



**Axial SpA
works silently.
We don't.**

A Gold Standard in Treatment and Care for Axial Spondyloarthritis

Part of the *Aspiring to Excellence* Programme

Call for Evidence

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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
- 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
- Will Gregory, Consultant Physiotherapist, Northern Care Alliance NHS Foundation Trust – Salford Care Organisation, Co-chair Rheumatology Physiotherapy UK, Vice President, British Society for Rheumatology
- Claire Jeffries, NASS Trustee and Physiotherapy Clinical Specialist in Hydrotherapy & Rheumatology, Solent NHS Trust
- Dr Lesley Kay, NASS Trustee, National Clinical Lead for Rheumatology GIRFT Programme NHS England, and Consultant Rheumatologist at The Newcastle upon Tyne Hospitals NHS Foundation Trust
- Carol McCrum, Consultant Physiotherapist
- Wendy Rakison, person with axial SpA
- Gemma O’Callaghan, Occupational Therapist, The Newcastle upon Tyne Hospitals NHS Foundation Trust
- Debbie Wilson, person with lived experience
- Lara Wiseman, 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 with a range of stakeholders to develop a Gold Standard in Treatment and Care for Axial Spondyloarthritis, 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 study found that people with axial SpA don't see managing their condition as linear, or one that can be defined by a pathway. Instead, living with axial SpA is a series of touchpoints that often need 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

In addition, the criteria for inclusion is such that evidence outside of particular types of research, in this case randomised controlled trials, is barely included.

Our steering has determined that the Gold Standard should address the missing parts of the treatment and care jigsaw. The evidence that informs it should include the broadest range of sources, including audit results, consensus development statements, case studies, and personal testimony.

Our aim is to produce something that is rigorous and which balances clinical considerations and lived experience. It should be achievable by all rheumatology services - whether large or small, and 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?

In our initial thinking behind a Gold Standard, we felt there was an opportunity to tell a much broader story than is currently being told by existing guidelines, standards, and pathways.

A Gold Standard can help to address inequalities across the system 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, all the while acknowledging that not all services have axial SpA clinics, or someone who specialises in the condition, and may have a general rheumatology clinic.

Outcomes of a Gold Standard in Treatment and Care

Over time, we hope that the Gold Standard will become operational for all services that see people with axial SpA. It should also be able to address health inequalities and regional differences in the delivery of care.

To support implementation of the standard, a set of tools will be developed to help departments to improve, regardless of their size.

As part of this process, we aim to develop a national minimum data set for axial SpA which currently does not exist as it does for other condition areas. We also hope that it helps to establish research priority areas and create an evidence base to encourage commissioners to agree financial support to develop services.

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](#)

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.

Workstream One: Organisation of Care

- Shared decision making
- Pathways and ongoing care
- Primary and community care
- Peripheral issues (outside the spine)
- Surgery

Read what questions we are trying to answer in each area

Workstream Two: Pharmacological Interventions (medication)

- Shared decision making
- Information, support, and education
- Application of existing guidelines and guidance from BSR, ASAS and NICE

Read what questions we are trying to answer in each area

Workstream Three: Therapy-led Interventions

- Physiotherapy
- Hydrotherapy
- Occupational therapy
- Osteopathic
- Chiropractic

Read what questions we are trying to answer in each area

Workstream Four: Extra-axial Care

- Fatigue management
- Extra-musculoskeletal manifestations (EMMs)
 - Inflammatory bowel disease/gastroenterology
 - Uveitis or iritis/ophthalmology
 - Psoriasis/dermatology
- Podiatry
- Mental health
- Reproductive health
- Cardiovascular health
- Bone health

Read what questions we are trying to answer in each area

Workstream Five: Living with axial SpA

- Supported self-management
- Employment & Education
- Guidance for loved ones and carers
- Wellbeing management

Read what questions we are trying to answer in each area

Submitting evidence

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. Your experiences and interventions will play a vital role in developing the Gold Standard.

When submitting your evidence, we will ask you to choose which workstream it relates to. If you don't know, don't worry, there is an option for 'Don't know/not sure', and we can make sure it goes into the right category.

For people with lived experience

If you are a person with lived experience, you may have had a new way of being able to communicate with health care professionals, or been able to work with your health care team to develop a different way of approaching your condition. We want you to tell your story of how this 'intervention' - as we call it - has helped you.

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

Please return this form to aspiringtoexcellence@nass.co.uk

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

For health care professionals

If you are a health care professional, you may have introduced an intervention locally to help improve your service and outcomes for people with axial SpA. For example, your evidence might be in the form of audit data, feedback, or focus groups.

If you have more than one, please submit each intervention individually.

[Evidence template for healthcare professionals \(Word version\)](#)

Please return this form to aspiringtoexcellence@nass.co.uk

[Evidence template for healthcare professionals \(Survey Monkey\)](#)

Closing date for submissions is 26 July 2024

Thank you for your contribution