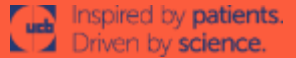




# Act on Axial SpA : A Gold Standard Time to Diagnosis

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

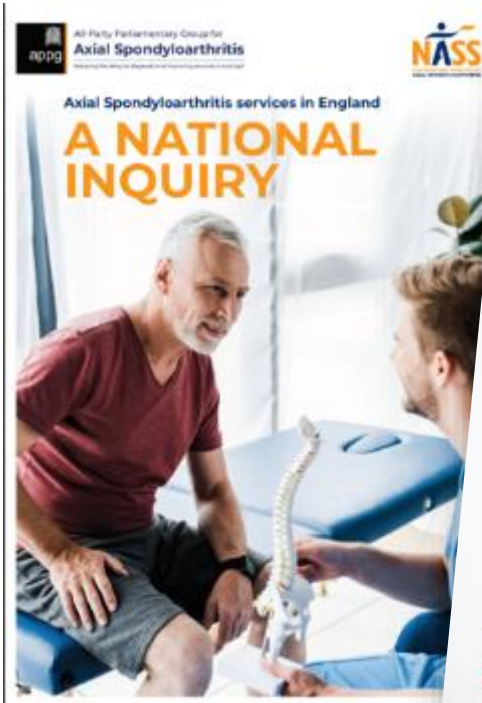
Campaign fully funded by UCB



act on  
Axial SpA

# What is the Act on Axial SpA programme?

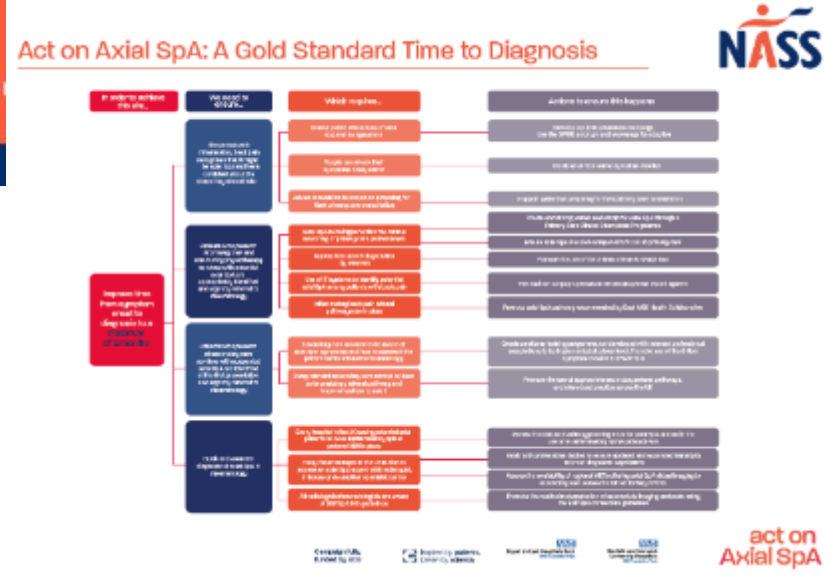
Act on Axial SpA is our vehicle for delivering our Gold Standard ambitions.



