



Act on Axial SpA: A Gold Standard Time to Diagnosis



Get axial SpA diagnosed fast.

Find out more at

actonaxialspa.com

**act on
Axial SpA**

Campaign fully
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 Inspired by patients.
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Royal United Hospitals Bath
NHS Foundation Trust


Norfolk and Norwich
University Hospitals
NHS Foundation Trust

**“Aged 17, I saw a rheumatologist.
I had been in pain for five years,
and I was exhausted. I could see
no hope of living in any other way.
Today, with a diagnosis,
I’m living my best life.”**

Bethany



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Calling Time on Delay

– A Gold Standard Approach

In July 2019, I was in Parliament for a meeting with parliamentary officers of our newly formed All Party Parliamentary Group (APPG) on axial SpA.

They asked me to explain all of the reasons for the delay to diagnosis in axial SpA and to offer a route map of solutions to address them. I left the meeting feeling that I hadn't answered their questions satisfactorily. I reflected on the literature, where studies on delayed diagnosis tend to talk about 'factors associated with delay', but what they don't typically do is follow the journey of the person living with axial SpA to understand that journey from the moment of symptom onset to diagnosis.

With that realisation in mind, I approached two of our medical advisors, Prof. Karl Gaffney and Dr. Raj Sengupta, and we worked together to map out the delay to diagnosis from a 'follow-the-patient' perspective, identifying four broad sets of delays. We then created a set of proposals to address each of these, and wondered what quantum of time to diagnosis might be achievable if our proposed solutions were implemented effectively. We concluded that it should be feasible for someone to be diagnosed with axial SpA within 12 months of symptom onset, and set out to develop a written proposal for a Gold Standard time to diagnosis with a target of one year.

I then approached colleagues at UCB who shared our aspirations and emerging strategy and encouraged me to consider a five year timescale in which we could develop a Gold Standard proposal and implement its recommendations in full. Spurred on by the possibility of a larger programme of work that would have the potential for significant impact, we began to test out the idea of a gold

standard approach in collaboration with clinicians. I was heartened by how positively the idea was received, and developed a growing sense that a Gold Standard approach might galvanise efforts to improve diagnosis in axial SpA.

Dr. Sengupta announced our ambitious goal at a meeting of the APPG in January 2020, and in July we launched a national consultation process to engage patients, clinicians, commissioners and policymakers, seeking their response to a document we developed to set out our ideas. The 202 responses to the consultation confirmed that we were on the right track and led us to develop more specific proposals which we began to test out in the early part of 2021. My grateful thanks to all of those people who have contributed in various ways to the consultation and programme development process, culminating in a consensus development workshop in May 2021.

This report outlines our final set of proposals to achieve a Gold Standard of one year, under the campaign name Act on Axial SpA. We will work closely with people living with axial SpA, primary and community care, secondary care, professional bodies, commissioners, Parliamentarians and policymakers as our campaign seeks to focus and streamline efforts to achieve earlier diagnosis. The report set out proposals for programmes addressing public awareness of axial SpA, healthcare practitioner education, referral pathways, and service quality improvement in order to improve patient experience, diagnosis and outcomes.

The campaign website, actonaxialspa.com, provides an online resource which we hope will become the largest and most comprehensive resource on axial SpA diagnosis

anywhere in the world. It contains information and diagnosis support tools for the public, including an online symptom checker, as well as newly created and curated resources for healthcare professionals (HCPs), which guide them through research articles, best practice examples, quality improvement tools and case studies for each of our four solutions as we follow the patient journey.

We are publishing this report at a time when the UK is beginning to emerge from the Covid-19 pandemic. In England, the Best MSK Health Collaborative has been established to restore and improve MSK services and reduce the variation in service provision. One of the collaborative's outputs is a new axial SpA pathway and we were involved in its development. Act on axial SpA will encourage the widespread implementation of the pathway in order to achieve earlier diagnosis. The APPG on axial SpA will continue to press the case for early diagnosis and raise the profile of the condition within Parliament. In Scotland, we continue to work through the Cross Party Group on MSK Health, in Wales we will work with the newly established MSK Pathway Steering Group and in Northern Ireland we will seek opportunities to engage the administration.

My heartfelt thanks to those organisations that have given their support to this document; over the coming months we will call for every NHS organisation and relevant professional body to endorse it and commit to supporting its implementation. My thanks to the Chair and Co-Chair of the APPG - Tom Randall MP and Lord Campbell Savours – former APPG Chair, Derek Thomas MP and all of the Parliamentarians who are supporting this work.



8.5

Years to diagnosis

The current average delay to diagnosis from when symptoms start is 8.5 years, during which irreversible damage to the spine may have occurred.

I want to acknowledge the phenomenal leadership and vision of our clinical collaborators Prof. Karl Gaffney and Dr. Raj Sengupta, and also thank Dr. Stephen Zhao and Rosie Barnett for their incredible help and support on the background literature and documentation and Nick Clarke who provided a patient perspective. This programme would not have been possible without the outstanding and steadfast support of UCB whose commitment, passion and insight has been incredibly energising. Finally, I want to thank the outstanding team at NASS who have worked tirelessly for the best part of a year to bring this ambitious programme to life, and in particular Dr. Lisa Swinger and Liz Marshall. Thank you!

**Dr. Dale Webb, FRSA, FRSPH
CEO, NASS**

“As an MP living with axial SpA, I am excited to see this programme come to life. This will be the springboard to a better future for many young people and a vehicle to effect real change.”

Tom Randall, MP

Delayed diagnosis of axial SpA and its impact

Axial spondyloarthritis (axial SpA) is a life-long inflammatory condition that primarily affects the spine and sacroiliac joints. The term axial SpA encompasses both ankylosing spondylitis (AS), where clear structural changes to the spine can be observed via x-ray, and non-radiographic axial spondyloarthritis (nr-axial SpA) which is diagnosed from other clinical features and magnetic resonance imaging (MRI) (1). The fact that cases present differently and may require different diagnostic approaches to confirm the disease is one of the first clues as to why diagnosis of this condition can prove challenging.

Axial SpA is more common than people realise, affecting 1 in 200 adults in the UK, which is more than the number of people with multiple sclerosis and Parkinson's disease combined (2, 3). The primary symptom is chronic lower back pain, for which between three and seven million GP consultations take place each year in the UK (4), therefore it is perhaps not surprising that this symptom alone does not immediately trigger thoughts of axial SpA.

1 in 200 people in the UK have axial SpA making it more common than MS and Parkinson's combined.

