






Left Waiting, Left Behind:

The Reality of Living with Arthritis

A lived experience survey

Arthritis UK

Acknowledgement and contributions

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Foreword

Deborah Alsina MBE, Chief Executive, Arthritis UK

There are over 20 million people living with a musculoskeletal (MSK) condition in the UK. Of these more than 10 million adults, young people and children are living with arthritis. That's one in six of us affected by unpredictable levels of pain, fatigue, disability, mental health challenges and financial strain on a daily basis.

However, despite affecting so many lives, this report clearly shows that people with arthritis are not getting a diagnosis soon enough, nor are they receiving the care and support they urgently need to manage their condition effectively. This points to a clear lack of prioritisation; arthritis and other MSK conditions are not considered a major public health issue by health leaders across the UK.

This report also demonstrates that the impact of arthritis is unequal – people from lower socio-economic backgrounds and those living with inflammatory arthritis report worse experiences across all areas of life. Younger adults who receive a diagnosis often struggle more than their older peers, impacting heavily on their life choices.

Furthermore, many people living with arthritis are also living with other long-term health conditions, all of which have a significant impact on an individual's quality of life. For example, four out of five people with osteoarthritis (OA) have at least one other long-term condition.[1] The argument for addressing arthritis as a major contributor of comorbidities cannot be overstated.

Without the prioritisation of arthritis and other MSK conditions at a local and national level, there is a danger that people with these conditions will continue to face numerous barriers when attempting to access the services, care and support they need to live well.

We urge policymakers to take action by recognising arthritis and related MSK conditions as a major public health issue, ensuring adequate investment and coordinated efforts across governments to deliver high-quality services and support. People with arthritis must have equal access to personalised treatment and care, regardless of where they live, and be empowered to take an active role in decisions affecting their lives.

Action is also needed to improve the quality and availability of arthritis and MSK health data. To embed training for all frontline healthcare professionals to enhance diagnosis and support. And to protect people from being pushed into poverty due to their condition through a compassionate benefits system and stronger workplace support.

Executive summary

'Left Waiting, Left Behind: The Reality of Living with Arthritis' summarises the findings of a lived experience survey and presents a powerful snapshot of the reality of living with arthritis. Told through lived experiences and personal stories, it covers experiences of diagnosis, treatment, management and support, along with the personal and financial costs.

Many people with arthritis aren't able to live the life they want to lead because of their condition, and the impact of living with arthritis isn't being felt equally. People from lower social grades, younger adults and those with autoimmune inflammatory conditions are being disproportionately impacted, facing greater challenges and more frequent barriers.

Over 10 million adults, young people and children in the UK are living with a form of arthritis – a condition which is one of the leading forms of disability in the UK and can affect anyone. And yet, arthritis and its impact are largely misunderstood and/or minimised by healthcare practitioners, the public and policymakers.

To improve the lives of those living with it, arthritis, and associated MSK conditions, must be recognised as a major public health issue. They must be given adequate levels of investment, alongside targeted and joined-up work across governments.

The experiences shared in this report are not an inevitable part of living with arthritis. Things can and should be done differently. Through the development and improvement of consistency in service provision through targeted frameworks, the inclusion of lived experience in decision making, improvements in data quality and collection, and the introduction of new training for frontline healthcare professionals we can ensure that people with arthritis can lead full and fulfilling lives.

We surveyed people:

- with any type of arthritis condition, with or without a formal diagnosis
- over the age of 18
- living in the UK

This report draws on the findings of an online survey of 7,928 people living with arthritis in the UK, commissioned by Arthritis UK and carried out by YouGov in 2024. Findings were weighted to ensure they are broadly representative of the people with arthritis across the UK. The link to the full set of questions, breakdown of the demographics of the survey respondents, as well as data tables for this report can be found in Appendix 2.

Main findings

Arthritis affects every aspect of life

For example, physical health, hobbies, relationships and mental health. People with arthritis feel underinformed and unsupported.

The impact of arthritis is uneven and unfair

There are clear and consistent health inequalities with younger adults, people with autoimmune inflammatory conditions and people from lower social grades reporting a poorer experience living with their arthritis.

People are waiting too long

For both diagnosis and treatment, people feel they are waiting too long. But the value of a diagnosis is clear, as it validates experiences and opens doors to treatment and support.

Barriers to effective care are preventing people from living the lives they want to lead

People feel they are not receiving timely and effective treatment, impacting their ability to live well.

People with arthritis are being financially squeezed

Arthritis can increase the personal cost of living whilst simultaneously impacting the ability to earn.

Policy recommendations

The reality of living with arthritis is clear, and we urge policymakers to take action. This means:

- Recognising arthritis and related MSK conditions as a major public health issue. To deliver high-quality services and support, arthritis and MSK conditions require adequate levels of investment, alongside targeted and joined-up work across governments.
- Ensuring people with arthritis have equal access to personalised treatment and care no matter where they live, as well as the ability to take an active role in decisions that affect their lives.
- Improving the quality and availability of arthritis and MSK health data.
- Embedding training for all frontline healthcare professionals to improve diagnosis and support for people with arthritis.
- Protecting people from being pushed into poverty as a result of their arthritis, through a compassionate benefits system and improved workplace support.

Introduction

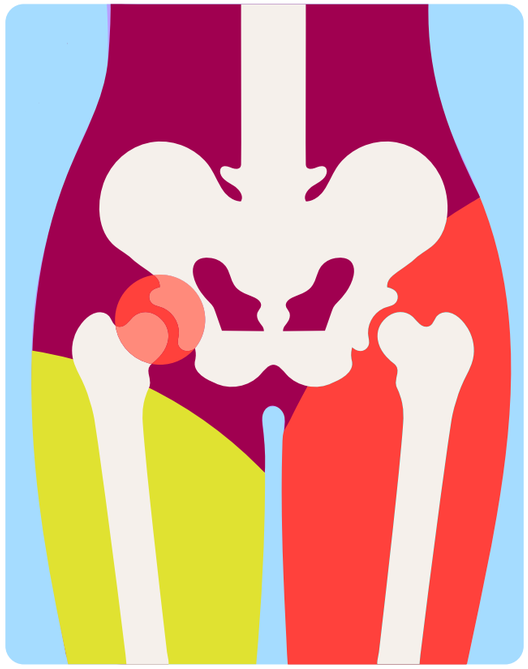
What is arthritis?

Arthritis refers to painful, stiff and/or restricted joints. Arthritis symptoms are common in conditions that cause joint damage or inflammation. There are many different forms of arthritis, the most prevalent include osteoarthritis, autoimmune inflammatory arthritis conditions (including rheumatoid arthritis, psoriatic arthritis and axial spondyloarthritis), crystal arthritis (such as gout), or as a symptom of inflammatory connective tissue diseases (such as lupus). Arthritis is also used as an umbrella term for a range of conditions where arthritis is the main symptom and may not be a single condition. Everyone's experience of arthritis is unique; it is an unpredictable, fluctuating condition that can affect every aspect of a person's life.

Musculoskeletal (MSK) conditions are characterised by problems with the muscles, bones, joints and adjacent tissues (such as ligaments and tendons) which can lead to temporary or lifelong limitations in functioning and a person's ability to live independently. It is typically characterised by pain and limitations in mobility and dexterity (how easily we can use our hands or body to perform tasks), including conditions such as tendon injuries and sprains, arthritis and fibromyalgia. When it comes to quality of life, good MSK health is as vital as the state of our mental health, playing a critical role in maintaining mobility, dexterity, independence and overall quality of life.[2] Around a third of the UK population (that's over 20 million people) live with an MSK condition.[3]

Types of arthritis

Certain types of arthritis such as rheumatoid arthritis, psoriatic arthritis and axial spondyloarthritis are autoimmune inflammatory conditions. Here the immune system (the body's natural self-defence system) attacks and inflames the joints and surrounding tissues, causing swelling, pain, stiffness and joint damage. Any joint in the body could be affected and people often experience fluctuating and unpredictable levels of disease activity. People will typically be treated with medicines that aim to reduce the pain and swelling in joints. These are called disease-modifying anti-rheumatic drugs (DMARDs) and include biological therapies.



Another main type of arthritis is osteoarthritis (OA), which happens when the body can no longer maintain and repair one or more joints – commonly affecting hands, hips and knees, the impact on the body can be systemic.

The cartilage (the smooth cushioning substance covering the ends of bones) becomes thin and uneven, preventing the joint from moving easily. The body's attempts to repair these changes can lead to pain, stiffness, swelling and changes to the shape of the joint.

Conditions such as gout are types of crystal arthritis, where people have severe but self-limiting arthritis episodes caused by microscopic urate crystals being deposited in and around the joints. Gout is a type of inflammatory arthritis where the immune system attacks joints and surrounding tissues where urate crystals have formed, causing episodes of severe inflammation, stiffness, pain and damage (gout flares). Urate crystals form in joints when the body's urate (uric acid) level is persistently too high.

The impact of arthritis goes beyond the condition itself. One in 10 people with rheumatoid arthritis will be diagnosed with interstitial lung disease, putting them at increased risk of early death.[4] People with gout are at 29% higher risk of chronic kidney disease than people without gout[5] and people with OA are nearly 3 times more likely to also have ischaemic heart disease or heart failure than those without OA (potentially because of shared underlying risk factors).[6]

Prevalence of arthritis

Over 10 million adults, young people and children in the UK have at least one form of arthritis and it is one of the leading causes of pain and disability.[7] The Global Burden of Disease study (2023) continues to identify MSK conditions as a leading cause of years lived with disability (YLDs) worldwide, highlighting their public health significance.[8]

Overview of methodology

A survey of 7,928 adults (aged 18+) living in the UK was conducted between July and August 2024. Arthritis UK commissioned YouGov to provide a sample of individuals with backgrounds broadly representative of those living with arthritis in the UK.[a] Arthritis UK supplemented this sample to improve representation, and additional participants were recruited through targeted social media outreach.[b]

All responses were weighted to be broadly representative of the UK population of people with arthritis and analysis was conducted by Arthritis UK. Figures reported are weighted unless otherwise stated.

Respondents were grouped into three groups depending on their only or most impactful type of arthritis:

1) Osteoarthritis

2) Autoimmune Inflammatory Conditions

3) Arthritis Other or Arthritis Unknown (including Gout)

Our survey used social grades to determine the social classification of respondents and divided the cohort into two groups – higher social grades (ABC1) and lower social grades (C2DE). Social grades are calculated using an algorithm usually based upon the occupation and employment status of the Chief Income Earner in the household. For further detail, please see Appendix 1.

Please note, this report contains material of a highly sensitive nature including mention of suicide, which some readers may find distressing.

a YouGov recruited 5,144 participants (unweighted).

b An additional 2,784 participants were recruited by Arthritis UK (unweighted).

Chapter 1

The impact of arthritis

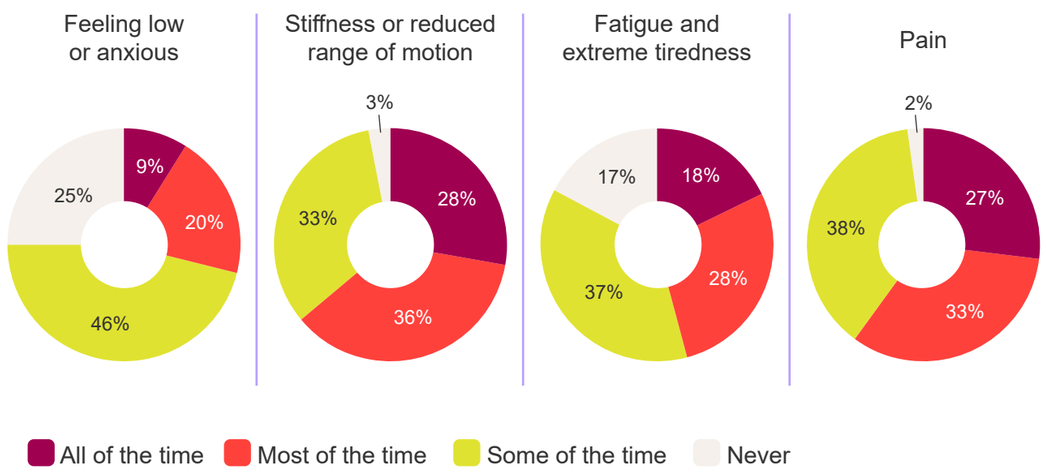
More than a condition

Arthritis is more than just a condition. The impact is huge, affecting the ability to work, care for family, move free from pain and live independently.

> **I'm in constant pain and low mood, no energy and alone most of the time. It's a living hell.**
>
> Male, aged 45-64, Osteoarthritis, England

Of our survey respondents, **nearly 1 in 3 (32%)[a] say arthritis severely or very severely impacted their life in the past year.** Symptoms can be debilitating and for some, can mean living in constant pain. Arthritis can interfere across many different aspects of life and have a significant impact on mental health, causing people to feel isolated and experience stigma from others.

Figure 1 – How often, if at all, have you experienced the following symptoms in the past 12 months because of your arthritis condition(s)?



Base: all survey respondents

a 32% (N=2,558) of respondents selected either 'Severely' or 'Very severely' to the question 'In the past 12 months, to what extent, if at all, have your arthritis symptoms interfered with the following aspects of daily life? – Your life overall'.

b 60% (N=4,775) of respondents selected either 'All of the time' or 'Most of the time' to the question 'How often, if at all, have you experienced the following symptoms in the past 12 months because of your arthritis condition(s)? – Pain'.

Six in 10 people (60%)[b] are living in pain most or all of the time due to their arthritis **(Figure 1)**. The impact of living with pain can be debilitating and often makes simple tasks of daily living more difficult. Previous research[9] has found people with arthritis are more likely to suffer from anxiety, depression and low self-esteem, and they have high levels of associated mortality and suicide, compared with those with no major health conditions. The loss of the ability to carry out daily functions due to arthritis is also associated with the onset of depressive symptoms.

In our survey, 1 in 4 (25%)[c] people report that arthritis makes them feel low in mood or anxious most or all of the time. Nearly 1 in 5 (19%)[d] told us they feel isolated most or all of the time due to their arthritis.

These emotional challenges are not experienced in isolation and are often made worse by the stigma surrounding arthritis and the lack of understanding of its true impact.

Nearly 1 in 5 (18%)[e] of the people we surveyed reported experiencing stigma because of their arthritis and more than 4 in 10 felt that people did not understand their condition or the impact of their arthritis on their life (42%[f] and 44%[g]).

Younger adults are often faced with disbelief or are dismissed as 'too young' to have arthritis. This leads to delays in diagnosis, stigma at work or university and lack of understanding in social and healthcare settings.

