

Inflammatory Bowel Disease (IBD) plus axial SpA – raising awareness in Gastroenterology

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.

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- 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](#) (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

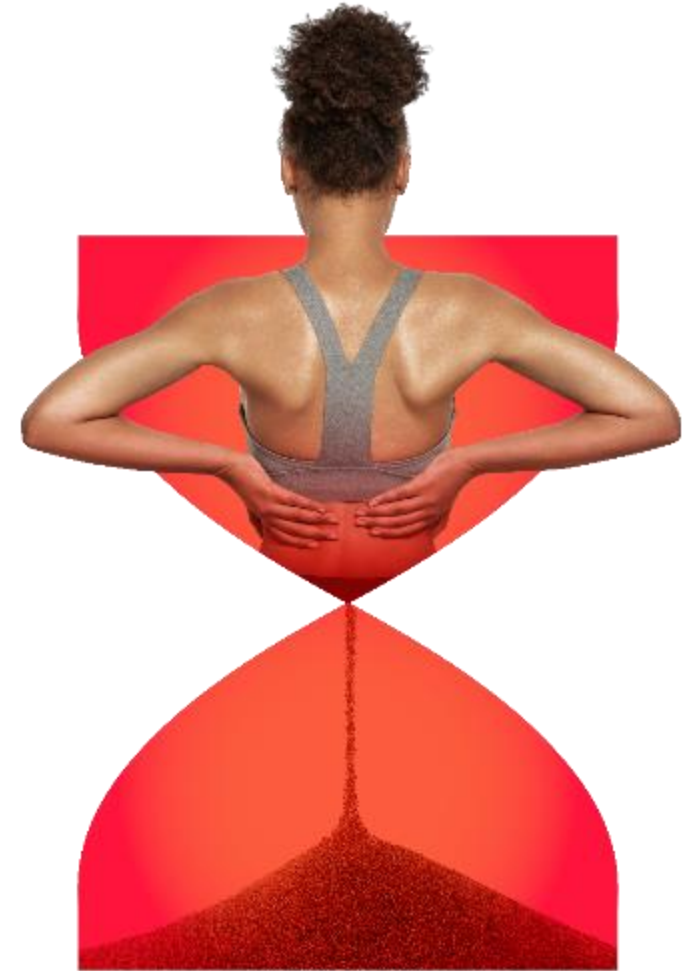
- Act on Axial SpA www.actonaxialspa.com
- NASS resources for patients <https://nass.co.uk/resources/>
- NASS helpline for patients 02087 411 515 and asknass@nass.co.uk
- NASS guidebooks order <https://nass.co.uk/homepage/health-professionals/resources-for-your-patients/guides-to-living-with-axial-spa-as/>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

A red poster for axial spondyloarthritis (SpA) awareness. It features the NASS logo in the top left. The central text reads 'Back pain? Don't wait until it's too late.' Below this, it 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 positioned to the right of the text. On the right side, there is a photograph of a woman from behind, holding her lower back, with a large hourglass shape overlaid on her back. The top half of the hourglass is white, and the bottom half is filled with a brown, granular substance, suggesting the passage of time. At the bottom of the poster, there are several small logos and text: 'act on Axial SpA', 'Campaign fully funded by UCB', 'Inspired by patients. Driven by science.', 'Royal United Hospitals Bath', and 'Hertford and Newark University Hospitals'.

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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

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Axial SpA



campaign: Act on
funded by UCS.

Inspired by scientists,
Driven by science.

Royal United Hospital, Bath

Health and Research
University Research
with Professor Paul



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Axial SpA what are the key symptoms?

Inflammatory arthritis effecting 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-Vagas 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 inflammatory bowel disease?

Axial SpA works silently. We don't.

7% of people with axial spondyloarthritis including ankylosing spondylitis (AS) have inflammatory bowel disease*

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 inflammatory back pain and IBD 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.

*Prevalence of extra-articular manifestations (psoriasis, uveitis, inflammatory bowel disease) in axial spondyloarthritis: a systematic review and meta-analysis. *Ann Rheum Dis*. 2014;73(11):2055-62.

Funded by:    
 In partnership with:   
 Norfolk and Norwich University Hospitals

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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.



