



All-Party Parliamentary Group for
Axial Spondyloarthritis



Axial SpA
works silently.
We don't.

Axial SpA in England: Are NHS services improving?



Funded by:



About the APPG

All-Party Parliamentary Groups (APPGs) are cross-party groups that meet, relatively informally, to discuss a particular issue of concern. Groups are made up of parliamentarians from both the House of Commons and the House of Lords. Whilst APPGs have no formal place in the legislature, they are an effective way of bringing together parliamentarians and interested parties to help highlight a topic and the opportunities that exist for improving outcomes in the area. APPGs allow campaign groups, charities, and other non-governmental organisations active in the field to become involved in discussions and influence politicians.

The All-Party Parliamentary Group for Axial Spondyloarthritis was established in January 2019 with the remit of overseeing the implementation of NICE Guideline 65: *Spondyloarthritis in over 16s: diagnosis and management*ⁱ and the corresponding Quality Standard 170: *Spondyloarthritis*ⁱⁱ - key guidance for encouraging earlier diagnosis and improved management of axial spondyloarthritis.

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About the National Axial Spondyloarthritis Society (NASS)

Our purpose:

To transform the diagnosis, treatment and care of people with axial SpA so everyone can live well with it.

Our cause:

Axial SpA is an inflammatory condition of the spine and joints. It works silently, leaving people in increasing pain and exhaustion.

What we do:

We campaign to transform diagnosis and treatment.

We provide support to empower people living with the condition.

Acknowledgements

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- Tom Randall MP, Chair of APPG for Axial SpA
- Dr Dale Webb, CEO, NASS
- Simon Whalley, M&F Health

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Foreword

Tom Randall MP,
Chair of the All Party Parliamentary
Group for Axial Spondyloarthritis

Axial spondyloarthritis (axial SpA) is a condition that is close to my heart. I was diagnosed with the disease when I was about 20, having first presented with symptoms in my mid-teens. With an average delay in the UK of eight and a half years between the onset of symptoms and the receipt of a diagnosis, waiting 'just' a few years for my own diagnosis means that I was one of the comparatively lucky ones. This delay means the UK compares poorly with other countries, and is something that quite simply has to change.

I am therefore delighted that the All-Party Parliamentary Group on Axial Spondyloarthritis, in partnership with the National Axial Spondyloarthritis Society (NASS), is publishing its second report exploring the uptake of key spondyloarthritis guidance and provision of axial SpA care across the NHS.

Much has happened since the first report was published by the APPG and NASS in early 2020. The Covid-19 pandemic placed fundamental challenges upon the health system, the effects of which are still being felt today. We are also beginning a new era of health care commissioning and service delivery in England through the establishment of new models of care, spearheaded by Integrated Care Boards (ICB) and Primary Care Networks (PCN). The hope is that these organisations will help to facilitate the delivery of truly joined-up and person-centred care, however, as always, this will be reliant on a number of wider factors and is something that we cannot take for granted.

Reflecting on the findings of the APPG's first report it was clear that, despite some encouraging signs of progress, there were significant gaps that needed to be addressed in the context of axial SpA service availability and widespread variation across the country. The findings of this new report show that this is still very much the case. Whilst excellent work is being taken forward by national policy makers, clinical champions and by groups such as NASS and others, the reality on the ground is that there are still too many areas where core elements of an effective axial SpA pathway are not in place. The hope is that this variation lessens with the ongoing rollout of flagship policy initiatives. The APPG looks forward to playing its part in supporting these efforts where it can.

My hope therefore is that this report can act as a further rallying call to all those who have a stake in the organisation, commissioning and delivery of axial SpA care. I truly believe that we are on the cusp of achieving a fundamental step-change for the condition across the UK and I am determined that this potential is fully realised in the coming years. Doing so will unlock life-enhancing benefits for both current and future generations and is an opportunity we simply cannot afford to pass up.



Foreword

Professor Yeliz Prior
British Society for Rheumatology
Vice President, Representing Health
Professionals in Rheumatology

I am pleased to write a foreword for this report, written in partnership by the APPG for Axial Spondyloarthritis and NASS. Around 1 in 200 adults in the UK live with axial SpA and diagnosis still takes between 5 - 8 years. It's therefore vital to highlight important and necessary improvements in the provision of care for this condition across services in the UK.

Delayed diagnosis leads to worse health and social outcomes for patients, and increased burden on primary care services. I have experienced this delay at first hand. Even working as an advanced clinical specialist occupational therapist in rheumatology and a researcher, my axial SpA diagnosis was significantly delayed, with wide ranging negative consequences on my personal and work life.

Therefore, as a health professional in rheumatology, researcher and someone with lived experience, I am absolutely delighted for these timely recommendations.

The APPG has an important role in raising public awareness of axial SpA and supporting the need for education programmes for primary care practitioners to recognise the early signs and symptoms of inflammatory back pain to increase referrals to rheumatology and enable patients' timely access to diagnosis and treatment. It's greatly encouraging to see parliamentarians come together in this forum to find solutions, debate issues, and hold the NHS, policy makers and government to account to support this strategy.

Public awareness and understanding of axial SpA, its symptoms and early warning signs, will be essential to reduce the lengthy delays for diagnosis to access clinically and cost-effective

treatments for axial SpA. Beyond that, we need well-staffed and resourced rheumatology teams to ensure patients receive the best quality care and that referrals can be dealt with promptly. Health Education England's workforce plan must provide for increases in the number of consultants, specialist nurses, specialist physiotherapists, occupational therapists, podiatrists, clinical psychologists, MSK radiologists and pharmacists working in rheumatology to achieve this. We would also like to see musculoskeletal (MSK) conditions and rheumatology prioritised in the NHS Long-term Plan, NHS Mandate and in commissioning arrangements.

Healthcare Quality Improvement Partnership's National Early Inflammatory Arthritis audit (NEIAA) delivered by the British Society for Rheumatology, will be extending data collection to look at axial SpA and a wider range of rheumatological conditions. Its most recent report reveals that over half of patients referred to rheumatology receive their diagnosis outside of the 3-month NHS Constitution window, a delay that has increased since the pandemic. Addressing the workforce crisis and more effective referral pathways in primary care is critical to reducing diagnostic and treatment delays in axial SpA.

I have welcomed the opportunity to contribute to the meetings of the APPG for Axial Spondyloarthritis, hearing the personal stories of patients, as well as the experiences of other clinicians across the UK. We look forward to working alongside NASS with parliamentarians, those affected, NHS England, and the NHS to implement the recommendations in this report.