> **Arthritis gradually impacts every area of life, and gradually you feel your world getting smaller as you measure every activity you do by the amount of pain and stiffness you experience or anticipate experiencing.**
>
> Female, aged 45-64 years, Osteoarthritis, Scotland

> **[In my] experiences as a young 'healthy looking' person […] arthritis has stigma and misconceptions around young people, [for example] recognising that you are one of the youngest in waiting rooms, using mobility aids, [and a] blue badge.**
>
> Female, aged 18-44, Autoimmune Inflammatory Condition, Northern Ireland

c 25% (N=1,912) of respondents selected either 'All of the time' or 'Most of the time' to the question 'How often, if at all, does your arthritis condition(s) cause you to feel low in mood or anxious?'.

d 19% (N=1,486) of respondents selected either 'All of the time' or 'Most of the time' to the question 'How often, if at all, do you feel isolated because of your arthritis condition(s)?'.

e 18% (N=1,426) of respondents selected either 'Strongly agree' or 'Somewhat agree' to the question 'I have experienced stigma from other people because of my arthritis'.

f 42% (N=3,176) of respondents selected either 'Strongly disagree' or 'Somewhat disagree' to the question 'I feel like generally other people understand my arthritis condition(s)'.

g 44% (N=3,301) of respondents selected either 'Strongly disagree' or 'Somewhat disagree' to the question 'I feel like generally other people understand the impact of arthritis condition(s) has on my life'.

Living a full life with arthritis

Arthritis symptoms were reported as having an impact across many different aspects of daily life:

46% Nearly 1 in 2 people reported that their ability to **exercise** was affected severely or very severely by their arthritis symptoms.[h]

40%
Said arthritis had a negative impact on their **relationships**.[j]

31%
Said that their ability to **carry out regular tasks** was affected severely or very severely by their arthritis symptoms in the last 12 months.[i]

33%
Said that their arthritis symptoms interfered with their **ability to get around** in the last 12 months.[i]

30%
Said that their **sleep** was affected severely or very severely by their arthritis symptoms in the last 12 months.[i]

32%
Said that their **hobbies and interests** were affected severely or very severely by their arthritis symptoms in the last 12 months.[i]

8%
Said arthritis affected their **ability to have a family**.[k]

h 46% (N=3,625) of respondents selected either 'Very severely' or 'Severely' to the question 'In the past 12 months, to what extent, if at all, have your arthritis symptoms interfered with the following aspects of daily life? – Ability to exercise'.

i Respondents selected either 'Very severely' or 'Severely' to the question 'In the past 12 months, to what extent, if at all, have your arthritis symptoms interfered with the following aspects of daily life?' – Ability to get around (33% N=2,583), hobbies and interests (32% N= 2,532), ability to carry out regular tasks (31% N=2,417) and sleep (30% N=2,388).

j 40% (N=2,766) of respondents selected 'Strongly agree' or 'Somewhat agree' to the question 'To what extent do you agree or disagree with the following statements? Having arthritis has had a negative impact on my personal relationships'.

k 8% (N=347) of respondents selected 'Strongly agree' or 'Somewhat agree' to the question 'To what extent do you agree or disagree with the following statements? Having arthritis has affected my ability to have a family'.

Effective arthritis management is essential for improving long-term outcomes and enhancing quality of life. When well-managed, arthritis symptoms can be significantly reduced, helping them to maintain mobility, independence, participation in daily activities, remain in employment and reduce the impact of their condition on their mental health.[10]

> **Life is just a challenge with arthritis and one [has] to rise to it every day. It does get you down.**
>
> Female, aged 65+, Osteoarthritis, England

Despite this, **more than 1 in 3** (36%)[l] **surveyed felt that their condition was not well-managed.** The term 'well-managed' was not defined in the survey and was open for the respondent to interpret; this likely means aspects of the healthcare they have received, and aspects of self-management (where one can own their health and wellbeing), were considered when answering the question.

l 36% (N=2,859) of respondents selected either 'Strongly disagree' or 'Somewhat disagree' to the question 'My arthritis condition is currently well-managed'.

Bobbie's story

Cheshire, England

I was diagnosed with arthritis as a teenager. I wasn't prepared for the impact it would have on my life, or the toll it takes daily.

Your whole lifestyle changes when you get arthritis; you lose your identity a little bit. Things you used to be able to do you can't do anymore. I was really sporty, involved in everything and all of a sudden, I couldn't do that anymore. Your whole personality, your whole life changes. And you're left asking 'who am I?' For a long time, your disease defines you.

Everyone can live in pain for a while; that's part of life. It's a different thing to live in constant pain, that's when it starts doing funny things to your mind. The impact it has on your body and your mental health, but people don't see it because it's joint pain.

If you break your arm, you wear a cast and people know you'll get better. But with arthritis there's no signal to the outside world that the person is in pain; it's all hidden and silent and it can eat away at you. I wasn't ready to get better physically before I learned how to live with the condition mentally. There is a grieving process following diagnosis.

I had to leave my job as there was no flexibility in my workplace to manage flare ups and fatigue. In the end I started my own company, and I now offer that flexibility to other people.

In my opinion, mental health support following a diagnosis is the best thing people can be offered. You can feel very alone and isolated in that period immediately after diagnosis, and you hear a lot about things you're not going to be able to do going forward.

People need a chance to process what's happening and start to look to the future in a more positive way.

Chapter 2

Uneven and unfair

Living in pain

Health inequalities are avoidable and unfair differences in health status between groups or communities.

It has been 15 years since the Marmot Review was published[11], a report highlighting stark health inequalities across society. The report revealed that people living in the most deprived neighbourhoods not only face shorter life expectancies but also spend a greater proportion of their lives living with disability, compared to those in the wealthiest areas. A decade later, the follow-up *Marmot: Ten Years On*[12] report showed that these inequalities were worsening, with health outcomes continuing to decline in disadvantaged communities. Simply put, the health system works less well for poorer people.

This was no different in our survey, which overwhelmingly found that arthritis does not impact everyone equally, with people from lower social grades (C2DE), people with Autoimmune Inflammatory Conditions (such as rheumatoid arthritis) and younger adults with arthritis report more negative experiences.

We found people in the lower social grades (C2DE) consistently reported worse experiences compared to people in the higher social grades (ABC1).

They report their arthritis is less well managed[a] and that they experience more severe symptoms of pain **(Figure 2)** – a pattern we see across conditions and age groups.[b]

Previous research has shown that pain, specifically chronic pain[c], affects people differently. A previous Arthritis UK (formerly known as Versus Arthritis) report, 'Chronic Pain in England: Unseen, Unequal, Unfair'[13], highlighted concerning health inequalities and trends in people with chronic pain, many of whom have an MSK condition. Among people living in the most deprived quintile[14,d], about 4 in every 10 men (37%) and between 4 and 5 in every 10 women (45%) reported chronic pain. For those living in the least deprived quintiles, about 3 in every 10 men (27%) and 3 in every 10 women (33%) reported chronic pain.

Researchers from Keele University, funded by Arthritis UK in partnership with the Nuffield Foundation, have found that people with an MSK pain condition from more deprived backgrounds initially reported worse pain and disability. Worryingly, while all groups of patients showed improvement with treatment over time, **this inequality gap between the groups remained six months later and even widened**. Additionally, the study found that opioid (pain relief) prescriptions were more common among patients living in the most deprived areas, with 30% of people from deprived areas given opioid prescriptions compared to 19% of people in less deprived areas.[15]

Pain relief use is widespread, long-term, and prescription prevalence increases with deprivation despite not being evidence-based nor in line with guidelines.[16]

Although the Marmot Review and other national reviews and initiatives have documented and highlighted health inequalities, there is clear evidence that people living in poorer areas are in poorer health and receiving poorer outcomes compared to those living in richer areas.

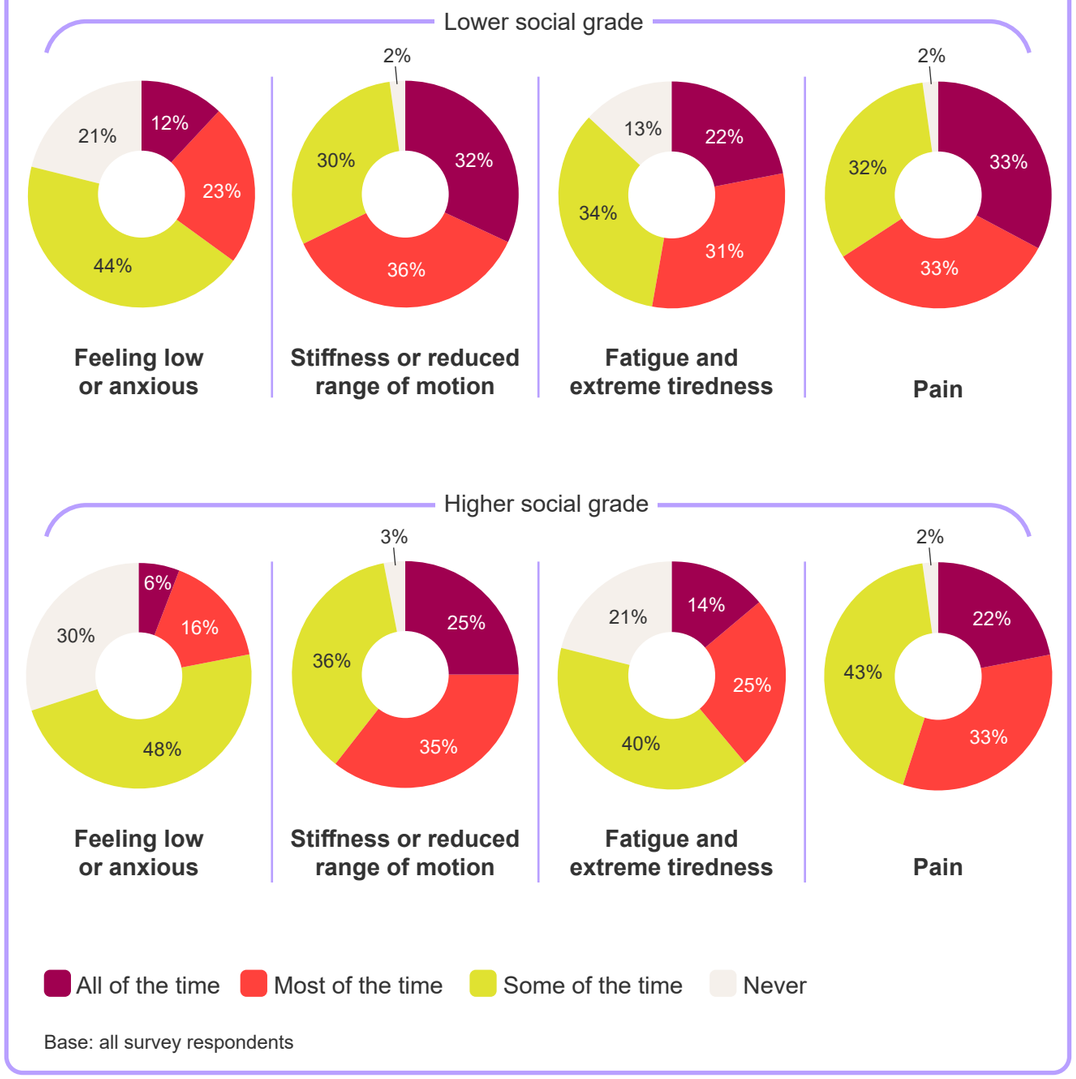
a 39% (N=1,417) of those from lower social grades (C2DE) selected either 'Strongly disagree' or 'Somewhat disagree' to the question 'My arthritis condition is currently well-managed'. This is in comparison to 33% (N=1,333) for those from higher social grades (ABC1).

b Please refer to data tables.

c Chronic pain refers to persistent or recurrent pain that has gone on for more than three months.

d The Index of Multiple Deprivation, commonly known as the IMD, is the official measure of relative deprivation for small areas in England. Quintile 1 is the least deprived and quintile 5 the most deprived.

Figure 2 – How often, if at all, have you experienced the following symptoms in the past 12 months because of your arthritis condition(s)? By social grade

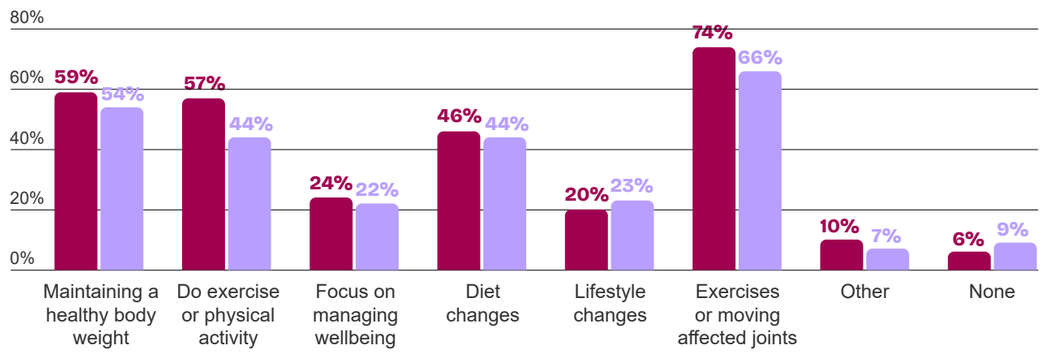


Base: all survey respondents

Managing my arthritis

People with arthritis from lower social grades were less likely to report using most self-management strategies over the past year to help manage their arthritis compared to those from higher social grades (as seen in **Figure 3**).[e]

Figure 3 – Over the last year, which of the following, if any, have you done to help manage your arthritis condition(s)? By social grade



Base: all survey respondents

Individuals from lower social grades consistently rated each self-management technique as less useful than those from higher social grades.[f] For example, among those who used exercise or physical activity to manage their arthritis in the past year, 25% of respondents from lower social grades found it 'Not useful at all' or 'Not very useful', compared to only 19% from higher social grades.[g]

This could reflect lower health literacy, differing health beliefs, unequal access to reliable information, reduced availability of support (such as organised classes), access difficulties (particularly in the case of travelling to a gym or class) or wider social determinants. Even when only considering those individuals who reported the most severe symptoms, those from lower social grades are more likely to report self-management is less useful.[h]

e Respondents answered the question 'Over the last year, which of the following, if any, have you done to help manage your arthritis condition(s)?'. They could select as many options as they wanted.

f Please refer to data tables.

g 25% (N=393) of those from lower social grades selected 'Not useful at all' or 'Not very useful' to the question 'Over the last year, which of the following, if any, have you done to help manage your arthritis condition(s)? - Do exercise or physical activity'. This is compared to 19% (N=427) of those from higher social grades.

h Please refer to data tables

'Too young for arthritis'

Younger adults (18-44 years) report worse experiences than older adults.