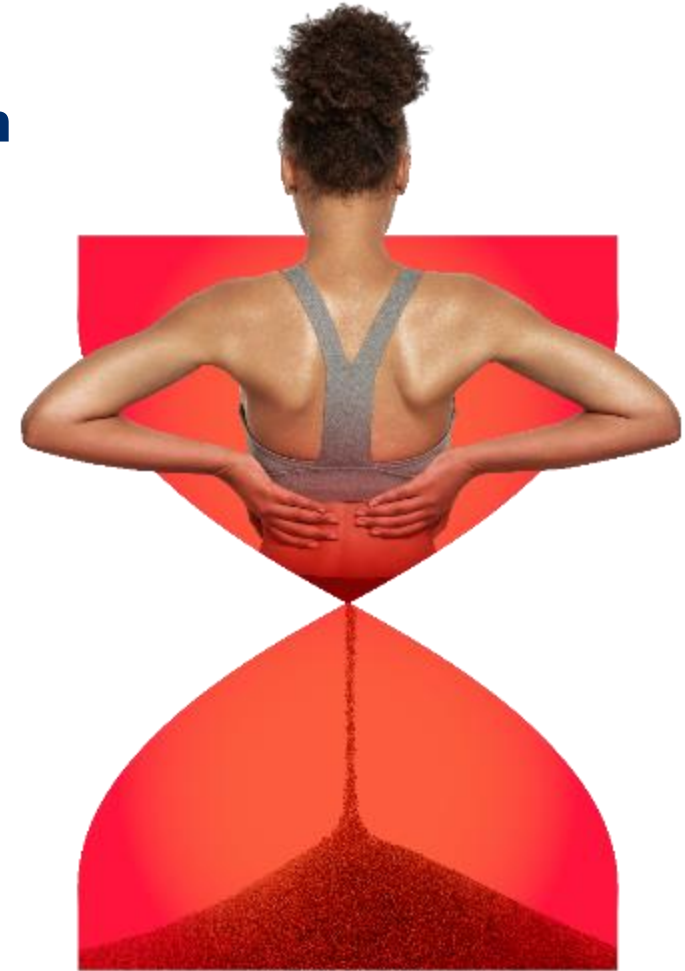
- Men with axial SpA show a higher rate of radiological progression compared with women.
- Non-radiographic axial SpA (nr-axSpA) is more prevalent in women. (67% vs 33%)
- Ankylosing Spondylitis or radiographic axial SpA is more prevalent in men. (67% vs 33%)
- Women with axial SpA have, in general, 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)

- Xavier 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 gastroenterology

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

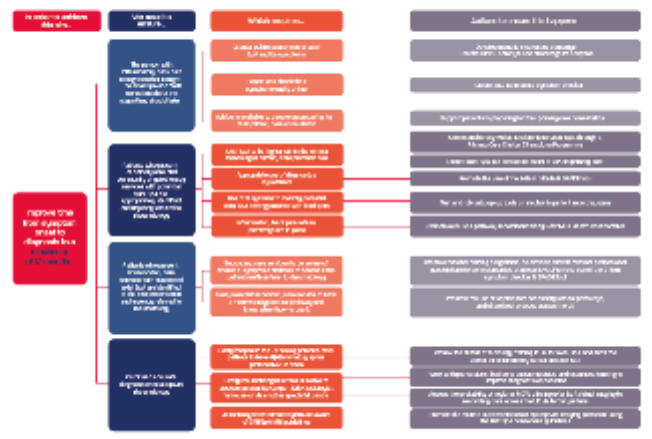
Help the person with inflammatory back pain to recognise that it might be axial SpA

