National Axial Spondyloarthritis Society
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Axial SpA works silently. We don't.

NASS Submission to Major Conditions Strategy Consultation by the Department of Health

27 June 2023

1. Tackling the risk factors for ill health

Axial spondyloarthritis (axial SpA) including ankylosing spondylitis (AS) is a form of inflammatory arthritis, whose causes are genetic and environmental.

Smoking can affect disease progression and pain levels in axial SpA. It can reduce the efficacy of biologic medication. It is likely that many people will not know this and so the risks of smoking need to be factored into health professional consultations regularly, with discussions about general risk such as cancer, and more specific risks which may impact day to day life[1]

Opportunities for secondary prevention:

- **Increased public awareness can lead to more timely visits to primary care:** a You Gov poll in 2021 showed that 91% had not heard of the condition[2], despite a prevalence of 1:200 of the UK adult population. Improved public awareness can lead to earlier diagnosis.

- **Earlier diagnosis can slow down or prevent disease progression:** axial SpA is a progressive condition and if left untreated can lead to worse outcomes. Exercise and anti-inflammatory medication are the cornerstones of treatment; if the right exercise advice and support, along with medication, are offered earlier, it can help to ensure that people have less stiffness and pain, and in some cases prevent or slow down progression to radiographic axial spondyloarthritis, or ankylosing spondylitis, when the spine can irreversibly fuse[3].

- **Physical activity and specialist physiotherapy keep people active and able to remain in work.** Continued access to advice from specialist rheumatology physiotherapists is essential to ensure that people are doing

[1] https://pubmed.ncbi.nlm.nih.gov/36270658/
[2] https://www.actonaxialspa.com/1673-2
[3] Danve A, Deodhar A. Treatment of axial spondyloarthritis: an update. Vol. 18, Nature Reviews Rheumatology. Nature Research; 2022. p. 205–16

- the correct exercises, and to ensure adherence, as research shows that those diagnosed earlier are often less engaged with self-management and exercise. not everyone is able to tolerate land based exercise and require hydrotherapy or aquatic physiotherapy which should take place in water 33 to 36 degrees Celsius, several degrees warmer than a swimming pool as cold water can be painful to exercise in when in flare.

- **Regular monitoring via PROMs and PREMs and physical measurements can flag trends in disease progression.** Ongoing measurement of symptoms is key. The condition can often progress slowly and pain levels can increase gradually meaning that people don't always recognise how much their condition has progressed, or the effect that it may have on their mental health. Regular use of PROMs and PREMs is key to ensure trends are spotted in sufficient time. The main measurements used in axial SpA are the Bath Indices which measures daily activity, function and mobility. Many teams also use the FACIT-F tool which measures fatigue, one of the most debilitating symptoms of axial SpA. For mental health the Hospital Anxiety and Depression Scale (HADS) is most commonly used.

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2. How can we better support local areas to diagnose more people at an earlier stage?

The average UK time to diagnosis for axial SpA is 8.5 years, has not improved[4] [5] and is longer than the international mean of 6.7 years[6]. There are significant benefits to timely diagnosis:

- **Diagnostic delay costs the UK economy £18.7 billion** p.a.[7] Reducing time to diagnosis to one year would save an average patient £167,000.
- **Reducing delay improves functional impairment and quality of life[8].**

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[4] Sykes M et al., Delay to diagnosis in axial spondyloarthritis: are we improving in the UK?, *Rheumatology*, 2015; 54; 2283 - 2284
[5] NASS, 2023, unpublished data
[6] *Zhao S et al. 'Diagnostic delay in axial spondyloarthritis: a systematic review and meta-analysis', Rheumatology 2021*
[7] Wilsher S et al. 2022: *The economic costs of delayed diagnosis of axial spondyloarthritis in the UK*, London: NASS
[8] Yi E et al. 2020 Clinical, Economic, and Humanistic Burden Associated With Delayed Diagnosis of Axial Spondyloarthritis: A Systematic Review, *Rheumatol. Thera.* 2020 Mar;7(1):65-87.

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- **Reducing delay alleviates pressures in primary care and secondary care**[2] if patients are identified on first presentation and referred to rheumatology.

Following a national consultation, the National Axial Spondyloarthritis Society published a route map to achieve diagnosis within one year[9] with solutions[10] following the patient from symptom onset to diagnosis.

- **Public awareness and action:** A NASS public awareness campaign (video views 1.1 m, social media views 2.4 m) resulted in 14,000 people completing an online symptom checker.
- **Identification and referral in primary care:** To elevate axial SpA in the clinical reasoning of primary care practitioners, NASS appointed 12 clinical champions to: create national learning resources; undertake quality improvement initiatives; and promote decision-support tools including the PRIMIS GP alert.
- **Internal referral pathways:** Those with symptoms may present at secondary care services. Internal referral pathways into rheumatology can ensure the patient is not referred back to their GP, reducing diagnostic delay.
- **Imaging and reporting:** 29% of NHS Trusts outsource MRI reporting to non-MSK radiology services. Outsourced MRI should be monitored closely and local accountability arrangements put in place[11].

