

Second Group Meeting: Minutes

All-Party Parliamentary Group on Axial Spondyloarthritis July 2019

Introduction

This document contains the minutes from the second meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA) including ankylosing spondylitis (AS). The meeting - *Assessing the uptake of key NICE guidance for Axial SpA* - took place on Tuesday 9th July in Committee Room 11 of the Houses of Parliament.

Meeting Minutes

1. Welcomes and scope of the meeting

Lord Campbell-Savours (Labour Life Peer) welcomed attendees to the second meeting of the APPG on Axial SpA and provided a brief recap of the inaugural session of the group. A key output from the inaugural meeting was the dissemination of a group Freedom of Information (FOI) request, which saw a series of questions developed around the NICE Guideline and Quality Standard for Spondyloarthritis circulated to every Clinical Commissioning Group (CCG) and NHS Hospital Trust in the country. The FOI was taken forward to better establish what axial SpA (AS) service provision across the country currently looks like and to understand where the gaps are, therefore informing how the APPG could best focus its efforts to ensure it has the maximum impact in terms of helping to improve outcomes for those affected by the condition.

Dr Dale Webb (Chief Executive of the National Ankylosing Spondylitis Society, NASS) emphasised the importance of the group taking forward activity that could support the overarching goal of providing national oversight around the implementation of key NICE axial SpA (AS) guidance across the country. He explained how many of those with axial SpA (AS) weren't receiving the standard of care they should expect, and how he therefore hoped that the FOI initiative could help to address this, in line with the wider NASS *Every Patient, Every Time* campaign.

2. Presentation from Dr Jon Packham, Consultant Rheumatologist, Haywood Hospital

Dr Jon Packham provided attendees with an overview and an expert interpretation of the FOI request results that had been gathered by the APPG and NASS in advance of the second group meeting. Dr Packham explained that the NICE Guideline and Quality Standard for Spondyloarthritis are the first to advise both clinicians and commissioners on what good clinical care for axial SpA (AS) patients should look like, and it was therefore of high importance to ensure that they were being implemented effectively across the country. The request was comprised of 10 questions, structured around a recommended quality framework for patients, covering key areas of care that should be in place to ensure best practice, including recognition and referral, diagnosis in specialist care settings, information and support, pharmacological and non-pharmacological management, flare management, organisation of care and mental health and wellbeing support. The framework was developed by NASS based on the Guideline and Quality Standard, but also including areas not covered in these documents, but were important to patients. The results were provisional as a number of CCGs and NHS Trusts had not responded within the statutory time frame.

Dr Packham described the current average 8.5-year delay to diagnosis for axial SpA (AS) patients, and the factors that often contribute to this, such as poor symptom recognition. The fact that the results to the FOI showed that **53% of CCGs did not have a specific Inflammatory Back Pain (IBP) pathway in place** therefore was of great concern and suggested much more needs to be done at a local level to ensure patients are diagnosed as quickly as possible. Dr Packham explained how achieving better

recognition of symptoms at a primary care level was a crucial component to supporting this ambition – results of the FOIs however demonstrated that **only 28% of respondents had a specific awareness programme in place to raise awareness of the condition in primary care.**

Once someone with suspected axial SpA (AS) has been identified and referred, Dr Packham described that there will still significant challenges in terms of ensuring appropriate access to diagnostic tests. The results of the FOI showed that **32% of patients with suspected axial SpA (AS) were not routinely referred for a full spinal MRI**, although Dr Packham explained that some areas may be providing patients with an initial X-ray instead, which can be considerably cheaper. Ultimately, the NICE guidelines state that patients with symptoms of axial SpA (AS) should be receiving an MRI scan if the results of an initial X-ray were negative, and this was something that Dr Packham suggested could represent a future area of exploration for the group.

Dr Packham highlighted the importance of ensuring that appropriate information and support is available for those diagnosed with axial SpA (AS), particularly as a new diagnosis can cause significant worry and confusion. Whilst the FOI results suggested that the majority of areas were providing patients with some kind of written or verbal information following diagnosis, **only 47% of areas ensured that a patient was given a named contact within the team.** Having a named contact is a crucial way of ensuring someone has continuity of care and receives the support they need, and therefore this was seemed to be an area that needs to be addressed.

Another crucial aspect of high-quality care for those with axial SpA (AS) is the local availability of specialist physiotherapy services, which are particularly important when a patient is experiencing a flare-up of their condition. Worryingly, of those that responded to the question, **only 45% said that they routinely provided patients with a general care plan to support patients during a flare.** Furthermore, **almost a third of providers were unable to offer access to a specialist physiotherapist for patients**, despite this representing a cornerstone of essential axial SpA (AS) management. In addition to this Dr Packham explained that there was growing evidence suggesting that the availability of hydrotherapy pools, a key component of physiotherapy management, were becoming increasingly restricted.