They report worse mental health struggles because of their condition[i] and the least understanding from others around their condition (7 in 10 younger adults feel other people don't understand the impact arthritis has on their life).[j,k]

In addition, younger adults are more likely to experience stigma, isolation, and are more likely to find that arthritis impacts their personal relationships and family planning.[l,m,n,o]

> **I feel like it's not taken seriously because I'm young, I feel like I've lost the side of myself that used to be very active. I'm constantly told that I can do things because I'm young and look able bodied.**
>
> Non-binary person, aged 18-44, Arthritis Other, Scotland

> **I am young and diagnosed. I was laughed away for many years as a teen with joint pain. Even following my diagnosis it has taken me time to get health professionals to take me seriously and be on my side. I have finally found a doctor I click with and feel I am getting better service, sadly probably due to the great deterioration in my clinical signs. I feel as a young person with rheumatoid arthritis, doctors struggle to separate us from older people with the disease... I want to live my life normally in my 20s, not feel like I'm wasting them in pain and so fatigued.**
>
> Female, aged 18-44, Autoimmune Inflammatory Condition, England

i 38% (N=107) of respondents aged 18-44 years selected 'All of the time' or 'Most of the time' to the question 'How often, if at all, does your arthritis condition(s) cause you to feel low in mood or anxious?'. This is compared to 32% (N=1,196) for adults aged 45-64 years and 17% (N=609) for adults aged 65+ years.

j 71% (N=197) of respondents aged 18-44 years selected 'Strongly disagree' or 'Somewhat disagree' to the question 'I feel like generally other people understand my arthritis condition(s)'. This is compared to 51% (N=1,895) for adults aged 45-64 years and 30% (N=1,083) for adults aged 65+ years.

k 71% (N=197) of respondents aged 18-44 years selected 'Strongly disagree' or 'Somewhat disagree' to the question 'I feel like generally other people understand the impact of arthritis condition(s) has on my life'. This is compared to 53% (N=1,951) for adults aged 45-64 years and 32% (N=1,152) for adults aged 65+ years.

l 50% (N=139) of respondents aged 18-44 years selected 'Strongly agree' or 'Somewhat agree' to the question 'I have experienced stigma from other people because of my arthritis'. This is compared to 26% (N=959) for adults aged 45-64 years and 9% (N=329) for adults aged 65+ years.

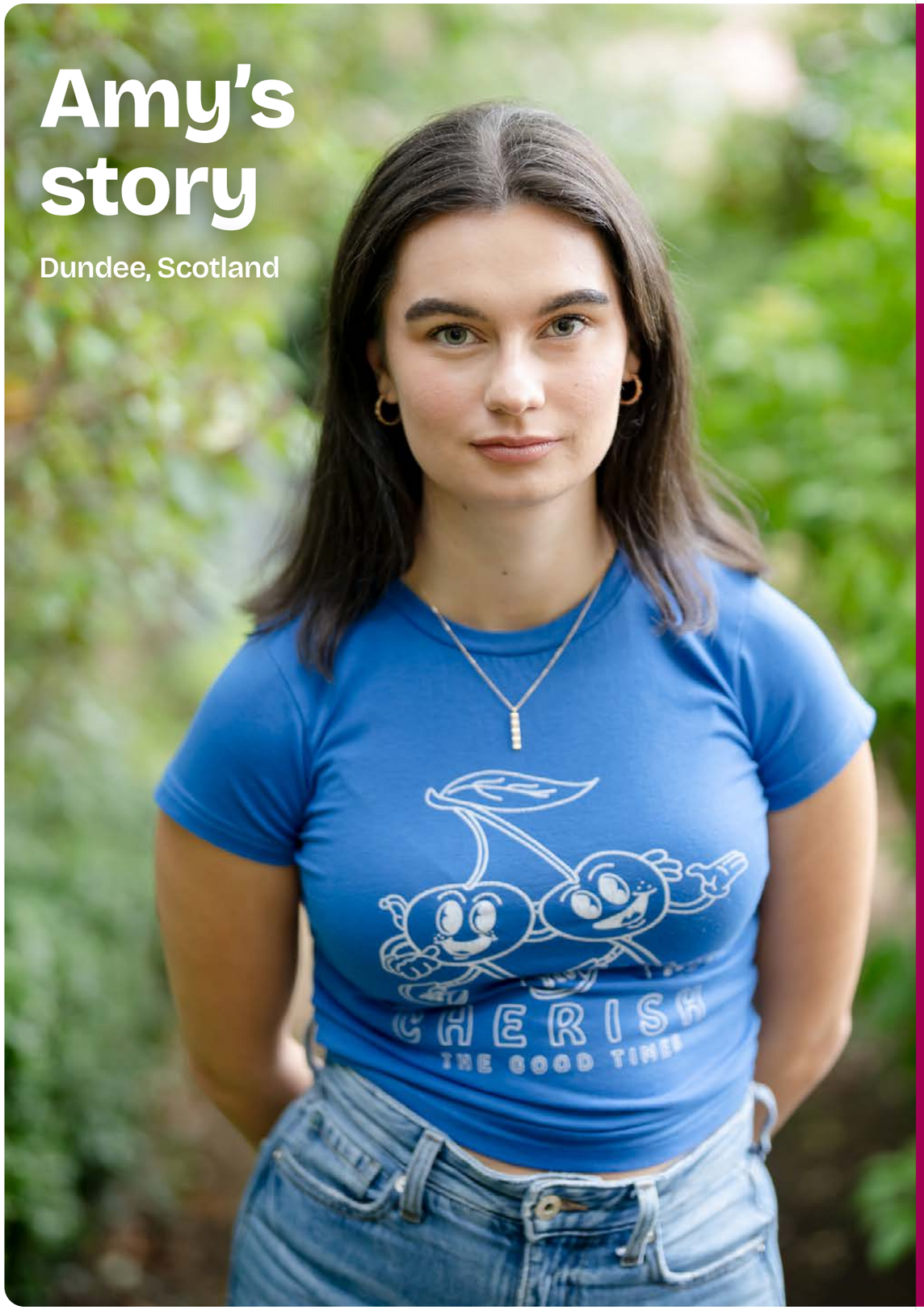
m 34% (N=94) of respondents aged 18-44 years selected 'All of the time' or 'Most of the time' to the question 'How often, if at all, do you feel isolated because of your arthritis condition(s)?'. This is compared to 25% (N=943) for adults aged 45-64 years and 12% (N=449) for adults aged 65+ years.

n 60% (N=160) of respondents aged 18-44 years selected 'Strongly agree' or 'Somewhat agree' to the question 'Having arthritis has had a negative impact on my personal relationships'. This is compared to 47% (N=1,634) for adults aged 45-64 years and 31% (N=972) for adults aged 65+ years.

o 43% (N=91) of respondents aged 18-44 years selected 'Strongly agree' or 'Somewhat agree' to the question 'Having arthritis has affected my ability to have a family'. This is compared to 10% (N= 221) for adults aged 45-64 years and 2% (N=36) for adults aged 65+ years.

Amy's story

Dundee, Scotland



I suffered with chronic pain and hypermobility from a young age.

Then I was diagnosed with inflammatory arthritis as a teenager and put on medication almost immediately which stabilised me. I was also referred to a pain clinic which helped me to manage my chronic pain effectively. Without this I think my mental health would have really deteriorated.

I felt my health was not a priority for my teachers because I did well at school. This made things hard for me in school as I was silently struggling. It's the small things that make the biggest difference. At one point I asked my school for a supportive chair, but I was refused. I had to fight to get the smallest things in place. Now I'm at university and training to be a doctor. I'd love to specialise in paediatrics. My university is supportive, and I get extra time for my assignments and exams.

My rheumatology team is good, but I'm sometimes frustrated by the attitudes of other healthcare professionals who look at me and take pity because all they see is a young person with arthritis. It's annoying as I feel quite positive about my life and I'm excited for my future. I'm finishing university this year and about to enter the workforce.

I'm excited about becoming a doctor, but I am concerned about how I'll manage my fatigue. Junior doctors work long hours with few rest breaks, and that makes me nervous. My concern is that I won't specialise as quickly as my peers. However, I hope by telling my story I can change things for other young people with arthritis. It's not all bad news, and we can thrive with the right support.

Experiences of people with Autoimmune Inflammatory Conditions

Although people with all forms of arthritis report poor experiences across support and treatment, those with Autoimmune Inflammatory Conditions reported the worst experiences, regardless of age.[p]

Despite being more likely to report being well managed in comparison to other conditions[q], people with Autoimmune Inflammatory Conditions reported experiencing more pain, fatigue, low mood or anxiousness, and isolation.[r,s,t,u]

Again, although all condition groups experienced a negative impact on relationships and family planning, people with Autoimmune Inflammatory Conditions comparatively reported the worst experiences.[v,w]

p Please refer to data tables

q 53% (N=316) of those with Autoimmune Inflammatory Conditions selected ‘Strongly agree’ or ‘Somewhat agree’ to the question ‘My arthritis condition is currently well-managed’. This is in comparison to 45% (N=2,928) for those with Osteoarthritis and 45% (N=364) for those with Arthritis Other/Unknown.

r 66% (N=390) of those with Autoimmune Inflammatory Conditions selected ‘Most of the time’ or ‘All of the time’ to the question ‘How often, if at all, have you experienced the following symptoms in the past 12 months because of your arthritis condition(s)? – Pain’. This is in comparison to 61% (N=3,975) for those with Osteoarthritis and 50% (N=411) for those with Arthritis Other/Unknown.

s 64% (N=381) of those with Autoimmune Inflammatory Conditions selected ‘Most of the time’ or ‘All of the time’ to the question ‘How often, if at all, have you experienced the following symptoms in the past 12 months because of your arthritis condition(s)? – Fatigue or Extreme Tiredness’. This is in comparison to 44% (N=2,860) for those with Osteoarthritis and 43% (N=346) for those with Arthritis Other/Unknown.

t 43% (N=256) of those with Autoimmune Inflammatory Conditions selected ‘Most of the time’ or ‘All of the time’ to the question ‘How often, if at all, have you experienced the following symptoms in the past 12 months because of your arthritis condition(s)? – Feeling Low or Anxious’. This is in comparison to 27% (N=1,754) for those with Osteoarthritis and 28% (N=225) for those with Arthritis Other/Unknown.

u 31% (N=179) of those with Autoimmune Inflammatory Conditions selected ‘Most of the time’ or ‘All of the time’ to the question ‘How often, if at all, do you feel isolated because of your arthritis condition(s)?’. This is in comparison to 18% (N=1,160) for those with Osteoarthritis and 18% (N=146) for those with Arthritis Other/Unknown.

v 56% (N=313) of those with Autoimmune Inflammatory Conditions selected ‘Somewhat agree’ or ‘Strongly agree’ to the question ‘Having arthritis has had a negative impact on my personal relationships’. This is in comparison to 40% (N=2,210) for those with Osteoarthritis and 36% (N=244) for those with Arthritis Other/Unknown.

w 27% (N=102) of those with Autoimmune Inflammatory Conditions selected ‘Somewhat agree’ or ‘Strongly agree’ to the question ‘Having arthritis has affected my ability to have a family’. This is in comparison to 6% (N=196) for those with Osteoarthritis and 11% (N=49) for those with Arthritis Other/Unknown.

Change is needed

Our findings highlight the consistent health inequalities experienced by people with arthritis.

People in lower social grades experience greater levels of pain, worse management of their condition, and are less likely to use self-management techniques, or find them useful. Younger adults and people with Autoimmune Inflammatory Conditions are also disproportionately affected, reporting higher levels of stigma, isolation, and impact on their daily lives.

These inequalities mirror wider patterns in health inequalities across society and the health system, as outlined in the Marmot Review, and they remain evident more than a decade later.

Tackling these inequalities requires more than improvements in healthcare alone. It demands action to address the wider social factors that shape health, alongside ensuring equitable access to reliable information, services and support. Reducing the gap in experience for people with arthritis is not only essential for improving individual lives but also for building a fairer and more effective healthcare system.

Chapter 3

Waiting too long

The value of a diagnosis

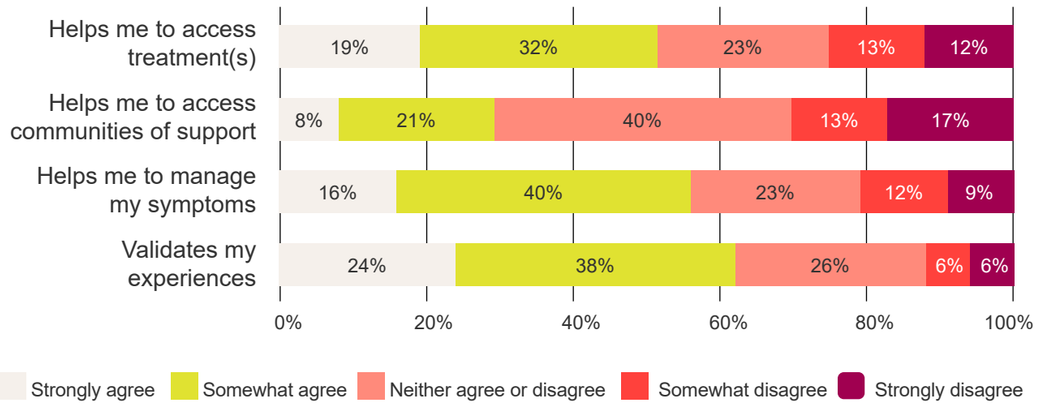
Receiving a diagnosis of arthritis is a vital step that brings clarity, validation, and access to treatment and support. For many, it confirms that their symptoms are real and begins the path to managing their condition. However, this chapter reveals that too many people face long and often difficult waits – not only for a diagnosis but also for the treatment they need afterward. Differences were also seen in experiences – with the worst delays and barriers reported amongst lower social grades (C2DE), younger adults and those with Autoimmune Inflammatory Conditions.

Getting a diagnosis can be hugely beneficial and both those with and without a diagnosis see a value in being diagnosed.

Among people with a diagnosis[a]

People with an arthritis diagnosis see clear value in receiving a diagnosis, with the greatest perceived benefit being validation of their experiences. In fact, more than 6 in 10 people (62%) agree that having a diagnosis validates their experiences **(Figure 4)**.[b] When examined by condition groupings, validating experiences remained the most widely reported benefit of getting a diagnosis.[c]

Figure 4 – Having a diagnosis from a healthcare professional...



