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# Axial Spondyloarthritis Playbook: reducing time to diagnosis and improving patient experience

GETTING IT RIGHT FIRST TIME
Inspired by patients. Driven by science.
Norfolk and Norwich University Hospitals NHS Foundation Trust
Royal United Hospitals Bath NHS Foundation Trust
act on Axial SpA

# Foreword

## Dr Lesley Kay, National Clinical Director for musculoskeletal conditions, NHS England & Clinical co-lead for rheumatology, GIRFT programme, NHS England

I am delighted to see this playbook launched, representing a further development of the work between NHS England's Getting It Right First Time (GIRFT) team and the National Axial Spondyloarthritis Society towards the shared aim of improving access to the right care for people with axial spondyloarthritis.

NASS and GIRFT collaborated with the British Society for Rheumatology to develop a national best practice pathway for axial spondyloarthritis. This playbook is closely aligned to that pathway and utilises tools from the GIRFT Further Faster handbooks.

I hope that primary, community and rheumatology teams now use this playbook to review their own services. Undertaking a gap analysis exercise can help to identify your service's priorities for quality improvement, and this playbook demonstrates good practice for implementation. NASS has developed this tool to help you understand where you are performing well and where you might need to implement measures in this playbook, as well as benchmarking yourself against the national picture as the playbook is implemented around the country.

This is a living document, so we would be grateful for feedback on how you have used it, your successes and any barriers you have faced and overcome.

This represents a major step forward in supporting clinicians and services across the whole pathway to improve the access to care for people living with axial spondyloarthritis.

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# How to use the playbook

## A practical guide, supported by tools and examples.

- **This guide provides a “best practice” approach to support you in reducing the time to diagnosis in axial SpA locally, as well as the essential support that patients should receive when they are diagnosed.**
- **It is organised along key sections of the pathway and provides checklists against which you can assess your current practice.**
- **It also focusses on data as a tool to understand current performance, assess unmet need and measure improvement.**
- **Resource links take you to guidance, templates, tools and case studies.**
- **You can review the checklists, set your priorities and collect local data.**

# An implementation plan on a page

**This section sets out a sequence of activity to work through alongside the following pages. The numbers in each step link to the relevant good practice point.**

## Understand the need and collect data

- Collect data on time to diagnosis and on the local axial SpA population (5.6)
- Identify the local axial SpA lead (3)
- Use the NASS economic model to assess the financial impact of delayed diagnosis at local level (4)
- Identify the key contacts in primary care, non-rheumatology secondary care & radiology (20, 27)
- Ask patients what they think of the service (7)

## Implement some quick wins

- Develop local relationships with colleagues in:
  - Primary care
  - Extra musculoskeletal manifestation (EMM) services
  - Radiology (18,22, 27)
- Put up axial SpA symptom posters with a link to the NASS symptom checker (11, 12)
- Order free materials for self-management, signpost patients to Your SpAce and order NASS guides (31, 32)

## Axial SpA service development

- Set up an axial SpA clinic and service, with dedicated capacity (2, 25)
- Develop local inflammatory back pain (IBP) pathways, referral processes and criteria (1, 17, 18)
- Implement best practice axial SpA MRI protocol with MSK radiology (26, 27, 28)
- Design and deliver a local self-management programme (32, 35)
- Provide access to physiotherapy / OT, signpost to NASS branch and provide a helpline to support patient self-management (33, 34)

## Strengthen the quality of referrals

- Create an ongoing education programme for colleagues in:
  - Primary care
  - EMM services (15, 21)
- Develop and implement referral processes / tools from EMM specialties (22, 23)
- Ensure ongoing education and communication between radiology and rheumatology on use of MRI (28)

## Axial SpA service enhancement

- Work with primary care to identify patients presenting with chronic back pain (17)
- Work with EMM clinicians to identify patients presenting with chronic back pain and EMMs (23)
- Adopt electronic tools to help identify patients with potential axial SpA (16, 18, 23)
- Use NASS materials to raise awareness locally and target people with chronic back pain (12, 14)
- Work with NASS to set up a local NASS branch for your patients (34)

Build patient participation into these areas to understand their needs and perspectives and incorporate them into changes. (7, 8)

# Checklist: Enablers to ensure high quality care

| Check | Good Practice |
|---|---|
| ☐ | **1.** An Inflammatory Back Pain pathway is in place, adapting national pathways such as GIRFT, to suit local needs. |
| ☐ | **2:** Depending on the availability of local resources, there is a specialist axial SpA service with a multi-disciplinary team. |
| ☐ | **3:** As a minimum, there is a lead who has a special interest in axial SpA and who co-ordinates axial SpA care locally. |
| ☐ | **4:** An ability to demonstrate potential savings locally of earlier diagnosis of axial SpA using the NASS/UEA economic model. This will help to create a business case. |

