

**A Gold Standard in Treatment and Care for Axial Spondyloarthritis**  
**Part of the *Aspiring to Excellence* Programme**

**We want to hear from you**  
**Share your experiences of axial SpA health care services**



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Driving improvements in axial SpA care

## About NASS

We are the National Axial Spondyloarthritis Society (NASS) and we seek to transform the diagnosis and care of people living with axial spondyloarthritis (axial SpA), including ankylosing spondylitis (AS).

It's an often invisible and misdiagnosed condition, leaving people feeling powerless, in increasing pain and extreme exhaustion.

We campaign policy makers for early diagnosis and better services. We work with the NHS to get axial SpA identified and diagnosed quickly. We're determined that everyone receives effective care.

We make sure people with axial SpA get the latest information and the support they need to tackle living with the condition. And we build an active community, online and through our local branches across the UK. We are with them all the way.

Axial SpA works silently. But we don't.

## About *Aspiring to Excellence*

Axial SpA has been under prioritised and overlooked within the healthcare system for many years. As a result, people often experience delayed diagnosis and inconsistent quality of care despite a national guideline. This leaves people living in pain for years feeling unheard, dismissed, and anxious about their future.

We want to change this.

*Aspiring to Excellence* was established to ensure that every person with axial SpA gets the best care, every time. Working with the NHS Transformation Unit, we partner with rheumatology teams to catalyse improvements in their departments and the wider NHS. We offer these teams protected time so that they can work on projects that will improve patient experiences.

We create a learning environment with service improvement experts on hand, enabling data driven conversations which will improve care, creating a service that people with axial SpA value and trust.

And we build a powerful network of health care professionals who can collaborate and support each other through change.

Together, we will drive improvements in care for people living with axial SpA.

Read more about [\*Aspiring to Excellence\*](#)

## The Steering Group

The Gold Standard in Treatment and Care for Axial Spondyloarthritis is a collaborative effort between people with lived experience and health care professionals, led by NASS. Thank you to the steering group who have co-designed the consultation process.

- Sian Bamford, Advanced Practice Physiotherapist, Royal Free NHS Foundation Trust
- Professor Lettie Bishop, Professor of Exercise Immunology Loughborough University
- Patricia Bissett, Rheumatology Specialist Occupational Therapist, NHS Greater Glasgow and Clyde
- Robin Brittain, person with axial SpA
- Caroline Brocklehurst, person with axial SpA
- Amy Cole, person with axial SpA
- Clare Clark, Senior Partnership and Engagement Officer, NASS and person with axial SpA
- Zoë Clark, Programme Manager, NASS and person with axial SpA
- Dr Aisling Coy, Consultant Rheumatologist, Salisbury NHS Foundation Trust
- Victoria Cullwick, person with axial SpA
- Alasdair Davie, Advanced Clinical Specialist Physiotherapist in Rheumatology and Aquatic Physiotherapy, NHS Greater Glasgow and Clyde
- Joe Eddison, Programme Manager, NASS and person with axial SpA
- Dr Jane Freeston, Consultant Rheumatologist, Leeds Teaching Hospitals NHS Trust
- Craig Gunn, person with axial SpA
- Will Gregory, Consultant Physiotherapist, Northern Care Alliance NHS Foundation Trust – Salford Care Organisation, Co-chair Rheumatology Physiotherapy UK, Vice President, British Society for Rheumatology
- James Hillery, person with axial SpA
- Claire Jeffries, NASS Trustee and Physiotherapy Clinical Specialist in Hydrotherapy & Rheumatology, Solent NHS Trust
- Dr Lesley Kay, NASS Trustee, National Clinical Director for MSK NHS England, Consultant Rheumatologist at The Newcastle upon Tyne Hospitals NHS Foundation Trust
- Carol McCrum, Consultant Physiotherapist
- Dr Melanie McInnes, person with axial SpA and Health Services Researcher
- Gemma O’Callaghan, Occupational Therapist, The Newcastle upon Tyne Hospitals NHS Foundation Trust
- Georgie Wishart, person with axial SpA

We are also very grateful to Lucy Davies and Alex Vincent from the NHS Transformation Unit and cohorts three and four of Aspiring to Excellence for their contributions at the teams’ quarterly learning sessions.

