

Act on Axial SpA Primary Care Presentation

Campaign fully
funded by UCB



act on
Axial SpA

NASS

- 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.

NASS

- Helpline
- Website
- Branches





Exercise

Discover the importance of exercise in managing axial SpA (AS)

[Read more >](#)



Living with AS

Help and advice on working, travelling, pregnancy and driving

[Read more >](#)



Medication

Find out what medications are used to manage your axial SpA (AS)

[Read more >](#)



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Your SpAce

<https://nass.co.uk/about-as/your-space>

New online programme for people with axial SpA to:

- Learn more about their condition
- Discover new ways to manage their symptoms
- Meet other people with axial SpA

Consists of:

- Short videos sharing information and lived experiences
- Downloadable resources to create a personalised toolkit
- Free monthly online meetups



Free to access on the NASS website from 10:30 Thurs 30 March 2023

[Order free promo packs](https://nass.co.uk/homepage/health-professionals/resources-for-your-patients/guides-to-living-with-axial-spa-as/) (postcards to hand to patients and A4 posters)

<https://nass.co.uk/homepage/health-professionals/resources-for-your-patients/guides-to-living-with-axial-spa-as/>

Where to find resources



- Act on Axial SpA www.actonaxialspa.com
- NASS resources for patients <https://nass.co.uk/resources/>
- NASS helpline for patients 02087 411 515 and asknass@nass.co.uk
- NASS guidebooks order <https://nass.co.uk/homepage/health-professionals/resources-for-your-patients/guides-to-living-with-axial-spa-as/>
- NICE <https://www.nice.org.uk/guidance/ng65>
- ASAS/EULAR updated guidelines

<https://ard.bmj.com/content/early/2022/10/21/ard-2022-223296>

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

The poster has a red background. In the top left is the NASS logo. The main 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. On the right side, a woman in a pink tank top is shown from behind, holding her lower back, with her body framed by a white hourglass shape. At the bottom left, it says 'act on Axial SpA'. At the bottom right, there are four small logos: 'Campaign fully funded by UKRI', 'Inspired by patients. Driven by science.', 'Royal United Hospitals Bath', and 'Hartlepool and Newcastle University Hospital NHS Foundation Trust'.

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Axial SpA what are the key characteristics?

- Inflammation occurs where tendon attaches to bone
- Inflammation is followed by some wearing away at the site of attachment
- As inflammation reduces, healing takes place and new bone develops
- Movement becomes restricted when bone replaces elastic tissue of ligaments or tendons
- Repetition of this process can cause vertebrae to fuse



Could your
persistent back
pain be axial SpA?

Serious and Irreversible damage can be done with each passing year.
See your GP.

Get axial SpA diagnosed.
Find out more at actonaxialspa.com

act on
Axial SpA



campaign also
funded by OCB.

Powered by donations.
Driven by science.

King of United Kingdom's Best
Spine Surgeons

Spine Health and Research
University Hospitals



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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

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?

NASS
Axial SpA works silently. We don't.

40% of people with acute anterior uveitis have spondyloarthritis!

26% of people with axial spondyloarthritis including ankylosing spondylitis (AS) have acute anterior uveitis!

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 45)

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
to find more information, tools to support you and patient stories.

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Axial SpA key statistics

- 1 in 200 of the adult population in the UK have axial SpA (AS). That's twice as many as multiple sclerosis and Parkinson's disease.
- Onset typically starts late teens early 20's (average age 26yrs)
- 8.5 years average time to diagnosis in the UK, from symptom onset.
- 59% of people with axial SpA report experiencing mental health problems compared to 25% of those with musculoskeletal conditions overall.
- **Affects the same number of females and males.**
- 85-90% of people with axial SpA carry the HLA-B27 gene
- 91% of the UK population have never heard of axial SpA



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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

Key signs to consider when women present in primary care

Presentation in women is often less likely to be in line with the traditional symptoms of axial SpA and requires a more holistic assessment.

- Women present differently to men.
- Where men meet modified New York (NY) criteria more often, women have greater subjective disease activity.
- Women are more likely to wide spread pain.
- Women have more functional impairment, despite less damage.
- Women more often have non-radiographic axial SpA with negative imaging.
- Women are more likely to have extra musculoskeletal manifestations such as enthesitis, IBD, Psoriasis.
- Women are more likely to have a lower CRP inflammatory markers and a higher incidence of negative HLA-B27



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What are the treatments for axial SpA?

