

Programme background

Act on Axial SpA: Champions in Primary Care

Introduction

This document provides all of the key information you need about **Act on Axial SpA: Champions in Primary Care**. It describes our vision for the programme, sets out our broader strategy to achieve a Gold Standard time to diagnosis of one year and explains why the programme is needed.

We set out who can apply for the programme, describe the benefits to participants and their host organisations and provide the timescale for application and selection.

Our vision

We want to create a cadre of around 20 clinical champions in primary care and community services whose work ensures that axial spondyloarthritis (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.

Programme participants will embark on a two-year development programme.

- They will receive leadership development support, training in the theory and methods of quality improvement and assistance with identifying and implementing improvement projects.
- They will work together in a national learning network to foster community-building, the exchange of ideas and good practice and act as catalysts for change.

- They will co-create a body of knowledge, methods, tools and experience and work to share their learning with primary and community services across the UK.
- We will seek to engage regional decision makers and connect to musculoskeletal policy at national level - this wider system involvement will be key to successful dissemination.

Our broader strategy: *Act on Axial SpA* – A Gold Standard Time To Diagnosis

In the UK, people living with axial SpA wait an average of 8 ½ years to receive their diagnosis and during this time experience significant amounts of pain and anxiety. They often pay a heavy psychological price for this delay. Symptoms typically begin in early adulthood when people are trying to establish careers, start relationships and families, so a delay to diagnosis can be incredibly disruptive to someone at a key age in life.

In June 2021, following a consultation period, we published a set of proposals to achieve a Gold Standard time to diagnosis of one year, thereby enabling more patients to access appropriate treatment earlier and improve their health and well-being. You can access the report here: https://www.actonaxialspa.com/wp-content/uploads/2021/06/NASS_A-Gold-Standard-time-to-diagnosis_DIGITAL_28pp_compressed.pdf

The overarching programme is called *Act on Axial Spa*. It is fully funded by UCB who has had no editorial control on the contents, and undertaken in partnership with Norfolk and Norwich University Hospitals NHS Foundation Trust and Royal United Hospitals Bath NHS Foundation Trust. NASS is the first organisation in the world to propose a Gold Standard time to diagnosis – the interrelated programmes we are developing represent the largest intervention of its kind in axial SpA anywhere in the world. You can find out more about the programme and our proposed initiatives on our bespoke website: www.actonaxialspa.com.

We aim to reduce diagnostic delay in four areas:

- Delay 1: Helping the person with symptoms to recognise that it might be axial SpA and take action, specifically, going to primary care
- Delay 2: Ensuring that patients who present in primary care with potential axial SpA are urgently referred to rheumatology
- Delay 3: Ensuring that patients who present in secondary care with potential axial SpA are urgently referred to rheumatology
- Delay 4: Ensuring quick and accurate diagnosis once the patient arrives in rheumatology.

In June 2021 we launched the first phase of our awareness campaign to address delay one. During 2022 – 2024 we will implement the other initiatives set out in the report and assess the impact of the programme.

Why is this programme needed?

Primary care and community services have a critically important 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 SpA¹. However, time and again, people with axial SpA report to NASS that their GP and MSK clinicians failed to identify their axial SpA, misdiagnosing it as mechanical pain or ascribing psychosomatic reasons.

Misconceptions about the condition remain among primary care professionals, with GP textbooks still referring to the late stages of axial SpA with a focus on male predominance and late disease features such as fusion of the spine². The GP might not ask the right questions, might refer for the wrong MRI, refer to a different speciality depending on the main

¹ Rudwaleit M, van der Heijde D, Khan MA, Braun J, Sieper J. How to diagnose axial spondyloarthritis early. *Ann Rheum Dis* 2004; 63:535–43

² Simon C, Everitt H, Dorp F van, Burkes M. Oxford Handbook of General Practice. Oxford Handbook of General Practice. Oxford University Press

presenting symptom, or be concerned about the cost of referral. Those testing negative for HLA-B27 are often assumed to have mechanical back pain as are those without raised inflammatory markers in their blood.

A recent study³ explored musculoskeletal physiotherapists' awareness, knowledge and confidence in screening for signs, symptoms and risk factors of suspected axial SpA and criteria for rheumatology referral. It found that only 67% (88/132) identified inflammatory pathologies as a possible cause of persistent back pain, only 60% recognised the axial SpA vignette compared to non-specific low back pain (94%) and radicular syndrome (80%), and awareness of national referral guidance was evident in only 50% of 'clinical reasoning' and 20% of 'further subjective screening' responses. There was also misplaced confidence in recognising clinical features of axial SpA ($\geq 7/10$) compared to knowledge levels shown, including high importance given to inflammatory markers and HLA B27 (median = 8/10). It concluded that musculoskeletal physiotherapists may not be giving adequate consideration to axial SpA in back pain assessments. Awareness of national referral guidance was also limited. Professional education on screening and referral for suspected axial SpA is needed to make axial SpA screening and referral criteria core knowledge in musculoskeletal clinical practice, supporting earlier diagnosis and better outcomes.

Primary care professionals report numerous barriers to diagnosing axial SpA⁴, including low prevalence among patients with chronic back pain, the lack of a definitive diagnostic test, the slow progression of the condition and the intermittent nature of the pain that patients experience.

³ Steen E, McCrum C & Cairns M Physiotherapists' awareness, knowledge and confidence in screening and referral of suspected axial spondyloarthritis: A survey of UK clinical practice *Musculoskeletal Care*. 2021;1–13

⁴ Lapane, K.L., Khan, S., Shridharmurthy, D. *et al.* Primary care physician perspectives on barriers to diagnosing axial Spondyloarthritis: a qualitative study. *BMC Fam Pract* **21**, 204 (2020). <https://doi.org/10.1186/s12875-020-01274-y>

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

One of the themes emerging from discussions of the All Party Parliamentary Group on axial SpA is the need to strengthen local clinical leadership for the condition in primary care in order to ensure earlier detection and referral.

A clinical champions programme seeks to address this deficit within primary care and community services

Who can apply?

Programme participants might be First Contact Practitioners, GPs, community MSK physiotherapists or other NHS primary and community services professionals.

Benefits to participating clinical champions and their host organisations

Those participating 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. We will seek CPD accreditation.

Their work will 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 upskilled primary care workforce, one would expect to see a better understanding of medication, exercise, fatigue and mental health in axial SpA.

NASS is engaging a specialist provider who will design and deliver the programme on our behalf. Participants will not receive a financial award per se; what they will receive is two years of development support. In addition, NASS will reimburse costs for travel, meals and accommodation for learning events. The financial value of the award is £5,000 per participant.

Timescale

Programme formally launched	7 February
Deadline for programme applicants	4 May
Interviews with shortlisted applicants	25 May
Programme commences	15 June
Programme ends	May 2024

Application and questions

Please complete the accompanying application form and submit your application to Dr Dale Webb dalewebb@nass.co.uk by 10 a.m. on 4 May.

Interviews will be held with shortlisted applicants on 25 May.

If you have any questions, please don't hesitate to contact Dale Webb.



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Axial SpA