

Act on Axial SpA: A proposal for an Integrated Pilot

Introduction

NASS invites expressions of interest for a health economy to work with us to co-design and test a programme of interrelated interventions that seek to reduce the time to diagnosis of axial SpA to one year from symptom onset.

The individual components of the programme have either already been developed, being trialled or are in the process of being created. We anticipate that the co-creation element will be in large part be about local adaptation of the interventions. However, we want to ensure that those working with us have the freedom to identify and test new solutions.

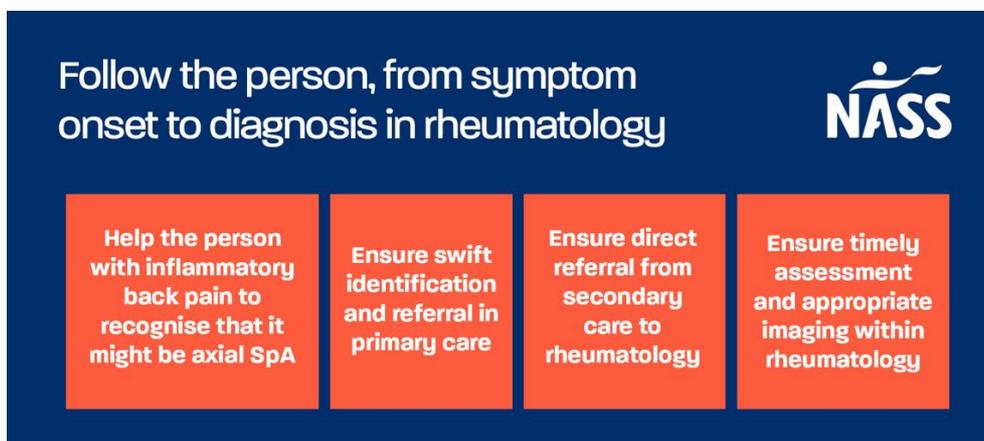
This document describes our broader set of aims in diagnostic delay, our work to date, our aims for the pilot, support from NASS, measurement, key requirements and our proposed timeline.

It represents the first statement of our thinking and we fully expect it to evolve as we enter into discussion with interested parties.

We welcome discussions with potential interested partners in the first instance, through September, after which we may seek a written application for consideration. Please contact Joe Eddison at joeeddison@nass.co.uk to arrange a discussion.

Our aims

In June 2021 we published a route map to achieve a Gold Standard Time to Diagnosis of one year [Gold Standard Core Implementation Document](#)¹. This was based on a national consultation with patients, healthcare professionals and healthcare professional bodies. It identified four delays to diagnosis and four solutions. The solutions are:



Raising public awareness - our vision:

General public awareness of axial SpA and its symptoms is significantly improved from the baseline position of 1 in 10. 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.

Primary care - our vision:

All patients who present to primary care with suspected axial SpA are appropriately identified and urgently referred to rheumatology. Axial SpA is higher within the clinical reasoning of primary care professionals. Primary care information systems prompt consideration of axial SpA for appropriate patients. Inflammatory back pain referral pathways are in place.

Secondary care - 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.

¹ Webb D, Swingler L, Barnett R, Sengupta R, Marshall L, Hamilton J, Zhao S & Gaffney K. Act on axial SpA: A Gold Standard time for the diagnosis of axial SpA (2021). London: National Axial Spondyloarthritis Society

Rheumatology - our vision

All patients presenting to rheumatology services for axial SpA have timely and appropriate investigations that enable the rheumatologist to make an accurate diagnosis first time. 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.

We published a driver diagram which identifies four areas for improvements, the strategy to achieve each of them, and the proposed interventions to achieve those strategies [Gold Standard Driver Diagram](#).

Our progress to date

Raising public awareness

In June 2021 we launched the first phase of a public awareness campaign, mostly through digital channels but with some print media as well. We sought to explain axial SpA as a condition and its key symptoms, and then direct those concerned to our online symptom checker and set of resources to help them prepare for their GP appointment. Based on market testing, we created a first set of collateral including videos and posters [available here](#). We created an online symptom checker which brings together the three validated sets of inflammatory back pain criteria. We also created a special website aimed at the general public and healthcare professionals. In the first year:

- Our social media content reached 1.35m people
- Our campaign videos have been viewed 750,000 times
- Our website was visited by 45,000 users
- 4,000 people completed our online symptom checker.

