

# Act on Axial SpA Primary Care Presentation

Campaign fully  
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act on  
Axial SpA

# What is Axial Spondyloarthritis (Axial SpA)?

Umbrella term for inflammatory arthritis affecting spine and Sacroiliac joints.

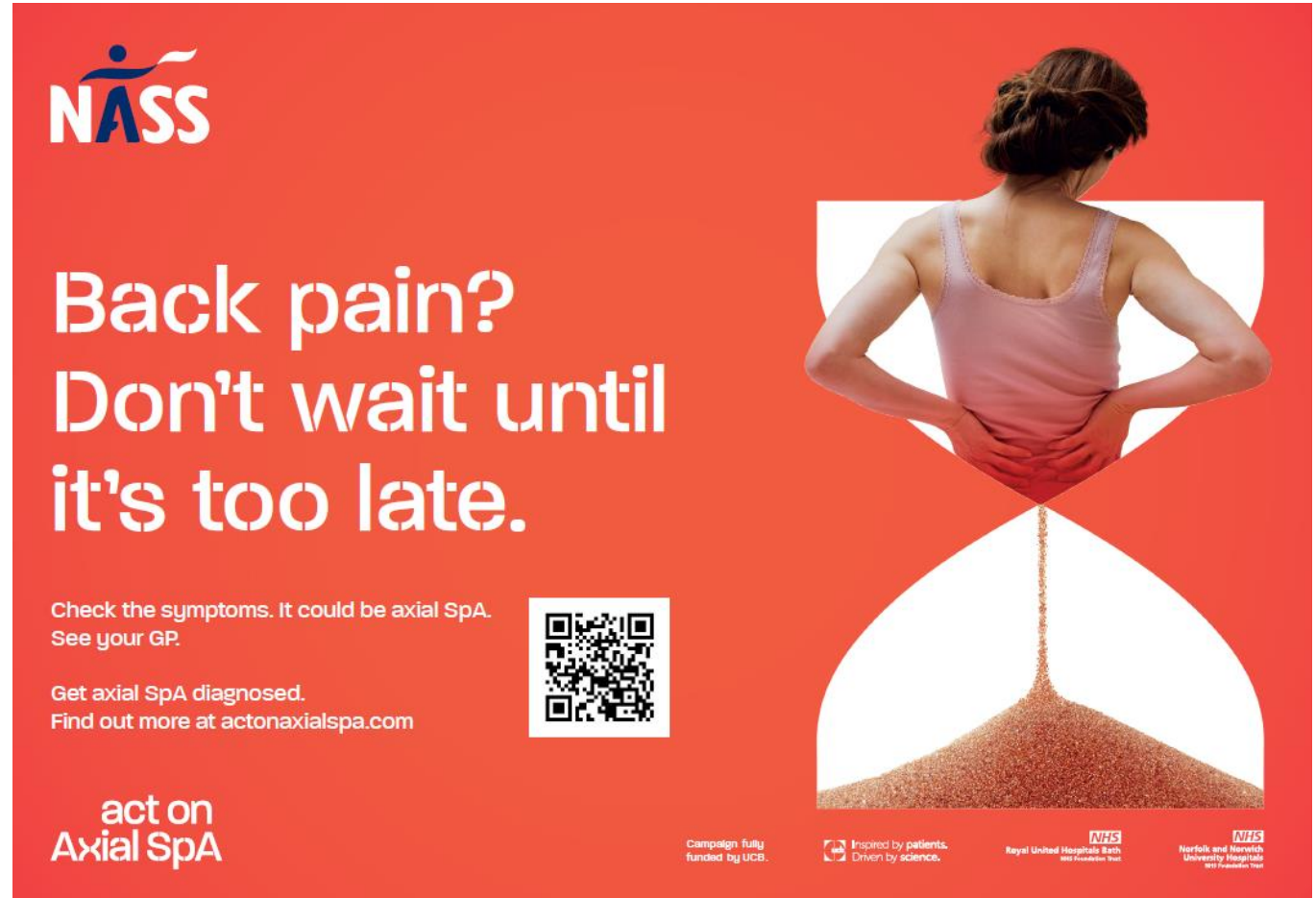
- Ankylosing Spondylitis (AS) radiographic Axial SpA
  - Changes to the sacroiliac joints seen in x-ray
- Non radiographic Axial SpA (nr-AxSpA)
  - X-ray changes not present
  - Inflammation is visible on MRI
  - Person has a range of other symptoms



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# Axial SpA what are the key characteristics?

