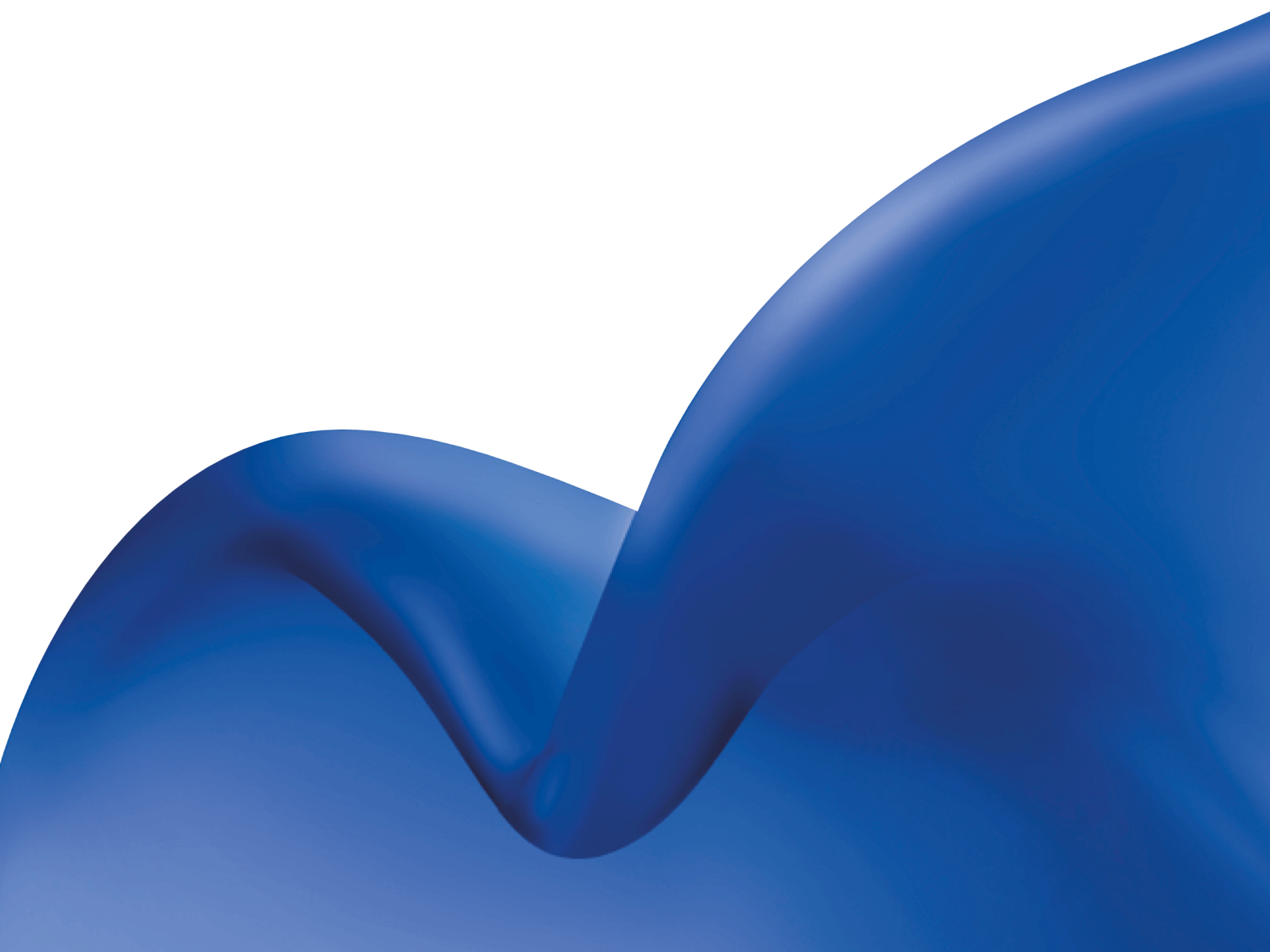


September 2014



## **Self-management of chronic musculoskeletal disorders and employment**

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The Work Foundation transforms people's experience of work and the labour market through high quality applied research that empowers individuals and influences public policies and organisational practices. For further details, please visit [www.theworkfoundation.com](http://www.theworkfoundation.com).

## Executive summary

This study considers the self-management of chronic musculoskeletal disorders (MSDs) in the workplace. Self-management can be defined as an individual's ability to manage the symptoms, treatment, physical, social and psychological consequences of living with a chronic condition. Self-management can empower individuals with a better understanding of, and control over, their symptoms and provide them with the tools to ensure their condition is understood and accommodated by others. Work can have social, psychological and economic benefits for an individual living with an MSD, as well as economic benefits for wider society, underlining why it is important to research the underexplored relationship between self-management and the workplace.

The research consisted of interviews with individuals living with a chronic MSD who were either in work, or planned to return to work in future. **The study offers two important contributions to our understanding of self-management and work. Firstly, it offers an insight into self-management at work, and the processes and components that contribute towards fostering or undermining successful self-management. Secondly it offers a view of work as a form of self-management, whereby partaking in work was an important way in which individuals managed several (often psychological) aspects of their condition, albeit often not without compromising the management of some of the physical symptoms of their MSDs.**

**It was found that individuals are currently for the most part responsible for achieving satisfactory self-management in the workplace when other stakeholders (including, employers, line managers, healthcare professionals and government) could contribute more. In turn individuals are making compromises such as stalling their career progression or foregoing a social or home life in order to continue working. These compromises, and the pressure which individuals find themselves under to self-manage without adequate support are made all the more perverse when one considers the role that work has to play in contributing to the management of an individual's mental wellbeing. If the benefits of work as self-management are to be truly realised, then the way in which self-management at work is supported needs to be significantly improved.**

A **summary of the results** from the interviews follows. Firstly self-management was discussed more generally:

- Most participants had a high familiarity with the concept of self-management, understanding it to mean having control over one's condition and not becoming overwhelmed by it. Self-management was also constructed as a gradual process, whereby competency to self-manage developed, and could also fluctuate, over time.

- The nature of the individual and the nature of the condition had a bearing on self-management. Some individuals conceived of the management of their condition as a 'fight', while others spoke about approaching the condition with a positive attitude, or 'getting on with it'. Specific aspects of the condition, including the way in which the disease course is unique to each individual, and that the first onset of symptoms are often very hard to control before appropriate medication is being received, had implications for how the disease was managed. The symptoms of pain and fatigue were cited as being key for keeping under control, while it was also noted that the often invisible nature of the condition increased the difficulty of self-managing successfully.
- Participants discussed the many ways in which they gathered information to assist them in managing their condition. Medical professionals, patient organisations, and the internet were key sources of information. Participants discussed general self-management techniques, which included learning one's limits, pacing oneself, resting, appropriate exercise, and making mental adjustments to living with a chronic condition. All of these were underpinned by the need for an effective drug regime.

The interviews then also explored self-management in the workplace in more detail:

- The size and type of organisation that the participant worked for was instrumental in facilitating or impeding self-management. Larger organisations were found to have better support structures in place, while smaller organisations often lacked the necessary resources to support individuals. Public sector organisations also tended to offer more support than private sector organisations, which were often construed as being primarily motivated by profit. There were many participants who were self-employed, an option which was seen as hugely advantageous because of the control it offered the individual over their working pattern and therefore their condition.
- External bodies such as trade unions, occupational health, and government funded initiatives could often provide the catalyst for adjustments in the workplace. However, some individuals also viewed these interventions negatively, especially if they had not made initial contact with them themselves, as they were seen as evidence of an employer believing an individual was not coping in their current role.
- The role of line managers was very important. Individuals reported varying degrees of awareness among line managers. The relationship between the line manager and the individual was key, as a strong relationship that had developed over time often meant the line manager had a greater degree of understanding, and also that the individual felt trusted and more able to ask for adjustments. Many participants were reluctant to ask for help from their line managers, citing the key reasons as being fear of negative judgement and fear of job loss.
- In general participants found their colleagues lacked awareness about MSDs. Linked

to this there were varying degrees of disclosure to colleagues. The sentiment was expressed that participants did not want to be singled out as different to colleagues.

- The various adaptations in the workplace are outlined in a table on page 76. There were examples of where a participant's employer had reneged on promises to provide adjustments. Other participants had not asked for adjustments, perhaps because they were wary of doing so. There were also examples of individuals who felt they could not request a specific adjustment because they had made another request in the past, or planned to make another in the future, suggesting they considered their employer as having a finite amount of support to offer.

Below are a **summary of the recommendations** organised by the stakeholder group they are addressed to. For the recommendations in full, please see page 85 onwards.

#### **The Individual.**

- Appreciate that understanding how to manage your condition at work takes time.
- Realise that others have a role to play in managing your condition.
- Equip yourself with information that will help you to manage your condition in the workplace and share it with others.
- Be 'Solutions-focused' and recognise that you may have to take the lead in some conversations with your manager.

#### **Government.**

- Increase awareness of and participation in Access to Work.
- Provide extra assistance for employees working in small organisations.
- Invest in more Specialist Nurse roles.
- Ensure work is considered a clinical outcome by healthcare professionals.

#### **The Employer.**

- Understand your responsibilities as an employer to people with disabilities and long term health conditions.
- Aim to help employees with chronic MSDs to feel a valuable and mainstream part of your workforce.
- Educate your workforce about chronic conditions.
- Foster career progression options for individuals with MSDs.

### **The Line Manager.**

- Work to build a good relationship with an employee living with an MSD.
- Be proactive: seek out information about MSDs, and be proactive in asking how the employee can be supported to do their job.
- Consider mental as well as physical health.
- Ensure that you take opportunities to praise an employee with an MSD when they have performed well.

### **Colleagues.**

- Educate yourself about chronic conditions.
- Understand that people with MSDs may need to work in different ways to you.

### **Healthcare Professionals.**

- Be aware of the wealth of information you have about condition management and share it with your patients.
- View it as part of your role to ask patients about their work lives.
- Understand that you are crucial in establishing a stable foundation in terms appropriate diagnosis and medication regime upon which an individual can learn to self-manage.

### **Patient Organisations.**

- Do more to share the wealth of resources and information you have on self-management and employment.
- Support a diverse range of sources from which patients can get advice.
- Increase the dissemination of information to raise awareness among employers and other employees.

### **Family and Friends.**

- Educate yourself about MSDs.
- Appreciate that the time following first symptom onset and diagnosis is likely to be the most challenging.
- Be aware that friends or family members with MSDs may need to make sacrifices in their home or social lives in order to continue working.

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# 1. Introduction

Employment brings social and economic benefits to both the individual and society. It is therefore important that health conditions do not impede an individual's successful participation in the workforce. Musculoskeletal conditions are one of the major causes of lost working days through sickness absence, reduced productivity at work, and premature exit from the labour market. This research aims to combat these issues by looking at how self-management is related to work, and how it can improve employment outcomes for people living with a chronic MSD.

This study builds on findings from previous research conducted by The Work Foundation. A Fit for Work report published in 2012 called, 'Taking the strain: The impact of musculoskeletal disorders on work and home life' conducted a quantitative survey of people with MSDs to explore how their condition had affected their employment and home lives. One of the findings showed that individuals with MSDs who played a role in self-managing their condition were less worried about retaining their job (2012:24) than those who did not self-manage their condition. This study therefore aims to explore the meaning of self-management for people with MSDs, and understand the role that self-management plays in supporting entry to, or continued participation in, the workforce. These topics have been explored by reviewing existing literature and conducting interviews with people of working age with an MSD.

## 2. Background: MSDs among the working age population

The term 'musculoskeletal disorders' (MSDs) covers a broad range of disorders that affect the joints, bones, muscles and connective tissue. MSDs include rheumatoid arthritis, osteoarthritis, ankylosing spondylitis and low back pain. MSDs are widespread, with the General Lifestyle Survey recording self-reported chronic sickness of the musculoskeletal system at a rate of 139 per 1000 people in 2011, the highest rate for any single category of conditions. The Global Burden of Disease 2010 Study shows that 21.3% of the total years lived with disability in the world are attributable to MSDs, second only to mental and behavioural problems (Hoy et al., 2014).

MSDs represent a burden to both the health and work sectors. According to the Royal College of General Practitioners, adults consulting their GP with a musculoskeletal problem accounted for 20% of all GP consultations in 2006 (17% of all consultations for men, and 23% of all consultations for women) (Royal College of General Practitioners, 2006)<sup>1</sup>. MSDs are also the largest single cause of days of work lost due to sickness absence; in 2013, 30.6 million days of sickness absence could be attributed to musculoskeletal problems (ONS, Labour Force Datasets).<sup>2</sup> Some with MSDs find themselves distanced from the labour market and claiming social security benefits as a result of their condition. Research using data from 2009 found that 37% of Employment and Support Allowance claimants reported a musculoskeletal condition as their main health condition (Sissons et al., 2011:13)<sup>3</sup>.

It is erroneous to consider MSDs as conditions which only affect older, or economically inactive, populations. Figure 1 shows data from the Dutch Musculoskeletal Complaints and Consequences Cohort Study (DMC) (Picavet and Hazes, 2003:644). The study used nationally representative data which asked respondents about their health, including MSDs. Rather than all MSDs being more common among older age groups compared to younger age groups, different types of MSDs had different prevalence patterns across different age cohorts. Some MSDs correlated with age in an inverse U-shape, meaning that the highest prevalence was found in the middle of the age distribution. These can be described as age dependent MSDs. The presence of some MSDs did not fluctuate with age, while others increased with age and can be described as age related diseases.

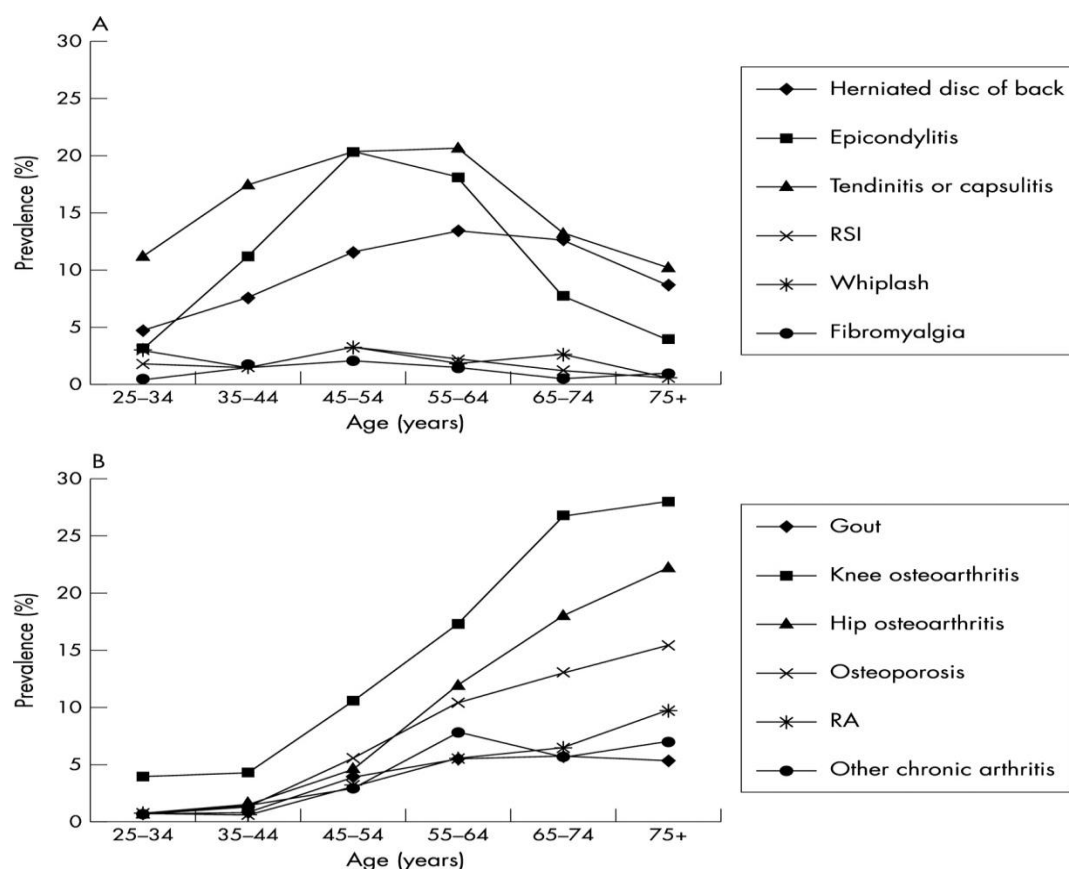
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<sup>1</sup> <http://www.arthritisresearchuk.org/arthritis-information/data-and-statistics/musculoskeletal-pain-and-disability/how-big-is-the-burden-on-general-practice.aspx>

<sup>2</sup> [http://www.ons.gov.uk/ons/dcp171776\\_353899.pdf](http://www.ons.gov.uk/ons/dcp171776_353899.pdf)

<sup>3</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/214556/rrep774.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214556/rrep774.pdf)

**Figure 1: DMC3 study, The Netherlands.**



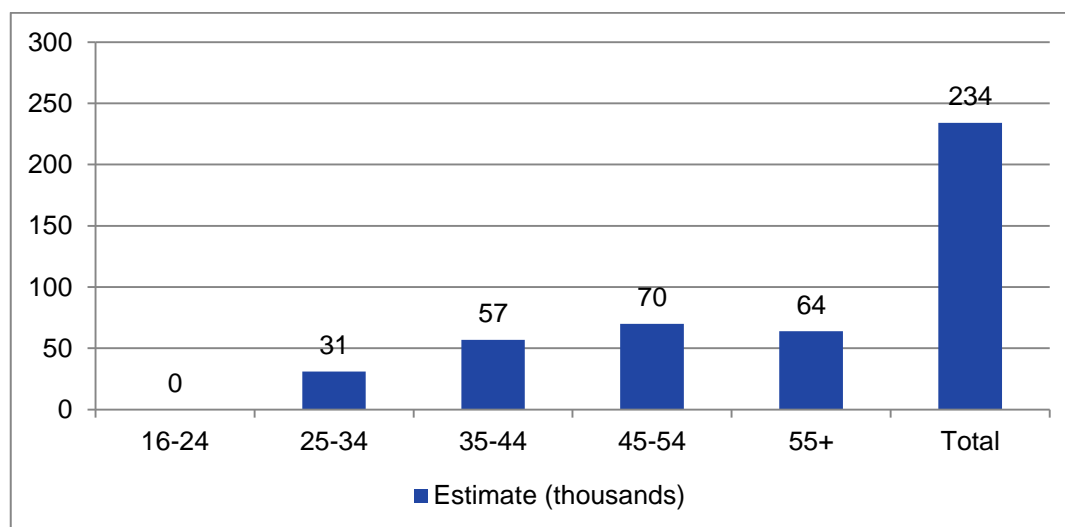
Source: Picavet, H S J et al. Ann Rheum Dis 2003;62:644-650.