Follow the person, from symptom onset to diagnosis in rheumatology

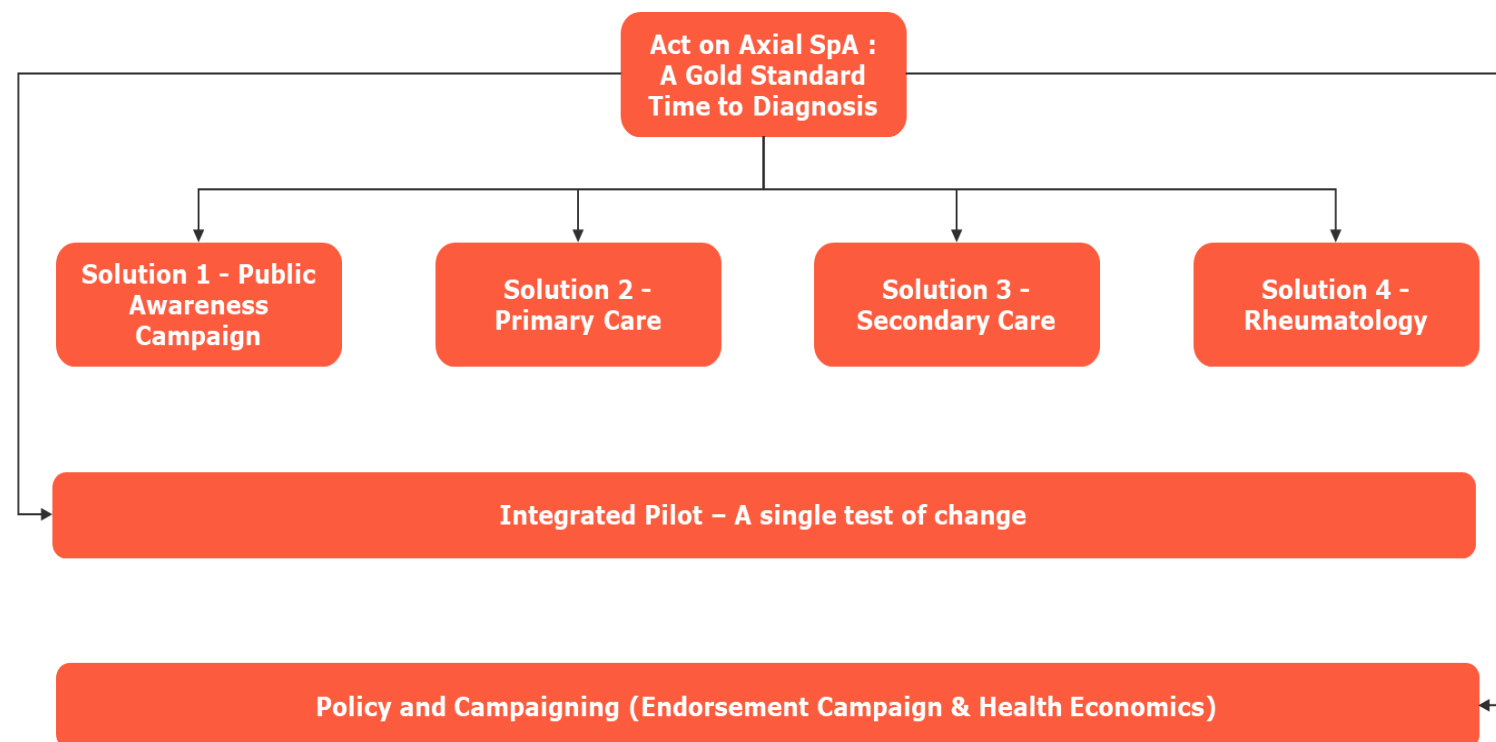
**NASS**

- 