



Axial SpA  
works silently.  
We don't.

# Driving down diagnostic delay in axial SpA



First impact report of the  
*Act on Axial SpA* campaign

October 2022

Funded by:



In partnership with:



act on  
Axial SpA



**Axial SpA  
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We don't.**

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# Foreword

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It should be possible for every person experiencing symptoms of axial spondyloarthritis (axial SpA) to receive a diagnosis within one year of symptom onset. In 2020, the respondents to our national consultation process – health care professionals (HCPs), professional bodies and patients – all agreed that this ambition could be realised, and in June 2021 NASS published a route map to achieve a Gold Standard time of one year.

Starting from a current baseline average of 8.5 years, the achievement of this goal will require transformational change. This includes a significant increase in awareness of the condition among HCPs and the general public, a critical mass of clinical leaders who will drive up health care performance in axial SpA, the widespread use of technology to ensure that axial SpA is higher within clinical reasoning and to support diagnosis, the routine use of pathways to ensure that patients are referred directly to rheumatology for assessment, and consistent use of agreed national protocols for imaging.

Above all, to attain such a dramatic change in time to diagnosis we must win hearts and minds, build a movement of people who want to work with us to create change, and demonstrate proof of concept for our ideas.

This report describes our work and impact to date.

We have been successful in building the burning platform for change through national inquiries, Freedom of Information requests and research studies. This includes commissioning the first economic model of the economic costs of delayed diagnosis. It estimates that the cost to the UK economy is £18.7 billion per year, and the total average cumulative cost per person is £193,512, most of which is borne by the individual.

We have brought these estimates, and other new data, to the attention of Ministers, other Parliamentarians, policymakers, and HCPs. We have influenced the funders of the National Early Inflammatory Arthritis Audit to include new datapoints on time to diagnosis so that, for the first time, we will have comprehensive national audit data to track changes in performance. We have supported the Best MSK Health Collaborative to embed our approach in a new national axial SpA patient pathway. We are working with 19 rheumatology departments to implement the Gold Standard through our *Aspiring to Excellence* programme, and our new cadre of 12 *Champions in Primary Care* will be working together to drive improvement in identification and referral of suspected axial SpA patients. We have presented our burning platform to conferences and regional SpA academies. We are building a social movement for change.

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We have demonstrated proof of concept in our public awareness campaign which in its first phase has reached 1.5 million through social media, with 900,000 people watching our campaign videos, and already 5,000 people completing the online symptom checker.

Much more is to come. At the end of 2022, the All Party Parliamentary Group on axial SpA will publish the results of a new Inquiry into the implementation of NICE Guideline 65 (NG65). We will publish landscape reviews of education and training and current practice in ophthalmology, gastroenterology, dermatology and radiology. Next Spring, we will publish the first ever axial SpA Patient Quality Standards which includes the diagnostic part of the pathway. We will be pressing NICE, EULAR, and ASAS to integrate these standards into their existing

guidelines and standards, as well as working with our 19 *Aspiring to Excellence* rheumatology departments and others to incorporate them into routine clinical practice. We will also be selecting one health economy to work with and co-design an integrated pilot to test all of the programme's interventions in one locality, in effect maximising the dosage of intervention to reduce diagnostic delay. We will build on our investigatory work in secondary care services with the development of educational resources.

My heartfelt thanks to all of our clinical partners and associates, to the team at UCB who have done so much to support and champion this work, and to the incredible staff at NASS who are so committed to achieving a Gold Standard time to diagnosis.



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



# Acknowledgements

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NASS wishes to express our sincere thanks to UCB for funding this programme, without which it would not have been possible to bring our plans to life.

We would like to thank Prof. Karl Gaffney, Norfolk & Norwich University Hospitals NHS Foundation Trust and Dr. Raj Sengupta, Royal National Hospital for Rheumatic Diseases Bath, for being such committed and enthusiastic partners to the programme.

NASS would like to thank the organisations that endorsed our plans to end the delay to diagnosis of axial SpA and continue to support us in delivering on our plans. Eight organisations fully endorsed the Gold Standard route map:

- All Party Parliamentary Group (APPG) for Axial SpA
- Arthritis Action
- Arthritis and Musculoskeletal Alliance (ARMA)
- AStretch
- British Society of Spondyloarthritis (BRITSpA)
- British Society of Skeletal Radiologists (BSSR)
- Institute of Osteopathy
- Primary Care in Rheumatology and Musculoskeletal Medicine (PCRMM)
- Royal College of Chiropractors

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Eddison J, Webb D, Marshall L, Hamilton J, MacAulay F & Mafusire LA; Driving down diagnostic delay in axial SpA – First impact report of the *Act on Axial SpA* campaign (2022) London: The National Axial Spondyloarthritis Society.