Executive summary



59% of NHS Trusts in **England** have an inflammatory back pain pathway.



45% of NHS Trusts provide an **education programme** for primary care, an encouraging **increase of 38** percentage points from 2019.



14% of people with axial SpA received their **diagnosis within the 8 week period** recommended by GIRFT.



Whilst still less than a third (**32%**) of patients are offered written co-produced **axial SpA care plans**, this does represent a doubling of the proportion compared to 2019.



There has been a drop in access to **rheumatology physiotherapy** from **81%** to **71%**.



47% of Trusts offer a **specialist axial SpA clinic**.



21% of rheumatology teams are able to refer directly for **psychological support**.

Recommendations in brief

1. All Integrated Care Boards (ICB) should adopt the Best MSK Health Collaborative and Getting it Right First Time (GIRFT) in Rheumatology axial SpA pathway as part of local MSK improvement planning.
2. Education programmes should be in place locally for primary care practitioners to recognise the signs and symptoms of inflammatory back pain.
3. Local services should optimise resources, including diagnostic testing, at the point of referral and ensure that patients see the appropriate clinician at their first appointment to ensure the 8-week target of referral to treatment is met.
4. Specialist physiotherapy needs to be recognised by ICB planning as a key component of a multidisciplinary team (MDT) approach in both the diagnosis and management of axial SpA within rheumatology, to help manage resource and give the best possible outcomes for patients.
5. Trusts should have access to specialist axial SpA services and support within their ICB to help diagnose and manage complex cases.



NASS welcomes this report from the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA).

In December 2018 we launched in Parliament our *Every Patient, Every Time* campaign which aims to ensure widespread implementation of the Nice Guideline 65 (NG65) on Spondyloarthritis. Since then we have worked in partnership to create transformational initiatives that bring this aspiration to life.

First, we developed *Aspiring to Excellence*, which is now the largest quality improvement programme in axial SpA anywhere in the world, with 19 rheumatology departments working together to achieve earlier diagnosis and high quality care.

Then we created *Act on Axial SpA*, which aims to follow the patient from symptom onset to their diagnosis in rheumatology and reduce the time to diagnosis at each point in the pathway. It includes public awareness campaigns, the creation of a cadre of clinical champions in primary care, the development of new educational and training resources for secondary care and the promotion of imaging protocols.

We have published research showing that the total cost of delayed diagnosis to the UK is £18.7 billion per year. We commissioned new research to identify what patients value and need in the diagnosis and management of axial SpA. We have undertaken Freedom of Information requests to look at the practice of secondary care referrals and the knowledge and practice of radiologists in axial SpA.

This inquiry, coming on the back of the Covid-19 pandemic, shows that there is much still to do to achieve widespread implementation of NG65.

We recognise the significant pressures on our healthcare professional (HCP) colleagues, but are heartened by the support and commitment of those HCPs who work with us to create the conditions for change at local level.

We have been pleased to work with the APPG to shine a light on the initiatives that we and others have introduced, and discuss the key areas covered in NG65.

We are building a burning platform for change, and creating new momentum and partnerships with HCPs to ensure that every patient, every time receives early diagnosis and the best care.

Dr. Dale Webb, FRSA, FRSPH
CEO of NASS

About axial SpA

Axial SpA is an inflammatory disease of the spine and joints. Inflammation where muscles attach to the bones, causes extreme pain. If left untreated it can permanently fuse bones together.

It's an invisible and misdiagnosed condition. Often leaving people feeling powerless, in increasing pain and extreme exhaustion.

Approximately 1 in 200 of the adult population in the United Kingdom have axial SpA^{iv}. Significantly, the average age of onset is just 26 yearsⁱⁱⁱ, which means that most of those who develop the condition will live with its symptoms for the majority of their adult life.

Despite the relatively high prevalence of axial SpA and the significant impact that it has on those living with the condition, awareness remains low by both the public and many health professionals. This is reflected in the current average delay of 8.5 years between the onset of axial SpA symptoms and diagnosis^v, during which time the condition can deteriorate considerably, and irreversible damage can occur.



What we did - background

A Freedom of Information (FOI) request was sent to all NHS Trusts in England. The request included a set of questions based on the NG65: *Spondyloarthritis in over 16s: diagnosis and management* and the corresponding Quality Standard (QS170).

The questions were largely a repeat of a set sent in 2019, with one new question on written care plans, and another on the information received when a patient is considering biologic therapy.

The questions were split into four key areas:

- Recognition and referral
- Diagnosis in specialist settings
- Information and support
- Ongoing management

We also sought to include some of the oral evidence given at APPG meetings on topics where applicable, as well as sampling some of the data from a report published alongside this, *'What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?'*

In total, 85/125 trusts responded (68%). Due to a smaller sample size compared to the previous results, there may be small differences in the comparative figures in the 2019 inquiry.

An FOI request was also sent to all Integrated Care Boards (ICB). Responses were received from 36/40 (90%). Most ICBs were unable to either answer the questions posed, or responded as a collection of Clinical Commissioning Groups with variation within the board. It was therefore decided not to include these results in full as they did not provide reliable data. A further comment piece has been added on page 22 to discuss this in more detail.

'What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?'



As part of their *Aspiring to Excellence* quality improvement programme, NASS commissioned Headstrong Thinking Limited to undertake independent research with a sample of more than 900 people living with axial SpA. The study aimed to identify the needs and values of people living with axial SpA in diagnosing and managing the condition and to assess the extent to which these are reflected in people's experiences of services. This report has used some of the results from this piece of research to reflect the views of people with axial SpA on the delivery of services.

Results and comment

Recognition and referral

Inflammatory back pain pathways

What we asked

Does your Trust have a local inflammatory back pain pathway in place?

Why this is important

NICE Quality Statement 1 says: 'Adults with suspected axial or peripheral arthritis are referred to a rheumatologist', whilst the NICE Guideline 1.1.5 states that 'If a person has low back pain that started before the age of 45 and has lasted for longer than 3 months, refer the person to a rheumatologist for a spondyloarthritis assessment' if they meet an additional set of criteria.

The current average time to diagnosis for people with axial SpA remains at 8.5 years. NASS launched their *Act on Axial SpA* campaign in 2021, which aims to reduce the time to diagnosis to just one year. For this to be achieved, all patients who present to primary care with suspected axial SpA should be appropriately identified and urgently referred to rheumatology^{vii} via a recognised pathway.

Results – 2022 vs 2019

2022 (n=85)	2019 (n=116)
Yes 59%	Yes 65%
No 41%	No 35%

Raising awareness in primary care

What we asked

Do you have a local education programme for primary care practitioners including GPs and First Contact Practitioners (FCP)?

