

Axial SpA: A Patient Perspective

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National Axial Spondyloarthritis Society
23 April 2022



My personal experience

Getting diagnosed and living with axial SpA

STRESS

What is so special about me?



MONTANE
FUSION
a SPINE event



MONTANE
FUSION
a SPINE event

“Being accepted by the AS community because I choose to be so active. So many almost disapprove and I get so tired of hearing ‘well, you can’t have it all that bad then.’”

Run *and* exercise *and* manage condition

Manage condition

My NASS experience

Helping others diagnosed and living with axial SpA



Who are NASS

A bit more about us...

- We are the National Axial Spondyloarthritis Society (NASS) and we seek to transform the diagnosis and care of people living with axial SpA.
- It's an invisible and misdiagnosed condition. Often leaving people feeling powerless, in increasing pain and extreme exhaustion.
- So we campaign policy makers for early diagnosis and better services.
- We work with the NHS to get axial SpA identified and diagnosed quickly. We're determined that everyone receives effective care.
- We make sure people with axial SpA get the latest information and the support they need to tackle living with the condition.
- And we build an active community, online and through our local branches across the UK. We are with them all the way.

Axial SpA may work
silently. But we don't.

Our Information and Support Service

Where to signpost your patients

NASS Helpline

- Helpline is open Monday to Friday between 10 and 4
- Phone, email and social media
- In 2021 responded to 1515 calls and 6000+ emails
- Average call length is 20 minutes
- Help people understand axial SpA, how it's managed and how to navigate the NHS and the benefits system while supporting their emotional needs

0208 741 1515



asknass@nass.co.uk



NASS Branch Network

- Network was 40 years old in 2021 and we have 80+ branches
- Offer regular physiotherapy and hydrotherapy led by qualified physiotherapists
- Physical benefits include improved mobility and flexibility and reduced stiffness
- Offer a place to seek advice and support from professionals and peers
- They are a place where friendships are built



NASS Guides and AS News

- Distribute 40,000+ guides a year
- Many via rheumatology departments
- Updated in 2022
- AS News – Members magazine posted twice a year

