



# The Silent Treatment:

Why an Arthritis Diagnosis Matters

## Acknowledgements

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# Foreword

Deborah Alsina MBE, Chief Executive, Arthritis UK



Over 10 million adults, young people and children in the UK are living with a form of arthritis.<sup>1,2</sup> While arthritis isn't a single condition and there are many different types, arthritis is characterised by pain and stiffness in one or more joints. Depending on the intensity of symptoms, arthritis can have a significant impact on someone's life as it can affect everyday activities. Due to this impact, arthritis is one of the leading forms of disability in the UK.<sup>3</sup>

Despite arthritis affecting so many lives, people face barriers to accessing the care and support they need. This report shows that barriers to care are present right from the start, with many experiencing delays to a diagnosis.

And while arthritis is associated with pain and stiffness, it can also cause fatigue and affect people's mental health and ability to work.<sup>4</sup> As people wait for a diagnosis, they are without treatment and support that could help them manage their symptoms. A delayed diagnosis can also lead to further complications and make the condition harder to treat.

We heard powerful stories from people about the impact of their symptoms on daily life – on their ability to work, care for family, to get out and see friends or enjoy hobbies. And the feelings of loneliness this can cause. Therefore, for people with arthritis, a diagnosis is vital not just because it can open the door to treatment and care but also because it is validating and provides the relief of finally being seen.



**A diagnosis is vital not just because it can open the door to treatment and care but also because it is validating and provides the relief of finally being seen.**

A delayed diagnosis also costs the NHS and the economy.<sup>5,6</sup> Without the right care at the right time, people may require more serious, repeated and prolonged care from the NHS over a long term. Additionally, a delayed diagnosis without the right support means that people may struggle to stay in or get back into work, at an unnecessary cost to the economy.

Importantly, a diagnosis is not just a medical process or conversation, it's also an opportunity to provide the reassurance, communication and support people need to understand and manage their condition. It's one of the most important first steps in a person's journey of living with a long-term condition such as arthritis. Therefore, it is critical for the diagnosis to not only be timely but framed to set someone up for the road ahead.

This report captures the delays and barriers that people face throughout the diagnosis pathway, beginning when people first experience symptoms. The limited societal understanding of arthritis and its symptoms means people may downplay symptoms and delay seeking medical advice. Once they do enter the health system, they may face additional delays. Despite the best efforts and dedication of health professionals, they are working in a stretched system that has not historically prioritised musculoskeletal (MSK) health. It means people's symptoms may be missed, there are delays to diagnostic tests, referrals and appointments, and limited availability of health professionals and services to deliver the multidisciplinary support people need.

The barriers around an arthritis diagnosis also demonstrate a broader issue. At a system level, MSK conditions lack the strategic prioritisation, national strategy, dedicated local or regional leadership and sustained infrastructure seen in other conditions.

Urgent action is needed now to improve the rate and experience of diagnosis for people with arthritis. This requires dedicated national and local efforts spanning public health, primary, community and secondary care across diagnosis pathways. People with arthritis should not be left in pain, in the dark, or given the silent treatment whilst they wait for a diagnosis. Getting it right from the outset will deliver benefits across the health and social care system and wider economy, allowing people with arthritis to get control of their lives back.

**We urge UK governments and the NHS to take this report and its findings seriously and to act upon its recommendations.**

# Executive summary

**This report brings together insights from people with arthritis and health professionals to highlight the barriers faced in achieving a timely and personalised diagnosis for arthritis conditions. It also identifies what matters to people with arthritis and what a 'good' diagnosis experience and conversation should look like.**

People with arthritis require timely access to care, treatment and support. This report shows that without the right support, arthritis can be debilitating and life changing. It also clearly illustrates that a diagnosis isn't just important for the treatment and care it opens up, but because it can be validating for the person living with arthritis. The findings also demonstrate that people require clear personalised information about their condition to enable them to access treatment and support to help manage their condition.

This report examines the importance of a timely diagnosis, the damage caused by delays to diagnosis, and why personalised holistic care is essential to enable people with these conditions to live well.



# Policy recommendations

The importance of a timely and personalised arthritis diagnosis is clear and can make all the difference. We urge UK governments and national health bodies to take action in the following areas to make this a reality:

- Improve public awareness of arthritis symptoms to help reduce delays in people seeking medical advice.
- Strengthen musculoskeletal content as part of the medical curriculum and encourage training that improves health professionals' ability to diagnose and care for people with arthritis.
- Improve the collection and quality of data on musculoskeletal conditions in primary and community care.
- Prioritise the timely diagnosis of early inflammatory arthritis so everyone can access treatment and slow the progression of the condition.
- Ensure that NICE guidance for osteoarthritis is being implemented and equivalent guidance is developed in Scotland.
- Ensure people with arthritis are receiving personalised information, signposting and support to manage their condition as part of the diagnosis pathway.
- Embed wider support including third sector support into diagnosis pathways to help people live well.
- UK governments should consider conducting in-depth economic analysis on the total cost of delayed diagnosis for both osteoarthritis and inflammatory arthritis.

# Introduction

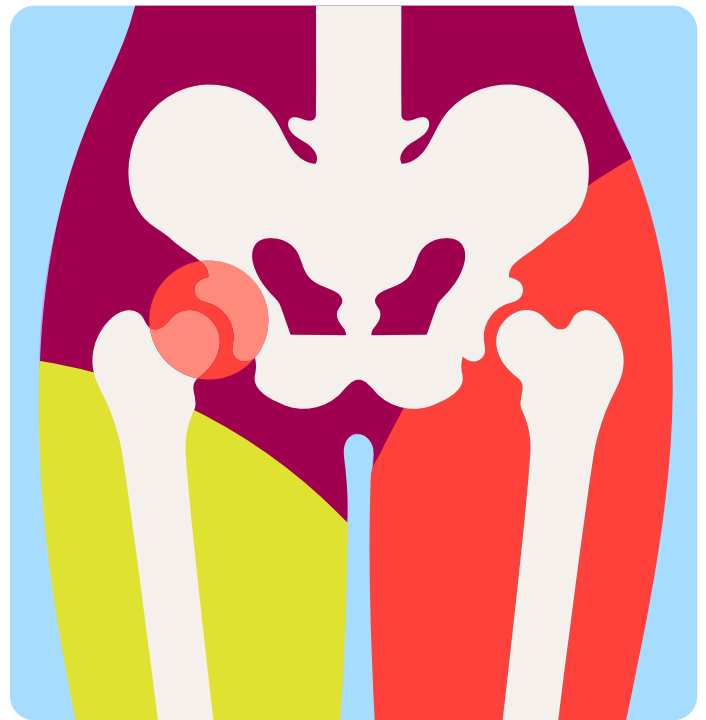
## What is arthritis?

**Arthritis refers to painful, stiff and/or restricted joints.**

Although there are many different forms of arthritis, this report focuses on the most prevalent which includes osteoarthritis, crystal arthritis conditions such as gout, and inflammatory arthritis conditions including rheumatoid arthritis, psoriatic arthritis, and axial spondyloarthritis.

Despite key differences in the diagnosis pathway, there are also common themes that people with osteoarthritis and inflammatory arthritis have shared that this report explores.

Due to its complexity, this report does not focus on juvenile idiopathic arthritis (JIA) – a group of arthritis conditions that present before children are 16 years old – as we believe this warrants a separate investigation.



## Types of arthritis

### Osteoarthritis

This happens when the body can no longer maintain and repair one or more joints – commonly affecting hands, hips, and knees. The cartilage becomes thin and uneven, preventing the joint from moving easily. The body's attempts to repair these changes can lead to pain, stiffness and swelling.

Prevalence:

**10 million**  
people in the UK have  
a probable diagnosis  
of osteoarthritis.<sup>1,2</sup>

### Rheumatoid arthritis

This is a type of inflammatory arthritis where the immune system attacks the body's joints, causing inflammation, swelling, pain, stiffness and damage to the joints.

Prevalence:

**450,000**  
people in the UK have a  
recorded diagnosis of  
rheumatoid arthritis.<sup>2,7</sup>

### Axial spondyloarthritis

This is a type of inflammatory arthritis where the immune system attacks the spine and sometimes joints causing inflammation, stiffness, pain, and damage.

Prevalence:

**60,000**  
people in the UK have a recorded diagnosis of axial spondyloarthritis (of an estimated 220,000).<sup>8</sup>

### Psoriatic arthritis

This is a type of inflammatory arthritis linked to psoriasis where the immune system attacks the body's joints, causing inflammation, swelling, stiffness, pain and damage to the joints. Psoriasis is an autoimmune condition affecting the skin and around 1 in 4 people who have psoriasis have psoriatic arthritis. Some people may develop psoriatic arthritis without noticeable skin psoriasis.

Prevalence:

**200,000**  
people in the UK have a probable diagnosis of psoriatic arthritis.<sup>2,7</sup>

### Gout

This is a type of inflammatory arthritis where the immune system, which is the body's natural self-defence system, attacks joints and surrounding tissues where urate crystals have formed, causing episodes of severe inflammation, stiffness, pain, and damage. Urate crystals form in joints when the body's urate (uric acid) level is consistently too high.

Prevalence:

**1.6 million**  
people in the UK have a probable diagnosis of gout.<sup>2,9</sup>

## Overview of methodology

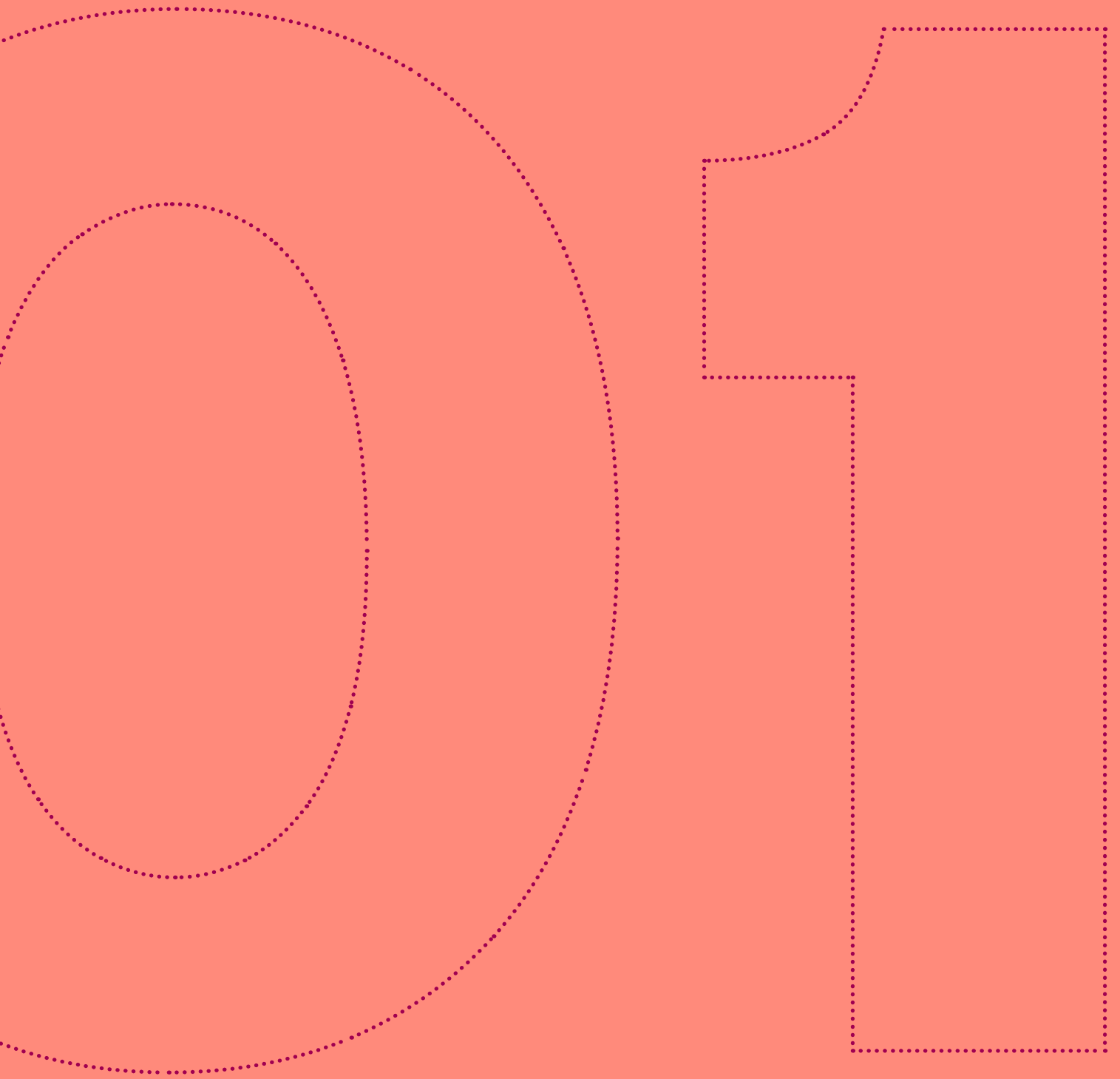
The report draws on findings from multiple sources, including:

- Arthritis UK's previous policy and statistical reports and surveys, including those published under our previous name Versus Arthritis.
- Findings from a series of small-group qualitative workshops held in England, Scotland, Wales and Northern Ireland in 2024, involving 35 people with arthritis. These findings will be referred to throughout the report as the 'lived experience workshops'.