Why this is important

Quality Statement 1 asks for 'Evidence of local arrangements to raise awareness of signs, symptoms and risk factors of axial [and peripheral] spondyloarthritis in primary care'.

People with axial SpA tend to present to primary care with chronic low back pain, a symptom that accounts for 6% to 9% of all primary care appointments^{vii}. People with axial SpA find it difficult to convey their symptoms^{vii} and it is

often reported that GPs are reluctant to investigate chronic low back pain further. There is a limited amount of axial SpA training on the GP syllabus or indeed at undergraduate level physiotherapy training, for those who may go on to become FCPs.

Results – 2022 vs 2019

2022 (n=85)	2019 (n=116)
Yes 45%	Yes 7%
No 45%	No 93%
Don't know/ not sure 10%	

Oral evidence at APPG

The seventh meeting of the APPG in October 2021 looked at *Axial SpA and Primary Care: Improving identification and onward referral*. Presenters and contributors included those working within primary care, national policy makers from NHS England and people living with axial SpA. The main points raised were:

- Symptom assessment is difficult for GPs as the most common symptoms for inflammatory arthritis are similar to other conditions presenting in primary care
- There has been an increased pressure on GP workload with a 2016 report by the Kings Fund showing contacts increasing by 15% from 2010 to 2015^x
- A GP practice covering a population of 2,000 might see one potential axial SpA patient in a year out of one or two per day with back pain. This further highlights the need to improve awareness amongst primary care health professionals or these people may be missed
- Rheumatology is a small part of the medical curriculum
- Regular dialogue between primary care health professionals and rheumatology teams is vital
- Local champions in MSK health need to be utilised
- The role of FCPs could be vital in identifying people with axial SpA
- FCPs offer advanced MSK assessment and are able to integrate with the surrounding system, plus focus on population health and personalised care
- FCPs are also able to share their knowledge with their colleagues in primary care
- The Best MSK Health Collaborative has worked to establish standardised and streamline pathways, including in axial SpA
- There is a need for urgent and emergency guidance to be updated to help with early identification
- Developments include an MSK data set for primary care, standardising of service provision and the publication of specialist advice and guidance documents

- Pop-up tools are a way to help GPs differentiate between mechanical and inflammatory back pain
- GPs need to be allowed the time to ask questions and properly examine the 'soft signs' of axial SpA, but this is very difficult given the increase in caseload
- The collaboration and integration that was gained during the pandemic should not be lost, and rheumatology services should be optimised to ensure that capacity is used to its best potential
- The axial SpA pathway is available on the NHS Futures platform.

Patient view

The NASS report '*What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?*' revealed a number of overarching themes from people when visiting primary care. Patients reported feeling that they didn't feel believed or were diagnosed with a sports injury or other condition. In the quantitative results, half (50%) agreed or agreed strongly with the statement 'my GP didn't seem to know anything about axial SpA before I got a diagnosis'. The feeling of not being believed was particularly impactful, leading to self-doubt^{ix}.

Comment

Results from 2019 measured against 2022 show that there appears to have been a slight decrease in the number of local inflammatory back pain pathway in place. With the introduction of the Best MSK Health Collaborative and the standardised pathways, it is hoped that this might improve over time.

On a more positive note, it is heartening to see the increase in education sessions being delivered to primary care, and the strides forward by secondary care in supporting their primary care colleagues to recognise axial SpA.

There is no doubt that this is a difficult time for primary care, with increasing workload and more complex cases to deal with. There is clearly a need to support GPs and FCPs to be able to recognise the symptoms of axial SpA and refer on quickly and appropriately, ensuring people feel that they have been listened to and get that all-important diagnosis to help them live their best life.

Diagnosis in specialist care settings

Time to diagnosis

What we asked

Are you aware of the average current waiting time from when a patient is referred from their GP to receiving their diagnosis? By this we mean from the moment the referral is received by rheumatology until the patient receives an official diagnosis.

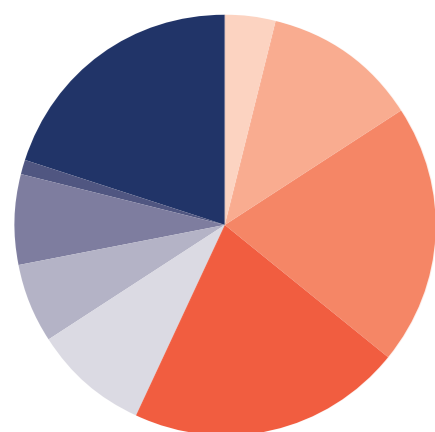
Why is this important

The GIRFT report recommends that routine referral to treatment (RTT) times for all conditions that require specialist rheumatology care should not exceed eight weeks.

Capturing the time from referral to treatment is key; swift diagnosis and appropriate treatment can ensure that people with axial SpA are able to manage their condition more effectively.

Results – 2022 vs 2019

2022 (n=85)



- Less than 1 month – 4%
- 1 to 2 months – 12%
- 2 to 3 months – 20%
- 3 to 4 months – 21%
- 4 to 5 months – 9%
- 5 to 6 months – 6%
- 6 to 12 months – 7%
- More than 12 months – 1%
- Don't know/not sure – 20%

2019 (n=116)

The question asked in 2019 was slightly different: 'What is the average current waiting time to diagnosis for a patient referred with inflammatory back pain?'. This was changed for the 2022 inquiry as it had been interpreted differently by organisations who responded. 34% of patients received their diagnosis inside of the 3-month NHS Constitution window.

Patient view

In the NASS report 'What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?' respondents were asked about some of the different aspects of getting a diagnosis and rated them each, firstly with regard to how positive their own experiences had been, and then based on how important they thought they were for patients. There was a disparity between what respondents rated as important and what they themselves had experienced, with only a fifth or less saying they had had a very or quite positive experience of these aspects ^{xi}.

Comment

Pressures on the NHS following the pandemic are still very much in play, which is reflected in the increased time it takes for a diagnosis compared to 2019. The recent recommendations from the GIRFT report ^{xii} see the management of non-inflammatory conditions being moved from secondary to community care, which should in turn help to use rheumatology capacity more efficiently and bring down the waiting times.

In a separate FOI request, NASS also asked NHS Trusts about waiting times for MRI. 89% of trusts responded that waiting times are longer than 4 weeks ^{xiii} which would of course have a significant impact on time to diagnosis from referral.

Information and support

Information at diagnosis

What we asked

How do you ensure patients are given information and support following their diagnosis?

