



Meeting the care priorities of people with rheumatic and musculoskeletal conditions: priorities for action

Findings from the RHEUMAPS study

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Unwanted variation in care

Around one third of the UK population live with a rheumatic and musculoskeletal disorder (RMD)¹. Inflammatory RMDs such as rheumatoid arthritis, psoriatic arthritis and axial spondyloarthritis, and rarer rheumatic conditions such as systemic vasculitis and lupus, are looked after by hospital-based specialists. Other common non-inflammatory conditions such as osteoarthritis and fibromyalgia are mainly looked after in primary care. Some people have more than one type of RMD, for example, rheumatoid arthritis and osteoarthritis.

Across the devolved UK nations, care for people with RMDs is delivered across very different geographical, policy and organisational contexts to populations with diverse needs.



Services have evolved in different ways and with varying resources to try to meet these demands. For example, a visiting rheumatology service from Aberdeen visits Kirkwall in the Orkney Isles to provide services to a population of around 22,000. Otherwise, patients face a round trip of 500 miles to Aberdeen. Different challenges are found, for example, in Glasgow and areas of Wales, which have some of the highest levels of deprivation in Europe, and central London with a very densely populated and ethnically diverse population.

¹ Versus Arthritis, *The State of Musculoskeletal Health 2023* <https://versusarthritis.org/media/duybjug/versus-arthritis-state-msk-musculoskeletal-health-2023pdf.pdf> [accessed 2nd October 2023]

National audits have highlighted significant unwanted variations in access to care and outcomes for people with RMDs across the UK¹²³. Furthermore, significant geographical variations in the Rheumatology workforce can contribute to long waiting times and delays in the care pathway⁴.

Health inequalities in RMDs

Health inequalities are “unfair and avoidable differences in health across the population, and between different groups within society”⁵. The PROGRESS framework⁶ is a useful way to think about the individual factors that contribute to variations in care and health outcomes in RMDs. It considers factors such as where people live, their ethnicity, occupation, gender/sex, religion, education, socioeconomic status, and social capital.

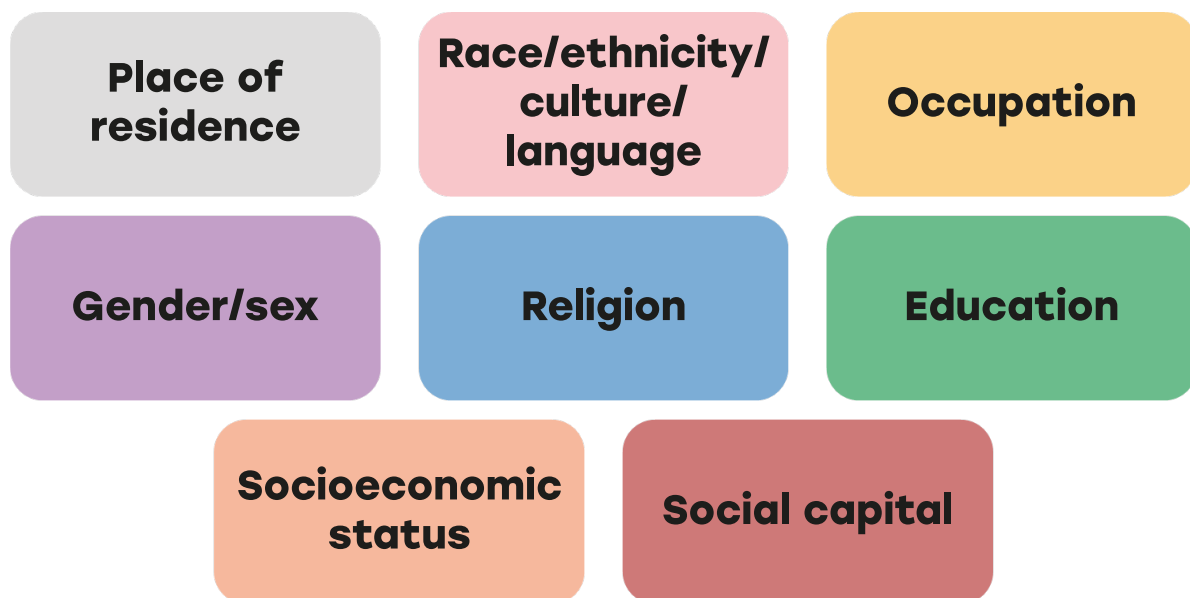


Figure 1. The PROGRESS framework and factors that contribute to health inequalities.

It has subsequently been expanded to PROGRESS-Plus⁷ which considers additional context-specific characteristics (e.g., age, disability, and instances where a person may

² Kay, Lanyon and MacGregor, ‘Getting it Right First Time’ - Rheumatology: GIRFT Programme National Specialty Report (2021), <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/Rheumatology-Jul21h-NEW.pdf> [accessed 2nd October 2023]

³ British Society for Rheumatology, National Early Inflammatory Arthritis Audit (NEIAA) – Homepage, <https://arthritisaudit.org.uk/pages/home> [accessed 2nd October 2023]

⁴ British Society for Rheumatology, Rheumatology workforce: a crisis in numbers (2021), <https://rheumatology.org.uk/Portals/0/Documents/Policy/Reports/BSR-workforce-report-crisis-numbers.pdf> [accessed 2nd October 2023]

⁵ NHS England, What are healthcare inequalities? (2022), <https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities> [accessed 2nd October 2023]

⁶ O’Neill J et al. Applying an equity lens to interventions: using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. J Clin Epidemiol. 2014 Jan;67(1):56-64. doi: 10.1016/j.jclinepi.2013.08.005

⁷ <https://methods.cochrane.org/equity/projects/evidence-equity/progress-plus>

be temporarily at a disadvantage such as on discharge from hospital or in respite care) that can contribute to health inequalities.

Table 1 gives examples of factors that have been shown to contribute to health inequalities in RMDs.

Ethnicity	Socioeconomic status	Age	Place of residence
<p>Higher prevalence of some conditions in specific ethnic groups, and differences in treatment outcomes⁸</p> <p>Delayed presentation/referral to specialist care, divergent culturally influenced views on medication, and health literacy</p>	<p>Lower socio-economic status associated with poor disease outcomes in rheumatic diseases^{9,10}</p> <p>Delayed presentation/referral to specialist care, disparate treatment, lifestyle choices and co-morbidities, medication adherence, health literacy</p>	<p>Multiple chronic health problems in older age¹¹</p> <p>Difficulties in accessing care, greater risk of treatment complications, polypharmacy (taking multiple different medications)</p>	<p>Some evidence* of higher prevalence and poorer disease outcomes in rural dwellers with RMDs¹²</p> <p>Delayed presentation/access to specialist care and services, divergent attitudes on health and medication</p>

Table 1. Examples of factors contributing to health inequalities in RMDs. * Studies were generally small and of low quality and overall the relationship between clinical outcomes and place of residence is unclear.

⁸ Bergstra, S. A. (2023). Health inequalities across patients with early inflammatory arthritis of different ethnicities: what could be the driving factors?. *Rheumatology*, 62(1), 7-8.

⁹ The Lancet Rheumatology (2021). Socioeconomic deprivation worsens rheumatoid arthritis. *The Lancet Rheumatology*, 3(10), e671. [https://doi.org/10.1016/S2665-9913\(21\)00292-7](https://doi.org/10.1016/S2665-9913(21)00292-7).

¹⁰ Dey, M., Busby, A., Elwell, H., Lempp, H., Pratt, A., Young, A., ... & Nikiphorou, E. (2022). Association between social deprivation and disease activity in rheumatoid arthritis: a systematic literature review. *RMD open*, 8(1).

¹¹ Lee, J., Singh, N., Gray, S. L., & Makris, U. E. (2022). Optimizing Medication Use in Older Adults With Rheumatic Musculoskeletal Diseases: Deprescribing as an Approach When Less May Be More. *ACR Open Rheumatology*, 4(12), 1031-1041.

