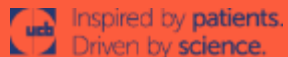




Act on Axial SpA : A Gold Standard Time to Diagnosis

18 months into for Act on axial SpA - A Gold Standard Time to Diagnosis, the story so far and what's next.

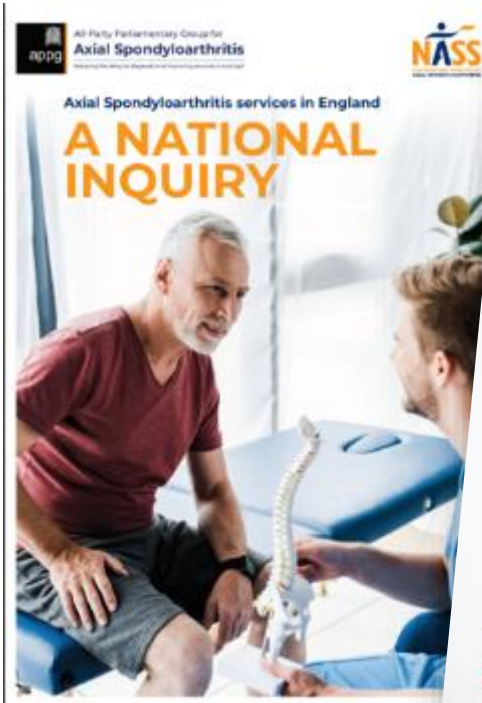
Campaign fully
funded by UCB



act on
Axial SpA

What is the Act on Axial SpA programme?

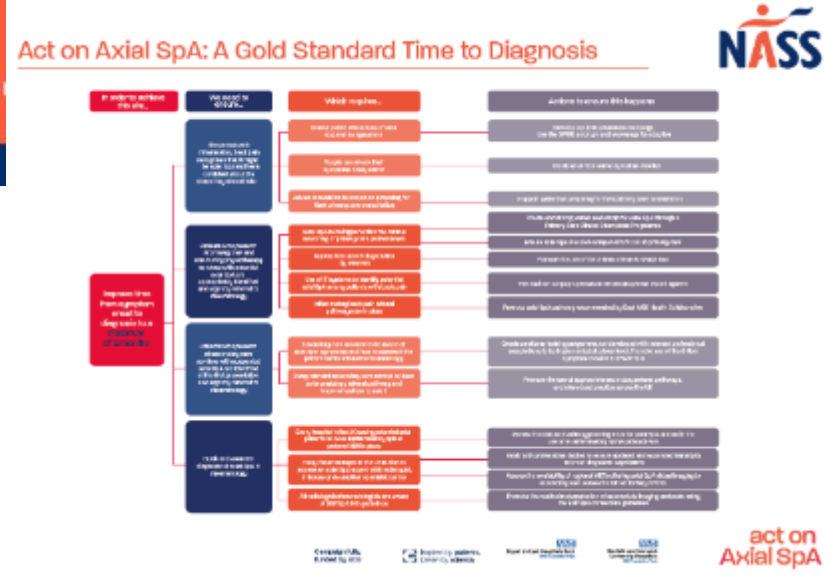
Act on Axial SpA is our vehicle for delivering our Gold Standard ambitions.



