

Ninth Group Meeting: Reflecting on the current ‘state of the nation’ in Axial SpA

All-Party Parliamentary Group on Axial Spondyloarthritis Minutes October 2022

Introduction

This document contains the minutes from the ninth meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting – *Reflecting on the current ‘state of the nation’ in Axial SpA* – took place in person, on the 18th of October, in the House of Commons.

Formal APPG Business

1. Welcome and introductions

The APPG Chair, Tom Randall (Conservative MP for Gelding), opened the meeting by reflecting on the ever-changing political and policy landscape, and why it is important to take stock on the status of axial SpA within it. Tom then outlined the aim of the session (to explore the barriers to early diagnosis of Axial SpA) and briefly introduced the cohort of speakers, who would each provide an overview of different components of the system – with an overarching focus on diagnosis. Tom closed his introduction by referring to the specific achievements of the APPG, including the introduction of the first ‘State of Nation’ report, the development of a set of minimum service specifications, the creation of the first cross-stakeholder therapy coalition, a parliamentary debate on axial SpA, several meetings held with government Ministers, and close engagement with policymakers. Tom highlighted that there is still more to do to ensure future diagnostic times are brought down to one year.

2. APPG Update: reflecting on key APPG milestones

Dr Dale Webb (CEO of NASS) reflected on the impact of the pandemic on axial SpA services and provided a taster of the ‘State of the Nation’ inquiry results ahead of their full launch on the 30th of November. The inquiry centred on the outcomes of a freedom of information request sent to every NHS Trust in England in September 2022 (which follow-up on one made in 2019). Worryingly, this request elucidated that only 58% of NHS Trusts have an ‘Inflammatory Back Pain Pathway’ in place, 46% have a dedicated axial SpA clinic, and 45% have primary care education programmes on axial SpA. In relation to diagnosis, the results showed that 65% of NHS Trusts know their average waiting time, and 35% report a waiting time of three months or less (which is a decrease from 63% in 2019). 71% of Trusts meanwhile have access to a specialist physiotherapist and 22% of Trusts offer access to psychological services – which are areas of continued concern.

Dale reiterated that Trusts do not have a good understanding of diagnostic times, and service provision seems to be deteriorating. There were complementary results from a freedom of information request sent to UK NHS Trusts and Health Boards – which will be available in April 2023 – that showed the increased use of recommended MRI protocols. However, awareness of national spondyloarthritis guidance remains poor. Another area of concern was the increase in MRI times and a reliance to outsourcing (often to non-specialist services, which can lead to quality problems).

Dale finished the overview by highlighting the need for a continued focus on service improvement and a reduction in time to diagnosis.

Presentations

3. Presentation from Dr Lesley Kay (Consultant Rheumatology, National Clinical Lead for Rheumatology, GIRFT)

The first presentation, by Dr Lesley Kay, reflected on a changing axial SpA policy landscape. Lesley started by giving some background to the ‘Getting It Right the First Time’ (GIRFT) programme, which comprises 40 streams working together to identify unwarranted variation in services; GIRFT is the largest quality improvement programme in the NHS. As part of the programme, 75% of rheumatology practices have been

assessed (so far), making up the largest dataset ever assembled for rheumatology. The programme is unique as it is clinician-led and has buy-in from the rheumatology community.

Following on from this overview, Lesley described the findings of the programme, such as:

- The fragility of rheumatology services – with the average practice having four consultants.
- Lack of consistent definition of what rheumatology is – as it's a relatively young speciality.
- That there needs to be a focus on four core condition pathways (of which axial SpA is one) – Lesley recommended that the rheumatology needs to concentrate on these four core conditions, that add most value to patients, making a difference where other specialities can't, and work with other services to provide care for other conditions.
- High-quality community services are needed for people with non-core conditions.
- Services must work together.

In the second part of her talk, Lesley discussed the #BestMSKHealth Collaborative (which is part of the Elective Recovery programme). She described some of the best practices in this initiative during the pandemic, like the bringing together of professionals from a range of disciplines to solve challenges, reach a consensus, and provide thought leadership. Lesley reiterated the necessity of working together to solve elective care problems: cooperation across the entire pathway, all ages, and all conditions. This collaborative is especially unique as the core pathways have been co-produced (with people with lived experiences and patient organisations), and there is a new emphasis on inequalities. There is also a solidified structure, with regional leads (including on rheumatology) – the #BestMSKHealth Collaborative focuses on community delivery, supporting local system leads to delivery services in line with the programme.