¹² Hollick, R. J., & Macfarlane, G. J. (2021). Association of rural setting with poorer disease outcomes for patients with rheumatic diseases: results from a systematic review of the literature. *Arthritis Care & Research*, 73(5), 666-670.

Delivering equitable care in practice

Recognising the unwanted variation in care and health inequalities in RMDs, there is a drive to support local services to meet the needs of their local population. However, achieving this in practice, in the context of significant resource constraints, is challenging.

Firstly, when planning local, regional and national services to effectively meet the needs of people with a broad range of RMDs, we need to understand **how many people** in each region have the condition(s), **where they live, who they are** (e.g., their age, sex, ethnicity), **what services are currently available** (and where these services are in relation to people who need them). The problem is that much of the **data we have is patchy and collected by different systems that don't talk to each other**. Some conditions are looked after mainly in primary care and are not picked up just by looking at hospital records. Lack of these essential data makes it **hard to plan and target healthcare services** to meet patient's needs.

Secondly, we need to **understand people's care priorities** and the **elements of health services necessary to meet these priorities**. This includes the availability, ease of access to and timeliness of pertinent information, specialist, and community-based services, as well as support for self-management. These might be different for different groups of patients with RMDs. However, most of the available evidence on patient priorities for care is focused on symptoms such as pain and fatigue, and the attainment of specific treatment targets and healthcare outcomes such as improved disease activity, usually within specific RMDs.^{13,14} It is not clear what resources and service components are important, absent, could be improved or currently working well to meet these priorities. Furthermore, it is unclear whether specific groups of people are more likely to report dissatisfaction with the ability of services to meet these needs. Understanding these aspects will help us to improve care experiences for people who live with RMDs.

¹³ Nair, B. V., Schuler, R., Stewart, S., & Taylor-Gjevre, R. M. (2016). Self-reported barriers to healthcare access for rheumatoid arthritis patients in rural and Northern Saskatchewan: a mixed methods study. *Musculoskeletal Care*, 14(4), 243-251.

¹⁴ Koehn, C. L., Lendvov, K., Ma, Y., Li, L., Hoens, A. M., Souveton, M., & Esdaile, J. M. (2017, October). Patient Experiences of Rheumatoid Arthritis Models of Care: An International Survey. In *ARTHRITIS & RHEUMATOLOGY* (Vol. 69). 111 RIVER ST, HOBOKEN 07030-5774, NJ USA: WILEY.

Study aims

The RHEUMAPS study aims to address these gaps by:



Understanding the **priorities for care** across different groups of patients with a broad range of RMDs, and the **resources and components of service** that are **important to meet these needs**.



Measuring the **prevalence of RMDs**, individual socio-demographic characteristics and **health outcomes across different geographical areas in Scotland and Wales** using national administrative healthcare data.



Developing **interactive maps to provide timely and accessible data to inform local, regional, and national service planning** and evaluation for people with RMDs.

In this report we focus on what we have found out about individual priorities for care, the extent to which people were satisfied with the ability of current services to meet these priorities and factors predicting dissatisfaction with services. We discuss the resources and components of service needed to address the gaps identified.

Methods: what we did



We conducted a **cross-sectional web-based survey** of people living in the UK who reported an RMD diagnosis made by a healthcare professional.



The survey was **co-designed with our patient partners** and communicated via national RMD charities and social media between August and November 2021.



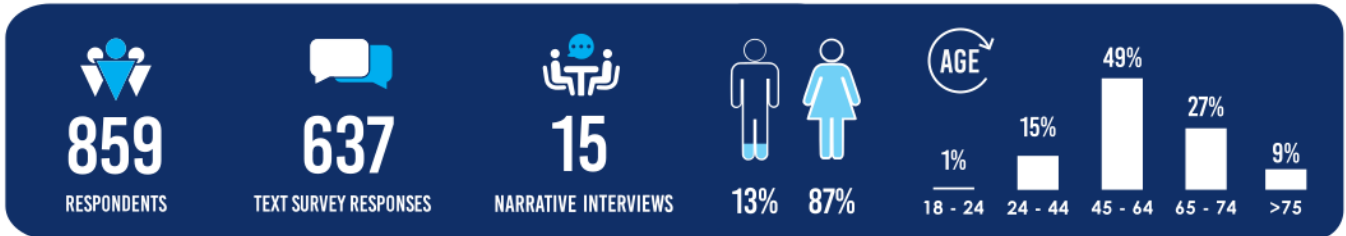
From the survey we used **statistical models** to identify factors related to dissatisfaction with care.



These were explored further with **narrative interviews with people living with RMDs across the UK**. The interviews and free text responses within the survey were analysed thematically to provide a deeper understanding of care priorities.

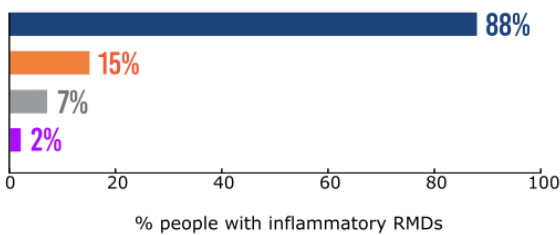
Results: what we found

Between August and November 2021, we surveyed people living with rheumatic and musculoskeletal conditions in the UK:

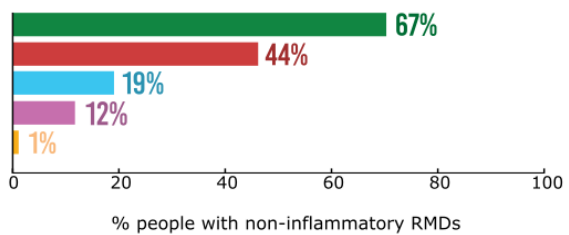


We collected data on males and females of different ages living across the UK with a broad range of rheumatic and musculoskeletal conditions:

INFLAMMATORY



NON-INFLAMMATORY



- Inflammatory Arthritis
- CTD/vasculitis
- Polymyalgia Rheumatica
- Gout
- Osteoarthritis
- Fibromyalgia
- Metabolic bone diseases
- Joint hypermobility
- Other

We heard from people across the UK living in both urban and rural areas, and from people who were working and others who were not:

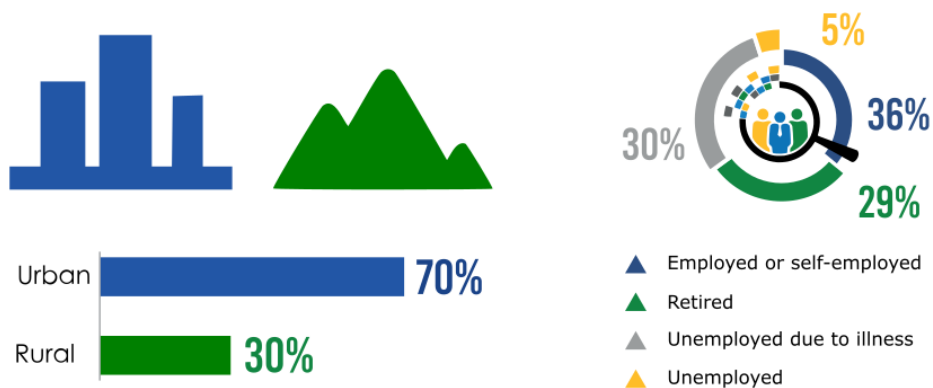


Figure 2. Selected characteristics of survey respondents

85% of respondents reported having an inflammatory condition, 47% reported only having an inflammatory RMD, 15% reported only having a non-inflammatory RMD, and 38% reported having both an inflammatory and non-inflammatory RMD.

As anticipated, rural dwellers with RMDs tended to be older (40% were over 65 years vs. 35% of urban dwellers). Rural dwellers were also less likely to live in the most deprived areas (16% for rural dwellers vs. 27% for urban dwellers), measured using the Index of Multiple Deprivation. However, area-based measures of deprivation can miss hidden pockets of deprivation, particularly in rural areas.