People with axial SpA also often experience other symptoms as part of their condition, such as fatigue, morning stiffness, sleep disturbance and reduced function/mobility (5, 6), as well as other musculoskeletal manifestations (hip or hind foot arthritis, enthesitis, dactylitis and extra-skeletal manifestations including acute anterior uveitis (AAU), inflammatory bowel disease (IBD), and psoriasis in one-third of patients (7). All of these symptoms can impair quality of life further by adding considerable additional physical, emotional and economic burden. It is therefore critical that individuals receive the care that they need as soon as possible to improve their quality of life (8-12) and long-term outcomes.

Sadly the current time to diagnosis in the UK averages 8.5 years from symptom onset (13) despite various guidelines and recommendations to improve referral of patients with chronic lower back pain, and two recent systematic reviews have found significant delays to axial SpA diagnosis worldwide with a global mean of 6.7 years (13-21). This delay is unacceptable. Axial SpA typically starts in the second or third decade of a person's life, often derailing hopes and dreams at a critical time for attempting to establish careers and relationships (16). A delayed diagnosis during these formative years can therefore be extremely disruptive. Some people report not feeling listened to or believed about their symptoms, while others feel helpless and withdraw from care completely, leading to further diagnostic delay (17). People with delayed diagnosis may also suffer from a less favourable response to treatment and worse outcomes in disease activity, fatigue, function, spinal mobility and radiographic damage to the spine (8, 18-20). These individuals also experience difficulty sleeping and have a higher prevalence of mental health and psychosomatic disorders (20). One study demonstrated impaired spinal mobility to be twice as high in individuals with a diagnostic delay of over six years, in comparison to individuals diagnosed in less than six years (8). A recent systematic review of the literature found that people with delayed diagnosis also had a greater likelihood of depression, negative psychological impacts, work disability, worse quality of life and higher healthcare costs (8) and

that the disease had a significant societal impact, due to economic factors such as work disability and healthcare cost. Diagnostic delay was consistently related to a higher risk of work disability or unemployment and associated with job loss (8). Specifically, one study in Ireland demonstrated that unemployment rose from 20% among people diagnosed with axial SpA within four years, to more than 40% among those with a delay of over 10 years.

Several factors have been independently associated with a longer diagnostic delay: including female sex, HLA-B27 negativity, lower education levels among patients, prior diagnosis of mechanical back pain, presence of uveitis, psoriasis or enthesitis and young age of symptom onset (18, 21-24). Presence of peripheral arthritis and IBD have been associated with earlier diagnosis and treatment (13, 25, 26) leading to better outcomes and treatment responses (18, 19). The shorter time to diagnosis in individuals with peripheral musculoskeletal manifestations is likely due to the fact that GPs have been consistently prompted via the early arthritis initiative to refer patients with swollen joints to rheumatology (13, 25, 26). This reflects the impact that educational tools can have on improving early referral to rheumatology for individuals with suspected inflammatory arthritis.

Evidence emphasises the importance of recognising the condition early. We know that targeted awareness-building and education can positively impact time to diagnosis. GPs were found to improve substantially the

In the UK, people living with axial SpA wait an average (mean) of **8.5 years** to receive their diagnosis (1, 2) This means that there are potentially thousands of people at any one time who are living with debilitating and painful symptoms, but with no agreed clinical explanation or treatment path.

Almost
40%
of individuals with
axial SpA do not
contact a healthcare
practitioner within
a year of symptom
onset

(2)

recognition and referral of people with suspected axial SpA (27, 28) after receiving education about SpA, with one recent multi-centre study demonstrating over 40% improvement in referral (27). Equally, among physiotherapists, good awareness of the NICE 2017 guidance on axial SpA and continuing professional development was associated with better awareness and knowledge of axial SpA features (29).

Evidence suggests that we need to promote/provide sustained education and awareness among the public and healthcare professionals - as part of a broader set of change mechanisms - to ensure that axial SpA is at the forefront of clinical reasoning. It is therefore critical that initiatives designed to improve knowledge and awareness and to ensure early specialist referral and diagnosis are embedded and sustained within care pathways. Greater public awareness of axial SpA and its wide range of symptoms will also help to tackle this unacceptable delay to diagnosis.

“Parenting my children was 10 times more difficult and I got very low. Once I’d received my diagnosis and got the right treatment, I was able to trek along the Great Wall of China.”

Poppy

“My pain became so bad that, at times, I couldn’t get out of bed. I relied on crutches to remain mobile. It’s amazing to think of that now. An earlier diagnosis may have prevented all of that.”

Rowena

“Especially for younger people this diagnosis doesn’t mean your ambitions and goals have to disappear. With the right medication, and if you build healthy habits, it’s possible to live the life you want to lead.”

Max

The patient journey to diagnosis

A person with back pain does not realise that it might be axial SpA

Axial SpA represents a relatively uncommon cause of a very common symptom – chronic lower back pain (30). Up to 80% of the population may experience back pain at some point within their lifetime. Thus, many individuals with undiagnosed axial SpA, lacking awareness of axial SpA, attribute their symptoms to over-exercise, injury or other life stressors; only two thirds of people with axial SpA report contacting a healthcare practitioner within 12-months of developing symptoms (31). Many individuals attempt to self-manage their condition until either self-management fails or the condition worsens, and they are prompted to seek professional advice (32-34). Furthermore, those who have sought clinical help but remain undiagnosed often feel dismissed or unheard by the healthcare system and cease to come forward for long periods, as their disease worsens.

Primary care practitioner may not recognise axial SpA

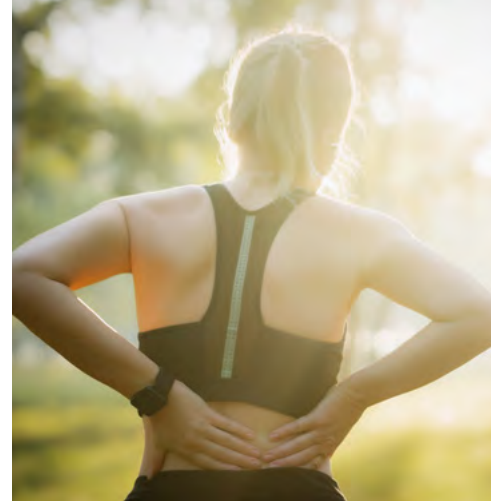
People with undiagnosed axial SpA usually first present with chronic lower back pain to their general practitioners (GPs) or other non-rheumatology primary care providers. However, there is a low level of specialist knowledge of axial SpA in primary care (29, 35-40). Approximately 40% of people with axial SpA also report seeking treatment pre-diagnosis from osteopaths or chiropractors, many of whom may not have specialist knowledge on axial SpA (41). In addition, in a recent survey of chiropractors and osteopaths, the principal perceived barrier to onward referral was reluctance by the GP to accept their professional opinion (16). Patients may also find difficulty conveying their symptoms, and as reported in patient interviews (17, 32) have experienced negativity or reluctance from GPs to investigate further.