Base: all those with a diagnosis or who have seen a healthcare professional

a 88% (N=6,629) of respondents who had seen a healthcare professional had received a diagnosis.

b Of those with a diagnosis, 62% (N=3,658) of people responded 'Somewhat agree' or 'Strongly agree' to the question 'To what extent do you agree or disagree with these statements: Having a diagnosis from a healthcare professional: Validates my experiences'.

c 70% (N=348) of those with Autoimmune Inflammatory Conditions responded 'Somewhat agree' or 'Strongly agree' to the question 'To what extent do you agree or disagree with these statements: Having a diagnosis from a healthcare professional: Validates my experiences'. This is compared to 61% (N=3,095) of those with Osteoarthritis and 62% (N=215) with Arthritis Other/Unknown.

People with Autoimmune Inflammatory Conditions consistently reported greater perceived value in receiving a diagnosis across all areas than those with Osteoarthritis or those with Arthritis Other/Unknown, although value was found for all different aspects of having a diagnosis across all condition groupings.[d]

> **It's difficult not to wonder [if] it had been diagnosed and treated fully earlier on, if the impact on my life (and the NHS) could have been lessened [or] delayed.**
>
> Female, aged 18-44, Autoimmune Inflammatory Condition, Scotland

> **I have never truly received an official diagnosis for either osteoarthritis or fibromyalgia… What I have is not evident but to me makes life painful and difficult.**
>
> Female, aged 65+, Arthritis Other/Unknown, Scotland

Among people who have seen a healthcare professional but remain undiagnosed[e]

Nearly 6 in 10 people (59%)[f] said they were upset ('Somewhat bothered' or 'Very bothered') that they did not have a diagnosis for their arthritis condition. Noticeably, those from lower social grades were more likely to report being upset by not having a diagnosis, with nearly 7 in 10 people responding that this bothered them (68%), compared to 5 in 10 (50%) from those in the higher social grades (ABC1).[g]

Additionally, of this group who had seen a healthcare professional but who had not received a diagnosis, most felt that having one would help most with accessing treatment (68%), followed by managing symptoms and validating their experiences (64%, 63%).[h]

d Those who selected 'Strongly agree' or 'Somewhat agree' to the question 'Having a diagnosis from a healthcare professional… – Helps me to manage my symptoms', 65% (N=336) Autoimmune Inflammatory Conditions, 55% (N=2,959) Osteoarthritis, 57% (N=215) Arthritis Other/Unknown. 'Helps me to access communities of support', 43% (N=196) Autoimmune Inflammatory Conditions, 28% (N=1,182) Osteoarthritis, 29% (N=84) Arthritis Other/Unknown. 'Helps me to access treatments', 69% (N=354) Autoimmune Inflammatory Conditions, 50% (N=2,593) Osteoarthritis, 55% (N=198) Arthritis Other/Unknown.

e 11% (N=818) of respondents who have seen a healthcare professional have not received a diagnosis.

f 59% (N=466) of respondents who had seen a healthcare professional but were without a diagnosis selected either 'Very bothered' or 'Somewhat bothered' to the question 'How bothered are you, if at all, that you do not have a diagnosis for your arthritis condition?'.

g Of respondents who had seen a healthcare professional but were without a diagnosis, 68% (N=255) of respondents from lower social grades selected either 'Very bothered' or 'Somewhat bothered' to the question 'How bothered are you, if at all, that you do not have a diagnosis for your arthritis condition?'. This is compared to 50% (N=206) for those from higher social grades.

h Of respondents who had seen a healthcare professional but were without a diagnosis, 68% (N=500) of respondents selected either 'Somewhat agree' or 'Strongly agree' to the question 'If I had a diagnosis from a healthcare professional, I believe it would … – Helps me to access treatment(s)'. This was followed by 64% (N=482) for 'Helps me to manage my symptoms' and 63% (N=469) for 'Validates my experiences'.

Waiting too long for a diagnosis

Despite the value in receiving a diagnosis, many people are waiting far too long to receive one. Without a timely diagnosis, many individuals are unable to access the vital support they need – support that can significantly affect both their physical and mental health.

Of those with a diagnosis, nearly 4 in 10 (38%) respondents felt the process of getting a diagnosis took too long.[i] More than 5 in 10 reported unreasonable waits or delays getting an appointment with the relevant specialist (54%)[j] and more than 4 in 10 reported unreasonable waits or delays in accessing tests or test results (44%)[k] **(Figure 5)**.

Social grade

Respondents from lower social grades were more likely than higher social grades to agree that the diagnostic process took too long[l], to report unreasonable delays in tests or test results[m] and to report unreasonable delays in getting an appointment with a relevant specialist.[n]

This difference by social grade has been found in previous research, where those from lower socioeconomic status were less likely to receive a consultation for their osteoarthritis[17] and drug initiation for those with rheumatoid arthritis was found to be slower for those from a lower socioeconomic status when compared to those from higher socioeconomic status.[18]

Condition

Across all condition groupings, too many people report experiencing delays in receiving a diagnosis. Individuals with arthritis – whether osteoarthritis or autoimmune inflammatory arthritis – continue to face significant barriers to timely diagnosis.

i Of those with a diagnosis, 38% (N=2457) of respondents selected 'Somewhat agree' or 'Strongly agree' to the question 'To what extent do you agree or disagree with the following statements? – The process of getting a diagnosis took too long'.

j Of those who had seen a healthcare professional for their arthritis condition, 54% (N=3,601) of respondents selected 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition… – Unreasonable waits or delays getting an appointment with the relevant specialist'.

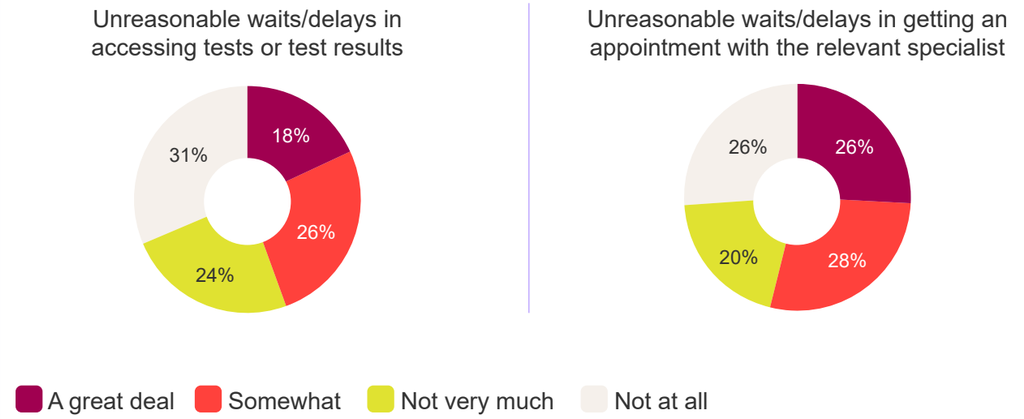
k Of those who had seen a healthcare professional for their arthritis condition, 44% (N=2,992) of respondents selected 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition… – Unreasonable waits/delays in accessing tests or test results'.

l Of those with a diagnosis, 40% (N=1,181) of those from lower social grades (C2DE) responded 'Somewhat agree' or 'Strongly agree' to the question 'To what extent do you agree or disagree with the following statements? – The process of getting a diagnosis took too long'. This is compared to 36% (N=1,208) for higher social grades (ABC1).

m Of those who had seen a healthcare professional for their arthritis condition, 49% (N=1,484) of those from lower social grades (C2DE) responded 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition… – Unreasonable waits/delays in accessing tests or test results'. This is compared to 40% (N=1,412) for higher social grades (ABC1).

n Of those who had seen a healthcare professional for their arthritis condition, 58% (N=1,750) of those from lower social grades (C2DE) responded 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition… – Unreasonable waits or delays getting an appointment with the relevant specialist'. This is compared to 51% (N=1,746) for higher social grades (ABC1).

Figure 5 – To what extent did you experience any of the following when trying to identify your arthritis condition?



Base: of those who had seen a healthcare professional for their arthritis condition

Of those surveyed, those with Autoimmune Inflammatory Conditions reported the biggest difficulty accessing a timely diagnosis. Over half (52%) of those with Autoimmune Inflammatory Conditions agreed that the diagnostic process took too long, compared to Osteoarthritis (36%) and Arthritis Other/Unknown (39%).[o] The increased delays for those with Autoimmune Inflammatory Conditions may be attributed to the rarity and complexity of inflammatory conditions[19] alongside the fact that osteoarthritis is the most common form of arthritis with well-recognised symptoms.[20]

This is particularly important as early referral is crucial, especially for inflammatory conditions.[19] National Institute for Health and Care Excellence (NICE) guidelines for rheumatoid arthritis recommend starting first-line treatment as soon as possible, ideally within 3 months of onset of persistent symptoms.[21] In the latest data from the National Early Inflammatory Arthritis Audit (NEIAA), only 44% of patients receive a rheumatology appointment within 3 weeks.[22] The key challenges that emerge in the NEIAA report are around staffing levels, inefficient triaging and regional variation. The cumulative delays at each level of the diagnosis pathway means that people aren't receiving the care they urgently need. In a further example, the average time to diagnosis is 8.29 years for those with axial spondyloarthritis, with 56% of that delay occurring from first GP appointment to rheumatology referral, as reported by the National Axial Spondyloarthritis Society (NASS).[23]

While for some, osteoarthritis can be diagnosed and managed in primary and community care, people still face barriers to receiving a diagnosis. Some healthcare professionals avoid using the term 'osteoarthritis', referring instead to 'wear and tear', reinforcing the false belief that osteoarthritis is an inevitable part of aging and that nothing can be done.[24]

o Of those with a diagnosis, 52% (N=268) of those with Autoimmune Inflammatory Conditions responded 'Strongly agree' or 'Somewhat agree' to the question 'To what extent do you agree or disagree with the following statements? – The process of getting a diagnosis took too long'. This is compared to 36% (N=2,037) for Osteoarthritis and 39% (N=150) for Arthritis Other/Unknown.

Age

Younger respondents reported substantially greater challenges in getting a timely diagnosis: 6 in 10 (60%) of 18-44-year-olds agreed that the process of getting a diagnosis took too long (compared to 44% of 45-64-year-olds and 29% of people over the age of 65).[p] This pattern is found regardless of the type of arthritis experienced.[q]

They were also more likely to report unreasonable waits or delays for both relevant specialist appointments (67%, compared to 60% for 45-64 years and 47% for 65+ year olds)[r] and tests or test results (56%, compared to 50% for 45-64 years and 38% for 65+ year olds).[s] These age patterns were consistent even within condition types.[t]

However, too many are told that they are 'too young to have arthritis', leading to misclassified or overlooked symptoms. This can result in ongoing pain and potential risk of further joint damage. In some cases, symptoms may simply not be taken seriously.

> **I think [part] of the delay in receiving my diagnosis was my age – I was 29 when I was diagnosed with rheumatoid arthritis but had been having severe symptoms for several years. These symptoms were not taken seriously because I was thought 'too young' to have rheumatoid arthritis.**
>
> Female, aged 35-44, Autoimmune Inflammatory Condition, Scotland

p Of those with a diagnosis, 60% (N=130) of those aged 18-44 years responded 'Strongly Agree' or 'Somewhat agree' to the question 'To what extent do you agree or disagree with the following statements? – The process of getting a diagnosis took too long'. This is compared to 44% (N=1,438) for those 45-64 years and 29% (N=888) for those aged 65 and older.

q Please refer to data tables.

r Of those who had seen a healthcare professional for their arthritis, 67% (N=168) of those aged 18-44 years responded 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition… – Unreasonable waits or delays getting an appointment with the relevant specialist'. This is compared to 60% (N=1,999) for 45-64 years and 47% (N=1,434) for those aged 65 and older.

s Of those who had seen a healthcare professional for their arthritis condition,: 56% (N=141) of those aged 18-44 years responded 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition… – Unreasonable waits/delays in accessing tests or test result'. This is compared to 50% (N=1,672) for 45-64 years and 38% (N=1,179) for those aged 65and older.

t Please refer to data tables.

Symptoms not taken seriously

In addition to long waits, people face additional barriers to getting a diagnosis.

Nearly half (48%) of respondents felt their symptoms were not taken seriously or underplayed when they were trying to identify their arthritis condition with a healthcare professional.[u] This perception was most prominent among key subgroups:

- Lower social grades: 50% felt their symptoms were underplayed at diagnosis, versus 44% in those from higher social grades.[v]
- People with Autoimmune Inflammatory Conditions: 56% reported that symptoms were not being taken seriously or being underplayed by healthcare professionals (compared to 47% of those with Osteoarthritis and 49% of Arthritis Other/ Unknown).[w]
- Younger adults (18-44 years): 63% reported that their symptoms were underplayed, and this perception decreased with increased age (54% for those 45-64 years and 39% for those 65+ years).[x] This pattern of younger adults reporting symptoms underplayed persisted even when looking within condition groupings.[y]

> **I've been told that I've been too young for immunosuppressive medications... The rheumatologist doesn't listen and in the past would just say the pain is nothing they can help with.**
>
> Female, aged 18-44, Autoimmune Inflammatory Condition, Scotland

u Of those who had seen a healthcare professional for their arthritis condition, 48% (N=3,328) of respondents selected 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition – My symptoms not being taken seriously or being underplayed by healthcare professionals'.

v Of those who had seen a health care professional for their arthritis condition, 50% (N=1,592) of those from lower social grades (C2DE) selected 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition – My symptoms not being taken seriously or being underplayed by healthcare professionals'. This is compared to 44% (N=1,620) in those from higher social grades (ABC1).

w Of those who had seen a health care professional for their arthritis condition, 56% (N=308) of those with Autoimmune Inflammatory Conditions selected 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition – My symptoms not being taken seriously or being underplayed by healthcare professionals'. This is compared to 47% (N=2,698) of those with Osteoarthritis and 49% with Arthritis Other/Unknown (N=322).

x Of those who had seen a healthcare professional, 63% (N=161) of those 18-44 years selected 'A great deal' or 'Somewhat' to the question 'To what extent, if at all, did you experience any of the following when trying to identify your arthritis condition – My symptoms not being taken seriously or being underplayed by healthcare professionals'. This is compared to 54% (N=1,911) of those aged 45-64 and 39% (N=1,255) of those aged 65 and older.

y Please refer to data tables.

The impact of waiting for treatment

Even after receiving a diagnosis, many people continue to face significant barriers in accessing the treatments they need.

Waiting for treatment can have a broad and significant impact on people's lives, affecting multiple areas including the ability to work, social activities, caring responsibilities, and mental health (as shown in **Figure 6**). The degree and nature of impact varies by social grade, condition type and age.