## **Introduction**

**NASS is working to develop a Gold Standard in Treatment and Care for Axial Spondyloarthritis. That is, what people with axial SpA should expect from the healthcare professionals who support them from the point of diagnosis.**

## **Background**

In 2022, NASS published research which looked at *What do patients value and need in the diagnosis, treatment and care of axial spondyloarthritis* as part of *Aspiring to Excellence*. Our aim was to provide a lived experience perspective to balance the mainly clinical view expressed through National Institute for Health and Care Excellence (NICE) Guideline 65. The NICE Guideline is a set of national recommendations on what treatment and care people with axial SpA should get.

The study found that people with axial SpA don't see managing their condition as being in a straight line. Instead, living with axial SpA needs a holistic (rounded), as well as clinical, approach. From the research, we were able to develop a set of ten values-based quality standards. These standards, and the wider research results, will be firmly embedded in every area we cover with the Gold Standard in Treatment and Care.

## **What do we mean by a Gold Standard in Treatment and Care?**

Although national and international guidelines and quality standards exist, they are limited in key ways:

- They discuss what should be included in the management of axial SpA but not how it should be provided
- They make clear that exercise, physiotherapy and (to a lesser extent) hydrotherapy play a key role in treatment and care, yet do not specify the frequency and intensity of therapy, nor the extent to which they should be driven by health care professionals or people with the condition
- They do not look at the wider health care professional community and the role that they play
- The guidelines do not include mental health or self-management

Our steering group wants the Gold Standard to address the missing parts of the treatment and care jigsaw. The evidence we gather should include the broadest range of sources, including audit results, statements which have been agreed by experts, case studies, and personal testimony.

Our aim is to produce something that balances clinical considerations and lived experience. It should be achievable by all rheumatology services - whether large or small, a specialist axial SpA clinic or one that includes people with axial SpA in a general rheumatology clinic. But it should also be aspirational.

## **Why is a Gold Standard needed?**

When we first started thinking about a Gold Standard, we felt there was an opportunity to tell a much broader story than is currently being told..

A Gold Standard can help to address health inequalities for people with axial SpA, and give services a standard to measure against when delivering care. People with axial SpA also need a clear picture of what 'good' looks like, and what they should be asking for and expecting.

Historically, axial SpA has often been 'tagged on' to other condition areas or included in broader areas which meant that it was often lost. This presents an opportunity to produce in-depth and axial SpA specific standards, whilst acknowledging that some services will have limits to what they can achieve.

## **Outcomes of a Gold Standard in Treatment and Care**

Over time, we hope that the Gold Standard will become the go to guidelines for all services that see people with axial SpA, and improve treatment and care overall for those patients. We hope that this work will ensure patients with axial SpA receive consistently excellent treatment.

## **What will the Gold Standard in Treatment and Care cover?**

We have worked closely with the steering group and *Aspiring to Excellence* teams, firstly to establish the main areas that need to be covered, and also what questions we think need to be answered for people with axial SpA and the health care professionals delivering their care.

## **How you receive your care**

In this section we want to find out what has worked for you when it comes to how your care has been delivered. So for example, how often you see different members of your health care team, what you discuss at appointments and how you get in touch with different members of the team (eg, is there a helpline you can call, can you book emergency appointments).

You might also want to talk about the role that your GP plays in helping to manage.

[Read what questions we are trying to answer in each area](#)

## **Medication**

For this section, we won't be discussing WHAT medication you might have been prescribed. Instead, we want to know about the discussions that you had with your health care team and how a decision was made to prescribe specific medications. Were you offered information, support and education after you were prescribed?

[Read what questions we are trying to answer in each area](#)

## **Therapy-led**

Whilst medication can help us all to live well, to really have a well-rounded approach to management, therapies are very important. This could be physiotherapy (at the hospital or privately), hydrotherapy, occupational therapy. Or maybe you have visited an osteopath or chiropractor who has helped you to manage your axial SpA. Are a member of a NASS branch and would like to share how this has improved your axial SpA.