Follow the person, from symptom onset to diagnosis in rheumatology

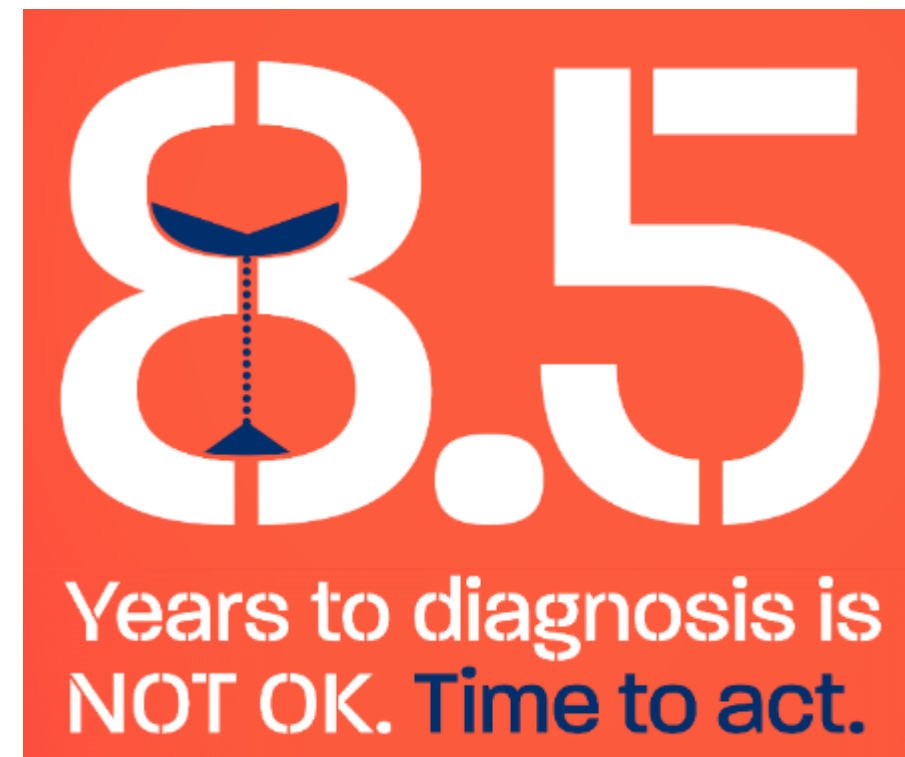
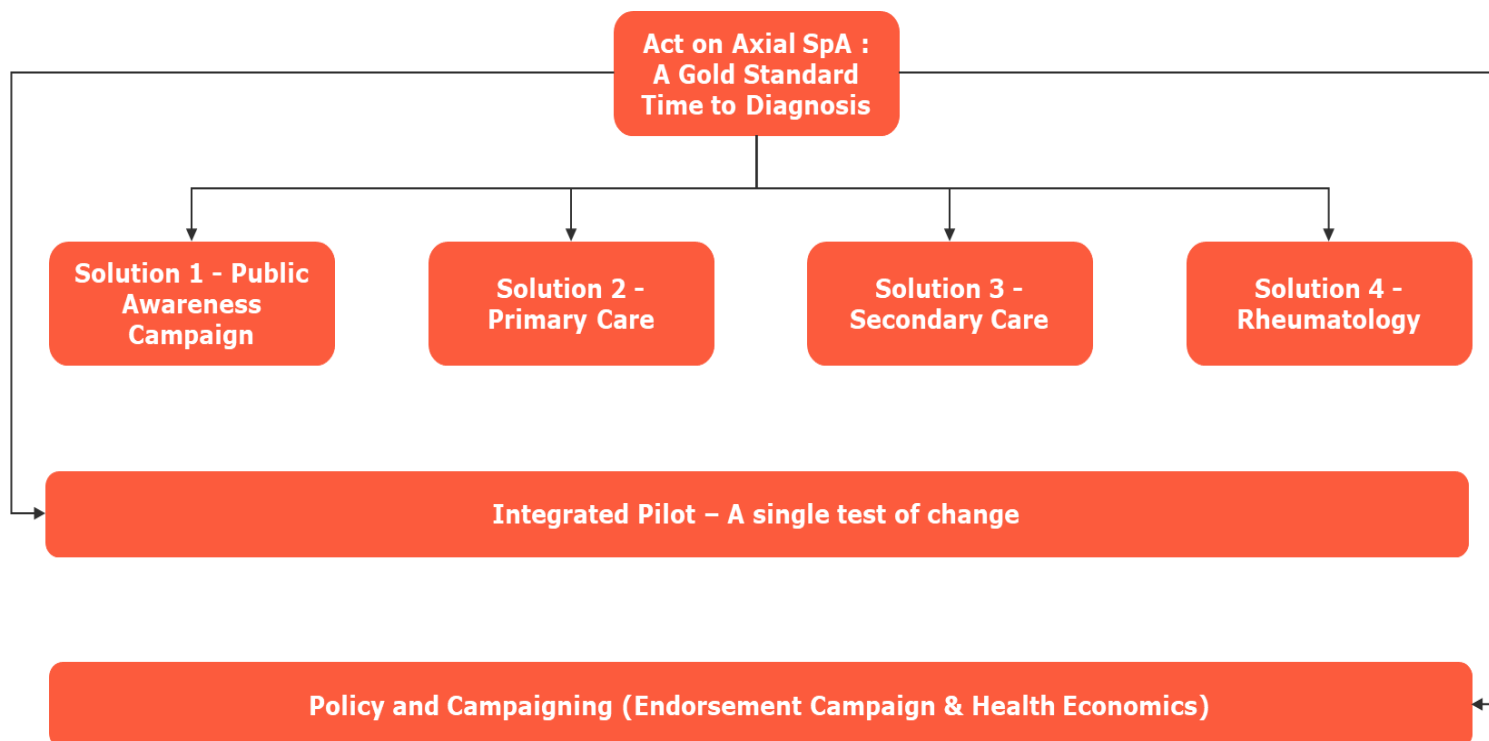
NASS

