appg All-Party Parliamentary Group for
Axial Spondyloarthritis
Reducing the delay to diagnosis and improving services in axial SpA

Seventh Group Meeting: Primary Care & Axial SpA

All-Party Parliamentary Group on Axial Spondyloarthritis Minutes October 2020

Introduction

This document contains the minutes from the seventh meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting - *Axial SpA and Primary Care: Improving identification and onward referral* - took place virtually, on 20th October.

Formal APPG Business

1. Welcome and introductions

APPG Chair Tom Randall (Conservative MP for Gedling) welcomed attendees to the seventh meeting of the APPG on Axial SpA and set out the vital role of primary care in reducing the average 8 ½ year delay to diagnosis of the condition. He acknowledged the current pressures facing primary care, particularly in the context of the workforce, whilst also setting out some of the opportunities to work towards improvements provided by new models of commissioning and the changing NHS policy environment.

2. APPG Update

Tom Randall provided a brief update on the recent work of the All-Party Parliamentary Group, included a recent meeting between the APPG and the Health Minister Edward Argar MP. This meeting focused on hydrotherapy services and provided an opportunity to highlight the importance of these facilities for those living with axial SpA (and other conditions) and the need to ensure that facilities are prioritised for reopening as part of the wider restoration of services following the pandemic. There was an encouraging discussion at the meeting and the Department’s formal response is expected in the coming weeks.

Presentations

3. Presentation from Dr Louise Warburton (Associate Medical Director and GPwSI in Rheumatology, Shropshire Community NHS Trust

Dr Louise Warburton’s presentation focused on the main challenges faced by GPs in diagnosing axial SpA. This started with an assessment of the scope of the problem. GPs often experience difficulties in this area as many of the symptoms associated with inflammatory arthritis are common across those accessing primary care more generally. In a joint symptom survey led by Dr Sam Hider in 2019 which involved 4,549 adults, it was found that 52.3% were consulted for a musculoskeletal problem. Many of these patients reported persistent joint pain, swelling and stiffness, but these symptoms were also common amongst people consulting primary care for non-musculoskeletal reasons. This makes it even harder for GPs or first contact practitioners (FCPs) to carry out symptom assessment and determine the appropriate course of referral to secondary care.

There are also significant pressures on general practice. The workload of GPs was already growing in volume and complexity before the pandemic, particularly due to the increased presence of comorbidities that require specialist input from multiple areas. Dr Warburton reflected on how the knowledge base required of GPs has had to increase as a result. She also shared the findings of research from the King’s Fund in 2016 which found that there has been a 15% overall increase in contacts, a 13% increase in face-to-face contacts and a 63% increase in telephone contacts in recent years. This increase in demand should also be contextualised by the falling GP numbers and reduced capacity over the same period.

Dr Warburton explained that on average, GPs with a list size of 2,000 patients are likely to come across one case of axial SpA every 12 months. This contrasts with the significant number of patients presenting with back pain, which is likely to be 1 or 2 during every surgery. There is subsequently a pressing need to improve awareness of axial SpA amongst GPs, FCPs and additional roles across primary care networks, including addressing the misconception that axial SpA does not affect women. A fast-track assessment service for people with symptoms indicative of axial SpA should also be introduced as typical MRI protocols will not be sufficient. This will require a low threshold of suspicion and prompt onward referral to rheumatology departments.

Dr Warburton then shared an example of best practice service provision in Shropshire. Since 2016 there has been an integrated MSK service involving collaboration with the local acute trust and the use of a single point of electronic referral. This system works effectively and ensures that axial SpA patients have swift access to a trained team of clinicians who meet regularly and collaborate with rheumatology teams. Rolling out similar schemes more widely could help to support many of the ambitions in the area.

4. Presentation from Dr Dinny Wallis (Consultant Rheumatologist, University Hospital Southampton NHS Foundation Trust)

Dr Wallis provided attendees with the secondary care perspective in the area. the presentation also reflected on the scope of the problem and the challenges involved in recognising axial SpA symptoms. During a 12-month period, 7% of the population will consult GPs with low back pain - despite this high prevalence, rheumatology teaching comprises a very small part of the medical curriculum, although Dr Wallis did acknowledge the significant competing pressures in this area.