Some MSDs, such as ankylosing spondylitis, have a likely onset age of between 15 and 35 (NHS Choices, 2012<sup>4</sup>). The onset of rheumatoid arthritis most commonly occurs during middle age, but is also common in the 20s and 30s (Arthritis Foundation, 2008)<sup>5</sup>. Furthermore, as people's working lives become extended, age related MSDs will become increasingly relevant to the workforce. Figures 2 and 3 illustrate that MSDs caused or worsened by work are more prevalent among older age groups for both men and women. It is important to remember that there are many MSDs that are not caused by work, and are instead attributable to, for example, the autoimmune system or the ageing process.

<sup>4</sup> <http://www.nhs.uk/Conditions/Ankylosing-spondylitis/Pages/Introduction.aspx>

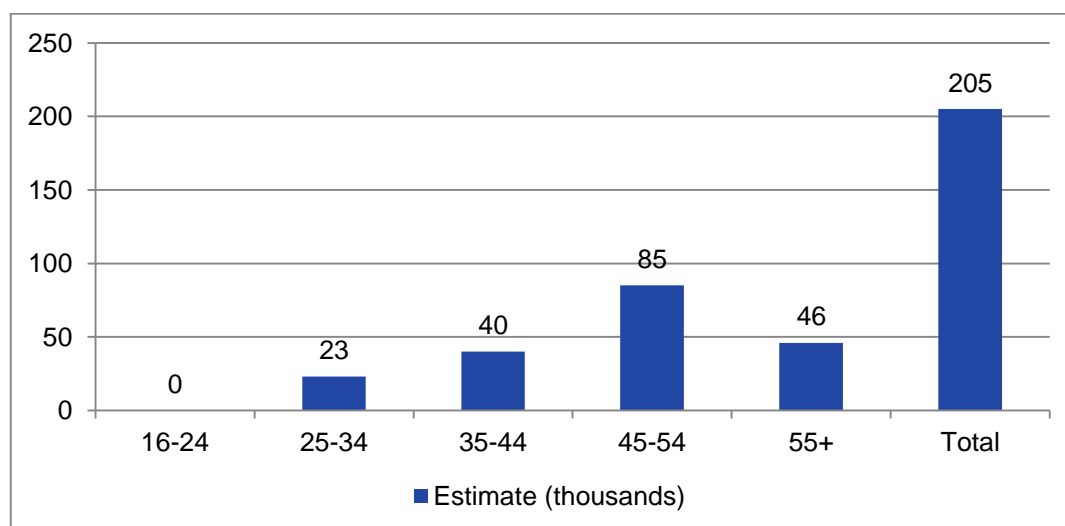
<sup>5</sup> [http://www.arthritis.org/files/images/newsroom/media-kits/Rheumatoid\\_Arthritis\\_Fact\\_Sheet.pdf](http://www.arthritis.org/files/images/newsroom/media-kits/Rheumatoid_Arthritis_Fact_Sheet.pdf)

**Figure 2: Estimated prevalence of self-reported musculoskeletal disorders caused or made worse by work, by age and gender, for people working in the last 12 months, 2011/12 - Men.**



Source: Labour Force Survey.<sup>6</sup>

**Figure 3: Estimated prevalence of self-reported musculoskeletal disorders caused or made worse by work, by age and gender, for people working in the last 12 months, 2011/12 - Women.**



Source: Labour Force Survey.

<sup>6</sup> <https://handson.hse.gov.uk/hse/public/tableadvanced.aspx?b=simple&a=tablesimple&ShortCode=MDPA1>

A delineation between MSDs caused directly by work and MSDs as a broader category must be highlighted. Current literature regarding MSDs and work often focus on conditions that have been specifically caused by the work environment. However, this unintentionally presents the problem as smaller than it is. MSDs that have not been caused by work often play a significant role in an individuals' ability to participate successfully in the workforce but are often not considered in relation to employment.

There are also variations in MSD rates between different occupational groups. Table 1 shows that households where the reference person worked in a semi-routine or routine job had higher rates of MSDs than households where the reference person worked in intermediate, managerial or professional occupations.

**Table 1: MSD rates by socio-economic group.**

Socio-economic classification of household reference person	Rate (No. per 1000 people)
Managerial and Professional	88
Intermediate	159
Small employers	131
Lower supervisory and technical	154
Semi-routine and routine	184

Source: ONS, General Household Survey, 2010.

In summary, MSD is an umbrella term for a wide range of conditions, which represent a high economic burden in terms of disability rates, use of healthcare services, sickness absence and economic inactivity. It is erroneous to consider MSDs as a condition that only affects older age cohorts, with different types of conditions having different relationships to age. MSDs that are caused by work are often presented separately to MSDs attributable to other sources; this distinction has the potential of underestimating the challenge that MSDs pose in the workplace. The following section looks at why work can be beneficial for individuals living with an MSD.

### 3. The importance of work for people with MSDs

Work is the main means of obtaining economic resources, which are needed for material well-being and societal participation (Waddell and Burton, 2006:vii). Work is often also crucial to social roles, status and individual identity (Waddell and Burton, 2006:vii). There is a difference between 'good' and 'bad' jobs, with low quality work contributing to higher incidences of ill health, the corollary being that high quality work which offers security, variety, worker autonomy and control, appropriate reward and clear procedural justice fosters good health (Coats and Max, 2005).

Problems at work for people with MSDs can have far reaching consequences. The National Rheumatoid Arthritis Society surveyed people living with rheumatoid arthritis (RA), finding that problems experienced at work relating to their condition had an impact on other areas of their life. For example, nearly half of respondents (47%) stated that their social life had been affected, 27% said they had experienced financial problems and 26% reported said they had experienced difficulties with their family, partner, or other relationships (NRAS, 2007:17).

Waddell and Burton (2006) found that people who are disabled or sick should, health condition permitting, be encouraged and supported to work because of the multiple benefits that work can bring. These include:

- Positive therapeutic effects.
- Recovery and rehabilitation.
- Better health outcomes.
- Minimisation of long term physical, social and mental effects of long term sickness absence.
- Reduction in the risk of long term incapacity.
- Promotion of full participation in society.
- Reduction of poverty.
- Improved quality of life and wellbeing.

(Waddell and Burton, 2006:viii)

Despite these findings, work is often not considered as an explicit outcome by health professionals, and the clinical treatment of a person's MSD is often carried out in isolation to the considerations of their current or future working lives. An aim of this report is to see how existing understandings of self-management apply in the workplace.

## 4. What is self-management?

The delivery of healthcare has traditionally been dominated by an acute model of care, which sees patients existing as passive recipients of expert advice and treatment from healthcare professionals (Lawn and Schoo, 2010:206). While this model may be appropriate for acute illnesses, it is not well suited to chronic conditions, including many MSDs. Given their first hand experience of their condition, people with MSDs are often knowledgeable about their illness, and have valuable contributions to make in terms of how to best manage and treat their condition. A new emphasis on the importance of involving patients in their own care is gaining increasing recognition within the NHS (NHS, 2012). By recognising this and encouraging patients to take the lead in managing their condition, greater self-confidence and independence can be fostered.

Self-management will be defined in this study as follows:

*“Self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established.”*

— Barlow et al. 2002:178

This definition was chosen because it is often used in other literature, takes a holistic approach to self-management and the areas of one’s life it affects, and because experts from patient organisations consulted in the preparation of the report favoured this definition. Self-care and self-efficacy are two related, yet distinct concepts that sit alongside self-management. Appendix one establishes further clarity about each term.

Self-management is viewed as beneficial as it can empower the patient to have responsibility over the decisions and actions being made about their condition (Newman and Mulligan, 2004:1467). Self-management can also be linked to reductions in the use of formal care and medication as symptoms are better managed and controlled (Munir et al., 2009). Specifically, in the context of work, self-management could mean that workers are more likely to be able to manage their symptoms effectively and remain in the workforce (Munir et al., 2009:109-110).

## 5. What does self-management mean in practice?

### Self-management behaviours

Self-management behaviours describe the actions and thoughts that a patient uses to manage their condition. These behaviours can include: appropriate exercise and diet, mental strategies to cope with pain, knowledge and ability to advocate for changes in medication, strategies to cope with fatigue and the ability to set and achieve goals related to one's condition. A broad range of factors including social support, spirituality, gender and financial security have all been found to play a role in either promoting or constraining successful self-management (Auduly, 2013). Research has also indicated that individuals with chronic conditions who are younger, 'middle-class', better educated and female are more likely to engage in self-management (Corben and Rosen, 2005:4), and that psychological resources such as maintaining a positive outlook and cultivating discipline and motivation also contribute to effective self-management (Schulman-Green et al., 2012:139). Furthermore, different individuals have different pre-existing levels of self-efficacy (for example see Reeves et al., 2008), which is closely linked to their ability to self-manage. Various personal characteristics mean that different people have different capacities to self-manage, and indeed some people do not want to self-manage their condition at all (Corben and Rosen, 2005:3).

Self-management behaviours develop over time, and are based on both implicit and incremental learning from experience as well as more explicit learning and evaluation of actions (Nio Ong et al., 2011). Auduly et al (2012) identified four phases of self-management, as newly diagnosed people learnt how to manage their condition over time:

- Seeking effective self-management strategies.
- Considering costs and benefits.
- Creating routines and plans of action.
- Negotiating self-management that fits one's life.

(Auduly et al., 2012:331)

The final phase is of particular interest to this study, as once the participants had identified self-management strategies that worked for them, a final phase of adjustment occurred where these strategies were used, rejected, or adapted to fit with their day to day lives. The researchers discovered, for example, that younger people with chronic conditions often found it hard to embed some self-management behaviours into their lives as they were less likely to have a clear routine and a stable job. Auduly et al (2012) concluded that there is a



need for more research regarding how individuals integrate self-management into their everyday lives.

## Supported self-management

Specific interventions also exist which increase an individuals' ability to self-manage their chronic condition. These are often termed 'supported self-management'. Individuals have different capacities to self-manage, depending on their personal characteristics, however supported self-management has been found to develop self-efficacy (Barlow et al., 2002:183; Alderson et al., 1999; Du et al., 2011:308). Even individuals who are initially less confident and motivated can develop new skills and competencies through self-management support and education (Hibbard and Greene, 2013). This study will also work from this understanding that regardless of pre-existing attributes, all people living with an MSD have the potential to improve their self-management capabilities in workplace settings if given the right support.

Supported self-management comes in many forms, and should not be considered as some sort of unified whole (The Health Foundation, 2011:3). It can range from the provision of educational information (either verbally, or using printed materials); to specially designed exercise classes; to one-to-one support and advice; to a peer or health professional led course lasting several sessions and covering physical and emotional aspects of condition management (Du et al. 2011:303). These activities should not be seen as mutually exclusive, as the spectrum of approaches often complement one another when used simultaneously (Lawn and Schoo, 2010:210).

Supported self-management in the form of workshops or courses was first developed by the academic Kate Lorig at Stanford University. Lorig created a course called the Arthritis Self-Management Programme, and later other courses including the Chronic Disease Self-Management Programme.<sup>7</sup> The arthritis programme included the following components:

- Techniques to deal with problems such as pain, fatigue, frustration and isolation.
- Appropriate exercise for maintaining and improving strength, flexibility, and endurance.
- Appropriate use of medications.
- Communicating effectively with family, friends, and health professionals.
- Healthy eating.
- Making informed treatment decisions.

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<sup>7</sup> <http://patienteducation.stanford.edu/programs/cdsmp.html>

- Disease related problem solving.
- Getting a good night's sleep.<sup>8</sup>

These components can be found in the self-management programmes which now exist in the UK, many of which adhere to Lorig's Stanford Model.

Recent innovations in supported self-management have also seen interventions made available digitally. Multiple patient organisations and charities have provided online forums and resources to help individuals to self-manage<sup>9</sup>. Carpenter et al., (2012) examined the use of online cognitive behavioural therapy (CBT) to improve the self-management skills of individuals with chronic lower back pain. The study found that the group receiving the online intervention scored better on all outcomes, including pain severity ratings, when compared to the wait-list group yet to receive the treatment. There have also been efforts outside of experimental settings to make resources available online, with the Health Foundation launching an online resource centre in 2011 to support self-management designed for commissioners, providers and patients.<sup>10</sup>

There are many initiatives that are not explicitly labelled as 'supported self-management' which help people to self-manage their chronic condition. An example of this is the way in which principles of patient empowerment are becoming embedded in how the NHS works. Activities being implemented to empower patients which therefore in turn also encourage self-management include 'Patient Online', an initiative where patients have access to online services such as booking and cancelling appointments, accessing online records and ordering repeat prescriptions.<sup>11</sup>

The principles of self-management are also present, although not necessarily explicitly stated, in work being done by patient organisations. For example, Arthritis Care's 'Arthritis Champions', are trained volunteers that increase awareness and self-management of arthritis by working with community groups and health and social care professionals, as well as providing direct advice and support to people living with arthritis.<sup>12</sup>

Supported self-management has been reported to improve a number of outcomes. The 'Expert Patient Programme' has been found to moderately improve self-efficacy and energy levels (Rogers et al., 2008:23). Mendelson, McCullough and Chan, (2011) evaluated a programme to improve self-management through education and exercise using a wide range of measures and found that participants experienced a statistically significant improvement in self efficacy, participation in exercise, self reported health status, disability and pain levels,

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<sup>8</sup> <http://patienteducation.stanford.edu/programs/asmp.html>

<sup>9</sup> <http://www.arthritis.org.uk/LivingwithArthritis/Self-management/Waystoself-manage>

<sup>10</sup> <http://www.health.org.uk/news-and-events/press/new-online-resource-launched-to-support-self-management/>

<sup>11</sup> <http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/~media/Files/CIRC/POA/RCGP-Road-Map.ashx>

<sup>12</sup> <http://www.arthritis.org.uk/@2973/NorthEngland/arthritis-champions>

and ability to set realistic goals.

Self-management, and the acknowledgement of the important and often expert role that people with long term conditions can play in their own care, is still relatively new in healthcare, and there is evidence of resistance to its implementation. For example, Snow et al., (2013) found in their qualitative study that people with a detailed knowledge of their condition (in this case type 1 diabetes) had expertise that was regarded as inappropriate by healthcare professionals in standard healthcare interactions.

## 6. Placing self-management within broader healthcare trends

There is an increasing emphasis within the NHS for patients to be central to decision making about their care, especially people with long term conditions. The goal is to have informed, empowered patients who are able to take the lead in managing their condition. The NHS Mandate (2013) states that, “involving people in their own care” as the first of four key areas that need to be addressed in order to enhance the lives of people with long term conditions. The ability to self-manage is a key component of this model of healthcare, although self-management may not always be explicitly acknowledged.

The Department of Health report, “*No decision about me, without me*” (2012) highlights the aspiration within the NHS to make ‘shared decision making’ the norm (page 5) . The report states that shared decision making is the principle that a patient and their clinician should work together to, “clarify options and goals for their care, treatment and self-management, sharing information about those options and aiming to reach agreement on the best course of action” (page 5). It also highlights that a key component of successful decision making is the patient having access to the appropriate information as well as having health professionals who support patients to be empowered and involved in their own healthcare. The principles of self-management can be seen to underpin the principles of shared decision making.

