Review of direct referrals to rheumatology for suspected axial SpA

A UK survey of internal referral processes and practices

November 2022

Campaign fully funded by UCB.

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NHS Royal United Hospitals Bath NHS Foundation Trust

NHS Norfolk and Norwich University Hospitals NHS Foundation Trust

act on Axial SpA

National Axial Spondyloarthritis Society (NASS) – about us

Our purpose:

To transform the diagnosis, treatment, and care of people with axial SpA so everyone can live well with it.

Our cause:

Axial SpA is an inflammatory condition of the spine and joints. It works silently, leaving people in increasing pain and exhaustion.

What we do:

We campaign to transform diagnosis and treatment. We provide support to empower people living with the condition.

This report should be cited as follows:

Eddison J, Webb D, & Hamilton J; Review of direct referrals to Rheumatology for suspected axial SpA (2022) London: National Axial Spondyloarthritis Society.

Our *Act on Axial SpA* campaign: A Gold Standard time to diagnosis

The current time to diagnosis of axial SpA in the UK averages approximately 8.5 years from symptom onset. This delay is unacceptable and has serious consequences for the patient. Our *Act on Axial SpA* campaign sets out a roadmap to reduce the time from symptom onset to diagnosis to just one year.

Find out more by visiting:

www.actonaxialspa.com

Foreword

In 2021, following a national consultation process, we published a route map to achieve a Gold Standard time to diagnosis in axial SpA of 12 months[1] and identified four broad areas in which improvements could be made. One of these is secondary care services.

Our vision is that patients with suspected axial SpA who present at a range of services - including ophthalmology, gastroenterology, dermatology and orthopaedics – are identified at the first presentation and urgently referred to rheumatology. Relevant secondary care services should be aware of axial SpA symptoms and how to assess if the patient merits referral to rheumatology. Every UK hospital seeing potential axial SpA patients should have a rheumatology referral pathway and all specialists should know when / how to use it.

To understand current arrangements for the identification and referral of axial SpA in secondary care, we surveyed, via a Freedom of Information (FOI) request, all UK Trusts and Health Boards.

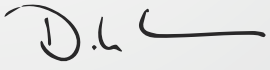
Our study has found that specialties associated with Extra Musculoskeletal Manifestations (EMMs) are able to routinely refer patients directly to rheumatology for suspected axial SpA. However, while direct referrals are accepted in most UK acute care settings, referrals are mostly reliant on consultant to consultant letters or calls. Some areas of best practice do exist with formal internal referral proformas, systems or processes in place.

This further highlights the need to increase awareness within other specialties of axial SpA and the need to refer patients urgently to rheumatology for assessment. We propose that the Gold Standard for internal referrals to rheumatology for axial SpA should be via a formal internal referral pathway. We recommend that standardised screening tools should be available and routinely utilised in assessing the appropriateness of a referral to rheumatology.

With the informal nature of internal referrals across the UK it is difficult to track referrals on hospital systems and therefore clearly identify how often direct referrals are being made. We call for more widespread development and uptake of internal referral processes, use of screening tools and the ability to track referrals.

We want to ensure that secondary care clinicians know the signs of axial SpA, when and how to refer and are working with clinicians in dermatology, gastroenterology and ophthalmology to review existing educational provision, which may lead to the creation of best practice materials to raise awareness, support identification such as screening tools and how to refer for suspected axial SpA.

We have already published examples of protocols, pathways, and screening tools on our dedicated campaign website www.actonaxialspa.com and call on health care professionals to adopt our Gold Standard and utilise these best practice examples.



Dr. Dale Webb, FRSA, FRSPH
CEO, NASS

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[1] Webb D, Swingler L, Barnett R, Sengupta R, Marshall L, Hamilton J, Zhao S & Gaffney K. Act on axial SpA: A Gold Standard time for the diagnosis of axial SpA (2021). London: National Axial Spondyloarthritis Society.

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NASS wishes to express sincere thanks to UCB for funding the *Act on Axial SpA* programme, which includes this report.

