

Agenda:

Understanding and addressing gender inequalities in axial SpA diagnosis, care and outcomes

April 2023

Meeting Agenda

TENTH MEETING OF THE APPG ON AXIAL SPONDYLOARTHRITIS: <i>Understanding and addressing gender inequalities in axial SpA diagnosis, care and outcomes</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. Supporting comments from Co-Chair Professor Yeliz Prior (Vice President, British Society for Rheumatology)	17:30 (10 minutes)
PRESENTATIONS	
2. Presentation 1: Gender disparities in axial SpA – a first-hand perspective Sophie Matthew (NASS member) to provide a first-hand perspective of the barriers faced as a woman in being diagnosed with axial SpA and living with the condition	17:40 (10 minutes)
3. Presentation 2: Qualitative findings on the realities faced by women in living with axial SpA Alison Drury (Director, ThinkVivid) to share insights from a new qualitative research programme exploring experiences and perspectives of living with axial SpA amongst female participants	17:50 (10 minutes)
4. Presentation 3: Axial SpA and women – a clinical overview Dr Helena Marzo-Ortega (Chair, British Society for Spondyloarthritis) to provide a clinical overview of the challenges and realities women experience in achieving axial SpA diagnosis and managing their condition, alongside opportunities for improving delivery of care moving forwards	18:00 (10 minutes)
5. Presentation 4: Primary care, MSK and gender Dr Michael Mullholland (Honorary Secretary, Royal College of General Practitioners) to provide a perspective from the RCGP on the barriers and opportunities for improving recognition and management of musculoskeletal health disorders within primary care	18:10 (10 minutes)
GROUP DISCUSSION	
6. Question & Answer Session Tom Randall MP and Professor Yeliz Prior 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 people’s own experiences of the differences in axial SpA recognition and management between men and women? 2. What opportunities exist to improve organisation and delivery of axial SpA care with a specific focus on women? 3. What does ‘good’ look like in the next 12 months? 4. Is there any specific activity that attendees would like to see taken forwards by the APPG beyond this meeting? 	18:20 (35 minutes)
7. Summary of Next Steps Tom Randall MP provide a summary of the key discussion areas and suggested next steps	18:55 (5 minutes)
8. 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 the [NASS website](#) or contact the APPG secretariat via appgspa@mandfhealth.com