Common misconceptions about axial SpA also remain in primary care. The Oxford Handbook of General Practice still refers to late stages of axial SpA, with a focus on males and late disease features such as fusion of the spine and SIJs (42). This perspective persists from historical knowledge of the disease, for example its strong genetic association with the human leukocyte antigen B27 (HLA-B27) gene; yet up to 25% of axial SpA patients are HLA-B27 negative (43). Women are more likely to be HLA-B27 negative, contributing to the perception that it is a predominantly male disease. Also, the presence of radiographic changes, historically critical for identifying ankylosing spondylitis (AS), are more common in males. But we now know that early disease does not usually display as structural bony changes on radiographs, and ~50-70% of individuals with this non-radiographic axial SpA are female. Despite this knowledge, a recent study reported that GPs still believe that AS is almost exclusively a male disease (35).

Person with symptoms suggestive of axial SpA is not directly referred to rheumatology services

A 2019 APPG inquiry found that only 21% of the 191 clinical commissioning groups (CCGs) and 99 provider Trusts had a specific inflammatory back pain pathway from primary care to rheumatology (44). Without this pathway, many cases of unexplained chronic back pain may be referred to orthopaedics or chronic pain management services, leading to unnecessary, ineffective treatments or even surgery (45).

Similarly, consultants in ophthalmology, gastroenterology and dermatology respectively miss axial SpA symptoms in individuals presenting with AAU, IBD and psoriasis, each of which, as an extra-skeletal manifestation of axial SpA, could be indicative of the disease. In the multicentre Screening for Axial SpA in Psoriasis, Iritis (AAU), and Colitis



cohort, 48% of people with psoriasis, AAU or colitis, <45 years of age with >3 months undiagnosed back pain were diagnosed with axial SpA if using a three-stage evaluation approach (clinical evaluation, laboratory results [HLA-B27, CRP] and radiography, MRI) (46); 69% were diagnosed with axial SpA after the clinical evaluation alone (47). These figures suggest that many opportunities to identify, diagnose and treat axial SpA are being missed.

Rheumatologist may not have the most up-to-date understanding of axial SpA and appropriate investigations

The diagnosis of axial SpA is complex, whereby individual symptoms or tests in isolation are insufficient to either diagnose or rule out axial SpA; rather a combination of axial SpA symptoms, physical examination, appropriate diagnostic tests and imaging should lead to diagnosis. However, not all rheumatologists have specialist knowledge of axial SpA or feel confident implementing or interpreting the appropriate investigations, particularly MRI scans. Just one-third of NHS hospitals perform the recommended MRI protocol for axial SpA (48, 49). Interpretation of MRI is also challenging and depends on the expertise of the radiologist. A recent study found inconsistencies in the use of MRI in clinical practice (50) resulting in challenges in interpreting MRI in diagnosis (50, 51). However, consensus recommendations for MRI use in the diagnosis of axial SpA have been published (51). Their adoption, supported by training of rheumatologists/radiologists in the interpretation of MRI in the context of suspected axial SpA, should help standardise practice and achieve consistent, reliable diagnosis (52).

The roadmap to reducing delay to diagnosis

A national consultation process

Over an 11 month period we undertook a national consultation process which included people living with axial SpA, healthcare professionals, professional bodies, communications experts and commissioners. We undertook a scoping literature review, then created a consultation document which set out our analysis and proposals (53). We created a survey and sent it and the consultation document to hundreds of organisations and individuals. We received 202 responses with all respondents supporting the principles behind the proposals and the aspiration for a Gold Standard time of one year.

We had to adapt our consultation processes in light of the Covid-19 pandemic and we were especially grateful that clinicians were able to remain engaged despite the enormous pressures that the pandemic created on the NHS. We held a workshop with public health specialists, journalists and documentary makers and other communications experts to develop our thinking about public awareness campaigning. We invited a group of stakeholders to comment on a 'concept note' for a primary care champions programme. In May 2021 we held a consensus development workshop with 75 stakeholders to share our draft final recommendations and seek their input.

An integrated campaign using multiple change levers

- There is a wealth of literature suggesting that the key to creating sustainable improvements in healthcare is an integrated whole-system approach that uses multiple change levers (54). Act on axial SpA employs a multi-lever approach, building on work that NASS has already begun. The campaign should, therefore be viewed in a holistic way.

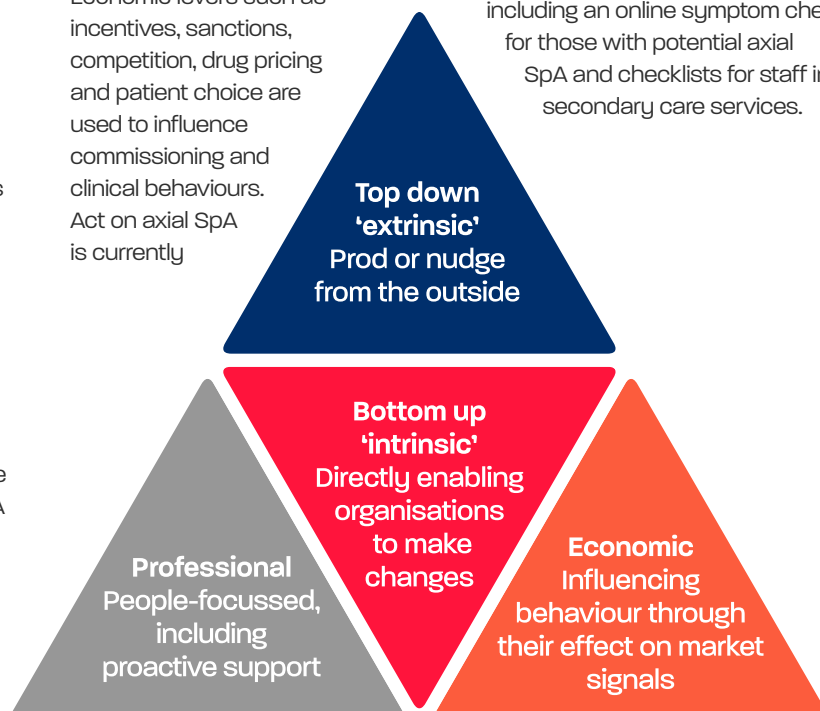
- First, are the top down or extrinsic levers, typically governmental approaches that include legislation, regulation and performance management systems. In 2019 NASS worked with Parliamentarians to form the axial SpA APPG with the specific intention of creating a top down lever that would seek to ensure the effective implementation of the NICE Guideline on the diagnosis and management of spondyloarthritis. Act on axial SpA will periodically report progress to the APPG.
- Top down levers are balanced by bottom up levers that tap into the intrinsic motivators of clinicians that want to provide the best for their patients. In 2019 NASS created *Aspiring to Excellence* to provide rheumatology teams with the quality improvement tools and support to improve care at local level. Most of the 11 hospitals involved are trialling different approaches to reducing time to diagnosis and may provide examples of best practice as the campaign unfolds.
- Economic levers such as incentives, sanctions, competition, drug pricing and patient choice are used to influence commissioning and clinical behaviours. Act on axial SpA is currently