Why this is important

NICE Quality Statement 4 says 'Adults with spondyloarthritis are given information about their condition, which HCPs will be involved with their care, and how and when to get in touch with them'.

Getting a diagnosis of any condition can be daunting, but can be especially so for axial SpA which has low public awareness and can have a range of related conditions and EMMs. Getting access to information early on can help people with axial SpA to confidently manage their condition between appointments, and to be given time to digest and formulate any questions that they may have for follow up appointments.

Results – 2022 vs 2019

	2022 (n=84)	2019 (n=116)
Written information	98%	94%
Verbal information	96%	96%
Access to a helpline	95%	85%
Named contact in the team	56%	55%
NASS self-management session	23%	-
Group educational sessions	24%	24%
Other *	43%	43%

*'Other' in 2022 included access to physiotherapy education and exercise sessions (31%), signposting to the NASS website (17%), NASS branches (5%), self management apps (2%) and signposting to the Versus Arthritis website (1%).

Information on biologics

What we asked

What guidance are patients with axial SpA given when deciding whether to access biologic treatment?

Why this is important

The NICE Guideline 1.4.5 states 'The choice of treatment should be made after discussion between the clinician and the patient about the advantages and disadvantages of the treatments available'.

Shared decision making is key when people are considering their treatment options and should not be the sole decision of the clinician.

Results

2022 (n= 85)

Written information	94%
Discussion with rheumatologist/ rheumatology nurse specialist / other HCP	94%

All patients were offered one or the other

This question was not asked in 2019.

Care plans

What we asked

Do you provide patients with individual care plans when they are newly diagnosed?

Why this is important

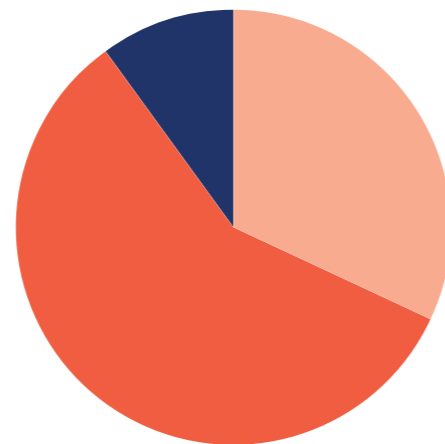
A quote in the 'What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?' report said

"Living with axial SpA is what happens between appointments and there is so much of that time and so little time in an appointment."^{xiv}

Self management is a key element of day to day living with axial SpA. Having an individual care plan gives people with axial SpA the confidence they need.

Results – 2022 vs 2019

2022 (n=85)



Yes, we provide full care plans discussed and assembled with patients – 32%

Yes, care plans as part of their diagnosis letter – 58%

No – 10%

Information on flares

What we asked

Does this [care plan] include specific information on flares?

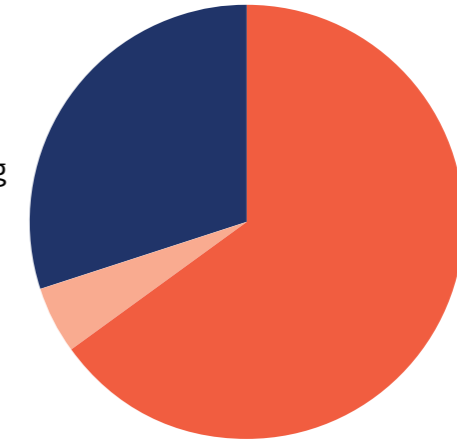
Why this is important

The NICE Guideline 1.7.1 states 'Manage flares in either specialist care or primary care depending on the person's needs'.

Axial SpA is characterised by periods of flare which can last days, weeks or even months. These flares are debilitating and exhausting, and can affect people's ability to think clearly about what they need. It is important that people with axial SpA have a plan in place to ensure that they can cope as well as possible during these times.

Results – 2022 vs 2019

2022 (n=78)



Yes – 65%

No – 30%

Don't know/not sure – 5%

In 2019 we asked the question "What percentage of patients with axial SpA (AS) have a written care plan to support them with a flare?" rather than two separate questions on general care plans and flare information. (n=116)

On this occasion, 12% were offered specific flare care plans, whilst 4% were offered general care plans.



Access to physiotherapy

What we asked

For this area, we asked two questions in the follow up inquiry as there was some discrepancies on how the term 'specialist physiotherapist' was interpreted in the 2019 inquiry:

Does the rheumatology department have access to a specialist physiotherapist? Respondents were asked to tick all that apply.

What percentage of adults with axial SpA are referred to a specialist physiotherapist as described above for a structured exercise programme within your local area when first diagnosed?

Why this is important

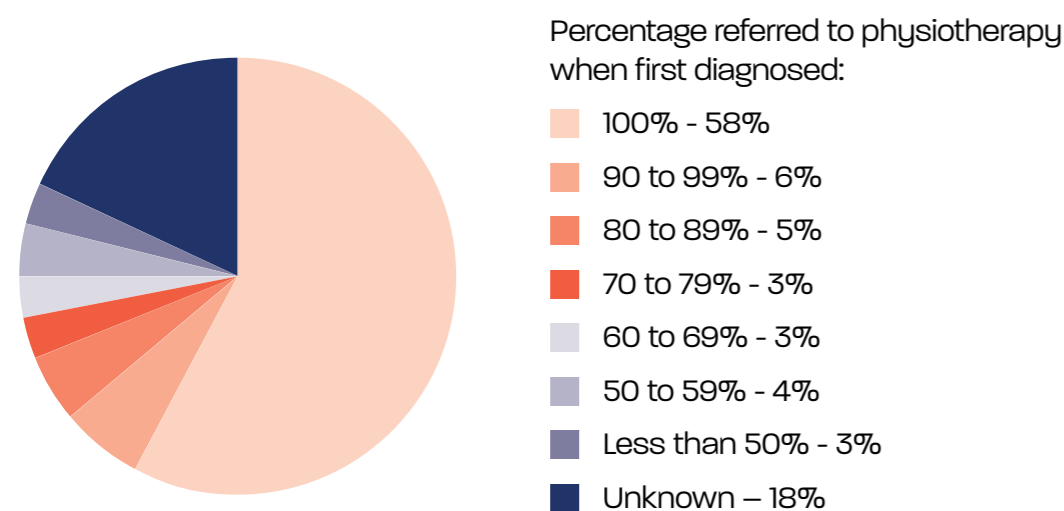
The NICE Guideline 1.5.1 recommends: 'Refer people with axial spondyloarthritis to a specialist physiotherapist to start an individualised, structured exercise programme, as does Quality Statement 3 in the Quality Standard.'