Priorities for care



Individual health priorities included remaining physically active, and better management of pain and fatigue to enable people to actively participate in work and engage in social activities with their family and friends.



Health priorities were **similar across people with a range of different RMDs**, irrespective of where people lived, their age, sex, and work status.



Service priorities to help meet these personal goals included chronic pain services, complementary medicine services, sports and exercise medicine and mental health services.



Care delivery priorities included access to multidisciplinary RMD care services at one location and seeing the same members of the care team to ensure consistency of care.

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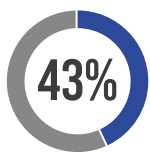
I am not able to meet my priorities such as taking the children out... being able to play with them... go on holiday without having to plan everything carefully to ensure I have toilets nearby, no steps to walk up and short journeys. I used to love going on long walks in the countryside with my dog and children and can no longer do that.

”



Factors predicting dissatisfaction with health services

We explored the extent to which people were satisfied with the ability of current services to meet their care priorities and factors predicting dissatisfaction with care. To do this we examined factors associated with answering “no” to the question “Do the services you currently access for your RMD(s) enable you to meet your care priorities.” This included socio-demographic factors, factors related to aspects of their RMD condition, and patient experiences of the availability and access to services and information.

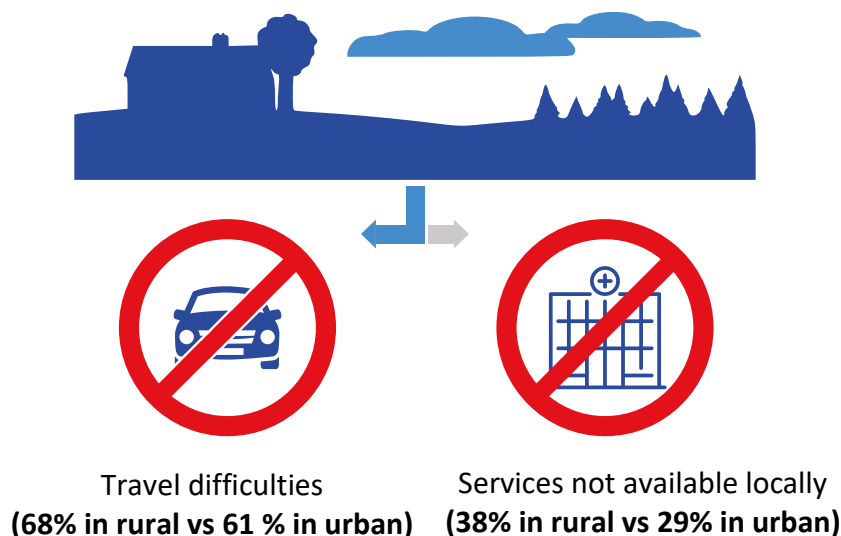


Felt current services did not enable them to meet their care priorities.

Socio-demographic factors predicting dissatisfaction with health services

Being **female**, of **younger age**, living in areas with **higher levels of deprivation**, and being **out of work due to illness** was associated with dissatisfaction with current services.

Rural dwellers were not more likely to be dissatisfied with services, but **some aspects of services had a greater impact on rural dwellers** such as travel difficulties to access care and certain services not being available locally.



Lack of support to work for was highlighted as a particular problem for several patients we spoke to:



“

Neither have there been, since the time I was forced to give up the job I loved, any interest in what I can do and what I'd like to be able to do. I hope that these days, with greater mental health awareness, there would be support in place for anyone coming to terms with the implications of a chronic illness diagnosis.

”

Musculoskeletal health-related factors predicting dissatisfaction with health services

People with **non-inflammatory RMDs** and those who reported **longer time between symptom onset and care seeking** tended to report greater dissatisfaction with services.



There are no solutions given other than continue to take drugs. Accessibility to complimentary therapy is not available. There is no holistic approach to care and acknowledgement that people want to continue to work and maximise their contributions to the wider world.



Those reporting a diagnosis of a non-inflammatory RMD tended to be **younger women** and we frequently heard about a **sense of abandonment and isolation in their experiences of self-managing their condition.**





“

Follow up care and support from services would have helped me from feeling isolated... [but I'm] simply left to get on with it, with no hope of improvement and an even bleaker future going forwards.

”

“

GP tells you it's all about pacing. Impossible when you have children. Pain clinics are a waste of time. Once diagnosed, you are left to manage your condition yourself. Very difficult to do when you don't have any clue how to manage it properly.

”



Experiences with accessing relevant information and services that predict dissatisfaction with health services

Accessing information



1/3 reported difficulties accessing information about their RMD condition.

People told us they commonly looked for health information using general web searches, charity websites and the NHS (including information obtained directly from clinical services and the NHS website), see Figure 3.

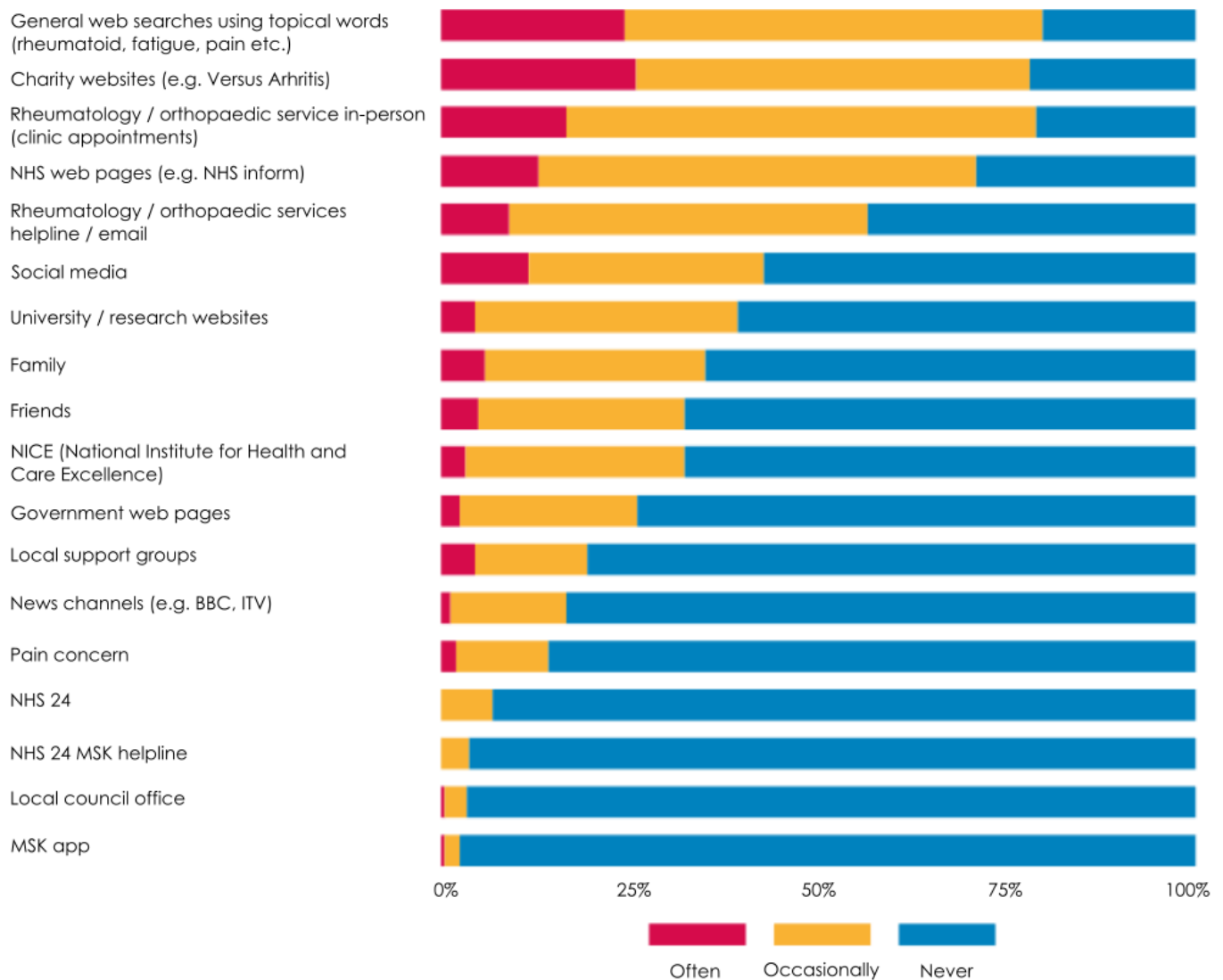


Figure 3. The different resources people use to find information about their condition and care

The **availability of relevant information**, particularly for **non-inflammatory conditions and support to work**, was identified as an **important service gap**. Figure 4 shows most people are unaware of, and have not accessed, work-related support services.