Ensure swift identification and referral in primary care

Ensure direct

Ensure timely

Act on Axial SpA: A Gold Standard Time to Diagnosis

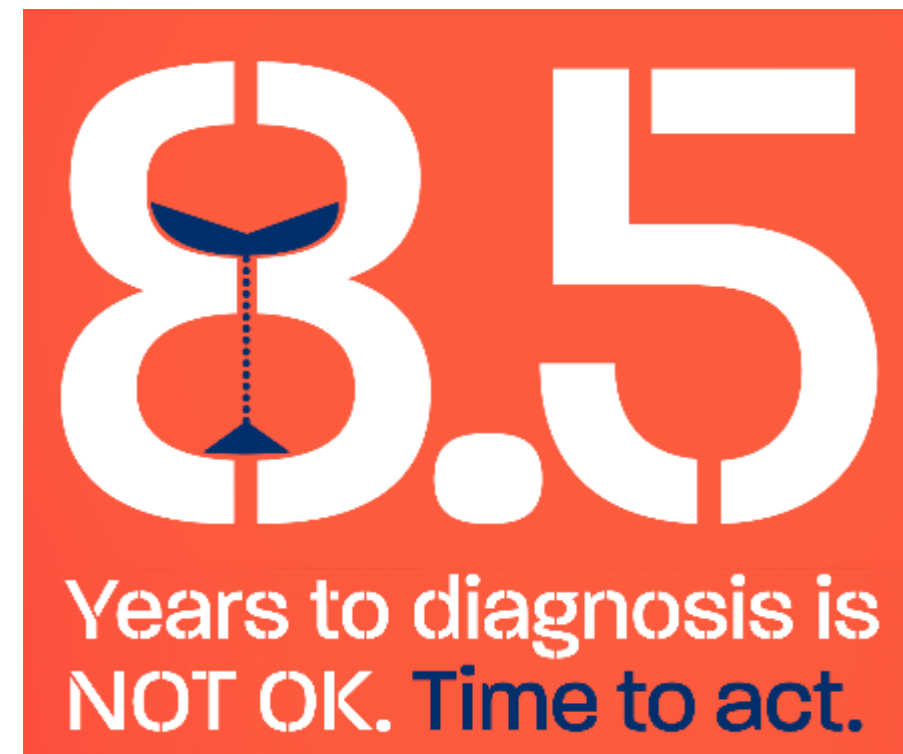
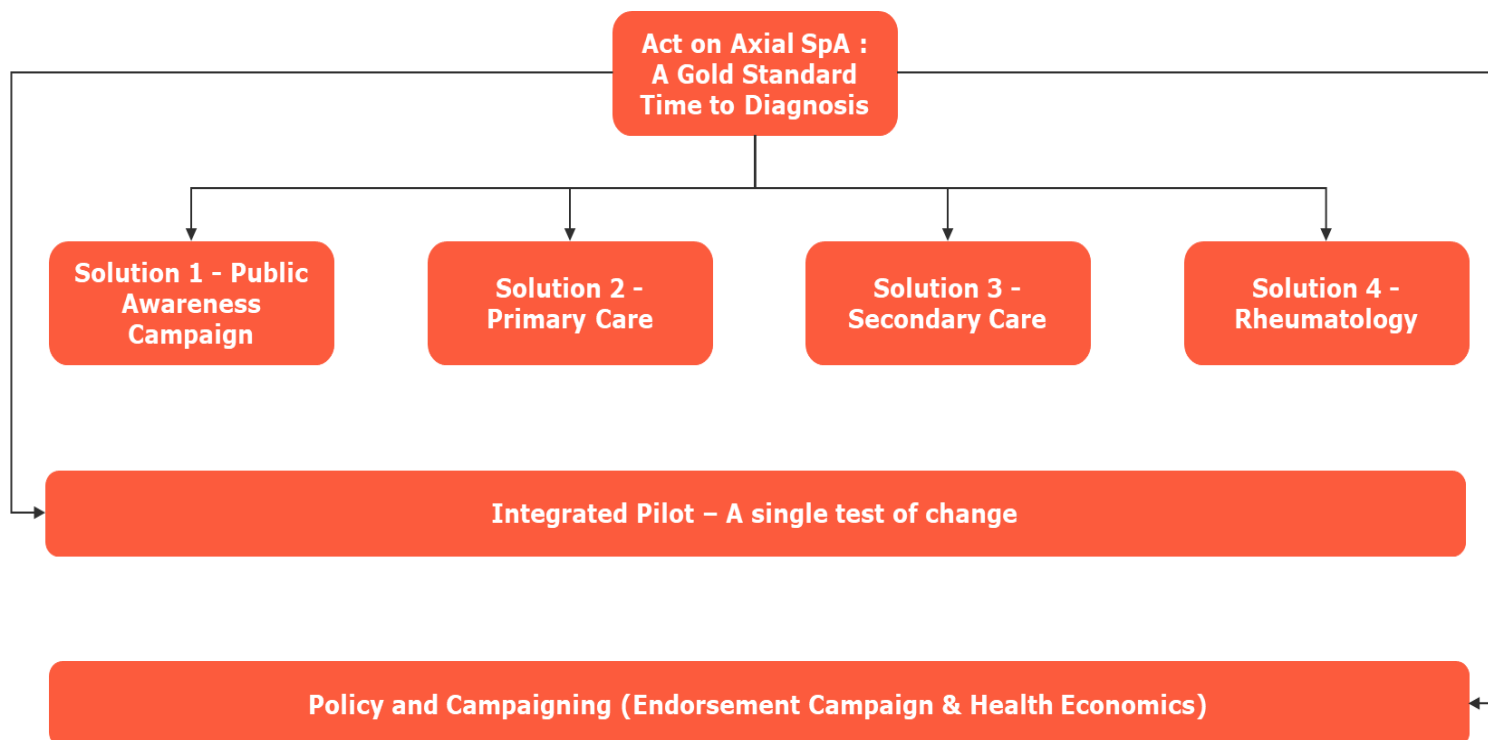


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What is the *Act on axial SpA* campaign?

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



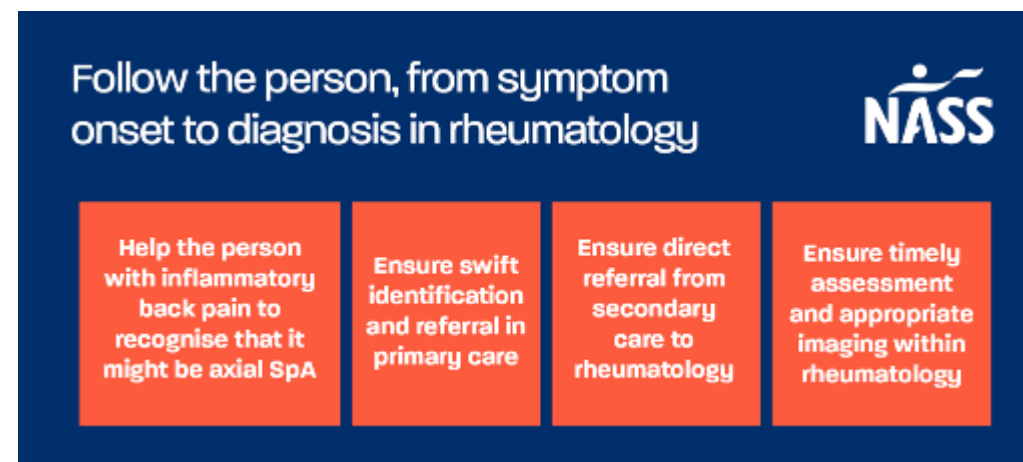
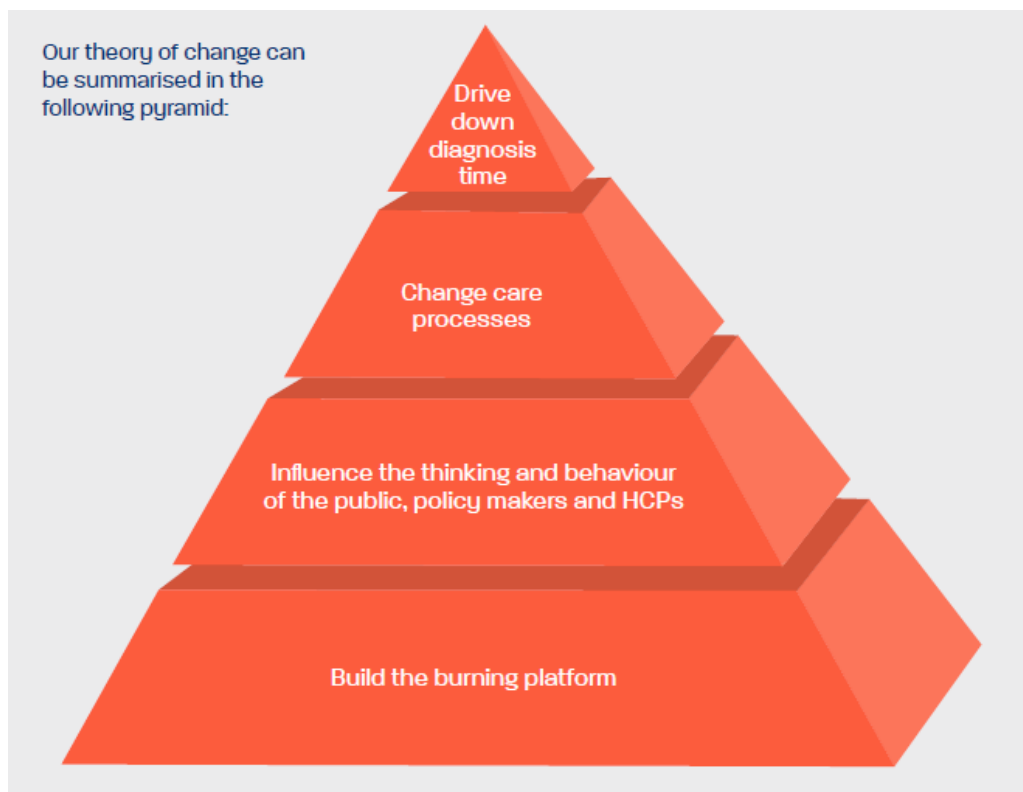
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Our *Act on Axial SpA* theory of change