Executive summary

Key findings:

- We received responses from 119 (78%) Trusts and Health Boards, with 110 utilised for the analysis
- All responding 110 UK NHS Trusts and Health Boards reported that they accept direct internal referrals between specialties into rheumatology
- No Trusts or Health Boards reported requiring patients to be referred back to primary care rather than allowing direct referral
- 48% (n = 51) reported using screening tools to help with referrals for suspected axial SpA
- 46 Trusts used the PEST tool within dermatology
- 57 (54%) told us that they can track internal referral volumes on their systems.

Recommendations:

1. **Recommendation one:** The Gold Standard for internal referrals to rheumatology for axial SpA should be via a formal internal referral pathway.
2. **Recommendation two:** Standardised screening tools should be available and routinely utilised in assessing the appropriateness of a referral and accompany any referral to rheumatology.
3. **Recommendation three:** It should be possible for Trusts and Health Boards to track internal referrals in sufficient detail on patient information systems to enable measurement of referral volumes.
4. **Recommendation four:** There needs to be a consistent effort to raise awareness of axial SpA in secondary care to ensure clinicians know the signs of axial SpA, and when and how to refer.

Introduction

This report is part of our *Act on Axial SpA* campaign to implement a Gold Standard time to diagnosis which we launched in June 2021. It sits alongside other work in the campaign to shine a light on the impact that waiting on average 8.5 years for a diagnosis has on individuals living with axial SpA.

The findings from the research are key to helping us influence the thinking and behaviour of policy makers, system leaders and health care professionals (HCPs) that will translate into streamlined, improved, high quality care pathways and ultimately drive down diagnosis time, including identifying any areas where there is the greatest need for improvement.

What we did - background

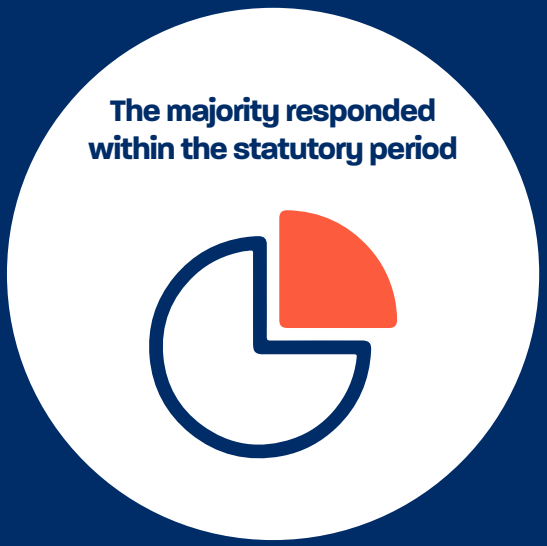
NASS developed an eight-question survey in conjunction with key clinical advisors. It was sent out via a Freedom of Information (FOI) request in late April 2022 to all UK hospital Trusts, Health Boards and secondary care providers.

The survey was sent to 153 organisations to assess the current provision across the UK in terms of:

- Direct internal referrals to rheumatology from the key specialties of dermatology, gastroenterology, and ophthalmology
- The method of internal referrals and potential best practice processes / protocols
- The use of defined screening tools within those specialties for assessing potential axial SpA
- The ability of providers to track internal referral volumes and an estimation of the current frequency of referrals.

We received responses from 119 providers (78%) with the majority responding within the statutory period, but reflective of current NHS pressures we also included responses received outside that period. Nine of the 119 (8%) respondents submitted nil returns as they do not offer rheumatology services and have been discounted from the analysis within this report. As part of responses, we received 19 examples of pathways, protocols, or process documents in support of the submissions.

As part of the analysis, we also utilised other publicly available data sources to understand if our findings are consistent with these. Principally, the National Early Inflammatory Arthritis Audit (NEIAA)[2] which identifies for England and Wales the source of referrals that lead to an axial SpA diagnosis. We also explored outpatient activity data available via NHS Digital[3] which compiles outpatient activity data by specialty and diagnosis.



[2] https://arthritisaudit.org.uk/pages/about
[3] https://digital.nhs.uk/data-and-information/publications/statistical/hospital-outpatient-activity

Results, comment and analysis

Internal direct specialty to specialty referrals

What we asked and why

Studies have found that clinicians in ophthalmology, gastroenterology and dermatology miss axial SpA symptoms in individuals presenting with Acute Anterior Uveitis (AAU), Inflammatory Bowel Disease (IBD) and psoriasis. Therefore, we asked:

"Does your Trust have an internal referral pathway to rheumatology from dermatology, gastroenterology, and ophthalmology?" and "What referral protocols are in place? e.g., are patients referred back to the GP with consideration / instruction to refer onward for rheumatology opinion."