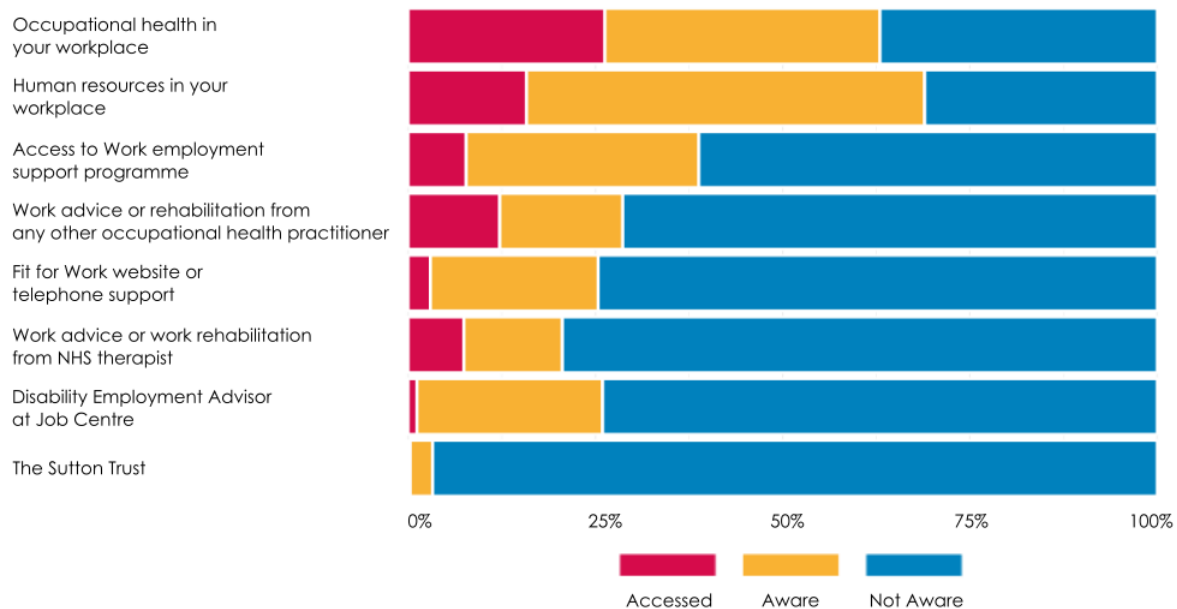


Figure 4. Work-related support services people are aware of or have accessed in connection to their RMD

Information to support work

People told us they **commonly accessed condition-specific charity websites, clinical services and friends/family for work information, rather than symptom focused resources** such as the Pain Toolkit. Common work topics on charity websites included advice on how to self-manage RMDs at work (the importance of posture, regular breaks) and purchasing of equipment.

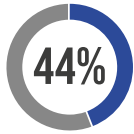
Navigating work information on charity websites was challenging. External signposting to NHS and government resources was variable and often absent (e.g., information on Access to Work, occupational health support, employment benefits). Differences in work policy across the UK devolved nations was often not acknowledged.

Suggested improvements included **using simpler language and signposting to 'bona fide' information.** Patients wanted **positive patient stories**, help with **'soft skills'** e.g., how to have constructive conversations with employers, and **better employer training** as not all employees had access to occupational health services.

Accessing services



Reported difficulties accessing services for their RMD.



Reported difficulties attending services due to caring responsibilities.

Most people identified seeing the same health care staff who know them and their condition(s), and the availability of local specialist health care services, as important factors enabling them to manage their condition(s), see Figure 5.

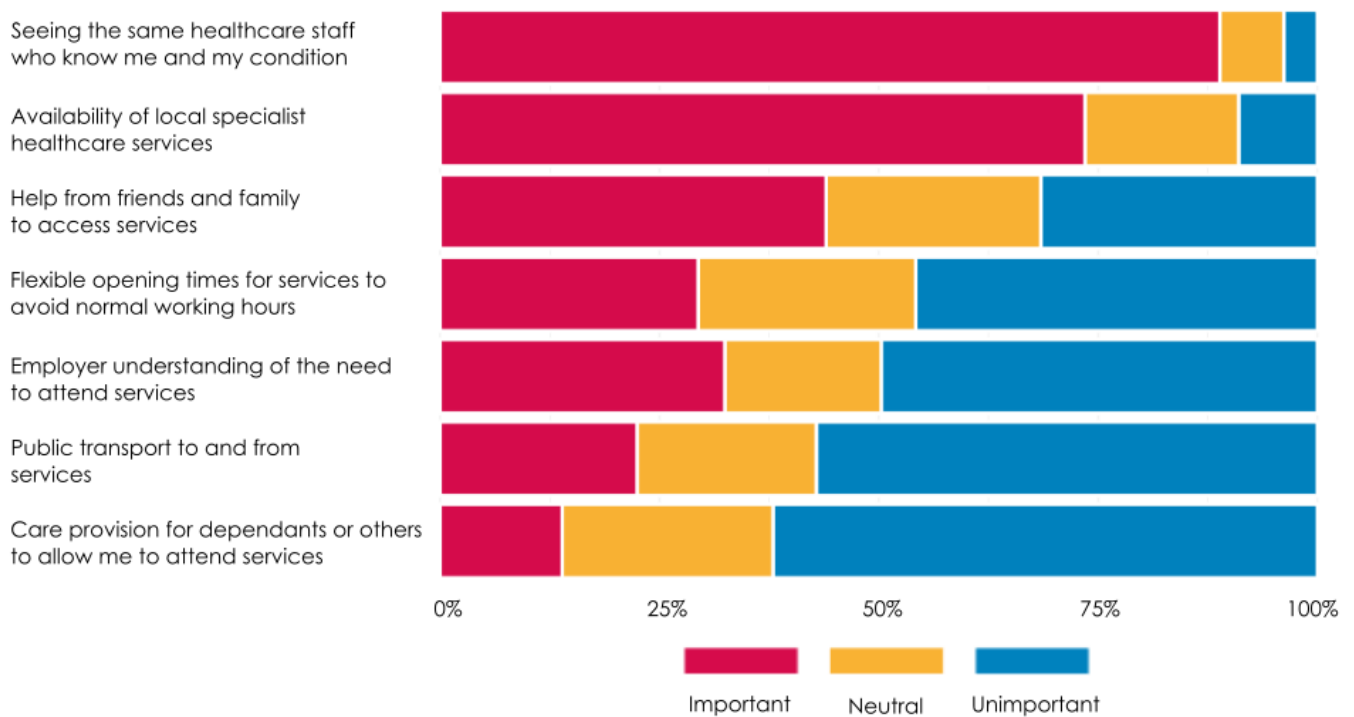


Figure 5. Importance of key factors that help people access services to manage their condition(s)

The availability of chronic pain services was a particular issue. Managing pain was identified as a key priority, but people frequently described difficulties accessing chronic pain clinics, and even when they were accessible, found them unhelpful. We often heard about a perceived lack of understanding of the far-reaching impact of chronic pain on their daily life.

From the interviews and free-text survey responses, we heard that transport issues included: the availability of public transport; physical difficulties accessing transport even when it was available; and the often long and convoluted journeys to attend appointments by patient transport services. As a result, people often relied upon *'goodwill with family and friends having days off work'* to enable them to attend appointments.