One component of shared decision making is for people with long term conditions to have a personal care plan (Department of Health, 2012). A care plan is an agreement between the individual with a long term condition and their healthcare professional outlining how they will manage their condition day to day.<sup>13</sup> Care plans can include: an exercise and eating plan, support services that the individual wants, and goals the individual wants to work towards (which may include returning to work). Creating the plan and the activities listed in the plan can in itself be regarded as self-management. However, the 2013 GP patient survey found that only 3% of all patients had a written care plan, and of those over a quarter (28%) said they did not help to write the plan, indicating that the aspiration of shared decision making is far from being realised.

Self-management has also been explicitly introduced into mainstream healthcare by The Health Foundation, who ran a programme in eight sites across England from 2007-2012.<sup>14</sup> The programme, ‘Co-Creating Health’ involved self-management training for patients and training for healthcare professionals on how to support self-management, and broader

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<sup>13</sup> <http://www.nhs.uk/Planners/Yourhealth/Pages/Careplan.aspx>

<sup>14</sup> <http://www.health.org.uk/areas-of-work/programmes/co-creating-health/about/>

service improvement to better support self-management. The North Bristol NHS Trust, who participated in the programme from 2007-2010, was the one Trust to focus specifically on self-management for people with musculoskeletal pain.<sup>15</sup> A total of 20 self-management programmes were run for patients, and 41 participants completed the training for healthcare professionals. The study team reported difficulties in recruiting clinicians to the training programme, which they suggested may indicate the lack of time that individuals had to attend the training, or a reluctance to engage in a programme which signifies a change of culture and ways of working.

This study examines how these new trends within healthcare consider, or should consider, employment.

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<sup>15</sup> <http://www.health.org.uk/areas-of-work/programmes/co-creating-health/related-projects/north-bristol-nhs-trust/North-Bristol-NHS-Trust-work-so-far/>

## 7. Self-Management and Work

Existing supported self-management interventions predominantly focus on symptom management (Johnson et al., 2013), and not the context in which self-management might take place. There is an argument that supported self-management should take a more holistic, biopsychosocial approach in order to maximise its impact (Glasgow et al., 2012; Rogers et al., 2008). Self-management in the context of the workplace is one area in need of further research. This report takes a broad definition of employment, which includes employees, but also individuals who are workers, self-employed, contractors, directors, and office holders.<sup>16</sup>

For people with an MSD, their condition cannot exist in isolation from their working lives. Research has demonstrated that most employees with chronic conditions carry out self-management of symptoms, such as taking medication, in the workplace as well as outside of the workplace (Munir et al., 2008).

A person's MSD is often a part of their working life because they choose, or are forced by circumstance, to disclose their condition to their employer. Individuals with chronic health problems must often disclose their illness to their employer as a consequence of taking sickness absence for repeated or prolonged periods of time, or due to having fluctuations in their work ability as a result of their condition (Munir et al., 2008). Others may disclose their condition in order to receive support and workplace adjustments (Munir et al., 2005). For people with an MSD who work, or want to work, self-management is intertwined with employment.

However, some workplaces may not be conducive to self-management behaviours. Munir et al. (2009:113) found that participants in their study (who were employees with one of the following chronic conditions: musculoskeletal pain, arthritis and rheumatism, asthma, depression and anxiety, heart disease, diabetes), were not likely to monitor and respond to their symptoms in the workplace (apart from older workers with asthma). Reasons for this included: inadequate workplace policies, flexibility and accommodation for chronic conditions. An alternate explanation suggested by the authors was that some conditions do not require active management and monitoring in the workplace. This research suggests that the specific workplace context is important for facilitating self-management, and must be considered when equipping people with chronic conditions with self-management skills.

The skills and competencies that supported self-management encourages are often relevant to managing MSDs in the workplace. Shaw et al., (2012) found that elements of generic self-management programmes for musculoskeletal chronic pain (namely learning strategies to

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<sup>16</sup> <https://www.gov.uk/employment-status/overview>

tackle activity interference, negative self perceptions and interpersonal challenges) were highly relevant to work. Allaire, Li and LaValley (2003) found that fatigue was one of the most common employment barriers for people with rheumatoid arthritis; self-management interventions which focus on symptom management are designed to assist with this.

Self-management is a key determinant of people with MSD's ability to successfully participate in the workforce. Research suggests that individuals who are aware of their condition and are able to negotiate necessary workplace adjustments are more likely to have improved health and work outcomes (Gignac, 2005). Gignac et al. (2004) found that employees with arthritis experienced reduced symptoms and increased psychological wellbeing if one or more workplace adjustments were made to improve the management of their condition.

Self-management interventions focussing on work or which are based in the workplace are gaining increasing recognition, especially in the USA where health insurance often forms a part of employment packages and can be used to fund interventions (The Health Foundation, 2011). Allaire, Niu and LaValley (2005) tested a job retention intervention for people with a chronic condition, consisting of a counsellor working one-on-one with a participant to identify workplace barriers and solutions, providing counselling, guidance, education and self-advocacy skills (2005). Results indicated that the incidence of job loss was both delayed and reduced among those who had received the job retention intervention. This result was still significant at 48 months post intervention (Allaire, Niu and LaValley, 2005). The MS Society's Working Yet Worried toolkit is another example of a specific workplace intervention for chronic conditions (MS Society, 2010). The toolkit is a booklet containing information on disclosing MS to an employer, legal rights, negotiating workplace adjustments, and managing emotional and physical symptoms. With regards to MSDs, patient organisations such as Arthritis Care and the National Rheumatoid Arthritis Society provide information on their websites about working with an MSD. NRAS, for example, provides information on the 2010 Equality Act, and Arthritis Care provides information about work for people living with arthritis and also for employers and healthcare professionals. However, work specific programmes are in their infancy, often only existing in the form of academic, one off interventions, conducted for research purposes.

In summary, people living with MSDs need to be able to manage their condition to engage successfully in employment. Existing supported self-management initiatives can provide people with chronic conditions with the skills related to symptom management and building self-confidence which are highly relevant to the workplace. However, work is not often considered explicitly as an outcome, and the ways in which self-management skills translate into the workplace need to be investigated further. There are some supported self-management initiatives for chronic conditions which are specifically designed for the workplace, and those that have been evaluated have shown positive results. However, such initiatives are limited.

## Research Aims

- How do individuals with an MSD self-manage their condition in the workplace?
- How are individuals currently supported to self-manage their condition in the workplace and how well does this support work?
- Are there barriers to effective self-management in the workplace?
- How could self-management be improved for those with MSDs in the workplace?
- What roles do different groups (clinicians, employers, patient organisations, people living with an MSD) have to play in the self-management of MSDs in the workplace?



## 8. Methodology

Semi-structured interviews were conducted with working age individuals with an MSD diagnosis. Interviewees were asked about how they self-manage their condition at work, and what support they received for doing so.

The sampling criteria were as follows: Interviewees must be of working age, and either currently working or seeking work. Participants were recruited through patient organisations and charities. Interviews were conducted over the telephone, transcribed, and then analysed using thematic analysis to identify common themes raised by participants. The thematic analysis was inductive in nature, in that themes were developed through close reading of the interview transcripts. The interviews and the analysis were conducted by two researchers to establish inter-rater reliability by arriving at the eventual thematic analysis by interrogating and assimilating one another's interpretations.

Qualitative interviews with participants of self-management programmes were chosen as an appropriate approach for two main reasons. Firstly, self-management is based on an understanding that the patient has the ability to lead the treatment of their condition. If the study were to prioritise the perspectives of healthcare professionals, or employers, it is felt that the recognition of patient's abilities and expertise would be undermined. That said, research in this area could be fruitfully extended by investigating the attitudes of employers and healthcare professionals *alongside* patients. Secondly, the study stems from earlier quantitative work conducted by The Work Foundation which identified that self-management could be linked to lower levels of concern about job loss (Zheltoukhova et al., 2012). A qualitative methodology offers the opportunity to explore the processes by which self management is carried out in the workplace context. Furthermore, semi-structured interviews were used because it was felt they gave the necessary structure to explore the specific research aims, but were also open enough to allow what was important to participants to be explored.

In total 15 interviews were conducted. Interviews were conducted until the interviewers felt saturation was reached, meaning that there were no substantially new themes emerging when another interview was conducted.

A number of biases can be identified in the sample: the majority of participants were female (12 women and 3 men took part in the study), and the majority of participants had office based jobs (although some participants had active jobs, and some had jobs which required a mixture of manual and non-manual tasks), meaning that male voices and the voices of those engaged in manual work are underrepresented in the study. Furthermore, participants were recruited through charitable organisations, meaning that to participate the individual had responded to an advert in a newsletter or on an online forum, suggesting that the

participants may be more proactive and engaged with issues concerning their condition than other people living with an MSD. It is important to consider the implications of these factors when interpreting the results.

## 9. Results

The following section presents the results from the thematic analysis of the interview data.

### 1. Participants' understanding of self-management.

All participants were able to offer a definition of the term self-management, and explain what it meant to them. While self-management exists as a relatively new notion within the healthcare profession, the participants were comfortable and familiar with the idea.

Participants were asked to describe the main features of self-management to the interviewer. One of the central components of the definition of self-management for participants was the idea of taking responsibility for one's condition. One participant defined self-management as taking responsibility for one's condition, and realising that an individual's actions could play a role in how they experienced their condition.

*"It means to me like not negating responsibility for your condition, but realising that what you do has a role"*

— Participant 3

Participants also used more imperative language, and talked about self-management being about not letting their condition overwhelm or rule them.

*"I've got to make changes to make sure this illness doesn't overwhelm me and I've got to take charge of it really."*

— Participant 5

Some expressed this need to be in charge of their condition in terms of themselves or their lives in a more holistic sense. It was important to not be overwhelmed by one's condition because then the condition was not the central or guiding feature of the participant's life.

*"And I refuse to let this condition rule my life."*

— Participant 13

For the majority of individual's interviewed, self-management was about personally taking control of one's condition and the resulting effects that it had on their life:.

*"You're taking control basically is self-management."*

— Participant 5

There was also the understanding that medical professionals could only provide a limited set of solutions for individuals living with MSDs or other chronic conditions, and that ultimately it is up to the individual to find solutions to living with a chronic condition, once again highlighting the importance of taking responsibility and control for how the disorder is managed.

*“Doctors can’t change your life, because with arthritis you have to change your life around.”*

— Participant 10

The role of medical professionals was identified by some as being limited both in terms of scope and time. The role of rheumatologists was expressed as being most pertinent at the beginning of the onset of the condition, when identifying appropriate medication. Rheumatologists were also crucial in that they were the ones to provide a diagnosis of an MSD, with many participants reporting delays in receiving a correct diagnosis and therefore living with unknown and uncontrolled symptoms for some time. Beyond this, individuals tended to take responsibility for the MSD themselves, often justifying this on the grounds that personal experiences of how one feels was the crucial insight which individuals living with an MSD uniquely possessed.

*“Yes, I think the initial hard work was all done by the specialist, and all the detective work and trial and error with the drugs. But the rest now is down to me, I’m the one living with this, I am the only one that knows how I feel.”*

— Participant 7

An individual and the self-management of their condition does not exist as a binary distinction. It is not the case that the individual is either self-managing or not, but rather that individuals have different capacities to self-manage in different contexts and at different times. A key distinction to be made about the gradations of self-management is the process by which individuals become capable of self-managing following the initial onset of the condition.

Several factors contributed towards the capacity to self-manage being a gradual process. Many individuals described a significant gap between the onset of symptoms and receiving an appropriate diagnosis, following which it also took time to receive appropriate medication and for symptoms to be brought under control. Furthermore there was also the possibility of the condition flaring meaning that the symptoms which individuals were managing could change rapidly and unexpectedly. This indicates that self-management capabilities develop and are adapted for each individual over time.

One individual described the process by which their mind-set changed, and they therefore became more able to self-manage their condition, as akin to bereavement.

*"I think my mind-set was changed.. I think I almost went through the seven steps of like loss and all the rest of it. I was angry about it, I was in denial. Then I sort of thought if I take these drugs and find out all about it then I'll be as right as rain."*

— Participant 15

An individual's capacity to self-manage is a process as opposed to static, and is also a process that can be sped up or slowed down. One interviewee explained that they were not given sufficient information by their doctor about the nature of their condition, implying that they would have liked to have been given access to more information so that they could have begun to educate themselves more quickly about their MSD.

*"They have to have knowledge before they can... they have to understand their illness. And being given that one little flimsy leaflet on rheumatoid arthritis isn't enough for a patient to fully understand their illness. Self-management gets better the longer you have an illness."*

— Participant 7

The process of equipping oneself with knowledge of one's condition and how it could be managed or treated was something that many participants said they were proactive in doing, and which they did through a variety of means.

*"I think because I've had it for such a long time now, and I am proactive in sort of looking at stuff and thinking that might help, or right this is a problem what can I do about it."*

— Participant 12

Interviewees identified personal attributes which they believed made them particularly good at looking after and controlling their condition. One individual described how an acute awareness of how their body felt made them able to look after their condition well, combined with being a "sensible patient".

*"I think I am a sensible patient, and as I said I think I am an expert patient. I know exactly how I feel and how my body is, but there are a lot of people who aren't."*

— Participant 7

However, some participants pointed out that personal attributes can fluctuate, and that an individual's mood could lead to variations in their ability to self-manage.

*"I think we can all be effective and non-effective depending on how your mood is. We all have times when you're down I suppose"*

— Participant 12

For others it was external personal factors, as opposed to personality traits, that were decisive in their ability to self-manage. Money was identified as one of these external factors, as having adequate savings meant the individual had time to adapt to living with their new condition without encountering serious financial problems. Education was also a factor, with one interviewee explaining that being well educated made one more capable of successfully negotiating the support networks and sources that were available, aiding their ability to self-manage.

*“Education, if you have education, if you’ve got a good education.. I am not talking about the way you’ve been brought up, but if you have a degree, if you have a good education then you’re more likely to be able to help yourself.”*

— Participant 10

For some the term self-management was not a useful one, as it was seen as lacking in substance and not adequately capturing what an individual living with a chronic condition does or should do.

*“For me personally I just feel like it’s a buzz word, and it’s just.. when it becomes a buzz word, I feel there’s not enough substance behind it. If you’re going to talk about self-management, really tell me what self-management is. Tell me all about it, and how I can learn and use it.”*

— Participant 13

**In summary, most participants had a high level of familiarity with the concept of self-management. In general the term was understood to mean having control over one’s condition, and not letting oneself be overwhelmed by the condition and its symptoms. Tied to this was the idea that medical professionals had a limited role to play in the management of the condition, as ultimately it was the individual who was best placed to understand and manage their MSD. Self-management was also constructed as a gradual process, whereby competency to self-manage developed, and can also fluctuate, over time. Personal traits were important in determining one’s capacity to self-manage, with a positive mind-set and a proactive attitude, as well as external factors such as a high level of education and a strong financial position contributing to high self-management capabilities.**

**It was also the case that most of the individuals interviewed considered themselves to be competent, or good, at managing their condition, and saw or imagined that others experienced difficulties. This may in part be due to the sampling bias which meant that individuals who felt confident about living with their condition were more likely to be willing to talk about it with an interviewer, but may also reveal that individuals tend to each find ways to adapt and successfully live with their chronic condition, as opposed to being overwhelmed by it.**

## 2. The individual, the nature of musculoskeletal conditions, and self-management.

The nature of the individual and their personality, and how the condition presented itself was another theme that arose when discussing factors contributing towards an individual's capacity to self-manage. It was quite common for individuals to describe their approach towards their illness with combative language. Some, for example, described their relationship with the symptoms of their condition as a fight.

*"If I just go into it, sleeping at night is very very difficult so I wake up tired in the morning if that makes sense. I really have to fight."*

— Participant 1

Others discussed conquering the condition. Again this suggested that for many, living with an MSD was not always about accepting the MSD and its symptoms and letting it become part of one's life, but instead actively pushing against the symptoms being experienced and trying to suppress the impact that they were having on the person's life. However, some participants expressed reservations about their efforts to fight their illness, citing that it could make their symptoms worse.

*"Sometimes I try and work through it, which probably isn't a terribly good idea. Drink lots of strong coffee. I think I just try and get on with it, and get more sleep. I try and conquer it."*

— Participant 3

Despite some participants having great clarity about how they approached their condition and their mind-set and outlook, others found this more difficult and they could not clearly express exactly how they approached managing their condition. As one participant stated when asked what it was about them that made them able to cope with their MSD:

*"I don't know. I don't know whether it's partly just what I am like."*

— Participant 3

Other interviewees described their approach to their illness not in adversarial terms, but in terms of 'getting on with it'. This approach was quite different to thinking of oneself as fighting the illness as the individual attempted to limit the influence the condition had over their daily lives. For these individuals, not moaning or complaining were key aspects of managing their condition. Interviewees expressing this self-management approach were critical of others they had come across who they perceived as grumbling about their long term condition, and viewed it as attention seeking behaviour. 'Getting on with it' appeared to be connected with the length of time since diagnosis, meaning the individual could draw on their experiences of managing their condition, instead of allowing it to become a central feature of their daily life.