- 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 – Programme Overview

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



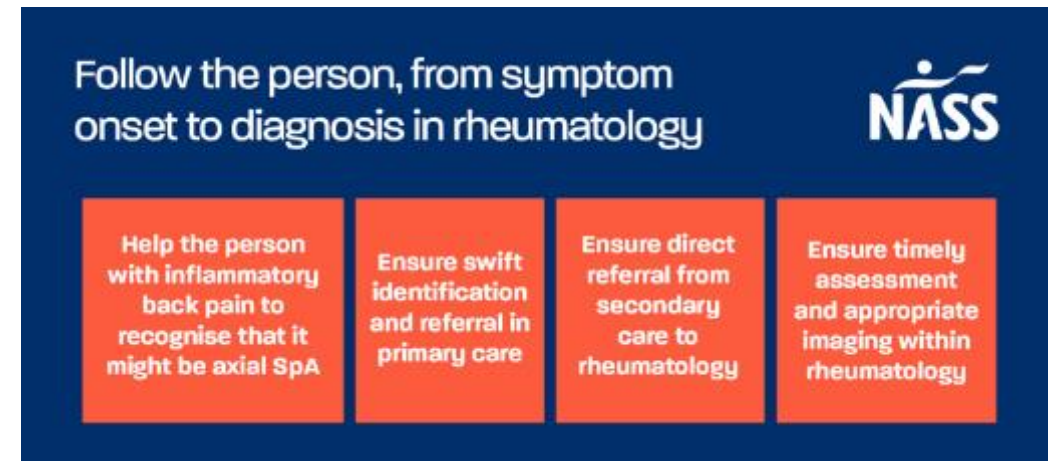
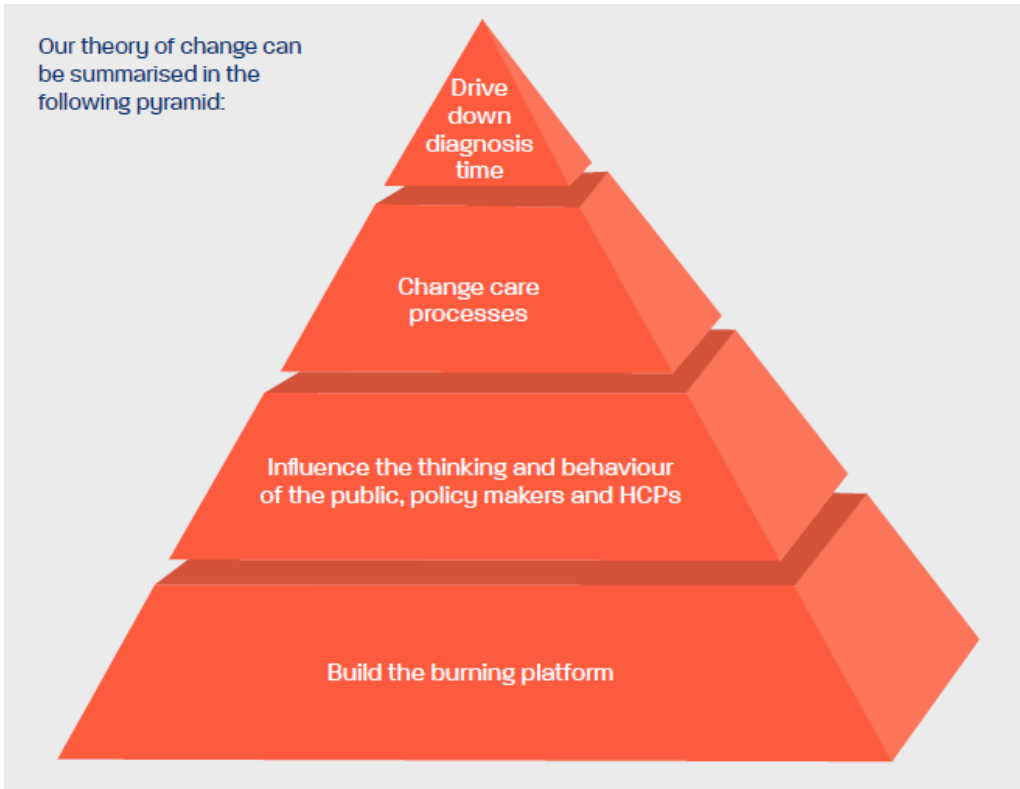
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Creating a social movement and our theory of change

