Inaugural Meeting Minutes

All-Party Parliamentary Group on Axial Spondyloarthritis
March 2019

Introduction

This document contains the minutes from the inaugural meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA) including ankylosing spondylitis (AS). The meeting - *The impact of delayed diagnosis and the opportunities for improving outcomes* - took place on Tuesday 19th March in Committee Room 9 of the Houses of Parliament.

Meeting Minutes

1. Welcome and business of the APPG set out

Lord Campbell-Savours (Labour Life Peer) welcomed attendees to the inaugural meeting of the APPG on Axial SpA and provided a brief overview of his own experiences of living with axial SpA (AS) and the impact that the condition has had on him and his Parliamentary career. He spoke jointly with Derek Thomas MP (Conservative MP for St Ives, West Cornwall and the Isles of Scilly) about the importance of establishing a new Parliamentary group in the area and their hope that doing so would help raise the profile of this long-overlooked condition and lead to improved outcomes for all those affected.

Dr Dale Webb (Chief Executive of NASS) echoed these comments and highlighted the group's ambition to ensure widespread implementation of the National Institute for Health and Care Excellence (NICE) Quality Standard for Spondyloarthritis and that it would seek to work collaboratively with stakeholders to achieve this.

Derek Thomas MP led the formal business of the group, which included election of the following officers:

- **Chair:** Derek Thomas MP
- **Co-Chair:** Lord Campbell-Savours
- **Vice Chair:** Dr Rupa Huq MP
- **Officer:** Andy Slaughter MP
- **Officer:** Ed Vaizey MP
- **Officer:** Baroness Masham

2. Presentation from Hannah Scott and Max Poplawski, People with lived experience of axial SpA (AS)

Max and Hannah provided attendees with an overview of their personal experiences of living with axial SpA (AS) and the respective journeys they faced to receive an accurate diagnosis of the condition.

Max Poplawski explained to attendees that despite suffering increasingly severe symptoms of axial SpA (AS) since the age of 13, he didn't receive a confirmed diagnosis of the condition until he was almost 18. Attendees heard that doctors had consistently mistaken his symptoms for growing pains and the effects of him being heavily involved in a variety of sporting activities (such as rugby and swimming).

Alongside Max's pain intensifying as he progressed through his teenage years, he also began to develop additional symptoms that are common in those with axial SpA (AS), such as gastrointestinal issues and severe swelling of joints. As he was entering his A-level years, Max regularly needed to attend lengthy hospital appointments and was bedbound for days at a time. His gastrointestinal complications meanwhile severely affected his appetite and left him unable to participate in the sporting activities that had been such a major part of his life. Attendees heard how these developments had a significantly detrimental impact on his education and wider sense of mental wellbeing at the time.

Max explained that eventually receiving a confirmed diagnosis of axial SpA (AS) meant he could finally start to address his symptoms, manage the condition more effectively and improve his quality of life as a result. This could be achieved with the support of specialist practitioners and appropriate treatment. He also explained that in spite of the considerable challenges he has and continues to live with, he is ultimately grateful for the experiences and the knowledge he has gained from living with the condition, as it has helped to make him a stronger person.

Attendees heard how **Hannah Scott** had a markedly different route to diagnosis of axial SpA (AS) compared to Max. Hannah was diagnosed with the condition at the age of 31, although her first engagement with the health system in this journey was actually to visit a chiropractor for poor posture. After this visit however, Hannah went on to develop severe pain and found herself increasingly fatigued. Three GP visits and various tests eventually prompted referral onto a specialist, who was able to confirm a diagnosis of axial SpA (AS). This diagnosis arrived about 5 months after the initial onset of symptoms.

Despite this relatively quick diagnosis, Hannah's symptoms persisted, and the group heard how maintaining her existing job became increasingly difficult for her. This was in part due to the fact that commuting was becoming ever more challenging and because of the considerable impact that having to stand on the tube or walk short distances had on her. As a result of this, Hannah explained that she changed her working routine and took up work as a private music teacher, drawing on her longstanding background in music. This change provided her with greater working flexibility and also placed fewer physical demands on her.