Physically accessing services was an issue for people no matter where people lived. For example, those living in urban areas often reported difficulties accessing public transport and struggled with inconvenient appointment times. However, **travel difficulties to access care were more frequently reported in rural dwellers.** **Slow broadband speeds** were important issues for both urban and rural dwellers.

Caring responsibilities not only affected people's ability to access services, but also impacted directly on their own health, which wasn't considered when planning their care needs.



I have elderly parents living 400 miles away who are dependent on me. My husband is supportive but (his) work demands and long hours result in caring for family being on me. Daughter is now a teenager but when she was younger this was much harder. The impact of this on my arthritis is not considered.





Pain is difficult to manage. Caring for my husband (younger than me) is beginning to prove difficult as his dementia worsens and no social care involvement regarding my health.



However, it wasn't just the presence or absence of local specialist services or physical access that mattered. People also told us it was important to:



Know **where to go for help** – a 'map and compass' to signpost to relevant self-management support.



Have **timely access** to community-based and specialist services.

This was particularly important for **chronic pain services, complementary medicine, mental health services and support to work.**





Lack of services provision in county and long waits for appointments where services are available. Lack of information on what services are available and how to access them.

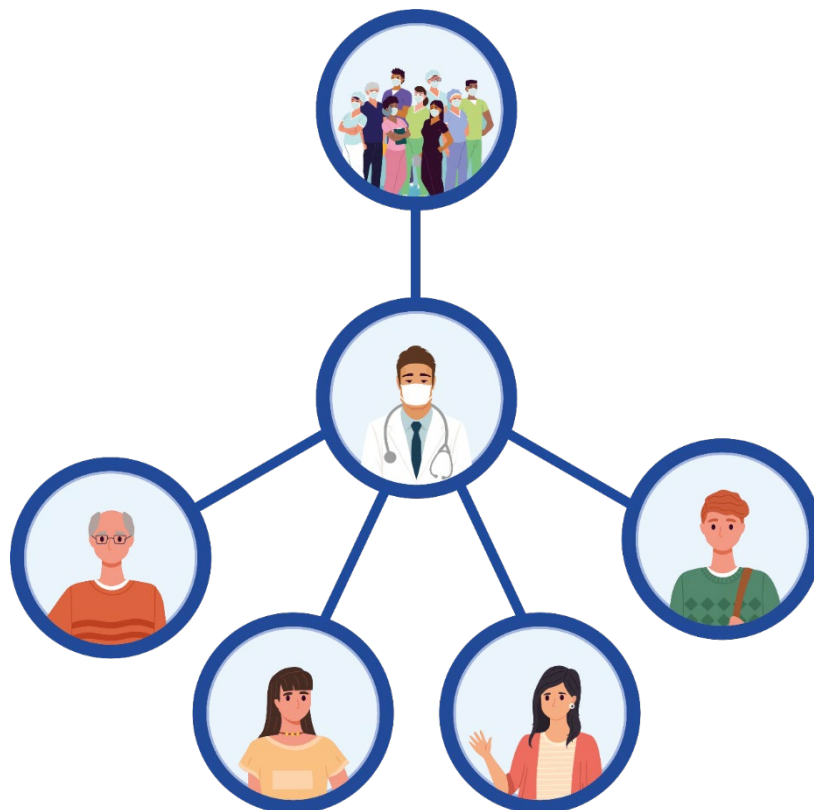


Lack of certain services means that I feel unsupported at times and feel that there are moments when I feel that I'm floundering. Not knowing which way to turn for the help I need.

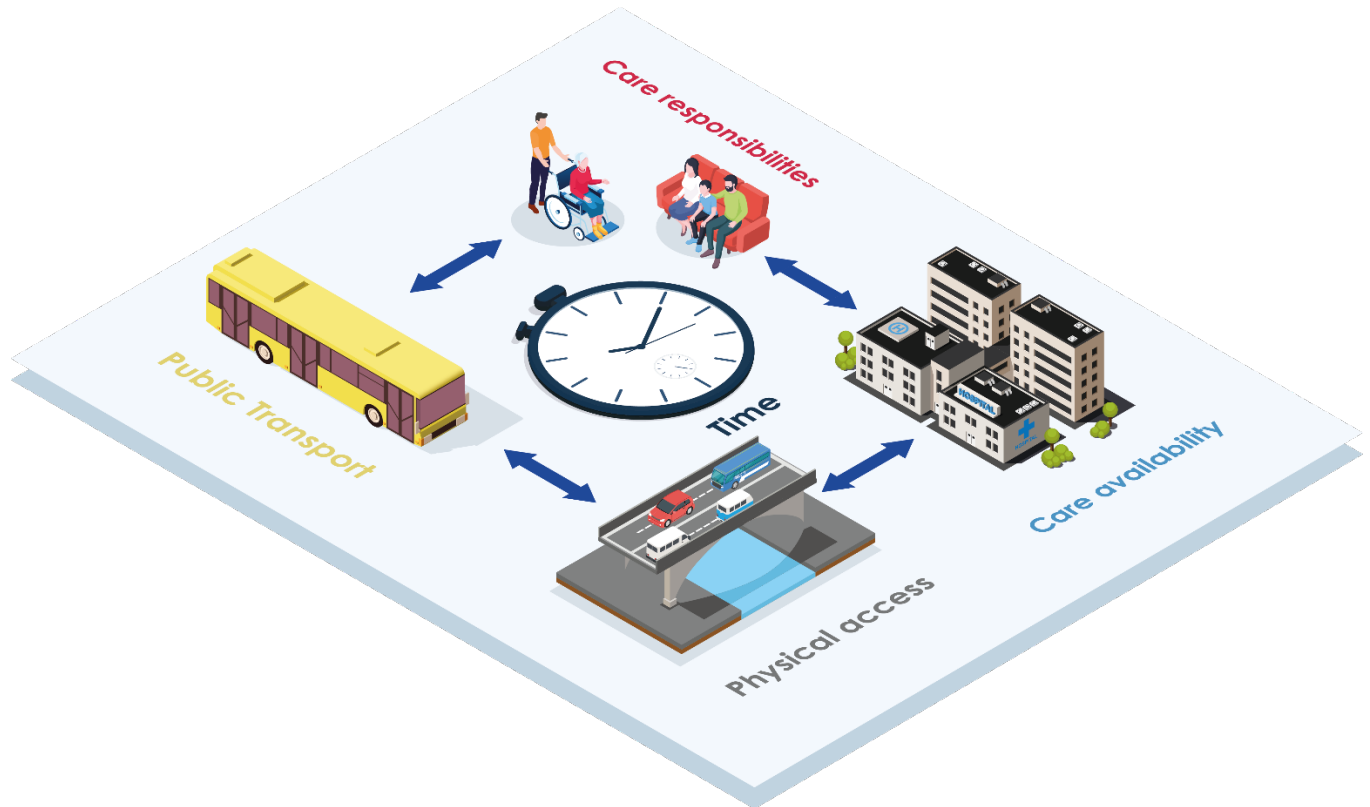




You need access to people... whether it's a physio, OT, Specialist Nurse on a regular basis who can then take any queries back to the team and then feedback these queries back to the team within a couple of week, not wait to see someone for over a year. We are trying to live with these conditions and still need support and access to rehab and advice all through this and beyond.



Often, a complex interaction of factors shaped an individual's ability to access services.



Factors independently associated with dissatisfaction with health services

We entered all the factors above that were associated with dissatisfaction with health services into a statistical model. This enabled us to identify factors independently predicting dissatisfaction with health services. These are summarised in Figure 6 below.

