

APPG for Axial Spondyloarthritis

One Year on from the establishment of Integrated Care Systems: how is Axial SpA faring

November 2023

Introduction

This document sets out the minutes from the eleventh meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting – *One year on from the establishment of Integrated Care Systems: how is axial SpA faring* – took place in the House of Commons on Tuesday 14th November, between 17:30-19:00.

Formal APPG Business

1. Welcome and introductions

Tom Randall MP (Conservative Member for Gedling and Co-chair of APPG on Axial Spondyloarthritis)

Tom Randall welcomed those in attendance to the meeting and briefly touched upon the successes and challenges of both the work of the group and the wider state of play across the NHS following the formal establishment of Integrated Care Systems (ICS's) across England in 2022.

From an axial SpA perspective, Mr Randall highlighted a recently tabled Westminster Hall debate to mark World Arthritis Day (12th October), alongside ongoing engagement that was taking place with Government stakeholders around issues that had been raised by the group and to support the consideration of core issues within the development of the Government's flagship Major Conditions Strategy document. He emphasised the importance of axial SpA receiving greater exposure and prioritisation when it came to clinical decision making.

Mr Randall also spoke to the changing political landscape, both in recent times, with the re-organisation of Ministers within the Department of Health and Social Care, whilst also recognising that a forthcoming General Election could further change the political calculus. With the above in mind, Mr Randall explained how he felt it was more important than ever to ensure that decision-makers on the ground, for instance those within ICSs, were supported and encouraged to put in place the strongest measures that would support the best possible outcomes for those living with axial SpA.

Dr Dale Webb (Chief Executive of the National Axial Spondyloarthritis Society)

Dr Webb echoed Tom Randall's welcome and the ambition of better understanding the current approach ICSs are taking to axial SpA, and the opportunities that exist to improve this, within the context of the overarching group aim to support oversight of the implementation of NICE's guidance on axial SpA. Dr Webb then introduced four key areas of relevance to the discussion, and which should also be considered for inclusion within the Major Conditions Strategy.

1. **Diagnostic delay** – There is now, for the first time, a national patient driven dataset on time to diagnosis, with the first report published. The report has shown that overall, at a national level, there has been a decline in overall time to diagnosis, and alongside this, there are pockets of excellence across the UK that have shown significant decreases in diagnosis times.
2. **Primary Care Champions** – Important work is being conducted behind the scenes on primary care information systems and resources to facilitate faster diagnosis of axial SpA.
3. **Role of hydrotherapy** – Dr Webb met then-Minister Ed Argar to discuss the role of hydrotherapy in managing symptoms for those with axial SpA, as part of a wider cross-sector initiative to raise the profile of hydrotherapy services and protect access to them.
4. **Gold Standard for axial SpA** – NASS also continues to support the goal of ensuring a defined approach to diagnosis, treatment and care of axial SpA, that goes above and beyond what is included within current guidelines.

All of these initiatives were having a notable impact on the quality of care and experience of those living with axial SpA, however more needs to be done to recognise and spread best practice where it exists, and to ensure axial SpA is better included within key national policy and guidance documents.

Presentations

2. Dr Claire Charlesworth (NASS member / GP, Nuffield Road Medical Centre, Cambridge)

Dr Charlesworth described her experiences of living with axial SpA for the past 25 years (whilst only being diagnosed for four of those), highlighting the struggles that patients typically face in achieving a formal diagnosis. As a GP, she spoke to the lack of attention that musculoskeletal conditions are given during medical training and how her fellow GPs would in many cases not know the correct approach to take if a patient presented with inflammatory signals of axial SpA, such as sacroiliitis.

It was noted that this is due to the broader perception that musculoskeletal conditions are not an immediate priority for the NHS, where surgery waiting times, cancer referrals and workforce issues dominate. Dr Charlesworth suggested that part of wider GP education should encompass the ability to be able to equip patients with the correct information and resources to allow them to self-manage their condition, which is only possible if the care of axial SpA, and musculoskeletal and rheumatology patients more broadly, is dealt with in a multi-disciplinary manner.