Lesley concluded by speaking about the National Early Inflammatory Arthritis Audit, which has been recently recommissioned for its third iteration. Axial SpA will feature more prominently in this audit – it did feature in the second iteration but not comprehensively – and the four core pathways will be central. This audit is necessary, as quality measurement is not common in rheumatology clinics. Therefore, this mandated collection of data across practices, through the audit, provides an opportunity to measure important qualities like diagnostic delays, patient outcomes, and patient experiences. This 'live' data will be available to all NHS staff on the 'Model Healthcare System'.

Lesley finished her presentation on a positive note, elucidating that 'things are coming together' for axial SpA, given the increase in data availability and influx of tools to support commissioning; these factors are complemented by a shared vision. There are also areas for stretch, that Lesley asked the group to recognise: the need for a collaborative approach (collectively raising questions on what local systems are doing) and establishment of accountability practices.

4. Presentation from Joe Eddison (Programme Manager, Act on Axial SpA, NASS)

The second presentation was from Joe Eddison, a Programme manager at NASS, on NASS' 'Act on Axial SpA' campaign. Firstly, Joe precluded the release of NASS' impact report '*Driving down diagnostic delay in axial SpA*'. Joe then described his own experience of living with axial SpA – from getting food poisoning to being diagnosed with reactive arthritis in 2005 and receiving the axial SpA diagnosis seven years later. Specifically, he mentioned how critical the diagnosis of the condition was to his quality of life, as it enabled treatment with biologics which have had a transformative impact on his ability to manage symptoms. Joe said he felt 'incredibly lucky' that he was diagnosed relatively quickly, in comparison to other patients, as he was already in the system.

The second part of the presentation centred on NASS' campaign to create social movement through a theory of change – with the programme following the patient from symptom onset to diagnosis. Joe spoke about particular stages: how to make the case for change; how to influence behaviour change on a person, practice, and policymaker-level; how to use influence to change processes; and the final outcome (driving down of diagnostic time).

Joe then discussed NASS' achievements and mentioned how the APPG has been a 'catalyst' for the work. Other notable milestones were the APPG inquiry on axial SpA and setting the standard time for diagnosis (through the GIRFT pathway). He also mentioned the policy work that has been carried out to 'shine light' on other areas, like the economic cost of delayed diagnosis, and the parliamentary activity related to axial SpA.

Complementary to ongoing work around improved data collection, Joe also described the 19 'Aspiring to Excellence' sites that have been set up. As part of the social movement campaign, Joe referred to the successes of the NASS' public awareness work which raised awareness amongst the public and featured in prominent newspapers. Finally, he spoke about what is being done to change care processes, such as the *Aspire to Excellence* programme (which now has three cohorts of 19 rheumatology teams) and the *Champions in Primary Care* programme (to champion axial SpA in primary care). Joe reflected on how these programmes could be brought together to create system change.

Joe concluded his presentation by summarising the wide range of actions that are starting to bring tangible change to processes. However, there is more to do to translate this work into cutting down diagnostic times.

5. Presentation from Dr Sanjeev Patel (President, the British Society for Rheumatology)

Dr Sanjeev Patel delivered the penultimate presentation, on the current state of play in rheumatology from the perspective of the British Society of Rheumatology (BSR). Firstly, he introduced the Society which is the leading UK specialist medical society for rheumatology and musculoskeletal care, and is made up of many multi-disciplinary professionals, interacting with a variety of patients.

The second section of the presentation centred on the BSR's concerns related to rheumatology, of which there are two: access to primary care and workforce. Sanjeev first spoke about the transformation of primary care over the last 25 years, with its status as the 'bedrock' of the NHS being lost. Now, patients often struggle to see their GP, increasing referrals by non-GP grades. He gave an example of how the system is evolving and bringing new challenges like remote appointments, which can benefit diagnostic times, but can also lead to misdiagnosis and inappropriate referrals (to non-rheumatological work). Through this he highlighted the need to improve this interface.

The second concern, workforce, is a widespread issue. Sanjeev spoke about the workforce crisis – with staff shortages plaguing the NHS. However, there are also rheumatology-specific challenges, like poor exposure of the field to doctors in training, and poor progression opportunities for other health professionals (like nurses, physiotherapists, and pharmacists).