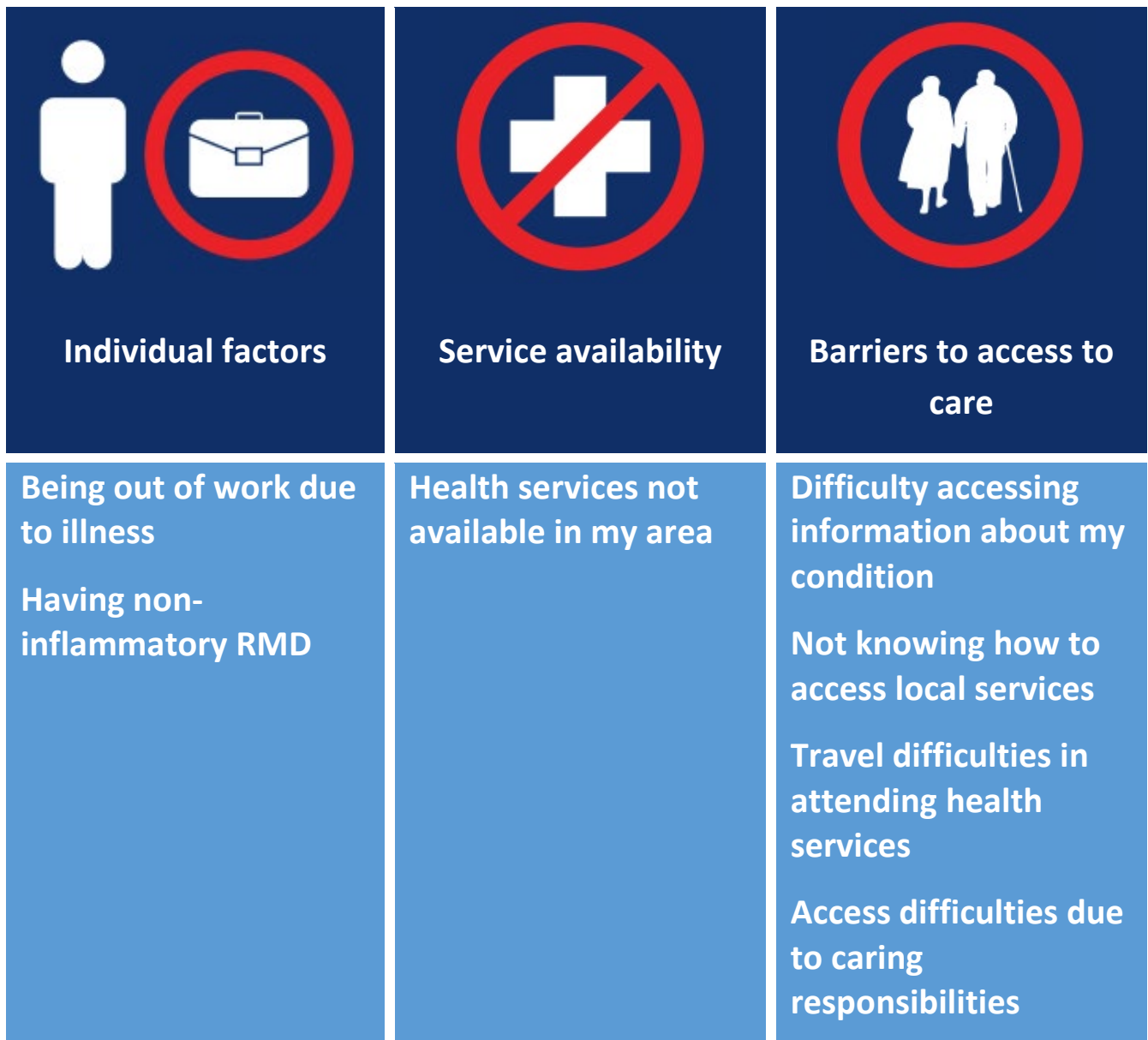


Figure 6. Factors associated with dissatisfaction with care amongst people with RMDs

Summary of findings

What we already know

Pain and fatigue continue to represent a significant burden for those with RMDs and are associated with a poorer quality of life and work impairment.

Access to services varies considerably across the UK.

What this study adds

We have identified a **common set of care priorities** across a broad range of RMDs.

Almost half of those surveyed were dissatisfied with the ability of services to enable them to meet their care priorities.

Younger adults, those with **non-inflammatory conditions**, and those who are **out of work due to illness** were more likely to be dissatisfied with services.

We have identified **key resources and service components** that are important to meet these needs:



Information about non-inflammatory RMDs and support to work



Signposting to existing resources and timely access to relevant services

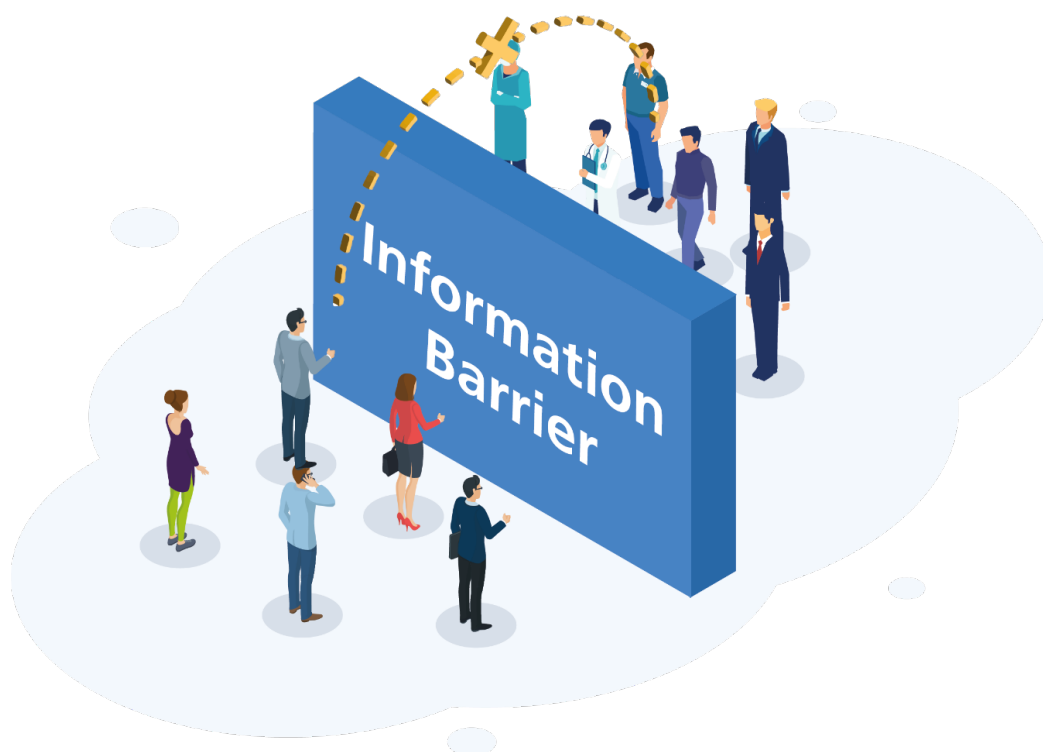


Support for self-management and for those with caring responsibilities to access care

Key messages to improve care experiences

People with RMDs need timely access to information and services in a way that's meaningful to them

Multiple resources and interventions already exist in practice; however, we have identified specific problems with accessing information and services and specific groups of people for whom this is challenging. We need to carefully **consider access and pathways into existing RMD services** and whether they **meet the needs of local populations**, considering the age, ethnic make-up, economic features, and geography of each region. This is particularly important as more Rheumatology services are moving to **Patient Initiated Follow-up (PIFU)**. People particularly valued **seeing healthcare staff who know them and their condition**. Attention needs to be paid to how best to support this within an increasingly task focused and resource poor healthcare system where care is often dispersed across several providers.



People with RMDs have identified support to (remain in) work as a priority need

Musculoskeletal conditions are one of the **most common causes of days lost from work** in the UK and people deciding to stop work earlier than intended. Evidence from research studies shows how people with RMDs can be effectively supported to remain working and **several resources and interventions already exist**.

However, as the findings from this survey show, the **results of important research are frequently not translated into tangible benefits** for patients. Navigating existing resources was challenging; people often accessed condition-specific resources which provided variable amounts of information, with limited signposting to more comprehensive resources.



