

Third Group Meeting: Minutes

All-Party Parliamentary Group on Axial Spondyloarthritis January 2020

Introduction

This document contains the minutes from the third meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA) including ankylosing spondylitis (AS). The meeting - *Reducing the current 8.5-year delay to diagnosis* - took place on Wednesday 29th January in the Boothroyd Room, Portcullis House.

Formal APPG Business

1. Welcome and AGM

Lord Campbell-Savours (Labour Life Peer) and Derek Thomas (Conservative MP, St Ives) welcomed attendees to the third meeting of the APPG on axial SpA (AS) and provided a brief recap of the progress achieved by the group since its inaugural meeting in March 2019. Most notably, the group launched the first national inquiry into the provision of axial SpA (AS) services in England. The inquiry involved the dissemination of a Freedom of Information Request to every Clinical Commissioning Group (CCG) and NHS Trust in England, asking a series of questions regarding how comprehensively key NICE Spondyloarthritis guidance was being implemented at a local level. Derek Thomas MP added that following a period of recent political instability, there was now a real sense of momentum in Parliament and a desire to drive forward improvements across key domestic issues, with a particular focus on the NHS. He hoped therefore that this meeting would provide a springboard for tangible progress in axial SpA (AS) in the coming months.

Lord Campbell-Savours set out the agenda for this third group meeting and its focus on exploring the barriers and opportunities for improving the current average 8.5-year delay to axial SpA (AS) diagnosis. The Labour Peer briefly spoke about his own experiences of being diagnosed with axial SpA (AS) and noted how comparatively lucky he was to be diagnosed within two years of the onset of symptoms. He reiterated the importance of the APPG and allied stakeholders taking forward action to help raise awareness of the condition and working to achieve earlier diagnosis for those affected.

Dr Dale Webb (Chief Executive of the National Axial Spondyloarthritis Society, NASS) provided a brief recap of the findings from the APPG inquiry, highlighting the key gaps in provision of axial SpA (AS) care it revealed. The results showed that only 21% of CCGs have a specific inflammatory back pain pathway in place, and that less than half of respondents offered a specialist axial SpA (AS) clinic. One-fifth of services do not have access to a specialist rheumatology physiotherapist, whilst only a quarter offered direct access to psychological services via secondary care for those who require it. Dr Webb reiterated the fact that many areas were clearly failing to meet the standards of care set out by NICE, which are having significant implications on both time to diagnosis as well as appropriate treatment and outcomes for patients. Dr Webb told attendees that the report showed that there was still much to be done.

Prior to the presentations taking place, Derek Thomas (Chair) and Lord Campbell-Savours (Co-Chair) coordinated the APPG's formal business, including the election of officers. The following Parliamentarians were elected as Officers to the APPG :

Chair:	Derek Thomas (<i>Conservative</i>)	Officer:	Baroness Masham of Ilton (<i>Crossbench Peer</i>)
Co-Chair:	Lord Campbell-Savours (<i>Labour Peer</i>)	Officer:	Dr Rupa Huq (<i>Labour</i>)
Vice-Chair:	Tom Randall (<i>Conservative</i>)	Officer:	Kerry McCarthy (<i>Labour</i>)
Officer:	Andy Slaughter (<i>Labour</i>)	Officer:	Munira Wilson (<i>Liberal Democrat</i>)

Presentations

2. Presentation from Zoë Clark

Zoë Clark provided attendees with a moving and powerful insight into her own personal experiences of living with axial SpA (AS) and her struggle to obtain a correct diagnosis. Zoë's symptoms started at 20 whilst

studying at University, and ultimately it took 7 years for her to be accurately diagnosed with axial SpA (AS). This delay had a huge impact on her academic, social and professional life. Her first symptoms saw dramatic swelling in the ankles, wrists and elbows and despite seeing a number of different healthcare practitioners, it took a long time before she was referred to a rheumatologist. Unfortunately, Zoë was then misdiagnosed as having rheumatoid arthritis and was treated with methotrexate and high doses of steroids, which caused very challenging side-effects and didn't successfully manage her pain and fatigue.

Zoë explained how the incorrect diagnoses and impact of her condition left her socially isolated and unable to live independently, at a time when she was trying to complete a demanding four-year Master's Degree in Osteopathy. Attendees heard how living with undiagnosed axial SpA (AS) represented a frightening time and she ended up having to largely sacrifice her social life due to the difficulties of balancing her degree with the pain and fatigue she regularly experienced.

Input from a new rheumatologist resulted in a changed diagnosis of psoriatic arthritis (PsA) for Zoë, leading to further inappropriate medication and continued absence of the specialist support she needed. During what was thought to be a routine check-up 18 months ago, Zoë was seen by another new rheumatologist who undiagnosed PsA (putting all her symptoms down to Ehlers-Danlos Syndrome, which Zoë also has) and discharged her from their care. Despite this being a huge shock, it gave Zoë a push to see a new rheumatologist at a new hospital and insist on this time being properly screened for axial SpA (AS). After a consultation and MRI scan of the whole spine, a diagnosis was finally reached. This took 7 years, even with Zoë's medical knowledge and questioning her diagnosis frequently.