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*



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

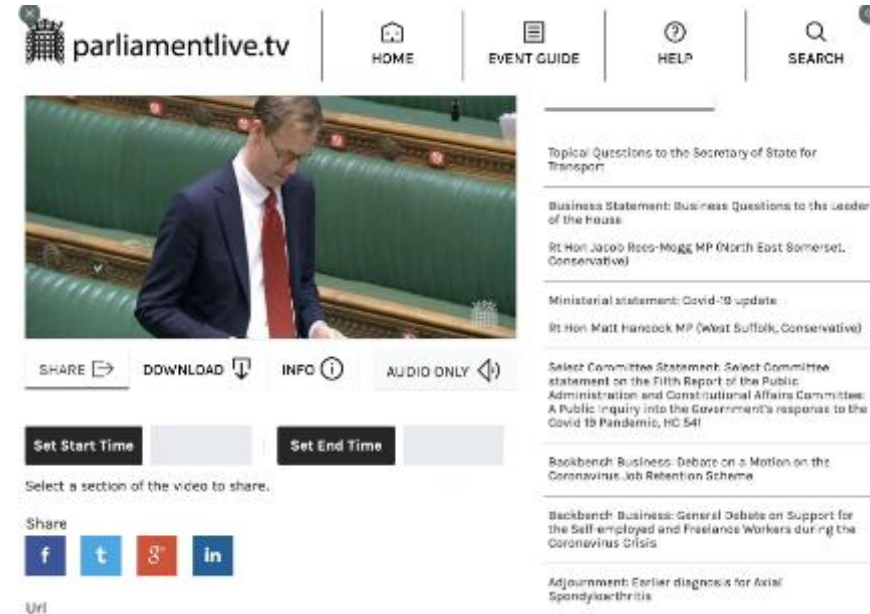
£167k
per person

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

SHARE DOWNLOAD INFO AUDIO ONLY

Set Start Time Set End Time

Select a section of the video to share.

