

# Eighth Group Meeting: Rheumatology Physiotherapy

## All-Party Parliamentary Group on Axial Spondyloarthritis Minutes

### May 2022

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#### Introduction

This document contains the minutes from the eighth meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting - *Axial SpA and Rheumatology Physiotherapy: Reducing variation in service provision* - took place virtually, on 3<sup>rd</sup> May.

#### Formal APPG Business

##### 1. Welcome and introductions

APPG Chair Tom Randall (Conservative MP for Gedling) opened the meeting setting out the vital role of physiotherapy care in the management of axial SpA. This began with reflection of his personal experience of living with axial SpA and how specialist physiotherapy has often been a crucial factor in determining whether he is able to manage the discomfort and flare-ups that he faces every day. He then set out the key context for the meeting, including the findings from the APPG's own inquiry in 2019/20 which found that a fifth of NHS services were not able to provide access to a specialist rheumatology physiotherapist for those with axial SpA. This is despite the presence of NICE guidance recommending that everyone with a diagnosis of axial SpA is referred to a specialist physiotherapist for a structured exercise programme. Many axial SpA patients are subsequently missing out on access to one of the most important ways to improve the management of their condition.

##### 2. APPG Update

Tom then provided a brief overview of the APPG's plans for the remainder of the year and how these would seek to align with broader developments in the NHS policy landscape. This includes the delivery of a second national audit report to help build a clearer picture of the current state of play in axial SpA across the NHS. The report will assess how key aspects of care have changed from the first national audit and provide decision-makers with key insights to support service planning at national and local levels. Findings from the report will be shared at the next meeting of the APPG session in the Autumn. There are also plans to host a parliamentary reception event in partnership with NASS towards the end of the year. This will provide an important opportunity to look back on the considerable progress that has been made since the group was set up in 2019, as well as looking ahead with a view to informing future priorities. Before welcoming the first speaker, Tom referenced that further details about the event will be shared closer to the time.

#### Presentations

##### 3. Presentation from Roger Stevens (Chair NASS Portsmouth Branch)

Roger Stevens's presentation focused on the benefits that specialist rheumatology physiotherapy can provide for axial SpA patients and the subsequent negative impact of restricted access. This began with details of his personal background and his diagnosis with axial SpA that he received at the Royal Naval Hospital during the 1990s. In contrast with the physiotherapy support that he had received for other conditions, Roger described the limitations of the offering for axial SpA and the lack of advice that was given during his first appointment. This prompted some scepticism from Roger towards physiotherapy in general, until Roger joined the local NASS branch in Portsmouth which has had a transformative impact on his ability to manage the condition, through providing access to proper specialist care and advice. The Portsmouth branch benefits from access to high-quality, specialist physio care, alongside the provision of a 6-week system of hydrotherapy sessions for newly diagnosed patients and physio-led courses that include guidance on land exercises. All of this provides the platform for patients to develop tailored exercise programmes that truly reflect their individual needs.

This service excellence has enabled Portsmouth to take part in various national courses for physios and other healthcare professionals focused on the treatment and management of axial SpA. Local interest in axial SpA and the specialist support that is needed for patients has also grown. Roger then went to describe the experience of another individual who was recently referred to physiotherapy care by her consultant and how

the lack of support that she received during her first appointment largely mirrored his own experience nearly 30 years ago. This provided a clear indication that despite the significant general progress that has been made during this time, a great deal of additional specialist training still needs to be provided. Roger concluded by referencing the important role of NASS in both reducing the delay to diagnosis but also ensuring that ongoing treatment and management is in place for patients further down the axial SpA pathway through a specialised dedicated physiotherapy team.

#### **4. Presentation from Dr Yeliz Prior (Senior Research Fellow, Clinical Occupational Therapist and Vice President of the BSR)**

Dr Prior shared the perspective of the British Society for Rheumatology (BSR) and some of the challenges facing the physiotherapy workforce. This began with an overview of the role of the BSR in bringing together expertise from across the rheumatology profession and harnessing a variety of experience and skills to ensure members are supported to the very best of their combined ability. Membership of the BSR spans across clinicians, scientists, academics and researchers to ensure that all perspectives are considered in the development of best practice guidance.

