

APPG on Axial Spondyloarthritis: Gender inequalities in axial SpA diagnosis, care and outcomes

Meeting Minutes

April 2023

Introduction

This document sets out the minutes from the tenth meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting – *Understanding and addressing gender inequalities in axial SpA diagnosis, care and outcomes* – took place in the House of Commons on Wednesday 19th April, between 17:30-19:00.

Formal APPG Business

1. Welcome and introductions

The APPG Chair, Tom Randall (Conservative MP for Gelding), opened the meeting by reflecting on the importance of exploring the impact that axial SpA has on women and the inequalities that women may face. He highlighted that the session will delve into the differences in waiting times, symptoms and outcomes faced by women and how imperative it is to see change within the system to address this.

Tom introduced his Co-chair, Professor Yeliz Prior (Vice President of the British Society for Rheumatology) and the four speakers – explaining how they will help to cover between them key themes in the context of axial SpA and women. Professor Prior provided her own reflections on the topic, and the impact that axial SpA has had on her life following her own diagnosis of axial SpA.

Presentations

3. Presentation from Sophie Matthew (NASS member)

The first presentation, by Sophie Matthew (NASS member living with axial SpA), provided a first-hand perspective on gender disparities in axial SpA. Sophie started her presentation by detailing her journey to diagnosis: Sophie's symptoms began around the age of 15, and she spent many years visiting different healthcare professionals (HCPs) to uncover their cause. She had a six-year delay to diagnosis due to multiple reasons, one of them being the misconception that '*women don't get axial SpA*', especially at a young age. Sophie reflected that the misconceptions about women and axial SpA resulted in her having a number of unnecessary procedures – such as dental operations – all of which carried financial and emotional implications. Sophie explained how she feels some sadness about the delay she experienced and the factors causing it, particularly as an earlier diagnosis may have slowed down a fusion.

Her experiences with HCPs as a woman living with axial SpA have changed over time. Sophie expressed that becoming aware of the National Axial Spondyloarthritis Society (NASS) and getting access to a hospital where she was able to have increased interface with female HCPs was a particular source of help. Before that, all her interactions were with male HCPs, who may not always consider '*female*' issues, or would be embarrassed to discuss them. Sophie raised several topics that she would have appreciated a conversation about, including managing sex with a diagnosis of axial SpA, pregnancy, and menopause. Sophie said that topics like the impact of taking HRT whilst also managing axial SpA symptoms were not typically proactively discussed.

Pregnancy and parenthood were central messages in Sophie's presentation. Women living with axial SpA may receive mixed information about pregnancy and birth – indeed, Sophie mentioned that she knew someone who was told that she could not have children because of the disease. Another challenge is medication and pregnancy; Sophie explained how she stopped taking her medication as she did not know how it may impact on her chance of conceiving, but then experienced "unbearable" pain as a result. After breastfeeding, she also experienced a flare of the condition, which HCPs did not inform her as a possibility.

Sophie described the difficulties of parenting as a woman with a disability. She mentioned that women will often experience different axial SpA symptoms compared to men, such as increased fatigue, which make it difficult to be a young parent. She described feelings of "failure" as a result, for example, at not being able

to pick up her children, and said that finding people with similar experiences supported her through these stages of life. She noted that having access to a network of women facing similar issues would have been hugely helpful at an earlier point.

Sophie closed her presentation by mentioning the general health system issues facing women with axial SpA, including sexist language and stereotyping. For example, when Sophie had a severe back injury, it was not considered as seriously as it should have been because she was not *'crying'* (due to her high pain threshold). She noted that HCPs may have preconceptions about how women are supposed to behave when they are unwell, leading to differences in management and treatment approaches. Addressing these disparities would have considerable benefits moving forwards.

4. Presentation from Alison Drury (Director, ThinkVivid)

The second presentation was from Alison Drury, a Director at ThinkVivid (research and planning consultancy), who discussed the qualitative findings from new research on the realities faced by women living with axial SpA. The research involved an in-depth look at the following:

- Length to diagnosis, the experience of seeking a diagnosis, and experience of living with axial SpA.
- The possible impact of gender bias in the classification and management of axial SpA.

During the research, 21 people (including ten women) were involved in online focus groups, and there were also four individual online interviews with trans or non-binary participants. The focus groups each involved three to four people and allowed sharing of experiences and detailed discussions.

Alison explained how the qualitative study generated some interesting results, aligning with Sophie's reflections in the previous presentation. Alison described how the delay to diagnosis appeared to be one of the greatest overall issues affecting women living with axial SpA and that the journey to achieving diagnosis was often traumatic. Some of the reasons for this delay included: the misconception that *'women don't get axial SpA'*; the different symptomatology presented by women (like hip stiffness instead of back pain); HCPs associating different conditions with women (e.g., myalgic encephalomyelitis or fibromyalgia); and lack of recognition of physical pain, with an assumption that the distress is due to a mental health condition.

