Consequently, three studies were conducted to address these knowledge gaps and better understand patient activation. The findings of these studies were synthesised into a framework reporting factors related to patient activation within inflammatory arthritis that may be amenable to intervention.

A systematic literature review reported that interventions targeting patient activation in long-term conditions can be effective but that no specific format or style of delivery was more effective than others.

Qualitative interviews conducted at two timepoints explored how patients who were skilled at managing their health considered patient activation to incorporate many of the ways that they already self-managed. This included knowing what techniques (both pharmacological and non-pharmacological) suited them and reduced the impact of their symptoms, and when and how to seek appropriate help, including navigating the National Health Service (NHS). They identified that the PAM did not always reflect the fluctuating nature of their conditions.

A survey study administered at two time points reported associations with PAM scores and a range of clinical, demographic and psychosocial variables across a sample of rheumatology patients in England. Regression analysis confirmed that self-efficacy, health literacy, illness beliefs and health locus of control significantly contributed to variance in PAM scores.

Longitudinal, mixed-methods data indicate that patient activation is more than the items listed in the PAM. It incorporates several factors including health literacy, illness beliefs, self-efficacy and health locus of control underneath a broader umbrella of

skills and abilities. Training healthcare professionals about the nature of patient activation in rheumatology may contribute to conversations being more collaborative and equip them with the skills to effectively support patient activation.

List of abbreviations and acronyms

ACR	American College of Rheumatology
AMED	Allied and Complementary Medicine Database
AS	Ankylosing Spondylitis
ASMP	Arthritis Self-Management Programme
BIPQ	Brief Illness Perception Questionnaire
BMI	Body Mass Index
BRI	Bristol Royal Infirmary
BSR	British Society of Rheumatology
CCG	Clinical Commissioning Group
CCH	Co-Creating Health
CCM	Chronic Care Model
CDSMP	Chronic Disease Self-Management Programme
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COPD	Chronic Obstructive Pulmonary Disorder
CS-PAM	Clinician Support for Patient Activation Measure
DMARD	Disease-Modifying Antirheumatic Drugs
EPP	Expert Patient Programme
EULAR	European League Against Rheumatism
GP	General Practitioner
HAQ	Health Assessment Questionnaire
HLOC	Health-related Locus of Control
HLQ	Health Literacy Questionnaire
IA	Inflammatory Arthritis
JIA	Juvenile Idiopathic Arthritis
MSK	Musculoskeletal
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NLM	National Library of Medicine
NPP	Normal Probability Plot
NRS	Numerical Rating Scale
NSAIDs	Nonsteroidal Anti-Inflammatory Drug

NTIS	National Technical Information Service
PACIC	Patient Assessment of Chronic Illness Care
PAM	Patient Activation Measure
PROM	Patient Reported Outcome Measure
PRP	Patient Research Partner
PsA	Psoriatic Arthritis
RA	Rheumatoid Arthritis
RASE	Rheumatoid Arthritis Self-Efficacy Scale
RCT	Randomised Controlled Trial
SLE	Systemic Lupus Erythematosus
SPSS	Statistical Package for the Social Sciences
VIF	Variance Inflation Factor

List of Figures and tables

List of tables

List of Figures

Contents

Chapter 1: Introduction to the thesis

This thesis addresses patient activation and its relevance to patients managing inflammatory arthritis (IA). The thesis reports three studies related to patient activation. Firstly, a systematic review of the literature regarding patient activation interventions in randomised controlled trials, delivered to participants with long-term physical health conditions. Secondly, a qualitative interview study at two time points investigating patient perceptions of patient activation. Finally, a survey of people living with IA in the UK, administered at two timepoints, to identify their levels of patient activation and the association of patient activation with a range of clinical, demographic and psychosocial variables. These findings are synthesised into a framework describing aspects of patient activation that may be amenable to intervention.

This chapter introduces the thesis, briefly describes inflammatory arthritis and its management and some of the aspects of self-management. The chapter provides the rationale, structure, aims and objectives of the thesis. Lastly, the chapter introduces the researcher and the patient research partner.

1.1 Inflammatory arthritis

IA is an umbrella term that describes several long-term conditions including rheumatoid arthritis (RA), psoriatic arthritis (PsA), ankylosing spondylitis (AS) and systemic lupus erythematosus (SLE) (Versus Arthritis, 2019). Symptoms often include pain, fatigue, stiffness and psychosocial issues such as disturbed sleep and psychological distress (Gettings, 2010; Hill, 2006). These conditions can impact people in a range of physical and psychosocial ways to a varying degree and commonly require significant life adaptations. The consequences of IA often include reduced mobility and unpredictable fluctuations or “flares” in disease activity and symptoms (Homer, 2005). IA can be associated with lower life expectancy and increased rates of disability (Gonzalez et al., 2007).

Diagnosing IA depends on the precise condition and involves classification against specific criteria. For RA, the criteria are the American College of Rheumatology (ACR)/European League Against Rheumatism (EULAR) classification criteria (Aletaha *et al.,* 2010). For PsA, diagnosis is confirmed using the Classification Criteria for Psoriatic Arthritis (Helliwell and Taylor, 2005). AS is diagnosed using the New York Criteria (van der Linden, Vaulkenburg and Cats, 1984) and SLE diagnoses are confirmed using the European League Against Rheumatism/American College of Rheumatology Classification Criteria for Systemic Lupus Erythematosus (Aringer *et al.,* 2019). Diagnosis is generally conducted or confirmed by a rheumatologist. IA is managed in secondary care with specialist rheumatology teams. These often focus on managing the physical symptoms and reducing disease activity and underlying disease damage (Gettings, 2010; National Audit Office, 2009). Additional psychosocial support to help individuals self-manage their condition is increasingly being offered in specialist services, however, access to this type of support is often inconsistent across the country (House of Commons Committee of Public Accounts, 2010).

1.2 Methods of managing inflammatory arthritis

There is currently not a cure for IA. However, there are pharmacological and non-pharmacological treatments available to manage the symptoms and reduce the impact of disease on patients (National Institute for Health and Clinical Excellence Guideline, 2009). This includes aiming to reduce pain, increase mobility and physical function, and to support people to live well and cope with their long-term condition. Multiple good practice recommendations for care and patient education propose that people receive personalised one-to-one care to effectively manage their condition (Zangi *et al.*, 2015; Kennedy *et al.*, 2005). Patients should also receive care with a multidisciplinary approach in order to manage their IA and this secondary care is generally delivered in rheumatology departments. This can include support from occupational therapy, physiotherapy, podiatry and specialist nurse care as well as maintaining links and monitoring from primary care.

1.2.1 Pharmacological treatment for IA

Pharmacological treatment for IA commonly includes non-steroidal anti-inflammatory drugs (NSAIDs) for pain relief based on patients' requirements and to complement prescribed treatment regimens (Crofford, 2013). Disease modifying anti-rheumatic drugs (DMARDs) are commonly used as an initial response to IA symptoms (NICE, 2009). They are often used in conjunction with corticosteroids taken either orally or injected directly into joints to target them specifically (NICE, 2009). Biological therapies are a specific type of DMARD that aim to reduce tumour-necrosing factors that contribute to inflammation (Arthritis Care, 2017). They are used when other DMARDs are not effective. Recently biosimilar medications (i.e. a biological medication developed once the patent on the original biologics expires) have been introduced and many patients have swapped to biosimilar medications to cost-save for the NHS (Manova et al., 2018).

1.2.2 Non-pharmacological support for IA

Non-pharmacological support for IA includes the wider multi-disciplinary team, and often pertains to broad psychosocial challenges to support people to live well with IA (Luqmani *et al*., 2006; Luqmani *et al.,* 2009). These approaches aim to improve outcomes related to disability and function, mobility and overall quality of life (NICE, 2009). Nurse-led care is common within rheumatology and includes providing education and psychosocial interventions as well as monitoring biomarkers and physical health outcomes (Ndosi et al., 2011). While people living with IA often experience elevated levels of psychological distress (Gettings, 2010), there are rarely resources provided for psychologists to be based in specialist rheumatology departments. A large proportion of non-pharmacological support to help people to live well with inflammatory arthritis includes self-management support and/or patient education. This will be discussed in more detail in chapter 2. Patients thus need to be sufficiently activated in order to engage in managing the complexities of their IA.

1.2.3 Thesis aim

To develop a framework to describe factors that may be amenable to intervention in patient activation in the context of inflammatory arthritis.

1.2.4 Thesis objectives

- To identify the evidence surrounding patient activation interventions in long-term physical health conditions.
- To understand how skilled self-managers with IA conceptualise patient activation.
- To understand how skilled self-managers at different levels of activation perceive and enact patient activation over time.

- To explore longitudinal changes to patient activation (measured using the PAM), and its associations with related constructs in patients with IA.
- To develop a framework to describe patient activation in patients with IA.
- To identify factors that influence patient activation and may be amenable to intervention.

1.3 Researcher perspective

1.3.1 Researcher experience

The researcher has experience working with people with a range of long-term conditions to support them to self-manage. Some of this was with people with rheumatic conditions but initially the researcher had only a limited amount of knowledge and experience within rheumatology. This has increased following exposure to literature, relevant conferences, observing clinical staff and meeting patients. Working closely with a patient research partner (PRP) has brought additional context to the researcher's understanding of life with rheumatic conditions. The researcher's perspective is also formed by life with a long-term health condition and the challenges this poses.

1.3.2 Statement of epistemological position

Research is informed by the perspectives held by researchers on what we can know (ontology) and how we can know it (epistemology) (Braun & Clarke, 2013). Clarifying one's position explicitly is a research strength as it provides context for the researcher's position and how it shaped the research (Meyrick, 2006).

The researcher takes a pragmatic approach to this research. Researchers who are pragmatists understand truth and reality to be whatever is appropriate for the study needs and research questions (Dures et al., 2011). This approach does not reject epistemologies as a whole, instead it suggests that considering appropriate methods to generate useful data is more valuable than limiting oneself to a single methodological viewpoint (Morgan, 2007). Research exists and is conducted in social contexts but there is no commitment to a single perception of reality, allowing perceptions of reality to be singular or multiple dependent on the needs of the study (Cresswell, 2003; Creswell and Clarke, 2011). Research exists and is conducted in social contexts but there is no commitment to a single perception of reality, allowing perceptions of reality to be singular or multiple dependent on the needs of the study (Cresswell, 2003; Creswell and Clarke, 2011). This is a third option compared to the realist approach to research (representing a single, knowable and accessible reality) typically captured using quantitative research or a more relativist model of reality (where multiple realities exist dependent on context, interpretation and position) typically used in qualitative studies (Clarke and Braun, 2013).

Mixed-methods research is often pragmatic as this position is helpful for the flexibility required to approach 'real world' research questions with appropriate methods (Johnson and Onwuegbuzie, 2004). This allows the research question to be more of a consideration than the lens through which the phenomena are studied (Hanson *et al.,* 2005). It is not that epistemologies are denied consideration in pragmatic research, rather the priority and intention remain focussed on developing useful knowledge appropriate to the needs of the research. Given that the studies included in the thesis include both qualitative and quantitative research methods, the research questions for these studies could not be fully answered with a realist or relativist epistemology alone.

Consequently, the mixed-methods approach throughout the thesis suits the pragmatic position held by the researcher. The studies and thesis benefitted from designs that valued flexibility, practicality and consideration for the impact of the research (Dures et al., 2011).

1.4 A note on language throughout the thesis

It has been acknowledged that referring to people with IA as "patients" places their condition at the forefront of their identity when discussing them. Instead, the accepted way to refer to them is as "people with IA". The term patients will be used throughout this thesis for the purpose of clarity and brevity. This will help to distinguish between people with rheumatic conditions and the wider population. However, the researcher is aware of the issues with this terminology. The use of the word "patient" does not reflect a lack of concern for recognising people's holistic identities, of which their diagnoses are just one part.

1.5 Patient involvement in research

The research design, data collection and analysis has been supported by the work of a patient research partner (PRP). The PRP provided input about living with a rheumatic condition and considered research with reference to this. Evidence demonstrates that patient and public involvement in health research contributes to studies meeting recruitment targets, and that it also strengthens the findings (Ennis and Wykes, 2013; Ocloo and Matthews, 2016). Patient involvement specifically in rheumatology has identified substantial barriers to living well with rheumatic conditions that were under-represented in research (Hewlett *et al.,* 2006). Therefore, there is a clear benefit to including patients in research. It was anticipated that, over the course of the PhD, working with a PRP who had experiential knowledge of the topic would result in more specific feedback and contributions to the project.

During the PhD, the PRP attended supervisory team meetings, contributed to the planning of studies and reviewed the findings and analysis. He was involved in the dissemination of the findings of the studies about patient activation in inflammatory arthritis. Members of the supervisory team and the researcher provided any necessary training and contextual information to support the PRP to carry out his role, and his involvement in specific studies is noted in the pertinent chapters.

1.6 Thesis structure

To achieve the aims and objectives set out above, this thesis is structured into ten chapters. The next two chapters are background chapters reviewing the literature and contextual frame in which the research is set. Five chapters are dedicated to the methods and findings of three studies investigating patient activation in long-term conditions, specifically inflammatory arthritis. Study one is a systematic review of the existing research on the effectiveness of interventions targeting patient activation in long-term conditions, and has a single chapter dedicated to it. Studies two and three are longitudinal studies and combine the data analysed at each time point into a single results chapter for each study. The thesis ends with two chapters that discuss the findings and contributions to knowledge as well as the proposal of a framework to describe patient activation in inflammatory arthritis, with recommendations for further research and implications for practice as a result of this development.

Chapter 2: Approaches to health and healthcare

The first section of this chapter reviews how health and healthcare have been conceptualised previously. This will be followed by a summary of a range of models of both health and healthcare that are relevant to the concept of patient activation that is investigated in the next chapter.

The way that health and healthcare have been understood has evolved over time. There has been a shift away from a paternalistic approach that viewed people as passive recipients of care targeting only the biomedical challenges. Instead, research has led healthcare to take a more holistic approach that sees people as involved in managing their own health in collaboration with healthcare professionals. The changes of status and responsibilities for patients are most evident for people with long-term conditions.

2.1 The biomedical model

The conceptualisation of illness has previously focused on the biomedical model, which understood experiences of illnesses as being caused by disease or physical dysfunction. This model placed disease as the singular cause of illness with all experiences of illness and symptoms having an underlying pathophysiology (Wade and Halligan, 2004). The model's aim was a return to health, defining this as the "*absence of disease*". If the cause of disease was removed, then a person would be healthy and no longer experience symptoms related to that cause. This approach was applied universally and did not account for whether ill health was acute (short-lived) or chronic (long-term).

The biomedical model had an assumption of dualism, in which the body and consciousness are separate entities (Albery and Munafo, 2007). Therefore, treating physical health challenges did not require consideration of the mind. The psyche was presumed to be independent from the experience of physical health. It was expected that compliance with medical routines would lead directly to a positive outcome regardless of other factors that could contribute to ill health (Engel, 1977). The use of the term "compliance" here reflects some of the developments in terminology over this time, particularly related to patients and their uptake of prescribed regimens. This implies that patients are expected to comply with the recommendations provided to them. There are similar implications with the term “adherence”, suggesting that a patient will continue to follow the instructions of a healthcare professional providing that they have been informed of the details, justification and guidance (Treharne *et al.*, 2006). A shift in terminology towards referring to “concordance” or “collaboration” has begun. This reflects agreement and communication between patients and healthcare professionals and the value of patients being involved in determining the direction of care (Treharne *et al.*, 2006).

The biomedical model of health had consequences for healthcare systems and care delivery. These consequences included healthcare being a very paternalistic practice as the focus of consultations revolved around identifying the underlying disease; this relied on the biological expertise of healthcare professionals. They were viewed as the experts and providers of information, with little opportunity for patients to contribute to the decision-making process. Both patients and healthcare professionals expected healthcare professionals to lead consultations and be responsible for informing patients of both the diagnostic process and any treatments required (Engel, 1980). This approach did not empower patients to feel involved and engaged in their own care and was not collaborative in any way.

2.1.1 Criticisms of the biomedical model

The biomedical model has since been heavily criticised for its reductionist conceptualisation of illness and for the limitations in accounting for the wide variety of experiences of illness (Wade and Halligan, 2004). There was a clear need to consider other factors (both intrinsic and extrinsic to patients) that contributed to health. This model also assumed that healthcare encounters focused on acute conditions that had the potential to return to health. In comparison, long-term conditions that did not always lead to a cure needed a different understanding. The lack of consideration of the contributions of social, psychological or behavioural factors to the experience of illness positioned patients in a passive role, or a “victim of circumstance” (Wade and Halligan, 2004). This denied them the opportunity to contribute to the management of their condition. This model of understanding illness may have been more appropriate in circumstances when someone was acutely ill but was less helpful in capturing peoples' experiences in living with long-term conditions or unexplained illnesses. Wade and Halligan (2004) also described a need for a model that accounted for personal context and that recognised the role that patients and their free will played in the management and outcomes of their health.

2.2 Moving toward patient-centred care: the biopsychosocial model

Due to these criticisms, the biopsychosocial model sought to describe the experience of illness differently, encompassing social and psychological factors which can contribute to the presentation of an illness (Engel, 1977). The assumption was that these many factors would interact with each other and contribute to the dynamic and complex experience of health. This more holistic approach to health is considered more flexible and comprehensive (Albery and Munafo, 2007). However, since this model's development, suggestions have been made that it is not possible to know all the factors that contribute to the presentation of an illness and these may be even broader than biopsychosocial aspects (Borrell-Carrio, Suchman and Epstein, 2004). Another potential criticism of this model is that there is no guarantee that a healthcare professional working to this approach will (or should) give equal consideration to all three aspects (bio-, psycho-, and social) of health (Benning, 2015).

The biopsychosocial model was initially described with relation to psychiatric conditions, but has since been applied to physical health conditions (Engel, 1980). While the biological aspect often continued to take precedence, Richter (1999) recommended that healthcare professionals consider that the psychosocial difficulties people experience remain as important as biomedical factors in someone's health care. This emphasised the responsibility of healthcare professionals in engaging patients to co-operate in behaviour change to improve their condition. This implies a continuing primarily passive role for patients (Engel, 1980).

2.3 The Chronic Care Model

The Chronic Care model (CCM) (Wagner, 1998) retained a biopsychosocial focus and is a model of healthcare and the context of care delivery. The CCM proposed that healthcare systems are often designed to provide acute care and that long-term conditions are often managed sub-optimally. A large proportion of healthcare remains focused on supporting people with long-term conditions and NHS England has estimated that 70% of budgets for acute services were used by people with long-term conditions (NHS England Care Quality Commission, Health Education England and Public Health England, 2014). Given that the resources required to help people manage long-term conditions is so great, the CCM initially proposed that outcomes would substantially improve if clinical systems were adapted to best suit these patients and their needs (Wagner, Austin and Von Korff, 1996). Therefore, the chronic care model described how three separate, interrelated "galaxies" were important for providing care (Wagner, 1998):

- the community, with the resources available to it;
- the healthcare system;
- the provider organisations.

Between these three galaxies, Wagner (1998) reported six aspects of healthcare that were deemed essential to providing effective care for long-term conditions:

- Community links and resources.
- Healthcare organisations with strong support for self-management and prioritising the care of long-term conditions (Bodenheimer, Wagner and Grumbach, 2002).
- Self-management support that reflected the role of patients in solving problems related to their health and having the practical tools they require to care for themselves (Bodenheimer, Wagner and Grumbach, 2002).
- A delivery system design that included a separation between acute and long-term care services and staff who were ready to support people to self-manage (Bodenheimer, Wagner and Grumbach, 2002). This focus on wider systemic improvements was particularly embraced as part of the Co-Creating Health project (Wallace *et al.*, 2012) which will be discussed in more detail in section 2.1.6.
- Decision support that was prompt, clear and pitched at a level to avoid overwhelming individuals.
- Clinical information systems that provide feedback to patients and healthcare

professionals on outcomes, reminders and contribute to decision-making in a collaborative way (Bodenheimer, Wagner and Grumbach, 2002).

The CCM aimed to be integral to the way that care is delivered to people with long-term conditions. There is evidence for improved care following interventions based on this model, in terms of improved biomedical outcomes (Coleman *et al.*, 2009). A crucial dimension of the CCM was self-management support (Glasgow *et al.*, 2005a).

2.4 Self-management

The shift to increase the responsibility of willing patients increased awareness of self-management. Self-management can be considered from two perspectives. The first is that it is a series of skills, tools and approaches someone can use to manage their health (Bodenheimer and McGregor, 2005). The second understands self-management to be the process of shifting the dynamics of the patient-healthcare professional relationship to be one of equals where they make decisions together and bring different skills and expertise to the partnership (De Silva, 2011; Bodenheimer and McGregor, 2005.

Self-management focuses on the patient as someone actively involved in their own care (Bandura, 1997). It includes the activities that people do for themselves to maintain their health and wellbeing. This incorporates meeting their emotional and social requirements and preventing further problems related to their health (Department of Health, 2005). Self-management is a major focus in healthcare policy and in the development of care pathways for long-term conditions (Ong, Jinks and Morden, 2011). A key concept related to self-management is self-efficacy, which will be discussed in detail in section 2.7.2. Self-efficacy is defined as:

> *"People's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives."* (Bandura, 1994).

Healthcare services slowly began to move towards people becoming more actively involved in their care. The Nursing and Midwifery Code of Practice noted that healthcare professionals have a duty to *"recognise and respect the contribution that* *people can make to their own health and wellbeing"* and *"encourage and empower people to share decisions about their treatment and care"* (Nursing and Midwifery Council, 2018, section 2). The move towards personalised care intended for all strands of healthcare to provide support for people to manage their health (Hibbard and Gilburt 2014). This support reflected the conceptualisation of self-management to include the new style of collaborative relationship between patients and healthcare professionals working as equals (De Silva, 2011). There was an expectation that patients would take increased responsibility for managing their condition within and outside of consultations (Barlow *et al.*, 2002). Self-management offered the opportunity for healthcare professionals to work more holistically on aspects of health beyond medical management, and to consider behaviours, social roles and the emotional impact of a long-term condition (Lorig and Holman, 2003).

The growing acceptance of the biopsychosocial model gave people with long-term conditions a role as experts in living with their diagnosis. Healthcare policy and providers expected people to develop skills to manage their health and become more involved in making decisions about their condition (Hibbard *et al.*, 2004), to the point that the NHS Constitution (NHS England, 2015) provided a list of responsibilities for patients as well as their rights. By the beginning of the 21st century, self-management interventions were designed to support people to self-manage using a biopsychosocial understanding of ill health.

2.5 Flagship self-management-based interventions

The initial steps towards a more person-centred approach to managing care for long-term conditions advanced substantially with the introduction of self-management programmes. These often sat outside of usual service provision, not part of routine healthcare but an add-on (Lorig and Holman, 2003). These interventions were often multi-week, group-based and sought to increase self-efficacy. This was typically achieved through group members watching peers achieve their goals and increasing their confidence in self-management. In this way, the peers modelled positive self-management behaviours to other group members. This would increase other group members' belief that they too could hold greater control over their health (Barlow *et al.*, 2002; Abraham and Gardner, 2009).

Some of the seminal early self-management programmes were the Chronic Disease Self-Management Programme (CDSMP) and the Arthritis Self-Management Programme (ASMP). These were developed and conducted in Stanford by Kate Lorig and her colleagues in the late 1990s (Lorig *et al.*, 2001) and largely recruited people with arthritis in the first few trials (Vadiee, 2012). They focused on providing information around topics such as sleep, relaxation, noticing and managing cognitions around health, dealing with emotion and problem-solving strategies. The groups allowed the opportunity for discussions aimed at group members learning from one another and validating their concerns and challenges as legitimate (Lorig *et al.*, 2001). The overall aim was to give group members the skills and confidence to manage their conditions and lead them towards improved problem-solving and decision-making to make best use of resources to collaborate with healthcare professionals and change health-related behaviours (Grover and Joshi, 2015). These interventions were revolutionary because of their focus on building self-efficacy with a view to promoting behaviour change. This was an alternative to focusing on providing information and assuming participants would make changes as a result. The link between participants' knowledge of what they should do and the behaviour they subsequently carried out was strengthened with the increase in self-efficacy.

There is evidence to suggest that as well as contributing to improved outcomes following participation in self-management programmes (Lorig, Ritter and Plant, 2005), increased self-efficacy contributes to people feeling more in control over their health (Dures *et al.*, 2016a). This is in line with Bandura's model of self-efficacy (Bandura, 2004; Griffiths *et al.*, 2005), where group members modelled helpful changes to their peers to bring about the anticipated increases in self-efficacy as an outcome of the programme.

Participants who completed the CDSMP and ASMP programmes have reported a substantial increase in their knowledge about their condition, both through the group itself and after feeling empowered to seek out additional information about their condition (Wilson, Kendall and Brooks, 2007). What is important to note is that the evidence suggested that CDSMPs did not contribute towards significant changes in physical symptoms and levels of disability, but rather left people feeling less distressed and more confident about coping with their condition (Lorig *et al.*, 2001).

Common limitations of group-based interventions apply when critiquing the CDSMP and ASMP (i.e., confidentiality issues between group members and the risk of primarily recruiting those who are already very engaged). Additionally, the lack of impact on physical symptoms was viewed as a limitation by Lawn and Schoo (2010) in their review of approaches to self-management. They also recognised that this method did not have an impact on the actions and approach of healthcare professionals. A greater cultural shift towards collaborative self-management was required as an encounter with an unsupportive healthcare professional had the potential to contribute to setbacks in someone's self-management abilities and confidence, with poor self-management support reducing the effectiveness of interventions.

The outcome of these initial programmes led to self-management based interventions of this type becoming widespread. This included interventions in a variety of contexts, both generic and condition-specific (Lawn and Schoo, 2010). These interventions typically involved a psychoeducational focus with a structure inspired by Kate Lorig's CDSMPs.

One such intervention was the Expert Patient Programme (EPP), which was developed in the UK in partnership with the Department of Health during 2002. It was taken up on a substantial scale, with 98% of primary care organisations participating (Vadiee, 2012). The intention of this initiative was to introduce this form of self-management intervention into the NHS to understand how acceptable and successful it was within a UK context (Kennedy, Rogers and Gately, 2005). This entailed patient tutors, with a range of health conditions, leading 6-week standardised programmes for their peers based on improving self-management skills. These skills included managing medical consultations with preparation, and practical solutions to set priorities for discussions, communicating about their conditions and goal setting (planning small changes for the week ahead that adhered to specific guidelines to make them more likely to be achievable) (Wilson, 2008). The focus was not to improve the symptoms of patients' conditions but rather to improve life with the condition. These patient tutors were volunteers who had undergone a criminal record check and been interviewed to ensure suitability for the opportunity. They received four days of training in how to deliver the course, the ethos of the programme and how to facilitate groups, and were required to commit to contributing to two programmes each year. The rationale behind this was that group participants were more likely to learn from someone like themselves who could become a role model to group members (Wilson, 2008).

Like the CDSMPs, the EPP provided the opportunity to practise problem solving, action planning and relaxation strategies such as breathing and imagery exercises with the group. Information was provided as part of the programme. However, group members reported that this information was often either not sufficiently thorough or to a level of detail that was beyond what participants felt they needed (Wilson, Kendall and Brooks, 2007). This implies a challenge of presenting a level of detail and complexity that was appropriate for a group of varying abilities.

While the lay-led aspect of the EPP and their personal stories were valuable features of the programme (Barlow, Bancroft and Turner, 2005), feedback provided by participants suggested that having a healthcare professional present for parts of the intervention would offer the opportunity for knowledge provision (Turner *et al.*, 2015). However, General Practitioners demonstrated limited engagement with the EPP (Barlow, Bancroft and Turner, 2005; Blakeman *et al.*, 2006). These issues may have limited discussion if group participants wanted to discuss something of risk or requiring complex condition-based knowledge that went beyond the skills of the lay tutor or the rigid, pre-planned programme manual (Wilson, 2008).

Like the findings of the CDSMP, the EPP demonstrated significant improvements in self-efficacy, participation in activities and social roles and psychological wellbeing. Similarly to the CDSMP, there were no significant improvements at follow-up in pain, energy levels or usage of health services (Wilson, 2008). The EPP began to bring the issue of generic versus condition-specific interventions into the consciousness of the UK healthcare system. Overall, there has been mixed opinion on whether condition-specific, rather than generic, approaches to self-management support are better. Feedback from the EPP suggested that participants found it beneficial to discuss condition-specific information and the shared understanding that came from having similar experiences with their conditions (Ngooi and Packer, 2017). This indicates that while generic programmes have benefits, condition-specific forms of support can be one way of reducing the challenges involved in pitching the level of educational detail appropriately. This information can be more focused for the relevant condition (De Silva, 2011). Rogers *et al.* (2005) conducted a national evaluation of the EPP and identified that many participants would prefer condition-specific self-management support to obtain their preferred level of detail in the education sections. Course materials for specific long-term conditions would also benefit the delivery of the EPP (Vadiee, 2012).

Recruiting participants from secondary care for the EPP proved to be challenging. The evaluation report suggested that work was needed to encourage healthcare professionals to engage with the lay-led philosophy and approach to care, as well as to engage NHS trusts to implement such programmes (Kennedy, Rogers and Gately, 2005). It was apparent that systemic change was required, as well as training healthcare professionals to effectively work with expert patients and work collaboratively to improve care for people with long-term conditions in the NHS. Critical analysis also suggested that the EPP contributed towards the reinforcement of healthcare professionals' power as it centred around patients being encouraged by healthcare professionals to join the programme instead of attending through proactive self-referral (Wilson, 2001). This could have been for several reasons. The EPP being based in a hospital setting may have contributed to healthcare professionals inadvertently being gatekeepers as patients may not have felt able to attend freely compared to if the programmes had been based in the community. Alternatively, patients who required additional self-management support may have benefitted from the encouragement of healthcare professionals to attend.

Based on the clear need for wider cultural change to support self-management, the Co-Creating Health (CCH) project (Wallace *et al.*, 2012) was developed. This was based on the Chronic Care model (Wagner, 1998) and piloted similarly structured, condition-specific self-management programmes across multiple sites in the UK in four different long-term conditions. The focus of the study was on incorporating self-management support into routine care pathways through several means. The first was the standardised group programme based on the CDSMP delivered with a healthcare professional and a patient partner working in collaboration. This pairing was reported to be challenging in some circumstances, particularly around finding time for the professionals and lay tutors to prepare for the group sessions, as well as managing the lay tutors' own health during this time (Wallace *et al.*, 2012). There were benefits to this pairing though, as group participants were generally positive about the combination of professional knowledge and the authentic lived experience of the lay tutors (Ahmad, Wallace and Turner, 2009). However, there was no clear instruction on how to formalise arrangements between the two tutors to determine the responsibility split and to support the lay tutors in these group interventions. This meant there was a great deal of diversity in the support and levels of responsibility held by the lay tutors, particularly around the organisation and administration of the course (Wallace *et al.*, 2012).

The group programmes were delivered in conjunction with two other strands of the project. The second of these was a training scheme to support healthcare professionals in supporting people to self-manage during their routine clinical contact. Supporting patients to self-manage was deemed to be the responsibility of a range of healthcare professionals. This included GPs, nurses, medics and allied health professionals. The third strand of the project were service development projects focusing on sustainable implementation of co-produced self-management support (Wallace *et al.*, 2012). The intention was for these three arms combined to bring about a cultural shift in the way that self-management was approached in the NHS. This could move healthcare professionals towards including self-management support more often in their daily practice (Wallace *et al.*, 2012). In this the CCH project moved beyond the focus of the EPP to increase peoples' knowledge and ability to manage their health, and to a programme designed to bring about changes to the wider healthcare system.

From the self-management programme arm of CCH, participants at the beginning of the interventions were often passive in managing their health. The end evaluations demonstrated substantial improvements in how able and willing group members generally were to self-manage (Wallace *et al.*, 2012). The training aimed at healthcare professionals to encourage them to collaborate with patients was well received and demonstrated small changes in the techniques used in clinical settings to support self-management, however the study authors recognised that the small sample sizes limited the generalisability of the findings.

CCH continued the growing implementation of self-management support in the NHS and the consciousness of NHS staff. However, this study demonstrated the need for self-management support that was longer term and more embedded into the mind-set of healthcare professionals and within services to bring about systemic change (Wallace *et al.*, 2012). Implementing this more embedded self-management support would go beyond offering this type of intervention as an "add-on", to supporting patients to follow up on their goals, bringing about changes to behaviour and supporting patients to act as a collaborative partner in their care (Wallace *et al.,* 2012).

2.6 Self-management in the NHS

2.6.1 Current environment for self-management in the NHS

Focus on self-management and empowering patients continued to grow following CCH, and this was a major focus of the NHS Five Year Forward View document (NHS England Care Quality Commission, 2014). Systems such as personal health budgets and self-management support coaches were established and departments continued to make room for empowered people to be able to manage their own conditions, take the lead in planning their care and accessing structured education, specialist advice and emotional support when required (Hibbard and Gilburt, 2014).

As the number of people living with long-term conditions continued to rise (Roberts *et al.*, 2016), this remained one of the largest challenges for healthcare systems. There was an increase in focus on managing long-term conditions in individuals, identifying people who may be struggling to self-manage, and individualising care (Roberts *et al.*, 2016). Self-management interventions formed an integral part of care and took a variety of forms, including a combination of professional and lay person led self-management courses such as the CCH, EPP and CDSMP. There was also a growth in telephone and internet-based support and the beginnings of integration of informal opportunities for self-management support as part of routine care (Hibbard and Gilburt, 2014).

Healthcare professionals are expected to create a suitable environment for empowering people to self-manage. This has begun to be incorporated into routine practice in the current healthcare climate, strengthened by research evidence indicating the benefits of healthcare professional behaviours for self-management. For example, there are recognised relationships between empowering behaviours from nursing staff for inpatients and one's ability to self-manage post-discharge (Jerofke, Weiss and Yakusheva, 2014). Evidence suggests that the knowledge and skills that healthcare professionals have in order to support self-management and engage in collaborative care vary, and healthcare professionals have struggled to identify their learning needs (Do *et al.*, 2015; Hooft *et al.*, 2015).

Focussing interventions on specific populations or based on demographic factors has offered the opportunity to increase support for people who may not have engaged with other services or who may be more vulnerable to risks following poorly managed conditions, or for whom a more generic approach would not be appropriate. Examples of this included working with patients with low health literacy (see section 2.2.4), severe mental health problems, or with older people with knee pain (Rademakers and Heijmans, 2018; Goldberg *et al.*, 2013; Ganji *et al.*, 2018). The integration of self-management into stepped care models has led to services beginning to implement tailored self-management at a variety of levels (Korpershoek *et al.*, 2016). Stepped care refers to the approach to healthcare where all patients have access to interventions that are low intensity or targeted at those functioning best, and those with greater need or with higher risks are offered more intense support (Von Korff *et al.*, 2015).

The influence of patients' wider networks and communities is becoming increasingly relevant as a consideration to the NHS. However, this is still growing as a perspective and currently much self-management support does not take the wider context and environment into consideration (Rogers *et al.*, 2011). The consideration of communities and networks can help to support individuals to participate in meaningful activities that promote positive self-management behaviour and increased wellbeing. Social prescribing has begun to do this by referring patients to services designed to improve their health and wellbeing without directly meeting biomedical needs (Tierney *et al.*, 2020). This was intended to build social networks that increase cohesion and camaraderie with networks that may not occur naturally but require nurturing and developing. This linking was taken a step further by the GENIE intervention that intended to move beyond the concept of actively self-managing patients to active and engaged networks (Band *et al.*, 2019). This work built on the idea that social isolation was a factor in poor health outcomes and developed the Generating Engagement in Network Involvement (GENIE) study. This developed a questionnaire to map participants' social network, guide them to select activities they have an interest in to develop their wellbeing, and use a local database to match participants up to these activities (Rogers, 2018). These types of support reflect the expansion of how self-management is reflected in the NHS and how commissioners have implemented systems to focus on the wider social determinants of self-management support.

Research has moved towards a greater understanding of the evidence base and concepts underlying self-management. This has led to further study into concepts such as patient engagement, self-efficacy and patient activation in detail. These will be discussed in the latter half of this chapter and in the next chapter.

2.6.2 Criticisms of self-management based approaches

Self-management based interventions are still subject to criticisms about whether those who would benefit most from support are neglected (Wilson, Kendall and Brooks, 2007). There is a risk that these approaches and the research studies that contribute to their development, tend to attract people who are likely to already be engaged with their health and able to manage to some degree, or believe in the benefits of managing their own health (Hochhalter *et al.*, 2010).

Self-management based interventions like the EPP have been accused of continuing to perpetuate the model of medical dominance because people may feel coerced into, or expected to accept, receiving such an intervention to manage their health, or when it is expected as a responsibility rather than making an informed, empowered choice (Gilbert, 2005). The growth of self-management support has also been met with criticism for placing the blame for poor health management with individuals for their failure to effectively make behavioural changes, instead of tackling wider systemic factors that contribute to people being passive or unable to make health-related behaviour change (Wilson, Kendall and Brooks, 2007). This perspective does not consider the other forms of systemic and structural inequalities and factors that contribute to someone's health. Some of these inequalities include the deprivation of local authority governments and the impact this has on healthcare provision and life expectancy (Public Health England, 2017). Other factors such as housing, transport, work availability and recreation facilities also impact on health in ways that go beyond an individual's ability to self-manage their health (Buck and Gregory, 2018; British Academy, 2014). Consequently, self-management placing blame on individuals for not effectively managing their health does not consider the other contributors to health and the role that policy makers play in peoples' health. The behaviour and attitude of health professionals also has the potential to be a barrier to self-management, instead perpetuating power imbalances and disempowering patients.

2.7 Models and theories underlying self-management principles

The preceding section described the emergence of self-management in healthcare. As self-managing a health condition requires patients to make behavioural and cognitive changes, this section will examine the relevant underpinning cognitive and behaviour-change theories. This will provide both a sense of the background research that contributed to an understanding of patient activation and the additional detail for concepts that are captured in studies later in this thesis.

2.7.1 Social Cognitive Theory

Social Cognitive Theory has been prominent in research related to person-centred care and self-management. This theory posits that people can learn by observing others modelling helpful behaviours (Bandura, 2004). Modelling behaviours have been reported as part of the benefit of group self-management interventions as they offer group members access to behaviour that they may not yet be confident enough to attempt themselves and to view the intended behaviour being reinforced (Bandura, 2004). The benefits of peer modelling are particularly relevant for patients as it provides personal comparison for managing conditions that healthcare professionals are not able to offer because of their different perspective. For this reason, patients can learn better from these groups compared to one-to-one contacts with health professionals.

2.7.2 Self-efficacy

Self-efficacy is one of the "*core determinants*" of social cognitive theory (Bandura, 2004, p.143). It is defined as:

> *"… an individual's belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control, and willingness to take on and persist with new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal"* (Coulter and Ellins, 2006, p.89)

Self-efficacy refers to an individual's belief that they are able to carry out behaviours related to managing their health (Bandura, 2004). Self-efficacy is a vital component of how people learn to self-manage and is often targeted during self-management interventions: research has demonstrated that self-efficacy can be increased through intervention (Wallace *et al.*, 2012; Hewlett *et al.*, 2011). Increased self-efficacy is associated with learning from vicarious experiences (Rosenstock, Strecher and Becker, 1988).

Self-efficacy has an impact on how people consider making health-related behaviour change, how well they are able to return to maintaining health-related behaviours after a setback and how likely it is that someone will continue to maintain behaviours longer term (Dures and Hewlett, 2012). However, self-efficacy doesn't necessarily mean that someone is going to take steps to change their behaviour, although it does consider that someone's personal expectations are major determinants of behaviour change (Gwynn *et al.*, 2016). People may not carry out behaviours that they feel confident they could achieve for a variety of reasons as other determinants also contribute to behaviours (Bandura, 1998). For example, external factors such as climate, finances or access to facilities may prevent people who have high self-efficacy to exercise from doing so.

2.7.3 Health Locus of Control

The concept of Health Locus of Control (HLOC) found its origin in Rotter's social learning theory (Rotter, 1954) and relates to whether people believe that outcomes occur as a result of actions that they can take charge of (internal locus of control), or because of factors that are outside of their control (external locus of control). Wallston *et al.* (1976) developed the concept more specifically to consider how much someone feels they are responsible for their health. This resulted in the creation of the HLOC Scale, based on the hypothesis that a person with an internal HLOC would be more likely to take steps to improve their situation. Research that initially tested this concept suggested that people with an internal HLOC participated in more preventative health behaviours, sought further information more often and had increased knowledge about their health (Wallston and Wallston, 1978).

The Multidimensional HLOC scale was developed with people diagnosed with rheumatoid arthritis (Wallston, 2005) and is one of the most common methods of capturing health locus of control. This measure separated HLOC into internal (one's health being impacted by the actions of the self) and external (separated into two categories: chance, and the actions of powerful others). A factor that Norman and Conner (1996) proposed to have contributed to the mixed results evident in early HLOC studies was how much people valued their health. They proposed that if people did not value their health then they would be less likely to follow the anticipated health-behaviour patterns. Wallston (1989) began to move towards the integration of HLOC into a wider theory of health behaviour, inspired by social learning theory. This included a consideration of locus of control, health value and self-efficacy as a moderator.

2.7.4 Health literacy

"Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (Nutbeam, 1998, p357).

Health literacy is often conceptualised to include a variety of skills, including being able to comprehend and evaluate health related information to make decisions related to one's health (Buchbinder *et al.*, 2011). Other skills covered under this umbrella term include the ability to discern reliable sources of health-related information and navigate health services to obtain the support needed to manage one's health (Diviani *et al.*, 2015). Paasche-Orlow and Wolf (2007) note that the context in which health literacy is measured with abilities and complexity of health-related tasks can vary enormously between and within people and health conditions. Health literacy has so far been understood as a skills-based construct and can be a gateway to positive increases in other health-related outcomes such as improved physical health and lower rates of anxiety and depression (Smith *et al.*, 2013). This includes patient activation (Goodworth *et al.*, 2016a), which will be discussed in detail in the next chapter.

Health literacy can be a clinical risk or a personal asset, depending on how else people manage and perceive their health (Nutbeam, 2008). Someone with high self-efficacy and low health literacy may feel confident and able to manage problems independently of healthcare professionals. However, with low health literacy they may lack the ability to recognise warning signs indicative of health problems that require intervention and the ability to identify a clear path to intervention when these problems necessitate doing so. Low health literacy can have a profound impact on how people make use of their health care services. People may experience feelings of discomfort, disempowerment, shame and distrust because of not being able to fully understand information in clinics and may decrease attendance as a result (Paasche-Orlow and Wolf, 2007).

Health literacy is categorised into functional, interactive and critical forms (Nutbeam, McGill and Premkumar, 2017).

- Functional health literacy refers to the basic ability to gather information related to one's health and successfully apply it to prescribed activities.
- Communicative health literacy describes the ability to establish meaning from a variety of sources and types of information in order to apply it to managing health. This includes the ability to apply information to circumstances that have changed, or to make decisions after considering information.
- Critical health literacy is the ability to manage health based on the analysis of health-related information. Low critical health literacy may be a barrier to people seeking information from healthcare professionals or managing a long-term condition effectively.

Low health literacy is widespread and screening exercises have estimated that between 43% and 61% of adults in England would be unable to comprehend and use health information they have been provided in its entirety (Rowlands *et al.*, 2015). As a result, health literacy can profoundly affect someone's ability to self-manage and take active responsibility for their own health. Low health literacy could be a barrier to people engaging with patient activation interventions (Sola, Couturier and Voyer, 2015).

2.7.5 Stages of Change model

This model is commonly applied to health-behaviour change, but was developed to describe the stages through which people may move when considering changes to addiction-related behaviour (Prochaska and DiClemente, 1982). The stages were:

- Precontemplation: Where people are unaware of the change they may make and aren't able to consider behaviour change.
- Contemplation: Where people are aware of the problems currently lying ahead of them and the changes required to resolve the problem.
- Preparation: Where people have made the decision to change their behaviour but have not yet taken steps towards changing their behaviour.
- Action: When people are testing out the behaviour change to understand the effects and how to manage the challenges and setbacks associated with the behaviour change.
- Maintenance: Maintaining behaviour change despite obstacles, life events and

potential setbacks (Prochaska and DiClemente, 1986).

The model was designed for people to move in an upward spiral towards behaviour change and to account for people relapsing in behaviour during maintenance, with the opportunity to move towards action and maintenance again. Accounting for change not always being linear was also considered so this model can be viewed in a non-linear way and with people returning to earlier stages (Ogden, 2012).

2.8 Criticisms of models of health and healthcare

A consideration of models in health psychology is that they have been constructed with the intention to understand encounters with health and healthcare via experiences (Kernick, 2006). However, in some ways this could contribute to reductionist conceptualisations of health that the introduction of the biopsychosocial model intended to avoid (Crossley, 2000). The models may not consider the range of experience in people's realities and the wider systemic and contextual factors. Like the self-management programmes critiqued for the responsibility given to patients, these models also place responsibility for the psychological impact of their health with individuals (Murray & Chamberlain, 1999). However, these models have contributed towards research and clinical practice to improve quality of life, design interventions and improve health-related outcomes.

2.9 Chapter Summary

This chapter has demonstrated the complexities of self-management and long-term conditions. Models of health and healthcare have been used in several ways to better understand how people can self-manage long-term conditions. This has included explaining the nature of health conditions and ways to approach behaviour change to improve patients' health. Additionally, models have informed the design of interventions and ways to understand and capture outcomes related to health. In order to effectively self-manage a health condition, including being able to initiate and continue behavioural and cognitive activities to self-manage, patients require a sense of responsibility for managing their own health. Patient activation refers to one's ability and willingness to take responsibility for their own health and encompasses many types of self-management behaviours and skills. Patient activation and its relevance to wider literature will be discussed in the next chapter.

Chapter 3: Patient Activation

The previous chapter introduced self-management and raised the issue that a patient needs to be engaged to effectively self-manage their condition. This chapter introduces patient activation and how it is distinct from similar concepts, looks at how it is captured and examines the literature on how it is conceptualised and understood.

3.1 Defining patient activation

3.1.1 Definitions and description

Patient activation is defined as the knowledge and skills that someone has in order to take responsibility for managing their own health as well as how likely it is that they will do so (Hibbard and Greene, 2013; Hibbard *et al.*, 2015). Patient activation has been described as a broad, multi-dimensional self-management self-concept (Hibbard and Mahoney, 2010). Patient activation is considered to incorporate associated concepts such as self-management behaviours (e.g. how closely patients follow medication routines), health literacy and self-efficacy (Hibbard *et al.*, 2004; Do *et al.*, 2015).

Where patient activation is high, patients are confident and proactive in managing their health, seeking information when required to make decisions about their health, and carrying out positive health-related behaviours. Alternatively, when patient activation is low, people are passive, unable or unwilling to take responsibility for managing their health, and very dependent on healthcare professionals for information and direction.

Higher levels of activation are associated with fewer emergency admissions, fewer days as an inpatient, and lower healthcare costs (Hibbard *et al.*, 2015). On an individual level, increased activation is associated with better outcomes overall (McCusker *et al.*, 2016). Therefore, there is value in understanding patient activation to benefit both a resource-scarce NHS and individual patients. The NHS Five Year Forward View places people managing their own conditions at the core of NHS intentions and goals for the near future and consequently, the concept of patient activation has become prominent within the UK (Chew *et al.*, 2017; NHS England Care Quality Commission, 2014).

3.1.2 How does activation differ from engagement, enablement and empowerment?

Given the rising interest in patient activation and significant increase in publications related to the concept in the last five years, there is variation in how patient activation is defined and conceptualised. Some researchers consider patient activation as a way of capturing other constructs (Solomon, Wagner and Goes, 2012; Foot *et al.*, 2014). Hibbard and Greene (2013) consider patient activation to be an aspect of patient engagement and as something that contributes towards the intention of being activated.

Whilst the term patient activation is often used interchangeably with patient engagement, empowerment or enablement (Graffigna, Barello and Bonanomi, 2017; Higgins, Larson and Schnall, 2016), another school of thought considers the four terms to be independent concepts in their own rights. To manage the challenges of semantics and overlapping concepts, definitions of each of these terms will be provided for the purpose of this thesis. This will include references to how each of these constructs overlap with the current definition of patient activation.

- As introduced in section 3.1.1, patient activation is the knowledge and skills that someone has in order to take responsibility for managing their own health as well as how likely it is that they will do so (Hibbard and Greene, 2013; Hibbard *et al.*, 2015). Patient activation is broad and includes additional skills like the acquisition and use of health-related information, practical skills pertaining to how people manage their health, and determination to become or remain empowered to manage their health.
- Patient enablement is how well patients can comprehend and cope with their health (Hudon *et al.*, 2011). Patient enablement is often captured immediately after a consultation in order to understand how well positioned the person is to act based on the content and effectiveness of the interaction from the patient's perspective. Patient enablement has been considered a transitional construct that contributes towards increased self-efficacy.
- Patient empowerment occurs when people believe that they have an active role in their own care and move towards contributing to health-related decision making (Alegría *et al.*, 2008). This construct and definition are very

closely related to patient activation but are distinct within this thesis because patient activation is a broader construct that incorporates other skills. Instead, patient empowerment focuses on the belief that they have a role and does not incorporate the actions people take. While patient empowerment has been researched, reviewed and captured with reference to patient activation, it has also been investigated separately. The Health Empowerment Model (Schulz and Nakamoto, 2013) inferred that health literacy and empowerment were distinct but closely related, and the combination of high health literacy and empowerment contributes to an effective self-manager. The authors considered the impact of low health literacy, which could lead to either a patient requiring high support or a self-manager who was potentially at risk as they had little understanding/knowledge. Alternatively, someone with high health literacy who is not empowered may be unnecessarily reliant on healthcare professionals for support.

- Patient engagement is defined as the steps people take to make the best use of the healthcare provision that they are able to access (Gruman *et al.*, 2010). This could be considered part of the skills and behaviours contained within patient activation. Sometimes patient activation has been viewed as how engaged a patient is and the two terms have been used interchangeably (Do et al., 2015). The Patient Engagement Model (Graffigna, Barello and Bonanomi, 2017) proposes that engagement is a mechanism towards improving patient activation, along with positive emotions and a good relationship between patient and healthcare professional. However, this model was developed without formally confirming the mediating effect of these various factors, which limits its credibility. The homogenous sample also limits generalisability. Patient engagement has also been used interchangeably with patient activation, although the two concepts are different (Toscos *et al.*, 2019).

The conceptual overlap between these constructs and patient activation can lead to confusion. Therefore, the definitions of these constructs above will be used for the duration of this thesis for clarity. Table 3.1 summarises the conceptual differences between these concepts.

Table 3.1: Conceptual differences between patient activation, enablement, engagement and empowerment

Concept	**Patient activation**	**Patient enablement**	**Patient empowerment**	**Patient engagement**
Belief in the role one has in shaping the outcomes of one's health	Y		Y	Y
Determination to remain involved in managing one's health	Y			
Skills in acquiring information	Y			
Ability to make effective use of healthcare provision	Y			Y
Ability to comprehend health-related information	Y	Y		
Ability to practically cope with one's health	Y	Y		

3.2 Measuring patient activation

3.2.1 Hibbard PAM development and validation

The Patient Activation Measure (PAM) (Hibbard *et al.,* 2004) is often considered to be the beginning of patient activation gaining traction as a concept. Consequently, it is not possible to discuss patient activation without referring to the PAM. Upon the publication of the PAM, Hibbard et al. (2004) highlighted the importance of patients' belief in their role and responsibility in managing their health. The development of the PAM also offered the potential value of stratifying people into activation levels in order to design and target appropriate interventions to support them to self-manage.

The development of Patient Reported Outcome Measures (PROMs) requires testing the validity of these PROMs to ensure that they measure what they intend to. There are multiple types of validity and each are important to ensure the quality of a measure. Types of validity include:

- Content validity reports how well a PROM captures suitable content related to the construct it intends to measure (Frost *et al.,* 2007). Content validity is incorporated in the development of PROMs by collecting qualitative data from participants have experience that is relevant to the construct that the PROM intends to capture. This includes using data from these participants to determine items that are appropriate for the PROM.
- Construct validity refers to how well the PROM relates to the construct it should capture (Frost *et al.,* 2007). Construct validity could be tested by comparing the responses to items in the PROM of interest to responses to other PROMs that capture similar or relevant constructs. This could be to determine whether there is a relationship or no relationship depending on the relation between the constructs.
- Face validity captures the extent to which the PROM appears to be clear about what construct it captures from the perspective of both patients and professionals (Coolican, 2013).
- Test-retest reliability captures the stability of a PROM over time when there has been no meaningful change in the construct being measured from the patient perspective. This is calculated by having the same participants complete the measure multiple times in order to investigate the correlation between their scores on the different completion times (Coolican, 2013).
- Criterion validity captures how well a PROM performs against a gold standard capturing this construct. This could be captured qualitatively, biomedically or using another PROM (Frost *et al.,* 2007).
- Sensitivity to change captures changes in PROM scores within participants that is anticipated when there has been a meaningful change in the construct being measured from the patient's perspective (Fitzpatrick et al., 1998).

The original long-form PAM was developed through the process noted below:

- A literature review that reached a definition of patient activation that identified six domains that constitute patient activation and these were elaborated to develop 18 domains.
- Discussion with a panel of 21 experts in their field (although the professional breakdown of expertise is not provided) using consensus methods to contribute to the conceptual definition of patient activation by identifying domains of activation. This ordered the total 18 domains in rank of importance. These focus groups contributed to increased content validity of the measure.
- Two focus groups of participants with undisclosed long-term conditions who were recruited from newspaper advertising for the first phases of development. The focus groups offered the opportunity to review and alter the domains as necessary. Gathering the patient perspectives on activation increased the measure's content validity.
- A total of 80 potential items were listed and refined following cognitive testing with 20 participants living with unspecified long-term conditions. The items were reduced to 75 items in the questionnaire.
- A pilot study where 100 participants with unspecified long-term conditions completed the 75-item questionnaire. Rasch analysis reduced the questionnaire to 21 items. Removing items that did not contribute additional information following Rasch analysis increased the content validity of the PAM. This pilot study would also have contributed to increased face validity.
- The research team conducted additional testing to confirm the rigour of the measure. This included establishing test-retest reliability with 30 participants from the pilot study a fortnight after they first completed the measure. The findings indicated that of the 30 participants, 28 had a score upon retesting that was within the 95% confidence interval of their initial test estimate. While it is not always possible to capture criterion validity, this was reviewed during the development of the PAM (Frost *et al.,* 2007).
- Criterion validity was determined via interviewing ten participants from the pilot study, split into five who had scored lowest and five who had scored highest. The interviews focused on how participants managed their health

and responded to specific challenges posed by the researchers. Independent judges determined from reading the transcripts whether participants were high or low scorers, and nobody was misclassified during this process.

- The PAM was further refined with a sample of 486 participants formed of a combination of health employees and cardiology patients (Hibbard and Mahoney, 2010; Hibbard *et al.,* 2004). Nearly a quarter of these did not have a long-term condition, but it was this stage of the process that contributed to the understanding of four levels of patient activation. This led to a restructure and the measure becoming 22 items.
- Finally, a sample of 1,515 participants who were 45 years old and above were recruited to complete the PAM via telephone. The findings indicated similar results to that of the 100-participant pilot survey. This sample was randomly selected, and demographic information was not provided, including whether these participants had health conditions.
- Sensitivity to change was not captured during this initial development of the PAM but is an important form of validity to consider.

The short form 13-item PAM (Hibbard *et al.*, 2005) was later developed following secondary analysis of the initial large survey that was used in the 2004 report. These secondary data were analysed using Rasch analysis to identify items that could be removed from the original PAM.

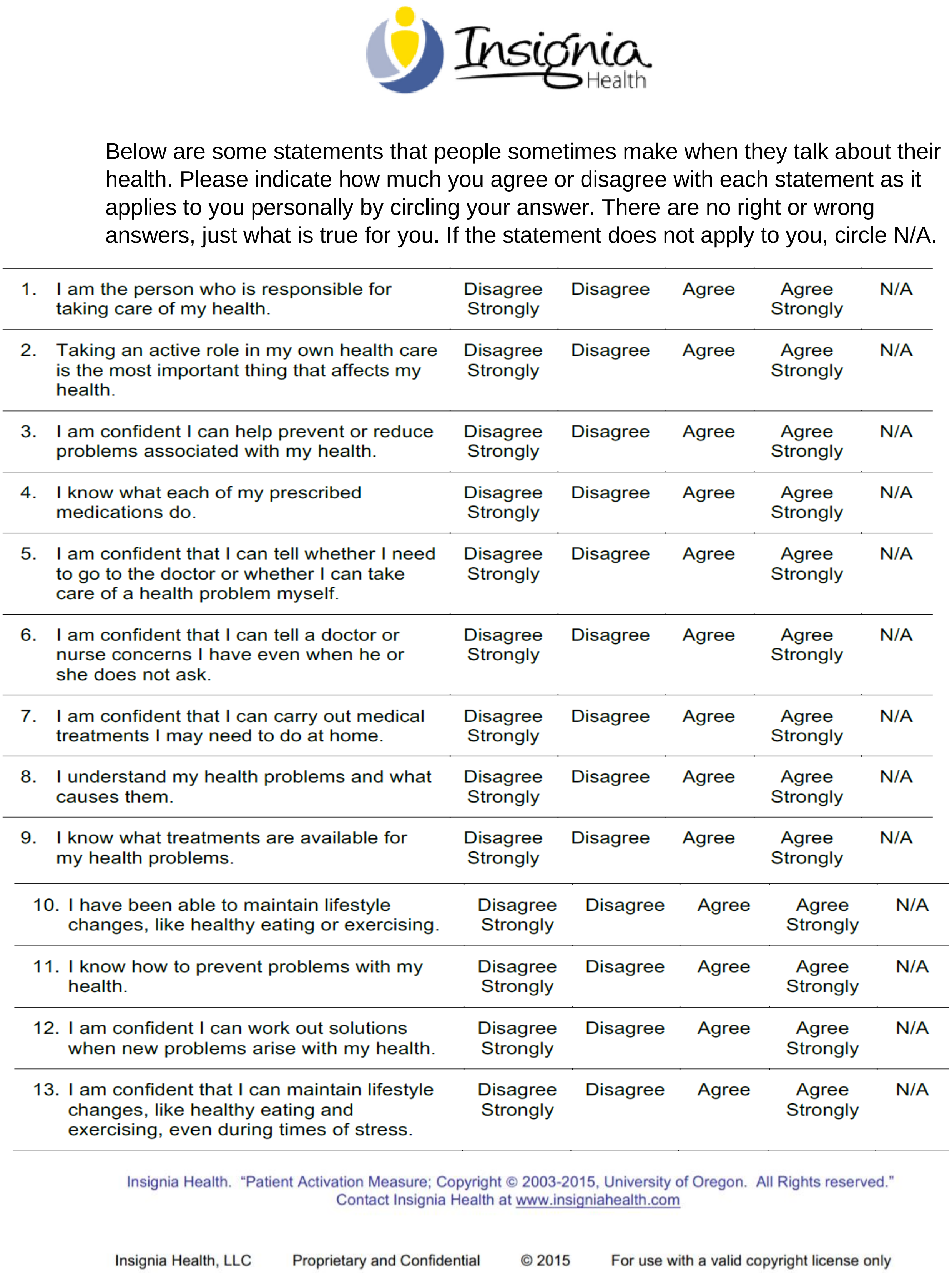
The PAM categorised people into four developmental stages of activation from level 1 (completely passive in health management) to level 4 (able to sustain active health management after a setback). Additional details on these stages are available in table 3.2. These stages were proposed as developmental but not necessarily linear in both directions meaning that people can move to both lower and higher PAM levels (Hibbard *et al.,* 2004). However, this description did not clarify whether people are able to skip stages as their patient activation changes. The PAM also provides patients with a PAM score between 0 and100 depending on their responses to the items.

Participants can respond to the 13 items with “disagree strongly”, “disagree”, “agree”, “agree strongly” or “N/A”. The algorithm that calculates scores and levels from the raw data and the cut-off points for what scores lie in which level are not publicly available. The 13-item PAM (Hibbard *et al.*, 2005) is presented in figure 3.2.

Table 3.2: Description of PAM Levels

Level	**Description of Level**
1	Patients are either disinterested or unable to take active responsibility for their health, being led by healthcare professionals instead.
2	Patients have some awareness that they could take active responsibility for their health, but there is still much they are unable or unwilling to do.
3	Patients are taking active responsibility for their condition and continuing to develop their skills and confidence.
4	Patients can maintain active responsibility for their condition, despite fluctuations or setbacks.

Figure 3.2: 13-item PAM (Insignia Health, 2018):



Insignia Health

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. There are no right or wrong answers, just what is true for you. If the statement does not apply to you, circle N/A.

1.	I am the person who is responsible for taking care of my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I know what each of my prescribed medications do.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I am confident that I can carry out medical treatments I may need to do at home.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8.	I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9.	I know what treatments are available for my health problems.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10.	I have been able to maintain lifestyle changes, like healthy eating or exercising.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11.	I know how to prevent problems with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12.	I am confident I can work out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13.	I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

The PAM's intended applications were to offer tailored support to patients based on their individual needs and evaluate the efficacy of self-management interventions or person-centred care (Hibbard *et al.,* 2004). The PAM has also been used as a process measure, as increasing patient activation can improve peoples' engagement with managing their health (Roberts *et al.,* 2016). The consequence of this is that the PAM could be used as a clinical tool to design self-management support, an outcome tool to determine how successful the intervention was, and the process measure to explain the change in outcome.

The PAM creators proposed that for those people living with low levels of activation, very small behaviour changes could have a big impact and contribute to patients feeling more ready to take the next step in actively managing their health (Hibbard, 2007). The PAM has demonstrated a ceiling effect: patients with lower levels of activation appeared to experience the greatest change in PAM scores after an intervention and those at the higher end of the scale experience much less change (Hibbard *et al.*, 2007). This implied that targeting interventions designed to increase patient activation had the most benefit when it was aimed at those who are currently struggling and that interventions aimed at supporting those actively managing their condition should be different to best accommodate their needs.

One of the factors that may have contributed to this ceiling effect is a recruitment bias where the participants recruited are those who are engaged enough at baseline to participate in an intervention. Harvey *et al.* (2012) carried out a survey as part of a health promotion trial with employees with health insurance. The study reported that people were still able to make progress within PAM levels even at higher levels, which challenges the reported ceiling effect. These changes were associated with various health behaviours. However, the study is limited by the follow-up rate of 51%, meaning that much of the population didn't provide data to gain a full picture. The non-responders were also described as having lower PAM scores although the full comparison data were not published; this is likely to have impacted on the findings demonstrating increased average PAM scores. People with lower PAM scores may also be less engaged in research related to their health and as a result maybe more likely to drop out of research studies.

The debate about how patient activation is conceptualised is ongoing. Some researchers followed the proposed model of four discrete stages where people are either "activated" in managing their condition or not, whereas others viewed PAM scores as potentially fluctuating points on a continuum (Linden, 2015). There has been debate around how patient activation behaves and changes over time. The short form of the PAM (Hibbard *et al.,* 2005) was developed in line with the guidance of the Institute of Medicine Summit (Adams *et al.*, 2004) with the intention that measurements should be able to capture information at multiple time points to understand people's abilities over time. Some studies propose that PAM scores can be maintained, although this may have been impacted by the presence of an open referral to inpatient support when required as part of the study (Moljord *et al.,* 2017). However, one study demonstrated a reduction in mean PAM score at a group level (Rijken *et al.*, 2014). This study however had mixed results for individuals, with around 20% increasing in PAM levels, 40% demonstrating a decreased PAM level and 40% remaining at the same level. There are a variety of different contextual factors that may have impacted on PAM scores both within and between studies. These include the presence of an intervention, such as in the case of Moljord *et al.*'s work (2017); how much the health condition studied was likely to fluctuate; and how consistent and accessible healthcare has been during the period of data collection.

Ledford, Ledford & Childress (2013) sought to understand patient activation from the perspectives of healthcare professionals as well as patients. They compared PAM scores from patients with an assessment of patient activation as perceived by healthcare professionals that had been determined using Likert-type scales related to behaviour in clinic. This included patients' actions such as asking for clarification, asking questions and how easily they allowed the professional to stay "on-message". These two different measures of patient activation were compared to a third perspective. This third perspective was that of a researcher who had developed a taxonomy of behaviours presumed to be related to patient activation and coded the clinical interactions against the taxonomy. Behaviours included in the taxonomy included seeking information, expressing preferences, discussing third-party experiences, or providing precise health-related information. The intention was to understand how well the patient-reported PAM data correlated with behaviours in this taxonomy and with the professionals' perspective. The PAM did not correlate with either the researcher or healthcare professionals' taxonomy of patient activation, although the two professionals' measures correlated with one-another. This reflects a mismatch between healthcare professionals' understanding of how patient activation may be enacted according to their experience and clinical judgement, compared to how the PAM captures people's levels of patient activation. Given this difference, it may well be that patient activation means different things to different patients in varying contexts depending on their role or circumstances. This study was strengthened by the triangulation of multiple types of data, a comparatively large sample size of 19 for qualitative research, and added rigor by using multiple coders within the professional groups who discussed the discrepancies to reach consensus.

There is currently limited qualitative research investigating patients' perceptions of the PAM and how closely it aligns with the concept of patient activation according to the literature. Understanding how patients feel about patient activation, what it means to them, and how they are currently performing and have previously performed patient activation can provide insight for healthcare professionals working with patient populations. It would also allow them to identify those who need support to actively manage their own health, and ways in which they can continue to work collaboratively and effectively with those who are keen to be primarily responsible for their own health.

Research into patient activation often focuses on understanding how reliable and valid the PAM is in varying populations and applications, as well as translating it for use in other languages (Armstrong *et al.*, 2016). Research has often taken the form of reviewing Patient Recorded Outcome Measures (PROMs) alongside the PAM or gathering data from patients to understand how effective the PAM is in certain circumstances (Chew *et al.*, 2017). However, despite large uptake of the PAM across the UK and internationally, it is evident that there is still a lot that is unknown about how the measure is used in research and practice within the NHS (Roberts *et al.*, 2016).