Results

All responding UK NHS Trusts and Health Boards reported accepting direct internal referrals between specialties into rheumatology. For most, this is done via consultant-to-consultant referrals rather than formal pathways. These are usually completed using dictated letters, emails or directly on the Electronic Patient Record.

63% (n=69) of NHS organisations reported that they accept direct referrals from all three specialties. A further 14% (n=15) did so for either one or two of the specialities: this was usually because the other service does not exist within their Trust/Health Board. The remaining 24% (n=26) indicated that there were no 'formal' pathways, but all did identify informal processes.

Positively, no Trusts or Health Boards identified that they require patients to be referred back to primary care rather than allowing direct referral. A small proportion (17%; n=19) of responses did indicate that there were some exceptions, such as if the referral is for out of area for patients, or it is clinically deemed to be a non-urgent referral not related to the existing condition originally referred for. This further highlights the need for increasing awareness of axial SpA presentation in other specialties and how to refer. This will ensure that clinicians do consider EMMs to be related and suitable for internal referral.

Our analysis

We are pleased that practice across the UK is for internal direct referrals to be available but see this as a minimum standard. We believe a Gold Standard diagnostic approach is that direct referrals are made through formal pathways or protocols. We will support HCPs by publishing, via **www.actonaxialspa.com,** anonymised best practice examples that could be adapted and adopted locally.

Use of screening tools

What we asked and why

Screening tools are commonly used within health services as part of assessment processes and give clinicians a common framework and objective measurement. They provide a consistent approach to testing for the presence of a disease or condition to help ensure patients receive effective treatment. For axial SpA it would be beneficial for screening tools to be available and utilised by those specialties that are recognised with EMMs.

"Does your Trust utilise any screening tools such as Dublin Uveitis Evaluation Tool (DUET) or Psoriasis Epidemiology Screening Tool (PEST)"

Results

107 Trusts/Health Boards answered the screening question. 48% (n=51) reported using screening tools. Most (n=46) identified using the PEST tool within dermatology, three utilised the DUET ophthalmology tool and seven reported using other tools such as PSARC, SPADE, BASDAI, EARP, PASI, DLQI and EASI (see Annex 2). One Trust shared an AAU screening tool.

This shows that the use of screening tools is not routine across the specialties surveyed when referring to rheumatology and these were virtually non-existent within gastroenterology and ophthalmology. A reasonable proportion of the overall responses (43%, n=46) did indicate that they utilise the PEST tool in patients with psoriasis to identify any joint pain or inflammation and utilise this in referrals. It was not stated if the use of PEST was mandatory for a referral to be accepted or used at the clinician's discretion.

Our analysis

We are concerned that it is not routine practice for the use of appropriate screening tools in the identification and referral of axial SpA. There are benefits to both the referring clinician in screening tools by giving them a structured measurable assessment and by rheumatology in accepting referrals and ensuring early access to information to help diagnostic analysis. To support this, we will be working with clinicians from within gastroenterology and ophthalmology in consultation with rheumatologists and professional bodies in developing screening tools for axial SpA. We will also be building them into any educational resources we produce.

Tracking of internal axial SpA referrals

What we asked and why

Data are a key driver in measuring impact and in turn creating a case for, and catalysing, change. We know that data related to axial SpA care represent a challenge and as part of our work to drive down diagnostic delay we are changing that. To help understand how much of a factor internal direct referrals are we need to better understand how often they are the source of patients referred to rheumatology and how often that leads to a definitive diagnosis.

"Are you able to track internal referral volumes on your systems?" and "How often do you receive referrals for suspected axial SpA in rheumatology from dermatology, gastroenterology and ophthalmology?"

Results

105 responders answered the question regarding the ability to track internal referrals on systems. 54% (n=57) reported that they can track internal referral volumes on their systems; a small sub-sample did qualify their response that they could not track the source or the condition, only whether it was an internal vs GP / primary care referral.

On referral volumes, respondents were asked to give an indication of how often this happens and there was significant variation on how regular referrals were seen from dermatology, gastroenterology, and ophthalmology. These are summarised in the table below.