*“The condition, because I’ve had it for so long, I just know – there’s not a lot known about it and I get on with it.”*

— Participant 9

The same interviewee also talked about using a positive mental mind-set to approach their condition, and spoke about how a positive attitude can mean symptoms are not experienced as severely.

*“I think it’s your outlook on life, and I suppose I’ve had it for a long time, I got it when I was in my 20s but when people start wallowing in it and you can get really depressed with it. You can understand why you would be but – that just makes everything worse doesn’t it? I think as well, if I didn’t have a more positive look on things, I think that makes you – you are depressed and obviously the pain probably gets worse doesn’t it, and everything just feels, it’s all magnified isn’t it.”*

— Participant 9

A variation to taking a positive approach towards their condition described by participants was to focus on their capabilities. Instead of focusing on and lamenting the things that their illness prevented them from doing, it was more useful to participants to focus on all of the things they could do.

*“But it’s getting your mind-set prepared, actually okay there are things I can’t do, but there’s loads more things that I can do.”*

— Participant 13

Participants often spoke of the fact that they did not want their condition to be a central component of their identity. Indeed, one participant described how, unlike other people, they did not allow their condition to take over them:

*“Whereas there are people who they let it consume them and then they get a bit obsessed with the whole reality of it and the facts of doing everything, they can’t cope with change can they really?”*

— Participant 9

The extent to which participants’ MSDs formed part of their identity was also revealed when they spoke about their disability status. Results revealed hugely divergent notions around self-perceptions of being disabled which to an extent could be linked to the severity of an individual’s condition. However, it seemed that beyond this individuals were either comfortable or uncomfortable with labelling themselves as disabled according to how they conceived of themselves, regardless of their symptoms. Some participants did not think their experience of their condition equated to having a disability.



*“well I don’t like to class myself as having a disability”*

— Participant 5

However, others spoke about a period of acceptance, and how over time they came to see their illness as meaning that they were a disabled person.

*“But actually took mine, thank god someone decided I should apply for a Blue Badge. In fact I was saying to my daughter only a couple of weeks ago, I think I’ve finally accepted I am disabled, because of this illness.”*

— Participant 7

The way in which someone conceives of themselves and their condition has important ramifications for the sort of support or assistance that is offered to them, or which they seek, and how they then make use of it.

As well as the personal internal attributes pertaining to mind-set and self-identity, an individual’s financial status and their education were influencing factors in a person’s ability to self-manage. One participant explicitly spoke about how their savings allowed them to take time out from work to adjust to their condition before seeking a job setup that was suitable for them. Without a financial cushion, the participant explained that they would not have been able to cope with the onset of, and requisite adaptation to, their condition.

*“Fortunately I had savings, so I lived off my savings for a while, because the benefits weren’t doing their job. Without savings, without education somebody just working in a sandwich bar and get in that situation, I don’t know how they would cope, honestly I have no idea.”*

— Participant 10

Education was also viewed by some participants as being advantageous in that it equipped an individual with the skills to get the assistance that they needed, implying that someone who was not as well educated would have difficulties advocating for themselves and accessing support.

The nature of MSDs was found to have a bearing on how an individual is able to self-manage. For many of the interviewees there was a delay between experiencing symptoms and receiving an appropriate diagnosis. It also often took an extended period of time for symptoms to come under control, and for the medication regimes most suitable for the individual to be established. This meant that the onset of the condition was a hugely challenging time for the individual, as they experienced symptoms which were either unidentified or uncontrolled. One participant described how the decline following the onset of symptoms can be very rapid, meaning that one can be caught off guard, and unable to react to limit the damaging effects of early symptoms.

*“rheumatoid arthritis you kind of.. it’s not like.. you find yourself in a very very bad place, very quickly. Which means that you don’t have time to make any adjustments.”*

— Participant 10

Another participant described their approach following the onset of their condition as survival, suggesting that during this period it was very difficult to respond to symptoms in a way which brought them under control to reach a state where they felt settled. The participant described this period as lasting from four to five years, from getting the correct medication and learning how to structure their life so their symptoms were under greater control.

The early stages of living with an MSD are made more challenging by the fact that the way in which the disease will manifest itself is unique to the individual. It was through personal experience and living with the illness that participants learnt how to cope with it; second hand information was often not very useful because of the highly individualised nature of MSD symptoms. As one respondent put it:

*“I didn’t know that everyone is an individual as far as this thing goes.”*

— Participant 15

The interview results indicated that when individuals first experience symptoms and are trying to adapt to living with a chronic condition it is difficult to prioritise work, despite recognising the importance of adapting their work life to fit with their chronic condition.

*“Quite honestly in the throes of when you’re going through diagnosis, medication, not being able to sleep, fatigue, it was almost the last thing on my mind then, it’s like just battle through. But in reflection, had I had all my faculties back then maybe I’d have questioned it harder. But that would have made life easier for me I think.”*

— Participant 15

With regards to the specific symptoms associated with MSDs, pain was a huge component of the participants’ experiences of living with an MSD. There were serious implications for individuals if their pain was not under control as it had knock on effects for their wellbeing more generally. Poor mental health can also affect one’s ability to work, and several participants discussed depressive symptoms. One participant, for example, talked about the physical, emotional and mental repercussions of living with pain:

*“obviously the pain is affecting a lot on my sleep, and obviously when you’re not so very well.. for me I get very tearful, I can’t concentrate and it’s causing an awful lot of problems.”*

— Participant 10

Some participants voiced pain management as being the most important component of managing their condition, because the repercussions of uncontrolled pain were so serious.

*“That’s the most important thing, is keeping on top of your pain, because if you’re in pain you just shut down, you just don’t move much and you’ll get bad health.”*

— Participant 7

Fatigue was raised as a serious, and often very consistent feature of people’s everyday experiences of living with MSDs. Feeling fatigued was not at all akin to feeling very tired; feeling tired can be remedied by going to sleep, but participants explained that sleep had little effect on fatigue. One participant explained that there was a lack of awareness about what fatigue was and how it affects an individual:

*“Fatigue I don’t think you can understand it, unless you medically or trained in it, if you know what I mean.”*

— Participant 15

Participants explained that fatigue had an impact on their ability to function, and that they had to struggle against their feelings of fatigue in order to go about daily activities.

*“you get quite a lot of fatigue with rheumatoid arthritis. Periods when it just seems very difficult to function, to do anything because you just want to sleep.”*

— Participant 3

Fatigue was reported as being a particularly difficult symptom because there was no medication to control or reduce it. The only way in which individuals could tackle fatigue was by resting, which in turn necessitated considerable mental adjustment in terms of an individual’s expectations about the amount they could do each day.

*“It affects everything and the biggest problem I have is the fatigue. It’s not tiredness, it’s totally drained and that is my biggest problem I would say because you can take the pain with the cocodamol and paracetamol and that. But there’s absolutely nothing you can do about the fatigue and that doesn’t really get much better even with the injections.”*

— Participant 11

This adjustment in terms of what can be achieved in a day often meant that participants would expend their energy while at work, and then use their time at home to rest and recover, meaning that their home life was sacrificed for the sake of their working life. This rebalancing of energy expenditure can be considered a form of self-management, albeit, it could be argued, an unsatisfactory one.

*"I come home and go to bed, yeah. I don't go to sleep, I just, it's back to this fatigue thing, I come home, and I have to lay down. So I suppose in that way yeah, I suppose you could say that work is affecting life."*

— Participant 11

As a result of the perceived lack of awareness reported by the participants about what fatigue meant, participants reported that others would not understand and therefore not be empathetic or supportive if they told them they were feeling fatigued. Some interviewees explained that they sometimes used other condition symptoms (e.g. pain or headaches) to communicate they were feeling unwell, when in fact they would be feeling fatigued.

*"I just felt the fatigue gets to me sometimes. I can't believe.. you can't phone in and say I'm a bit tired to come into work. So I just said I'm ill, and sort of gloss over it. I have done and I probably will do in the future."*

— Participant 15

The results also indicated the issue that living with an MSD is made more challenging because many of the symptoms are often invisible. Participants talked about how this meant that it was more difficult for others to understand the nature of their MSD and to offer appropriate support. For some participants, it was even expressed as others being suspicious of their condition because there was a lack of physical evidence for its existence.

*"I think people get very wary of when – because mine is more or less an invisible disability because to look at me you wouldn't think that I was taking as many drugs."*

— Participant 2

Another participant similarly explained that the invisibility of their condition could be a disadvantage, because others were less inclined to help when they were struggling.

*"People wouldn't know. Sometimes that can go against me, because it's a bit like you're trying to do something and then you know that you're struggling to do something. And people go.. they don't accept it."*

— Participant 13

One participant even reported wearing their wrist splints when they felt unwell, despite the problem not necessarily being their wrists, as a physical signifier of their condition and how they were feeling:

*“I used to wear a wrist splint on the days that I felt particularly bad. Because even if it wasn’t my wrist, I just felt it would be a good way for people to know that everything wasn’t ok, without having to tell people.”*

— Participant 2

However, despite the negative repercussions of MSDs often being invisible conditions, some participants also talked about how this could be a good thing as it meant they were not easily identifiable as unwell or disabled, and therefore were not automatically thought of or treated as different.

*“The invisibility of it, that’s a very good way to put it, invisibility of it is really really difficult. If I was blind and had a white stick people would understand why I may react in certain ways and in certain situations. Also at the same time I don’t want to be singled out, because I have a spinal disability with my spine. It’s a difficult one.”*

— Participant 13

The symptoms of MSDs were also reported as being unpredictable, making it difficult to manage the condition, and difficult to plan for the future as the condition could flare unexpectedly.

*“But as I say, it’s a moveable beast, it’s when you think that things are settled then things sort of come up again.”*

— Participant 2

*“Yes, because you can’t plan anything and you don’t know if you’re not going to feel well.”*

— Participant 9

Some participants dealt with this unpredictability with the idea that no one, regardless of whether they have a long term condition or not, knows what the future holds, and for them, their MSD may be one specific cause of uncertainty in the future.

*“you never know what’s going to be round the next corner, none of us do”*

— Participant 15

**The nature of the individual and the nature of the condition were found to have a bearing on self-management.**

**Different individuals took a different approach to coping with their MSD. Some conceived of their relationship with their condition as a fight, and as something which they needed to conquer. Others, however, spoke about having a more positive**

attitude, and ‘getting on with it’, ensuring that they did not allow their condition to become an overbearing component of their identity. Linked to these differing attitudes were variations in how individuals conceived of their own disability status, which in turn has implications for how self-management is conducted and how support is received.

The nature of the condition also presented challenges for self-management. Participants reported delays between first experiencing symptoms and receiving an appropriate diagnosis, and then further time being taken to establish appropriate medication regimes. The time it took for the condition to be diagnosed and treated, combined with the fact that the course of MSDs are unique to each individual, and the inherent unpredictability of symptoms, mean the early stages of an MSD are very difficult to self-manage. Participants spoke about how self-management in context of work was a particularly low priority when they were first diagnosed. The specific symptoms of pain and fatigue were cited as being key for keeping under control. It was also noted that the often invisible and misunderstood nature of these symptoms increased the difficulty of self-managing them successfully.

### 3. Methods of self-management.

Interview results provided a range of examples of the methods individuals used to manage their MSDs.

The interviews revealed three main ways by which individuals gathered knowledge which assisted them in self-managing their condition: they were either given that information proactively by others, they sought out information from third parties themselves, or they used their own first hand experiences of living with their MSD. There were some examples of external groups or individuals proactively giving information to participants which could be used to assist with self-management. One interviewee, for example, described how their doctor had given them leaflets which informed them about sources of support.

*“I remember one of the consultants did hand me leaflets about National Rheumatoid Arthritis Society [NRAS] and stuff and said there are support networks and things.”*

— Participant 3

However, the evidence also suggested that the individual themselves must be receptive to receiving this information if they are going to benefit from it. One participant spoke about the efforts they went to in order to ensure they attended talks or groups recommended by their consultant:

*“he’s been my consultant for the past 18 years so every group, every talk or anything that he’s offered for me to go on, I’ve changed my working day, I’ve taken leave, taken flexi. And I’ve gone on them because I’ve just thought the more information I know about it the better it is for me.”*

— Participant 5

Rather than information from secondary sources such as leaflets, books and talks, there were also instances where information was proactively sought by individuals in the form of direct advice, often from medical professionals, and in particular specialist rheumatology nurses.

*“I’ve taken a lot of guidance from the rheumatoid arthritis consultant and in particular her nurses.”*

— Participant 7

However, medical professionals proactively providing information and advice was not universal, and there were examples of interviewees who had not had self-management related information provided to them by healthcare staff. Indeed, one participant explained that they did not expect healthcare professionals to provide them with information and advice, and that they should instead take the initiative themselves:

*“Not really. They haven’t really got the time for that. I feel that it is, you have to get out there and find out stuff.”*

— Participant 6

There were many examples of interviewees having to be more proactive in gathering information which would enhance their ability to self-manage. Participants described how they sought out information when they had a specific problem that they needed to deal with. As the following participant states, it appeared to be the case that living with an MSD for longer provided one with the opportunity to be more proactive, as symptoms were often more under control and the individual had an understanding of what their condition entailed.

*“I think because I’ve had it for such a long time now, and I am proactive in sort of looking at stuff and thinking that might help, or right this is a problem what can I do about it.”*

— Participant 12

Several participants were also proactive in that they read leaflets or journals that they were sent, and appeared to aim to build up a broad knowledge of their condition, as opposed to targeting their information gathering to tackling specific issues when they arose.

*“How I self-manage, I read everything that gets sent to me, like I am with Arthritis Research and stuff like that, so whenever the journals come out I read up about everything.”*

— Participant 12

Being proactive about information gathering for self-management was often facilitated by the internet, and in particular many participants would use online patient forums to share information with others, with ‘Facebook’ and internet forums provided as examples..

Although the use of the internet appeared to open up many avenues through which participants could access information that would assist them in self-managing their condition, it is worth remembering that some individuals may not have the requisite computer skills or facilities to use the internet for such purposes. Furthermore, there was some evidence to suggest that using internet searches as a source of information meant that there was a degree of unpredictability regarding what the searcher comes across. This may mean that there are negative consequences to using internet searches; for example, the individual may not find the information they are looking for, or they may come across incorrect information. However, individuals may also come across information inadvertently which is beneficial to their self-management. One participant described how they came across the main charitable organisation for people with rheumatoid arthritis by searching their rheumatologist online.

*“By Google-ing my consultant I found out about NRAS and then signed up to them and took it from there.”*

— Participant 15

Despite participants often reporting either being given information, or seeking out further information to aid with self-management, the highly individualised nature of MSDs meant that for many a significant mode by which information was gathered was through personal experience and trial and error.

*“Trial and error. I listen to my body now.... I just have to listen to my body much more so if I feel tired, then I would just go and lie down.”*

— Participant 2

The importance of personal experience in gaining information and understanding about one’s illness, and therefore improving self-management capabilities also threw light on the limited ways in which some participants believed medical professionals could contribute to the management of their condition, as they did not have first hand experience of living with the individual’s MSD.



*“Yeah, a lot of it’s trial and error. Obviously you know your own body better than any professional. So you know what will work best for you and what will be more beneficial to you.”*

— Participant 14

Several participants still expressed that there was not enough information available to people living with MSDs, and in particular participants suggested that information was lacking about self-management in the context of work.

*“I don’t think there’s enough knowledge about your rights at work, about what can be done.”*

— Participant 10

The table below summarises the major channels through which knowledge and support is passed to the individuals with MSDs, and demonstrates the vast array of ways in which individuals are equipping themselves with information to enhance their self-management.

SOURCE	EXAMPLE
Books	<p><i>“Also [I] very carefully selected a few books. I think I ordered a billion leaflets from Arthritis Research UK and I’ve read them all.”</i></p> <p>— Participant 7</p>
Charities	<p>In the form of helplines and support services:</p> <p><i>“Telephone, they have a helpline number so I’ve been ringing them for some advice because at first I was having quite a few problems with work and they put me in touch with obviously disability support officers.”</i></p> <p>— Participant 14</p> <p>As well as in terms of the literature they can provide:</p> <p><i>“they’ve been giving me a lot of booklets to give to me employers about ..... Just basically trying to broaden everyone’s knowledge of the condition”</i></p> <p>— Participant 14</p>
Family and friends	<p><i>“He’s been an absolutely star throughout this whole thing. He’s had to learn a lot as well, it’s not just the person. I am very fortunate in having family and friends.”</i></p>

— Participant 15

*“I’ve had both my parents totally understanding and not doing the ‘pull yourself together’ thing. I’ve just heard that some people go through quite a lot of it.”*

— Participant 15

While most had positive experiences of their family supporting them through the condition, on participant explained how his ex-wife had a low level of understanding about his condition and so was less able to assist him.