- Inflammatory pain
- Functional impairment
- Onset typically starts late teens early 20's (average age 26yrs)
- Can have lifelong impact and long term implications if left untreated
- Diagnosis is difficult and often delayed

A red poster with a white hourglass shape in the center. Inside the top of the hourglass is a woman from behind, holding her lower back in pain. The bottom of the hourglass is filled with a pile of red sand. The NASS logo is in the top left corner. The text "Back pain? Don't wait until it's too late." is in large white font. Below it, smaller white text says "Check the symptoms. It could be axial SpA. See your GP." and "Get axial SpA diagnosed. Find out more at actonaxialspa.com". A QR code is to the right of this text. At the bottom left, it says "act on Axial SpA". At the bottom right, there are several small logos and text: "Campaign fully funded by UCB.", "Inspired by patients. Driven by science.", "NHS Royal United Hospitals Bath and Somerset NHS Foundation Trust", and "NHS Norfolk and Norwich University Hospitals NHS Foundation Trust".

**NASS**

## Back pain? Don't wait until it's too late.

Check the symptoms. It could be axial SpA.  
See your GP.

Get axial SpA diagnosed.  
Find out more at [actonaxialspa.com](http://actonaxialspa.com)

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NHS  
Royal United Hospitals Bath  
and Somerset NHS Foundation Trust

NHS  
Norfolk and Norwich  
University Hospitals NHS Foundation Trust

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# Axial SpA what are the key symptoms?

Inflammatory arthritis affecting spine and Sacroiliac joints.

1. Back pain started before the age of 40
2. Back pain developed slowly
3. Chronic back pain lasting greater than 3 months
4. Back stiffness upon waking
5. Back pain improves with exercise / movement
6. Back pain worse with rest
7. Alternating buttock pain
8. Regular waking at night

**Symptoms starting slowly**  
**Pain in the lower back**  
**Improves with movement**  
**Night time waking**  
**Early onset** (under 40)

Complete the NASS symptom checker\*: [Symptom checker](#)

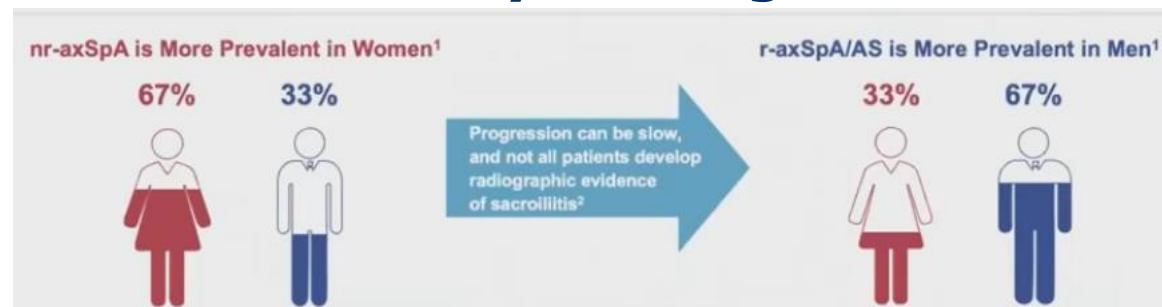
\*Sieper J, van der Heijde D, Landewe R, Brandt J, Burgos-Vargas R, Collantes-Estevez E, et al. New criteria for inflammatory back pain in patients with chronic back pain: a real patient exercise by experts from the Assessment of SpondyloArthritis International Society (ASAS). *Annals of the rheumatic diseases*. 2009;68(6):784-8.

Rudwaleit M, Metter A, Listing J, Sieper J, Braun J. Inflammatory back pain in ankylosing spondylitis: a reassessment of the clinical history for application as classification and diagnostic criteria. *Arthritis Rheum*. 2006;54(2):569-78.

Calin A, Porta J, Fries JF, Schurman DJ. Clinical history as a screening test for ankylosing spondylitis. *JAMA*. 1977;237(24):2613-4

# Gender in axial SpA

**Axial SpA affects both women and men from a young age. It is no longer seen as a male disease. Females have a 2 year longer time to diagnosis around the world.**



- Men with axial SpA show a higher rate of radiological progression compared with women.
- Non-radiographic axial SpA (nr-axSpA) is more prevalent in women. (67% vs 33%)
- Ankylosing Spondylitis or radiographic axial SpA is more prevalent in men. (67% vs 33%)
- Women with axial SpA have, in general, higher disease activity scores (higher BASDAI, lower ASQoL, lower BASMI)
- Women with axial SpA also have more peripheral manifestations compared to males (enthesitis, IBD, Psoriasis and Peripheral Arthritis)

- Xabier Michelena, Clementina López-Medina, Helena Marzo-Ortega, Non-radiographic versus radiographic axSpA: what's in a name?, *Rheumatology*, Volume 59, Issue Supplement\_4, October 2020, Pages iv18–iv24, <https://doi.org/10.1093/rheumatology/keaa422>  
 - Boonen A et al. Semin Arthritis Rheum. 2015;44(5):556-562  
 - Rudwaleit M and Sieper J. Nat Rev Rheumatol. 2012;8(5):262-266

# Extra-musculoskeletal manifestations (EMM) of axial SpA?

Extra-musculoskeletal manifestations (EMMs) are common, important features of axial spondyloarthritis (axial SpA).