- 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



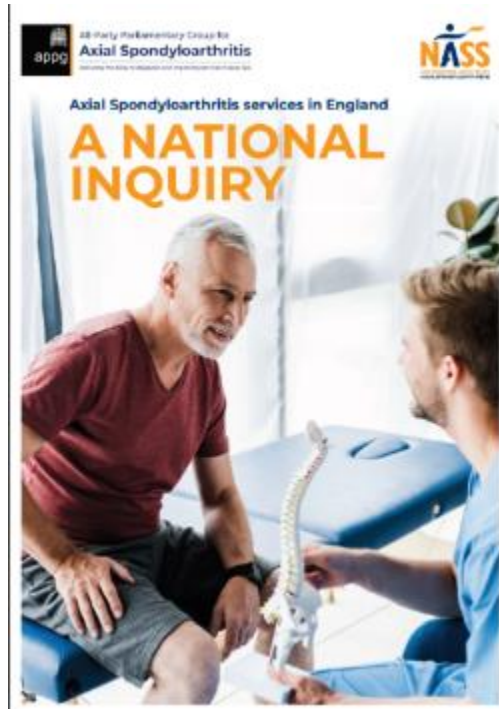
Building the Burning Platform - APPG

Creation of the
APPG



All-Party Parliamentary Group for
Axial Spondyloarthritis

Reducing the delay to diagnosis and improving services in axial SpA

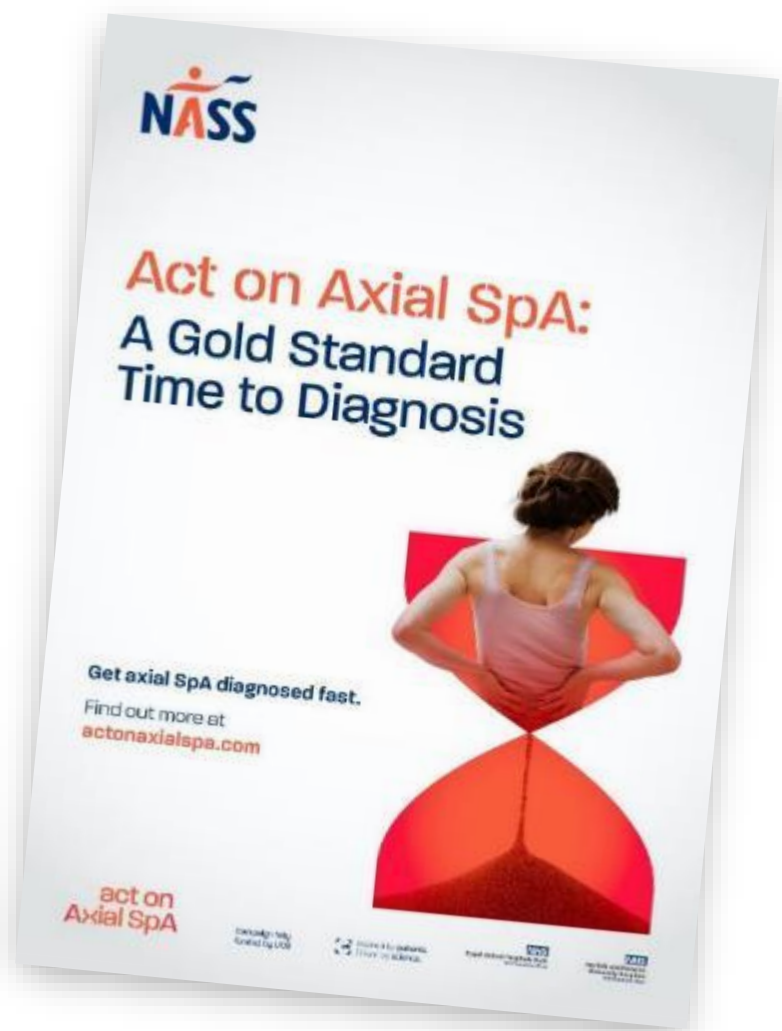


APPG inquiry on
axial SPA and NG65

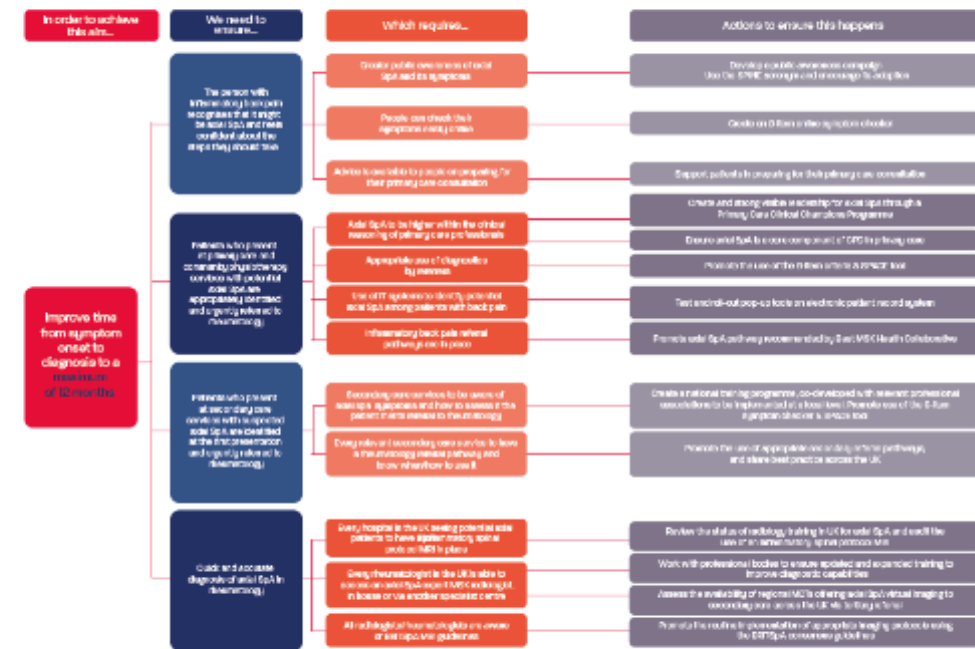
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Building the Burning Platform – Gold Standard