Dr Packham also stressed the importance of patients being able to access mental health services, particularly as axial SpA (AS) patients are three times more likely than the general population to experience some form of mental health challenge during their life. Despite this, **only 25% of providers offer access to psychological services in combination with a rheumatologist**, suggesting that there is lots more that can be done to better support patients and their quality of life. Dr Packham concluded by welcoming this first national audit of the availability and quality of axial SpA (AS) services across the country, the results from which clearly demonstrate that there is significant room for improvement. He felt that the initiative was an important step on the path to keeping providers and commissioners accountable for the implementation of the NICE guidelines and highlighted the need for the recruitment of more specialists to ensure that the guidance was delivered in full.

3. Presentation from Dr Antoni Chan, Consultant Rheumatologist, Royal Berkshire NHS Foundation Trust

Dr Antoni Chan provided attendees with an overview of the work that he and his team have taken forward initially in their local service, and eventually across Berkshire more widely, to successfully implement the NICE Guideline for Spondyloarthritis, to help ensure that patients receive the best level of care possible.

Dr Chan explained how the publication of the NICE guideline in 2017 had provided the local team with a roadmap to ensure the service could benchmark itself against recommended best-practice and to identify key target areas for improving the quality of care. The NICE guideline included 84 specific recommendations and Dr Chan described how he and his colleagues used these to identify five core

service delivery areas: Referral, Diagnostics, Education & Support, Treatment, and Flare and Long-Term Care. To help inform their progress in these areas, a baseline audit was carried out between February to July 2017 to help understand existing delivery levels against the key recommendations. A follow-up audit was carried out between January to May 2019 to assess the impact of the implementation of their local best practice pathway.

Dr Chan highlighted that a key area of local focus was ensuring that those with symptoms of axial SpA (AS) were able to access the dedicated service as quickly as possible. After leading a concerted effort to increase GP and patient awareness of the symptoms of axial SpA (AS), Dr Chan spoke of how he moved to doing full spine MRIs routinely as recommended in the NICE guidance. This he said, helped to diagnose an additional 10% of patients that would otherwise have been undiagnosed through the previous MRI procedure. As a result of his work, Dr Chan and his colleagues managed to reduce local diagnosis waiting times from 9.8 years (2013) to 4.4 years (2019).

Steps were also taken to improve the provision of patient information, in line with recommendations from the NICE guideline. This incorporated the development of an updated axial SpA (AS) patient pathway booklet, alongside a dedicated exercise and information booklet and wider availability of physiotherapy-led group exercise and education sessions. These initiatives have included the delivery of personalised flare management plans and enhanced flare and long-term condition management protocols. A telephone advice line is available and the service also offers weekly flare clinics and patient outcome data is collected electronically.

Dr Chan explained how after steps were taken to audit their own local service, it occurred to him and his colleagues that other organisations across the South Coast were likely to be facing similar issues to theirs. The decision was therefore taken to set up 'SCAN' - the South Coast Axial Spondyloarthritis Network - to help organisations share best practice and overcome shared problems. Dr Chan explained how the group meets twice a year and is made up of 9 centres from across the South Coast. As part of SCAN's work programme, a baseline audit of all 9 centres was conducted at the start of 2018, which helped to identify localities where immediate attention was required. The results of the follow-up audit in March 2019 saw a substantial improvement in results. The work from SCAN is shared nationally through conference presentations to allow quick dissemination and uptake with the aim of improving patient care.

Despite the positive progress that had been made, Dr Chan stressed the importance of continually looking to make further improvements. These improvements were driven by real-world data collection and measurement against key NICE guidance areas and informed through co-production of projects with multidisciplinary input and peer supported review. Dr Chan summarised the success of the SCAN approach to service improvement and suggested that there was significant scope to make improvements in other parts of the country too.

Key to achieving improved patient care was having the data collection metrics in place to understand current performance, and potential gaps in service provision. Dr Chan also suggested that having a dedicated axial SpA (AS) champion embedded within each local area would have significant benefits in terms of helping to raise awareness of the condition and its signs and symptoms amongst non-specialist colleagues, and ultimately ensure that the key elements of good care are in place to help provide the best possible patient outcomes.

4. 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.

Data on the impact of a dedicated Inflammatory Back Pain (IBP) pathways

- Dr Andrew Keat, retired Consultant Physician and Rheumatologist, asked if there was any hard evidence which demonstrated that the availability of a dedicated IBP pathway led to better outcomes for patients, or whether this was an area of unmet need?
 - Dr Jon Packham explained that in creating the guidelines, the NICE economic model developed allowed NICE to find the approximate cost of a pathway and the cost per patient. Whilst there wasn't extensive data in the area, Dr Packham indicated that NICE felt that IBP pathways represented the most successful option from a health economic perspective. Dr Antoni Chan added that the IBP pathway is useful in reducing delays to diagnosis and that tools were available at a local level to help capture the data.