Download

<https://nass.co.uk/resources/>

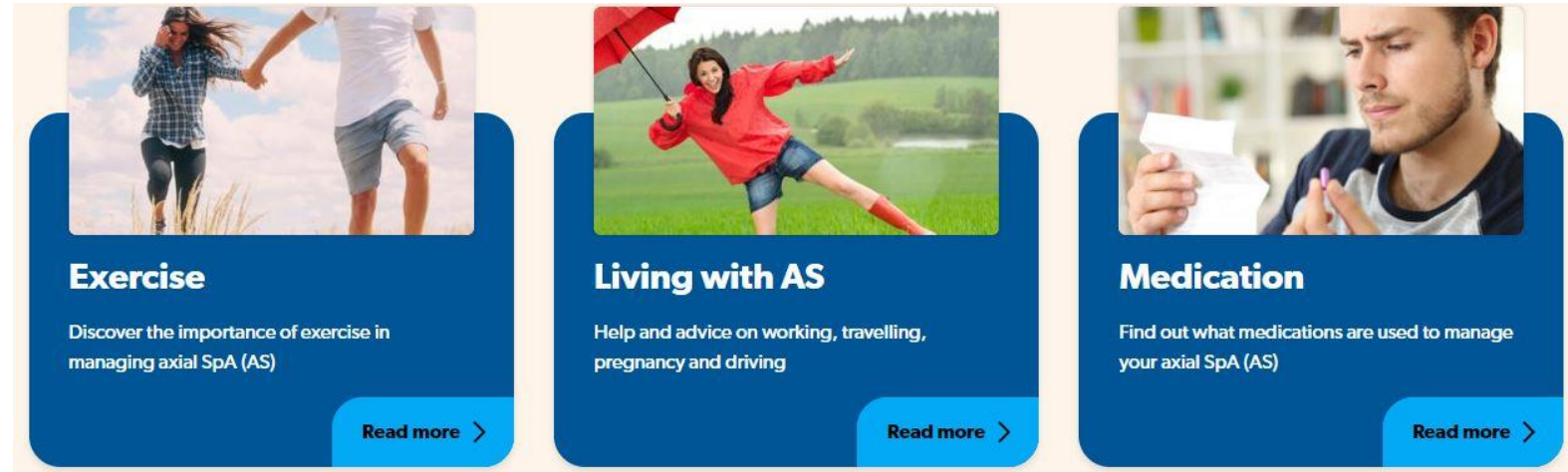
Order

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



NASS website

- About axial SpA
- Medication
- Exercise
- Living with axial SpA
- My AS My Life
- COVID-19 information



Self-Management programme 2020 -2022

My AS, My Life

- Want to reduce isolation and help people understand and self manage their axial SpA
- Between March 20 and end Feb 22, ran 74 Facebook Live sessions
- Cover exercise, axial SpA in depth, research and wellbeing
- Videos uploaded to YouTube and My AS, My Life page with extra resources
- 180,000+ views



Dealing with anxiety

Dave Smithson, Director of Operations at Anxiety UK, shares his top advice for managing anxiety

[Watch the video >](#)

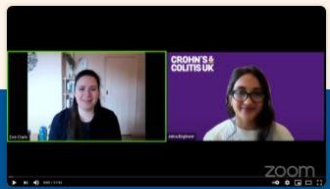
Anxiety UK

For advice, support and Helpline information, visit the Anxiety UK website

[Visit the website >](#)

Read more about managing anxiety

Visit our page dedicated to helping you deal with anxiety, including further resources and links

[Visit the page >](#)


How can axial SpA (AS) be linked to the gut?

Learn more about inflammatory bowel disease

[Watch the video >](#)

Crohn's and Colitis UK

Visit the Crohn's and Colitis UK website to learn more

[Visit the website >](#)

Axial SpA (AS) and the gut

Watch our interview with Microbiologist, Professor Julian Marchesi, who discusses the gut bacteria and how it can affect our health

[Watch the video >](#)

Would you like to run a session?

Self-Management Programme

Pilot self-management sessions

Wanted to help people build the skills and confidence to take control of their axial SpA