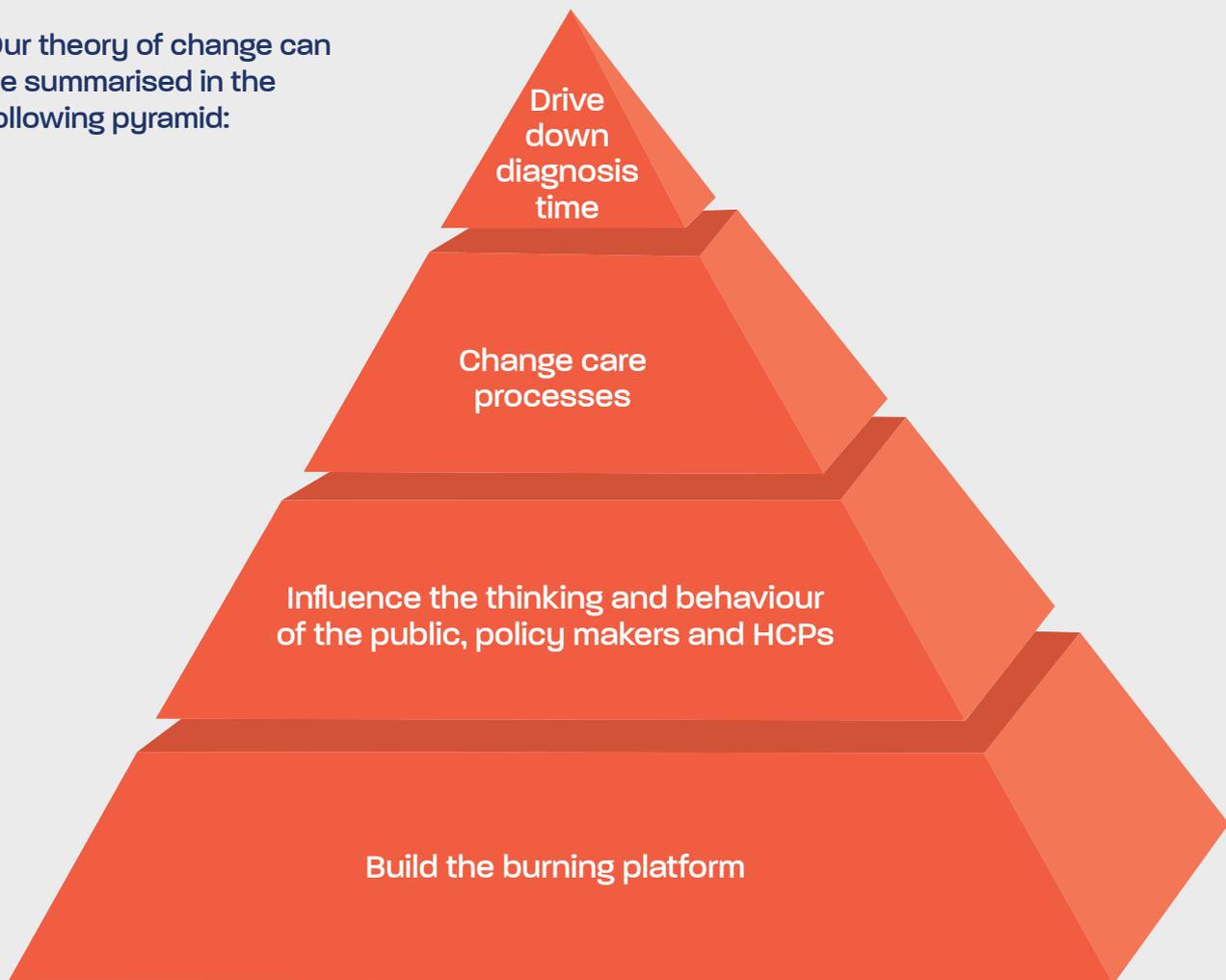
# Our approach to achieving a Gold Standard time to diagnosis

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The *Act on Axial SpA* campaign is designed around two key considerations:

- A broad theory of change that describes how we can create system-wide change
- An understanding of the patient journey from symptom onset to diagnosis by a rheumatologist.

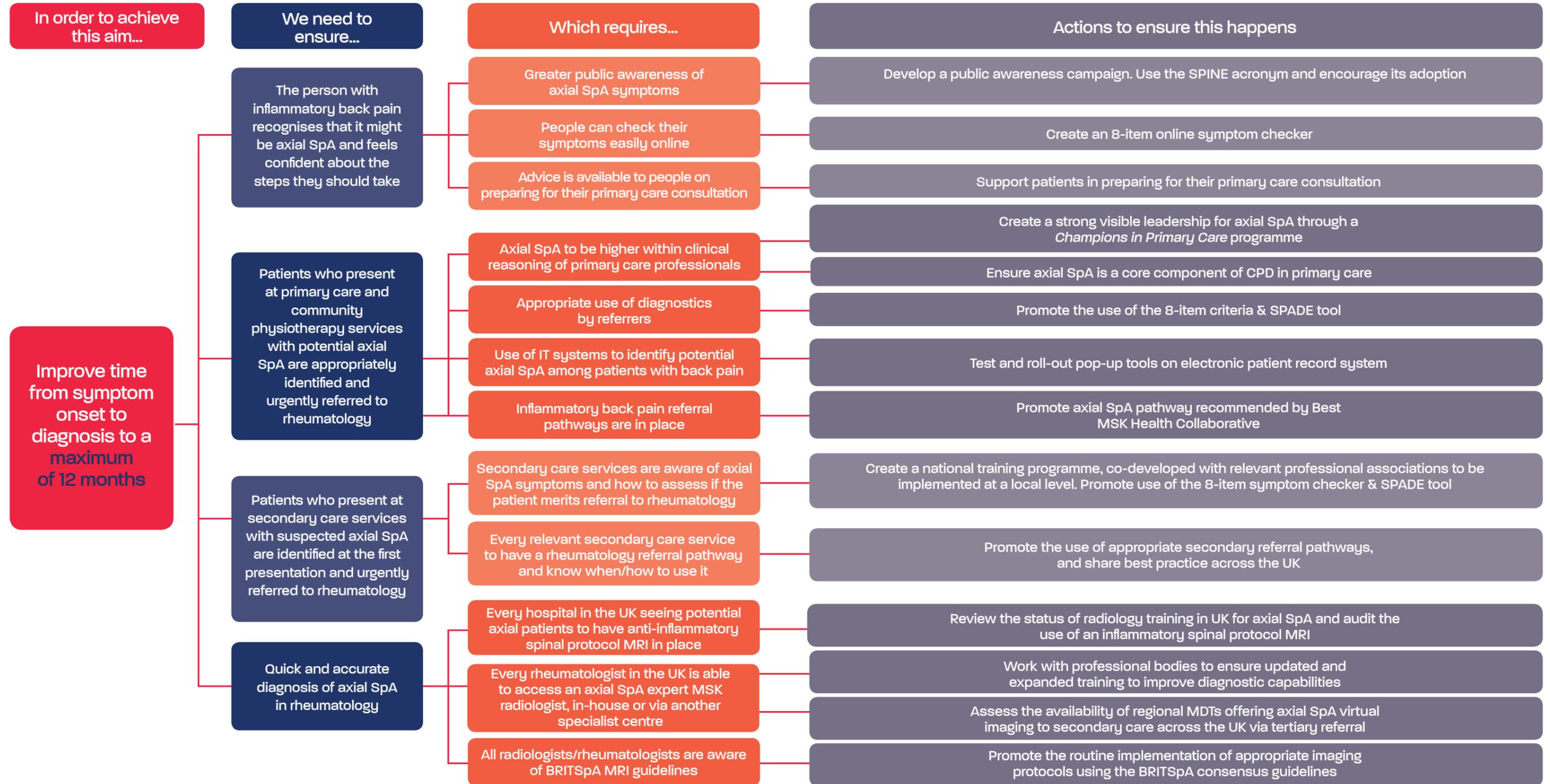
Our theory of change can be summarised in the following pyramid:



We will first build a 'burning platform', setting out why action and change is needed; we will use this to influence the thinking and behaviour of the public, policy makers and HCPs; we will use a range of levers to create change in care processes; these will result in earlier diagnosis.