- Exercise
- NSAIDs
- bDMARDS
 - Anti TNFi
 - IL17i
 - JAKi



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What is the *Act on axial SpA* campaign?

Act on Axial SpA is our vehicle for delivering our Gold Standard ambitions.



Follow the person, from symptom onset to diagnosis in rheumatology

NASS

Help the person with inflammatory back pain to recognise that it might be axial SpA

Ensure swift identification and referral in primary care

Ensure direct

Ensure timely

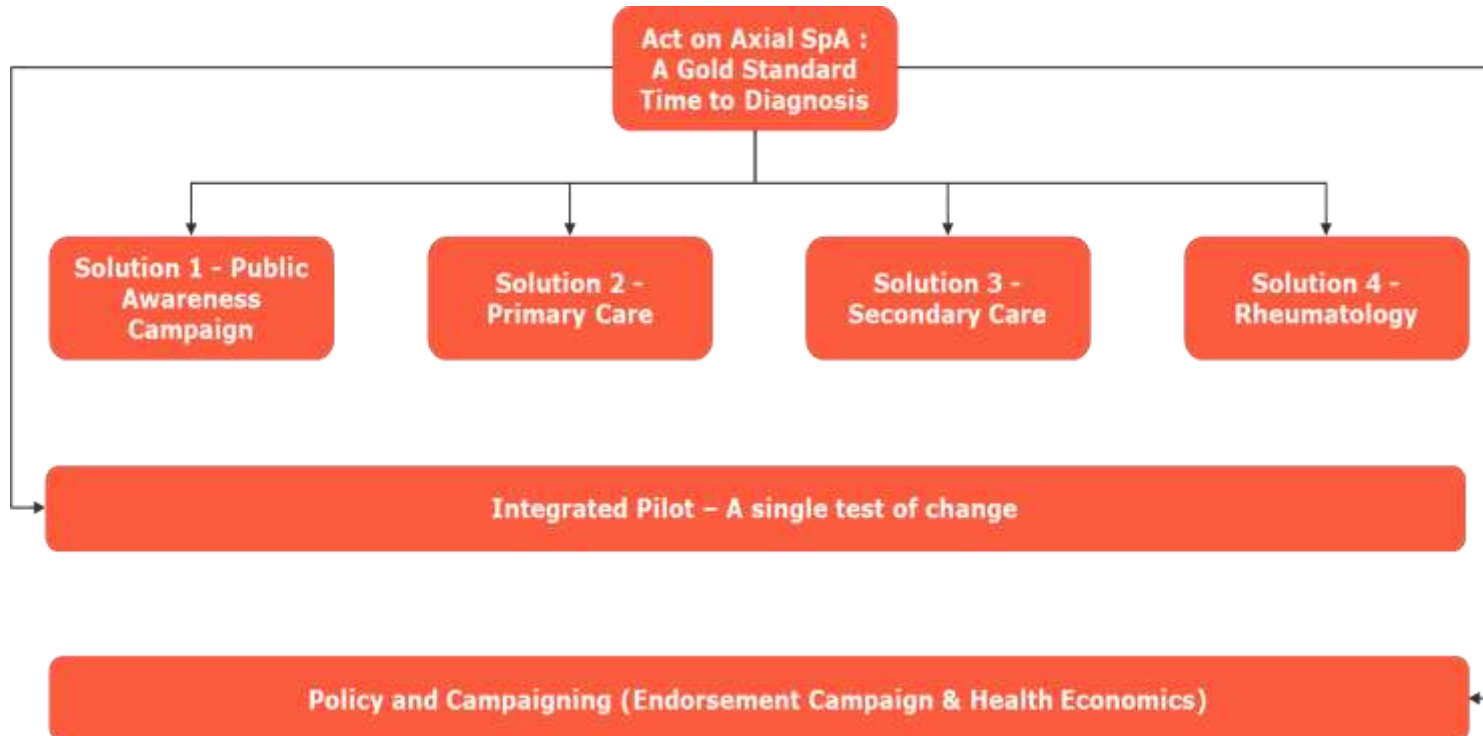
Act on Axial SpA: A Gold Standard Time to Diagnosis



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What is the *Act on axial SpA* campaign?