3.2.2 Potential limitations of the PAM

There were several limitations to the methods employed during the development of the PAM that are limitations of the research and of the PAM itself. Firstly, while the details of the development process were provided, it was not clear what expertise the professionals were bringing to the consensus building exercise. Additionally, the demographic data provided about participants in the pilot studies were very limited. It was unclear what long-term conditions they were living with or what their background was. As they provided domains that were incorporated into the measure and were a vital part of the development process, this contextual information would have been valuable to further understand the PAM and its intended applications.

The participants recruited from advertisements could be assumed to be literate enough to read and comprehend the newspaper advertisement and engaged enough in health-related matters to apply for the research. This means that the PAM was likely developed using patients who were already had higher patient activation and engagement. The use of participants of 45 years and older also limits the generalisability of the findings of the validation study.

One particular limitation of the PAM is that the model conceptualising patient activation was developed after the measure (Hibbard and Mahoney, 2010). This suggests that the measure was developed without a clear theoretical grounding of how patient activation changes, develops and could be captured. The development of the model following the PAM development has the potential to contribute towards a model that does not reflect the data collection for the studies related to the model, and instead confirms the domains captured in the pre-existing measure. Given the published guidelines that suggest that the theoretical framework should predate the development of a PROM (Patrick *et al.*, 2007), the chronology of the development of the PAM and the patient activation model contravenes this.

3.2.3 Use of the PAM in the NHS

Patient activation is of growing interest to the NHS because evidence suggests that people with increased levels of patient activation have lower healthcare costs and can self-manage more effectively (Do *et al.*, 2015). This initial evidence was a major driving force in the uptake of licences and encouragement of usage of the PAM given the current resource and financial strain within the NHS (British Medical Association, 2016). This also reflects the ongoing shift from paternalistic healthcare to person-centred care discussed in chapter two.

NHS England has invested in 1.8 million PAM licences to support people to actively manage their health and is working towards implementing the PAM as a tool across 47 clinical practice sites for people with long-term conditions (Armstrong *et al.*, 2017). The interest in patient activation was also reflected in several large collations of research evidence by organisations such as the Health Foundation (Armstrong *et al.*, 2017) and on behalf of NHS Wales (Rix and Marrin, 2015). This provided national credibility for the PAM and solidified its place as the most influential approach to capture patient activation.

Roberts *et al.* (2016) embarked on a series of studies to capture how the PAM was being used within the NHS. One of these included critiques of the PAM from people living with the consequences of strokes. They described it as being too broad for the skills that they developed as a result of their health changes. A focus on the different skills and knowledge that forms patient activation in different conditions implied that the PAM may be interpreted differently by people depending on their health condition. Additionally, if patients felt the PAM didn't capture their experiences of managing their health condition, the validity of findings using the PAM in relevant studies should be considered before drawing generalisable conclusions. While this article discusses patient activation from a range of different perspectives and case studies, they often included small sample sizes which may limit the generalisability of findings and included convenience samples which may have been impacted by using the stroke nurses who recruited participants.

The way that the PAM was implemented allowed it to be used in ways beyond ensuring that patients are receiving appropriate self-management support (Hibbard *et al.*, 2004). It became a tool for triaging (Bristol Clinical Commissioning Group, no date) as well as becoming central in a pilot stratifying services to determine what support to offer to patients (Coleman and Price, 2017). The findings of this pilot suggested the need for incorporating the PAM into practice within primary care and secondary care (Armstrong et al., 2017). The pilot also suggested that the implementation of the PAM across services has the potential to help people know and use their PAM results. Additionally, the authors suggest that services could develop care plans based on these measures to move towards inter-organisational, coherent person-centred care.

An ethnographic study investigating how the PAM was accepted and implemented in NHS services identified that the PAM was being used but with a great deal of flexibility depending on the healthcare professional (Chew *et al.,* 2017). This was often because patients required support from healthcare professionals to complete the measure and this support took the form of rephrasing items for clarity. This contributes towards barriers to validity, for instance, patients giving socially desirable answers and healthcare professionals prompting them to reconsider their responses. This co-completion was viewed as a way of developing a shared understanding of peoples' concept of and amount of patient activation within a therapeutic exercise (Chew *et al.*, 2017). Depending on how patients' responses are interpreted by healthcare professionals, the measure may have become more flexible over time, and concept of patient activation has become less precise and fixed. This work was strengthened by a very large sample size (112 interviews) and across a range of sites to get some variety across the different contexts. The addition of 123 hours of events and clinical appointments and 180 documents over two years provided a rich level of detail to add weight to these findings.

Research into patient activation has grown to incorporate a better understanding of the role that carers play in supporting those with long-term conditions, and how successfully healthcare professionals provide the kind of support required for people to take responsibility for their own health (NHS England, 2015a). Some of the literature being published around patient activation has begun to include identifying how to support people who might benefit from further support. This would be carried out through risk stratification in collaboration with primary care and clinical commissioning groups (CCGs) and has been proposed by Hibbard and Helen (2014).

3.2.4 Ways of capturing patient activation

It is clear that the PAM is the dominant measure for capturing patient activation. However, there are alternatives. One of these is the Patient Assessment of Chronic Illness Care measure (PACIC) (Glasgow *et al.*, 2005). This measure is intended to capture how closely to Wagner's chronic care model (CCM) (Wagner 1998) people believe the care they have received has been. The PACIC was adapted from an outcome measure developed for clinicians to determine how much they included aspects of the CCM in their own practice. The participants recruited to validate the measure reported how often they experienced the types of care discussed in each of the 20 items, from "never" to "always". The PACIC includes three items dedicated solely to the measure of patient activation and the remaining items capture skills related to actively managing health, e.g. problem solving or goal setting. Gibbons *et al.* (2005) suggest that the PACIC measures a single, unidimensional trait instead of the previously thought five separate factors, and Glasgow *et al.* (2005) have found that is correlates moderately well with PAM ($r=0.43$, $p<0.001$).

The Health Literacy Questionnaire (HLQ) (Osborne *et al.*, 2013) was developed in order to capture health literacy but also has a subscale related to actively managing one's health. For this reason, this could act as an alternative to the PAM, but it is less focused on patient activation. The HLQ was developed following concept mapping, and the items developed were reviewed by researchers and clinical staff in four primary care centres in Australia. The measure was reviewed with cognitive interviews and then two samples calibrated the measure. The measure also went through several stages of validity testing to add rigor and strengthen findings of studies that use the HLQ. The measure was developed with 52% of the study sample participants having a musculoskeletal long-term condition and is focused on the understanding of health literacy as discussed by Nutbeam (2008).

3.3 Literature on patient activation using the PAM

Since Judith Hibbard and her colleagues introduced and refined the PAM, many studies have focused on developing and trialling interventions to help patients become more engaged in their healthcare and to improve their outcomes (Roberts *et al.*, 2016).

The studies investigating how to improve patient activation (as measured by the PAM) have focused on improving skills that demonstrate patient activation. These skills include question formulation within consultations or people's contributions to decision making around their conditions (Hibbard and Greene, 2013). Interventions targeting patient activation are the topic of the systematic review in chapter 4.

Identifying factors involved in increased patient activation has become a major focus of the literature, with the intention to better understand the relationship between patient activation and various clinical, demographic and psychological variables. Much of this work has been centred around populations with diabetes and generalisability to rheumatology patients may be limited (Remmers et al., 2009; Rask et al., 2009; Hibbard *et al.*, 2008), although some studies have focused on other long-term health conditions and participants at risk of developing health conditions.

There is a correlation between health literacy and patient activation levels, as captured using the PAM (Hibbard *et al.*, 2008). For this reason, health literacy has been recommended as a gateway to increasing patient activation (Goodworth *et al.*, 2016). It is evident that health literacy can profoundly affect someone's ability to self-manage and could be a barrier to people engaging with patient activation interventions (Sola, Couturier and Voyer, 2015).

Studies have described a relationship between self-reported health status and patient activation (Chen, Mortensen and Bloodworth, 2014; Rijken *et al.*, 2014; Hibbard *et al.*, 2008) in different long-term conditions. However, these studies have been impacted by collecting the self-report and patient activation data at different points (Rijken *et al.,* 2014). The usefulness of the findings of one study might be because it focuses on self-rated mental health rather than physical health (Chen, Mortensen and Bloodworth, 2014). Goodworth *et al.* (2016) found that objective measures of function were not related to patient activation levels and instead supported the idea that self-report measures of function could, therefore, be more relevant in patient activation.

Given that self-efficacy can be a predictor of illness beliefs (Osborn, 2011), it is of consequence in patient activation research. Literature has repeatedly demonstrated self-efficacy to be associated with patient activation (Skolasky *et al.*, 2008; Do *et al.*, 2015; Goodworth *et al.*, 2016). This is attributed to people self-managing more effectively or feeling more confident about taking steps to change behaviours if they have high self-efficacy (Dixon, Hibbard and Tusler, 2009).

Various demographic factors are thought to impact patient activation levels, and ones of particular interest include sex, age, ethnicity, and level of education. Gleason-Comstock *et al.* (2016) identified that gender was a modifier for patient activation levels in the relationship between depression and patient activation in older adults. Hendriks and Rademakers (2014) also identified gender as a factor in a model of patient activation and found associations with other health outcomes in patients with diabetes. However, in a study deliberately attempting to investigate sex differences in patient activation, the authors did not identify a significant difference in PAM scores between men and women (Hendriks *et al.*, 2016). They recognised the limitations of the cross-sectional study where many other important factors were not adjusted for which could have impacted the findings of the research. One of these important factors was whether participants lived alone or with other people, which may have had an impact on patient activation between the sexes. These mixed findings suggest the need for further research to clarify these relationships, particularly in under-researched populations. Of these, rheumatology patients are one such population.

Ethnicity appears to be predictive of patient activation scores in people with mental health diagnoses (Eliacin *et al.*, 2018), and this could be attributed to a perception of less-equitable relationships between patients and healthcare professionals in people with ethnic minority backgrounds (Alexander, Hearld and Mittler, 2014). Given how crucial the collaborative relationship is for patients to be able to actively manage their health (Dures *et* al., 2016b), an imbalance of power would likely contribute towards patients feeling further disempowered, disengaged and less likely to self-manage effectively. Given that only 19% of healthcare professionals within the NHS in 2017 were from ethnic minorities, this is likely also a factor in how well represented patients from an ethnic minority may feel (NHS Workforce Statistics, 2018). The relationship between ethnicity and factors that have been demonstrated to be associated with patient activation (such as health literacy, completed years of education and socioeconomic status) also require consideration (Gwynn *et al.,* 2016; Hawley and Morris, 2016). While there is still no established literature associating inequalities in access to healthcare and patient activation, it is likely that they play a part and, therefore, should be a focus of further research.

Age is another demographic factor of interest in patient activation studies. An inverse relationship between age and patient activation has been identified, suggesting that people are generally less able or willing to take active responsibility for their health as they age (Gleason *et al.*, 2016). One explanation is that this is the result of additional challenges around declining mobility, cognitive function or increasing multimorbidity, or access to interventions limited by poor mobility, low confidence, or access to technology. Alternatively, it is possible that this is the result of generational shifts from a current generation of older people who made use of the NHS before collaborative care began to inform the culture of healthcare interactions. Older adults may have different perceptions of the role of a patient if their understanding of healthcare was formed primarily before the shift from biomedical to a biopsychosocial understanding of health had really begun.

Education level has also been demonstrated to be associated with PAM scores. Hendriks and Rademakers (2014) identified that high education levels were associated with higher PAM scores in patients with type II diabetes. Findings are similar to the results of studies with participants with other health conditions (Goodworth *et al.*, 2016; Donald *et al.,* 2011). Rijken *et al.* (2014) identified in their national patient activation survey in the Netherlands that higher education levels (university level or a high vocational equivalent) increased the likelihood of an increase in PAM scores at follow-up. They found that this was regardless of the participants' initial PAM scores and levels. This could potentially be attributed to people with higher education levels being more able to learn from experiences to more easily actively manage their health, or they may be more competent using language to communicate challenges and comprehend information provided by healthcare professionals. It is also possible that education levels are a proxy for income levels, with people earning higher wages being more likely to have received higher levels of education and having more confidence and personal resources in order to access support. Therefore, this may be a factor associated with patient activation and related outcomes.

Patient activation as captured by the PAM has been demonstrated to be associated with improved health outcomes such as blood pressure, specific blood results such as haemoglobin levels and body mass index (BMI) (Hibbard and Greene, 2013; Harvey *et al.*, 2012). The studies identifying these relationships are limited by their cross-sectional nature and there has been limited longitudinal work investigating whether these relationships remain stable or fluctuate over time dependent on healthcare interactions and resources. Their findings confirmed the initial understanding that some, but not all, self-care behaviours are associated with high PAM scores (McCusker *et al.*, 2016; Hendriks & Rademakers, 2014). Self-care and monitoring behaviours have been demonstrated to be associated with PAM scores included regular foot checks for people with diabetes and maintaining a healthy BMI (Rask *et al.*, 2009; Zimbudzi *et al.*, 2017a; Hendriks *et al.*, 2016). However, some of these findings were impacted by poor response rates to the questionnaires (Zimbudzi *et al.*, 2017a; Hendriks *et al.*, 2016) which could mean that those more likely to engage in these positive health behaviours are more likely to take part in research studies. Some health behaviours demonstrated a relationship with patient activation levels less consistently. For example, regular exercise was linked to increased PAM scores (McCusker *et al.*, 2016; Harvey *et al.*, 2012) but not found to be associated in a different study (Zimbudzi *et al.*, 2017b). However, these investigations have focused on a variety of different populations, including some without diagnosed physical health conditions (Harvey *et al.*, 2012). This suggests the need for research with participants with specific long-term conditions to determine and potentially confirm or challenge these relationships. Additionally, clarifying whether specific health behaviours and monitoring activities are related to patient activation in rheumatic conditions can help identify ways in which people are likely to manage their health. This means that behaviours people may neglect can be identified and targeted in clinic.

The association between PAM scores and healthcare costs has been consistently demonstrated. People with high PAM scores have been demonstrated to have lower healthcare costs, along with fewer emergency admissions and fewer overnight inpatient stays in hospital (Hibbard *et al.*, 2004; Hibbard, Greene and Tusler, 2009; Remmers *et al.*, 2009). However, there have not been data suggesting that patient activation scores have been associated with greater or fewer visits to primary care providers. Wong *et al.* (2011) reported that those who are more activated were more likely to feel like they have enough time with healthcare professionals to discuss their concerns and remain part of the decision-making process. This may be because of increased confidence to manage health conditions while being aware of when and how to seek help to reduce the risk of it becoming an emergency.

A great deal of literature around patient activation has focused on confirming whether patient activation is amenable to change through intervention and how. Some of the approaches taken to determine how to increase patient activation will be discussed briefly in this section. The effectiveness of interventions targeting patient activation in long-term conditions will be discussed in chapter four with a systematic review.

Attempts to increase patient activation often took place within outpatient clinical environments. Developing certain skills related to patient activation, such as question formulation, problem-solving, or health monitoring aimed to create small increases in confidence and changes to behaviour (Tzeng *et al.*, 2015). Implementation research recognised that people living in challenging circumstances with low patient activation were likely to be overwhelmed by contemplating taking responsibility for their own health (NHS England, 2018). Therefore, the focus remained on small, sustainable behavioural change. One example was the introduction of a coaching session to increase the number of engagement and biomedical questions asked during a consultation (Ibe *et al.*, 2017). The study aimed to investigate intensity of exposure for the most efficient increases to patient activation. The findings suggested that an increase in the length of the session was associated with the patient asking more questions in a later consultation.

The intention of encouraging people to make the best use of consultations has been a common aim of patient activation interventions. This has the unintended consequence of placing the onus on patients to be responsible for the level of collaboration within consultations. However, collaboration clearly must involve both parties and one response to this was the development of a Clinician Activation Measure (CS-PAM) aimed to capture how well healthcare professionals support people to actively manage their health (NHS England, 2015a). This measure has not been taken up to the same degree that the PAM has but it does begin to redress the balance in responsibility between both parties involved in a collaborative healthcare partnership. Targeting healthcare professionals for training to increase self-management support has also contributed to responding to this imbalance. Eikelenboom *et al.* (2016) conducted a randomised control trial comparing primary care practices where practice nurses were tailoring self-management support to patients compared to control practices. They found that practices that had received the training intervention did not contribute to significant differences in PAM scores at follow-up but there was a significant difference in the number of patients having care plans and self-monitoring. This may suggest that the intervention did have an impact on people making steps to manage their health, but this was not reflected in their ability and willingness to do so. Alternatively, the PAM was not sufficiently sensitive to capture the changes in participants' improved self-management skills following the intervention.

Resource-based interventions have grown in popularity, particularly incorporating regular monitoring into a patient's self-management. These are interventions that offer information or monitoring to patients in the form of electronic health records, internet-based applications or the provision of equipment for health monitoring i.e., blood pressure machines or activity trackers. Online health records or interactive web-based portals offering information and tailored messages have formed one strand of patient activation-based research. Solomon, Wagner and Goes (2012) declared their study to have been the first using an internet-based intervention and participants with different long-term conditions targeting patient activation. They identified significant differences between groups in favour of the intervention after giving participants access to an interactive web portal with interactive information sessions and the ability to book appointments and organise prescriptions. Alternatively, provision of health monitoring equipment has formed the basis for interventions. These have been particularly popular in populations with long-term conditions such as diabetes where this monitoring is required to maintain a stable condition (Riippa, Linna and Rönkkö, 2014; Heinrich *et al.*, 2012).

Interventions into patient activation have focused far less on patients currently admitted to hospital. While studies have looked at supporting people following discharge from inpatient care, including one looking at the benefit of self-referral on patient activation for people with mental health diagnoses (Moljord *et al.*, 2017), there has been limited work investigating patient activation while people are undergoing inpatient care. The work that has been conducted has aimed to increase inpatients' ability to seek information and make decisions (Rost *et al.*, 1991). As the study predates much of the post-2004 work on activation, the authors captured patient activation using the number of questions asked and in terms of metabolic control of their diabetes and the likelihood that patient activation conceptualisation has changed substantially during this time.

More recently, research into patient activation aimed to better understand adherence to pharmacological interventions in long-term conditions. Sendra-García *et al.* (2019) published preliminary analysis investigating the associations between patient activation and factors related to compliance and adherence in their treatment regimes in a rheumatology context. Participants were dichotomised into "activated" and "not-activated". The studies identified that participants receiving biological therapies were more likely to be activated compared to those receiving DMARDs. However, participants on DMARD regimes were more likely to be medication adherent compared to those on biological therapies. While the participants characterised as activated were more likely to follow their prescribed regime, this association was not significant and suggests a complex relationship between patient activation and treatment management.

3.4 Developments in patient activation conceptualisation

3.4.1 Hibbard & Mahoney (2010) model

The dominant model conceptualising activation was expanded by Hibbard and colleagues after their development of the PAM (Hibbard and Mahoney, 2010). This paper elaborated the initial theory of activation involving four stages, each building on the other in a hierarchy (Hibbard *et al.,* 2004) where people became more able to develop through the stages and engage in more complex behaviours as they became more activated (Hibbard *et al.*, 2015).

The authors suggested that those with high levels of negative emotion and limited confidence in their ability to self-manage were often low in activation (Hibbard and Mahoney, 2010). By making a very small behavioural change to trigger a small amount of individual success, however, the model suggested that confidence and activation had the potential to grow as people felt more in control of their health. They described it as a “broaden and build” theory, where the experience of positive emotions contributes building blocks to increased activation. However, experiencing repeated failures in efforts to actively manage health or change behaviours would lead to people being less involved and less confident in managing their health. Patient activation is described as a learned behaviour, but the authors do not elaborate on the potential external sources of learning that contribute to people becoming activated.

The work published in the 2010 article described survey research carried out by the authors supporting their hypothesis that there would be a relationship between participants’ activation levels and the positive and negative emotions they experienced. This contributed to their conclusion that the PAM accounted for 21% of variation in positive emotions experienced by participants, and 20% of negative emotions. This does leave a substantial percentage of unexplained variance that is not accounted for by the PAM.

3.4.2 Condition-specific patient activation

Since 2010, patient activation has often been conceptualised using Hibbard’s broaden and build model (Shively *et al.*, 2012; Rijken *et al.*, 2014). However, some work has begun developing more holistic models of explaining patient activation and relevant factors involved. These are often condition-specific to capture the intricacies that are relevant to the experience of certain health conditions. This builds on the assumption that the contextual factors that impact on living with a long-term condition differ based on the condition and on feedback from patients that they value condition-specific support (Lorig, Ritter and Plant, 2005). This work would require condition-specific theoretical groundings. Additionally, while patient activation is not condition-specific as a concept, the self-management research demonstrated a "preference" for condition-specific interventions (Ngooi and Packer, 2017).

One of the earliest condition-specific studies was that of Chen *et al.* (2014). They proposed a conceptual framework to describe factors relating to activated behaviours in people with depression. They were interested in factors related to healthcare setting (such as the extent of the collaborative-care relationship) and factors described as "neighbourhood" (incorporating demographic factors and the availability of healthcare resources). Results indicated that participants' health status, race and the locality they lived in (defined using census divisions) were significantly related to activation levels. They also identified that people using outpatient secondary care clinics or emergency departments generally had lower patient activation. While this model provided evidence for some of the demographic associations in patient activation, and considered the impact of wider healthcare factors, the authors did not measure the personal characteristics that they referred to in their initial conceptual framework.

In comparison, Goodworth *et al.* (2014) investigated variables that were associated with patient activation in people with multiple sclerosis (MS) with a focus on psychosocial factors. They identified that depression, quality of life (specific to life with MS), and self-efficacy were correlated with patient activation. They also found that employment and education levels were associated with activation. While this study was limited by its single-site recruitment, it was wider in its investigation into personal and contextual factors associated with patient activation. The authors also proposed the value of targeting health literacy to increase patient activation scores following their confirmation of the relationship between education levels and patient activation.

Similar work has been carried out in people with Chronic Obstructive Pulmonary Disease (COPD) (Korpershoek *et al.*, 2016), which demonstrated that very few of the participants were at higher levels of the PAM. Multiple regression demonstrated that anxiety, illness perception, any comorbid conditions and BMI accounted for only 17% of the variance in PAM scores. This indicates substantial variance in patient activation scores yet to be explained within a COPD population. Gleason *et al.* (2016) confirmed the findings of illness perceptions contributing to patient activation in their study, which investigated factors related to patient activation in older people with functional difficulties. Education level and financial security were not significantly associated with patient activation, in comparison to other studies (Hendriks and Rademakers, 2014; Chen, Mortensen and Bloodworth, 2014). This suggests that varying personal and contextual factors may be relevant to increased patient activation in populations living with different health conditions. Blakemore *et al.* (2016) also conducted a comparable study in older adults with multiple long-term conditions and followed up with participants six months later. They identified that patient activation scores were largely stable over time, but health literacy, depression, retirement, and social support had significant contributions to variation in patient activation. However, the response rate for the study was low at 34%, and consequently this may have impacted upon the results. The older adults who took part in the study may have been more likely to be retired and well in order to have the time and health to take part.

3.4.3 Potential for a rheumatology patient activation model

Much research into patient activation has focused on looking at what concepts are related to patient activation with the intention to better understand the relationship between patient activation and various clinical, demographic, and psychological variables. Much of this work has been centred around populations with diabetes (Remmers *et al.*, 2009; Rask *et al.*, 2009; Hibbard *et al.*, 2008), although studies have also focused on other long-term health conditions and participants at risk of developing health conditions. So far there has been limited research into musculoskeletal disorders. There is benefit to understanding whether present findings apply to rheumatology patients.

There is still limited research into the wider construct of patient activation, how it relates to fluctuating physical conditions, and how best to use information about patient activation to target the type and level of support people receive in self-managing (Roberts *et al.*, 2016). Understanding the factors that contribute to increased patient activation in people with rheumatic conditions would be beneficial to planning service provision. Developing an understanding of the factors that impact patient activation and the spread of PAM scores and levels across a rheumatology population would help understand what factors contribute towards patient activation that may be amenable to intervention.

While the PAM has been used as an outcome measure, there has been limited longitudinal research focused on patient activation in a rheumatology context. The first of these was a survey study investigating what variables were associated with patient activation in a sample of older adults who lived with functional difficulties (Gleason *et al.*, 2016). These difficulties included a range of long-term conditions. The study identified that patient activation was associated with self-perceived health, low mood, social support, and challenges with carrying out daily activities. The second of these is a survey study of people living in Salford in the north of England. The sample was formed of older adults with at least one long-term condition and identified relationships between PAM scores and health literacy, age, social support, quality of life, and whether participants were retired. These two studies did not differentiate between participants with and without rheumatic conditions (Gleason *et al.*, 2016; Blakemore *et al.*, 2016). Patient activation remains one of the less well understood concepts in self-management research overall (Roberts *et al.*, 2016). The model described by Hibbard and Mahoney (2010) does not account for wider personal and contextual factors which may impact on patient activation, including any condition-specific issues. A survey to understand and map patient activation scores would contribute to the understanding of patient activation. Combined with a detailed qualitative investigation about how people understand and perform patient activation, this can begin to fill the gaps in the understanding of patient activation.

Given that it appears that interventions to improve self-management are also more successful if they are condition-specific (Lorig, Ritter and Plant, 2005), condition-specific research could form the foundation for developing theory-led, rheumatology-specific interventions targeting activation in the future.

3.5 Ethics considerations of patient activation

There are some ethics-related considerations that require discussion when approaching patient activation. The increase in interest in patient activation within healthcare services (and the NHS in particular) has the opportunity to support patients to take on responsibility and autonomy to manage their health that allows them to feel more confident and in control about managing their condition. However, this may not always be the case and some patients may experience adverse effects as a consequence of this shift in responsibility. There is a risk that the initial promising evidence relating to higher patient activation and lower healthcare costs may lead to patients being pressured to take additional responsibility for their own health and to self-manage to a greater extent than they feel able to as it is expected as a moral responsibility (Gibert, DeGrazia and Danis, 2017). This may contribute to more people taking on responsibility they do not want or are unable to manage, or patients being stigmatised by healthcare professionals for not taking on this responsibility. This could be extended to concern that those who are actively self-managing and still experience flares or challenges with their health could experience shame or judgement from healthcare professionals for not self-managing well enough to anticipate and prevent this.

Additionally, an important consideration when working in the field of patient activation and implementing self-management support is that those who choose not to actively self-manage and take on this responsibility will have valid reasons for doing so and should not face stigma or limited access to support they require. It is possible that asking those who are already dealing with complex and limiting life circumstances to take on additional self-management responsibility that they would not welcome is not in their best interests. The choice not to self-manage is a valid option for self-management and is rarely captured by outcome measures such as the PAM. Similarly, the term "*dangerous self-manager*" (Yadav *et al.*, 2018) refers to patients with confidence to self-manage but limited knowledge to make use of when self-managing. While this approach to self-management is described in stigmatising language, it is also a valid choice for patients self-managing.

Other ethical concerns are that when patients complete the PAM as a tool to determine the course of their healthcare, it is not clear what responsibility they may be asked to take or they may not understand that how they complete the PAM might have implications for their care. This is particularly relevant given the number of people who required support to complete the PAM in the case studies and the fact that 42% of adults of working age are unable to comprehend basic health information (Chew *et al.*, 2017; Public Health England, 2015). With the vast number of people who would require this support to complete the PAM, the measure may not be as person-centred as it intends to be. There could be unintended consequences of patients ending up with inadequate support and without the self-management support that it is in their best interests (de Iongh, 2018) because they haven't asked for support they need to complete their measure or it has been co-completed with healthcare professionals with different priorities.

Another issue to be considered when integrating an outcome measure such as the PAM to stratify care is that the outcome may reduce autonomy for some patients. For example, those who are in the higher levels of the PAM receiving clinical care may be offered low-intensity resources as a form of self-management support. However, they may be sufficiently aware of their support needs to believe they need more intensive support but may not be able to access this as a consequence of their seemingly active self-management. The use of outcome measures in this way also asks patients to value their own health and does not account for fluctuations in priorities or recognise that health may not necessarily be a priority for patients (Gibert, DeGrazia and Danis, 2017).

Context that is important to consider when considering how to provide self-management support includes the range of equity in access to services, socio-economic circumstances and other wider determinants of health. Patients with long-term conditions across the UK are self-managing in unequal circumstances. The additional facilities and resources that are available to support effective self-management (for example, access to safe open spaces for exercise, access to healthier and affordable foods in shops rather than being reliant on more local shops with limited stock, access to personal transport for more convenient access to clubs, classes and additional support such as hydrotherapy, massage and physiotherapy that also come with additional costs) may not be available to everyone. Access to these resources mean that those who wish to engage in positive health behaviours will be able to do so more easily. Geographic inequity in healthcare contributes to health inequalities and how far local budgets need to stretch based on the services available (Rice and Smith, 2001).

This is without the consideration that barriers to self-management also include a lack of stable access to housing, caring responsibilities or other life burdens, other life complexities such as job insecurity, financial concerns and fewer social resources (Hardman, Begg and Spelten, 2020). Not all are self-managing equally and these issues may make people less likely or able to engage in preventative self-care. The push towards patient activation and expecting people to take this additional responsibility may increase these health disparities and while those who are already in a position to self-manage effectively could benefit from the support offered, self-management support that includes regular attendance or work between sessions will see increased burden for the most vulnerable patients (Hardman, Begg and Spelten, 2020).

These ethical considerations about access to support and the potential implications of introducing additional self-management support should be considered carefully to reduce the impact of health inequalities and to avoid widening the gap between those who have the resources to self-manage effectively and those who do not.

3.6 Summary of thesis rationale

- Patient activation describes how willing and able someone is to take an active role in managing their health (Hibbard and Greene, 2013). It is a multidimensional construct incorporating associated concepts such as self-management behaviours (e.g. adherence to treatments), health literacy, and self-efficacy (the belief in one's ability to achieve a desired outcome) (Hibbard et al., 2004; Do *et al.,* 2015).

- The dominant method of capturing activation is the extensively used "Patient Activation Measure" (PAM) (Hibbard *et al.,* 2004). The PAM identifies beliefs that people have about themselves and the responsibility they hold for managing their health (Hibbard and Mahoney, 2010). This conceptualises activation as involving four stages, each building on the other in a hierarchy (Hibbard *et al.,* 2004). As patients become more activated, they are more able to move through the stages and become more able to engage in more complex behaviours (Hibbard, 2015). While it is understood that providing information alone is insufficient to activate patients (Rix and Martin, 2015), factors that do contribute to increasing patients' confidence and ability to actively manage their health are less well understood.
- Additionally, little is known about the factors involved in patient activation in IA patients. As it appears that interventions to improve self-management are more successful if they are condition specific (Lorig, Ritter and Plant, 2005), condition-specific research can form the foundation for developing a theory-led, rheumatology specific intervention targeting activation.
- There has been limited longitudinal research focused on patient activation in a rheumatology context and there are gaps in the knowledge within this field. Patient activation skills across rheumatology populations alone are unclear, as well as any factors that explain variation in patient activation.
- There is no current systematic review investigating the effectiveness of interventions that specifically target patient activation for long-term, fluctuating conditions.
- The aim of this thesis is to address these knowledge gaps. The following chapter begins with a systematic review of the literature investigating the effectiveness of interventions targeting patient activation.

Chapter 4: Systematic Literature Review

Following the identification of a gap in the knowledge related to the effectiveness of patient activation interventions reported in chapter 3, this chapter reports a systematic review of existing evidence around the effectiveness of interventions targeting patient activation in people with long-term physical health conditions. This chapter is reported according to PRISMA guidelines (PRISMA, 2009).

4.1 Background

A description of patient activation and its current understanding was provided in the previous chapter.

4.2 Need for review

While there have been several reviews of the literature into patient activation in the UK, these have focused on documenting the evidence behind the Patient Activation measure (PAM), and how the PAM is being utilised in the NHS (Mukoro, 2012; Armstrong *et al.*, 2016; Rix and Marrin, 2015). There has been progress with systematic reviews into patient empowerment, a related concept, with the measures used to capture it being reviewed in an attempt to understand how to target and support people to manage their health (Barr *et al.*, 2015). The aim of that review was to identify methods of capturing a variety of concepts including patient activation. However, the published review deviated from the planned protocol and no longer included patient activation in the final synthesis (Barr *et al.*, 2015), meaning that patient activation remained un-reviewed. Given that this is an ever-increasing field of applied health research, developing the evidence base to determine what are appropriate, feasible, and effective interventions is likely to be of interest to health providers and clinical commissioning groups (CCGs).

At the time of the initial searches for this thesis there had not been a systematic review of the literature into interventions targeting patient activation in long-term physical health conditions. Therefore, a systematic review was conducted between October 2016 and June 2017. During the update of the review presented in this thesis, a newly completed doctoral thesis was identified that included a systematic review investigating the effectiveness of self-management interventions in increasing patient activation (Alexander, 2018). However, there were some differences between that systematic review and the one presented in this thesis. The Alexander (2018) systematic review only looked at studies that used the PAM as an outcome measure. As there are other ways of capturing patient activation (albeit none as extensively used as the PAM), there was benefit in updating the review presented in this thesis, which included other measures of patient activation as well as the PAM. Additionally, given that questions about the validity of the PAM also remain (as discussed in chapter 3), this adds benefit to reviewing the literature in further detail.

There have been a range of approaches used in delivering interventions targeting patient activation in long-term conditions. Therefore, collating and synthesising the evidence around whether these interventions are effective would be beneficial.

4.3 Methods

4.3.1 Definitions

For this review, patient activation was defined as the ability, confidence, and skills someone possesses to actively manage their health, as well as the belief they hold that their role is valuable in their healthcare (Hibbard *et al.*, 2004). It is most commonly captured using the Patient Activation Measure (PAM) (Hibbard *et al.,* 2004; Hibbard *et al.*, 2005), but other outcome measures have been used, such as the PACIC (Glasgow *et al.*, 2005), and proxy measures such as participants' knowledge about their condition, decision making, and self-management behaviours.

The definition was deliberately broad to accommodate interventions that may target a wide variety of aspects of patient activation. The definition used for this review was also closely connected to concepts such as patient empowerment, enablement, and patient engagement. The overlap identified in terminology that described health behaviours that reflect someone being invested in managing their health and taking steps to be involved in the collaborative healthcare process was discussed in detail in section 3.1.2. The definitions discussed in this section were used for the purpose of the review and for reference when screening articles. When one of these concepts was covered in a study considered for inclusion, the definition considered by the study authors was compared to the operational definition of patient activation for the review. A study was included if its definition for any of these concepts overlapped with the definition for patient activation, even if it used a measure of patient empowerment (as was the case in some included studies). These terms were defined to identify occurrences where one term has been used in a way that also meets the definition for patient activation for the purposes of this review.

4.3.2 Objective

This study systematically reviewed the literature to investigate effectiveness of interventions targeting patient activation in people with long-term physical health conditions compared to a control group.

4.3.3 Eligibility criteria

The full inclusion and exclusion criteria are available in appendix A. Studies were included if they were:

- Randomised controlled trials (RCTs). Pragmatic randomised trials were included. The decision to include only RCTs risked losing feasibility or cohort studies by exclusion. However, this did ensure the effectiveness of the interventions was compared to a control group and ensured the best possible evidence quality.
- Recruiting adults over 18 years old. Studies with participants under eighteen years of age were excluded as it is possible that children and adolescents respond differently to managing health conditions. The results may have also been biased as a result of factors such as parental support, responsibility and other age-related or developmental factors.
- Not primarily investigating the management of a mental health diagnosis. However, studies involving participants with a primary physical health diagnosis and a comorbid mental health diagnosis were included.
- Related to patient activation, captured as a primary or secondary outcome measure pre- and post-intervention.
- Written in or translated into English.
- Published in or after 2004, when Hibbard *et al.* (2004) published the seminal paper on patient activation, along with the first measure of patient

activation. This decision reflected the changes and growth in interest in patient activation since then.

- Focussed on long-term fluctuating physical health conditions, defined as those likely to physically impact the person diagnosed for a period longer than three months (Wagner *et al., 1996*), which contributed to significant changes in function (Perrin, Gortmaker and Walker, 1993). This allowed for people to have made a certain level of life adaptation to accommodate their condition, and to potentially have experienced some fluctuation in their health during this time. The definition was consulted when studies arose where it was unclear whether the health condition could be considered long-term and/or fluctuating.

As the main interest was learning about how people learn to live with physical long-term conditions, studies with participants with specifically a primary mental health diagnosis were excluded. However, as mentioned above, studies which recruited participants with physical health conditions with a comorbid diagnosis of anxiety or depression were included in the review. There was the risk that this may have an impact on how participants would learn to manage their condition, however this distress may occur as a result of living with the physical health condition (Gettings, 2010). The experience of this distress may be different compared to people living with an initial mental health diagnosis. Another factor that contributed to this decision was that behaviour change interventions may be different for those with a primary mental health diagnosis. There are often baseline differences between people with mental health conditions compared to physical health conditions, and often a lower baseline of patient activation in those with depression compared to a physical health diagnosis (Chen, Mortensen and Bloodworth, 2014). Terminal illness was not excluded as people could be receiving palliative care for varying lengths of time. However, it is possible that the interventions to support people to take responsibility for their health would be different.

4.3.4 Search strategy

The search strategy was developed with support from a specialist subject librarian at the University of the West of England.

The search strategy was:
(("patient activation" OR "patient engagement" OR "patient empowerment") AND ("long term condition" OR "chronic condition" OR "chronic disease" OR "chronic illness" OR "long term illness")) AND intervention AND random*

Searches were carried out during January 2017 and rerun in July 2019 to update the review.

Studies were identified through a variety of means. This included searching the following online databases from inception to January 2017 (and later between January 2017 and July 2019) for appropriate abstracts: PsycINFO, Medline, AMED and CINAHL. As patient activation is a concept that could be relevant to a variety of types of health professionals working with long-term physical conditions, databases were selected to include a variety of multi- and interdisciplinary research. Search alerts were set up so that any publications matching the search criteria between the searches and synthesising the findings were flagged to the researcher. This allowed them to be considered for inclusion.

Additional studies were sourced by reviewing the reference lists from key publications and articles related to patient activation, as well as articles that were already included in the review. Grey literature was reviewed, to identify research which may not have been fully published yet or relevant theses. This could reduce the risk of publication bias, as it was possible that trials which found positive changes were more likely to be published in journal format (Green and Higgins, 2008). Grey literature reviewed included theses from WorldCat dissertations, articles in Papers First, grey literature databases including NTIS, Open Grey, and Grey Lit Report, and searching for book chapters via the NLM catalogue.

Finally, as a last method of identifying suitable studies for inclusion, key journals “Patient Education and Counselling” and “Health Education & Behaviour” were searched by hand from 2004 to July 2019. This reflected the requirement that studies needed to be published after 2004 to be considered for inclusion and offered the opportunity to identify any possible papers for inclusion which may have been missed by prior searches. Hand searching, search alerts for recent publications matching the search criteria, and snowballing led to the identification of eight further studies.

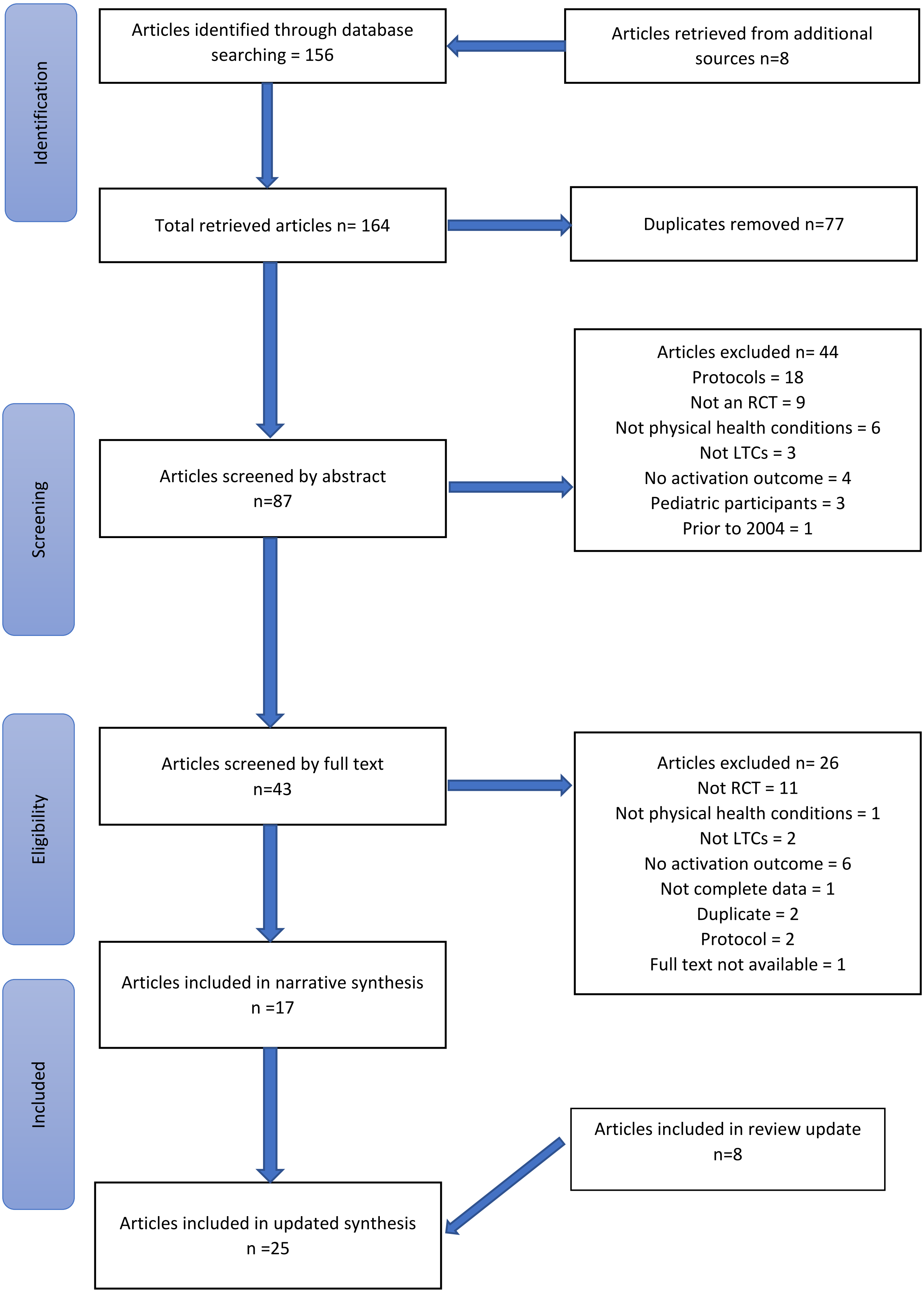
The Cochrane Risk of Bias tool (Higgins and Green, 2011) was selected to determine quality in the studies. A proportion of these studies were checked by Dr Emma Dures as a second reviewer. Consensus meetings were held for the duration of the review to discuss and determine risk of bias. In addition, a third colleague added their opinion on a sub-set of papers. Dr Dures' role as a second reviewer in data extraction and risk of bias added rigor to strengthen the accuracy of this process. However, because the review also contributed towards an assignment as part of the PhD process, it was important to ensure the researcher retained ownership of the review. Consequently Dr Dures' role was more limited than might typically be research best practice. Multiple reviewers determining studies' inclusion and quality are considered best practice to increase the reliability (Siddaway, Wood and Hedges, 2019). Therefore, the limited role of the second reviewer here is a potential limitation in the study. Steps were taken where possible to ensure that the researcher retained ownership but increased reliability e.g., discussing uncertain cases with Dr Dures in order to reach a decision about inclusion. However, this potential limitation should be acknowledged.

Study quality was categorised using the Cochrane guidelines (Higgins and Green, 2011), and this was considered when synthesising the findings of the review to understand the impact of evidence quality on studies' results.

4.3.5 Study selection

Study selection was carried out throughout January and February 2017 by the researcher and updated during July 2019 following re-running the searches.

Figure 4.3: PRISMA diagram with inclusion and exclusion



4.3.6 Data extraction

Data extraction was carried out using the Cochrane RCT review form (Higgins and Green, 2011) (see appendix B). Modifications were made to extract information about the long-term condition studied, how patient activation was captured and additional details about intervention delivery. The data extraction was carried out by the researcher. The data extraction forms were checked by Dr Dures as a second reader to confirm accuracy.

There was a great deal of variety in the studies available, the outcome measures used (including proxy measures for activation) and the forms of interventions (particularly in terms of duration as this ranged from the provision of resources as a one-off intervention to face-to-face support that spanned months. Consequently, a meta-analysis was not possible in the analysis of the review. Instead, a narrative synthesis was carried out to draw together the evidence and findings of the review.

4.4 Search update

During July 2019, the database searches were replicated, along with the grey literature searches and journal hand searches between January 2017 and July 2019. In total, eight additional studies were identified for inclusion in the review. The data from these were extracted independently by the researcher and are included in the summary tables.

4.5 Results

Data extraction table 4.5 and 4.5a contain the brief descriptions of the interventions, the participants, and the findings. Given the search strategy, populations and interventions were so heterogeneous that a narrative synthesis was confirmed as the most appropriate strategy for synthesising the findings.

Table 4.5: Summary of study design and long-term conditions

Authors	**Study design**	**Long-term conditions**
Lussier *et al.*, 2016	Randomised controlled trial	Hypertension diabetes or dyslipidaemia
Wagner *et al.*, 2012	Cluster randomised trial	Hypertension
Grønning *et al.*, 2012	Randomised controlled trial	Rheumatoid arthritis, psoriatic arthritis or unspecified polyarthritis
Solomon, Wagner and Goes, 2012	Randomised controlled trial	Asthma, diabetes, hypertension and other unspecified long-term condition
Hibbard *et al.*, 2007	Randomised controlled trial	Diabetes, high blood pressure, lung disease, high cholesterol, arthritis, heart disease
Kvale *et al.*, 2016	Randomised controlled trial	Cancer
Maindal *et al.*, 2011	Cluster randomised controlled trial	Dysglycaemia
Shearer, Cisar and Greenberg, 2007	Randomised controlled trial	Heart disease
Ryvicker *et al.*, 2013	Cluster randomised trial	Hypertension

Eikelenboom *et al.*, 2016	Cluster randomised trial	Diabetes, asthma, COPD, cardiovascular conditions
Wolever *et al.*, 2010	Randomised controlled trial	Diabetes
Shively *et al.*, 2012	Randomised controlled trial	Heart failure
Smidth *et al.*, 2013	Cluster randomised trial	COPD
Lorig *et al.*, 2009	Randomised controlled trial	Diabetes
Lorig *et al.*, 2010	Randomised controlled trial	Diabetes
Jäger *et al.*, 2017	Cluster randomised controlled trial	No specified conditions noted
Weymann, Härter and Dirmaier, 2013	Randomised controlled trial	Back pain or diabetes
Denig *et al.*, 2014	Pragmatic randomised control trial	Diabetes
Kangovi *et al.*, 2017	Randomised clinical trial	Diabetes, obesity, hypertension
Körner *et al.*, 2019	Randomised controlled trial	Cancer

Cortez *et al.*, 2017	Cluster randomised trial	Diabetes
Dolovich *et al.*, 2019	Pragmatic randomised controlled trial	COPD, hypertension, osteoarthritis, diabetes, heart disease, cancer, stroke
Huntink *et al.*, 2018	Cluster randomised controlled trial	Unspecific cardiovascular conditions
Xue, 2014	Randomised controlled trial	Diabetes
Schumacher *et al.*, 2017	Randomised controlled trial	Cancer, angina, diabetes, congestive heart failure, arthritis, stroke, depression, high blood pressure, atrial fibrillation, COPD

Table 4.5a: Data Extraction Table. N = number of participants, SD = standard deviation, p = significance level, r = effect size value

Authors	**n**	**Demographic information**	**Format and contents of intervention**	**Duration of intervention**	**Activation Outcome Measure**	**Findings**	**Effect Size**
Lussier *et al.*, 2016	221	Average age (in years) 58.2 (SD: 6.85) 42% female 72.3% had education beyond 18	Online text with information, with a subgroup attending a single nurse-led workshop	E-learning: had unlimited access (intervention took 45-75 mins to complete) Single 90-	PACIC	Activation subscale was significantly different between usual care and e-learning in favour of the intervention (p<.05) Activation was not significantly different	Usual Care and E-learning: Cohen's d= -0.10, r = -0.05 E-learning and workshop: Cohen's d = 0.04, r = 0.02

				minute workshop		between e-learning and workshop vs. usual care or e-learning (p>.05)	Usual Care and workshop: Cohen's d = -0.07, r = -0.03
Wagner *et al.*, 2012	453	Average age 54.8 years (12.44) 70% female 50% white, 46% black, 3.7% other 70% had education beyond 18	Online access to clinic information, ability to enter and track blood pressure data. Goal setting and question answering functions built into this online access	Ongoing access for up to 1 year	PAM, patient Empowerment Scale, PACIC	Not a significant change in PAM scores between groups (p=0.49) There was a significant difference in empowerment between groups (p=0.02) PACIC was not significantly different between groups (p=0.82)	Patient empowerment raw effect size: 1.1, p=.02
Grønning *et al.*, 2012	141	Average age 58 (11) 69% female, 38% educated beyond 18	Group patient education sessions provided by nurses with 2 one-to-one follow-ups	6 weekly group sessions, 3 hours long and 2 individual appointments approximately 45 minutes each	PAM	At 12 months, there was a trend towards higher PAM scores in favour of the intervention group, but the difference was not statistically significant (p=.069)	N/A

Solomon, Wagner and Goes, 2012	201	49% of participants were 55-64 years old 52% female, and 62% were college graduates 86% were white	Emails with self-delivered content covering evidence-based information and problem-solving opportunities	Weekly for 12 weeks	PAM	There was a significant between group difference post-test in favour of the intervention group for patient activation (p=.04)	F(2,55) = 6.47, P = .003, effect size r = .R436
Hibbard *et al.*, 2007	479	Average age of 60 69% female 96% white	Group face-to-face intervention based on CDSMP	6 weekly sessions 2.5 hours long each	PAM	Activation is changeable and there were significant changes following the intervention (p<0.001)	Insufficient information available to understand treatment effect
Kvale *et al.*, 2016	79	100% were female Approximately 80% white Average age 58 Between 53% and 60% of participants had college education	Motivational interviewing session with health goal setting and barriers to success	Single session	PAM	There was not a significant difference in PAM scores between groups at 3 months (p=.51)	N/A
Maindal *et al.*, 2011	509	Average age 62.2 Between 66.3% and 68.5% of participants had vocational education 46% female	Group sessions with a 1:1 interview before and afterwards. This included information giving. Practical element included physical exercise and action planning	2 one-to-one interviews and 8 group sessions over three months (18 hours of intervention in total)	PAM	There were no significant differences in patient activation scores between the groups post intervention (p=.18)	N/A

Shearer, Cisar and Greenberg, 2007	87	Average age 76.03 (8.32) 35.% female 93% white, 46% college educated	Scripted telephone calls discussing participants' role in self-management, discussing concerns, and information giving	Six calls in total from nurses	Self-Management of Heart Failure scale (SMHF)	There was a significant interaction with group by time for self-management behaviours at follow-up (p=.01)	r = 0.29 p > 0.05
Ryvicker *et al.*, 2013	587	Average age 64.2 (10.8) 67% female 100% were black 40% had lower than a high school level education	Emails and monitoring equipment Augmented intervention provided information and goal setting	Ongoing access over 12 months	PAM	There was not a significant difference in PAM scores in the interventions compared to control in the multivariate models (p>0.05)	N/A
Eikelenboom *et al.*, 2016	664	Average age 65.4(10) 57% female 28.7% had self-rated "high level" of education	Personalised self-management plan based on profile and offering access to varied types of support (internet-based, information based and exercise groups)	Single session	PAM	There was not a significant difference in PAM scores between groups at 6 months (p=.59)	N/A
Wolever *et al.*, 2010	56	Average age 53(7.93) 77% female 39% white, 57% black, 4% other 41% of participants had a college education	Telephone coaching contact focused on challenges, goals and priorities for the future. Self-care was discussed and participants set goals	Telephone sessions weekly for 8 weeks, then 4 fortnightly and a month break before the final call	PAM	There was a significant difference between groups in favour of the intervention in PAM scores (p<.001)	Cohen's d: 0.71 r = 0.34

Shively *et al.*, 2012	84	Average age 66.1(10.76) 98.8% male 77.4% white Average of 14.8 years education	Sessions with nurses to focus on increasing confidence and knowledge, improving skills and self-care behaviour. People set goals, asked questions and discussed barriers to active self-management	Individual support over 6 months	PAM, Self - Care of Heart Failure Index (SMHF)	Intervention group had a significant increase in PAM scores over time compared to the control group (p=.03)	Group x time F = 3.73 Partial n^2 = 0.06 P = 0.03 Observed power = .67
Smidth *et al.*, 2013	744	Average age 67.1 51.1% female	Group session chaired by experts with topics including self-management support, clinical information, and contact details for their doctors	4 x 2.5-hour sessions	PACIC	There was a significant difference in activation between the intervention and internal control group (p<.05) and between the intervention group and the internal control group (p<.02) in favour of the intervention	Intervention to control: 0.12 [95% CI: 0.00;0.25], (p<.05) Intervention to external control: 0.14 [95% CI: 0.03;0.25], (p = 0.014)

Lorig *et al.*, 2009	345	Intervention group: Average age 67.7 (11.9) 62.4% female 15.2 years of education 64% white Control group: Average age 65.4 (65.4) 66.2% female 15.7 years of education 70.6% white	Structured groups facilitated by peer leaders covering information and activities e.g. relaxation and goal setting	6 weekly 2.5-hour sessions	PACIC	Significant between group differences in changes to PAM scores were found at 6 months in favour of the intervention group (p=.02)	Insufficient information available to understand treatment effect
Lorig *et al.*, 2010	761	Average age 54.3 73% female Average of 15.7 years of education 76% white	Website access for information, threads and messages for discussion and activities facilitated online by peer lay leaders Exercises involve information, problem solving and relaxation.	6 weeks of regular access	PAM	Significant between group differences in PAM scores were found at 6 months in favour of the intervention group (p=.02)	r = -0.05 p = 0.72
Jäger *et al.*, 2017	273	Average age 72.2(8.9) 55.7% female 4.8% had university education	Provision posters, brown bags as prompts for medication and information tool for participants	Resources available for 9 months	PAM	There was not a significant difference in PAM scores between groups at comparing pre and post intervention scores (p=.48)	N/A

			attending primary care appointments				
Weymann, Härter and Dirmaier, 2013	561	Average age 51.8 (13.1) 60% female 55% had over 10 years education	Online information, with reply options to respond to the content (The intervention group was provided with tailored information according to their knowledge, circumstances and coping style)	Ongoing access over 3 months	Health education impact questionnaire, preparation for decision making scale, health related knowledge	The outcome measure used does not provide a global score, but the analysis indicated that there was not a significant main effect for intervention x time for any of the subscales with the exception of Knowledge (p=.04)	Health-related knowledge: .53 (p=.04)
Denig *et al.*, 2014	344	Average age 61.8 (8.5) 44% female Between 38% and 40% were considered to have "low educational attainment"	Decision made developed for participant to understand risk of different heath conditions attached to an electronic health record: Participants reviewed treatment aims and options and were given a hardcopy to takeaway	Single session	Diabetes empowerment scale	There was not a significant difference in empowerment around psychosocial management of diabetes between groups following the intervention (p = 0.92).	N/A

Kangovi *et al.*, 2017	302	Approximately 75% female 94.7% African American Average age 56.1 (12.6) in control group and 56.6 (13.6) in intervention group	Semi-structured interview to set goals, signposting from community health-worker to achieve goals 6 months of telephone, text message or visits for support Finally, there was ongoing access to a weekly peer group for social support	Support over 6 months	PAM	There was not a statistically significant difference between groups in patient activation following the intervention. (p= .66)	N/A
Körner *et al.*, 2019	89	Average age 54 (SD: 12.21) Approximately 77% female 86% white 41.9% had over 17 years of education	Provision of a workbook covering self-management skills such as problem solving, communication, relaxation techniques and reviewing social support. Participants worked through this independently and were not offered support with this.	6 weeks	Health Education Impact Questionnaire	There was not a statistically significant difference between groups in patient empowerment following the intervention (p=.11), but there was at follow-up (p=.01)	N/A

Cortez *et al.*, 2017	238	Average age 57.8 (SD: 9.43) 66% of control group and 67% of intervention group female 34% of control group and 27% of experimental group educated to 18	Groups covering information provision, myths and facts and preparing for self-care Telephone calls individually between each cycle of 3 meetings	9 meetings of 2 hours each over 11 months	Diabetes empowerment scale	There was not a statistically significant difference between groups in patient activation following the intervention (p=.82)	N/A
Dolovich *et al.*, 2019	312	Average age of intervention group 78.1 (SD: 6.3) and control group 79.1 (SD: 6.6) 60.4% of control and 63.9% of intervention group female 58.8% of intervention group and 48.7% of control group had post-18 education	Participants were provided with an electronic health record where professionals contributed to a care plan Professionals provided ad hoc follow-up support along with use of the electronic health record	Ongoing access over 6 months	This information is not specifically provided.	There was not a statistically significant difference between groups in patient activation following the intervention (p=0.08)	r = 0.17. Significance not provided.
Huntink *et al.*, 2018	2184	Approximately 35% female Average age of intervention group 72.6 (SD:9.2) and control group 71.6 (SD: 9.7)	Practice nurses received training in motivational interviewing to support patients in intervention practices	Single session	PACIC and PAM	There were significant differences between groups in favour of the intervention for both PACIC and PAM scores at follow-up (P< 0.01)	Insufficient information available to understand treatment effect

Xue, 2014	221	64.3% female 95% white. Average age 62.9 (10.8) 59.3% had at least college-level education	Monthly support groups led by a peer facilitator (the control group received the same group from a professional facilitator) Goal setting follow-up calls from peer facilitators	12 months	PACIC	There were not significant differences in PACIC score between the control and intervention groups following the intervention (p=0.75)	Insufficient information available to understand treatment effect
Schumacher *et al.*, 2017	69	Average age 72.6 (8.8) 57% female 23% white and 77% identified as "non-white" 19% had some or full college education	Face to face visit from a health coach to identify ways their condition may worsen, to contact support and set goals Three telephone calls over the next month	1 month	PAM	There was a statistically significant difference between groups in favour of the intervention at follow-up (p= 0.04)	Insufficient information available to understand treatment effect

Table 4.5b: Risk of Bias Summary Table

✓ **Low risk of bias**

☒ **High risk of bias**

- **Unclear risk of bias**

Article	**Random Sequence Generation**	**Allocation Concealment**	**Blinding of participants and personnel**	**Blinding of outcome assessment**	**Incomplete outcome data**	**Selective outcome reporting**	**Other sources of bias**
Lussier *et al.*, 2016	✓	✓	☒	✓	☒	-	-
Wagner *et al.*, 2012	✓	-	☒	☒	✓	-	-
Grønning *et al.*, 2012	✓	✓	✓	✓	✓	-	✓
Solomon, Wagner and Goes, 2012	✓	-	✓	✓	☒	-	-
Hibbard *et al.*, 2007	-	-	☒	-	✓	-	✓
Kvale *et al.*, 2016	-	-	☒	-	✓	-	☒
Maindal *et al.*, 2011	✓	✓	✓	-	☒	-	-
Shearer, Cisar and Greenberg, 2007	-	-	-	-	☒	-	☒
Ryvicker *et al.*, 2013	✓	✓	✓	✓	☒	-	-
Eikelenboom *et al.*, 2016	✓	✓	☒	-	-	-	-
Wolever *et al.*, 2010	✓	✓	☒	✓	✓	-	☒
Shively *et al.*, 2012	✓	-	☒	-	☒	-	☒
Smidth *et al.*, 2013	✓	-	☒	☒	-	-	-

Lorig *et al.*, 2009	✓	-	☒	-	✓	-	-
Lorig *et al.*, 2010	✓	-	☒	-	✓	-	-
Jäger *et al.*, 2017	-	-	☒	-	☒	-	✓
Weymann, Härter and Dirmaier, 2013	☒	-	-	-	-	-	✓
Denig *et al.*, 2014	✓	✓	-	-	-	-	☒
Kangovi *et al.*, 2017	✓	✓	☒	✓	✓	-	☒
Körner *et al.*, 2019	✓	✓	☒	☒	✓	-	☒
Cortez *et al.*, 2017	-	-	☒	-	-	-	-
Dolovich *et al.*, 2019	✓	-	☒	☒	✓	-	-
Huntink *et al.*, 2018	-	-	☒	-	-	-	-
Xue, 2014	-	-	☒	-	-	-	✓
Schumacher *et al.*, 2017	✓	✓	☒	✓	☒	-	✓

4.6 Description of included studies

4.6.1 Participants

Of the 25 studies, there were 9918 participants with 4722 assigned to intervention groups and 5196 assigned to control groups. Ten studies had an average age in the 6th decade of life (i.e., 50-59), nine had an average age in the 7th decade (60-69), five studies had an average age in the 8th decade (70-79) and one study did not specify an average age. In all but six studies, the majority of participants were female and the majority of studies had a sample that recruited mainly white people. Two studies (Ryvicker et al., 2013; Kangovi et al., 2017) recruited solely or almost completely participants who were black and one study (Schumacher *et al.*, 2017) worked with a sample that self-reported that they were non-white. Education levels ranged across the review but most studies involved samples with at least 1/3 of participants having attended post-18 education.

There was a range of long-term, physical health conditions that participants were living with across the review. Heart disease and diabetes were particularly common with 6 and 13 studies recruiting participants with these conditions respectively. Four studies recruited participants with types of arthritis. However, two of these did not specify the type of arthritis and one recruited osteoarthritis. Only one study specifically reported recruiting patients with IA, highlighting the lack of representation for IA patients in patient activation interventions.

4.6.2 Outcomes measured

While 15 studies used the PAM as the measure of patient activation, six used the PACIC (Glasgow *et al.*, 2005) as the outcome measure. This measure was intended to capture how closely to Wagner's CCM people believed the care they have received had been (Glasgow *et al.*, 2005) and included three items dedicated solely to patient activation. However, the remainder of the items in the measure capture concepts that are relevant to actively managing health, e.g. problem solving or goal setting. Gibbons *et al.* (2017) suggest that the PACIC measures a single, unidimensional trait instead of the previously thought five separate factors, and Glasgow et al. (2005) have found that this correlated moderately well with the PAM ($r=0.43$, $p<0.001$).

The PACIC has been demonstrated to have good reliability (Gibbons *et al.*, 2017). However, the validity of the subscales has been contested because of the aforementioned shift in conceptualisation to a single captured trait (Dattalo *et al.*, 2012). Lussier et al. (2016) was the only study included in the review that reported only the patient activation subscale. This was noted in their "other risks of bias" section.

The Diabetes Empowerment Scale was used in two studies within the review. It is an eight-item measure that is intended as a measure of self-efficacy (Anderson *et al.*, 2000). This demonstrates how the overlap in definition between patient activation, empowerment, and (in these circumstances) self-efficacy has contributed to outcome measures being used across several different constructs.

There did not appear to be a specific outcome measure that was associated with significant between-group differences at follow-up more than other outcome measures.

4.6.3 Control groups

The types of control for comparison in most cases was usual care. Some studies included a basic intervention for the control group and an augmented version for the intervention group (e.g. Ryvicker et al., 2013). In one study, the two groups received the same intervention, but the control group received it from a professional rather than a peer facilitator as the study intended to identify if peer-support was effective (Xue, 2014). With Weymann et al. (2015), a baseline website was available, compared to the intervention which was tailored to individuals' needs. One study (Smidth *et al.,* 2013*)* used an additional external control group to attempt to further increase validity.

4.6.4 Interventions

Many interventions included information provision, goal setting, and problem-solving barriers to active self-management. Determining priorities for change was a common factor in supporting participants to set goals, as well as the opportunity to report back on their progress towards their goals. Some interventions gave participants access to a portal to track information and results related to their own health to monitor it, and some studies also gave participants access to monitoring equipment such as blood pressure machines in order to be responsible for tracking their own health. During group interventions, discussions often focused on topics facilitated by a group leader and involved other activities such as relaxation exercises and goal setting.

Interventions that were resource-based tended to be more open-ended, with participants determining how to make use of them. Two of these internet-based interventions were set up so that the control group had open access to the information and the intervention group were provided with tailored information (Weymann *et al.*, 2015; Solomon, Wagner and Goes, 2012).

Some studies also provided individual, tailored coaching to participants to allow them to access the support they needed in a holistic way. This included onward referrals to additional interventions, signposting to services and practical support such as food bank access (Kangovi *et al.*, 2017; Eikelenboom *et al.*, 2016b). Participants in these studies received follow-up support, sometimes with multiple forms of support available (Dolovich *et al.*, 2019).

The delivery style varied enormously within studies as anticipated and has been demonstrated in other systematic reviews into patient empowerment (Kuijpers *et al.*, 2013). Overall, there did not appear to be a trend in favour of either remote or face-to-face interventions.

4.6.5 Adherence

Most studies did not report adherence to the treatment protocol. In some circumstances where the intervention consisted of the provision of resources or information provided to participants online, it was not possible to capture adherence. Gronning *et al.*, (2014) deliberately did not capture adherence. Studies that reported adherence to the treatment protocol had good levels of adherence (Wolever *et al.*, 2010; Körner *et al.*, 2019)

4.6.6 Serious adverse events

No specific serious adverse events associated with the intervention were reported. One of the critical incidents reported by Dolovich *et al.* (2019) was not directly related to the intervention. It was reported that one participant had their driving licence revoked during the study as a consequence of their responses to a cognitive test. It was unclear whether the exercise that contributed to the loss of the driver's licence was directly part of the study, but it was reported that the participant in question found this distressing.

4.7 Narrative on the included studies

Overall, there was mixed evidence for the effectiveness of patient activation interventions in the variety of interventions available. There was also evidence that changes in patient activation are maintained or improved over a follow-up period post-intervention. However, few studies provided information about follow-up after the interventions (Lorig *et al.*, 2009; Lorig *et al.*, 2010; Maindal *et al.,* 2011). This corroborates survey findings that patient activation scores were stable over time in a cohort that have not received an intervention as well as findings of a similar systematic review (Blakemore *et al.*, 2016; Alexander, 2018). By this logic, any increases in patient activation observed following an intervention could expect to be maintained similarly.

While there was evidence to suggest that some interventions contributed to increased patient activation in comparison to the control groups, there was not a specific format or style of delivery that was more likely to have an effect. Additionally, the duration of interventions (i.e. the length of time people had access to resources, or the number of sessions in group or individual interventions) did not appear to have an impact on effectiveness. Similarly, there was not a clear pattern where group or one-to-one interventions were more effective.