Hannah explained to attendees that she had managed to achieve better control of her axial SpA (AS) with the help of medication and exercise, alongside the adjustments she had made to her working patterns. She also now gives herself longer breaks after performing in concerts, to ensure she is able to recover more effectively. Hannah told the group that despite the problems she has faced, she was grateful for her fast diagnosis as she couldn't imagine suffering her symptoms for years without having the professional support she has around her. She closed by urging stakeholders in the room to do all they can to further reduce the time it takes for those with axial SpA (AS) to receive a diagnosis, and to work towards improved outcomes for all those with the condition.

3. Presentation from Dr Andrew Keat, Consultant Rheumatologist, NASS Medical Advisor and Trustee

Dr Andrew Keat provided attendees with an overview of the clinical perspective of axial SpA (AS), how the condition should be managed and the challenges and opportunities that exist for service delivery. Dr Keat began by outlining some of the main symptoms of axial SpA (AS) and identifying that most people with the condition experience pain in the sacroiliac joints, which are bones within the pelvis, and the spine. He highlighted however that as explained by Max and Hannah in their earlier presentation, the symptoms are not solely confined to joints, with pain, stiffness, tiredness and inflammation of the eye, skin and bowel all also very common.

Dr Keat explained that whilst there was no precise figure of the number of people in the UK that have axial SpA (AS) - due to a lack of comprehensive studies in this area - the best available data suggested that as many as 1 in 200 adults in the UK were likely to have the condition. Dr Keat also highlighted how delays in diagnosis mean that many young people lose the most important years of their life. The current average delay to diagnosis from when symptoms start is 8.5 years, by which time irreversible damage to the spine may have occurred. Diagnostic changes can typically take years to show on an x-ray, however he explained that advances in MRI scanning techniques meant it was now possible to pick up the condition significantly more quickly following initial onset of symptoms.

Dr Keat stressed the importance of managing axial SpA (AS) effectively, highlighting the barriers that those with the condition face. In addition to the clear physical challenges, Dr Keat explained that patients are more likely to experience a range of social difficulties as well, such as higher divorce rates, being less likely to be involved in meaningful employment and being less likely to have children. These factors are exacerbated the longer it takes for someone to receive a diagnosis.

Despite these significant challenges, Dr Keat suggested that the medical profession has slowly been getting better at understanding the causes of axial SpA (AS) and recognising the considerable impact it has on individuals and the NHS as a whole. The treatment options available for patients have also improved hugely in recent years, with new advances in nonsteroidal anti-inflammatory drugs (NSAIDs) and biologics providing a range of effective new therapies to help limit the progression of disease and support better management of symptoms.

Dr Keat recognised that much more needs to be done however and concluded by issuing a call to action to achieve markedly earlier diagnosis of axial SpA and ensuring that all those with the condition receive the best possible long-term specialist care, to support them living as fulfilled a life as possible.

4. Presentation from Sarada Chunduri-Shoesmith, Associate Director for Implementation Support, NICE and Nicola Greenway, Quality Manager for Quality Standards Programme, NICE

Representatives from NICE provided attendees with an overview of the development process behind the new Quality Standard for Spondyloarthritis and considerations for how the APPG and stakeholders could support its effective implementation. Nicola Greenway began by welcoming the establishment of the new APPG and describing her encouragement that the group was focusing on driving uptake of new NICE guidance and the NICE Quality Standard for Spondyloarthritis.

Nicola provided an overview of NICE and their functions as the national body that provides guidance and advice across an extremely broad range of health and social care areas. NICE Guidelines are developed with extensive input from specialists and set out systematic recommendations on the diagnosis, management and treatment of that condition or topic. Quality Standards meanwhile provide a significantly condensed set of 'Quality Statements', usually around half a dozen key recommendations that can have a particularly positive impact on improving quality of care and reducing local variation in the quality of service delivery. A complete Guideline will take up to 3 years to develop, whereas the development of a Quality Standard will take around 10 months.

Once a Quality Standard is published, Nicola explained that NICE will look to work with stakeholders in the area to help disseminate and promote it amongst key audiences, including healthcare professionals and patients. It was highlighted however that whilst NICE were able to support efforts to raise awareness of their guidance, they weren't able to 'enforce' implementation and that ultimately, Guidelines and Quality Standards were not mandatory.