Achieving a Gold Standard Time to Diagnosis – Improve time from symptom onset to diagnosis to a maximum of 12 months

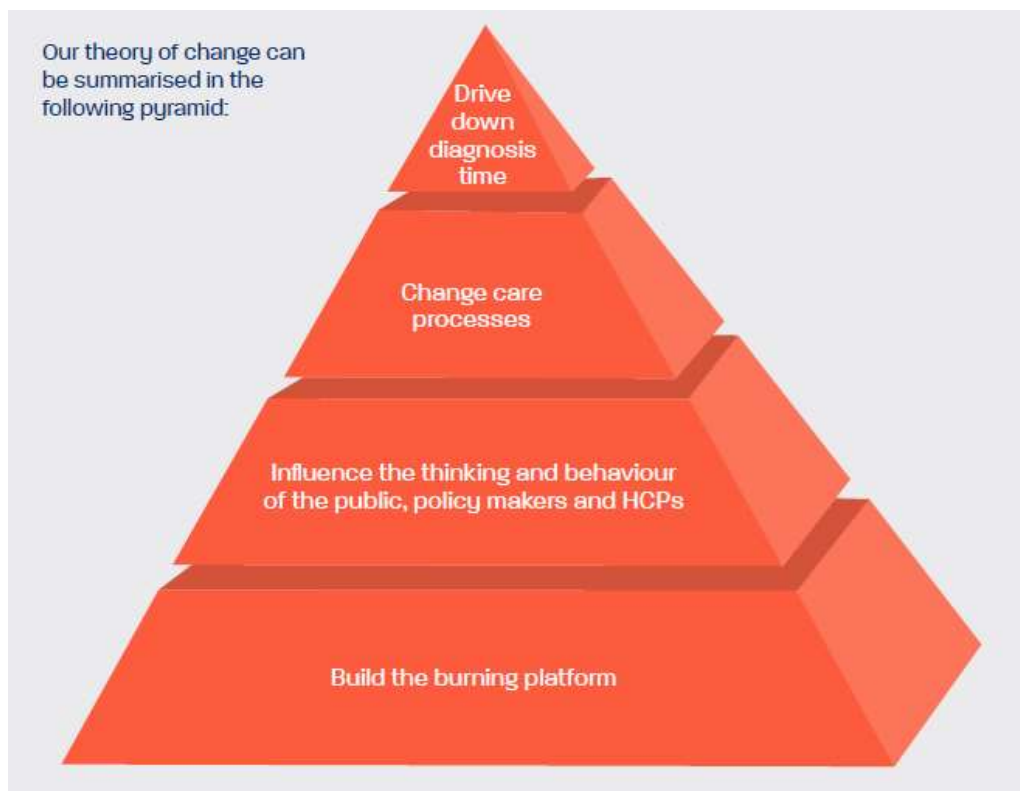


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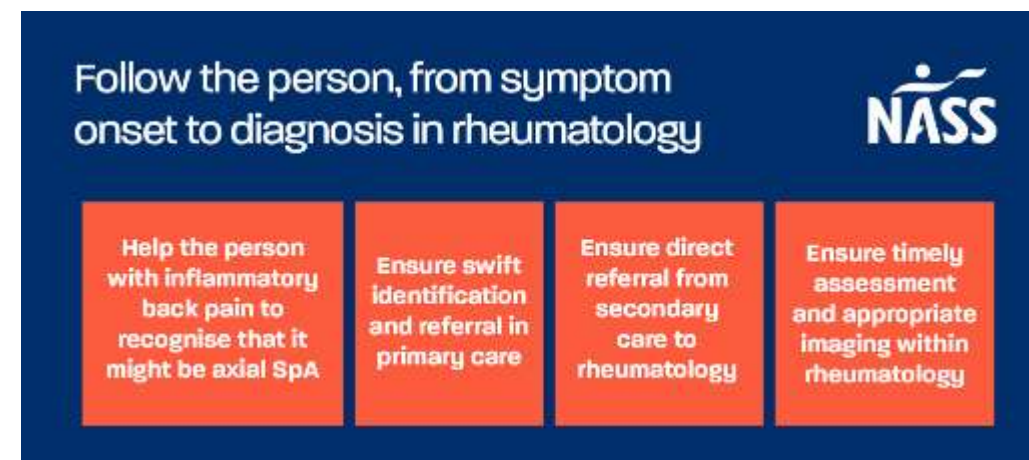
Our *Act on Axial SpA* theory of change

The Act on axial SpA campaign is designed around:

1. A theory of change on how to create system-wide change



2. The patient journey from symptom onset to diagnosis



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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