## Resource Links

### Guidance:

- GIRFT Axial Spondyloarthritis Pathway
- Economic model toolkit
- GIRFT Rheumatology National Report

### Case studies / publications:

- Pathway example 1 (Salford)
- Pathway example 2 (Newcastle)
- Pathway example 3 (Royal Berkshire)
- Pathway example 4 (Belfast)

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# Checklist: Data and measurement frameworks to assess service provision, establish baselines, create improvement targets and monitor progress

| Check | Good Practice |
|---|---|
| ☐ | **5**. If in England or Wales, ensure data are submitted to the National Early Inflammatory Arthritis Audit (NEIAA) and ask patients to complete the NASS patient survey on time to diagnosis. In Scotland and Northern Ireland ask patients to complete the NASS patient survey to identify your current time to diagnosis and measure changes and improvements. |
| ☐ | **6**. Have a data capture system in place beyond the data captured in NEIAA and the NASS patient survey to analyse service effectiveness including:<br>• Number of new potential axial SpA referrals<br>• Capacity for reviewing new axial SpA referrals<br>• Time from referral to 1st appointment<br>• Proportion of these referrals diagnosed with axial SpA at 1st appointment<br>• Proportion of new patients offered a follow-up appointment versus discharge<br>• Proportion requiring advanced investigations<br>• Time from request to MRI report<br>• Proportion of MRIs requested being supportive of axial SpA diagnosis<br>• Proportion of new potential axial SpA referrals who fulfil NICE and/or ASAS spondyloarthritis referral criteria<br><br>These points can be adapted to suit local needs and the data available. |

## Resource Links

### Guidance:

- NASS axial SpA diagnosis measurement framework
- NHS England measurement for improvement guide

### Tools:

- NASS time to diagnosis patient survey
- National Early Inflammatory Arthritis Audit (NEIAA)

### Case studies / publications:

- Uveitis & IBP audit example (Royal Free)
- IBD & Psoriasis audit example (SWAG)
- Time to diagnosis audit example (Royal Free & Salford)
- Example data capture system (SWAG)

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# Checklist: Embedding the patient perspective in service development and improvement, and working collaboratively on treatment plans

| Check | Good Practice |
|---|---|
| ☐ | **7:** The axial SpA service has an ongoing patient and public involvement group that routinely gathers and utilises feedback from their patients on the service. |
| ☐ | **8:** Patient and public involvement feeds into the design of Improvement projects. |
| ☐ | **9:** Diagnosis appointments are in person, at a face to face, online or telephone appointment, rather than in writing, so patients feel able to ask questions. |
| ☐ | **10:** Shared decision-making plays a key role when discussing treatment options with newly diagnosed patients, meeting their needs as well as clinical needs. |

## Resource Links

### Guidance:

- NHS England Experienced-Based co-design (EBCD) guidance
- Health Research Authority – Public Involvement

### Tools:

- A toolkit for collaborative agenda setting, focus forms and management plans
- NASS quality standards in axial SpA – A values based approach

### Case studies / publications:

- Rheumacan – patient involvement focus
- Belfast Axial SpA Patient Involvement Project

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# Checklist: Public Awareness materials for use locally, including the NASS symptom checker

| Check | Good Practice |
|---|---|
| ☐ | **11:** Direct people to the NASS online symptom checker; people can print off the results and take them their primary care professional for further investigation if appropriate. |
| ☐ | **12:** Put up NASS awareness posters in public spaces in the local area. These display the symptoms of axial SpA and direct people to the symptom checker. |
| ☐ | **13:** People attending First Contact Physiotherapy (FCP) appointments for chronic back pain are sent a symptom checker in advance which they take to their appointment and forms part of the FCP assessment. |
| ☐ | **14:** Encourage the use of the Trust/Board local social media platforms to share NASS social media adverts. |

## Resource Links

### Tools:

- NASS Symptom Checker
- Symptom Checker Poster
- NASS information – What is axial SpA
- Public awareness materials

### Case studies / publications:

- Belfast public awareness campaign
- NASS national public awareness campaign

# Checklist: Primary Care educational resources, triage tools and linking primary to secondary care

| Check | Good Practice |
|---|---|
| ☐ | **15:** There is programme of primary care education and training on axial SpA through local or regional in-service training, delivered by rheumatology or primary care experts. |
| ☐ | **16:** Primary care has access to electronic tools that can help to identify patients that might have axial SpA. |
| ☐ | **17:** There are clear local processes for referring patients to rheumatology which includes advice and guidance where possible. |
| ☐ | **18:** Referrals from primary care into rheumatology should contain assessments of patient symptoms using tools such as the NASS symptom checker and SPADE. |
| ☐ | **19:** Primary care professionals consider physiotherapy or NSAIDs if appropriate for symptom relief whilst the patient is waiting to be seen in rheumatology. |