Share

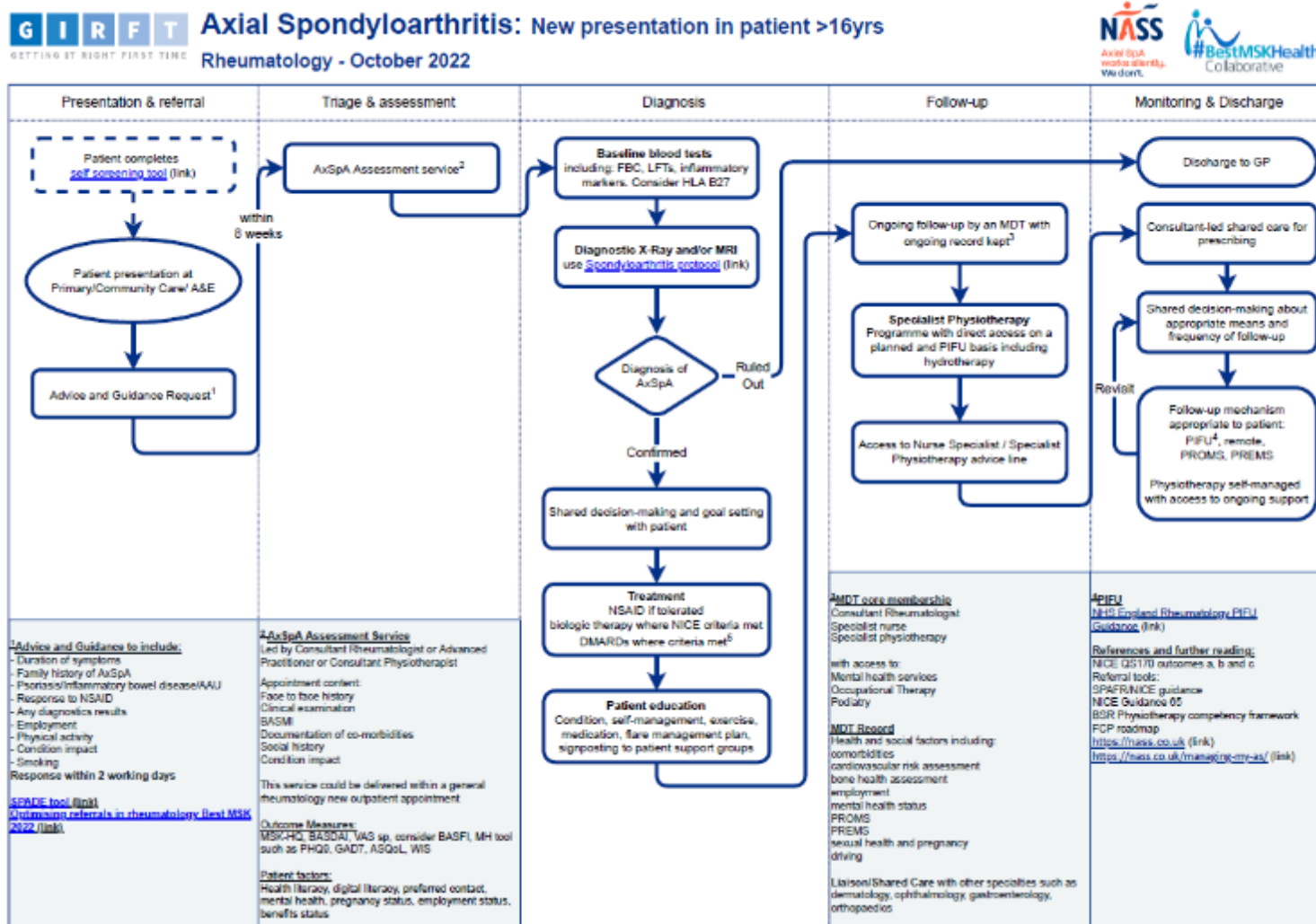
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- Topical Questions to the Secretary of State for Transport
- Business Statement: Business Questions to the Leader of the House
- Rt Hon Jacob Rees-Mogg MP (North East Somerset, Conservative)
- Ministerial statement: Covid-19 update
- Rt Hon Matt Hancock 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 response 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

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Best MSK / GIRFT axial Spondyloarthritis pathway (England only)

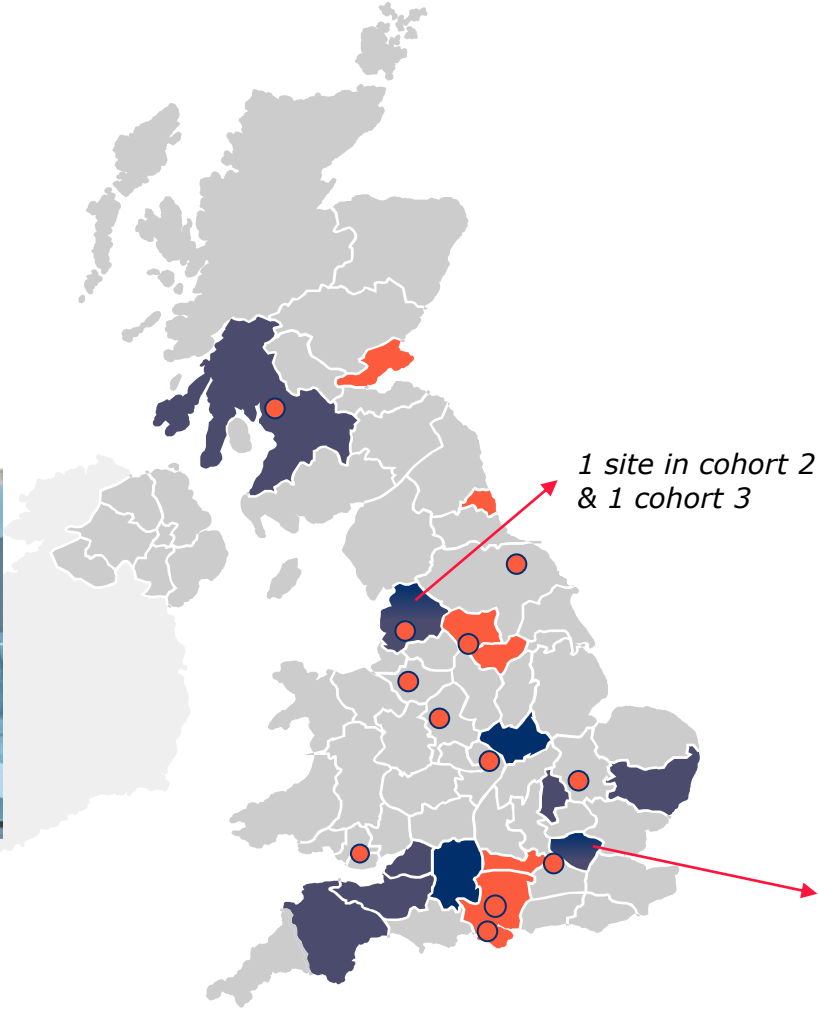


Catalysing change with our health care ambassadors

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

1 site in cohort 2
& 1 cohort 3

2 sites in cohort 2
& 1 cohort 3


Axial SpA and IBD - identification

Inflammatory Bowel Diseases such as Chron's or Colitis are one of the most common Extra Musculoskeletal Manifestations of axial spondyloarthritis.