To mitigate these challenges, Sanjeev recommended a three-pronged approach: increasing training and education around rheumatology; enhancing services (so they include physiotherapists, consultants, nurses, mental health support, and pharmacists); and improving the NHS for staff, with a focus on retention of staff and equitable access for allied health professionals. Overall, there is a need to work in a coordinated way to manage patients with complex conditions.

Sanjeev also posed a question to the audience 'how can we ensure that the recommended changes are operationalised in the NHS?', speaking about whether the NHS has the capacity to do so and the hinderance that the staff turnover plays. He focused on the opportunities presented by the ICSs, with the ICS leads offering an opportunity to deliver change and put in place necessary workforce planning. However, at the moment ICSs still face significant capacity and coordination challenges.

As a conclusion, Sanjeev outlined the priorities for the BSR, which included campaigning for workforce change, investigating the homecare medicine delivery service, supporting departments to set up a quality review scheme, and the National Early Inflammatory Arthritis Audit.

6. Presentation from Dr Toby Wallace Gregory (GP with Special Interest in Musculoskeletal and Sports Medicine, Derwent Practice, North Yorkshire)

The final presentation was by Dr Toby Wallace, who is the NASS Primary Care Clinical Champion for North Yorkshire. Toby first outlined the focus of the programme, which hopes to encourage the sharing of knowledge and best-practice between clinicians and across systems to improve outcomes for patients (with the local champions being the 'enablers of change'). The focus of the programme is to improve the identification of axial SpA to decrease time to diagnosis. In total, there are 12 Champions across the UK driving axial SpA care in primary care services.

After detailing the programme, Toby went on to discuss the challenges facing patients; these barriers can be split into four categories, patient, disease, system, and clinician-driven. Currently the biggest challenge in primary care is the mismatch between patient demand and workforce capacity. This is compounded by the time limits in consultations, that make it difficult for clinicians to diagnose the condition, especially as patients often present with multiple symptoms. Some symptoms, like back pain, can relate to multiple disorders, and others, like heart pain, may lead clinicians down the wrong investigative path (as it is difficult to ‘prioritise’ the symptom to follow).

Furthermore, issues with capacity lead to poor continuity of care, with patients not regularly seeing the same clinician. Other wider challenges include a lack of diagnostic criteria, resulting in inappropriate biomarker testing (that may not necessarily indicate an absence of axial SpA), and limited rheumatology and axial SpA education in medical or other professional training. Together, these barriers generate mental, physical, and financial impacts on patients, and can also widen disparities – particularly given the interaction of gender with the time of diagnosis.

Spring-boarding off these challenges, Toby provided some ideas and mechanisms to improve time to referral for axial SpA patients in primary care. He highlighted that engaging primary care colleagues is critical, and benefits should be easily demonstrated (e.g. preventing repeat consultations). Specifically, Toby outlined the benefit of education and promotional programmes for both patients and clinicians. Other methods to tackle these challenges include using IT, like templates with NICE criteria, to support clinical reasoning and referrals to secondary care. Also, there is a need to engage with secondary care teams, making them aware of the work being done in primary care and working jointly to improve referral pathways.

Toby concluded by speaking about the benefits of the *Primary Care Clinical Champions* workstreams who will support the identification and implementation of quality improvement projects, whilst also working collaboratively to ensure that axial SpA is higher in the clinical reasoning of primary care clinicians.

7. Question and Answer Session

Tom Randall thanked the speakers for their presentations and handed over to Dr Dale Webb, to facilitate the group discussions. Dale introduced four broad questions to the audience: how well is the NHS and health system doing on axial SpA; how to protect rheumatology given the changing policy landscape; can the NHS operationalise the necessary changes; and how to ensure local engagement and accountability – given the changes to the ICS structure? A summary of the following discussion is detailed below.

How well is the NHS doing on axial SpA?

- An audience member raised that inflammatory back pain isn’t widely known amongst GPs. Work is needed here – to raise awareness of the condition in primary care.
- There was also a suggestion that we don’t currently know how well we are doing and that an element of this is how there is variation in quality of data capture between localities, highlighting that it’s not always possible to know what is being done well and what isn’t; therefore, there is a need to iron out unwarranted variation.
- Dr Toby Wallace mentioned how the data in primary care is often limited due to the nature of coding; for example, free-text coding is not possible to search through – unless it is put into re-coding .
- An audience member raised that there are challenges in day-to-day practice, like the huge backlogs (leading to inability to fit people in), and MRI waiting times, which is why first-contact practitioners need to work together to improve pathways (getting the right patient to the right person). However, the main problem is the data: there need to be efforts to implement change in daily data collection, so that data is not only collected via a two-yearly audit.