- Insights from surveys with primary, community and secondary health professionals, regarding their experience and opinions of the inflammatory and osteoarthritis diagnosis pathways.<sup>a</sup>

The report covers the diagnosis pathway from when people first experience symptoms to when they receive their diagnosis. It also covers barriers and experiences across the diagnosis pathway and at the point of diagnosis. Each chapter includes recommendations aimed at improving the diagnosis pathway or experience for people with arthritis.

<sup>a</sup> 100 primary and community health and care professionals and 55 secondary health and care professionals, recruited through Arthritis UK's professional networks. These findings are not nationally representative.



# **The cost of a delayed diagnosis**



**This chapter provides an overview of the impact of a delayed diagnosis on people with arthritis and in turn how it can cost the individual, the healthcare system and wider economy.**

It's clear that many people are waiting longer than they should have to for their arthritis diagnosis. This was a theme of Arthritis UK's [\*Left Waiting, Left Behind: The Reality of Living with Arthritis\*](#) report, where people reported experiencing delays across all conditions. Of those with a diagnosis, nearly 4 in 10 (38%) respondents felt the process of getting a diagnosis took too long. More than 5 in 10 (54%) reported unreasonable waits or delays in getting an appointment with the relevant specialist and more than 4 in 10 (44%) reported unreasonable waits or delays in accessing tests or test results.<sup>4</sup> Similarly, delays in diagnosis were a key theme in the lived experience workshops across both osteoarthritis and inflammatory arthritis.

# Impact on the individual: the importance of a diagnosis

A delayed arthritis diagnosis can have a substantial impact on people, especially those whose symptoms are causing significant deterioration in both mental and physical health.<sup>10,11</sup> Early functional decline can be a major issue for some people with new onset arthritis. Delays in diagnosis are therefore highly likely to accelerate this decline<sup>12</sup> and lead to later commencement of treatments that will likely reduce their potential benefit. Physical and mental impairments also affect people's capacity to earn an income and can have a longer-term impact on people's pensions. Without treatment and information, people don't have the tools and knowledge that could support them to manage their condition.

With a diagnosis, people can begin to understand and educate themselves, which can help them feel more in control. Some research also suggests that a diagnosis can support people to better adapt or accept their health state. For example, it can influence how people perceive their condition and, in some cases, can have a more significant impact on determining their mental health and pain levels compared to the severity of their condition.<sup>12</sup> This demonstrates the importance that a diagnosis can have in framing people's perception of their condition and how they cope with their symptoms.

In the lived experience workshops, people stressed how validating it was to receive a diagnosis and how it made them feel like they were not on their own. One participant shared how it was like finally putting all the jigsaw pieces together. This is reflected in the [Left Waiting, Left Behind](#) report, with validation being the most widely reported benefit of getting a diagnosis.<sup>4</sup>

The importance of a diagnosis for people with arthritis cannot be underestimated – in terms of the treatment and support it offers for proactive symptom management, the role it can play as part of secondary prevention, and the validation it can provide for those who have been struggling without answers.



**[A] diagnosis helped me feel that I wasn't going mad.**

Lived experience workshop participant



**[The diagnosis] provided relief that explained a lot of things.**

Lived experience workshop participant



**I think the validation is so important, [it provides] a huge sense of relief that [I] haven't been imagining it... would have been really good to have it some years previously when I was still working, because I've been in so much pain at work.**

Lived experience workshop participant

# Impact on the health system

Alongside the impact on the individual, a delayed diagnosis can also come at a cost to the NHS. A 2017 analysis projected that the NHS would spend £118.6 billion on treating osteoarthritis and rheumatoid arthritis over the subsequent decade.<sup>5</sup> MSK conditions including arthritis accounted for the third largest area of NHS programme spending at £4.7 billion in 2013/14. Although updated data is not publicly published anymore, this figure has almost certainly increased since.

A delayed diagnosis can also influence people's longer-term outcomes and whether they require more intensive interventions such as joint replacement surgery or have increased and repeated use of healthcare services.<sup>13</sup> This demonstrates the important role that early diagnosis plays as part of secondary prevention. For inflammatory arthritis, early diagnosis directly impacts remission and reduces the risk of permanent joint damage, persistent pain and disability in the long term.<sup>14</sup> Therefore, delayed diagnosis can lead to higher costs overall for the health system, as patients may then need intensive treatment with high-cost medicines for longer periods.<sup>15</sup> For osteoarthritis, there are currently no disease-modifying drugs. However, there are recognised interventions such as physical activity and weight management that help maintain mobility and reduce pain.<sup>16</sup>

Research has also shown that people with osteoarthritis have increased rates of General Practitioner (GP) consultations and hospital admissions compared to people without osteoarthritis.<sup>17</sup> There is now also a growing body of evidence highlighting the association between premature mortality and osteoarthritis, particularly when affecting the knee joint.<sup>17,18,19</sup> People have to see their primary and community care practitioners multiple times to get a diagnosis and the care they need. Research

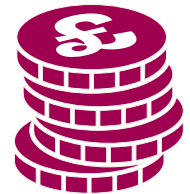
into osteoarthritis of the knee has found that the opportunity for non-surgical intervention is reduced by time lost between symptom onset and diagnosis.<sup>20</sup>

If people with osteoarthritis receive a diagnosis accompanied by information on self-management and referral to appropriate services such as physiotherapy and podiatry, it is possible that this could delay or prevent more intensive treatment further down the line.<sup>21</sup> While early diagnosis for osteoarthritis may not present with the same clinical urgency as inflammatory arthritis, if people receive effective early intervention for osteoarthritis, it could play a role in reducing the long-term burden of osteoarthritis on the healthcare system.

**Analysis in 2017 projected that over the next decade, the healthcare cost of treating the two most common forms of arthritis would reach**

**£118.6 billion.**

(York Health Economics, 2017)



**People with osteoarthritis have increased rates of GP consultations and hospital admissions compared to people without osteoarthritis.**

(Swain et al., 2023)



# Arthritis and other long-term conditions

Arthritis is often comorbid with other long-term health conditions. For example, people with osteoarthritis have a 24% higher risk of having cardiovascular disease and 61% higher risk of having diabetes mellitus.<sup>22</sup> The relationships between conditions are complex but many have shared risk factors, such as increased body weight contributing directly to knee osteoarthritis, or people struggling to be physically active because of painful arthritis or other MSK conditions. There are also links between mental health and arthritis; for example, 1 in 5 (20%) with osteoarthritis experience symptoms of depression and anxiety, and the prevalence of depression in people with rheumatoid arthritis is 2 to 3 times higher than in those without the condition.<sup>23,24</sup>

Therefore, early diagnosis of arthritis accompanied by effective care and treatment could help to mitigate the risk of developing other long-term health conditions. The growing number of people living with multiple long-term conditions poses a significant burden on the NHS, as people will often require engagement with multiple health services.<sup>25</sup>



**1 in 5**

**people with osteoarthritis experience symptoms of depression and anxiety.**

(Stubbs et al., 2016)



# Impact on the economy

Alongside the cost to the NHS, arthritis and MSK conditions have an impact on the economy as they can affect a person's ability to work. People with arthritis are 20% less likely to be in work than someone without arthritis.<sup>26</sup> A study has estimated the economic cost of a delayed axial spondyloarthritis diagnosis to be £193,512 per person. The total annual cost was estimated at £3.1 billion and £12.5 billion in the UK based on the prevalence of axial spondyloarthritis at 0.3% and 1.2% respectively.<sup>6</sup> These significant costs are primarily due to productivity losses and out-of-pocket expenses.

Additionally, the National Early Inflammatory Autoimmune Diseases Audit (NEIAA), previously known as the National Early Inflammatory Arthritis Audit, found that in 2024, most early inflammatory arthritis patients report that their symptoms significantly impact their employment. At diagnosis, 75% of those who were unemployed said this was due to their arthritis, highlighting the importance of early intervention.<sup>14</sup>

While there has been some recent analysis conducted on the impact of delayed diagnosis for inflammatory arthritis, such as the study on delayed axial spondyloarthritis diagnosis mentioned earlier, this only represents analysis on one condition. There is a previous audit from the National Audit Office (NAO), which provides economic modelling, on the economic benefits of early diagnosis and treatment for rheumatoid arthritis, but this analysis is from 2009.<sup>27</sup> Additionally, there is limited analysis on this issue in relation to osteoarthritis. Therefore, there is a need for updated, systematic economic analysis that covers the breadth of inflammatory arthritis conditions as well as osteoarthritis.



**I had to take time off work for quite a long time.**

Lived experience workshop participant



People with arthritis are **20% less likely** to be in work than someone without arthritis.

(Rajah et al., 2023)

The economic cost of a delayed axial spondyloarthritis diagnosis is estimated to be

**£193,512**

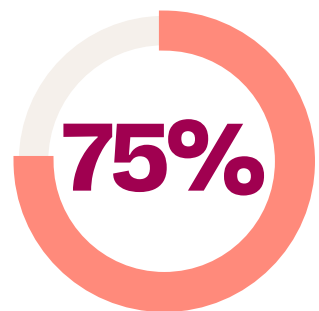
per person.

(Zanghelini et al., 2025)



At diagnosis, **75%** of those who were unemployed said this was due to their arthritis.

(NEIAA, 2025)



## Chapter conclusion:

A delayed diagnosis can have an impact on the individual, the health system and the economy, demonstrating the importance of ensuring people receive a timely diagnosis accompanied by the treatment and care they need. While there is various research available on the impact of a delayed arthritis diagnosis, nation-specific analysis covering osteoarthritis and inflammatory arthritis would support governments to understand the overall impact on the economy and the cost of inaction.



## What needs to happen

**Arthritis UK would welcome working with UK governments to conduct in-depth economic analysis of the total cost of delayed diagnosis for both osteoarthritis and inflammatory arthritis.**

**Stakeholders:** All UK governments and health departments.

**Implementation:**

- ✓ All governments should consider funding a review into the full system-wide costs of delayed diagnosis for osteoarthritis and inflammatory arthritis, including how it impacts NHS costs and the cost of lost productivity.



# Ken's story

Stirling, Scotland



There was a sense of validation in eventually getting diagnosed because I'd suspected I had arthritis but was dismissed for 20 years which left me angry, frustrated and feeling like I was banging my head against a brick wall. I'd gone to the GP with swollen knees, pain in my hips and lower back so it was a relief to finally know what I was dealing with, if you don't know, where do you start?

I'd been injured in a car accident as a child which I think caused the pain in my right hip that started in my late 20s, then I got pain in my right knee but I cracked on. By my early 30s it had really started to slow me down so I saw a GP who said I was 'doing too much'. I've been told I'm 'too active', 'too young for surgery' then they said I needed surgery but the waiting lists were too long.

I was finally diagnosed with osteoarthritis at 50, after nearly 20 years of no help, which took the wind out of my sails because, having worked with lots of elderly people, I knew how it would impact my life. The biggest benefit was knowing what I was up against so I could research, adjust my lifestyle, diet and stop the nightshifts and 14-hour days.

Delayed diagnosis really impacted my life and basically cost me my job. I'd been in nursing for 38 years and the wait for diagnosis meant I'd deteriorated so badly I was forced to retire early in 2019, although I did go back to help through COVID-19 because they needed me.



Over the years arthritis wears you down, lowers your mood and expectations. I was prescribed antidepressants around three years ago and that felt almost as bad as the arthritis diagnosis because I didn't want to admit I was that low or accept that I might need some support. My wife was relieved when I eventually said I'd talk to my GP about it because she thinks I've been depressed for years.