*“my ex-wife didn’t understand my arthritis one little bit. And it was difficult to explain things to her and I think it’s just the whole awareness of the condition”*

— Participant 8

GP

There was evidence that GPs offered very specific advice with regards to how individuals should self-manage their condition:

*“And he said I should get a job that’s more physically active than sitting at a desk.”*

— Participant 8

However, it appeared that for most interviewees, GPs played a secondary and less important role to the rheumatology team that supported them.

Internet search

*“I know I suppose most people have access to the internet. I think that is the most easiest and most direct way to take charge of this, because it is so much good information out there and help, which is all free ostensibly, because all you have to do it get on sites.”*

— Participant 15

*“No, I’m sure if I Googled then I could find it. I’m not at the point yet where I feel I need to push for it.”*

— Participant 9

Despite the internet generally being viewed as a positive thing,

and a very rich source of information, some participants talked about not wanting to be exposed to the information and experiences posted online:

*“You go on the web and you read that stuff it’s all quite depressing so I don’t like to read into it really.”*

— Participant 9

#### Journals

Some participants spoke about gaining a quite clinical understanding of their condition:

*“How I self-manage, I read everything that gets sent to me, like I am with Arthritis Research and stuff like that, so whenever the journals come out I read up about everything.”*

— Participant 12

#### Online forums

Online forums were a very important source of knowledge for many participants, both because they offered a wealth of information and because they offered a sense of community and support.

*“Well I’d say I do look at Health Unlocked quite a lot to see because then if there are people that – it’s a really unknown entity when you first are diagnosed. And so you don’t know anything about the drugs, the disease, you don’t know what’s normal, you don’t know – it’s just reassuring to know that there are other people that are in the same position as you, that you don’t feel quite so isolated.”*

— Participant 2

*“Because I’m on a lot of groups and there’s a lot of forums but then again, you’re talking to people that are going through it and you learn a lot from it, what you can do to try and help yourself.”*

— Participant 5

However, some individuals did not like the less positive information which being part of a forum exposed them to.

*“I was part of the forum, a website forum. But it was quite depressing!”*

— Participant 9

There was also the factor that forums offered a good alternative to face to face support groups, as they offered a broader range of information that the individual could access when it suited them.

*“Well people put questions on and have a moan and things like that. And you can pick things up from it and at least you know that you’re not the only one because we don’t have groups round here and to be perfectly honest, I’m not a group person. But I wouldn’t want to go and sit in a group listening to a lot of people whingeing. To look on the forum of a morning when I go on my computer, you’ve got about 8 or 9 things on there that you just look through.”*

— Participant 11

Personal experience

As has been discussed previously, personal experience of one’s own condition was a hugely important source of information for individuals and self-managing their condition.

*“Yeah, a lot of it’s trial and error. Obviously you know your own body better than any professional. So you know what will work best for you and what will be more beneficial to you.”*

— Participant 14

Rheumatologist

The rheumatology team were often an important source of information for participants.

*“I’ve taken a lot of guidance from the rheumatoid arthritis consultant and in particular her nurses.”*

— Participant 7

However, some participants felt that their rheumatologists did little to impart information to them.

*“I’m not saying he’s blasé about it, but he probably forgets that he knows probably everything there is to know, and he can’t transmit any or much or all of that to a person.”*

— Participant 15

There was also a time limited aspect expressed in terms of when information from rheumatologists was most important. One participant explained that earlier in the course of the illness was a more important time for rheumatologists to be sharing information with them.

*“So at this point in time, the medical professionals have got a really big part to play in my condition because I’m still learning and they’re still learning about my condition. So it should basically I need to step back and listen to them and they’re telling you things for your own good and telling you that the hours that you’re working aren’t benefiting for yourself and you need to listen to them. So they do have a big part to play in my condition.”*

— Participant 14

Some participants also had negative experiences with their rheumatologist, in that they felt the time pressure of their appointments with them made it very difficult to have a discussion.

*“This is probably just an NHS moan but they set you out your 5 minute time slot anyway so I don’t know what you could really accomplish if you had problems. .. always running about an hour late anyway. You never feel like you can just have a chat, even if you wanted to.”*

— Participant 9

#### Specialist nurses

There was a considerable amount of praise for specialist nurses, who often could provide detailed information and advice, and were also often reachable by phone.

*“I just phone up one of my specialist nurses. Because they know fine, that’s no disrespect to my GPs, but my old one and my current one are very fantastic. But I’d rather go to somebody who is more specialised in the care of rheumatoid.”*

— Participant 12

*“It’s not just the consultant, I think we have rheumatologist specialist nurses that are only a phone call away.”*

— Participant 5

#### Support groups

Most participants who were members of support groups reported positive experiences, with the groups acting as sources of information but also providing solidarity for its members.

*“I am also a member of the NRAS arthritis.. they have a very good group here in Newcastle, and the group meets quite regularly.”*

— Participant 10

*“I have become involved in a local self help group for Arthritis Care which is run by colleagues in the hospital. So we meet on average once a month and that can be ok, we occasionally get guest speakers but what we were doing 12 months ago was mobilising ourselves to try and keep our department open.”*

— Participant 1

There were some instances of interviewees not finding their support group very helpful, the problem being that the content of the sessions were predominantly negative.

*“While that group is great, I don’t find it helps me that much, because all I’m hearing is people moaning.”*

— Participant 13

A major component of the self-management of an MSD for participants was learning one’s limits and learning to pace oneself. It emerged that learning to pace oneself was a self-management technique which took time to develop, and often resulted from knowledge accumulated about the illness through personal experience and trial and error. There was not a short cut to adapting how one paced oneself effectively.

*“it took me a very long time to get used to not being able to push myself or do things physically as I wanted to.”*

— Participant 5

For some participants, pacing yourself meant having to make serious adjustments to their daily routines, in order to allow them to live at the appropriate pace. For some, for example, this meant reducing their working hours from full to part time so that they could continue with

activities outside of work. Pacing oneself also required flexibility day to day, depending on whether the individual was having a good or a bad day.

*“Or it’s knowing my limitations and not pushing myself through it. If I’ve got a really bad day, I will just rest and do a little bit of gentle walking and that’s it. I have to do that.”*

— Participant 13

Another self-management strategy was simply resting, and making time to do so. Some participants built opportunities to rest into their daily lives

*“I listen to my body now. I used to, before I was diagnosed, I was like a whirlwind and would just never stop. But now, I just have to listen to my body much more so if I feel tired, then I would just go and lie down.”*

— Participant 2

Although pacing oneself and rest were identified as key self-management strategies among participants, these would not be relevant if the participant did not have appropriate medication. As one participant responded when asked how they managed their condition:

*“I take lots of drugs! But then, I do take lots of drugs but then as well, I know like now after so long I know my limits and I know not to – I wouldn’t go and run a marathon for instance.”*

— Participant 9

Many participants described a period of months or years over which their medication was not stable and health professionals sought an effective drug regime for them, during which time their condition was unstable and very difficult to manage. It appeared that it was often the correct combination of drugs for the individual that marked the beginning of improvements in, and control over, their condition.

*“It got a lot worse and then it got better with drugs.”*

— Participant 3

Exercise was also a technique used by participants to self-manage their condition. Some participants even had specialist input from trainers or instructors to develop exercise sessions that were specifically designed for their condition.

*“And I do rest a lot and do physical exercise like swimming and pilates and things.”*

— Participant 6

However, for some participants exercise was not seen as an option that was often available to them, as other symptoms of their MSD constrained their ability to exercise.

*"I am really careful not to do too much ..... I try to exercise, but it's all limited to my flare ups."*

— Participant 7

Participants also spoke about self-management activities they carried out to manage their mental health. One participant, for example, explained various exercises linked to the practice of mindfulness to relax themselves and also to cope with the pain of their condition.

*"I try and do some breathing exercises, relaxation exercises. Mindfulness, just to focus your mind away from the pain."*

— Participant 12

For many participants, the adjustment that was needed mentally in terms of accepting that they had to live with a chronic condition was one of the most challenging parts of adapting to life with an MSD.

*"And I think that – getting used to the illness I think the mental side took me a long time to get used to."*

— Participant 5

Finally, some participants described how they would do things to distract themselves in order to mentally deal with the physical symptoms of their condition, particularly pain. One participant explicitly identified what they were doing as avoidance strategy.

*"I tend to like, if I've got pain, I tend to do things. Yes avoidance strategy I think it's called in the trade isn't it."*

— Participant 3

**In summary, individuals gathered information to assist them in the management of their condition by either being given it, by actively seeking it out, or through first hand personal experience. Medical professionals, patient organisations, and the internet were key sources of information relevant to self-management. That said, participants still also expressed a desire for there to be more information available about MSDs, and in particular about MSDs and work.**

**Participants also discussed general self-management techniques, which included learning one's limits, pacing oneself, resting, appropriate exercise, and making mental adjustments to living with a chronic condition. All of these were underpinned by the need for an effective drug regime which kept symptoms under control.**



#### 4. Factors influencing self-management in the workplace.

In order to successfully partake in the world of work, an individual with an MSD needs to be able to manage their symptoms in the context of work. While the general principles described above hold true in the workplace setting, there are also many work specific factors which influence how an individual controls their condition in the workplace which determine whether they are able to engage in work successfully or unsuccessfully.

Results from the interviews highlighted many ways that workplace factors facilitated or impeded self-management, and how the individual coped and negotiated these factors. The *size and type of organisation* where the individual worked had an influence on their ability to manage their condition. It was found that participants who worked for larger organisations tended to describe more support structures in place for them to access, and a greater proactivity on the part of the employer to accommodate people with disabilities.

*“But as an employer, again what goes in your favour is because they are a large employer, they are very proactive on people with disabilities.”*

— Participant 13

One participant gave an outline of the facilities that their large employer was able to offer to them:

*“So from the institution there are lots of things that are on offer. So there’s occupational health unit, there is physiotherapy. I also see the university doctor. I’ve got a disabled parking permit, I’ve had physiotherapy, acupuncture, counselling.”*

— Participant 2

In comparison, smaller companies were often described as being unable to invest in people with disabilities. Participants employed in small organisations spoke about the limited way in which their organisations could help them, often stating that to some extent this was understandable, as small companies would not necessarily have the resources to invest in disabled employees.

*“it’s hard for obviously small companies, you can’t discriminate but then it takes a lot of investment. You can see it from their point of view I guess.”*

— Participant 9

The challenges of working in a small company were not only focused on investing in adjustments or support for individuals with MSDs; participants discussed that a small workforce may be less able to deal with fluctuations in staffing. One participant described how their condition worsened when they had to take on more responsibilities at work owing to a staffing shortage across the organisation.

*"Last year the team were very understaffed because some individuals went off sick and I'd been working there for 14 years so I do know my job. I think the pressure to try and do other people's jobs as well as your own just got too much for me. It was a very stressful time for me and I think that made my illness a lot worse. And I did have to go and see HR about it because it was getting too much for me."*

— Participant 5

The type of organisation also played a role in facilitating and impeding self-management. It tended to be the case that participants in public sector organisations described a greater range of support on offer.

*"I have found because I work in the public sector that my employers have been really accommodating and have lots of support mechanisms in place to support people like me."*

— Participant 2

One participant had seen the transition of the organisation they were working for from public to private ownership, and described how they felt the transition to a profit oriented business coincided with a decline in the support that she was given.

*"14 years ago it was the council that I worked for and they were extremely good employers. And then 10 years ago it went to being a business, it went to an arm's length company and I think that's when the change was made. Because it went more to 'we're a business, we're making money' even though it's social housing. And that's when the change was made really, from local government to being a business."*

— Participant 5

Several participants in the sample were self-employed, and several had engineered this employment arrangement as it allowed them to better manage their condition. Participants cited many benefits to being self-employed in terms of the management of their condition. A major factor was that self-employment allowed the individual to have a greater degree of control over when they worked and what work they took on.

*"Also self-employed for several participants - I am the sole director of a company, so I manage my own work, decided what work there is."*

— Participant 3

For one participant, having control over their work was the reason they moved from 'traditional' employment to self-employment, explaining that they would not have been able to continue working as an employee because:

*"I made the big decision that I just couldn't do a normal job and work for a normal company."*

*The only way I could stay in work was to work for myself, where I was more in control of things.”*

— Participant 7

Control over workload also meant that self-employed participants often had control over their hours, and could structure their day in a way which suited their condition and provided them with enough time to rest. One participant, for example, structured their working week so that they had a four day weekend, allowing for longer periods of rest and recovery from fatigue.

*“To answer your question being self-employed I managed my own hours, so I tried to have Mondays and Fridays off, so that I had a four day weekend.”*

— Participant 12

Alongside offering control over workload, working from home was cited as a positive aspect of self-employment, allowing for the effective management of one’s condition. One participant described how a key benefit of working from home was that they no longer had to commute, and therefore could be resting in bed right up until they started their working day.

*“Working from home very useful part of self employment. - I’ve got the best of both worlds, I can get up at the very last moment in the mornings and walk down the stairs, and I’m at work. When I’m working I’m comfortable, and when I finish work I am home within thirty seconds.”*

— Participant 7

**In summary, the size and type of organisation the participant worked for was instrumental in facilitating or impeding self-management. Large organisations were found to have better structures in place and be more proactive in supporting individuals with long term conditions. Smaller organisations, on the other hand, often lacked the necessary resources to support individuals, with participants voicing this as their employer being unwilling to ‘invest’ in them.**

**Public sector organisations also tended to offer more support than private sector organisations, which were often construed as being primarily motivated by profit, and therefore more acutely aware of the ‘cost’ the individual posed to the company. There were also many participants who were self-employed, an option which was seen as hugely advantageous because of the control it offered the individual over their working pattern and therefore their condition.**

External organisations besides patient organisations and healthcare professionals, which are covered throughout the report, assisted the individual with managing their MSD in the workplace. There were examples of external agencies being the last port of call, and also potentially the catalyst for change within the workplace. For example, one individual

described how they had to involve their union in order for her employer to recognise their MSD.

*"[I needed to] take a key safe off a wall and I'd been asking for a drill for over 12 months. And I still hadn't got it and I had to go to the Unison to get them to realise me condition. But because I'd made a fuss, they made me go to occupational health within work but that made me feel very stressed out because I just thought I'd managed for so long and all I needed was one bit of help."*

— Participant 5

However, as can be seen in the above quote, there were also instances in which external bodies were seen as an imposition or as a threat. In this instance the involvement of an occupational health team was interpreted by the individual as their employer being unsure whether they were able to manage in their role.

Access to Work, the government funded scheme to provide practical support for people with disabilities and health conditions to start or stay in work, was used by several participants. Access to Work provided a wide range of adjustments for individuals, most often adjustments to their workstation to make them more comfortable. It tended to be the case that participants had found out about Access to Work themselves, as opposed to being signposted to it by their employer.

*"I can't remember how I found out about Access to Work. I went to see them and then they.. I can't remember if it was me or them that approached the college, but it certainly wasn't anything that was actually offered to me by my employers."*

— Participant 12

The benefits of an external agency providing support for an individual with an MSD to work were summed up by one participant as removing the onus from the participant to advocate for themselves and offering a more objective assessment of the participant's needs and resulting benefits, thus removing the worry of being labelled a 'problem' employee.

*"That would be the thing, by the employers maybe not having to come to me, but offering, or having an outside agency saying we'd like to have a discussion with you and your employee or something, about what might be helpful. So I'm not seen as the problem, not as an expense, but as a how to help your employee, and which will help your business."*

— Participant 15

**In summary, the role of patient organisations and healthcare professionals are discussed throughout the report, but there were also other organisations external to an individual's place of work which contributed to the management of their condition. These included trade unions, occupational health, and government funded initiatives.**

**These bodies could provide the catalyst for adjustments in the workplace, as well as providing an objective assessment of an individual's needs and removing the onus for action away from the individual. However, some individuals viewed external organisations negatively, especially if they had not made initial contact with them themselves, as they were seen as evidence of an employer believing an individual was not coping in their current role.**

The *nature of the role* that the participant worked in was also instrumental in an individual's capacity to self-manage. For example, some participants talked about choosing careers that were less manual than they would have otherwise chosen, as their MSD symptoms would have worsened in a more physically demanding job. One participant described how they had refocused their nursing career because general nursing would have taken too severe a toll on their body.

*"It certainly affected my career choices. I was quite active before and I would have done something much more physical and active so I have had to choose my career path. I couldn't stay in general nursing for very long because manual handling of patients and being on your feet and the physical tiredness, so that's when I opted to go more into occupational health where you're based in the workplace."*

— Participant 6

There were also more specific activities that participants cut down on in order to make their job and self-managing their condition more compatible. One participant, for example, had reduced the amount of work related travel they did in order to make themselves less tired.

*"I suppose the other thing I do now is try to do as little as possible travel, because I know I find it tiring."*

— Participant 3

The same participant had also almost completely stopped the part of their role where they facilitated group sessions. They cited in part the fact that their condition would not allow them to run the sessions, but also that the quality of the sessions would be compromised if they were to run them, suggesting that both the management of their symptoms, but also the quality of their contribution to their employer were factors in deciding to stop running group sessions.