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



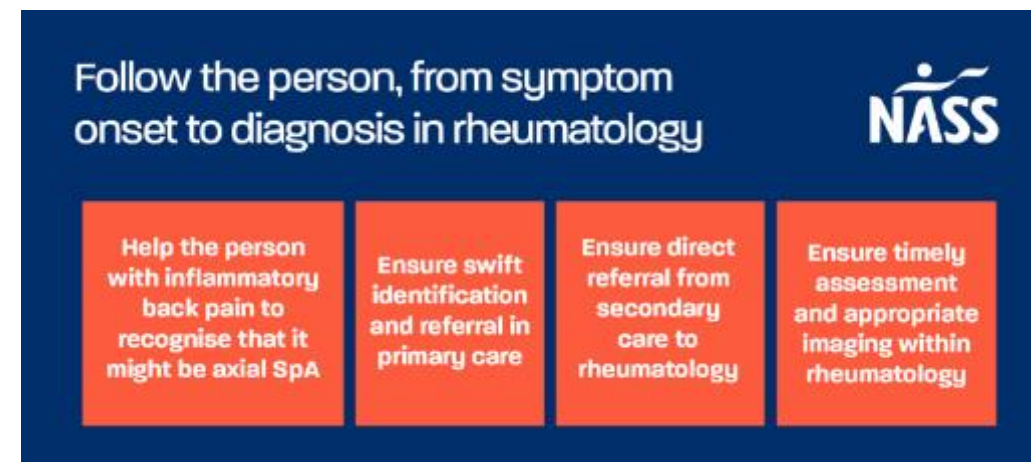
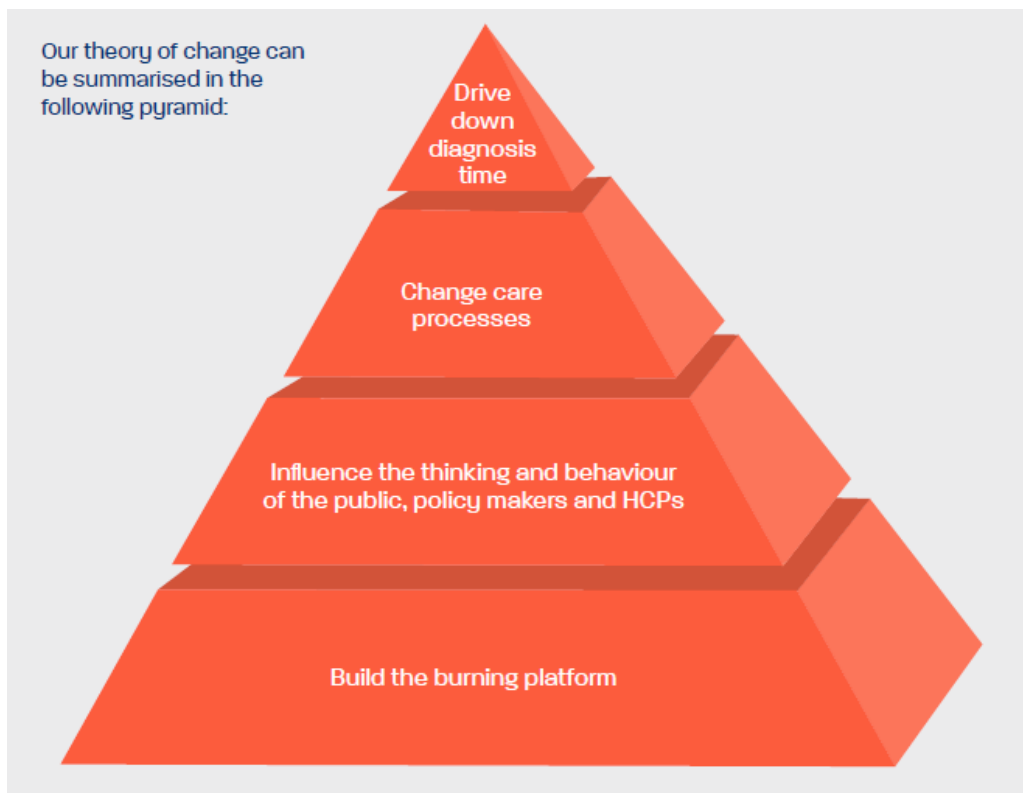
act on  
Axial SpA