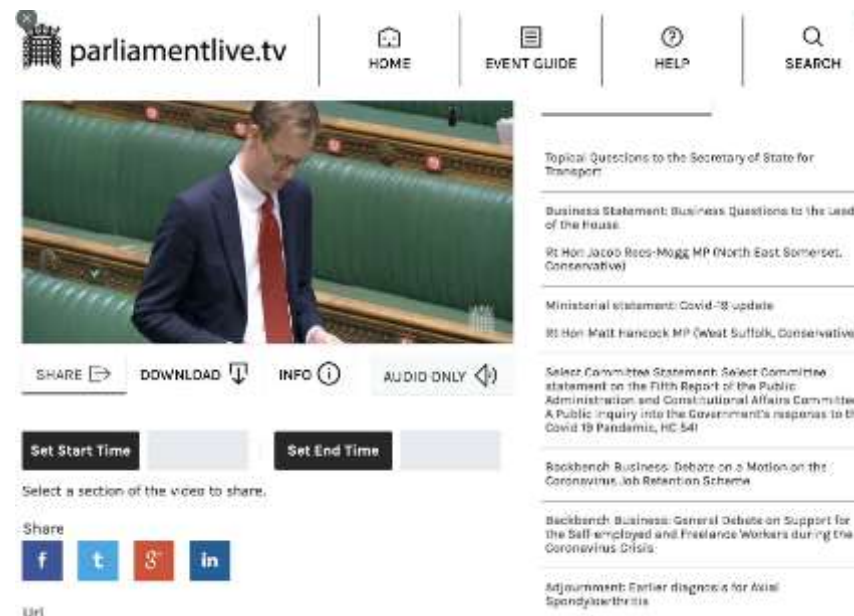
£167k
per person

Making the case in Parliament



All-Party Parliamentary Group for **Axial Spondyloarthritis**

Reducing the delay to diagnosis and improving services in axial SpA

parliamentlive.tv

HOME EVENT GUIDE HELP SEARCH

Topical Questions to the Secretary of State for Transport

Business Statement: Business Questions to the Leader of the House

Rt Hon Jacob Rees-Mogg MP (North East Somerset, Conservative)

Ministerial statement: Covid-19 update

Rt Hon Matt Hancock MP (West Suffolk, Conservative)

Select Committee Statement: Select Committee statement on the Fifth Report of the Public Administration and Constitutional Affairs Committee: A Public Inquiry into the Government's responses to the Covid-19 Pandemic, HC 541

Backbench Business: Debate on a Motion on the Coronavirus Job Retention Scheme

Backbench Business: General Debate on Support for the Self-employed and Freelance Workers during the Coronavirus Crisis

Adjournment: Earlier diagnosis for Axial Spondyloarthritis

Set Start Time Set End Time

Select a section of the video to share.