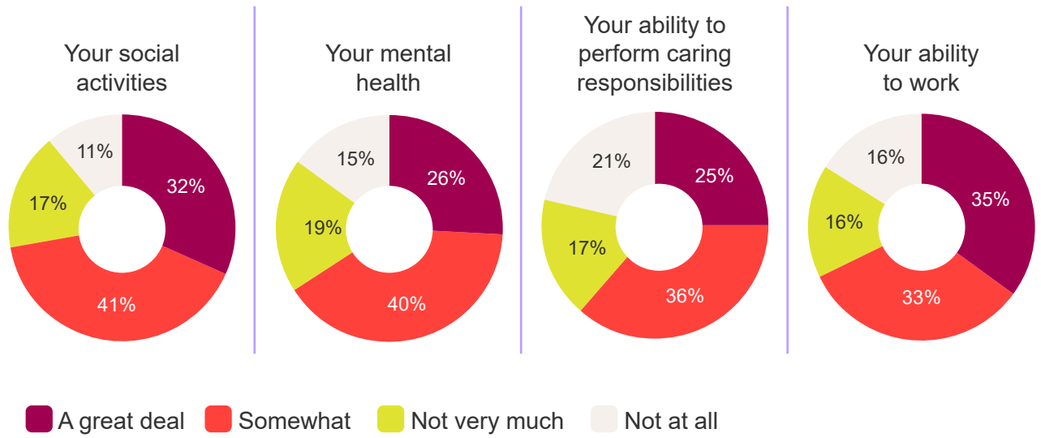
Mental health

The mental health impact of waiting for treatment can be particularly difficult. Two in 3 people (66%) said that waiting for treatment had impacted their mental health 'Somewhat' or 'A great deal'.[z]

This is supported by existing literature, which finds that long waits for care can result in deteriorating physical, mental and social wellbeing for patients.[25]

This survey also found that the impact of waiting for treatment on mental health was felt more acutely by younger adults, with nearly 8 in 10 of those aged 18-44 years reporting that waiting had an impact on mental health ('Somewhat' or 'A great deal', compared to 76% of those aged 45-64 years and 52% of those aged 65+ years[aa]). This may reflect a greater willingness in younger age groups to report an impact on their mental health or perhaps reflects a greater disruption and restriction on the lives of younger adults.[26]

Figure 6 – Has waiting for treatment(s) had an impact on any of the following?



Base: Those that are currently waiting for treatment or had been on a waiting list in the last 12 months

z Of those that are currently waiting for treatment or had been on a waiting list in the last 12 months, 66% (N=1,612) answered 'A great deal' or 'Somewhat' to the question, 'Has waiting for treatment(s) had an impact on any of the following: Your mental health'.

Social grade

People living in the most deprived areas are disproportionately affected by treatment delays.[27] We know from other research that they are more likely to have multiple health conditions, experience faster deterioration, develop complications while waiting, and ultimately face poorer health outcomes.[28]

In this survey, we also see that lower social grades report worse outcomes across all areas compared to higher social grades, both in terms of the proportion affected and those most severely impacted.

Of those who have waited in the past 12 months for treatment(s) or who are currently on a waiting list:[bb]

- Ability to work: Nearly 1 in 2 (47%) of those from lower social grades reported 'A great deal' of impact on their ability to work whilst waiting for treatment(s) (78% reported 'A great deal' or 'Somewhat'). This is compared to 1 in 4 (24%) in those from higher social grades (60% reported 'A great deal' or 'Somewhat').[cc]
- Mental health: 3 in 10 (31%) of those from lower social grades reported 'A great deal' of impact on their mental health whilst waiting for treatment(s) (70% reported 'A great deal' or 'Somewhat'). This is compared to 22% in those from higher social grades (62% reported 'A great deal' or 'Somewhat').[dd]

This chapter highlights the crucial role a diagnosis can play for people with arthritis: it validates their experiences and opens pathways to treatment and support. However, people face challenges in obtaining a diagnosis and getting their symptoms taken seriously. Even after receiving a diagnosis, many face delays in accessing treatment which has wide-reaching consequences on their daily life, affecting their mental health and ability to work. Striking inequalities also emerge across demographics, with those in lower social grades reporting the greatest difficulties in both obtaining a diagnosis and the impact of waiting for treatment.

aa Of those that are currently waiting for treatment, or had been on a waiting list in the last 12 months, 77% (N=80) of those aged 18-44 years answered 'A great deal' or 'Somewhat' to the question, 'Has waiting for treatment(s) had an impact on any of the following – Your mental health' . This is compared to 76% (N=985) of those aged 45-64 years and 52% of those (N=546) aged 65+ years.

bb Of those who are currently waiting or have been on a waiting list in the past 12 months (N= 2,570).

cc Of those who are currently waiting or have been on a waiting list in the past 12 months, 47% (N=374) of those from lower social grades (C2DE) selected 'A great deal' to the question 'Has waiting for treatment(s) had an impact on any of the following... – Your ability to work'. This is compared to 24% (N=209) of those from higher social grades. 78% (N=625) from lower social grades selected 'A great deal' or 'Somewhat', compared to 60% (N=515) of those from higher social grades.

dd Of those who are currently waiting or have been on a waiting list in the past 12 months, 31% (N=352) of those from lower social grades (C2DE) selected 'A great deal' to the question 'Has waiting for treatment(s) had an impact on any of the following... – Your mental health'. This is compared to 22% (N=263) of those from higher social grades. 70% (N=791) from lower social grades selected 'A great deal' or 'Somewhat', compared to 62% (N=756) of those from higher social grades.

Tina's story

Ferryside, Wales

I live with osteoarthritis and psoriatic arthritis. I've been waiting for a double shoulder replacement and surgery on my wrist for three years. For two years, I haven't been able to lift my shoulders and have relied on my husband for basic aspects of life.

He is my rock. He does everything for me: cutting up my food, even brushing my hair because I can't lift my shoulders high enough. Before he goes to work, he gets cups ready, my bowl for cereal and makes sure bottles are open for me.

In early 2024 I came off my biologic medication in preparation for surgery, but the operation date never came. It became so unbearable that I even considered going private, but it would have cost around £18,000 per shoulder.

I had my first shoulder operation in October 2024 and finally had my second in August 2025. I had to chase my second operation up numerous times, and eventually they were able to fit me in quickly – if I hadn't had it in August, I would have had to wait until February.

It's such a relief to have had the surgery, but it's a 'wait and see' as to whether the long wait will impact my recovery or have caused permanent damage.

On the other side of the coin, I am still waiting for my right wrist surgery and have now been referred to the same specialist for my left wrist as it's getting worse.

I know it's not just me on a waiting list, but people don't see what happens when you close the front door and try to get on with life despite being in constant pain.

Chapter 4

Barriers to effective care

Treatments for arthritis

The chapter highlights the widespread challenges faced by people with arthritis in accessing effective treatment and support. Many individuals experience difficulties communicating with healthcare professionals, face financial and logistical barriers to accessing treatment, and find that their current treatments do not adequately address symptoms. These issues are exacerbated by factors such as social grade, gender and employment status.

There is no curative treatment for arthritis

For those with autoimmune inflammatory arthritis, there is a range of options available. For many, these can reduce pain, slow disease progression and improve function. There is a lack of treatment options for osteoarthritis and symptoms can vary greatly from person to person. For some with osteoarthritis, symptoms can be mild and come and go. For others, symptoms are continuous and debilitating, causing significant pain and disability.

People across all conditions, however, may benefit from supported self-management techniques. These techniques enable people to develop the skills, confidence and resources to help better manage their condition. This may include increasing physical activity, maintaining weight in a 'healthy' range, avoiding exacerbating factors and pacing daily activities.[29]

Our survey found that 92% of people have used a self-management technique in the last year.[a] Out of everyone, the most common techniques being joint exercise (70%), maintaining a healthy body weight (56%) and taking part in exercise or physical activity (51%).[b]

a 92% (N=7,274) of people selected an any option from the question 'Over the last year, which of the following, if any, have you done to help manage your arthritis condition(s)', respondents could select from as many as they wished.

b Percentage of people who selected the corresponding option from the question 'Over the last year, which of the following, if any, have you done to help manage your arthritis condition(s)', respondents could select from as many as they wished. Joint exercise (70%, N=5,580), maintaining a healthy body weight (56%, N=4,464), undertaking exercise or physical activity (51%, N=4,064).

Key approaches, treatments and support available for osteoarthritis (OA)

Whilst there is no cure for osteoarthritis, there are treatments and support that may provide relief from the symptoms.

Non-drug interventions

- Support from physiotherapists (for example, therapeutic exercise).
- Biomechanical supports, including orthotics, braces and supports (although not routinely offered[30]).
- Support from occupational therapy to help with daily activities.
- Support for any associated mental health difficulties.
- Aids and adaptations, including walking aids, home adaptations and gadgets.
- Lifestyle changes such as improved diet and physical activity.
- Supporting self-management behaviour such as symptom-reducing behaviours, like therapeutic exercise.
- WorkWell schemes to support people with arthritis to stay in work.

Interventions involving medicines

- Pain medicines, such as non-steroidal anti-inflammatory tablets, creams and gels; short-term weak opioids.
- Corticosteroid injections (used for short-term relief).

Surgery

- Joint replacement surgery (mainly at the hip or knee) where other treatments have not helped.

Key approaches, treatments and support available for autoimmune inflammatory arthritis

Treatment for autoimmune inflammatory arthritis is more varied and for some, can reduce symptoms significantly.

Non-drug interventions

- Smoking cessation (to reduce the risk of severe symptoms and improve chances of remission).
- Support from physiotherapists (for example, therapeutic exercise).
- Biomechanical supports, including orthotics, braces and supports.
- Pain management programmes.
- Support from occupational therapy to help with daily activities.
- Lifestyle changes such as improved diet and physical activity, with higher BMI linked to reduced disease-modifying anti-rheumatic drug (DMARD) effectiveness.
- Support for any associated mental health difficulties.
- Aids and adaptations, including walking aids, home adaptations and gadgets.
- Supporting self-management behaviour such as symptom-reducing behaviours, like therapeutic exercise.
- WorkWell schemes to support people with arthritis to stay in work.

Interventions involving medicines

- Early, intensive treatment of inflammation with DMARDs, including biological and targeted therapies, and sometimes steroids.
- Pain medicines, such as non-steroidal anti-inflammatory tablets, creams and gels; short-term weak opioids.
- Steroid injections into a joint.

Surgery

- Joint replacement surgery (mainly at the hip or knee) where other treatments have not helped.

While existing treatments can help manage symptoms, they are not consistently available or accessible to all who need them. Each person's experience of arthritis is different and personalised care and timely access to treatment are key to managing their condition. Treatment options must expand to address the range of arthritis and MSK conditions and further investment is needed in musculoskeletal research to expand the range of treatments available for people with arthritis.

Communication around treatment

Clear and consistent communication is essential not only between patients and healthcare professionals but also among healthcare professionals managing arthritis care. Issues in communication can lead to delays, fragmented care, inconsistent advice and unmet patient needs.[31]

In this survey, issues were reported across all aspects of communication with healthcare professionals including having reviews as often as needed, healthcare professionals communicating with each other and having an opportunity to talk about individual needs and preferences (as shown in **Figure 7**).[c]

Strikingly, most people (58%)[d] disagreed ('Somewhat' or 'Strongly') that they could access reviews to discuss the status of their condition and treatment as often as needed. Patient initiated follow-up (PIFU)[32] is an example of an approach which empowers patients to manage their own condition, allowing a person to initiate an appointment when they need one, based on their own circumstances. It can be a key intervention to help providers and systems manage their waiting lists, see those most in need more quickly whilst avoiding unnecessary appointments, and make the best use of NHS resources. Clear, consistent and accessible information about PIFU and its purpose is key to successful implementation. This includes clarity for patients and hospital staff on the difference between PIFU and discharge.

It is important that patients are provided with clear and timely information about when they can expect to receive their treatment. Arthritis UK worked with NHS England, and other leading charities to develop core principles to help deliver personalised, patient-centred communications to patients waiting for planned care. This guidance sets out key communication principles that can be used by providers at a local level.[33]

Allowing patients to have these reviews when they needed them also helps prevent some patients staying on ineffective medications, experiencing preventable flare-ups of their condition, or stopping treatment because of unmanaged side effects (all of which led to worse health outcomes and unnecessary strain on NHS resources).

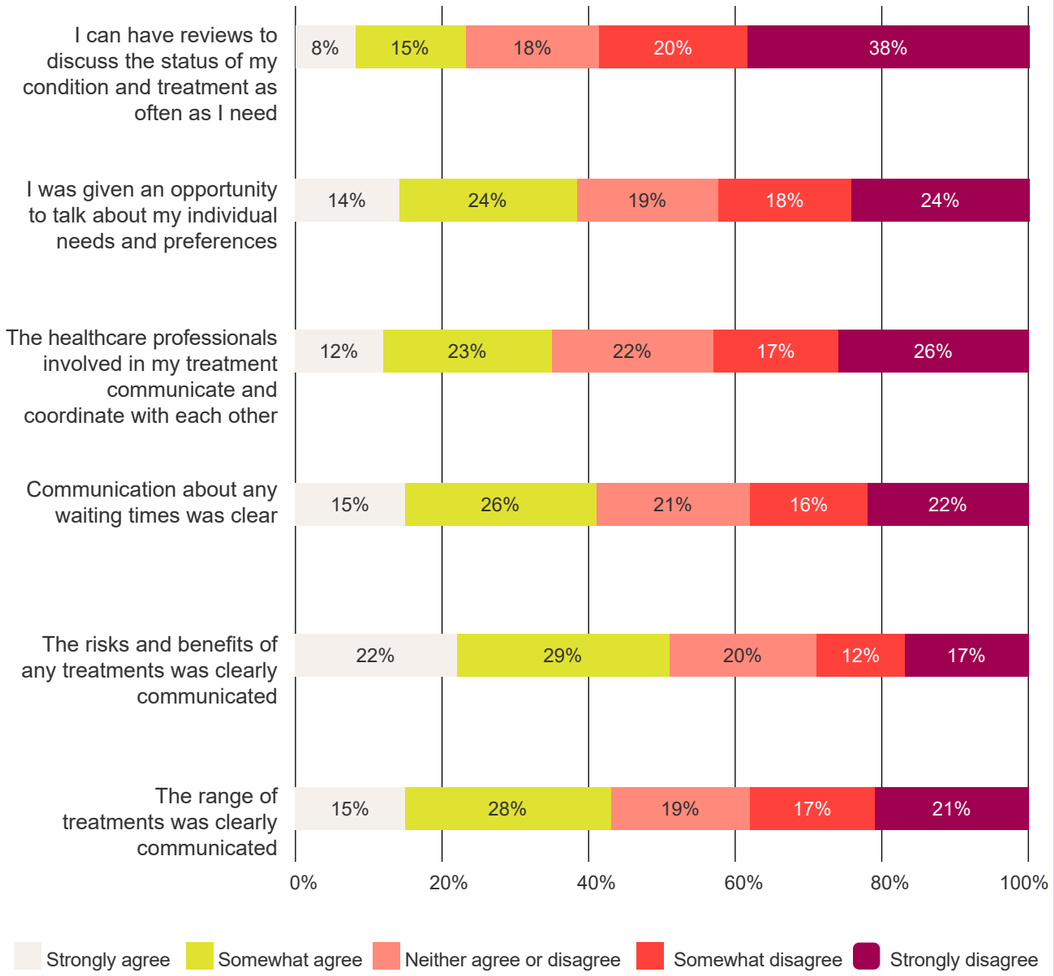
Additionally, for all aspects of communication with healthcare professionals, females report worse outcomes, even when looking within each condition grouping[e], further increasing disparities across groups. This aligns with other research showing that clinician interactions often differ by gender.

c Of N=7,745 who had received treatment.

d 58% (N=3,673) of respondents selected 'Strongly disagree' or 'Somewhat disagree' to the question 'Thinking about the communication with your healthcare professionals regarding your arthritis condition(s) overall, to what extent do you agree or disagree with the following statements? – I can have reviews to discuss the status of my condition and treatment as often I need'.

e Please refer to data tables.