commissioning a research study to estimate the full economic costs of delayed diagnosis in the UK in order to influence policy makers and commissioners and use in our Parliamentary lobbying.

- Professional levers include education and training, clinical audit, peer review and guidelines. The UK has multiple initiatives including regional SpA Academies, the National Early Inflammatory Arthritis Audit and the Getting it Right First Time programme.

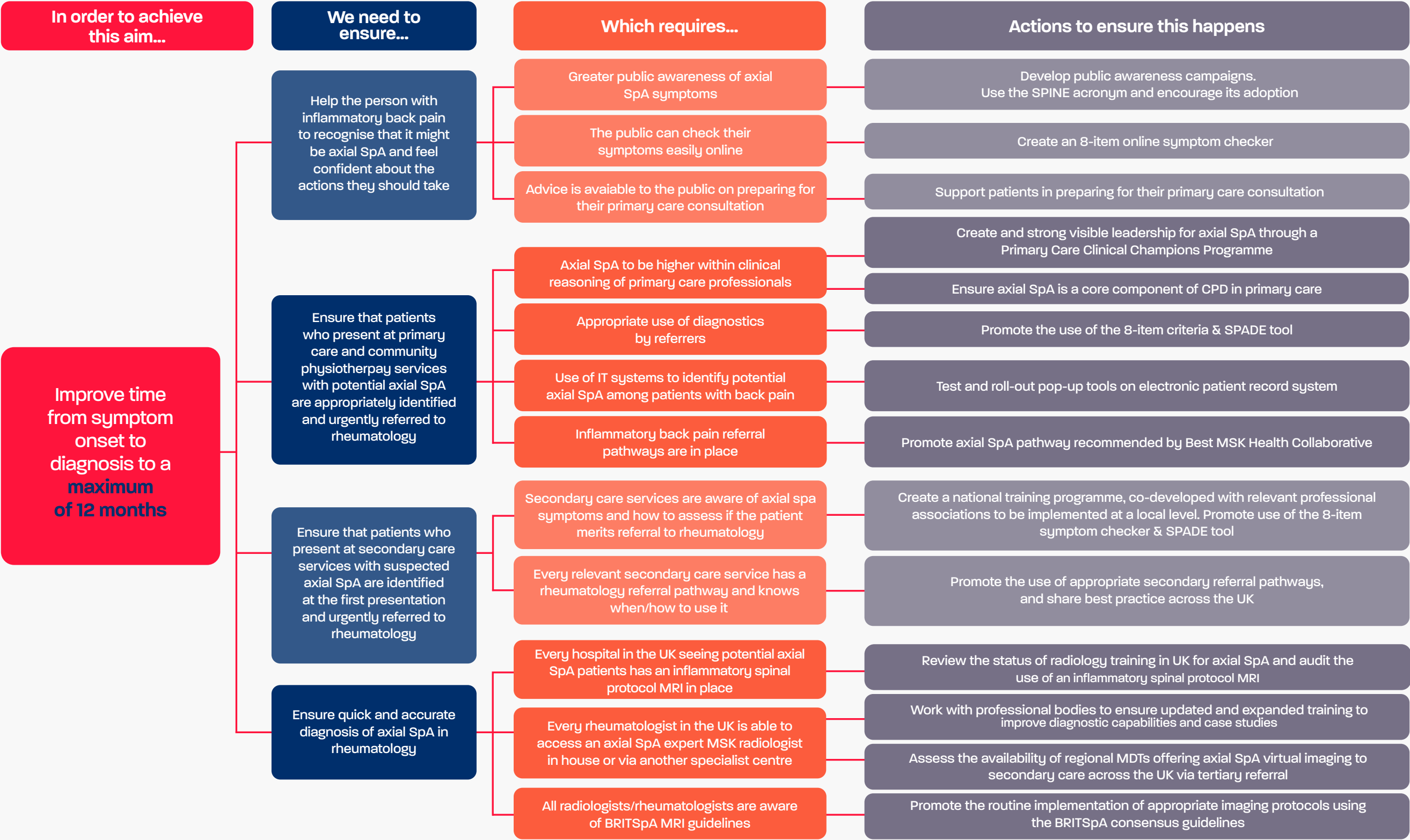
Another way to articulate this is to propose that interventions are either system focussed or people focussed. Some might argue that one or the other is more important, and indeed the debate about whether behaviour is shaped more by social structure or human agency is one that has occupied sociologists since Weber and Durkheim in the late 19th century.

Act on axial SpA draws on both sets of interventions: system interventions including referral pathways to simplify and standardise care, and the use of automation in electronic patient records, and people interventions including an online symptom checker for those with potential axial SpA and checklists for staff in secondary care services.



Driving change

The Driver Diagram (below) summarises our thinking on the four primary changes that the campaign seeks to achieve, the strategy to achieve each of them and then the specific interventions required to ensure that we achieve our goal. The remainder of this document sets out those proposals in greater detail.



Helping someone with inflammatory back pain to recognise that it could be axial SpA and feel confident about the actions they should take

The first delay to diagnosis of axial SpA is late presentation by the patient to primary care. Improving public awareness of the condition and its sign and symptoms, and understanding what to do if one has the correct symptoms, is critical to achieving earlier presentation in primary care.

