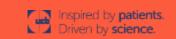


# Acute Anterior Uveitis (AAU) plus axial SPA – raising awareness in Ophthalmology











### 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.

- Helpline
- Website
- Branches













## 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 <u>www.actonaxialspa.com</u>



- NASS resources for patients <a href="https://nass.co.uk/resources/">https://nass.co.uk/resources/</a>
- NASS helpline for patients 02087 411 515 and asknass@nass.co.uk
- NASS guidebooks order <a href="https://nass.co.uk/homepage/health-professionals/resources-for-your-patients/guides-to-living-with-axial-spa-as/">https://nass.co.uk/homepage/health-professionals/resources-for-your-patients/guides-to-living-with-axial-spa-as/</a>
- NICE <a href="https://www.nice.org.uk/guidance/ng65">https://www.nice.org.uk/guidance/ng65</a>
- 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



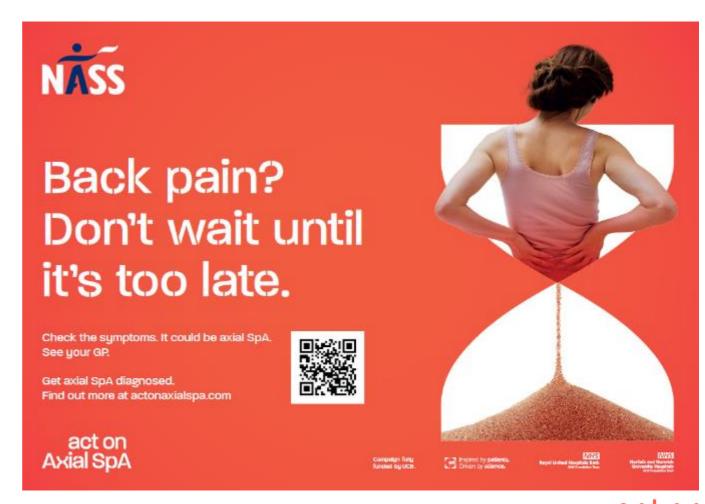








- Inflammatory pain
- Functional impairment
- Onset typically starts late teens early 20's (average age 26yrs)
- Can have lifelong impact and long term implications if left untreated
- Diagnosis is difficult and often delayed





# 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





Compage fully funded by UCS.