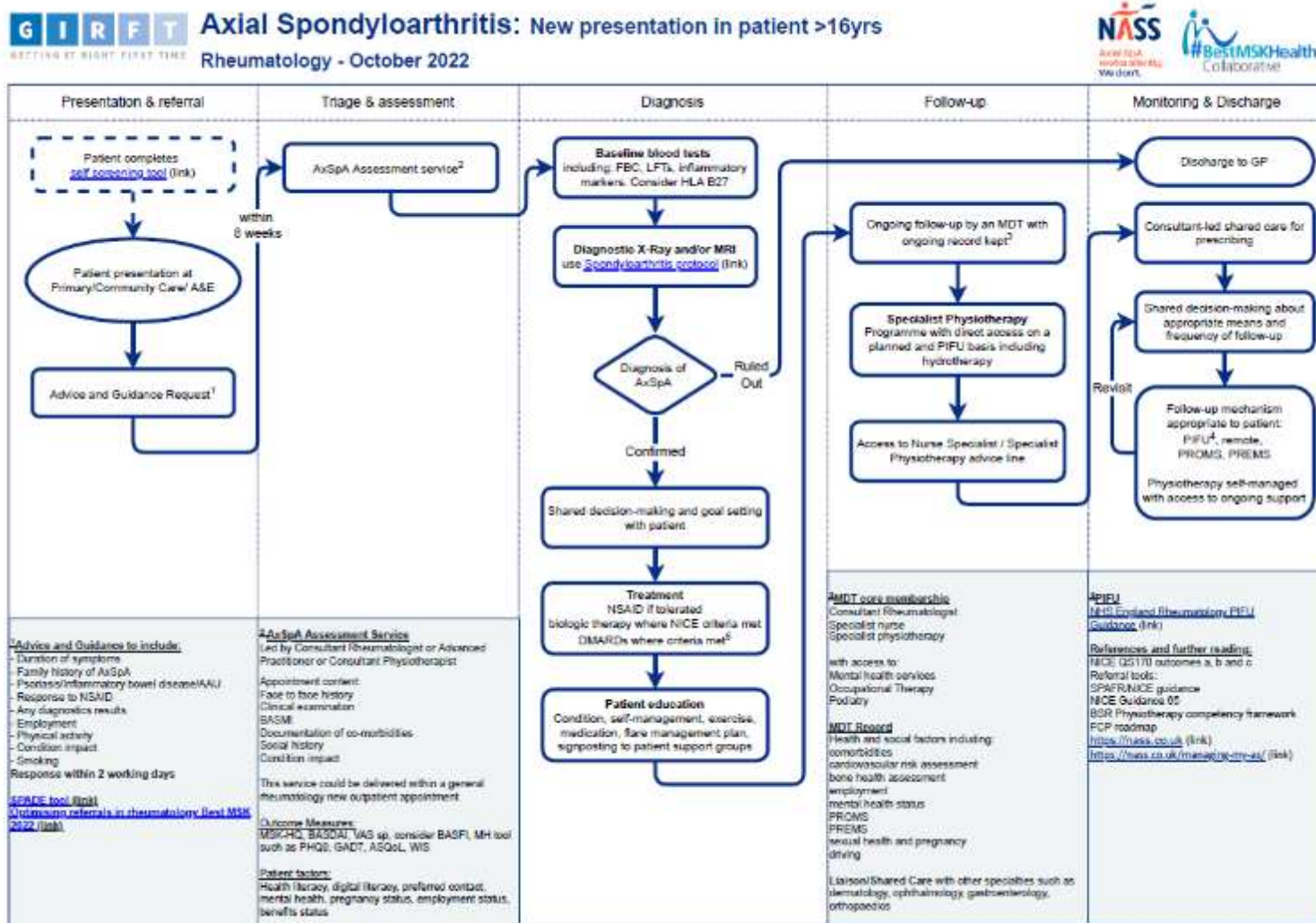
Share

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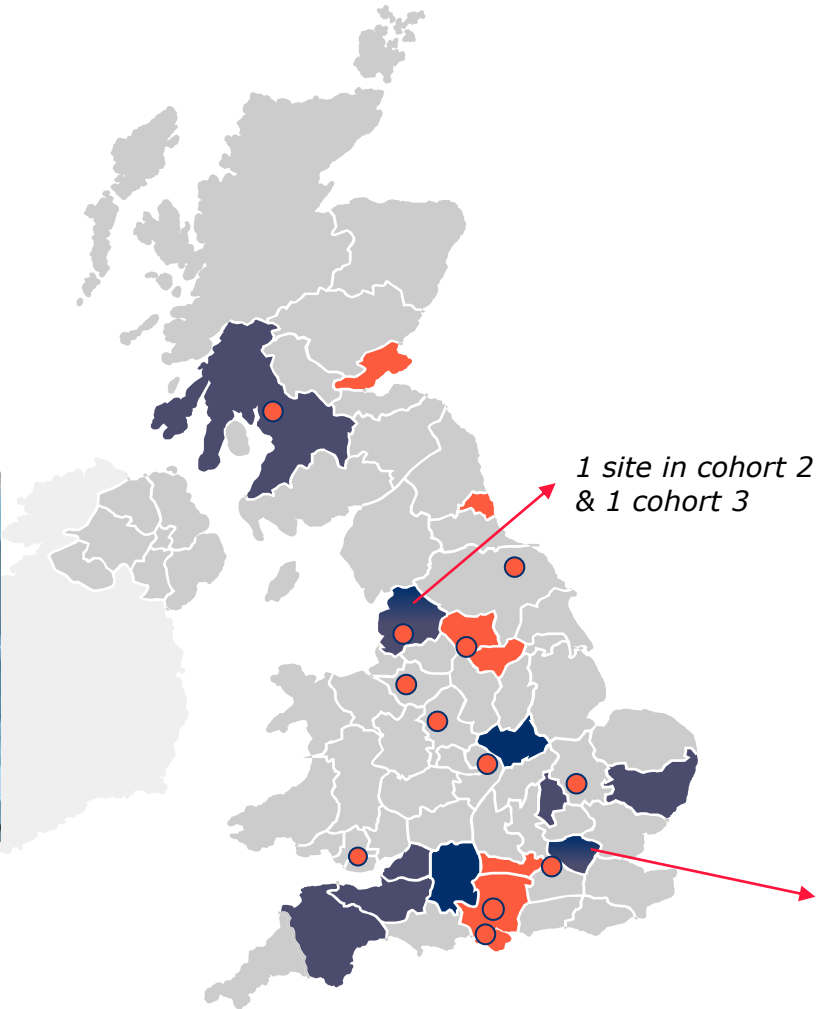
Best MSK / GIRFT axial Spondyloarthritis pathway (England only)