Specialty	Dermatology	Gastroenterology	Ophthalmology
Weekly	8	5	2
Monthly	27	25	17
Quarterly	17	23	29
Less Often	31	34	36
Never	8	4	7

Note: There were 19 blank returns as they saw this outside the FOI process, or they were unable to get these data.

The results seem at odds with the NEIAA data (which relate to England and Wales only), where the volumes of newly diagnosed axial SpA patients are very low both in actual numbers and proportions. Across the last three editions of the audit annually there have only been six or seven patients referred from secondary care. Alongside this there is a known issue with the coding of outpatient data, where funding per appointment is fixed regardless of condition or diagnosis. To illustrate, when we reviewed the NHS Digital report on outpatient activity by Primary Diagnosis in 2020/21 there were only 655 and 907 first and follow up appointments respectively coded to direct AS or Spondyloarthritis codes, with that rising to 4,355 and 6,484 when including all spondyloarthritis codes. This would mean that of the estimated 220,000 people living with axial SpA in the UK only 3% are engaging with health care services; this is likely a large underestimate. If we look back to before the COVID-19 pandemic this stood at 11,321 appointments or 6%. The FOI findings around lack of ability to track internal referrals further heightens the need for improved data collection.

Our analysis

We are concerned that it is not routine practice to track internal direct referrals and, even when they are tracked, we lack depth in the data. This is a big hindrance in creating a coherent analysis of the size of the issue with lack of identification of potential axial SpA patients and appropriate onward referral. As a result, it is difficult for us to conclude whether the levels of internal referrals are appropriate, but we can conclude that better data are required. To support this, we are working with local rheumatology teams on the issue of outpatient coding but more than that we are working with our 19 *Aspiring to Excellence* rheumatology teams across the UK to develop a Gold Standard time to diagnosis audit. This will include data points on each referral point and will provide a standardised, repeatable measurement framework we can use to determine how often patients are directly referred to rheumatology.

Conclusion

The analysis shows that across the UK it is possible for clinicians to refer directly to rheumatology when they suspect axial SpA, without the need, in the most part, for referral back to primary care.

The system is reliant on clinicians being able to identify potential axial SpA in their patients for onward referral, showing that education and awareness is critical. We are still unable to determine the exact scale of the challenge as for most NHS organisastions these internal referrals are not tracked, and where they are it is a challenge to identify the source. This, coupled with the low uptake of axial SpA patients within the NEIAA in England and Wales, prevent us having a clear picture on how often these direct referrals are made and result in an axial SpA diagnosis.

The use of screening tools is inconsistent across the UK, with a strong indication that the Psoriasis Epidemiology Screening Tool (PEST) is used by dermatologists but very limited examples within gastroenterology or ophthalmology. The development of screening tools would give a clearer framework for clinicians to use for identification and referral.

Recommendations

Recommendation one: The Gold Standard for internal referrals to rheumatology for axial SpA should be via a formal internal referral pathway.

There are already some examples of internal referral protocols, screening tools and multidisciplinary working available that Trusts and Health Boards can adopt and adapt to their local system. The use of informal clinician to clinician referrals should be the minimum standard rather than the Gold Standard practice.

Recommendation two: Standardised screening tools should be available and routinely utilised in assessing the appropriateness of a referral and accompany any referral to rheumatology.

The use of screening tools is inconsistent across the UK with a strong indication that PEST is used by dermatologists but very limited examples of similar tools being used within gastroenterology or ophthalmology. The development of screening tools would give a clearer framework for clinicians to use for identification and referral.

Recommendation three: It should be possible for Trusts and Health Boards to track internal referrals in sufficient detail on patient information systems to enable measurement of referral volumes.

Data are a key driver in measuring impact and in turn creating a case for, and catalysing, change. This could be supplemented in England and Wales by a greater uptake of patients into the NIEAA annual data set, with clear reference made to referral source including specialty.

Recommendation four: There needs to be a consistent effort to raise awareness of axial SpA in secondary care to ensure clinicians know the signs of axial SpA, when and how to refer.

The system is reliant on clinicians being able to identify potential axial SpA in their patients for onward referral, showing that education and awareness is critical. This further highlights the need for increasing the awareness of axial SpA presentation in other specialties and for education about how to identify and refer.