## Resource Links

### Guidance:

- GIRFT Axial Spondyloarthritis Pathway
- NICE NG65 - Spondyloarthritis

### Tools:

- SPADE tool
- NASS primary care education presentation
- Ardens MSK templates
- Hints & tips video tool
- Referral template for osteopaths & chiropractors
- Advice & Guidance Templates (NHS Futures)

### Case studies / publications:

- Example referral form 1 (SWAG)
- Example use of NASS Symptom Checker in primary care (Stoke)
- Example referral form 2 (Royal Free)

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# Checklist: Referral from other secondary care services including ophthalmology, dermatology and gastroenterology

| Check | Good Practice |
|---|---|
| ☐ | **20:** Rheumatology teams know who the local leads are for uveitis, psoriasis and IBD and engage with them. |
| ☐ | **21:** Rheumatology delivers regular education and training on axial SpA to secondary care colleagues in other services. |
| ☐ | **22:** Local communications and arrangements for referrals are in place fitting the local service model (e.g. simple emails, phone calls, joint clinics to a formal referral pathway). |
| ☐ | **23:** Secondary care professionals have simple tools to help them with the identification, assessment and triage of axial SpA (posters, symptom checker, referral processes, triage tools). |

## Resource Links

### Guidance:

- GIRFT Axial Spondyloarthritis Pathway
- NASS report on secondary care referrals
- NASS report - recognising axial SpA in IBD
- NICE NG65 - Spondyloarthritis

### Tools:

- Resources for use in ophthalmology
- Resources for use in gastroenterology
- Resources for use in dermatology

### Case studies / publications:

- Example: psoriasis and IBD (SWAG)
- Example: uveitis (Royal Free)

# Checklist: Diagnosis in rheumatology with a focus on inflammatory spinal MRI protocols and working with radiology, plus the importance of specialist MDT services

| Check | Good Practice |
|---|---|
| ☐ | **24:** NICE Guideline NG65 should be followed to ensure the right diagnostic tests are performed. |
| ☐ | **25:** Diagnosis of axial SpA is ideally done within a specialist axial SpA clinic. As a minimum, diagnosis should be made by a clinician with special interest in axial SpA or inflammatory arthritis. |
| ☐ | **26:** For the diagnosis of suspected axial SpA, in patients where MRI is deemed clinically necessary by a rheumatologist, imaging of both the SIJs and spine is recommended with T1-weighted and fat-suppressed, fluid-sensitive sequences (including STIR*, fat-saturated† T2 or Dixon methods) utilised. |
| ☐ | **27:** All axial SpA MRIs are interpreted and reported on by specialist MSK radiologists either in-house or outsourced. Regular communication and working between rheumatology and radiology is key. |
| ☐ | **28:** Rheumatologists seeing patients with suspected axial SpA receive education to increase awareness of correct MRI protocols as per the BRITSpA recommendations. |
| ☐ | **29:** At their diagnosis appointment, patients should be given the opportunity to discuss what is important to them, understand who and how to contact if they need help between appointments and be signposted to NASS. |

## Resource Links

### Guidance:

- NICE NG65 - Spondyloarthritis
- BRITSpA recommendations on use of MRI
- NASS report – MRI in the diagnosis of axial SpA

### Tools:

- EULAR / ASAS imaging library
- Axial SpA & MRI podcast

### Case studies / publications:

- Southampton – MRI protocol implementation
- Berkshire – MRI protocol implementation

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# A playbook for reducing time to diagnosis for axial SpA

## Checklist: Information, support & self-management sign posting and service developments following diagnosis

| Check | Good Practice |
|---|---|
| ☐ | **30**: Provide information about the condition and treatment options in an accessible format and personalised for each patient, ensuring they know who to contact and how if support is needed. |
| ☐ | **31:** Signpost patients to NASS Your SpAce programme for bitesize information, self-management tools, and peer support. |
| ☐ | **32:** Offer the full range of NASS guides to patients and provide personalised information and self-management support. |
| ☐ | **33:** All newly diagnosed patients should be referred to physiotherapy as a minimum for a personalised home-based exercise regime with metrics taken for baseline. Further onward referral to occupational therapy, psychology and podiatry services should also be considered. |
| ☐ | **34:** Provide information on the local NASS branch for physiotherapist-led exercise and peer support. Where no local branch is available, signpost to the all-UK NASS Online branch. If there is no local NASS branch, consider contacting colleagues and NASS to establish a branch. |
| ☐ | **35:** Design and deliver supported self-management sessions to axial SpA patients. |

### Resource Links

**Guidance:**

- NG65 1.3 Information and support
- 2021 EULAR recommendations for self management
- British Society for Rheumatology Axial SpA Guideline

**Tools:**

- Order free materials for patients
- Find your local NASS branch

**Case studies / publications:**

- NASS Supported Self-management Programme
- NASS Advanced Therapies Guide

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