The cornerstone of treatment for axial SpA is a combination of medication to reduce inflammation and exercise. In a condition that is characterised largely by pain and stiffness, exercise allows patients to maintain flexibility, range of movement and posture as well as helping to improve sleep and general health and wellbeing.

Results – 2022 vs 2019

2022 (n=85)

Yes, we have a rheumatology physiotherapist	71%
Yes, we have an MSK physiotherapist	31%
No, patients are referred to community physiotherapy	13%
No, we have no access to physiotherapy from rheumatology	1%



2019

81% of providers had access to a specialist physiotherapist. Of those (n=92):

74% said that they referred 100% of their patients to a specialist physiotherapist. Of the other Trusts who had access to a specialist physiotherapist, 24% referred more than half, 2% referred less than half.

12% of reporting NHS Trusts said that they do not have access to a rheumatology specialist physiotherapist, and 7% did not have the information requested.

Oral evidence at APPG

The eighth meeting of the APPG looked at *Axial SpA and Rheumatology Physiotherapy: Reducing variation in service provision*. Presenters and contributors included people with axial SpA, professional bodies, Health Education England (HEE) and examples of best practice. The main points raised were:

- Physiotherapy, including hydrotherapy, can have a transformative impact on people's ability to manage their axial SpA
- Physiotherapy has proven to be a cost and clinically effective way of restoring movement and function, preventing disability, and improving the quality of life for patients living with axial SpA right across all different stages of the disease
- There is insufficient capacity across the physiotherapy workforce to deliver the level of care recommended by NICE
- Lack of capacity was exposed by a 2019 freedom of information request which found that patients were waiting up to 4 months to see a physiotherapist ^{xv}
- These waiting times have worsened following the pandemic, as the patients who deferred seeking help present in greater numbers
- Physiotherapy services have increasingly focused on trying to deliver support to patients who are on the waiting list through providing communication around the self-management of their condition

- The BSR's Workforce Report calls for all rheumatology services to have a dedicated physiotherapy service, the inclusion of specific commitments in the HEE workforce strategy ^{xvi} to train and recruit more physiotherapists, and an increase in the exposure to rheumatology during graduate curricula
- The Rheumatology Physiotherapy Capabilities Framework was released in October 2021 ^{xvii}
- The framework has proved to be an effective tool in enabling professional development and supporting business cases for the recruitment of new staff
- Individual sections in the document align to the patient journey including MSK screening, investigations, physiotherapy interventions, condition management, medication management and non-clinical capabilities
- New ways of delivering physiotherapy are being introduced including web-based physiotherapy and self-referral programmes to community services
- There are particular issues around training and in the availability of clinical placements
- One of the main issues relates to the lack of planning and assessment at national, regional, and local levels to determine how many physios are needed, and the lack of sustained funding to support clinicians to develop specialist expertise in areas such as rheumatology
- There is currently no consensus on the amount of physiotherapy that people with axial SpA should receive
- Local physiotherapy services should ensure that there is protected time for the training of new staff through engagement with their MSK leadership team.

Patient view

In the NASS report 'What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?', those diagnosed in the past five years were asked what support and information they had received in the first year after being diagnosed. The provision of support and information was variable. Over half of respondents said that they received access (e.g. phone support) to a specialist rheumatology nurse (57%); information about the medication prescribed e.g. side effects (57%); and information about the likely course of treatment (51%). However, one in six (17%) said that they did not receive any of the types of support or information on the list. ^{xviii}

The research also revealed that physical exercise is important to people with axial SpA– 15% each said 'advice / information about exercise' and 'get physio' would have been welcomed in the first few months after diagnosis, and 15% also said they would have liked to receive more information on the condition. Although 81% thought that advice on exercise was very important or important, only 54% had a positive experience of this. ^{xix}

Comment

There appears to be a discrepancy between the information and support that Trusts see themselves offering and what patients feel that they are receiving.

There has been a drop in the number of services which are able to offer rheumatology physiotherapy as well as the percentage of patients who are referred to physiotherapy on diagnosis. As this was identified as being so important to people with axial SpA upon diagnosis it needs to be addressed.

Ongoing management

Organisation of care and axial SpA clinics

What we asked

Does the Trust have a dedicated axial SpA clinic? By this we mean a day or time when patients with axial SpA are seen by a multi-disciplinary team.

Results – 2022 vs 2019

2022 (n=85)	2019 (n=116)
Yes 47%	Yes 44%
No 53%	No 42%

Why this is important

NICE Guideline 1.9.2 states 'Ensure that people with spondyloarthritis have access to specialist care in primary or secondary care settings throughout the disease course to ensure optimal long-term spondyloarthritis management', and 1.9.3 'Ensure that there is effective communication and co-ordination between all HCPs involved in the person's care particularly if the person has co-morbidities or extra-articular symptoms'.

Mental health and wellbeing

What we asked

Are axial SpA patients under the care of a rheumatologist offered access to psychological services?

Why this is important

Mental health is not specifically mentioned in the spondyloarthritis NICE Guideline; this is because it is already covered in a NICE guideline 'Depression in adults with a chronic physical health problem: recognition and management' ^{xx} which states:

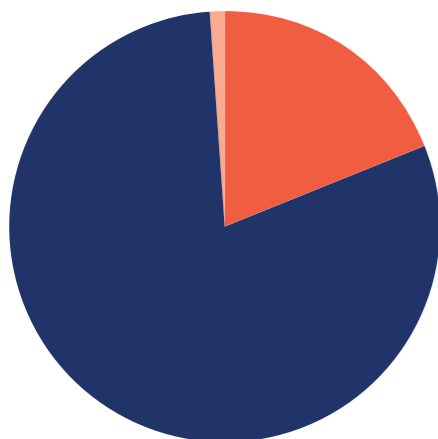
1.5.4.2 Collaborative care for patients with depression and a chronic physical health problem should normally include:

- Case management which is supervised and has support from a senior mental health professional
- Close collaboration between primary and secondary physical health services and specialist mental health services
- A range of interventions consistent with those recommended in this guideline, including patient education, psychological and pharmacological interventions, and medication management
- Long-term coordination of care and follow-up.