Finding Arthritis UK was invaluable, the online community is a great support. Arthritis UK also gives people the opportunity to speak up, explain the reality of living with arthritis every day and the impact it has on your whole life.



# Delays in the diagnosis pathway



**This section covers people’s diagnosis pathway from when they first begin to experience symptoms to when they finally receive a diagnosis. It also highlights the barriers people face at each stage of the diagnosis pathway.**

There are several factors that can impact the length of time it takes for someone to get a diagnosis. The cumulative delays at each level of the diagnosis pathway can add up and mean people aren’t getting the care they need.

# Delays at symptom onset

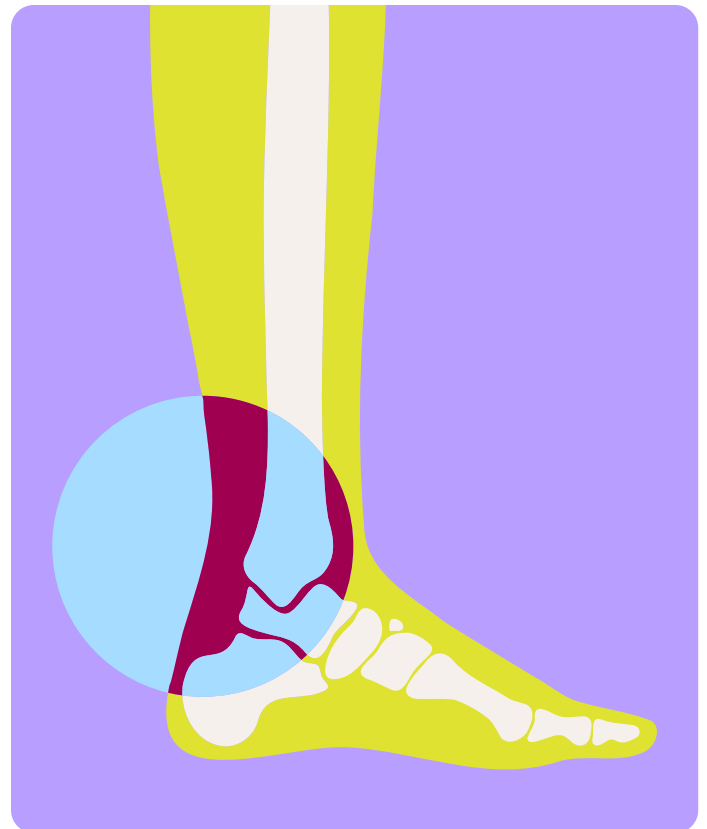
## People delay seeking medical advice

Often delays may begin when people first start experiencing symptoms. In the lived experience workshops, across both osteoarthritis and inflammatory arthritis, people did not suspect their symptoms were due to arthritis and assumed they were likely to go away on their own, which meant they delayed seeing a health professional. For example, a participant with axial spondyloarthritis assumed their pain was from sitting down for prolonged periods of time due to their job. Similarly, someone noticed knee pain but waited a year before seeing their GP as they thought the pain would go away on its own. A former midwife shared that she waited longer than she needed to when noticing pain in her feet as she also attributed it to her job and being on her feet for long hours.

A recurring theme was people attributing their symptoms to lifestyle and work, resulting in delays in seeking medical advice, which is especially crucial for inflammatory arthritis. A study comparing symptom recognition of inflammatory arthritis found that only a small proportion of people were able to recognise the signs of rheumatoid arthritis compared to signs for bowel cancer and angina, as there is a perception that MSK symptoms, even those of an inflammatory nature, are less concerning and therefore don't require urgent medical attention.<sup>28</sup> Research also found that patient delay due to lack of knowledge of rheumatoid arthritis and symptom evaluation was longer in patients of South Asian origin, highlighting ethnic disparities in delays to diagnosis.<sup>29</sup>

Delays in seeking medical advice have also been highlighted in relation to gout. A study exploring patients' experiences identified a variety of causes such as self-diagnosis and self-treatment contributing to a delay in seeking medical advice.<sup>30</sup>

For rheumatoid arthritis, a 2023 literature review found an average (mean) delay of 3.14 months from the onset of symptoms to first contact with a health professional.<sup>31</sup> The National Axial Spondyloarthritis Society (NASS) report on the average time to diagnosis for axial spondyloarthritis also found that the average (mean) time to a diagnosis is 8.29 years. Almost a third (32%) of the wait was from experiencing symptoms to seeking help from a GP.<sup>32</sup>



## Past experiences with the healthcare system

In the lived experience workshops, several people also delayed seeing their health professional because of their past experiences and difficulties with accessing health services. Some expressed the difficulty of explaining their symptoms to their GP within 10 minutes or even obtaining an appointment in the first instance.

A joint report from the Royal College of General Practitioners (RCGP) and The Patients Association, *Solving the NHS maze for patients and GPs*, highlights that one of the biggest barriers patients face is the struggle to see a GP in the first place, emphasising systemic barriers within the system.<sup>33</sup>

## Arthritis is poorly understood

We also asked people in the lived experience workshops what is needed to improve the diagnosis experience. A common theme was increased general awareness of arthritis to help people recognise symptoms. Common myths about arthritis, such as only older people develop arthritis, contribute to a limited understanding of the condition, which can hamper people's ability to recognise signs or seek help. A greater awareness that younger people can get arthritis would be helpful. People should also be made aware that there are different types of arthritis including red flag symptoms for inflammatory arthritis that should not be ignored. Importantly, people should be aware that there is treatment, support and information available to help manage their symptoms. Countering commonly held misperceptions and promoting a better understanding of arthritis could improve information-seeking behaviour, so people specifically look for information on arthritis on the Arthritis UK and NHS websites.

Other charities have also developed symptom checker tools to help people identify symptoms that might suggest inflammatory arthritis, such as the rheumatoid arthritis symptom checker from the National Rheumatoid Arthritis Society (NRAS) and the axial SpA symptom check from the National Axial Spondyloarthritis Society (NASS).<sup>34,35</sup> These tools could help encourage those with red-flag symptoms to seek medical advice.

It's about establishing a broader and better understanding of when people should 'think arthritis' when experiencing symptoms. This information could help people better decide whether they should seek medical advice earlier and help reduce some of the delays in the diagnosis pathway that begin at symptom onset.



**[I was] working in my first office job when I first started getting symptoms, assumed back pain related to sitting down.**

Lived experience workshop participant



**Last resort reaching out to GP.**

Lived experience workshop participant



**Heard of osteoarthritis and I associated it with being like an old person's illness. So, I just brushed it off that I didn't have that.**

Lived experience workshop participant

# Delays in primary care

MSK conditions such as arthritis can represent a significant percentage of primary care consultations, accounting for up to 30% of GP appointments in England.<sup>36</sup> Once people decide to reach out to their healthcare provider, their journey to a diagnosis is not always straightforward. Typically, people will contact their GP practice and depending on the specific practice, they may be provided with an appointment with a GP, nurse, first contact practitioner physiotherapist (FCP) or adjacent role. There is variation in who the patient may speak to.

## Pain not taken seriously

Several people across the lived experience workshops felt that their pain was not taken seriously and nearly half of the people (48%) surveyed for the [Left Waiting, Left Behind](#) report felt their symptoms were underplayed during the diagnosis process.<sup>4</sup> This was particularly the case for women, younger people and those from lower socio-economic backgrounds.

Often women's symptoms were attributed to hormonal changes such as the menopause or thyroid-related issues. While joint pain can be a common symptom of menopause, it should not be used to dismiss additional symptoms that might warrant investigation, especially as women face increased risk of developing arthritis during menopause.<sup>37</sup>

Furthermore, research into patient experience, from symptom onset to a diagnosis of gout, highlights that women face delays in diagnosis due to atypical symptom presentation and lack of awareness of gout in women.<sup>30</sup> This is due to the assumption that gout is a condition only affecting men given the higher prevalence of men with gout.<sup>38</sup>

Several women also spoke about how their symptoms were attributed to their weight. Again, living with overweight and obesity can increase people's risk of developing arthritis.<sup>39</sup> Given this risk factor, it makes it especially important that people's symptoms are not dismissed.

Furthermore, the availability and accessibility of weight management services varies significantly across the UK.<sup>40</sup> This could mean that patients whose symptoms are attributed entirely to their weight are left without a diagnosis and left without support to lose weight to have their symptoms taken seriously.

## Constraints within primary care

It should also be noted that primary care colleagues face immense pressure, especially those working in deprived communities, who see a higher burden of patients with comorbidities and complexities. Primary care practitioners have to assess patients within a limited time slot, which adds additional pressure to the consultation and the practitioner. The RCGP report on [The GP workforce Gap](#) also found that patient need is not being met by the number of sessions that GPs are currently being employed to deliver.<sup>41</sup>

**MSK conditions account for up to 30% of GP appointments in England.**

(NHS England, 2021)



## The role of the multidisciplinary team in primary care

In recognition of the growing demands of MSK conditions on primary care, the role of FCPs was recognised as an important component of primary care delivery for MSK conditions.

FCPs are usually advanced physiotherapists who assess and treat people with MSK symptoms. They are also trained to recognise red-flag symptoms and refer patients appropriately. However, FCP physiotherapists are not available in all GP practices. NHS Wales is also developing a service model that aims to provide greater access to therapy services in primary and community care for people with MSK conditions, which may include FCP or similar roles.

On average, FCPs have 20 minutes of consultation time compared to a GP's 10 minutes. Furthermore, as FCPs specialise in treating MSK conditions, research has shown that FCP roles can contribute to reduced time to diagnosis.<sup>42</sup> FCPs improve patient outcomes, reduce demand on GPs, cut medicine prescribing, and reduce referral and testing.<sup>43</sup> While the NHS Long-Term Plan (2019) pledged that all adults in England with an MSK condition will have direct access to MSK FCPs by 2023/24, with a goal of having 5,000 FCPs by 2030, the latest figure from the Chartered Society of Physiotherapists (CSP) in 2023 only found the number of FCPs to be at 1,376.<sup>44</sup>

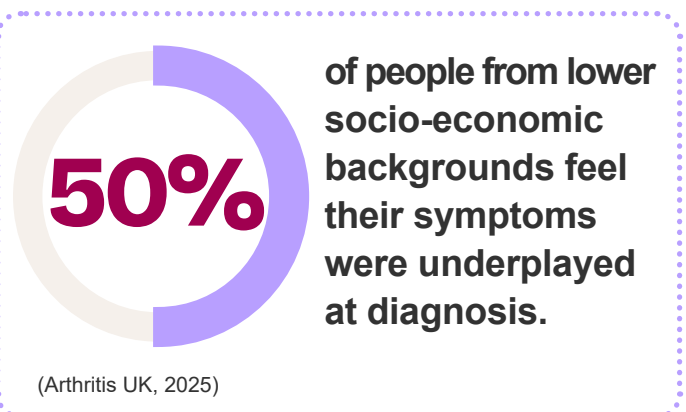
There may be a role for the multidisciplinary team either consisting of an FCP or adjacent role in the diagnosis pathway for people with arthritis, which could alleviate pressure on GPs. However, given the variation in availability of such roles and that patient expectation may still be to see a GP, it remains important for all

frontline health professionals involved in the diagnosis of arthritis to have the necessary knowledge and training to do so.

## Health inequalities: some experience longer delays

In *Left Waiting, Left Behind*, younger people shared that they were told they were 'too young to have arthritis', with 63% of younger adults between 18 and 44 reporting their symptoms were underplayed. Additionally, the report found differences based on socio-economic background, with 50% of those from lower socio-economic backgrounds feeling their symptoms were underplayed at diagnosis, versus 44% in those from higher socio-economic backgrounds.<sup>4</sup>

Other studies have also found that people from certain ethnicities can face longer GP delays, with one study finding this was due to non-white patients presenting with "atypical" MSK symptoms which can lead to misinterpretation by GPs.<sup>45,46</sup> Given the disparities highlighted in these studies, there is a need for further research on inequities relating to arthritis rates and experiences to better understand key barriers and effective interventions to address them. This is important, as diagnostic delay and poor diagnostic communication can act as early drivers of health inequalities,<sup>47</sup> shaping access to treatment, self-management support, employment adjustments and benefits long before formal care pathways begin.



