

Attendee Briefing

One Year on from the establishment of Integrated Care Systems – how is Axial SpA faring

November 2023

Introduction

This briefing paper has been produced for attendees in advance of the eleventh meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The document sets out key information about the meeting, advice on getting to Parliament and supporting details about the APPG.

Key meeting details

Meeting title: One year on from the establishment of Integrated Care Systems – how is axial SpA faring

Date & Time: Tuesday 14th April 2023 (17:30-19:00)

Venue: Committee Room 9, Committee Corridor, House of Commons, Westminster, London, SW1A 0AA

Key contact information on the day: Simon Whalley (07506 723324) / appgspace@mandfhealth.com or Jill Hamilton (07875 107747) / jill@nass.co.uk

About the meeting

The eleventh meeting of the APPG on Axial SpA, which is organised in partnership with the National Axial Spondyloarthritis Society (NASS), will explore how recently established models of NHS healthcare across England - Integrated Care Systems (ICSs) – are faring with respect to axial SpA.

It has now been more than a year since ICSs were first established across the NHS in England, created with the ambition to improve population health outcomes, address inequalities and help the NHS to support wider socioeconomic improvements in local areas.

Since their inception however, ICSs have faced considerable pressures, grappling with growing care backlogs, funding challenges and ongoing workforce industrial action. As a result of these challenges, progress against the overarching ambitions ICSs were established against has arguably been limited. Indeed, there is a sense that many local areas have had to spend considerable energy on operational ‘fire fighting’, rather than on working towards improving care pathways and supporting better health outcomes for populations.

Against this backdrop, this forthcoming meeting of the Axial SpA APPG will therefore seek to explore the current state of play for local ICSs, and specifically, how the commissioning and delivery of axial SpA care is faring.

We are delighted to feature presentations at the meeting from three expert speakers, who will provide perspectives covering the realities of living with axial SpA and what ‘good’ should look like for care in the new system; how frontline service delivery for axial SpA is changing; and the workings of ICSs and how they can be supported to achieve the best possible outcomes for those affected by axial SpA.

Following the three presentations, attendees will be invited to join a group discussion that will provide an opportunity to reflect on the key themes, and to explore how the APPG and other stakeholders can work effectively with new models of care to help raise the priority of axial SpA and support the needs of local populations.

This group discussion will inform the development of a series of recommendations which will be circulated to attendees following the meeting, and which will also be shared with national and local decision-makers involved in axial SpA care planning and service delivery.

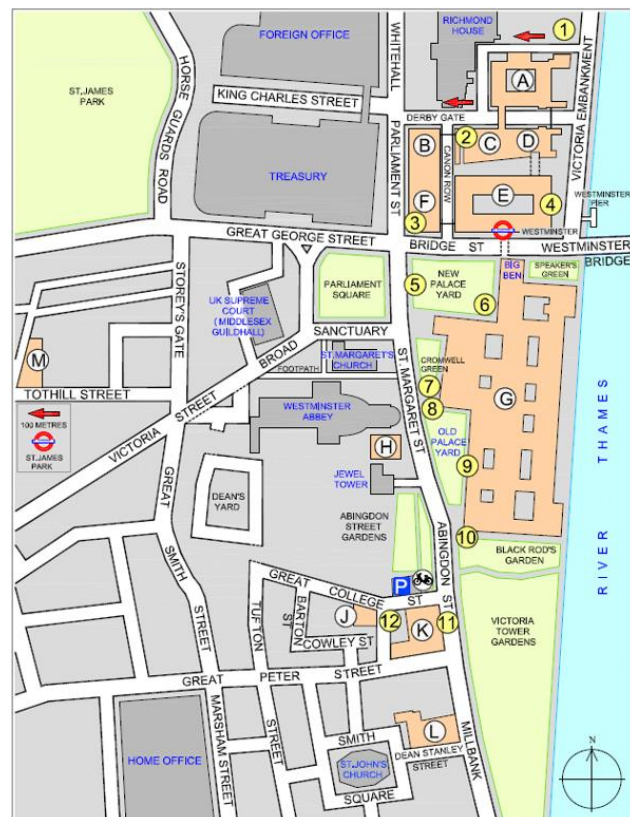
Getting to the meeting and entry timings

This meeting is taking place in Committee Room 9 in the House of Commons. The nearest Underground Station is *Westminster*, which is served by the Jubilee, Circle and District Lines. Upon arrival, you will need to make your way to the Cromwell Green Visitor Entrance (number 7 on the map included below) and pass through the airport-style security.

We would recommend that if you can, you allow a minimum of 30 minutes to clear security, as it can sometimes get very busy. On occasion, it has taken up to an hour to pass through security, although these instances are comparatively rare (and depend entirely on other Parliamentary business taking place that day). In case you do arrive significantly early, there is a café (Jubilee Café) situated just past security, which provides seating and light refreshments.

Once you have passed through security, Parliamentary officials will be able to direct you to Committee Room 8, which is located on 'Committee Corridor'. It may be useful to bring a printed copy of this document or your invitation card with you as a point of reference. Should you require any assistance on the day, please contact Simon Whalley (07506 723324) or Jill Hamilton (07875 107747).