Public awareness campaigns

We encourage NHS organisations, professional bodies, and private and public sector organisations to support the Act on Axial SpA campaign which has been designed to target people who are aged 40 and under in particular. Its aim is to help people understand the condition and its symptoms, empower people to consult primary care at the earliest opportunity and make clear the referral pathway if the primary care professional suspects axial SpA. The campaign will seek to create a sense of urgency but without scaremongering. The core components of the campaign strategy are:

- **A clear articulation of the problem:** On average it takes over eight years for axial SpA to be diagnosed. This is too long. Every year that passes without diagnosis can lead to deeper damage.
- **A defined campaign purpose:** To reduce the average time to diagnosis to one year.
- **A definition of how we will achieve our ambition:** The campaign will ensure that the public recognise the symptoms of axial SpA, know what to do next and what should happen if the healthcare professional suspects that they have axial SpA.
- **A core campaign concept** of 'a race to stop the progress of the condition' will underpin all of the campaign communications.

Our vision:

General public awareness of axial SpA and its symptoms is significantly improved. People with chronic, low-back pain lasting longer than three months - particularly those aged 40 and under - are aware that it could be related to axial SpA and are motivated to consult their GP/primary care professional at the earliest opportunity and within four months of symptom onset. The public can easily check their symptoms online, feel empowered and are aware of the referral pathway if the primary care professional suspects axial SpA.

Stories about people who have faced a long delay to diagnosis will be central to the campaign communications across all platforms, bringing the issue to life. The campaign will adopt a phased test and learn approach, to see what works most effectively in terms of messaging and delivery, and from there will make informed decisions regarding investment in bigger, more ambitious tactics.

Phase one communications to drive public awareness will test the act on axial SpA brand and key messaging and will include:

- **A media relations** programme, with an emphasis on the TV, radio programmes, podcasts and publications likely to be trusted by our target audience.
- **Social media activity** targeted by age: Instagram for those under 25s and Facebook for 25-45s.
- **Engaging with social media influencers** to primarily reach the under 25s audience.

- **Community poster campaign** across community centres, GP surgeries, leisure centres and other places that the key audience groups are likely to visit.

Phase Two is likely to include a concentrated local campaign in a single area, combining learning from Phase One and adding new communication tactics such as outdoor advertising, with a particular emphasis on public transport hubs. If these tactics result in an increase in rheumatology referrals the campaign may be extended to other parts of the UK.

"At first, I just thought I had sports injuries, nothing serious. Over the years, I saw doctors, physios and chiropractors who put my chronic pain down to sport injuries, growing pains, or weight issues."

Paul



Delay to diagnosis of axial SpA is linked to poorer outcomes including greater functional impairment and higher prevalence of depression

(8,18,20)

The SPINE acronym

Axial SpA is a complex condition to articulate and explain. To be successful in engaging the public requires a graduated approach to communication which takes the audience through an information journey, as follows:

- State what the condition is and raise awareness that someone's back pain might be axial SpA.
- Set out a small number of key symptoms that will resonate with the public and be easy to remember.
- Identify a larger number of symptoms which have a high degree of sensitivity and specificity and which provide a sound basis for recommending that the person consults primary health care.

To that end, act on axial SpA has developed the **SPINE** acronym, which sets out the following key symptoms:



Symptoms starting slowly
Pain in the lower back
Improves with movement
Night time waking
Early onset (under 40)



SPINE will be widely used in the act on axial SpA campaign and we encourage all supporting organisations to adopt the acronym in awareness raising work with the general public.



An eight-point set of inflammatory back pain criteria and online symptom checker

The campaign communications goes beyond media messaging and creates value for audiences by empowering people to explore the condition and their symptoms via a new online resource actonaxialspa.com. On the website, people can use an online symptom checker. It employs an eight-point set of inflammatory back pain criteria that combine the three extant validated sets of criteria (55-57). If the person gives the correct response to five or more items (see right) they will then be given information about consulting primary care.

Supporting patients in preparing for their primary care consultation

Actonaxialspa.com will include a range of resources for people to advise them about the need to book a primary care consultation. It will provide a print-out of the symptom checker results - with an explanation for the primary care professional on the criteria used.

- 1 Did your back pain start before the age of 40? **YES**
- 2 Did your back pain develop gradually? **YES**
- 3 Has your back pain lasted more than 3 months? **YES**
- 4 Do you experience stiffness in your back in the morning for at least 30 minutes? **YES**
- 5 Does your back pain improve when you move around? **YES**
- 6 Does your back pain improve when you rest? **NO**
- 7 Do you have pain in your buttocks, which moves from one buttock to the other? **YES**
- 8 Do you wake in the second half of the night because of your back pain? **YES**

Ensuring that patients who present at primary and community care with potential axial SpA are appropriately identified and urgently referred to rheumatology

Primary care and community services have a key role in identifying patients with suspected axial SpA and referring them directly to rheumatology. Most people with suspected axial SpA will consult primary care in the first instance, and around 5% of patients with chronic back pain attending primary care are estimated to have axial SpA (58). However, people with axial SpA frequently report to NASS that their primary care professionals failed to identify their axial SpA, misdiagnosing it as mechanical pain or sometimes ascribing psychosomatic reasons.

Primary healthcare professionals report numerous barriers to diagnosing axial SpA, including low prevalence, the lack of a definitive diagnostic test, the slow progression of the condition and the intermittent nature of the pain that patients experience (59). Even amongst MSK physiotherapists, awareness, knowledge and confidence in

screening for suspected axial SpA and referring to rheumatology is low, and a recent study concluded that this group of professionals may not be giving adequate consideration to axial SpA in back pain assessments (29).

A recent national inquiry into axial SpA services in England led by the APPG for axial SpA found that only 15%

of CCGs have specific programmes in place for educating primary care professionals about axial SpA (60).

Consequently, axial SpA is likely to be low within the clinical reasoning of most GPs and MSK clinicians and the condition lacks visibility within primary care.

Our vision:

All patients who present to primary care with suspected axial SpA are appropriately identified and urgently referred to rheumatology, as set out in a local inflammatory back pain referral pathway. Axial SpA is higher within the clinical reasoning of primary care professionals, supported by alerts on electronic patient records which prompt consideration of axial SpA for appropriate patients. Within England, there is widespread adoption of the Best MSK Health Collaborative axial SpA pathway.

“At the start of your GP appointment, explaining you are really concerned that you might have axial SpA is super helpful, ensuring you get what you need.”

Dr Daniel Murphy, GP,
Devon, UK



Strong, visible clinical leadership for axial SpA at local level in primary care

To strengthen clinical leadership and visibility for axial SpA in primary care and community services, we will create and support a cadre of clinical champions including First Contact Practitioners, GPs, community MSK physiotherapists, nurse practitioners and others. They will receive leadership development, training in using quality improvement methods, and support to identify and implement improvement projects within their local healthcare system. They will work together in a national learning network to foster community-building, the exchange of ideas and good practice and they will act as catalysts for change.