*"The thing I have almost completely decided to cut out now, is I used to do a lot of facilitation of groups and things. And I don't think I have the ability to do that for a whole day now, to the standard I want to do it."*

— Participant 3

Most participants appeared to believe that non-manual, office jobs were the best form of

working in terms of managing their condition. Participants working in such jobs believed they were fortunate to have non-manual work, with the assumption being that a manual job would have a negative impact on their condition.

*“Basically I work at a computer, I am lucky in the sense that it isn’t a typical manual job, because I don’t know where I’d quite be, or whatever.”*

— Participant 15

However, some participants stated that it was important for their self-management to be able to move around the office every so often rather than being sedentary. Several participants described how they would get up, walk around and stretch at intervals during the day when they were working at a desk. A completely sedentary job appeared to not be conducive to a well managed condition and one participant explained that their doctor had advised them to find a job that was more active than their current office job.

*“Oh he does yeah [give me advice about work], that’s a constant, he knows I do too much, he understands .....why I do what I do. And he said I should get a job that’s more physically active than sitting at a desk.”*

— Participant 8

Despite there being some divergent opinions as to the benefits of manual and non-manual jobs, those who worked from home unilaterally reported positive experiences in terms of this allowing them to manage their condition successfully.

*“So I’m at home all the time. That helps me being able to manage my condition better. If I am having a really bad day and it’s really awful, I will lie on my spare bed.. I won’t lie on my bed, I will lie on my spare bed, or I’ll lie on the sofa and do some work like that.”*

— Participant 13

Another way in which an individual’s specific role affected their capacity to self-manage was the seniority of one’s position. As one participant explained, being less senior and having a less demanding work schedule meant that they could rest surreptitiously during work hours without anyone noticing.

*“I can have a few minutes shut down and nobody really notices. That’s alright, but don’t tell my boss that!”*

— Participant 15

There were examples of more senior employees having greater control over their working hours and therefore also being able to respond to fluctuations in their condition. However, an equally common theme that arose in the interview data was participants taking decisions to

limit their own career progression and remain in less senior roles to maintain successful management of their condition.

*"I decided not to go for the head of the area but to take a role that would allow me to put myself and my condition first."*

— Participant 2

Some spoke of the frustration of remaining in more junior roles, when they knew their skills would allow them to take on more responsibility.

*"it's frustrating that is where I am stuck at career wise .....there's no chance of career progression. It can be quite frustrating .....doing the same thing knowing I'm not going to get anywhere."*

— Participant 8

Alongside seniority, was the individual's level of qualification. One participant in particular highlighted how their degree level education, and resulting increased earning capacity, allowed them to work a reduced number of hours and still earn what they considered to be a suitable salary. Interestingly the participant had also managed the structure of their work so that they worked at weekends, and thus got a higher pay rate than if they worked during the week, maximising their earning potential in as few hours as possible.

*"I do two jobs, the two jobs I have, fortunately I've got a degree, which means that my pay is better than if I didn't have one. Working weekends I am on the enhanced pay rate, so I am very, very fortunate that I have this degree that I am able to have this job that pays really well for the limited amount of hours that I'm doing. I'm extremely fortunate, I can't tell you how fortunate I am because I know that anybody else in my position would be starving."*

— Participant 10

Working hours were an important factor for many participants in order for them to be able to successfully manage their condition. For some part time work was the only option which allowed both the ability to work and adequately manage their symptoms. One participant, for example, described how their condition would flare whenever they tried to increase their hours, and consequently to manage the flares, were advised by their doctor to remain part-time.

*"But every time I tried to up my hours to four days or five days, I always seemed to have a flare being ill and I just thought me doctor just discussed it with me and he said I really don't think that working full time is the best for you, you need to reduce your hours again."*

— Participant 5

It is also important to remember that a participant's MSD was not the only factor dictating how they structured their work. Other factors and obligations constrained and influenced choices being made about their working hours and the roles they undertook. One participant, for example, worked part time in order to control their symptoms, but had also negotiated a term time contract because of their childcare responsibilities.

*"I work 3 days' work, I work Tuesday, Wednesday and Thursday. And I work 5 ½ hours a day. But I also work in term time, I've negotiated a term time contract."*

— Participant 4

There were other instances whereby these other obligations and factors had a negative impact on a participant's working hours and therefore their condition, which led to difficulties in self-managing. A participant described how they worked compacted hours because their condition meant they would become increasingly tired in the afternoon and so would rather complete the bulk of their work during the morning. However, this participant had financial obligations to their ex-partner and children, and did not feel they were in a position to reduce their hours and earning capacity, and thus suffered as a result of being less able to control the symptoms of their condition.

*"I reduced my hours to 35 a week but I work 8 till 3 and I don't bother with lunch because I think – well I eat on my desk but I don't take a lunch break because it's a waste of time really. So I'm working 35 hours plus at the moment. It doesn't help."*

— Participant 11

Greater flexibility and control over working hours was identified as something which would be hugely beneficial to allowing participants to successfully manage their condition.

*"As far as helping me, perhaps being a bit more lenient with my hours, that would have really helped. Because I kept killing myself to get up early so that I could be in work for half eight or nine o'clock. Potentially a flexi time of sorts would really help someone with rheumatoid arthritis. Because classically the symptoms are at their worst, in the mornings. First thing in the morning you can.. it's like a diesel engine, it takes a while to warm up. I am not a petrol engine, I am diesel."*

— Participant 7

**The nature of the role was also linked to how an individual self-managed their condition. Many participants had made changes to their role in order to better manage their MSD. For example, participants had chosen less manual careers to put less stress on their bodies, and there were also individuals who had cut down on work related travel, or stopped doing some components of their job which they knew aggravated their condition. In general non-manual jobs were viewed as being better for MSDs.**



Seniority was also a factor, with jobs with less responsibility offering opportunities to rest surreptitiously during the day. There were also participants who had not applied for promotions, or taken jobs below their level of qualification in order to avoid overly stressful responsibilities, while at the same time taking a hit to their sense of fulfilment and motivation.

Working hours were also something that was adjusted to allow for appropriate rest, and for many participants part time was the only viable working pattern which allowed them to manage their condition. Participants also spoke about the importance of flexible working hours, allowing them to react accordingly when their condition fluctuated unexpectedly.

It was also found that the relationship and interactions that the individual had with their line manager were hugely important. The level of awareness that a line manager had about an individual's condition was important in terms of providing appropriate support. Some participants described how their line manager had been willing to find out more about their condition.

*"She was very understanding and she wanted to find out more and I sort of sent her information on the tiredness aspect that comes into it as well."*

— Participant 2

The same participant also spoke about how their manager understood their condition and how it specifically affected her, suggesting that it is very helpful if managers are able to build up a highly personalised understanding of an individual's condition.

*"So we work it quite well really that she knows my condition, she knows how it affects me. And I think that helps tremendously that she's aware of that as well."*

— Participant 2

Participants had also made attempts to better inform their line managers about their condition, including providing them with booklets about MSDs:

*"Also ... there was an NRAS booklet ... I took that booklet and I gave it to my supervisor to read."*

— Participant 10

There was also a desire among some participants for managers to be more proactive in equipping themselves with information.

*"I think for a start off I think as far as information is concerned, I think the managers should have taken it upon themselves to understand my illness better."*

— Participant 7

It was also the case that the relationship that an individual had with their manager was instrumental in the extent to which the manager facilitated or impeded self-management. One way in which this played out was that an employee felt as though they had earned, or were owed, adjustments or accommodations from their line manager because of the hard work they had contributed in the past. In this instance, the granting of adjustments was framed as a reciprocal exchange; where the employee also had to offer something (in this instance hard work) in order to feel at ease with requesting an adjustment.

*"Part of it I think is because I know that I've worked so hard and my employer and the one particular line manager knows how hard that I have worked. So from that respect I know that she would always be very tolerant and that I could more or less ask her for anything [in terms of adjustments]."*

— Participant 2

The length of time that someone had the same line manager often offered an opportunity to build a relationship which was then conducive to self-management. One employee often described how having had the same manager for a long period of time meant she felt it was understood that she was committed to her job, the fear being that the repercussions of her condition (for example, sickness absence) may be misinterpreted as a lack of commitment.

*"And I've had the same boss for 14 years and she's really good and she knows that I always want to try and do more because I love my job as well because now I work for housing and I've worked myself up as well from being in the office."*

— Participant 5

There were perhaps ways of sidestepping the need to build up a relationship with a specific line manager over a long period of time. One participant described how they had a 'passport' in their work file, something which was given to all disabled employees within the organisation, which outlined their health condition and the assistance they needed, meaning that a new manager did not necessarily represent having to start from scratch in terms of manager awareness of the employee's condition.

*"[I have a] passport in my file so if I get moved to another manager... [they don't] have to go over all my health issues again with me."*

— Participant 4

Another recurring theme was that many individuals were reluctant to ask for help from their

manager, or did not want to receive adjustments or assistance, for fear that they would be marked out as different and less capable of doing their job.

*"I just feel, they're always judging you because they think you're not capable at your job if you're asking for these adjustments. Or they feel that you won't be able to do your work correctly."*

— Participant 14

There were examples of some participants not requesting adjustments because they did not want to attract what they perceived to be negative attention and thus threaten their employment status.

*"I don't know, I just feel that there's a lot of people looking for work. I just don't want to cause any waves, I'd rather having the attention away from me."*

— Participant 10

Another participant explained that she hid the symptoms of her condition so as not to appear vulnerable and expose herself to a higher risk of losing her job. Like other participants, the interviewee cited their understanding of current labour market conditions, with high levels of job loss, as a catalyst for not wanting to appear less able to do her job than other employees.

*"It [the attitude of managers and colleagues] makes you feel like you have to hide how you're really feeling just to fit in and not be seen as in this day and age when people lose their jobs a lot. She's not the fittest therefore if we're downsizing a company, get rid of that one first and keep the fitter ones. There's all sorts of social aspects to performing in the job place and not appearing vulnerable or ill."*

— Participant 7

Some participants spoke more specifically about this fear of job loss and increased awareness of difficult labour market conditions being something that was directly inculcated by managers. One participant described the transformation within their department to a 'rule by fear' mentality.

*"Because it's a bit rule by fear in this department these days. It really is, they'll try and get rid of you if you've been off too long with your health etc."*

— Participant 1

The same participant, who was themselves also a manager, described how they also took part in enforcing disciplinary actions if employees took what was considered an unacceptable amount of sick leave. However, they also explained that they personally had

been allocated a larger amount of 'allowed' sick leave following an assessment of their condition.

***“Q: And so you feel pressure from your management to do that?”***

*A: Yes. Absolutely. I am a manager so I also, you try and give a message to your staff that, of getting into work even when you're not well. Our department it's roughly, after 8 days off in a year you can be subject to disciplinary actions. But I have a trigger, I actually have 20 days for that, because that's been assessed and agreed over the years because of my condition.”*

— Participant 1

Participants had several suggestions for how their managers could better assist them in the management of their condition. One point made was that in general, an atmosphere of trust and openness would help, which could be linked to how an individual manager works directly with an employee, but also the approach that an organisation takes towards people with long term conditions.

***“Q: But how do you think that the management of conditions such as rheumatoid arthritis can be improved in the workplace?”***

*A: I think it probably is back to being about having a sort of spirit of openness, and trust I think.”*

— Participant 3

Participants also wanted their employer to be more proactive in offering them assistance. As described above, some participants were extremely reluctant to ask for adjustments for fear of judgment or being deemed not component; a proactive approach by managers would avoid this.

*“Maybe by my employer actually proactively coming to me and offering stuff.... rather than me having to go to them.”*

— Participant 15

Linked to the approach that managers take, was also the point made by one participant that they wanted reassurance. In a labour market climate where many participants were fearful of job loss, and with people with chronic conditions feeling particularly vulnerable, assurance that someone with an MSD is doing a good job is particularly important.

*"I don't know sometimes reassuring that... maybe reassurance... They don't get told that you've done a good job. It's very rare you get told, you get that reassurance. When you've got a physical illness I think a bit of reassurance now and then would be great."*

— Participant 10

As well as managers, fellow colleagues had a role to play in supporting the management of an individual's condition. One of the major barriers to providing this support was a lack of awareness around chronic conditions, and MSDs in particular.

***"Q: What do you think can be done to improve the management of your condition in the workplace?"***

*A: Better awareness, people understanding a bit more about it."*

— Participant 1

However, having a good understanding is often not enough for those trying to manage their condition in the workplace. As the same participant explained, they had very supportive colleagues, but the issue was that their support did not very often translate into actions. It is unclear what led to this inaction, but it may be that colleagues' awareness did not stretch to knowing what they could *do* to help.

*"I think overall my department has been very supportive. Certainly if I can be blunt, they say the right things, sometimes they do them as well which is always nice."*

— Participant 1

A lack of awareness or a limited level of awareness on the part of colleagues may also be due to the variable levels of disclosure on the part of individuals with an MSD; interviewees had quite different attitudes towards discussing their condition with colleagues. Some participants described how they very deliberately disclosed their condition to all of their colleagues, in order to account for why one would sometimes be absent from work and to remove pressure from herself which may have existed if it was unknown that she had a chronic condition.

*"Yes. I made sure that everyone knew, so that people wouldn't wonder why is [I was] not coming to these evening events, or not missing anything, or just looking really tired. I didn't want to have any.. to wonder why. I thought if they know, knowledge is everything. They can do whatever they want with the information, I wasn't being pressured. I made sure everyone knew."*

— Participant 7

Other participants were more ambivalent about telling colleagues about their condition.

*"I don't hide it. I don't hide it but I don't announce it either."*

— Participant 13

A notable finding was that some participants did not always directly disclose their condition or that they were experiencing symptoms. Instead participants would use some alternative, more widely understood, representation of illness to communicate to their colleagues that they were feeling unwell. One participant, for example, explained that she would tell colleagues she had a headache when in fact she was experiencing a flare up of her arthritis, because a headache was more widely understood and empathised with.

*"When I'm at work sometimes the pain will affect my concentration. Sometimes I would.. if I'm not well, if things are a bit on top of me, in front of my colleagues I will say to them I have a headache, rather than go about the arthritis thing."*

— Participant 10

Participants also communicated that they did not want to feel different from their colleagues, a theme which has already emerged in relation to being reluctant to disclose one's condition and ask for help. One participant also suggested that everyone in their office should receive a workstation assessment in order to ensure that everyone's desk was suitable for them, but also in order that those with disabilities were not treated any differently to those without.

*"It would be great if everybody could get this assessment. Regardless or not you have a disability, I think everybody in their own right if you're working in front of a desk, seven hours a day or seven-eight hours a day, I think everybody should get a desk assessment. That way it puts everybody on the same footing."*

— Participant 10

**The role of line managers was very important. Individuals reported varying degrees of awareness about MSDs among line managers, and varying willingness on the part of line managers to increase their awareness. The relationship between the line manager and the individual was key, as a strong relationship that had developed over time often meant that the line manager had a greater degree of understanding, and also that the individual felt trusted and more able to ask for adjustments if they'd the opportunity to prove themselves to be a motivated and committed employee in the past. Many individuals were reluctant to ask for help from their line managers, citing the key reasons for this being fear of negative judgement, and fear of job loss. Individuals wanted their relationship with their line manager to be more open, and they also wanted their line manager to be more proactive in offering them support.**

**In general, and despite some clear exceptions, participants found colleagues lacked awareness about MSDs. Linked to this, however, were varying degrees of disclosure on the part of participants, with some being very open about their MSD, and others**

preferring not to be as vocal about their diagnosis. This lack of awareness and at times limited disclosure meant that participants would sometimes communicate that they were feeling unwell to colleagues by describing more commonly understood symptoms (e.g. a headache) rather than the actual MSD symptoms they were experiencing. There was also the sentiment expressed that participants did not want to be singled out as different to colleagues, which practices such as universal workstation assessments could help to foster.

The table below presents the actual adjustments to the working environment that individuals managed to bring about. One participant put plainly how their workplace making the necessary adjustments required would be beneficial to all parties involved.

**“Q: If you had these adjustments, what benefits do you think you will get from them?”**

*A: Well my hands would be better. I would be probably able to work more productively. I would feel mentally and physically better and yeah, it’s a win win for everybody really.”*

— Participant 1

ADJUSTMENT	EXAMPLE
Adaptive equipment	<p>Many of the participants had been given equipment to use at their workstation. These included aids for typing, rests and supports, and ergonomically designed equipment.</p> <p><i>“I speak to my computer and it dictates to my computer.”</i></p> <p>— Participant 1</p> <p><i>“Well I have all the equipment. I have a rest for me hands, for me keyboard. I have a foot rest, I have a specially adapted chair. I have a special mouse as well that I can just rest me hand on so it’s not putting pressure on me wrist and me hand.”</i></p> <p>— Participant 5</p>
Workstation	<p>The actual positioning of one’s workstation was also an adjustment that some participants had. One interviewee, for example, worked in an office that used hot desking, but their desk was off limits so that the adjustments and adaptations could be specifically made and remain in place.</p> <p><i>“So they’ve said my desk isn’t available for hot desking, no one else can sit at my desk or use my things.”</i></p>

— Participant 5

The same participant described how they had a desk on the edge of the open plan office, as they were keen to avoid contracting office illnesses. They also cleaned their own desk more thoroughly than the office cleaners to ensure that their workstation was as hygienic as possible and to minimise the possibility of becoming unwell. The participant was affected more seriously than most people by common illnesses because they were taking immunosuppressant medicine.