The patient journey is described in the following driver diagram (on pages 8 and 9). It summarises our thinking on the four primary changes that our campaign seeks to achieve, the strategy to achieve them and the specific interventions required to ensure that we achieve our goal.

# Act on Axial SpA: A Gold Standard Time to Diagnosis



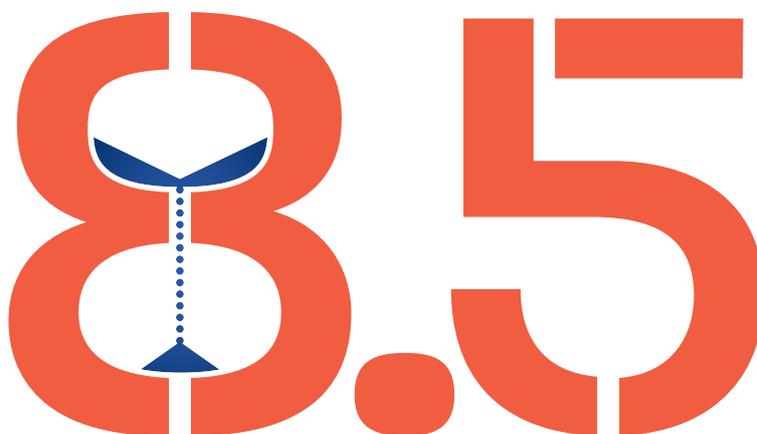
# Building the burning platform

A Burning Platform can be a powerful driver of change. It represents a specific and urgent message that sets out a problem, the likely result if nothing is done to address it, the opportunities to do so and the likely result if those opportunities are realised. In axial SpA in the UK, the average time to diagnosis has remained stubbornly at 8.5 years and was in danger of being normalised without urgent transformative intervention.

We sought to establish the extent of the problem and solutions by:

- Working with Parliamentarians to create an All Party Parliamentary Group (APPG) on axial SpA with the specific remit of having oversight of NG65
- Undertaking an inquiry on behalf of the APPG on axial SpA to assess the extent to which NG65 was being implemented across England
- Convening a national consultation process with HCPs, professional bodies and people living with axial SpA to determine the delays to diagnosis from a patient pathway perspective and the potential solutions
- Commissioning new economic modelling to estimate the full economic costs to the UK economy of diagnostic delay
- Commissioning research to establish the values and needs of patients in the diagnosis and treatment of the condition
- Using a Freedom of Information request to establish the use of direct referrals within secondary care
- Funding a cross-sectional study in secondary care to determine the prevalence of undiagnosed axial SpA in inflammatory bowel disease in patients with chronic back pain.

The rest of this section describes our work to build a burning platform.



**Years to diagnosis of axial SpA is too long.**

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

Get axial SpA diagnosed fast.  
Find out more at [actonaxialspa.com](http://actonaxialspa.com)

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## The All Party Parliamentary Group (APPG) on axial SpA

In the absence of any top-down mechanism to monitor the implementation of NG65 concerning the diagnosis and treatment of spondyloarthritis, we worked with Parliamentarians to establish the APPG in early 2019. Its remit was to provide oversight to encourage effective national implementation of the recent NICE Guideline.

### APPG Enquiry 2019

Following the group's inaugural meeting in March 2019 it was agreed that, as a first step, a formal inquiry should be undertaken on behalf of the APPG to explore the extent to which key areas of the NICE Guideline had been adopted across the country, and to get a better sense of the gaps that need to be addressed. We developed a 10 question quality framework, based largely on the NICE Guideline recommendations and accompanying Quality Standards. Commissioners and providers reviewed these questions to ensure that the information requests were reasonable. We sent the survey to all Clinical Commissioning Groups (CCGs) and NHS Trusts in England in the form of a Freedom of Information request. 100% of CCGs responded and 88% of provider Trusts. We analysed the data at national level and presented the results to the APPG on 9th of July 2019.

The inquiry found widespread failing in the implementation of NG65 including:

- Only 21% of CCGs had a specific inflammatory back pain pathway in place: this is crucial to ensure swift referral into rheumatology. 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
- Only 15% of CCGs had programmes in place for educating GPs about axial SpA: poor symptom recognition in primary care results in slow or non-referral to rheumatology. Continuous professional development is key to ensuring that primary care professionals can identify potential axial SpA at the earliest presentation.

### National consultation to propose a Gold Standard, 2020 – 2021 and subsequent route map

In July 2020, on the back of the APPG inquiry report, we launched a national consultation process to engage patients, HCPs, commissioners, and policymakers, seeking their response to a document we developed which 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 through a series of roundtable discussions. The consultation process demonstrated a large degree of consensus on the reasons for delayed diagnosis and potential solutions, and above all showed a shared desire to create transformational change in this area.

## The economic cost of delayed diagnosis of axial spondyloarthritis in the UK, 2021 - 2022

From recent systematic reviews we knew that diagnostic delay in axial SpA has a very real and considerable impact on people's quality of life and the impairment of their physical function. We knew that people also pay a heavy psychological price for delayed diagnosis. What we didn't know was the full economic cost.

We commissioned the University of East Anglia to estimate the total costs to the UK economy, including lost productivity, costs from out of pocket expenses and costs to the NHS.

So, what does delayed diagnosis of axial SpA cost the UK economy each year? The answer is £18.7 billion. For someone whose symptoms start at an average age of 26, and who has an average time to diagnosis of 8.5 years, the total cumulative cost per person is £193,512. The cost for women is greater than that for men. The majority of these costs are borne by the individual through lost productivity and out of pocket expenses.

If the NASS Gold Standard time of one year was achieved this would reduce the average cost of receiving a diagnosis down to £25,798, saving individuals around £167,000.



## What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis? 2021 - 2022

Much is made of the concept of patient-centredness, of ensuring that patients' needs, and values guide clinical decisions. But to what extent are axial SpA services patient-centred? More fundamentally, do we really know what people with axial SpA value and need from such services? To date, our answers to those questions have been partial and based on anecdote.

Services for the diagnosis and treatment of axial SpA clinical care are informed in the UK by NG65 (2017) and Quality Standard 170 (2018), and internationally by the European Alliance of Associations for Rheumatology (EULAR) Recommendations (updated in 2022) and the Assessment of Spondyloarthritis Society (ASAS) Quality Standards (2020). Whilst there was some patient input into the development of these documents, they express a predominantly clinician-based view of what should be provided in diagnosing and managing axial SpA.

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This is a significant deficit that NASS has sought to address. We 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.