4.8 Risk of bias

The risk of bias for the studies is summarised in table 4.5b. Dr Dures reviewed the risk of bias of seven randomly selected papers from the first set of papers incorporated into the review.

4.8.1 Random sequence generation

Seven studies used computer generated randomisation and two used random number tables which contributed to low risks of bias in their studies. Seven studies did not provide enough information for a clear risk of bias to be determined and thus had an unclear risk of bias.

4.8.2 Allocation concealment

Fourteen studies did not provide information about how allocation concealment was arranged. In eight studies there was lower risk of bias because allocation was centrally done by a computer or using opaque envelopes. In some cases, there was not enough information reported to determine the risk of bias.

4.8.3 Blinding of participants and personnel

The nature of self-management interventions means it is often not possible to blind participants and personnel to allocation. Therefore, this contributed to a high risk of bias in many of the studies. In some circumstances, study researchers and other clinical staff were blinded to participants' condition (Schumacher *et al.*, 2017; Lussier *et al.*, 2016).

4.8.4 Blinding of outcome assessment

Some studies arranged for outcome measure completion to be supported by researchers that were blinded to allocation (Wolever *et al.*, 2010; Kangovi. *et al.*, 2016; Schumacher *et al.*, 2017). Fifteen studies did not provide enough information to determine the risk of bias for outcome assessment and therefore this was unclear.

4.8.5 Incomplete outcome data

Many of the studies conducted their analysis using intention-to-treat analysis to reduce the risk of bias due to incomplete outcome data. Some studies did not specify if they conducted this type of analysis. Overall attrition was mixed, including one study where a GP withdrew from the study which removed their cluster from the study (Jäger *et al.*, 2017). This range of attrition contributed to variation in overall risk of bias for these studies in this category.

4.8.6 Selective outcome reporting

This was impacted by the fact that few studies provided information about protocols in order to clarify whether all outcomes had been reported. For this reason, all studies had an unclear risk of bias.

4.8.7 Other sources of bias

A major risk of bias in this review was that of participants' self-selecting. People already engaged and interested in actively managing their health might be more likely to participate in this type of research. Some studies had very small samples that may have been underpowered for a RCT. Some studies were potentially biased by the payment of participants for their time which may have contributed to the findings of studies being impacted. The overall moderate risk of bias in the studies limits the usefulness of the findings and contributes to there not being strong evidence for what is most effective in improving patient activation.

4.9 Findings of review prior to update

The initial findings of the review identified that interventions with a structure covering pre-determined topics appeared to have better outcomes compared to those that were more open-ended and responsive based on the needs of participants at the time of assessment. This added weight to the collaborative nature of patient activation with a role for healthcare professionals to facilitate participants' increases in activation. However, the inclusion of the additional studies at the time of the review update meant that these findings were no longer accurate. There was not a clear type of intervention that was more effective.

4.10 Discussion

Overall, there was evidence to suggest that patient activation is amenable to intervention as some of the studies included in the review demonstrated significant between-group differences in favour of the intervention arm. Therefore, they could be considered effective. Change may have occurred via increased self-efficacy given that techniques that increase self-efficacy were common in the interventions (e.g. modelling behaviour with fellow group members, building confidence through goal setting). Health literacy and participants' ability to monitor their health or communicate their concerns were often focuses of interventions and may contribute to change in patient activation. However, the studies included in this review often had high risk of bias. This involved small sample sizes, challenges with blinding and self-selection of participants leading to generally engaged samples. Many of the risk judgements had to be categorised as "unclear", suggesting a need for clearer reporting of patient activation interventions. This is particularly the case for outcome reporting, as protocols were not always available to compare the published studies with.

It would be beneficial for future research to confirm how participants made use of online interventions, including what they accessed, how often and how long for, to provide context for the findings around electronic interventions. The findings of this review indicate that there is no overwhelming evidence for the use of any specific format of interventions.

One challenge was that patient activation was not always the primary outcome measure, and this may have impacted the results of the included studies, as this may not have always been the focus of the study. This means they weren't specifically targeting patients because of their low patient activation. Given the ceiling effect identified with the PAM (Harvey *et al.,* 2012) and the likelihood that people more engaged with their health are more likely to participate in health research it is possible that this will have shaped the findings of the studies. This then could contribute to studies appearing to be less effective compared to a broader population of NHS patients with a wider range of PAM scores and patient activation.

It became evident during the searches that there were a variety of ways people conceptualised patient activation. Some studies (Shearer et al. 2007; Wagner et al., 2012; Weymann et al., 2015) considered the concept interchangeable with patient empowerment, and chose to capture this using measures including the PAM. Some studies (Kvale *et al.*, 2016; Shively et al., 2012) also referred to patient engagement, in a way that accommodated this review's definition of patient activation. There would be benefit in establishing how patient activation is understood and defined by authors in more detail to establish consistency, potentially in the form of a concept review. This, along with standardising the way patient activation is captured, would be helpful to compare the effectiveness of interventions more easily.

The Cochrane risk of bias tool focuses on reporting study design to establish the quality of studies (Armijo-Olivo *et al.*, 2012). However, it became evident that some challenges were in the reporting of the studies and not in the design and conduct of the trials. Information about how well participants engaged and used the interventions, including attendance of face-to-face sessions, and how often they made use of online or hard copy resources would be of value to determine whether this was associated with changes to participants' activation, as this information was generally not provided. Additional research into online interventions targeting patient activation would be useful if it had information about pages participants visited, how often, and how long for. This would have provided more information about the mechanisms and factors that may underlie the effectiveness of the intervention. Further intervention-focused research with larger sample sizes, recruited to be more representative of the UK population, and more details about adherence would be beneficial to confirm these initial findings.

The findings of this review have implications for practice to best support people living with long-term physical health conditions increase their patient activation levels. As no one approach is more effective than others there is scope for CCGs to offer patient activation interventions that are most appropriate for the needs, resource availability and circumstances of long-term condition patients in their area. This includes funds for intervention duration, availability of staff and space for face-to-face interventions versus telephone and remote based support and the digital literacy of patients in order to access internet-based support. For clinicians, it appears to be important that when there is information provision and goal-setting support available, patient activation interventions can be moderately effective and should be considered to support patients to actively manage their health.

4.11 Limitations

There are some limitations to the systematic review. Firstly, information was not always available in order to calculate effect sizes for the findings of the study and this made it more challenging to synthesise the findings of the review.

Secondly, the protocol limited potential studies to those published or translated into English and, consequently, some studies may have been missed. The search strategy was very specific, leading to a comparatively small number of titles and abstracts to screen. These narrow results from the detailed search strategy may have led to the exclusion of studies including relevant concepts that are described in an alternative way, including self-management interventions which may have covered the concept of patient activation but not described it in this way. Only RCTs were included and, as a result, alternative evidence may have been missed. As this is still a relatively new concept, the completion and publication of an RCT in the time since the increase in patient activation literature means that there is a great deal of research yet to come. This was evident given the number of protocols that were in the literature search for this review and the number of additional studies that were included in the review when it was updated in preparation for submitting this thesis.

Only one researcher carried out the screening and the data extraction, however the risk of bias for around one third of the included studies was determined by two people. The screening process was carefully documented, and this was reviewed with the second screener, along with data extraction.

4.12 Conclusion

Overall, there is evidence that patient activation is amenable to intervention, but no specific format or delivery style is most effective. Further information about engagement and attendance would be helpful, especially for questions about activation and how involved people are in managing their health. It is also clear that patient activation lacks a clear definition and conceptualisation and that this makes establishing the evidence base more challenging, and further work is needed in this field. There is also a lack of work related to patient activation interventions with rheumatology patients and this represents a knowledge gap.

Chapter 5: Qualitative Methods

This chapter presents and justifies the methods for a qualitative interview study designed to gain insight into how rheumatology patients understand and perform patient activation. It covers the study design, including method of analysis. The study findings are presented in Chapter 6.

5.1 Study aims and objectives

The main aim of the study was to gain insight into how skilled self-managers at different levels of patient activation perceive and understand this construct over time.

5.1.1 Study objectives

The study objectives were:

- To explore perceptions of the term, description, and concept of patient activation from the perspectives of IA patients that were skilled self-managers.
- To identify individual and contextual factors that skilled self-managers with IA believe contribute to patient activation.
- To explore skilled self-managers' experiences of actively managing their IA.
- To gather opinions from skilled self-managers with IA on the PAM as a method of capturing patient activation.
- To find out how these perceptions develop over 12 months.
- To identify potential variables for the survey study.

5.2 Qualitative interviews

5.2.1 Selecting study methods

Qualitative research focuses on words as data and considers the way that people see, understand and interpret the world and the meanings they attribute to experiences (Braun and Clarke, 2013; Madill and Gough, 2008). Qualitative methodologies have become increasingly popular in recent decades, with a growing interest in qualitative methods to gather and analyse word-based data (Madill and Gough, 2008).

In comparison to quantitative research, which seeks to remain objective and unbiased, qualitative research requires researchers to consider their own position, stance, and perspectives in order to understand what they bring to the research process (Braun and Clarke, 2013). Qualitative methods were appropriate for a study looking to understand how people perceive patient activation because of the opportunity to explore the complex perspectives of participants in their own words (Braun and Clarke, 2013).

Focus groups were considered as an alternative method of data collection for their flexible, responsive nature and the opportunity to consider a range of perspectives in a single session (Braun and Clarke, 2013). They have been a valuable method of data collection in relevant patient activation research, including the patient study that contributed to the development of the PAM (Hibbard *et al.,* 2004). However, it was ultimately decided that the increased the risk of participants feeling pressured to provide socially desirable responses and agree with dominant voices in the group and this was seen as a disadvantage (Reiskin, 1989). It was anticipated that the privacy of a one-to-one interview would be more likely to create an environment where participants felt comfortable enough to voice their perspectives. A qualitative questionnaire was also considered as a method of data collection, but the decision was taken to not pursue this. It was determined that a questionnaire study design would not provide the opportunity for an interactive dialogue between participants and the researcher and this would lead to less extensive data (Braun and Clarke, 2013).

5.2.2 Study methods

The study was designed to be longitudinal. Participants were invited to the second interview 12 months after their first to understand their experiences over time. An interview schedule for each set of interviews (see appendices G and H) was developed to form the basis for the semi-structured interviews, building on the literature on health-related behaviours, patient perceptions of the term and definition of patient activation, and enablers and barriers to self-management and active management of health. The questions in the initial interview schedule focused on whether (and if so, how) people learned to take an active role in managing their condition and what other factors and people impacted on how easily they could do this. Topics that were also covered included how participants interacted with their rheumatology teams and how they organised support when required. This schedule offered the opportunity for deviations from the plan, clarifications and further exploration of points as the opportunity arose within interviews. A pilot interview was conducted with the PRP in order to confirm the questions were appropriate and the interview had the potential to flow well.

Semi-structured interviews allowed the opportunity to understand beliefs that participants held about their health in a private space. The interview schedule offered a basic structure for participants to be asked the same initial set of questions. However, the researcher had the opportunity to react to individuals' responses for the purposes of clarifying details, exploring lines of enquiry and considering new ideas and perspectives to view the phenomena being discussed (Barriball and Alison, 1994). The longitudinal approach to data collection is particularly suitable for gathering experiential and contextual data from participants, and for following up with individuals' perspectives and experiences at the second interview to clarify their personal accounts and how these developed (Calman, Brunton and Molassiotis, 2013; Parkinson *et al.*, 2016). Individual interviews also allowed flexibility for participants living with a long-term health condition, who may require regular breaks to move around, or stretch to reduce mental fatigue or physical discomfort. Participants had maximum autonomy over how to manage taking these breaks if required, as data collection was carried out on a one-to-one basis.

5.3 Timeline explanation and justification

As the research focused on how patients understood the concept of patient activation, it was considered whether this understanding was fixed over time. Given the research indicating perceptions of patient activation can differ depending on activation level (Dixon, Hibbard and Tusler, 2009), and patient activation levels can vary over time, there was an interest in whether perspectives shifted over time. The two interviews for each participant were spaced a year apart to allow for participants to have a substantial period to continue to live with their condition and to potentially experience health fluctuations, contact with healthcare professionals, and seasonal changes and therefore discuss these events at the 2nd interview. The second interviews also provided an opportunity for member checking with participants to increase the credibility of the findings from the initial analysis (Nowell *et al.*, 2017). For the purpose of this study, member checking refers to discussing the overall findings and categories identified within the research with participants to understand if they feel the analysis and categories are credible and reflect their experiences.

5.4 Ethics

Ethics approval to carry out this research was granted by the West of Scotland 4 Research Ethics Committee (reference 17/WS/0143) following proportionate review and ratified by the University of the West of England as the research sponsor (reference HAS.17.08.007). The study took place in the Bristol Royal Infirmary at the University Hospitals Bristol NHS Foundation Trust (BRI) and Weston Area Health NHS Trust. Both recruiting sites carried out capacity and capability assessments and approved the research at these sites.

One aspect of the research study that was focused on from an ethics standpoint was ensuring participants could consent to each interview individually. This meant that participants confirmed when consenting to the first interview that they were happy to be contacted about the second interview. All participants confirmed that they were happy for this to be the case and this offered the opportunity to opt in to each interview in stages.

5.5 Participant identification and recruitment

As research has demonstrated a great deal of variation in patient activation levels in people with long-term conditions (Hibbard *et al.*, 2005), it was determined that there was a benefit to speaking with participants who have had more experience of managing their health to understand the factors involved that they have identified. One approach to screen for experienced self-managers might have involved asking potential participants to complete the PAM and only accepting those of confirmed PAM levels three and four. The risk of potentially making people feel like they were not of the preferred standard to participate in the research posed ethical concerns and pre-screening was ruled out as a technique for this study. Staff recruiting participants at both sites were guided to consider participants coming to clinics who appeared to be effective at self-management and actively taking responsibility for their condition.

Participants were eligible to take part if they were over 18 years old; diagnosed with a form of IA by a rheumatologist; able to provide informed consent to participate and able to communicate, read, and write in English. Potential participants were identified through their medical notes, which were accessible by their local rheumatology team, and provided with an information pack about the study either in person at a clinic appointment or by post. This research pack included a consent to contact form (Appendix C), an information sheet (Appendix D), and a reply-paid envelope (if the pack was sent through the postal service). Participants returned the consent to contact form to the researcher who answered any of the participant's questions if required and then organised the first interview for a time of mutual convenience. All patients who returned the reply slips were invited to interview.

The sample size was originally set at 25 participants. However, it was anticipated that recruitment would end when interview data were deemed to have reached saturation and no new codes were being identified from the transcripts (Guest, Bunce and Johnson, 2006). In total, 17 interviews were conducted.

The use of two sites that served different communities facilitated some socio-demographic variance within the sample. The two sites differed, with one being a large inner-city teaching hospital serving a large urban community (BRI) and one being a smaller, general hospital in a suburban area (Weston General Hospital). Convenience sampling was employed at both sites and participants were not selectively sampled based on sex, ethnicity, age, diagnosis, disease duration or education level.

5.6 Patient research partner involvement

In preparation for the interviews, the PRP reviewed the information sheet, consent forms and protocol (see appendices D, E and F) for the study to ensure the documentation was clear and appropriate. The researcher developed both interview schedules following discussion with the PRP and the first interview schedule was shared at a meeting with the Patient Advisory Group at the BRI for their comments and feedback from a range of perspectives. This group was set up for patients at this department to feed back about departmental issues, care, research ideas and other relevant issues (Kirwan, 2015).

Testing the interview schedule (see appendix G) for the first set of interviews with the PRP offered the researcher the opportunity to hone her technique and to ensure clarity and a flow of purposeful conversation. For the second set of interviews the interview schedule (see appendix H) was developed considering the findings from the first. As the interview schedule for these interviews was more flexible to account for individual follow-up questions, this interview schedule was not piloted with the PRP. The PRP also reviewed the findings of the research.

5.7 Interview process

The two face-to-face interviews for each participant took place approximately 12 months apart and were conducted by the researcher in non-clinical rooms at either the BRI or Weston General Hospital. Conducting interviews within outpatient departments had the possibility of contributing towards power imbalance with the researcher being viewed as the "professional" whose opinion was prioritised. Where possible, measures were taken to redress the balance of power. This included reducing the presence of clinical equipment in the room, offering participants the choice of seat, moving computer equipment and keyboard off the desk where possible and the researcher explaining that while they are a health researcher, they are non-medical and independent of the patient's direct healthcare teams. The researcher reassured participants that they should do whatever they felt necessary to maintain their comfort during the interview, including taking breaks if required. Participants were given opportunities to ask questions, after which they provided written consent. The interviews were audio recorded with participants' consent.

Initially participants completed brief questionnaires gathering demographic information (age, gender, education level, diagnosis and duration of disease) (see appendix I). This questionnaire pack provided a sense of the participants' overall health to situate and described the sample with reference to their health. It captured participants' abilities to carry out activities of daily living including self-care, mobilising, grip, and specific physical actions. This was done by having participants complete the

Health Assessment Questionnaire (HAQ) (Fries *et al.*, 1980). The HAQ is a measure of physical function and is routinely used as a tool to understand individual levels of disability in rheumatology patients in clinical settings and across relevant trials (Hewlett, Smith and Kirwan, 2002). The HAQ has 20 items that contribute to eight categories of function. The categories scores range from 0 (no difficulty) to 3 (unable to do activities even with the use of aids). The worst score for each of the categories are totalled and an average calculated. The final score is then between 0 and 3 with 3 meaning severe levels of disability.

Participants also completed the PAM in the questionnaire pack. The timing of participants' completion of the PAM was considered in order to gather naïve responses to the questionnaire. This decision was made because discussing patient activation strategies, perspectives and techniques may have prompted participants to respond differently to the items on the PAM.

The majority of the interview was taken up with discussing participants' experiences of managing their health, things that made this easier or more challenging, how they made decisions related to their health, and other topics covered in the interview schedule. As the PAM items often had a biomedical focus on self-management, it was hoped that the broader interview would allow participants to consider wider psychosocial ways they managed their health. Considering these alternatives would offer a more holistic view of patient activation and self-management.

Next, participants were asked whether they had heard the term "patient activation" previously, how they might define it, and their thoughts on the widely shared definition within the literature as outlined by Hibbard *et al.* (2015). Participants were reassured that there were no right or wrong answers in the way they defined these terms, and whatever definitions they used would be correct for them. This stage of the interview was intended to gather participants' perspectives on the term, description and scope of this concept as far as they understood it, and its applicability to their lives and health. Finally, participants were asked to review the PAM for a second time. They were encouraged to consider how relevant the measurement seemed to how they managed their condition and whether there were things they had discussed in the interviews or considered from their own lives that the PAM may benefit from including. The more holistic understanding they had from the interview might have made them more likely to recognise how the measure suited their needs or was insufficient.

Reviewing the PAM towards the end of the interview schedule to discuss how comprehensive participants felt it was had also been considered carefully. It offered the opportunity to gather participants' perspectives on how relevant they felt it was to the strategies and experiences they had discussed for the management of their own health. The timing may have also allowed them to appreciate behaviours and skills that they may not have immediately associated with patient activation.

The interview schedule for the second set of semi-structured interviews focused on reviewing how the year had progressed for participants and how they had managed their health during this time (this will be discussed in more detail in chapter 6). These interviews also focused on feeding back to participants the collective categories and perspectives captured in the first interviews, based on the whole sample. The intention was to validate these findings by asking participants whether these accurately captured their experiences and understandings of patient activation overall. As with the first interviews, the format was designed with opportunities to explore aspects of participant responses further and to follow up on individual perspectives and behaviours from participants' first interviews.

As the data collection progressed, the interviews became an iterative process. Ideas, perceptions and questions that arose in the analysis of early interviews were incorporated into later interviews (Bradley *et al*., 2007). Field notes and reflections kept by the researcher between interviews also contributed to the data collection process and provided context on the interview data as well as contributing to the planning of follow-up interviews for individuals (Furber, 2010) (see appendix J for an example).

5.8 Analysis

The interview recordings were transcribed by a university-approved, GDPR-compliant transcription service. The transcripts were checked against the original audio-recordings and reviewed by the researcher for accuracy. Participants were given pseudonyms in order to ensure anonymity and other potentially identifying data (e.g., relatives names, specifically named schools, towns and hospitals, the names of healthcare professionals) were removed and replaced with placeholder words or phrases.

The interview transcripts were subsequently imported into the NVivo for Windows 11 (QSR, 2012) software package that allowed for the coding and organising of data. This software was selected because of its capabilities for charting the processes of framework analysis.

5.9 Framework analysis

Data from the interviews were analysed using framework analysis (Ritchie and Spencer, 1994). The intention of framework analysis is to allow the opportunity to develop a thematic framework to capture and describe the data, and to compare between and within participants and both time points using the raw data (Ritchie and Spencer, 2013). This was done by developing a set of codes from the transcripts which were compiled into initial categories based on the first interview transcripts. This allowed comparison within participant perceptions across their two interviews and between different participants (Ritchie and Spencer, 1994).

The framework analysis approach to data collection is categorised as a form of thematic analysis (Gale *et al.*, 2013) but makes use of a matrix output to identify categories within the data and works with the research questions from the data collection process (Rabiee, 2004). It is a flexible tool that is suitable for approaches from a range of epistemologies, accommodates both inductive and deductive data analysis method and offers a systematic process to analysing qualitative data (Leal *et al.*, 2015; Gale *et al.*, 2013). Codes and framework categories are determined from both the data itself and the researcher's prior knowledge and perceptions (Braun and Clarke, 2006). This suited both the intention for this study to conduct research with an experiential aim and the pragmatic perspective held by the researcher (Parkinson *et al.*, 2016). The flexibility of framework analysis allows a focus on inductive coding and the opportunity to bring deductive concepts to the analysis process (Lacey and Luff, 2007).

Thematic analysis (Braun and Clarke, 2006) was considered as an alternative method of data analysis as it is similarly flexible, but it lacked a clear sense of how to review categories between participants as easily as framework analysis permitted. As this was a major aim for the research, the preference was to opt for a method that had been developed with this in mind. Grounded theory had also been considered as an approach for data analysis because of its intention to design a theory that was formed in the data (Raichle *et al.*, 2001; McLeod, 2001). However, the researcher considered whether using grounded theory to develop a theory that described how participants understood and performed patient activation may have been too restrictive. This is because it would not allow enough space for individual differences that did not contribute towards the theory.

The transparency of framework analysis also made it appropriate for sharing how the researcher reached initial conclusions when conducting analysis verification of the first interviews with participants taking part in their second interviews (Ward *et al.*, 2013). Framework analysis is suitable for concurrent data collection and analysis, both within and between participants. This meant that the first set of interview transcriptions could be analysed prior to the second set's collection (Srivastava and Thomson, 2009, cited in Ward *et al.,* 2013). Although much of the research using framework analysis is conducted with teams analysing concurrently (Parkinson *et al.*, 2016; Ward *et al.*, 2013), framework analysis was chosen as an appropriate fit for the project. This outweighed the limitation of it often being a team-based method of analysis with multiple coders.

5.10 Stages of framework analysis

5.10.1 Stage One: Familiarisation with the data

The interview transcriptions were checked for transcription errors and fully anonymised. This also formed an important aspect of familiarisation with the data.

Transcripts for each interview were repeatedly reviewed, and any sections of note requiring additional reflection or reading were highlighted or marked. After the data had been thoroughly reviewed, it underwent initial open coding by the researcher. The codes represented aspects of the data that appeared to be of interest or relevance to the researcher and the simplest way the data could be expressed coherently (Boyatzis, 1998). This coding was carried out in NVivo 11 (QSR, 2012). This involved attaching the codes to sections from the text of the interview transcripts. This allowed any codes to be linked to contextual information from the interviews and the words and phrasing of participants themselves. Field notes kept by the researcher were often read for context (see Appendix J). This process was ongoing while other interviews were being conducted which may have led to some aspects of the coding becoming slightly more deductive towards the later stages as the researcher had a sense of some of the shared experiences from participants so far. However, retaining an open mind to differences in experience, perspectives, and understanding remained a key part of the reflective process and preparation for each interview. One key aspect of the process was regular reference to the research aims and objectives, as advised by Ritchie and Spencer (2003).

5.10.2 Stage Two: Developing a framework

From these initial codes, an early theoretical framework was developed by the researcher. This involved reviewing and grouping the individual codes together into an initial coding framework and defining the recurring ideas, codes, and factors as categories and subcategories. The coding from the familiarisation process was again supplemented by field notes to understand the concepts underlying these categories to develop them further. These categories were named using participants' own words from the data extracts where possible to ensure these categories and definitions were true to the original data. Given that the research question focused on understanding experiences, developing an initial framework required this understanding to be grounded within the data to ensure a good fit between the analysis approach and the aims of the study. Following the guidance of Ritchie and Spencer (1994), developing this framework also included considering the a priori understanding to complement the factors being identified in the data.

This initial framework also included an “other” category to contain the initial codes that did not clearly fall into identified categories. This approach to organising the data was conducted by the researcher and developed by sharing the initial framework with the supervisory team, two of whom had reviewed transcripts from at least one of the interviews. Two members of the supervisory team (Professor Sarah Hewlett and Dr Emma Dures) reviewed two transcripts each to conduct initial coding which was reviewed with the researcher and discussed to compare perspectives. The PRP reviewed sections of the transcripts, along with the analysis as a whole.

5.10.3 Stage Three: Indexing

This initial framework was applied to the dataset by re-reviewing the transcripts and organising them into the categories of the framework as a way of organising the dataset (Parkinson *et al.*, 2016). This process is known as indexing and it was carried out using NVivo 11 (QSR, 2012). While there has been debate about whether computer-based tools are the best fit for qualitative data analysis, conducting this stage using this software allowed for the whole dataset be reviewed in one sheet to and retained the wider sense of the data (Furber, 2010).

Indexing offered the opportunity for the initial framework categories to be clarified and developed with reference to the whole dataset by the end of this stage. This involved creating a matrix with each participant occupying a row, and columns were formed of each category from the dataset (see Appendix F). The illustrative quotes taken from interview transcripts were added to this matrix to embellish the initial framework and provide examples of how the categories related to participants’ experiences. This allowed a look at individual participants’ perspectives and schemas around patient activation, whilst holding the wider context and framework in mind (Gale *et al.*, 2013).

Reviewing categories and subcategories led to some being altered for accuracy or the initial categories were determined to be too broad or insufficiently detailed to capture the factors that participants described around how they managed their health. The thematic framework was refined throughout the iterative analysis process to organise the data set, particularly around understanding how the thematic categories appeared within the transcripts across participants' interviews.

Where codes might have fitted into more than one category within the transcript, the definitions of the categories were reviewed and the codes placed into single categories to avoid double-placement (Rabiee, 2004). Comparing how the categories in the framework appear at various points within each interview looked to enhance the internal consistency of the framework and the researcher conducted some of these comparisons at this stage of the process as well as during the final interpretation stage (Rabiee, 2004).

5.10.4 Stage Four: Charting

The data were organised thematically by category (Leal *et al.*, 2015), and were organised between participants for phase one of this study, and within participants once data were collected for phase two. An example of this is available in appendix K. The purpose of this was to provide a précised version of the indexed data with it summarised in chart form for each category initially and reviewed for each participant at the second stage of data collection and analysis. This stage of the process aims to make the data more concise and more easily reviewed (Parkinson *et al.*, 2016). Each section of the chart included some key words describing the content of the category, either in participants' words or in a paraphrased summary (Lacey and Luff, 2007; Parkinson et al., 2016).

5.10.5 Stage Five: Mapping and interpretation

The mapping and interpretation stage of the framework analysis process is intended to synthesise the data (Ritchie and Spencer, 2003). This stage required the researcher to compare the categories against the initial interview transcripts, reflective field notes and any other aspects of the audit trail to review the contextual factors surrounding the data and to confirm these have been represented (Ward *et al.*, 2013). This also required the researcher to focus on reviewing the dataset to identify any additional patterns and make sense of the dataset as a whole with reference to the research aims (Parkinson *et al.*, 2016). Sub-categories and categories were again adapted, and the researcher shared the framework with the supervisory team again at this stage to discuss the findings.

Both data sets were analysed using framework analysis. The second set of interview data were coded separately but were compiled and charted into a single matrix once initial coding was complete.

5.11 Second interviews

In order to analyse the data collected during the follow-up interviews, the first set of analysis was reviewed in order to write a summary of the initial findings to present to participants. Given that this analysis was already completed, the initial framework was a structure in which the additional analysis could be incorporated in addition to a summary of how participants managed their conditions. For the participants who completed follow-up interviews, these follow-up data were coded and analysed with reference to the transcript and analysis of their first interview so that the within-participant summary was available to form part of the analysis.

Lewis (2007) described the process taken to incorporate follow-up data collected and analysed using the framework approach. This example was used as guidance given the limited descriptions available on synthesising data from multiple time points. Once the follow-up transcripts had been reviewed for familiarity and transcribed, they were coded in the same way as the first set of interview data. The coded transcript was then mapped on to the initial framework that had been developed as part of the initial data analysis. Any new categories that could be developed or adapted when the follow-up data were incorporated upon review of the dataset. The data were indexed, and the framework applied to the follow-up transcripts using the same procedure as described throughout section 5.10 but with the existing data also included. This allowed for pertinent aspects of the second round of analysis to be incorporated and summarised in key-word form.

The data and analysis were reviewed from multiple perspectives including:

- Following individual participants to understand the impact of the year's events on how they managed their health.

- Reflecting on the perspectives of health between participants and between timepoints to understand if they were substantially different from the original analysis or other participants' perspectives.
- Identifying whether there were any new behaviours, perceptions, or categories that appear to contribute to how people manage their health and have not been identified during the first interviews.

5.12 Quality

In order to ensure the data collection and analysis was rigorous and of sufficient quality for the findings to be deemed trustworthy, several criteria were consulted in the protocol development stage and regularly referred to throughout the process.

Leal *et al.* (2015) described six strategies designed to increase rigor in studies using framework analysis. These were: *transparency, researcher triangulation, discussion and refinement of the thematic framework, credibility, use of quotes and comparison within research literature* (Leal *et al., 2015* p. 140). These strategies have been implemented throughout this study. Regarding transparency, the analysis was clearly documented to demonstrate that it was systematic and thoughtful. The matrices and charts available for each stage of analysis are provided in the appendices (L and M) to demonstrate how the analysis progression was visible and trackable.

While the analysis was conducted by the researcher, the process of developing the initial thematic categories was documented and shared with the supervisory team (most notably the PRP), and this was discussed and refined throughout data collection and analysis. Two members of the supervisory team independently reviewing transcripts also contributed to researcher triangulation. Their observations were compared to the initial framework developed by the researcher. Comparison and discussion indicated that there was congruence between the perspectives of the three researchers. The definitions of the framework categories were also refined throughout this iterative process.

There was further refinement of the thematic framework when the findings were shared with the full supervisory team and discussed in detail. The addition of the second round of data collection offered the opportunity to return to the framework after several months in order to refine it. The second interviews included discussions around the categories included in the framework as a form of member checking and to potentially increase the credibility of the findings. This, along with discussion with the PRP and dissemination at several research conferences allowed feedback to be offered by third parties to increase the credibility of the findings.

The results section reporting the analysis in chapter 6 presents quotes demonstrating each aspect of the framework, and appendices L and M demonstrate the progression of the framework throughout the analysis process including the use of quotes. This chapter will also make use of existing publications to place the findings of this study within the context of the wider field and research literature.

Another source of guidance which was consulted in order to ensure quality was the "big tent" criteria described by Tracy in 2010. This set of criteria described a model to ensure good quality qualitative research. The criteria set out in this model are determined to be: "*worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence*" (Tracy, 2010 p. 837). Again, steps were taken by the researcher to conduct the highest quality research possible.

The topic has regularly been deemed to be relevant to current practice and literature in several ways. Tracy (2010) specifically recognises the strength in focusing research efforts on understanding how a concept demonstrates change over time. The refocusing of the concept of patient activation to include patients' perspectives is novel and is timely given the substantial increase in patient activation research and implantation described in chapter three.

Attempts were made to maintain rigour and sincerity about the data collection and analysis process in order to increase the credibility of the findings and the overall quality of the research (Tracy, 2010). Data were collected until the point of saturation and all participants from the first data collection phase were invited to return for a second interview to gather as much data as was ethical to support the claims being made in the analysis. There was regular reflection and discussion about the data gathered from the interviews and supplemented by field notes and other reflective writing. Additionally, the descriptions above of the analysis process were intended to be as detailed as possible and the appendices show the procedures taken and demonstrate a clear audit trail of the raw data and the analysis process.

Approaching the research with reflexivity and focusing on the role the researcher played in the interpretation of the data as well as the way participants responded in interviews was important to retain sincerity. As discussed earlier in this section, regular reflection and discussion with the supervisory team were prioritised throughout the process.

The concept of credibility in this context describes the "*trustworthiness… and plausibility of research findings*" (Tracy, 2010 p.842). The aim was to produce credible research findings that rang true to participants and were perceived as dependable enough to potentially inform clinical decisions. One factor that Tracy (2010) describes as contributing to credible research is thick description. This is description that is of sufficient depth to capture detail and contextual meaning. The results reported in chapter six have been written with this intention in mind. Similarly, the tacit knowledge that might have been present around the experience of managing a long-term condition in the context of the NHS in England required recognition. As the researcher lives with a different long-term condition, care was taken to try and identify tacit knowledge around life with a rheumatic condition from participants' perspectives. Triangulation and member checking, as discussed previously, were conducted as intended by the study protocol.

The sense of resonance and meaningful coherence within Tracy's (2010) criteria for good qualitative research were intended in the planning of the research and the writing of the thesis. There was effort to ensure a good fit between the aims of the study and the methods, as well as how the findings were analysed and described. The significant contribution to knowledge is discussed in chapter one and is another important marker of study quality in qualitative research.

Chapter 6: Qualitative Results and Discussion

Chapter 5 introduced the methods that were used for this study. This chapter reports the synthesised findings for both data collection points and discusses these findings.

6.1 Participants

Seventeen participants were recruited from two rheumatology departments in the South West of England. The researcher undertook all the interviews herself both to ensure consistency and to become immersed in the data in order to be familiar with it more quickly. One participant had a relative join her for the interviews at both timepoints as she preferred not to be interviewed alone. All interviews took between 45 and 90 minutes.

Of the seventeen participants, there were twelve women and five men. Thirteen were living with RA, three with PsA and one participant had a diagnosis of SLE. There was substantial range in disease duration, but all participants had been diagnosed for at least two years at the time of the first interview. Details on the participants are available in table 6.1. Participants reported a range of education levels, from no formal qualifications to postgraduate study. HAQ scores were between 0 and 1.05 with an average score of 0.45 (SD: 0.37) indicating mild disability. Participants demonstrated generally high levels of patient activation as captured by the PAM, with four at level two, four at level three and six at level four. Four of these participants completed the PAM by responding with the same response to all items, and consequently rendered their completion invalid according to the guidance of Insignia Health who licence the measure (2017). However, the measure still provides them with a score and these scores are still listed below in table 6.1a in order to provide context about their current activation. This is because the study intended to understand more about patient activation. In light of participants' critiques of the PAM the decision was taken to report the data in its entirety to further understand patient activation with reference to participants' own abilities.

The high PAM scores and levels were anticipated and confirmed that this sample was suitable to discuss experiences of managing health conditions. The generally high PAM scores from those who completed the measure could also suggest that as a sample, the group were motivated to be engaged in research relevant to their health. Due to a requirement for deidentified data to be shared with the PAM licencing company as part of the licence agreement, the first three participants did not complete the PAM as the consent form and information they were provided about the study did not refer to this for them to provide informed consent. A minor amendment to the ethics approval was sought during this time for later participants to be aware of this issue when completing the PAM as part of the study.

Table 6.1: Summary of participant demographics (n=17)

	Average (Standard deviation)
Age (years)	58.64 (11.02)
Disease duration (years)	16.26 (11.47)
PAM level (to nearest level from 1-4) (n=14)	3
PAM Score on the scale of 1-100 (n=14)	68.6 (12.17)
HAQ Score (between 0-3)	0.45 (0.37)

Details about individual participants are available below in Table 6.1a. Participants are presented in chronological order for their first interview, and their demographic data is intended to provide contextual information about each participant.

Table *6.1a:* Individual Participant Information (with pseudonyms)

Participant	**Sex**	**Age (years) at time of 1st interview**	**Diagnosis**	**Disease Duration (years)**	**Highest level of education**	**HAQ Score**	**PAM Level**	**PAM Score**
Mary	Female	48	RA	13	International diploma	0	N/A	N/A
Joanna	Female	54	RA	2	GCSEs	0.35	N/A	N/A
Lindsay	Female	57	RA	8.5	National diploma	0.4	N/A	N/A
Tony	Male	71	RA	26	National Vocational Qualification	1.05	4	100
Jim	Male	68	RA	28	English language certificate	0	4	90.7
Jackie	Female	69	RA	35	National Vocational Qualification	0.95	4	75
Avril	Female	73	PsA	15	Bachelor's degree	0.2	3	63.1

Mark	Male	46	RA	2	O-Levels	0	2	51
Jan	Female	71	RA	12	No formal qualifications	0.25	2	51
Richard	Male	49	PsA	12	O-Levels	0.6	2	48.9
Cheryl	Female	54	PsA	3	Certificate of Secondary education	0.85	3	70.2
Greta	Female	65	RA	10	O-Levels	0.25	4	77.7
Christine	Female	39	SLE	6	Postgraduate diploma	1	3	63.1
Patricia	Female	64	RA	21	Bachelor's degree	0.7	3	63.1
Stuart	Male	45	RA	15	GCSEs	0	2	53.2
Anne	Female	53	RA	30	O-Levels	0.4	4	100
Meryl	Female	71	RA	38	No formal qualifications	0.8	4	80.9

RA= Rheumatoid Arthritis

SLE= Systemic Lupus Erythematosus

PsA= Psoriatic Arthritis

The following section will describe the framework analysis categories (and the relevant subcategories) that contributed to understanding patient activation in IA patients. This meets the aims of this study to identify factors that participants believed contributed towards actively managing their condition and their experiences of doing so. It was identified during the data collection process that the discussions around the PAM and its contents often did not fit clearly into a coherent narrative for analysis. Additional aims were to gather opinions from participants on the PAM as a method of capturing patient activation and their perceptions of the description of patient activation. Consequently, these data were reviewed as part of the framework analysis for any sections of the transcripts that were appropriate for coding and indexing but the data from these questions were also separated and analysed as a standalone dataset using content analysis. These findings are presented in section 6.8.

As discussed in sections 5.9 and 5.10¸ framework analysis results in a framework comprising categories and sub-categories. The analysis presented here are based on the findings of both sets of interviews synthesised and combined for clarity and brevity. However, specific details about the second interviews and participants' responses to the member checking exercise are covered in section 6.9.

These categories presented in Table 6.2 are the result of several iterations of reviewing and clarifying potential framework categories along with reflective logs, discussions with the supervisory team and consultation of literature. Codes were not allocated to more than one category. Although the categories were distinct and definitions for each were developed, they were closely related and often influenced each other. As the intention of the analysis was to understand participants' perceptions, it was written using participants' words as much as possible. For some categories, subcategories were created to clarify and refine the findings of the study. These are related aspects of a single category contained within the overarching idea. Separating some categories into subcategories helped to demonstrate different aspects of the overarching idea of the category. Some categories did not require this and would not have been clearer for including separate subcategories.

The interview data, which particularly covered the first three aims of the study noted in section 5.1.1 and the analysis outlined above led to the development of six main categories encapsulating the patient perspective on patient activation. Category definitions are available in appendix N. The matrices are also available to understand how many participants referenced each framework factor in their interviews. These are below in Table 6.2.

The findings presented in this chapter reflect a summary of the data, particularly where patterns and commonalities occurred across the data. Occasionally, participants had diverging views or approached aspects of patient activation differently. Sometimes these are documented in the chapter where contradicting views appears to fit in a similar framework category. In others, the researcher reflected on and discussed the differing views with the PRP and the supervisory team in order to determine how to interpret and present the

In other circumstances, particularly where participants were managing multiple conditions, it was unclear whether their self-management was around actively managing their rheumatic condition or another health issue. Where this was the case, the researcher tried to unpick this during interviews where possible or reflected on the data and messiness during the analysis process. The findings have been analysed and written to reflect the rheumatology-specific aspects of participants' self-management where possible.

Table *6.1b:* Framework analysis categories reporting how participants understand patient activation

“You do it because you have to”: Determined independence
“You find ways to do different things”: Making small changes
“If you have a problem just phone up”: Navigating the system • “If I have that knowledge then it helps”: How to seek and get help and information • “If I feel there’s a concern, I will raise it”: Collaborating with healthcare professionals

"I think I've recognised what works for me, and what I need": Knowing oneself - "I knew it was obviously something shook up in my body": When to seek help and information - "It just helps me": Knowing what techniques work for individuals - "I know what each tablet is for": Health-related knowledge
"There are people far worse than me": Positive perspectives on health
"Just does a lot of fetching and carrying": Practical social support

6.2 "You do it because you have to": Determined independence

This framework category describes participants' sense of needing to "get on with it" (Mary) and not let their rheumatic condition rule their lives. Participants often stated that they needed to learn to live with their condition in order to manage their health and their day-to-day lives. There was a broad consensus that getting on with things was often because participants had responsibilities that continued despite their rheumatic condition.

"Yes, obviously it's …. painful but you just you've got to cook lunch for [family] and you just. I just got on with it really and some days were more painful than others." (Meryl)

"You can't just live life with your feet up, you've got to do things" (Lindsay)

"Yeah, you do it because you have to, but it was a struggle … I suppose there's that sense of not being able to look after them [children] properly, because I couldn't do the physical stuff. Although I did, because I made myself do it, but it was hard." (Mary)

Some participants identified that this did not mean that continuing with activities was easy, or that they were always able to do so. They described the challenges and barriers involved in learning to live with their condition and make the best of life.

"I've never missed work because of [condition], even though there's been times when it's actually a struggle" (Mary)

"I cope because I have to, I've got no choice, but it doesn't mean to say I don't get upset occasionally" (Tony)

For some, the sense of responsibility for dependents or work (unpaid or paid) occasionally was a barrier to them being able to recuperate and reduce the impact of their symptoms.

"And in those days, I guess, because I didn't have the kids and [husband] was around, I was probably able to sit and relax … so I think if I had the luxury of being able to do what I wanted to do with it, then there would be more rest involved" (Mary)

"I do sometimes think, well please not today. I just don't want to be tired today, but yeah so you do a bit of forward thinking I hope I am going to be alright." (Johanna)

Others deliberately attempted to work against the impact that their condition had to feel more in control. This was often described using the language of struggling, with the alternative being to "*give in*".

"Your mindset sometimes gets to the point of I'm damned if I'm going to give in to this." (Greta)

"I find very often, with me personally, it's mind over matter. I won't give in." (Jackie)

"Sometimes it's easy to just give in, if you've got the pain. I think sometimes if you just keep persevering with it …" (Cheryl)

This cognitive dichotomy between *"giving in"* and *"persevering"* did not always lead to a "boom and bust" behaviour pattern. This occurs when someone perseveres in activity until they reach the point of exhaustion (Hewlett *et al.*, 2011). Greta described the challenges she faced when trying to find a balance between *"giving in"* and taking the rest she needed to in order to manage longer term. Sometimes this meant that she could carry on because she felt she needed and wanted to, but in a more measured way.

"[Feeling] the need to do things, the need to get things done in the house, but also the need not to give in to the disease, which is very, very stupid and the opposite of what you should be doing. I don't mean give in, but pace yourself, it's not giving in, but in my head at the time it's not getting the better of me, I'm going to wash this floor." (Greta)

The description Greta gave of feeling like she was "stupid" but also identifying her meta-cognitions about her condition provides a sense of how she is beginning to step back from life with her condition to critically analyse how she manages and how helpful her coping mechanisms are. This may reflect the patient activation process of being able to skilfully consider how someone manages their health by distancing themselves from their immediate responses and actions.

Sometimes, carrying on also included experimenting with how much participants were able to do, or pushing through to do a little more so they didn't feel held back by their condition.

"I would say to someone keep positive and sort of live within your [limits], just try and do a little bit more and don't think "I can't do so-and-so because I've got arthritis". Just try and if it proves that you can't do it well you've had a little go." (Meryl)

"Don't just sit down and put up with it, carry on and see how you go on." (Jan)

In some circumstances, participants reflected that their daily activities and responsibilities were beneficial and protective as a way of finding determination to cope with life and their condition. This provided a sense of wider context in their life that helped them to feel less like they were ruled by their condition:

"I find very often, with me personally, it's mind over matter. I won't give in. I have to give in sometimes if it gets … and I know I'm going to do something silly, but I try to manage it

daily, by carrying on. You know, I don't do physiotherapy, I do my ironing and I do my housework, and I carry on like that." (Jackie)

"If I just sat in a chair it wasn't going to get any better probably." (Cheryl)

Participants also considered that the idea of actively managing their health was a moral responsibility (Dwarswaard *et al.*, 2016):

"I mean clearly if every patient, if every person was more active in terms of looking after their own health it would solve a lot of problems in terms of getting appointments and whatever. People wouldn't need as many. It would help." (Mark)

Participants reported a need to "do it because they needed to". Sometimes the belief that participants needed to carry on and get on with life was intrinsic and self-generated. As part of learning to actively take responsibility for their condition, many participants identified themselves as very determined people who were willing to persevere with doing what was important or necessary for them. For them, this formed part of their identity and coping mechanisms. This intrinsic motivation reflected a sense of determination that contributed to their feelings of engagement with activity:

"I'm quite a determined, independent person. I just have to get on and do it, regardless" (Mary)

"Being self-determined counts for more than anything else and I had to look after my wife and I just got on with it, okay so I'm hurting, I've got to do it" (Tony)

"I've just got to get on, I've got to do this, I've got to do that" (Avril)

"There's nothing I can't do or won't do just because I won't let it get in the way" (Richard)

Many participants sometimes recognised that their perseverance could be impaired by fluctuations and flares that were out of their control. In these circumstances they often reported being focused and carrying out necessary tasks, for example self-care and caring for children. Where possible, they would make room for doing this in a more paced way to account for symptoms of a flare:

"In the morning, obviously you've got to get yourself up, get yourself ready, so you have to move then, to clean yourself and to dry yourself." (Mary)

"[When feeling unwell] I know then that I need to rest, just take things, just try and slow down and until I'm feeling a bit better with it, carry on taking the medication, and gradually build yourself back up to it." (Jan)

"Well, a flare up will change [how I manage], yeah. I could, sometimes it will not work, or I'll put off a job, or something that I was doing. Or I'll ask another family member to do some things. Just put things on hold for a little bit. It could be a job, I might put a job off for a few days until I'm feeling better." (Stuart)

This determination reflects the aspect of patient activation that is often central to its definition in publications, that someone feels that for their own sake they must take responsibility for managing their health (Dwarswaard *et al.*, 2016). This appeared to be central to how participants made decisions and lived their lives, reflecting a rejection of passivity that is the alternative to active management.

Participants often reported doing as much for themselves as possible instead of depending on those around them. This was a combination of preference, pride, and a sense of responsibility for themselves.

"I'm that sort of person anyway, I'm sort of like, I don't need anyone else, I'm fine" (Mary)

This independence also reflected participants' attempts to retain control over parts of their lives when they were able:

"I said well while I can still do it, I will do it" (Cheryl)

"We had to buy a different hoover … just so that I can feel a bit more independent and still do it myself, on a good day." (Christine)

Patient activation was reflected in this category as a clear sense that participants felt the responsibility for their own health:
"Overall you are the only one that can manage it [condition]" (Joanna)

"I am personally responsible for my own health, it's not my Consultant… I'm responsible so I strongly agree with that" (Patricia)

For participants, actively managing their condition and taking responsibility for their health was often closely connected with independence. As a result of this, those who were able to do less than they could before their diagnosis struggled to deal with these changes:
"Being very independent, quite fiercely independent, it was quite hard to have to accept I couldn't do certain things" (Mary)

"That is the toughest part … nobody can give you a way out" (Tony)

This reflects findings of prior rheumatology self-management research where patients have clarified that independence is a valuable treatment outcome for them, particularly after the initial, acute phase of their condition (Carr *et al.*, 2003; Yoshida and Stephens, 2004). The space that participants had created for their illness and how it related to their identity was broadly beneficial as they focused on how it made them determined to do particular activities. However, other arthritis patients could report that their illness contributing to their identity in a way that sees them paying more attention to their symptoms, consequently having lower activity levels.

Participants feeling the responsibility for their condition closely reflects the definition of patient activation described by Hibbard *et al.* (2004) that has been embraced in the literature and is outlined in section 3.1. However, the sense of responsibility occasionally being a barrier to participants' rest and recuperation might provide some insight into how patients learn to actively manage their condition at level 4 of the PAM. At this level, patients can make use of strategies and resources to problem-solve for alternative solutions if responsibilities are preventing them from balancing rest with responsibility. This might also reflect the confidence held by patients who are at level 4 according to the PAM in testing skills and being aware when they require recuperation time.

The balance between “giving in” and “persevering” and its relevance to patient activation could reflect some of the learning processes required to move from moderately skilled active management of a condition to the requirements of level 4 of the PAM. Knowing when to stop, and how to respond may form part of the process of establishing how to actively respond to cues in one’s health when presented with challenges.

The way these participants identified themselves as determined demonstrates some of the resilience required to manage a fluctuating condition. The “mind over matter” that Jackie referred to could be interpreted as an expression of self-efficacy, with a belief that she could carry out some activities and carry on even if things are challenging. However, it may also be interpreted as a reflection on how participants felt that being determined made more things possible.

Participants reported that there was nobody else they could rely on to manage their condition and symptoms for them. Consequently, the responsibility lay with them. This reflects an internal HLOC (Wallston, 2005) whereby participants felt the success of their self-management, and consequences of their choices and decisions were the result of their own skills and efforts. This sense of independence and confidence to manage without support has the potential to contribute towards the self-management style that has been referred to as being a “dangerous self-manager” (Náfrádi *et al.*, 2017; Yadav *et al.,* 2018). This occurs when somebody has the confidence and self-management skills in the form of patient activation to choose to manage their own health. However, this person’s health literacy would not be enough to identify when they need additional support and their health is at risk. Therefore, participants perceived an effective self-manager to have this sense of independence for managing their own health but combined with health literacy skills to recognise if they do not have sufficient support (which will be discussed in more detail in section

6.7). This does not incorporate those who feel they need additional support but to whom this support is not available.

The findings of this framework category partially relate to an internal health locus of control. The feeling that the outcome of one's health would, in this example, be determined by the individual is reflected in this category.

6.3 "You find ways to do different things": Making small changes

For many participants, actively taking responsibility for their health came in the form of smaller, day-to-day decisions or tweaks to their lifestyle that allowed them to continue with health behaviours, activities or identities that they valued. These smaller changes were discussed at length and were considered to capture actively managing a condition, as opposed to making broader lifestyle changes. Participants reported the changes they had made which often focused on common self-management skills such as pacing, goal setting, altering their routines, and organising or adapting equipment to suit their physical requirements. Given that changing health-related behaviour is generally accepted to be challenging (Kelly and Barker, 2016), making changes and introducing skills in small, manageable ways is to be expected and means that these behaviour changes are more likely to be successful (Hibbard and Mahoney, 2010).

Participants described the volume of micro-decisions and changes that were involved in managing their life with a rheumatic condition overall:

"It does affect your whole lifestyle, even how you sit in the chair, the chairs you've got, the chairs at the table, it's little things like that and you did, getting in and out of the car, but even when you're in the car, does it stop you driving, because have you changed from a manual gearstick to automatic." (Avril)

"That's the mentality of it, making small changes to manage over the year" (Jim)

These changes were often practical to be able to continue carrying out self-care and domestic tasks, and it was clear that this required planning and thought from participants:
"I have learnt that lesson, don't just pick up the basket, even if it's only for a few items, take the smallest trolley in with you, because by the time you get round and you put even just a few items in, that really weighs down quite a lot." (Lindsay)

"I can step over and step in to the bath but it's the actual bending your knees to a right angle to sit down and even worse, getting back up because your arms aren't strong enough to push you up and you can't bend your knees enough. So I have to sort of let the water out of the bath and then the narrowest of the bath sort of roll over onto my tummy and then get on my hands and knees. It's a bit of a beached whale. So a good many years it's been showers you know." (Meryl)

"Drying my hair sometimes, a normal hairdryer I find too heavy to dry my hair and I've only got short hair, but I have to hold my hand up and hold on to the hair dryer while using the brush in the other hand I find it too heavy to hold a normal hair dryer. I've got a travel one which is only light and it does the same job. You do, you find ways to do different things." (Cheryl)

Those who were better at actively managing were more likely to identify and tackle external challenges to their self-management. One of these challenges was physical health preventing people from carrying out valued activities in the way they did prior to their IA diagnosis. Participants described how they responded to this by making changes that allowed them to maintain activities. This included doing activities differently, or perhaps missing out on aspects of activities in order to stay engaged with their social circles, to remain lightly active, or to fulfil a role they valued:
"*I just think I keep going, I go to darts, I go to skittles, I don't play because the balls are too heavy now, but I still go*." (Jan)

Small changes that participants had been proactive in introducing also included physical adaptations to carry out activities:

"Physically, I've got things at home, like, there's raised toilet seats, we bought a new mattress and a bigger bed that was higher. We changed our car to a higher car. That was really important. I'm really weak in my left leg so we had to change to an automatic." (Christine)

"I know that I'll struggle getting back up off it. I try and get arms on a chair if I can, I changed my car so I've got a higher seat on the car." (Greta)

Participants also approached health-related decisions in smaller, more manageable ways rather than broader lifestyle changes. They reported how walking a dog once a day, or using an upstairs toilet helped them engage in exercise without making them feel overwhelmed:

"I try to keep active, try to go out every day and walk, even if it's only from one end of [town] to the other." (Avril)

"I've got a downstairs toilet, but if I want to go to the loo, I usually go upstairs, just to get a bit of exercise going up and down the stairs. It hurts my ankles and it hurts my knees, but I still do it rather than, you know getting up out of the chair and walking a couple of paces … There's lots of things you can do within your own home without even leaving your own home." (Cheryl)

"I still see them [friends] but they tend to come to me now" (Joanna)

These attempts to remain engaged in things that participants valued were discussed with reference to the ways that participants felt they had lost aspects of their life because of their condition. They made use of the skills they developed where possible to do what mattered to them and to introduce healthy behaviours:

"*Okay. It came on very, very suddenly. Myself, I was very active both in my work and also used to play lots of sports and that kind of thing, do DIY, walk the dogs, just generally an active person, and physically fit and healthy. And suddenly, in a really short space of time, while constructing a shed, or workshop, in the garden, my hands started to swell for absolutely no reason. So much so that I couldn't hold the tools that I was using.*" (Stuart)

Pacing was the most commonly noted strategy that was required to manage a rheumatic condition, with most participants referencing it at least once during their first interviews. Pacing is considered part of the process of becoming an expert in one's health, along with the ability to plan and prioritise (Schulman-Green *et al.*, 2012). Understanding how to adapt, make changes to and pace their activities allowed participants to manage their lives:

"Regarding like doing my housework, don't … I've only got a bungalow, but don't do the whole bungalow at once. You know, do your lounge, and if you feel you need to sit down, sit down" (Jackie)

"I've learnt that… you've got to pace yourself really well." (Mary)

"You take more time to do it, but you still do it" (Jan)

Other participants described changes they made in order to continue with activities and roles that they valued in a modified way. One prominent example was Jackie, who described how she had incorporated a planning process into packing for a holiday. She reported that without this planning, the potential temperature changes on her trip would render her unable to continue to travel:

"I'm planning right, what am I going to wear on … and what's going to be comfortable for me to stay warm and to be able to move? If I'm out in the cold, and I start creaking, and it starts hurting, then I might as well go and sit down. I have to pre-plan it… I can't just think oh, I'll take that … because I like the look of it"

Her organisation and forward-thinking often went under-valued by those around her while she centred her health in this planning process:

"*Yes, [husband] thinks I'm … without saying it, sort of making perhaps a bit of a fuss of what I'm taking. I don't think any of them really understand, to be honest, how my mind works, about what clothes I take… They don't realise what's behind it." (*Jackie*)*

Considering all these possibilities reflected the experience and thought that Jackie had used to problem-solve ways to approach her travelling and continue to do things that mattered to her. Problem-solving skills are considered a form of self-care that contributes to improved patient outcomes (Paasche-Orlow and Wolf, 2007) and are common features in self-management programmes because of the benefits of being able to more helpfully respond to situations (Hibbard and Greene, 2013). Problem solving is considered to be an aspect of patient activation most commonly seen at level 4 of the PAM as it is deployed in order to return to, or maintain, effective self-management during a flare-up (Hibbard and Helen, 2014). How patients perceive barriers also shaped their problem-solving abilities. In a prior study, participants with low patient activation considered themselves as the major barrier to being able to effectively and actively cope with their condition (Dixon, Hibbard and Tusler, 2009).

This reflects prior research into how patients adjust to living with long-term conditions and health-related behaviour change. It also closely matches the sense that participants report of needing to take responsibility for their condition and living well (Dixon, Hibbard and Tusler, 2009). Given that research into specific self-care behaviours such as exercise and patient activation has often been contradictory (Harvey *et al.*, 2012; Zimbudzi *et al.*, 2017) and that some but not all self-care behaviours have been associated with patient activation (McCusker *et al.,* 2016), it is likely that the underlying organising, planning and problem-solving skills contributed to success with participants' self-management.

6.4 "If you have a problem just phone up": Navigating the system

When participants discussed the way that they managed their health and how they took responsibility for it, one skill they regularly used was learning to navigate the NHS. This included being able to work with healthcare professionals to get the support, tests and medications required.

Overall, participants demonstrated a range of abilities in order to access the health and support they needed. This appeared to be key to their sense of managing. There was an expectation for some participants that taking responsibility for their health included always taking the lead in appointments, but this was not always the case. Participants who discussed their future health had a clear sense of actions they would take to gather further health-related information.

Something that impacted this framework category was that data collection took place in two departments that use a direct access system. This allows long-term patients with a relatively stable condition to have fewer unnecessary review appointments with a rheumatologist, but they can call a telephone line for advice, support and to arrange appointments if they are required. This process is described by Kirwan *et al.* (2003) who report that in this initial trial of the system, there were no significant differences in disability at follow-up between participants receiving direct-access care and a control group receiving usual care. However, participants who had been receiving direct access care had significantly higher levels of satisfaction and confidence in the system of care in comparison to the control group.

Within this framework category there are two subcategories: How to seek and get help and information and collaborating with healthcare professionals.

6.4.1 "If I have that knowledge then it helps": How to seek and get help and information

This subcategory refers to participants' ability to select appropriate ways to get help and information about their condition. Within this sample, participants reported using a variety of sources of help and information. They sought answers to queries using friends, relatives and often the internet. This did not necessarily mean that they needed to find it independently, but participants often chose to use NHS web-resources or charitable organisations as reputable sources of support and information. For physical aspects of their conditions, participants generally sought support from a healthcare professional and were able to select an efficient and appropriate route to contact them depending on the urgency of the issue. Given that there has been a documented relationship between use of urgent care sources and patient activation, the literature suggests that those who are activated are more likely to be able to recognise setbacks in their health, and to seek help earlier (Hibbard and Helen, 2014). These two separate framework subcategories reflect this in practice, with participants making judgements about effective but measured sources of support to know when problems are occurring and to promptly seek care:

"I know they say you shouldn't read everything, but there are some good sites on there. You have got the NHS one for a start, and you have got the arthritis association haven't you…so they are genuine sites." (Joanna)

"I've got books and I've got, just in terms of basic, when I first got diagnosed I wanted to know everything there was about it. And then, basically, for me, I think if I have that knowledge then it helps me manage the situation." (Anne)

Participants reported critiquing information for accuracy and trustworthiness, demonstrating their critical and communicative health literacy skills to identify information and consider its relevance to their own health (Ledford, Cafferty and Russell, 2015). The skills to review information identified, and effectively apply it to their personal circumstances were fundamental to the process of gathering information for participants. Participants particularly made use of online resources. There were repeated references to credibility, trustworthiness and being sceptical about information gathered online unless it was from a reputable source.

Participants had clear ideas about the kind of support they would seek out when they required it. They reported a preference for rheumatology clinics rather than their GP for the specialist knowledge and valued the consistency of seeing someone who knew them and their experiences personally:

"If you go to your doctor and yes the doctor is a GP, they don't specialise in rheumatoid, that's why you get sent to the hospital about it" (Lindsay)

"That's me taking control and going to see this lady doctor who's been fabulous. I then phoned up, and said I wanted to see my consultant again, from [hospital] so she saw me out at [town], because I wasn't happy." (Jackie)

"When you are under a consultant you trust them, and the nurse you see more often. You trust in what they are doing and the doctor [GP] doesn't know any of that. Alright, he might read reports when he gets back…" (Jan)

However, there were several things participants mentioned that contributed to them trying to resolve problems themselves. One of these was the delay in organising an appointment to see a healthcare professional:

"If I ring the doctor and I need to see them urgently, they will generally fit me in today, but other than that, it can be, when I wanted to speak to my own doctor, as opposed to a doctor, I had to wait nearly three weeks, which is not ideal, but it's not their fault." (Avril)

"I mean in terms of the health service in general doctor's appointments now are tricky, you wait two weeks for a doctor's appointment, they then tell you that you need a blood test, that's another two-week wait. And then of course then you need to book an appointment to see your GP to discuss the results, that's another two-week wait." (Mark)

Another reason that participants chose not to seek support from healthcare professionals was a fear of wasting resources. This was particularly the case for participants who had prior work experience within the NHS, contributing to a need for purpose during appointments:

"I know you've got the nurse emergency number that you can ring but you don't like wasting her time" (Cheryl)

"The NHS is very badly stretched, it's got a lot of people doing a lot of jobs and they don't have time for general chit chat. If you've got a problem, they'll deal with it but you have to go and see them officially when you want one, they're doing, you can't go and see somebody and have a chat." (Tony)

The direct access system was commonly referred to as a comforting and quicker option to pursue:

"I've got the direct access between appointments if you have a problem just phone up, which is great … I like the fact that I can, that it's there. I wouldn't want to go through the GP, it's like sometimes it just takes forever. So the fact that I can come straight here if I've got a problem is great" (Mary)

"Within 24 hours they will phone me back, so that's a peace of mind." (Tony)

"The support I get from the hospital is good. I just ring a number and two or three days later I can get an appointment, which is very helpful. The GP, he will only ever refer me back down to here anyway." (Richard)

Participants reported that they did not always seek out support for flares, often choosing instead to rely on plans that have been suitable before. They appeared able to use their experience from previous flares along with information about the severity and impact of a flare in order to judge how best to manage it. Where they could proactively manage the flare without healthcare professional intervention, they generally chose to do so:
"I look at ways that I could probably sort [a flare] myself" (Avril)
"[Seeking help] took a while because I thought give it a month or two" (Jim) In these circumstances Jim found that his initial instincts were accurate and that he was able to manage the impact of his medication change himself.

Aspects of this subcategory in particular reflect some of the ways that there may be a "hidden curriculum" that does not reflect conscious patient education or learning but captures knowledge and abilities that underpin patient' abilities to learn to self-manage (Kentli, 2009). The kind of challenges that require self-management as opposed to specified levels of care may not always be explicitly described to patients and these are judgements that they learn to make themselves.

Ledford, Cafferty and Russell (2015) found that participants with higher patient activation were more likely to receive favourable responses from healthcare professionals when sharing health information that they had researched themselves. High levels of critical health literacy are required to effectively gather health-related information on the internet in the current digital age, and this is particularly relevant given how widely used internet and technology-based systems are becoming in healthcare (Kim and Xie, 2017).

The value of patients being able to effectively consider and report personal knowledge has been reflected in prior research. As an example, healthcare professionals with increased knowledge about their patients' life circumstances were more likely to develop a care plan that takes patients' personal skills and resources into account (Bilello *et al.*, 2018). In the same study, participants' preferences for prompt access to healthcare professionals were also an important consideration in the sources of support they sought out. Some of the skills discussed in this framework category demonstrate forms of functional health literacy, with participants appearing able to determine the most appropriate person in their healthcare team to approach and creating an opportunity to discuss their needs.

6.4.2 "If I feel there's a concern, I will raise it": Collaborating with healthcare professionals

This sub-category highlights the roles participants played in decision making, care planning, and agenda setting when in appointments in a clinical setting. While they all generally implied that being more active in consultations demonstrated being more involved in managing one's health generally, the extent to which individual participants were currently involved differed. This framework category closely matches the taxonomy of activated behaviours captured by Ledford, Ledford and Childress (2013) describing behaviours in clinic.

When in appointments, participants reported feeling able to ask clarifying questions, a general confidence in being able to disagree with the opinions of healthcare professionals, and a keenness to be involved in (but not always leading) decision making. Participants conveyed the value of collaboration and working in conjunction with healthcare professionals as partners with different roles. This was particularly evident when reviewing item one of the PAM, in which participants were asked how much they agreed that they are ultimately the one responsible for their health condition:

"So I mean question one… I've put agree because actually there's only so much I can do and therefore the health service have a degree of responsibility as well." (Mark)

"Obviously with help with doctors, but overall you are the only one that can [manage a condition]" (Joanna)

This doesn’t necessarily line up with the sense of independence for health described in the framework categories, but perhaps reflected more of a collaborative process that participants felt they should have a role in.