*“[To avoid] coughs and sneezes and the usual sort of thing, so I sit more on the outskirts. So that’s another thing that they’ve put in place .... and I just do the cleaning of my desk myself, anti-bacterial wipes and things and just clean my own desk.”*

— Participant 5

Some participants also made adjustments in the sense of how they used their workstation, for example, one participant left their desk regularly to walk and stretch as they knew it was not good for their condition to sit for very long periods of time.

*“I get up every 20 minutes and stretch because I do know if I’m sitting at a desk for too long, - I get up and walk to the printer or something.”*

— Participant 9

Flexible hours

*“The adjustments of being able to stay at home and if I’m feeling tired, leave a bit early or go in a bit later, working from home then those sorts of adjustments have been very helpful.”*

— Participant 2

Working from home

*“I work from home one day so I’m working from home today and so that means if my condition is bad playing up – at the moment today my hands are both really swollen.”*

— Participant 2

Number of hours

There were a lot of examples of full time not being a suitable



working pattern for participants.

*“Personally I think the better way for me to be able to manage my condition at work, longer term, would be to work part time rather than full time. I think working full time with this condition you can only do for so long.”*

— Participant 13

Many participants had some form of part time working arrangement, allowing them the time to rest and successfully keep their symptoms under control.

*“That’s why working part time is essential because whilst I’m at work it takes it’s hold on me, but I need that time to recover afterwards.”*

— Participant 10

Disabled parking permit

*“I have a disabled parking permit for work and then I don’t have to walk very far.”*

— Participant 2

Medical treatments

*“I’ve had physiotherapy, acupuncture, counselling [through my employer].”*

— Participant 2

Responsibilities

There were examples of participants who had not taken promotion opportunities, or applied for jobs below their skill set in order to take on less responsibility and afford themselves more time to manage their condition.

*“Hugely. It [the condition] had a huge impact. I’ve changed my role because it was really very full on role before.”*

— Participant 2

One participant had even relocated out of London in order to seek a slower paced working life with fewer responsibilities.

*“I knew I needed to slow down, and that was all related to myself. That we decided okay let’s move back to Wales.”*

— Participant 7

Some participants who restructured their responsibilities within their existing role, saving more strenuous tasks for when their condition was in a better state.

*“Actually I do different kinds of job at different times in the day, to fit in with my illness....So I do the easier physical job in the morning and the more difficult quilting in the afternoon, when my joints improve up a bit.”*

— Participant 7

While many participants were able to describe a range of adjustments that they themselves or others had implemented to their workstation, others did not have adjustments, or were unsatisfied with their existing adjustments, for a variety of reasons. For some participants, there had been a delay in receiving a workstation assessment, or an initial promise to conduct an assessment had been reneged upon.

*“Oh we’ll need to do an assessment, a work environment assessment. Which they never did in the end.”*

— Participant 7

Other participants had simply not asked for any adjustments to their working environment. One participant explained that they had never asked for any changes to be made, but also appeared wary of asking for additional assistance.

*“They haven’t, but to be fair I haven’t asked for any. I just thought I will try and get on with what I’ve got. I almost don’t want to ask for stuff.”*

— Participant 15

Another interviewee who worked in an office that used hot desking described how getting a desk to herself was not an option, meaning she had to use workstations not designed to accommodate her condition, which could lead to her condition worsening.

*“Also we are hot desking, so I can’t get like a desk for myself that can be adjusted to my needs, because sometimes I’m working with keyboards that are hurting my hands.. Or a chair that aren’t correct and not properly adjusted, and that kind of thing.”*

— Participant 10

For some acquiring adjustments to their workstation was conceived of something to balance with other required adjustments. One participant, for example, explained that they were reluctant to ask for an adapted keyboard because they were thinking of asking to reduce their working pattern to four days a week which may make their employer less amenable to providing workstation adjustments.

*"I know there are special keyboards and that sort of thing. But I haven't asked because I don't... I don't know, maybe because I'm thinking of maybe going back to four days a week, would she want to invest, quote unquote in me, and then I'm going down to four days a week."*

— Participant 15

**The various adaptations in the workplace which participants had achieved are outlined in the table above. However, there were examples of participants' whose employer had reneged on promises to provide adjustments or assessments for adjustments. Other participants had not asked for adjustments, perhaps because they were wary of doing so. Furthermore there were some individuals who felt they could not request a specific adjustment because they had made another request in the past, or planned to make another in the future, suggesting they thought of their employer as having a finite amount of support to offer.**

## 10. Discussion

This study has two important contributions to make to our understanding of self-management, having examined it in the context of work. Firstly, the study offers an insight into self-management *at work*, and the processes and components that contribute towards fostering or undermining successful self-management. Secondly the study offers a view of work as a form of self-management, whereby partaking in work was an important way in which individuals managed several (often psychological) aspects of their condition, albeit often not without compromising the management of some of the physical symptoms of their MSDs.

The findings have demonstrated the multiple ways in which individuals self-manage their condition at work. This included initiatives such as pacing oneself, and taking the necessary rest, by either readjusting how they performed their working day, or recovering from work by resting at home and foregoing leisure activities. Many individuals had made more drastic adjustments to their working lives in order to provide themselves with enough time to rest. Such adjustments included working part time, working from home, becoming self employed, or taking jobs below their qualification level which would be less strenuous. Beyond these adjustments, some individuals also had adjustments made to their workstation in some form of ergonomic equipment, while some had also limited more manual aspects of their job or developed their career in order that their role did not involve things which put too much pressure on their joints.

Many factors were found to impede or promote self-management in the workplace. These included the size and type of organisation, the attitude of the line manager and employer, the nature of the role itself, the seniority and length of service of the individual (both of which often gave them more leverage to request adjustments), and the support offered by external organisations as well as family and friends. The role of the individual was also key in achieving successful self-management in the workplace, and the study found that it was the individual's ability to negotiate other limiting or facilitating factors that was instrumental to achieving successful self-management in the workplace. The study found that it was the individual's own knowledge of their condition, confidence, and ability to advocate for themselves which allowed them to achieve workplace adjustments and accommodations in which their condition was being adequately managed. There were examples of where individuals were not able to achieve this, for example because they did not have the confidence to educate their colleagues about MSDs, or because they did not feel they had worked for an employer for long enough to request an adjustment, meaning that opportunities to better manage their condition at work were missed. While the adjustments that participants had achieved, and the balance they had managed to find in order to control their symptoms was often impressive, it must be remembered that there are other stakeholders with a role to play, and that at present the responsibility frequently lies far too

heavily with the individual. Those who do not work in a supportive setting or do not possess the personal attributes that foster good self-management may not be able to manage their condition at work well, may not be given the opportunity to develop better self-management skills and may experience less favourable work outcomes (e.g. sustained job retention, full skills utilisation, and so on).

The study also illuminates the idea of work as self-management. The individuals in the study worked for a range of reasons, including out of a sense of obligation, and for financial reasons. Work also gave participants independence, self-esteem and fulfilment. Self-management is not only about controlling the physical symptoms of the disease, but also about the psychological and social aspects of living with a chronic condition. Work is very important for managing aspects of living with an MSD, and in particular the aspects relating to mental wellbeing. Every interviewee had experience of going to work when they felt unwell, and the majority reported doing so on a regular basis. However, there is a balance to be struck, and we found examples where individuals would at times compromise the management of their physical symptoms in order to maintain the management of their psychological and social wellbeing. This need to manage aspects of one's condition beyond the physical symptoms needs greater understanding. As described above, individuals are currently for the most part responsible for achieving satisfactory self-management in the workplace when other stakeholders could contribute more, and in turn are making compromises such as stalling their career progression or foregoing a social or home life in order to continue working. These compromises, and the pressure which individuals find themselves under to self-manage without adequate support are made all the more perverse when one considers the role that work has to play in contributing to the management of an individual's mental wellbeing. **If the benefits of work as self-management are to be truly realised, then the way in which self-management at work is supported needs to be significantly improved.**

## 11. Recommendations

The following recommendations are organised by stakeholder group, offering targeted suggestions for improving the self-management of MSDs in the context of work.

### The Individual

- **Appreciate that understanding how to manage your condition at work takes time** as you learn how your condition affects you and your work personally. Everyone is an individual. Some workplace solutions will take a while to be developed, and it may be that different solutions are needed in the future as your condition changes. The time when you first start to experience symptoms will often be the most challenging period for managing your condition; as you learn more about your MSD and others around you learn how to support you things will improve. Avoid making drastic decisions about work until your treatment plan has settled and you feel you have some control over it.
- **Realise that others have a role to play in managing your condition.** Don't try or expect to manage your MSD alone. Your healthcare team can give you advice about your condition and how your work can be adapted, employers have a duty to make reasonable adjustments for you, and patient organisations have a wealth of knowledge, experience and resources they can share.
- **Equip yourself with information** that will help you to manage your condition in the workplace and share it with others. By raising your own awareness, and the awareness of others, your capacity to self-manage your condition at work will increase, as will support and understanding from others. **Arthritis Care** (<http://www.arthritiscare.org.uk>), **NRAS** (<http://www.nras.org.uk/>), **NASS** (<http://nass.co.uk/>) and **Arthritis Research UK** (<http://www.arthritisresearchuk.org/arthritis-information.aspx>) all have information and resources related to MSDs and work. You could also try online forums such as **Health Unlocked** (<https://healthunlocked.com/>), or find a **local group** to get involved with (<http://www.arthritiscare.org.uk/InyourArea>). You can also find out about workplace adjustments by contacting **Access to Work** (<https://www.gov.uk/access-to-work>).
- **Be 'Solutions-focused'** and recognise that you may have to take the lead in some conversations with your manager, especially if they are uncertain about what you want. Think about how work adaptations which work for you will also work for your manager – this means identifying the anxieties and concerns your manager will have about flexible working or other adaptations by showing how they will help you remain

productive at work. Managers like it when you take them a potential solution rather than just landing them with a problem!

## Government

- **Increase awareness of and participation in Access to Work.** Access to Work is an excellent initiative for assisting individuals with disabilities and long term conditions to enter or stay in work. However, Access to Work's current design places too much of an onus on employees to seek support by asking them to contact the scheme and to present an eligibility letter to their employer (<https://www.gov.uk/access-to-work/how-to-claim>). There also exists a general lack of awareness of Access to Work. By raising the profile of Access to Work, for example, by including Access to Work in Disability Confident materials, and by giving it a more prominent position in online information, greater employer proactivity and higher awareness can be achieved.
- **Provide extra assistance for employees working in small organisations.** This can in part be remedied by improving awareness of Access to Work, which asks smaller organisations to share little or none of the costs involved in providing adjustments for employees. Health for Work in England (<http://www.health4work.nhs.uk/>), Healthy Working Lives in Scotland (<http://www.healthyworkinglives.com/>) and Healthy Working Wales (<http://www.healthyworkingwales.com/>) offer a good array of resources and advice which can be accessed by SMEs but need to be much better advertised in order that businesses make use of them and can then offer the appropriate support that will allow individuals with MSDs to manage their condition in the workplace.
- **Invest in more Specialist Nurse roles.** For many people with chronic MSDs the advice and support they receive from specialist nurses to confidently self-manage their condition and to make informed decisions about work is often invaluable. If we are to increase the success with which people with chronic illnesses such as some MSDs remain active at work then investment in more specialist nurse roles will yield a healthy return.
- **Ensure work is considered a clinical outcome by healthcare professionals.** Successful integration into the workforce is not considered an Outcome under the Clinical Commission Group Outcome Indicators Set 2014/15. Including work as an outcome in the indicator set would incentivise GPs to recognise the important role that work often plays in an individual successfully managing their condition in work settings.

## The Employer

- **Understand your responsibilities as an employer** to people with disabilities and

long term health conditions. You must provide people with chronic or fluctuating MSDs with reasonable adjustments to allow them to do their job. Government guidelines can be found here -

<https://www.gov.uk/government/publications/employing-disabled-people-and-people-with-health-conditions/employing-disabled-people-and-people-with-health-conditions>.

- **Aim to help employees with chronic MSDs to feel a valuable and integrated part of your workforce.** Individuals with an MSD often do not want to be thought of as 'different', for fear that others may not think they are capable of performing their role or that they are letting their colleagues down. This can make them feel worried about their job security and impede their ability to request support, which ultimately will negatively affect their performance at work. Furthermore all employees can benefit from ensuring their work environment is not detrimental to their health. Consider offering the whole workforce regular workstation assessments and opportunities to discuss adjustments, meaning individuals with chronic conditions are not singled out and those previously unwilling to request adjustments are included. Also create opportunities to discuss an individual's MSD which are separate to discussions about performance. Recognise that people with chronic MSDs are as motivated by interesting and challenging work as any other employee – try to avoid workplace adjustments which make the job more routine or less rewarding.
- **Educate your workforce about chronic conditions.** An educated workforce is likely to be more supportive of colleagues living with MSDs. Arthritis Care offers one day workshops targeted at businesses or organisations (<http://www.arthritiscare.org.uk/PublicationsandResources/Selfmanagement/Workshoptocourses/Courselist/ArthritisAwareness>).
- **Foster career progression options for individuals with MSDs.** Having a chronic condition should not mean that you have to limit your employment aspirations. Consider how the adjustments needed by an individual can be combined with career development opportunities.

## The Line Manager

- **Work to build a good relationship with an employee living with an MSD.** The relationship you have with that employee is key to them being able to express concerns or requirements to you that will help them to manage their condition in the workplace. Being empathetic, supportive and a good listener are great qualities here.
- **Be proactive.** Seek out information about MSDs, and be proactive in asking how the employee can be supported to do their job. Currently the onus is too much upon the employee to come forward with information and requests, meaning that some



individuals are not seeking and receiving the support they need. The employee is often the best-qualified person to say what solutions work best for them, so be guided by them in coming up with a mutually beneficial solution.

- **Consider mental as well as physical health.** Many people with MSDs continue to work because it is good for their mental wellbeing. However, the pressures of work can also harm someone's mental health. Be vigilant not only of how an employee is managing the physical aspects of their condition but also the mental aspects.
- **Ensure that you take opportunities to praise an employee with an MSD when they have performed well.** While this recommendation holds true for all employees, individuals with a chronic condition may be more concerned about their job performance and security meaning that positive feedback on their performance is even more valuable.

## Colleagues

- **Educate yourself about chronic conditions.** By being better informed you are better placed to support and understand a colleague living with an MSD.
- **Understand that people with MSDs may need to work in different ways to you** in order to control their symptoms. This may include, for example, working from home sometimes, working reduced or compressed hours, working flexibly, or rebalancing the responsibilities they have. They will sometimes be sensitive that they are not 'pulling their weight' in the team so take opportunities to reassure them that their contribution is valued.

## Healthcare Professionals

- **Be aware of the wealth of information you have about condition management and share it with your patients.** Share your own experiences and understandings, and also signpost your patient towards resources which will provide them with knowledge of their condition. Also, try to prioritise job retention or return to work as one of the clinical outcomes or treatment targets of the care you provide your patients.
- **View it as part of your role to ask patients about their work lives.** Many of your patients living with MSDs will want to work, and the financial, psychological and social benefits that work can bring should not be underestimated. Work is important in achieving a more holistic form of condition management, while in turn the management of the physical symptoms of an MSD need to be considered in the context of work. If one is to take a biopsychosocial approach to disease management, then the incorporation of work is crucial.

- **Understand that you are crucial in establishing a stable foundation upon which an individual can learn to self-manage.** Individuals are often only able to begin to build their capacity to self-manage when they have an appropriate diagnosis and are receiving the correct medication regime. Therefore it is crucial that health professionals are able to provide rapid diagnoses and effectively develop medication regimes, in order that the patient is empowered to begin taking control over their condition as quickly as possible.

## Patient Organisations

- **Do more to share the wealth of resources and information you have on self-management and employment.** Continue to share these resources and look for new avenues and audiences with which to share them. For example, resources could be sent directly to GPs, employers or trade unions; or information could be written specifically for family members or line managers. By casting the net as wide as possible in terms of raising awareness, there will be greater support for building self-management capabilities.
- **Support a diverse range of sources from which patients can get advice.** Some individuals do not enjoy attending face to face groups, while others do not find it easy to access their information online. Continue to pursue as many mediums for sharing information and advice as possible, including leaflets, books, articles, social media, online forums, groups, events, talks, and so on. Do not assume that including the same information in different formats is unnecessary duplication.
- **Increase the dissemination of information to raise awareness among employers and other employees.** One of the major barriers to self-management in the workplace for individuals living with an MSD is the lack of understanding that their colleagues and employer have of their condition. By making more widely available either an MSD specific, or more general chronic condition information session for workplaces, this lack of understanding can be overcome.