The results are striking. Respondents reported feeling disbelieved by HCPs when seeking a diagnosis. They didn't feel listened to or valued, and sometimes the clinicians seemed to lack empathy and understanding of their pain and anxiety. A significant proportion had to pay privately to get their diagnosis, with those on higher incomes more likely to have done so. Respondents felt that there was a lack of joined up thinking about different specialisms when it came to their diagnosis, and they lamented the dearth of support and information available from the NHS immediately after receiving a diagnosis. There was a discrepancy between what people expect of their health care providers and the care they received, with many feeling that they should have been provided with care that was not forthcoming. Of concern to us, those groups that were most likely to have had negative experiences of NHS services were women, younger people, those on lower incomes and those with a more recent diagnosis.

The overall message from the study is that people with axial SpA do not think that they are receiving high quality care. At the same time, it is clear that people with axial SpA know very well what they do want. We have used the results of the study to develop a set of patient quality standards and refined them following consultation with a sample of people living with

the condition. We will publish the first ever axial SpA Patient Quality Standards in the Spring of 2023.

### **Secondary Care Freedom of Information: Direct Referrals, 2022**

We want to ensure that 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.

To understand current arrangements for identification and referral of axial SpA in secondary care, we surveyed, via a Freedom of Information request, all UK Trusts and Health Boards.

Our study has found that specialties associated with Extra Musculoskeletal Manifestations (EMMs) are able routinely to refer patients directly to rheumatology for suspected axial SpA. However, while direct referrals are accepted in most UK acute care settings, referrals are mostly reliant on consultant to consultant letters or calls. Some areas of best practice do exist with formal internal referral proformas, systems or processes in place.

This further highlights the need for increasing the awareness of axial SpA presentation in other specialties and education is required about how to identify and refer appropriate patients. We propose that the Gold Standard for internal referrals to rheumatology for axial SpA should be via a formal internal referral pathway.

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We recommend that standardised screening tools should be available and routinely utilised in assessing the appropriateness of a referral and accompany any referral to rheumatology.

With the informal nature of internal referrals across the UK it is difficult to track referrals on hospital systems and therefore clearly identify how often direct referrals are being made. We call for more widespread development and uptake of internal referral processes, use of screening tools and the ability to track referrals.

We want to ensure that secondary care HCPs know the signs of axial SpA, when and how to refer, and so we are working with HCPs in dermatology, gastroenterology and ophthalmology to review existing educational provision, which may lead to the creation of best practice materials to raise awareness, support identification such as screening tools and how to refer for suspected axial SpA.

We have already published examples of protocols, pathways, and screening tools to our dedicated campaign website [actonaxialspa.com](http://actonaxialspa.com) and call on HCPs to adopt our Gold Standard and utilise these best practice examples.

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

As a result of the analysis, we are proposing four recommendations aimed at ensuring delays to direct referrals are reduced:

- 1. Recommendation one:** The Gold Standard for internal referrals to rheumatology for axial SpA should be via a formal internal referral pathway.
- 2. Recommendation two:** Standardised screening tools should be available and routinely utilised in assessing the appropriateness of a referral and accompany any referral to rheumatology.
- 3. Recommendation three:** It should be possible for NHS Trusts and Health Boards to track internal referrals in sufficient detail on patient information systems to enable measurement of referral volumes.
- 4. Recommendation four:** There needs to be a consistent effort to raise awareness of axial SpA in secondary care to ensure HCPs know the signs of axial SpA, when and how to refer.

### **Prevalence of axial SpA in inflammatory bowel disease: 2022**

We also funded a cross-sectional study in secondary care to determine the prevalence of undiagnosed axial SpA in inflammatory bowel disease (IBD) in patients with chronic back pain. The researchers estimate prevalence at 5% with a mean symptom duration of 12 years. The study demonstrates a significant hidden disease burden of axial SpA among IBD patients. Early identification and referral from gastroenterology is needed to shorten the delay to diagnosis and allow access to appropriate therapy.

# Influencing the thinking and behaviour of the public, policy makers and health care professionals

From its launch in June 2021, the *Act on Axial SpA* programme collateral has been used to influence several key areas related to the diagnosis of the condition, providing the levers to make the case for real change.



Photo credit:  
Adams Wedding Photography

## Making the case in Parliament

Since the consultation process was launched at the All Party Parliamentary Group for Axial SpA, the APPG has been supportive of the process, in particular the Chair Tom Randall MP, who lives with axial SpA. In September 2020, Tom Randall secured an adjournment debate in the House of Commons focussed on the delay to diagnosis. As a result, the Health Minister at the time, Helen Whatley MP, agreed to a meeting to discuss a possible public awareness campaign.

A reshuffle within the Department of Health and pressures of COVID have meant that there was a delay to the meeting taking place. However, we were able to secure a meeting in June 2022 with Minister Gillian Keegan MP, which was attended by Tom Randall and Dale Webb. An initial proposal was shared and was warmly received by the Minister. We presented new modelling data on the total UK cost of delayed diagnosis to the Minister and her team and are in ongoing discussion about the costs and their implication for interventions to improve diagnosis times.

As part of a more general article in the House of Commons House Magazine on long-term conditions, Tom Randall was able to highlight the current delay and the impact that it has on those who are seeking a diagnosis.

In Scotland, NASS presented our plans for the programme to the Cross Party Group (CPG) for Arthritis and Musculoskeletal Conditions. We are now in contact with the Convenor of the group Pam Duncan-Glancy MSP with a view to submitting motions recognising the Gold Standard and tabling questions to the Health Minister directly addressing the delay in Scotland.

In 2022 the APPG launched a second inquiry into the delivery of care for people with axial SpA. The inquiry will map out the current plans in place in the Integrated Care Systems throughout England for local inflammatory back pain pathways and the diagnosis of axial SpA.

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## Bringing the Gold Standard to UK policy

In 2020, NHS England launched the Best MSK Health Collaborative, a programme which aims to improve the quality and value of Musculoskeletal (MSK) health provision and sustain the delivery of personalised, evidence-based, integrated health care. We were pleased to be able to contribute to the axial SpA patient pathway and ensure that the Gold Standard Route Map was included. Our routemap is also cited on the NHS Futures website, where all the key evidence and resources are collected to help with MSK service improvement.

In Wales, we are in regular contact with the newly appointed clinical leads in the Welsh Government. They will be developing a programme similar to the Best MSK Health Collaborative in England and are keen to work with us on the development of the pathway for axial SpA. We are hopeful that early involvement in this project will lead to the implementation of the Gold Standard route map.