There was a clear sense that participants felt able to disagree with health professionals to varying extents to develop a plan for their care:
“I’ll wait until he’s finished waffling on and ask him at the end. Oh yeah, if there’s something I want an answer to, I’ll make sure he answers it” (Tony)

“They listen to me. If I say I'm not very keen on doing that, it's not a case of close the book then, you won't take the tablets, I don't ever feel that. I don't ever … they will listen, and I mean, they've given me an option once with some tablets, and carcinoma was mentioned, in a leaflet, and I just said oh, I'm not taking that.” (Jackie)

“I’m still not convinced changing the medication has helped but I’ll discuss that with the doctor when I see him again.” (Richard)

Participants who felt comfortable and able to raise concerns, offer opinions or take the lead in appointments reported a sense of openness and comfort in doing so. This reflects strong communicative health literacy as participants were able to clearly raise the issue and outline the problems they experienced:
“I will raise, if I feel there’s a concern, I will raise it, and to I think it’s only by being able to raise it and discuss it that I can get my own mind around it … it is a case of being, I suppose open, being honest.” (Greta)

Participants also used practical strategies to be able to communicate challenges with their health efficiently:
“I take my folder with me everywhere of all my letters…. I’d done a summary from my letters of all the things that I’d been sent for and what, and that’s in the notes now.” (Mary)

Some participants were less confident around taking charge in appointments:

"Ah yes. I'm not too good at taking the lead. Sitting here chatting with you I'm not too good. I'm alright coming in and saying how I am but I'm not a patient that can say "well so-and-so, now I think I ought to have so-and-so" (Meryl)

While healthcare professionals were likely to be the ones to suggest specific treatment options because of their specialist knowledge, participants generally had an openness to trusting them and trying strategies out, having brought up the initial issues:
"Yeah I don't know that I would have the conviction to say 'I disagree with you', I might say, what I tend to do, if I've gone there with a problem, I will initially say 'I think it's this, this and this', but if they came back and said 'No, no', I'd say 'Okay we'll go down that route and see how it goes'. (Patricia)

Some participants referred to the sense that there was only so much the healthcare professionals could do, and that other patients may have higher expectations for these appointments:
"A lot of people that think oh well I'm going to go to Rheumatology, or I'm going to my GP and they're going to wave a magic wand and it's all going to disappear." (Cheryl)

"If you go to see a doctor, unless you tell them everything, there's no way they can make a decision, or what is best necessarily for you" (Greta)

"So I do think that lots of people could, not do more, but my husband's a bit like that, he thinks there's a tablet for everything." (Jackie)

At times, participants were critical of the way they believed other patients viewed healthcare professionals and the passive way these patients managed their conditions:
"It's them acknowledging and recognising and acknowledging that there's things that they can do, or ought to be doing to help them manage their condition." (Mary)

Some participants recognised ways that other patients may feel less able to assert themselves and their wishes in consultations:

"I suppose, maybe I'm different from other people. There are people that don't feel confident in discussing things, but then if you don't discuss it with your health care provider, or whoever it may be." (Cheryl)

The ability to disagree with healthcare professionals was particularly important given the often-present power imbalance between patient and healthcare professional (Becker and Roblin, 2008). The immediate and personal support that participants discussed appeared to give them the confidence to continue life self-managing as actively as possible, knowing that they had the service available as a safety net if they required it. The descriptions above of effective, useful contact from their rheumatology team suggest a positive working alliance. As patient activation has been positively associated with working alliance, the participants appeared to bring optimistic and open contributions to the therapeutic relationship (Eliacin *et al.*, 2016).

Given that Meryl's PAM level was a level 4, this reflects that the measure may not capture her reluctance to take the lead, even if she was comfortable raising issues to healthcare professionals.

For participants in this study, they often viewed healthcare professionals as a guide to support them and their health:
*"Just stay in touch with the medical professionals - whether it's GPs or specialists and they can guide you on the right track medication wise." (*Richard)

Given the documented relationship between clinicians valuing patient activation and patients' overall healthcare outcomes, it is clear that participants would also be more likely to take responsibility for their condition if they had a supportive consultant and nursing team (Bastas-Bratkic, Weismuller and Brady, 2018). Healthcare professionals have been criticised for potentially focusing too much on their own goals, rather than those set by patients (Volpp, 2018). This is what Tony may have meant earlier in this section, when he referred to waiting for his doctor to finish "waffling on" to have the opportunity to focus the consultation on the information he needed. However, patient activation interventions rarely focus on providing training and support to healthcare professionals and consequently this burden may fall to patients to be activated and confident enough to take the lead without prompting. There are training and resources aimed at encouraging patients to contribute to conversations, e.g., the "Ask 3 Questions" initiative that provides summary questions for patients to ask appropriate questions about their care (Joseph-WIlliams *et al.*, 2017). The intention of this is for patients to understand their options, the risks and benefits of the options available, and the likelihood of these risks/benefits occurring. This has been implemented across primary and secondary care services within the NHS but is primarily a patient-focused resource.

There is a clear need for further training for healthcare professionals to support patients to actively manage their condition by communicating and prioritising their needs and information requirements. One way this is currently being provided is in the form of agenda setting interventions for patients and healthcare professionals. This was included in the CCH Programme in both the self-management arm and the healthcare professionals training and was considered a key enabler of self-management (Newbronner *et al.*, 2013). Given that question formulation is a common aspect of patient activation interventions (Ngooi and Packer, 2017) and that patient empowerment interventions have demonstrated that activated participants are more able to extract information from healthcare professionals (Roberts, 1999), this is another vital skill in actively managing a health condition that participants have discussed in this subcategory.

Given that patients with low health literacy have been found to receive less preventative care (Rowlands *et al.*, 2015), the experience within clinics for patients may differ based on how focused consultations are on preventative care. The relative contributions of patient and healthcare professional could depend on whether there are current issues requiring reactive care. Responding to current difficulties would likely require more of the healthcare professionals' specific biomedical knowledge and thus would shape the consultations. The findings of this subcategory are in line with prior research indicating that people with higher patient activation are also more likely to rate their patient experience more positively (Mosen *et al.*, 2007). This may be due to a greater ability to work collaboratively with healthcare professionals.

6.5 "I think I've recognised what works for me, and what I need": Knowing oneself

This category describes the participants' experiences of their own body that appeared to be vital to their ability to take charge in managing their condition effectively. Participants had a clear sense of what techniques for self-care were useful for them and relied on a knowledge of their own body and condition to know when they needed additional help and information from the sources described above. This is distinct from participants knowledge of how to seek help when it was required. Their sense of knowing their body included demonstrating knowledge of the healthcare-related routines required to manage their health. This particularly referred to regular appointments, treatment regimens and requirements from them to manage their health. Three subcategories contributed to this overall category: "when to seek help", "what works for me", and "how my healthcare works".

6.5.1 "I knew it was obviously something shook up in my body": When to seek help and information

When asked about how they knew when they needed to seek help, participants' answers often differed based on their circumstances. A common aspect of their responses was that it related to the duration and severity of a flare-up compared to how they understood their day-to-day health. Participants were aware of their baseline, as well as a sense of their fluctuations and how their body felt during a flare. This allowed them to identify when something was out of the ordinary to monitor this in case support was required:

"I am tuned in, I am. I do find, it's awful really, but I am very tuned in" (Jackie)

"Because I know my condition, I know I can manage it and I know usually taking the medication, it's sort of level at all times and as soon as something's wrong, I know, so even through pain or swelling." (Richard)

Sometimes participants felt clearly when there was something with their body that needed attention:

"I thought what's happened to me? I knew it was obviously something shook up in my body." (Jim)

"Listen to your body basically, you have to listen to it and you know something isn't right, or something's changed, and change it accordingly. Either stop taking that medication and then seek medical advice." (Greta)

When participants referred to this sense of knowing their own body, this was explored further during the interviews and they were asked about how they had come to understand this. Participants could not always describe how they developed the awareness to identify the onset of an issue:

"I don't think I consciously do it either, I think sometimes it's just a case of I realise when I'm pushing my luck, so I draw back" (Mary)

Some experienced clear warning signals of a change to their health:

"It's obviously because the main areas where it was, it's mainly the knees, so … if my knees swelled up, then I know that that isn't right." (Anne)

Participants also used this knowledge to anticipate if they were likely to be overly active, or more likely to contribute towards a "boom and bust" pattern of over- and under-activity (Hewlett *et al.*, 2011), as Mary described her awareness of when she was "pushing her luck".

6.5.2 "It just helps me": Knowing what techniques work for individuals

Participants used a wide range of techniques and products specifically targeting the symptoms of their condition. These included both pharmacological and non-pharmacological techniques and allowed participants to manage the impact of their condition. They relied on this toolkit to manage fluctuations and occasionally some specific routines for flares, as well as being aware of what techniques they had available to deal with the specific symptoms they were experiencing. This contributed to confidence in managing symptoms and meant that they were potentially less likely to seek excessive support from healthcare professionals:

"*I think I've recognised what works for me, and what I need, whether I get or can have what I need.*" (Mary)

"But I like to try things anyway and try for myself, see if it's beneficial or not. If it's not then it's fine, you know, go on to something else." (Stuart)

"I know what to do [to manage] and I think I'll do that." (Christine)

"I go to an Osteopath every six weeks, occasionally I go more frequently if I've got, if I've had things are tighter or whatever, and that obviously helps a lot, it's just, and the other thing is I do find the sun helps." (Avril)

"It's about knowing what suits you … what works for me might not work for someone else" (Jim)

Participants did not always use analgesic medication as a part of their routine. However, sometimes they were a preferred tool when experiencing flares, in order to continue living life:
"I think to myself right, I need to stay in the warm today, might take a couple of paracetamols if its really bad, put a bit of Deep Heat on" (Jackie)

"A necessary evil" (Christine)

Participants were sometimes reluctant to use them too often:
"The painkillers usually do it, but I try not to take too many of them, because I just don't want to become reliant on them really." (Lindsay)

"I might take a couple more pain killers or something, but it doesn't change my lifestyle, no." (Jan)

Medication regimens prescribed by healthcare professionals as part of a toolkit to self-manage were rarely discussed, despite how commonly this has been associated and discussed in conjunction with patient activated behaviours (Mosen *et al*., 2006). When participants talked about their medication, it was implied that they took it regularly and monitored their regular reviews as well as their intake, when appropriate:

"I should go to a pharmacist, because that's where I get my repeat prescriptions from, they offer that service, so it might be, I'm due to go there this afternoon to pick up my prescription, so I might ask about [annual review]." (Avril)

"*I have been given more freedom by the consultant to up my steroids by 2 milligrams to 5 milligrams based on blood tests rather than waiting and getting delayed and more ill."* (Christine)

It was unclear whether prescribed pharmacological medications were rarely mentioned as part of self-management was because people did not consider that taking them was part of their routine, or whether it was simply assumed that they would adhere to the routines. One participant who did not adhere to her medication justified her decision to stop taking her medication because she felt that she was managing well without them after a period of inconsistently taking them:

"I just kept forgetting to take them. And in the end I thought oh, there's no point now, I'll see how it goes. And it seems to have been okay. So it wasn't really a conscious decision, but because it seemed to be okay, I thought well, let's try it. I knew I'd be coming here soon, so I thought well I'll have a word with [nurse] and see what he says and obviously he was fine about it." (Mary)

This may reflect an example of the potentially "dangerous self-manager" (Náfrádi *et al.*, 2017) if the decision had been taken without a knowledge of what the medications do. However, this was not explored in detail during the interview.

6.5.3 "I know what each tablet is for": Health-related knowledge

Participants demonstrated knowledge of their condition, their responsibility for effectively managing their routine, and why certain behaviours, investigations and interventions needed to be performed. The knowledge and skills discussed in this category closely reflect functional health literacy as an aspect of patient activation that participants perform regularly:

"At my doctor's surgery you have to go for like a rheumatology test. It's the nurse she just checks the medication you are on, and she will talk to you about things. And she sent me

for a bone scan last year and I am due another one at the moment an appointment with her." (Joanna)

"I'm aware of other options, certainly with the biological medication that leaves you vulnerable to infection etc., but it stops the progression of the disease." (Mark)

This knowledge allowed participants to advocate for themselves if they felt they were not receiving sufficient contact with healthcare professionals, or if they were concerned about how prompt processes were:

"If it comes back in a letter, you'll see the Consultant in say four months, you will get the letter from the hospital then in four months, but then you have to ring in to make the appointment and then the next space is might be another month again, so that's five months rather than four months that you've seen. So you do need to be proactive with actually making sure that you've got that appointment on the four months, rather than it might be five or six months before you actually see someone again." (Lindsay)

Participants demonstrated knowledge about their medications that contributed to them being able to play a role in decision making, including some understanding of the reasons for medication changes. One example is Jim, who had reviewed and discussed his move from one medication to a biosimilar medication following the expiry of the patent. He demonstrated his knowledge of the process and the rationale behind this medication change:

"[biosimilar]'s exactly the same. They've taken, what I understand is they've taken an element of it out which is a cost- effective saving" (Jim)

Participants were generally keen to be informed about these matters in order to feel in control of their condition:

"And I started to understand about RA, really, looking up lots of different things, the leaflets I was given then, the explanation I was given. And I was really interested in finding out." (Stuart)

"I like to be informed to a point, and I know there's information out there if I need more." (Mary)

This is in line with prior qualitative research indicating that patients often differed with the amount of information they required to self-manage, and Mary being "informed to a point" offered her the opportunity to seek out more information if required rather than being initially overwhelmed. Given that people with low health literacy have been found to disengage from seeking out information if the information provided is unclear, it is presumed that the information provided was acceptable to participants and they felt able to seek out further clarification if required (Parsons and Adams, 2018).

6.6 "There are people far worse than me": Positive illness beliefs

Participants often made sense of their health and how they managed it by comparing their own experiences with those around them to make them more determined to take action. These were often relatives with rheumatic conditions, but sometimes friends, peers at support-groups or patients in waiting rooms when they visited their rheumatology department. These downward comparisons seemed to be a factor in their coping, particularly as participants generally viewed themselves to be comparatively well and with good function and symptom control. This has been identified in prior research about how downward comparisons have motivated people to make changes to their health to avoid moving towards the downward comparison (Martinez *et al.*, 2018).

"So yeah, as I say I do manage it, ninety-nine per cent of people wouldn't know there's anything the matter with me." (Avril)

"*[Mother] has always had a far more significant problem with it than I have. Her hands don't move, she's in a nursing home now. So it's had a drastic impact on her health It hasn't had a drastic effect on my life, particularly. I probably put it down to luck because there are a percentage of people that do get lucky and maybe I'm just one of them…"* (Mark)

"My daughter only goes out a couple of times a week. She has it in her legs as well, so she has it worse than I." (Jan)

"When you then speak to other people at the group you realise that it affects people in different ways. That's been really helpful." (Greta)

The perceived benefits of comparison could be because their own experiences were normalised following the opportunity to see how other patients manage similar or potentially worsening symptoms (Dwarswaard *et al.*, 2016). The use of the local patient groups that Greta refers so here also reflects findings of a systematic review looking to understand the impact of social networks and groups on self-management (Vassilev *et al.*, 2014). This review identified the value of sharing experiences with social groups and how social comparison with network members contributed to self-management. In this way, peer support groups may be a form of intervention for this aspect of patient activation and are a common feature of third sector service provision for patients with long-term conditions.

People were generally keen not to end up with the health of whoever they were comparing with their own. This contributed to the determination to act. Participants also felt their general health and situation were positive in comparison to others, echoing the benefits of downward comparison identified in prior health research (Suls, Martin and Wheeler, 2002):
"Not really. I don't normally get ill, touch wood. I'm not a sicky person. I've had this for 12 years and never lost a day of work through it" (Richard)

"There's an awful lot of people out there who are an awful lot worse off than I am and it's just a case of getting on with it" (Cheryl)

Sometimes this feeling of good health contributed to participants feeling fraudulent, or like they didn't need, or shouldn't be using the services they were offered:
"They just sort of come round. Because I am so well-managed I feel a bit of a fraud. I am so well managed now I don't have to go to the GP very often and I don't really have to use direct access." (Meryl)

"*I mean I shouldn't really see a consultant because there are people far worse than me. I'm sure 99 percent of people with RA are worse than me, so I shouldn't really get to see a consultant."* (Mark)

This comparison captured participants' sense that their condition was not as impactful as it might have been. One factor that may have contributed to this is that participants' levels of disability (as captured by the HAQ) were low with an average score of 0.45. Illness beliefs that helped them to feel as though their condition was not as serious as those around them gave them the confidence to "get on with it" (Cheryl). Illness beliefs have been suggested to play a role in patients' self-regulation in health behaviours for long-term conditions (Broadbent *et al.*, 2006). Positive perceptions of the severity, perceived illness duration and the impact of the condition contribute to how patients adjust to life with a long-term condition (Graves *et al.*, 2009). Understanding and working with patients to overcome unhelpful thoughts that prevent them from effectively managing and living well with their condition would be a relevant intervention to support those to feel more positive about their health (Graves *et al.*, 2009). In the circumstances of this study, the fact that participants' conditions were not as serious and limiting as they could be might have contributed to increased confidence in managing and choosing to carry out behaviours that others may perceive to be too risky. This is particularly relevant as a statistically significant relationship has been identified previously between illness perceptions and HAQ scores in rheumatoid arthritis patients (Rose *et al.,* 2012). The low levels of disability of participants in this PhD study may have been associated with the positive illness beliefs that participants had.

The association between illness beliefs and patient activation has been documented (Rask *et al.*, 2009), and people enjoying high levels of good health are more likely to demonstrate high patient activation scores (Bilello *et al.*, 2018). Particular health beliefs that are open to intervention can increase health literacy. These may include perceptions of risks, expectations about the impact of symptoms on one's life and expectations about the nature and severity of one's condition (McCormack *et al.*, 2016).

The impact of illness beliefs on life with a rheumatic condition has been explored qualitatively with participants diagnosed with a range of diagnoses (Berenbaum *et al.*, 2014; Chisholm *et al.*, 2016; Pouli *et al.*, 2013). These studies have reported the need for reassurance about the future for some interview participants who had more pessimistic illness beliefs (Berenbaum *et al.*, 2014), particularly with relevance to the fluctuating nature of the condition and the struggle to respond to this. Chisholm *et al.* (2016) identified participants who conducted social comparisons but to peers with more favourable health. Information was not provided about participants' health and physical function in order to understand the context behind their experiences and the data.

6.7 "Just does a lot of fetching and carrying": Social support

Although participants attempted to be independent where possible (as discussed in section 6.2), a factor that contributed to them being able to effectively manage their health was their support networks. This often came in the form of partners, family, friends and neighbours and they demonstrated love and care for the participants. While participants often did not seek support from their loved ones related to the overall management of their condition such as accompaniment to clinic appointments or discussing the impact of their conditions, they did often ask for physical, practical help. This was often housework, driving, lifting or carrying:

"It is more the practical stuff of opening things, that I've needed help with." (Mary)

"Yeah [family] carry the bags in for me, from the car yeah they will, they lift things down shelves for me, when I can't reach them, and stuff like that, change lightbulbs and that." (Lindsay)

"Just does a lot of fetching and carrying for me. If I can't open something, she'll open it for me. If I can't lift something, she'll lift it for me. So yes, it's just helping out." (Richard)

"If I need to go and shop, my husband will always go with me, so he will take the brunt of that. He'll push the trolley and I just sort of trail behind him saying "I want that, I want that",

yeah, otherwise, and the other option is I send him with the list, to do the shopping." (Patricia)

Sometimes this was flexible depending on participants' needs at that time:
"We share the workload, really. If I'm doing well, I'll do more and if she's doing well, she'll do more." (Stuart)

"When I'm really bad in flare, my mum comes and stays…and she'll do the school runs, and things like that" (Christine)

This is in line with the perspective of participants in other qualitative research into self-management, reflecting that while sometimes this support was necessary, patients did not want too much support from their loved ones (Dwarswaard *et al.*, 2016).

Given the documented emotional impact of living with a rheumatic condition (Gettings, 2010), the researcher had anticipated that actively managing a condition would also require emotional support from participants' friends, family and other social connections. However, participants often did not refer to specifically relying on their loved ones for emotional support. It is possible that the practical help being provided by participants' loved ones were offering peace of mind for both them and their friends and family. Similarly, participants did not necessarily welcome support during appointments and one participant explicitly referenced choosing not to have her partner accompany her to appointments:
"My husband really really wants to come to appointments with me but I let him come to one recently" (Christine)

Sometimes a wider circle of social support provided participants with practical help:
"[Neighbours] see me struggling, getting in and out of the car and getting things like having my shopping delivered and what have you, they see me there struggling and they'll come and help. They'll help get everything into the kitchen, I put it away from there." (Tony)

Social support has been discussed as a valuable part of maintaining health-related behaviour change (Michie and Abraham, 2013) and has been integrated into the HLQ (Osborne *et al.*, 2013) because of its value in how people make use of their social network to effectively manage their health. Given that those without a social network are less likely to engage in health-related behaviours and that rheumatology patients in the UK have reported both the value of being understood by their social network and the isolation when they do not have one, this has relevance for how to support people to prepare to make behaviour changes (Lauder *et al.*, 2006; Dures *et al.*, 2016b). Social context and environment has also been previously under-represented in self-management support, despite how relevant and important it is to how people make and maintain health-related behaviour change (Rogers *et al.*, 2011).Social support has also been identified as having associations with both health outcomes and health-related quality of life (Wan *et al.*, 2016; Gong and Mao, 2016).

As rheumatology patients have identified a gap between the need for additional social and emotional support and current service provision (Dures *et al*., 2014) it should provide a valuable target for intervention. However, interventions targeting patient activation might be unlikely to focus on improving social support as this is often less amenable to change. Instead, social skills or communication training may support people to build social networks. This could include social network approaches to embrace collective self-management so that individuals are not required to be entirely self-sufficient with their self-management and can consider the roles of others and how they can contribute to their self-management (James *et al.*, 2020). Again, this is an example of where network mapping such as the GENIE intervention may be a future intervention implemented to focus on this aspect of patient activation, either in rheumatology departments or through specialist links worker or third sector provider (Band *et al.*, 2019).

6.8 Patient activation perceptions and opinions on the PAM

The final part of the interview schedule focused on the definition and methods of capturing patient activation. This was discussed with participants to understand how closely their perspectives matched the items on the PAM.

This section was introduced by asking participants if they had heard the term patient activation before, and what they would guess that the term meant. The term "patient activation" was not specifically presented to patients before the day of the interview, however it was available on both the study title and on the consent form that participants signed, referred to in the patient information sheet and participants did complete the PAM before the interview. Participants generally stated that they had not heard the term before, but some mentioned that it must be relevant to the study. When asked to speculate what that term may mean, responses varied. Some participants suggested that how they lived now was likely to be "patient activation", others made references to *"perhaps getting more active, with what you're doing"* (Cheryl)**.**

Some definitions were closer to the understanding of the term used in the literature: *"I suppose it's just about being proactive, just generally, it's about everybody being proactive."* (Greta)

"The only thing I can think of is the patient actively seeking help, but I have a suspicion that's not it." (Patricia)

"Giving a bit more power to the patient…" (Christine)

"How you understand arthritis. Sort of how you understand it and how you deal with it in your mind sort of thing. That's what I think it might be related to" (Meryl)

"I would guess that it meant more patient input, I suppose, more patient-led." (Stuart)

The researcher provided the definition of patient activation used by Hibbard *et al.* (2004) for patients to discuss. This offered the opportunity to explore participants' perceptions of what patient activation specifically involved, including the behaviours, knowledge and skills they perceived to be relevant. Particular behaviours referenced by participants at this stage included managing treatments and taking steps to continue to improve the management of their condition:

"Making sure that they take their meds on a regular basis, probably making sure that they get the rest that they need throughout the day, yeah, and maybe asking for help off of other people to do things as well." (Anne)

"Somebody that has a relationship with their medical team, medical professionals, and is given feedback with medication, whether it's working or not. What they could be doing within their own lifestyle to benefit their own condition, I think." (Stuart)

Anne had a very specific visual image when presented with the term, saying:
"It makes me think of something chemical like, [chuckling], there's going to be an alarm going off any minute."

Some participants referred to a perception they held about the term activation and its imagery of "*switching someone on*" (Richard). This would imply that, to these participants, the responsibility for "activating patients" lies with healthcare professionals. This would still leave patients passive yet being encouraged to take responsibility for their health, rather than proactively doing so.

The terms patients suggested as an alternative to patient activation that still reflect the skills, experience and knowledge they drew upon to manage their health, varied. These included "*engagement*" and "*sort yourself out*". These placed the expectations for self-management and responsibility for one's health more firmly with patients.

Finally, participants' perceptions of the PAM were discussed. The researcher clarified when introducing this block of questions and emphasised again at this point that she did not develop this definition, and she was not related to the group of researchers that developed the PAM. She encouraged participants to respond honestly to explain what they liked and did not like about the questionnaire. This included stressing that there were no wrong answers and she was interested in participants' thoughts about the questionnaire from those who really liked it, those who did not like it at all and everything else in between. The intention from this introduction was to reduce the risk of participants feeling pressure to give socially desirable answers if they perceived the researcher to be personally connected with the outcome measure, or with an agenda. If they asked the researcher what her thoughts were, this was redirected with gentle steering and the phrase "I'm interested in what your thoughts are, but I can tell you a little about mine later".

Participants' feedback on the PAM covered a wide range of perspectives. Some participants felt that this measure was entirely appropriate and fit for their understanding of patient activation, capturing the things that they felt demonstrated how they took responsibility for their health:

"No, I think the questions here are quite good, yeah … I think they're really good, bold questions." (Jim)

"I agree with all of it actually." (Jackie)

"It covers all the general things on there." (Jan)

"I think most of them are relevant." (Richard)

Others recognised that their understanding of patient activation was broader and gave specific suggestions for where they performed behaviours or had knowledge or skills that were not captured in the PAM. For Lindsay, she felt like how she managed work reflected being able to effectively and actively manage her condition:

"This here basically is just asking you basically all these questions are tailored for how you're getting on at home, or how you're managing your medication basically, and I think work is a big part of everybody's life if they go to work and there's not enough questions or studies about how work has an impact."

Other participants provided critiques on the phrasing of items of the PAM that did not reflect their experience of actively managing their health. Item one of the PAM ("*I am the person who is responsible for taking care of my health*") (Hibbard *et al.,* 2004; Hibbard *et al.,* 2005) was critiqued by several participants who made reference to the benefits and necessity of working collaboratively with healthcare professionals, as referenced in section 6.4.2. While participants recognised that they had a valuable part to play in being responsible for their health, they did not feel they held this responsibility alone. They referenced the responsibilities held by healthcare professionals, particularly when it came to determining the course of medical treatment and for their knowledge:

"I mean things like that, the top one, I'm the person responsible for managing. Yes, but then you see you need help with the medical professionals." (Mary)

"Yeah number one when all said and done, yeah which you are really aren't you, you are responsible for managing your own health condition. With obviously with help with doctors, but overall you are the only one that can…" (Joanna)

"Well that first one, I know really disagree with that, because at some stage it's got to be what the Consultant says, you can't just come in and say yes I'd like this, I'd like that." (Lindsay)

"I mean question one on the person responsible for managing my health condition, I would agree strongly, but I've put agree because actually there's only so much I can do and therefore the health service have a degree of responsibility as well." (Mark)

"You've got to do your bit at helping. [Healthcare professionals] are there to sort of instruct and do what they can to help but you've got to do your bit as well I feel. You know, sort of go half-way to meet them sort of half-way." (Meryl)

This suggests more of a mixed health-related locus of control, where these participants felt both personal responsibility for their health, but that doctors or powerful others also had a role to play (Wallston, 2005). This also reflects some of the complex nature around patients' expectations of both their role and that of the healthcare professionals. The independence they wanted to retain, the collaborative relationship participants discussed being optimum and yet the sense here that healthcare professionals were also ultimately responsible for patients' health conditions suggested some conflicting perspectives.

Item three on the PAM ("*I am confident I can help prevent or reduce problems associated with my health")* and item eleven ("*I know how to prevent problems with my health)* were commonly cited by participants as problematic and not aligned with their understanding of managing their conditions. At this point participants often referred to setbacks or flares that they were often unable to prevent or predict. Given that flares within arthritis are common, being able to respond effectively to fluctuations and changes in a long-term condition must be a part of self-management (Box, Bonney and Greenfield, 2005). Participants reported that they felt that this question did not reflect the unpredictable and permanent nature of their conditions:

"I don't know that you could sort of actually prevent it" (Meryl)

"I know how to prevent further problems with my health condition, because you can't prevent it, once you've got it, you've got it." (Anne)

"I know how to prevent further problems with my health condition, again, I've put agree, because again, there's always the unknown, that we don't have control about, so again, so rather than strongly agree, I've put agree." (Greta)

"I am confident that I can take actions that will help prevent and minimise, I don't can't strongly agree, because you don't always know what you should be doing." (Patricia)

"And the reason I put 'agree with' in 11 is, I know how to manage physically but I can't control what my body does in terms of flare. So that was the only reason I put 'agree', otherwise I would have put 'strongly agree'." (Christine)

"I've put, 'disagree" with a couple of things. For example, 'I know how to prevent further problems with my health condition.' And I've put, 'I disagree.' And the reason I put that is because the random nature of the condition, you know, I suppose, thinking about it, I can limit, perhaps, to a certain degree, further problems. But I certainly can't prevent it, other than taking the medication…" (Stuart)

The phrasing of items in the PAM may have been interpreted by participants as being black and white, without much interpretation for middle ground in collaborative care or the fluctuating nature of conditions. However patients may still be actively managing health conditions working collaboratively with healthcare professionals. They could also be able to manage their condition even in the presence of unpredictable flares and fluctuations.

The interpretation of "problems" from item 11 of the PAM could also be broad. Anne seemed to feel that the problems referenced was the onset of her arthritis, whereas Christine interpreted problems as potential flares.

The PAM is intended to be a generic measure suitable for all kinds of conditions. However, patients with long-term conditions have reported it is not always suitable for conditions that fluctuate (Roberts *et al.*, 2016). Developing an understanding of what contexts are most appropriate for the use of the PAM and its acceptability to patients will allow for changes in how the measure is used in practice.

"Generally of course it's my responsibility to you know … And I guess for number nine (I know what treatments are available for my health problems)*, again, to a point, because I know the medication that I was offered, and I know the names of both of them, what I don't know is whether anything has changed or whether there is anything else available."* (Mary)

"I know the different medical treatments, options available for my health condition, well you don't really know them all at the beginning. I mean going back probably a couple of years ago, the Consultant would say "Well you've got lots of options and then we'll give you like two leaflets to take away", you wouldn't be given all of them and you would pick between all of them, you tend to get two at a time" (Lindsay)

Some participants reflected on the responses that they had provided to the PAM in light of the discussions had within the interview:

"I don't want to be patronising but I consider myself quite educated, and whether a lot of people would be able to go into, I mean I don't think I'd gone in, really picked out the detail in them, but I think they probably could almost cut it down a bit, but that's only nit-picking" (Avril)

"So even though I agree and everything seems wonderful, actually a lot of the questions I agree with simply because of my own research rather than what information I maybe should have been given." (Mark)

How participants carried out their own research to find out information, attend talks and groups, and ask questions was important to them, and having this reflected in the PAM was a suggestion. Mark noted that doing his own research to gather knowledge felt more like actively managing his condition than passively receiving information unprompted from healthcare professionals. This reflected the idea that actively managing a rheumatic condition may be a skill learned outside of rheumatology departments (Roberts, 1999):
"I'm in favour of it in that I actually think that not just within Rheumatology but within health completely, we need to be taking responsibility for our own health and seeking advice and doing things to improve our health" (Patricia)

6.9 Specific second interview findings

This section is shorter as much of the data gathered for the second interviews were discussing topics and aspects related to the framework and the first interviews. Relevant data abstracts that are incorporated into the overall framework were included in the preceding subsections. Additionally, if findings from the second interviews did not provide detail that was novel it was not included in this current subsection.

Nine participants returned for a second interview. Of the eight participants who did not return for a second interview, two were unable to as they were now working and were no longer able to commit to meeting during their working hours. One was no longer well enough to continue to participate, two were not able to attend due to other life commitments and three were lost to follow-up.

During the second interviews, each participant had the opportunity to individually review their year and their health during this time. Many of them had experienced flares and specific life challenges and reflected on how they managed their health in the time since the first interview:

"You get your ups and downs, you get your flare ups but you cope with them. You have to, don't you?" (Jan)

"My usage of [pain medication] goes up in August, always has done for the last [number] years, I have children at home. I'm always really careful with it." Christine

"I got healthier in one way because I walk *a lot now, I use the bus a lot, I have my car but I do walk"*

Within the interviews, participants noted that they reviewed and reconsidered aspects of their self-management. One participant set a goal to return to swimming during the interview as she had recognised that she wasn't doing enough exercise, and another participant reported how she had found herself considering how much her health and self-management had improved over the last year when preparing to return to the second interview.

The researcher also provided participants with a summary of the findings of the research (see Appendix O) and discussed this in detail with them. She was clear that the findings provided a general summary of participants' data and therefore there may have been things that did not seem credible or accurate for individuals but she would welcome feedback on these. Participants responded to this summary positively, generally taking time to embellish the summary points with descriptions of their experiences and how they felt it resonated with them. They also provided positive feedback about how they felt it resonated with their experiences:

"I can't think of anything [to add], I think you've covered the full area" (Mary)

"I think you've really covered everything here" (Jan)

"[positive illness beliefs] was the only one I didn;'t agree with, I think everything else kind of rang true" (Christine)

"I think it's been really good to behonest, it's nice to see that the other people are of the same mindset really" (Jim)

"That's an absolute yes…I think all the points" (Jackie)

6.10 Study strengths and limitations

6.10.1 Strengths

This study was strengthened by the patient and public involvement contributing to a carefully considered interview schedule that was piloted to ensure it was accessible and easily understood by participants. The member checking exercise and opportunity for participants to clarify the findings, contribute additional detail and correct where they felt aspects of the framework were not credible.

6.10.2 Limitations

The attrition rate for the second interviews limited the opportunity to investigate the temporal aspect of patient activation with all participants. This also would have limited the helpfulness of the member checking as some participants whose health was now good enough to work full time or those who were now too unwell to interview did not have the opportunity to discuss the findings with the interviewer in a second interview.

6.11 Summary

Skilled self-managers summarised that they actively managed their conditions by being determined and independent about managing their health, finding ways to make small, sustainable behaviour change and effectively navigating the NHS. They reported that knowing what techniques suited them individually, having positive perceptions about their health and good social support. They felt that while aspects of the PAM reflected how they performed patient activation it was not suitable for capturing the fluctuating nature of their IA and the collaborative nature of care. These findings were confirmed by study participants at the follow-up interviews.

Chapter 7: Quantitative Methods

The qualitative study provided a sense of how rheumatology patients understood patient activation, and the behaviours, skills and knowledge that they believed contributed to how they managed their health. After reviewing the findings of that study, the nature of patient activation in a wider sample needed to be understood. This included establishing how stable the construct of patient activation remains over time, and investigating factors that were significantly associated with patient activation in a sample of patients with inflammatory arthritis. This contributed to the overall aim of the thesis to describe patient activation, and factors which contribute to patient activation, in the context of inflammatory arthritis. This chapter reviews how the survey variables were selected. Next, it describes the methods selected in order to conduct a survey to understand patient activation across a wider population as captured using the PAM.

7.1 Study aims and objectives

7.1.1 Aim

The aim of this study was to describe the nature of patient activation (measured using the PAM) in patients with IA.

7.1.2 Study objectives

- To identify levels of activation in an opportunity sample of patients.
- To examine changes in PAM scores in a cross-section of patients with inflammatory arthritis at two different timepoints. This will include within-patient changes at both timepoints, as well as between-patient variation at each timepoint.
- To understand changes to PAM scores in this sample over time.
- To examine the associations between PAM scores and other related constructs and demographic characteristics.

7.2 Rationale

As discussed in Chapter 3, there is limited evidence demonstrating patient activation levels and scores in rheumatology patients. This information on activation will be relevant in understanding the types of interventions that may be appropriate for rheumatology patients, as well as investigating whether activation fluctuates. This has implications for the timing, length and opportunities for patients to top-up the skills, knowledge and confidence offered by potential interventions. The stability of patient activation also has implications for service design and delivery as if patient activation fluctuates, there can be difficulty in aligning services to individuals' needs and activation levels.

The previous interview study was designed to be broad and exploratory in order to inductively gather data on participants' experiences and perceptions of patient activation. The major findings formed a framework of factors that participants felt captured how they actively managed their health. Understanding how these framework categories mapped onto current existing theory and factors relevant to patient activation was the next step of the process. This moved the project in a more deductive direction and allowed the researcher to test whether these factors were relevant in a wider rheumatology population. This survey investigated some of these, along with other factors associated with patient activation in order to identify those that are statistically significant contributors to differences in PAM scores. These factors may be amenable to intervention in order to increase patient activation.

7.3 Study design

The survey study was designed following consultation with the PRP, an independent statistician, and the researcher's supervisory team to ensure scientific rigour and potential benefit to the patient population.

The study design was a longitudinal, quantitative survey with two phases of postal data collection that were nine months apart. Postal survey packs are a commonly used method of collecting survey data (Kelly *et al*., 2003) in order to efficiently gather large amounts of data. Postal surveys were selected to allow participants to complete the measures at their leisure in a time and location that suited them in order to make participation as easy and accessible as possible. This method also offered the opportunity to gather data from a wide geographical area easily and efficiently. Additionally, in comparison to telephone data collection with a researcher, this allowed participants' responses to remain anonymous by returning their survey responses without providing any identifying information. Completing the pack on paper also gave participants the time to consider their responses to questions and reread them if necessary. This reduced any risk of them feeling pressured to give less considered responses or more socially desirable answers over the telephone.

Offering the option to complete the survey electronically was considered as an alternative method of data collection. The benefit of this would be that participants could decide how they preferred to complete the survey pack. This method could also reach participants who may have been otherwise unable to participate, e.g. those lacking the mobility to be able to access and use the postal system (Wright, 2005). However, the decision was taken not to include this additional method of data collection. The reason was to reduce the risk of participants responding differently to internet-based data collection compared to pen and paper completion.

7.4 Timeline explanation and justification

One of the aims of this study was to compare the two data collection time points in order to identify if the PAM changed over time. Following a review of the literature, the decision was taken to set the follow-up data collection point at nine months. Other studies that had conducted multi-timepoint surveys into patient activation had used differing follow-up lengths. These have included six months (Blakemore *et al*., 2016), eighteen months (Rijken *et al*., 2014), and up to three years (Aung *et al*., 2016). Nine months offered the opportunity for participants to experience fluctuations in their health, to have the opportunity to actively manage setbacks, and to be able to make use of some of the skills the PAM asks about in the measure's items (e.g., being able to raise concerns with health professionals). Given that one of the aims of the study was simply to map natural changes over time, and there was no planned intervention during this time, the precise timescale was somewhat arbitrary and it was simply important that time passed.

7.5 Survey pack design

The measures in the survey pack (see Appendices P and Q) were chosen for a variety of reasons, including their psychometric properties, prior use with patients with rheumatic conditions, and minimal participant burden. Some of the copies of measures in the appendices are inspection copies in order to comply with copyright.

The format and order of the measures in the survey pack went through multiple iterations to improve clarity and flow.

The researcher determined what measures to include in the survey pack based on several sources of information. One of these were the findings of the qualitative interviews and Table 7.6 demonstrates how the framework categories discussed in chapter 6 were captured in the survey. Other constructs of interest were identified from the literature review detailed in section 8.3. Once the constructs had been determined, appropriate measures that captured them were selected for the survey pack.

7.5.1 Demographic factors included in the survey

The inclusion of most constructs and outcome measures included in the survey was decided on following the analysis of the first phase of qualitative data (see chapter 6). However, some factors were included in the survey pack after reviewing recent literature. Section 3.3 summarised the evidence available related to demographic factors and patient activation.

7.6 Measures included in the pack

The measures in the survey pack included:

7.6.1 Measure used to capture patient activation

- Patient Activation Measure: Short form (PAM) (Hibbard *et al.*, 2005):

  The PAM is a commercially licenced measure designed to capture patient activation over 13 items and categorise patients into one of four activation levels ranging from one (passive) to four (actively managing their health). It is the most widely used measure to capture patient activation, having been used internationally and translated into a wide range of languages (Hibbard, Greene and Tusler, 2009). The PAM was the dependent variable for the data analysis and was selected because it was the dominant measure used to capture patient activation. Details on how to score the PAM are available in section 3.2.1.

7.6.2 Measures used to capture variables that may be related to patient activation

- Rheumatoid Arthritis Self Efficacy Scale (RASE) (Hewlett *et al.*, 2001):

  The RASE is a 28-item measure, developed to capture self-efficacy in British rheumatology patients (Hewlett *et al.,* 2001). It was selected for its clarity, appropriateness for a sample of British rheumatology patients and its strong psychometric properties with good construct, face and content validity as well as good reliability (Hewlett *et al.,* 2008). The measure is scored by providing responses to the items based on how participants feel they could do the precise activities. The responses range from 1 (strongly disagree) to 5 (strongly agree) and final scores range from 28 to 140.

- Brief Illness Perceptions Questionnaire (BIPQ) (Broadbent *et al.*, 2006):

  This 9-item measure captures participants' understanding of the timeline and nature of their condition, the emotional impact of their health changes and the impact to their sense of identity. It also includes an open-ended question focused around the causes they attribute to their illness. The first 8 items are numerical with participants circling on a scale of 0 to 10. Items 3, 4 and 7 are reverse scored to calculate the final total. The higher the final total score, the more threatening and severe the participant views their illness to be. The final score could be between 0 and 80. Item 9 is the more open-ended item and the responses to these can be analysed separately by grouping into categories.

- Multidimensional Health Locus of Control Scale – Form C (Wallston, Stein and Smith, 1995):

  This 18-item measure captures participants' beliefs about how much of their health is related to their own personal control or because of chance. It captures data on four subscales that determine how much participants feel changes to their health are due to their actions, to chance, to doctors or powerful others. Participants respond to the items with one of six responses: "strongly disagree, moderately disagree, slightly disagree, slightly agree, moderately agree or strongly agree". Each item contributes to the four subscales and the higher the score on each subscale, the higher the participants' locus of control in this type is. The subscales for doctors and powerful others have a range of 3 to 18 with higher scores indicating greater locus of control here. The internal and chance subscales have a range of final scores from 6 to 36. This measure was selected because of its dominance as a measure of health locus of control.

- Health Literacy Questionnaire (Osborne *et al.*, 2013)

This 44-item measure captures participants' abilities to navigate the healthcare system confidently, to gather and apply health-related information and to work with healthcare providers. There are nine total subscales capturing various dimensions of health literacy in this measure. The measure was selected because of the breadth of types of health literacy it captures and because it was appropriate for remote data collection, rather than the "test" style measures that other health literacy measures often employ. The nine subscales are:

  - Subscale 1 Feeling understood and supported by healthcare provider.
  - Subscale 2 Having sufficient information to manage my health.
  - Subscale 3 Actively managing my health.
  - Subscale 4 Social Support for health.
  - Subscale 5 Appraisal of health information.
  - Subscale 6 Ability to actively engage with healthcare providers.
  - Subscale 7 Navigating the healthcare system.
  - Subscale 8 Ability to find good health information.
  - Subscale 9 Understanding health information enough to know what to do.

Participants are presented with statements to respond to, and scores for the first five scales range from 1 (strongly disagree) to 4 (strongly agree). For the last four scales the scores range from 1 (cannot do/always difficult) to 5 (always easy). Mean scores for each subscale are calculated based on participants' responses to the items in the subscales. The higher the score, the greater the health literacy for participants.

- Positive and Negative Affect Scale (Watson *et al.*, 1988):

This 20-item measure, selected for its use in prior patient activation research (Hibbard and Mahoney, 2010) has been demonstrated to reliably capture participants' positive and negative affect. It has been validated for use with rheumatology patients and was selected for these reasons (Zautra *et al.,* 1995). Participants provide a numerical value for how strongly they have felt each emotion recently from 1 (very slightly or not at all) to 5 (extremely). Both positive and negative affect have 10 items listed each, and this contributes to a total score for each that can range between 0 and 50. The higher the score, the greater positive or negative affect the participant has experienced recently.

7.6.3 Measures of clinical status and health

- Fatigue Numerical Rating Scale (Fatigue NRS) (Nicklin *et al.*, 2010):

This is a brief measure of fatigue from the Bristol Rheumatoid Arthritis Fatigue Scale, asking participants about their fatigue levels over the 24 hours prior to their completion of the survey. There are three items and they each capture a different aspect of the fatigue: average level over the last week, the effect it has had on participants and how well they have coped. Participants respond from 0 to 10 for each of these. For the average level and the effect of fatigue, higher scores report more debilitating fatigue. For the coping item, higher scores reflect participants positively coping with pain. For the purpose of this study, only the average level was used.

- Pain Numerical Rating Scales (Pain NRS):

This is a brief measure of pain based on the measure of fatigue present in the Bristol Rheumatoid Arthritis Fatigue Scale, asking participants about their pain levels over the 24 hours prior to their completion of the survey. This and the fatigue NRS were selected because they have been identified as being sensitive to change in patients with IA (Hawker *et al.,* 2011). The "average" level over the last week was the measure included in this study. Participants respond from 0 (no pain) to 10 (pain as bad as you can imagine). The higher the score, the greater the level of pain.

7.6.4 Demographic information

- Demographic information collected included sex, age, ethnicity, rheumatic condition and disease duration.
- Health Assessment Questionnaire (HAQ) (Fries *et al.*, 1980):

The disability component of the HAQ captures participants' level of physical disability, and the impact that the rheumatic condition has on participants' level of physical function. This is commonly used to situate the sample in studies with rheumatology participants. Details about how to score the HAQ are available in section 5.7.

7.7 Concepts of interest

Table 7.6: Links between qualitative findings and quantitative survey

Framework analysis overarching category	**Constructs to be captured**	**Measure used with examples of key items**
"You do it because you have to" Determined independence	Patient activation, self-efficacy	PAM e.g., item 1: "I am the person who is responsible for taking care of my health" RASE: e.g., item 16 "I believe I could explain to friends and family when I do or do not need help" PANAS e.g., item 16: "Determined"
"You find ways to do different things": Making small changes	Self-management behaviours e.g. pacing, adaptation, problem solving	RASE examples: "Believe I could pace myself and take my arthritis into account to help deal with tiredness". "Believe I could plan or prioritise my day to deal with difficulties of doing everyday tasks"
"If you have a problem just phone up": Navigating the system	Health literacy	HLQ – items about deciding which healthcare professional to see, making sure they understand problems, get health information by yourself, ask questions to get the health information you need

“I think I've recognised what works for me, and what I need”: Knowing oneself	Health literacy	Lots of HLQ questions related to knowing when to seek help. However, it is possible that perhaps the sense of “knowing oneself” isn’t easily captured in a tangible way using measures. Therefore, it was not specifically captured in this study.
There are people far worse than me”: Positive illness beliefs	Illness beliefs	BIPQ: “How concerned are you about your illness?” “How much does your illness affect your life?”
“Just does a lot of fetching and carrying”: Practical social support	Sense of social support	HLQ: “If I need help, I have plenty of people I can rely on”, “I have strong support from family and friends”

7.8 PRP involvement

The PRP was consulted throughout the study. This included input into the study design, including his perspective on postal surveys as opposed to electronic data collection and the time period of follow-up. He was involved in selecting the constructs being captured with reference to the findings of the qualitative study. He reviewed the outcome measures included and the format and order of the final survey pack. His feedback contributed to a final survey pack design that was as accessible as possible, easy to follow, and with clear wording and layout. The PRP completed the survey pack as a pilot in order to review for clarity and length, and discussed his experience at a follow-up meeting. He also reviewed and consulted on the protocol (see Appendix R), patient information sheet (see Appendix S) and other study documents prior to applying for ethics approval.

7.9 Ethics

Ethics approval to carry out this research was granted by the Yorkshire and the Humber South Yorkshire Research Ethics Committees (reference 18/YH/0227) following proportionate review and ratified by the University of the West of England as the research sponsor (reference HAS.18.06.191). All six recruiting sites carried out capacity and capability assessments and approved the research at these sites.

Consent to participate in the research was presumed based on participants having completed and returned the anonymous questionnaire survey pack to the researcher. The option to tick to be posted the second survey pack allowed participants to only take part in the research to the point they were comfortable with. For this reason, a second pack was not sent to participants who had received the first survey pack but not returned it. This was because they had not yet provided a form of agreement to take part in the study. This was also the case with participants who completed a first survey but did not tick the option to receive a second one. These participants were not sent a second survey pack as they had not consented to receiving ongoing correspondence about the study.

7.10 Participant identification and recruitment

7.10.1 Inclusion criteria

Participants were eligible to take part if they were:

- over 18 years old;
- living with a diagnosis of IA confirmed by a rheumatologist;
- a patient at one of the recruiting sites;
- able to communicate, read, and write in English.

7.10.2 Identifying the patient population

The intention was to ensure a range of participants were represented in the sample of this study. In order to access a range of patients to form the sample, recruitment took place at six rheumatology departments throughout England. These secondary care departments were selected to cover diverse geographical locations, urban and rural communities, ethnically and socioeconomically diverse areas, and varying size and scope of the rheumatology department. The inclusion criteria were also deliberately broad to ensure as many interested patients as possible could participate. The collaborating rheumatology units across hospitals in England were:

- Bristol Royal Infirmary, Bristol;
- Haywood Hospital, Stoke-On-Trent;
- Torbay Hospital, Torquay;
- North Shields Hospital, Northumbria;
- St Peter's Hospital, Chertsey;
- Weston General Hospital, Weston-Super-Mare.

Participants were identified by the researcher based in Bristol, or a collaborator at the recruiting sites, by reviewing the clinic lists and screening for inclusion. Those who were eligible were approached and offered the opportunity to participate in the research or the packs were posted to them with an invitation to participate.

This was an opportunity sample, with no pre-determined sampling framework. The aim was to capture all those who were interested in participating. One limitation of this, which will be discussed in more detail in section 10.10, is that this will have contributed to a sample of participants who were more likely to be already engaged.

This is because those who are already proactively managing their health condition are more likely to consider taking part in a research study related to their condition (Bombak and Hanson, 2017).

7.10.3 Sample size

The intention was to collect approximately 350 datasets across the six sites at the first time point. This target sample size was based on the Draper & Smith (1998) guidance that there should be at least 10 participants for each independent variable being measured. The list of variables is available in 7.11.2.

Approximately 700 survey packs were provided across all sites (i.e. 100-120 per site), assuming an estimated return rate of 50%. This estimation was based on similar postal surveys following these methods that have been used previously in rheumatology (Sanderson *et al.*, 2010).

7.11 Study procedure

Recruitment took place between August and October 2018. Eligible patients were given a study information pack when they attended an outpatient clinic appointment at their rheumatology department or received a pack through the post from the department. This information pack contained a patient information sheet (see Appendix S), an invitation to participate from the local clinical lead (see Appendix T), the survey pack, a reply slip and a reply-paid envelope. Potential participants were asked to read the patient information sheet, and providing they wanted to participate, they were asked on the patient information sheet to sign the consent form and complete the survey pack. Participants had the option of completing survey packs in clinic or taking them home, then posting them back to the researcher in Bristol using the reply-paid envelope.

While there was an opportunity to follow-up with non-responders for the second surveys, there was not an opportunity to contact patients who had been given initial survey packs to prompt them to complete them. This is because consent was only presumed once participants had returned their questionnaire pack which included their consent to receive future surveys. This choice was made as there was at this point, an unknown delay between participants' returning their survey packs in the post and the packs being received by the researcher in Bristol. Choosing not to send a reminder was intended to avoid undue coercion of participants with reminders either unnecessarily early, or without their consent to receive follow-up information. Given that there was a risk of attrition, it was decided that sending a reminder letter for the second phase of data collection would be acceptable provided that participants had confirmed they were happy to receive the second survey pack. Non-responders to the second pack were sent an identical chase pack with a reminder letter 2 months later (Appendix U).

The survey packs were labelled with unique pack numbers. Each local site kept a record of which patients had been handed which survey pack number. The researcher kept the sites regularly updated on which packs had been returned in the post for the sites' records. Study participants were allocated a unique ID number and data was entered from the returned survey pack into a password-protected spreadsheet on SPSS for Windows (SPSS Inc. Chicago. Illinois). The hard copies of the survey packs were then stored in a locked filing cabinet within the researcher's office.

7.12 Analysis

7.12.1 Descriptive statistics

Once all data were collated onto one spreadsheet on SPSS for Windows (SPSS Inc. Chicago. Illinois), the data were reviewed and cleaned. Any data sets with insufficient data were excluded. This occurred when the response to one full demographic factor or the responses to one full measure were missing or when there were so many items missing in a measure that a score could not be calculated or there was insufficient data to impute the final value. Following the guidance of Insignia Health (2017), any participants who had responded with either "Strongly Agree" or "Strongly Disagree" for all items on the PAM were excluded. Frequencies were calculated and the data visually screened to reduce the risk of a data entry error being incorporated into the final analysis. Disease duration was calculated by calculating the current age minus the age at diagnosis.

Descriptive statistics were calculated to identify the mean, median, standard deviation, variance, maximum and minimum values for all continuous variables. The skew and kurtosis were also checked for all continuous variables. For discrete variables the frequencies of responses were calculated. Cronbach's alpha was also calculated for each measure at both timepoints to understand the internal consistency of each measure in this sample.

The BIPQ data provided by participants was collated and a content analysis conducted. This information is available in Appendix V.

7.12.2 Regression analysis

A regression analysis is a way of predicting the value of one variable based on participants' responses, and once all the relevant variables are entered, the overall model is assessed as well as the impact of each individual variable (Pallant, 2005). For this analysis, the participants' PAM scores were the continuous dependent variable, and there was a series of independent variables.

An a-priori plan was developed on theoretical grounds with each variable being added after controlling for the prior variables (Pallant, 2005). The variables of interest were:

1. Self-efficacy (RASE);
2. Internal Health Locus of Control (MHLC subscale);
3. Illness beliefs (BIPQ);
4. Health Literacy (9 HLQ Subscales);
5. Positive affect (PANAS positive and negative subscales).

To conduct a multiple regression, certain assumptions need to have been met. Each of these will be discussed in turn:

1. Sample size of N> 50+8m (m = number of independent variables) based on the formula of Tabachnick and Fidell (2007). However, the authors note that if the dependent variable is skewed then more cases are needed. While this will be discussed in detail in chapter 8, the recruitment was sufficient that this sample size was large enough to proceed with analysis.

2. Multicollinearity occurs when any of the independent variables are highly intercorrelated. Alternatively, it occurs during singularity, when an independent variable is a combination of other independent variables (Pallant, 2005). Multicollinearity is checked in SPSS for Windows (SPSS Inc. Chicago. Illinois) as a routine part of the analysis process. An intercorrelation of above 0.9 would indicate multicollinearity and would require one of the correlated variables to be removed from the analysis.
3. A normal distribution of residuals about predicted dependent variable scores is also required and this is investigated as part of the regression analysis process.
4. Linearity is required to be able to generalise findings beyond the sample present in the analysis (Field, 2013). This occurs when residuals and predicted dependent variables have a "straight line relationship" and is confirmed by reviewing the scatterplot plotting the regression standardised residuals against the regression standardised predicted values (Pallant, 2005).
5. Homoscedasticity occurs when "*the variance for the residuals about predicted DV scores is the same for all predicted scores*" (Pallant, 2005).
6. Outliers needed checking to ensure they did not impact on the regression. Tabachnick and Fidell (2007) define outliers as participants' scores with standardised residual variables above 3.3. or less than -3. Following a review to establish whether the means of variables required trimming, it was established that there were very few outliers within the data. Of those that were present, few were extreme enough to be placed outside of the whiskers of a standard box plot created in SPSS. In order to avoid distorting the data as much as possible, participants' data were not removed when their responses contributed to outliers.
7. Assumptions of the independence of residuals refers to the way that residuals (i.e. the difference between the actual and the predicted scores for dependent variables) are distributed (Pallant, 2005). This, along with confirming the impact of outliers, normality and homoscedasticity are measured using a Normal Probability Plot of the Regression Standardised Residual and Scatter plot. If there is no deviation from normality, the points would form a bottom-left to top right diagonal line that is straight. Outliers will be evident in the

scatterplot. The review of the scatterplot and the regression standardised residuals plot confirmed that the dataset was appropriate to proceed with the anticipated multiple regression.

If any of these assumptions are violated, findings from the regression cannot be generalised beyond the sample available (Field, 2013).

7.12.3 Logistic regression

To understand whether the same variables contribute to understanding the variation in PAM levels as in PAM scores, a multinomial logistic regression was also performed. This type of regression is suitable for categorical dependent variables such as PAM levels. This was performed in the same way, with a stepwise method forming the basis for the selection of the independent variables. The independent variables for this regression were selected based on which dependent variables were statistically significant predictors of PAM scores in the multiple regression.

The specific assumptions that need to be met to conduct a logistic regression are as follows:

1. Linearity, which refers to the likely linear relationships between predictors and outcomes. If the interaction term between the PAM level and the log transformation is significant, it can be assumed that this the relationship is not linear and the assumption cannot be met (Field, 2013).
2. Independence of errors, which means that for a logistic regression, the data for each case is not related to each-other (Field, 2013).
3. Multicollinearity, which is understood in the same way as multicollinearity in multiple regressions.

7.13 Second data collection analysis

For the second set of data collected in the follow-up survey packs, the process of analysis was identical to that discussed in 7.12.1. The only addition was a related sample t-test calculated in order to understand whether there were significant differences between participants' first and second PAM scores at both within and between patient levels.

7.14 Summary

This chapter introduced the methods for the survey investigating patient activation. The results of the study are presented in the next chapter.

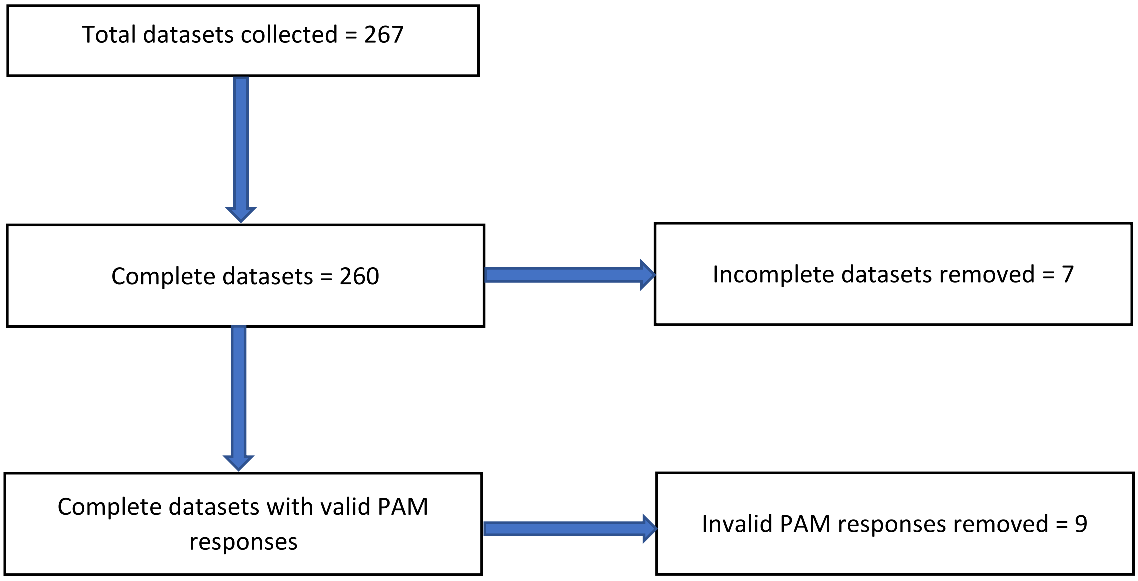
Chapter 8: Quantitative Survey Findings

The previous chapter introduced the methods that were used to gather quantitative data from participants related to patient activation and potentially associated personal and demographic factors. This chapter presents the findings of this data collection following statistical analysis.

8.1 Timepoint one

In total, there were initially 267 full datasets included in the analysis of the first data collection timepoint. Nine were excluded following the guidance of Insignia Health (2018) as they had responded to the PAM with the same responses for each item and seven were excluded due to missing data on any other outcome measures or demographic factors. Where appropriate, data were imputed for items that were missing within measures. This left 251 cases of data to be analysed (Figure 8.1). The initial protocol intended for 350 participants to complete data to allow for attrition. This reduction is a limitation as this target was not reached.

Figure 8.1: Flowchart of datasets and their inclusion or exclusion in the data



8.1.1 Demographic characteristics

Of the 251 cases eligible for analysis, 185 (74%) were female and 66 (26%) were male. The majority of participants (235, 94%) were white British, with a small number of other ethnicities represented (Table 8.1). The diagnosis most represented was RA with 66% of participants living with this condition. Participants with PsA and AS also represented a large proportion of the sample. The average age of participants was 59.3 years old (SD: 12.7), with an average of 14.5 years of disease duration (SD: 12.5). The average HAQ score was 0.75 (SD: 0.65), indicating mild levels of disability overall as the higher the score, the greater the severity of disability (Bruce and Fries, 2003).

Table 8.1*:* Summary baseline demographic characteristics

Variable	**N (%), or Mean (SD) and range**
Sex, N (%)	Female: 185 (74%) Male: 66 (26.3%)
Ethnicity, N (%)	White British: 235 (94%) Other White: 8 (3%) Black: 1 (<1%) Chinese: 1 (<1%) Other Asian: 2 (<1%) Other: 3 (1%) Prefer not to say: 1
Diagnosis, N (%)	RA: 166 (66%) SLE: 3 (1%) Inflammatory Polyarthritis: 1 (<1%) Ankylosing Spondylitis: 31 (12%) Juvenile Idiopathic Arthritis: 2 (<1%) Psoriatic Arthritis: 35 (14%) Other: 10 (4%) Don't Know: 3 (1%)
Age (years)	59.31 (SD: 12.69), range 22 to 88 years
Disease Duration (years)	14.48 (SD: 12.52), range <1 to 60 years
HAQ Score (Possible range: 0 to 3)	0.75 (SD: .65) range 0 to 2.55

8.1.2 PAM reporting

The analysis identified both levels and scores of patient activation (as captured using the PAM) in the sample of patients. The average PAM score was 58.3 (SD: 11.46) and scores were distributed between 33 and 90.7 out of a possible range of 0-100, indicating a wide range of patient activation between participants. PAM scores were distributed with a skew towards participants being more highly skilled (distribution graph is available in Appendix V). Given the non-normal distribution, the median and interquartile range also report useful information to understand central tendency for this data. These figures are 55 (median) and 51 (Q1) and 65 (Q4), respectively. Given the non-normal distribution of the data a Kruskal-Wallis test was performed in order to identify whether there were significant differences in PAM scores between participants recruited at the different sites. The findings of this test indicated that there were not significant differences in PAM scores between sites (Chi square = 4.45, p = 0.47, df = 5).

The most common PAM level was level 3, with 41.8% of the sample falling into this category.

Table 8.1a: Summary PAM levels at baseline

PAM Level:	Number of Participants:
1	42 (16.7%)
2	67 (26.7%)
3	105 (41.8%)
4	37 (14.7%)

8.1.3 Outcome measure reliability testing

As determined by the study protocol, Cronbach's alpha was calculated for each of the continuous outcome measures. The intention of this was to understand the internal consistency of each measure included in the survey pack. This captured how well each item on a measure relates to the other items (Pallant, 2007). A Cronbach's alpha coefficient of above 0.7 and above reflects good internal consistency, with responses to the items in the outcome measure correlating well with each-other

(DeVellis, 2003). All the measures that were tested for their internal consistency demonstrated Cronbach's alpha coefficients of above 0.7, reflecting acceptable internal consistency with the measures and this sample. While the assumption could be made that the measures all had good internal consistency as they were validated outcome measures, confirming this with the sample was useful for strengthening the validity of the study and its findings. The table of Cronbach's alpha coefficients for each measure is available in Appendix W.

8.1.4 Descriptive data for continuous variables

The table below provides details of the measures of central tendency for all the continuous variables being considered for inclusion in the regression model. As much of these data have non-normal distributions, the median and interquartile range are also provided.

Table 8.1b: Descriptive data

Variable	Mean (SD), range	Median (interquartile range)
Age	59.31 (SD: 12.69) Range 22 to 88 years	60 (Q1: 52 and Q3: 69)
Disease duration	14.48 (SD: 12.52) Range <1 to 60 years	11 (Q1: 5 and Q3: 20)
HAQ (possible range 0-3)	0.75 (SD: 0.65) Range 0 to 2.55	0.55 (Q1: 0.2 and Q3: 1.1)
RASE (possible range 28-140)	101.61 (SD: 15.24) Range 57 to 140	103.0 (Q1: 92 and Q3: 110)
Internal HLOC (possible range 6 to 36)	16.98 (SD: 6.14) Range 6 to 36	17 (Q1: 12 and Q3: 21)
Chance HLOC (possible range 6 to 36)	16.33 (SD: 6.47) Range 5 to 35	16 (Q1: 11 and Q3: 20)
Doctors HLOC (possible range 3 to 18)	11.31 (SD: 3.23) Range 3 to 18	11 (Q1: 9 and Q3: 14)
Powerful Others HLOC (possible range 3 to 18)	8.71 (SD: 3.57) Range 2 to 18	8 (Q1: 6 and Q3: 11)

BIPQ (possible range 0 to 80)	45.55 (SD: 10.13) Range 15 to 68	46 (Q1: 39 and Q3: 52)
HLQ 1 (possible range 1 to 4)	2.96 (SD: 0.71) Range 1 to 4	3 (Q1: 2.75 and Q3: 3.5)
HLQ 2 (possible range 1 to 4)	2.91 (SD: 0.48) Range 1.5 to 4	3 (Q1: 2.75 and Q3: 3.25)
HLQ 3 (possible range 1 to 4)	2.89 (SD: 0.47) Range 1 to 4	3 (Q1: 2.6 and Q3: 3)
HLQ 4 (possible range 1 to 4)	2.92 (SD: 0.57) Range 1 to 4	3 (Q1: 2.6 and Q3: 3.2)
HLQ 5 (possible range 1 to 4)	2.68 (SD: 0.53) Range 1 to 4	2.8 (Q1: 2.4 and Q3: 3)
HLQ 6 (possible range 1 to 5)	3.78 (SD: 0.73) Range 1 to 5	4 (Q1: 3.4 and Q3: 4.2)
HLQ 7 (possible range 1 to 5)	3.59 (SD: 0.66) Range 1.17 to 5	3.67 (Q1: 3.33 and Q3: 4)
HLQ 8 (possible range 1 to 5)	3.83 (SD: 0.63) Range 1.2 to 5	4 (Q1: 3.6 and Q3: 4.2)
HLQ 9 (possible range 1 to 5)	4.08 (SD: 0.55) Range 1.8 to 5	4 (Q1: 3.8 and Q3: 4.4)
Pain NRS (possible range 0 to 10)	5.43 (SD: 2.51) Range 0 to 10	6 (Q1: 4 and Q3: 7)
Fatigue NRS (possible range 0 to 10)	6.43 (SD: 2.28) Range 0 to 10	7 (Q1: 5 and Q3: 8)
Positive affect (PANAS) (possible range 0 to 50)	30.03 (SD: 8.85) Range 10 to 49	30 (Q1: 24 and Q3: 37)
Negative affect (PANAS) (possible range 0 to 50)	19.88 (SD: 7.73) Range 10 to 44	19 (Q1: 13 and Q3: 24)

Participants' responses to the measures often use the range of responses available and the medium value was often close to the mean value for each variable.