Alison detailed the results showing what it is like to live with axial SpA as a woman. She noted that the decision to take biologic treatments can be complex, with the results showing implications of accepting biologic treatments on women's life decisions, including pregnancy, childbirth, and menopause. HCPs often take the *'please tell us'* approach, focusing on pausing biologics rather than having conversations about pregnancy. Some women may delay taking biologics until pregnancy because of the perception that they are *'powerful drugs'*, despite delays potentially impacting disease progression. Participants also highlighted that there are often no proactive conversations about birth, breastfeeding, and interactions between HRT and biologics. Respondents welcomed early discussions on these topics with HCPs.

Alison raised other challenges that women living with axial SpA face, including around parenting and intimacy. Respondents said that physical health, especially fatigue, presents a real issue for women. This has a knock-on impact on feeling *'present'*, psychologically and emotionally, whilst managing the pain of axial SpA. Some women saw themselves as the main or only carer and nurturer of children, which has implications on feelings of being *'good enough'*. Similarly to Sophie, Alison noted that sex and intimacy are often not discussed and the responsibility falls on women to lead these conversations. Alison noted that women want platforms to stimulate conversations about these topics.

Finally, Alison concluded by noting that gender was identified as a key likely factor in the delay to diagnosis and that participants felt that there is insufficient support available at present, or proactive discussions taking place with HCPs about issues affecting women with axial SpA.

5. Presentation from Dr Helena Marzo-Ortega (Chair, British Society for Spondyloarthritis)

Dr Helena Marzo-Ortega, Consultant Rheumatologist and Chair of the British Society for SpondyloArthritis (BRITSpA) delivered the penultimate presentation, providing an overview of the key clinical differences in axial SpA. Helena highlighted how her presentation was focused on sex – that is, biological traits – acknowledging that the relationship with gender can be far more complex.

Helena started the presentation by saying that women with axial SpA are underdiagnosed, misdiagnosed, and misunderstood. Axial SpA has historically been viewed as a *'male disease'*, as men are much more likely to have early, visible symptoms when presenting. New advances in the last 20 years in the sensitivity of imaging have made it possible however to ascertain that women are also affected by the disease, starting at early ages (in the 20-30s). This period of life is typically when people are most active and are starting their careers – which is why, previously, men who were considered the *'breadwinners'* would be more likely to present to the doctor. There are also differences in biology between the sexes, meaning men are more likely to have higher levels of inflammation, and their disease progresses faster and shows on clinical and imaging tests more strongly.

Helena mentioned that despite the time to diagnosis already being long (8 years), female patients take longer still to get diagnosed – on average, around 7 to 9 months longer. She noted some of the reasons for this, including different disease symptomology (which may be more *"subjective"* and systemic, like fatigue) despite similar pain levels. Interestingly, female patients were more frequently diagnosed by rheumatologists; although in the interim, they *'go around the block'* due to low awareness of axial SpA amongst HCPs and many *'systemic'* symptoms overlapping with conditions. Women can often have more swelling in joints – which HCPs pay attention to and test – however axial SpA may not always be considered.

Helena spoke about the frequent misdiagnosis of female patients, who may be referred to ophthalmology clinics and other health services. Often fibromyalgia is considered – given that the inflammation of tendons and fibres in axial SpA can have a similar manifestation. However, fibromyalgia is not common in axial SpA and is more prevalent in other conditions, like lupus. Another difference between female and male patients is the impact of disease activity on life: disease activity tends to be worse in women than men, which influences the capacity for work and impacts job stability and productivity. Pain and severe frequency of pain is also higher in women, perhaps due to biological factors, which similarly greatly affects daily activities like house chores and childcare.

It was also highlighted that a woman's journey with axial SpA is not typically linear, and the disease is still generally much less understood in women than in men. This is compounded by the general lack of understanding of how women's life stages – like pregnancy and menopause – impact lots of major health conditions. With this in mind, there needs to be better communication within healthcare settings to identify the unique needs of female patients and to make the journey to diagnosis and effective management better – especially as each journey will be different.

Helena closed the presentation by recapping that the delay in diagnosis of axial SpA is greater in women and that women with axial SpA experience a higher burden of disease and lower quality of life. She reflected that there are biologically determined factors which play a role, which is why well-designed clinical trials stratified by gender and a greater understanding of sex biology (e.g., the impact of hormones) is needed. As well, national and local policies should better reflect the specific needs of women with axial SpA.

6. Presentation from Dr Michael Mullholland (Honorary Secretary, Royal College of General Practitioners)

The final presentation was provided by Dr Michael Mullholland, the Honorary Secretary at the Royal College of General Practitioners (RCGP), who gave an overview of the RCGP's perspective on the barriers and opportunities for improving recognition and management MSK disorders amongst women.