Dr Wallis then reflected on the development of rheumatology training for GPs and medical students. This began in 1992 when a group of rheumatologists worked together to develop guidelines on the undergraduate curriculum in the UK in the hope that basic rheumatological competencies would be incorporated. They advised that the curriculum should include education on the clinical presentation and natural history of common rheumatic syndromes, as well the clinical determination of a differential diagnosis following presentation with common manifestations. In 2000, a group of researchers reflected on the changes to clinical practice in the past 10 years and found that in 5 medical schools up to half the students may receive no clinical rheumatology teaching and the time allocated to rheumatology teaching had fallen from a median of 4 weeks to just over two weeks. From a European perspective, in 1999, the EULAR Standing Committee on Education and training proposed a curriculum focused on back pain, inflammatory back pain and destructive back pain including axial SpA. Meanwhile, in the current GP curriculum, there are specific references to being able to recognise patients with axial SpA.

Turning to the secondary care perspective, Dr Wallis described current service provision in Southampton University Hospital. Southampton has taken part in the National Axial Spondyloarthritis Society (NASS) Aspiring to Excellence Programme, which has supported an emphasis on improving time from presentation of axial SpA in primary care to the referral to rheumatology departments. This started with an assessment of current performance and the organisation of care in Southampton. An audit of 73 patients found that the median time from symptom onset to a rheumatology appointment is 1-2 years, although this can range from 0-14 years. 5 telephone interviews with patients who had a delay of over 8 years to diagnosis were also carried out to understand their perspective on why it took such a long time to get a diagnosis of axial SpA. Respondents referenced the commonality of back pain and a lack of clinical knowledge, whilst they also reported feelings of embarrassment.

Further investigations around the organisation of care in Southampton found that there is no specific inflammatory back pain pathway, the criteria for booking patient clinics are poorly defined, and there is also a lack of clarity as to whether the referring doctor reads the booking criteria. Dr Wallis then referenced the hospital's intention to carry out a survey to determine how GPs use the E-referral system and their overall confidence in diagnosing axial SpA. Key opportunities for improvement relate to engaging medical students and GP trainees in rheumatology teaching, providing educational content within the GP referral system, identifying local GP champions in musculoskeletal health, and developing close networks with other hospital colleagues such as in ophthalmology and dermatology. These were all learnings that could be applied across the system as a whole.

5. Presentation from Abigail Henderson (Head of FCP Programme, Chartered Society of Physiotherapy)

Abi Henderson’s presentation focused on the role of FCPs in recognising axial SpA. This began with an overview of the FCP model in primary care and bringing musculoskeletal expertise to the start of the patient pathway. FCPs offer an advanced MSK assessment that can identify any red flags and provide the basis for onward referral to a specialist. They can also provide a diagnosis and deliver first-line interventions around social prescribing, self-management, and physical activity.

The work of FCPs is underpinned by certain principles which support their capacity to diagnose axial SpA. These include integrating services with the surrounding musculoskeletal system, offering a population health and personalised care approach, and delivering good patient experience outcomes. FCPs tend to operate at a high level of practice based on their clinical experience and ability to manage complex caseloads. Their capacity to support and enable the diagnosis of axial SpA is improved by ensuring that they are integrated into local pathways and embedded into primary care teams. This involvement in primary care teams also provides a platform to share expertise and learnings.

Abi then outlined two case studies that involved the successful onward referral to a local rheumatology pathway from an FCP, before summarising the benefits of the FCP model for axial SpA patients. This relates to their position as the first point of contact, their capacity to deal with long-term and recurring problems, their management of an undifferentiated caseload and uncertainty, as well as their enhanced recognition of inflammatory conditions. Abi concluded by acknowledging the similar difficulties faced by FCPs in recognising the symptoms of axial SpA whilst also emphasising the vital role that they can play in reducing the delay to diagnosis.

6. Presentation from Chris Mercer (Clinical Lead for the Primary Care and Community Workstream, National BestMSK Health Programme)

Chris Mercer provided an overview of the Best MSK Health programme and how this is working to support improved outcomes for those affected by axial SpA. The programme serves as a key opportunity to build on the positive developments witnessed during the pandemic and the new integrated ways of working that have emerged. Chris explained how the emphasis of the programme is around supporting integration across the community, primary, secondary and tertiary care sectors, all of which is vital to the delivery of effective musculoskeletal care.