# Inflammatory arthritis: primary care

Early diagnosis is especially crucial for inflammatory arthritis, as it can impact long-term outcomes.<sup>31</sup> The 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.<sup>48</sup> For people with suspected inflammatory arthritis, they require urgent referral to rheumatology, ideally within six weeks of symptom onset. However, the proportion of patients being referred by their GP to a rheumatology service within the national target of three working days in England and Wales is currently 53%.<sup>14</sup> Another UK-wide study found even more substantive delays in primary care for the diagnosis of rheumatoid arthritis, with a median GP delay of 6.9 weeks.<sup>45</sup> The study found that patients made a mean of 4 GP visits before being referred.

This data is consistent with the stories people shared in the lived experience workshops, as people spoke of multiple visits to the GP with inflammatory arthritis symptoms.

It is important to note that while gout is a form of inflammatory arthritis, it is usually managed and treated within primary care. People will typically only be referred to secondary care if the diagnosis is unclear or if septic arthritis is suspected. Problems with gout diagnosis including misdiagnosis and delayed diagnosis have also previously been noted.<sup>30</sup>

## The challenge of spotting early symptoms

In the lived experience workshops, the overwhelming picture was that recognition of inflammatory arthritis was down to luck and signs were missed or not recognised.

One participant shared their story of finally being diagnosed with suspected psoriatic arthritis by a locum GP after visiting their usual GP multiple times.

Stories like this demonstrate that it can be challenging for primary care professionals to recognise the signs of inflammatory arthritis. It's especially difficult given the different types of inflammatory arthritis and the fact that some patients don't present with typical symptoms. A study looking at the primary care challenges in diagnosing and referring patients with rheumatoid arthritis found that the main perceived challenges for primary care practitioners were the difficulties in recognising early symptoms of the condition.<sup>49</sup> Furthermore, the 2009 NAO report, examining the efficiency and effectiveness of services for people with rheumatoid arthritis in England, featured similar findings and recommendations to those in this report, highlighting how little progress has been made in rheumatoid arthritis care since then.<sup>27</sup>

Despite the challenges associated with recognising signs of inflammatory arthritis, a recent survey of undergraduate medical training found a decrease in dedicated rheumatology teaching time compared to a similar survey conducted 25 years prior.<sup>50</sup> Therefore, with more limited rheumatology exposure as part of medical training, health professionals are missing out on the specialist knowledge and training that would support them to identify signs of suspected inflammatory arthritis and best practice when there is uncertainty. Supplementary training and courses, such as those delivered by Arthritis UK, could be beneficial here to boost confidence and fill in any knowledge gaps.



## Feedback from health professionals: Arthritis UK training sessions

Arthritis UK sends out a pre and post survey to all health professionals undertaking our training sessions to measure the impact on their practice.

The data from 2024 to 2026 found that following training, there was an average improvement in the following areas:

**44%** ↑

**increase** in knowledge and understanding of the training topic.

**29%** ↑

**increase** in MSK examination skills.

**30%** ↑

**increase** in confidence in diagnosing patients with MSK conditions.

**31%** ↑

**increase** in confidence in providing treatment and support to patients with MSK conditions.

## What should training for health and care professionals include to support with arthritis diagnosis and care?



### Osteoarthritis

- ✓ Recognition of osteoarthritis symptoms.
- ✓ Effective communication of the diagnosis which avoids unhelpful terminology such as 'wear and tear', with a clear explanation of what osteoarthritis is.
- ✓ Discussing self-management options with holistic signposting to resources such as those produced by Arthritis UK, and onward referral to services as appropriate.

### Inflammatory arthritis

- ✓ Guidance on the signs of inflammatory arthritis and initiating urgent referral processes.
- ✓ Guidance on testing.
- ✓ Identify those who may not be appropriate for rheumatology, to help reduce rheumatology waiting times.
- ✓ Set up a working relationship with local rheumatology team and establish best practice triage and referral procedures, for example the use of Advice and Guidance.

## Improving time to diagnosis

Other factors which have shown to have a positive impact on referral times for suspected inflammatory arthritis include access to an Early Inflammatory Arthritis clinic where testing can be completed urgently, and a good relationship between primary care and rheumatology where primary care professionals are supported to make referral decisions. For axial spondyloarthritis specifically, NASS has developed a playbook which provides a 'best practice' approach to reducing the time to diagnosis and ensuring patients receive essential support when they are diagnosed.<sup>51</sup> The implementation of this playbook could make a big difference for the diagnosis of axial spondyloarthritis.

The Getting It Right First Time (GIRFT) [\*National Speciality Report on Rheumatology\*](#) has also identified the need for clearer criteria to support GPs, FCPs and allied health professionals (AHPs) working in primary care and community settings, on when cases should be referred and also when they shouldn't. Clearer criteria can result in rheumatology teams seeing a reduction in the backlog of patients who don't have inflammatory arthritis.<sup>15</sup> Arthritis UK welcomes this report, and more must be done to ensure implementation of the report's recommendations.

### Health professional perspective: findings from primary and community care survey



In our primary and community health professional survey, almost all respondents said they felt confident in spotting in the signs of inflammatory arthritis, but only a third (31%) said they felt very confident. Where there is uncertainty, specialist advice and guidance can be an important resource during diagnosis.

Three quarters (74%) of those surveyed said they had access to a clinical rheumatology service where they could access advice and guidance, with almost all saying they found the guidance useful. Of those who did not have access to such a service, the majority (80%) felt that it would be very useful to them in supporting patients with inflammatory arthritis. This demonstrates that primary care professionals value a good working relationship with rheumatology colleagues that allows them to sense-check suspected cases.

Referrals to early inflammatory arthritis pathways have been associated with reduced delays in diagnosis.<sup>52</sup> However, 4 in 10 (42%) of those surveyed did not have access to one. Instead, many referred directly to rheumatology but cited long waits for patients to be seen. Other barriers to timely diagnosis for inflammatory arthritis included access to blood tests, complex presentations, a lack of experience and knowledge, and strict referral criteria from rheumatology. ►

## Health professional perspective: continued



**When asked what they thought could improve the patient journey for people with inflammatory arthritis, primary and community care respondents suggested:**

- Rapid investigations, alongside early and accurate referral.
- Increased public awareness of common symptoms so patients feel empowered to advocate for themselves if they are suspicious of inflammatory arthritis.
- Further training and education to spot clinical signs of inflammatory arthritis.
- Improved collaboration between primary and secondary care.
- Reduced waiting times for rheumatology.



**People not taking it seriously... a lot of these conditions are what they call relapsing-remitting, flaring... conditions where they come and go. That makes it harder to get it taken seriously because you might be bad for a week or two. And then it goes away and they think, oh, well, you're all right now, doesn't matter. Don't need to think about it anymore.**

Lived experience workshop participant



**It just makes me sad that everyone goes through that length of journey to get the diagnosis.**

Lived experience workshop participant



**I actually reached out and I went to my GP several times throughout those years.**

Lived experience workshop participant



**Unless you just happen to stumble across somebody who will take you seriously... they're just not putting the whole picture together.**

Lived experience workshop participant

# Osteoarthritis: primary care

For most people, osteoarthritis can be diagnosed and managed in primary and community care. However, many people with osteoarthritis tell us that getting a diagnosis and accompanying support can be difficult. While there are NICE guidelines on the diagnosis and management of osteoarthritis, these are not always being implemented, especially around the information and support people receive.<sup>16</sup> This was previously highlighted in the *[Not Just 'a Touch of Arthritis'](#)* report.

Additionally, in the lived experience workshops, people with osteoarthritis expressed that they were not always given a clear diagnosis. One person was told they 'probably have osteoarthritis' or were given the generic label of arthritis. In some cases, people were told they have 'wear and tear', reinforcing the false belief that osteoarthritis is an inevitable part of ageing and that nothing can be done.<sup>53</sup>

## The 'label' of osteoarthritis

Several people with osteoarthritis in the lived experience workshops spoke about having to see their health professional multiple times, as they didn't have clarity on why they were experiencing symptoms such as pain and stiffness. Or they had received a generic descriptor of 'arthritis' without additional information. A research study involving participants with knee osteoarthritis found dissatisfaction with the vague information they received, with the lack of precision in explanation being perceived as both a lack of interest and knowledge on the part of the health professional.<sup>53</sup>

In some cases, based on clinical judgement, a health professional may determine that it is not appropriate or helpful to label someone with osteoarthritis. However, for those who are struggling with symptoms or have underlying

risk factors (such as overweight and obesity and limited physical activity) that may put them at risk of developing or worsening symptoms, a formal diagnosis accompanied by clear information and guidance can be beneficial to support proactive disease management. NICE guidelines recommend tailoring information for people with arthritis to their individual needs and advising people on where they can find further information on their condition that challenges common misconceptions.<sup>54</sup>

Additionally, given the increased risk of people with osteoarthritis living with or developing multiple long-term conditions, it can be beneficial for people to know they have osteoarthritis as part of their overall health management. The presence of any long-term condition is associated with a drop in quality of life, but when arthritis or back pain is present as one or more of the long-term conditions, the drop is greater.<sup>55</sup> The pain and functional limitation of arthritis make it harder to cope when living with multiple long-term conditions. Simple everyday tasks such as grasping small objects or standing and sitting can be more difficult with arthritis. Unless specifically addressed, the associated disability commonly stops people with multiple long-term conditions from being able to manage their own health and maintain independence.

**When arthritis or back pain is present as one or more of the long-term conditions, the drop in quality of life is greater.**

(Arthritis UK, 2017)



## Health professional perspective: findings from primary and community care survey



When diagnosing osteoarthritis, most of those surveyed used the term as part of the diagnosis conversation, with half (49%) always using the term and a third (33%) using 'osteoarthritis' often.

We asked those who preferred not to refer to the term 'osteoarthritis' during the diagnosis conversation, why they preferred not to use it. They mentioned not wanting to overly medicalise a largely natural process, referring to age-related changes instead. Interestingly, they also described how osteoarthritis was a poorly understood term in society and they therefore need to manage patient perceptions and expectations.

## The framing of osteoarthritis

As evidenced in the primary and community care survey, some health practitioners prefer not to use the term 'osteoarthritis' due to concerns around overmedicalisation or providing the patient with a label of a chronic condition. Therefore, at the first appointment, it is important to assess patient severity and choose the language accordingly when delivering a diagnosis. If the diagnosis is accompanied by an explanation of osteoarthritis that focuses on management, a clear plan of action, and on the person's needs – an osteoarthritis diagnosis can be reframed. It does not have to be a chronic label that causes the person with arthritis worry, but it can empower them to understand their condition and management. There is also some evidence that the type and quality of care

people receive may differ depending on whether they have been diagnosed with osteoarthritis or joint pain. This is potentially due to perceived differences in disease in patients with an osteoarthritis diagnosis, demonstrating the importance of the diagnostic label.<sup>56</sup>

## Clinical diagnosis of osteoarthritis

One of the reasons why a health professional may be hesitant to make and record a diagnosis of arthritis is anxiety linked to best practice guidelines that recommend against using X-rays or other scans to make a diagnosis.<sup>16</sup> Instead, guidelines emphasise the importance of the clinician listening to the person describing their symptoms and then examining the affected joint. In some cases, health professionals may not feel sufficiently confident to make accurate diagnoses based on clinical examination alone.<sup>57</sup> Therefore, supplementary training through a short course, such as those provided by Arthritis UK, could be helpful to outline best practice in diagnosing and managing osteoarthritis, and subsequently strengthen clinical confidence.

There is also an element of patient expectation that health professionals are navigating, particularly where people may request imaging and feel uncertain with a clinical diagnosis alone. Additionally, in early disease an X-ray may be normal even if they are experiencing symptoms of osteoarthritis, which can be confusing for patients. Shared decision-making is therefore a key part of the response, enabling clinicians and patients to explore concerns, expectations and diagnostic reasoning together. When combined with clear education and signposting to relevant osteoarthritis resources, this approach can help people better understand how osteoarthritis is diagnosed and feel more confident in agreed management plans.

## Health professional perspective: findings from primary and community care survey



In our primary and community health professional survey, the majority of respondents felt confident diagnosing people with osteoarthritis clinically without the need for a scan; 52% felt very confident and 37% felt somewhat confident. This confidence may however be reflective of the demographic of respondents, as 75% had previously engaged with Arthritis UK through our health information offering and 42% had completed our training aimed at health professionals. Therefore, respondents represent health professionals with an interest in MSK health and those who are familiar with best practice.

**When asked about barriers and challenges faced when diagnosing osteoarthritis, respondents shared the following:**

- Accessing further tests and the ability to rule out alternative diagnosis.
- Considering a holistic view of the patient, taking into account other conditions and their lifestyle.
- A lack of training around osteoarthritis diagnosis.

