

Fourth Group Meeting: Minutes

All-Party Parliamentary Group on Axial Spondyloarthritis July 2020

Introduction

This document contains the minutes from the fourth meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting – *Exploring the impact of COVID-19 on Axial SpA* - took place virtually, on Wednesday 15th July.

Formal APPG Business

1. Welcome and introductions

APPG Chair Derek Thomas (Conservative MP for St Ives, West Cornwall and The Isles of Scilly) welcomed attendees to the fourth meeting of the APPG on Axial SpA and provided a brief overview of the meeting's scope and objectives, which were focused around understanding the impact that COVID-19 is having on axial SpA and identifying potential opportunities to improve outcomes in the area.

Derek highlighted the significant challenges that all of us had experienced since the start of the outbreak in March and how it was vitally important to learn lessons from the pandemic, including those in the area of axial SpA. He explained that as we continue to emerge from the immediate crisis period, our attention should turn towards understanding how we can help to build resilience within services and continue to work towards improving overall axial SpA outcomes, including the ambition of reducing the average delay in diagnosis.

APPG Vice-Chair Tom Randall (Conservative MP for Gedling) provided attendees with an overview of his own experiences of living with axial SpA during the recent lockdown period. Tom was diagnosed with axial SpA in his late teens and has been living with the condition for over 20 years. He explained the challenges of not being as physically active during lockdown as he usually would be and the difficulties that everyone living with axial SpA has faced. Tom thanked everyone for their time and continued support of the group and outlined his enthusiasm for working towards improving axial SpA outcomes whilst serving as an MP.

Before introducing speakers for the five presentations scheduled for the group's meeting, Derek Thomas provided apologies on behalf of APPG Vice-Chair Lord Campbell-Savours, who was unfortunately unable to join the session due to conflicting Parliamentary business.

Presentations

2. Presentation from Frances Reid (NASS Member)

Frances provided attendees with a short overview of her experiences as someone living with axial SpA during the recent pandemic. Frances explained how she had been first diagnosed with axial SpA in early 2019 and that her initial course of treatment hadn't been at all effective, causing numerous side-effects and leading her to be temporarily put on steroids. At the outbreak of COVID-19, Frances had been waiting five months for a rheumatology appointment that would help to place her on a different treatment, but she explained how reports that those on immunosuppressants could be especially vulnerable to COVID-19 created a deep sense of anxiety for her and her family, both in terms of what treatment approach was best and also the extent to which they should be shielding.

Frances also described the sense of confusion about her personal level of risk. At an initial appointment Frances was told by her nurse that she was at 'moderate-risk', however she received a letter a few weeks later from the local rheumatology department which said that she was in fact at 'high-risk', seemingly driven by her relatively poorly controlled condition and use of steroids. There was also confusion about how she should access her appointments. Despite initial suggestions that her care would move to a virtual forum, Frances received no further communication about this and ended up turning up at the hospital for her scheduled appointment, only to be then turned away as they were unable to see her face-to-face due to COVID restrictions.

Frances was also told that due to the impact of COVID-19, her Trust weren't able to arrange for her, or other patients, to have their treatment switched at that time. Frances explained that this was a real blow and was

also coupled with not being able to do other things that helped to manage her condition, including swimming and physio care. However, following further appointments that did take place virtually, the Trust reversed its decision and switching patients onto new treatments was allowed again. Three weeks later she was placed on new medication, Cosentyx, which she described as 'life-changing'.

Looking ahead, Frances said that she would strongly support the delivery of increased virtual appointments (particularly those taking place via video, due to the visual contact) and would also like to see more virtual ways of tracking how one's condition changes, for instance being able to submit BASDAI or Bath Indices scores to your local service through online portals, which would hugely improve being able to manage people's condition effectively. Frances closed her presentation by thanking NASS for all the support and advice they had provided during lockdown, which had made a huge difference.