Figure 7 – Thinking about the communication with your healthcare professionals regarding your arthritis condition(s) overall, to what extent do you agree?



Base: Those who had ever used medicines or treatments to manage their arthritis condition(s)

In one example, women's reports of pain were more likely to be perceived as exaggerated and resulted in differences in recommend treatment.[34] While this survey was unable to breakdown questions by ethnicity, we know that ethnicity can be an additional compounding factor to someone's experience with healthcare. Research from King's College London has found that the prevalence of long-term conditions such as chronic pain were twice as high in Black women as the general population.[35]

Mary's story

Belfast, Northern Ireland

I have several musculoskeletal conditions, mainly rheumatoid arthritis. I am on orthopaedic and spinal waiting lists which are the longest in the UK. You can wait years for any type of treatment.

I was first put on a waiting list in 2019 for assessment for shoulder surgery following an MRI which showed early damage. It was almost two years later before I was assessed again via a phone call from the surgeon.

I then met a consultant in March 2025, but unfortunately the results from my previous MRI could not be found, which meant the consultant was unable to confirm options. Following an X-ray, I was told that my rheumatoid arthritis was still active and that I needed to wait a further six months to allow the medication to stabilise things.

I am now waiting for my arthritis to calm down before I can have any procedures, whilst also waiting to see a spinal surgeon which has a waiting list of 14 months. I am having to pay privately both for physiotherapy and an assessment for surgery as the level of pain is significant and impacting all aspects of my life.

There are serious workforce issues in Northern Ireland. As a result, we are exponentially worse with our waiting lists. Another issue is the poor communication about how long we might have to wait with no support or advice offered. It's like being deafened by silence as all I can think about is the pain and the lack of support.

I had to retire early from full time work. I can no longer stand for any length of time, and the fatigue and pain has become worse. I am lucky as my husband is so supportive; I don't know how I would cope on my own.

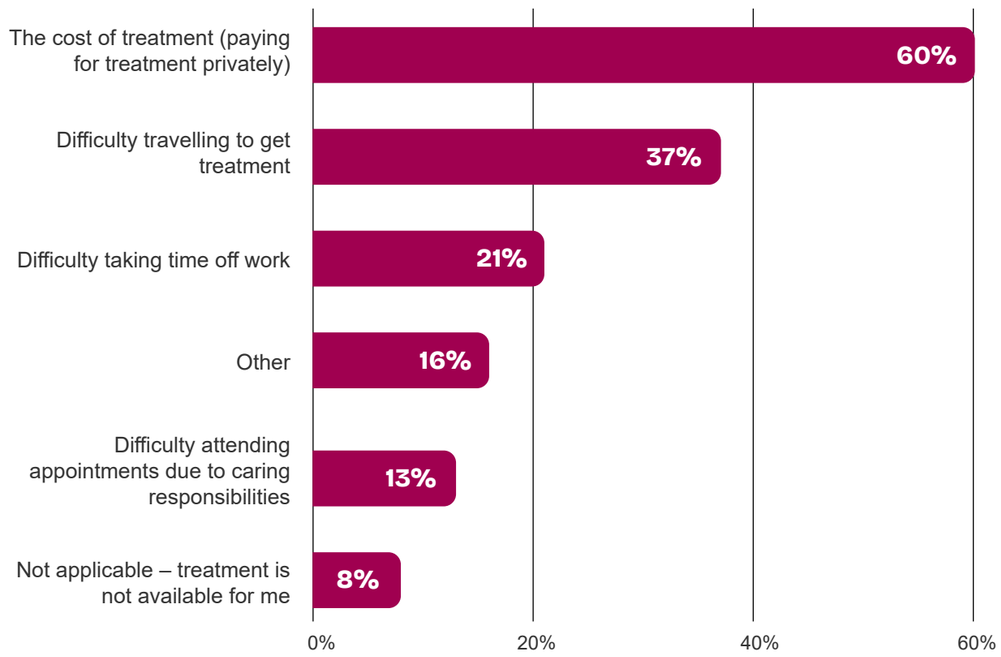
Barriers to accessing treatment

Accessing effective treatment can be a critical part of managing arthritis, yet many face significant obstacles that prevent them from getting the care they need. These barriers can be financial, logistical, or related to workplace challenges, and they often vary depending on social grade and age.

Cost of treatment

Among those who identified barriers to accessing treatment for their arthritis condition[f], the most frequently cited issue was the cost of treatment (paying for treatment privately), reported by 60% of respondents (**Figure 8**).

Figure 8 – Have any of these made it harder for you to access treatment for your arthritis condition(s)? (Select all that apply)



Base: Those who identified barriers to accessing treatment for their arthritis condition

f 36% (N=2,843) reported no barriers to accessing treatment for their arthritis condition(s), 12% (N=986) said they had not tried to access treatment . A total of 3,708 respondents reported barriers to treatment.

> **Living in a rural part of the country and having to travel 40 miles to see my consultant hurts due to the pain of travelling. No options as alternative. Axial spondyloarthritis totally dominates everything that I try to do whether it be routine, necessity or exertion.**
>
> Male, aged 45-64, Autoimmune Inflammatory Condition, England

> **I pay for all my medicine and appointments privately as I could not be seen by the NHS in a timely manner. It is extremely expensive.**
>
> Female, aged 45-64, Autoimmune Inflammatory Condition, Wales

Social grade

There were also clear differences by social grade in the types of barriers experienced in accessing treatment for arthritis, possibly reflecting differences in employment types and flexibility:

- Travel difficulties were more commonly reported by those in lower social grades (C2DE 42%) compared to higher social grades (ABC1 33%).[g]
- Conversely, those in higher social grades were more likely to report cost of treatment (paying for treatment privately) as a barrier (63% versus 57% in lower social grades).[h] This may be a reflection that higher social grades have more disposable income and are able to consider the cost of treatment, whereas those from lower social grades cannot.

g 42% (N=710) of those from lower social grades (C2DE) selected 'Difficulty travelling to get treatment' to the question 'Have any of these made it harder for you to access treatment for your arthritis condition(s)?'. This is compared to 33% (N=543) from higher social grades (ABC1).

h 63% (N=1,037) of those from higher social grades (ABC1) selected 'The cost of treatment (paying for treatment privately)' to the question 'Have any of these made it harder for you to access treatment for your arthritis condition(s)?'. This is compared to 57% (N=962) from lower social grades (C2DE).

Inadequate treatments

Even when people with arthritis receive treatment, many feel it doesn't adequately address their needs, with noticeable disparities in how effective treatments are across different groups. In this survey, overall treatment was reported to have helped relieve pain the most and fatigue the least, however, **many still report treatment isn't helping them live the life they want to lead.**

Respondents reported that treatment was most helpful in alleviating pain, with over 5 in 10 (58%)[i] saying it has helped (somewhat or a great deal). However, 4 in 10 (42%)[j] find that treatment has not helped (not at all or not very much) in alleviating pain.

Social grade

People from lower social grades reported that treatment was less helpful overall[k], particularly in relieving pain[l] and stiffness[m], compared to those from higher social grades backgrounds.

Biggest unmet need: Fatigue

Across all forms of arthritis, fatigue[n] emerged as the symptom least alleviated by treatment. 70% of respondents said their treatment helps 'Not at all' or 'Not very much' with fatigue.[o] This issue was consistently reported as the biggest unmet need across all condition types, social grades, age and across gender.[p]

Fatigue is clearly an overwhelming priority and often one of the biggest daily challenges of those with arthritis. Yet, from this survey it is clear that it is not being treated effectively and is overlooked and under-prioritised, and although some interventions for managing fatigue exist, they're not widely available to people with MSK conditions. This large research gap has previously been identified by Arthritis UK in partnership with Kennedy Trust, and a review has recently been carried out into the research gaps around fatigue.[36] It explored what is already known on the ways of measuring, assessing and treating severe fatigue associated with rheumatic and related MSK conditions.

i 58% (N=4,312) of respondents selected 'Somewhat' or 'A great deal' to the question 'Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped with the following? – Pain'.

j 42% (N=3,099) responded 'Not at all' or 'Not very much' to the question 'Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped with the following? – Pain'.

k Please refer to data tables.

l Of those who had received any form of treatment, 61% (N=2,339) of those from higher social grades (ABC1) selected 'A great deal' or 'Somewhat' to the question 'Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped with the following? – Pain'. This was compared to 55% (N=1,876) from lower social grades (C2DE).

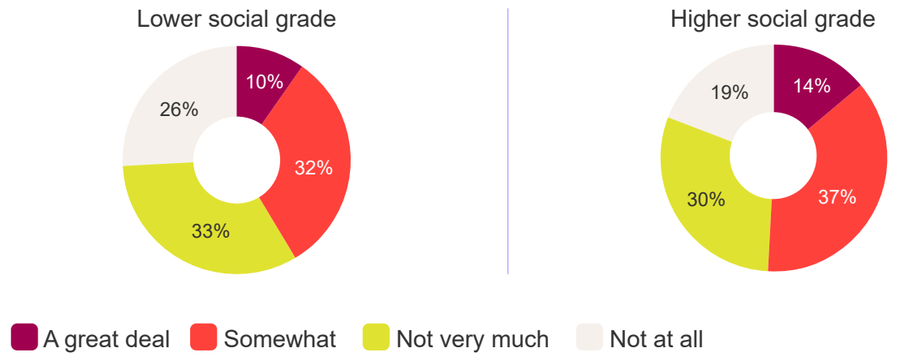
m Of those who had received any form of treatment, 55% (N=2,068) of those from higher social grades (ABC1) selected 'A great deal' or 'Somewhat' to the question 'Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped with the following? – Stiffness'. This is compared to 49% (N=1,653) from lower social grades (C2DE).

n Fatigue is an extreme, sometimes overwhelming, physical, and mental tiredness, that doesn't get better with rest or sleep.

o Of those who had received any form of treatment, 70% (N=4,312) of respondents selected 'Not at all' or 'Not very much' to the question 'Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped with the following? - Fatigue'.

p Please refer to data tables.

Figure 9 – Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped you live the life you want to lead? By social grade



Base: those that are currently waiting for treatment or had been on a waiting list in the last 12 months

Living the life they want to lead

When asked whether treatment helps them 'live the life they want to lead', more than half (54%)[q] of respondents said that treatment does not help them ('Not at all' or 'Not very much'). This concern was more pronounced among people in lower social grades **(Figure 9)**, where 59% felt that treatment was not helping them live the life they want to lead, compared to 50% in higher social grades.[r]

This chapter shows that people with arthritis face significant barriers to effective care, including communication gaps, financial challenges and disparities in treatment effectiveness. While treatments often ease pain, symptoms like fatigue remain largely unaddressed, and many feel their treatment doesn't support the life they want to lead. People with arthritis need access to personalised and holistic healthcare to successfully manage their conditions. This includes health and care systems that treat them as active partners in decision making, including regular reviews and developing personalised care and support plans tailored to their needs.

q Of those who had received any form of treatment, 54% (N=3,781) of respondents selected 'Not at all' or 'Not very much' to the question 'Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped with the following? – Helping you live the life you want to lead'.

r Of those who had received any form of treatment, 59% (N=1,903) from lower social grades (C2DE) selected 'Not at all' or 'Not very much' to the question 'Thinking about any treatments you have ever received for your arthritis condition(s), has the treatment(s) helped with the following? – Helping you live the life you want to lead'. This is compared to 50% (N=1,757) of those from higher social grades (ABC1).

Chapter 5

The personal cost of arthritis

Arthritis isn't just a condition that impacts people physically, many people with arthritis are struggling financially across the UK.

Arthritis comes with extra and often hidden costs that significantly affect people's daily lives. Among the most prominent is the ability to stay in work, as well as the way in which the condition(s) can influence decisions about early retirement. Many people report that their condition limits not only how they work and their access to work, but whether they can work at all.

The economic impact is considerable, for both individuals and wider society, which will only become more prominent with an aging UK population. Individuals with arthritis are 20% less likely to be in employment than those without the condition.[37] In addition, arthritis and MSK conditions are among the leading causes of workplace absence in the UK – accounting for 23.4 million days lost in work in 2022, up from 23.3 million in 2021.[38]

What's more, the cost of working days lost due to osteoarthritis and rheumatoid arthritis was estimated at £2.58 billion in 2017 rising to £3.43 billion by 2030.[39]

These issues, coupled with the rising cost of living, is exacerbating financial issues that exist for people with arthritis. Previous research by Arthritis UK found individuals with MSK conditions were faced with additional costs of around £1,700 per year due to additional expenses such as energy, medicines, food and travel that were needed to manage their condition.[40]

Ensuring that people with arthritis can access, stay in, or return to work must be a priority for employers and policymakers across the UK.

Life is super hard and I feel the person I was has gone. I love[d] working and was independent but now I can't do anything for myself.

Female, aged 18-44, Autoimmune Inflammatory Condition, England

My standard of living has been affected as I'm no longer able to work. I live off my savings and a basic PIP [Personal Independence Payment].

