

We want to hear from you

Share your experiences of axial SpA health care services



What we are doing

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.

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. Our aim is to produce something that balances clinical considerations and lived experience. It should be achievable by all rheumatology services 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 give services a standard to measure against when delivering care. And give people with axial SpA a clear picture of what they should be asking for and expecting.

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 with our steering group to put together the different areas of axial SpA care we would like to look at:

- How you receive your care
- Medication
- Therapies
- How axial SpA affects you in other ways
- Living with axial SpA

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.

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.

Your experiences will play a vital role in developing the Gold Standard. **Closing date for submissions is 16 August 2024**