People with RMDs need sustainable community resources to support them to self-manage their conditions

Living with an RMD is often not only physically but emotionally debilitating and many people **lose confidence and self-belief**. People need **timely support to change behaviour and build confidence to self-manage**, so they can access support services and start to manage their condition in the context of their life and location. Whilst some people can navigate this space very well, others struggle or arrive too late to self-management. **Community-based self-management programmes** can provide such support, including access to multi-disciplinary expertise and continuity of care. However, across the UK, integration of self-management support within care pathways is patchy and most initiatives **only receive short time-limited funding**. This makes it difficult for patients and healthcare staff to keep up to date with what is locally available. The lack of service sustainability and support also undermines the confidence of healthcare professionals in community based self-management support.



Recommendations

Access to information and services

Comprehensive and relevant information must be available in a timely and accessible way, particularly **pain and fatigue**, to meet the diverse needs of people with a broad range of RMDs, including **younger adults** and those with **non-inflammatory conditions**.

Access and pathways to existing services and resources should be **evaluated in the context of local population needs and geography** and used to support local, regional and national service planning.

Support to work

Strategies need to be developed **to improve awareness and access to work-related support** for people with RMDs.

There needs to be better **signposting between RMD charity websites providing work resources** and to external resources, greater use of **positive patient stories**, and **clearer language**.

Support for self-management

Sustainable community-based self-management programmes should be developed and evaluated to enable people to take responsibility for self-managing their long-term conditions from initial diagnosis and as part of their overall treatment plan.

Development of an **overarching policy framework for sustainable self-management support** for long-term conditions to enable early access to visible support and ensure equitable and sustainable resourcing.

Potential solutions

Access to information and services

- Improving access to existing resources for managing pain and fatigue
- Supporting access to services for those with caring responsibilities
- Using population data to support local, regional and national service planning

Improving access to existing resources for pain and fatigue

The Lessening the Impact of Fatigue (LiFT) study¹⁵ has shown that a remotely delivered personalised exercise programme is effective at reducing the severity and impact of fatigue including a significant improvement in work productivity. We have received funding from the National Institute of Health Research (NIHR) to develop plans, together with policy makers, clinicians, charities, and patient partners, on help decide how to make this programme widely available to patients.

The study intervention was delivered by clinical staff (nurses, physiotherapists and occupational therapists) working within NHS services. Upskilling clinical staff provides an opportunity to offer sustainable solutions, embedded within the care team. This also supports the development of therapeutic relationships over time which patients highly value and is associated with improved patient outcomes.

Supporting access to services for those who encounter various barriers

Community (close to home) remote consulting rooms may offer a solution to overcome some of the difficulties accessing care services identified in this study. Remote consultations within a community pharmacy setting played an important role in the NHS response to the COVID-19 pandemic and could be expanded to support delivery of aspects of care for people with RMDs. This offers the opportunity to reduce travel

¹⁵ Bachmair, E. M., Martin, K., Aucott, L., Dhaun, N., Dures, E., Emsley, R., ... & Basu, N. (2022). Remotely delivered cognitive behavioural and personalised exercise interventions for fatigue severity and impact in inflammatory rheumatic diseases (LiFT): a multicentre, randomised, controlled, open-label, parallel-group trial. *The Lancet Rheumatology*, 4(8), e534-e545.

burden and allow people to attend appointments from a convenient location in a timely manner. This may be particularly useful for younger woman with children, those who are working, have caring responsibilities, and /or people who lack support and resources to use information technology at home.

Using population data to support local, regional and national service planning

There are opportunities to use the granular data collected on prevalence and outcomes in specific RMDs as part of the RHEUMAPS study, alongside clinical service data, to inform local, regional, and national service planning. For example, using Welsh data on osteoarthritis prevalence and outcomes (joint replacement therapy), alongside national orthopaedic service data (including information on the location of orthopaedic services and staff resources) to evaluate existing care resources in context of local burden of disease and need.

Support to work

- **Bringing together existing support to work resources**
- **Adapting existing work interventions and resources**

A map through the maze: bringing together work resources into one platform

The [**MRC/Versus Arthritis Centre for Musculoskeletal Health and Work \(CMHW\)**](#) focusses on **supporting patients with musculoskeletal conditions, their employers, and clinicians**. Key to enabling people to remain in work is access to self-management support and resources that empower them to understand their condition(s) and rights, manage it within their workplace, and identify and apply for adaptations/equipment to improve work capacity. In a recent survey conducted by Versus Arthritis, occupational health professionals identified the need for clearer information and resources to improve the support they could offer to people with RMDs.

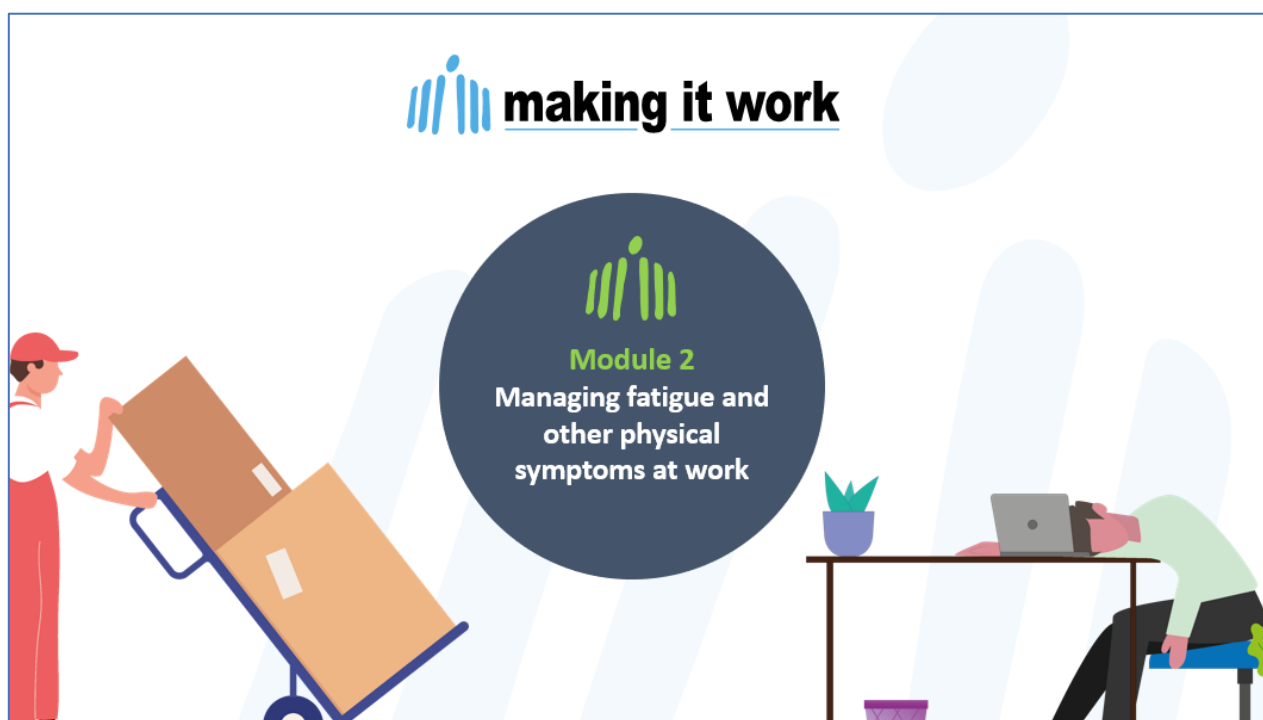
Several interventions, in different stages of development, have been designed to support (or are relevant to) people with musculoskeletal disorders to remain in work. The four recently funded [Nuffield Foundation Oliver Bird projects](#) also focus on support to work.

These interventions are designed for slightly different patient groups and with variations in mode of delivery but there is some overlap. Work is ongoing to bring these programmes **together in one platform** to be available to patients and clinical team members in such a way that they can make an informed choice as to which is most suitable for an individual person.