Sarada Chunduri-Shoesmith discussed how developing guidance in a health area is never enough to drive improvements by itself, especially as it currently takes an average of around seven years from publication of guidance for them to be implemented effectively. This delay is often due to differences in how guidance is interpreted at a local level, as well as both real and perceived financial barriers to their implementation and a potential lack of prioritisation at a local commissioning level. To help overcome these barriers, Sarada explained how NICE looks to raise awareness of the need for change in a given area, motivate and inspire organisations to get involved and provide practical support where possible. Sarada concluded by highlighting how this new APPG could play a key role in driving uptake of the guidance and making a real difference to the quality of services available to patients as a result.

5. Question and Answer Session

Derek Thomas MP thanked all the speakers for their presentations and opened the floor up to questions, in which a number of topics were raised. A summary of a selection of these questions has been included below.

Availability of specialist rheumatologists

- Baroness Masham, Crossbench Peer**,** asked if there were enough specialist rheumatologists available for patients to access across the country.
    - Dr Andrew Keat provided a brief response highlighting that in short, there are not currently enough areas across the country that provide appropriate centres of excellence for axial SpA (AS) care. He suggested that there was a long way still to go to ensure that the required levels of excellence were available to all those who needed them.

Axial Spondyloarthritis and the role of primary care

- Andy Slaughter, Labour MP for Hammersmith, asked why it took so long for GPs to diagnose axial SpA (AS).
    - Dr Jon Packham, Consultant Rheumatologist from Staffordshire, explained that the expectation wasn't necessarily for GPs to be able to diagnose axial SpA (AS), but rather be able to recognise the symptoms and therefore be able to refer individuals onto specialist care as needed.

  - It was suggested however that recognising the symptoms of axial SpA (AS) could be compared to asking GPs to spot the needle in the haystack of inflammatory back pain, and that much more work needs to be done around improving awareness of symptoms. One solution could be ensuring that there are axial SpA (AS)clinical champions available within local areas, as well as encouraging the establishment of informal networks where information on the condition filters down amongst GPs.

NHS Trusts and Guidelines

- Raj Mahapatra, NASS Chair, asked to what extent local NHS trusts take on the role of monitoring the uptake of NICE guidelines, and if they don't, then who should have responsibility.
  - Professor Peter Kay (National Clinical Director for Musculoskeletal Services, NHS England) flagged that he sometimes worried about the uptake of NICE guidance and there not being enough weight attached to supporting their uptake. He emphasised that ultimately flexibility is needed to ensure that commissioners are able to provide the best services for their local area and that this couldn't always be driven from a 'top-down' perspective. Rather, stakeholders needed to come together to take forward joined-up conversations about how implementation could be achieved in the best possible way.

HLA-B27 Test

- Lord Campbell-Savours queried whether GPs should be encouraged to provide diagnostic tests that could identify the HLA-B27 gene, a gene associated with axial SpA (AS), in those with relevant symptoms, and whether this could act as an effective way of more quickly diagnosing the disease.
  - Several responses highlighted that there would be considerable costs associated with delivering HLA-B27 gene tests on a widespread basis, and it is not a conclusive way to diagnose axial SpA (AS) as not everyone with the condition will carry the gene.

Global Best Practice

- Leaf Arbuthnot, Sunday Times journalist, asked if there were any best practice examples of axial SpA (AS) care or service delivery from other countries that we should be taking notice of within the UK.
  - Raj Mahapatra and Dr Andrew Keat suggested that whilst there were some examples of good practice from elsewhere, these were generally few and far between and that most other countries tend not to do much better than we do in the UK already. The one exception seemed to be Norway, which had managed to successfully reduce their delay to diagnosis time considerably in recent years. It was suggested that as part of the APPG's remit it could look to collect examples of good practice and help raise the visibility of these where appropriate.

Next Steps

Derek Thomas MP and Lord Campbell-Savours provided a brief summary of the discussions and reiterated their thanks to speakers and attendees for contributing to such a wide-ranging and rich discussion about key issues in the area of axial SpA (AS). It was agreed that whilst there was a long way to go, the group could have a significantly positive impact in terms of raising awareness of a long-overlooked condition and helping to improve its prioritisation within the NHS both nationally and locally.

To help take these issues forward, it was agreed that the group would conduct a series of Freedom of Information (FOI) requests to commissioners and providers across the country to better understand the current levels of uptake of NICE Spondyloarthritis guidance and the barriers and opportunities to making improvements. The results of these FOIs would be presented at the next group meeting, which would likely take place in early to mid-July, ahead of the anticipated Parliamentary Summer Recess.

Further information

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