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**

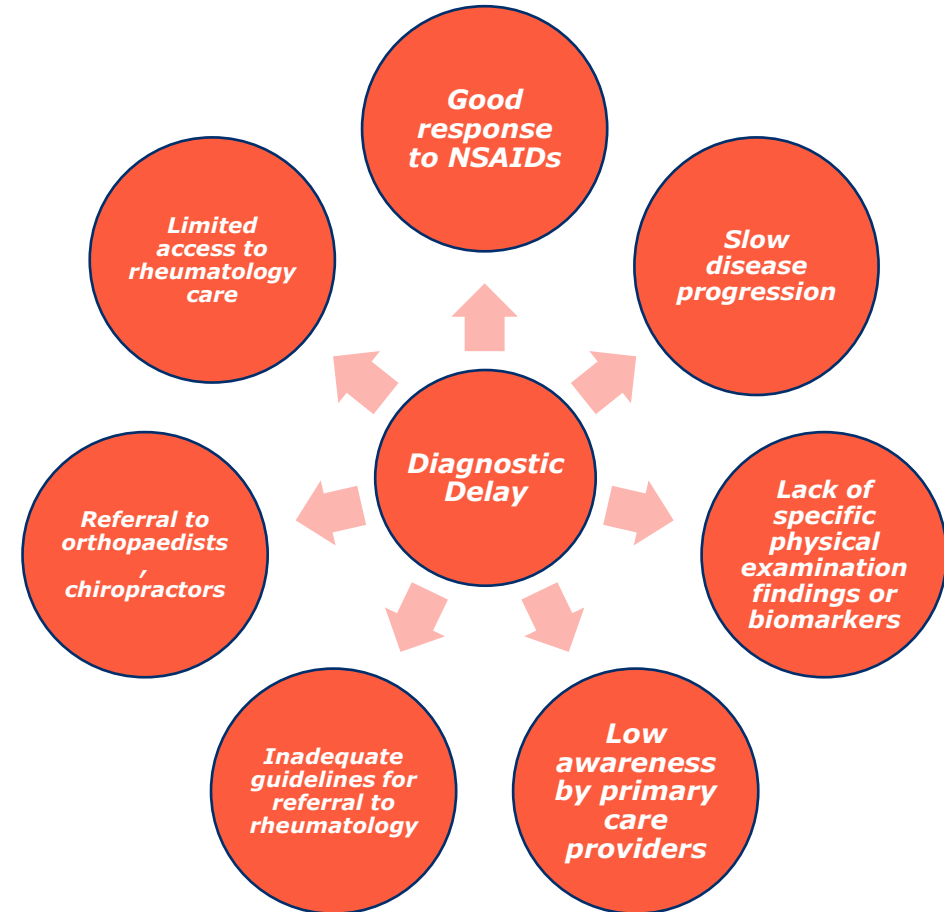
**Local Improvement
Projects**

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 NEIA
- 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 and read our first Act on Axial SpA campaign impact report.



Resources for primary care HCPs

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

NICE National Institute for
Health and Care Excellence



PRIMIS

eular | EUROPEAN ALLIANCE
OF ASSOCIATIONS
FOR RHEUMATOLOGY



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SPADE tool www.spadetool.co.uk

Developed by Dr Raj Sengupta and Team

- Inflammatory type back pain
- Heel pain (enthesitis)
- Peripheral arthritis
- Dactylitis
- Iritis or anterior uveitis
- Psoriasis
- Positive family history of axial SpA, reactive arthritis, psoriasis, IBD or anterior uveitis
- Good response to NSAIDs
- Raised acute-phase reactants (CRP/ESR)
- HLAB27
- Sacroiliitis shown by MRI



**Definitive
diagnosis of
Axial SpA**

This patient is very likely to have Axial SpA - assessment by a rheumatologist is recommended

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Axial SpA**

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



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

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

Campaign fully
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 Inspired by patients.
Driven by science.


Royal United Hospitals Bath
NHS Foundation Trust


Norfolk and Norwich
University Hospitals
NHS Foundation Trust