3. Presentation from Dr Dale Webb (CEO, National Axial Spondyloarthritis Society)

Dr Webb presented the results of a recent survey that was undertaken by NASS to better understand the impact that COVID-19 was having on those living with axial SpA during lockdown. Over 800 people living with axial SpA responded to the survey, which was carried out between May and July.

Responses to the survey, as well as feedback via the NASS helpline (which experienced a quadrupling of activity during the first few weeks of lockdown) highlighted the significant level of confusion that existed in regard to shielding advice for those living with axial SpA. Almost half of respondents (49%) were advised to shield, with an additional 13% not being told to shield but deciding to do so anyway. Responses indicated that there was a lot of late and conflicting advice in both primary and secondary care about shielding, which led to 8% of respondents stopping taking their medication as a perceived 'precaution'. Dr Webb explained that there are recent data which suggest that people on immunosuppressants may have improved clinical outcomes with COVID-19, as a result of an attenuated cytokine response.

Survey results also showed that around 50% of individuals reported having worse general health as a result of lockdown, with a similar proportion saying that their axial SpA specifically had also deteriorated during this period. 46% described lockdown as having an adverse impact on their mental health. Service access for those that needed it was mixed, with 1 in 4 of those needing access saying they were unable to do so (access to blood monitoring and biologic prescription were particularly disrupted).

Dr Webb provided an overview of how people had been accessing services, including a significant increase in the availability of virtual appointments. Respondents indicated a high level of satisfaction with virtual appointments (79%) and, looking ahead, although face to face care remained the preferred option for consultant and physiotherapist care, most respondents reported that they would also be happy for virtual appointments to continue with consultants and nurse specialists. Dr Webb concluded by highlighting the opportunities that existed for improving how people are able to self-manage their condition through increased digital care provision, which he felt would be an increased form of support going forwards.

4. Presentation from Dr Helena Marzo-Ortega (Chair of the British Society for Spondyloarthritis)

Dr Marzo-Ortega presented the results of a clinical survey undertaken to better understand the impact that COVID-19 has had on services and those working within them. 81 responses were received to the survey, representing a diverse geographical spread of axial SpA services based predominantly within England.

Responses to the survey revealed that there was a 52% reduction in the number of operational sites providing axial SpA care following the outbreak of COVID-19, with, as expected, considerable impact on the provision of face to face care – almost half of services (44%) weren't able to provide any face to face care for those in flare. Only 15% of services were able to provide any form of psychological support for patients, despite the increased pressures they faced, as highlighted though the preceding presentations. Dr Marzo-Ortega explained how the majority of services (80%) were able to maintain some form of flare management support, although there were worrying gaps in the number of services currently able (at the time of survey completion) to provide diagnosis and infusion therapy respectively.

Dr Marzo-Ortega highlighted the considerable increase in digital care availability as good news that had emerged from the pandemic, although flagged that only around half of services (54%) felt that they had the necessary skills in place to successfully deliver digital care, an area which required attention. This increase in

digital care had contributed to around 80% of services described their level of engagement with patients during the pandemic as 'good' or 'excellent', although 1 in 5 felt it was unsatisfactory.

In light of the recent challenges faced by services and the potential of future lockdowns, Dr Marzo-Ortega explained that there was a clear support for the idea of introducing some form of 'minimum service specification' for axial SpA, with only 4% saying that doing so would be a bad idea. Looking ahead, Dr Marzo-Ortega outlined four clear priorities that she felt needed to be embedded within axial SpA, based on her own experiences and based on results from the survey. This included upskilling the provision of available digital care, improving the way in which axial SpA patients are coded (drawing on the significant challenges that may clinicians reported in terms of identifying their high-risk patients), developing a set of minimum service specifications that are built around existing NICE Quality Standards, and continuing to work to reduce the average 8.5 year delay to diagnosis.