Creating the Gold Standard time to diagnosis and route map



Act on Axial SpA: A Gold Standard Time to Diagnosis

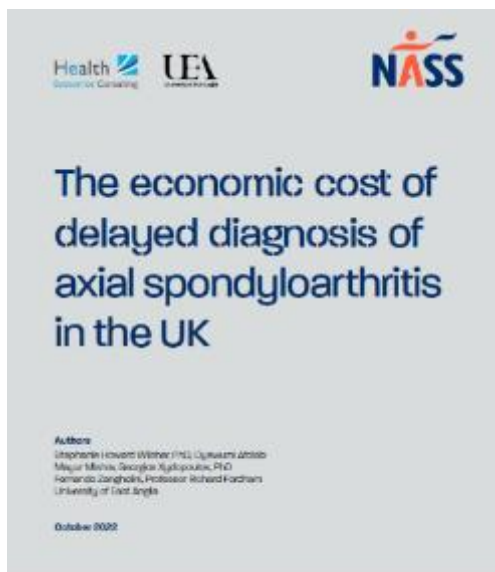


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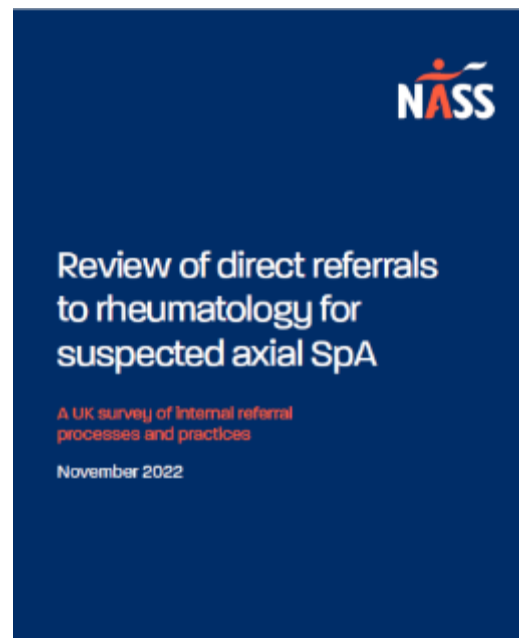
Building the Burning Platform – Research

Economic modelling on the full economic cost of delayed diagnosis



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A FOI of all UK trusts & Health Boards on internal direct referrals



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Patient values research – diagnosis & treatment



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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

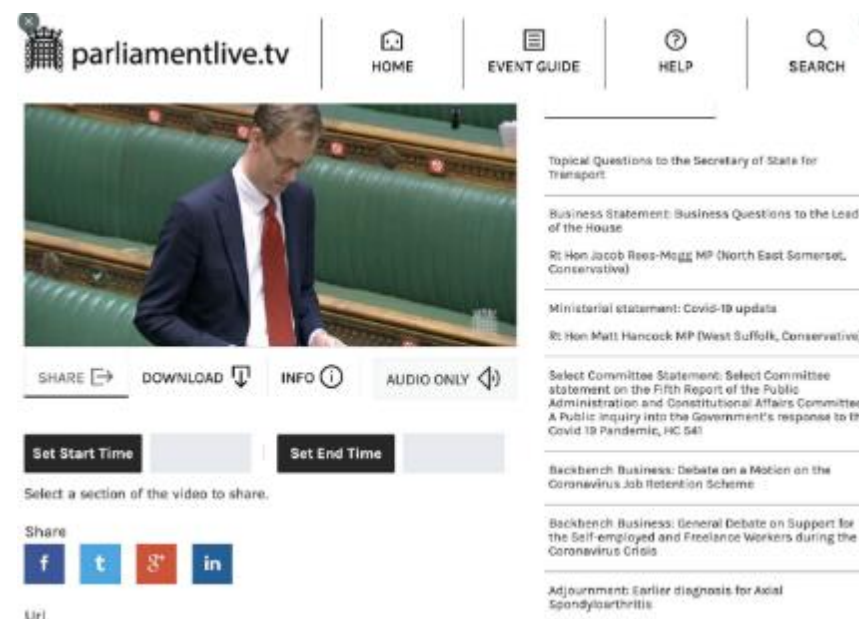
Influencing the thinking and behaviour of the public, policy makers and health care professionals