Axial SpA clinical champions will be active within the wider healthcare system, connecting to the national policy environment. Axial SpA clinical champions will co-produce a body of knowledge, methods, tools and experience and work to share their learning with primary and community services across the UK, collaborating with relevant professional bodies. They will promote relevant frameworks including the forthcoming rheumatology specialist physiotherapy Competency Framework (61).

Participating clinical champions will benefit from enhanced leadership skills and greater confidence in undertaking service improvement work. They will develop their networking skills and enlarge their professional network. They will gain access to resources and expertise as well as create new resources for other healthcare professionals. Their work will directly result in earlier identification of patients with suspected axial SpA and quicker referral to rheumatology. We also anticipate benefits in terms of better primary care management of axial

SpA patients: with an up-skilled primary care workforce, one would expect to see a better understanding of medication, exercise, fatigue and mental health in axial SpA.

Axial SpA as a core component of continued professional development

Act on axial SpA will work in partnership to encourage the prioritisation of MSK as a core component of continued professional development within primary care and to ensure screening for inflammatory conditions. The campaign will support Health Education England's Primary and Community Care Training Hubs, workforce education initiatives in NHS Education and Improvement Wales, and NHS Education for Scotland. We will promote our online resource, actonaxialspa.com, which brings together a wide range of educational resources for primary care professionals. The campaign will disseminate and embed axial SpA resources that are developed through the primary care clinical champions programme.

We want to ensure that primary care referrers have access to and use appropriate tools: we will promote the eight-item inflammatory back pain (IBP) criteria as well as the SPADE tool (www.spadetool.co.uk) which has been designed to assist medical professionals define the probability of axial SpA in a patient with chronic back pain, below the age of 40.

Primary care information systems that can flag patients with suspected axial SpA

To support primary care professionals to identify appropriate patients early, we will support the uptake of a pilot project in Bath that has successfully implemented a tool on the GP electronic patient record system. Under this pilot, when a GP types "back pain" the system

checks whether the person is under the age of 45, and whether they have previously had back pain. If the answer to these is yes, it prompts consideration of axial SpA. It can also be programmed to alert the GP of possible axial SpA if the patient has had AAU, psoriasis or IBD in the past.

Widespread adoption of the Best MSK Health Collaborative axial SpA pathway

The Best MSK Health Collaborative was developed in 2021 by NHS England and Improvement and is led by the National Clinical Director, Musculoskeletal Conditions. It seeks to restore and improve MSK services and reduce the variation in service provision. One of the Collaborative's outputs is the development of an axial SpA pathway. It reflects recommendations in this document, and is now being promoted to NHS regions. The campaign will promote the widespread adoption of the pathway and will monitor its implementation through Freedom of Information requests.



Ensuring direct referral to rheumatology for patients with suspected axial SpA attending secondary care services

Given the high prevalence of peripheral and extra-musculoskeletal manifestations of axial SpA, clinicians across ophthalmology, gastroenterology, dermatology and orthopaedic spinal surgery have a key role in screening undiagnosed patients for referral to rheumatology. These specialists may not be familiar with axial SpA or know how to assess for its probability. If they do suspect axial SpA, they may reroute the patient back to the GP or follow a standard 18-week secondary referral route, all of which adds to delay.

A national training programme

The act on axial SpA campaign will develop a national training programme for secondary care services to be implemented at a local level, led by rheumatologists and their teams. It will be developed in consultation with the professional organisations representing these specialist disciplines, piloted across the NASS *Aspiring to Excellence* sites and then refined for national roll-out. We envisage that the education package will resonate most effectively through a combination of online access to learning and face to face teaching sessions on site at the hospital base, such as lunch-time seminars on axial SpA signs and symptoms as well as reviews of real case studies on delay. The campaign will support rheumatology teams with promotional materials to promote the training delivery and its key messages.

The programme will create a set of learning tools to raise awareness of axial SpA symptoms and to ensure that the condition is on the checklist at first presentation of a new referral. A list of screening questions to raise during the consultation will also be provided. The programme will include statistics on the likely incidence of undiagnosed axial SpA among new patient referrals.

Our vision:

Patients with suspected axial SpA who present at a range of services - including ophthalmology, gastroenterology, dermatology, orthopaedics - are identified at the first presentation and urgently referred to rheumatology. Relevant secondary care services should be aware of axial SpA symptoms and how to assess if the patient merits referral to rheumatology. Every UK hospital seeing potential axial SpA patients should have a rheumatology referral pathway, and all specialists know when/ how to use it.

It will also create a toolkit to help rheumatology teams with the delivery of the educational package (digital/ online and face to face). There will be a targeted media and professional communications programme including presentations, exhibitions and poster case studies at events. The educational programme will be designed with sustainability in mind, to help ensure that the education of healthcare professionals in these disciplines can be embedded into local NHS practice.

Internal referral pathways

To reduce diagnostic delay, it is vital that specialists who suspect axial SpA are aware of and use their hospital's internal referral pathway to rheumatology, rather than sending the patient back to their GP. The campaign will audit this through Freedom of Information requests. Where there are gaps, we will engage with the relevant CCGs, Locality Networks, NHS Boards, Local Commissioning Groups, hospitals and regional NHS bodies to encourage implementation of appropriate referral infrastructure/ training. The referral pathway and

its use will be promoted through the education programme.

Sharing best practice of referrals

The campaign will collect best practice examples of relevant referrals/ pathways, creating digital publications and promoting these widely among the relevant stakeholder groups via actonaxialspa.com. It will build awareness of the website amongst our target healthcare professional audiences and ensure the highest quality data, clinical practice information and evidence-based best practice learning is made available to them to enhance their axial SpA diagnostic capabilities.

“Pain had been my reality for such a long time I didn’t know what was normal. At this point the rheumatologist diagnosed me with non-radiographic axial spondyloarthritis.

I had mixed emotions. I was over the moon to have an answer but all I really wanted to get was a diagnosis and a magic pill to cure me”

Max



Photograph by: Jonathan Blackham

up to
13%
of individuals with IBD
may have axial SpA
(62)

20-40%
patients with acute
anterior uveitis (AAU)
may have axial SpA
(60, 61)

25%
of individuals with
psoriatic arthritis
may also fulfil criteria
for axial SpA
(63)

Ensuring quick and accurate diagnosis of axial SpA in rheumatology

The delays when the patient is being assessed by rheumatology span several aspects of diagnosis, including the use of biomarkers, the application of classification criteria, imaging choices and the interpretation of these results (Figure 1). Our solutions to help reduce delay are focused primarily on the issue of imaging challenges and how these impact a swift and accurate diagnosis. Some of the imaging challenges include:

Inconsistencies in MRI acquisition: just one-third of NHS Trusts perform the recommended MRI protocol for axial SpA (48, 49).