The most common barrier that health professionals mentioned was dealing with patient expectations. Patients often expect a scan and can be reluctant to receive a diagnosis on clinical examination alone.



# The need for improved MSK data in primary and community care

The way osteoarthritis is diagnosed and subsequently recorded in primary care has implications for public health. Data in primary and community health records for MSK conditions, particularly osteoarthritis, is poor. Even when a person has a typical cluster of osteoarthritis symptoms, it may not be recorded as osteoarthritis and instead be recorded as 'joint pain'.

Better coding of osteoarthritis in primary and community care would provide better data that can help determine what support and treatments patients are getting and importantly, what they may not be accessing. The lack of complete and accurate coding can make it difficult for commissioners to understand the needs of their local populations, plan effectively, or target health improvements at people with osteoarthritis.

The inconsistent and poor recording of osteoarthritis is one part of an overarching issue with data on MSK services. Data collected and analysed on community MSK services is inconsistent and of a highly variable quality, which limits the ability to understand demand, capacity, and outcomes for people with MSK conditions (and where unwarranted variation exists). For inflammatory arthritis, there is the NEIAA which provides consistent, high-quality and accessible data from England and Wales. It has helped drive quality improvement and allows us to measure progress on key metrics, including access to treatment, and remission.

**However, there is no comparable database, audit or improvement programme for MSK conditions including osteoarthritis, which**

**are primarily diagnosed and managed in primary and community care.**

A UK-wide data collection and MSK audit for primary and community care would significantly improve understanding of the quality of MSK service provision and would improve transparency and accountability of providers and commissioners around access, delivery and outcomes achieved for community services.

There is also a strong case for widening the types of data we seek and value, via expansion of national PROMs and PREMs (Patient Reported Outcome and Experience Measures programme). Data collection should not just be focused on inputs and processes but also outcomes, including patient-reported outcomes. This could also include data capture on experiences of diagnosis. Experience data will enable local systems to invest in the areas that are of most value to patients.

Additionally, joining up and linking data across MSK care pathways is essential for improving coordination and evaluation of care delivered across multiple healthcare settings. MSK conditions are frequently managed across primary care (GP practices), community based MSK services (such as physiotherapy), and specialist secondary care services (such as orthopaedics, rheumatology), making integrated linked datasets important for understanding patient journeys, service utilisation and efficiency, and variations in outcomes and experiences. This information is vital to support evidence-based service planning, delivery and improvement.

# Delays in secondary care: inflammatory arthritis

Individuals with suspected inflammatory arthritis should receive their first rheumatology appointment within three weeks of referral from primary care.

However, in the latest data from the NEIAA, only 43% of patients receive their first rheumatology appointment within three weeks.<sup>11</sup> While NEIAA data only covers England and Wales, we know that people in Scotland and Northern Ireland also face delays. For example, in Scotland at the end of December 2025, only 21% of new outpatients were seen in under four weeks for rheumatology services.<sup>58</sup> As part of our [\*From Breaking Point to Recovery: Prioritising Musculoskeletal Healthcare in Northern Ireland\*](#) report reflecting on MSK services in Northern Ireland, our research found lengthy waiting lists, with some patients waiting nearly eight years.<sup>59</sup>

Similarly, in the diagnosis lived experience workshops, people reported delays in obtaining their first rheumatology appointment. Those who could afford to, turned to private rheumatologists due to the length of the wait, highlighting another component of inequitable access.

This also highlights the cumulative delays that people with inflammatory arthritis are facing when they enter the health system, beginning

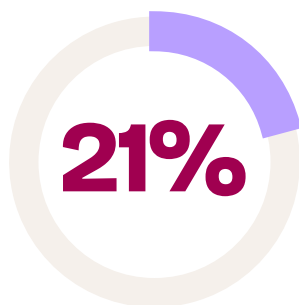
at primary care where they may have to wait for tests, require repeat visits, and then continue to face long waits following referral.

## Improving time to first rheumatology appointment

Within secondary care, several factors have been found to have a bearing on the provision of good quality early inflammatory arthritis care. This includes availability of an early inflammatory arthritis clinic which provides access to tests and triaging and availability of rheumatologists and staff capacity.<sup>60</sup> Additionally, more effective referrals from primary and community care could ensure rheumatology services are not overburdened with patients who do not have inflammatory arthritis and who can instead be managed in primary and community care. The *From Breaking Point to Recovery* report covering Northern Ireland found that there was considerable concern within rheumatology about the number of referrals received, including patients with non-inflammatory conditions such as fibromyalgia.<sup>59</sup>

At the end of 2025, only **21%** of new outpatients in Scotland were seen in under four weeks for rheumatology services.

(Public Health Scotland, 2025)



“ ”

Longest delay was seeing [the] rheumatologist in [the] first place.

Lived experience workshop participant

## Health professional perspective: findings from secondary care survey



When asked about the impact of Advice and Guidance services, secondary care respondents had mixed feelings, with some sharing that it had “negatively impacted in terms of additional workload for consultants” and “it is very time consuming and not adequately recognised in job planning”. While others said “through Advice and Guidance we avoid having to see in person approx. 30 to 40% of referrals” and that it had a “positive impact in terms of rapid answers to GPs with queries”. This feedback from secondary care health professionals shows how increasing primary care confidence in spotting signs of inflammatory arthritis alongside the proportionate use of Advice and Guidance needs to go hand in hand.

We also asked secondary healthcare professionals how they believed the diagnosis pathway could be improved. They suggested, “better GP education to reduce non-inflammatory arthritis referrals which would reduce waiting times”, “national standardised referral criteria” and “increase the time to review/diagnose as there is no funding or capacity to meet current targets”.

## Communication while people wait for a diagnosis

A diagnosis is an iterative process, and this is especially the case for inflammatory arthritis, where rheumatology teams try to pin down what type of arthritis someone has. In the lived experience workshops, people highlighted confusion around changing diagnostic labels. During the investigation process, it can be beneficial for people to receive communication around what the process may involve, potential timelines and an explanation of any uncertainty such as the type of arthritis someone might have. This could support people in feeling more empowered during the diagnosis process.



**One of the problems with these conditions is that they are really hard to diagnose because there isn't a single test.**

Lived experience workshop participant



**The diagnosis and the prognosis took quite a long time to be established. And initially, they said rheumatoid arthritis... when I visited a different doctor in Australia, they changed it. They say it's osteoarthritis...It took quite a long time to quite establish what kind of arthritis it is.**

Lived experience workshop participant

## Chapter conclusion:

The importance of an early diagnosis cannot be understated, especially for inflammatory arthritis where it can determine long-term outcomes and even remission. For osteoarthritis, an early diagnosis can mean supporting the person to manage their condition and even help prevent the need for more serious intervention such as joint replacement surgery, or having to visit their health practitioner multiple times to receive the clarity and care they need. There are delays at each stage of the diagnosis pathway that need addressing, beginning when people first start experiencing symptoms, through primary care and into secondary care for people with inflammatory arthritis. The longer it takes for people to get a diagnosis, the greater the risk to their physical and mental health. An early diagnosis can save people from months or even years of struggling alone and increase the likelihood of them getting the support they need.



## What needs to happen

**Establish public health strategies to improve recognition of arthritis symptoms in the general population to reduce delayed initial presentation to health professionals.**

**Stakeholders:** All four UK health departments, public health agencies, local health service providers, local health commissioners, voluntary sector.

**Implementation:**

- ✓ Health departments across the UK should fund national health campaigns to raise awareness of the symptoms of arthritis, including the importance of prompt early treatment for inflammatory arthritis.

**Organisations involved in developing medical education should strengthen MSK content and encourage training that improves health professionals' ability to diagnose and care for people with arthritis.**

**Stakeholders:** Organisations and professional bodies representing health professionals and agencies responsible for medical education and training.

**Implementation:**

- ✓ All frontline primary and community care staff are offered accredited training courses that give them the knowledge and skills they need to confidently diagnose and treat osteoarthritis and recognise suspected inflammatory arthritis.
- ✓ The inclusion of MSK training in undergraduate and postgraduate medical training is improved to better reflect the burden and prevalence of MSK conditions including arthritis.



# What needs to happen

**All four UK health departments to ensure improved data on MSK conditions in primary and community care.**

**Stakeholders:** All UK health departments.

**Implementation:**

- ✓ National organisations with responsibility for the collection, analysis and publication of health data should develop and implement a plan to improve the coding of osteoarthritis in primary care.
- ✓ A fully funded national MSK audit in primary and community care to drive equity and improvement in MSK service provision, with a focus on quality and outcomes that are important to patients.
- ✓ Local health systems should collect better and standardised data to understand the drivers of diagnostic health inequalities in particular population groups and identify targets and mechanisms for improvement.
- ✓ Local health systems should expand PROMs and PREMs (Patient Reported Outcome and Experience Measures programme) to widen the data we seek to include outcomes (including, crucially, patient-reported).



# What needs to happen

**Governments and health systems to prioritise the timely diagnosis of early inflammatory arthritis so that everyone can access treatment and slow the progression of the condition.**

**Stakeholders:** All UK governments, health departments and local health systems and commissioners.

## Implementation:

- ✓ Health departments to produce guidance to ensure timely treatment of early inflammatory arthritis and minimise regional disparities in care delivery.
- ✓ Health departments to ensure improved working and partnership between primary care and rheumatology units to improve local pathways and ensure that the right patients are being referred to secondary care.
- ✓ Health departments to ensure sufficient staffing in rheumatology clinics to enable early diagnosis and access to allied health professionals (such as physiotherapists, occupational therapists, psychologists) who can provide patient education and support following a diagnosis.
- ✓ Widespread implementation of the Getting it Right First Time (GIRFT)/ National Axial Spondyloarthritis Society (NASS) National Playbook on Axial Spondyloarthritis within Primary Care.
- ✓ NEIAA dashboard data should be used to support rheumatology departments and specialist centres to pinpoint unwarranted variation, track improvement over time and inform planning and investment. (England and Wales)



# What needs to happen

**Arthritis UK calls for the full and consistent implementation of NICE osteoarthritis guidance across all NHS settings in England, Wales and Northern Ireland and for the development of equivalent guidance in Scotland.**

**Stakeholders:** All UK health departments and local health systems.

## **Implementation:**

- ✓ This should be supported through audits by integrated care boards (ICBs), health boards and health and social care trusts, assessing adherence to guidelines including routine assessment and effective management of pain and function for people with an osteoarthritis diagnosis. Audits should also identify differential experience, provision and outcomes among groups disproportionately affected by health inequalities, to ensure equitable, evidence-based osteoarthritis care for all.
- ✓ In Scotland, development of an osteoarthritis pathway should be included in the Modernising Patient Pathways programme at the Centre for Sustainable Delivery.
- ✓ In Wales, work should continue to develop Osteoarthritis Community Health Pathways of Care.
- ✓ In England, the Getting It Right First Time (GIRFT) programme should continue to be supported to enable systems and providers to deliver the best evidence-based treatment across the whole pathway of care, to enable best outcomes.
- ✓ In Northern Ireland, the Department of Health (DoH) in collaboration with clinical leads, must ensure consistent patient pathways for treating osteoarthritis through effective diagnosis, triage and referral.



# Val's story

Pembrokeshire, Wales



It has been an incredibly difficult process receiving a diagnosis and treatment, even following a private route. There are many hurdles to overcome at a time when you feel unwell and very vulnerable.

My hands started swelling in July 2024 and I did wonder if it was rheumatoid arthritis because my mum had it.

The GP sent me to A&E who did blood tests and sent me home with gout medication. Within two weeks every joint was inflamed and painful, it was frightening and really knocked me off my feet.

I already had a private health assessment booked and, after tests, the doctor said it sounded like rheumatoid arthritis, so I went back to GP who agreed but explained he couldn't do anything until I'd been diagnosed by a rheumatologist and the waiting list was 12 to 15 months long.

I knew I couldn't wait that long in extreme pain. Fortunately, I had savings, so I found a private rheumatologist which was a nine week wait. By that point I could barely get out of bed and cried every day. It was quite a dark time for someone who is usually very positive and proactive. That's when I found Arthritis UK online and started doing their exercises which were a tremendous help, the only help I had at that stage.