# 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



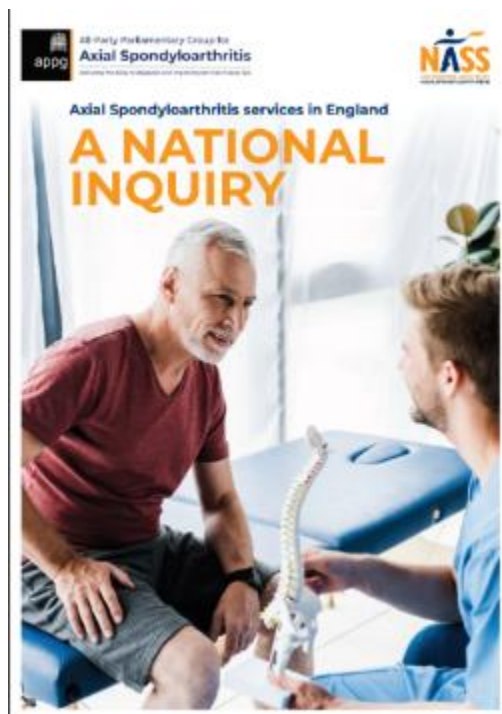
# Building the Burning Platform - APPG

Creation of the  
APPG



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

Reducing the delay to diagnosis and improving services in axial SpA

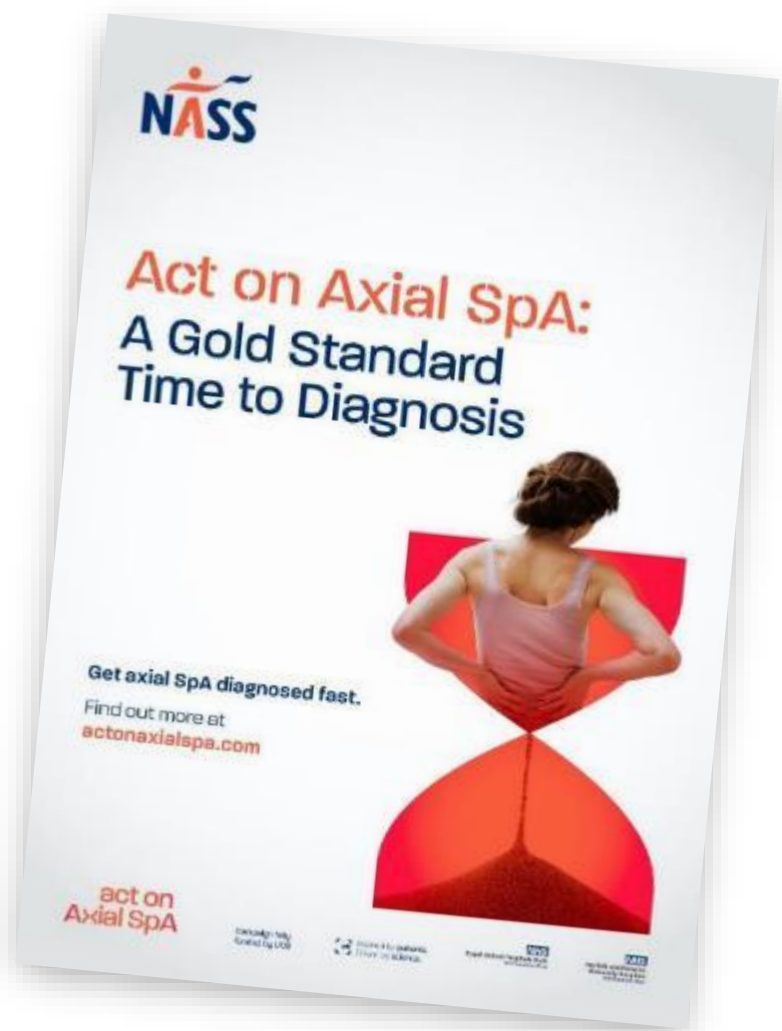


APPG inquiry on  
axial SPA and NG65

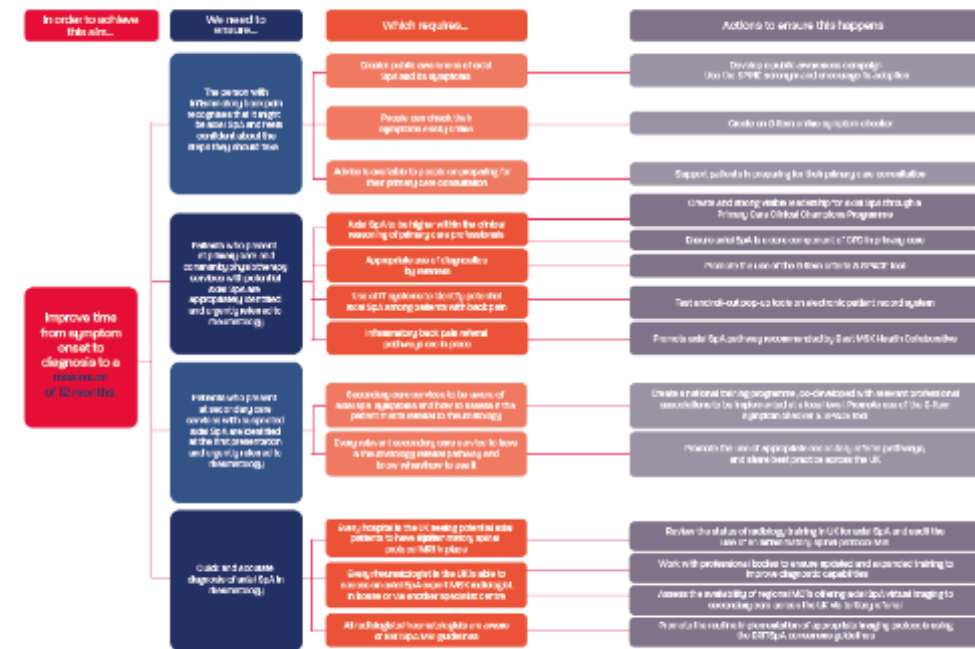
act on  
Axial SpA

# 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



act on Axial SpA