Zoë explained to attendees that whilst the condition was 'life limiting', a correct diagnosis had allowed her to receive proper medication and better physical and mental support, and this also meant she could better plan her life and make the necessary adjustments to achieve her ambitions and goals. She called for greater awareness of axial SpA (AS) across the general public and within healthcare, including ensuring appropriate training and continued axial SpA (AS) professional development for all healthcare professionals.

3. Presentation from Dr James Prior (Lecturer in Epidemiology at Keele University)

Dr James Prior provided attendees with a summary of a recently conducted systematic review into latest rates of diagnostic delay for axial SpA (AS) from across the globe. The systematic review looked at over 10,000 research articles, with 39 of these reporting on the average diagnostic delay experienced by patients with axial SpA (AS).

Dr Prior explained to attendees that the data from the review showed that when compared with other European countries, the UK had one of the longest average diagnostic delays (8.5 years) by mean - the European mean average typically sat between 5 – 10 years. When looking at the median average, the UK still had one of the longest average diagnosis delays, standing at around five years.

Dr Prior highlighted how the research showed that delays not only led to poorer health outcomes for individuals, but also had an increased economic burden for wider society. He drew on recent data from Italy which revealed that a three - year delay to diagnosis had a cost to the economy of at least €5 million.

The research also explored whether any particular patient characteristics could be associated with an increase in diagnostic delay. Dr Prior explained that across the 13 different characteristics identified during the study, gender, family history and age of onset made no difference to the length of delay. This was important, he stated, as future research in this area may be able to discount these characteristics as areas of concern. Other characteristics had a mixed impact on delay, from which no firm conclusion could be drawn. Dr Prior concluded by reiterating the case for reducing the average delay to diagnosis in the UK, which is currently far too high.

4. Presentation from Becky Adshead (Specialist Physiotherapist at Whipps Cross Hospital)

Becky Adshead provided attendees with an overview of the axial SpA (AS) care that she and her team are delivering as part of the early inflammatory back pain service at Whipps Cross Hospital.

Becky highlighted how delays in diagnosis often led to the under-treatment of axial SpA (AS) which negatively impacted on the overall clinical outcome of patients. She explained that first contact practitioners can often struggle to differentiate between inflammatory and mechanical back pain when patients present, which has

a knock-on impact on the likelihood of identifying axial SpA (AS) patients at the start of the pathway. She believed that a large part of the delay in diagnosis could be overcome with improvements in workforce education.

Becky explained that as part of the inflammatory back pain pathway at Whipps Cross, she had helped to establish an education programme for first contact practitioners around the signs and symptoms of axial SpA (AS). In her capacity as a specialist physiotherapist, Becky described how she had also set up a rheumatology course for physiotherapists to teach them about the different conditions that can present as inflammatory and mechanical back pain. Education was also delivered in gym-settings and other potential hubs to help filter patients to the most appropriate service.

Once a person was diagnosed with axial SpA (AS), Becky explained that providing effective management was a crucial aspect in ensuring that individuals were receiving the right treatment and support. Patients at Whipps Cross are able to have face-to-face appointments or video consultations, as well as having their condition monitored periodically through MySpA, an app-based service. Additional services are also offered alongside this to help provide extra support to patients, including signposting to the local NASS group and providing the ability to contact clinicians through email or telephone. Becky explained how this mix of services help patients to feel better supported.

Becky told attendees that the local service had now been running for eight years, and as a result of its implementation, had helped to reduce delays in diagnosis from 8.6 to 3 years. Despite this clear progress, Becky explained that there were clearly more people living with axial SpA (AS) that weren't yet diagnosed and therefore that there was still a lot more that needed to be done.

5. Presentation from Dr Raj Sengupta (Consultant Rheumatologist, The Royal National Hospital for Rheumatic Diseases, Bath)

Dr Raj Sengupta delivered a presentation exploring the development of a new 'Gold Standard' time to diagnosis for axial SpA (AS), developed in collaboration with NASS and Prof. Karl Gaffney. Dr Sengupta drew on the first three presentations which he felt clearly demonstrated the need for rapid improvements to be made in the speed at which axial SpA (AS) was being diagnosed across the UK. He explained that a new Gold Standard would help those living with axial SpA (AS) receive a timely diagnosis whatever their age, gender or location across the UK.

Dr Sengupta highlighted how he had worked with colleagues to identify several main points in the pathway which were primarily responsible for the delay in axial SpA (AS) diagnosis, and that a number of solutions had also been identified to help address these. Work on the Gold Standard is ongoing – including a wide-ranging consultation process – and it is hoped that it will be ready to launch towards the end of 2020, with implementation taking place from 2021 onwards.