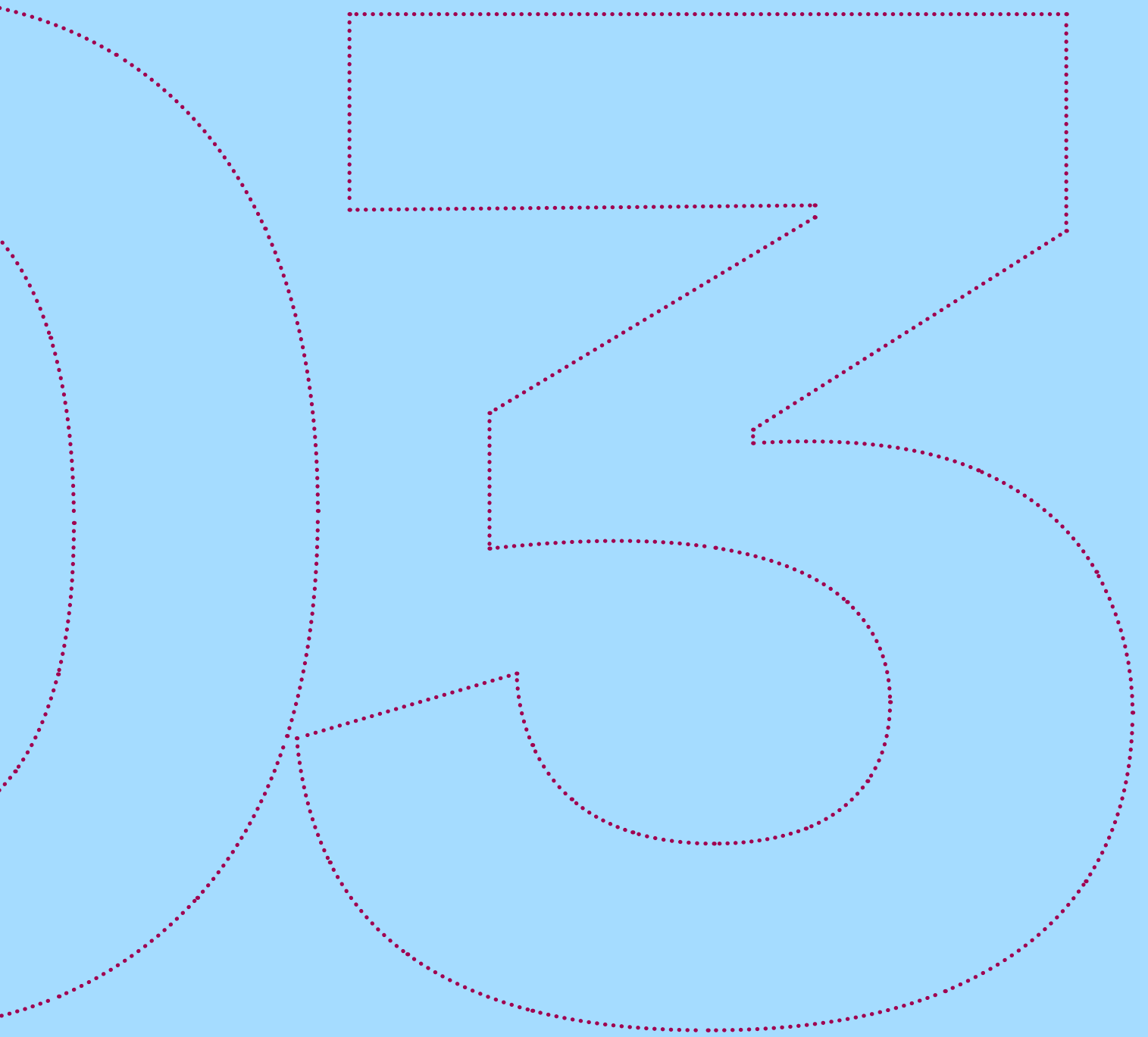
The private rheumatologist diagnosed rheumatoid arthritis within minutes then



aspirated and injected both knees and prescribed methotrexate which I had to pay for, then I went back to my GP who was very supportive. They had to add hydroxychloroquine which worked well enough with the methotrexate to get me back on my feet but, by July 2025 both knees were totally destroyed.

I knew it would be another long wait for a referral so the private rheumatologist referred me to a private orthopaedic surgeon and I had my left knee replaced in October 2025 and my right in February this year which cost £30,000. My savings are gone but, at 71, I didn't know how many years I had left and don't want to be in pain and unable to walk while on an NHS waiting list. This March my NHS rheumatology appointment finally came through, 20 months later, and I now have support.

The biggest surprise for me has been the blocks put in place by bureaucracy. We knew within weeks what we were dealing with, but I couldn't get support without a very long wait which was really frustrating. It's been a real journey, and I think you have to be mentally tough to keep pushing, keep going. I'm sure there are people who must feel like giving up but I want to encourage them that there will be a way through.



**More than just a label:  
personalisation, shared  
decision-making and  
holistic care**



**The identification of the condition and the diagnostic label is important for people with arthritis but represents only one part of the diagnosis process for them.**

This chapter focuses on the components of the diagnosis conversation and accompanying early information and care that people with arthritis have identified as important to improve the experience of receiving a diagnosis.

# Processing the diagnosis

In the lived experience workshops, people described how a diagnosis can provide clarity and relief, as it explains what has been causing their symptoms. However, people also highlighted that it can be overwhelming to come to terms with having a long-term condition. There was a consensus that there was not enough time during the consultation to process the diagnosis, ask questions and discuss a plan or what the future might look like.

Participants shared deeply emotional stories about the impact of their diagnosis on their identity, including fears around having to give up activities that were important to them.

Better communication around diagnosis is a key principle in the National Voices' [\*Our vision for improving patient experience of diagnosis\*](#) report.<sup>61</sup> It highlights the importance of adequate time and space to ask questions during the diagnosis appointment and afterwards.

## Good practice example:



A lived experience participant who shared their positive diagnosis experience, explained this was because the diagnosis was well articulated and based on an assessment of their needs. Following their diagnosis, they were referred to physiotherapy and podiatry. Additionally, they were given the contact number for a rheumatology nurse in case they had any further questions, giving them the opportunity to learn more about their condition, medicines and self-management.



# Impact on mental health

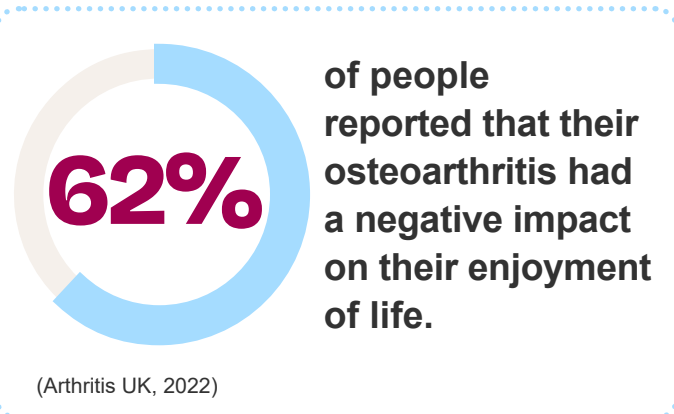
When people receive their diagnosis, they may not just be presenting with physical deterioration. They may often be struggling with other aspects of their wellbeing such as their mental health. According to NEIAA, between 2023-2024, 60% of patients had probable depression or anxiety at the time of diagnosis.<sup>11</sup> Similarly, the *From Breaking Point to Recovery* report in Northern Ireland which included osteoarthritis and inflammatory arthritis, found that people had developed mental health conditions while waiting for a diagnosis and treatment.<sup>59</sup>

Several participants across the inflammatory arthritis workshop highlighted that following a diagnosis, they would have appreciated the additional opportunity to discuss their mental health alongside the focus on getting them on medicines.

We also know that people with osteoarthritis can face similar struggles with their mental health.

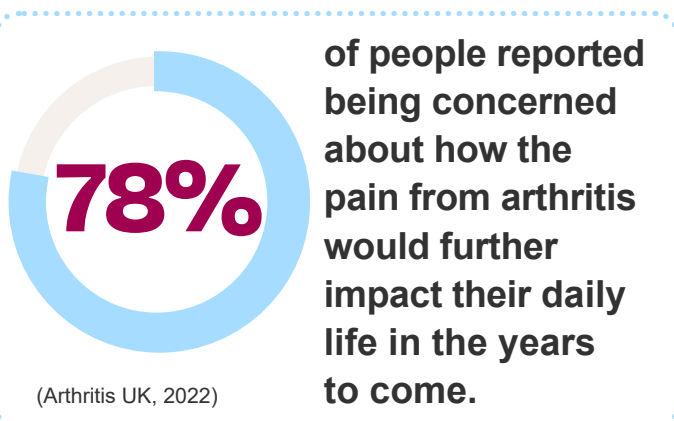
The *Not Just 'a Touch of Arthritis'* survey found that 62% of people reported that their osteoarthritis had a negative impact on their enjoyment of life, and 45% reported that their osteoarthritis negatively affected both their levels of anxiety and overall mental health. People were also worried about the future: 78% reported being concerned about how the pain from their arthritis would further impact their daily life in the years to come.<sup>57</sup>

This underlines the need for a holistic approach that factors in what people are struggling with at the point of diagnosis, including their mental health. Giving people the space to discuss their mental health could improve the diagnosis experience. Depending on need, they can then be signposted or referred to mental health services, which can play an important role in the overall management of their wellbeing.



**They treat the symptom but don't treat anything else. Not one question asked about how [it was] affecting [me] mentally, never been asked about physio. No compassion and support there.**

*Lived experience workshop participant*



**Think it was quite clear my mental health wasn't great, but that was never really discussed. It was well, you know, we'll get you on this treatment and these meds should do the thing that should help.**

*Lived experience workshop participant*

# Developing a care plan: personalised information and shared decision-making

Every person's needs at the point of diagnosis, and what they may need support with, will differ. Therefore, a care and support plan developed by a health professional, in partnership with the person with arthritis, can encompass all the key elements of their care that are important for them. This could cover mental health support and other elements such as pain relief, physical activity, self-management and treatment options.

Based on what people told us across the lived experience workshops, it's clear that people want a plan of the road ahead to navigate their treatment options. This should include signposting or referral to additional services based on a personalised discussion of their needs. People would also benefit from signposting to wider information around employment and social care and information on peer support in the community.

However, many people with arthritis aren't receiving the holistic information and support they need. Only 50% of people responding to the *Not Just 'a Touch of Arthritis'* survey, covering osteoarthritis, felt that a clear approach to treatment had been communicated to them in a timely way.<sup>57</sup> Additionally, the survey found that while 84% of patients had been prescribed or recommended oral relief medication, only 52% had been recommended exercise and only 42% had been recommended to change their diet or eat more healthily.<sup>57</sup> This is despite NICE guidance recommending exercise, weight management and information and support as core treatments for osteoarthritis.<sup>54</sup> The narrow focus on medication-based pain relief misses the opportunities to understand the overall impact of osteoarthritis on

a person's life and to address key risk factors that can improve symptoms and disease progression. One of the ways of rebalancing care so people have greater choice and control over their care and what matters to them, is through 'personalised care'. In the Government's 10 Year Health Plan for England, personalised and person-centred care features as a key component.<sup>62</sup> It acknowledges that good self-care depends on having the right knowledge, skills and support.<sup>63</sup>

For gout, the benefits of urate lowering therapy (ULT) are well-established to prevent long-term joint damage as outlined in the NICE guidelines.<sup>64</sup> However, a previous study found that ULT usage remains suboptimal.<sup>65</sup> Providing people with tailored information on gout alongside explaining benefits of ULT could support with adherence, as people would better understand the importance of preventative treatment from the outset following a diagnosis.



**What people need varies from person to person.**

*Lived experience workshop participant*



**British doctors just say arthritis [whereas] I got a care plan in Australia.**

*Lived experience workshop participant*

# Delivering patient centred care: the key role of health professionals

Health professionals in primary care and community services have a critical role to play in delivering and improving standards of care for people with MSK conditions. To effectively deliver personalised care, it is important that primary care professionals have the training to support them to do so. This includes training in shared decision-making to enable meaningful conversations about diagnosis, prognosis, uncertainty and management options, and to support people to feel informed, confident and involved in decisions about their care.