- 7% of people with axial spondyloarthritis including ankylosing spondylitis (AS) have inflammatory bowel disease ⁽¹⁾
- It is estimated that the prevalence of undiagnosed axial SPA in patients attending IBD clinics with self-reported chronic back pain is 5% ⁽²⁾
- Evidence suggests that up to 13% of individuals with IBD may have axial SpA ⁽³⁾

Gastroenterologists can play a key role in reducing the unacceptable 8.5 year delay to diagnosis of axial SpA.

- (1) Prevalence of extra-articular manifestations in patients with ankylosing spondylitis: a systematic review and meta-analysis, Carmen Stolwijk, Astrid van Tubergen, José Dionisio Castillo-Ortiz, Annelies Boonen, Annals of the Rheumatic Diseases 2015, 74:65–73
- (2) Chong Seng Edwin Lim, Mark Tremelling, Louise Hamilton, Matthew Kim, Alexander Macgregor, Tom Turmezei, Karl Gaffney, Prevalence of undiagnosed axial spondyloarthritis in inflammatory bowel disease patients with chronic back pain: secondary care cross-sectional study, Rheumatology, Volume 62, Issue 4, April 2023, Pages 1511–1518
- (3) Karreman MC, Luime JJ, Hazes JMW, Weel AEAM. The Prevalence and Incidence of Axial and Peripheral Spondyloarthritis in Inflammatory Bowel Disease: A Systematic Review and Meta-analysis. Journal of Crohn's and Colitis. 2016;11(5):631-42



Axial SpA and inflammatory bowel disease?








7% of people with axial spondyloarthritis including ankylosing spondylitis (AS) have inflammatory bowel disease!









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 inflammatory back pain and IBD 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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In partnership with:          

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Axial SpA and IBD - treatment

IBD and axial SpA patients respond to the same medications in a lot of cases, such as anti-TNFs.

- The presence of sacroiliitis or spondyloarthritis can be a trigger for using anti-TNFs to manage both IBD and potential spondyloarthritis symptoms.
- Important to note some biologics have differential effects on the two types of inflammation.
 - IL-12 and IL 23 inhibitors such as ustekinumab are not effective for axial SpA but are effective for Chron's disease.
 - IL-17 inhibitors are effective for the management of axial SpA but not IBD.



Due to treatment similarities and differences it is important for joint gastroenterology and rheumatology consultation to provide the optimal medication.

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What are the challenges for Gastroenterologists

Watch the video below by Professor Tim Orchard, Consultant Gastroenterologist and Chief Executive at Imperial College Healthcare NHS Trust, to understand what the challenges are for Gastroenterologists in identifying potential axial SpA in their patients.

- Presentation varies from patient to patient, historic misconception of a male only disease.
- Presentation is often in late teens, early 20's and 30's.
- Symptoms come and go over time.
- Primary care miss inflammatory back pain.
- Difficult to join the dots.



What are the key things Gastroenterologists should look for?

The key symptoms to look out for are:

- Critically chronic lower back pain – back pain for greater than 3 months
 - Ask your patients
- Secondary:
 - Pain particularly prevalent in the morning
 - Pain that radiates into the buttocks
 - Morning stiffness of greater than 30 minutes
 - Pain that is responsive to NSAIDs (although of course, not often used in IBD), another good indicator of inflammatory back pain.

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

Joint management between gastroenterology and rheumatology is key and will give the best outcomes for patients.

What additional tools can help?

NASS and other stakeholders have created resources to support Gastroenterologists in the identification of potential axial SpA.

The SPondyloArthritis Diagnosis Evaluation (SPADE) tool

- The SPADE tool (SPondyloArthritis Diagnosis Evaluation tool – www.spadetool.co.uk) was developed by Dr Raj Sengupta and team, based on research by Martin Rudwaleit and Ernst Feldtkeller*, to assist medical professionals in primary care in defining the likelihood that a patient has axial spondyloarthritis (axial SpA). When a patient with chronic back pain aged <45 years presents in clinic with no evidence of axial SpA changes on X-ray, simply access the tool via the website and tick the axial SpA features that apply, to determine the likelihood of axial SpA.
- Upon clicking “show results”, the likelihood that the patient has axial SpA will be shown on a graph, with instructions on how to proceed.
- Watch this video by Dr Raj Sengupta on the SPADE tool:



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(*) Rudwaleit M, Feldtkeller E, Sieper J. Easy assessment of axial spondyloarthritis (early ankylosing spondylitis) at the bedside. Annals of the rheumatic diseases. 2006;65(9):1251-2.

What additional tools can help?

NASS have developed a clinically validated symptom checker that helps patients to recognise when their back pain may be inflammatory and potentially axial SpA.