5. Presentation from Sue Brown (Chief Executive of the Arthritis and Musculoskeletal Alliance)

Sue Brown provided attendees with a brief overview of the work that ARMA had been taking forward in recent months to help support the musculoskeletal (MSK) sector in responding to the pandemic. Sue explained how the response from services across the country since the outbreak of COVID-19 had been mixed, with some being fantastic, and others not delivering the level of support that patients should expect.

Ms Brown highlighted the level of uncertainty that COVID-19 had caused for people living with MSK conditions and the significant increase in support that was provided by patient groups in the area. This demonstrated how important it is to have strong patient organisations in the sector, now more than ever. ARMA members had provided considerable advice to patients at the start of the pandemic around shielding and generally seeking to advise patients not to stop taking their medication, in response to conflicting information that was available. Sue explained how as the lockdown continued, concerns around catching the virus shifting to the challenges presented by not being able to access services when needed, particularly for those newly diagnosed or those in flare.

Ms Brown described that despite the guidance around acute inflammatory arthritis and suspected rheumatological conditions requiring urgent referral, lots of people found that they couldn't get appointments. There were also considerable challenges around accessing vital community care, whilst the types of service people access independently (e.g. physios and exercise classes) were also closed, creating real challenges for people trying to self-manage their MSK condition.

Despite the challenges, Ms Brown highlighted the numerous examples of really positive innovation that emerged during the pandemic, which was vital to keep hold of. A significant element of this was the increase in digital care, although acknowledged that virtual appointments didn't always work for all patients and she therefore encouraged services to consider individual patients needs in terms of modes of access moving forwards. Sue closed by calling for three areas of focus as we emerge from the immediate pressures of the pandemic, including the need for good communication between services and patients, catching up with the clinical backlog efficiently to make best use of available resources, and to keep hold and build on the innovations that have been especially beneficial for patients in recent months.

6. Presentation from Andrew Bennett (National Clinical Director for MSK Conditions, NHS England and NHS Improvement)

Andrew Bennett provided attendees with a broad presentation outlining the response that had been put in place since the emergence of COVID-19, an overarching vision for MSK service provision moving forwards, Mr Bennett described the massive challenge caused by COVID-19 and the restoration efforts that have been put in place to respond to the outbreak, with support from a high-level MSK Steering Group. He described the positive collaboration that had been witnessed since the emergence of COVID and how it was essential to hold on to this and build from it moving forwards to help meet the restoration challenge. Balancing the recovery of planned care whilst maintaining urgent and emergency provision was felt to be crucial, requiring a focus on risk, demand, capacity and productivity.

Mr Bennett highlighted the importance of ensuring that support for mental wellbeing is providing alongside physical support, building on the principles set out within the NHS Long-Term Plan. Alongside ongoing

recovery efforts, work was also underway to build a cross-framework strategy to help embed best practice from across the wider community and safeguard service provision moving forwards.

7. Question and Answer Session

Derek Thomas MP thanked the speakers for their presentations and opened the floor for a questions and answers session, which was chaired by Dr Dale Webb. A summary of this discussion has been included below:

What can be done to support the work of the system moving forwards

- In response to a question from Tom Randall MP around what help Parliamentarians and other stakeholders could provide to NHS England/Improvement to support the continued recovery of axial SpA and broader MSK services in the months ahead, Andrew Bennett highlighted the continued need for collaboration and aligned efforts. This had helped the adoption of a 'task and finish' approach to addressing the issues that had emerged since the start of the pandemic and would be crucial to meeting the challenges ahead.

Axial SpA and coding

- Dr Helena Marzo-Ortega highlighted the urgent need for an improved approach to the way in which axial SpA patients are coded within NHS services. She explained the considerable difficulties she and other clinical colleagues had experienced when trying to correctly identify levels of patient risk due to insufficiencies in the way patients have originally been coded and how this was leading to unnecessary anxiety and shielding for many individuals, which can have a significantly detrimental impact mentally.