Adapting and refining existing work interventions and resources

Whilst it may also be necessary to develop **new interventions** to address outstanding gaps, **existing interventions may be adapted**, including those developed in other countries and/or for different health conditions, to meet patient needs. An example is the Making it Work™ Canada programme.

Making it Work™ Canada is a hybrid programme of in person and online support for people with inflammatory arthritis to stay in work for as long as they wish to do so. It is currently being [adapted for use in the UK context](#) as an exclusively online resource, for a wider range of musculoskeletal conditions.



Versus Arthritis are planning to review the existing 'work' area of their website and 'Working with Arthritis' booklet. They are currently developing a self-management 'work related' resource to improve work confidence and capacity of people with arthritis. To inform this work they have developed a survey in partnership with the Society of Occupational Medicine. This is aimed at workplace professionals to identify gaps in training and resources to assist with workplace support. To complement this, they have also surveyed people living with arthritis on their experiences of obtaining work-related support. This, alongside the findings from this study, forms part of a wider piece of work to help Versus Arthritis understand what is required to address and remove barriers to work participation.

Improving community-based support for self-management

- **Sharing examples of self-management initiatives from across the UK**
- **Development of a national self-management Action Plan for MSK and other long-term conditions**

Sharing examples of self-management initiatives from across the UK

Whilst there are **several examples of excellent community-based resources available**, provided by third sector and other non-NHS partners, that have been shown to work well and be sustainable with proper peer support, most patients don't have access to these. Integration of self-management support within care pathways across the UK is patchy and most initiatives only receive short time-limited funding. Robust long-term evaluation of different approaches and shared learning will enable us to build on existing initiatives, create an evidence base to sustain these longer-term, and ensure equitable access across regions.

The **Island Self-Management Group** is an online group for those living with a physical long-term condition on one of Orkney's ferry-linked isles.

Participants can learn self-management techniques from qualified tutors and expert speakers and build friendships with others living with a long-term condition.

MySelf-Management has been active for over ten years (initially as a third sector and NHS partnership) to support self-management of health for those living with long-term conditions. This includes eLearning modules, the Highland Self Management Forum for professionals, online groups on Facebook for MySelf-Management members to stay in touch, and regular online wellbeing sessions.

Development of a national self-management Action Plan for MSK and other long-term conditions

NHS England has the **Best MSK Collaborative** and in Wales a **Quality statement for Musculoskeletal health** has been **published by the Welsh Government**. In Scotland, work on a new musculoskeletal digital pathway is beginning, and the national Self-Management Fund operated by the Alliance continues to support innovation and development for self-management of long-term conditions. However, there is a **compelling case for a musculoskeletal Action Plan for Scotland**, which can prioritise and coordinate work across sectors to meet the challenge of musculoskeletal conditions outlined in this report.



ALLIANCE



Future research agenda

We have identified specific groups of people whose care needs are not being met, components of services that are important to enable people with RMDs to meet their care priorities, and key gaps in existing care.

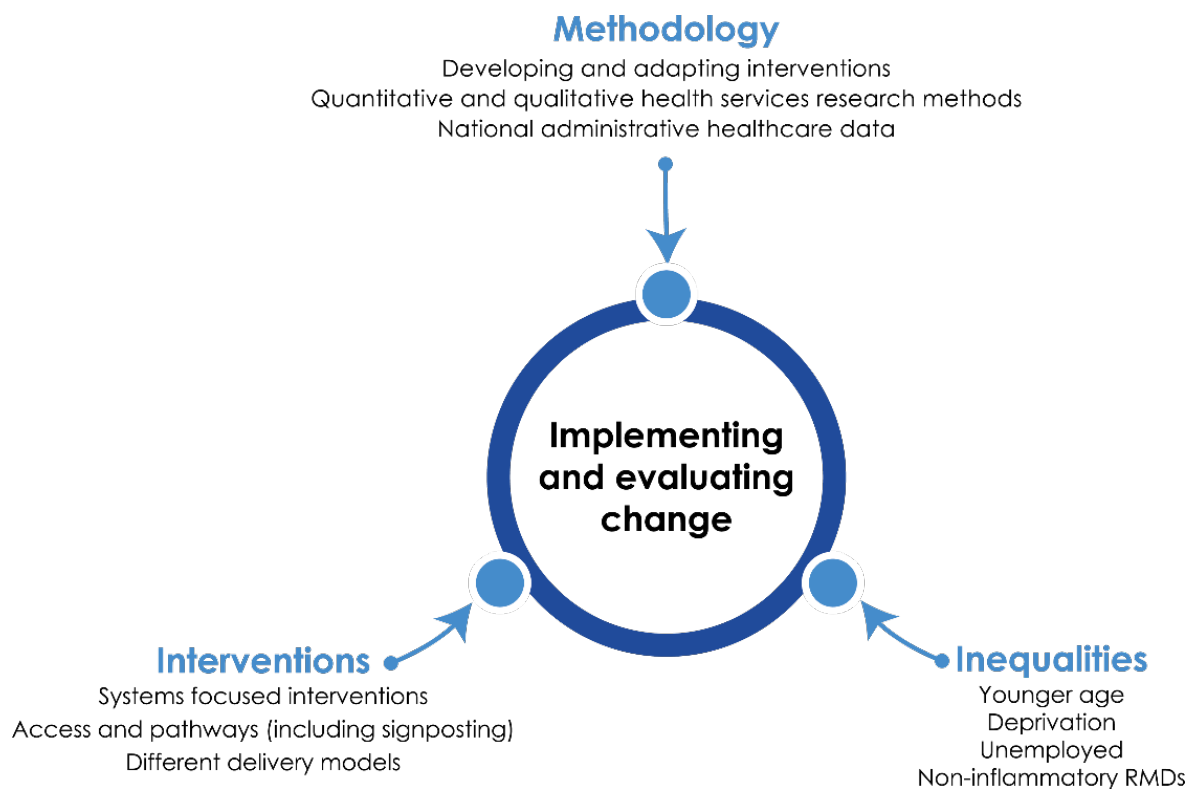
However, several resources and evidence-based interventions already exist, highlighting the importance of using robust implementation, health services and policy research methodology to effectively support translation of research findings into practice.

There is growing evidence of the formal and informal social care burden in RMDs, including informal care provided to those with RMDs by family and friends. However, many people with RMDs have caring responsibilities themselves, which affects their ability to access services and can have a direct impact on their own health. Having an RMD also significantly impacts on other social aspects of life, such as the ability to engage with family and friends, hobbies, and work. However, the exact burden of social care, and the complex interactions between the wider social determinants of health and health outcomes in RMDs, has yet to be fully quantified. Understanding this is essential to support the delivery of holistic, joined up care. For example:

- What are the impacts of having an RMD, for example, on social engagement, formal and informal care needs, and ability to undertake caring responsibilities?
- What is the relationship between social impacts and health outcomes in RMDs?
- How can we ensure that specialist and community-based services and support reach a broad range of people with RMDs across the life course, particularly those whose care needs are not currently being met?
- How can we make better use of health and social care datasets e.g., including those held by local authorities, as well as administrative health care data in primary and secondary care, to support timely iterative learning cycles that inform service improvements and measure the impact of change ?
- How can we better support the journey from research to practice and policy impacts?

To better understand these problems and develop solutions that work in practice, we need to undertake studies that use a **mixture of different research methods**. Combining complementary qualitative and quantitative methods offers a more comprehensive approach.

Furthermore, whenever we introduce changes to (or new) services and pathways, **timely evaluation must be embedded** in that process in a way that supports **iterative adaptation and sustainability**. Measuring longer term outcomes is particularly important for sustaining social and community-based self-management initiatives and support.



Conclusions



Care priorities are similar across conditions and geography, but rural dwellers have greater difficulty accessing services



We have identified specific groups of people with RMDs whose care needs are not being met



Key gaps include appropriate signposting and support to facilitate timely access to relevant information and services



We need to better target existing resources and interventions to meet the needs of specific groups of patients