Funded by Postcode Neighbourhood Trust to run 10 pilot sessions

- initial session covered pain, flares and fatigue

- attendees decided what they would like to cover in follow up sessions

- 98% said it was helpful to meet and share experiences with others

- 83% felt less isolated

- 73% felt more confident about approaching their rheumatology team

- 81% felt they had more ways to manage pain

- 75% felt more confident about managing flares

Funding allowed us to run 18+ further sessions during 2021-2022

Act on Axial SpA

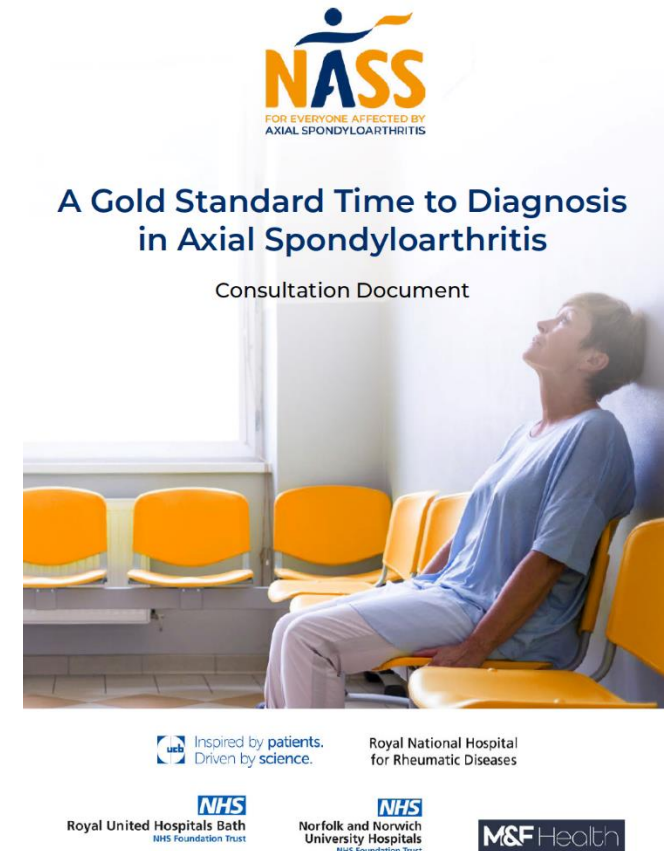
A Gold Standard Time to Diagnosis

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

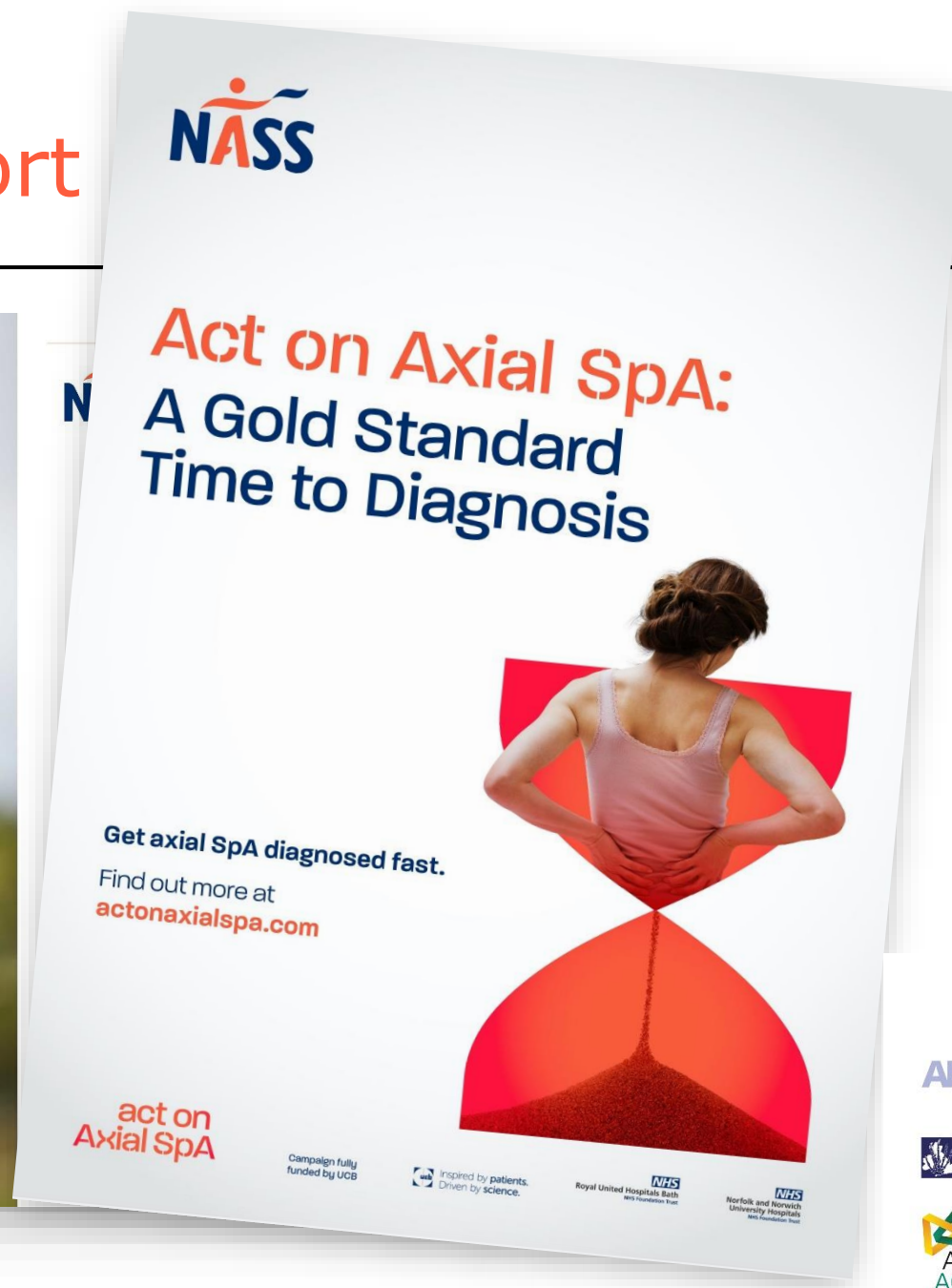
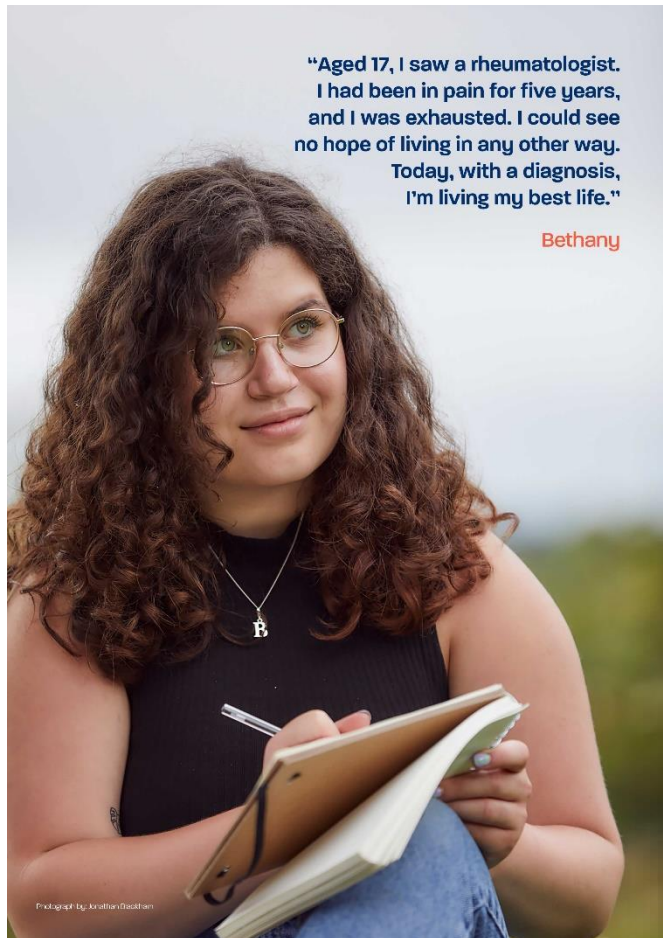
Consultation process