The [NASS symptom checker](#)

- This symptom checker was created by rheumatologists advising our Act on Axial SpA campaign which aims to reduce delay to diagnosis of axial SpA.
- A simple eight question survey, with a score of five or higher indicating inflammatory back pain and axial SpA. This aids referral to rheumatology.
- The symptom checker combines the three sets of validated criteria:
 - 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.

Your SYMPTOM CHECKER QUESTIONNAIRE results



1. Did your back pain start before the age of 40?
2. Did your back pain develop gradually?
3. Has your back pain lasted more than 3 months?
4. Do you experience stiffness in your back in the morning for at least 30 minutes?
5. Does your back pain improve when you move around?
6. Does your back pain improve when you rest?
7. Do you have pain in your buttocks, which moves from one buttock to the other?
8. Do you wake in the second half of the night because of your back pain?

Your answers to the symptom questionnaire suggest you may have inflammatory back pain and it is possible it could be caused by axial spondyloarthritis (axial SpA).
If you have not seen a health care professional e.g. a GP, about this back pain we recommend you make an appointment with your GP practice to discuss your symptoms. Please take this questionnaire with you and share it with your GP. If you are currently seeing or are waiting to see a health care professional e.g. a physiotherapist, about this back pain we recommend you take this questionnaire with you and share it with your health care professional at your next appointment.

Notes for the healthcare practitioner

A key indicator of axial SpA is persistent lower back pain. If you think your patient may have axial SpA you should refer them urgently to rheumatology, as per NICE guideline Spondyloarthritis in over 16s: diagnosis and management (NG65 2017). To assist you further, we recommend using the SPADE tool (spadetool.co.uk). Based on research by Martin Rudwaleit (1) and developed at the Royal National Hospital for Rheumatic Diseases, Bath, UK, the tool is designed to assist medical professionals in defining the probability of axial spondyloarthritis in a patient with chronic back pain.

This symptom checker was created by rheumatologists advising our Act on Axial SpA campaign which aims to reduce delay to diagnosis of axial SpA. The symptom checker combines the three sets of validated criteria (2, 3, 4).

1. Fardislar E, Rudwaleit M, Zickler H. Easy probability estimation of the diagnosis of early axial spondyloarthritis by summing up scores. *Rheumatology (Oxford)*. 2015 Sep;54(9):1649-50. doi:10.1093/rheumatology/kfv279. Epub 2015 May 16. PMID: 2598397
2. 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.
3. 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.
4. Calin A, Porta J, Fries JF, Schurman DJ. Clinical history as a screening test for ankylosing spondylitis. *JAMA*. 1977;237(24):2613-4.

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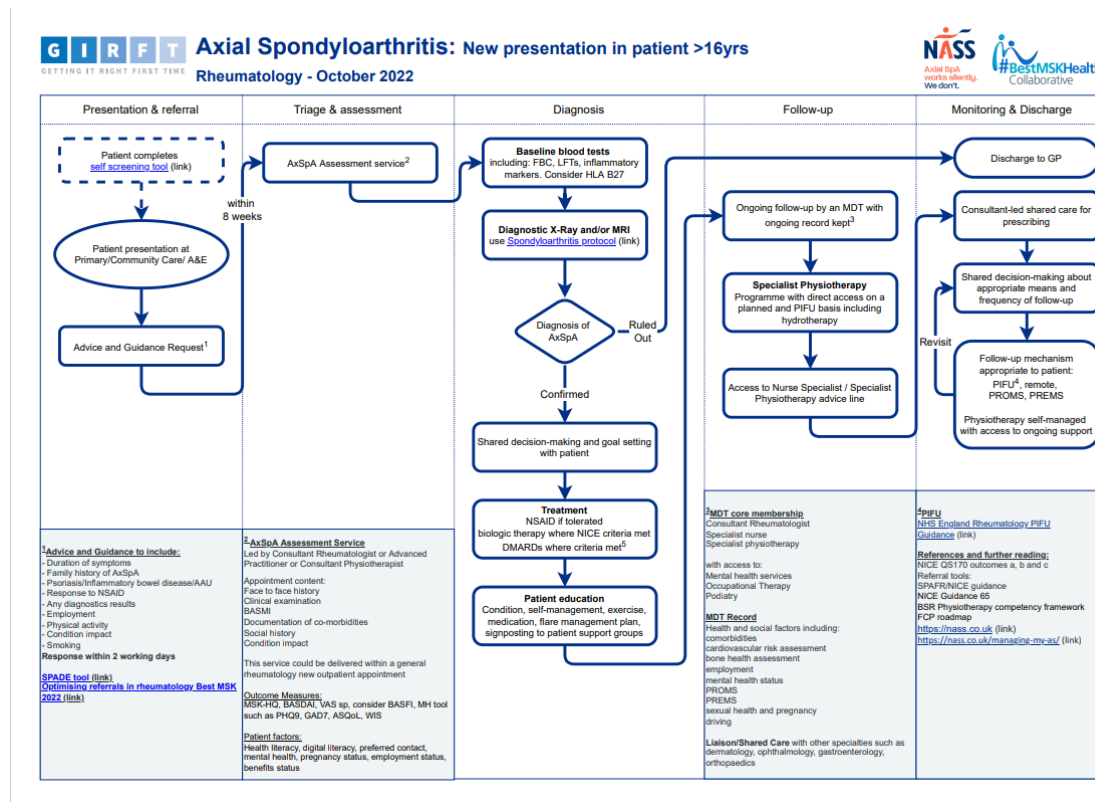
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Axial Spondyloarthritis pathway for England

NASS and other stakeholders have created resources to support Gastroenterologists in best practice for spondylarthritis management.