Question and Answer Session

Lord Campbell-Savours thanked the speakers for their presentations and opened the floor up to questions, in which a number of topics were raised. A summary of these questions has been included below:

6. GP and public awareness

- Dr Denis O'Brien, a GP from Liverpool, told attendees that from personal experience he had found it hard to keep axial SpA (AS) at the forefront of those working within primary care, as he feels that GPs may only see a handful of cases over the course of their careers. He therefore felt that the campaign to raise awareness of the findings from the APPG inquiry could help to address this, alongside increased the visibility of existing informatics.
- Dr Ian Bernstein, a GP Commissioner for North West London, welcomed the development of a new 'Gold Standard' and explained that as a commissioner, this kind of tool would provide him with an appropriate lever to influence the implementation of better axial SpA (AS) services within his local area. However, he also acknowledged that there was currently relatively limited education of primary care staff in the area of axial SpA (AS), not least because clinicians often prioritised other disease areas over musculoskeletal issues. He stated that in order to reduce the delay in diagnosis, more

needed to be done to encourage prioritisation of MSK as a core component of continued professional development (CPD) within primary care.

- Raj Mahapatra, NASS Chair highlighted a successful public health campaign in Switzerland which helped to educate people on the symptoms of axial SpA (AS) and achieve improved diagnosis rates as a result, alongside improved recognition of the condition within primary care. However, he also sounded a word of caution, stating that once the campaign finished, delays in diagnosis went back up, therefore showing that education and training initiatives needed to be sustained as much as possible.

7. Access to care

- Melanie Martin, Extended Scope Practitioner in Physiotherapy from the axial SpA (AS) service at Guys and St Thomas' NHS Trust suggested that one of the difficulties for patients to obtaining a diagnosis was the delay in getting a GP appointment. Once an appointment was made, back pain symptomatic of the condition had often subsided. She highlighted the Lambeth self-referral system, which allowed patients to go through a simple set of questions to indicate whether their symptoms aligned with axial SpA (AS), suggesting that this could be something rolled out more widely.
- Dr Denis O'Brien highlighted that there was actually a tendency in some other European countries to 'over-investigate', in part due to the local financial health system incentivising intervention. It was asked whether this was a factor for why European countries often diagnosed axial SpA (AS) earlier, rather than them necessarily having better education and/or training in place.

8. Supporting access to treatments and reducing wider system-costs

- Professor Karl Gaffney, Consultant Rheumatologist at Norfolk and Norwich Hospital, highlighted the hugely positive impact that getting a correct axial SpA (AS) diagnosis can have and explained that being placed on the right treatment, which follows diagnosis, was 'life transforming' for those living with the condition. He added that treatments for the condition had improved and become more affordable in recent years, providing more options for clinicians. He suggested to the group that any public awareness campaign should focus on getting patients 'through the door' of GP practices first and foremost.
- Helena Marzo-Ortega, Chief Executive of Brit-SpA, explained how she was delighted that the conversation surrounding axial SpA (AS) was progressing after so many years of frustration, and that it was hugely encouraging to see such a full room with policymakers and decision-makers taking an active interest in the area. She explained that whilst there would be challenges around the implementation of some of the areas that had been discussed, the benefits would be significant and would help to reduce overall costs for the NHS, as well as reduce lost productivity caused as a result of poor management of the condition.
 - This comment was echoed by Roger Stevens, Chair of NASS Portsmouth, who explained that he had been able to remain employed an extra seven years thanks to the treatment he received for his axial SpA (AS). This not only had a positive impact financially, but also made a tremendous difference to his mental health.

9. Future Campaigns

- An attendee asked whether the development of a new Gold Standard represented a good opportunity to encourage greater collaborate with other relevant organisations representing those involved in the axial SpA (AS) pathway, such as the Royal College of Physiotherapists and the Royal College of General Practitioners.
 - Dr Dale Webb, CEO of NASS, agreed with the importance of working in partnership, especially considering the vital role that first contact practitioners have in reducing delays in diagnosis. He went on to state that NASS wanted to create a network of primary care clinical champions



for axial SpA (AS) and would be actively working with other organisations such as the Chartered Society of Physiotherapy (CSP) to move this forward.

Next Steps

Derek Thomas MP and Lord Campbell-Savours provided a brief summary of discussions and reiterated their thanks to all four of the speakers and attendees for contributing to a wide-ranging and rich discussion. They suggested that the momentum from this meeting and the findings from the APPG inquiry provided an excellent basis on which to take the work of the APPG forward.

The Chairs explained that there were several steps that would be taken forward ahead of the fourth meeting of the APPG, details of which would be made available in due course. This will include every MP being sent a copy of the group's report, which will also be shared with commissioners and providers across the country. Parliamentarians from the group will seek to a meeting with the Minister to push for further action, as well as encouraging Parliamentary colleagues to carry out their own lobbying to help raise improvements within their respective localities.

Further Information

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