*Read what questions we are trying to answer in each area*

## **How axial SpA affects you in other ways**

Lots of people with axial SpA are affected by different areas physically, mentally and emotionally. Here we will want to hear from people about how they have been helped to manage their fatigue, have had help with their mental health and have had support around reproductive health.

There may also be other conditions which you needed help with such as bowels, skin and eyes which has meant that your health care services have provided joined up care. We also want you to tell us about the care you've received for your feet, heart and bones.

*Read what questions we are trying to answer in each area*

## **Living with axial SpA**

Living with axial SpA is what we all need to do on a daily basis. So what support have you had that's worked for you with self-management for example? Or maybe you have had employment or education support. Perhaps you are a carer or loved one of someone with axial SpA and want to share your experiences of the support you have received.

*Read what questions we are trying to answer in each area*

## **Sharing your experience**

We would love to hear from anyone who either has axial SpA, is a carer or family member, or a health care professional treating people with the condition or related conditions.

We would mainly like to hear about your positive experiences. Tell us about examples of best practice you have experienced, what worked well for you and why.

However if you think there are specific lessons that could be learned from your negative experiences, and have suggestions on how they could have been improved, we are also happy to hear about those.

## **For people with lived experience**

[Evidence template for people with lived experience \(Word version\)](#)

[Evidence template for people with lived experience \(Survey Monkey\)](#)

**Closing date for submissions is 16 August 2024**

## **Appendix 1: Existing guidelines for axial SpA**

Currently, four main sets of recommendations and guidelines exist at a national and international level for axial SpA.

### **Getting it Right First Time (GIRFT) in Rheumatology (2022)**

This report sets out how rheumatology services can be improved, and includes a set of 23 recommendations. These are broader than axial SpA, but many of them are relevant.

Crucially, the recommendations come with a pathway for axial SpA which was developed by Best MSK Health in England with GIRFT, including input by NASS. This pathway forms an excellent basis for the development of the Gold Standard in Treatment and Care.

[Read the GIRFT Recommendations](#) (short version)

[Read the GIRFT Recommendations](#) (detailed version)

[Read the GIRFT pathway for axial SpA](#)

Although the pathway was created for England, it could be applied across any UK nation.

### **ASAS-EULAR recommendations for the management of axial spondyloarthritis: 2022 update**

The Assessment of SpondyloArthritis International Society (ASAS) is an international group of experts in the field of spondyloarthritis. In 2022 they published a reviewed set of recommendations for the treatment of axial SpA. Whilst there are some recommendations on education and exercise, they are largely clinical.

[Read the ASAS-EULAR recommendations](#)

### **NICE Guideline 65 Spondyloarthritis in over 16s: Diagnosis and Management (2017)**

This covers both axial and peripheral (other joints outside the spine) SpA.

The guideline includes recommendations on:

- Recognition and referral
- Diagnosing SpA in specialist care
- Managing SpA
- Information and support

[Read the full NICE Guideline.](#)



## **NICE Quality Standard 170 Spondyloarthritis (2018)**

Following on from the publication of the NICE Spondyloarthritis Guideline, NICE published a Quality Standard for Spondyloarthritis.

A Quality Standard sets out the priority areas for quality improvement in health and social care. They cover areas where there is variation in care.

Each standard gives:

- A set of statements to help improve quality
- Information on how to measure progress

The NICE Quality Standard for Spondyloarthritis covers four areas:

- Adults with suspected axial or peripheral SpA are referred to a rheumatologist
- Adults with suspected axial SpA and an X-ray that does not show sacroiliitis have an MRI using an inflammatory back pain protocol
- Adults with axial SpA are referred to a specialist physiotherapist for a structured exercise programme
- Adults with SpA are given information about their condition, which health care professionals will be involved with their care, and how and when to get in touch with them

[Read the full NICE Quality Standard](#)

## **British Society for Rheumatology Guideline for axial SpA (2024)**

This guideline is currently under review and the updated version is due to be published later in 2024. We will use this particularly to inform the workstream looking at pharmacological intervention (medication).

[Read the scope of the guideline](#)