### Axial SpA what are the key symptoms?

NASS

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\*: <u>Symptom checker</u>



# 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 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





## 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

<sup>-</sup> Rudwaleit M and Sieper J. Nat Rev Rheumatol. 2012;8(5):262-266

Key signs to consider when women present in ophthalmology

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



<sup>-</sup> Tourmadre A et al. Arth Care & Res. 2013;65(9):1482-1489



Lee Wet al. Ann Dheum Die 2007,66,622,620

www.actonaxialspa.com

# What are the treatments for axial SpA?



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







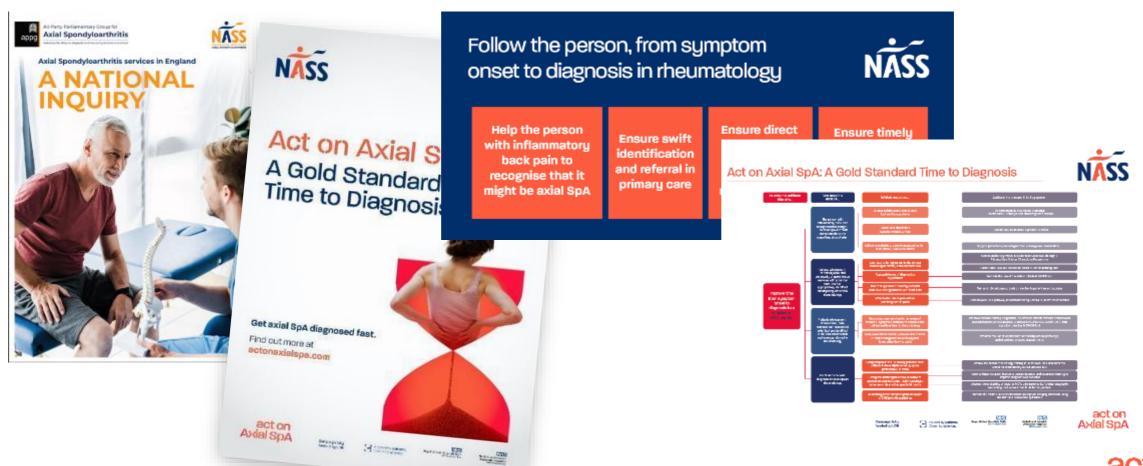


act on Axial SpA



# What is the Act on axial SpA campaign?

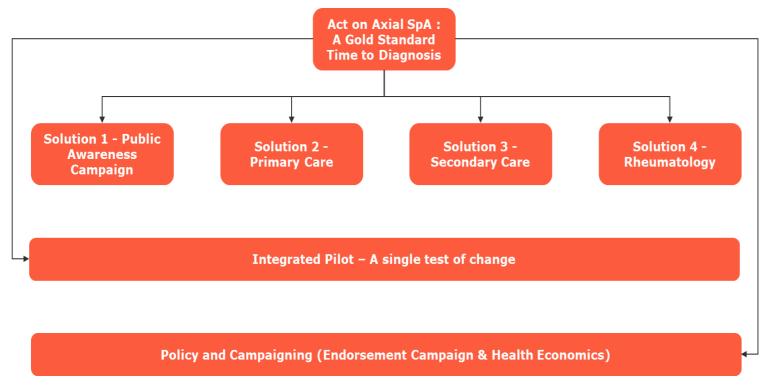
Act on Axial SpA is our vehicle for delivering our Gold Standard ambitions.