High inter- and intra-observer variability when assessing conventional SI joint X-rays (62-67).

Lack of significant improvement in reproducibility and performance of identification of radiographic sacroiliitis after training (62).

Lack of agreement around what constitutes a 'positive' MRI suggestive of axial SpA (68, 69) potentially leading to over-diagnosis or misclassification if used for diagnostic purposes without context (68, 70-77).

Lack of general awareness of the term axial SpA among UK radiologists: survey responses of 269 UK radiologists found that just 75% were aware of the term axial SpA and only 31% and 25% were aware of the ASAS definitions of positive MRI for the SI joints and spine, respectively (50).

Consensus recommendations for the acquisition and interpretation of MRI in the diagnosis of axial SpA have been recently developed by BRITSpA (51). Their national implementation should help standardise practice and allow for

a more consistent, reliable approach to diagnosis (51). Radiologists have an important role in the diagnostic pathway; therefore their engagement alongside rheumatologists will be critical. The imaging problems described call for better training of rheumatologists and radiologists in the use and interpretation of MRI in the context of suspected axial SpA (52). We will also identify and promote best practice examples of NHS Trusts and regional rheumatology/radiology MDTs that meet to discuss complex complex and challenging cases.

Our vision:

Every hospital in the UK seeing potential axial SpA patients has an inflammatory spinal MRI protocol in place. Every rheumatologist in the UK is able to access an axial SpA expert MSK radiologist in-house or via another specialist centre.

All radiologists and rheumatologists are aware of and use the BRITSpA MRI guidelines.

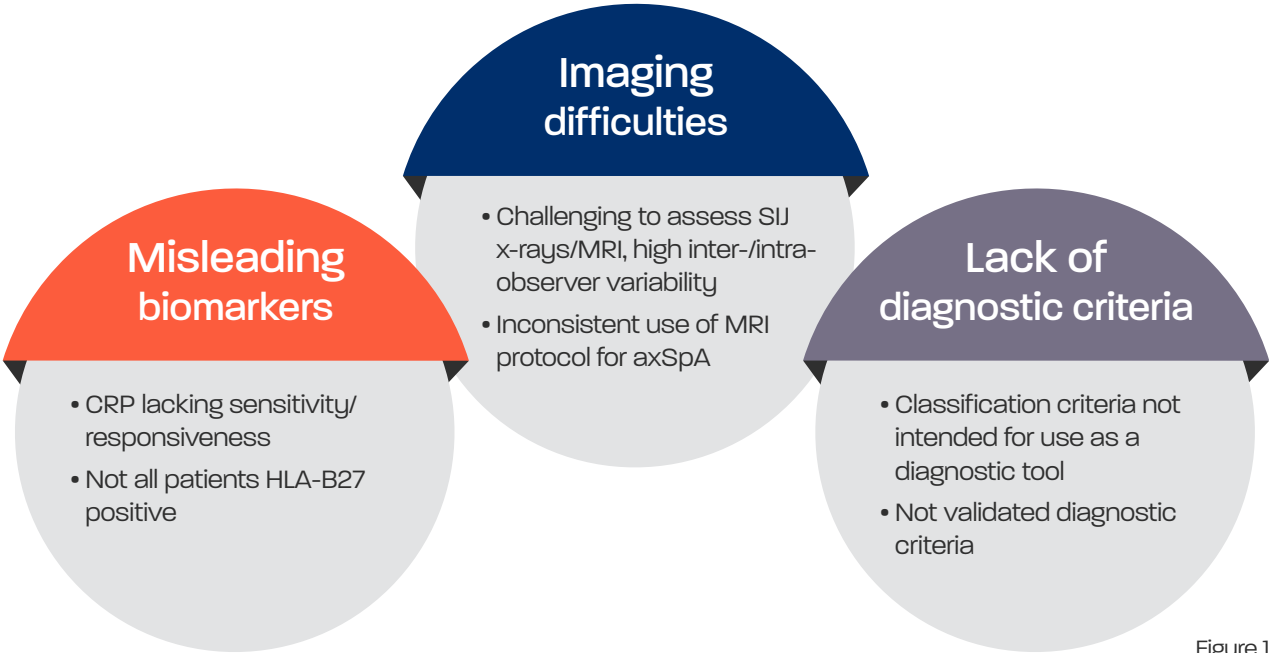


Figure 1



Understanding the radiology axial SpA diagnostic landscape across the UK

The campaign will work with relevant national bodies to review radiology training in axial SpA as well as audit the use of an inflammatory spinal protocol MRI through a Freedom of Information request to hospitals. This will deliver a full understanding of the current UK curriculum/opportunities on radiology diagnostics for axial SpA, for all levels of HCPs. It will also indicate which hospital sites require an MRI protocol update.

Updating radiology axial SpA diagnostics training curricula

Action on axial SpA will develop an up-to-date axial SpA MRI training programme, co-developed with rheumatologists and radiologists and endorsed by the British Society for Skeletal Radiologists, the British Society for Rheumatology and the Royal College of Radiologists. It will encourage professional organisations to update and expand their own training materials and promote guidance to reach undergraduate

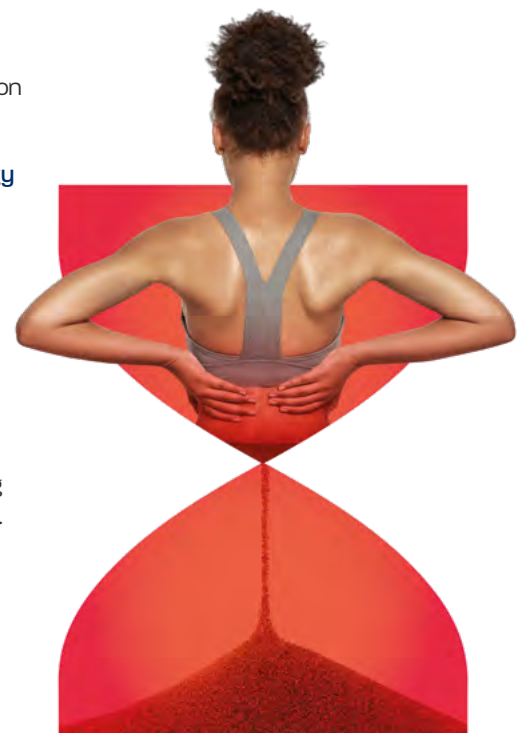
medical students, foundation and specialty HCPs. The campaign will support ongoing accreditation training and voluntary expert additional training via the NHS or professional bodies/ third parties. It will provide training materials through online learning, face to face teaching sessions on-site at the hospital and case studies. Using the BRITSpA consensus papers (50, 51) the campaign will promote best practice for the routine implementation of appropriate imaging protocols.