act on Axial SpA

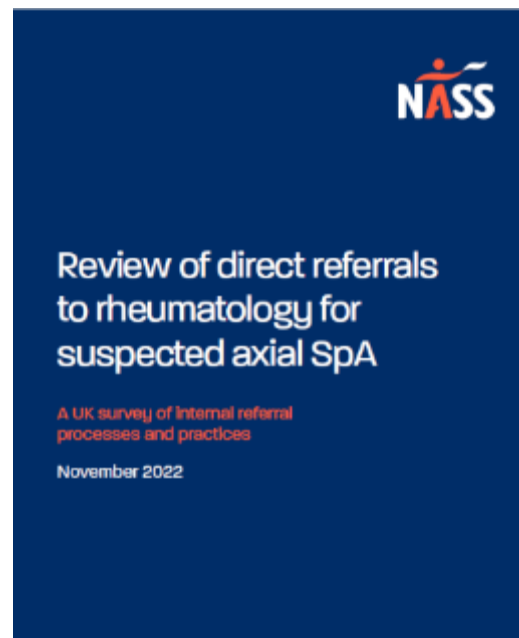
# Building the Burning Platform – Research

Economic modelling on the full economic cost of delayed diagnosis



act on Axial SpA

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



act on Axial SpA

Patient values research – diagnosis & treatment



act on Axial SpA

act on Axial SpA

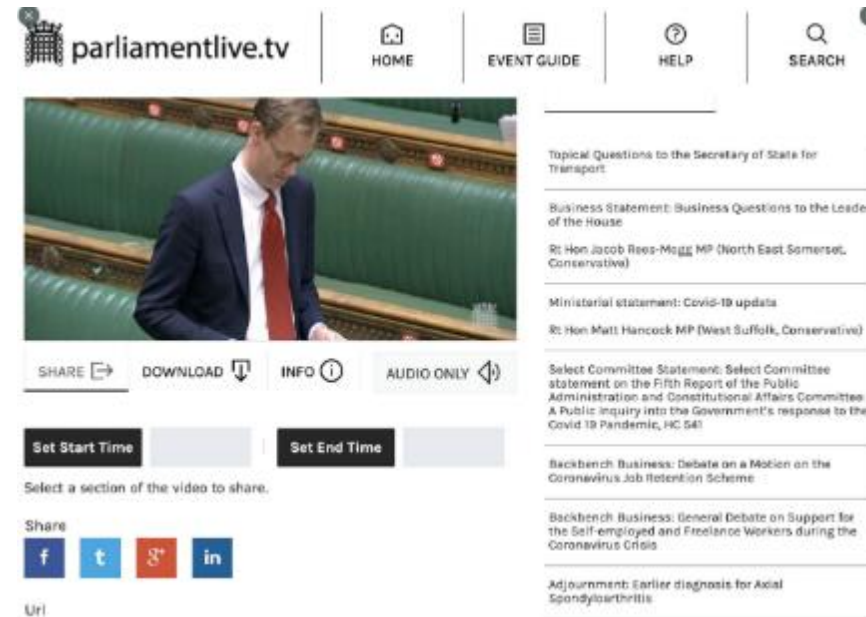
# Influencing the thinking and behaviour of the public, policy makers and health care professionals