## What is shared decision-making?



Shared decision-making is a key component of personalised care and part of the process of establishing a care plan. Shared decision-making ensures that individuals are supported to make decisions that are right for them, through a collaborative process between clinician and patient.<sup>66</sup>

As part of shared decision-making, decision support tools can support people to work in partnership with their health professionals to develop a care and support plan and make informed choices about their care. Arthritis UK has developed a suite of decision support tools for people with back and shoulder pain, and hip and knee pain (mainly caused by osteoarthritis) that can be used to facilitate such discussions and decision-making.<sup>67</sup>

A holistic approach is needed for the care and management of osteoarthritis, and busy health professionals must also be equipped to connect people to relevant resources, services and assets within their communities. These may include exercise and physical activity programmes, pain management support, peer support groups and local swimming or hydrotherapy facilities (where available), all of which can help improve health outcomes, wellbeing and people's sense of empowerment in managing their condition.

## Getting it Right First time (GIRFT) Further Faster Community MSK Services Handbook



In England, GIRFT's community MSK workstream has produced a handbook with checklists and resource links to help drive improvements to commissioned community MSK services. It includes links to decision support tools, relevant guidance and patient resources that can support health professionals to care for people with arthritis, including those newly diagnosed.<sup>68</sup>

# Availability of the multidisciplinary team

The multidisciplinary team plays a key role in delivering personalised care to people with arthritis. However, there are issues around the availability of such teams across primary and secondary care.

For example, the British Society for Rheumatology's workforce report has highlighted issues relating to the provision of specialist rheumatology nurses and psychology and physiotherapy services with expertise in managing inflammatory MSK conditions.<sup>69</sup> The latest NEIAA found that only 14% of rheumatology services have access to rheumatology-specific psychology.<sup>14</sup>

Increasing access to and availability of multidisciplinary teams is an important part of ensuring people have the best possible start when they are newly diagnosed. The European Alliance of Associations for Rheumatology (EULAR) also note the importance of the multidisciplinary team in the implementation of self-management strategies and also the importance of a holistic, patient centred approach that could result in improved patient experience of care and outcomes.<sup>70</sup>

Primary and community care teams, including physiotherapists, pharmacists and social prescribing link workers can also play an important role in supporting the varied needs of people with arthritis. This report previously highlights the role that first contact practitioners can play, but there is great variation in their availability. Additionally, the [\*From Breaking Point to Recovery\*](#) report also found that many GPs still do not have access to multidisciplinary teams.<sup>59</sup>

Alongside access to the multidisciplinary team, there are also issues when accessing community MSK services. This means that even if newly diagnosed people are being referred to services as part of multidisciplinary care, they may face delays in accessing such services. In England, community MSK services have the highest of all community service waiting lists.<sup>71</sup> Therefore, as part of delivering multidisciplinary and holistic care, ensuring timely access for people who are newly diagnosed is key.



## Health professional perspective: findings from primary and community care survey



### Osteoarthritis

#### Areas health professionals felt the diagnostic pathway could be improved included:

- Improving patient understanding of the condition and increased public awareness of how to manage it.
- Further education for clinicians around terminology, creating a more positive outlook on diagnosis and promoting empowering language.
- Improved resourcing of staff within primary care and ensuring they have the skills and time available to fully inform and support patients at diagnosis.
- Increased emphasis on early diagnosis and prevention among health professionals and the public.

- Improved access to holistic services such as physiotherapy, joint pain programmes and weight management services, including reducing waiting times for these services.
- Focusing on a community-based approach to diagnosis and support.

It's clear that primary care professionals want to provide people with osteoarthritis personalised care and access to holistic services, yet they are restricted in the current system. Where there are FCPs integrated into the GP practice, there may be more time and specific knowledge to support patients, however, the availability of FCPs is varied across the country. Additionally, access to many services is hampered by waiting times making it difficult for health practitioners to ensure patients are getting the support they need.

### Good practice example:



In Wales, the Multiprofessional Musculoskeletal Capability Framework for Primary Care was produced to set out the vision, ambition and approaches that are needed to provide high standards of care for people with MSK conditions across Wales.<sup>72</sup> The framework recognises the importance of care planning through shared decision-making that is aligned to meet the identified needs, wants and values of the individual, setting out capabilities for health professionals to deliver these needs. The implementation of this framework could ensure that people with osteoarthritis can better understand their condition and ways to reduce its impact on wider aspects of their life.



**Health professionals need to work together for a holistic and multidisciplinary system and have a proper care plan.**

Lived experience workshop participant

# The role of physical activity and movement

In the lived experience workshops, people spoke about their fear of movement or engaging in physical activity when they were experiencing symptoms in the lead up to their diagnosis. The fear of exacerbating pain or causing further damage to joints prevented people from engaging in physical activity. This is worrying given that engaging in physical activity can reduce people's risk of developing an MSK condition or for those who already have one, help to manage their symptoms.<sup>73</sup>

For osteoarthritis, physical activity and movement are part of core treatment and management.<sup>74</sup> But for people to confidently and safely engage with physical activity, they need the information and support to do so, and this must be communicated to them early on following a diagnosis. For rheumatoid arthritis, physical activity can improve disease-related manifestations such as fatigue as well as systemic outcomes such as reducing the risk of cardiovascular disease.<sup>75</sup> This is why it is critical health professionals feel confident to have these conversations around physical activity. For some people, signposting may not be sufficient to combat their fear, and they may require more direct support. Therefore, there should be different routes available to increase physical activity that are accessible to a wide range of physical capabilities. The availability of a range of programmes and services would also instil greater confidence in health professionals to discuss physical activity as they can then refer and signpost to appropriate support.

The Richmond Group's, *Millions more moving* report, also found that health professionals do not always feel confident or prepared to have conversations about physical activity with patients.<sup>76</sup> A positive development in this space is Moving Medicine, which is a resource designed to help health professionals integrate physical activity conversations into routine clinical care.<sup>77</sup> The report highlights the importance of equipping health professionals with the skills and confidence to support people with long-term conditions such as osteoarthritis to move more.

Engaging in physical activity can **reduce risk** of developing an MSK condition or help to manage symptoms.



(Arthritis UK, 2025)



**Great loss in life when it came to sports.**

*Lived experience workshop participant*

## Chapter conclusion:

Diagnosis should be more than just receiving a label. People need a personalised conversation that factors in their needs and sets them up for the road ahead, as they process being diagnosed with a long-term condition. People may need signposting or referral to a range of services, given the wider impacts of arthritis on people's lives such as on their mental health. Health professionals need the appropriate training and education to enable them to have effective diagnosis conversations. There also needs to be effective provision of multidisciplinary services and sufficient availability of Allied Health Professionals (AHPs) to deliver the wraparound support that people with arthritis need to thrive.



# What needs to happen

**Local health systems to ensure people with arthritis are receiving personalised information, signposting and support to manage their condition as part of the diagnosis pathway.**

**Stakeholders:** Local health systems.

**Implementation:**

- ✓ Ensure that a diagnosis of arthritis includes signposting to information and resources that can support them to understand their condition and ability to self-manage.
- ✓ Ensure people are being signposted to mental health support, as appropriate.
- ✓ Ensure that at the point of diagnosis people are made aware of the benefits of physical activity and staying fit and are supported to do so.
- ✓ Ensure people with arthritis are being offered a care plan, developed in partnership with the individual and aligned to local pathways of care. It should support them to understand and manage their condition and should review the impact on their physical and mental health and their general wellbeing.



# Pat's story

Belfast, Northern Ireland



I started getting pain in my left knee around 20 years ago but it went away, then, four years ago, it started again and became worse and worse. About three years ago I went to the doctor and an x-ray showed I had arthritis in my knee.

I was given painkillers and put my name down for the physio. It was nine months before I had an appointment, he gave me exercises then, the following week, said it would be our last appointment. I was really shocked and felt I'd just been left to it.

Ultimately it cost me my job as work became harder and I retired in April 2024, even though I felt I'd so much more to give, which left me feeling useless and wondering what my life was going to be.

Finding Arthritis UK gave me my life back, they showed me an understanding and compassion I'd not had from anyone else. I did a pain management course, was given information, support, and put in contact with people who felt like I did.

I now volunteer for Arthritis UK which makes me feel fantastic because I'm giving back. If a doctor had just handed me a business card for Arthritis UK I would have had help earlier and could maybe have kept my job. Nobody has ever really told me what kind of arthritis I have, or given me a full diagnosis which has massively impacted my life. I was very low and at times felt so depressed, like life was over for me. There was such a lack of information. If someone had just taken a few minutes rather than assuming I knew where to start with researching myself, just a few minutes to tell me, to explain different types of arthritis and the effects. It really is an awful thing to just assume. Not providing people with a clear diagnosis, information and support really takes away their freedom. I don't want anyone to be where I was.





**What could a  
diagnosis unlock?**



**Diagnosis is a crucial step in unlocking the right information and support. In the lived experience workshops, people spoke about the importance of diagnosis and the sense of validation it provides.**

Validation is important not just for people's psychological wellbeing but also in empowering people to look for and apply for the wider support they need. A formal diagnosis, with a name and clearly communicated information, equips people with the language and confidence they need to speak about their condition, explain how it affects them and help them to articulate their needs.

People reported that receiving a diagnosis enabled them to access support such as workplace adjustments and benefits like Personal Independence Payment (PIP), which for many improved their quality of life and independence. However, others continued to face barriers even after receiving a diagnosis. These challenges often stemmed from limited understanding of arthritis among employers and benefits assessors, as well as application

processes that do not reflect the fluctuating nature of the condition. This reinforces the need to improve awareness of arthritis, ensuring eligibility processes are fair, informed and responsive, so that people can access the support they need following a diagnosis.

Furthermore, it's not always clear to people what wider support is available for them. Providing personalised signposting at, or shortly after, diagnosis is therefore essential. The health professional does not have to be an employment or benefits expert, but engaging in simple signposting, such as to the Arthritis UK website, can unlock a range of information and support including on work and benefits. Access to these resources could make a big difference to someone's ability to work or access information about financial support.

# Employment support

Arthritis UK's *Left Waiting, Left Behind* report revealed that 50% of people living with arthritis said that arthritis had impacted their ability to work in some way, with stopping work reported as the biggest impact of having arthritis (39%).<sup>4</sup> These findings were echoed in the lived experience workshops, with several participants also sharing positive experiences around employment support. For example, people highlighted that they were offered adjustments, such as more time to work at home and ergonomic equipment, after they spoke to their employer about their condition. Having a formal diagnosis gave some people greater confidence to initiate discussions around work-related adjustments and support, as they could refer to a named condition and were able to develop a better understanding of what can support them to manage their condition.

While a diagnosis can empower some people to request adjustments at work, depending on the employer, this is not always guaranteed. Many people with arthritis remain unaware or feel unclear about their workplace rights, despite a diagnosis. Therefore, there remains a need for better signposting for people at diagnosis, to enable them to access the information that can support them to better understand their condition and advocate for themselves, and apply for adjustments and schemes relating to work. There is also a need for greater awareness and understanding of arthritis among employers, particularly how employers can make reasonable adjustments.

**50%**

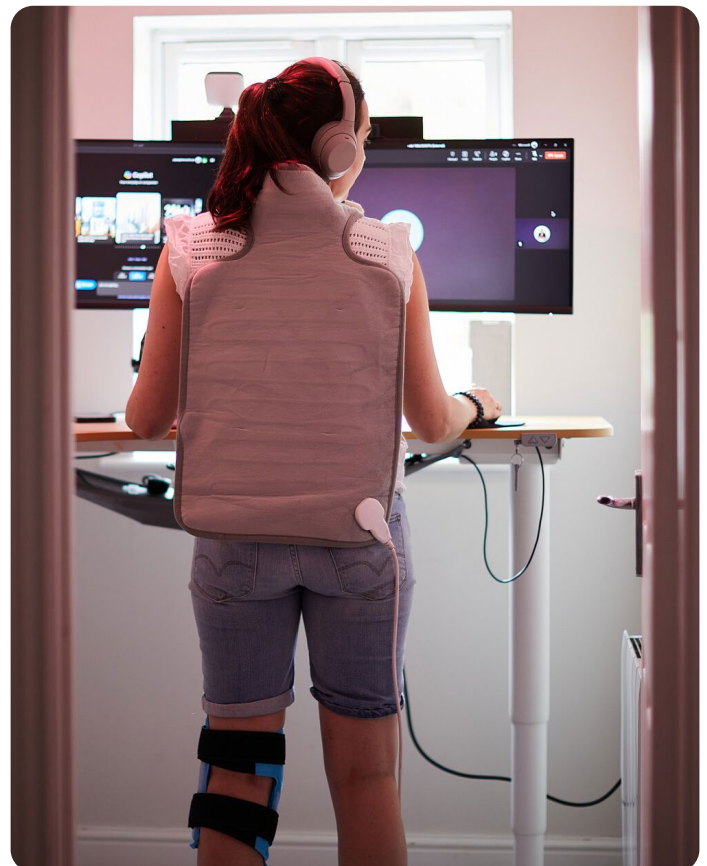
**of people said that arthritis had impacted their ability to work.**

(Arthritis UK, 2025)



**of people said stopping work was the biggest impact of having arthritis.**

(Arthritis UK, 2025)



# Accessing financial support

People with arthritis often face substantial financial pressures when managing their condition. Many incur significant out-of-pocket and indirect costs, including travel for appointments, adaptive equipment, privately sourced physiotherapy or treatments if waiting times are long, and supplementary medicines or therapies not fully covered by prescriptions.