How to protect rheumatology given the changing policy landscape?

- The importance of consistency was discussed, and how the MSK community needs to have a clear set of priorities so that rheumatology is not forgotten or fragmented against a wider MSK focus on hip and knee replacement. The importance of data visibility was also discussed, including the

suggestion that any audit data should go into the Model Healthcare System, making it visible to everyone.

- Limited understanding of outpatient appointments was considered, even at a basic level amongst decision-makers (despite the NHS Long Term Plan aiming to reduce outpatient appointments by a third). This lack of understanding may lead to not making the best use of the appointments and was felt to be a critical issue for decision-makers to address moving forwards.
- Dr Sanjeev Patel raised how there is limited interaction between the three key groups (payer, user, and provider), which also leads to a lack of accountability and data from a rheumatology and broader healthcare perspective. Large sums of taxpayers' money are potentially being moved without the interaction of these groups. Sanjeev stated that unless clinicians talk to other clinicians there is no way to move forward – and that there therefore needs to be a discussion around the interface, additional value, and data.
- An attendee highlighted how there needs to be education 'from the ground up' in undergraduate and postgraduate courses – a change in the curriculum is required to achieve this – and how clinicians should advocate to their university colleagues to ensure exposure of rheumatology as an important speciality.
- An audience member mentioned that there is a lack of accountability in terms of flow and that this is exacerbated by rheumatology not getting sufficient funding through incentive programmes like QOF, compared to other professions. This lack of incentive potentially means that GPs are not as robust at measuring musculoskeletal outcomes, as there is a lower financial priority attached to the area. a priority for them.
- Joe Eddison mentioned that he looked at digital data for outpatients during his NASS work, finding that there is an average of 4% of coded outpatient appointments (over the last 5 years).
- An audience member spoke about the need to work closely with partners in primary care and community providers, as axial SpA patients can often attend many specialities with the same problem. Even if it isn't axial SpA, there needs to be support in the community and an understanding of what to do with the patients. The integration piece is vital to preventing patients circling around the system – which is also costing money. The integration piece should also happen at a system level replicating what is done at a local level. Overall, a change in narrative around rheumatology was advocated for – so there is a greater understanding of what the specialty involves.

Can the NHS operationalise the necessary changes and ensure local engagement and accountability – given the changes to the ICS structure?

- The need to scrutinise what is being done to make changes within the current capacity of the system was raised by an attendee. Whilst there are a lot of 'controllable' factors that clinicians can change – there was a corresponding need to look at a wider picture for patients. Clinicians often see a small snapshot of a patient's journey – how therefore can wider awareness of axial SpA be increased, to support healthcare professionals to more consistently make the right, timely diagnosis?
- A commissioner attendee reflected on how he works at a system level and is aiming to mirror what is done at local level, for example through introducing 'Champions' at an ICS / region level who are aware of the issue of inflammatory backpain, so there is a consistent narrative. As part of this contribution, the challenge of axial SpA being potentially drowned out by orthopaedics and how to combat the difficulties with influencing change was also considered. The attendee closed by highlighting the need to compassionately protect workforce (who cannot work any harder) whilst at the same time increasing efficiency (through education) – so people can get the right service at the right time, to make best use of resources.
- The difficulties of achieving change within an ICS structure was considered, including understanding who the relevant musculoskeletal and rheumatological leads within a system actually are, and how to feed into / influence the system (who are often focused on the orthopaedic side).
- An attendee suggested how there was an opportunity to deliver increasingly integrated services and gave an example from Shropshire where there is one integrated referral service via a referral letter (meaning there is an 'educated triage' in the system) – making it possible to see when patients had multiple referrals over the last few years.

8. Meeting Close

Dr Dale Webb then passed back to Tom Randall MP who brought the meeting to a close. Tom thanked all attendees and the presenters for their contributions and reflected on the issues raised (e.g.: workforce, educational curricula, limited awareness) but also the positive stories (like the Primary Care Champions programme). Tom remarked that there is the need for more work in 2023 – with a particular focus on engaging with local systems – but also that there has been immense, and encouraging progress made in the axial SpA space so far.

Further Information

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

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