NHS England Getting it Right First Time (GIRFT) and Best MSK Health Collaborative axial Spondyloarthritis pathway*

- Getting It Right First Time (GIRFT) has worked with the National Axial Spondyloarthritis Society (NASS), to develop and share a [new pathway for Axial Spondyloarthritis](#) (axial SpA), supporting clinicians to provide the best patient care and allowing patients and commissioners to see what they can expect from a service.
- Pathways for inflammatory arthritis, Giant Cell Arteritis (GCA) and suspected GCA, and connective tissue disease are also available to view and download.



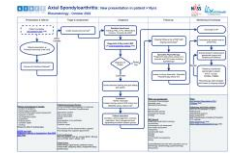
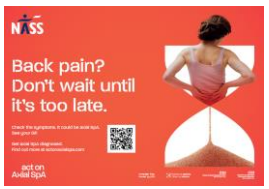
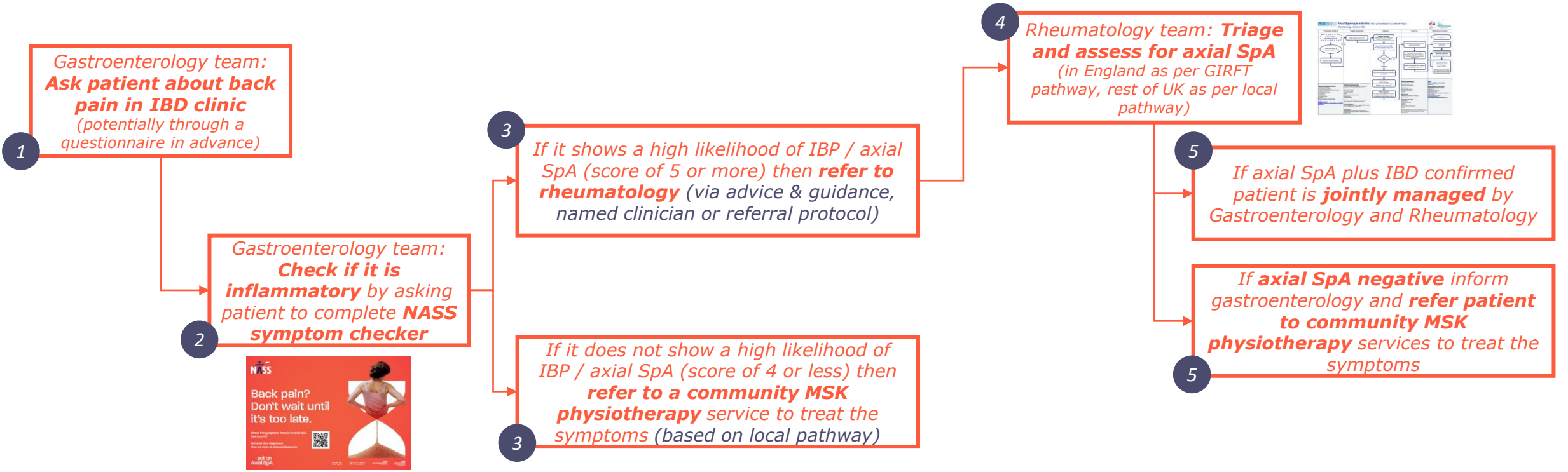
Referring to Rheumatology?

A simple message for swift appropriate identification and referral to rheumatology:

- ***All patients with a high suspicion of inflammatory back pain (IBP), as identified by the NASS symptom checker or ASAS criteria, plus IBD are directly referred to rheumatology.***
- *Patients with back pain not identified as inflammatory are offered musculoskeletal (MSK) physiotherapy.*
- *Ensure your patient is directly referred to a rheumatologist (or ask rheumatology for advice and guidance) if they have symptoms of inflammatory back pain. Reflecting your local pathway.*
 - Speak to your local rheumatology service
 - Do a direct consultant to consultant referral
 - Complete a request for advice and guidance
 - Add to a joint clinic or MDT meeting

Referring to Rheumatology?

NASS is advocating through the Act on axial SpA campaign a simple pathway that has the symptom checker embedded into it:



How to find out more

- Go to www.actonaxialspa.com and read our first Act on Axial SpA campaign impact report, find tools, resources and advice.

A dark blue rectangular banner with white and orange text. In the top right corner is the NASS logo. The main text reads 'actonaxialspa.com' in a large, orange, sans-serif font. Below this, in a smaller white font, 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'.


actonaxialspa.com
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www.nass.co.uk



act on
Axial SpA

Resources for Gastroenterologists

- [NICE Guideline NG65](#)
- [GIRFT / BEST MSK pathway](#)
- [NASS symptom checker](#)
- [SPADE Tool](#) ⁽¹⁾
- [ASAS / EULAR guidance](#)

Visit the NASS HCP toolkit to find these tools. [HCP toolkit - National Axial Spondyloarthritis Society \(actonaxialspa.com\)](#)

NICE National Institute for Health and Care Excellence

GIRFT
GETTING IT RIGHT FIRST TIME

SPADE
Spondyloarthritis
Diagnosis Evaluation Tool

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ASAS
Assessment of
SpondyloArthritis
International Society

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(1) Available at: <http://www.spadetool.co.uk/>