The most prevalent being –

- acute anterior uveitis (AAU),
- inflammatory bowel disease (IBD) and
- psoriasis.

Other EMMs are:

- Enthesitis
- Dactylitis



## Axial SpA and uveitis?

40% of people with acute anterior uveitis have spondyloarthritis<sup>1</sup>

26% of people with axial spondyloarthritis including ankylosing spondylitis (AS) have acute anterior uveitis<sup>2</sup>

**Ask your patients**  
Have you had back pain for more than three months?  
Could it be inflammatory?

**Symptoms starting slowly**  
**Pain in the lower back**  
**Improves with movement**  
**Night time waking**  
**Early onset** (under 40)

**If your patient has chronic back pain and uveitis refer to rheumatology**  
Help us reduce the 8.5 year diagnostic delay for axial spondyloarthritis.

visit [actonaxialspa.com](https://actonaxialspa.com)  
to find more information, tools to support you and patient stories.

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<sup>1</sup>Prevalence based detection of undiagnosed spondyloarthritis in patients presenting with acute anterior uveitis. The SALT Study (Laufer et al., 2015). <sup>2</sup>Prevalence based detection of undiagnosed spondyloarthritis in patients presenting with acute anterior uveitis. The SALT Study (Laufer et al., 2015).

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# UK Economy: Paying a high price



Delay to diagnosis  
of axial SpA costs  
the UK economy

**£18.7  
billion**

per year

#WaitingCosts



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

Average time to  
diagnosis from symptom  
onset is **8.5 years**



Affects the **young**  
with average age of  
symptom onset of **26**

**£187k**

Waiting for an axial SpA  
diagnosis costs  
each person an  
average of **£187k**


One year  
costs less...

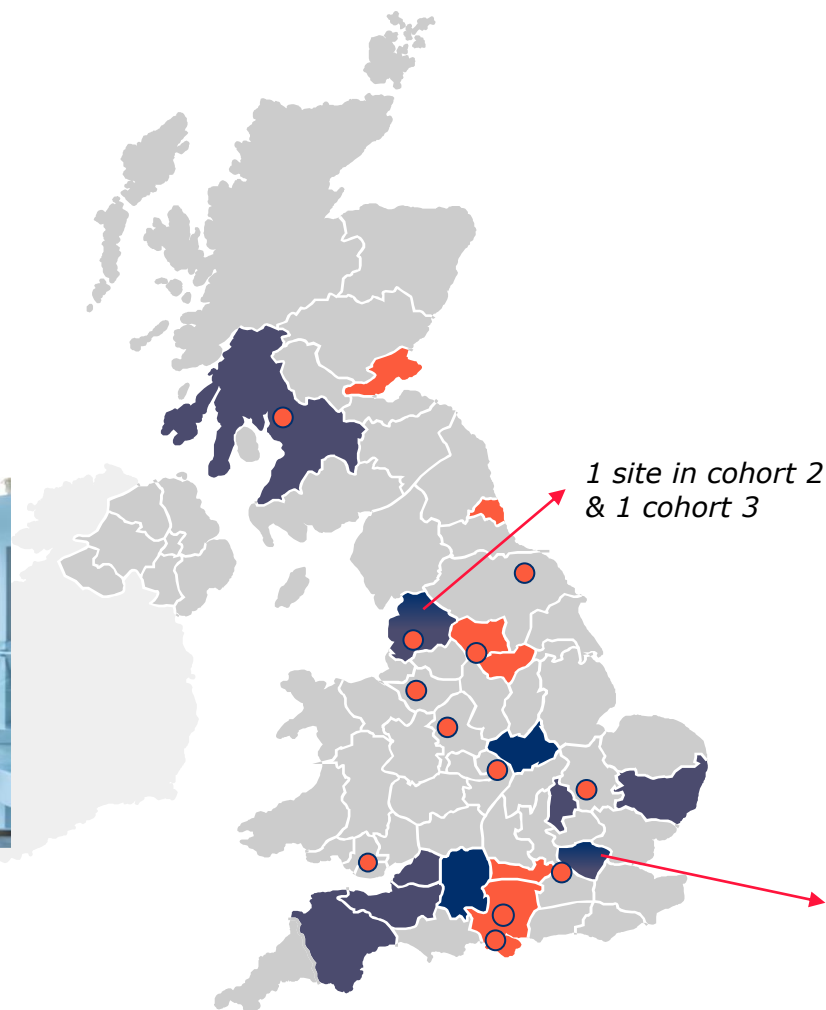
A Gold Standard  
time to diagnosis  
would save the UK  
economy