# 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



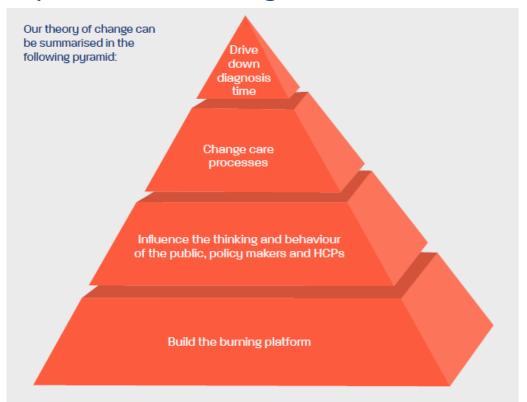




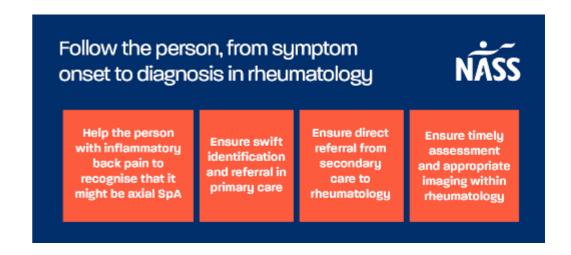
# Our Act on Axial SpA theory of change

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** 

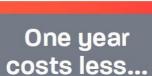




Average time to diagnosis from symptom onset is 8.5 years



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



Affects the young

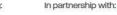
with average age of

A Gold Standard time to diagnosis would save the UK economy

per person

act on













## Making the case in Parliament



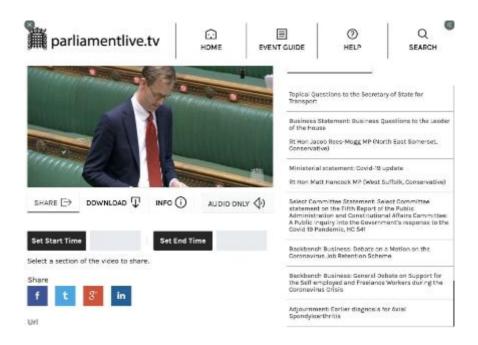


All-Party Parliamentary Group for

# **Axial Spondyloarthritis**

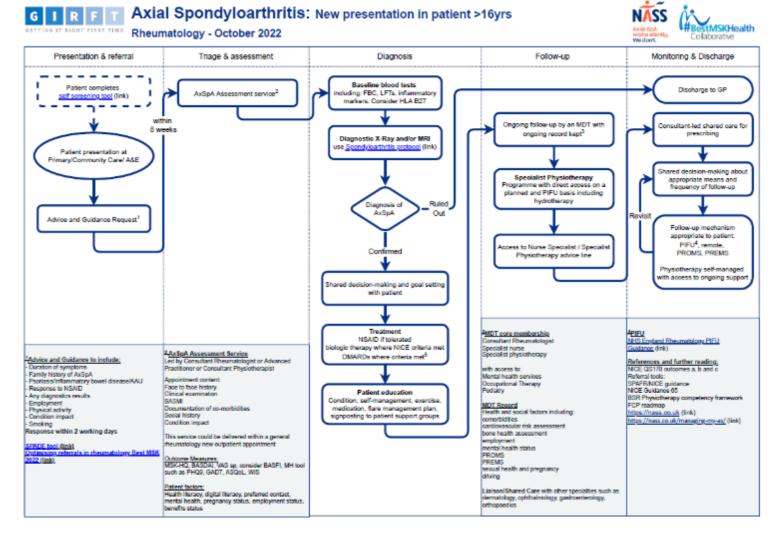
Reducing the delay to diagnosis and improving services in axial SpA







# Best MSK / GIRFT axial Spondyloarthritis pathway (England only)



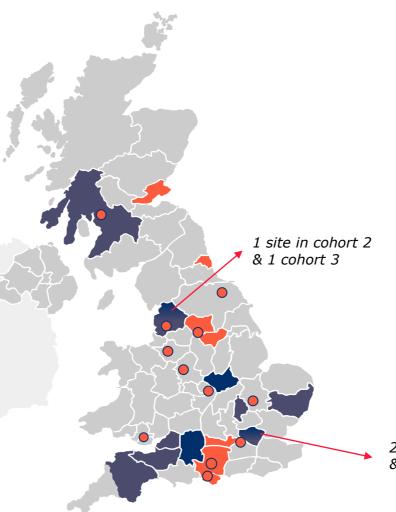


### Catalysing change with our health care ambassadors

#### Champions in Primary Care

Location of appointments for Champions in Primary Care programme







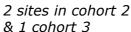
A2E Cohort 1 Current Cohort 1 participant rheumatology department / hospital



A2E Cohort 2 Current Cohort 2 participant rheumatology department / hospital



Cohort 3 participant rheumatology department / hospital





## Axial SpA and AAU - identification

Acute Anterior Uveitis (AAU) is the most common Extra Musculoskeletal Manifestations of axial spondyloarthritis.

- 40% of people with acute anterior uveitis have spondyloarthritis(1)
- 26% of people with axial spondyloarthritis including ankylosing spondylitis (AS) have acute anterior uveitis
- Evidence suggests the minimum prevalence of axial SpA in patients with AAU is 20.2%, with nearly one-quarter of patients previously undiagnosed despite many years of back pain(3)

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



<sup>(1)</sup> A novel evidence-based detection of undiagnosed spondyloarthritis in patients presenting with acute anterior uveitis: the DUET (Dublin Uveitis Evaluation Tool), Muhammad Haroon, Michael O'Rourke, Pathmas Ramasamy, Conor C Murphy, Oliver Fitzgerald, Annals of the Rheumatic Diseases, June 2014.

<sup>(2)</sup> 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 Karreman MC, Luime JJ, Hazes JMW, Weel AEAM.

<sup>(3)</sup> Sykes MP, Hamilton L, Jones C, et al. Prevalence of axial spondyloarthritis in patients with acute anterior uveitis: a cross-sectional study utilising MRI. RMD Open 2018;4:e000553. doi:10.1136/ rmdopen-2017-000553

### What are the challenges for Ophthalmologists

Watch the video below by xx, to understand what the challenges are for Ophthalmologists in identifying potential axial SpA in their patients.

- Presentation varies from patient to patient.
- 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.

Ask Harry / Nima for someone to recreate the video by Dr Fahd Quhill



# What are the key things Ophthalmologists should look for?

Watch the video below to understand what signs you should be looking for as an Ophthalmologists in identifying potential axial SpA in their patients.

- Critically chronic back pain back pain >3 months
  - Ask your patients
- Recurrent bouts of acute anterior uveitis
- Secondary:
  - Back pain started before the age of 40
  - Back pain developed slowly
  - Back pain improves with exercise
  - Back pain worse with rest
  - Regular waking at night

Embed Harry's UCB video that is at the link below:

https://cloud.info.ucb.com/NASS\_all\_conte
nt

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



### What additional tools can help?

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

#### The SPondyloArthritis Diagnosis Evaluation (SPADE) tool

• The SPADE tool (SPondyloArthritis Diagnosis Evaluation tool – <a href="www.spadetool.co.uk">www.spadetool.co.uk</a>) 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:





### 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-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.

#### Your SYMPTOM CHECKER QUESTIONNAIRE results



- 1. Did your back pain start before the age of 40?
- 2. Did your back pain develop gradually?
- Has your back pain lasted more than 3 months
- 4. Do your experience stiffness in your back in the morning for at least 30 minutes?
- 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 CP, 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, seeling 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 rext appointment.