Female, aged 45-64, Autoimmune Inflammatory Condition, England

The ability to earn

Arthritis significantly impacts people's ability to earn money and leads to additional financial costs, with the greatest burden falling on those already worse off. A study from the University of Leeds found that of those in work, people with arthritis earn an average of 4% less (approx. £1,505 less per year[a]) than those without the condition.[41]

In the past 12 months, more than 3 in 10 people (36%) said that arthritis affected their ability to earn ('Somewhat' or 'A great deal').[b] The impact was felt most among those with Autoimmune Inflammatory Conditions[c] and among people from lower social grades (C2DE).[d]

My arthritis has stopped me from taking management roles. Long meetings and expectations to work long hours sitting down have meant I have decided not to take these opportunities.

Male, aged 18-44, Autoimmune Inflammatory Condition, England

a £1,505 – calculated as 4% of the August 2025 UK average pre-tax salary of £37,648.

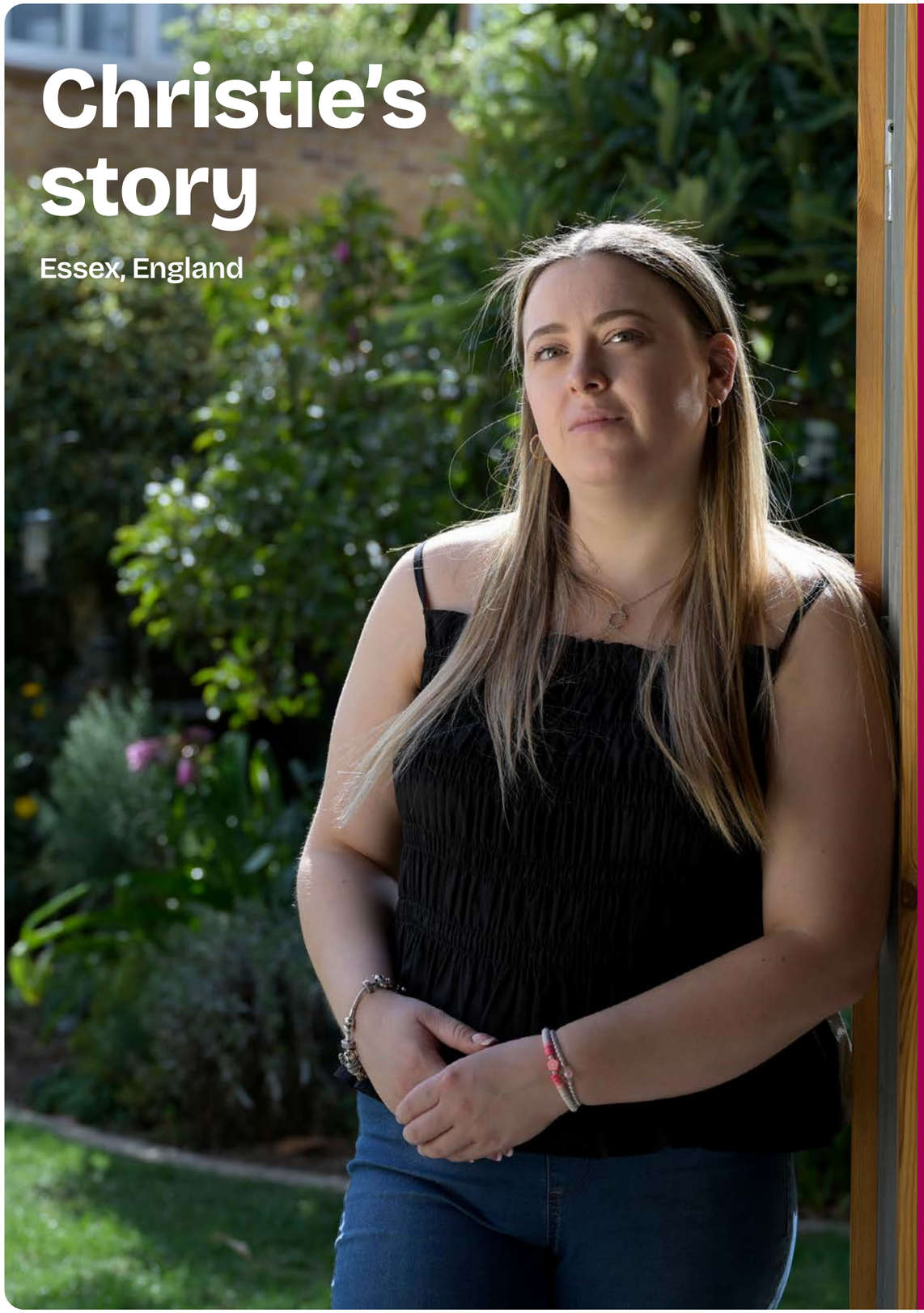
b 36% (N=2,605) of respondents selected 'Somewhat' or 'A great deal' to the question 'In the past 12 months, to what extent, if at all, has your arthritis had an impact on – Your ability to earn money'.

c 54% (N=311) of those with Autoimmune Inflammatory Conditions selected 'A great deal' or 'Somewhat' to the question 'In the past 12 months, to what extent, if at all, has your arthritis had an impact on – Your ability to earn money'. This is compared to 34% (N=2,049) for those with Osteoarthritis and 33% (N=245) for those with Arthritis Other/Unknown.

d 47% (N=1,556) of those from lower social grades (C2DE) selected 'A great deal' or 'Somewhat' to the question 'In the past 12 months, to what extent, if at all, has your arthritis had an impact on – Your ability to earn money'. This is compared to 25% (N=969) of those from higher social grades.

Christie's story

Essex, England



Just before I was diagnosed with psoriatic arthritis, I had to quit my job as I was unable to walk. The pain in my feet was too much.

I worked in retail and had no support whatsoever. I was basically deemed 'inefficient' to them, so in the end I felt like I had to hand in my notice to give me time to get better and focus on my health. I didn't work for a year after the diagnosis, but I ended up going back to the same place I had left because they were under new management and I explained more about my condition, hoping that I would be given better support.

I got the job there, but unfortunately that support hasn't properly materialised. I got given a chair for behind the tills so I could sit down, but other staff claimed it was a nuisance, so it got removed. I just don't feel I get any care there even though other staff know I suffer from a chronic condition, and I struggle daily. I am looking to leave the job as soon as possible, as I want to work somewhere they will listen to my access needs.

Employers need to understand the needs of those living with a chronic condition, especially in retail as it is a job where you're on your feet for so much of the day. I will be looking for a new company, one who allows me to sit down behind the tills, who understands my needs and will ask and check in to see how I'm doing each week. I don't feel like it is asking for too much.

Barriers in the workplace

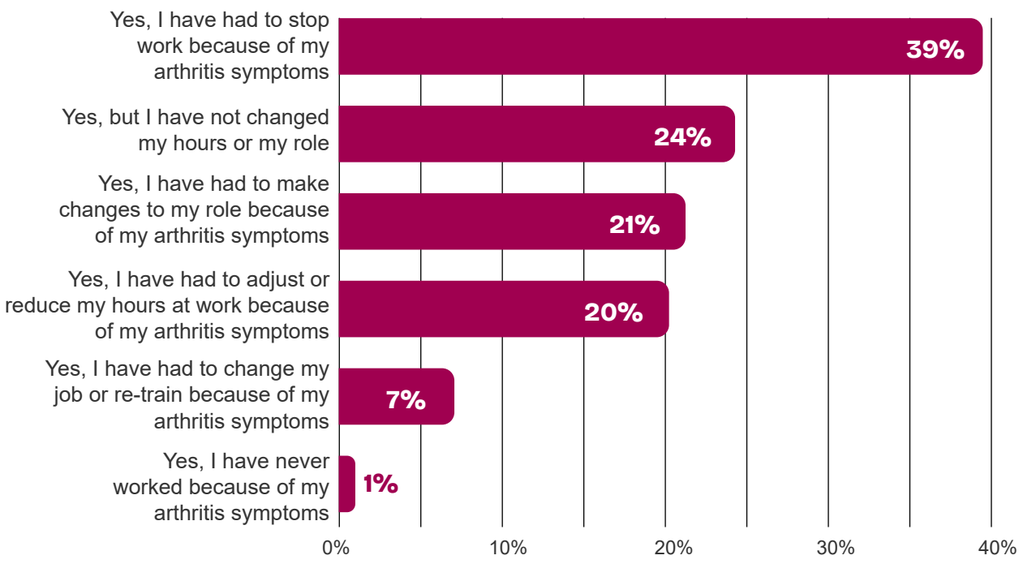
Alongside financial costs, workplace barriers are a significant factor preventing people with arthritis from being able to work as they need and want.

These difficulties have a significant impact on their stability and wellbeing, with arthritis often forcing people to change hours, roles or leave work altogether. Due to arthritis being an invisible, fluctuating condition, many employers do not understand the dynamic nature of pain, fatigue and flare ups that people with arthritis experience on a daily basis.

For example, 1 in 2 (50%)[e] people said that their arthritis had impacted their ability to work in some way. Of these individuals, stopping work was the biggest reported impact of having arthritis (39%)[f] **(Figure 10)**.

The main aspect of a role affecting an individuals' ability to work was physical or manual demands, with 8 in 10 people

Figure 10 – Has your arthritis condition(s) ever impacted your ability to work?



Base: Respondents whose reported their arthritis had impacted their ability to work

e 50% (N=3,953) of respondents selected any affirmative response to the multiple choice question 'Has your arthritis condition(s) ever impacted your ability to work?'.

f Of those whose arthritis had impacted their ability to work, the most frequently selected option was 'Yes, I have had to stop work because of my arthritis symptoms' at 39% (N=1,536).

(82%) saying it impacted their ability to work ('Somewhat' or to 'A great extent').[g] This was followed by limited flexibility in role (70%)[h], and lack of adjustments from employers (47%).[i]

Physical or manual demands remained the biggest reported issue affecting an individuals' ability to work across all age groups and across condition types.[j] Joint and spine symptoms were the largest reported factor impacting work, with more than 2 in 3 (68%)[k] respondents being affected. This was consistently the most reported issue across all condition types however, those with Autoimmune Inflammatory Conditions reported the worst outcomes for all aspects of arthritis impacting work when compared to other conditions.[l]

Social grade

Furthermore, the effects and impact of arthritis are disproportionately felt by individuals from lower social grades who consistently reported a greater impact of arthritis on their ability to work[m] and were more likely to say that arthritis influenced their decision to retire than respondents from higher social grades (ABC1).[n]

> **"I had to give up my work because I could no longer physically DO the work.**
>
> Female, aged 65+, Osteoarthritis, Wales

g Of those whose arthritis had impacted their ability to work, 82% (N=2,900) responded 'To a great extent' or 'Somewhat' to the question 'To what extent have the following aspects of your job impacted your ability to work – The physical/manual demands of my role'.

h Of those whose arthritis had impacted their ability to work, 70% (N=2,302) responded 'To a great extent' or 'Somewhat' to the question 'To what extent have the following aspects of your job impacted your ability to work – Limited flexibility'.

i Of those whose arthritis had impacted their ability to work, 47% (N=1,347) responded 'To a great extent' or 'Somewhat' to the question 'To what extent have the following aspects of your job impacted your ability to work – Lack of adjustments from my employer'.

j Please refer to data tables.

k 68% (N=4,891) of respondents selected 'To a great extent' and 'Somewhat' to the question 'To what extent, if at all, have any of the following specific aspects of your arthritis condition(s) ever impacted your ability to work– Arthritis symptoms in your joints and spine, including feelings of pain and stiffness'. This is compared to 58% (N=4,084) for 'Wider impacts of your arthritis condition(s), including fatigue (extreme tiredness that doesn't improve with rest), low mood, or anxiety' and 33% (N=2,151) for 'Attending healthcare appointments for your arthritis condition'.

l Please refer to data tables.

m Please refer to data tables.

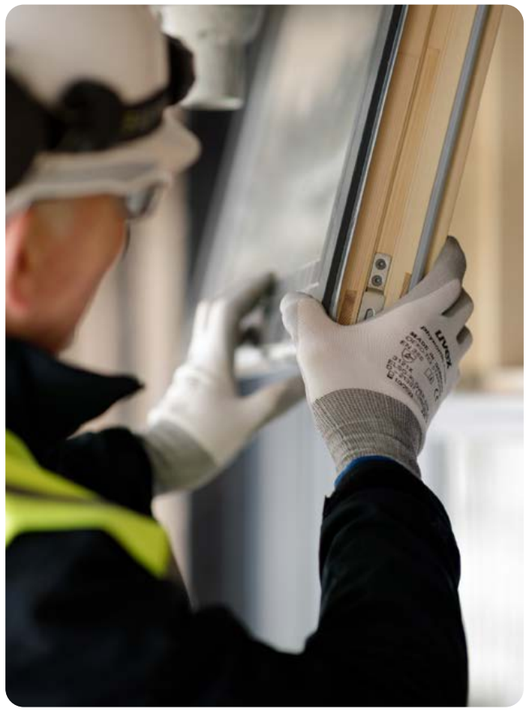
n Of those who had retired, 43% (N=733) from lower social grades (C2DE) selected 'To a great extent' or 'Somewhat' to the question 'To what extent, if at all, did arthritis play a part in your decision to retire?'. This is compared to 29% (N=646) of those from higher social grades (ABC1).

> **My work hours have gone from 40 [hours] a week to just 16 in 4 [hour] shifts as it's a lot of standing and running around... I love my job but it's getting near to me having to find a sitting job that I won't be happy in.**
>
> Female, aged 45-64, Osteoarthritis, England

Of those who reported arthritis had an impact on their ability to work:

Among those in higher social grades, 3 in 10 (30%) reported no changes to their working hours or roles.[o] Some reported making changes to their role (25%)[p] and adjusting/ reducing hours (23%)[q], hinting at some flexibility in work arrangements. 1 in 4 (28%) reported stopping work due to arthritis.[r]

In contrast, nearly half (49%) of individuals from lower social grades reported stopping work due to arthritis[s], with proportionally fewer reporting that they had not changed their hours or roles (19%).[t] In addition, fewer people from lower social grades reported having the option of working flexibly; with few saying they made changes to their role (16%)[u] or adjusted/reducing hours due to their arthritis (17%).[v]



Barriers in the workplace are not impacting everyone in the same way and are harsher for individuals in lower social grades. The type of work and flexibility available to individuals means individuals from higher social grades are better protected, as they benefit from more flexible working arrangements and options. This allows them to stay working for longer with their arthritis when compared to those from lower social grades.

o 30% (N=541) of those from higher social grades selected 'Yes, but I have not changed my hours or my role' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

p 25% (N=450) of those from higher social grades selected 'Yes, I have had to make changes to my role because of my arthritis symptoms' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

q 23% (N=421) of those from higher social grades selected 'Yes, I have had to adjust or reduce my hours at work because of my arthritis symptoms' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

r 28% (N=502) of those from higher social grades selected 'Yes, I have had to stop work because of my arthritis symptoms' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

s 49% (N=1,005) of those from lower social grades selected 'Yes, I have had to stop work because of my arthritis symptoms' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

t 19% (N=391) of those from lower social grades selected 'Yes, but I have not changed my hours or my role' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

u 16% (N=334) of those from lower social grades selected 'Yes, I have had to make changes to my role because of my arthritis symptoms' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

v 17% (N=350) of those from lower social grades selected 'Yes, I have had to adjust or reduce my hours at work because of my arthritis symptoms' to the question 'Has your arthritis condition(s) ever impacted your ability to work?'.

