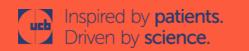


# Axial Spondyloarthritis Playbook: reducing time to diagnosis and improving patient experience













#### 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 <u>best practice</u> <u>pathway for axial spondyloarthritis</u>. 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.







- 1. How to use the Playbook
- 2. Implementation plan on a page
- 3. Enablers to ensure high quality care
- 4. Data and measurement frameworks to assess service provision, establish baselines, create improvement targets and monitor progress
- 5. Embedding the patient perspective in service development and improvement, and working collaboratively on treatment plans
- 6. Public Awareness materials for use locally, including the NASS symptom checker
- 7. Primary Care educational resources, triage tools and linking primary to secondary care
- 8. Referral from other secondary care services including ophthalmology, dermatology and gastroenterology
- 9. <u>Diagnosis in rheumatology with a focus on inflammatory spinal MRI protocols and working with radiology, plus the importance of specialist MDT services</u>
- 10. <u>Information, support & self-management sign posting and service developments following diagnosis</u>







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 Implement some quick **Axial SpA service** Strengthen the quality **Axial SpA service** development of referrals and collect data wins enhancement Collect data on time to Set up an axial SpA clinic Develop local relationships Create an ongoing Work with primary care to diagnosis and on the local and service, with dedicated with colleagues in: education programme for identify patients presenting axial SpA population capacity (2, 25) colleagues in: with chronic back pain (17) Primary care (5.6) Extra musculoskeletal Primary care manifestation (EMM) Develop local inflammatory EMM services (15, 21) Work with EMM clinicians to back pain (IBP) pathways, services Identify the local axial SpA identify patients presenting Radiology (18,22, 27) referral processes and lead (3) with chronic back pain and criteria (1, 17, 18) Develop and implement EMMs (23) referral processes / tools Put up axial SpA symptom from EMM specialties (22, Use the NASS economic Implement best practice posters with a link to the 23) Adopt electronic tools to model to assess the axial SpA MRI protocol with NASS symptom checker financial impact of delayed help identify patients with MSK radiology (26, 27, 28) (11, 12)diagnosis at local level (4) potential axial SpA (16, 18, 23) Ensure ongoing education Design and deliver a local and communication between self-management radiology and rheumatology Order free materials for Identify the key contacts in Use NASS materials to raise programme (32, 35) self-management, signpost primary care, nonon use of MRI (28) awareness locally and patients to Your SpAce and target people with chronic order NASS guides (31, 32) care & radiology (20, 27) Provide access to back pain (12, 14) physiotherapy / OT, signpost to NASS branch Ask patients what they think and provide a helpline to Work with NASS to set up a support patient selflocal NASS branch for your management (33, 34) 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	Resource Links
	<b>1.</b> An Inflammatory Back Pain pathway is in place, adapting national pathways such as GIRFT, to suit local needs.	Guidance:  - GIRFT Axial Spondyloarthritis Pathway  - Economic model toolkit
	<b>2:</b> Depending on the availability of local resources, there is a specialist axial SpA service with a multi-disciplinary team.	— GIRFT Rheumatology National Report
	<b>3:</b> As a minimum, there is a lead who has a special interest in axial SpA and who co-ordinates axial SpA care locally.	Case studies / publications:  Pathway example 1 (Salford)  Pathway example 2 (Newcastle)
	<b>4:</b> 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.	Pathway example 3 (Royal Berkshire)  Pathway example 4 (Belfast)





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

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:  • Number of new potential axial SpA referrals • Capacity for reviewing new axial SpA referrals • Time from referral to 1st appointment • Proportion of new patients offered a follow-up appointment versus discharge • Proportion requiring advanced investigations • Time from request to MRI report • Proportion of MRIs requested being supportive of axial SpA diagnosis • Proportion of new potential axial SpA referrals who fulfil NICE and/or ASAS	Check	Good Practice	Resource Links
and the NASS patient survey to analyse service effectiveness including:  Number of new potential axial SpA referrals Capacity for reviewing new axial SpA referrals Time from referral to 1st appointment Proportion of these referrals diagnosed with axial SpA at 1st appointment Proportion of new patients offered a follow-up appointment versus discharge Proportion requiring advanced investigations Time from request to MRI report Proportion of MRIs requested being supportive of axial SpA diagnosis Proportion of new potential axial SpA referrals who fulfil NICE and/or ASAS		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	— NASS axial SpA diagnosis  measurement framework  MHS England  measurement for
spondyloarthritis referral criteria  spondyloarthritis referral criteria  system (SWAG)		<ul> <li>and the NASS patient survey to analyse service effectiveness including:</li> <li>Number of new potential axial SpA referrals</li> <li>Capacity for reviewing new axial SpA referrals</li> <li>Time from referral to 1<sup>st</sup> appointment</li> <li>Proportion of these referrals diagnosed with axial SpA at 1<sup>st</sup> appointment</li> <li>Proportion of new patients offered a follow-up appointment versus discharge</li> <li>Proportion requiring advanced investigations</li> <li>Time from request to MRI report</li> <li>Proportion of MRIs requested being supportive of axial SpA diagnosis</li> <li>Proportion of new potential axial SpA referrals who fulfil NICE and/or ASAS</li> </ul>	NASS time to diagnosis patient survey  Case studies / publications:  Uveitis & IBP audit example (Royal Free)  IBD & Psoriasis audit example (SWAG)  Example data capture system (SWAG)