## Family and Friends

- **Educate yourself about MSDs.** You will be in a much stronger position to support your friend or family member if you have a good understanding of what it means to be living with an MSD and what they can still contribute to their work. There is a wealth of resources available through patient organisations and public sector bodies which look at MSDs and MSDs and work.
- **Appreciate that the time following first symptom onset and diagnosis is likely to be the most challenging.** Your family member or friend will take time to learn about and adapt to living with their condition, meaning that it can be very difficult for them when they first begin to experience symptoms. Understand that the

management of their condition will improve as they receive appropriate treatment, and that they will also become more capable of managing their condition themselves. The period of time following the initial onset of the condition is when they may need the highest degree of support, including in managing their working life. Help them avoid making precipitous decisions about leaving work until all avenues of support have been exhausted.

- **Be aware that friends or family members with MSDs may need to make sacrifices in their home or social lives in order to continue working.** In order to recover from the exertion of work, your friend or family member may need to take more rest when they are not working. This may mean they cannot participate in as many social activities, or need to forego some aspects of their home life in order to recover. While there is a balance to be struck between work and home life, understand that your friend or family member may need to make some sacrifices outside of work in order to continue working.

## References

- Alderson, M., Starr, L., Gow, S. and Moreland, J. (1999). The program for rheumatic independent self-management: a pilot evaluation. *Clinical rheumatology*, 18(4), 283-292.
- Allaire, S. H., Niu, J., and LaValley, M. P. (2005). Employment and satisfaction outcomes from a job retention intervention delivered to persons with chronic diseases. *Rehabilitation Counseling Bulletin*, 48(2), 100-109.
- Allaire, S. H., Li, W., and LaValley, M. P. (2003). Work barriers experienced and job accommodations used by persons with arthritis and other rheumatic diseases. *Rehabilitation Counseling Bulletin*, 46(3), 147-156.
- Arthritis Care (2014), *Ways to self-manage*, Retrieved on 27 August from <http://www.arthritiscare.org.uk/LivingwithArthritis/Self-management/Waystoself-manage>
- Arthritis Care (2014), *Arthritis Champions: Arthritis Care Community Champion Pilot Success*, Retrieved on 27 August from <http://www.arthritiscare.org.uk/@2973/NorthEngland/arthritis-champions>
- Arthritis Foundation. (2008). *Rheumatoid Arthritis Fact Sheet*. Atlanta: 2008. Retrieved on 27 August from [http://www.arthritis.org/files/images/newsroom/media-kits/Rheumatoid\\_Arthritis\\_Fact\\_Sheet.pdf](http://www.arthritis.org/files/images/newsroom/media-kits/Rheumatoid_Arthritis_Fact_Sheet.pdf)
- Audulv, Å. (2013). The over time development of chronic illness self-management patterns: a longitudinal qualitative study. *BMC Public Health*, 13(1), 1471-2458.
- Audulv, Å., Asplund, K., and Norbergh, K. G. (2012). The integration of chronic illness self-management. *Qualitative health research*, 22(3), 332-345.
- Bandura, A. (1986). The explanatory and predictive scope of self-efficacy theory. *Journal of Clinical and Social Psychology*, 4, 359-373.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., and Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient education and counseling*, 48(2), 177-187.
- Carpenter, K. M., Stoner, S. A., Mundt, J. M., and Stoelb, B. (2012). An online self-help CBT intervention for chronic lower back pain. *The Clinical journal of pain*, 28(1), 14.
- Coats, D., and Max, C. (2005). *Healthy work: productive workplaces: Why the UK needs more "good jobs"*. London: The Work Foundation.

Corben, S., and Rosen, R. (2005). *Self-management for Long-term Conditions: Patients' perspectives on the way ahead*. London: The King's Fund.

Corbin, J. & Strauss, J. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.

Department of Health. (2013). *The Mandate: A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015*. London: Department of Health.

Department of Health. (2012). *Liberating the NHS: No Decision about me, without me*. London: Department of Health.

Department of Health. (2005). *Self-Care – A Real Choice*. London: Department of Health.

Du, S., Yuan, C., Xiao, X., Chu, J., Qiu, Y., and Qian, H. (2011). Self-management programs for chronic musculoskeletal pain conditions: a systematic review and meta-analysis. *Patient education and counseling*, 85(3), e299-e310.

Gignac (2005). Arthritis and employment: An examination of behavioral coping efforts to manage workplace activity limitations. *Arthritis Care & Research*, 53, 328-336.

Gignac, Badley, Lacaille, Cott, Adam, Anis (2004) Managing arthritis and employment: making arthritis-related work changes as a means of adaptation. *Arthritis Care and Research*;51:909–16.

Glasgow, R. E., Kurz, D., King, D., Dickman, J. M., Faber, A. J., Halterman, E., and Ritzwoller, D. (2012). Twelve-month outcomes of an Internet-based diabetes self-management support program. *Patient education and counseling*, 87(1), 81-92.

GOV.UK (2014), *Employment Status: An overview*, Retrieved on 27 August from <https://www.gov.uk/employment-status/overview>

Hibbard and Greene (2013), What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs, *Health Affairs*, 32(2), 207-14.

Hoy, D. G., Smith, E., Cross, M., Sanchez-Riera, L., Blyth, F. M., Buchbinder, R., and March, L. M. (2014). Reflecting on the global burden of musculoskeletal conditions: lessons learnt from the Global Burden of Disease 2010 study and the next steps forward. *Annals of the rheumatic diseases*, annrheumdis-2014.

Johnston, V., Jull, G., Sheppard, D. M., and Ellis, N. (2013). Applying principles of self-management to facilitate workers to return to or remain at work with a chronic musculoskeletal condition. *Manual therapy*, 18(4), 274-280.

Lawn, S., and Schoo, A. (2010). Supporting self-management of chronic health conditions:

Common approaches. *Patient Education and Counseling*, 80(2), 205–211.

Mendelson, A. D., McCullough, C., and Chan, A. (2011). Integrating self-management and exercise for people living with arthritis. *Health education research*, 26(1), 167-177.

Multiple Sclerosis Society. (2010). *Working yet worried: A toolkit of information and resources for people with MS who are in employment*. London: MS Society.

Munir, F., Khan, H.T.A., Yarker, J., Haslam, C., Long, H., Bains, M., and Kalawsky, K. (2009). Self-management of health-behaviors among older and younger workers with chronic illness. *Patient education and counseling*, 77(1), 109–115.

Munir, Yarker and Haslam (2008), Sickness absence management: encouraging attendance or risk-taking presenteeism in employees with chronic illness?, *Disability and Rehabilitations*, 30(19), 1461-72.

Munir, F., Leka, S., and Griffiths, A. (2005). Dealing with self-management of chronic illness at work: predictors for self-disclosure. *Social Science & Medicine*, 60(6), 1397-1407.

National Rheumatoid Arthritis Society. (2007). *National Rheumatoid Arthritis Society Survey 2007*. Maidenhead: National Rheumatoid Arthritis Society.

Newman, S., Steed, L., and Mulliga, K. (2004). Self-management interventions for chronic illness. *The Lancet*, 364(9444), 1523–37.

NHS Choices (2014), *Ankylosing spondylitis*, Retrieved on 27 August from <http://www.nhs.uk/Conditions/Ankylosing-spondylitis/Pages/Introduction.aspx>

NHS Choices (2012), *Your health, your yay: What is a care plan?*, Retrieved on 27 August from <http://www.nhs.uk/Planners/Yourhealth/Pages/Careplan.aspx>

Office for National Statistics. (2014). *Full Report: Sickness Absence in the Labour Market, February 2014*. London: Office for National Statistics. Retrieved on 27 August from [http://www.ons.gov.uk/ons/dcp171776\\_353899.pdf](http://www.ons.gov.uk/ons/dcp171776_353899.pdf)

Office for National Statistics (2012). *Labour Force Survey statistics 2011-2012*. London: Office for National Statistics. Retrieved on 27 August from <https://handson.hse.gov.uk/hse/public/tableadvanced.aspx?b=simple&a=tablesimple&ShortCode=MDPA1>

Ong, B. N., Jinks, C., and Morden, A. (2011) The hard work of self-management: Living with chronic knee pain, *International journal of qualitative studies on health and well-being*, 6(3), 1-10.

Picavet, H. S. J., and Hazes, J. M. W. (2003). Prevalence of self reported musculoskeletal

diseases is high., *Annals of the rheumatic diseases*, 62(7), 644-650.

Reeves, D., Kennedy, A., Fullwood, C., Bower, P., Gardner, C., Gately, C., and Rogers, A. (2008). Predicting who will benefit from an Expert Patients Programme self-management course. *British Journal of General Practice*, 58(548), 198-203.

Rogers, A., Kennedy, A., Bower, P., Gardner, C., Gately, C., Lee, V., and Richardson, G. (2008). The United Kingdom Expert Patients Programme: results and implications from a national evaluation. *Medical Journal of Australia*, 189(10), S21-S24.

Royal College of General Practitioners. (2013). *Patient Online: The Road Map*. London: Royal College of General Practitioners. Retrieved on 27 August from <http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/~media/Files/CIRC/POA/RCGP-Road-Map.ashx>

Royal College of general Practitioners Birmingham Research Unit (2006), *Annual Prevalence Report*, Retrieved on 27 August from <http://www.arthritisresearchuk.org/arthritis-information/data-and-statistics/musculoskeletal-pain-and-disability/how-big-is-the-burden-on-general-practice.aspx>

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., and Whittemore, R. (2012). Processes of Self-Management in Chronic Illness. *Journal of Nursing Scholarship*, 44(2), 136-144.

Shaw, W. S., Tveito, T. H., Geehern-Lavoie, M., Huang, Y. H., Nicholas, M. K., Reme, S. E., and Pransky, G. (2012). Adapting principles of chronic pain self-management to the workplace. *Disability and rehabilitation*, 34(8), 694-703.

Sissons, P., Barnes, H. and Stevens, H. (2011). *Routes onto Employment and Support Allowance*. Sheffield: Department for Work and Pensions. Retrieved on 27 August from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/214556/rrep774.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214556/rrep774.pdf)

Snow, R., Humphrey, C., and Sandall, J. (2013). What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. *BMJ open*, 3(11), e003583.

Stanford School of Medicine (2014), *Chronic Disease Self-Management Program*, Retrieved on 27 August from <http://patienteducation.stanford.edu/programs/cdsmp.html>

Stanford School of Medicine (2014), *Arthritis Self-Management Program*, Retrieved on 27 August from <http://patienteducation.stanford.edu/programs/asmp.html>

The Health Foundation (2012), *North Bristol NHS Trust*, Retrieved on 27 August from <http://www.health.org.uk/areas-of-work/programmes/co-creating-health/related->

[projects/north-bristol-nhs-trust/North-Bristol-NHS-Trust-work-so-far/](http://projects/north-bristol-nhs-trust/North-Bristol-NHS-Trust-work-so-far/)

The Health Foundation. (2011). *Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management*. London: The Health Foundation.

The Health Foundation (2011), *New online resource launched to support self management*, Retrieved on 27 August from <http://www.health.org.uk/news-and-events/press/new-online-resource-launched-to-support-self-management/>

The Health Foundation (2011), *Co-creating Health: About Co-creating Health*, Retrieved on 27 August from <http://www.health.org.uk/areas-of-work/programmes/co-creating-health/about/>

Varekamp, I., Verbeek, J. H., and van Dijk, F. J. (2006). How can we help employees with chronic diseases to stay at work? A review of interventions aimed at job retention and based on an empowerment perspective. *International archives of occupational and environmental health*, 80(2), 87-97.

Waddell, G., and Burton, K. (2006). *Is work good for your health and wellbeing?*. London: Department for Work and Pensions.

Zhelatoukhova, K., O'Dea, L., and Bevan, S. (2012). *Taking the strain: The impact of musculoskeletal disorders on work and home life*. London: The Work Foundation.



## Appendix 1 – Defining self-management, self-care and self-efficacy

### Self-management

Self-management has been defined by Barlow et al. (2002:178) as follows:

“Self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established.”

Corbin and Strauss (1988) divided self-management into three distinct tasks:

- Medication or behaviour management (e.g. following a specific diet).
- Role management (e.g. adjusting previous roles to accommodate illness).
- Emotional management (e.g. managing anger, fear, frustration, or low mood resulting from the experience of having a chronic health problem).

These definitions use a holistic, biopsychosocial model of health, whereby self-management includes an individual’s ability to manage the physical, psychological and social aspects of their condition.

### Self-care

Self care is broader than self-management, which is defined by the Department of Health in their ‘Self Care’ (2005) report as encompassing:

“the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.” (Department of Health, *Self Care*, 2005:1)

Self-care can be defined along a continuum, in terms of the extent to which an individual provides care for themselves in a given activity. For example, brushing one’s teeth regularly is an activity comprising of 100% self care, while neurosurgery is 100% professional care.

Most activities related to care consist of a combination of self-care and professional care. Self-care can be promoted and supported through initiatives such as advice, information, and skills training (Department of Health, *Self Care* ??:3).

## Self-efficacy

Conversely, self-efficacy can be understood as a concept that exists as a sub-component of self-management. Self-efficacy refers to how *confident* a person feels about looking after their illness (The Health Foundation, 2011). Some of the literature identifies self-efficacy as a prerequisite to successful self-management (Varekamp and Verbeek, 2006:95) and that an individual must first have the self-confidence (i.e. the self-efficacy) to engage in behaviour change and self-management. Research indicates that the stronger someone's perceived self-efficacy, the more they will approach a task with effort and persistence (Bandura, 1986). The relationship between self-management and self-efficacy is bidirectional, as self-management interventions can enhance and increase self-efficacy (Barlow et al., 2002:183).

## Appendix 2 - Interview Topic Guide

*Introduce self. Explain that I am conducting research about how people with conditions that affect the joints, muscles and bones manage their condition in the context of work. Impress that there are no right or wrong answers; I want to hear your opinions and perspectives. If you don't understand, or don't think I've understood what you're saying, then please do stop me and ask. Assure confidentiality. Explain that participant does not have to answer a question if they do not want to.*

*Check they have sent their consent form in. Ask for permission to record.*

*Consent form? Any questions before we begin?*

- **Background information.**
  - Could you begin by telling me a bit about your condition?
    - Prompt: Onset of condition; diagnosis; (medication).
  - How has your condition affected your experiences of work?
    - Prompt: Employment history; work before diagnosis; work following diagnosis.
- **Self-management more broadly.**

*I'm interested in understanding the things that you do to look after, manage, and control your condition.*

- Are there things that you do to manage your condition? What are they?
  - Prompt: (Taking medication), exercise, coping strategies for pain, understanding and coping with fatigue (encourage participant to think beyond narrow definitions).
- How have you learnt to do these things?
  - Prompt: Trial and error, doctor told me, reading information online, forums, support group, etc.
- Have you heard of the term self-management?

- (If yes) – Where did you hear it? What does it mean to you? What do you think about the idea?
- (If no) – Explain meaning (using Barlow definition). Does that sound like something that is relevant to you? Do you think it describes things you currently do? Does it sound like something you would like to do more of or could benefit from?

*Tell me about the role that your doctor plays and the role that you play in managing your condition.*

- Do you have a personal care plan?
  - (If yes) – How was it offered to you? Did you play a role in creating it? How do you use it? Does it get reviewed?
  - (If no) – Explain what it is. Have you ever been offered one? Would you like to have one?
- **Self-management and work.**
  - How does your condition affect your ability to work?
    - Prompts: Have there been changes over time? Who or what has been responsible for these changes (e.g. symptom severity, support from employer, change in way condition is managed)?
  - How do the demands of your work affect your condition?
    - Are there specific tasks or duties that make managing your condition more difficult?
  - Have you ever gone into work when you are feeling unwell? Why?
  - Do you have to look after/ manage your condition while you are at work? How?
    - Prompts: How did you develop these strategies/ ways of managing your condition? Are you able to manage your condition effectively in work? Do you need support from other people to manage your condition?
  - Does your manager know about your condition?
    - (If yes) - How did you tell them, how did you find it, how did they respond?

- Have asked for any adjustments at work? How did this go? How were these responded to?
- Have these adjustments affected your attendance/ productivity/ performance?
- Have these adjustments had any negative effects (e.g. made you feel guilty/ as though you 'owe' your employer more)?
- How confident do you feel about asking for adjustments from your employer?
  - (If no) – Why have you not told them?
- How would/ does employer flexibility or adjustments help you to remain in work?
  - Do you think it makes/ could make you more productive?
  - Who do you think benefits from you being provided you adjustments (prompt: yourself, employer, family)? Can you see business benefits for your employer if they provide adjustments for you?
- Do your co-workers know about you condition? Prompt if yes: How did you tell them, how did you find it, how did they respond?
  - (If yes) - Do they provide you with any support for managing your condition?
  - (If no) – Why have you not told them?
- What could be done to improve the management of your condition in the workplace?
  - Prompts: Information available, role of doctor, role of employer.
- **End of questions.**
  - Is there anything you would like to add?

*Thank participant for their time. Clarify how participant can make contact with researcher.*

*Explain what will happen to interview data and that I will send a copy of final report.*

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