8.1.5 Outliers

The presence and impact of individual outliers in PAM scores and other measures were considered at this stage of the analysis. Given that multiple regressions are particularly sensitive to outliers (Pallant, 2007), extreme values in response to outcome measures needed to be identified in order to determine how much impact they had on the sample. A table of extreme values was generated in order to identify which cases had a substantial impact on the mean scores for each outcome measure and this is available in Appendix X. A mean value with the top and bottom 5% of all cases for each measure (or measure subscale, where appropriate) was also generated in order to review how much of an impact the extreme cases previously identified were having upon the mean. Given that the trimmed means did not substantially impact the mean value, no outliers were removed from the analysis.

8.1.6 Univariable analysis

Candidate variables for the multiple regression were identified using univariable analysis. The intention was to identify the relationship between PAM scores and all the variables in the analysis. Those variables without a significant correlation with PAM scores were removed as candidate factors from the full analysis.

Table 8.1c: Spearman's rank correlation coefficient tests of candidate variables and their relationship with PAM scores

Variable	**p**	**Correlation**
Age	0.03	-0.14
Disease duration	0.59	0.03
HAQ	<.01	-0.36
RASE	<.01	0.50
Internal HLOC	<.01	0.25
Chance HLOC	0.26	-0.07
Doctors HLOC	0.02	0.14
Powerful Others HLOC	0.97	<-0.01
BIPQ	<.01	-0.47
HLQ 1	<.01	0.27
HLQ 2	<.01	0.48
HLQ 3	<.01	0.41

HLQ 4	<.01	0.33
HLQ 5	<.01	0.38
HLQ 6	<.01	0.33
HLQ 7	<.01	0.30
HLQ 8	<.01	0.41
HLQ 9	<.01	0.42
Pain NRS	<.01	-0.33
Fatigue NRS	<.01	-0.31
Positive affect (PANAS)	<.01	0.41
Negative affect (PANAS)	<.01	-0.33

The findings of the univariable analysis presented in the table above indicated that the only continuous variables that did not have a significant correlation with PAM scores were disease duration, the chance HLOC subscale and the powerful others HLOC subscale. These variables were excluded from consideration in the multiple regression.

8.1.7 Reporting of regression assumptions

Following the protocol, a forced entry multiple regression was conducted with the PAM as the continuous dependant variable and the list of variables noted below as blocks of independent variables. The intention was to examine the relationship between PAM scores and other potentially related variables.

1. Sample size of N> 50+8m (m = number of independent variables. In this case there were 23 variables including the continuous demographic characteristics) based on the formula of Tabachnick and Fidell (2007). As discussed in section 8.1, the sample size of 251 cases was ultimately large enough to be appropriate for the analysis at this data collection point.
2. Multicollinearity was investigated during the analysis process. Overall, there were limited high intercorrelated variables. Those that were higher included the correlation between average pain level and overall BIPQ score (.701, p<.001) and fatigue and BIPQ score (.591, p<.001). The HLQ1 and HLQ2 scores were correlated (.677, p<.001), as well as the Fatigue NRS and Pain

NRS (.658, p<.001). These correlations fell above 0.5, but none of them reached the intercorrelation mark of .9 advised by Pallant (2007) that would have necessitated that one of the intercorrelated variables to be removed from the analysis. Only one of these intercorrelations fell above the suggested intercorrelation cut-off of 0.7 suggested by Field (2009) and as it was very marginally over this cut-off the decision was taken to retain it in the analysis. This decision was made following a review of both the tolerance and the Variance Inflation Factors (VIF) of the correlations. The tolerance refers to the amount of variability in the variable that is not explained by the remaining independent variables within the model. A tolerance of below .1 implies that there is a risk of multicollinearity (Pallant, 2007). In these circumstances, the tolerance of the BIPQ was .339, not near the risk level. The VIF has a cut-off value of 10 and hence any VIF above 10 implies multicollinearity. The VIF for the relevant factors were 2.95 (BIPQ), 2.31 (fatigue average score) and 2.83 (pain average score). These are below 10 and therefore do not suggest multicollinearity had a substantial confounding impact on the findings of the analysis.

3. To establish a normal distribution of residuals there was a review of the normal probability plot of the regression standardised residual (NPP) (see Appendices L and M*)*. The observed values lay apart from the line of best fit, suggesting deviations from normality (Pallant, 2005). None of the points in the scatterplot lay below -3 or above 3, suggesting that there were no extreme outliers (Tabachnick and Fidell, 2007).
4. The presence of linearity (i.e. a "straight line relationship" between residuals and predicted dependent variables (Pallant, 2005) required a review of the NPP. Again, there was some deviation from the line of best fit.
5. Homoscedasticity was established during the review of the NPP.
6. The impact of outliers was clarified with a review of trimmed means to identify and examine extreme values and cases (Appendix X).

Following a review by the researcher, it was evident that the non-normal distribution of PAM scores contributed to some of the assumptions for the analysis not being met. This means that the findings in their current form could not be generalisable beyond the study sample to a wider UK rheumatology population. To manage this, the analysis was performed as anticipated. A second review of the regression analysis was conducted with the non-normally distributed data having been transformed to move the distribution closer to a normal distribution. The intention of this was to confirm the findings and conduct a sensitivity analysis and increase the trustworthiness of the results. These additional findings are detailed in Appendices Z to CC and referred to at each stage of the analysis. However, the transformation of non-normal data could be considered unnecessary under the principles of central limit theorem. The central limit theorem proposes that the sample mean of data in a large enough sample will approach normality (Coolican, 2018).

8.1.8 Conducting the multiple regression analysis

The list of variables had been determined following the univariable analysis. Initially, all candidate variables were entered in a preliminary forced entry multiple regression. This was intended to identify variables that contributed to the model to a statistically significant degree at a 0.1 level (See Table 8.1d). The variables that contributed to the model and were taken forward to the final regression model were:

1. RASE total score (capturing self-efficacy);
2. Internal HLOC;
3. HLQ subscale 2 (Having sufficient information to manage my health);
4. HLQ 9 (Understanding health information enough to know what to do).

The findings of this preliminary model are available in table 8.1d. Overall, this initial regression model accounted for 42.7% of the variance in PAM scores within this sample. The multiple regression was calculated to predict PAM scores based on the predetermined list of independent variables. The regression equation identified: [F (22,228) = 9.47, p <.001] with an adjusted R^2 of 0.43.

Following this, the variables that did not significantly contribute to the regression model were removed from the syntax and the regression was rerun without these. The findings of this final model are also available in Table 8.1d.

This regression model accounted for 40.4% of the variance in PAM scores within this sample. The multiple regression was calculated to predict PAM scores based on the predetermined list of independent variables. The regression equation identified: [F (4,246) = 43.39, p<.001], with an adjusted R^2 of 0.404.

RASE scores, internal HLOC, and HLQ subscales 2 and 9 were significant predictors of PAM scores in participants. In the final model containing all of these predictors, HLQ subscale 9 recorded the highest beta value (β = 0.264 p< .01) with RASE scores demonstrating the next greatest beta value (β = 0.262, p< .001). This was followed by HLQ subscale 2 (β = 0.25, p< .001). Finally, internal HLOC had the next greatest contribution. (β = 0.16, p= .02).

Table 8.1d: Multiple linear regression to analyse the association between PAM scores and other personal and contextual factors captured by the survey:

Variables	**Preliminary multiple regression**			**Final multiple regression**		
	Standardised β	**95% CI**	**P value**	**Standardised β**	**95% CI**	**P value**
Sex	0.03	-1.84 to 3.61	0.52			
Age	-0.07	-0.17 to 0.04	0.21			
Ethnicity	-0.23	-1.4 to 0.94	0.70			
Condition	0.06	-0.22 to 0.70	0.30			
HAQ	-0.11	-4.27 to 0.46	0.11			
RASE	0.20	0.06 to 0.25	0.002	0.26	0.11 to 0.28	<0.001
Internal HLOC	0.10	-0.03 to 0.38	0.09	0.16	0.11 to 0.49	0.002
Doctors HLOC	0.05	-0.21 to 0.56	0.37			
BIPQ	-0.12	-0.33 to 0.05	0.15			
HLQ 1	-0.01	-2.53 to 2.26	0.91			
HLQ 2	0.21	1.35 to 8.42	0.007	0.25	3.29 to 8.62	<0.001
HLQ 3	0.05	-2.07 to 4.51	0.47			
HLQ 4	0.01	-2.64 to 2.89	0.93			
HLQ 5	0.07	-1.25 to 4.36	0.27			
HLQ 6	0.01	-2.95 to 3.13	0.95			
HLQ 7	-0.15	-5.94 to 0.89	0.15			
HLQ 8	0.04	-2.51 to 4.09	0.64			

HLQ 9	0.23	1.58 to 7.96	0.004	0.26	3.22 to 7.72	<0.001
Pain NRS	0.08	-1.04 to 0.40	0.39			
Fatigue NRS	-0.06	-0.39 to 1.09	0.36			
Positive affect (PANAS)	0.03	-0.14 to 0.21	0.68			
Negative affect (PANAS)	-0.03	-0.23 to 0.15	0.69			

Non-normal data were transformed to reduce the non-normality by taking the square root of data cases for relevant non-normal distributions. In the case of variables that had values of 0, the data were first transformed to add 1 to each of the responses to be sure that there were no issues in the data transformation caused by the 0s. The findings of this regression largely support the initial findings (with the exception of the RASE no longer being a significant predictor of PAM scores in the preliminary regression) and are available in Appendix Y.

8.1.9 Logistic regression

A logistic regression was also conducted. The intention of this was to determine whether the variables that accounted for variance in PAM scores also accounted for the variance in PAM levels. The assumptions for a logistic regression were met in the following ways:

1. The assumption of multicollinearity was assumed to have been met given that no variables were identified to have been interrelated during the linear regression process.
2. Similarly, the sample size was assumed to have been suitable for this method of analysis given that the sample size requirement had already been met for the prior linear regression analysis.
3. Independence of errors: this assumption was met as the dependent variable had mutually exclusive categories.

Again, an initial logistic regression was run with all candidate variables to identify the variables that were significant predictors of PAM levels at the 10% level based on the significance of the regression coefficient (**B**) for any PAM level.

Overall, the initial model was statistically significant, χ^2 (72, n = 251) = 187.15, $p < .001$. The model explained between 28.7% (McFadden test) and 56.8% (Nagelkerke test) of the variance in PAM levels. The following variables were taken forward to a final logistic regression:

1. Age
2. HAQ
3. RASE
4. BIPQ
5. Doctors HLOC
6. HLQ subscale 2
7. HLQ subscale 5
8. HLQ subscale 7
9. HLQ subscale 9
10. Pain NRS

Table 8.1e below reports parameter estimates for the model using PAM level 4 as the reference category.

These variables were then included in a backwards exclusion hierarchical regression based on how likely they were to predict PAM levels. Overall, this final model was statistically significant, χ^2 (30, n = 251) = 158.65, p < .001. The model explained between 24.3% (McFadden test) and 46.9% (Nagelkerke test) of the variance in PAM levels. Table 8.1f below reports parameter estimates for the model using PAM level 4 as the reference category.

Table 8.1e*:* Logistic regression to analyse the association between PAM levels and other personal and contextual factors captured by the survey:

	PAM Level 1						**PAM Level 2**						**PAM Level 3**					
Factor	**B**	**df**	**p**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**	**B**	**df**	**p**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**	**B**	**df**	**P**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**
Sex	-0.50	1	0.55	0.61	0.12	3.06	0.31	1	0.65	1.36	0.37	5.03	-0.05	1	0.93	0.95	0.30	3.01
Age	0.07	1	0.04	1.07	1.00	1.14	0.03	1	0.26	1.03	0.98	1.08	0.02	1	0.42	1.02	0.98	1.06
Disease duration	-0.00	1	0.90	1.00	0.94	1.06	<-0.01	1	0.90	1.00	0.95	1.05	-0.01	1	0.79	0.99	0.95	1.04
Ethnicity	0.22	1	0.64	1.24	0.49	3.13	0.28	1	0.34	1.32	0.75	2.33	0.18	1	0.49	1.20	0.72	2.02
Condition	-0.05	1	0.75	0.96	0.72	1.27	-0.03	1	0.82	0.98	0.79	1.21	0.06	1	0.51	1.06	0.89	1.28
HAQ	1.25	1	0.10	3.48	0.79	15.27	0.64	1	0.30	1.90	0.57	6.36	0.69	1	0.21	2.00	0.67	5.95
RASE	-0.10	1	0.00	0.91	0.86	0.97	-0.07	1	0.01	0.94	0.89	0.98	-0.04	1	0.08	0.96	0.92	1.00
Internal HLOC	-0.11	1	0.10	0.90	0.79	1.02	-0.08	1	0.13	0.93	0.84	1.02	-0.40	1	0.49	0.97	0.89	1.06
Chance HLOC	0.02	1	0.71	1.02	0.92	1.14	-0.01	1	0.76	0.99	0.91	1.07	-0.01	1	0.72	0.99	0.92	1.06

Doctors HLOC	-0.16	1	0.21	0.86	0.67	1.09	-0.18	1	0.06	0.83	0.69	1.00	-0.12	1	0.13	0.89	0.76	1.04
Others HLOC	0.10	1	0.34	1.10	0.90	1.35	0.05	1	0.56	1.05	0.89	1.24	-0.01	1	0.88	0.99	0.85	1.15
BIPQ	0.15	1	0.02	1.16	1.02	1.32	<-0.01	1	0.96	1.00	0.91	1.10	-0.03	1	0.44	0.97	0.89	1.05
HLQ 1	-0.15	1	0.84	0.86	0.21	3.60	-0.28	1	0.63	0.76	0.24	2.39	0.14	1	0.79	1.15	0.42	3.17
HLQ 2	-2.36	1	0.03	0.10	0.01	0.79	-0.42	1	0.63	0.66	0.12	3.61	-0.09	1	0.91	0.91	0.21	3.96
HLQ 3	-0.06	1	0.96	0.94	0.11	7.96	-1.07	1	0.21	0.34	0.07	1.83	-0.70	1	0.36	0.50	0.11	2.20
HLQ 4	-0.35	1	0.68	0.70	0.13	3.71	-0.18	1	0.79	0.83	0.21	3.26	-0.69	1	0.26	0.50	0.15	1.67
HLQ 5	-1.86	1	0.04	0.16	0.03	0.93	-0.74	1	0.26	0.48	0.13	1.73	-0.53	1	0.37	0.59	0.18	1.88
HLQ 6	0.62	1	0.48	1.86	0.34	10.09	0.14	1	0.85	1.14	0.27	4.80	0.72	1	0.28	2.05	0.56	7.54
HLQ 7	1.26	1	0.23	3.53	0.44	28.06	1.14	1	0.18	3.12	0.59	16.62	-0.31	1	0.68	0.73	0.17	3.22
HLQ 8	-0.20	1	0.84	0.82	0.12	5.70	-0.82	1	0.30	0.44	0.09	2.10	-0.37	1	0.59	0.69	0.18	2.66
HLQ 9	-1.63	1	0.11	0.20	0.03	1.45	-1.61	1	0.06	0.20	0.04	1.08	-0.44	1	0.57	0.64	0.14	2.93

Fatigue NRS	0.31	1	0.18	1.37	0.86	2.17	0.11	1	0.50	1.11	0.82	1.52	0.01	1	0.92	1.01	0.77	1.33
Pain NRS	-0.60	1	0.02	0.55	0.34	0.09	-0.13	1	0.44	0.88	0.62	1.23	<0.01	1	0.98	1.00	0.75	1.33
Positive affect (PANAS)	-0.08	1	0.17	0.93	0.83	1.03	-0.01	1	0.79	0.99	0.90	1.08	-0.03	1	0.48	0.97	0.90	1.05
Negative affect (PANAS)	0.07	1	0.25	1.07	0.95	1.20	<-0.01	1	0.99	1.00	0.91	1.10	0.01	1	0.88	1.01	0.93	1.09

Table 8.1f: Updated logistic review

	PAM Level 1						**PAM Level 2**						**PAM Level 3**					
Factor	**B**	**df**	**p**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**	**B**	**df**	**p**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**	**B**	**df**	**P**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**
Age	0.06	1	0.03	1.06	1.00	1.12	0.03	1	0.19	1.03	0.99	1.07	0.01	1	0.59	1.01	0.97	1.05
HAQ	1.28	1	0.05	3.58	1.01	12.72	0.80	1	0.14	2.23	0.77	6.47	0.53	1	0.28	1.71	0.65	4.45
RASE	-0.11	1	<0.01	0.90	0.85	0.94	-0.07	1	<.01	0.93	0.89	0.97	-0.05	1	0.02	0.96	0.92	0.99
BIPQ	0.16	1	<0.01	1.18	1.06	1.31	0.02	1	0.70	1.02	0.94	1.10	-0.06	1	0.88	1.00	0.93	1.06
Doctors HLOC	-0.14	1	0.18	0.87	0.72	1.07	-0.16	1	0.04	0.85	0.73	0.99	-0.11	1	0.09	0.89	0.78	1.02
HLQ subscale 2	-2.51	1	0.01	0.08	0.01	0.52	-0.89	1	0.23	0.41	0.10	1.75	-0.28	1	0.66	0.75	0.22	2.60
HLQ subscale 5	-1.56	1	0.03	0.21	0.05	0.82	-1.17	1	0.04	0.31	0.10	0.94	-0.84	1	0.10	0.43	0.16	1.16
HLQ subscale 7	1.62	1	0.02	5.07	1.30	19.84	0.94	1	0.09	2.57	0.86	7.70	0.25	1	0.61	1.28	0.49	3.32
HLQ subscale 9	-1.75	1	0.02	0.17	0.04	0.72	-1.68	1	0.01	0.18	0.06	0.64	-0.62	1	0.27	0.54	0.18	1.61
Pain NRS	-0.32	1	0.10	0.73	0.50	1.06	-0.07	1	0.63	0.93	0.71	1.24	0.02	1	0.85	1.02	0.80	1.31

8.2 Timepoint one discussion

The average PAM score was in line with the findings of prior studies gathering data on PAM results distributions across different populations (Gleason-Comstock *et al.*, 2016). However, the proportion of participants with level 4 PAM scores was lower than those within samples of older adults or a sample of participants from two large companies in the USA with and without long-term conditions (Gleason-Comstock *et al.*, 2015; Harvey *et al.*, 2012). This may be as a consequence of people living without long-term conditions over-estimating how able and willing they might be to manage a diagnosis based on their expectations of dealing with more minor or short-lived health problems. The distribution of PAM scores across the rheumatology sample in this PhD study was closer to those identified in a survey of patients with COPD (Korpershoek *et al.*, 2016).

The average PAM scores at the time of the first data collection were lower for the sample in this study that those identified in studies with other populations (Harvey *et al.*, 2012) and older adults with multimorbid conditions (Blakemore *et al.*, 2016).

The distribution of PAM levels across the sample demonstrates the range of experience and skills that rheumatology patients have in order to manage their health. There is a broad ability represented in this sample and the low correlation between PAM scores/levels and disease duration implies that people do not necessarily become more able to manage their health after a longer time living with their condition. The implication of this is that some people do not learn to manage their condition effectively within the early years of diagnosis and would benefit from support to self-manage even further down the line. Patients may not remain activated and could experience fluctuations in their ability and willingness to actively manage their health. The use of the PAM as a tailoring tool (Hibbard *et al.*, 2004) would be appropriate here to identify patients who would require additional support to manage their condition. This is particularly relevant as there were no specific demographic characteristics that were significantly associated with PAM scores that could help identify rheumatology patients more likely to passively live with their condition.

The majority of participants were white British. There has been limited research investigating detailing whether perceptions of patient activation are different for people from different backgrounds to this. However, a gap in PAM scores has been identified between research participants of different racial backgrounds in the USA (Hibbard *et al.*, 2008). It is possible that Western expectations of health may contribute to specific expectations of health and healthcare that shape patients' activation. This isn't represented in this study with a largely white British sample.

An important aspect of the findings is that positive and negative affect (captured using the PANAS) did not have a statistically significant relationship with PAM scores and therefore were not included in the regression model. This does not provide support for the model of patient activation proposed by Hibbard and Mahoney (2010) where they assert that positive and negative affect contribute to patients' levels of activation via their ability to carry out small behaviour changes related to their health.

The clear contribution of self-efficacy to patient activation reflects that a person's belief that they have an active role to play in their healthcare is related to the idea that they could carry out behaviours relevant to their health. As self-efficacy has been identified as a mechanism by which self-management interventions for long-term conditions have benefits (Blakemore *et al.*, 2016), this is not an unanticipated finding. The association between self-efficacy and patient activation strengthened prior findings where the two constructs had been associated (Skolasky *et al.*, 2008; Do *et al.,* 2015; Goodworth *et al.,* 2016). This contributes to the suggestion that increasing patients' confidence and belief in their ability to carry out activities related to their health increases their willingness to do so.

The association between health beliefs (captured by the BIPQ) and patient activation supports the findings identified in similar studies with other clinical populations (Chen, Mortensen and Bloodworth, 2014; Rijken *et al.*, 2014; Hibbard *et al.*, 2008). There was a moderate correlation between BIPQ as a measure of illness beliefs and the HAQ as a more objective measure (albeit of disability). This relationship suggests that how people perceive their health is more critical to their patient activation, rather than how severe their condition objectively is.

The internal locus of control scores within this sample supports the initial suggestions made by Sacks *et al.* (2017) that it is relevant to patient activation. This contributes to the understanding of patient activation as incorporating many other concepts, including locus of control (Smith *et al.*, 2013).

The lack of relationship between the demographic factors captured in the survey and PAM scores demonstrated that internal, psychosocial skills and abilities appear to be more valuable in increased patient activation than factors that are less likely to be in patients' control. The relationship between predictors of PAM scores and levels was explored in this study. Self-efficacy, HLOC and aspects of health literacy all significantly contributed to variance in PAM scores.

8.3 Timepoint two

The second data collection point allowed the researcher to explore changes to PAM scores in a sample of people with rheumatic conditions.

180 participants completed the follow-up survey pack, and the remainder of participants who completed a first questionnaires were lost to follow-up. Of the 180 participants who returned follow-up survey packs, 21 were excluded because they had not sufficiently completed the pack to be included in the analysis and 5 were excluded because they had completed the PAM in a way that rendered their completion invalid. 154 full data cases could be included in the analysis. This suggests that while the first sample of 251 participants from an anticipated 350 participant sample may have been sufficient to have met the sample size assumption, this smaller group of participants who completed both survey packs were unlikely to have had sufficient power to produce reliable results.

8.3.1 Demographic reporting and comparing completers to non-completers

The characteristics of those who completed the follow-up survey pack compared to those who did not were compared using the initial data to determine if there were significant differences between groups. These were carried out using a Mann Whitney U test for continuous variables and chi square tests for categorical variables. This analysis identified that there were not statistically significant differences between participants who completed both questionnaires and participants who were lost to follow-up in:

- Initial PAM scores: U = 7195, p = 0.62
- Initial PAM levels: χ^2 (3, n = 251) = 0.64, p = 0.890, phi = 0.05
- Sex: χ^2 (1, n =251) = 0.20, p = 0.66, phi = 0.28
- Age: U = 6947, p = 0.35
- Disease duration: U = 6415, p = 0.06
- Ethnicity: χ^2 (6, n = 251) = 9.89, p = 0.13, phi = 0.20
- Condition: χ^2 (6, n = 251) = 7.27, p = 0.40, phi = 0.17
- HAQ score: U = 6997, p = 0.40

The demographic information for the second timepoint analysis is shown in Table 8.2*:*

Table 8.3: Summary follow-up demographic characteristics

Variable	**N (%), or Mean (SD) and range**
Sex N, (%)	Female: 112 (73%) Male: 42 (27%)
Ethnicity N, (%)	White British: 146 (95%) Other White: 5 (3%) Other: 3 (2%)
Diagnosis N, (%)	RA: 107 (69%) SLE: 1 (<1%) Ankylosing Spondylitis: 19 (12%) Psoriatic Arthritis: 20 (13%) Other: 5 (3%) Don’t Know: 2 (1%)
Age (years)	61.06 (SD: 11.76) 26 to 84 years
Disease Duration (years)	16.66 (SD: 13.02) 1 to 61 years

Again, the trimmed means were reviewed in order to understand the impact that outlier cases had on the dataset and skew and kurtosis calculated to understand normality of data distribution. This information is available in Appendix Z.

8.3.2 PAM levels and scores at the second round of data collection

At the second timepoint PAM scores and levels were identified for participants. The average PAM score was 57.21 (SD: 12.0) and scores were distributed between 33 and 90.7. A Kruskal-Wallis test determined that there were no statistically significant differences in age (p =0.98), HAQ (0.62) or disease duration (0.77) between the groups that increased, decreased or remain the same in PAM levels. However, while the average PAM level often did not change, many participants experienced changes to their PAM scores between the two timepoints. Details of the distribution of PAM scores at this timepoint are available in Figure 8.3. Changes to PAM scores within participants are available in Figure 8.3a.

Figure 8.3: Distribution of PAM scores at follow-up

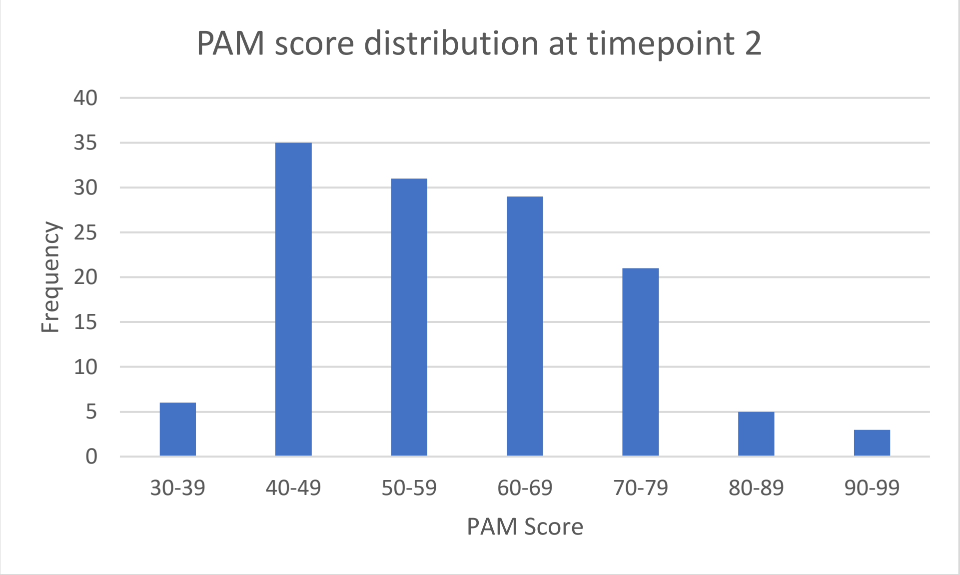
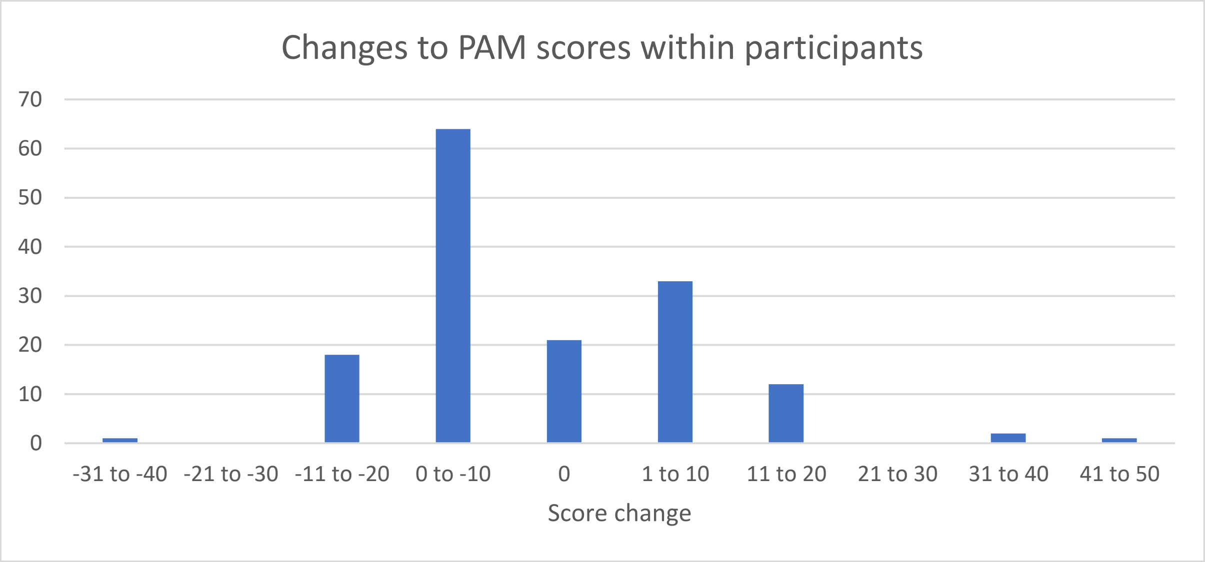


Figure 8.3a: PAM score changes within participants over 9 months

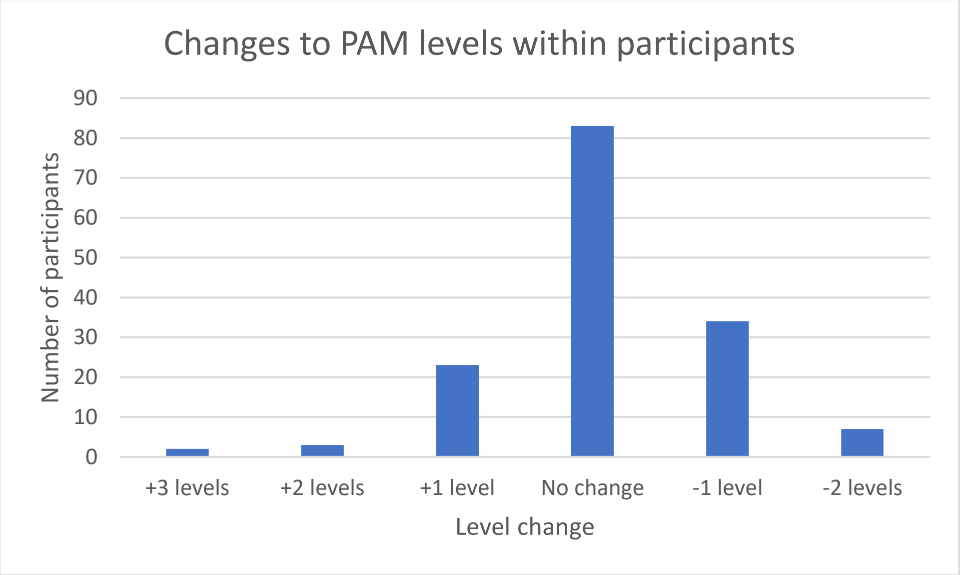


The most common PAM level remained level 3. 83 participants remained at the same PAM level, 41 went down at least one PAM level and 30 went up at least one PAM level at the second data collection point.

Table 8.3a: Summary PAM levels at follow-up

PAM Level:	Number of Participants:
1	34 (21%)
2	42 (27%)
3	57 (31%)
4	21 (14%)

Figure 8.3b: PAM level changes within participants



Like the first round of data collection, there was not a significant difference in PAM scores between sites when a Kruskal-Wallis test was conducted $\chi^2(5) = .5.23$, $p = .39$.

To achieve the aim set out for the study of reviewing change to PAM scores over time, a Wilcoxon matched-pair signed rank test was conducted to investigate if there were significant differences between participants' first and second PAM scores. With the 154 participants who fully completed both surveys, there was a statistically significant difference in participants' PAM scores between timepoint one and timepoint two, $Z = 3362.5$, $p = 0.02$.

8.3.3 Descriptive data for continuous variables

The table below provides details of the measures of central tendency for all the continuous variables being considered for inclusion in the regression model. In the event that these data have non-normal distributions, the median and interquartile range are also provided.

Table 8.3b: Descriptive data at second timepoint

Variable	**Mean (SD), range**	**Median (interquartile range)**
HAQ (possible range 0-3)	0.70 (SD: 0.63) Range 0 to 2.50	0.50 (Q1: 0.15 and Q3: 1.05)
RASE (possible range 28-140)	102.63 (SD: 14.78) Range 53 to 120	103.0 (Q1: 94.5 and Q3: 111)
Internal HLOC (possible range 6 to 36)	16.87 (SD: 5.28) Range 6 to 33	17 (Q1: 12.75 and Q3: 20)
Chance HLOC (possible range 6 to 36)	16.19 (SD: 6.0) Range 6 to 34	17 (Q1: 11 and Q3: 20)
Doctors HLOC (possible range 3 to 18)	10.81 (SD: 2.91) Range 3 to 18	11 (Q1: 9 and Q3: 13)
Powerful Others HLOC (possible range 3 to 18)	8.55 (SD: 3.10) Range 3 to 17	8 (Q1: 6 and Q3: 11)
BIPQ (possible range 0 to 80)	44.99 (SD: 11.15) Range 21 to 77	44 (Q1: 37.75 and Q3: 52.25)
HLQ 1 (possible range 1 to 4)	2.87 (SD: 0.65) Range 1 to 4	3 (Q1: 2.5 and Q3: 3.25)
HLQ 2 (possible range 1 to 4)	2.88 (SD: 0.51) Range 1 to 4	3 (Q1: 2.73 and Q3: 3)
HLQ 3 (possible range 1 to 4)	2.88 (SD: 0.48) Range 1 to 4	3 (Q1: 2.6 and Q3: 3.2)
HLQ 4 (possible range 1 to 4)	2.82 (SD: 0.58) Range 1.2 to 4	2.8 (Q1: 2.4 and Q3: 3.2)
HLQ 5 (possible range 1 to 4)	2.64 (SD: 0.51) Range 1.2 to 3.8	2.8 (Q1: 2.2 and Q3: 3)
HLQ 6 (possible range 1 to 5)	3.59 (SD: 0.83) Range 1.2 to 5	3.8 (Q1: 3.15 and Q3: 4)
HLQ 7 (possible range 1 to 5)	3.49 (SD: 0.73) Range 1 to 5	3.67 (Q1: 3 and Q3: 4)
HLQ 8 (possible range 1 to 5)	3.76 (SD: 0.66) Range 1.2 to 5	4 (Q1: 3.4 and Q3: 4)

HLQ 9 (possible range 1 to 5)	4.01 (SD: 0.62) Range 1 to 5	4 (Q1: 3.8 and Q3: 4.4)
Pain NRS (possible range 0 to 10)	5.11 (SD: 2.45) Range 0 to 10	5 (Q1: 3 and Q3: 7)
Fatigue NRS (possible range 0 to 10)	6.57 (SD: 2.20) Range 1 to 10	7 (Q1: 5 and Q3: 8)
Positive affect (PANAS) (possible range 0 to 50)	30.66 (SD: 8.23) Range 10 to 45	31 (Q1: 25.75 and Q3: 37)
Negative affect (PANAS) (possible range 0 to 50)	20.37 (SD: 8.47) Range 10 to 45	18 (Q1: 13.75 and Q3: 26)

8.3.4 Changes to other variables within participants

Data on the changes in mean and median between two data collection timepoints are available in Table 8.3c.

Table 8.3c: Changes in mean and median between the two data collection timepoints

Variable	**Time 1 mean**	**Time 2 mean**	**Change in means from time 1 to 2**	**Time 1 median**	**Time 2 median**	**Change in median from time 1 to 2**
RASE	101.61	102.63	+1.02	103.0	103.0	0
Internal HLOC	16.98	16.87	-0.11	17	17	0
Chance HLOC	16.33	16.19	-0.14	16	17	+1
Doctors HLOC	11.31	10.81	-0.5	11	11	0

Powerful Others HLOC	8.71	8.55	-0.16	8	8	0
BIPQ	45.55	44.99	-0.56	46	44	-2
HLQ 1	2.96	2.87	-0.09	3	3	0
HLQ 2	2.91	2.88	-0.03	3	3	0
HLQ 3	2.89	2.88	-0.01	3	3	0
HLQ 4	2.92	2.82	-0.1	3	2.8	-0.2
HLQ 5	2.68	2.64	-0.04	2.8	2.8	0
HLQ 6	3.78	3.59	-0.19	4	3.8	-0.2
HLQ 7	3.59	3.49	-0.1	3.67	3.67	0
HLQ 8	3.83	3.76	-0.07	4	4	0
HLQ 9	4.08	4.01	-0.07	4	4	0
Pain NRS	5.43	5.11	-0.32	6	5	-1
Fatigue NRS	6.43	6.57	+0.14	7	7	0
Positive affect (PANAS)	30.03	30.66	+0.63	30	31	+1
Negative affect (PANAS)	19.88	20.37	+0.49	19	18	-1

Wilcoxon signed rank tests were conducted to establish if there were significant changes to other variables within participant at the two data collection points. Of these, the variables that had demonstrated statistically significant changes between the two points of data collection were HLQ subscale 1 (Feeling understood and supported by healthcare providers), subscale 4 (social support), subscale 6 (ability to actively engage with healthcare professionals), subscale 8 (ability to find good health information) and subscale 9 (understanding health information enough to know what to do). Details are available in table 8.3d. These findings suggest that many of the variables were relatively stable between the two timepoints.

Table 8.3d: Wilcoxon signed rank tests reporting changes within participants

Variable	**Z score**	**P value**
RASE	-1.07	0.28
BIPQ	-0.06	0.95
HLOC Internal	-0.97	0.33
HLOC Doctors	-1.64	0.10
HLOC Chance	-0.44	0.66
HLOC Others	-1.07	0.29
HLQ Subscale 1	-2.41	0.02
HLQ Subscale 2	-1.37	0.17
HLQ Subscale 3	-1.27	0.20
HLQ Subscale 4	-3.13	0.002
HLQ Subscale 5	-1.58	0.12
HLQ Subscale 6	-3.49	<0.001
HLQ Subscale 7	-1.91	0.06
HLQ Subscale 8	-2.78	0.005
HLQ Subscale 9	-2.88	0.004
Fatigue NRS	-0.67	0.50
Pain NRS	-1.02	0.31
PANAS Positive	-0.12	0.91
PANAS Negative	-1.27	0.20

8.3.5 Timepoint two univariable analysis

For the second set of data, candidate variables for the multiple regression were again identified using univariable analysis. Similarly, variables without a significant correlation with PAM scores at the 5% level were removed as candidate factors from the full analysis.

Table 8.3e: Spearman's rank correlation coefficient tests of candidate variables and their relationship with PAM scores

Variable	**p**	**Correlation**
HAQ	<0.01	-0.41
RASE	<.01	0.55
Internal HLOC	0.1	0.13
Chance HLOC	0.70	-0.31
Doctors HLOC	0.20	0.10
Powerful Others HLOC	0.03	-0.18
BIPQ	<.01	-0.55
HLQ 1	<.01	0.35
HLQ 2	<.01	0.55
HLQ 3	<.01	0.41
HLQ 4	<.01	0.39
HLQ 5	<.01	0.42
HLQ 6	<.01	0.50
HLQ 7	<.01	0.47
HLQ 8	<.01	0.41
HLQ 9	<.01	0.42
Pain NRS	<.01	-0.28
Fatigue NRS	<.01	-0.31
Positive affect (PANAS)	<.01	0.37
Negative affect (PANAS)	<.01	-0.33

The findings of the univariable analysis presented in the table above indicated that the only continuous variables that did not have a significant correlation with PAM scores were the internal, chance and doctors HLOC subscales. These variables were excluded from consideration in the multiple regression.

8.3.6 Timepoint two multiple linear regression assumptions

1. Sample size of N> 50+8m (m = number of independent variables (Tabachnick and Fidell, 2007). While the sample size for the preliminary multiple

regression to identify candidate variables did not meet this assumption, the second confirmatory regression analysis did so.

2. Multicollinearity was investigated during the analysis process. As with the first round of data collection, there were limited high inter-correlated variables. High correlations existed between HLQ subscales 1 and 6 (.704, p<.001), 6 and 7 (.893, p<.001), 7 and 8 (.714, p<.001) and 8 and 9 (.762, p<.001). The researcher reviewed the VIF and the tolerance of the correlations. Again, none of the VIFs reviewed were above 10 which does not suggest multicollinearity had a substantial confounding impact on the findings of the analysis. While HLQ subscales 6 and 7 had low tolerances (.143 and .148 respectively), they were not below the 0.1 cut-off that suggests multicollinearity (Pallant, 2007).
3. The NPP was reviewed (see Appendix AA). There was some deviation from the line of best fit, suggesting some non-normality across the dataset. The scatterplot suggested there were some extreme outliers in this dataset with one residual reaching +3 on the standardised residual axis.
4. Because of the substantial deviation from the line of best fit on the NPP, linearity could also not be assumed for this sample and data collection point.

The review of the assumptions for the second round of data analysis suggested that not all of these were met. Consequently, the findings cannot be generalised beyond the sample who took part in data collection. As with the first set of data for this study, the non-normally distributed data were transformed in order to confirm the strength of the findings. This is discussed in more detail in section 8.3.7.

8.3.7 Timepoint two multiple linear regression

The list of variables had been determined following the univariable analysis. Initially, all candidate variables were entered in a preliminary forced entry multiple regression. This was intended to identify variables that contributed to the model to a statistically significant degree at a 0.1 level (See Table 8.3f). The variables that contributed to the model and were taken forward to the final regression model were:

1. HAQ
2. RASE total score (capturing self-efficacy)
3. Powerful others HLOC

4. BIPQ
5. HLQ subscale 2 (Having sufficient information to manage my health)
6. PANAS Negative affect

The findings of this preliminary model are available in Table 8.3f. Overall, the regression model accounted for 48.9% of the variance in PAM scores within this sample. The multiple regression was calculated to predict PAM scores based on the predetermined list of independent variables. The regression equation identified: F (17, 135) = 9.57, p<.001, with an adjusted R^2 of 0.49.

Following this, the variables that did not significantly contribute to the regression model were removed from the syntax and the regression was rerun without these. The findings of this final model are also available in Table 8.3f.

This regression model accounted for 49% of the variance in PAM scores within the sample. The multiple regression was calculated to predict PAM scores based on the predetermined list of independent variables. The regression equation identified: F (6, 146) = 25.36, p<.001, with an adjusted R^2 of 0.49.

All variables in this model were significant predictors of PAM scores in participants. In the final model, HLQ subscale 2 recorded the highest beta value (β = 0.34 p< .001). This was followed by RASE scores (β = 0.33, p< .001). Next, HAQ scores had the next greatest beta values (β = -0.21, p = <0.01), followed by PANAS negative affect (β = -0.19, p = 0.02) and BIPQ scores (β = -0.18, p = 0.04) and then finally the HLOC powerful others subscale (β = -0.13, p = 0.03).

The non-normal data were transformed to common logarithm (log10) to reduce the non-normality by taking the square root of data cases for relevant non-normal distributions. In the case of variables that had values of 0, the data were first transformed to add 1 to each of the responses to be sure that there were no issues in the data transformation caused by the 0s. The findings of this regression support the initial findings and are available in appendix BB. However, in the regression with data transformed to a more normal distribution did not have the powerful others HLOC subscale as a significant predictor in the final model.

Table 8.3f: Multiple linear regression to analyse the association between PAM scores and other personal and contextual factors captured by the survey:

Variables	**Preliminary multiple regression**			**Final multiple regression**		
	Standardised β	**95% CI**	**P value**	**Standardised β**	**95% CI**	**P value**
HAQ	-0.23	-7.33 to -1.15	<0.01	-0.21	-6.60 to -1.18	<0.01
RASE	0.26	0.08 to 0.36	<0.01	0.33	0.15 to 0.40	<0.001
Powerful others HLOC	-0.15	-1.04 to -0.09	0.02	-0.13	-0.95 to -0.05	0.03
BIPQ	-0.24	-0.47 to -0.04	0.02	-0.21	-0.38 to -0.01	0.04
HLQ 1	-0.15	-6.18 to 0.68	0.12			
HLQ 2	0.29	1.91 to 11.49	<0.01	0.34	4.56 to 11.26	<0.001
HLQ 3	0.10	-1.25 to 6.23	0.19			
HLQ 4	0.08	-2.28 to 5.37	0.43			
HLQ 5	0.09	-1.60 to 6.12	0.27			
HLQ 6	0.14	-2.23 to 6.19	0.35			
HLQ 7	-0.06	-5.82 to 3.75	0.67			
HLQ 8	-0.01	-4.54 to 4.12	0.94			
HLQ 9	0.01	-3.96 to 4.24	0.95			
Pain NRS	0.12	-0.24 to 1.43	0.91			

Fatigue NRS	-0.01	-0.91 to 0.81	0.16			
Positive affect (PANAS)	-0.03	-0.26 to 0.18	0.73			
Negative affect (PANAS)	0.16	-0.01 to 0.46	0.06	0.19	0.04 to 0.48	0.02

8.3.8 Logistic regression on PAM levels at follow-up

As with the first set of data, an initial logistic regression was run with all candidate variables to identify the variables that were significant predictors of PAM levels at the 10% level based on the significance of the regression coefficient (B) for any PAM level.

Overall, the initial model was statistically significant, χ2 (60, n = 154) = 181.65, p < .001. The model explained between 44.6% (McFadden test) and 74.6% (Nagelkerke test) of the variance in PAM levels. The following variables were taken forward to a final logistic regression:

- HAQ
- RASE
- Powerful others HLOC
- BIPQ
- HLQ subscale 1 (feeling understood and supported)
- HLQ subscale 3 (actively managing my health)
- HLQ subscale 5 (appraisal of health information)
- HLQ subscale 9 (understand health information enough to know what to do)
- PANAS negative affect

This final model was statistically significant, χ^2 (27, n = 154) = 143.39, p < .001. The model explained between 35% (McFadden test) and 65.2% (Nagelkerke test) of the variance in PAM levels. All the blocks within the model were statistically significant contributors to the model. In comparison to the first logistic regression model from the baseline data collection, BIPQ scores contributed more to variance in PAM levels at timepoint 2.

Table 8.3g: Logistic regression findings at follow-up

	PAM Level 1						**PAM Level 2**						**PAM Level 3**					
Factor	**B**	**df**	**P**	**Exp (B)**	**95% CI Lower**	**95% CI Upper**	**B**	**df**	**p**	**Exp (B)**	**95% CI Low**	**95% CI Upper**	**B**	**df**	**P**	**Exp (B)**	**95% CI Low**	**95% CI Upper**
HAQ	6.12	1	<0.01	491.74	15.13	15982.02	4.86	1	0.01	129.37	4.52	3705.8	4.92	1	<0.01	137.05	5.50	3413.32
RASE	-0.18	1	<0.01	0.84	0.74	0.94	-0.02	1	<0.01	0.85	0.77	0.94	-0.06	1	0.15	0.94	0.87	1.02
Internal HLOC	-0.11	1	0.33	0.90	0.72	1.12	-0.10	1	0.33	0.91	0.75	1.10	-0.08	1	0.33	0.92	0.78	1.09
Chance HLOC	-0.12	1	0.31	0.89	0.71	1.11	0.01	1	0.92	1.01	0.84	1.22	-0.05	1	0.57	0.95	0.80	1.13
Doctors HLOC	0.22	1	0.349	1.24	0.79	1.97	0.31	1	0.11	1.37	0.94	2.01	0.13	1	0.44	1.14	0.81	1.61
Others HLOC	0.56	1	<0.01	1.76	1.18	2.62	0.30	1	0.08	1.36	0.96	1.91	0.11	1	0.47	1.12	0.83	1.52
BIPQ	0.25	1	<0.01	1.29	1.07	1.55	0.12	1	0.12	1.13	0.97	1.30	0.08	1	0.22	1.09	0.95	1.24
HLQ 1	2.45	1	0.11	11.60	0.56	242.31	1.54	1	0.27	4.67	0.30	72.82	2.74	1	0.04	15.43	1.21	196.95
HLQ 2	-4.42	1	0.02	0.01	0.00	0.46	-2.57	1	0.10	0.08	0.00	1.65	-2.24	1	0.11	0.11	0.01	1.65
HLQ 3	-0.67	1	0.66	0.51	0.03	9.70	-2.07	1	0.05	0.13	0.03	1.00	-1.23	1	0.14	0.29	0.06	1.50
HLQ 4	-2.06	1	0.21	0.13	0.01	3.24	-1.50	1	0.30	0.22	0.01	3.826	-1.75	1	0.18	0.17	0.01	2.25
HLQ 5	-3.19	1	0.03	0.04	0.00	0.77	-0.96	1	0.46	0.38	0.03	4.94	-1.54	1	0.20	0.22	0.02	2.29

HLQ 6	-0.71	1	0.68	0.49	0.02	13.92	-0.76	1	0.59	0.47	0.03	7.55	-0.14	1	0.91	0.87	0.08	10.02
HLQ 7	-0.08	1	0.97	0.93	0.02	42.41	-0.05	1	0.97	0.95	0.04	20.96	-0.95	1	0.50	0.39	0.03	5.92
HLQ 8	1.76	1	0.36	5.83	0.14	246.54	1.31	1	0.45	3.71	0.12	112.79	2.24	1	0.16	9.38	0.41	214.23
HLQ 9	-3.28	1	0.08	0.04	0.00	1.47	-3.12	1	0.07	0.04	0.00	1.24	-2.59	1	0.09	0.08	0.00	1.54
Fatigue NRS	-0.33	1	0.36	0.72	0.35	1.47	-0.15	1	0.58	0.86	0.50	1.48	-0.37	1	0.13	0.69	0.43	1.12
Pain NRS	-0.41	1	0.19	0.66	0.36	1.23	-0.28	1	0.30	0.76	0.45	1.27	-0.35	1	0.13	0.70	0.44	1.11
Positive affect (PANAS)	0.05	1	0.60	1.05	0.88	1.25	0.04	1	0.63	1.04	0.89	1.21	0.02	1	0.81	1.02	0.89	1.16
Negative affect (PANAS)	-0.22	1	0.02	0.80	0.67	0.97	-0.20	1	0.03	0.82	0.69	0.98	-0.12	1	0.15	0.89	0.76	1.05

Table 8.3h: Final logistic regression at second timepoint

	PAM Level 1						**PAM Level 2**						**PAM Level 3**					
Factor	**B**	**df**	**p**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**	**B**	**df**	**p**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**	**B**	**df**	**P**	**Exp (B)**	**95% CI Lower Bound**	**95% CI Upper Bound**
HAQ	6.20	1	<.01	491.74	15.13	15982.0	4.86	1	0.01	129.37	4.52	3705.83	4.92	1	0.00	137.05	5.50	3413.32
RASE	-0.18	1	<.01	0.84	0.74	0.94	-0.16	1	<0.01	0.85	0.77	0.94	-0.06	1	0.15	0.94	0.87	1.02
Internal HLOC	-0.11	1	0.33	0.90	0.72	1.12	-0.10	1	0.33	0.91	0.75	1.10	-0.08	1	0.33	0.92	0.78	1.09
Chance HLOC	-0.12	1	0.31	0.89	0.71	1.11	0.01	1	0.92	1.01	0.84	1.23	-0.05	1	0.57	0.95	0.797	1.13
Doctors HLOC	0.22	1	0.35	1.24	0.78	1.97	0.31	1	0.11	1.37	0.94	2.01	0.13	1	0.44	1.14	0.812	1.61
Others HLOC	0.56	1	<0.01	1.76	1.18	2.62	0.30	1	0.08	1.37	0.96	1.91	0.11	1	.047	1.12	0.83	1.52
BIPQ	0.25	1	<0.01	1.29	1.07	1.55	0.12	1	0.12	1.14	0.97	1.30	0.08	1	0.22	1.09	0.95	1.24
HLQ 1	2.45	1	0.11	11.60	0.55	242.31	1.54	1	0.27	4.67	0.30	72.82	2.74	1	0.04	15.43	1.21	196.95

HLQ 2	-4.42	1	0.02	0.01	0.00	0.46	-2.57	1	0.10	0.08	<0.00	1.65	-2.24	1	0.11	0.11	0.01	1.65
HLQ 3	-0.67	1	0.66	0.51	0.03	9.70	-2.07	1	0.05	0.13	0.02	1.00	-1.23	1	0.14	0.29	0.06	1.50
HLQ 4	-2.06	1	0.21	0.13	0.01	3.24	-1.50	1	0.30	0.22	0.01	3.83	-1.75	1	0.18	0.17	0.013	2.25
HLQ 5	-3.19	1	0.03	0.04	0.00	0.77	-0.96	1	0.46	0.38	0.03	4.94	-1.54	1	0.20	0.22	0.02	2.29
HLQ 6	-0.71	1	0.68	0.49	0.02	13.92	-0.76	1	0.59	0.47	0.03	7.55	-0.14	1	0.91	0.87	0.08	10.02
HLQ 7	-0.08	1	0.97	0.93	0.02	42.41	-0.04	1	0.98	0.95	0.04	20.96	-0.95	1	0.50	0.39	0.03	5.92
HLQ 8	1.76	1	0.36	5.83	0.14	246.54	1.31	1	0.45	3.71	0.12	112.79	2.24	1	0.16	9.38	0.41	214.23
HLQ 9	-3.28	1	0.08	0.04	0.00	1.47	-3.12	1	0.07	0.04	<0.01	1.24	-2.59	1	0.09	0.08	0.00	1.541
Fatigue NRS	-0.33	1	0.36	0.72	0.35	1.47	-0.15	1	0.58	0.86	0.50	1.48	-0.37	1	0.13	0.69	0.43	1.12
Pain NRS	-0.41	1	0.19	0.66	0.36	1.23	-0.28	1	0.30	0.76	0.45	1.27	-0.35	1	0.13	0.70	0.44	1.11
Positive affect (PANAS)	0.05	1	0.60	1.05	0.88	1.25	0.04	1	0.63	1.04	0.89	1.21	0.02	1	0.81	1.02	0.89	1.16

Negative affect (PANAS)	-0.22	1	0.02	0.80	0.67	0.97	-0.20	1	0.03	0.82	0.69	0.98	-0.12	1	0.15	0.89	0.76	1.05

8.4 Timepoint two discussion

A feature of the research is that there was not a statistically significant change in PAM scores between the samples but some participants experienced substantial changes on an individual level. Individuals have been identified to have substantial changes in other PAM survey research (Aung *et al.*, 2015). The absence of significant differences in demographic factors between the groups that did have PAM score changes in both directions implies that there is no specific type of patient more likely to reduce or increase patient activation. The strong correlation between PAM scores at the first and second timepoint also reflect findings of other studies that collected PAM data at follow-up (Rask *et al.,* 2009).

In the comparisons across the two timepoints, most of the subscales on the HLQ did see significant changes for participants who completed both surveys. Longitudinal data on the HLQ is not available and the initial publication did not capture test-retest reliability (Osborne *et al.*, 2013). This could reflect either changes in participants' ability to gather, understand and apply health-related information, or could reflect the suggestion that the HLQ is particularly sensitive to fluctuations in participants' abilities.

While the data remain non-normally distributed at the second timepoint, they are less so. This was initially hypothesised to be because participants who had extreme scores at the lower end of the scale were the participants who did not complete the second round of data collection. However, there were no significant differences in initial PAM scores and levels between completers and non-completers.

The major differences in findings of the multiple regression between the first and second round of data analysis are that there are more variables that contribute to variance in PAM scores in the second round. The inclusion of the HAQ, powerful others HLOC (while internal HLOC was no longer a factor), BIPQ scores, and negative affect contributed to a broader conceptualisation of patient activation. The consistent contributions of RASE and HLQ subscale 2 add weight to the roles of self-efficacy and health literacy respectively in patient activation.

Yet again, the average PAM scores across the sample at follow-up were lower than in other studies with other health conditions (Rask *et al.*, 2009). This contributes to the argument that patient activation is different between conditions, with rheumatology patients being lower in their patient activation than patients with other health conditions. Alternatively, the PAM may be less appropriate for IA patients and their patient activation.

Negative affect did contribute to variance in PAM scores at the follow-up point. While the first round of data collection and analysis implied that affect did not contribute to patient activation to a statistically significant degree, this second round of analysis disagrees to a small extent with this finding. Given that the current model of patient activation is built around positive and negative affect (Hibbard and Mahoney, 2010) these findings do not provide clear support for this model.

While there was also some consistency in variables that contributed to variance in PAM levels, HLQ subscales were more often significant contributors to PAM levels. Therefore, the variables that contribute to PAM levels may be broader than the variables that contribute to PAM scores.

8.5 Study strengths and limitations

8.5.1 Strengths

One strength of the study was that approximately one third of the participants in the initial sample were male. As men are often under-represented in research of this kind, there is a benefit to understanding the impact of sex on PAM scores and levels. There was also good representation of different forms of IA beyond RA which is often the most represented in quantitative rheumatology research.

Another strength of this study was that participants were recruited from multiple sites across England. This was intended to reduce the risk of bias if all participants received their care from the same rheumatology department.

8.5.2 Limitations

One limitation is that the recruitment goal was not reached for the study. This was for pragmatic reasons owing to the timeline for recruitment that was possible in the remit of a PhD study.

Another challenge for the study is that outcome measures used in health contexts are often also written in a way that makes them inaccessible to people with low health literacy, so their responses may not be valid (Adams *et al.*, 2013). Outcome measures were selected to be as accessible as possible and the PRP was consulted in conjunction with this to select the contents of the pack. However, some of the outcome measures included more complex language, and this may have contributed to people with poor literacy or health literacy choosing not to participate.

During the formatting of the survey pack, the PAM was deliberately placed first to gather naïve responses to this questionnaire. However, there were no alternative versions of the survey with outcome measures in different orders to reduce order effects. Therefore, patients may have become tired or fatigued the further into survey completion they got. Data were also not collected on how participants perceived their care, and neither was the type of self-management support provided in the recruiting sites. The opportunity was missed to understand the interaction between patient activation and service provision factors. Education levels were not captured in this survey. This was for multiple reasons. Firstly, there were substantial challenges with standardising and categorising the wide range of education levels and qualifications in the qualitative interview study. The range would have undoubtedly been wider with a much larger sample in the survey study and it is possible there may not have been a way to use the data. Therefore, it did not seem justifiable to collect it from participants. However, it is a limitation of this study.

Another aspect of the data collection that was not comprehensive was that the HAQ was not collected in the second survey pack. This means that participants' level of disability may have fluctuated between the two data collection points. However, HAQ scores have been found to be relatively stable over time with changes in longitudinal studies considered to be related to the natural aging process (Sokka *et al.*, 2006).

Participants who completed a full data set for one or both time points in some circumstances needed to be excluded from the sample because of the way that they had completed the PAM. In line with the guidance provided by the licensers of the PAM, participants who respond to the measure with the same response for each item should be excluded from the analysis because of the assumption they have not meaningfully completed the measure. This means that the full range of PAM scores are not available as participants who respond 'strongly agreed' to all items would have a PAM score of 100 but consequently be removed from the analysis. The highest score across both data collection points possible for this study was approximately 90. This means that 10% of scores available in the PAM were not applicable for the study. While trying to reduce automatic responses to the measure, it does risk excluding participants who have completed the PAM with accurate and considered responses to all items.

Another limitation of this study was the high attrition rate between the first and second data collection point. As a result, the sample size at the second time point meant that the findings of the regression analysis were not generalisable.

Chapter 9: Patient Activation Framework

Following the research findings presented in chapters 4, 6 and 8, this chapter synthesises the aspects of patient activation that might be amenable to intervention into a single framework to inform future interventions. The factors will each be discussed in turn.

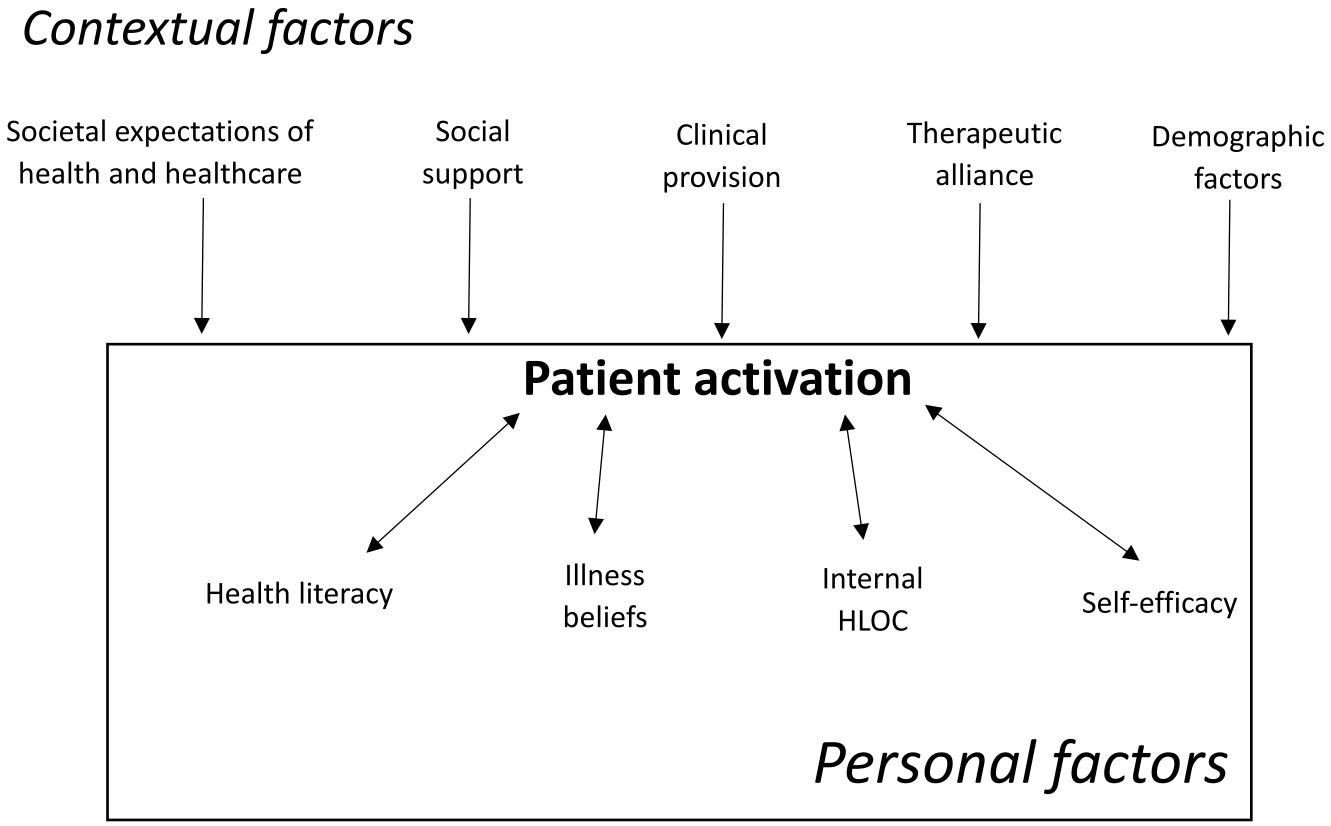
9.1 Framework overview

The framework presented in this section is built upon the idea of patient activation as a crucial aspect of the self-management process, particularly around commencing self-management. Within this framework, patient activation is a broad, umbrella concept that encapsulates other concepts, knowledge and skills that may be amenable to intervention.

The framework was developed by synthesising the findings from current literature, the systematic literature review, qualitative interview study, and quantitative survey study. The key factors were considered early in the process of the PhD during the systematic literature review. Potential factors were then considered at each stage of the PhD process with each new set of findings from the qualitative and quantitative studies. The findings would be discussed with the supervisory team as common themes across the studies were reviewed to identify potential factors. During this time the framework underwent several iterations of revision to reach its current form (see Appendix DD). On occasions where findings from one study suggested a framework factor that was not necessarily supported by another study (for example, the contribution of illness beliefs to PAM scores and levels was not consistent in the survey study), the factor was included and discussed with the wider supervisory team. The source of each factor in the framework and how it was identified during the course of the research is noted in the section dedicated to each factor.

Pertinent findings from all these sources were discussed with the researcher's supervisory team, including the PRP. This framework (see figure 9.1) has also been presented to an audience of rheumatologists at a local training day (see this in the list of outputs from the PhD in Appendix EE) to gather feedback and refine this in detail.

Figure 9.1: Framework of factors relevant to patient activation



The factors noted here under the umbrella of patient activation can be used as targets to increase patient activation directly or indirectly in patients with IA. Based on the findings of this research, they are considered to be part of the process of actively managing a condition by experienced self-managers and are statistically significant contributors to variance in patient activation in a sample of rheumatology patients in England. The framework was developed to be rheumatology specific following research covering a review of patient activation interventions in long-term fluctuating physical health conditions, discussing patient activation with experienced rheumatology patients, and identifying what is statistically associated with patient activation in a rheumatology sample. However, there are aspects of this that may be appropriate for other long-term conditions largely managed in secondary care, particularly fluctuating ones where people may experience periods of remission and flares of disease activity. For example, self-efficacy is a common target in self-management interventions across a range of long-term conditions. Given the lack of association between positive and negative affect in the survey study, this was not included in the framework. While a sense of positivity and determination was mentioned by participants in the qualitative study, this was specifically related to their perceptions of their health related to illness beliefs and did not necessarily reflect consistent positive affect beyond that.

The framework factors are:

- Health literacy (this is understood to contain three sub-types of health literacy: critical, communicative and functional health literacy);
- Illness beliefs (i.e., how severe and limiting someone perceives their IA to be).
- Self-efficacy (a common focus of most self-management interventions);
- Internal HLOC (the sense that someone's health is down to their own actions and behaviours);
- Societal expectations of health and healthcare;
- Social support;
- Clinical provision;
- Therapeutic alliance;
- Demographic factors.

Interventions targeting patient activation could be strengthened with a focus on these personal factors, provided that they are amenable to intervention in rheumatology patients.

It is considered that mediating relationships (i.e., it explains the relationship between the dependent and independent variables) are bidirectional and individual factors that are related to patient activation. Additionally, increased patient activation contributes to greater skill and confidence in these individual factors.