KEY	
(A) NORMAN SHAW NORTH	(1) CURTIS GREEN (VEHICLES ONLY)
(B) 1 DERBY GATE	(2) CANON ROW PASS OFFICE
(C) 1 CANON ROW	(3) PARLIAMENTARY BOOK SHOP
(D) NORMAN SHAW SOUTH	(4) PORTCULLIS HOUSE MAIN ENTRANCE
(E) PORTCULLIS HOUSE	(5) CARRIAGE GATES
(F) 1 PARLIAMENT STREET	(6) MEMBERS' ENTRANCE
(G) PALACE OF WESTMINSTER	(7) CROMWELL GREEN (VISITOR) ENTRANCE
(H) 7 OLD PALACE YARD	(8) ST. STEPHENS ENTRANCE
(J) FIELDEN HOUSE	(9) PEERS' ENTRANCE
(K) MILLBANK HOUSE	(10) BLACK ROD'S GARDEN PASS OFFICE
(L) 7 MILLBANK	(11) MILLBANK HOUSE MAIN ENTRANCE
(M) 14 TOTHILL STREET	(12) FIELDEN HOUSE



Meeting Agenda

TENTH MEETING OF THE APPG ON AXIAL SPONDYLOARTHRITIS: <i>AxSpA – One year on from the establishment of Integrated Care Systems</i>		
1. Welcomes and introductions Welcome and introductions from APPG Chair Tom Randall MP. Tom to set out the scope of the meeting and its objectives, as well as providing an update on recent APPG engagement with the Major Conditions Strategy development process.		17:30 (10 minutes)
PRESENTATIONS		
2. Presentation 1: Best practice axial SpA care Dr Claire Charlesworth (NASS member/GP, Nuffield Road Medical Centre, Cambridge) to provide an overview of what 'best practice' care looks like from a patient perspective, reflecting on the benefits of joined-up and multidisciplinary care, alongside reflections on where care is best delivered.		17:40 (10 minutes)

3. Presentation 2: The current state of play for Integrated Care Systems Ed Jones (Senior Policy Advisor – ICS Network, NHS Confederation) to share an overview of key ICS objectives, how they have performed during the first year of their establishment, alongside reflections of key learnings and opportunities for conditions such as axial SpA over the next 12 months.	17:50 (10 minutes)
4. Presentation 3: Local partnership working Dr Jon Packham (Consultant Rheumatologist, Midlands Partnership NHS FT) to provide an overview of current local System approach to axial SpA, with reflections on key priorities and improvement opportunities moving forwards.	18:00 (10 minutes)
GROUP DISCUSSION	
5. Question & Answer Session Tom Randall MP and Dr Dale Webb to jointly facilitate a group discussion that reflects on the four presentations, focusing on the below topic areas: <ol style="list-style-type: none"> 1. What are the key opportunities for engaging with emerging Integrated Care Systems across England, and the messages / arguments that will have the most impact? 2. What examples of good axial SpA practice would we like to see scaled up more widely across new models of care? 3. How can axial SpA help to meet key priorities that ICSs have on their agenda? 4. Is there any specific activity that attendees would like to see taken forwards by the APPG beyond this meeting? 	18:10 (45 minutes)
6. Summary of Next Steps Tom Randall MP provide a summary of the key discussion areas and suggested next steps	18:55 (5 minutes)
7. Meeting Close	19:00

Annex: About the All-Party Parliamentary Group on Axial Spondyloarthritis

The APPG on Axial Spondyloarthritis was formally established in March 2019 and represents a special interest group of cross-party MPs and Peers, jointly chaired by Tom Randall MP and Lord Campbell-Savours. The primary aims of the group are to raise awareness of axial SpA (AS) within Parliament and to support the widespread and effective implementation of key NICE guidance, including the Quality Standard for Spondyloarthritis, and support improved outcomes in axial SpA (AS) more broadly. The secretariat for the APPG is being provided by M+F Health, who work closely with the National Axial Spondyloarthritis Society (NASS).

Annex: Why has this APPG been established?

Despite affecting approximately 1 in 200 members of the adult population in the United Kingdom and having an average onset of just 24 years of age, axial SpA (AS) has traditionally been underprioritised and overlooked by policymakers and across the NHS. There is currently an average delay of 8.5 years between the onset of AS symptoms and diagnosis, during which time the condition can deteriorate considerably. A significant cause of this delay is the lack of awareness of AS among both the general public and within the healthcare system. There is also a huge variation in the quality of care that patients receive across England.

Encouragingly, the publication of the first NICE Clinical Guidelines for Spondyloarthritis ([available online here](#)) and development of a supporting Quality Standard ([available online here](#)) has provided an opportunity to push the case for reducing variation in the provision of services across the country and improving the quality of care that's available.

Whilst the introduction of these new pieces of guidance is welcome, there is currently no system in place to ensure their effective uptake at a local level. There has also traditionally been limited data available on the extent to which services for patients are being prioritised by commissioners and a lack of information on the levels of variation in service provision, although this is an area the group have started to address through the development of audit programme.

As the NHS in England continues its evolution in 2023, spearheaded through the work of Integrated Care Boards and Primary Care Networks, the APPG will seek to represent a collaborative and influential platform through which to highlight the need for effective and widespread implementation of key axial SpA best practice and improved axial SpA outcomes for all those affected by the condition.

Further information

For any further information about this meeting or the APPG on Axial Spondyloarthritis, please visit the [NASS website](#) or contact the APPG secretariat via appgspa@mandfhealth.com