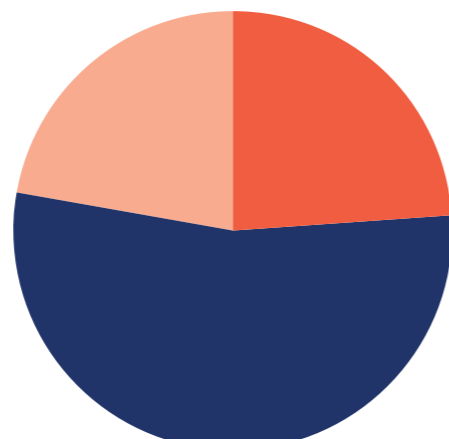
Results – 2022 vs 2019

2022 (n=85)



- Yes – 21%
- No – 88%
- Don't know/not sure – 1%

2019 (n=116)



- Yes – 24%
- No – 54%
- Other – 22%

Oral evidence at APPG

The sixth meeting of the APPG looked at *Axial SpA and Mental Health: Understanding the Impact & Identifying Opportunities for Improvement*. Presenters and contributors included people with axial SpA, expert clinicians, NHS England and examples of best practice. The main points raised were:

- Symptoms cause anxiety and embarrassment for young people and impacting on education education, leading to wider mental health and emotional challenges
- The mental wellbeing of those close to people with axial SpA is also affected, especially a sense of hopelessness
- For years the issue of mental health has been a taboo subject, but that has improved more recently
- There is a link between mental health and the ability to work; many people with axial SpA are unable to work which affect their self-worth
- Many people living with axial SpA experience psychological distress and 40% of patients report some depressive symptoms

- Pain, fatigue and disability often contribute to feelings of helplessness, social isolation and anxiety. These feelings are most prevalent in the year after diagnosis
- Symptoms are frequently overlooked during consultation processes
- Positive facilitators for emotional well-being included a definitive diagnosis, exercise, anti-TNF medication, work, good knowledge and self-management of the disease, as well as support from family and friends
- Mental health issues are often presented to rheumatology professionals as patients generally have a better relationship with their consultant as opposed to primary care
- These professionals will have had very little training in mental health support and the referral pathways are subject to variability and delays
- Mental health services are underfunded, particularly in research terms, and the ambition of parity between physical and mental health is still a long way off

- Services are also subject to significant variation in accessibility and are overwhelmed, particularly in the community sphere. This has only worsened during the pandemic
- They are also poorly aligned to the needs of patients with multi-morbidities due to the focus on risk as opposed to clinical need
- A roundtable held by the Arthritis and Musculoskeletal Alliance (ARMA) identified several key insights on factors that impact mental health for patients with MSK. This included long delays in diagnosis, feelings of isolation, and the problems associated with transitions
- For professionals, the roundtable advised that patients should be asked about their mental health. Professionals can be reluctant to do this due to fear of escalation and limited confidence in the referral process
- The experience of pain from axial SpA often has knock-on effects and can lead to other issues such as excess alcohol consumption or over-using medication as a nullifying strategy
- A key area of best practice would involve incorporating a clinical psychologist within the rheumatology team
- Best practice design should be guided by the recommendations of patients which will rely on clinicians listening to their perspectives and experiences
- Most rheumatology departments will find it difficult to provide appropriate resources to fund specialist mental health expertise despite being a clear unmet need
- Past work has demonstrated that patients can benefit enormously from just a short intervention and arguments were much more powerful when the financial benefit was highlighted.

Patient view

In the NASS report *'What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?'*, 35% of people agreed or strongly agreed with the statement 'My health professionals seem to look at me as a cluster of symptoms rather than a whole person' indicating that they do not feel their care is a joined up as it should be. In the same report, 58% of people said that they would have liked an assessment of their emotional wellbeing, yet only 13% had a positive experience of this ^{xxi}.

Comment

In 2019, respondents often cited alternative arrangements and also indicated that a clinic was being set up. The results from 2022 for specialist clinics where 'no' was indicated did often refer to access to a multi-disciplinary team, but not as a one-stop clinic.

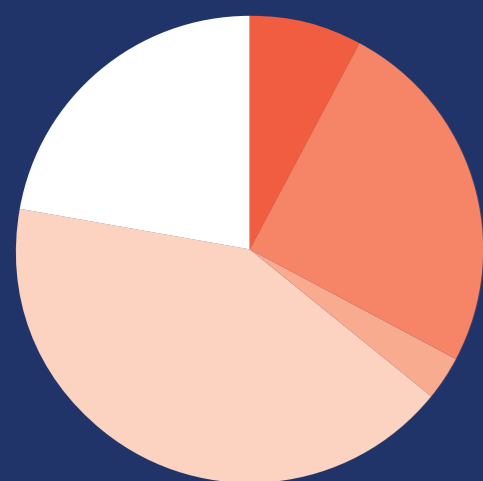
In terms of mental health provision, there has been a significant drop in access from rheumatology. The majority of services are only able to signpost to IAPT and community services, plus pain clinics in some cases. This is in line with the shortage of mental health services more broadly in England. Worryingly, only 40% of people surveyed by the Care Quality Commission said that they had definitely seen services enough for their needs in a community setting. ^{xxii} The role of occupational therapists to help with stress, less severe anxiety and low mood, rather than clinical depression, is also vital in the delivery of services for people with axial SpA.

Integrated Care Boards and axial SpA

As part of the inquiry, the APPG looked to the newly formed ICBs to answer questions on local pathways and plans in place for axial SpA and MSK more generally. Few were able to clearly define a single pathway in use for the board relating to axial SpA or inflammatory back pain, able to answer questions around the local referral responsibilities and protocols.

There were however some more consistent responses regarding the implementation of local planning for axial SpA and MSK services. We asked:

Has your ICB developed a plan for how it will meet the needs of local axial SpA patients? Please select the most appropriate option below.



- Yes – we have developed a standalone plan for axial SpA - 8% (3/36)
- Yes – axial SpA is incorporated within a specific local musculoskeletal ICB plan – 25% (9/36)
- Yes – axial SpA is incorporated within a general ICS planning document – 3% (1/36)
- No – axial SpA is not incorporated within a local planning document – 42% (15/36)
- Don't know / not sure – 22% (8/36)

We also asked:

If yes, please can you provide further details of the specific axial SpA components included within this plan including the appointment of an MSK Transformation Lead?

22% of ICBs had appointed an MSK Transformation lead already which was positive to see. It was slightly concerning however to see that the other ICBs did not think this was applicable, thought it was not something that would be decided at ICB level and asked to refer back to the local Trusts.

It would seem that now is the time to open dialogue with ICBs and ask that they review their local plans, and make them aware of the tools in place to help them with their axial SpA and MSK pathways.

Recommendations

As has been outlined earlier, since the last inquiry was carried out there have been significant inroads in the world of MSK. These, combined with the current pressures within the NHS due to the pandemic and rheumatology workforce crisis, mean that the recommendations in this document try to best reflect the current circumstances and are realistic in their asks of local services whilst also championing the needs of people with axial SpA.