What NASS is doing to support and drive change in this area

As an organisation we have a key role in advocating for change and influencing those in the health care system to make these changes in the interest of improving patient care. We are already playing a pivotal role in this with specific focus on those recommendations above.

NASS is curating best practice examples from across the NHS and our *Aspiring to Excellence* programme that will support improved standardised direct referral processes. These are being shared via our campaign website www.actonaxialspa.com to enable HCPs to use them locally.

As part of our work within secondary care we are working with clinicians from gastroenterology and ophthalmology to develop screening tools. These will be turned into key resources to help HCPs, be embedded in any e-learning / educational packages and shared via www.actonaxialspa.com as well as presented at annual professional conferences.

NASS has developed with our 19 *Aspiring to Excellence* sites an audit tool for measurement of time to diagnosis, and a key part of this will be the source of referrals. This will create a robust large dataset to show how often internal referrals are being made and leading to an axial SpA diagnosis. One of our latest *Aspiring to Excellence* participants, the South West Axial Spa Group (SWAG) of four rheumatology departments, is also looking at how to create a system based axial SpA dataset, the learning from which will be shared.

As part of our work within secondary care we are working with clinicians from dermatology, gastroenterology, and ophthalmology to review current education provision and then develop e-learning / training in consultation with professional bodies to aid identification, assessment and referral. These will be shared via www.actonaxialspa.com as well as presented at annual professional conferences.

8.5 Years to diagnosis is NOT OK. Time to act.

Annex one – What is axial SpA?

Axial spondyloarthritis (axial SpA) is an inflammatory disease of the spine and joints. Inflammation where muscles attach to the bones, causes extreme pain. If left untreated, it can permanently fuse bones together. It's an invisible and misdiagnosed condition. Often leaving people feeling powerless, in increasing pain and extreme exhaustion. There is currently an 8.5 year average time to diagnosis. [4].

Axial SpA is not rare. It affects 1 in 200 adults in the UK. This means it's as common as multiple sclerosis (MS) and Parkinson's combined.

People with the condition can also have a range of complications and co-morbidities:

- 26% of people will have uveitis[7]
- 9% will have psoriasis[8]
- 7% will have inflammatory bowel disease[9]
- 25% of people will have irreversible spinal fusion[10]
- There is a close association with osteoporosis[11]
- 59% report experiencing a psychological health concern at some point.

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[4] Mark P. Sykes, Helen Doll, Raj Sengupta and Karl Gaffney, Delay to diagnosis in axial spondyloarthritis: are we improving in the UK? Rheumatology, July 2015

[5] Louise Hamilton, Alexander MacGregor, Andoni Toms, Victoria Warmington, Edward Pinch, Karl Gaffney, The prevalence of axial spondyloarthritis in the UK: a cross-sectional cohort study, Biomed Central Musculoskeletal Disorders, December 2015

[6] MS in the UK, www.mssociety.org.uk, January 2016

[7] Carmen Stolwijk, Astrid van Tubergen, José Dionisio Castillo-Ortiz, Annelies Boonen, Prevalence of extra-articular manifestations in patients with ankylosing spondylitis: a systematic review and meta-analysis,, Annals of the Rheumatic Diseases 2015, 74:65–73

[8] Ibid

[9] Ibid

[10] S Carette, D Graham, H Little, J Rubenstein, P Rosen, The natural disease course of ankylosing spondylitis, Arthritis Rehum, 1983

[11] DM Wang, QY Zeng, SB Chen, Y Gong, ZD Hou, ZY Xiao, Prevalence and risk factors of osteoporosis in patients with ankylosing spondylitis: a 5-year follow up study of 504 cases, Clinical and Experimental Rheumatology, July 2015