## 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

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

f t g+ in

Uri

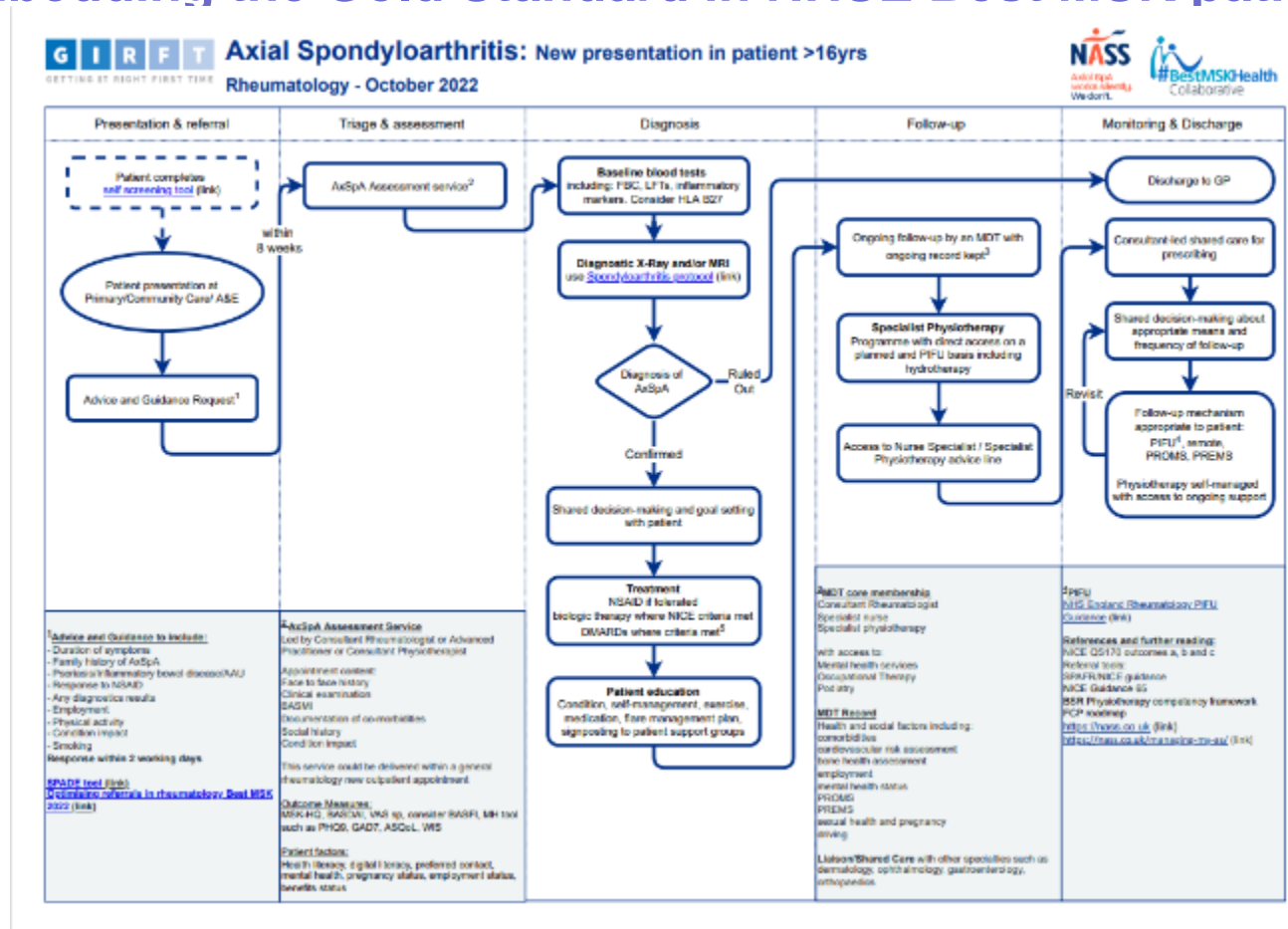
- Topical Questions to the Secretary of State for Transport
- Business Statement: Business Questions to the Leader of the House
- Rt Hon Jacob Rees-Mogg MP (North East Somerset, Conservative)
- Ministerial statement: Covid-19 update
- Rt Hon Matt Hancock MP (West Suffolk, Conservative)
- Select Committee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