## Improving data collection on time to diagnosis

National data collection and guidance are two key components of axial SpA diagnosis and improving care. The National Early Inflammatory Arthritis Audit (NEIAA) was commissioned by the Healthcare Quality Improvement Partnership (HQIP) and awarded to the British Society for Rheumatology (BSR) for delivery. The audit was originally designed to measure the performance of rheumatology departments against NICE QS33 For Rheumatoid Arthritis. The initial audit also contained some axial SpA data - the route of referral; symptom duration prior to assessment; and adherence to referral guidelines, including availability of baseline investigations (HLA B27 antibody testing, imaging).

In 2022, NASS was able to influence HQIP to include new data points relating to the diagnosis of axial SpA relating time from symptom onset to first contact with a HCP, time to referral, time to assessment and time to diagnosis. The collection of national, large-scale data will enable the programme to measure change over time and identify areas for improvement.

Alongside the work to influence NEIAA we have been working to build a complementary focussed data collection tool that will audit key data points across the patient journey to diagnosis.

To understand how we are influencing and catalysing change to drive down diagnosis we are setting up a measurement mechanism that will enable us to create a comprehensive dataset in collaboration with the 19 rheumatology teams that are participants of the NASS *Aspiring to Excellence* programme. It will help us to:

- Track changes in time to diagnosis
- Support the *Aspiring to Excellence* sites in monitoring their local performance and audit of the NG65
- Support the NHS England Best MSK and GIRFT axial SpA pathway development and ongoing monitoring of performance.

NASS is working with the *Aspiring to Excellence* teams to finalise the tool and the processes for completion and analysis. The plan is to launch the tool during quarter four 2022 and to share a baseline picture across the sites at the start of 2023.

## Influencing best practice

We are delighted that the Gold Standard Route Map is already catalysing change in axial SpA diagnosis, with teams taking on board the core implementation document to improve their services.



## Case study

The South West Axial Spondyloarthritis Group (SWAG),  
Dr Tom Williams, Great Western  
Hospitals, on behalf of SWAG

“We had long aspired to create a network in order to facilitate communication and collaboration between clinicians in the South West of England who share an interest in axial spondyloarthritis. *Act on Axial SpA* gave this aspiration a strong impetus and focal point, and came to fruition at the inaugural meeting of South West Axial Spondyloarthritis Group (SWAG) in November 2021. Not only was this a thought-provoking and high quality educational meeting, but it was clear that in SWAG, we have a community of multi-professional clinicians who share the ambition and enthusiasm needed to achieve the *Act on Axial SpA* goals and crucially have the means to work together to realise them.

SWAG have recently successfully applied as a network to be part of the NASS *Aspiring to Excellence* cohort for 2022/23. We are very excited about the prospect of working together with NASS and the NHS Transformation Unit to improve the current unacceptably long waits that people living with axial spondyloarthritis experience in obtaining their diagnosis. In particular, we hope to improve the quality and consistency

of data capture and analysis, so that we have a more detailed understanding of the patient journey from symptom onset through to diagnosis and long-term outcome; to facilitate streamlined inflammatory back pain referral pathways in order to support GPs and first contact practitioners to recognise potential axial spondyloarthritis and minimise delays for those patients in accessing a specialist; and to ensure all newly diagnosed axial spondyloarthritis patients can access high-quality and individualised education and support, in order to empower them to live well with their condition.

We hope and expect that the experience of working together on these quality improvement initiatives will improve care for our patients, but also provide rich learning opportunities and peer support for all our members. By engaging with trainees, specialist nurses and allied health professionals, SWAG will also help attract the future workforce needed to ensure that people living with axial spondyloarthritis get the high quality care that they need and deserve.”



## Case study

Sian Bamford, Advanced practice physiotherapist & Professor Hasan Tahir, Consultant rheumatologist, Royal Free London NHS Foundation Trust



Photo credit: Richard Battye

“The NASS Gold Standard time to diagnosis has been a great focus point for service improvement at the Royal Free London. Our first piece of work as part of the *Aspiring to Excellence* programme was to evaluate our local delay to diagnosis and to investigate where the delays to diagnosis were occurring. This work has helped to inform the development of a number of different work streams to try and improve our local delay to diagnosis and ultimately achieve the twelve month gold standard.

We have recently developed a pull-up banner that will be displayed within our hospitals

and local public spaces as part of our work stream to improve public awareness of axial spondyloarthritis.

A QR code for the NASS *Act on Axial SpA* symptoms checker has been incorporated into the design which we hope will facilitate earlier referral to specialist services when individuals discuss their axial spa symptoms with HCPs.

Having local service aims that are in alignment with the NASS national Gold Standard helps to support conversations with stakeholders to improve local services to reduce delay to diagnosis.”

## The Gold Standard reaching the wider rheumatology community

Throughout the last year, members of the NASS team have raised the awareness of the Gold Standard work through presentation at national and international conferences and events. For example, we had various poster presentations and a minor industry briefing at the 2022 British Society of Rheumatology conference on Delay to Diagnosis, at the 2021 Primary Care Rheumatology and Musculoskeletal Medicine Society’s annual conference, and at the 2022

ASIF annual meeting. Our health economics research was also published in the abstracts at the 2022 EULAR summit. Our published papers, posters, and presentations include:

- Delay to diagnosis in axial Spondyloarthritis – Time for a Gold Standard approach  
Webb D, Gaffney K, Sengupta R, et al. POS0059-PARE DELAY TO DIAGNOSIS IN AXIAL SPONDYLOARTHRITIS – TIME FOR A GOLD STANDARD APPROACH. *Annals of the Rheumatic Diseases* 2021;80:235-236.

- ‘Act on Axial SpA’: a gold standard time to diagnosis

Liz Marshall, Dale Webb, Fiona MacAulay, Karl Gaffney, Raj Sengupta, P270 ‘Act on Axial SpA’: a gold standard time to diagnosis, *Rheumatology*, Volume 61, Issue Supplement\_1, May 2022, keac133.269. Available at: <https://doi.org/10.1093/rheumatology/keac133.269>

- Delay to diagnosis in axial Spondyloarthritis – time for a gold standard approach

Webb D, Gaffney K, Sengupta R, Zhao S, Swinger L. Delay to diagnosis in axial Spondyloarthritis – time for a gold standard approach. EULAR conference. June 2021. Available at: <https://www.researchgate.net/publication/354067312>

The *Act on Axial SpA* campaign or Gold Standard work has also been cited in the following publications:

- *Rheumatology Physio Online: Digital*, P. (2020). A Gold Standard Time to Diagnosis in Axial Spondyloarthritis | *Rheumatology.Physio*. [online] Available at: <https://rheumatology.physio/a-gold-standard-time-to-diagnosis-in-axial-spondyloarthritis/>
- The Primary Care Rheumatology and Musculoskeletal Medicine Society: Claire Doherty (Admin) (2021). Act on Axial SpA - PCRMM. [online] PCRMM. Available at: <https://pcrmm.org.uk/act-on-axial-spa/>
- Doherty (Admin), C. (2022). End the delay to diagnosis in axial SpA. [online] PCRMM. Available at: <https://pcrmm.org.uk/end-the-delay-to-diagnosis-in-axial-spa/>

- Norfolk and Norwich University Hospitals NHS Foundation Trust: [www.nnuh.nhs.uk](http://www.nnuh.nhs.uk). (n.d.). Norfolk and Norwich University Hospitals NHS Foundation Trust» Raising awareness of axial spondyloarthritis. [online] Available at: <https://www.nnuh.nhs.uk/press-release/raising-awareness-of-axial-spondyloarthritis/>

### Our public awareness campaign activity

We designed our public awareness campaign to reach and engage an audience aged 40 and under who are experiencing persistent back pain and motivate them to find out more about axial SpA and use our website symptom checker.

The campaign strategy has three underlying principles:

- **A distinctive brand and messages that was built on audience research.** In designing the campaign our first step was to conduct research with our target audience and then develop a brand and a set of core messages using the insights we gathered from that work
- **Tell stories about life with axial SpA.** We have chosen case studies that reflect our different audience segments, to ensure the campaign is highly relevant and people can connect to the campaign messages
- **Prioritise media channels that are consumed by our target audience.** We are targeting Millennial and Gen Z audiences, who have distinct media consumption habits. They are social media savvy, using it both for leisure and to gather information, with low engagement in print news media, but read magazines and consumer media during their leisure time. To reflect these media consumption habits, we are prioritising social media and national consumer media in our campaign execution.

### Activity during year 1:

- Developed and launched the [actonaxialspa.com](https://actonaxialspa.com) website, where people can check their symptoms and find out information and stories about diagnosis and life with axial SpA
- Developed a **launch story** that showed that 91% of the public had not heard of axial SpA, to show the extent of the problem
- Produced a **comedy video** and three corresponding **case study videos** to launch the campaign on social media. We used comedy to connect with a cold audience who are social media savvy and know nothing about axial SpA
- Ran an 'always on' **social media advertising campaign**, testing different approaches and styles of ads
- Worked with an **influencer** to create social media content that told stories about life with axial SpA
- Ran an 'always on' **PR and media campaign**, prioritising the media outlets that we know are read by our target audience.

### Our public awareness campaign in numbers



Our campaign social media content has touched people **1.5 million** times



Our campaign videos have been viewed **881,086** times



Our media coverage has touched people **124 million** times with campaign messages



**13,891** symptom checker visits



**5,310** symptom checker completions

We've created conversations with people commenting on our content or people reacting (comments, likes or shares) on the content **5,186** times



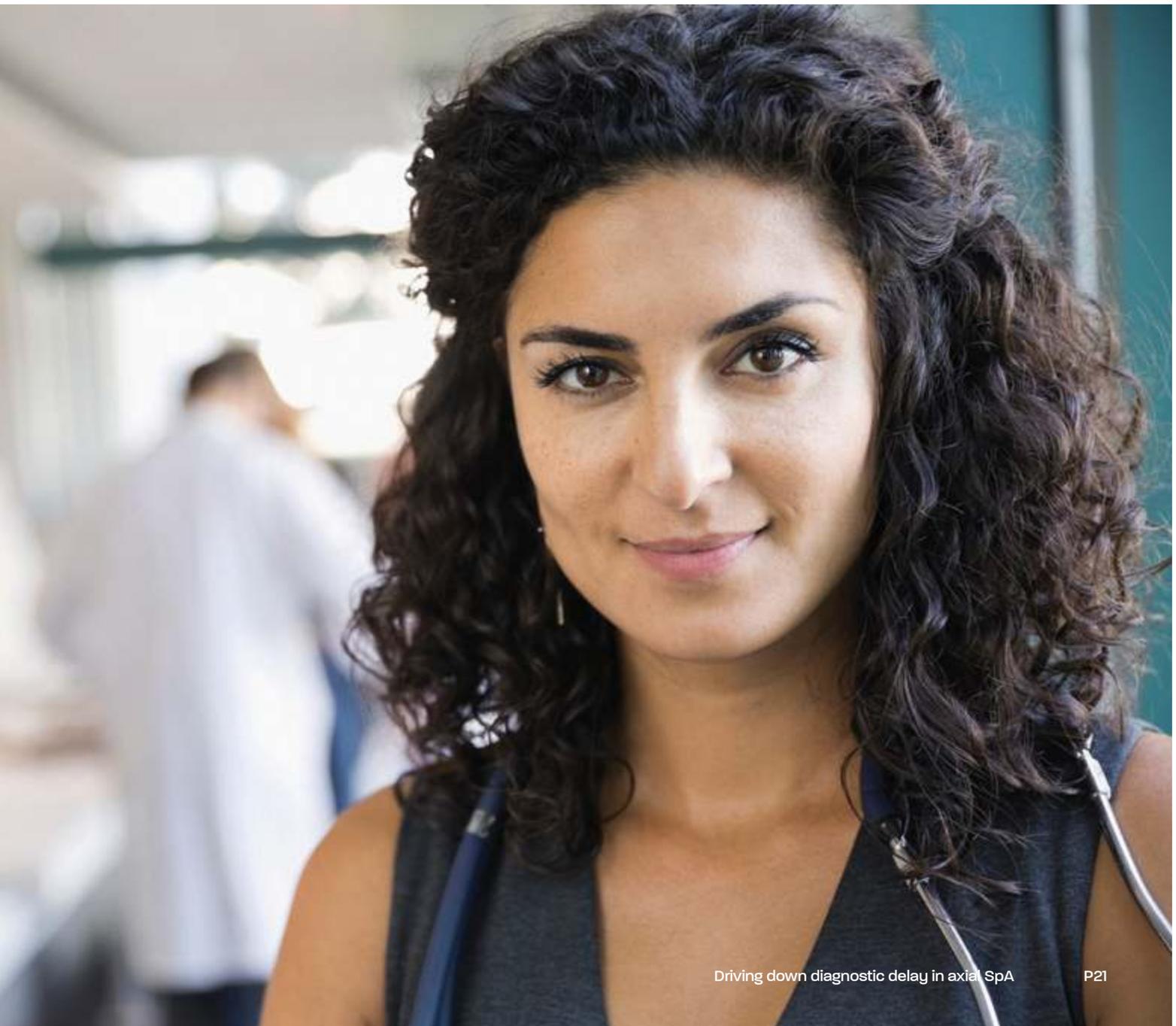
**61,965** hits on [actonaxialspa.com](https://actonaxialspa.com)

# Changing care processes

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The work that this report has already described provides the basis for driving real changes to care processes for the benefit of people waiting for an axial SpA diagnosis. We are achieving this by supporting health care teams and individuals to become recognised leaders, giving them the quality improvement methods and tools to transform care and drive the use of best practice approaches. The main

mechanisms for delivery of this are through our new *Champions in Primary Care*, our 19 *Aspiring to Excellence* teams focussed on diagnostic delay and by curating resources for HCPs via our dedicated campaign website. This will be supplemented by specific research identifying areas for improvement and creating calls to action for HCPs.