Annex two – Glossary of terms

- *Act on Axial SpA* – campaign to reduce the current 8.5 year time to diagnosis to a gold standard time of one.
- Acute anterior uveitis (AAU) - Acute anterior uveitis is an eye condition caused by inflammation in the front part of the eye between the cornea (the clear window at the front of the eye) and the lens. It is also sometimes referred to as iritis.
- All Party Parliamentary Group - informal, cross-party groups formed by MPs and Members of the House of Lords who share a common interest in a particular policy area, region, or country.
- *Aspiring to Excellence* – *Aspiring to Excellence* is a strategic partnership between NASS, BRITSpA and sponsoring companies AbbVie, Biogen, Lilly, Novartis and UCB. It is an award programme designed to encourage and recognise service improvement in axial SpA (AS) care.
- Axial spondyloarthritis - Axial SpA (AS) is a spectrum of disease whereby a person can have changes on an MRI but not x-ray (non-radiographic axial spondyloarthritis (nr axial SpA)) to spinal fusion (ankylosing spondylitis).
- BASDAI - The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) disease activity questionnaire contains six questions regarding subjective symptoms during the week prior to answering the questions.
- Clinical Commissioning Group - clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area in England.
- CRP – C-reactive protein is an inflammatory marker detected via blood test.
- DLQI – The Dermatology life Quality Index (DLQI) is a ten-question questionnaire used to measure the impact of skin disease on the quality of life of an affected person. It is designed for people aged 16 years and above.
- DUET – The Dublin Uveitis Evaluation Tool (DUET) is an algorithm for the best referral by ophthalmologists of acute anterior uveitis patients with possible underlying spondyloarthropathy.
- EARP – The Early Arthritis for Psoriatic Patients (EARP) questionnaire was developed in a joint dermatology-rheumatology early psoriasis clinic. It was designed to be user friendly and easy to administer. EARP is a rapid screening method for identifying PsA in people with psoriasis and includes 10 questions.
- EASI - An EASI score is a tool used to measure the extent (area) and severity of atopic eczema (Eczema Area and Severity Index).
- EMM – Extra Musculoskeletal Manifestations are co-existing conditions or presentations related to axial SpA.
- FOI - The Freedom of Information Act 2000 provides public access to information held by public authorities.
- HLA-B 27 - The HLA B27 gene is present in over 90% of people with axial SpA.
- IBP – inflammatory back pain
- Inflammatory bowel disease (IBD) - Inflammatory bowel disease (IBD) is a term mainly used to describe two long-term conditions that involve inflammation of the gut: ulcerative colitis and Crohn's disease.

- **MRI -** MRI (magnetic resonance imaging) is a type of scan that uses magnetism and radio waves to take pictures of inside the body. It is a key diagnostic tool in the diagnosis of axial SpA.
- **National Axial Spondyloarthritis Society (NASS) –** the only charity in the UK solely focussed on supporting people with axial spondyloarthritis including ankylosing spondylitis. Formerly known as the National Ankylosing Spondylitis Society.
- **NEIAA –** The National Early Inflammatory Arthritis Audit aims to improve the quality of care for people living with inflammatory arthritis, collecting information on all new patients over the age of 16 in specialist rheumatology departments in England and Wales.
- **NHS Trust -** provides goods and services for the purposes of the health service.
- **MDT –** multidisciplinary team
- **PASI -** PASI is an acronym for Psoriasis Area and Severity Index.
- **PEST –** Psoriasis Epidemiology Screening Tool (PEST) is a screening tool for Psoriatic Arthritis and is used to support dermatologists to identify patients for evaluation by a rheumatologist.
- **Primary Care -** the day-to-day healthcare given by a health care provider. Typically, this provider acts as the first contact and principal point of continuing care for patients within a healthcare system, and coordinates other specialist care that the patient may need.
- **PsARC –** The Psoriatic Arthritis Response Criteria (PsARC) is a tool used to evaluate and monitor psoriatic arthritis.
- **Psoriasis -** Psoriasis is an inflammatory skin condition that causes red, flaky, crusty patches of skin covered with silvery scales.
- **Rheumatology –** discipline specialising in immune-mediated disorders of the musculoskeletal system, soft tissues, autoimmune diseases, vasculitides, and inherited connective tissue disorders
- **Secondary Care -** medical care that is provided by a specialist or facility upon referral by a primary care physician and that requires more specialized knowledge, skill, or equipment than the primary care physician can provide.
- **SPADE -** The SPADE tool was designed to assist medical professionals define the probability of axial spondyloarthritis in a patient with chronic back pain, below the age of 45 with no definitive changes on X-ray.

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NASS is a registered charity in England and Wales (1183175) and Scotland (SC049746)