The impact of individual factors and how interventions may target them to improve patient activation will each be discussed.

9.2 Personal factors

9.2.1 Self-efficacy

Self-efficacy is one of the most commonly targeted concepts in self-management research and has been demonstrated to be amenable to intervention in many of the studies both within rheumatology and in wider health research (Lorig *et al.*, 2001).

The belief that there are things that somebody could do to improve their health contributes to their feeling of being able to take responsibility for actively managing their condition. The sense of being able to carry out specific self-care behaviours to take responsibility for one's condition can be a steppingstone to taking action to self-manage.

As discussed in section 2.7.2, self-efficacy is often increased following observing peers modelling positive behaviours and finding success. Mastering experiences, for instance through setting and achieving goals that are important to patients, can also contribute to increased self-efficacy and confidence. These activities may form meaningful and effective aspects of an intervention targeting patient activation. Self-efficacy is a key feature of self-management literature, was discussed by the skilled self-managers in the interview study, and was the most consistent significant contributor to variance in PAM scores and levels in the survey study. This stresses that self-efficacy is particularly valuable to patient activation across time and participants.

9.2.2 Illness beliefs

The sense of subjective severity that patients have of their condition and health contributes to them considering how to take responsibility for their health. Although illness beliefs as a term covers a wide range of potential beliefs, the beliefs particularly relevant from this research are those related to perceived condition severity. The qualitative interviews suggested that when the confident self-managers recruited felt their condition was less serious compared to others they saw and knew, they felt more able and inclined to manage their own health. This feeling of their condition being less severe contributed perspective and allowed them to feel more positive about activities they could still do. More precise research is needed about how best to target illness beliefs and subjective health status in long-term conditions and IA in particular (Coulter and Ellins, 2006).

In the survey study described in chapter 8, there was a moderate correlation between perceived condition severity (i.e. illness beliefs) as captured by the BIPQ and levels of disability as a proxy for disease severity captured by the HAQ. However, it could be suggested that it is illness beliefs that should be a focus for intervention rather than levels of disability because illness beliefs predict disability and this could be a useful mediator (Graves *et al.*, 2009). As noted in the qualitative study, particular health beliefs could contribute to increased health literacy. These included perceptions of risks, expectations about the impact of symptoms on one's life, and expectations about the nature and severity of one's condition (McCormack *et al.*, 2016).

The role of illness beliefs in patient activation was identified through the review of the literature and the qualitative study. Participants referred to how they managed their health in a positive way by comparing their own experiences with those around them to make them more determined to take action.

9.2.3 Internal HLOC

The internal locus of control reflects somebody's willingness to take an active role in managing their health. The contributions of an internal HLOC were demonstrated in the survey study and reflect the determination to manage one's health that experienced self-managers in the interview study described. The sense of internal HLOC was discussed by participants in the interview study, albeit without using this terminology. HLOC and the sense of responsibility that people felt for their condition was discussed in the interviews. HLOC can be underpinned by the broad foundations of patient activation and might be a state concept given that participants' HLOC did experience some changes across the two timepoints.

9.2.4 Health literacy

Health literacy was very well represented in the findings of the thesis, appearing with skills training during interventions in the systematic review, the skills and abilities being reviewed as vital for self-management in the interviews, and aspects of health literacy were statistically significant predictors of PAM scores and levels in the survey study.

Health literacy appears vitally important to how people can actively manage their health. Specifically, how people gather and apply knowledge to health-related challenges that occur over the course of living with IA. As discussed previously, the three different types of health literacy are (Nutbeam, McGill and Premkumar, 2017):

- communicative health literacy (how people establish meaning from sources);

- critical health literacy (ability to manage health based on analysing health-related information);
- functional health literacy (how someone gathers information related to their health and applies it to their life).

Health literacy overall includes many skills that are relevant to actively managing one's health. Skills-based training to increase peoples' health literacy, particularly the ability to judge when to seek appropriate medical help and do so can contribute to someone actively managing their condition in a more effective, safe, and confident way. Healthcare professionals in the UK reported that there were barriers to incorporating routine health literacy strategies into their clinical practice (Brooks *et al.*, 2019). They discussed a need for implementing health literacy assessment and interventions more widely into patient contact. This could be carried out by reviewing participants' health literacy before determining what interventions would be most suitable and confirming understanding regularly during face-to-face and telephone contact (Brooks *et al.*, 2019).

Interventions that currently target health literacy within rheumatology are often informal and can take the form of resources provided in clinic such as leaflets. They have been demonstrated to have a small and short-term impact on health literacy knowledge, but there is a lack of evidence about how much patient education interventions more generally target health literacy (Lowe *et al.*, 2013). Therefore, provision could be made to map this framework onto clinical interactions to understand how suitable they are for supporting patients with their activation.

9.3 Contextual factors

Contextual factors are not always amenable to intervention in routine clinical contact. As they do not contribute to the aim/objective of the thesis and could not easily be incorporated into an appropriate intervention, they are not discussed in detail here. However, they inform tailoring of support for patients and may contribute to additional risk of low patient activation. A knowledge of contextual factors can also determine appropriate examples of language, support, teaching examples (e.g. scenarios for problem solving practice), and finding patients peer groups that would meet their needs. Wider societal factors such as the environment where a patient lives, the cultural expectations of healthcare systems and other wider systemic factors are also not being discussed in this section as they are not amenable to change on an individual behavioural or cognitive level. However, they are not the primary focus of the framework, as the intention of the framework is to provide a pragmatic overview of patient activation. This framework could be mapped onto existing interventions or used as a tool to design interventions in collaboration with healthcare professionals and patient partners.

9.3.1 Social support

As described in the qualitative interviews, the confident self-managers that were recruited relied on the support around them in order to effectively and actively manage their condition. In these circumstances the support was often practical and allowed for participants to focus on other aspects of the management of their condition. The benefit of social support in active self-management is reported in the literature (Koetsenruijter *et al.*, 2016). In some circumstances, social support may be provided as an intervention e.g., individual community worker support (McEwen, 2010). However, it does not necessarily lend itself to immediate intervention in a clinical setting and therefore is a wider contextual factor relevant to patient activation. There are also indirect sources of social support that can impact patients and their self-management that can constitute interventions. One such example is the provision of resources by employers for employees’ and their family or friends to make use of such as leisure and wellbeing facilities or signposting to peer groups for social support.

In the discussion of the findings of the qualitative study, it was mentioned that rheumatology patients in a prior study had identified a gap between the need for additional social and emotional support and current service provision (Dures *et al.*, 2014). Consequently, there is a need for additional support for patients. Some of the studies covered in the systematic review provided forms of social support in the form of keyworkers, and the move towards social prescribing in the UK offers the opportunity for some of these gaps to be addressed (Drinkwater, Wildman and Moffatt, 2019). This may come in the form of third sector or more holistic clinically commissioned support that focuses on creating activated networks as much self-management support within the NHS does not consider social context and the environmental issues that contribute to and shape how people manage their health. Some steps have been taken to incorporate this into clinical practice and these should be expanded on and further implemented to create an environment which is more geared towards self-management (James *et al.*, 2020; Band *et al.*, 2019). The inequalities discussed in section 3.5 may persist and impact what enablers are present for someone to take on active self-management, and work to strengthen social networks and increase access to support will reduce some of these inequalities. Reducing the barriers to other determinants of health such as reliable public transport to resources and facilities can also contribute to social support interventions with a view to increasing patient activation.

9.3.2 Demographic characteristics

Demographic characteristics that are relevant to patient activation have been discussed in sections 3.3 and 7.3. The evidence suggests associations between specific demographic characteristics (i.e. age, race, sex, socio-economic status) and patient activation in a range of long-term conditions. While some participants mentioned that they felt there were certain demographics of people that may find it more challenging to self-manage (e.g. older adults), the survey study did not find that specific demographic characteristics were significant predictors of higher patient activation in a sample of rheumatology patients. Demographic characteristics are often not amenable to intervention but may help to understand people more likely to benefit from interventions or more likely to struggle to actively manage their conditions. Therefore, demographics have been included in a wider circle as these factors influence how interventions are tailored and targeted based on patients' demographic characteristics.

9.3.3 Therapeutic alliance

The collaborative relationship between patient and healthcare professional was discussed in detail by participants in the interview study. The relationship between patient activation and therapeutic alliance has been discussed in some recent research (Alexander, 2018; Chew *et al.*, 2017) and could contribute to patients feeling more able to take charge in appointments and carry out activities knowing they have the support and positive relationship with their healthcare team. Therapeutic alliance has also been identified as an attribute of patient engagement in a concept analysis because of the collaborative working relationship between patients and healthcare professionals. Participants formed and maintained these working relationships by contributing in a positive and meaningful way in decision making and the structure of patient-centred care (Zambelli Pinto *et al.,* 2012). Increased therapeutic alliance in one rheumatology study has been associated with increased belief from patients that they can follow their health regimens and prescribed treatments, greater agreement on action plans between patients and professionals, and more trust between the two parties (Fuertes *et al.,* 2015).

The movement towards collaborative care within the NHS sees patients taking on a collaborative role more commonly and becoming more skilled at doing so (NHS, 2019). However, for those with expectations that healthcare professionals will stay in a more biomedical "problem-solver" role, this would potentially contribute to them being less willing to manage their own health. Therapeutic alliance and the relationship between patient and healthcare professionals have been identified as a factor that can support patients who are less activated, with healthcare professionals checking in for self-management support (Alexander, 2018). In a mental health service, patient activation was found to increase following an intervention targeted at patients (Allen *et al.*, 2017). However, interventions that support both patients and healthcare professionals may be beneficial in order to support the development of effective collaboration between both parties. This was initially covered in the CCH and the courses were largely well received by healthcare professionals (Wallace *et al.*, 2012; Sharma *et al.*, 2011). Skills-based training for rheumatology professionals have begun to fill this gap (Halls *et al.*, 2018). This suggests that further interventions would be beneficial in the future.

9.3.4 Clinical provision

Given the relationship between quality of care and patient activation, the resources and skills of rheumatology departments will contribute towards patient activation (Hibbard *et al.,* 2004).

Participants in the interview studies discussed how much they valued prompt access to specialist care from healthcare professionals who knew the participants' experiences and had resources to contribute towards solving problems related to their IA. Interview study participants also noted how they felt the availibility and consistency of their care contributed to them effectively managing their health. This was particularly evident given how much they valued the direct access system avaialble in their departments. Therefore, this is noted as an important contextual factor to patient activation. While the responsibility for managing their health generally falls to patients, they will likely have little to no control over the service provision of their rheumatology department and limited control over what peer-support and third sector support is available locally.

While the NHS is known to be stretched and long-term conditions take up a substantial portion of costs and resources and the availability of support to patients does impact their self-management (NHS England Care Quality Commission, Health Education England and Public Health England, 2014). While the availibility of clinical support is not easily adapted and is unlikely to be impacted by individual intervention, it is a vital factor that contributes to how much of the responsibility for self-management falls to individuals and how supported they are in order to manage and deal with challenges that occur as a consequence of their conditions. This factor could also include the impact of institutions, hospital systems and management that contribute to how easily healthcare professionals and patients can engage in collaborative care together.

9.3.5 Societal expectations of health and healthcare

The expectations of what good health looks like and how healthcare systems support patients will likely contribute to how willing and able someone is to take an active role in managing their health. While a patient’s internal locus of control is discussed above, perceptions of health at a population level require broader public health campaigns to inform interventions, which will have limited effectiveness at an individual level in clinical settings. While rheumatology studies have reported that patients can feel a sense of shared responsibility for their health (Dures *et al.*, 2016a), this is not always the case. These expectations are likely shaped by locus of control, prior experiences, confidence to act, wider public perceptions of the NHS, and a host of other factors.

Chapter 10: Thesis discussion

The previous chapters have reported the results of the studies included in the thesis as well as some preliminary discussion. This chapter will review the novel findings of the thesis with reference to the original aims and objectives before evaluating the strengths and limitations of the research. The implications for research, clinical application, and theory will be discussed and a summary of the thesis will précis the original contributions to knowledge.

10.1 Thesis aim and objectives

10.1.1 Aim

To develop a framework to describe patient activation and factors which contribute to patient activation, in the context of inflammatory arthritis.

10.1.2 Objectives

- To identify the evidence surrounding patient activation interventions in long-term physical health conditions.
- To understand how skilled self-managers with IA conceptualise patient activation.
- To understand how skilled self-managers at different levels of activation perceive and enact patient activation over time.
- To explore longitudinal changes to patient activation (measured using the PAM), and its associations with related constructs in patients with IA.
- To develop a framework to describe patient activation in patients with IA.
- To identify factors that influence patient activation and may be amenable to intervention.

10.2 Contributions to knowledge

The three studies (systematic literature review, qualitative interviews, and survey) included in this thesis provided the following original contributions to knowledge:

- Evidence to suggest that interventions targeting patient activation can be effective but that there is no specific format of intervention that is most likely to be effective.

- Evidence that skilled self-managers perceive patient activation to involve the ability to prioritise and enact small changes. They believe another important aspect of patient activation is to determine when and how to get health related information and support as well as a sense of determination that they are responsible for their own health.
- Evidence that there are aspects of the PAM that are not applicable or relevant to patients with fluctuating long-term conditions.
- Evidence that actively managing rheumatology patients feel that the PAM does not capture their experience of patient activation.
- A description of the range and dispersion of PAM scores and levels across a sample of rheumatology patients, including evidence that these PAM scores and levels are lower than the scores in the samples of prior studies with different long-term conditions.
- The association between patient activation scores (as captured using the PAM) and self-efficacy, health locus of control, and health literacy as significant predictors that explain variance in PAM scores in a sample formed of rheumatology patients.
- The association between patient activation levels (as captured using the PAM) and self-efficacy, illness beliefs and aspects of health literacy. These factors are significant predictors that explain variance in PAM levels in a sample formed of rheumatology patients.
- Evidence to demonstrate that in a sample of rheumatology patients, the average score of the sample as a whole may exhibit statistically significant changes but individual patient activation scores are not static. These fluctuations can be in either direction.

The longitudinal design of two of the studies provided an opportunity to investigate the fluctuating nature of patient activation. This broadened the current understanding around the complex nature of patient activation within rheumatology patients. Discussing patient activation with experienced, perceptive self-managers provided value in reviewing how rheumatology patients understand and perform patient activation.

The development of a model of factors amenable to intervention to improve patient activation is an original contribution to knowledge and provides flexible guidance that can be easily implemented into tailored interventions clinically.

The novel findings that contribute to current knowledge will now be discussed in detail with reference to wider literature.

10.3 Interventions targeting patient activation

The systematic review investigated the effectiveness of interventions targeting patient activation in long-term fluctuating physical health conditions. The number of studies identified when the search was re-run 18 months after the initial searches demonstrates the increasing interest in patient activation. The findings indicated that while there was a wide range of formats, lengths and types of intervention included in the review, no one style or type of intervention was most effective for increasing patient activation. Consequently, interventions introduced into the NHS that target patient activation could be designed to suit individual departments or services according to their needs, resource availability, and the circumstances of long-term condition patients in their area. This includes funds for intervention duration, availability of staff and space for face-to-face interventions versus telephone and remote based support, and the digital literacy of patients in order to access internet-based support. Community-focussed interventions can focus on reducing health inequalities by increasing access to resources, widening patients' access to meaningful activities and identifying and mapping their networks.

10.4 Patient perceptions of patient activation

This thesis presents the novel finding that participants with rheumatic conditions had a broad and holistic sense of patient activation and of how they actively managed their health condition.

The wide range of skills, behaviours and knowledge that participants gathered in order to actively manage their condition was evident. Of interest was their ability to negotiate the NHS to gather the help, support and information that they required, as well as their ability to proactively seek out information themselves and evaluate what they had identified before applying it to their lives. This reflects aspects of health literacy contained under the wider umbrella of patient activation.

Other self-management techniques such as pacing, adaptation, and prioritising valued activities were incorporated into patients' perceptions of patient activation. This broad understanding with clear applied skills and behaviours relevant to rheumatology patients specifically contributes to the literature in a way that previous studies have not. This knowledge can prepare healthcare professionals for supporting rheumatology patients to actively manage their health, particularly those who are already skilled and for whom it can be difficult to clearly identify ways in which they may require support. The study provided an understanding of how current campaigns in place in the UK (e.g. the Ask 3 questions programme (The Kings Fund, 2013), agenda-setting tools for appointments etc.) are relevant to patient activation as the participants in this study perceived it. The data provided by participants provided a clear sense of the kind of care they valued to be able to effectively manage their health collaboratively. The direct access care system matched their preference for time-efficient specialist care that meant they were more likely to have contact with a clinician who knew their personal history. This supports the quantitative findings of a RCT introducing the direct access care system (Kirwan *et al.,* 2003) as well as findings of prior qualitative research into patient priorities for care (Ward *et al.*, 2007).

The relevance of health literacy to patient activation was identified in this thesis. Participants discussed being able and confident to do their own health related research and apply what they have learned to their own circumstances including making health-related decisions. When asked about how they had learnt to self-manage their health, participants discussed trial and error and being able to evaluate information and knowledge about their condition by following cues in their body. Skills demonstrating health literacy were present across much of participants' perceptions of patient activation and underpinned their sense of an active responsibility for their health.

The role of positive illness beliefs was a protective factor for participants in actively managing their health. They regularly reported feeling more motivated or able to make changes or carry out activities because they considered how they were healthier, with fewer symptoms than others they knew or had seen before. This research provides qualitative descriptions of participants' experiences of the relationship between illness beliefs and patient activation (Rask *et al.*, 2009).

One novel design of this qualitative study was meeting participants at the second timepoint to discuss their year of actively managing their condition, along with aspects of patient activation they had identified during this time. This design aspect offered a greater sense of participants' ongoing journey to actively manage their health, and in some ways the first interview had the potential to be a self-management intervention of its own accord. Discussing tactics to take responsibility for one's health, barriers and facilitators to this, and the skills that participants made use of along the way may have brought to light ways that they may like to self-manage individually. Alternatively, it may have led to them reconsidering how they managed their health and the active role they played in this over the course of the year in the knowledge that they would be re-interviewed. Research interviews acting as informal interventions is an issue particularly relevant to this study. Within the interviews, participants noted that they reviewed and reconsidered aspects of their self-management. Participants implemented self-management skills to allow them to retain activities or life roles that they personally valued.

Prior to this study, no research had been identified by the researcher into patient perceptions of the term "patient activation" in any condition. Neither has there been research into what factors, skills and behaviours patients believed were contained in this construct for rheumatology patients. Given that prior research has identified that skills and behaviours performed by patients captured in a behavioural taxonomy by clinicians did not necessarily correlate well with high scores on the PAM (Ledford, Ledford and Childress, 2013), a clearer understanding of how patients understood patient activation offers detail about how to describe the concept and skills involved to patients. Participants described that to them, the term "patient activation" was appropriate to describe the skills and behaviours they made use of to manage their condition. They did not report issues with the term and the balance of power and responsibility the term implies that have been reported elsewhere where clinicians are responsible for “activating patients” (de Iongh, 2018).

10.5 Patient perceptions of the PAM as a measure of patient activation

As literature so far has not identified how closely patients feel the PAM captures their understanding of patient activation, this has a clear contribution with relevance to both theory and practice. While there were mixed opinions on how closely participants in this study felt the items in the PAM captured their experiences of actively managing their condition, participants raised clear criticisms about the measure. Of these, the common reflection that participants could not always anticipate or prevent problems and fluctuations in their health was particularly vital. Participants’ perceptions were that while they could sometimes anticipate when they were likely to experience a flare because of overactivity, there were unpredictable circumstances outside of their control. Given that fluctuations and flares are common in IA (Walsh and McWilliams, 2012), and being able to respond effectively to changes must be a part of self-management, and participants felt the PAM did not meaningfully capture this aspect of managing their condition.

Similarly, the lack of clarity about the accuracy of health-related beliefs such as the nature of patients’ condition and what their medications do could also contribute to participants with inaccurate but strong health beliefs scoring more highly on the PAM than they ought to be. As the PAM does not offer the opportunity to clarify the source and accuracy of the health-related beliefs, this could contribute to patients becoming “dangerous self-managers” with high PAM scores but poor health-related knowledge acquired from unhelpful sources or retained from contact with healthcare professionals rather than proactive information seeking. This has implications for the relevance of the PAM in determining the patient activation and skills of patients with fluctuating health conditions of complex aetiology such as IA, and consequently the benefit of the PAM as a tailoring tool for self-management support in these circumstances.

Patient perceptions of the PAM are particularly valuable given the move towards stratifying services based on patient activation abilities (Coleman and Price, 2017; de Iongh, 2018). This approach to tailoring may initially appear to be beneficial and based on patients' individual needs. However, issues around the ethics of stratifying using the outcome measure have been raised (de Iongh, 2018, Gibert *et al*., 2017). The risk of only considering patients' PAM scores and missing out on the valuable additional contextual information that the interview study participants noted could lead to the person-centred and tailored approach to care being so in name only. Gibert *et al.* (2017) discuss the lack of clarity in the type of responsibility patients may be asked to take for their health, including the anticipated practical responsibility but also the moral responsibility that was raised by a participant in the interview study (Mark in section 6.2). Gibert *et al.* (2017) also note that causal responsibility may also become an expectation held of patients. Therefore, supporting people who are able and willing to take practical responsibility for their health should not also include encouragement for patients to do so out of a sense of duty or judgement.

Another ethical challenge that may occur when considering the role of patient activation in clinical decisions is that of encouraging patients who are able and willing to manage their health to feel autonomous and supported to do so without downplaying the role of wider health inequalities that impact self-management. Gilbert *et al.* (2017) suggested that this focus on individuals had the potential to place the burden of positive self-management solely at patients' feet and fail to recognise already present health disparities. If people are unable or unwilling to prioritise their health about other challenges or goals in their lives, this may be met with shame or stigma. This should be considered when using PROMs to determine and support patient activation or self-management.

10.6 PAM scores across a rheumatology population

The study identified the spread of PAM scores and levels across a sample of UK rheumatology patients. Additionally, data demonstrating how PAM scores and levels behave over time were collected during this study. This is a novel finding as this has not previously been investigated in a rheumatology population. Identifying personal and contextual factors that contribute to patient activation scores within the sample has the potential to contribute towards identifying factors for intervention that are appropriate, associated with patient activation, and represent skills that patients find beneficial. Identifying the demographic characteristics that were associated with high or low patient activation could be used to identify patients who are likely to have low patient activation for targeted additional self-management support.

10.7 Predictors of patient activation (as captured using the PAM)

Another contribution to knowledge arising from this study were the variables associated with patient activation (captured using the PAM) in a sample of rheumatology patients. While the non-normal distribution of the sample prevents these findings from being generalised to the wider rheumatology population, they suggest that different aspects of self-management could be associated with patient activation in patients with different long-term conditions. Crijns *et al.* (2019) reported no statistically significant relationship between a pain NRS and patient activation in their study with a sample of osteoarthritis patients, but the relationship was recognised in the study reported in this thesis. Therefore, this study strengthens the position that patient activation appears and behaves differently in different long-term conditions and, therefore, interventions to increase patient activation should be specific to the condition in their targeting.

A particularly notable finding within this study was that positive and negative affect (captured using the PANAS) rarely contributed to variance in PAM scores. Given that the current model of patient activation centres around positive and negative affect and the PAM is the dominant measure to capture patient activation, this presents findings that undermine the model. Health literacy, self-efficacy and illness beliefs appear to be much more relevant to variance in patient activation within this sample of rheumatology patients. This has not been identified in previous research into affect and patient activation.

10.8 PAM score/level behaviour over time in rheumatology patients

Given the limited longitudinal research into patient activation and the lack of longitudinal patient activation research within rheumatology, the findings of this thesis are novel. The behaviour of PAM scores and levels over time was of interest in order to understand how patient activation may change in an opportunity sample without any planned interventions. This also has implications for the potential impact of a patient activation intervention and how (if at all) to offer top-up support for patients.

The findings of this study identified that there was a significant change in PAM scores between the two data collection timepoints across participants. However, individuals had changes in PAM scores that contributed to average PAM scores for the sample remaining consistent. This appears to be representative of PAM scores in long-term conditions (Rijken *et al.*, 2014) but does not explain the substantial changes experienced by individuals in both directions from their baseline scores that contributed to balance in the average scores.

10.9 Research strengths

10.9.1 Patient and public involvement in the research

The key strength of the project was the way that the studies were designed, discussed and planned with substantial PRP involvement and with patients in mind. There was a clear sense of the potential patient benefit to the outcomes of the thesis and the researcher took time to review how acceptable the planned studies were throughout the process. Patients were consulted as key stakeholders in the project to reflect their voice. The clearest evidence of patient involvement was the presence and perspective of the PRP, whose contributions are described in detail throughout the thesis. He communicated often with the researcher, both face-to-face and by email to offer his perspective on the research. The PRP and the researcher also co-presented together during the PhD (see Appendices FF-II), most notably delivering a symposium at a national conference about patient activation.

The patient advisory group at the BRI were consulted with the research design at the beginning of the PhD, and the researcher regularly made efforts to discuss the design, results and implications of the project with patients and the public in order to gather a variety of perspectives and responses to consider throughout the PhD process.

10.9.2 The longitudinal nature of the research

Another strength of the research was that two of the three studies reported in this thesis were longitudinal. This is uncommon in both patient activation and rheumatology literature and represents an important opportunity to review self-management and associated skills and constructs in detail.

The longitudinal nature of the studies provided several benefits. Within the qualitative study, the opportunity to develop a rapport with participants during the first interview that could be maintained and built upon in the second interview was useful. Participants had already met and spent time with the researcher, reducing some of the risks of stilted conversation and allowing a better flow for discussions. The researcher already knew the participant and had some understanding of the context of their lives (but without making assumptions because they had met already). There was consistency in the interview style across both interviews as the researcher collected both datasets as the interviewer. This rapport may have potentially increased retention as the participants had already met and become comfortable with the researcher. On a practical level, being able to pick up on details of interest in the second interview or review anything that had been forgotten or may have required expansion from the first meeting was beneficial.

Meeting participants for a second time added context and observations for the researcher which provided increased insight into how participants responded to changes. It also provided retrospective context to details discussed in the first interview as during the individual review in the second interviews participants sometimes volunteered additional information or updates for ongoing aspects of their lives.

From a rigour and research design point of view, the opportunity to return to participants for the second interviews and present the findings of the first offers a strength as a form of member checking (Hannes, Lockwood and Pearson, 2010). While participants may have felt a sense of social desirability to agree with the findings, the risk of this was reduced by the way the topic was introduced and pre-empted with the researcher's introduction to that phase of the interview. Being able to discuss the findings of the study and the initial framework analysis in detail with participants, including aspects where it may not have appeared to be credible for them personally, was a strength.

10.9.3 Planning and integrating the mixed-methods research

The precise nature of what mixed-methods work entails has been debated but there is general agreement that working with mixed-methods typically involves (Denscombe, 2008):

- both quantitative and qualitative work within one project;
- determining the design of the project, including what order the quantitative and qualitative aspects of the project will be conducted in and how the findings will be prioritised;
- determining how the quantitative and qualitative findings of the project will relate to each-other;
- working within a pragmatic epistemology.

This thesis was developed, and the studies conducted, with a mixed-methods methodology as it was determined to be the most appropriate approach for the thesis and the specific research questions.

A strength of the research was the way that the studies built on the findings of each-other and were designed with the intention to be mixed from the beginning. The forethought on how the research findings would be triangulated later allowed the research design to use mixed methods in order to develop the framework of factors amenable to intervention. The intentions of integrating the findings were to increase credibility of the findings and reduce the impact of some of the limitations of each aspect of the study (i.e. gathering a sense of the prevalence of relationships between aspects of patient activation identified in the qualitative study and the PAM without having the social desirability of collecting these data in a face to face format) (Bryman, 2006).

Developing the strategy so that the data could be collected sequentially ensured that the initial findings of the first interview timepoint contributed to the selection of constructs and measures to be included in the survey, and the first round of survey data collection was complete prior to the second interviews. These second interviews could then also include discussion of participants' skills and activation relative to other rheumatology patients, as well as their perspectives on constructs that were identified as being associated with patient activation during the first survey analysis. Beginning with the systematic review provided a sense of the current literature in the field as well as identifying ways patient activation is currently being approached for interventions and in clinics. Subsequently, beginning the qualitative work after this allowed the research to continue in an inductive and open way. Given the timing of the studies there was a slight lead from the qualitative aspect of the project. There was a phase of interpretation and integration at the end of the data collection processes to review the findings as a whole (Dures *et al.*, 2011).

To understand the quality of the integration of both the qualitative and quantitative aspects of the data collection, an additional evaluation is proposed above and beyond the traditional assessment of quality for the two separate methods of data collection. This provides a sense of *"inference quality*" (Tashakkori and Teddlie, 2008). This incorporates aspects of internal validity, credibility as well as the appropriateness and quality of the studies' designs (Ihantola and Kihn, 2011).

10.9.4 Consideration of implementation

Another strength of the thesis was the ongoing focus on potential implementation and how the research is relevant to academic researchers, clinical staff, and patients. Given that patient activation is a construct that is receiving increasing focus and interest and there were several gaps in the knowledge identified at the beginning of the project, the need for research with a consideration for implementation strategy when designing the research project was necessary. Developing a theoretical understanding of patient activation could then be applied to evaluating and understanding how useful and acceptable the current provision for supporting self-management is.

10.9.5 Research rigour

Efforts were taken to conduct the research described in this thesis to the maximum rigour possible to increase the strength of the work. These attempts to conduct rigorous research are another strength of the research. Steps taken to ensure rigour included:

- Regular reflection throughout, but most specifically during the planning, data collection and analysis of the qualitative data. A reflective journal maintained throughout the PhD process by the researcher offered the opportunity for contemplation and to consider varying perspectives on the research (Appendix J).
- A selection of the full texts of the systematic review were reviewed by a second screener for clarity and a consensus exercise was conducted between the researcher and second screener to clarify agreement for inclusion. Additionally, the risk of bias exercise was conducted with a second screener. Again, a consensus exercise was conducted between the researcher and second screener to clarify agreement.
- Triangulation efforts were incorporated into study protocols including the review of interview transcripts by members of the supervisory team, discussion of analysis categories and codes with the PRP, and a review of the completed analysis with members of the supervisory team. This regular independent review, as well as the member checking and suggestions made by the participants during member checking and independent colleagues throughout the PhD process reduced the risk of researcher bias.
- Transparency was a priority throughout the process. Sharing the initial findings during the second interviews with interview participants provided a sense of how categories were developed and interpreted by the researcher.
- Attempts were made to reduce the risk of socially desirable answers and conformity from the interview study participants, with the researcher introducing herself as such and reminding participants at appropriate intervals that she was separate from their healthcare team. It was anticipated that this may have helped participants to feel like they could be more open and honest about how they managed their health and the relationship they had with their

healthcare team without feeling the need to provide socially desirable responses.

- For the quantitative research, an analysis protocol was developed prior to the collection of the data to ensure that the results were not shaped by researcher bias or reduced to data dredging (Ioannidis, 2005). The data analysis plan was developed following discussion with a statistician and reviewed in detail at a later date.

10.10 Research limitations

There were several limitations of the research. The majority of these were related to the studies' methods.

The qualitative study focused on participants who were good self-managers but consequently this contributed to a sample that was made up of participants who were already engaged and interested in managing their health. These participants were all white, many of them had prior experience as a research participant, they had largely been in professional work, and those who were in the circumstances to be able to access higher education had done so. This was beneficial for understanding how these experienced participants understood patient activation, but the qualitative findings were limited in their transferability as a result. Their experiences of proactive self-management would have led to them having substantially different encounters with healthcare professionals and this should be considered when putting the findings of this study into context. This is particularly relevant given that increased therapeutic alliance is associated with improved self-management skills (Ehde *et al.*, 2015).

Including several participants who were passive self-managers with low patient activation would have offered an alternative perspective and strengthened the study. The decision had been taken not to recruit these participants because identifying these lower PAM level participants would have necessitated a screening process and this had the potential to be distressing or inconvenient for participants. Consequently, screening was not included in the study design.

While this was one of the few studies capturing patients' perspectives on patient activation in rheumatology, including interviews with clinicians in the rheumatology field would have provided an additional, rich perspective on how they work collaboratively with activated rheumatology patients.

Another limitation is that the retention rates for both the interview and the survey studies were moderate overall. While all the participants lost to follow-up for the interview study had been contacted and the reasons for their discontinued participation were established, ultimately not all participants could be contacted for a second interview. This likely had an impact on the findings of the follow-up interviews and had an impact on how the interviews progressed. Additionally, the sample of participants in this study who completed the PAM at both interviews was very low. This then provided limited information about how we can consider participants' perspectives in light of their PAM scores. However, this limitation was mediated with the survey study capturing a much greater sample of rheumatology patients' PAM scores and levels in order to understand their current skills and abilities.

In some ways, the rapport and prior contact that had made the longitudinal interviews a strength did have drawbacks. For participants who felt as though little had changed in the year between interviews, they sometimes described having little to report as things were "business as usual". In some ways, an additional strand of data collection in the research design, such as regular diary entries or reflections over the year may have offered additional structure and served as a reminder of how participants had managed their health during the intervening year at the second interview.

The survey study also had several limitations. With hindsight, collecting data on co-morbidity may have been beneficial in order to identify whether there were significant differences in either patient activation or predictors of patient activation in these participants compared to those with a single diagnosis. Given that there are associations between multimorbidity and patient activation and additional challenges involved in navigating healthcare with multiple diagnoses (Blakemore *et al.*, 2016), it is possible that there were differences in patient activation that originated from managing multiple conditions in this sample.

The decision to use the Health Literacy Questionnaire as the outcome measure capturing health literacy was made because it was convenient for capturing without any sort of quiz or test for participants to increase the risk of shame, or checking of answers. However, consequently this led to capturing nine separate dimensions of health literacy in the form of the subscales. These nine separate variables may have weakened the strength of the findings because there were so many variables and a much larger sample size was needed.

While the sample was intended to be as representative as possible of rheumatology patients in the UK, the skewness of the sample meant that the findings could not be generalised to a wider population.

Finally, some aspects of interest identified in the qualitative study were not followed up during the survey for a variety of reasons (presented in Table 7.8). This may be considered a limitation of this research.

10.11 Implications for research

10.11.1 Methodology

The use of longitudinal research methods to assess patient activation and overall self-management constructs offered increased insight into how rheumatology patients actively manage their health. The two sets of interviews offered the opportunity for analysis to be approached between participants and within participants using framework analysis. Longitudinal qualitative self-management research is uncommon within the field of rheumatology but in these circumstances provided a detailed sense of patient activation within a temporal context.

10.11.2 Knowledge implications

- The findings of the thesis contribute to understanding the self-management of rheumatology patients and factors that could support them to feel more able to take responsibility for their own self-management. Illness beliefs have been demonstrated to contribute to increased ability to effectively self-manage, and it is possible that patient activation is the mediating factor to improved self-management because of its relationship with illness beliefs.

- The systematic review identified that, while there are conceptual differences between patient activation, patient engagement, patient enablement and patient empowerment, the terms are often used inter-changeably within publications.
- The model of factors amenable to intervention in patient activation provides a theoretical grounding on which self-management interventions can be mapped.

10.11.3 Clinical implications

- The PAM does not necessarily capture aspects of patient activation as rheumatology patients understand the concept. There are aspects of the measure that they feel are not appropriate for their needs. The source of patients' knowledge and information is important to them and the PAM does not account for this. Additionally, the use of the PAM with fluctuating health conditions has some challenges as it does not account for the unpredictable fluctuations and flares that can occur with IA. The PAM should be considered as a tool that captures aspects of patient activation but is not a comprehensive measure. For this reason, when the measure is used in clinic, PAM scores and levels should be supplemented with clinical judgement and discussion with patients about how well they feel they are actively managing their health. This will contribute to ethical care planning based on the understanding that patients' PAM scores and levels may change substantially between routine follow-up appointments in rheumatology.
- These issues with the PAM may contribute to a "false positive" where someone completes the PAM with strong beliefs that they are aware of the nature and cause of their condition (with inaccurate information). Consequently, healthcare professionals should consider PAM responses in context to reduce the risk of this false positive where patients have a higher PAM level or score than may be appropriate.
- Patients with a strong ability to actively manage their rheumatic condition generally value prompt access to their rheumatology units. This is because of both the specialist knowledge about rheumatic conditions these healthcare

professionals hold and the consistency of support from professionals who understand and can recall patients' personal experiences. The direct access care system was particularly appreciated as a method of accessing the kind of care participants valued because they could make prompt use of secondary care support rather than negotiating the barriers of primary care through general practitioners. This adds to the evidence supporting this type of care and the benefits it has within a rheumatology setting.

- Rheumatology healthcare professionals or units who intend to focus on increasing a patient's activation would benefit from incorporating regular reviews and preparations for any increases or reductions in patient activation into the care planning process. As learning to actively manage a rheumatic condition appears to be an ongoing process that does not necessarily relate to disease duration, healthcare professionals should also consider the possibility of changes to patient activation as a factor when making clinical judgements and decisions with patients. The findings of the thesis also have implications for the NHS services that are currently designed to provide a stratified, stepped care service with the PAM as a method of determining the form of support their patients require. While average PAM scores across the survey study sample remained similar over time, some individuals saw substantial changes. This should be considered when implementing such a service design.
- Patients tended to prioritise and make decisions around their daily life with their condition in order to preserve roles they valued and to be able to carry out activities that were important to them. This sense of participants' making use of their values to self-manage their health suggests that there may be a role for Acceptance and Commitment Therapy (Hayes, Strosahl and Wilson, 1999) in patient activation interventions.
- Reviewing, assessing and supporting patients to develop health literacy skills is a key component of supporting them to actively manage a long-term condition. This health literacy ability contributes to a curriculum of learning to manage long-term conditions, including how to deal with flare-ups, setbacks and accessing appropriate support for these challenges. Patients need to learn how to seek out different types of support for long-term conditions (e.g.

physiotherapy access via primary or secondary care, or how to organise additional pharmacology treatments in the event of a flare-up), as well as when and how to get answers to questions. These are examples of health literacy skills that could be targeted during an intervention or resources to guide patients to actively manage their health more effectively.

- The current emphasis of patient activation interventions within the NHS appears to be focused on developing methods to support people who are currently passive in the management of their health condition to take as much responsibility as they can. However, as identified in the survey study there are a broad range of skills and most of the rheumatology patients in the sample were at PAM level 3. Consideration should be given to how best to support patients with low patient activation without overburdening them or preventing other patients learning to manage their health receiving the support they need.
- Given the difference between PAM levels 3 and 4 largely depends on people's abilities to return to self-management and respond to setbacks, the way that patients are supported to prepare for fluctuations and flares (if support is provided) will differ based on their activation level and self-management skills. Stepped interventions to deal with flares and planning how to return to actively managing one's condition can be developed prior to flares, if this is possible.
- Supporting patients who have high levels of activation but lower levels of health literacy (the "dangerous self-managers" referred to by Yadav *et al.* (2018)) requires consideration. Health literacy assessments could identify these patients at risk. The value of health literacy in patient activation has been demonstrated and improving these skills can contribute to higher levels of patient activation overall.
- Training healthcare professionals within rheumatology in understanding the nature of patient activation according to patients will help to clarify the concept, contribute to conversations being more collaborative where appropriate, and provide healthcare professionals with the skills to effectively assess levels of patient activation in a holistic way.

10.12 Directions for future research

Given the substantial increase in interest in patient activation within the NHS currently, future research building on the findings of this thesis should take the form of implementing intervention support based on the needs of departments and services as well as the resources available. The priority should be that the support is easily implemented and grounded in theory, particularly as the systematic review identified no strong evidence about a single format that is most suitable. The interventions to increase patient activation would ideally focus on the factors identified within this thesis as being amenable to intervention. This might compromise group programmes or as training opportunities for healthcare professionals to incorporate support into routine care and clinical practice. Research to identify appropriate forms of intervention and determine the acceptability of these interventions to patients, healthcare professionals and commissioners should be the next step.

A combination of the research findings and review of the literature in preparation for the thesis has also identified a need for increased health literacy skills both for people with rheumatic conditions and across the population more broadly. This requires further examination, and health literacy training at a broader, population level may be a direction for future research.

There is also a need for further research about how to provide ongoing support and how to structure services to support people with high patient activation in order to understand what kind of ongoing support is appropriate for them. The introduction of sustainability and transformation plans in the NHS are built on the foundations of patient activation and increasing this in the patient population (NHS England Midlands and East, 2016; Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group, 2016). Evaluating the effectiveness and implementation of these plans with a more holistic patient-centred sense of patient activation would be useful. This is particularly relevant given the financial benefits of increased patient activation identified in the literature.

Given some of the issues identified by interview participants, there is a need for future research into an appropriate alternative or alterations to the PAM for rheumatology patients. This could contribute towards a more holistic assessment of patient activation for patients with fluctuating conditions.

10.13 Concluding thesis summary

Patient activation is more than the PAM and has been under-represented in long-tern condition research, particularly in rheumatology. The findings presented in this thesis report the broad range of skills, beliefs and behaviours that are incorporated in patient activation in IA. This has implications for the use of the PAM in clinical practice, as it is a tool best used when incorporated with collaborative conversations with patients about how they prefer and are able to manage their health, as well as clinical judgement from healthcare professionals.

Skilled self-managers reported that being determined and independent about managing their health, finding ways to make small, sustainable behaviour change, effectively navigating the NHS, knowing what techniques suited them individually, having positive perceptions about their health, and good social support were key to how they actively managed their conditions. They felt that while aspects of the PAM reflected how they performed patient activation it was not suitable for capturing the fluctuating nature of their IA.

While there has been a substantial amount of research into identifying factors associated with patient activation, this has not been previously conducted with rheumatology patients. Self-efficacy, illness beliefs, health literacy and an internal HLOC were associated with variance in PAM scores. The first three factors were also predictive of variance in PAM levels. Positive and negative affect was not associated with PAM scores, despite being fundamental to the prior conceptualisation of patient activation. The framework of factors presented in the thesis suggests that self-efficacy, illness beliefs, health literacy, and internal HLOC are personal factors amenable to intervention for people with IA.

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Appendices

Appendix A: Systematic review inclusion and exclusion criteria

Inclusion Criteria:

Studies that relate to:

- People with chronic physical conditions as participants.
- An intervention with a measure of patient activation as a primary or secondary outcome measure.
- Randomised control trials and pragmatic randomised control trials where there is an intervention.
- The review will only include studies that are written in English, or translated to English.
- Articles since 2004 (increase in patient activation lit at this time).
- The participants will be adults (over 18 years old) There were no limitations on multi-morbidity, so people with more than one physical health condition will be considered.

Exclusion:

- Studies with mental health diagnoses as the primary chronic condition.
- Studies with participants under 18.
- Studies with no measure of patient activation (matching the definition).
- Studies prior to 2004.
- Studies with participants without a chronic physical health condition.
- Studies not written in English or translated to English.
- Studies that are not RCTs or a pragmatic RCT.
- Studies without an intervention.
- Protocols without data.
- Duplicates.

Appendix B: Blank Cochrane risk of bias tool

Date form completed *(dd/mm/yyyy)*	
Name/ID of person extracting data	
Reference citation	
Study author contact details	
Publication type *(e.g. full report, abstract, letter)*	
Notes:	

General Information

Risk of Bias assessment

(See Handbook Chapter 8. Additional domains may be added for non-randomised studies.)

Domain	Risk of bias Low High Unclear	Support for judgement *(include direct quotes where available with explanatory comments)*	Location in text or source *(pg & ¶/fig/table/other)*
Random sequence generation *(selection bias)*	☐ ☐ ☐		
Allocation concealment *(selection bias)*	☐ ☐ ☐		
Blinding of participants and personnel *(performance bias)*	☐ ☐ ☐	Outcome group: All/	
(if separate judgement by outcome(s) required)	☐ ☐ ☐	Outcome group:	
Blinding of outcome assessment *(detection bias)*	☐ ☐ ☐	Outcome group: All/	
(if separate judgement by outcome(s) required)	☐ ☐ ☐	Outcome group:	
Incomplete outcome data *(attrition bias)*	☐ ☐ ☐	Outcome group: All/	
(if separate judgement by outcome(s) required)	☐ ☐ ☐	Outcome group:	
Selective outcome reporting? *(reporting bias)*	☐ ☐ ☐		
Other bias	☐ ☐ ☐		
Notes:			

Appendix C: Interview consent to contact form

Dear

Invitation to take part in an interview

I am writing to tell you about a research project for which I am helping PhD student Bethan Jones and her research supervisors. Bethan would like to find out more about the ways that patients have learned to live with their arthritis, including what they have found helpful and whether this changes over time.

This research is being run in rheumatology units in two hospitals across England. It is led by Bethan Jones and her research supervisors from the University of the West of England, who are based in the Bristol Royal Infirmary Rheumatology Unit.

I am enclosing the patient information sheet about the study for you to read. Taking part in research is voluntary and if you would prefer not to do so nobody will be upset and your treatment will not be affected.

If you would be interested in taking part, please complete the enclosed slip and return it to the researcher Bethan Jones in the prepaid envelope provided.

Thank you for taking the time to read the enclosed information.

Yours sincerely

Consultant Rheumatologist

Understanding Patient Activation: an interview study

Invitation to take part in an interview

Reply slip

☐ **Yes** *I would be interested in hearing more (I understand this does not commit me)*

☐ **No** *Thank you, I would prefer not to be involved*

Name:

Address:

Tel Number (s):

Email:

Appendix D: Information sheet for qualitative interviews

How people with inflammatory arthritis understand Patient Activation: an interview study

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the study is being done and what it will involve. Please read the following information and discuss it with friends and relatives if you wish. If anything is not clear or if you would like more information, you are welcome to get in touch with Bethan Jones. Her contact details are at the end of the document.

Who is asking you to take part?

I am Bethan Jones, and I am a student at the University of the West of England. I am inviting you to take part in a research study that will contribute to my PhD.

What is the purpose of the study?

The purpose is to find out what you have learned about living with arthritis. I am interested in what has been helpful to manage your arthritis, how you have found this out and if this changes over time.

Why have I been invited to take part?

You have been invited to take part because you are living with a type of inflammatory arthritis. I am inviting patients to take part from two NHS hospitals in England.

What will I be asked to do if I take part?

I will ask you to take part in two interviews and to complete a questionnaire called the Patient Activation Measure. At each interview, I will ask you about your experiences of learning to live with arthritis. I will audio-record the interview and type it up. Everything that you say will be confidential. The interview will last for around one hour and will take place in a non-clinical room in your local rheumatology department. I will offer you refreshments and I will pay your travel costs to attend. I will then contact you approximately one year after the first interview to see whether you are interested in taking part in a second interview with me.

Do I have to take part?

No, taking part is voluntary. It is up to you to decide whether to take part. If you do decide to take part, I will ask you to sign a consent form at each interview, and I will give you a copy to keep. If you decide not to take part you do not have to give a reason, nobody will be upset and the care you receive will not be affected. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. You can withdraw from the study by contacting Bethan Jones on the details provided below.

What are the possible risks of taking part?

I hope there will not be any risk to your wellbeing from discussing your experiences of having arthritis. However, if the interview makes you feel worried or concerned about your arthritis, I will arrange for you to see your clinical nurse specialist or rheumatologist.

What are the possible benefits of taking part?

There is not likely to be any direct benefit of taking part to you, but some people may find it helpful to discuss how they manage arthritis. However, I think this study will benefit people with arthritis in the future as we understand more about how people learn to live life with arthritis over time.

Will my taking part in this study be kept confidential?

Yes. When the interview is typed up it I will take out all names of people and places. My reports will not contain the names of people or places from the interviews. The audio recordings will be deleted as soon as I have typed up each of the interviews.

What will happen to the results of the research study?

The findings will be reported in professional publications, journals and conferences. This will include direct quotes from the interviews, which will be anonymised. They will also be published in my doctoral thesis. In addition, I will send a summary of the results to everyone who takes part in the study**.** A copy of your anonymised questionnaire answers will also be sent to Insignia Health, a commercial company outside of the NHS who offer us the licence to use the Patient Activation Measure. They are not directly working on the study, but your name and any identifying information will be removed to keep this data anonymous. They use this information to improve, refine and understand how the questionnaire is completed.

Will you keep my information and contact me again?

After the second interview is over, we may retain your contact details to get in touch with once more with information about future research going on in this project, but you do not have to read it or ask to take part. This information will be retained for one year following completion of your second interview, and then it will be destroyed.

Who is funding the study?

This research study is funded by Arthritis Research UK.

Who has reviewed the research?

It has been approved by the include West of Scotland REC 4 for the Health Research Authority. (REC
project ID 219233) and the University of the West of England (UWE) ethics committee.

What do I do now?

If you are interested in taking part in an interview, please complete and return the slip in the reply-paid envelope. I will then contact you with further information.

Central study contact details: Bethan Jones
Rheumatology Research
Level 5, Zone B
Bristol Royal Infirmary
Bristol
BS2 8HW

0117 342 7415
Bethan8.jones@live.uwe.ac.uk

Study Team:

Bethan Jones, PhD Student (UWE Bristol)
Emma Dures, Senior Research Fellow (UWE Bristol)
Sarah Hewlett, Professor of Rheumatology Nursing (UWE Bristol)
Diana Harcourt, Professor of Appearance & Health Psychology (UWE Bristol)
Andrew Hunt, Patient Partner (Bristol Royal Infirmary)

If you have any concerns about participating in this study and would like to receive free independent advice please contact PALS (Patient Advice and Liaison Service) on:

0117 342 1050 or via email on psct@uhbristol.nhs.uk.

Appendix E: Interview consent forms

UWE Bristol | University of the West of England

CONSENT FORM

How people with inflammatory arthritis understand Patient Activation

Please initial box

1. I confirm that I have read and understand the information sheet dated 15/05/2017 for the above study, and I have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in a research interview. ☐
4. I agree to the interview being recorded and understand that names will be removed from the typed transcript. ☐
5. I agree that anonymised quotes from interviews will be used in academic journal publications, conference presentations, reports, and a doctoral thesis. ☐
6. I understand that relevant sections of my medical records and data collected during the study may be looked at by responsible individuals from the NHS Trust where I receive my care, or from regulatory authorities. I understand that this will only happen where it is relevant to my taking part in this research. I give permission for these individuals to have access to my medical records. ☐
7. I agree to be contacted about a second interview in approximately 12 months' time. ☐

______________________ Name of Participant	_______________ Date	_____________ Signature
______________________ Name of Person taking consent (if different from researcher)	____________ Date	_____________ Signature
______________________ Name of Researcher	_______________ Date	_____________ Signature

CONSENT FORM

Understand Patient Activation: An Interview Study (follow-up)

Please initial box

1. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
2. I agree to take part in this second research interview. ☐
3. I agree to this interview being recorded and understand that names will be removed from the typed transcript. ☐
4. I agree that anonymised quotes from this interview will be used in academic journal publications, conference presentations, reports, and a doctoral thesis. ☐
5. I understand that relevant sections of my medical records and data collected during the study may be looked at by responsible individuals from the NHS Trust where I receive my care, or from regulatory authorities. I understand that this will only happen where it is relevant to my taking part in this research. I give permission for these individuals to have access to my medical records. ☐
6. I understand that an anonymised copy of my questionnaire data will be shared with a commercial company outside the NHS who licence the Patient Activation Measure. ☐
7. I agree to be contacted about similar research in the future. ☐

____________________ Name of Participant	____________ Date	____________ Signature
____________________ Name of Person taking consent (if different from researcher)	____________ Date	____________ Signature
____________________ Name of Researcher	____________ Date	____________ Signature

Appendix F: Qualitative study protocol

Understanding Patient Activation: a longitudinal interview study

Protocol – 24th July 2017 (Version 2)

Principal Investigator
Bethan Jones PhD student, University of the West of England (UWE), Bristol

Project team members

Emma Dures	Senior Research Fellow, UWE, Bristol
Sarah Hewlett	Professor of Rheumatology Nursing, UWE, Bristol
Diana Harcourt	Professor of Appearance & Health Psychology, UWE, Bristol
Andrew Hunt	Patient Research Partner, Bristol Royal Infirmary

Contact details
Bethan Jones
Rheumatology Research
Level 5, Zone B
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Bristol
BS2 8HW

Tel: 0117 342 7415
Email: Bethan8.jones@live.uwe.ac.uk

Glossary:

IA	Inflammatory arthritis
PAM	Patient Activation Measure
UWE	University of the West of England, Bristol
UHB	University Hospitals Bristol

Summary of the study:

Inflammatory arthritis (IA) describes several long-term conditions including rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, connective tissue disease and systemic lupus erythematosus (Arthritis Research UK, 2016). Inflammatory arthritis impacts people in a variety of ways, often requiring significant life adaptations to cope with the diagnosis. People can experience pain, fatigue, reduced mobility, low mood, increased anxiety, and unpredictable fluctuations or "flares" in symptoms (Homer, 2005). Because IA is often managed in specialist departments in secondary care, people are expected to develop skills to manage their condition (Hibbard, Stockard, Mahoney & Tusler, 2004).

Research indicates that there are a variety of factors that can impact how someone manages their health, and one of these is a concept called patient activation (Hibbard et al., 2004). It is defined as how willing and able someone is to take an active role in dealing with their health (Hibbard and Greene, 2013).

Higher levels of patient activation are associated with fewer emergency hospital admissions, fewer days as an inpatient and lower healthcare costs (Hibbard et al., 2015). Therefore, there is a value in understanding activation to reduce strain on the NHS. For individuals, people who are more activated are also more likely to stick to their treatment schedules, and have better outcomes overall (McCusker et al., 2016).

In order to understand patient activation in people with inflammatory arthritis, interviews will be carried out with people living with arthritis to understand how they manage their health, what factors have an impact on the way they cope with arthritis, and what skills they have to reduce the impact of their condition on their life. The study will be longitudinal, and participants will be re-interviewed 12 months after their initial interview to understand how their perceptions of patient activation develop over time, and whether they have learned or recognised any additional ways of managing their health actively during this time.

This study (funded with a PhD scholarship from Arthritis Research UK) will contribute to the development of a framework to describe patient activation in IA. Understanding people's experiences of managing their health, and what has had an impact on this can contribute to the framework. Seeing the same people again a year later for a second interview can help understand whether actively managing their health has changed, and identify what they think has contributed to this. They will also have the opportunity to reflect on their last interview, to see if their understanding of patient activation has changed. This longer-term approach can help

us to understand changes over time, particularly as inflammatory arthritis is a long term condition (Lorig et al., 2001).
The main aim of the study is to understand how people at different levels of patient activation perceive and understand this construct over time.

The study objectives are:

- To explore perceptions of the term, description, and concept of “patient activation” from the perspectives of people with IA.
- To identify individual and contextual factors that people with IA believe contribute to patient activation.
- To explore people’s experiences of actively managing their IA.
- To gather opinions from people with IA on the PAM as a method of capturing patient activation.
- To find out how these perceptions develop over a period of 12 months.

Having a framework to describe patient activation in people with inflammatory arthritis offers the opportunity for a theory-driven intervention to support people in taking the next step to actively manage their health condition. This study will help to ensure that any future intervention is focused sufficiently on rheumatology related contextual factors to suit people living with inflammatory arthritis.

Background:
Models of illness have an impact on the way that care is delivered to people living with long term health conditions. The previously dominant biomedical model has been criticised for not considering the impact of other social, psychological and behavioural factors that can contribute to people’s experience of living with health conditions (Wade & Halligan, 2004). This can imply that people are passive in their experiences, and doesn’t consider how people can influence their health.

Because of these criticisms, the biopsychosocial model has encompassed these additional factors which can contribute to outcomes (Engel, 1977) and describe people’s experiences in a more holistic way. This shift gives people with long term conditions more of a position as experts in living with their health condition with more responsibility to self-manage their condition. People are expected to develop skills to manage their illness, become more involved in making decisions about their condition in collaboration with health care professionals, and develop knowledge about behaviours which help manage their health (Hibbard, Stockard, Mahoney & Tusler, 2004).

Research indicates that there are a variety of factors that contribute to how engaged someone becomes in managing their health, and one of these is a concept called patient activation (Hibbard et al., 2004). It is defined as being how willing and able someone is to take an active role in dealing with their health (Hibbard and Greene, 2013). It appears to be a multidimensional construct, incorporating associated concepts such as self-management behaviours, health literacy, and self-efficacy (the belief in one’s ability to achieve a desired outcome) (Hibbard et al., 2004; Do, Young, Barnason & Tran, 2015).

Higher levels of activation are associated with fewer emergency admissions, fewer days as an inpatient and lower healthcare costs (Hibbard et al., 2015). Therefore, there is a value in understanding activation to benefit a resource-scarse NHS. On an individual level, increased activation is associated with greater adherence to treatment schedules and better outcomes overall (McCusker et al., 2016). In the context of inflammatory arthritis, activation might also involve behaviours such as regular stretching to reduce stiffness, having and acting on a plan for when their condition flares up, and managing stress levels by scheduling in time to practice relaxation techniques (Dixon, Hibbard and Tusler, 2009).

The dominant model of explaining activation is captured in the extensively used "Patient Activation Measure" (PAM) (Hibbard et al., 2004), with the PAM described as identifying the beliefs that people have about themselves and the responsibility they hold for managing their health (Hibbard & Mahoney, 2010). A licence is required to use the PAM in research, and this is being applied for using the funding in place for the research study.

The PAM and the underpinning model describe activation as involving four stages, each building on the other in a hierarchy (Hibbard et al., 2004). Hibbard proposes that people become more able to develop through the stages and become more able to engage in more complex behaviours as they become more activated (Hibbard et al., 2015). While it is believed that providing information alone is not sufficient to activate patients (Rix and Martin, 2015), factors which do contribute to increasing people's confidence and ability to actively manage their health are less understood.

However, little is known about the dimensions and factors involved in patient activation in the context of people with IA. Therefore, gathering qualitative data on patients' perceptions of activation, and how it changes over time, could contribute to an understanding of the concepts and contextual and psychosocial factors underpinning patient activation as a construct.

Design and methods:

The study design is longitudinal and will include two phases, using qualitative methods of data collection and analysis. The two phases will require NHS Research Ethics (REC), university ethics, and local research governance approvals in a combined application before data collection can commence.

<u>Phase 1:</u>

Method:

Rheumatology patients with a diagnosis of IA will be invited to take part in two face-to-face interviews, approximately 12 months apart. The interviews will help develop an understanding of participants' thoughts, feelings, beliefs and personal circumstances. By using a semi-structured format this will allow for all participants to be asked the same initial set of questions. However each interview will be able to progress based on the participants' responses, in order to gather more information, ask for clarification and open up new lines of enquiry.

These interviews will be facilitated by Bethan Jones, a PhD student with prior experience of conducting semi-structured interviews in a research context. The interview schedule has been developed by the research team, and reviewed by a patient group associated with one of the research sites.

The interview includes questions on personal and contextual factors which might have an impact on activation, and explores participants' thoughts on the definition and dominant model of activation and use of the Patient Activation Measure (PAM) (Hibbard et al., 2005) to measure activation. Asking participants about their understanding of self-management, and strategies they use, including things which have challenged them will provide insight into their current activation, and how they engage with this (Dixon, Hibbard & Tusler, 2009). Asking implicitly about what skills they feel they have developed and what they found beneficial in this learning process will allow the opportunity to develop an understanding of the information and skills necessary. These interviews will also offer the opportunity to gather data from participants about how they believe their active role in managing their health is related to concepts such as self-efficacy and self management.

Recruitment:

As there is a great deal of variety in patient activation levels in people with long term conditions (Hibbard et al., 2005), there is a benefit to speaking with participants who have had more experience of managing their health to understand the factors involved that they have identified. People will be eligible to take part if they are over 18 years old, with a diagnosis of IA, able to provide informed consent to participate and are able to communicate, read and write in English sufficiently to participate.

To gather a sufficient range of experiences participants will be sampled from two rheumatology departments in the Southwest: the Bristol Royal Infirmary and Weston General Hospital. Eligible patients will be given study information pack when they attend for an outpatient clinic appointment, or through the post. The information pack will contain an invitation to participate from the local clinical lead, a Patient Information Sheet, a brief information slip about a related longitudinal survey study, a reply slip and reply-paid envelope. The reply slip will offer patients the options of hearing more about taking part in the longitudinal interview study, being contacted at a later date with information about the longitudinal survey study, or declining to be involved with the either research study. Patients who are interested in taking part in the interviews will contact Bethan Jones to arrange a mutually convenient time to meet.

This protocol relates to the longitudinal interview study only. A separate protocol and ethics application will be made for the longitudinal survey study, which will start at a later date.

Data Collection:

A total of 20-25 interviews will be conducted across the two sites. Prior to the start of the interviews, Bethan will obtain written consent from the participant for the Phase 1 interview and to be contacted in 12 months' time about a second interview. Participants will also be asked to provide brief demographic data about themselves and their conditions. The semi-structured interviews will be carried out in non-clinical rooms with Bethan Jones at the hospital site, and are expected to last approximately one hour. With participants' consent, the interview will be audio recorded. The interviews will be held in a non-clinical room on a hospital site during regular working hours. *Bethan Jones is GCP trained, and has read the lone working policy information at the University of the West of England. As the interviews will take place within a busy department during working hours, it is anticipated that no additional lone working training will be required.*

Participants will also complete the PAM (Hibbard et al., 2005), and feedback their experiences of doing so. They will be informed that these scores will also be calculated as part of the data collection process.

Data analysis:
The interviews will be transcribed and all identifying information will be removed for the purpose of confidentiality. Participants will be given pseudonyms in order to ensure anonymity. The transcribed data will be analysed using framework analysis (Ritchie and Spencer, 1994). This will include becoming familiarised with the transcripts, coding each line in turn, and developing initial categories based on the initial transcripts. Further interview transcripts will be applied by comparison to these categories and codes, and a matrix will be created describing the framework with each transcript forming a row on the matrix. This will allow the opportunity to compare people's perceptions within their interviews and between participants (Ritchie and Spencer, 1994). This will be carried out by Bethan Jones throughout the data collection process, with support and supervision from the rest of the research team.

Study Two - Phase Two: Follow-up Interviews

This phase involves interviews with the same group of participants 12 months after their initial interview.

Method:
As with phase one, the data collected will be via face-to-face interviews conducted by Bethan Jones. The structure and focus of the second set of interviews will be informed by the findings and reflections following the first phase, and following discussions with the study team. However it is anticipated that this interview will allow participants to discuss what they believe has contributed to any changes in patient activation, and how they view their experiences of being activated or doing things to actively manage their condition since their last interview.

Sampling and recruitment:
The sample will be formed of people who participated in phase one, and no additional recruitment will be carried out. Phase 1 participants will be contacted by telephone, letter or email approximately 12 months after their Phase 1 interview, and invited to participate in a second face-to-face interview.

Data collection:

As in phase one, the interviews will take place in a non-clinical room at the participants' usual rheumatology department and be audio recorded (with the participants consent). Participants will also complete the PAM once again, to understand if their patient activation level has changed over time and whether this is reflected in their interviews.

Data analysis:

The participants' PAM scores will be analysed using paired t tests to identify change between the two points of data collection. This information will contribute to identifying if changes to participants' perspectives on activation are reflected in the measures. The transcribed, anonymised data will be analysed using a qualitative approach called framework analysis, which will involve using the data from both phases one and two, as this data is collected (Ritchie and Spencer, 1994). The benefit of using this type of analysis is that it allows data to be compared both between participants, and within participants across both of their interviews.

Project management and the research team

This research will contribute to a PhD project at the University of the West of England (UWE), and is supervised by a team with significant experience in rheumatology, the impact of long term health conditions, qualitative methodology, and patient perspectives on living with IA.

Bethan Jones, a PhD student with a background in health psychology in long term conditions, has designed this study and will conduct the data collection and analysis. Dr Emma Dures, a Senior Research Fellow at UWE and chartered psychologist, is Bethan's Director of Studies. Dr Dures similarly has a background in health psychology and substantial experience of designing and conducting mixed methods and qualitative research. Professor Sarah Hewlett (Professor of Rheumatology Nursing, UWE) is Bethan's second supervisor. Professor Hewlett is a clinical academic who is at the forefront of research into patient involvement, self management, and understanding the impact of IA on patients' wellbeing. Further supervision is provided by Professor Diana Harcourt, who has substantial experience of the psychological impact of living with a long term condition; and Mr Andrew Hunt, a patient partner who brings lived experience of living with IA to the team.

Throughout the study there will be regular whole team meetings as required, and fortnightly meetings between Bethan Jones and Dr Dures for ongoing day to day management of the study.

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Appendix G: Interview schedule for first qualitative interviews

This is a guide to the semi-structured interviews, and the researcher may ask additional questions for clarity, or for further information following participants' responses.

Before commencing the interview:
The researcher will obtain signed consent, ask patients to complete the demographic/clinical questionnaire, and ask for permission to turn on the audio recorder.

Part A: People's experiences of actively managing their condition.

1. Tell me a little about your experience of having arthritis.
    - What are your symptoms?
    - What sort of impact does this have on your life?

2. I'm interested in how you manage the impact of arthritis on your life. What kind of things did you learn when you were beginning to manage your arthritis?
    - How did you find this out?
    - Did you try other things before then? What wasn't helpful?
    - Are there aspects of your arthritis that you find particularly challenging to deal with?
    - How do you manage your health now?

3. What kind of decisions do you make around your arthritis? These can be about broader things medications or treatments, or ways in which you've had to change your lifestyle. They can also be smaller ones, like how you manage your daily activities.
    - What prompts you to make these decisions?
    - How did the last time you did that go?

Part B: Identifying individual and contextual factors that contribute to active management

4. I'm interested in the kind of things you can do to help your arthritis, and the things that others also do to help your arthritis. What sort of things do you do to help your arthritis?

    - What other people are involved in helping with your arthritis? What do they do?
    - How does that factor impact your health? How do you manage that?
    - What things are most important for you to manage your arthritis?

5. What sort of relationship do you have with your health care team? How do they support you?
    - What is the most helpful thing they do to support you?
    - What changes, if any, would you make to your healthcare?

6. How do you know if you need more support, or information about your arthritis?
    - What do you tend to do then?
    - If you were talking to a new patient, what would be your top tip for dealing with arthritis?

Part C: Exploring perceptions of "Patient activation"

7. If I used the term "patient activation", what would that mean to you? You may not have heard it before, so what would you guess it means?
    - Opportunities for clarification on participants' definitions here.