Supporting access to hydrotherapy care

- Attendees highlighted the essential nature of hydrotherapy care in managing axial SpA and concerns around the continued disruption axial SpA was having on these services. Speakers agreed that this was a vital area of care, acknowledging that there were hydrotherapy capacity issues in some areas of the country even before the pandemic.
 - Andrew Bennett explained how the NHS was trying to open up community services, including hydrotherapy, although this had to be done within the constraints of infection control issues, PPE, resource availability and changing Government guidance. He said that additional support to enable self-management strategies for people at home may be needed due to short and medium-term constraints. This could help mitigate the continued disruption to hydrotherapy.

Online and digital care

- Dr Chan and Zoe Clark contributed to a discussion around delivering high-quality virtual and digital axial SpA care in the coming months. Dr Chan provided examples of how his local services in Reading had responded to the outbreak and that moving forwards, the ambition was to provide a more flexible approach through 'hybrid clinics', which could offer both virtual and in-person access options for patients, based on their need and preference.
 - In response to a question from Dr Webb, Dr Chan highlighted different patient sub-groups who would have different digital access needs. For instance, face to face care would be more appropriate for those newly diagnosed with axial SpA or who need physical examination. He suggested that around 30-40% of his local patients who are in a more stable condition could particularly benefit from remote access, although emphasised the critical importance of patient engagement and consent on these issues. He also cautioned against age necessarily representing a barrier to digital care, with many older patients finding virtual appointments significantly easier compared to those in-person.
 - Zoe Clark described her own experience of both living with axial SpA and also providing physio and osteopath services virtually, including through NASS's website and social media channels. Ms Clark described the significant opportunities that can be realised through wider roll-out of virtual care for long-term management and encouraging people to exercise more.

- Claire Jeffries spoke about her own experiences of providing specialist physiotherapy care for her local NHS Trust and the difficulties that needed to be overcome in terms of IT provision and lack of existing digital infrastructure.
- Sue Brown also highlighted the issues around digital poverty and the existing inequalities that may potentially be exacerbated through virtual care, providing the example of cohorts of younger people who may not be able to afford enough data to access digital appointments.

Managing the clinical backlog and looking ahead

- Andrew Bennett contributed to a discussion around how best the clinical backlog in axial SpA should be managed, and whether triage or online assessments should be used. Ways of addressing the backlog is currently being explored by system-leaders, both within MSK and across the NHS as a whole. Shared decision-making approaches are a particular area of consideration that can help with this and resources are being developed in this area. Mr Bennett highlighted that there was still a place for all modes of access and that it would be important to incorporate a shared decision-making process between clinicians and patients about what the best approach is on an individual basis.
 - Sue Brown encouraged all parts of the system to plan for a potential second-wave of COVID-19 – even if this didn't come to pass. She suggested that there were real lessons that could be adopted to help ensure that some of the more negative experience from the initial lockdown weren't repeated.

8. Discussion Overview & Launch of the NASS 'Gold Standard' Consultation

Dr Webb provided a brief overview of the discussions and the next steps that the group will take forward, including capturing the recommendations that have emerged from the session and sharing them with senior Government and NHS stakeholders.

Dr Webb also set out details of a ground-breaking new consultation that has been launched by NASS to help inform the development of a 'Gold Standard Time to Diagnosis' in axial SpA. The programme is ultimately seeking to reduce the current 8.5-year average delay in axial SpA diagnosis to a reality where axial SpA is diagnosed within a year.

To help identify the key barriers and opportunities for achieving this vision, NASS and leading national axial SpA clinical experts have identified four key reasons for the delay in diagnosis, alongside the corresponding solutions to overcoming them. As a next step, NASS are now seeking to engage a broad range of key stakeholders involved in the national and local organisation and delivery of axial SpA services on these proposals, as well as those living with the condition.

Further consultation details and a supporting video are [available on the NASS website here](#).

Further Information

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