Key clinical workstreams relate to spinal care, orthopaedics and rheumatology as well as supporting workstreams across data and personalised care. Chris described his role in leading the primary care and community workstream which reaches into many other parts of the national programme, reflecting how around 75% of care for musculoskeletal patients occurs in this setting. The workstreams include specific activity around pathways to look at high volume and low complexity conditions such as axial SpA, whilst there is also an emphasis on increasing access to specialist advice and guidance and improving data collection. Improving the robustness of data collection is vital to enabling improved service planning and resource management.

Chris then shared some examples of the pathways that have been developed across primary and community care, including a description of what patients can expect to happen at each step of their journey through the system. This pathway often ends with patients being sent back to primary care. Supporting guidance documents have been developed for commissioners to help identify transformational opportunities. The implementation of this work is enabled by a variety of partnerships and collaborative agreements across NHS England and with arm’s length bodies, charities, and patient groups.

Turning to the specific field of rheumatology, Chris shared the speciality recommendations for this area, which includes the ambitions for standardised and streamlined pathways for the early identification of inflammatory arthritis and axial SpA. This prioritisation is reflected in pathway development, with two pathways for inflammatory arthritis currently out for consultation. These all contain guidance as to what investigations and interventions should take place at each stage for patients living with axial SpA.

Chris concluded by setting out the importance of axial SpA within the BestMSK Health programme and the next steps for this work. These include urgent and emergency guidance updates around early identification, the development of a musculoskeletal data set for primary care, standardising service provision, and the publication of specialist advice and guidance documents.

7. Question and Answer Session

Tom Randall MP thanked the speakers for their presentations and passed over to Dr Dale Webb, the Chief Executive of NASS, to facilitate the group discussion. Before doing this, Dr Webb was keen to clarify that the discussion is not seeking to cast blame at any particular part of the system and referenced the unacceptable abuse that has recently been directed towards some individuals working in primary care. A summary of the group discussion has been included below:

Visibility of axial SpA in primary care

- All the presenters were asked to reflect on what steps can be taken to increase the visibility of axial SpA in primary care. Dr Warburton referenced the potential role of reminders/prompts while GPs are conducting consultations, as well the benefits of identifying enthusiastic GP champions. Chris Mercer and Abi Henderson both emphasised the important role for FCPs who bring a growing understanding of axial SpA and how they can share this understanding with GPs and other primary care colleagues. These individuals should be embedded and integrated into primary care.
- Dr Raj Sangupta (Consultant Rheumatologist, Royal United Hospitals, Bath) provided an overview of the work he is leading to translate the common features of axial SpA to a digital interface and how this can be integrated into general practice. This interface carries out background checks after a GP enters back pain as a symptom to identify any other potential signs of axial SpA. Studies are currently planned to validate and check this tool which could develop into a widely used and accessible method of determining the need for onward referral.
- Frances Reid (Chair of NASS Cambridge) shared her perspective as an axial SpA patient and her experiencing of requiring a hip score sheet before she could have a discussion about her symptoms with a GP. This is especially challenging as patients don’t generally know what to look for when discussing their symptoms. Work should be done to help GPs narrow down symptom presentation. Building on this, Dr Warburton explained the importance of allowing sufficient time for GPs to ask questions and properly examine the ‘soft signs’ of axial SpA, although this is constrained by the current pressures on general practice.

The relationship between primary and secondary care

- The presenters were also asked about the relationship between primary and secondary care. Dr Wallis shared her experiences from Southampton hospitals where relationships between these different sectors are generally good. Key factors that help those relationships include regular dialogue and ready access to advice and guidance to support the referral process and respond to the queries of GPs. Dr Warburton built on this emphasising the value of accessibility and building friendly relationships. These relationships have been damaged by the lack of clinical meetings involving both GPs and consultants due to capacity pressures on both sides. Chris Mercer also contributed to this area mentioning the importance of finding a balance in referral, and ensuring that secondary care colleagues are not inundated with cases of inflammatory back pain.

National musculoskeletal programme

- The discussion then turned to the national musculoskeletal programme. Chris Mercer described how the pandemic has led to significant opportunities in this area in terms of multi-disciplinary working, cross-sector discussions and the enhanced use of digital tools. He also touched on the engagement that has been undertaken at a regional level to support the delivery of the programme.
- Andy Bennett, (National Clinical Director for MSK) was also invited to provide his perspective. He acknowledged the present challenges across musculoskeletal care, many of which have been complicated by the experience of the pandemic. He also touched on the opportunities provided by the past 18 months and the need to carry over the ethos of collaboration and integration to the restoration services. Reducing the time to diagnosis is a key target and work to meet this will be led in primary and community care. Rheumatology capacity will be optimised to ensure non-

inflammatory conditions are best managed in the community, with direction developed collaboratively rather than in silo. This can provide the vehicle for local adaption and adoption.