### *Champions in Primary Care*

The All Party Parliamentary Group on Axial Spondyloarthritis has discussed on numerous occasions the critical need to improve the visibility of the condition within primary care and create stronger clinical leadership in this area. In response, NASS created *Champions in Primary Care*. Our vision is to create a cadre of clinical champions in primary care and community services whose work ensures that axial SpA is higher within the clinical reasoning of primary care professionals, so that patients who present with suspected axial SpA are identified at the first presentation and urgently referred to rheumatology.

Our Champions have embarked on a two-year development programme focussed on quality improvement and leadership. Participants are supported to deliver a key improvement project aligned to our Gold Standard implementation plan.

Two major milestones were achieved in the spring and summer of 2022 with the appointment of our technical provider, NHS Transformation Unit who will deliver the development programme and with the recruitment of the first twelve participants to the programme with further recruitment ongoing. The programme was formally launched at the end of September 2022.

The participants are now being given the skills and knowledge to drive forward their improvement projects while supported by NASS and each other to share learning and spread improvement. All proposed projects are related to the Gold Standard driver diagram with a focus on: the education of clinicians in primary care on axial SpA; the development of direct referral pathways; the utilisation of alerts and pop-ups in clinical systems to identify axial SpA patients; and improving links between primary and secondary care teams.

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# Aspiring to Excellence



## Driving improvements in axial SpA care

### *Aspiring to Excellence*

Our *Aspiring to Excellence* quality improvement programme is now into its third year with 19 rheumatology teams participating. All those departments are now focussed on the Gold Standard time to diagnosis and driving improvements in their area. We are also developing links between these departments and the *Champions in Primary Care* to improve links between the two to drive joined-up care. As we move forward, we will publish learning reports from *Aspiring to Excellence* showing how diagnostic delay can be tackled, shining a light on the solutions that have worked and sharing best practice across the sector.

We have started to curate learning from improvements already made by rheumatology teams. These best practice examples are promoted via our dedicated website [actonaxialspa.com](http://actonaxialspa.com) so that HCPs across the UK can adopt them in their practice. From the first two cohorts of *Aspiring to Excellence* we have seen what can be achieved in diagnostic delay, some examples are shown on the following pages:



### University Hospitals Southampton:

The Southampton Team introduced a new e-referral pathway for patients with suspected axial SpA. This has resulted in patients being booked into a dedicated clinic run by a rheumatologist with a special interest in axial SpA and ensuring the standardisation of secondary care assessment. The system also links to a document highlighting the features of inflammatory back pain and the recommended primary care investigations, increasing awareness in primary care.

The hospital had no standard inflammatory back pain MRI protocol, leading to some

patients not having the right imaging. The rheumatology team, in conjunction with a specialist MSK radiologist, implemented a new whole spine shortened protocol. This led to a reduction in time for the patient in the scanner and of radiologist reporting time, whilst maximising the sensitivity of the imaging for axial SpA. This combined with the use of a range of educational interventions (email, presentations, junior doctor induction pack amendments) has resulted in the proportion of patients having the correct type of scan increased to over 90%.



### Salford Care Organisation, part of the Northern Care Alliance NHS Foundation Trust:

Salford created and implemented a Salford-wide Inflammatory Back Pain (IBP) pathway, combined with awareness raising for First Contact Practitioners (FCPs) and GPs. This led to a pathway for rapid diagnosis including screening and access to diagnostic services. Salford audit and survey data have demonstrated that they have delivered a shorter time to diagnosis when compared to the national average. Salford's delay from initial appointment in rheumatology to formal diagnosis has

validated the use of Early Inflammatory Arthritis slots for new patients with axial SpA queries. Salford has achieved a mean average from symptom onset to diagnosis of 6 years (lower than the 8.5 nationally) and a median of 4 years (lower than the 5.5 nationally).



### Leeds Axial SpA team at Chapel Allerton Hospital, part of Leeds Teaching Hospitals NHS Trust:

The team introduced a new electronic tertiary referral Multi-Disciplinary Team (MDT) form which was published on the SpA service website to facilitate tertiary referrals. By the end of year one, the team successfully developed a regional MDT network infrastructure and in the 22 tertiary

referrals received post implementation from across the North of England the mean time to resolution has reduced from over 4 months to just 5 working days, leading to swifter referral, assessment, and diagnosis. It has also driven improved user experience with positive feedback such as:

*“As a general rheumatologist in a small District General Hospital the virtual SpA MDT has proved invaluable, especially since COVID. It is fantastic to have the expertise ‘at your fingertips’ and also the team approach on the call. You can make your case fit the times you have available, and it saves a day long round trip for our patients. I am so pleased to have access to this tertiary advice without the travel - not to mention the parking! Thanks Leeds SpA team, you have really helped me out of some complicated clinical conundrums!”*