Furthermore, patients have highlighted that GP's, who act as the "gatekeepers" of primary care, should be more involved in the management and treatment of axial SpA patients. This includes, but is not limited to, managing flares, ensuring access to appropriate treatments and day-to-day diet management. Dr Charlesworth called for there to be further emphasis on GP education and to ensure those working in primary care are equipped with the correct skills to facilitate both improved management and treatment of axial SpA patients. As part of this, GP's need to be able to recognise the inflammatory markers that may indicate an MSK condition and therefore raise the index of suspicion.

Finally, Dr Charlesworth addressed the need for clearer criteria to be used for the diagnosis of axial SpA. Part of this includes early referral to rheumatologists, timely access to MRIs in order to assess disease progression as well as improved communication and collaboration between general practice, rheumatology and the wider patient care network. However, without sufficient allocation of resources and capital funding, the diagnostic delay experienced by those suffering with axial SpA will continue.

3. Ed Jones (Senior Policy Advisor, ICS Network, NHS Confederation)

Ed Jones provided an overview of the ICS Network, and the impact of the health system reforms, whereby the NHS in England was split into 42 separate systems. Mr Jones explained how ICSs have four key priorities to operate against:

- improving population health and healthcare
- tackling unequal outcomes and access
- enhancing productivity and value for money
- helping the NHS to support broader social and economic development.

Looking at the broader NHS landscape, it was acknowledged that health inequalities had been widening since 2010, there had been significant increases in the number of individuals living with long-term conditions in the UK and that in the last 10 years, there had been a 16% rise in the number of overall hospital admissions. Looking forward, Mr Jones explained how ICSs and the NHS are seeking to shift to a model of prevention rather than treatment and that, in the future, more emphasis should be placed on primary and community care, rather than on emergency care services.

With this context in mind, the ICS Network released their second annual report into "*The state of integrated care systems 2022/23*" in August '23. Data from the report shows that, despite mounting pressures being placed on the NHS, with ongoing workforce issues being particularly acute, progress is nonetheless being made in certain key areas, such as improving population health and enhancing overall productivity.

Mr Jones highlighted that primary care is still the lynchpin for many different diseases and that appropriate management and upskilling in primary care will allow for the implementation of efficiency drivers throughout the system. In the long term, this will allow more patients to gain access to appointments followed by timely referrals into the appropriate follow-on service should they need it. Mr Jones acknowledged that restructuring the NHS again would be akin to flying a plane whilst trying to fix it and that instead, we should leverage the skills already in the system and shift the focus over to a multi-disciplinary and holistic response to patient care.

Finally, in the context of axial SpA, it was acknowledged that there needed to be a redesign of the patient care pathway that would not only facilitate earlier diagnosis but also appropriate access to treatment and management. However, this is only possible if there was greater collaboration between commissioners, clinicians and providers, patients and industry.

4. Dr Jon Packham (Consultant Rheumatologist, Midlands Partnership NHS FT)

Dr Packham, who sits on the MSK implementation for the Staffordshire ICS, acknowledged that across the 42 different ICSs in England, each one was at a different stage of their respective decision-making processes with regards to planning and implementation for MSK conditions, which results in significant national variation. Whilst axial SpA is no longer a common condition, with around 220,000 adults living with the disease across the UK, it is still viewed as a lower priority when it comes to commissioning and planning for more common conditions, for example cardiovascular and respiratory diseases.

One opportunity for addressing this could potentially be through each ICS across England being designated with responsibility for a 'less common' condition - based on clinical expertise in an area - and then developed pathways and relevant guidance to support optimal pathway development and care delivery. This approach would offer a regional example of best practice that could be replicated by other areas throughout the ICS network, allowing for tailored local adoption to suit specific circumstances. This would avoid a scenario where individual Trusts or care systems are left to each produce from scratch different pathways to try and achieve a specific outcome (for instance, earlier diagnosis of axial SpA), and would as a result likely lead to greater efficiencies and a reduction in unwarranted variation.