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

Reducing the delay to diagnosis and improving services in axial SpA

Making the case in Parliament



parliamentlive.tv

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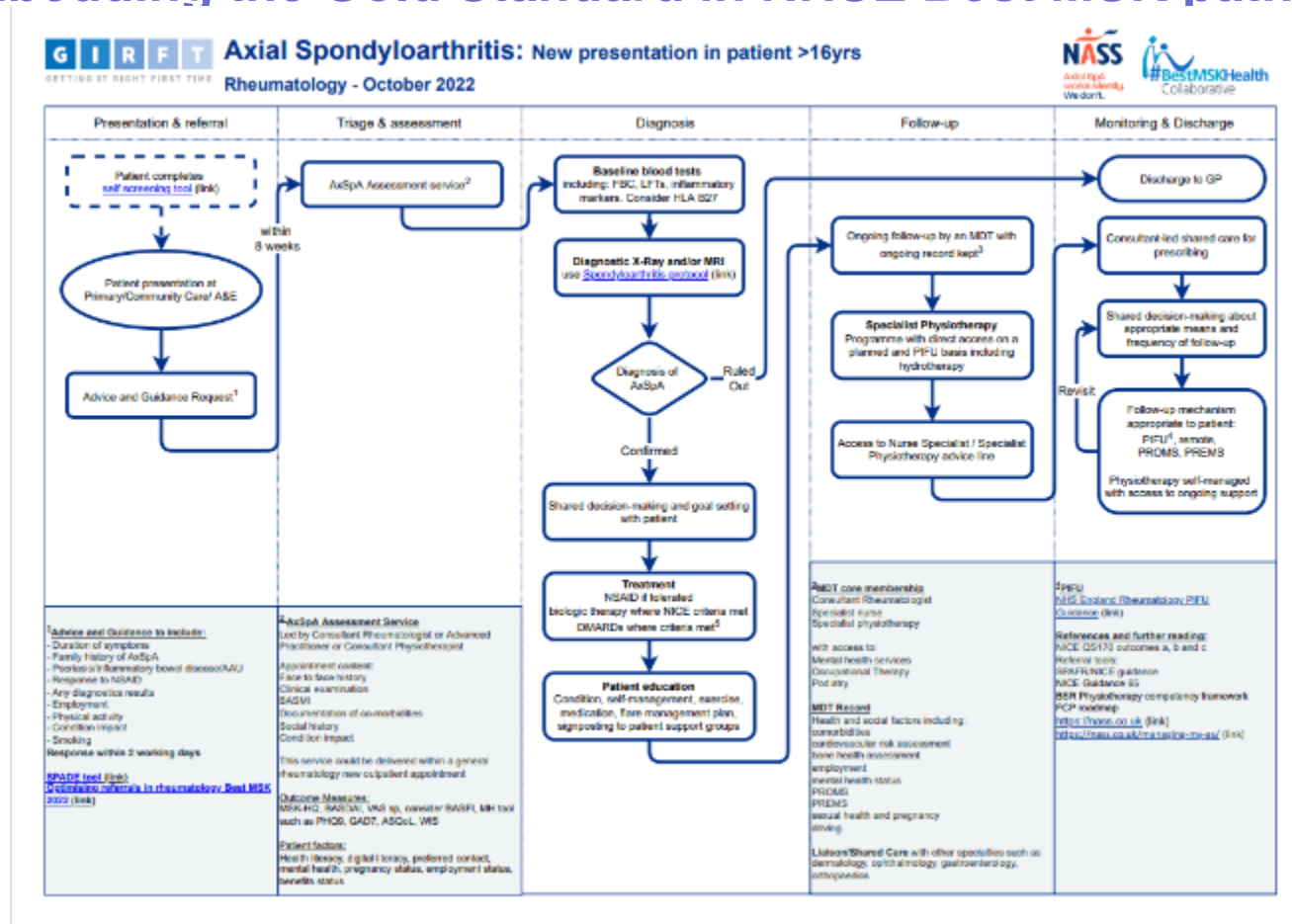
Uri

- 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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Axial SpA

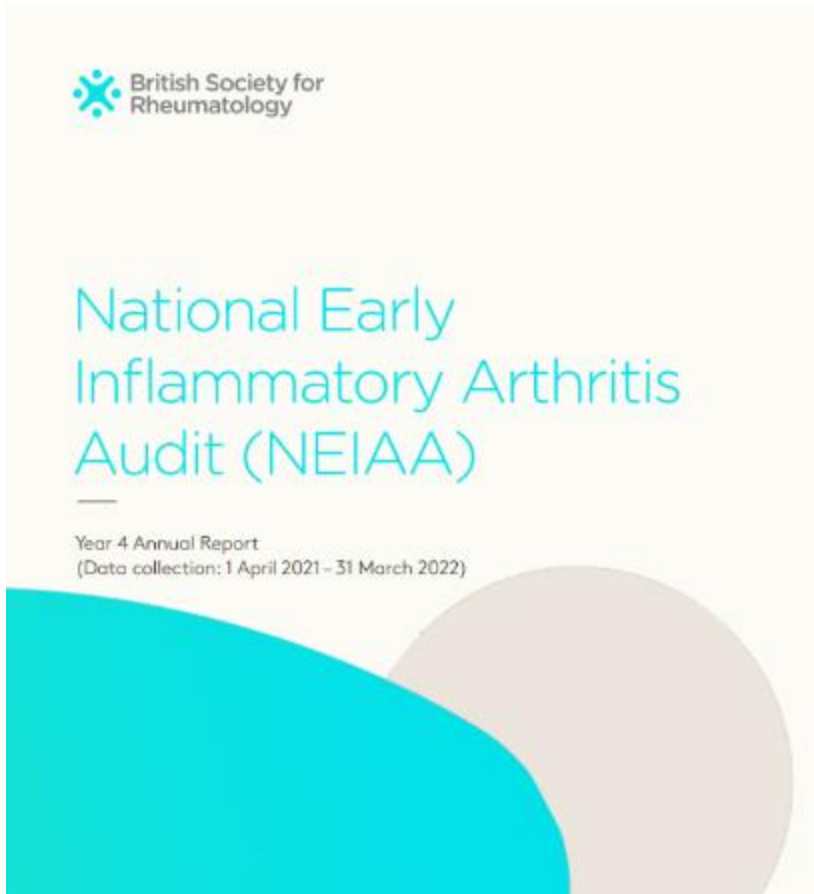
Influencing the thinking and behaviour of the public, policy makers and health care professionals