Michael highlighted how GPs typically remain the first point of contact for many patients and are a source of *'holistic'* care – GPs aspire to be allied with women on their individual patient journeys and hope to address some of the key disparities they face. To help provide perspective on different diagnostic journeys men and women affected by axial SpA can face, Michael provided attendees with two case studies - Bill and Jane – and their paths through the system.

- Bill, a doctor, had back pain for years and attributed this to having a desk job and getting old. It became increasingly difficult for Bill to move around and he was eventually persuaded to get a specialist opinion. Bill's X-ray showed spinal changes, which led to him being diagnosed with axial SpA. His clinician prescribed him an initial treatment which didn't suit him; later, he was later prescribed a different class of therapy which revolutionised Bill's life. It took Bill around 15 years to receive effective treatment, but he likely had the conditions long before then; his position as a doctor helped speed up his patient journey.

- Jane, a 39-year-old woman with multiple health and mental health conditions, found day-to-day tasks more difficult but put it down to her other conditions. She had an X-ray which showed no abnormalities, despite increased morning stiffness. She was then referred to cardiology, getting prescribed steroids which helped significantly. Jane did not have a good experience in referrals to rheumatology – as there were no changes in her clinical tests – eventually taking the treatment into her own hands and going down the private route. To get treatment, for a relatively young woman, took 10 years.

Michael used these examples to showcase different presentations and behaviour between men and women. It was explained that women are more likely to appear more frequently in GP clinics than men, and are also more likely to have non-specific symptoms, which can be similar to other common conditions presenting in primary care. Michael mentioned that guidance for axial SpA is complicated, often needing four or more symptoms before referral, so it can take time to collect the required history. This sometimes means if *'traditional'* axial SpA symptoms are not present, GPs may find it difficult to identify likely presentation of the disease. Historically, there was also little awareness of non-radiographic disease, which is why men with a spinal presentation of axial SpA may have been diagnosed more quickly – although awareness is growing.

Attendees also heard how a GP covering a typical patient population of around 2,000 may rarely see individuals affected by axial SpA, despite many patients presenting with back pain or other non-specific symptoms. Michael stressed that it is important women feel able to approach their GP to discuss their health concerns, recognising that the responses to the Women's Health Strategy have shown too many examples of negative experiences in this context, which is something that the RCGP is working to address.

Michael closed his presentation by providing an overview of some of the broader challenges facing general practice, including continued shortages of staff and difficulties in maintaining continuity of care. Despite these challenges, attendees heard how GPs are determined to meet the needs of their local populations. He recognised that women's health is not being sufficiently prioritised at present, and that there are systemic gender and ethnic inequalities that need to be addressed. Michael then spoke about possible solutions, highlighting existing rheumatology training initiatives for those working in primary care (including collateral previously developed with NASS) and opportunities for improving *'continued professional development'*. Michael also referenced the potential represented through *'women's health hubs'*, as examples of integrated care models where women could increasingly attend one place for their health needs. Michael closed by highlighting how GPs can increasingly provide improved holistic care for women, although noting the distinction between the specialist support or treatment that is best placed within secondary care.

7. Question and Answer Session

Professor Yeliz Prior facilitated a group discussion that reflected on the four presentations, focusing on the below topic areas:

What opportunities exist to improve organisation and delivery of axial SpA care with a specific focus on women?

- It was highlighted that there needed to be more bespoke service available for female patients. There is a growing number of first contact physiotherapists in primary care who represent a valuable potential resource to support this – to make this a reality, steps need to be taken to combat the misconception that physiotherapists are not *'educated enough'* to make referrals.
- Attendees reflected on how sex is often not talked about amongst women diagnosed with axial SpA and the opportunities that existed to improve this.
 - Dr Marzo-Ortega highlighted that at the clinician level, there needs to be improved empathy and recognition of the pressures and needs of individuals. She was sympathetic that GPs are the *'gatekeepers'* and people are coming in with common symptoms, like backpain. Still, Helena said it is important to take into consideration the whole picture – for example, when a young person, who wouldn't normally present at a medical practice, keeps coming back. Helena also noted that the work to raise awareness at a local and national level needs to continue.

- Professor Prior reflected that the journey for women with axial SpA is not linear, and they needed improved advice at specific stages of their lives. Other attendees agreed, noting the need to offer care that was more bespoke, and to have more proactive conversations about topics like pregnancy and pharmacological treatment. There may also be a need for another forum to talk about motherhood and sex.
- Sophie Matthews reflected that it was a physiotherapist that talked to her about sex. She appreciated that other HCPs may not have time to discuss the topic, but not everyone with axial SpA knows about being able to draw upon NASS and its supporting facilities. Sophie noted there needs to be an empathetic interest in these areas and a creation of a network for young women.
- Alison Drury mentioned that we need to normalise topics like sex by mentioning them more frequently. There is also a need to raise awareness of related factors, including with effective signposting and provision of peer support. This may avoid, for example, women with axial SpA making the decision to not have children (due to the condition) without talking to a clinician.