act on  
Axial SpA



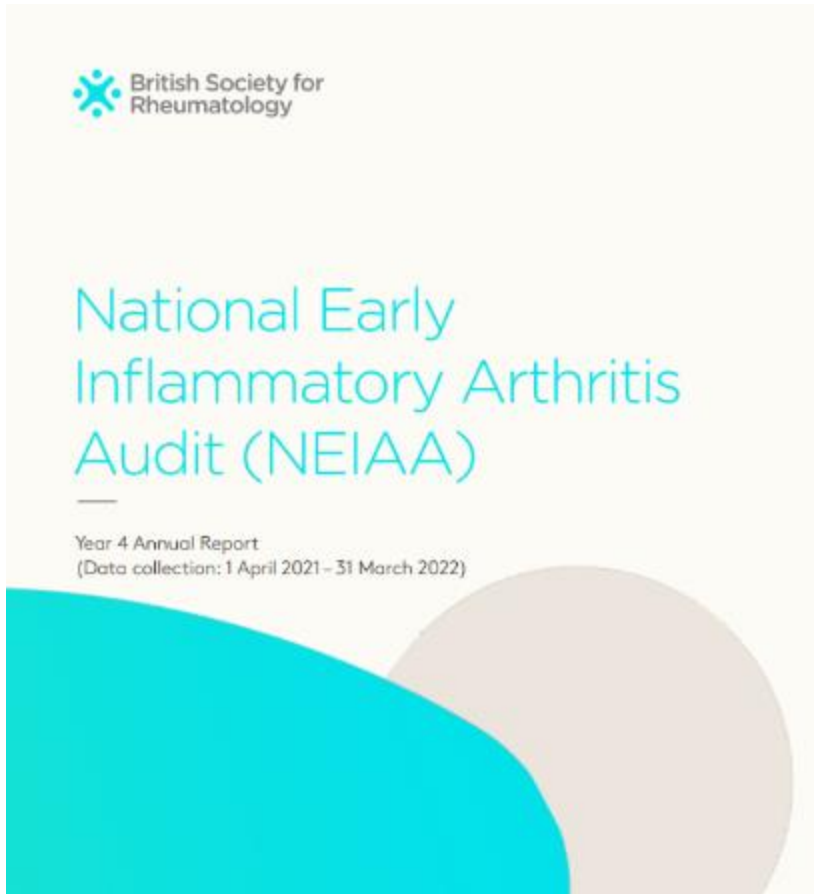
# Influencing the thinking and behaviour of the public, policy makers and health care professionals