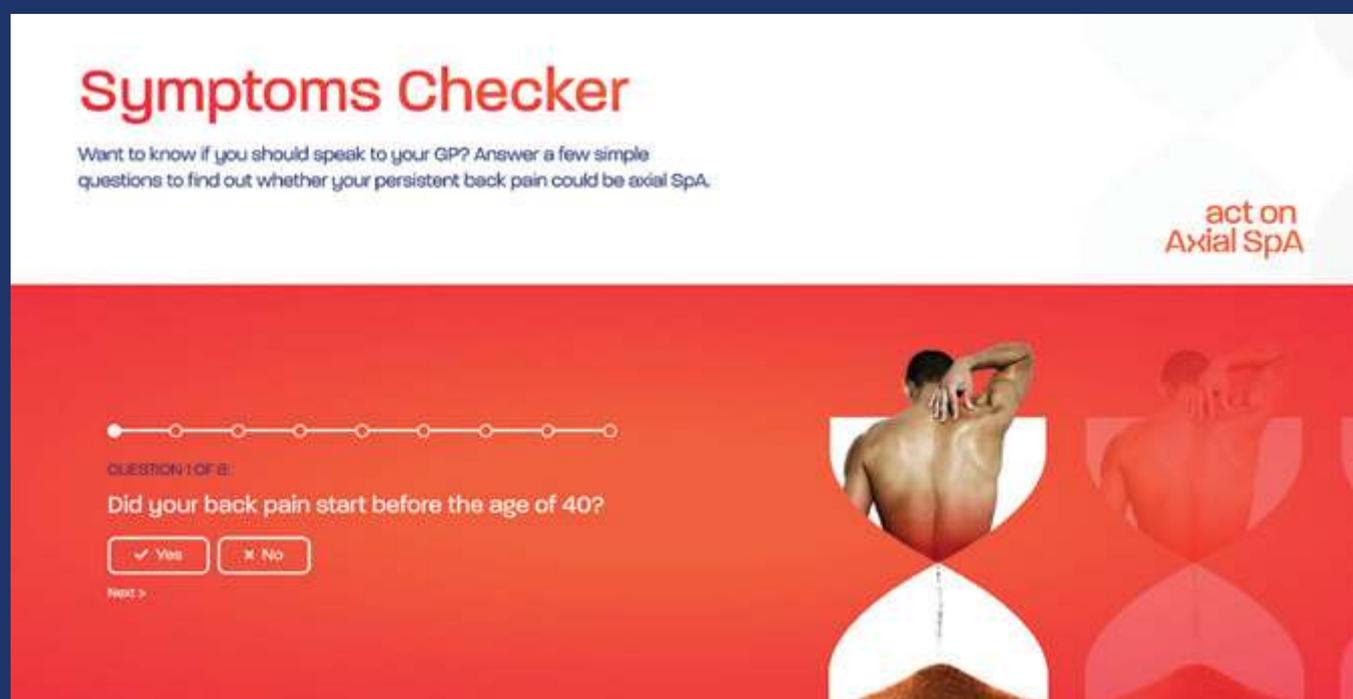
**Rheumatologist**

# Reducing the delay to diagnosis

The result of all our actions and the work of those in health care systems making changes and improvements to drive down diagnostic delay should result in a significant reduction in the time to diagnosis. We are working to build a social movement to drive change, by shining a light on why change is needed, build collective action, provide people with the skills, tools, and

the time to drive transformational change to care processes.

For the first time in the UK, we will have comprehensive data at national level to track changes in time to diagnosis for axial SpA through the National Early Inflammatory Arthritis Audit, and data from *Aspiring to Excellence*.



## Symptom checker follow up survey

Our public awareness campaign targets people aged 40 and under who are experiencing lower back pain and encourages those experiencing symptoms to check them through our 8-point symptom checker. In the campaign's first year we have seen that by telling emotionally compelling and relatable stories about axial SpA, we can motivate people to find out more about the condition and use our online

symptoms checker. To understand what has happened to those completing the symptom checker we have surveyed people who gave us their email address and consent.

In the first year of the campaign, 4,034 people had completed the survey, of whom 650 had provided us with their email address and consent to make contact. We have constructed a follow-up survey and data collection is ongoing.

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From the first 44 completed returns, the following results are available:

- The actions of those experiencing symptoms after symptom checker completion:
  - 27 (62%) printed off the results and / or consulted their GP
  - 10 (23%) undertook more research about axial SpA and their symptoms.
- The actions of GPs once patients presented to primary care:
  - 9 (36%) got a referral to a rheumatologist
  - 7 (28%) underwent diagnostic tests such as x-ray, MRI, or HLA B27 test
  - 6 (24%) were referred to a physiotherapist or other service.
- Some received swift referral to rheumatology, but some lengthy delays still exist with waits ranging from 2 weeks to 12 months. This was quicker for the patients that went privately.
- People are still waiting for a diagnosis, but some are diagnosed quickly:
  - 14 (33%) have received a diagnosis
  - 11 (26%) did not receive a diagnosis
  - 18 (42%) are still waiting.
- The symptom checker completion has driven to people getting an axial SpA diagnosis:
  - 8/44 have received a positive diagnosis of axial SpA, Ankylosing Spondylitis, or inflammatory arthritis.
- Time from symptom onset to diagnosis still varies significantly with the sample ranging from 2 years up to 35 years
- Those still awaiting a diagnosis have been waiting a long time since they first experienced symptoms from 9 months to 20 years.

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The analysis further highlights the need to improve diagnostic delay and that there is varying experience. It shows that raising awareness, engaging people and translating that into simple easily accessible actions can result in people getting a swifter diagnosis. The power of the symptom checker is shown in the qualitative feedback received:

*“I wasn’t aware that axial SpA existed until I read an article and visited your website.”*

*“It has been really helpful finding NASS and knowing others have similar things. It has helped me get some answers even if a bit disappointed. If it had not been for the symptom checker, I wouldn’t have thought of axial SpA and sought a second opinion.”*

*“My GP would never have investigated axial SpA if I had not printed the symptom checker results.”*

*“Thankfully, I have a very good GP who takes seriously any long-term health condition - bloods and scan all done within 3 weeks.”*

*“GPs need more awareness of AS, also a lot more education needed for people with back pain to recognise the symptoms.”*

*“Hindsight is a wonderful thing. All those little issues with inflammation, eyes, urinary tract, bowel problems, aches in the morning and new mattresses.... Suddenly they all fall into place. Opportunities lost to have more adventures earlier in my life, career choices restricted due to fatigue that I didn’t realise I should have sought help for. Put it on billboards and every media, tell our young people what isn’t normal and how to access information and help.”*

*“It’s tough. I have all the clinical symptoms, but no visible damage on MRI so Dr’s refusing to diagnose.”*

*“Doctors really need to listen more.”*

*“I kept being fobbed off and told it was a problem caused by my weight but I put on weight due to not sleeping and not being able to be as active.”*

**Anonymous patients**

We will continue to follow up those completing the symptom checker and publish further analysis as the survey sample increases.



“At the age of 17, I saw a rheumatologist. At this point I had been in pain for five years, and I was exhausted. I could see no hope of living in any other way, I could see no life beyond this struggle. But now I have my diagnosis, I’m a journalist, in a job I love, living my best life.”

Bethany Dawson, 22, London



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