Dr Packham explored that referral from primary to secondary care for symptoms of axial SpA is not solely the responsibility of GPs and that back pain more broadly is dealt with by primary care physicians. There would therefore need to be further education across the primary care sector to ensure no axial SpA patients slip through gaps in the system. It was noted that the current NICE guidelines for the diagnosis of axial SpA are based on the Braun criteria (which is due for an update with the Baraliokos team), these are in practice considered to be convoluted and difficult to interpret, therefore leading to a need for reconsideration.

Dr Packham concluded his presentation with an update on his forthcoming research study, whereby a cohort of 800 patients under 50, with back pain for over 3 months, will have several diagnostic tests and assessments. The study will also contain representation from a matched cohort without back pain so that clinical markers of axial SpA (including inflammation or fusion observable on MRI scans and inflammatory biomarkers) can be established. Dr Packham looked forward to sharing further updates with the group in due course.

5. Key Group Discussion Themes

Opportunities to address limited clinical awareness

- Attendees considered how throughout the healthcare network, there was a significant knowledge gap when it came to skills being in place to accurately and consistently identify signs and symptoms of axial SpA. It was agreed that achieving stronger GP and wider primary care education would address a significant barrier in cutting the current diagnostic delay as patients would be less likely to present to GPs with recurring symptoms, such as back, hip and broader joint pain. Attendees agreed that leveraging the outputs from the NHS Workforce Plan would be key to achieving wider education.
- It was also noted that in undergraduate training for all allied health professions, very little time is given to MSK or rheumatological conditions. Ensuring that newly trained health professionals, such as GPs and nurses, are supported to address this knowledge gap is paramount to ensuring the issues experienced by those living with axial SpA are not compounded further.
- Finally, attendees considered that when patients presented to healthcare professionals with symptoms of axial SpA, a holistic approach should be taken. This means that the symptoms, such as a back or joint pain, should not be viewed as episodic, but rather be viewed against a wider and more individualised case history. Attendees suggested that the integration of tools into GP data systems that flag if symptoms, such as back and joint pain, have been reported before would play a key role in helping to prevent repeat presentations of those living with axial SpA.

Generating axial SpA traction across the ICS network

- Attendees considered how individual ICSs could become examples of best practice in a specific disease area, particularly in relation to pathway redesign for a condition such as axial SpA. It was suggested that there would have to be a concurrent sharing of data, best practice and broader information on a national scale in order to maximise the benefits of locally developed expertise. Looking at MSK, rheumatological and other 'less common' conditions, it was felt that there would need to be close coordination with local clinical experts in a given disease area in order to drive change within their locality. It was also noted that patient and professional organisations, such as NASS, would be vital to the sharing of expert knowledge as well as relaying the needs of the patient population.
- Whilst such an approach is likely to be met with significant barriers when it comes to achieving required resourcing (including both the workforce and funding of such a project), attendees felt that adopting this model, whereby a "gold-standard" pathway was developed for an uncommon condition by one ICS, would provide clear benefits for the other 41 systems and lead to long term savings as a result.

How axial SpA can support key NHS policy aims

- Attendees considered how better inclusion of axial SpA within ICS's workplans could play a significant supporting role towards the aims of recent flagship NHS and Government policy, including through reducing the backlog, freeing up capacity elsewhere in the system and helping to keep people in the workforce for longer.
- In parallel, it was agreed that achieving the consideration of axial SpA within the Major Conditions Strategy and the ongoing implementation of the NHS Workforce Plan should represent key aims for the sector, and would help to play an important role in driving up standards of care and helping patients to receive a diagnosis more quickly.

6. Meeting Close

Tom Randall MP closed the meeting by acknowledging the valuable perspectives that had been shared via the expert presentations and the clear value in achieving increased consideration of axial SpA within local ICS delivery plans. He added that he will continue to put key calls to action forward to Government Ministers and will seek to stay involved in the plans around the forthcoming release of the Major Conditions Strategy.

Following the meeting, key areas of discussion will be incorporated within an ICS-facing briefing document, that will seek to capture key reasons and opportunities for better adopting axial SpA within local commissioning plans. This will be shared with APPG members who may wish to engage with respective local ICS stakeholders.

Further information

For any further information about this meeting or the APPG on Axial Spondyloarthritis, please visit the [NASS website](#) or contact the APPG secretariat via appgspa@mandfhealth.com.