Development time of NICE guidance

- Dr Andrei Calin, Vice-President of NASS, asked about the development process of the NICE Spondyloarthritis guidelines and the evidence they used to underpin their diagnostic recommendations, referencing the previous 'Calin criteria' for inflammatory back pain he developed. He stated that in his experience GPs had found the current NICE guidance complicated to use.
 - Dr Jon Packham suggested that in his experience of being involved in the development of guidance, NICE realised that the existing guidance was relatively clunky to use, and although it worked, new research evidence was needed to ensure that GP screening could be better implemented.
 - NICE showed that the Calin criteria to identify inflammatory back pain works at least as well as other criteria. However, it is now known that inflammatory back pain fails to identify a sufficiently large proportion of axial SpA (AS) patients presenting to GPs to use as screening tool on its own.

Commissioner and provider roles in influencing the delivery of axial SpA (AS) care

- GP Commissioner Dr Ian Bernstein suggested that from his experience, commissioners often give a free hand to Trusts in how they choose to deliver local axial SpA (AS) services, and therefore any restrictions in the availability of core care components found through the FOI results were not necessarily attributable to them. Instead, he suggested that restrictions often came from the hospitals themselves, and he was aware of many rheumatologists expressing their opinion that a dedicated axial SpA (AS) clinic often wasn't deemed as necessary.
 - It was suggested that whilst the NHS has many of the building blocks to improve outcomes in an area in place, it was often a lack in availability of necessary clinical leads required to successfully implement them that stood in the way of progress being made.

Availability of specialist physiotherapists and radiologists

- Several attendees highlighted concerns that there weren't enough specialist physiotherapists in place to be able to ensure that all those with Axial SpA (AS) received the necessary level of care they should be entitled to. More broadly, it was suggested that there were significant recruitment problems within the physiotherapy sector as a whole, and that an additional 500 physiotherapists were needed each year to keep up with demand, on top of those already in training. Attendees also commented on the shortfall in the numbers of specialist radiologist within the system, and the problems this created for ensuring timely diagnosis of those with symptoms.
 - The wider challenges in the system were acknowledged, and it was felt that whilst steps should still be taken to improve the availability of dedicated axial SpA (AS) experts, a more flexible approach would be needed. Dr Packham suggested for instance that if

clinicians from a more diverse group of health professions were available to provide routine clinical care, this would allow experts like Dr Chan to dedicate more of their time to driving forward service improvement, both at a local level and across the country.

- Dr. Chan highlighted that in line with the NHS Long Term Plan, there is a need to engage with wider workforce including First Care Practitioner (FCP) Physiotherapists who will be working within Primary Care Networks. FCPs are likely to be assessing patients with musculoskeletal issues early and there will be an opportunity to identify patients with axial SpA (AS).

Access to hydrotherapy services

- NASS Members Gillian Eames and Roger Stevens both raised concerns around apparently diminishing access to hydrotherapy pools across the country. Gillian described her current situation in which she has to regularly travel from London to Bath to access the care she needs, as she has no access to adequate services where she lives. She stated that she wished there was more specialist centres available across the country allowing patients to have a greater choice of where to be seen. Roger Stevens added that patients from across Hampshire and the South Coast came to use their hydrotherapy facilities at Queen Alexandra Hospital in Portsmouth, and the hugely negative impact there would be if this facility were no longer available.
 - Dr Antoni Chan emphasised the importance of ensuring specialist hydrotherapy facilities were available across the country and explained how he thought the main solution to funding was for organisations to join together to help with a lack of resources. Integration and collaboration between organisations within a locality will be key to ensuring best use of resources and ongoing provision of services to patients.

Helplines and Access to 111

- The potential of having an axial SpA (AS) specialist embedded within the NHS 111 call centre was suggested, to help ensure that patients are directed appropriately to the best resource at a time of crisis. The group heard how one attendee had to wait over ten hours to get through to the right person.
 - Dr Jon Packham felt that this could be a fruitful area to look into. He wasn't sure what processes NHS 111 currently had in place around axial SpA (AS), but suggested that it should be feasible for them to take steps to incorporate key elements of the IBP pathway within their question and answer matrix.

Next Steps

Lord Campbell-Savours and Dr Dale Webb provided a brief summary of the discussions and reiterated their thanks to both speakers and attendees for contributing to such a wide-ranging and rich discussion about current axial SpA (AS) challenges, and the opportunities that exist for addressing these, particularly within the context of some of the sobering FOI results.

Lord Campbell-Savours and Dr Webb discussed what steps could be taken forward to build on the FOI findings and maximise awareness of what needs to be done to ensure those with axial SpA (AS) receive the best care possible. They stated that the group would use the results as the basis for an inquiry report which would give practical advice about how gaps in service provision could be addressed. This would then be shared with all MPs to help them lobby for improvements in the service provision in their respective local areas and support constructive engagement with commissioners on how best to achieve that. Communication on behalf of the group would also be taken forward with commissioners directly.

The inquiry document will be presented at the next meeting of the group, alongside a wider progress update on communication the group is taking forward. The next meeting of the APPG will likely take



place in early December, in line with the broader Parliamentary calendar, with further details being circulated to attendees in the coming weeks.

Further information

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