Analysis from 2017 found that on average, MSK conditions can result in additional annual costs of around £1,700 per person. This figure will have now likely increased.<sup>5</sup> Access to benefits – such as Personal Independence Payment (PIP), the Universal Credit health element, or Employment and Support Allowance (ESA) – can therefore be vital in helping individuals meet these extra costs and manage their condition effectively.

For people experiencing symptoms for a significant period of time prior to their diagnosis, they may already have incurred additional costs in the search for their diagnosis. When people are newly diagnosed, they may face anxieties about finances, especially if they are struggling with symptoms that are impeding everyday

activities or their ability to work, if they are of working age. Being able to access financial support is especially important for people with arthritis as they can earn less, are less likely to be in work, and older workers are more susceptible to retiring earlier.<sup>26,78,4</sup>

This again highlights the importance of signposting, at point of diagnosis, to government websites and local authority or charity resources such as those provided by Arthritis UK, which include details of the financial support available for people with arthritis. Although, for those in the lived experience workshops who did apply, they reported challenges to accessing government benefits. Therefore, while a diagnosis can empower people to seek financial support, many still face barriers to qualifying. Improving assessors' understanding of arthritis as a long-term, fluctuating condition – including within PIP and Adult Disability Payment processes in Scotland – would support more accurate, compassionate and informed decisions about eligibility.

Analysis from 2017 found that on average, MSK conditions can result in additional annual costs of around

**£1,700**

per person.

This figure will have now likely increased.

(York Health Economics, 2017)



Accessing financial support is especially important for people with arthritis, as they can earn less, are less likely to be in work, and older workers are more susceptible to retiring earlier.



(Rajah et al., 2023; Office for National Statistics, 2025; Arthritis UK, 2025)

# Supporting independence

Some people with arthritis may also require additional support to help them live independent lives. For example, local authorities have duties to provide care and support to those with eligible care needs, including aids and adaptations in the home. The Care Act 2014 sets out the duty to provide community equipment (aids of any value and minor adaptations costing less than £1,000) free of charge to those who cannot complete two or more daily living activities.<sup>79</sup>

However, in an Arthritis UK survey 80% of people with eligible needs were unaware of their local authority's duty to provide community equipment.<sup>80</sup> Additionally, under the Housing

Grants Construction Regeneration Act 1996, people who need an adaptation over the value of £1,000 (such as ramps or wet rooms) can apply for a means-tested disabled facilities grant (DFG). When receiving a diagnosis of arthritis, people should be signposted to relevant local authority assessment processes, if this is something that would be beneficial for them.



# Stigma and public perception

It is important at the point of diagnosis that people are provided with a clear explanation and information about their condition, supplemented with signposting to relevant services, to counter any unhelpful beliefs or potential stigma. This is because arthritis is often misunderstood, or even stigmatised by society, which can negatively impact the individual.

In the lived experience workshops, people highlighted that having a diagnosis did not always make it easier to speak to friends and family about their condition, due to the limited understanding and perception of arthritis. This was also reflected in the [Left Waiting, Left Behind](#) report, where nearly 1 in 5 (19%) respondents to the survey shared that they feel isolated most or all of the time due to their arthritis.<sup>4</sup> 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%) of the people that were surveyed reported experiencing stigma because of their arthritis, and more than 4 in 10 (40%) felt that people did not understand their arthritis or the impact of the condition on their life. Younger adults reported worse mental health struggles due to their condition and are more likely to experience stigma and isolation.<sup>4</sup>

In the lived experience workshops, we heard from someone who found it difficult to talk openly about their arthritis to their family because of how much it had affected their mental health. A young person in their twenties also shared they didn't like the way their friends treated them after they disclosed their arthritis diagnosis, due to the limited understanding of how arthritis can affect some people. These testimonies highlight the difficulties people face in being able to talk openly about arthritis and the feelings of loneliness and shame this can foster, even following a diagnosis.

For gout, negative views and myths about the condition persist which can cause embarrassment or shame for people newly diagnosed. A study has found that emphasising that gout is a form of arthritis may give patients greater confidence in accepting the diagnosis and communicating it to others.<sup>30</sup> Arthritis UK's Primary Care Centre has also co-produced online resources that feature clips and tips from people with arthritis on a platform called [Healthtalk](#), which aims to debunk commonly held myths.<sup>81</sup>

This demonstrates the importance of tackling common misconceptions and the perception of arthritis. While not everyone who has arthritis may have such impactful symptoms, for some, life with arthritis can feel challenging. However, the impact arthritis can have is not always well understood. Or the fact that it can occur in younger people. By raising awareness of the impact that arthritis can have on individuals and debunking long-held unhelpful beliefs, it could help address some of the stigma people with arthritis experience. Therefore, following a diagnosis, it is helpful to situate people's perception of their condition within the broader social and cultural understanding of arthritis. This makes it especially important for them to be provided with a clear explanation and information, supplemented with signposting to counter unhelpful beliefs.

Nearly

**1 in 5**

**people with arthritis shared that they feel isolated most or all of the time.**

(Arthritis UK, 2025)




# The role of the voluntary sector

At the end of each lived experience workshop, people were asked what they thought was required to improve the diagnosis experience for arthritis. One of the emerging themes was awareness of the kind of support available for people, such as being signposted to Arthritis UK resources. As discussed above, signposting to resources can help people access information about employment and financial support.

The information provided by the voluntary sector, including a range of arthritis charities, can support people to better understand their conditions and learn about self-management options. The voluntary sector can and does already play a significant role in providing information and services for people with long-term conditions, and this support should be signposted to patients at the point of diagnosis.

Signposting at the point of diagnosis means that people can receive additional vital information that can help them feel more in control, through providing information on their condition. It can also help them access support and services. Importantly, the information does not only focus on the management of their symptoms but also the wider impact that arthritis can have on their lives. This means that people can access a holistic package of information to support themselves.

In England, we welcome the government's funding for Diagnosis Connect – a service aimed at ensuring patients can be referred directly to charities and support organisations as soon as they are diagnosed, to complement their NHS care. Given the burden associated with MSK conditions on both the individual and system, the inclusion of MSK conditions should be a priority.



Arthritis UK has a range of information available on our website relating to specific conditions, self-management, a customised exercise programme and our free Helpline for queries. People can also access an online community to connect with other people with arthritis, which can be especially beneficial if people are feeling isolated due to their condition. Additionally, people can access online tools, such as the My Arthritis app, to help them manage their symptoms.<sup>82</sup>





## Survey findings from Arthritis UK online information and support sessions

Once people attend an Arthritis UK online information and support session, they are provided with a survey. The latest survey, consisting of 130 respondents from November 2025 to March 2026, found that having a confirmed diagnosis helps to make the follow-up support more effective for people with arthritis.

**People with a diagnosis compared to those without a diagnosis, strongly agreed or agreed with the following:**

	With a diagnosis	Without a diagnosis
Feel part of a community	69%	27%
Plan to make changes or actions	60%	27%
Feel able to reduce the impact of their condition	61%	45%
Know where to get information to manage their condition	85%	63%
Improved understanding of their condition	67%	54%
Found sessions useful and relevant	83%	72%
Satisfied with the information received	89%	63%



**When you say I have pain, it's ignored, if you say arthritis, it's not dismissed (like pain).**

Lived experience workshop participant



**Biggest benefit is my blue badge.**

Lived experience workshop participant



**Might be useful to have discussion [about] your work at diagnosis... information and signposting.**

Lived experience workshop participant

## Chapter conclusion:

The feeling of validation that people express when they finally receive a diagnosis is important to acknowledge. After months or even years of searching for answers, people now have a name for a condition, that they can begin to better understand how best to manage. An important component of this is ensuring that people are being signposted to information that informs them about the wider support available. However, the limited general awareness of arthritis means that unlocking that additional support in the form of work adjustments, government benefits and schemes aimed at those with a disability or long-term health condition, is not easy. If people with arthritis are to live a life without limits, in which they can thrive, they must not face challenges to access vital support.



# Oscar's story

London, England



When they told me I had psoriatic arthritis two years ago, I was 100% in denial, absolutely convinced that they had misdiagnosed me. I'm a personal trainer, a yoga teacher and I just could not accept I might have a lifelong condition that needed to be managed by medication.

I'd started feeling stiff a year earlier, then my finger started clicking, then I woke up one morning and my feet wouldn't work, but I put it all down to exercise. I saw two GPs who gave me horrendous advice before seeing a musculoskeletal therapist who did an ultrasound on my feet and fingers and the inflammation was obvious. Then I saw a rheumatologist who found a couple of patches of psoriasis on my scalp and they made the diagnosis.

I found the hardest part of the journey was, for me, the impact on my identity. I was in pain all the time but trying to hide it because I've always been fit and strong and having that taken away from me felt so tough.

I was hobbling around like a 90-year-old and from diagnosis to finding the right medication I deteriorated so badly I thought I might need a wheelchair. I was eventually prescribed Adalimumab and, just a month later, I was back strong man training and I'm currently fitter than ever. I feel very fortunate to be in remission, but I'm smart enough to recognise I'm not invincible.

I'd never met anyone with an autoimmune arthritic condition, especially someone as young as me and when I was diagnosed I felt embarrassed. I share my own experience because there needs to be more knowledge available, more awareness and more support.



# What needs to happen

**Wider support including third sector support should be built into diagnosis pathways to help people live well.**

**Stakeholders:** National and local health systems and employers.

**Implementation:**

- ✓ National and local health systems should work with the Voluntary, Community and Social Enterprise (VCSE) sector to help patients access and benefit from their support services.
- ✓ Local health systems should ensure that patients are signposted to welfare, employment and occupational health support and guidance to help them find or stay in work if they choose.
- ✓ Local health systems to ensure signposting to local authority information about accessing aids and adaptations, if such support is required.
- ✓ Local health systems to ensure that people are being signposted to peer support groups.
- ✓ Fully deliver Diagnosis Connect in England (and in all UK nations) so people diagnosed in either primary or secondary care are automatically signposted to the VCSE sector and ensure arthritis and other MSK conditions included.



# Conclusion

## People with arthritis should not have to struggle alone.

Without a diagnosis, they are too often left in the dark, searching for answers as their physical and mental health deteriorates, potentially taking a toll on all aspects of their lives. The longer it takes for people to get a diagnosis and accompanying care, the greater their risk of requiring more intensive treatment and engagement with the health service. A delayed diagnosis can cost the NHS and the wider economy in the long term.

**Urgent action is needed to ensure that people with arthritis are getting a timely diagnosis that is the gateway for the care and support they need. Crucially, diagnosis should be more than just a label and must be the conversation starter that unlocks the wider support that can empower people, through shared decision-making and personalised signposting and referrals.**

Despite hard work and dedication from health professionals, they are working in a system where MSK health has not been prioritised. Primary and community health professionals, who are usually the first stop for people with MSK symptoms, are facing systemic barriers around staffing and capacity which need to be addressed. They should also be supported through improved training to better recognise, diagnose, triage and support people with arthritis. Additionally, governments and health systems need to prioritise tackling the barriers to the urgent and timely diagnosis of early inflammatory arthritis.

There also needs to be a transformation in the understanding and awareness of arthritis. It is not just an inevitable part of ageing. There are different types of arthritis, including inflammatory arthritis which requires urgent treatment, and osteoarthritis, for which there is much that can be done. This shift in perception is important for early recognition of symptoms and to ensure that diagnosis can unlock the care and wider support people need, without the stigma often associated with arthritis.

**While life with a newly diagnosed long-term condition can be daunting, a diagnosis should be a key step in setting people up to feel that they are not alone. That with the right support, they can live a life of their choosing. A diagnosis is more than just a label; it is the gateway to information, care and support that can be life-changing.**

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