Launched at the APPG in July 2020

- Consultation: n. 202 responses, July-August 2020
- Workshop on public awareness campaign, March 2021
- Stakeholder engagement on proposal for primary care clinical champions programme, March 2021
- Consensus development workshop, May 2021



Our flagship report





All-Party Parliamentary Group for
Axial Spondyloarthritis



British Society of
Skeletal Radiologists



British Society for SpondyloArthritis



The Primary Care
Rheumatology and
Musculoskeletal
Medicine Society



The Royal College of
Chiropractors



act on Axial SpA

June 22, 2021

[Actonaxialspa.com](https://actonaxialspa.com)

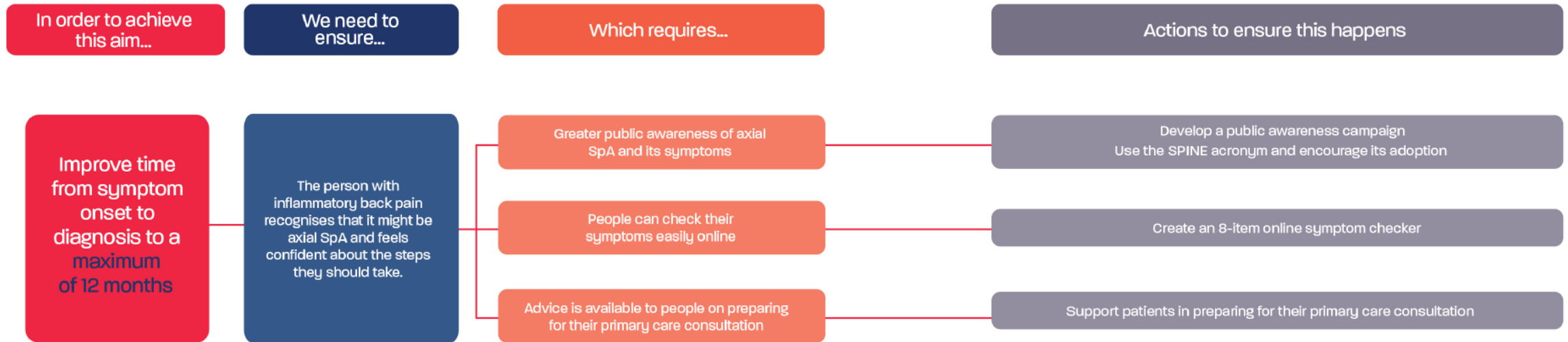
The website will become the largest resource in the world on axial SpA diagnosis: providing information, support, research, best practice, quality improvement tools, case studies



Axial SpA
works silently.
We don't.

Improving public understanding of axial SpA

and empowering people to take action





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

Check the symptoms. It could be axial SpA.
See your GP without delay.

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

act on
Axial SpA



Campaign fully
funded by UCB.

 Inspired by patients.
Driven by science.


Royal United Hospitals Bath
NHS Foundation Trust


Norfolk and Norwich
University Hospitals
NHS Foundation Trust



Could your persistent back pain be axial SpA?

Serious and irreversible damage can be done with each passing year.
See your GP without delay.

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

act on
Axial SpA

www.nass.co.uk



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NHS Foundation Trust

Symptoms starting slowly


Pain in the lower back

Improves with movement

Night time waking

Early onset (under 40)

8-point online symptom checker

 For Healthcare Professionals For The General Public News


Search

Symptoms Checker

Home > Symptoms Checker

Want to know if you should speak to your GP? Answer a few simple questions to find out whether your persistent back pain could be axial SpA.

act on Axial SpA




QUESTION 1 OF 8:

Did your back pain start before the age of 40?

☒ Yes ☐ No

Next >



- Combining Seiper et al. 2009, Rudalweit et al, 2006 and Calin et al. 1977

8-point online symptom checker

Your SYMPTOM CHECKER QUESTIONNAIRE results



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

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).

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 healthcare professional.

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. Feldtkeller E, Rudwaleit M, Zeidler H. Easy probability estimation of the diagnosis of early axial spondyloarthritis by summing up scores. *Rheumatology (Oxford)*. 2013 Sep;52(9):1648-50. doi: 10.1093/rheumatology/ket176. Epub 2013 May 16. PMID: 23681397
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.

Campaign fully funded by UCB

Inspired by patients. Driven by science.