What does ‘good’ look like in the next 12 months?

- Professor Prior reflected on the psychological impact of axial SpA and typical differences in behaviour between men and women. She asked about what would ‘good’ look like in the next 12 months.
 - Alison Drury noted that when patients are presenting to clinicians again and again, and getting pushback, they may stop seeking support to avoid the feelings of rejection – and therefore, how important it was to prevent this from happening.
 - Helena Marzo-Ortega agreed that there may often be other comorbidities with depression, which is why it is important to develop better links with secondary care to provide mental health support for women with chronic conditions – helping to address both physical and mental health components of axial SpA.
 - Dr Dale Webb (NASS CEO) referred to the importance of creating a sense of hope amongst patients. Due to advances in treatment, individuals can now lead a good life with axial SpA, but this ultimately requires receiving a diagnosis, typically enabled by early recognition within primary care. Dale therefore called for an increase in clinical visibility for axial SpA and for the condition to be higher up on the GP agenda. Increased collaboration with the RCGP and active partnership could help to achieve this.
 - Dr Webb also reflected on how women not being believed by HCPs is a common theme heard by NASS; there is sexism in the healthcare system and women may be prescribed psychological treatments instead of the correct medication. Therefore, NASS is launching the national axial SpA policy standards – which include details on conversations around sex. Support for its implementation would support considerable improvements in individual outcomes.
- An audience member asked about the impact of virtual consultations on primary care and the ability to provide a diagnosis.
 - Dr Mullholland reflected that initial conversations between a patient and GPs are increasingly digital and that GPs had to learn how to recognise who needs to come in for an appointment. This is a challenge in primary care, and GPs had to be trained differently to conduct virtual appointments effectively. This learning should be spread to other groups, like FCNs and FCPs – to ensure a storyline of who is seen and maintained. Michael added that GPs don’t have all the answers but are using digital technology to increasingly enable timely diagnoses.
- There was a question from an attendee about the NICE guidelines and how closely these are adhered to. Michael mentioned that these do not necessarily represent strict criteria for GPs but rather guidance that could be used for referral. The challenge is seeing younger patients who are more active and may acquire injuries in other ways.

- An audience member asked Michael whether GPs differentiate back pain when they see patients. Michael responded that this should be the case, and he would expect trainees to look at what could be causing the pain – whether is MSK or not.
- Michael Mullholland also reflected that it would be helpful to introduce risk-based system for other diseases, like axial SpA, to enable better diagnosis.

Is there any specific activity that attendees would like to see taken forwards by the APPG beyond this meeting?

- An audience member asked Dr Webb about the YourSpace platform from NASS and whether physiotherapists will be able to signpost patients to it.
 - Dr Webb explained that YourSpace is a self-management platform that will be expanded to eventually include the topics discussed in the meeting.
- The role of AI and implementing it within practice was highlighted by an attendee – it was suggested that HCPs may be *'hitting walls'* in its role in improving axial SpA identification, despite the potential it represented. It was suggested that the APPG could help to facilitate discussions around increasing its uptake.
- An audience members said there is a need to write to NHS so they update their definition of axial SpA, which was outdated and potentially causing confusion. It was explained that NASS were currently working on this item and would share any progress updates as soon as possible.
- Dr Mullholland suggested that improved community services and interfaces for patients were needed. Often, once an individual receive a diagnosis from secondary care, they will likely routinely present at their GPs to discuss specific topics. However, GPs may not have this specialist knowledge and cannot always easily refer back to other services – which is why expert physiotherapists and nursing teams, in the community, are needed.
- It was also suggested that NASS and the APPG could investigate carrying out another FOI, asking which trusts provide access to specialist rheumatology clinics with advice about pregnancy, to aid with referral.
- Generally, it was agreed that there was a clear need for increased visibility raising and advocacy that could improve awareness of the disparities faced by women affected by axial SpA and encourage involved stakeholders to draw on the opportunities highlighted in this discussion.

8. Meeting Close

Tom Randall MP closed the meeting by reflecting on his personal experience as a man living with axial SpA and his professional experience advocating for the condition. Tom explained how this discussion alone had already broadened his perspectives on how women are uniquely affected by axial SpA and the importance of trying to address some of the disparities they face. He was looking forward to raising these issues within Parliament and encouraging action amongst national and local-level colleagues.

Further Information

For any further information about this meeting or the APPG on Axial SpA, please contact appgspa@mandfhealth.com