Utilising rheumatology and radiology services with axial SpA expertise or capacity

Tertiary referral pathways have also been shown to be valuable. The campaign will promote tertiary referral centres to assist with interpretation of difficult imaging cases and explore ways to create greater access to diagnostic imaging interpretation support across the UK.

24

Average age
of onset



Our supporters

This document has been endorsed by key stakeholders in the field of musculoskeletal health, supporting the vision for a better future for people with axial SpA. You can find a full list of endorsements at

www.actonaxialspa.com





Years for diagnosis of axial SpA is too long

- Recognise the symptoms
- Check NICE guidelines
- Refer to rheumatology

Get axial SpA diagnosed fast.

Go to www.actonaxialspa.com for information and advice
from some of the world's leading experts on the condition.

Glossary of terms

All Party Parliamentary Group (APPG)

All-Party Parliamentary Groups (APPGs) are informal cross-party groups that meet, relatively informally, to discuss a particular issue of concern.

Acute anterior uveitis (AAU)

Acute anterior uveitis is an eye condition caused by inflammation in the front part of the eye between the cornea (the clear window at the front of the eye) and the lens. It is also sometimes referred to as iritis.

Ankylosing spondylitis (AS)

See axial spondyloarthritis

Axial spondyloarthritis (Axial SpA)

Axial spondyloarthritis (axial SpA) is an inflammatory arthritis where the main symptom is back pain. Axial SpA is an umbrella term and it includes: ankylosing spondylitis (AS), 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

This new initiative is part of the Pathways for Better Health Programme by NHS England, will significantly increase the resource to support MSK service delivery.

Biomarkers

A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease.

Clinical Commissioning Groups (CCGs)

NHS commissioning is the process of assessing needs, planning and prioritising, purchasing and monitoring health services. CCGs operate in England.

Chiropractor

Chiropractors are healthcare professionals who work to help treat problems with the bones, joints and muscles that support the body (the 'musculoskeletal system').

Classification criteria

Classification criteria are standardised definitions that are primarily intended to create well-defined picture of the key shared features in the majority of patients with a disease or condition.

CRP

A CRP or c-reactive protein blood test is used to measure levels of inflammation.

Dactylitis

Dactylitis is severe inflammation of the finger and/or toe joints.

Early arthritis initiative

The National Early Inflammatory Arthritis Audit (NEIAA) aims to improve the quality of care for people living with inflammatory arthritis, collecting information on all new patients over the age of 16 in specialist rheumatology departments in England and Wales. It was commissioned by the Healthcare Quality Improvement Partnership as part of the National Clinical Audit Programme.

Enthesitis

Enthesitis is inflammation of the entheses, the sites where tendons or ligaments insert into the bone.

Extant

Still in existence

Extra-musculoskeletal manifestations (EMMS)

Disease-related characteristics that are not related to the musculoskeletal system - in axial SpA this includes inflammatory bowel disease (IBD), psoriasis, and acute anterior uveitis (AAU).

First Contact Practitioners

First contact practitioners (FCPs) are experts in musculoskeletal health such as physiotherapists and osteopaths, who form part of a primary care practice. FCPs are usually the first health professional a patient will see in a GP practice about a musculoskeletal complaint.

Generic back pain

About 8 in 10 people have one or more bouts of low back pain over their lifetime. In most cases, it is not due to a serious disease or serious back problem, and the exact cause of the pain is not clear. This is called nonspecific or generic lower back pain.

Getting It Right First Time (GIRFT)

Getting It Right First Time (GIRFT) is a national programme designed to improve medical care within the NHS by reducing unwarranted variations.

HCPs

Health Care Professionals: anyone who is professionally qualified to deliver clinical / medical healthcare.

Health Education England's Primary and Community Care Training Hubs

Health Education England's training hubs provide the infrastructure for multi-professional training and education in primary care to support recruitment, retention and return of all staff groups.

HLA-B27/Human leukocyte antigen B27 HLA-B27 gene

There is a strong association between axial SpA and the HLA B27 gene. Although HLA B27 is present in over 75% of people with axial SpA, only about 1 in 15 people who are HLA B27 positive go on to develop the condition.

Inflammatory bowel disease / IBD

Inflammatory bowel disease (IBD) is a term mainly used to describe two long-term conditions that involve inflammation of the gut: ulcerative colitis and Crohn's disease.

Mechanical back pain

Mechanical back pain arises from structural changes which may be in the spinal joints, vertebrae or soft tissues.

Musculoskeletal (MSK)

Musculoskeletal (MSK) conditions affect the joints, bones and muscles.

Multiple sclerosis

Multiple sclerosis (MS) is a condition that can affect the brain and spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance.

MRI / magnetic resonance imaging

Magnetic resonance imaging (MRI) is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

Osteopath / osteopathy

Osteopaths are allied healthcare professionals, who are trained in the musculoskeletal (MSK) system and its relationship with other systems of the body.

Parkinson's disease

Parkinson's disease is a brain disorder in which parts of the brain become progressively damaged over many years.

Peripheral arthritis

Peripheral arthritis usually affects the large joints of the arms and legs, including the elbows, wrists, knees, and ankles.

Peripheral musculoskeletal manifestations

In axial SpA, peripheral manifestations include peripheral joint disease, enthesitis and dactylitis

Psoriasis

Psoriasis is an inflammatory skin condition that causes red, flaky, crusty patches of skin covered with silvery scales.

Psoriatic arthritis (PsA)

Psoriatic arthritis (PsA) affects joints (such as the knees or those in the hands and feet), as well as areas where tendons join to bone (such as the heel and lower back).

Psychosomatic disorders

A psychosomatic disorder is a physical illness which is caused or made worse by mental health.

Radiography

Radiography is an imaging technique using x-ray.

Radiographic damage

Where changes to the sacroiliac joints and spine can be seen on x-ray.

Rheumatologist / rheumatology

Specialists in the diagnosis and treatment of conditions which affect the joints, muscles, and bones.

Sacroiliac joints / SIJs

The sacroiliac joints at the base of the spine, connecting the spine to the hips.

SpA Academies

SpA academy is a series of educational events relating to spondyloarthritis for health care professionals.

SPADE tool

The SPADE tool is an online tool designed to assist medical professionals define the probability of axial spondyloarthritis.

Uveitis

See acute anterior uveitis.

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