Royal United Hospitals Bath NHS Foundation Trust

Norfolk and Norwich University Hospitals NHS Foundation Trust

act on
Axial SpA



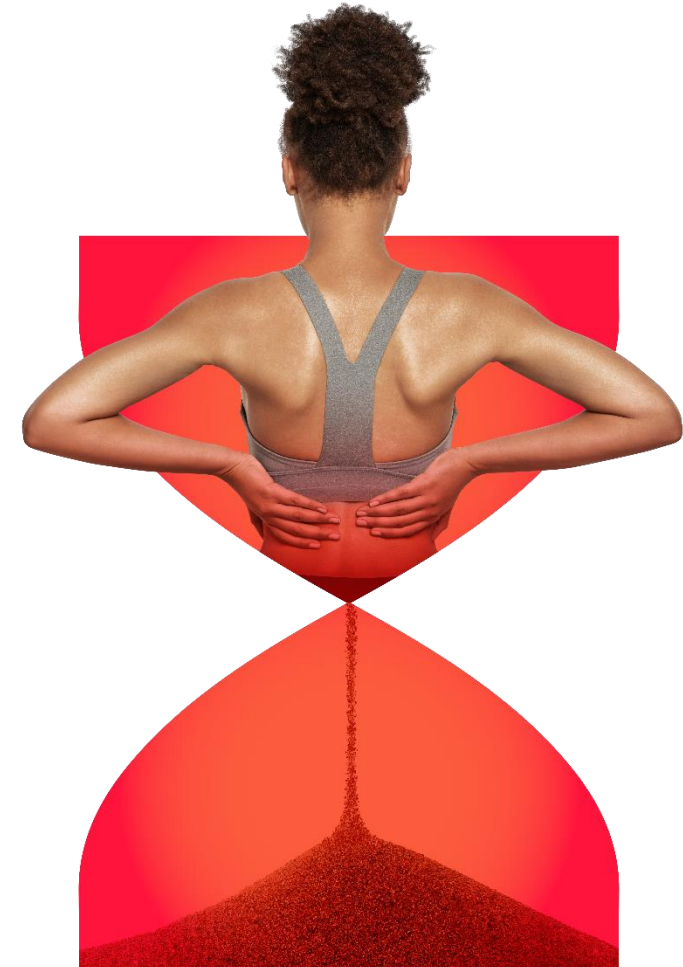
Preparing for your GP appointment

Dr Daniel Murphy's Top Tips: How to prepare for a GP appointment if you think you may have axial SpA

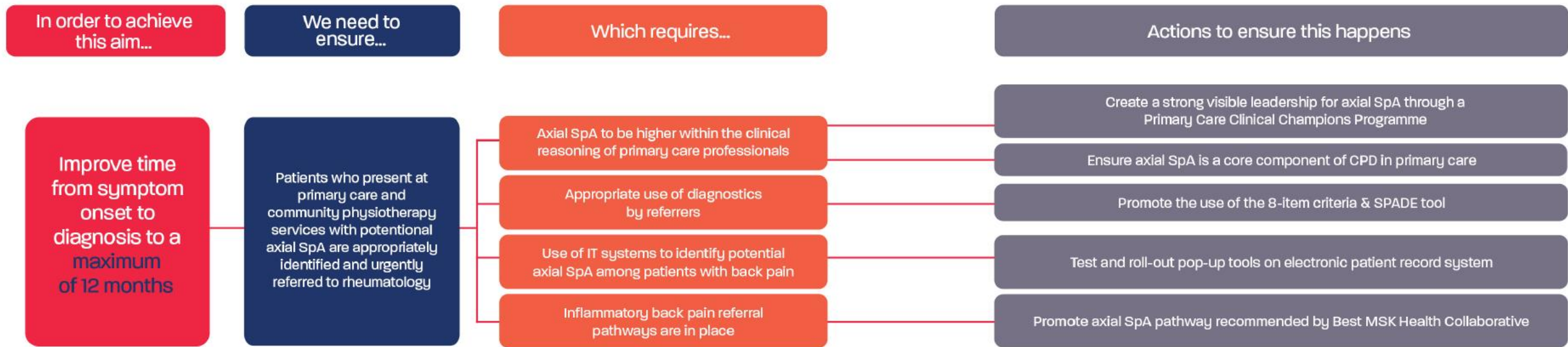
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It's not unusual for people with axial spondyloarthritis to say they didn't feel equipped for their initial conversation with their GP about symptoms. It can be overwhelming, or upsetting trying to explain and convey your concerns – particularly during such a short appointment.



Ensuring early identification within primary care and urgent referral to rheumatology



Primary care

- Create and support a cadre of axial SpA primary care clinical champions
- Axial SpA as a core component of CPD
 - Feed into HEE's Primary and Community Care Training Hubs
 - Promote actonaxialspa.com
- Promote projects using electronic patient record system to identify appropriate patients early

Primary Care

Could you be a Champion in Primary Care?

- Leadership development and training in using Quality Improvement methods
- Support to implement improvement projects
- Work together in a national learning network; active within the wider healthcare system
- Co-produce a body of knowledge, methods and tools
- Applications close 4 May 2022
- Email **goldstandard@nass.co.uk** to find out how to apply

Thank you
Any questions?