8. Can I tell you what some researchers think it means?
    - Give definition "skills, ability and likelihood that someone will take an active role in managing their health". What do you make of that?
    - How does that fit in with the experiences you described to me earlier?
    - Describe what active health management means to you, and what that would look like with your condition. How closely does what you do now fit that?
    - Do you think there is a better phrase? If so, what would it be?

Part D: Gathering opinions on the Patient Activation Measure:

9. Can I ask you to complete this questionnaire, and while you are doing this, let me know what you think of it?
    - Do the questions seem relevant for your experience of living with arthritis?
    - Does it make sense?

    - How does that fit with what you think about actively looking after your arthritis – is everything you expect to see there?

Part E: Close

10. Are there any issues that we have not talked about that you would like to raise?
    - Thank you very much for your time and valuable contribution to the study.
    - Confirm consent to contact for interview in 12 months' time.

The second interview schedule will be informed by the findings of the first interview, and individuals' responses to their interview.

Appendix H: Interview schedule for second qualitative interviews

- How have you managed your health since we last spoke? What has changed?
- What has really worked for you in the way you've coped?
- What has been a challenge?
- *Individual follow-up questions*
- Something that's really struck me following my conversations with all these people is that … feed back –
    - How does this sit with you?
    - Do parts of that not apply to you?
    - Why do you think this is the case?
    - What would make this closer to your experiences?
- Locus of control related question
- Have you seen your GP/consultant/another healthcare professional in the last year? How often? What did that conversation look like?
- Did you change anything about how you managed your health after our conversation? Has anything occurred to you since
- What prompted you to take action? "penny dropping"?
- Has your condition fluctuated much since we last spoke? How have you responded to this?
- Giving in versus choosing not to take action?
- Engaging social support

Appendix I: Demographic pack for qualitative interviews

Understand Patient Activation: An Interview Study

Pre-interview questionnaire

Date: ________________ **Study ID:** ______________

Thank you for agreeing to take part in this study

This questionnaire will help the researchers make sure that they talk to a wide range of people with types of inflammatory arthritis. Your answers are confidential to the researchers, and although other people will see the results of the overall study, they will not be able to link your name to the answers you give on this sheet.

A) This section asks about your demographic details

1. Gender: Male / Female (Please circle)
2. Date of birth: __ __ **/** __ __ **/** __ __ __ __ (Day / Month / Year)
3. What is your highest level of qualification?

   ____

B) This section asks about your inflammatory arthritis

1. How long have you been diagnosed with inflammatory arthritis?

   _______________ (Years, Months)

This section asks about your usual ABILITIES over the PAST WEEK (Please tick)

	Without ANY difficulty	**With SOME difficulty**	**With MUCH difficulty**	**Unable to do**
1. DRESSING AND GROOMING Are you able to:				
- Dress yourself, including tying shoelaces and doing buttons?	__________	__________	__________	__________
- Shampoo your hair?	__________	__________	__________	__________
2. RISING Are you able to:				
- Stand up from an armless straight chair?	__________	__________	__________	__________
-Get in and out of bed?	__________	__________	__________	__________
3. EATING Are you able to:				
- Cut your meat?	__________	__________	__________	__________
- Lift a full cup or glass to your mouth?	__________	__________	__________	__________
- Open a new carton of milk (or soap powder)?	__________	__________	__________	__________
4. WALKING Are you able to:				
- Walk outdoors on flat ground?	__________	__________	__________	__________
- Climb up five steps?	__________	__________	__________	__________

Please tick any aids or devices that you usually use for any of these activities:

_____ Cane
_____ Walking frame
_____ Crutches
_____ Wheelchair

_____ Devices used for dressing (button hook, zipper pull, long handled shoe horn etc)
_____ Built-up or special utensils
_____ Special or built-up chair

Other: ____ (Please specify)

Please tick any categories for which you usually need help from another person:

_____ Dressing and grooming
_____ Rising

_____ Eating
_____ Walking

	Without ANY difficulty	**With SOME difficulty**	**With MUCH difficulty**	**Unable to do**
5. HYGIENE Are you able to:				
- Wash and dry your entire body?	__________	__________	__________	__________
- Take a bath?	__________	__________	__________	__________
- Get on and off the toilet?	__________	__________	__________	__________
6. REACH Are you able to:				
- Reach and get down a 5lb object (e.g. a bag of potatoes) from just above your head?	__________	__________	__________	__________
- Bend down to pick up clothing from the floor?	__________	__________	__________	__________
7. GRIP Are you able to:				
- Open car doors?	__________	__________	__________	__________
- Open jars which have been previously opened?	__________	__________	__________	__________
- Turn taps on and off?	__________	__________	__________	__________
8. ACTIVITIES Are you able to:				
- Run errands and shop?	__________	__________	__________	__________
- Get in and out of a car?	__________	__________	__________	__________
- Do chores such as vacuuming, housework or light gardening?	__________	__________	__________	__________

Please tick any aids or devices that you usually use for any of these activities:

_____ Raised toilet seat
_____ Bath seat
_____ Jar opener (for jars previously opened)
_____ Bath rail
_____ Long handled appliances for reach

Other: ____ (Please specify)

Please tick any categories for which you usually need help from another person:

_____ Hygiene
_____ Reach
_____ Gripping and opening things
_____ Errands and housework

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Insignia Health

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. There are no right or wrong answers, just what is true for you. If the statement does not apply to you, circle N/A.

1. I am the person who is responsible for taking care of my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I am confident that I can carry out medical treatments I may need to do at home.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I know what treatments are available for my health problems.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I have been able to maintain lifestyle changes, like healthy eating or exercising.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11. I know how to prevent problems with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12. I am confident I can work out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13. I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Appendix J: Reflective note example

5/12/2017

Lots of discussion on the challenges of parenting and balancing this responsibility with a rheumatic condition. Sometimes they report how their caring role (and the enjoyable aspects of spending time with their children) doesn’t go away regardless of how they feel. Is this something that I’m underplaying the value of because I am not a parent or is it more about the general life responsibilities that they are finding the balance of? Perhaps do some reading around the role of parenting and rheumatology and the impact of that – pay attention to it as I progress through the interviews. Noticing my own challenge of not validating any boom and bust type techniques to manage childcare, and not trying to challenge them either. I also wonder if I’d be paying this amount of concern about my response if it was other responsibilities I could relate to more e.g. work, older adult care.

Appendix K: Example of analysis

Perceived social support - often practical. *Participants did receive some help to manage their condition, but what support they chose was often practical instead of emotional.*	“When [husband] is here is does help, he will drive if we are going out for the day. Or even the shopping he will do all the driving and push the trolley.”
	“They are all there and if I need anything I can say “can you do this. Like getting things down off the top of cupboards”
	“Probably the only person that has been involved is my husband”
	“I’ll do things like building computers for people, repairing them…. And in return they’ll help me”
	“I find if I help others they help me”
	"things like the garden, I get the bloke across the road to do it, he’ll come over and do it for me in return I look after his computer. "
	"Just does a lot of fetching and carrying for me. If I can’t open something, she’ll open it for me. If I can’t lift something, she’ll lift it for me. So yes, it’s just helping out."
	"I think I would manage if I was on my own but it is nice to have someone there to help you"
	“I don’t lift things. Like I’ve got books for the shop to sell, so I only bring them in when my husband’s there to carry them, I wouldn’t carry them, because even like that, for just from the car in here, would, I’d, I’d be suffering tonight in my shoulders”

Appendix L: Charting following first interviews

	“You do it because you have to”: Determined independence	“You find ways to do different things”: Making small changes	“If you have a problem just phone up”: Navigating the system		“I think I've recognised what works for me, and what I need”: Knowing oneself			“There are people far worse than me”: Positive perspectives on health	“Just does a lot of fetching and carrying”: Practical Social Support
			“If I have that knowledge then it helps”: How to seek and get help and information	"If I feel there’s a concern, I will raise it “: Collaborating with healthcare professionals	“I know what each tablet is for”: Health-related knowledge	“I knew it was obviously something shook up in my body”: When to seek help and information	"It just helps me”: Knowing what techniques work for individuals		
Mary	"Get on and do it regardless" - sometimes it’s a struggle but you "have to do the things that need to	"Now do two days from home." - "life might have been easier if I'd done something that way,	Aware of resources but "I like the fact that I can"	Personal service, and value of people "acknowledging that there's things that they can do	Aware of three-monthly blood tests and review phases, along with having enough detailed knowledge to	"Your body's actually telling you that's what you need to do" - internal. External - friend	"I think I've recognized what works for me, and what I need, whether I get or can have what I need"	"I am lucky in that respect" [support network]	"It is more the practical stuff of opening things, that I've needed help with"

	be done". Self-described as independent	rather than that way"		to help manage" with HCPs	know they have "changed the policy"	advised getting seen			
Joanna	"I am determined". "you are the only one that can" [manage condition]	Shifted work pattern to remain in work and retain energy. "	"I know they say you shouldn’t read everything, but there are good sites on there."	Can trust doctor and will be taken seriously.	Describes routine and aware of next appointment due				Will ask for practical help and partner automatically drives, pushes trolleys
Lindsay	"independent that’s the word yeah" - but will ask for help and accept offers	Swap to shopping basket, tries to reduce trips up-stairs to spare energy	"not much point" in seeing GP as will be referred to rheum. "Screen" gets in way of solving problems	"It's got to be consultant" leading rather than patient. Feels empowered in appointments. "Just want		Assertive, happy to return and know when things can be resolved on the day	Avoid reliance on medication. Rest	"I'm not going to end up with fingers like that, that can't do all the things she wants to do. It helps"	Bag carrying, lifting and DIY work from others

				to try" and HCP mediates. "not going until something's done"					
Tony	"I cope because I have to, I've got no choice". Being determined	Practical problem solver - levers to keep cooking	Direct access - peace of mind. Looks for support elsewhere too	"finished waffling and ask him at the end" - will ensure queries are responded to.	"I know the way the NHS works". Manages medication himself to avoid being disengaged		Identified techniques, that doesn't work for him. "Modify life to suit regime"		Exchange system with whole estate
Jim		Does own cooking to stay healthy, paces things to keep doing DIY and gardening	Advises using rheumatology team. Reading scientific reports for info	Aware of value of time, but likes reassurance and generally guided.	Aware of daily fluctuations and the challenges involved	Prolonged period of flare up	Knows limits for alcohol for them personally	"I'm very fortunate" - lifestyle comparison to help manage	Cooking help from partner

				Positive - will "do anything"					
Jackie	Can't resolve everything with tablets, sometimes you have to do things yourself. "On my own…. I'm better and able to cope"	Pacing to keep catering, trial and error, planning to stay warm and keep a going out. Make best of self. Shower, not bath	Also seeks help for relatives using skills. Confident calling and asking for appointment - preference for rheum	Guiding plan as doesn't want tablets. Determines choices based on offers given	Efficiency of NHS awareness - biosimilars		Creams and techniques to complement the changes required	"At this moment in time, I'm quite happy with what's going on. Because I feel I've taken control again."	Lifting support from family
Avril	Got to find ways to live with this - although feels upset by this	Manages limits	Preference for rheum but aware of options such as pharmacist	Some confusion about who to approach with what challenges, but directed by HCPs	Able to discuss and describe routine of monitoring. Aware of sense of own body and condition	Routine of regular appointment to help	Know limits	Comparison of poor joins. "99% of people wouldn't know there's anything	Carrying and lifting, but able to organise backup if not available

								the matter with me"	
Mark	"Carry on as normal"	Exercise to prevent fractures and bigger degeneration	Frustrated by delays in GP services, often uses internet	"Health service have a degree of responsibility "			doesn’t find anything in particular necessary	"[mum] has always had a far more significant problem with it than I have". Some people get "lucky"	
Jan	"Carry on and see how you go" - cautious confidence		Takes research and potential solutions to HCPs	Joint decision making	Risks and activity of biological medication	Seeking solutions - e.g. injections	Knows best time of day top get things done, medication preferences etc.	"[daughter] has it in her legs as well, so she has it worse"	"husband's there if I need him"

Richard	Resigned to pain but "won't let it get in the way". Chooses not to involve others		Often online, but prefers direct access to GP. Seeks help during flareups	Sees HCPs as "guide". Plans discussions in advance		Flare up not resolving in several days	Still going through trial and erorr process but has sense of what works for them	" I’m not a sicky person. I’ve had this for 12 years and never lost a day of work through it"	" If I can’t open something, she’ll open it for me. If I can’t lift something, she’ll lift it for met."
Cheryl	Push through - sometimes to boom and bust. Gentle moving better than nothing. "If we can manage we will try and do it ourselves"	Downstairs toilet to keep exercises	Variety of sources - uses peers	no "magic wand" for HCPs			"You do what you feel comfortable with"	"there’s an awful lot of people out there who are an awful lot worse off than I am "	"He does, he does manual things like maintenance stuff if we need stuff doing. "

Greta	Aware imbalance of pacing vs "giving in". Fear vulnerability. "I'm capable of doing that myself"	Only using chairs with arms to be able to get out, holding on stairs. Practical, adaptable change	Looks for information first by self	assuption of HCPs making decision for you - but frustration at expectations for HCP. Value of personal relationship	Offers suggestions for healthcare monitoring - proactive		"Still learning" - has tested and found routine	"When you then speak to other people at the group you realise that it affects people in different ways. That's been really helpful" - sought out peer contact	"I probably I would say my family is probably more practical, emotion, doesn't come into it "
Patricia	Getting through - looking back and amazed at coping	Still learning small changes matter -	Problem solving research using internet. Generally only	Doesn't have conviction to disagree with HCPs, but sees			Clear sense of health behaviours that help, as		Domestic responsibility with husband

		beginning with pacing	seeks in-person help for flare and rheum preference	dialogue. Assumption HCP will pre-warn of risky side effects			well as activities		
Christine	Plough on, then crash. Now can change things with pacing but it's not going away. Make life as good as possible. Reports wanting "Independence, completely"	Bite sized chunks, switch to automatic to keep driving	Lots of own research in search of power and control. Seeks help from peers but aware of individual differences	Struggled with inconsistency of care			"mentally I've really struggled with having to give up everything. And also, the rounds of medication, I've still not found the right medication, the right immune suppressant"	"life can be worse", try and see positive	Husband support, parental support during a flare

Stuart	Preparation, positive thinking, don’t "give up"	Find balance between elimination diet and enjoyable food	Charity help, but confidence to drop in to clinic in person if necessary. Ladder of severity to solution	Gp focused previously, but less reliant on rheumatology	Limited understanding demonstrated	Searching for tests, for answers	"But I like to try things anyway and try for myself, see if it’s beneficial or not. If it’s not then it’s fine, you know, go on to something else"	"I can do almost anything I want to do" - even if it isn’t the same	Flexible workload with wife
Anne	"you just get on with it.. There's nothing you can do..""Pretty much independent "						Identified preference after setback	"So when you’ve seen that, it’s just a case of like, and had she done exactly the same as me, she	

								wouldn’t have been as bad. "	
Meryl	"Little bit of determination" - just getting on with it even if some days hard. Plans to retain independence - doesn't have someone to ask for help	Adapted way to sleep. Change trolley in supermarket to keep being able to. Lots of adaptation	Google	Appreciate balance and happy to discuss and suggest but not comfortable taking the lead	Reports sense of feeling when a flare is coming			"if he can do it, he is obviously been diagnosed years then I thought well I’m sure I can cope"	Neighbours supporting and feels able to ask for help

Appendix M: Charting second interviews

	“You do it because you have to”: Determined independence	“You find ways to do different things”: Making small changes	“If you have a problem just phone up”: Navigating the system		“I think I've recognised what works for me, and what I need”: Knowing oneself			“There are people far worse than me”: Positive perspective on health	“Just does a lot of fetching and carrying”: Practical Social Support
			“If I have that knowledge then it helps”: How to seek and get help and information	"If I feel there’s a concern, I will raise it “: Collaborating with healthcare professionals	“I know what each tablet is for”: Health-related knowledge	“I knew it was obviously something shook up in my body”: When to seek help and information	"It just helps me”: Knowing what techniques work for individuals		
Mary									
Joanna									

Lindsay	"You can't live life with your feet up"		Seeks advice from HCPs and from own research. Reads all the leaflets for medications. Benefitted from online GP system and internet as a tool.	Able to refuse new medication plan and discuss with HCP. Found seeing different HCPs challenging.	Did on research about anti-inflammatory to pas on to consultant. Created folder of health summary.	"I don't go to the doctor for every silly little thing"	Describes how side effects of steroids more challenging than the symtpoms	Caring for parent with RA	Partner did the dog walking.
Tony									
Jim	"Work from the top. If you don’t you give up on life. That's the mentality of it, making small changes to manage"	Found a balance to continue playing golf	Does own research including academic research		prepared for travel and practical problem solving based on medication needs - fridges etc.		Still travelling abroad for heat. Dietary changes.	Sense of illness being invisible when other people visibly suffer too - perspective. "mind	Spouse provides a lot of practical support, particularly around house

								works differently"	
Jackie	Gotten through difficult year - "I'm on my own"	sensible but enjoyable shoes, pacing doing the house	Comfortable postponing appointment to manage independently for a while and review at a more crucial time	Wish HCPs had been more open with her during last year		Needed more help over last year, but lots of health changes	walking for health. "lotions and potions"	Sat in waiting rooms and "realises how lucky you are"	Relatives doing jobs around house - "I've asked for practical help"
Avril									
Mark									
Jan	"You like to keep your independence as long as you can".	"You take more time but you still do it"			Tracks blood count numbers	"Helps to figure it out by yourself, because you're		Has friends with the condition and that helps.	

						doing something that suits you"			
Richard									
Cheryl									
Greta									
Patricia									
Christine	"Independence is my most prioritised thing, and just getting on with it sometimes"		"[GPs] just refer me. So I tend to go direct to the rheumatology nurse helpline"		Has permission to manage steroids herself based on blood tests than risk delay awaiting confirmation.	"My body won't let me do those things". Trying to unpick the impact of different health conditions.	"My use of oramorph goes up in August, I have kids at home. My family" Previously would have pushed through, now		Family helps, partner has flexible working and supportive parent to add help.

							learned balance		
Stuart									
Anne									
Meryl									

Appendix N: Summary of framework categories

“You find ways to do different things”: Making small changes	This category recognises the ways that participants have chosen or recognised smaller decisions they make in order to manage their health or stay focused with activities they value. These smaller changes often have been determined through trial and error and focus on common self-management behaviours such as adaptations, pacing, goal-setting and tweaking routines.
“If you have a problem just phone up”: Navigating the system	This recognises a specific skill participants have of navigating the NHS in order to work with healthcare professionals in all forms in order to get the support, tests and medications required. Sometimes this refers to decision making in collaboration with healthcare professionals or knowing how best to get the support they need.
“If I have that knowledge then it helps”: How to seek and get help and information	This subcategory refers to participants knowing appropriate ways to get help and information about their condition - whether by doing so themselves and evaluating the information or by choosing a suitable and efficient route to speaking to a healthcare professional.
“If I feel there’s a concern, I will raise it”: Collaborating with healthcare professionals	This specifically refers to in-consultation working with healthcare professionals to play a part in decision making, determining the aim and direction or care or to be an active participant in appointments.
“I think I've recognised what works for me, and what I need”: Knowing oneself	This category describes the participants experience and sense of their own body that they used to determine what techniques for self-care were useful for them, when they may need additional help or information (separately to how they went about doing this). This also included knowing the routines around managing their health and what was required in order to maintain their health.
“I know what each tablet is for”: Health-related knowledge	This sub-category covered both participants' understanding of their own condition and the biological aspects involved in it and the practical aspects of managing as well as a sense of how they were currently coping.
“I knew it was obviously something shook up in my body”: When to seek help and information	Participants were generally aware of when they needed more help and information to manage a flare-up or their condition.
“It just helps me”: Knowing what techniques work for individuals	Participants closely connected actively managing their condition with having a sense of what was useful for them to manage the physical aspects of their condition.
“There are people far worse than me”: Positive perspectives on health	This category refers to the comparisons participants used to recognise that their health was often better than others they knew. These comparisons were not always conscious or explicit but formed a part of how participants viewed life with their condition.

“Just does a lot of fetching and carrying”: Practical Social Support	Participants did receive some help to manage their condition, but what support they chose was often practical instead of emotional.

Appendix O: Summary of findings for participants

I interviewed people who were skilled at managing their health to find out what they thought this looked like and what things were important to them to manage their health.

I met 17 people overall at various stages of learning to manage their condition. We talked about various things that contributed to them feeling like they were actively managing their condition. Not everyone agreed on everything, but the major factors that came up in these conversations were:

· **Being determined and "just getting on with it" sometimes**. The idea of "doing it because you have to", and trying not to let your health condition rule your life. This sometimes meant doing what you can even if you're feeling poorly, or sometimes asking for help to make sure things get done. This recognises that people had responsibilities (jobs, family, children, housework, social responsibilities) that couldn't be rescheduled even if they were having a bad day. Sometimes flares meant that people did need to rest and take things easy, and people figured out when this was the case through trial and error.

· **Making small changes to manage big life goals**. This means that sometimes to do an overall big life change (e.g. getting more exercise) this had to me done through smaller steps (like using stairs more, or a short walk with a dog). People were organised and often very good at planning, things in advance to reduce the risk of upsetting their symptoms. Sometimes these changes were to keep doing an activity people enjoyed, or practical changes.

· **What works for me.** Everyone I spoke to had a clear sense of the things (whether it is rest, heat, diet, hydrotherapy etc.) that made a difference to their condition and made it easier. They described how they had to learn this, and that knowing this made a difference to their flare-ups was useful (knowledge is power!).

· **Independence where possible.** People were very independent and tried to do as much for themselves as possible rather than asking other people. When they did get help it was often practical – opening jars, carrying things down from high shelves, driving etc.

· **Learning to navigate the NHS.** People had found out how best to organise the system so that they could see their rheumatology team when needed (and often preferred to see their rheumatologist rather than their GP). They knew when to seek help and when they could manage their flareups themselves, and how to do this, sometimes knowing how to chase health professionals for the tests or reviews they need.

· **Positive sense of their own health.** People generally felt quite positive about their own health compared to other people. A lot of participants I spoke to have or had older relatives with rheumatic conditions, and this seemed to be a factor in them feeling lucky compared to other people they knew.

Appendix P: Survey pack for quantitative study

How people manage their health conditions: A survey study

Thank you for agreeing to take part in this study. Your answers are confidential to the researchers, and we are interested in everybody's views. If you have been diagnosed with more than one health condition, we ask that you answer these questionnaires thinking about your rheumatology condition.

Some of the questions in this survey may seem repetitive. This is because I am using a number of established questionnaires that cannot be changed. Please answer all the questions in the survey.

Bristol research team contact:
Bethan Jones
Bethan8.jones@live.uwe.ac.uk
0117 342 7415

HAQ **Date:**

____

1. About you

Are you [ ] male
[ ] female
[ ] other
[ ] prefer not to say

How old are you?
……………………………………years

What is your ethnic group?
[ ] white British
[ ] black British
[ ] other white
[ ] other black
[ ] Asian
[ ] Chinese
[ ] other ethnic group ……………………………………………
[ ] prefer not to say

What rheumatic condition(s) do you attend the rheumatology clinic for?
Please circle:

Rheumatoid arthritis	Scleroderma	Adult with juvenile idiopathic arthritis
SLE / lupus	Ankylosing spondylitis	Psoriatic arthritis
Inflammatory polyarthritis	Don’t know	Other (please specify) …………………………………..

How old were you when you were diagnosed with this condition?

…………………………..……………………………………

This section asks about your usual ABILITIES over the PAST WEEK (Please tick)

	Without ANY difficulty	**With SOME difficulty**	**With MUCH difficulty**	**Unable to do**
1. DRESSING AND GROOMING Are you able to:				
- Dress yourself, including tying shoelaces and doing buttons?	__________	__________	__________	__________
- Shampoo your hair?	__________	__________	__________	__________
2. RISING Are you able to:				
- Stand up from an armless straight chair?	__________	__________	__________	__________
-Get in and out of bed?	__________	__________	__________	__________
3. EATING Are you able to:				
- Cut your meat?	__________	__________	__________	__________
- Lift a full cup or glass to your mouth?	__________	__________	__________	__________
- Open a new carton of milk (or soap powder)?	__________	__________	__________	__________
4. WALKING Are you able to:				
- Walk outdoors on flat ground?	__________	__________	__________	__________
- Climb up five steps?	__________	__________	__________	__________

Please tick any aids or devices that you usually use for any of these activities:

_____ Cane
_____ Walking frame
_____ Crutches
_____ Wheelchair

_____ Devices used for dressing (button hook, zipper pull, long handled shoe horn etc)
_____ Built-up or special utensils
_____ Special or built-up chair

Other: ____ (Please specify)

Please tick any categories for which you usually need help from another person:

_____ Dressing and grooming
_____ Rising

_____ Eating
_____ Walking

	Without ANY difficulty	**With SOME difficulty**	**With MUCH difficulty**	**Unable to do**
5. HYGIENE Are you able to:				
- Wash and dry your entire body?	__________	__________	__________	__________
- Take a bath?	__________	__________	__________	__________
- Get on and off the toilet?	__________	__________	__________	__________
6. REACH Are you able to:				
- Reach and get down a 5lb object (e.g. a bag of potatoes) from just above your head?	__________	__________	__________	__________
- Bend down to pick up clothing from the floor?	__________	__________	__________	__________
7. GRIP Are you able to:				
- Open car doors?	__________	__________	__________	__________
- Open jars which have been previously opened?	__________	__________	__________	__________
- Turn taps on and off?	__________	__________	__________	__________
8. ACTIVITIES Are you able to:				
- Run errands and shop?	__________	__________	__________	__________
- Get in and out of a car?	__________	__________	__________	__________
- Do chores such as vacuuming, housework or light gardening?	__________	__________	__________	__________

Please tick any aids or devices that you usually use for any of these activities:

_____ Raised toilet seat
_____ Bath seat
_____ Jar opener (for jars previously opened)
_____ Bath rail
_____ Long handled appliances for reach

Other: ____ (Please specify)

Please tick any categories for which you usually need help from another person:

_____ Hygiene
_____ Reach
_____ Gripping and opening things
_____ Errands and housework

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. There are no right or wrong answers, just what is true for you. If the statement does not apply to you, circle N/A.

1. I am the person who is responsible for taking care of my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I am confident that I can carry out medical treatments I may need to do at home.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I know what treatments are available for my health problems.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I have been able to maintain lifestyle changes, like healthy eating or exercising.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11. I know how to prevent problems with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12. I am confident I can work out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13. I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Rheumatoid Arthritis Self Efficacy Scale (RASE)

We are interested in finding out what things you believe you could do to help you with your arthritis. We want to know what you think you **could** do, even if you are not actually doing it at the moment. Please tick one column for each question.

Do you believe you **could** do these things to help you with your arthritis?

	Strongly disagree	**Disagree**	**Neither disagree nor agree**	**Agree**	**Strongly agree**
I believe I *could* use relaxation techniques to help with pain					
I believe I *could* think about something else to help with pain					
I believe I *could* use my joints carefully (joint protection) to help with pain					
I believe I *could* think positively to help with pain					
I believe I *could* avoid doing things that cause pain					
I believe I *could* wind down and relax before going to bed, to improve my sleep					
I believe I *could* have a hot drink before bed, to improve my sleep					
I believe I *could* use relaxation before bed, to improve my sleep					
I believe I *could* pace myself and take my arthritis into account to help deal with tiredness					
I believe I *could* accept fatigue as part of my arthritis					
I believe I *could* use gadgets to help with mobility, household tasks or personal care					
I believe I *could* ask for help to deal with the difficulties of doing everyday tasks					
I believe I *could* do exercises to deal with the difficulties of doing everyday tasks					

	Strongly disagree	**Disagree**	**Neither disagree nor agree**	**Agree**	**Strongly agree**
I believe I *could* plan or prioritise my day to deal with difficulties of doing everyday tasks					
I believe I *could* educate my family and friends about my arthritis to help with the strains that arthritis can make on relationships					
I believe I *could* explain to friends and family when I do or don't need help					
I believe I *could* discuss any problems with my partner or family					
I believe I *could* make time for leisure activities, hobbies or socializing					
I believe I *could* save energy for leisure activities, hobbies or socializing					
I believe I *could* focus on the positive when I'm feeling down					
I believe I *could* use relaxation to deal with worries					
I believe I *could* allocate time for relaxation					
I believe I *could* use a relaxation tape or instructions to help me relax					
I believe I *could* use regular exercise					
I believe I *could* be aware of my limits in exercise					
I believe I *could* manage my medication, knowing how and when to take it					
I believe I *could* look out for and avoid side-effects of my medication					
I believe I *could* seek help with persistent side-effects					

Instructions: Each item below is a belief statement about your inflammatory arthritis with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6).

Multidimensional HLOC scale

For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher the number you circle. The more you disagree with a statement, the lower the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

	Strongly disagree	**Moderately disagree**	**Slightly disagree**	**Slightly agree**	**Moderately agree**	**Strongly agree**
If my arthritis worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6
As to my arthritis, what will be will be.	1	2	3	4	5	6
If I see my doctor regularly, I am less likely to have problems with my arthritis.	1	2	3	4	5	6
Most things that affect my arthritis happen to me by chance.	1	2	3	4	5	6
Whenever my arthritis worsens, I should consult a medically trained professional.	1	2	3	4	5	6
I am directly responsible for my arthritis getting better or worse.	1	2	3	4	5	6
Other people play a big role in whether my arthritis	1	2	3	4	5	6

improves, stays the same, or gets worse.						
Whatever goes wrong with my arthritis is my own fault.	1	2	3	4	5	6
Luck plays a big part in determining how my arthritis improves.	1	2	3	4	5	6
In order for my arthritis to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
Whatever improvement occurs with my arthritis is largely a matter of good fortune.	1	2	3	4	5	6
The main thing which affects my arthritis is what I myself do.	1	2	3	4	5	6
I deserve the credit when my arthritis improves and the blame when it gets worse.	1	2	3	4	5	6
Following doctor's orders to the letter is the best way to keep my arthritis from getting any worse.	1	2	3	4	5	6
If my arthritis worsens, it's a matter of fate.	1	2	3	4	5	6
If I am lucky, my arthritis will get better.	1	2	3	4	5	6
If my arthritis takes a turn for the worse, it is because	1	2	3	4	5	6

I have not been taking proper care of myself.						
The type of help I receive from other people determines how soon my arthritis improves.	1	2	3	4	5	6

Brief Illness Perception Questionnaire (BIPQ)

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all										understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

0	1	2	3	4	5	6	7	8	9	10
not at all affected emotionally										extremely affected emotionally

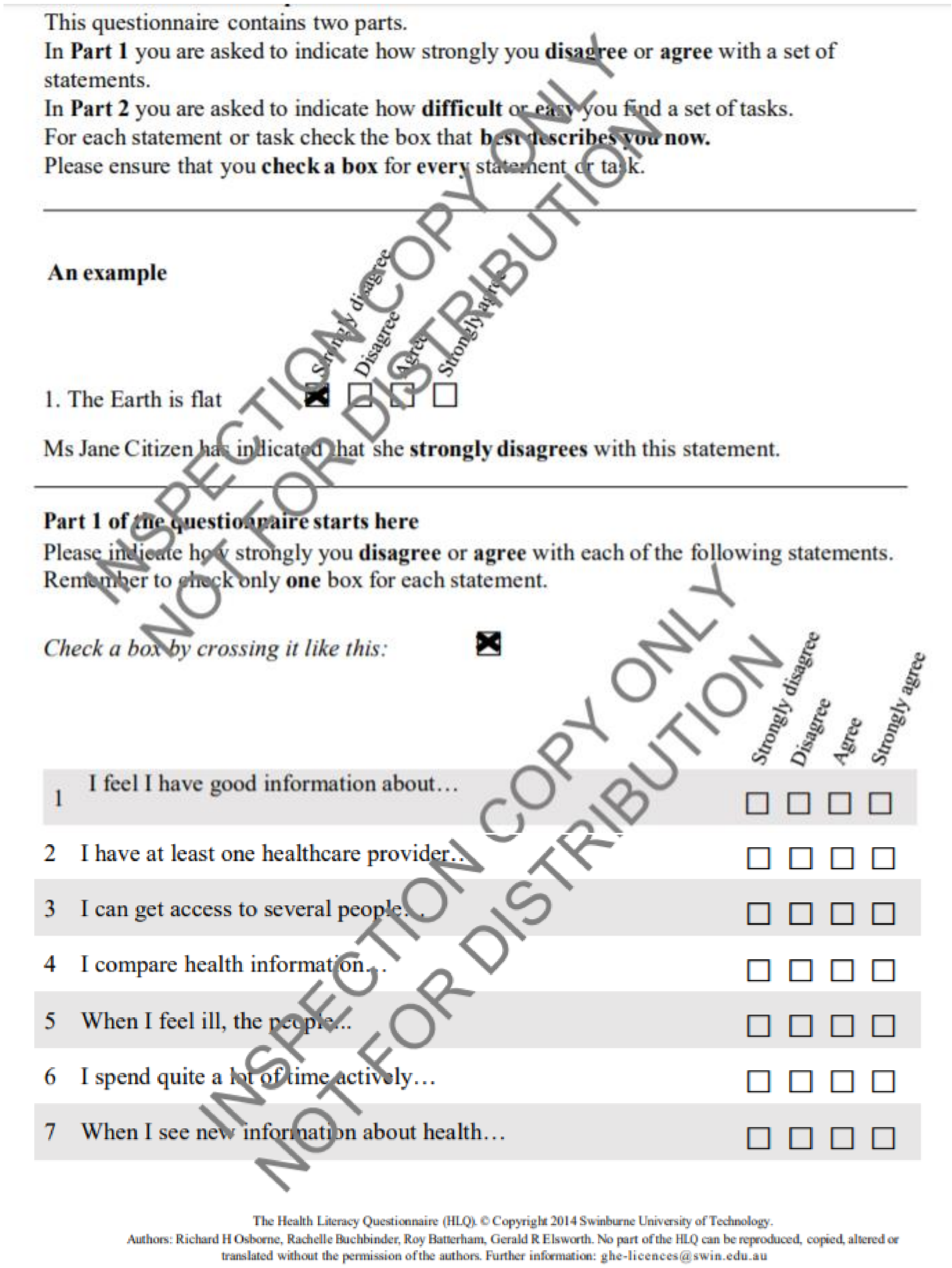
Please list in rank-order the three most important factors that you believe caused your illness. ***The most important causes for me:-***

1. ____________________________________

2. ____________________________________

3. ____________________________________

Health Literacy Questionnaire (HLQ)



This questionnaire contains two parts.
In **Part 1** you are asked to indicate how strongly you **disagree** or **agree** with a set of statements.
In **Part 2** you are asked to indicate how **difficult** or **easy** you find a set of tasks.
For each statement or task check the box that **best describes you now.**
Please ensure that you **check a box** for **every** statement or task.

An example

	Strongly disagree	Disagree	Agree	Strongly agree
1. The Earth is flat	☒	☐	☐	☐

Ms Jane Citizen has indicated that she **strongly disagrees** with this statement.

Part 1 of the questionnaire starts here

Please indicate how strongly you **disagree** or **agree** with each of the following statements.
Remember to check only **one** box for each statement.

Check a box by crossing it like this: ☒

		Strongly disagree	*Disagree*	*Agree*	*Strongly agree*
1	I feel I have good information about…	☐	☐	☐	☐
2	I have at least one healthcare provider…	☐	☐	☐	☐
3	I can get access to several people…	☐	☐	☐	☐
4	I compare health information…	☐	☐	☐	☐
5	When I feel ill, the people…	☐	☐	☐	☐
6	I spend quite a lot of time actively…	☐	☐	☐	☐
7	When I see new information about health…	☐	☐	☐	☐

Please indicate how strongly you **disagree** or **agree** with each of the following statements. Remember to check only **one** box for each statement.

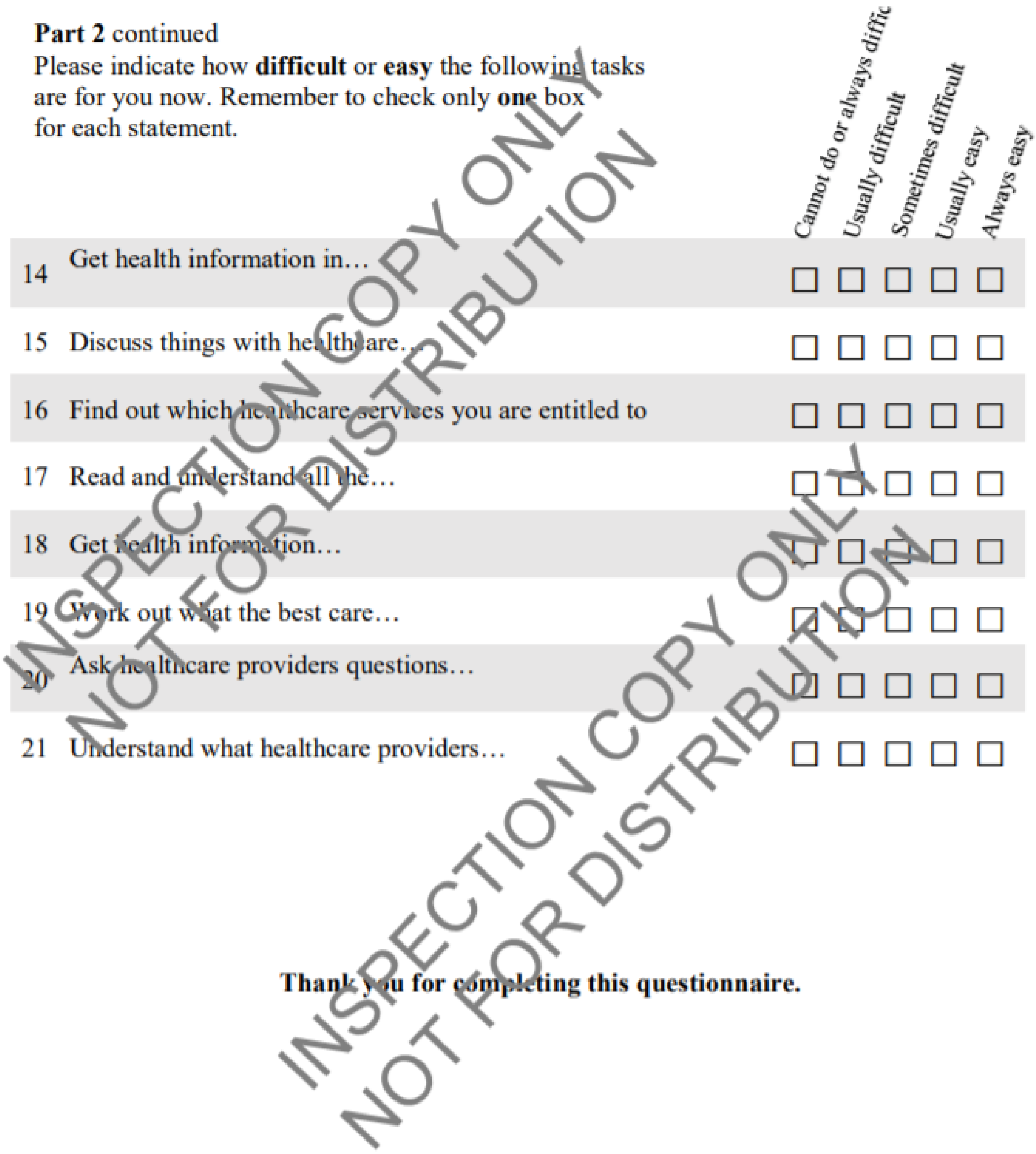
		Strongly disagr	Disagree	Agree	Strongly agree
8	I have at least one healthcare provider…	☐	☐	☐	☐
9	I make plans for what I need to do to…	☐	☐	☐	☐
10	I have enough information to help me…	☐	☐	☐	☐
11	If I need help, I have plenty of…	☐	☐	☐	☐
12	I always compare health information…	☐	☐	☐	☐
13	Despite other things in my life, I make time to be healthy	☐	☐	☐	☐
14	I am sure I have all the information I need…	☐	☐	☐	☐
15	I have at least one person who can come to medical appointments with me	☐	☐	☐	☐
16	I know how to find out if the health information I receive…	☐	☐	☐	☐
17	I have the healthcare providers I need to help me…	☐	☐	☐	☐
18	I set my own goals…	☐	☐	☐	☐
19	I have strong support from family…	☐	☐	☐	☐
20	I ask healthcare providers about…	☐	☐	☐	☐
21	There are things that I do regularly…	☐	☐	☐	☐
22	I can rely on at least one healthcare provider	☐	☐	☐	☐
23	I have all the information I need…	☐	☐	☐	☐

Please continue to the next page.

Part 2 of the questionnaire starts here
Please indicate how **difficult** or **easy** the following tasks are for you **now.** Remember to check only **one** box for each statement.

Check a box by crossing it like this: ☒

		Cannot do or always difficult	*Usually difficult*	*Sometimes difficult*	*Usually easy*	*Always easy*
1	Find the right…	☐	☐	☐	☐	☐
2	Make sure that healthcare providers…	☐	☐	☐	☐	☐
3	Find information about…	☐	☐	☐	☐	☐
4	Feel able to discuss your health…	☐	☐	☐	☐	☐
5	Confidently fill medical forms in…	☐	☐	☐	☐	☐
6	Find health information from several different places	☐	☐	☐	☐	☐
7	Have good discussions about…	☐	☐	☐	☐	☐
8	Get to see the healthcare providers you need to…	☐	☐	☐	☐	☐
9	Accurately follow instructions…	☐	☐	☐	☐	☐
10	Get information about health so you…	☐	☐	☐	☐	☐
11	Decide which healthcare provider…	☐	☐	☐	☐	☐
12	Read and understand…	☐	☐	☐	☐	☐
13	Make sure you find the right place…	☐	☐	☐	☐	☐



Part 2 continued
Please indicate how **difficult** or **easy** the following tasks are for you now. Remember to check only **one** box for each statement.

		Cannot do or always diffic	Usually difficult	Sometimes difficult	Usually easy	Always easy
14	Get health information in…	☐	☐	☐	☐	☐
15	Discuss things with healthcare…	☐	☐	☐	☐	☐
16	Find out which healthcare services you are entitled to	☐	☐	☐	☐	☐
17	Read and understand all the…	☐	☐	☐	☐	☐
18	Get health information…	☐	☐	☐	☐	☐
19	Work out what the best care…	☐	☐	☐	☐	☐
20	Ask healthcare providers questions…	☐	☐	☐	☐	☐
21	Understand what healthcare providers…	☐	☐	☐	☐	☐

Thank you for completing this questionnaire.

Bristol Rheumatoid Arthritis Fatigue scale (BRAF) NRS

Fatigue Rating Scale

1. Please circle the number which shows your average level of fatigue during the past 7 days

No fatigue 0 1 2 3 4 5 6 7 8 9 10 Totally
exhausted

2. Please circle the number which shows the effect fatigue has had on your life during the past 7 days

No effect 0 1 2 3 4 5 6 7 8 9 10 A great deal of
effect

3. Please circle the number which shows how well you have coped with fatigue over the past 7 days

Not at 0 1 2 3 4 5 6 7 8 9 10 Very well
all well

Pain Rating Scale

1. Please rate your pain by circling the one number that best describes your pain at its **worst** in the last week

No pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you
can imagine

2. Please rate your pain by circling the one number that best describes your pain on the **average** in the last week

No pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you
can imagine

Positive and Negative Affect Scale (PANAS)

This scale consists of a number of words that describe different feelings and emotions. Read each item and then enter the appropriate number in the space next to that word. Indicate to what extent you feel this way on average:

1	2	3	4	5
Very slightly or not at all	A little	Moderately	Quite a bit	Extremely

_____ interested	_____ irritable
_____ distressed	_____ alert
_____ excited	_____ ashamed
_____ upset	_____ inspired
_____ strong	_____ nervous
_____ guilty	_____ determined
_____ scared	_____ attentive
_____ hostile	_____ jittery
_____ enthusiastic	_____ active
_____ proud	_____ afraid

There will be another survey to complete in 9 months' time. If you are happy to receive this, **please tick this box** and we will organise to send the survey out to you. This means that you give permission for the research team to access your address via your rheumatology team. We will only send you the second survey if you tick the box to confirm that you are happy to receive it: ☐

Thank you for taking the time to complete the survey. Please return it to the research team in Bristol using the prepaid envelope.

If you have any questions please feel free to contact the research team at any time using the details on the front page of this survey.

Appendix Q: Follow-up survey pack for quantitative study

How people manage their health conditions: A survey study

Follow-up Survey

Thank you for agreeing to take part in this study, and for completing the first survey last year. Your answers are confidential to the researchers, and we are interested in everybody's views. If you have been diagnosed with more than one health condition, we ask that you answer these questionnaires thinking about your rheumatology condition.

Some of the questions in this survey may seem repetitive. This is because I am using a number of established questionnaires that cannot be changed. Please answer all the questions in the survey.

Bristol research team contact:

Bethan Jones

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0117 342 7415

A) This section asks about your usual ABILITIES over the PAST WEEK

(Please tick)

	Without ANY difficulty	**With SOME difficulty**	**With MUCH difficulty**	**Unable to do**
1. DRESSING AND GROOMING Are you able to:				
- Dress yourself, including tying shoelaces and doing buttons?	_________	_________	_________	_________
- Shampoo your hair?	_________	_________	_________	_________
2. RISING Are you able to:				
- Stand up from an armless straight chair?	_________	_________	_________	_________
-Get in and out of bed?	_________	_________	_________	_________
3. EATING Are you able to:				
- Cut your meat?	_________	_________	_________	_________
- Lift a full cup or glass to your mouth?	_________	_________	_________	_________
- Open a new carton of milk (or soap powder)?	_________	_________	_________	_________
4. WALKING Are you able to:				
- Walk outdoors on flat ground?	_________	_________	_________	_________
- Climb up five steps?	_________	_________	_________	_________

Please tick any aids or devices that you usually use for any of these activities:

_____ Cane
_____ Walking frame
_____ Crutches
_____ Wheelchair

_____ Devices used for dressing (button hook, zipper pull, long handled shoe horn etc)
_____ Built-up or special utensils
_____ Special or built-up chair

Other: ____ (Please specify)

Please tick any categories for which you usually need help from another person:

_____ Dressing and grooming _____ Eating _____ Rising
_____ Walking

	Without ANY difficulty	**With SOME difficulty**	**With MUCH difficulty**	**Unable to do**
5. HYGIENE Are you able to:				
- Wash and dry your entire body?	________	________	________	________
- Take a bath?	________	________	________	________
- Get on and off the toilet?	________	________	________	________
6. REACH Are you able to:				
- Reach and get down a 5lb object (e.g. a bag of potatoes) from just above your head?	________	________	________	________
- Bend down to pick up clothing from the floor?	________	________	________	________
7. GRIP Are you able to:				
- Open car doors?	________	________	________	________
- Open jars which have been previously opened?	________	________	________	________
- Turn taps on and off?	________	________	________	________
8. ACTIVITIES Are you able to:				
- Run errands and shop?	________	________	________	________
- Get in and out of a car?	________	________	________	________
- Do chores such as vacuuming, housework or light gardening?	________	________	________	________

Please tick any aids or devices that you usually use for any of these activities:

_____ Raised toilet seat
_____ Bath seat
_____ Jar opener (for jars previously opened)
_____ Bath rail
_____ Long handled appliances for reach

Other: ____ (Please specify)

Please tick any categories for which you usually need help from another person:

_____ Hygiene
_____ Reach
_____ Gripping and opening things
_____ Errands and housework

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. There are no right or wrong answers, just what is true for you. If the statement does not apply to you, circle N/A.

1. I am the person who is responsible for taking care of my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I am confident I can help prevent or reduce problems associated with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I know what each of my prescribed medications do.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I am confident that I can carry out medical treatments I may need to do at home.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I know what treatments are available for my health problems.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I have been able to maintain lifestyle changes, like healthy eating or exercising.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11. I know how to prevent problems with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12. I am confident I can work out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13. I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

We are interested in finding out what things you believe you could do to help you with your arthritis. We want to know what you think you **could** do, even if you are not actually doing it at the moment. Please tick one column for each question.

Do you believe you **could** do these things to help you with your arthritis?

	Strongly disagree	**Disagree**	**Neither disagree nor agree**	**Agree**	**Strongly agree**
I believe I *could* use relaxation techniques to help with pain					
I believe I *could* think about something else to help with pain					
I believe I *could* use my joints carefully (joint protection) to help with pain					
I believe I *could* think positively to help with pain					
I believe I *could* avoid doing things that cause pain					
I believe I *could* wind down and relax before going to bed, to improve my sleep					
I believe I *could* have a hot drink before bed, to improve my sleep					
I believe I *could* use relaxation before bed, to improve my sleep					
I believe I *could* pace myself and take my arthritis into account to help deal with tiredness					
I believe I *could* accept fatigue as part of my arthritis					
I believe I *could* use gadgets to help with mobility, household tasks or personal care					
I believe I *could* ask for help to deal with the difficulties of doing everyday tasks					
I believe I *could* do exercises to deal with					

the difficulties of doing everyday tasks					
	Strongly disagree	**Disagree**	**Neither disagree nor agree**	**Agree**	**Strongly agree**
I believe I *could* plan or prioritise my day to deal with difficulties of doing everyday tasks					
I believe I *could* educate my family and friends about my arthritis to help with the strains that arthritis can make on relationships					
I believe I *could* explain to friends and family when I do or don't need help					
I believe I *could* discuss any problems with my partner or family					
I believe I *could* make time for leisure activities, hobbies or socializing					
I believe I *could* save energy for leisure activities, hobbies or socializing					
I believe I *could* focus on the positive when I'm feeling down					
I believe I *could* use relaxation to deal with worries					
I believe I *could* allocate time for relaxation					
I believe I *could* use a relaxation tape or instructions to help me relax					
I believe I *could* use regular exercise					
I believe I *could* be aware of my limits in exercise					

I believe I *could* manage my medication, knowing how and when to take it					
I believe I *could* look out for and avoid side-effects of my medication					
I believe I *could* seek help with persistent side-effects					

Instructions: Each item below is a belief statement about your inflammatory arthritis with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6).

For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher the number you circle. The more you disagree with a statement, the lower the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
If my arthritis worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6
As to my arthritis, what will be will be.	1	2	3	4	5	6
If I see my doctor regularly, I am less likely to have problems with my arthritis.	1	2	3	4	5	6
Most things that affect my arthritis happen to me by chance.	1	2	3	4	5	6
Whenever my arthritis worsens, I should consult a medically trained professional.	1	2	3	4	5	6
I am directly responsible for my arthritis getting better or worse.	1	2	3	4	5	6
Other people play a big role in whether my arthritis improves, stays the same, or gets worse.	1	2	3	4	5	6
Whatever goes wrong with my arthritis is my own fault.	1	2	3	4	5	6
Luck plays a big part in determining how my arthritis improves.	1	2	3	4	5	6
In order for my arthritis to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6

Whatever improvement occurs with my arthritis is largely a matter of good fortune.	1	2	3	4	5	6
The main thing which affects my arthritis is what I myself do.	1	2	3	4	5	6
I deserve the credit when my arthritis improves and the blame when it gets worse.	1	2	3	4	5	6
Following doctor's orders to the letter is the best way to keep my arthritis from getting any worse.	1	2	3	4	5	6
If my arthritis worsens, it's a matter of fate.	1	2	3	4	5	6
If I am lucky, my arthritis will get better.	1	2	3	4	5	6
If my arthritis takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
The type of help I receive from other people determines how soon my arthritis improves.	1	2	3	4	5	6

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all										understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

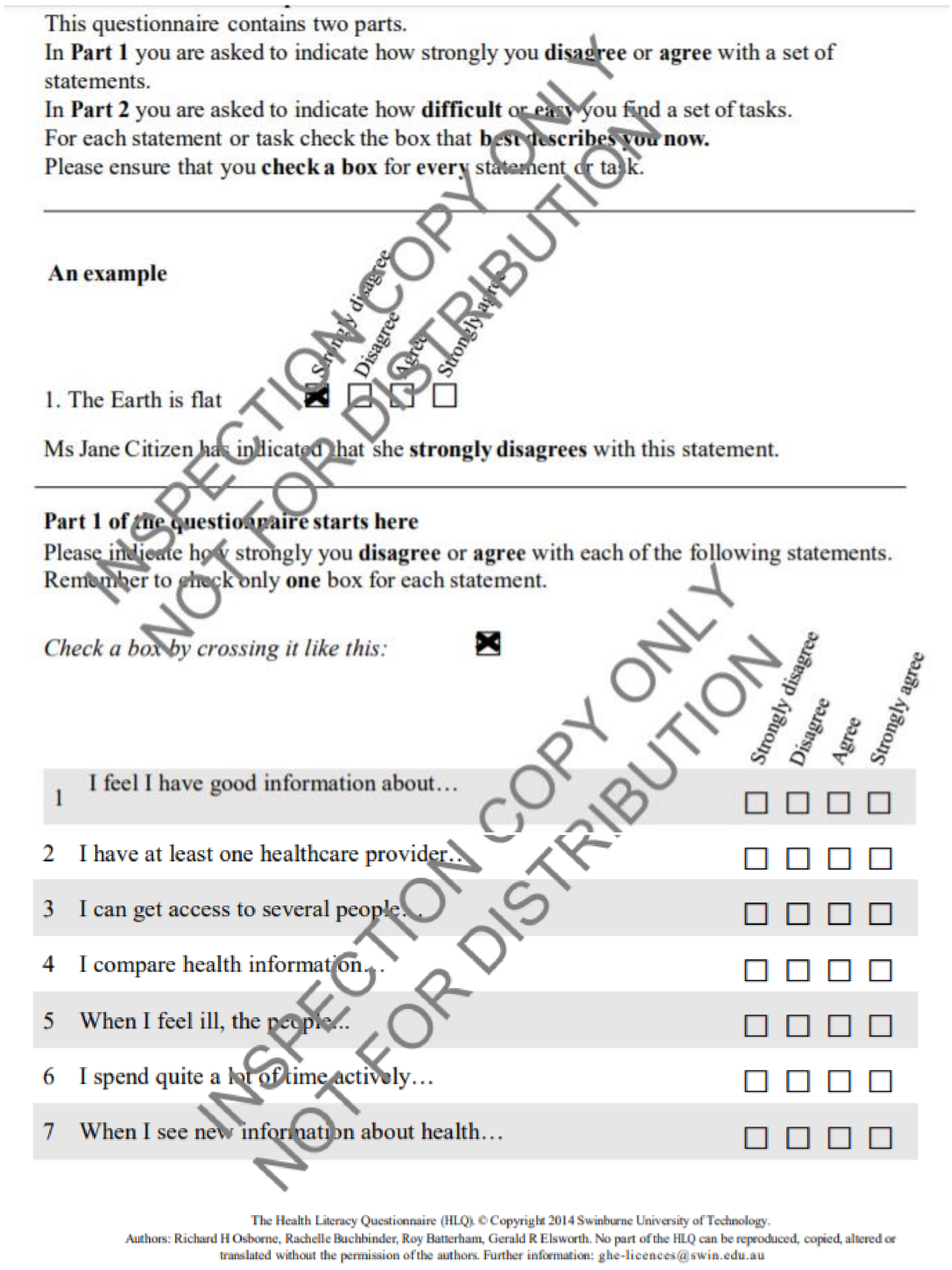
0	1	2	3	4	5	6	7	8	9	10
not at all affected emotionally										extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your illness. *The most important causes for me:-*

1. ______________________________

2. ______________________________

3. ______________________________



This questionnaire contains two parts.
In **Part 1** you are asked to indicate how strongly you **disagree** or **agree** with a set of statements.
In **Part 2** you are asked to indicate how **difficult** or **easy** you find a set of tasks.
For each statement or task check the box that **best describes you now.**
Please ensure that you **check a box** for **every** statement or task.

An example

	Strongly disagree	Disagree	Agree	Strongly agree
1. The Earth is flat	☒	☐	☐	☐

Ms Jane Citizen has indicated that she **strongly disagrees** with this statement.

Part 1 of the questionnaire starts here

Please indicate how strongly you **disagree** or **agree** with each of the following statements.
Remember to check only **one** box for each statement.

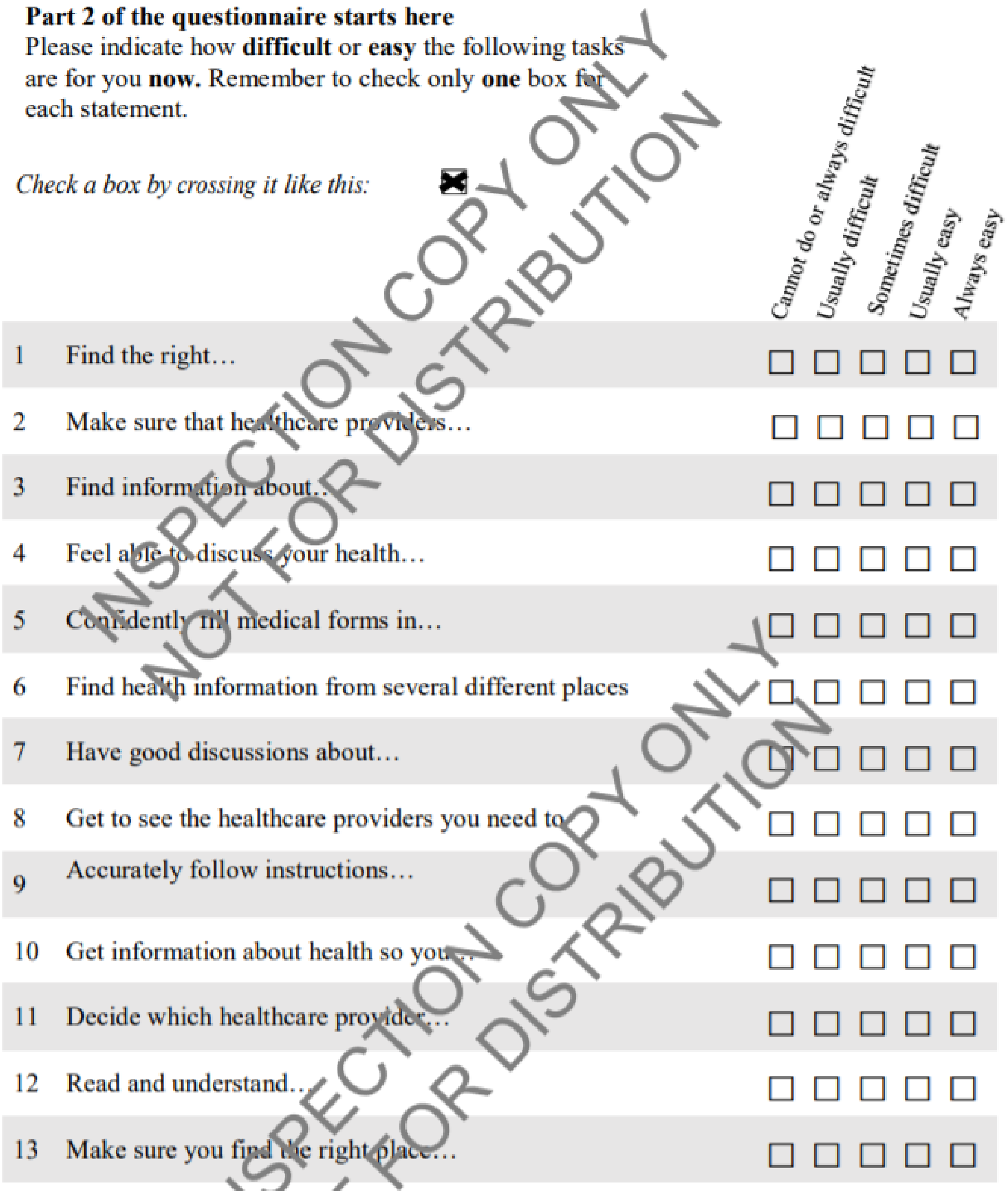
Check a box by crossing it like this: ☒

		Strongly disagree	Disagree	Agree	Strongly agree
1	I feel I have good information about…	☐	☐	☐	☐
2	I have at least one healthcare provider…	☐	☐	☐	☐
3	I can get access to several people…	☐	☐	☐	☐
4	I compare health information…	☐	☐	☐	☐
5	When I feel ill, the people…	☐	☐	☐	☐
6	I spend quite a lot of time actively…	☐	☐	☐	☐
7	When I see new information about health…	☐	☐	☐	☐

Please indicate how strongly you **disagree** or **agree** with each of the following statements. Remember to check only **one** box for each statement.

		Strongly disagr	Disagree	Agree	Strongly agree
8	I have at least one healthcare provider…	☐	☐	☐	☐
9	I make plans for what I need to do to…	☐	☐	☐	☐
10	I have enough information to help me…	☐	☐	☐	☐
11	If I need help, I have plenty of…	☐	☐	☐	☐
12	I always compare health information…	☐	☐	☐	☐
13	Despite other things in my life, I make time to be healthy	☐	☐	☐	☐
14	I am sure I have all the information I need…	☐	☐	☐	☐
15	I have at least one person who can come to medical appointments with me	☐	☐	☐	☐
16	I know how to find out if the health information I receive…	☐	☐	☐	☐
17	I have the healthcare providers I need to help me…	☐	☐	☐	☐
18	I set my own goals…	☐	☐	☐	☐
19	I have strong support from family…	☐	☐	☐	☐
20	I ask healthcare providers about…	☐	☐	☐	☐
21	There are things that I do regularly…	☐	☐	☐	☐
22	I can rely on at least one healthcare provider	☐	☐	☐	☐
23	I have all the information I need…	☐	☐	☐	☐

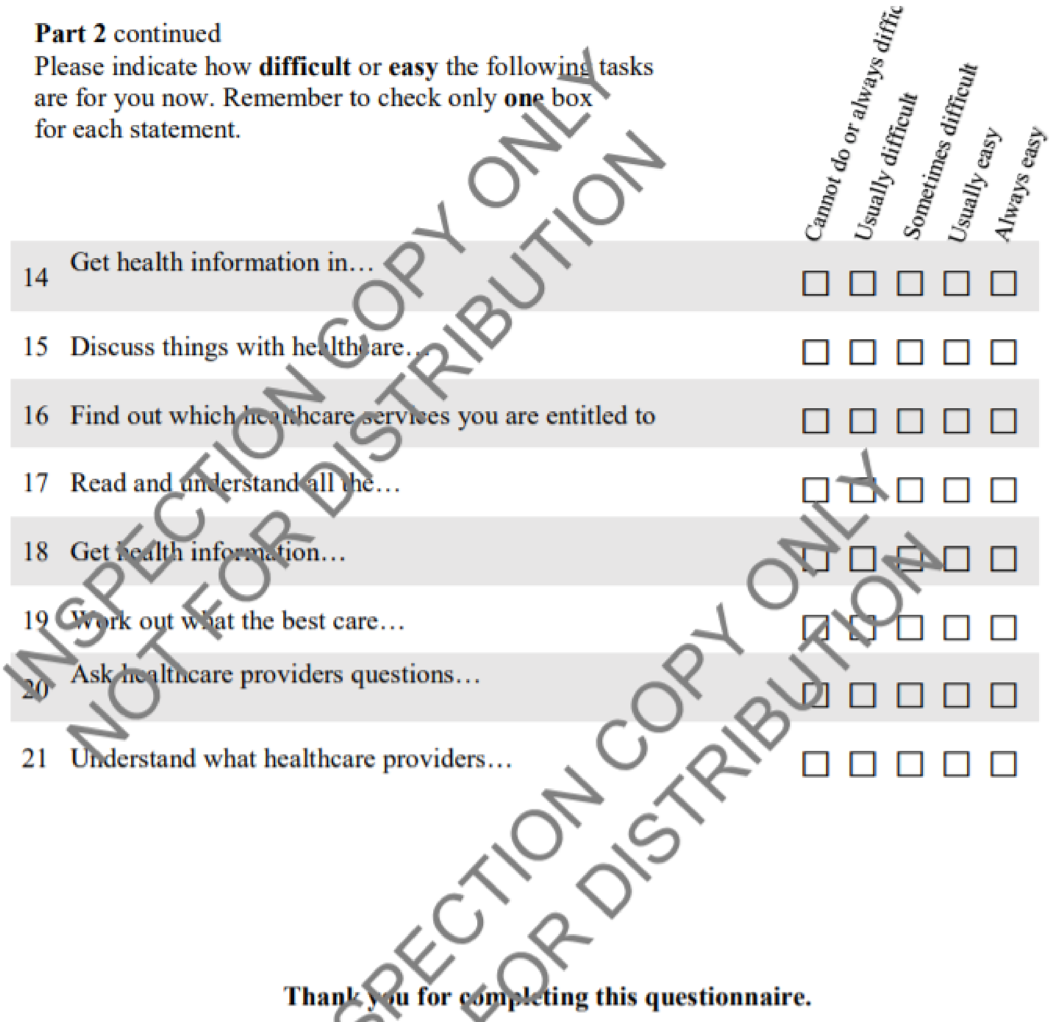
Please continue to the next page.



Part 2 of the questionnaire starts here
Please indicate how **difficult** or **easy** the following tasks are for you **now.** Remember to check only **one** box for each statement.

Check a box by crossing it like this: ☒

		Cannot do or always difficult	*Usually difficult*	*Sometimes difficult*	*Usually easy*	*Always easy*
1	Find the right…	☐	☐	☐	☐	☐
2	Make sure that healthcare providers…	☐	☐	☐	☐	☐
3	Find information about…	☐	☐	☐	☐	☐
4	Feel able to discuss your health…	☐	☐	☐	☐	☐
5	Confidently fill medical forms in…	☐	☐	☐	☐	☐
6	Find health information from several different places	☐	☐	☐	☐	☐
7	Have good discussions about…	☐	☐	☐	☐	☐
8	Get to see the healthcare providers you need to	☐	☐	☐	☐	☐
9	Accurately follow instructions…	☐	☐	☐	☐	☐
10	Get information about health so you…	☐	☐	☐	☐	☐
11	Decide which healthcare provider…	☐	☐	☐	☐	☐
12	Read and understand…	☐	☐	☐	☐	☐
13	Make sure you find the right place…	☐	☐	☐	☐	☐



Part 2 continued
Please indicate how **difficult** or **easy** the following tasks are for you now. Remember to check only **one** box for each statement.