Embedding the Gold Standard in NHSE Best MSK pathway



Influencing the thinking and behaviour of the public, policy makers and health care professionals

Improving data collection on time to diagnosis



8. When did you first experience your inflammatory back pain symptoms? *

Please input date (M/d/yyyy)

9. When did you first see your GP with regards to this problem? *

Please input date (M/d/yyyy)

10. When were you referred by a GP or another health care professional to a rheumatologist? *

Please input date (M/d/yyyy)

11. What was the date of your first appointment with a rheumatologist? *

Please input date (M/d/yyyy)

12. Which health care professionals did you see prior to your axial spondyloarthritis diagnosis and how many times did you see them?

	1-5 times	5-10 times	10+ times
GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physiotherapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Osteopath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chiropractor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Influencing the thinking and behaviour of the public, policy makers and health care professionals

Influencing best practice in axial SpA services



Case study

The South West Axial Spondyloarthritis Group (SWAG), Dr Tom Williams, Great Western Hospitals, on behalf of SWAG



Case study

Sian Bamford, Advanced practice physiotherapist & Professor Hasan Tahir, Consultant rheumatologist, Royal Free London NHS Foundation Trust



Presenting the Gold Standard to the wider rheumatology community



Influencing the thinking and behaviour of the public, policy makers and health care professionals

Our public awareness campaign activity



Our public awareness campaign in numbers



Our campaign social media content has touched people **1.9 million** times



Our campaign videos have been viewed **1,002,376** times



Our media coverage has touched people **206 million** times with campaign messages



23,008 symptom checker visits



8,772 symptom checker completions


We've created conversations with people commenting on our content or people reacting (comments, likes or shares) on the content **7,798** times