#### Notes for the healthcare practitione

A key indicator of axial SpA is persistent lower back pain. If your think your patient may have axial SpA you should refer them urgerfly to rheumatology, as per NCE Guideline Spondigioenthals in over 16st diagnosis and management (NGSS 2017). To seasit your further, we recommend using the SPADE tool (spedetool.co.uk). Based on research by Martin Rudwelett (1) and developed at the Royal National Hospital for inheumatic Diseases, Bath, UK, the tool is designed to assist medical professionals in definine the probabilitur of axis spondiuscribittis in a patient with Chrisric back pein.

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).

- Feldtkeller E, Rudwalett M, Zeidler H. Easy probability estimation of the diagnosis of early axial spondujoarthritis by summ source. Pharmatrology (Portner), 2013 Sants 2001/848-50 dot 10.1003/the matrology/det/26. Early 2013 May 18. DMID: 238
- Steper J, van der Heijde D, Landewe R, Brandt J, Burgos-Vages R, Collanties-Estevez E, et al. New criteria for inflammatory back path in patients with chronic back pain: a real patient cercise by acperts from the Assessment of SpondyjoArthrit informational Systems (ASAS) Annels of the Line matter feasoese 2000;05(67):73.
- Rudwelett M, Metter A, Listing J, Sieper J, Braun J. Inflammatory back pain in ankylosing spondylitts: 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, Pites JF, Schurman DJ. Clinical history as a screening test for ankylosing spondylitis. JAMA 1977;237(24):2913-4

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### What additional tools can help?

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

#### The Dublin Uveitis Evaluation Tool

- The Dublin Uveitis Evaluation Tool (DUET)\* algorithm –
  which prompts referral to rheumatology if a patient has
  AAU, is HLA-B27 positive, or has co-existing psoriasis or
  peripheral arthritis. The algorithm was found to have high
  sensitivity and specificity (96% and 97% respectively)
- Read more about the DUET here: <u>A novel evidence-based</u> <u>detection of undiagnosed spondyloarthritis in patients presenting with acute anterior uveitis: the DUET (Dublin Uveitis Evaluation Tool) |</u>
  Annals of the Rheumatic Diseases (bmj.com)

#### **Axial SpA and AAU poster**

- NASS with clinical advisors have developed a simple poster for Ophthalmologists to act as a prompt for identifying potential axial SpA.
- Find and download the poster here: <u>NASS HCP toolkit</u>



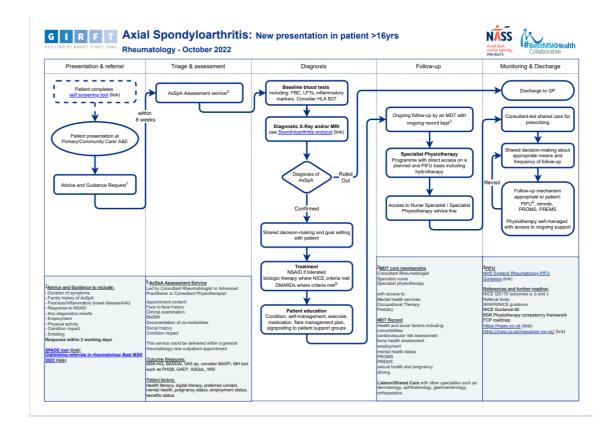


### Axial Spondyloarthritis pathway for England

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 <u>new pathway for Axial Spondyloarthritis</u> (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 AAU 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?

#### **Collaboration is key:**

 Watch the video below between Mr Harry Petrushkin and Dr Steven Zhao (rheumatologist) discussing joint management below:

> Embed Harry speaking to Steven Zhao UCB video that is at the link below:

https://cloud.info.ucb.com/NASS\_all\_ content





### How to find out more

• Go to <u>www.actonaxialspa.com</u> and read our first Act on Axial SpA campaign impact report, find tools, resources and advice.







## 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. <u>HCP toolkit - National Axial</u> <u>Spondyloarthritis Society (actonaxialspa.com)</u>