- Dr Lesley Kay (Clinical lead, Getting it Right First Time – GIRFT – Rheumatology workstream) was also invited to share her perspective in the context of her work on Getting it Right First Time's rheumatology workstream. She brought attention to the development of musculoskeletal pathways on the NHS Futures platform and invited attendees to comment and promote these resources, before touching on the appointment process for local and regional rheumatology leads. Many of the appointments to date for these positions have been orthopaedic surgeons and it is vital that these individuals are aware of their responsibility for promoting rheumatology.

Diagnostic testing for Axial SpA

- Finally, the discussion turned to the diagnostic process and efforts to improve the acceptance of referrals from healthcare professionals to rheumatology departments. Dr Warburton described how work needs to be carried out to ensure a proper conversation is taking place particularly around the referral process for inflammatory spinal protocol MRI. Many radiology departments do not accept referrals from this scan due to the difficulty in interpretation. Chris Mercer added to this point when he set out the huge potential for over-diagnosis with spinal MRI and the need for caution when requesting spinal MRI scans.
- Victoria Carter (NICE implementation team) was then invited to share her perspective on the discussion and provide an update on the recent work of the organisation. She applauded the work of the APPG in highlighting some of the challenges involved in the implementation of the NICE guideline for Spondyloarthritis and how this has prompted the organisation to carry out an impact report to assess the implementation and uptake of the recommendations in NG65. Victoria also reflected on the potential role of GP pop-ups in supporting the implementation of NICE guidelines and how the forthcoming impact assessment report can provide a strong platform for communication programmes. Victoria highlighted her willingness to receive correspondence from attendees about their experience of axial SpA and discuss how this can be incorporated as part of the forthcoming Impact Report.

8. NASS Activity Update

After bringing the discussion to a close, Dr Dale Webb provided an update on the activity of NASS. This began with a reminder of the role of the APPG and ensuring the effective implementation of NICE Guideline NG65. A key focus from NASS in supporting this aim has been its development of the *Aspiring to Excellence* programme. The first report of this programme involving six hospitals was launched at an ARMA webinar on 12th November, which focused on the role of patient organisations in rheumatology and implementing the GIRFT report.

Dr Webb also touched on the launch of the *'Act on Axial SpA: A Gold Standard Approach'* campaign and the roadmap to achieving the time to diagnosis of one year. This started with setting up the *'Actonaxialspa.com'* website with the aim that this platform will become the largest resource in the world on axial SpA diagnosis, providing information, support, research, best practice, quality improvement tools and case studies.

A patient awareness campaign has also been established in tandem to take people on a journey towards wider knowledge of axial SpA symptoms. This has been supported by a social media campaign targeting younger audiences and the development of the SPINE demographic which breaks down a complex condition into 5 key symptoms. An 8-point online symptom checker has already been used by over 1,200 people, whilst guidance is also in place to support people to prepare for both their GP and rheumatology appointments. These resources are all orientated around empowering patients to know about their condition. After just a few months of the campaign, the social media activity has reached over 450,000 people, whilst video content has been viewed 375,000 times. Coverage has also been published in the Mirror, Daily Express, Men's Fitness, Chat magazine, and regional press.

Dr Webb then outlined the next programme of work which is due to start in January next year. This is designed to create and support a cadre of roughly 20 axial SpA primary care clinical champions. These individuals will receive leadership development training using Quality Improvement methods, support to implement improvement projects, work together in a national learning network, and feedback into the wider healthcare system.

9. Meeting Close

Dr Webb then passed back to Tom Randall MP who brought the meeting to a close. Tom reflected on the quality of the group discussion and the importance of working with the primary care sector to improve the identification of axial SpA and reduce the delay to diagnosis. He referenced the work of the APPG in taking forward these issues before thanking all the presenters and attendees for their contributions.

Further Information

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

The work of the APPG in 2021 is made possible through funding from NASS and sponsorship from Novartis and UCB. Sponsors do not have editorial control over the content or outputs of the APPG. Further information on the APPG is available on the NASS website.