## 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"/>

act on  
Axial SpA

# 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

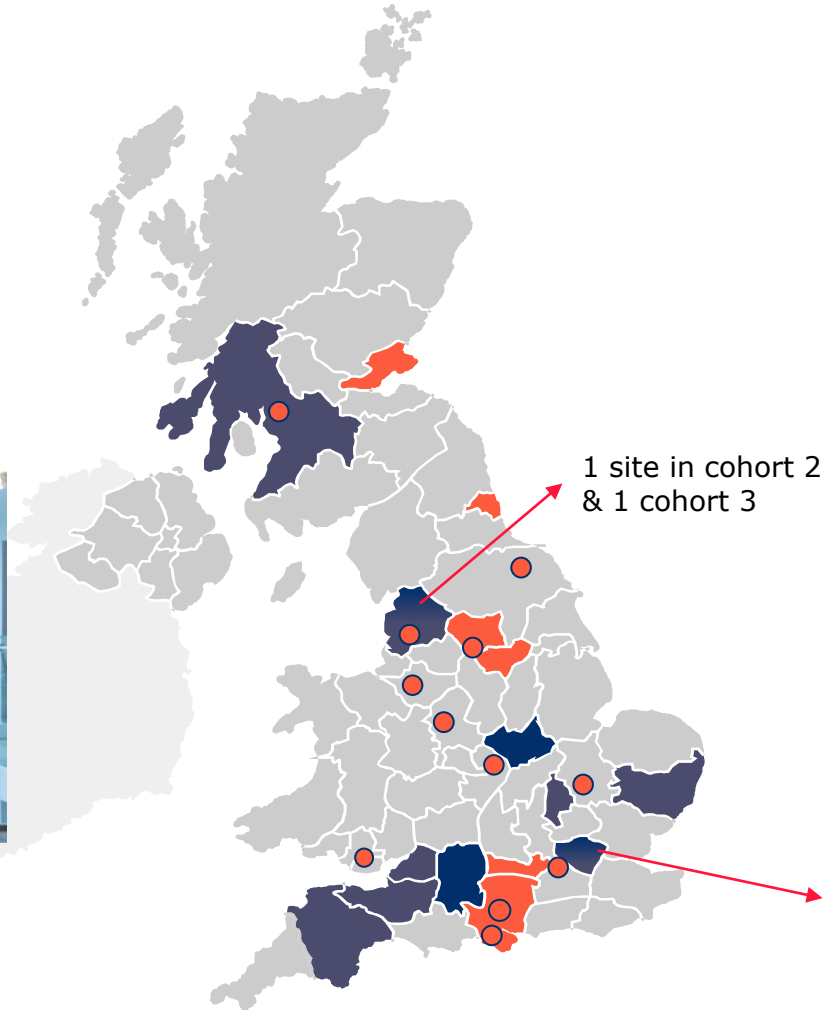


**104,819** hits on [actonaxialspa.com](http://actonaxialspa.com)

# 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

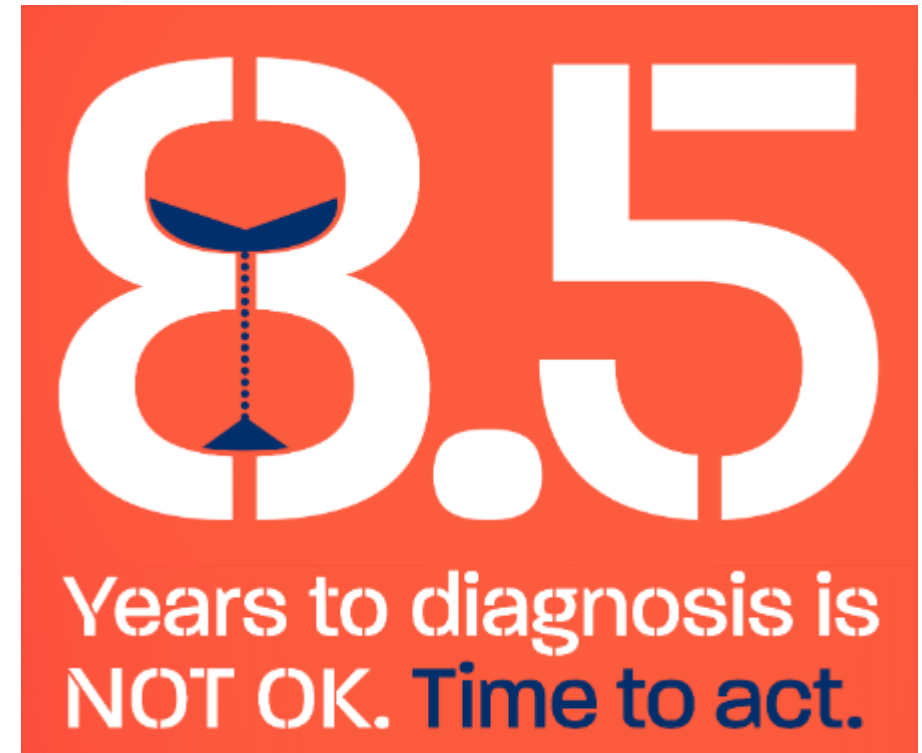


**A2E Cohort 3**  
Cohort 3 participant rheumatology  
department / hospital

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](http://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](http://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

act on  
Axial SpA