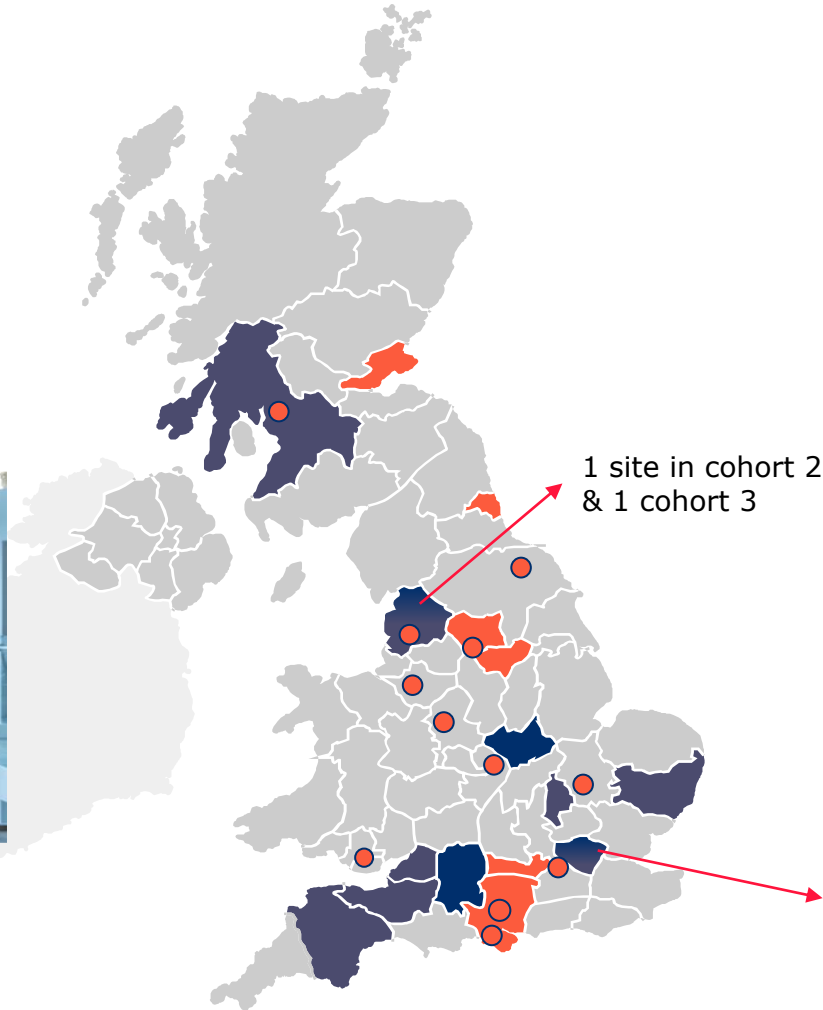


104,819 hits on actonaxialspa.com

Changing Care Processes

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

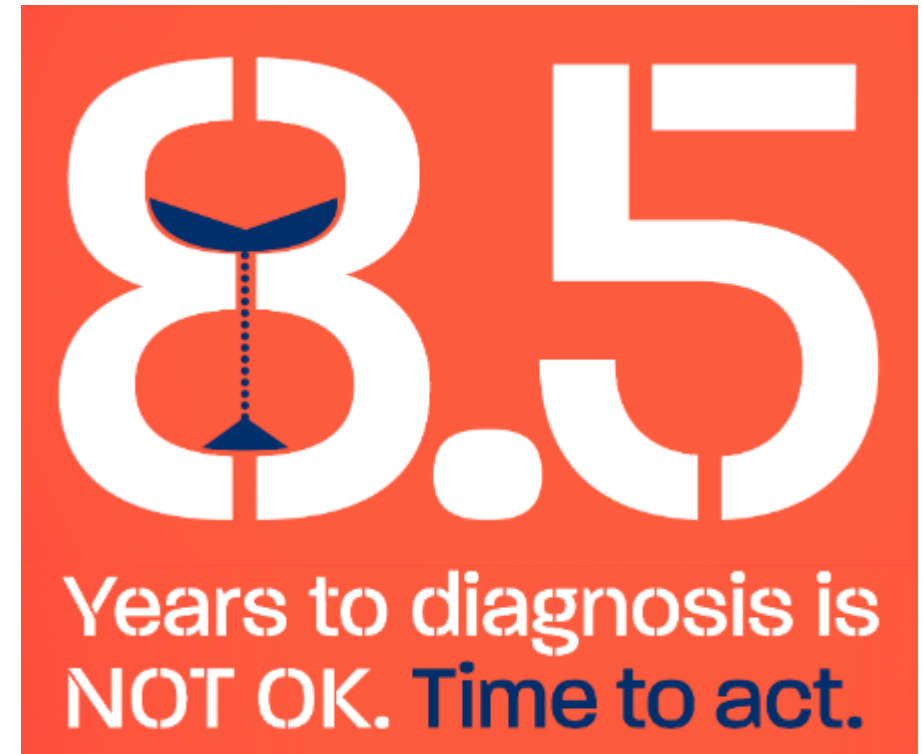


A2E Cohort 3
Cohort 3 participant rheumatology
department / hospital

2 sites in cohort 2
& 1 cohort 3

Reducing the delay to diagnosis - conclusion

- We are building a social movement for change.
- We are influencing the thinking and behaviour across rheumatology.
- We are starting to see tangible changes in care processes.
- We have more work to do to translate this into the achievement of a one year time to diagnosis.



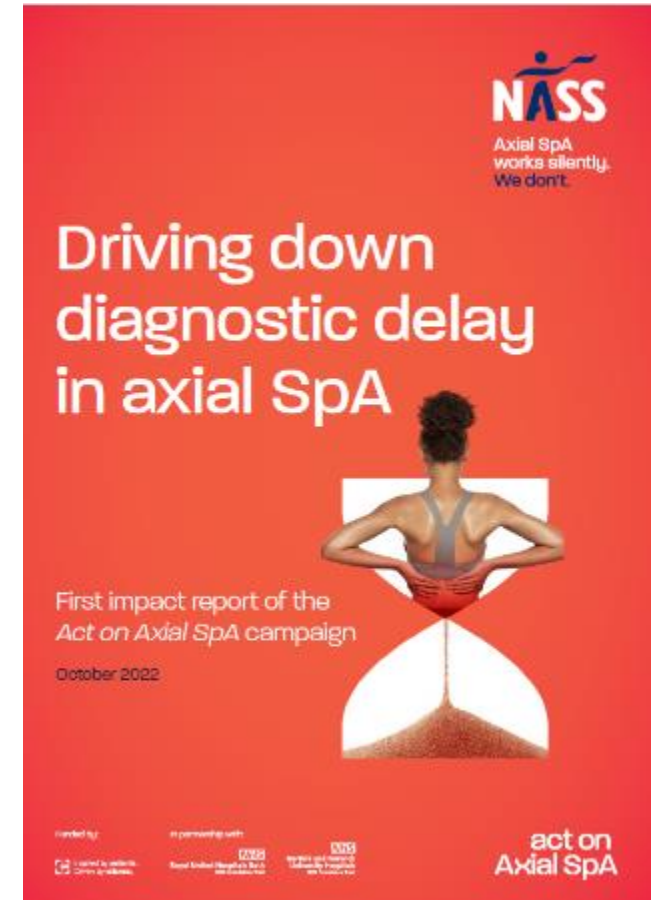
How to find out more


- Go to www.actonaxialspa.com and read our first *Act on Axial SpA* campaign impact report.





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

www.nass.co.uk









Axial SpA works silently. We don't.

Driving down diagnostic delay in axial SpA



First impact report of the *Act on Axial SpA* campaign
October 2022

Funded by:  
in partnership with:   
act on Axial SpA

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