We are about to survey those who have completed the online symptom checker to understand their journey to diagnosis.

Primary care

In early 2022 we launched Champions in Primary Care, a two year quality improvement and leadership development Programme that aims to raise clinical visibility for axial SpA within primary care and create a culture of leaders working together in a national network to drive change to ensure early identification and referral. We have made our first round of appointments and the programme will begin in earnest in September of this year.

Our champions will also provide a test bed to implement a new pop up tool to assist primary care professionals in identifying patients with suspected axial SpA, this has been developed by Dr Raj Sengupta and PRIMIS.

We will be developing plans to promote our symptom checker and SPADE tool ([see here](#)) as well as promote examples of best practice inflammatory back pain referral pathways.

Secondary care

We are currently commissioning reviews of the current provision of secondary care education on axial SpA in dermatology, gastroenterology and ophthalmology. These will be used to inform the creation of an E-learning training programme for these specialties in late 2022 / early 2023.

We have recently undertaken a freedom information request to assess the use of internal referral pathways and screening tools which we will publish in the autumn.

Rheumatology

We are about to undertake a Freedom of Information request to look at the implementation of the BRITSpA MRI consensus guidelines. We are currently commissioning a review of the current provision of radiology education on axial SpA which will be used to inform the creation of an E-learning training programme over the next 12 months.

Our aims for the pilot

Our programme will only truly work if we are able to support the patient from the moment of symptom onset right through to their diagnosis in rheumatology. The best awareness campaign may fail if, when the patient gets to primary care, the professional has no understanding of the condition, and no referral pathway in place. Likewise, the patient will not benefit if, when they get to rheumatology, the wrong MRI is done or the image is assessed by someone without an understanding of axial SpA.

Only an integrated programme, that follows the person from symptom onset to diagnosis, can truly be successful. Therefore, we want to create an opportunity to determine the maximum potential effectiveness of the four solutions working in consort to reduce time to diagnosis. We want to use the learning and results to demonstrate to others – particularly to Government Health Departments – what might be possible with full implementation of the Gold Standard approach.

Support from NASS

NASS will provide five types of support:

- All of our existing and forthcoming awareness raising collateral will be made available, plus E-learning packages for healthcare professionals, plus any best practice guidance or processes that we curate through the broader programme
- We will develop the marketing strategy, targeting people within your area who are aged 40 and under who may be experiencing low-back pain. We may seek your support to consult local people who fall within

the target audience to test the campaign and would value any insights you can provide on the local media environment.

- We will implement the marketing campaign marketing/awareness raising opportunities, such as local radio station, newspapers, and out of home advertising
- Our Healthcare Professional Engagement Officer which will work in your locality with a range of health professional organisations to promote all of the materials associated with the programme
- Our leadership team will work with you in co-designing the programme, providing you with a measurement framework and reviewing progress throughout the pilot. We will also provide project management / administrative support.

The pilot site will not receive a financial award per se; we will provide strategic, staffing and collateral support including the production of new materials as required.

Measurement

We want to measure the effectiveness of the programme, specifically time from symptom onset to diagnosis in rheumatology, with baseline measurement and data collection throughout the period of the pilot. We will work with you to set up the data systems required to create a baseline position and measure changes in time to diagnosis within rheumatology. This will build on work we are doing with the 19 *Aspiring to Excellence* departments to create a common audit tool on time to diagnosis.

There may be opportunities to partner with academic institutions or secure funding for a research study alongside the pilot.

Key requirements

Here we set out some potential selection criteria:

- A rheumatology department that has a background in improvement work and a strong motivation to co-create the design, engage local partners, and actively champion the pilot within their local health system
- Leadership in local primary care
- Good connections between primary care and rheumatology
- Significant diverse population size
- Local infrastructure for NASS to use in the marketing campaign
- Coterminal with an Integrated Care System / Health Board area that has a clear commitment to improving care in this area
- Strong links into national MSK leadership would be advantageous

Timeline

We want to give adequate time to co-design the pilot, set up relevant data systems and stakeholder engagement, run an initial test, and then undertake a 'full dosage' implementation, with time for analysis and write up.

September – October:	Discussions with potential sites; site selection
November – February 2023	Co-design, create data collection system
March 2023 onwards	Start to collect data
March – December 2023	Initial implementation, periodic review and adjustment
2024:	Full dosage implementation, analysis and write up