**£167k**  
per person

# Catalysing change with our health care ambassadors

## Champions in Primary Care

 Location of appointments for Champions in Primary Care programme



**A2E Cohort 1**  
Current Cohort 1 participant  
rheumatology department / hospital



**A2E Cohort 2**  
Current Cohort 2 participant  
rheumatology department / hospital



**A2E Cohort 3**  
Cohort 3 participant rheumatology  
department / hospital

2 sites in cohort 2  
& 1 cohort 3



# Our new Champions in Primary Care

- Shining a light on the issues facing achieving timely diagnosis in axial SpA
- Championing change and drives improvement in axial SpA care
- Sharing the story of change to showcase best practice improvements in axial SpA
- Spreading learning across healthcare systems to help other adopt change

## Champions in Primary Care programme

*A cadre of clinical champions in primary care and community services whose work ensures that axial spondyloarthritis (or axial SpA for short) is higher within the clinical reasoning of primary care professionals, so that patients who present with suspected axial SpA are identified at the first presentation and urgently referred to rheumatology.*

**Leadership  
Development**

**Quality Improvement  
Training**

**Local Improvement  
Projects**

**Action learning sets, Shared learning community, Celebrating Success**

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# Primary care – Barriers for diagnosis of Axial SpA

- Lack of awareness about the disease amongst primary care workforce
- Non-specific findings on physical examination
- Diagnostic delay M-5.5 and F-8.8 NEI
- Lack of set diagnostic criteria
- Lack of biomarkers for diagnosis
- Lack of streamlined rheumatology pathways



Marina N et al 2020, Recognizing Axial Spondylarthritis: A Guide for Primary Care, A review, Mayo clinic

Crossfield S et al Changes in ankylosing spondylitis incidence, prevalence and time to diagnosis over two decades, BMJ, RMD open, Vol7 ,3

Russell M et al 2021, Diagnostic delay is common for patients with axial spondylarthritis: results from the National Early Inflammatory Arthritis Audit British Journal of Rheumatology , 61, 2

Marina N et al 2020, Recognizing Axial Spondylarthritis: A Guide for Primary Care, A review, Mayo clinic

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# Champions' proposals to reduce diagnostic delay



- Create awareness of Axial SpA in primary care via education/learning modules
- Improve identification and screening in primary care
- Use of screening tools ( SPADE/PRIMIS), guidelines (NICE/ASAS) and templates (ARDENS) to maximize the efficacy of patient consultations
- Improve referral pathways to Rheumatology
- Improve patient awareness / education and patient management in primary care
- Utilisation of best MSK practice guidelines for identification and referrals

# How to find out more

- Go to [www.actonaxialspa.com](http://www.actonaxialspa.com) and read our first Act on Axial SpA campaign impact report.

A dark blue rectangular banner with white and orange text. In the top right corner is the NASS logo. The main text 'actonaxialspa.com' is in large, bold, orange lowercase letters. Below it, in white, is the text: 'The website is the largest resource in the world on axial SpA diagnosis: providing information, support, research, best practice, quality improvement tools, case studies'. At the bottom left, there is a small white URL 'www.nass.co.uk' followed by a horizontal red line.

  
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diagnosis: providing information, support, research, best  
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# Resources for primary care HCPs

- [NICE Guideline NG65](#)
- [GIRFT / BEST MSK pathway](#)
- Ardens MSK Template
- [SPADE Tool](#) <sup>(1)</sup>
- Accurx Floreys
- [Primis Pop up Tool](#)
- [ASAS / EULAR guidance](#)

**NICE** National Institute for  
Health and Care Excellence

**GIRFT**  
GETTING IT RIGHT FIRST TIME

**SPADE**  
Spondyloarthritis  
Diagnosis Evaluation Tool

**PRIMIS**

**eular** | EUROPEAN ALLIANCE  
OF ASSOCIATIONS  
FOR RHEUMATOLOGY

**ASAS**  
Assessment of  
SpondyloArthritis  
international Society

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

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