This integrated approach has been effective at the Royal Free NHS Foundation Trust, resulting in a reduction of one year[2].

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3. How can we better support and provide treatment for people after a diagnosis?

Regular access to services that keep people well and active is essential. Continued access to specialist rheumatology physiotherapists is essential to ensure people do the correct exercises for them. Some patients can't tolerate land based exercise and require hydrotherapy or aquatic physiotherapy which should take place in water 33 to 36 degrees Celsius,

[9] Webb D et al. A Gold Standard time for the diagnosis of axial SpA (2021) NASS
[10] *www.actonaxialspa.com*
11 Eddison J et al. The Use of MRI in the diagnosis of Axial SpA (2023) NASS

several degrees warmer than a swimming pool which can be painful to exercise in. Self-referral should be available to ensure that support is timely.

- The spinal team at NHS Fife reduced DNAs for physiotherapy by using a personal outcomes approach during the initial consultation with the patients to aid engagement by finding out what matters to them, what they hope for and what they want to be different in their lives[12] It facilitated a conversation focused on the patient to ensure they feel listened to and understood to aid motivation. This helps to formulate an asset-based approach to wellbeing using the person's own knowledge and skills to help patients change by constructing solutions rather than focusing on problems.

Standardised frameworks can streamline services for maximum efficacy for the NHS and patients. The Rheumatology Physiotherapy Capabilities Framework increases understanding of physiotherapy capabilities, helps to prioritise investment, and provides a reference for rheumatology and MSK triage services throughout the UK. It's supported by a wide expert working group and involved an extensive external review process.

Supported self-management can ensure that people can live their day to day lives. For this to work effectively, management plans need to be developed as a collaboration between patient and health professional. NASS has developed a toolkit to help health professionals to structure their conversations with their patients[13].

Ongoing access to helplines & urgent appointments for flare management and mental health support are vital. As a fluctuating condition, people with axial SpA may need access to their health care teams at more than their regular bi-annual or annual appointment.

The third sector is uniquely placed to support people to self-manage and live well, as well as support the NHS.

- NASS runs a supported self-management programme, delivering online sessions working with local health care teams to provide support for their patients, reaching 1100 to date.

[12] Barnett R, Webb D & Davies L, Driving improvements in axial SpA services: Building strong foundations through Aspiring to Excellence (2021) NASS
[13] https://nass.co.uk/homepage/health-professionals/aspiring-to-excellence/time-flies-tools-to-help-make-the-most-of-consultations/

- We have developed an online self-management programme aimed at the newly diagnosed which offers bitesize help in living with pain, fatigue and flares. Developed in partnership with patients and health professionals. It consists of short videos sharing information and lived experience, downloadable resources to create a personalised toolkit and free monthly online meetups[14].

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4. How can we better enable health and social care teams to deliver person-centred and joined-up services?

Axial SpA is a complex condition which should be managed in a specialist clinic by a multidisciplinary team (MDT). Treatment in a specialist axial SpA clinic improves outcomes. Teams include a consultant rheumatologist, specialist physiotherapist, rheumatology nurse specialist and occupational therapist, and may also include a pharmacist, clinical psychologist, MSK radiologist and podiatrist.

Allied health professionals have a key role in supporting lifestyle interventions. For example, people with axial SpA are at increased risk of work disability. Occupational therapists work with patients to identify their priorities and provide advice accordingly, focusing on patients' health assets and helping them to develop skills to optimise self-management. OTs are best placed to identify and help resolve early work instability with targeted job retention vocational rehabilitation.

Seeing the right health care professional at the right time can help with resourcing and outcomes. If smaller rheumatology departments are unable to run an MDT clinic, alternative arrangements to help units with more complex patient needs include access to colleagues to discuss individual cases, and the opportunity to refer to other teams within the ICB that operate an MDT service.

Departments with small patient cohorts and limited resources have been able to run specialist clinics. Alternatives include therapy-led clinics with fast-track access to a consultant, or running clinics less frequently.

[14] https://nass.co.uk/about-as/your-space/

The first appointment should be with a professional with the ability to diagnose or offer treatment when waiting for a diagnosis. This could be a rheumatologist, but also physiotherapist.

People need to be actively involved in their care. What patients want from their interaction with HCPs:[15]

- Listened to, heard and taken seriously.
- Investigations to be carried out in a timely manner.
- Symptom management when waiting for a referral.
- Opportunity to discuss all symptoms.
- Diagnosis face to face or online, not in writing.
- Referral to physiotherapy.
- Active involvement in discussions about medication options.
- Access to a flare helpline.
- Time to discuss the impact of axial SpA, such as sex life, fertility, pregnancy, menopause, relationships, home life, medication side effects, emotional wellbeing, work, and social life.
- Time to discuss flares and symptoms and their impact.

NASS has a toolkit for HCPs to support collaborative agenda setting, assist in preparing for appointments and help develop management plans[16].

Patient Initiated Follow can be beneficial but used cautiously in fluctuating conditions. Axial SpA often progresses very slowly which may not be apparent to someone living with the condition. It is critical that PIFU is done in conjunction with active monitoring of regular outcome measures to identify trends in disease progression and early signs a patient may need to come back in.