		Cannot do or always diffic	*Usually difficult*	*Sometimes difficult*	*Usually easy*	*Always easy*
14	Get health information in…	☐	☐	☐	☐	☐
15	Discuss things with healthcare…	☐	☐	☐	☐	☐
16	Find out which healthcare services you are entitled to	☐	☐	☐	☐	☐
17	Read and understand all the…	☐	☐	☐	☐	☐
18	Get health information…	☐	☐	☐	☐	☐
19	Work out what the best care…	☐	☐	☐	☐	☐
20	Ask healthcare providers questions…	☐	☐	☐	☐	☐
21	Understand what healthcare providers…	☐	☐	☐	☐	☐

Thank you for completing this questionnaire.

Fatigue Rating Scale

1. Please circle the number which shows your average level of fatigue during the past 7 days

No fatigue 0 1 2 3 4 5 6 7 8 9 10 Totally exhausted

2. Please circle the number which shows the effect fatigue has had on your life during the past 7 days

No effect 0 1 2 3 4 5 6 7 8 9 10 A great deal of effect

3. Please circle the number which shows how well you have coped with fatigue over the past 7 days

Not at all well 0 1 2 3 4 5 6 7 8 9 10 Very well

Pain Rating Scale

3. Please rate your pain by circling the one number that best describes your pain at its **worst** in the last week

No pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain on the **average** in the last week

No pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine

This scale consists of a number of words that describe different feelings and emotions. Read each item and then enter the appropriate number in the space next to that word. Indicate to what extent you feel this way on average:

1	2	3	4	5
Very slightly or not at all	A little	Moderately	Quite a bit	Extremely

_____ interested	_____ irritable
_____ distressed	_____ alert
_____ excited	_____ ashamed
_____ upset	_____ inspired
_____ strong	_____ nervous
_____ guilty	_____ determined
_____ scared	_____ attentive
_____ hostile	_____ jittery
_____ enthusiastic	_____ active
_____ proud	_____ afraid

If you would like to receive a summary of the study results, **please tick this box** and we will organise to send one to you. We will only send this if you tick the box to confirm that you are happy with this:

☐

Thank you for taking the time to complete these questionnaires. Please return these to the research team in Bristol using the prepaid envelope in the question.

If you have any questions please feel free to contact the research team at any time using the details on your information sheet.

Appendix R: Quantitative study protocol

How people manage their health conditions: A survey study
Protocol – 5th April 2018 (Version 1)

Principal Investigator
Bethan Jones PhD student, University of the West of England (UWE), Bristol

Project team members

Emma Dures	Associate Professor in Rheumatology and Self-Management, UWE, Bristol
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Diana Harcourt	Professor of Appearance & Health Psychology, UWE, Bristol
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Funded by a PhD Scholarship by Arthritis Research UK.

Glossary:

IA	Inflammatory arthritis
PAM	Patient Activation Measure
UWE	University of the West of England, Bristol
UHB	University Hospitals Bristol

Summary of the study:

Inflammatory arthritis (IA) describes several long term conditions including rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, connective tissue disease and systemic lupus erythematosus (Arthritis Research UK, 2016). These conditions impact people in a variety of physical and psychosocial ways, commonly requiring significant life adaptations to cope with the diagnosis. Some of the consequences of IA include pain and fatigue, reduced mobility, low mood, increased anxiety, and unpredictable fluctuations or "flares" in disease activity and symptoms (Homer, 2005). IA is generally managed in secondary care settings with specialist rheumatology teams, with an overall focus on managing the physical symptoms and reducing joint damage and disease activity (Gettings, 2010; National Audit Office, 2009).

Research indicates that there are a variety of factors that contribute to how engaged someone becomes in managing their health, and one of these is a concept called patient activation (Hibbard et al., 2004). It is defined as how willing and able someone is to take an active role in dealing with their health (Hibbard and Greene, 2013). Higher levels of patient activation are associated with fewer emergency hospital admissions, fewer days as an inpatient and lower healthcare costs (Hibbard et al., 2015). Therefore, there is a value in understanding activation to reduce strain on the NHS. For individuals, people who are more activated are also more likely to adhere to their treatment schedules, and have better outcomes overall (McCusker et al., 2016).

However, little is known about the dimensions and factors involved in patient activation in the context of people with arthritis, and ways in which they might change over time. Consequently, activation is considered to be one of the lesser-understood concepts in self-management research (Roberts et al., 2016). The PI has previously conducted a qualitative study to identify potential variables associated with activation. The PI would now like to look at these associations in a large sample, over time.

The study will provide an opportunity to look at patient activation scores (captured using the Patient Activation Measure) plus a range of demographic, clinical and psychosocial factors in a large sample of people with IA. These data will be collected with the same sample, at two timepoints, enabling analysis of changes over time. Data analysis will examine the relationship between these psychosocial factors, as well as other demographic factors to understand what may have an impact on patient activation. The purpose of repeating the questionnaires later are to identify whether patient activation changes over time in this population, and to explore whether constructs that were related at phase one continue to be related at phase two.

This study (funded as part of a PhD scholarship from Arthritis Research UK) will contribute to the development of a framework to describe patient activation in IA. Having a framework to describe patient activation in people with IA offers the opportunity for a theory-driven intervention to support people in taking the next step to actively manage their health condition. This study will help to ensure that any future intervention is focused sufficiently on rheumatology related contextual factors to suit people living with IA.

The main aim of the study is to describe associations between patient activation (measured using the PAM) and a range of clinical, demographic and psychosocial variables.

The study objectives are:

To examine the relationship between PAM scores and other related constructs and demographic characteristics
To identify levels of activation in a cross-section of people with IA
To examine changes in PAM scores in a cross-section of people with IA
To explore and map changes to these scores over time.

Background:
Models of illness have an impact on the way that care is delivered to people living with long term health conditions. The previously dominant biomedical model has been criticised for not considering the impact of other social, psychological and behavioural factors that can contribute to people's experience of living with health conditions (Wade & Halligan, 2004). This can imply that people are passive in their experiences, and doesn't consider how people can influence their health.

Because of these criticisms, the biopsychosocial model has encompassed these additional factors which can contribute to outcomes (Engel, 1977) and describe people's experiences in a more holistic way. This shift gives people with long term conditions more of a position as experts in living with their health condition with more responsibility to self-manage their condition. People are expected to develop skills to manage their illness, become more involved in making decisions about their condition in collaboration with health care professionals, and develop knowledge about behaviours which help manage their health (Hibbard, Stockard, Mahoney & Tusler, 2004).

Research indicates that there are a variety of factors that contribute to how engaged someone becomes in managing their health, and one of these is a concept called patient activation (Hibbard et al., 2004). It is defined as being how willing and able someone is to take an active role in dealing with their health (Hibbard and Greene, 2013). It appears to be a multidimensional construct, incorporating associated concepts such as self-management behaviours, health literacy, and self-efficacy (the belief in one's ability to achieve a desired outcome) (Hibbard et al., 2004; Do, Young, Barnason & Tran, 2015).

Higher levels of activation are associated with fewer emergency admissions, fewer days as an inpatient and lower healthcare costs (Hibbard et al., 2015). Therefore, there is a value in understanding activation to benefit a resource-scarse NHS. On an individual level, increased activation is associated with greater adherence to treatment schedules and better outcomes overall (McCusker et al., 2016). In the context of IA, activation might also involve behaviours such as regular stretching to reduce stiffness, having and acting on a plan for when their condition flares up, and managing stress levels by scheduling in time to practice relaxation techniques (Dixon, Hibbard and Tusler, 2009).

The dominant model of explaining activation is captured in the extensively used "Patient Activation Measure" (PAM) (Hibbard et al., 2004), with the PAM described as identifying the beliefs that people have about themselves and the responsibility they hold for managing their health (Hibbard & Mahoney, 2010). A licence is required to use the PAM in research, and this has already been obtained for the research study.

The PAM and the underpinning model describe activation as involving four stages, each building on the other in a hierarchy (Hibbard et al., 2004). Hibbard proposes that people become more able to develop through the stages and become more able to engage in more complex behaviours as they become more activated (Hibbard et al., 2015). While it is believed that providing information alone is not sufficient to activate patients (Rix and Martin, 2015), factors which do contribute to increasing people's confidence and ability to actively manage their health are less understood.

However, little is known about the dimensions and factors involved in patient activation in the context of people with arthritis. There has also been limited longitudinal research focused on patient activation in a rheumatology context and it is considered to be one of the lesser-understood concepts in self-management research (Roberts et al., 2016). A survey to understand and map patient activation scores, therefore, can complement the qualitative research study to contribute to the understanding of patient activation and its progression, or otherwise, over time,

The study will provide an opportunity to look at patient activation scores (captured using the Patient Activation Measure) plus a range of demographic, clinical and psychosocial factors in a large sample of people with IA. These data will be collected with the same sample, at two timepoints, enabling analysis of changes over time. Data analysis will examine the relationship between these psychosocial factors, as well as other demographic factors in order to understand what may have an impact on patient activation. The purpose of repeating the questionnaires at a later date are to identify whether patient activation changes over time in this population, and to explore whether constructs that were related at phase one continue to be related at phase two.

Design and methods:
The study design is longitudinal and will include two phases, using quantitative methods of data collection and analysis. The study requires NHS Research Ethics (REC), Health Research Authority and university ethics, and local research governance approvals in a combined application before data collection can commence. The research has been designed following consultation with patient research partners, a statistician, and the chief investigator's supervisory team to ensure scientific rigour and potential benefit to the patient population.

Phase 1:
Recruitment and Sampling:
People will be eligible to take part if they are:
Over 18 years old
Living with a diagnosis of IA
A patient at one of the collaborating units
Able to provide informed consent to participate
Able to communicate, read and write in English

The intention is to ensure a range of patients (i.e. age, gender and disease duration) are represented in this study. However there is the potential for this diversity to not be reflected in the participant characteristics. In order to access as broad a range of people as possible, recruitment will take place at six rheumatology units throughout England. The units have been selected to cover diverse geographical locations, urban and rural communities, ethnically and socioeconomically diverse areas, and the size and scope of the rheumatology department. The inclusion criteria are also deliberately broad to ensure as many interested patients as possible can participate.

The collaborating rheumatology units across hospitals in England are:
Bristol Royal Infirmary, Bristol
Haywood Hospital, Stoke-On-Trent
Weston General Hospital, Weston-Super-Mare
Torbay Hospital, Torquay
Northumbria
St Peter’s Hospital, Chertsey

Eligible patients will be given a study information pack when they attend for an outpatient clinic appointment, or sent the pack through the post. This information pack will contain an invitation to participate from the local clinical lead, a Patient Information Sheet, a consent form, the questionnaires, a reply slip and a reply-paid envelope. Approximately 700 survey packs will be provided across all sites (i.e. 100-120 per site), assuming an estimated return rate of 50%. This estimation is based on similar postal surveys following these methods that have been used previously in rheumatology (Sanderson *et al.*, 2010).

Data Collection:

An estimated total of 350 datasets will be collected across the six sites. This target sample size is based on the Draper & Smith (1998) guidance that there should be at least 10 participants for each independent variable being measured, and to gather a sufficient number of participants for a thorough analysis. Potential participants will be asked to read the information sheet, which will have information about how to contact the research team to ask any questions they may have, or to request further information. Providing they would like to participate, they will be asked on the information sheet to sign the consent form and complete the questionnaires. Participants will have the option of completing these in clinic or at home, then posting them back to the central study team in Bristol using the reply-paid envelope.

The survey packs will all be labelled with unique pack numbers. Each local unit will keep a record of which patients have been handed which survey pack number. The Bristol team will inform each collaborating centre of which surveys have not been returned.

The measures in the survey pack have been chosen for a variety of reasons, including their psychometric properties, prior use with people with rheumatic conditions, and the briefest version has been selected where possible to reduce participant burden.

The measures in the survey pack will include:

Demographic information about participants – sex, age, ethnicity, rheumatic condition and disease duration.

Health Assessment Questionnaire (HAQ) (Fries et al., 1980):

The disability component of the HAQ will capture participants' level of disability, and the impact that the rheumatic condition has on participants' level of function.

Patient Activation Measure: Short form (PAM) (Hibbard et al., 2005):

The PAM is a commercially-licenced questionnaire designed to capture patient activation over 13 items and categorise patients into one of four activation levels ranging from 1 (passive) to 4 (actively managing their health). It is the most widely used measure to capture patient activation, having been used internationally and translated into a wide range of languages (Hibbard, Greene and Tusler, 2009). The PAM will be the dependent variable for the data analysis.

Rheumatoid Arthritis Self Efficacy Scale (RASE) (Hewlett et al., 2001):

Self-efficacy is the belief someone has that they will be able to carry out a task, instead of their actual ability to do so (Hewlett et al., 2001). The RASE is a 28-item measure, developed to capture self-efficacy in British people living with rheumatoid arthritis.

Brief Illness Perceptions Questionnaire (BIPQ) (Broadbent et al., 2006):

This 9-item measure captures participants' understanding of the timeline and nature of this condition, the emotional impact of their health changes and the impact to their sense of identity, and an open-ended question focused around the causes they attribute to their illness.

Pain Numerical Rating Scale (NRS) & Fatigue NRS:

This is a clear and brief measure of pain and fatigue levels, asking participants about their pain/fatigue levels over the last 24 hours.

Multidimensional Health Locus of Control Scale – Form C (Wallston, Stein & Smith, 1995):

The use of this questionnaire will offer the opportunity to confirm whether locus of control is related to patient activation in a sample of rheumatology. This 18-item measure captures participants' beliefs about how much of their health is related to their own personal control or because of chance.

Health Literacy Questionnaire (Osborne et al., 2013)

This 44 item measure captures participants' abilities to navigate the healthcare system confidently, to gather and apply health-related information and to work with healthcare providers.

Positive and Negative Affect Scale (Watson *et al.,* 1988):

This 10 item measure, selected for its use in prior patient activation research (Hibbard & Mahoney, 2010) has been demonstrated to reliably capture participants' positive and negative affect. It has been validated for use with people with rheumatic conditions (Zautra et al., 1995).

This will also be the case for follow-up questionnaires to optimise the response rate.

Data analysis:

The analysis will be carried out by Bethan Jones, a PhD researcher with prior experience in quantitative data analysis, with support and supervision from the rest of the research team. Study participants will be allocated a unique ID number. The database which notes participants' names and their allocated ID number will be password protected, and only accessible to the study team. Data collected for the study will be entered directly on a computer which is password protected in a locked office, according to local hospital policy. Hard copies of the signed consent forms will be stored in a locked filing cabinet within the same office.

Phase one data will be analysed using SPSS for Windows, and will involve multivariate analysis to investigate the relationship between multiple factors and participant scores on the PAM. As the PAM is a continuous measure, this analysis is likely to be in the form of multiple regression analysis. Descriptive statistics will describe the spread of PAM scores across the sample, and multivariate analysis will investigate the relationships between PAM scores and other variables.

Phase 2: Timepoint two Questionnaires

This phase involves collecting questionnaire data from the same group of participants 9 months after their initial participation. It will be noted on the initial questionnaire that participants can tick to agree to receive the second questionnaire. If participants do not tick agreeing to the second questionnaire being sent out, they will not receive the next set of questionnaires.

Method:
The PI will make a visit to each site before timepoint two, and will liaise with the research team at the site to get the postal addresses of all the patients who took part from that site. This will be based on the comparison of ID codes from returned questionnaires and the records held by the sites that notes which participant has been given each questionnaire. Participants will be asked to complete the questionnaires and return them in a reply paid envelope to the research team at UWE.

Recruitment and Sampling:
The sample will be formed of people who participated in phase one, and no additional recruitment will be carried out.

Data collection:
Data collection for phase two will be carried out the same way as phase one. The questionnaires included will not differ from the original questionnaire pack. Sites will note which people have received which questionnaire number, in order to track participants who returned the questionnaires for follow-up. A reminder questionnaire may be sent if the follow-up survey is not returned within 6 weeks, in order to increase retention rates. The research team will collaborate with sites in the same way as previously noted to establish who requires a reminder pack sent out.

There will also be a checkbox asking if participants would like a summary of the results posted to the home address using the same method as the second questionnaires (i.e. comparing ticked boxes on uniquely numbered questionnaires and working with sites retaining the addresses of participants).

Data analysis:
Phase two data will be analysed using multivariate analysis to understand the relationships between the variables, and to understand what contributes to variations in PAM scores reported by participants. Data analysis will also investigate whether there has been a significant change within participants' PAM scores over time, and to describe the sample at the follow-up point.

Dissemination:
The research method and findings will be presented in the Principal Investigator's PhD thesis. It is intended that the research findings will also be presented at appropriate academic conferences in rheumatology or psychology, and submitted for publication to an appropriate academic peer reviewed journal. The results will be fed back to the teams at the sites that participated in the research.

Project management and the research team
This research will contribute to a PhD project at the University of the West of England (UWE), and is supervised by a team with significant experience in rheumatology, the

impact of long term health conditions, mixed-methods data collection and analysis, and patient perspectives on living with IA.

Bethan Jones, a PhD student with a background in health psychology in long term conditions, has designed this study and will conduct the data collection and analysis. She has also completed Good Clinical Practice training.

Dr Emma Dures, Associate Professor and chartered psychologist, is Bethan's Director of Studies. Dr Dures similarly has a background in health psychology and substantial experience of designing and conducting mixed methods research. Professor Sarah Hewlett (Professor of Rheumatology Nursing, UWE) is Bethan's second supervisor. Professor Hewlett is a clinical academic who is at the forefront of research into patient involvement, self management, and understanding the impact of IA on patients' wellbeing. Further supervision is provided by Professor Diana Harcourt, who has substantial experience of the psychological impact of living with a long term condition; and Mr Andrew Hunt, a patient partner who brings lived experience of living with IA to the team.

Throughout the study there will be regular whole team meetings as required, and fortnightly meetings between Bethan Jones and Dr Dures for ongoing day to day management of the study.

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Appendix S: Patient Information Sheet for survey study

How people manage their health conditions: A survey study

Patient Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the study is being done and what it will involve. Please read the following information and discuss it with friends and relatives if you wish. If anything is not clear or if you would like more information, you are welcome to get in touch with Bethan Jones. Her contact details are at the end of the document.

Who is asking you to take part?

I am Bethan Jones, and I am a student at the University of the West of England. I am inviting you to take part in a research study that will be part of my PhD.

What is the purpose of the study?

I am interested in finding out how people with rheumatic conditions manage their health, and how confident and able they feel to do this. I am also interested in how peoples' opinions of how they self-manage change over time, which is why this study involves completing 2 sets of questionnaires.

Why have I been invited to take part?

You have been invited to take part because you are living with a type of inflammatory arthritis. I am inviting around 350 people to take part from six NHS hospitals in England. We are interested in everyone's answers to understand people's experiences.

What will I be asked to do if I take part?

If you decide to participate, it will involve the following:

- Completing the questionnaires and about you, and your health and returning them to us in the next 2 months. You will also be asked for some brief details regarding your age, gender and the length of time since you were diagnosed with your rheumatic condition. We think that this will take around 30 minutes to fill in.
- Agreeing to be contacted 9 months after your first questionnaire to be sent a second set of questionnaires.
- Completing this second set of questionnaires and return them to us.
- We may send you a reminder about the study a little while after the second questionnaire. We think it is important that you decide whether you take part in private, so we may not know who has already responded in that time and who has decided not to take part in the research. Please accept our apologies in advance if you have already replied, or already decided you don't want to take part, when you receive the reminder. You do not have to take part in either questionnaire, can ignore the reminder.

Do I have to take part?

No, taking part is voluntary. It is up to you to decide whether to take part. If you do decide to take part, you will be asked to complete and return the first set of questionnaires within two months. If you decide not to take part you do not have to give a reason, nobody will be upset and the care you receive will not be affected. If you do decide to take part, you are still free to withdraw at any time and without giving a reason, we will retain any data you have already completed as part of this study unless you specifically ask us to delete this information. If you do ask us to remove your information we will destroy hard copy documents you have completed and will delete any electronic data. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. You can withdraw from the study by contacting Bethan Jones on the details provided below or the department that provided you with this information pack.

What are the possible risks of taking part?

It is not expected that this study has disadvantages to you personally, but completing the questionnaires will take up to 30 minutes of your time. If you find that completing the survey that you are feeling low or anxious about your condition then we suggest contacting your GP or rheumatology team to talk about this. Alternatively, if you would like support from other sources you may find it useful to contact:

- NRAS (National Rheumatoid Arthritis Society) https://www.nras.org.uk

Freephone Helpline: 0800 298 7650 helpline@nras.org.uk

- Arthritis Research UK https://www.arthritisresearchuk.org

  1 Helpline 0800 5200 520

What are the possible benefits of taking part?

There is not likely to be any direct benefit to you from taking part in this study. However, I think this study will benefit people with arthritis in the future as we understand more about how people learn to live life with arthritis over time.

Will my taking part in this study be kept confidential?

Information collected about you will be kept confidential. We will lock the forms you return to us in the project office, and any information we store about you on the secure University of Bristol computer will be password protected. No-one else outside the research team will have access to any identifying information and all identifiable information will be kept securely. A researcher may look at your medical notes to check that the study is being carried out correctly. The department in your local NHS trust that recruited you will keep a copy of your name attached to your ID number so that we know who has responded to the questionnaires, and this link will not leave the NHS trust.

What will you do with my data?

UWE is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UWE will keep identifiable information about you for up to 12 months after the study has ended, and your responses to the questionnaires for 5 years.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The NHS site will keep your name and contact confidential and will not pass this information to UWE. The NHS site will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from UWE and regulatory organisations may look at your medical and research records to check the accuracy of the research study. UWE will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

You can find out more about how we use your information by contacting Bethan Jones or another member of the study team.

What will happen to the results of the research study?

The findings will be reported in professional publications, journals and conferences. They will also be published in my doctoral thesis. A copy of your anonymised questionnaire answers will also be sent to Insignia Health, a commercial company outside of the NHS who offer us the licence to use the Patient Activation Measure. They are not directly working on the study, but your name and any identifying information will be removed to keep this data anonymous. They use this information to improve, refine and understand how the questionnaire is completed.

Who is funding the study?

This research study is funded by Arthritis Research UK.

Who has reviewed the research?

It has been approved by the Health Research Authority, a Research Ethics Committee (REC Project ID 235922) and the University of the West of England (UWE) ethics committee.

What do I do now?

If you are interested in taking part, please complete and return the questionnaires in the reply-paid envelope. If you have any questions or would like more information before you decide whether to participate, you can contact the study team on the details below.

Central study contact details: Bethan Jones
Rheumatology Research
Level 5, Zone B
Bristol Royal Infirmary
Bristol
BS2 8HW

0117 342 7415
Bethan8.jones@live.uwe.ac.uk

Study Team:
Bethan Jones, PhD Student (UWE Bristol)
Emma Dures, Associate Professor in Rheumatology and Self-Management (UWE Bristol)
Sarah Hewlett, Professor of Rheumatology Nursing (UWE Bristol)
Diana Harcourt, Professor of Appearance & Health Psychology (UWE Bristol)
Andrew Hunt, Patient Partner (Bristol Royal Infirmary)

If you have any concerns about participating in this study and would like to receive free independent advice please contact PALS (Patient Advice and Liaison Service) on:
0117 342 1050 or via email on psct@uhbristol.nhs.uk

If you wish to talk to my academic supervisor about any concerns relating to this study, please contact Dr Emma Dures on: 0117 342 7418 or via email on emma2.dures@uwe.ac.uk

Appendix T: Invitation letter to participate

Dear

Invitation to take part in an interview

I am writing to tell you about a research project for which I am helping PhD student Bethan Jones and her research supervisors. Bethan would like to find out more about how people with rheumatic conditions manage their health, and how confident and able they feel to do this

This research is being run in rheumatology units in six hospitals across England. It is led by Bethan Jones and her research supervisors from the University of the West of England, who are based in the Bristol Royal Infirmary Rheumatology Unit.

I am enclosing the patient information sheet about the study for you to read. Taking part in research is voluntary and if you would prefer not to do so nobody will be upset and your treatment will not be affected.

If you would be interested in taking part, please complete the survey pack and return it to the researcher Bethan Jones in the prepaid envelope provided.

Thank you for taking the time to read the enclosed information.

Yours sincerely

Consultant Rheumatologist

Appendix U: Chase letter for second survey pack

Local site logo

Dear Sir/Madam,

Reminder of an invitation to take part in a follow-up survey study

A few weeks ago, we sent you an invitation to take part in a follow-up survey study. This is a reminder of our invitation and a copy of the follow-up survey.

Please accept our apologies if you have already completed and returned the follow-up survey, or if you have already decided that you do not wish to take part.

Yours sincerely

Bethan Jones

PhD Student

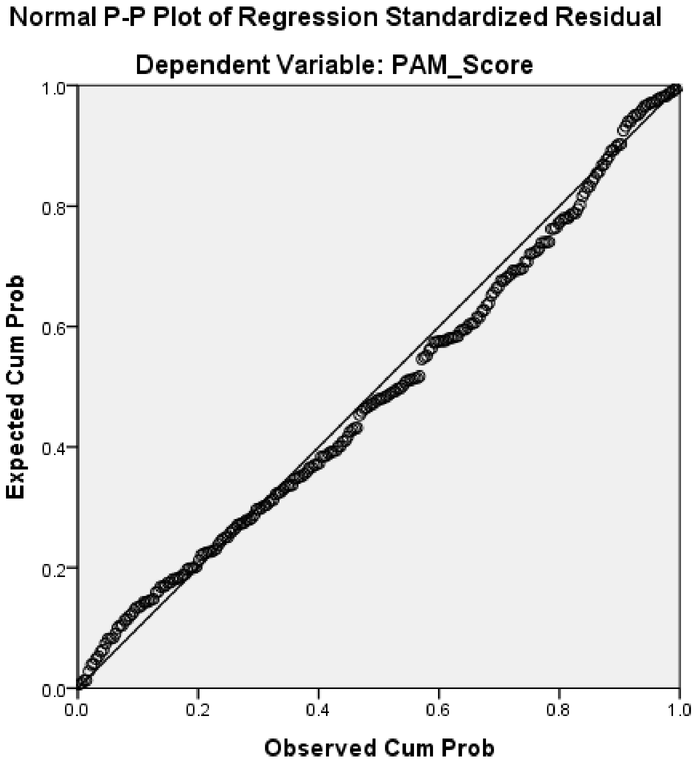
Appendix V: Summary of BIPQ data

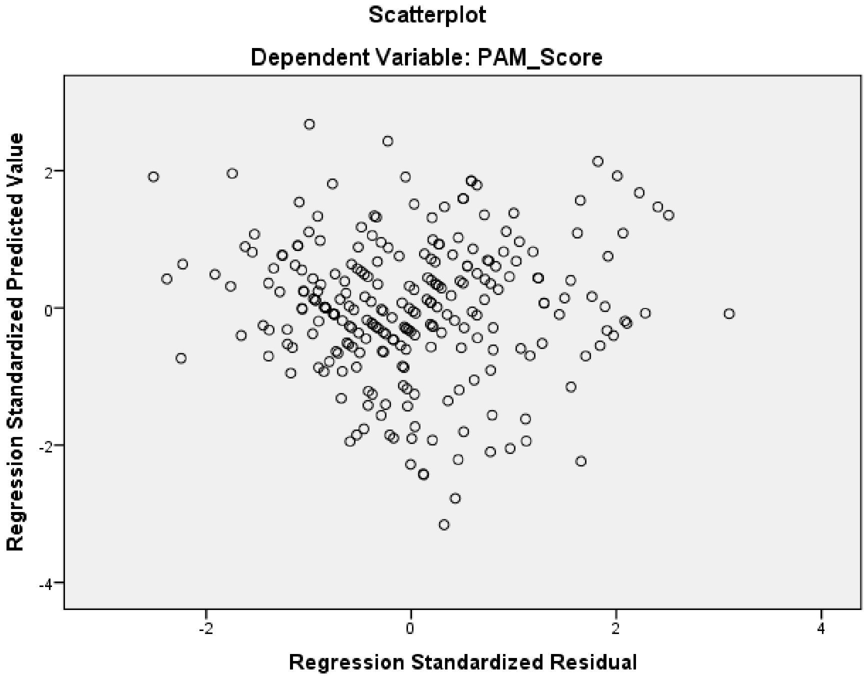
First data collection round categories of responses to the item *"Please list in rank-order the three most important factors that you believe caused your illness. The most important causes for me:"*

Category (first set of data)	**Number of responses**
Stress	60
Age	18
Heredity/Genetics	101
Bad Luck	18
Don't Know	32
Overactivity	25
Underactivity	7
Other autoimmune condition or pre-existing health issue	26
Diet	16
Immune system problem/infection	34
Occupation/Work	42
Lifestyle-related factors (including sleep)	18
Fall/accident	18
Depression/Anxiety/Worry	7
Wear and tear/impact on joints	9
Don't think there is a specific cause	3
Trauma	9
Significant life events	10
Medication / other health treatment	7
Inflammation	1
Hormones/menopause/pregnancy	6
Weather/climate	5
Other (listed separately)	22
Neglect (self or NHS)	12
Chemicals/pollutants/smoking	7
Total	494

Category (Follow-up data)	**Number of responses**
Stress	40
Age	11
Heredity/Genetics	81
Bad Luck	19
Don't Know	8
Overactivity	12
Underactivity	3
Other autoimmune condition or pre-existing health issue	29
Diet	9
Immune system problem/infection	20
Occupation/Work	33
late intervention	3
Lifestyle-related factors (including sleep)	13
Fall/accident	16
Depression/Anxiety/Worry	4
Wear and tear/impact on joints	5
Don't think there is a specific cause	2
Trauma	3
Significant life events	4
Medication / other health treatment	6
Inflammation	4
Hormones/menopause/pregnancy	12
Weather/climate	1
Other (listed separately)	24
Neglect (self or NHS)	12
Chemicals/pollutants	1
Total	375

Appendix W: Probability plot, scatterplot and Shapiro-Wilk results for first timepoint multiple regression





	Statistic	**Df**	**p Value**
PAM	0.969	251	0.000
HAQ	0.910	251	0.000
RASE	0.980	251	.001
Locus of Control: Internal	0.980	251	.002
Locus of Control: Chance	0.976	251	.000
Locus of Control: Doctors	0.982	251	.003
Locus of Control: Powerful Others	0.971	251	.000
BIPQ	0.993	251	.296
Health Literacy Questionnaire Subscale 1	0.846	251	<.001
Health Literacy Questionnaire Subscale 2	0.724	251	<.001
Health Literacy Questionnaire Subscale 3	0.942	251	<.001
Health Literacy Questionnaire Subscale 4	0.977	251	<.001
Health Literacy Questionnaire Subscale 5	0.978	251	<.001
Health Literacy Questionnaire Subscale 6	0.937	251	<.001
Health Literacy Questionnaire Subscale 7	0.949	251	<.001
Health Literacy Questionnaire Subscale 8	0.938	251	<.001
Health Literacy Questionnaire Subscale 9	0.936	251	<.001
PANAS Positive Affect	0.985	251	<.001
PANAS Negative Affect	0.933	251	<.001
Fatigue NRS Average level	0.912	251	<.001
Pain NRS Average level	0.965	251	<.001

Appendix X: Cronbach’s alpha coefficients

Measure:	Cronbach’s Alpha Coefficient:
PAM	.87
RASE	.93
Locus of Control	.78
BIPQ	.75
Health Literacy Questionnaire (total measure)	.95
PANAS	.70

Appendix Y: Trimmed mean information for first survey dataset

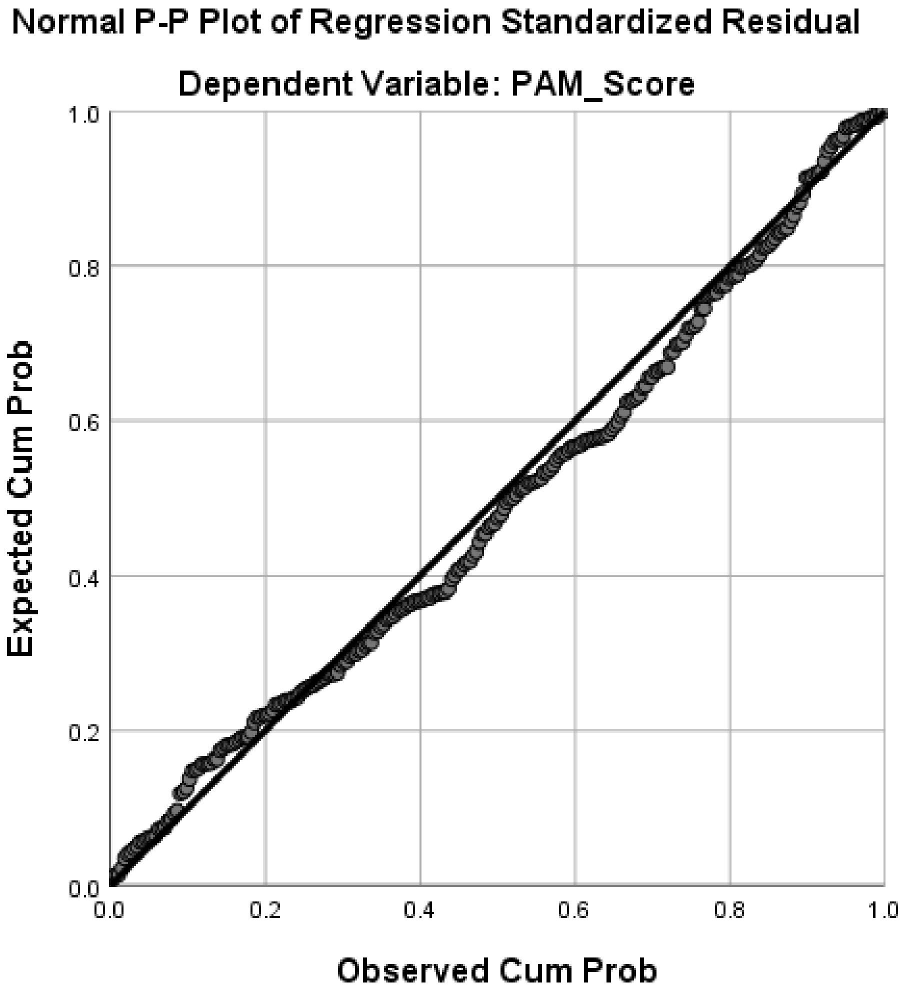
Outcome Measure	**Mean (Standard deviation)**	**5% Trimmed Mean**
PAM	58.31 (11.46)	57.86
HAQ	0.75	0.70
RASE	101.61 (15.24)	101.8
Locus of Control: Internal	16.98 (6.14)	16.81
Locus of Control: Chance	11.32 (3.23)	11.32
Locus of Control: Doctors	16.33 (6.47)	16.13
Locus of Control: Powerful Others	8.71 (3.57)	8.58
BIPQ	45.55	45.64
Health Literacy Questionnaire Subscale 1	2.99 (.83)	3.01
Health Literacy Questionnaire Subscale 2	2.94 (.65)	2.91
Health Literacy Questionnaire Subscale 3	2.89 (.47)	2.89
Health Literacy Questionnaire Subscale 4	2.92 (.57)	2.92
Health Literacy Questionnaire Subscale 5	2.68 (.53)	2.69
Health Literacy Questionnaire Subscale 6	3.78 (73)	3.81
Health Literacy Questionnaire Subscale 7	3.59 (.66)	3.62
Health Literacy Questionnaire Subscale 8	3.93 (.63)	3.86
Health Literacy Questionnaire Subscale 9	4.08 (.55)	4.10
PANAS Positive Affect	30.03 (8.85)	30.11

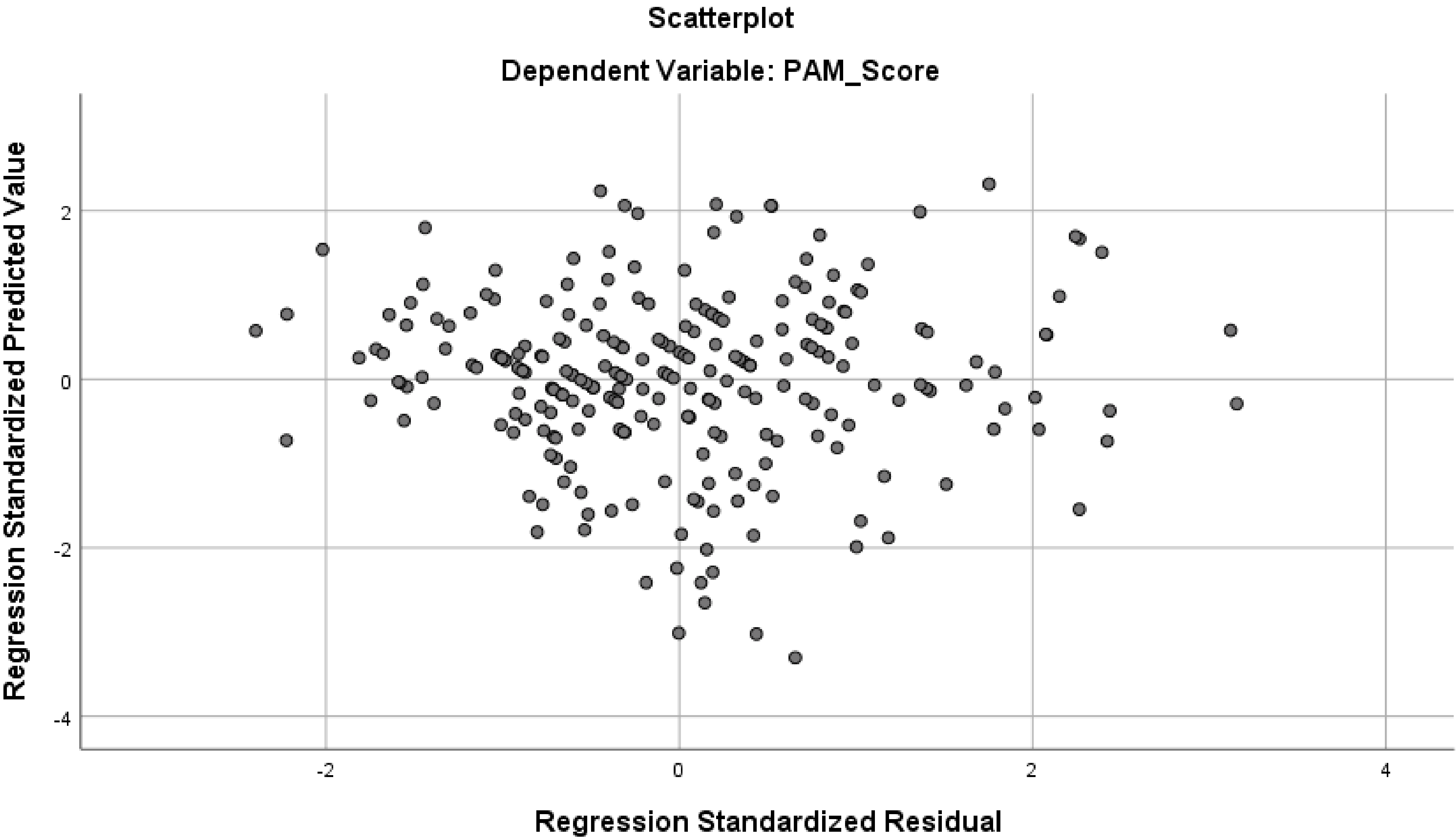
PANAS Negative Affect	19.88 (.7.72)	19.37
Fatigue NRS Average level	6.43 (2.27)	6.54
Pain NRS Average level	5.42 (2.51)	5.46

Appendix Z: Transformed confirmatory multiple regression

Variables	Preliminary multiple regression			Final multiple regression		
	Standardised β	**95% CI**	**P value**	**Standardised β**	**95% CI**	**P value**
Sex	0.04	-1.70 to 3.83	0.45			
Age	-0.08	-0.17 to 0.04	0.21			
Disease duration	-0.01	-0.11 to 0.09	0.88			
Ethnicity	-0.02	-1.39 to 0.97	0.73			
Condition	0.06	-0.22 to 0.71	0.29			
Square root HAQ	-0.10	-11.73 to 1.78	0.15			
Square root RASE	0.20	1.01 to 4.89	<0.01	0.31	2.91 to 6.27	<0.01
Square root Int HLOC	0.09	-0.32 to 3.04	0.11			
Square root Docs HLOC	0.05	-1.28 to 3.71	0.34			
BIPQ	-0.12	-0.33 to 0.05	0.15			
Square root HLQ 1	-0.01	-7.88 to 7.38	0.95			
Square root HLQ 2	0.21	4.61 to 28.12	<0.01	0.30	13.75 to 34.08	<0.01
Square root HLQ 3	0.05	-6.69 to 14.80	0.46			
Square root HLQ 4	0.01	-8.44 to 9.71	0.89			

Square root HLQ 5	0.07	-4.24 to 13.48	0.31			
Square root HLQ 6	0.03	-9.15 to 12.92	0.74			
Square root HLQ 7	-0.19	-24.24 to 1.21	0.08	-0.12	-16.12 to 1.05	0.09
Square root HLQ 8	0.05	-8.82 to 15.68	0.58			
Square root HLQ 9	0.23	5.83 to 30.39	<0.01	0.28	12.64 to 32.71	<0.01
Square root Pain NRS	0.09	-1.41 to 5.35	0.25			
Square root Fatigue NRS	-0.09	-5.49 to 1.35	0.23			
Square root Positive affect (PANAS)	0.03	-1.49 to 2.21	0.70			
Square root Negative affect (PANAS)	-0.04	-2.27 to 1.31	0.60			

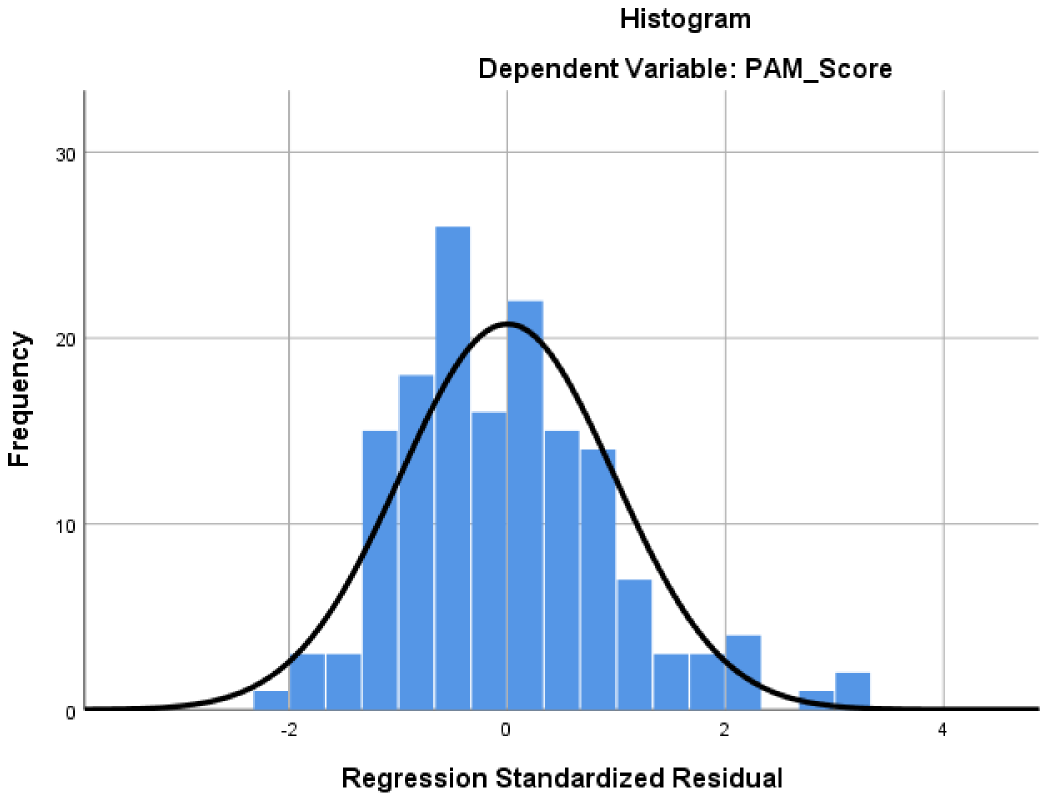

Normal P-P Plot of Regression Standardized Residual
Dependent Variable: PAM_Score
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0
0.0
0.2
0.4
0.6
0.8
1.0

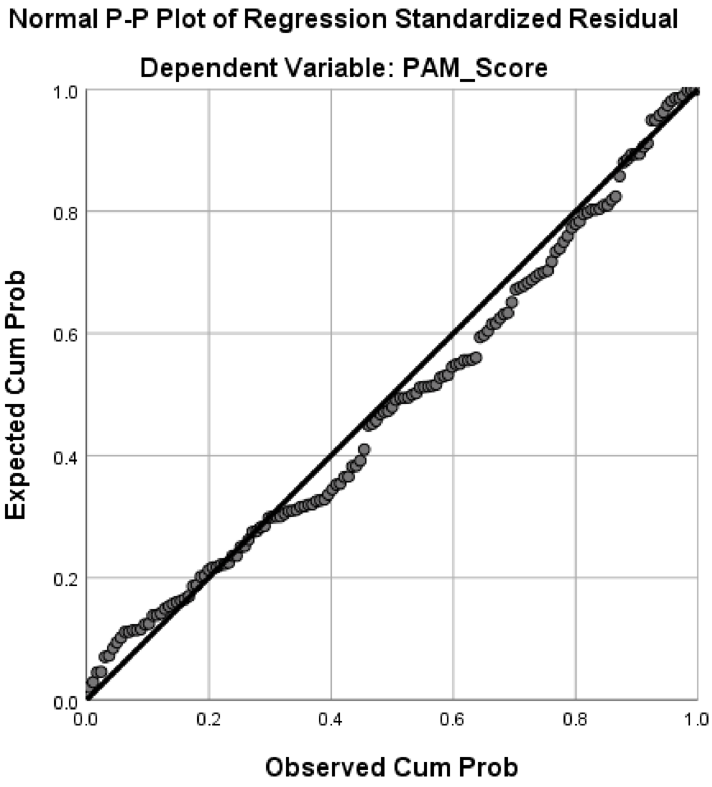

Scatterplot
Dependent Variable: PAM_Score
Regression Standardized Predicted Value
2
0
-2
-4
-2
0
2
4
Regression Standardized Residual

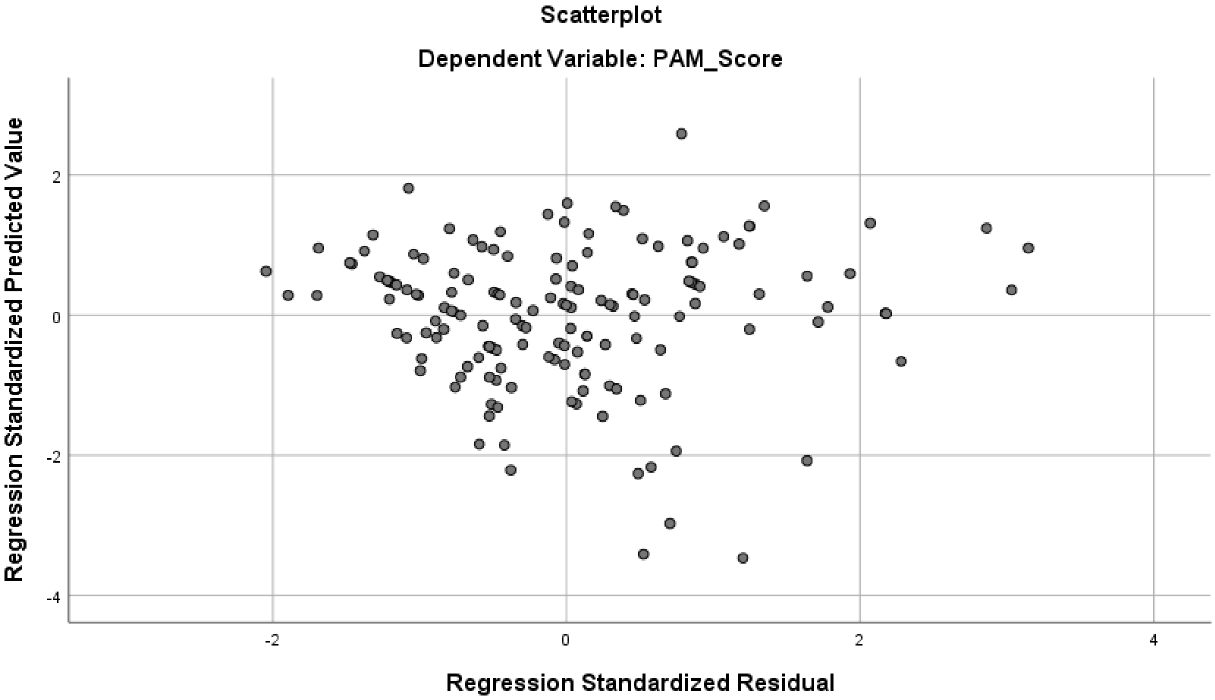
Appendix AA: Trimmed mean information for second set of survey data

Outcome Measure	Mean (Standard deviation)	5% Trimmed Mean
PAM	58.43 (13.13)	57.68
RASE	103.23 (14.69)	103.46
Locus of Control: Internal	17.03 (5.40)	16.86
Locus of Control: Chance	15.99 (6.07)	15.85
Locus of Control: Doctors	10.90 (2.91)	10.91
Locus of Control: Powerful Others	8.54 (3.19)	8.47
BIPQ	44.34 (11.63)	44.27
HLQ Subscale 1	2.93 (.66)	2.96
HLQ Subscale 2	2.92 (.51)	2.93
HLQ Subscale 3	2.89 (.48)	2.89
HLQ Subscale 4	2.85 (.60)	2.85
HLQ Subscale 5	2.66 (.51)	2.66
HLQ Subscale 6	3.65 (.84)	3.69
HLQ Subscale 7	3.54 (.72)	3.58
HLQ Subscale 8	3.8 (.65)	3.83
HLQ Subscale 9	4.05 (.63)	4.09
PANAS Positive Affect	30.83 (8.27)	31.06
PANAS Negative Affect	20.1 (8.38)	19.55
Fatigue NRS	6.44 (2.33)	6.53
Pain NRS	5.01 (2.53)	5.02

Appendix BB: Probability plot, scatterplot and Shapiro-Wilk results for second timepoint multiple regression




Normal P-P Plot of Regression Standardized Residual
Dependent Variable: PAM_Score
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0


Scatterplot
Dependent Variable: PAM_Score
Regression Standardized Predicted Value
Regression Standardized Residual
2
0
-2
-4
-2
0
2
4

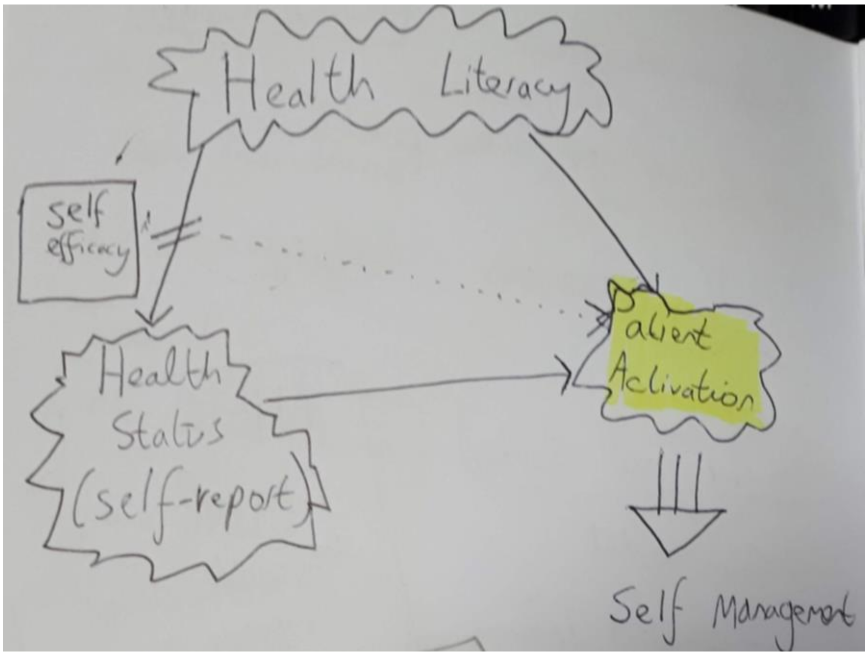
Variable	Statistic	Df	p Value
PAM		154	
HAQ	0.90	154	<0.01
RASE	0.97	154	<0.01
Locus of Control: Internal	0.98	154	0.01
Locus of Control: Chance	0.98	154	0.01
Locus of Control: Doctors	0.99	154	0.11
Locus of Control: Powerful Others	0.98	154	0.01
BIPQ	0.99	154	0.18
Health Literacy Questionnaire Subscale 1	0.94	154	<0.01
Health Literacy Questionnaire Subscale 2	0.92	154	<0.01
Health Literacy Questionnaire Subscale 3	0.97	154	<0.01
Health Literacy Questionnaire Subscale 4	0.97	154	<0.01
Health Literacy Questionnaire Subscale 5	0.97	154	0.01
Health Literacy Questionnaire Subscale 6	0.95	154	<0.01
Health Literacy Questionnaire Subscale 7	0.95	154	<0.01
Health Literacy Questionnaire Subscale 8	0.90	154	<0.01
Health Literacy Questionnaire Subscale 9	0.92	154	<0.01
PANAS Positive Affect	0.92	154	<0.01
PANAS Negative Affect	0.97	154	<0.01
Fatigue NRS Average level	0.97	154	<0.01
Pain NRS Average level	0.92	154	<0.01

Appendix CC: Transformed confirmatory multiple regression on second round of multiple regressions

Variables	Preliminary multiple regression			Final multiple regression		
	Standardised β	**95% CI**	**P value**	**Standardised β**	**95% CI**	**P value**
HAQ	-0.25	-32.03 to -6.26	<0.01	-0.22	-27.51 to -4.91	<0.01
RASE	0.25	14.45 to 76.70	<0.01	0.29	25.11 to 78.98	0.01
Powerful others HLOC	-0.18	-20.01 to -3.54	<0.01	-0.14	-16.84 to -1.41	<0.01
BIPQ	-0.28	-0.51 to -0.06	0.01	-0.11	-0.29 to 0.06	0.19
HLQ 1	-0.18	-38.10 to 2.04	0.07	-0.08	-23.19 to 6.63	0.27
HLQ 2	0.27	4.73 to 64.95	0.02	0.32	18.54 to 63.65	<0.01
HLQ 3	0.08	-11.25 to 35.96	0.30			
HLQ 4	0.11	-14.42 to 30.63	0.48			
HLQ 5	0.20	-6.02 to 34.53	0.17			
HLQ 6	-0.13	-9.99 to 47.28	0.20			

HLQ 7	-0.13	-48.39 to 19.55	0.40			
HLQ 8	-0.03	-36.29 to 29.19	0.83			
HLQ 9	-0.02	-35.87 to 31.53	0.90			
Pain NRS	0.09	-4.22 to 14.42	0.28			
Fatigue NRS	0.06	-7.70 to 15.59	0.50			
Positive affect (PANAS)	-0.06	-18.83 to 8.64	0.47			
Negative affect (PANAS)	0.11	-3.79 to 18.44	0.20			

Appendix DD: Example of framework development



Appendix EE: List of Invited talks, workshops and presentations disseminating findings of the PhD

Poster Presentations

Jones, B., Dures, E., Hewlett, S., Harcourt, A. & Hunt, A. (2017) *Patient Activation in inflammatory arthritis: Developing a framework to inform interventions.*

Presented at:

- Centre for Health and Clinical Research Conference, Bristol. 17th January 2017.
- Health and Applied Sciences Postgraduate Conference, Bristol. 19th June 2017

Jones, B., Hewlett, S., Harcourt, D., Hunt, A. & Dures, E. (2018) *How effective are interventions targeting patient activation in people with long-term physical conditions? A systematic review.*

Presented at:

- Versus Arthritis Fellows meeting, Loughborough. 15th March 2018
- British Society for Rheumatology Annual Conference, Liverpool. 3rd May 2018. (*included on poster tour*)
- European League Against Rheumatism (EULAR) Annual Congress, Amsterdam. 15th June 2018.

Jones, B., Hunt A., Harcourt, D., Hewlett, S. & Dures, E. (2019) *The Patient Activation Measure (PAM): what do patients with rheumatic conditions think about it?*

Presented at:

- British Society for Rheumatology Annual Conference, Birmingham. 1st May 2018.
- European League Against Rheumatism (EULAR) Annual Congress, Madrid. 13th June 2018.

Conference Abstracts

Jones, B., Hewlett, S., Harcourt, D., Hunt, A. & Dures, E. (2018). How effective are interventions targeting patient activation in people with long-term physical conditions? a systematic review. Ann Rheum Dis. volume 77, (Supp). p A829

Jones, B., Hewlett, S., Harcourt, D., Hunt, A. & Dures, E. (2018) *How effective are interventions targeting patient activation in people with long-term physical conditions? A systematic review.* Rheumatology, Volume 57, Issue suppl_3, 1 April 2018, key075.502.

Jones, B. (2018). i040 Patient activation: what is it? *Rheumatology*. Volume 57, Issue suppl_3, 1 April 2018, key075.040

Jones, B., Hunt A., Harcourt, D., Hewlett, S. & Dures, E. (2019) *The Patient Activation Measure (PAM): what do patients with rheumatic conditions think about it?* Rheumatology, Volume 58, Issue suppl_3, kez108.056.

Jones, B., Hunt A., Harcourt, D., Hewlett, S. & Dures, E. (2019) *The Patient Activation Measure (PAM): what do patients with rheumatic conditions think about it?* Ann Rheum Dis. volume 78, (Supp 2). p 656

Invited talks/workshops

- Jones, B. (2017) *Patient Activation - what is it, and why should it matter to me?* [BRI Rheumatology Patient Advisory Group meeting], Bristol Royal Infirmary. 13th September 2017.
- Jones, B. (2018) *Patient Activation – what is it?* British Society for Rheumatology Annual Conference, Liverpool. 2nd May 2018.
- Jones, B. (2018) *Patient activation: A survival guide for clinicians*. Vitality 360 Away Day, Bristol. 10th November 2018.
- Jones, B. (2019) *Patient activation in rheumatic conditions: what does it mean to patients?* Versus Arthritis Fellows Meeting, Loughborough. 14th February 2019.
- Jones, B. (2019) *Patient activation: A summary of the evidence.* South West Rheumatology fellows away day, Bristol. 29th June 2019.

- Jones, B. (2019) *Patient activation: what does it mean for me?* Arthritis Action Eastbourne Group, Web-based presentation. 15th August 2019.
- Jones, B. (2019) *What is patient activation and why does it matter?* British Pain Society (Pain Management Special Interest Group), Bristol. 12th September 2019.
- Jones, B. (2019) *What is patient activation and why does it matter?* Manchester Royal Infirmary Rheumatology team, Manchester. 15th November 2019.
- Jones, B. (2019) An introduction to p*atient activation.* British Society of Rheumatology Core Skills Course, Bristol. 25th November 2019.

Appendix FF: Abstract for Centre for Health and Clinical Research conference 2017

Background:

Self-management is an increasingly referenced concept in healthcare policies in the UK, following a shift to view people with chronic illness to be experts in their own condition (Dures et al., 2014). People are expected to be more involved in making decisions in collaboration with health care professionals, and to develop knowledge about managing their health (Hibbard, et al. 2004). Patient activation is how willing and able someone is to take an active role in dealing with their health (Hibbard and Greene, 2013). It appears to be a multidimensional construct, associated with self-management behaviours such as treatment adherence, health literacy, and self-efficacy (Hibbard et al., 2004; Do et al., 2015). Evidence suggests that patient activation is associated with fewer days in hospital and fewer emergency admissions (Hibbard & Greene, 2013). The Patient Activation Measure (PAM) stratifies patient activation scores into four developmental stages, with people developing their active role further over time (Hibbard et al., 2004).

However, little is known about the dimensions involved in patient activation in context of inflammatory arthritis. There has also been limited qualitative research focused on patient perspectives on the concept of activation. Therefore, research to understand PAM scores and perceptions of activation over time can contribute to a model to describe patient activation within Rheumatology.

Aims and Objectives:

The project will be split into three studies:

- Study one is a systematic review on the effectiveness of prior interventions targeting patient activation in long-term conditions. Understanding how research has captured changes in patient activation in other populations, the duration of interventions, and outcome measures used will inform the next two studies.
- Study two will carry out semi-structured interviews, repeated 12 months later, with a purposive sample of people diagnosed with inflammatory arthritis. This will focus on their perspectives of the concept of activation. The interview

schedule will cover personal and contextual factors which participants believe impact activation, and their thoughts on the PAM (Hibbard et al., 2005). The interviews will aim to map developments in their understanding of activation over time.

- Study three will investigate changes to participants' PAM scores over time, to identify whether patient activation fluctuates, and describe the relationships between patient activation and related constructs. Participants will be surveyed across several sites, providing data at two separate points in time over 12 months. They will complete the PAM and other outcome measures, to be determined following study one.

Outcomes:

The final aspect of the project will involve compiling all the data, and determining core components for a framework to describe patient activation in this context. The framework could form the foundation for developing a theory-led, rheumatology specific intervention targeting activation in the future to facilitate people taking greater responsibility for their own self-management.

Appendix GG: Summary of session for British Society for Rheumatology (BSR) conference 2018

Patient activation is a concept related to self-management and refers to how willing and able somebody is to take active responsibility for their health. There is growing interest in patient activation, particularly around the Patient Activation Measure (PAM). This validated measure stratifies patient activation scores into four developmental stages, with people developing their active role further over time, and is increasingly used within health contexts to evaluate interventions and to tailor self-management support to individuals.

There is some evidence to suggest that high levels of patient activation are associated with better individual outcomes, a greater sense of control over their condition and increased confidence to manage their health. Activated patients are less likely to require emergency admission to hospital, and have fewer nights of inpatient hospitalisation overall, so there is considerable benefit to the NHS to support people to manage their health.

The session covers an introduction to the evidence supporting patient activation, and how patient activation has been targeted in interventions. Initial findings from a qualitative study of people living with rheumatic conditions about personal and contextual factors that impact how they manage their health will be presented, along with participants perceptions of the PAM. The session will detail about how patient activation is becoming a useful construct to measure within the NHS, and review the evidence about how the PAM is currently being used in these contexts. The experience of a patient living with a rheumatic condition will provide an understanding of the process of becoming activated, and some of the challenges and benefits for them will be reviewed, as well as their perspectives on patient activation overall.

Appendix HH: Abstract BSR conference 2018 and European League Against Rheumatism (EULAR) 2018

Background:

Patient activation is an increasingly referenced concept in the self-management of long-term physical conditions. It refers to someone's ability to take an active role in self-managing their health. There has been a substantial increase in the number of studies trailing interventions targeting patient activation in a variety of formats. This study aimed to identify the effectiveness of interventions targeting patient activation in people with long-term conditions. The findings from this review will contribute to maximising the impact of current rheumatology interventions, and to increase the understanding of patient activation to develop a framework to describe its core components within a rheumatology context.

Methods:

Studies that were randomised control trials of interventions targeting patient activation in adults with long-term physical conditions were included in the review. PsycINFO, Medline, AMED, CINAHL, and ProQuest were searched during January 2017, as well as a variety of grey literature locations, snowballing and hand-searching to identify potential studies for inclusion. The Cochrane Collaboration's Risk of Bias Tool was used to determine the methodological quality of included studies, and any differences were resolved by the two reviewers. Authors were contacted if any additional information was required to extract data or to clarify risk of bias.

Results:

17 papers were included in the review. There was a great deal of heterogeneity in the types of interventions available targeting patient activation in a variety of populations, and a meta-analysis was not possible as a result. Interventions were delivered via face to face, telephone, internet and resource-based approaches. The studies also included a mix of group and individually delivered interventions. Outcome measures used also varied, including both direct and proxy measures for patient activation.

The findings suggest that in studies with interventions that are more structured, there appear to be a trend towards differences in patient activation scores between groups in favour of the intervention. It is possible that these increases in patient activation may occur with an increase in health literacy, as the literature suggests an association between the two constructs. This is discussed in terms of a proposed model for patient activation for rheumatology.

Conclusions:

There is moderate evidence for the benefit of increasing structure in interventions targeting patient activation. There is no evidence for a medium of delivery that is most effective in people with long-term conditions. There is a need for increased research into patient activation within Rheumatology.

Appendix II: Abstract BSR conference 2019 and EULAR 2019

Background:

Patient activation describes the skills, abilities and confidence someone has to actively manage their health. The most common way of capturing patient activation is by using the Patient Activation Measure (PAM), and the NHS has begun to integrate use of the measure into services as an outcome measure or as a tool to tailor care. The PAM has been widely adopted and used in a variety of populations both within the NHS and internationally, but case studies have reported that some patients found that the PAM was too broad to capture the skills they used to manage their health. There has been limited research gathering patients' perceptions of the suitability and acceptability of the PAM, particularly within a rheumatology context.

Objectives:

To gather participants' opinions on the PAM as a method of capturing patient activation.

Methods:

Seventeen participants living with a rheumatic condition in the South West of England participated in semi-structured interviews as part of a wider qualitative study investigating perceptions of patient activation. Participants completed the PAM at the beginning of the interview. In the last phase of the interview, they were asked to review and reflect on the PAM, including individual survey items and how closely they matched their experiences. Relevant sections of the interviews were analysed iteratively and participants' perspectives were grouped into themes.

Results:

Participants' feedback on the PAM ranged, and some participants reported that the PAM entirely captured how they perceived patient activation and the way that they managed their conditions. However, this was not the case for all participants. Aspects of the PAM that participants felt were not sufficiently recognised included how they managed the psychological impact of their condition, and how they discussed their condition with loved ones. Participants commonly reported that they thought the phrasing of certain PAM items did not match the lived experience of their conditions.

For example, PAM items capturing how well patients could prevent further problems was identified as a challenge for participants living with a fluctuating condition, and participants commented that the PAM does not check from where participants received or sought this information. The distinction between whether patients independently researched information about diagnoses and medications or received this passively from healthcare professionals also appeared important to some participants, as well as whether this information was accurate.

Conclusion:

The PAM survey is generally considered a reliable and valid measure of patient activation, but there may be aspects of it that do not capture the realities of living with a long-term fluctuating condition. Rather than a stand-alone measure, the PAM would be best used in conjunction with healthcare professionals' clinical judgement to capture peoples' understanding of their conditions and how well they are able to recognise and respond to flare-ups and fluctuations.