1. **All Integrated Care Boards should adopt the Best MSK Health Collaborative and Getting it Right First Time in Rheumatology axial SpA pathway as part of local MSK improvement planning.**

The NICE Guideline Development Group (GDG) for NG65 identified the recognition and appropriate referral of axial SpA as its key priority for original health economic analysis ^{xxiii}. The group advised that delayed diagnosis is a significant issue in all spondyloarthritis, but that people with axial SpA symptoms are subject to particularly damaging delays, often because their symptoms are misidentified as mechanical back pain.

Implementing a referral pathway for people with suspected axial SpA can not only reduce the time to diagnosis and streamline services, it can also have a positive economic impact, reducing societal and individual costs. A study by NASS published in 2022, showed that the 8.5 year average time to diagnosis for someone with axial SpA costs the UK economy £18.7 billion per year ^{xxiv}. This is comprised of costs to the individual but also costs to society as a result of productivity losses.

A study by Aggarwal and Malaviya in 2009 was used by the GDG for NG65 to highlight that undiagnosed axial SpA will result in worse BASDAI and BASFI ^{xxv}. This means that individuals with axial SpA will have worse fatigue and pain levels, and more functional impairment. People who are diagnosed early and put on the correct pathway including medication and physiotherapy, will have a better response to treatment and consequently should need fewer interventions when living with axial SpA.

The introduction of a single nationally recognised pathway by the Best MSK Health Collaborative and GIRFT ^{xxvi} presents an opportunity for standardised diagnosis and treatment for patients.

Everyone with the signs and symptoms of inflammatory back pain (IBP) should be referred directly to rheumatology. A single pathway will not be as effective unless it is integrated into local MSK planning overall, with all points of entry into the system for possible axial SpA diagnosis covered. This means that the pathway is not simply from primary care into rheumatology, but community, paediatric/adolescent and pain services should also be considered as possible entry points.

It is important to recognise that local planning and structures will mean that the Best MSK Health Collaborative and GIRFT pathway is not always an exact fit. This is why the term 'adopt' rather than 'implement' has been used to reflect local needs.

Further research in this area is planned for 2023 by the British Society for Rheumatology.

2. **Education programmes should be in place locally for primary care practitioners to recognise the signs and symptoms of IBP.**

It is vital that education and training continues for primary care and community practitioners to ensure that the signs of IBP are recognised and patients begin the pathway to diagnosis.

Implementing screening and pop-up tools can help primary care colleagues to feel confident in their referrals when they have a large and varied case load.

Keeping open dialogue between primary and secondary care will also enable primary care practitioners to consult with colleagues when they have patients that they would like to refer but need further guidance.

NASS also has a range of resources as part of the *Act on Axial SpA* campaign^{xxvii} that will help health professionals to deliver these sessions, including an endorsement campaign which gives individuals and units the opportunity to gain recognition for their support.

3. Local services should optimise resources, including diagnostic testing, at the point of referral and ensure that patients see the appropriate clinician at their first appointment to ensure the 8-week target of referral to treatment is met.

The GIRFT report recommends that routine referral to treatment (RTT) times for all conditions that require specialist rheumatology care should not exceed eight weeks^{xxviii}. There are numerous ways that the RTT time can be streamlined to ensure that this is more likely to happen.

Tests for inflammatory markers and HLA-B27 should be ordered by the GP at the point of referral.

As has already been mentioned, there is a long delay for many Trusts for MRI. When a referral is received by a rheumatology department, it should be triaged quickly and an MRI booked in. Results should be available at the first rheumatology appointment, or at a minimum at the second. The first rheumatology appointment should take place within 4 weeks of referral to ensure a speedy time to treatment.

Trust rheumatology teams should work as an MDT MSK team and make the best use of resources with an optimal workforce model for the clinic. The first appointment should therefore be with the right professional with the ability to diagnose or offer treatment when waiting for a diagnosis. This could be a rheumatologist, but also physiotherapist.

All services will have different issues which cause delay to diagnosis and treatment and so data need to be collected via the National Early Inflammatory Arthritis Audit to allow services to address the individual issues that they have.

Finally, there needs to be sufficient new patient capacity available for timely appointments, which may require a change in management, such as moving those who are managing well to Patient Initiated Follow up^{xxix}, and the Best MSK Health Collaborative and GIRFT recommendation to move non-inflammatory conditions to be managed in the community^{xxx}.

4. Specialist physiotherapy needs to be recognised by ICB planning as a key component of a MDT approach in both the diagnosis and management of axial SpA within rheumatology, to help manage resource and give the best possible outcomes for patients.

The NICE Guideline specifies that patients should have access to specialist physiotherapy advice, but there is no clear definition of what specialist means; that is whether it is specific to rheumatology or more generally applies to MSK conditions. Within the MSK physiotherapy workforce it is nationally accepted that there are specific specialists for lower limb, spines or hands as examples. These professionals, whilst being specialists, would not of course be suitable to assess and manage a patient with suspected or confirmed axial SpA.

Therefore, it is vital to have specific specialist rheumatology or axial SpA dedicated physiotherapy staff. Outside of rheumatology services there can also be a misconception that physiotherapists are generalists; this needs to be tackled at ICB level to ensure that the appropriate workforce is appointed to manage axial SpA patients.

A lack of rheumatology undergraduate training, and recruitment and retention problems in physiotherapy are often cited as significant barriers to providing specialist physiotherapy care. Many Trusts also have physiotherapists on rotation which gives little time for education and training to be effective, with physiotherapists often moving on fairly quickly and never building the expertise effectively to support the axial SpA population.

It is clear, however, that specialist physiotherapists have a vital role to play in the diagnosis and management of axial SpA. Advanced practitioners in physiotherapy are able to diagnose people with axial SpA, and they can also provide help to manage symptoms while a patient is waiting for a diagnosis. These physiotherapists, used well, are able to free up others in the team.

Similarly, specialist physiotherapists - in rheumatology or axial SpA - with the appropriate clinical experience can support patients to self-manage their condition well and minimise utilisation of health and social care.

5. Trusts should have access to specialist axial SpA services and support within their ICB to help diagnose and manage complex cases.

Ideally, all patients with axial SpA will be able to access an MDT at a one stop clinic. The most common components of such a team include a consultant rheumatologist, specialist physiotherapist, rheumatology nurse specialist and occupational therapist. The team may also include a pharmacist, clinical psychologist, MSK radiologist and podiatrist.