Out of options

> **I feel unseen, I wanted to keep working but the company I worked for didn't see arthritis as a disability and would not change my workload as my condition got worse, now I am unemployed and 50.**
>
> Female, aged 45-64, Osteoarthritis, Scotland

When people with arthritis are not supported in the workplace they are forced into a difficult choice. For many, the only option is to leave the workforce altogether. Of those respondents who were retired[w], 1 in 3 (35%)[x] people said that arthritis had played a part in their decision to retire ('Somewhat' or to 'A great extent'). This was higher in those who were of working age (64 years and under) with 61% affected, compared to 30% of those 65 years and over.[y] This pattern held true even when looking within condition groupings.[z]

Those with Autoimmune Inflammatory Conditions were more likely to report that their arthritis played a part in their retirement (57%)[aa], regardless of age.[bb] Differences were also seen by social grade, with those from lower social grades more likely to retire due to arthritis (43%) than higher social grades (29%).[cc]

In addition to early retirement, we also asked people if they were in receipt of government benefits or financial support. Of those who were receiving support, over half (52%)[dd] said that this was in part, or only because of their arthritis, and almost 1 in 5 (17%)ee said that it was only because of their arthritis. For those unable to continue working, or those who can't work as much as they'd like, this additional support can be a lifeline.

w Those retired N=4,083.

x Of those that are retired, 35% (N= 1,424) answered 'Somewhat' or 'To a great extent' to the question 'To what extent, if at all, did arthritis play a part in your decision to retire?'.

y Of those that are retired, 61% (N=433) aged under 65 answered 'Somewhat' or 'To a great extent' to the question 'To what extent, if at all, did arthritis play a part in your decision to retire?'. Compared to 30% (N=991) of those aged 65 and over.

z Please refer to data tables.

aa Of those that are retired, 57% (N=65) of those with Autoimmune Inflammatory Conditions answered 'Somewhat' or 'To a great extent' to the question 'To what extent, if at all, did arthritis play a part in your decision to retire?'. This is compared to 35% (N=1,244) with Osteoarthritis and 29% (N= 115) with Arthritis Other/Unknown.

bb Please refer to data tables.

cc Of those that are retired, 43% (N=733) in lower social grades (C2DE) answered 'Somewhat' or 'To a great extent' to the question 'To what extent, if at all, did arthritis play a part in your decision to retire?'. Compared to 29% (N= 645) in higher social grades (ABC1).

dd Of those receiving government benefits or financial support, 52% (N=2,053) answered 'Yes, only because of my arthritis condition' or 'Yes, in part because of my arthritis condition' to the question 'You stated that you currently claim government benefits or financial support… Is this because of your arthritis condition(s)?'.

ee Of those receiving government benefits or financial support, 17% (N=683) answered 'Yes, only because of my arthritis condition' to the question 'You stated that you currently claim government benefits or financial support… Is this because of your arthritis condition(s)?'.

The cost of living with arthritis

In addition to the impact on the ability to earn, living with arthritis – and disabilities more broadly – often leads to extra expenses[42], such as the need for specialised equipment and higher travel costs to get to work.[43]

This is a trend seen more widely across the UK. Research from SCOPE found that disabled households need an extra £1,095 each month just to have the same standard of living as non-disabled households.[44] When looking to the future, the extra costs of disability are predicted to reach £1,224 per month by the 2029 to 2030 financial year.

In the past 12 months, more than 4 in 10 (42%) said their arthritis had increased their personal expenditures ('Somewhat' or 'A great deal'[ff]), through additional expenses such as paying for treatments, heating or travelling to appointments. The impact was felt most among those with Autoimmune Inflammatory Conditions[gg] and among people from lower social grades.[hh] These are the same groups whose ability to earn is most affected, showing that people with arthritis are not being proportionately impacted and the reality for some is much worse than for others.

Arthritis significantly impacts people's ability to work and to stay in work. Flexible working options are not universally accessible across industries and as a result people with arthritis are unable to access the same level of support that allows them to stay in work. In addition, arthritis can increase the cost of day-to-day living due to the additional needs people with arthritis may have. When looking at both the decreased ability to earn and the increased personal expenditure, those from lower social grades and those with Autoimmune Inflammatory Conditions were significantly affected.

> **I just feel dismissed and like no one understands the pain I put up with daily. Every day is a struggle to keep working and stay positive. I dread the winters now and because energy is so expensive and I only work part-time, keeping the house warm enough to keep my pain at bay is increasingly difficult.**
>
> Female, aged 45-64, Osteoarthritis, Northern Ireland

ff 42% (N=3,255) of respondents selected 'Somewhat' or 'A great deal' to the question 'In the past 12 months, to what extent, if at all, has your arthritis had an impact on – Any additional financial expenditures to manage your arthritis'.

gg 56% (N=329) of those with Autoimmune Inflammatory Conditions selected 'Somewhat' or 'A great deal' to the question 'In the past 12 months, to what extent, if at all, has your arthritis had an impact on – Any additional financial expenditures to manage your arthritis'. This is compared to 42% (N=2,633) with Osteoarthritis and 37% (N=292) with Arthritis Other/Unknown.

hh 47% (N=1,641) of those from lower social grades selected 'Somewhat' or 'A great deal' to the question 'In the past 12 months, to what extent, if at all, has your arthritis had an impact on – Any additional financial expenditures to manage your arthritis'. This is compared to 38% (N=1,509) from higher social grades.

Conclusion

Our research clearly highlights the stark reality of living with arthritis in the UK today. Through the voices of those living with the condition we can better understand the ways in which it is impacting them. They told us that arthritis is impacting their wider physical and mental health, their relationships and family, and their ability to be independent. They told us they can't live the life they want to lead because of their arthritis.

Those who had received a formal diagnosis told us how validating the experience was and how it opened doors to further treatment and support. However, for many the process of getting a diagnosis is taking too long, they feel like they aren't being listened to, and their pain isn't being taken seriously. People with arthritis are being dismissed. Unfortunately, those who are able to access further support told us that they still face barriers to effective and timely treatment that has huge consequences on their daily lives.

People living with arthritis also find that their ability to fully participate and stay in the workforce is impacted by their condition. They may require more flexibility and workplace adjustments but find that they are not accommodated for and these workplace barriers can force people out of work altogether. This financial pressure is compounded by the fact that many people living with arthritis also face an increased cost of living due to the management of their condition. This might include higher heating bills, increased travel costs and/or specialised equipment. People are facing financial strain due to their arthritis.

Across all these areas of life, our research found that not everyone is impacted equally. In fact, those from lower social grades, younger adults and those with Autoimmune Inflammatory Conditions consistently reported worse experiences.

What needs to change

Although arthritis is one of the leading causes of disability in the UK and affects people of all ages, public health funding remains disproportionately low, and there is a persistent lack of public awareness and understanding of these conditions amongst healthcare professionals and leaders.

Arthritis is often wrongly dismissed as an inevitable part of ageing or shrugged off as ‘just a bit of arthritis’. All too often, arthritis isn’t adequately included in national or local health plans, and this leads to a postcode lottery that negatively impacts people living in the most deprived areas. This is unacceptable and must change for everyone living with arthritis across the UK.

Policy recommendations

1

Arthritis must be recognised as a major public health issue.

Governments across the UK must prioritise arthritis and MSK health across healthcare systems. Along with the MSK framework in Wales[45], there should be MSK frameworks in England, Scotland, and Northern Ireland, each with sustainable funding to ensure consistency in service provision for all people living with arthritis regardless of location. This is because MSK healthcare needs sustainable leadership, targeted and joined-up action and high-quality data collection at national, regional and local level to really deliver high-quality services and support for people with arthritis.

2

Everyone should have equal access to personalised treatment and care no matter where they live, and lived experience should inform the development of local health services.

There must be a greater focus on eliminating health inequalities and ensuring people living in poverty have timely access to treatment and care when they need it. Lived experience should inform the development of local services, and people with arthritis should be involved in the co-design and co-production of those services. Health boards and integrated care systems should have lived experience at the heart of policy and decision making.

3

Improve the quality of arthritis and MSK health data.

Without transformation in MSK health data, we cannot build an accurate picture of the impact of MSK conditions and the quality of services people with MSK conditions need to access. The quality, coverage, availability, and use of MSK data must be improved across the UK and routine data should be widely collected. Poor data on MSK conditions within primary and community settings makes it harder to tackle poor services and target resources where they are most needed, including supporting people to return to work. We believe there should be a fully funded national MSK audit in primary and community care to drive improvement in MSK service provision.

4

Training courses for all frontline healthcare professionals to better diagnose and support people with arthritis.

People’s experiences with healthcare professionals when seeking a diagnosis varies and many people do not feel that their condition is taken seriously. A barrier to diagnosis can mean their symptoms are being missed by their healthcare professional. This is especially true for young people. All frontline healthcare professionals, including social prescribing link workers, clinical pharmacists, health coaches and care coordinators, should be offered new accredited, short training courses that give them the knowledge and skills they need to be able to confidently diagnose and support people to manage their arthritis. Further, Health Education and Improvement Wales (HEIW) has developed a multi-professional MSK capability framework [46] for practitioners providing care to people with MSK conditions in primary and community care adult settings in Wales. This model can be adapted and used across the UK.[47]

5

No one should be plunged into poverty due to their arthritis.

We need a compassionate benefits system that supports people with arthritis and doesn’t punish people for being unable to work. People with arthritis can face additional financial hardship due to their condition. Understanding their needs through properly trained disability employment advisors and more efficient management of advisor waitlists will empower them to find productive employment that enables them to live fulfilling, independent lives. Greater awareness of employment support programmes such as Access to Work, the impact of meaningful reasonable adjustments and greater awareness of health and safety measures can help employers ensure that people with arthritis are productive members of the workforce.

Appendix 1: Detailed methodology

Participant recruitment

A survey of 7,928 adults (aged 18+) living in the UK was conducted between July and August 2024.

Primary recruitment was conducted through YouGov, who were commissioned to provide a sample of individuals with backgrounds broadly representative of the UK arthritis population. YouGov used its online panel to achieve a demographically and geographically diverse cohort aligned with national prevalence data. In total, YouGov recruited 5,144 participants (unweighted).

To supplement this core sample and improve representation among under-represented groups in YouGov's panel, additional participants were recruited through targeted outreach by Arthritis UK. This included engagement through the charity's networks and targeted social media campaigns. An additional 2,784 participants were recruited via this route (unweighted). Full demographic breakdown of respondents can be found in the data tables.

Weighting and representativeness

The final full dataset was weighted to reflect the UK population of people with arthritis, based on the demographic profile of three arthritis categories (those who have osteoarthritis, autoimmune inflammatory arthritis conditions, and other/unknown arthritis conditions). Condition groupings were weighted by age and gender, region and social grade. An overall weighting was applied to reflect the breakdown of these groups. This weighting process ensures that the findings are broadly representative of the arthritis community across the UK. All figures reported are weighted unless otherwise stated and all analysis was conducted by Arthritis UK.

Ethnicity

A limitation of this survey was the inability to get a representative sample of this population by ethnicity. Overall, respondents from an ethnic minority background totalled 4% (N= 426 unweighted). For that reason, we have not analysed questions by ethnicity.

Multimorbidity

51% of the respondents[a] had at least one additional long-term condition in addition to their arthritis, which could be classified as one of the condition groupings within the Major Conditions Strategy[48]:

- 25% reported being diagnosed with a cardiovascular disease (stroke, heart disease or diabetes) (N=1,761 unweighted)
- 17% reported being diagnosed with chronic respiratory disease (asthma) (N=1,374 unweighted)
- 16% reported being diagnosed with a mental health illness (N=1,478 unweighted)
- 10% reported being diagnosed with cancer (N=661 unweighted)
- 0.3% reported being diagnosed with Alzheimer's or dementia (N=26 unweighted).

a N=4,036 (weighted).

Notes for interpretation

The denominator for each question will be the full dataset (N=7,928) unless otherwise stated. Those who did not answer the question or selected 'Don't know' or 'Prefer not to say' have been excluded from the denominators of percentages.

The percentages in charts are rounded, so may not add up to 100%. Charts will exclude those who selected 'Don't know', 'Prefer not to say' or 'Not applicable to me'.

Age groupings
The survey was only open to those 18 years of age and older. For interpretation, ages are then grouped into three; 18-44 years (younger adults), 45-64 years and 65+ years (older adults).

Condition groupings
Individuals who reported more than one arthritis condition were asked to select the condition they felt had the greatest impact on their life. Individuals were then grouped based either on their *only* arthritis condition or their *most impactful* arthritis condition. Therefore, when we refer to groups – such as 'people with Osteoarthritis' – we mean individuals for whom osteoarthritis was either their only condition or the one they identified as having the greatest impact on their life. Conditions were then collated into 3 groups:

1. Osteoarthritis
2. Autoimmune Inflammatory Conditions
3. Arthritis Other or Arthritis Unknown (including Gout)

When referring specifically to any of these groupings, we have capitalised to reflect it as a grouping name.

Social grade
Throughout the report, we refer to the variable 'social grade'. Social grade is calculated based on the chief income earner of the household and involves the use of an algorithm. It considers a variety of variables such as their job title, the type of work they do, whether they are self-employed, the type of organisation they work for, how many people work at their organisation, how many people they manage, and many other attributes. The definition of each social grade is standardised and held by the Market Research Society (MRS), and you can read more on their website.[49]

The creation of this variable was undertaken by YouGov. Respondents have been grouped into two categories, ABC1 (higher social grades) and C2DE (lower social grades). Demographic differences between social grades are small, and for detailed demographic differences, please refer to the data tables.

Treatment questions
In the treatment section of the survey, due to the challenges of distinguishing treatments for different types of arthritis, participants were asked to reflect on their experiences of all their arthritis conditions collectively. As such, analysis of these questions does not refer to any one specific arthritis condition of respondents.

Appendix 2: Survey questions and data tables

For the full set of questions asked, a breakdown of the demographics of the survey respondents, as well as data tables for this report, please use the link below.

Click here to access survey questions and data tables

Alternatively scan the QR code below.

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