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

Check	Good Practice	Resource Links
	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.	Guidance:  NHS England Experienced- Based co-design (EBCD) guidance  Health Research Authority - Public Involvement
	8: Patient and public involvement feeds into the design of Improvement projects.	Tools:  A toolkit for collaborative  NASS quality standards in
	<b>9:</b> 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.	agenda setting, focus forms and management plans  axial SpA – A values based approach
	10: Shared decision-making plays a key role when discussing treatment options with newly diagnosed patients, meeting their needs as well as clinical needs.	Case studies / publications:    Rheumacan - patient   Belfast Axial SpA Patient   Involvement Project







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

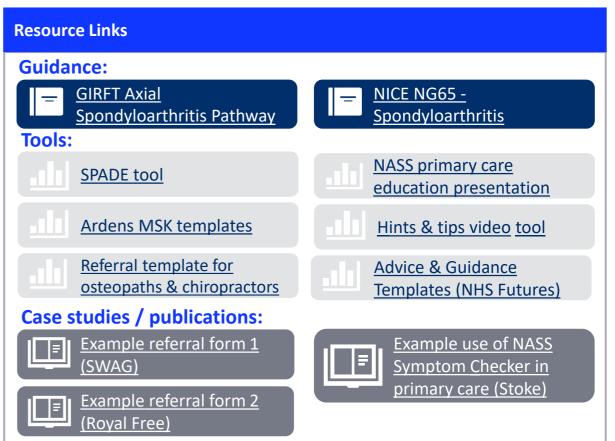
Check	Good Practice	Resource Links
	11: Direct people to the NASS online symptom checker; people can print off the results and take them their primary care professional for further investigation if appropriate.	Tools:  NASS Symptom Checker  Symptom Checker Poster
	<b>12:</b> Put up NASS awareness posters in public spaces in the local area. These display the symptoms of axial SpA and direct people to the symptom checker.	NASS information – What is axial SpA  Public awareness materials
	<b>13:</b> 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.	Case studies / publications:    Belfast public awareness   NASS national public awareness campaign   awareness campaign
	<b>14:</b> Encourage the use of the Trust/Board local social media platforms to share NASS social media adverts.	





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

Check	Good Practice
	<b>15:</b> 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.
	<b>16:</b> 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.
	<b>18:</b> Referrals from primary care into rheumatology should contain assessments of patient symptoms using tools such as the NASS symptom checker and SPADE.
	<b>19:</b> Primary care professionals consider physiotherapy or NSAIDs if appropriate for symptom relief whilst the patient is waiting to be seen in rheumatology.









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

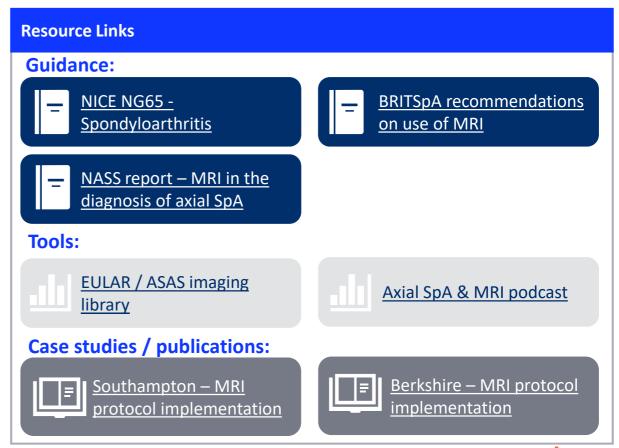
Check	Good Practice	Resource Links
	<b>20:</b> Rheumatology teams know who the local leads are for uveitis, psoriasis and IBD and engage with them.	Guidance:  - GIRFT Axial Spondyloarthritis Pathway  - NASS report on secondary care referrals
	<b>21:</b> Rheumatology delivers regular education and training on axial SpA to secondary care colleagues in other services.	NASS report - recognising axial SpA in IBD  Tools:  NICE NG65 - Spondyloarthritis
	<b>22:</b> 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).	Resources for use in ophthalmology  Resources for use in gastroenterology
	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).	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
	<b>24:</b> NICE Guideline NG65 should be followed to ensure the right diagnostic tests are performed.
	<b>25:</b> 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.
	<b>26:</b> 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 <sup>†</sup> T2 or Dixon methods) utilised.
	<b>27:</b> 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.
	<b>28:</b> Rheumatologists seeing patients with suspected axial SpA receive education to increase awareness of correct MRI protocols as per the BRITSpA recommendations.
	<b>29:</b> 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.





#### 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
	<b>30</b> : 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.
	<b>31:</b> Signpost patients to NASS Your SpAce programme for bitesize information, self-management tools, and peer support.
	<b>32:</b> Offer the full range of NASS guides to patients and provide personalised information and self-management support.
	<b>33:</b> 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.
	<b>34:</b> 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.
	<b>35:</b> Design and deliver supported self-management sessions to axial SpA patients.