Allied health professionals have a key role to play in supporting lifestyle interventions in diagnosed patients. For example, people with axial SpA are at increased risk of work disability, which has dire consequences on the individual, families and the social system. Specialist occupational therapists are best placed to identify and help resolve early work instability with targeted job retention vocational rehabilitation.

It is important to recognise that some smaller rheumatology units may struggle to find the resource to run such a clinic. In these cases, alternative arrangements can be put in place to help units with more complex patient needs, including access to colleagues to discuss individual cases either in person or via an online meeting, and the opportunity to refer to other teams within the ICB who are able to operate an MDT service.

There are examples of rheumatology departments with small patient cohorts and limited resources that have still been able to run specialist clinics. In addition, there are alternative arrangements such as a therapy-led clinic with fast-track access to a consultant if deemed necessary, or running clinics less frequently.

Conclusion

This inquiry has found that axial SpA services in England have not improved overall since the last inquiry, and in some areas the situation is worsening. This is not surprising given the impact of the pandemic and the current rheumatology workforce crisis.

There have been positive developments since the last inquiry was published in early 2020. These include the creation of the Best MSK Health Collaborative, the work of the Getting It Right First Time in Rheumatology programme and the national initiatives introduced by NASS.

But there is still work to be done. It is hoped that the recommendations in this report will help to bring further focus on the areas that need it most, and to support ICBs and health care providers to determine where improvements are needed most locally.

The APPG calls upon all Integrated Care Boards in England to implement the recommendations in this report which will help to improve time to diagnosis, treatment and care for people with axial SpA. Further to this, the recommendations should help to better use resources for teams struggling with capacity and reduce the pressures on rheumatology services.



Glossary of terms

All-Party Parliamentary Group (APPG)

Cross-party groups that meet, relatively informally, to discuss a particular issue of concern.

Anti-TNF therapy

A treatment which interferes with the action of a protein called tumour necrosis factor (TNF) which is over-active in people with axial SpA.

Aspiring to Excellence

A quality improvement programme led by NHS Transformation Unit which brings rheumatology teams together to work with experts in service improvement to collaborate on the planning and implementation of projects that will transform health care for people with axial SpA.

Axial spondyloarthritis

An umbrella term and it includes: ankylosing spondylitis where changes to the sacroiliac joints or the spine can be seen on x-ray; and non-radiographic axial spondyloarthritis where x-ray changes are not present but inflammation is visible on MRI or you have symptoms.

Best MSK Health Collaborative

A new programme with the aim of sustaining the delivery of evidence-informed, personalised, high-quality integrated health care of value to all with an MSK condition.

The Bath AS Disease Activity Index (BASDAI)

A set of 6 questions designed to determine levels of pain and fatigue in those with axial SpA.

The Bath AS Functional Index (BASFI)

A set of 10 questions designed to determine the degree of functional limitation in those with axial SpA.

Biologic therapy

Biologic medicines are complex proteins which target specific molecules believed to be involved in axial SpA. The biologic treatments currently approved for axial SpA are anti-TNF and IL-17a inhibitors.

Care Quality Commission (CQC)

The independent regulator of health and social care in England.

Champions in Primary Care

A group of health professionals working in primary care and community services who work to champion axial SpA amongst their peers to ensure axial SpA is higher within their clinical reasoning.

Clinical Commissioning Groups (CCGs)

NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in each of their local areas in England. On 1 July 2022 they were abolished and replaced by Integrated Care Systems as a result of the Health and Care Act 2022.

Extra Musculoskeletal Manifestations (EMM)

Co-existing conditions or presentations related to axial SpA.

First Contact Practitioner (FCP)

A registered health professional who are a part of a GP surgery and is the first point of contact for patients, usually in the field of MSK. These are most commonly physiotherapists but can also be other allied health professionals such as osteopaths.

Freedom of Information Request (FOI)

An ask to any public sector organisation for information they hold.

Future NHS

A collaboration platform that empowers everyone working in health and social care to safely connect, share and learn.

Getting it Right First Time in Rheumatology (GIRFT)

A national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change.

GP

Doctors who treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment.

Improving Access to Psychological Therapy (IAPT)

An NHS service designed to offer short-term psychological therapies to people suffering from anxiety, depression and stress.

Inflammatory back pain (IBP)

A condition of pain localised to the axial spine and sacroiliac joints that is chronic and is differentiated from mechanical back pain by a set of key diagnostic features.

Integrated Care Boards (ICB)

A statutory NHS organisation responsible for developing a plan in collaboration with NHS trusts/foundation trusts and other system partners for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the defined area.

Integrated Care Systems (ICS)

Partnerships of NHS bodies and local authorities, working with other relevant local organisations, that come together to plan and deliver joined up health and care services to improve the lives of people in their area

Magnetic resonance imaging (MRI)

A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

Musculoskeletal (MSK) conditions

A broad term, encompassing around 200 different conditions affecting the muscles, joints and skeleton.

Multi-disciplinary team (MDT)

A mechanism for organising and coordinating health and care services to meet the needs of individuals with complex care

National Institute of Health and Care Excellence (NICE)

A public body which publishes guidelines in four areas: the use of new and existing medicines, treatments and procedures), clinical practice guidance, guidance for public sector workers on health promotion and ill-health avoidance and guidance for social care services and users.

NHS Constitution

The principles and values of the NHS in England, setting out rights to which patients, public and staff are entitled, and pledges which the NHS is committed to achieve.

NHS Trust

An organisational unit within the National Health Services of England serving either a geographical area or a specialised function.

NICE Guideline for Spondyloarthritis (NG65)

Spondyloarthritis in over 16s: diagnosis and management – national guidance for clinicians diagnosing and managing people with axial SpA.

NICE QS170

Spondyloarthritis quality standard.

Occupational therapist

A healthcare professional that focuses on developing, recovering, or maintaining the daily living and working skills of people with physical, mental, or cognitive impairments.

Peripheral spondyloarthritis (SpA)

Inflammation and pain in joints and/or tendons primarily located outside the spine.

Physiotherapy/physiotherapist

Treatment which helps with movement and function when someone is affected by injury, illness or disability. Physiotherapists are healthcare professionals practicing physiotherapy.

Primary care

General practice, community pharmacy, dental, and optometry services.

Primary Care Networks

Groups of primary care practices working together to focus local patient care.

Rheumatology

A branch of medicine that deals with the investigation, diagnosis and management of people living with rheumatic and musculoskeletal diseases which tend to affect soft tissues, joints, bones, cartilage, tendons, ligaments and muscles.

Secondary care

Any care an individual receives for their illness or condition that occurs beyond the primary care they have already received.

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