To ensure that services meet the needs of the population, co-production with patients is vital. This includes people who access the services, carers and the third sector.

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[15] Headstrong Thinking Limited, *What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis?* (2022) NASS
[16] https://nass.co.uk/homepage/health-professionals/aspiring-to-excellence/time-flies-tools-to-help-make-the-most-of-consultations/

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5. How can we make better use of research, data and digital technologies to improve outcomes for people with, or at risk of developing, the major conditions?

A simple digital survey / audit tool has been developed to improve time to diagnosis in axial SpA. In October 2022 NASS developed a time to diagnosis audit. In the first six months, 39 NHS Trusts have signed up to the audit and 400 patients have submitted their journey. Participating Trusts receive individual feedback and benchmarked data. The audit is completed by patients, removing the need for clinicians to spend their time entering data. It complements the National Early Inflammatory Arthritis Audit.

A Pop-up tool in GP surgeries has shown proof of concept to prompt primary care professional to consider axial SpA in presenting patients, leading to quicker referral[17]

Screening tools can also play a part in prompting visits to primary care and onward referral. NASS's online symptom checker uses validated criteria that people experiencing low back pain can complete[18] They receive a print out to take to their GP/FCP. The SPADE tool supports GPs in assessing the probability of axial SpA. Ardens have an MSK template which include the NICE criteria for axial SpA, and is used by FCPs.

Machine learning techniques may help to contribute to early recognition of axial SpA and timely diagnosis[19]

A stratified screening process for early identification of axial spondyloarthritis can facilitate rapid diagnosis[20]

Work in Berkshire demonstrated that by using ePROs regularly with stable patients, some routine appointments could be moved from 6 monthly to 12 monthly, and appointments were switched from face to face to video consultation. This resulted in a saving of 250 hours of clinical

[17] https://www.nottingham.ac.uk/primis/documents/case-studies/axspa-original-project-in-bath-case-study.pdf
[18] https://www.actonaxialspa.com/symptoms-checker/
[19] https://pubmed.ncbi.nlm.nih.gov/31044386/
[20] Passalent L et al. 'Bridging the gap between symptom onset and diagnosis in axial spondyloarthritis', *Arthritis Care and Research'* 2021, 74, 6: 997 – 1005

time which was utilised for more 'flare' slots to see patients that really needed seeing[21]

Digital technology is vital to supporting self management. NASS has delivered online sessions for 1100**+** people which includes managing pain, flares and fatigue, night pain and sleep, exercise and posture, medication and work. It was positively evaluated to show reductions in isolation, improvements in confidence in self-management as well as bringing back patients who were lost to follow up[22].

Monitoring apps can play a crucial role in supporting people to live well and have better outcomes. The My Pathway app, developed by Sheffield Teaching Hospitals NHS Foundation Trust. The app is used by patients to track appointments, access information and provide feedback on their health and ensures that patients are actively participating in their treatment and care.

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6. How can we better support those with mental ill health?

Up to 55% of people with axial SpA also have mental ill health. Many people with axial SpA also have some sort of mental health issue in their lifetime, with figures reported up to 60%[23] This is often related to the burden of disease and pain, but can also be linked with being unable to work and being left with financial difficulty.

Health professionals outside of the condition area find ill mental health difficult to tackle. Health professionals caring for people with axial SpA often lack the knowledge to be able to broach the subject of mental health, and as a result do not feel able to raise it. There are also often barriers to referral within secondary care to services with patients often having to return to their GP. Secondary care teams should be able to refer directly to psychological services. This would allow early intervention before people's mental health

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[21] Chan A et al., 'Improving Care and Capacity Through Capturing and Recording Patient Reported Outcomes with Digital Solutions in Spondyloarthritis', *American Congress Rheumatology* 2021 https://acrabstracts.org/abstract/improving-care-and-capacity-through-capturing-and-recording-patient-reported-outcomes-with-digital-solutions-in-spondyloarthritis/).

[22] https://nass.co.uk/about-as/your-space/

[23] Tianjiao M et al. Depression in patients with ankylosing spondylitis, *Rheumatology and autoimmunity,* 2022: 2,2: 69-75

spirals. Rheumatology teams could use tools such as HADS to help them better identify when someone may be needing mental health support.

Mild to moderate ill mental health can be addressed with access to an occupational therapist. Occupational therapists can offer a range of support mechanisms for mental health including mindfulness and stress management. Access to an occupational therapist can also help to manage pain levels which can result in better managed mental health and function.

Online resources can help with mild to moderate ill mental health. There are numerous online resources that people with mild ill mental health can access which all health professionals should know to signpost to[24]
As an example of best practice, the rheumatology team at the Royal Berkshire Hospital worked to improve the identification of people with moderate ill mental health by 25% using HADS. 90 patients participated in the HADS screening. Patients were invited to watch a self-help video which the department had developed with a clinical psychologist on managing anxiety and depression. They were also directed to further online mental health resources, self-management sessions and talking therapies.

[24] https://www.silvercloudhealth.com/uk