Turning to the specifics of axial SpA, Dr Prior described how musculoskeletal (MSK) disorders are primarily managed in the community, whilst rare diseases are normally left to specialist multidisciplinary (MDT) teams in secondary care. Physiotherapy has proven to be a cost and clinically effective way of restoring movement and function, preventing disability, and improving the quality of life for patients living with axial SpA right across all different stages of the disease. Unfortunately, there is insufficient capacity across the physiotherapy workforce to deliver the level of care recommended by NICE.

This lack of capacity was exposed by a 2019 freedom of information request which found that patients were waiting up to 4 months to see a physiotherapist. These waiting times have worsened following the pandemic, as the patients who deferred seeking help present in greater numbers. Physiotherapy services have increasingly focused on trying to deliver support to patients who are on the waiting list through providing communication around the self-management of their condition. 50% of hospital departments don't have physiotherapists embedded in their MDT, whilst these workforce shortages are reflected across other members of the MDT team including consultants, nurses, occupational therapists, podiatrists, psychologists and pharmacists. The shortages all impact on the quality and safety of care, as well as the effectiveness of preventative approaches and rates of earlier diagnosis.

Dr Prior then concluded by providing an outline of the key recommendations arising from the BSR's workforce report. These included calls for all rheumatology services to have a dedicated physiotherapy service, the inclusion of specific commitments in the Health Education England (HEE) workforce strategy to train and recruit more physiotherapists, and an increase in the exposure to rheumatology during graduate curricula. There was also a specific request for APPG members to write to their local Integrated Care System (ICS) to ask about rheumatology workforce planning.

#### **5. Presentation from Amanda Hensman-Crook (Consultant MSK Physiotherapist and Health Education England National Workforce Transformation Team MSK Subject Matter Expert Lead)**

Amanda set out how she wanted to raise awareness of the recent educational standards that have been introduced to improve the early identification and diagnosis of axial SpA. There have been three significant educational developments since October 2020, including the First Contact Practitioners and Advanced Practitioners in Primary Care, the UK Advanced Practice MSK Standards, and the MSK Rheumatology Advanced Practice Standards. These standards are all designed to ensure that clinicians are trained to the right academic level of practice and have proof of capability academically.

The first contact practitioners' guidance provides a training pathway for all MSK clinicians. Clinicians can enter the programme through either the taught or portfolio route which both require the same level of knowledge and attributes. E-modules are a particularly important element of the programme and ensure that clinicians have sufficient capability to manage MSK conditions and that they can apply a personalised care approach to individual patients with shared decision-making. Clinicians are also supported to look beyond just the MSK

condition to consider any wider comorbidities involved. This roadmap has also been recently endorsed by the CQC. Turning to the UK Advanced Practice MSK Standards, Amanda referenced the importance of alignment across all MSK specialties. This has been achieved through the establishment of the MSK partnership and the development of one MSK standard at Advanced Practice Level. These standards are due to be signed off imminently and will be operational across all health educational institutions to flatten unwarranted variation.

Finally, a framework has been written and agreed for the MSK Rheumatology Advanced Practice Standard. This will provide specific population health leadership across all four pillars of clinical practice and support efforts to improve the early identification and diagnosis of axial SpA.

#### **6. Presentation from Will Gregory (Consultant Physiotherapist, Salford Royal Hospital)**

During his presentation, Will Gregory covered the recent publication of a rheumatology physiotherapy capabilities framework and how this can support the upskilling of the wider rheumatology workforce. He began by sharing a definition of the role of the physiotherapist as a *“healthcare professional who helps you remain active and independent both at home and at work. They’re experts in assessing movement, addressing individual needs, helping to improve function and managing pain”*.

Following this, Will provided an assessment of current physiotherapy service provision using case studies from the South Coast axial SpA network and in the North West. Both studies exposed the significant variation in access to specialist rheumatology physiotherapists between different local trusts. For example, the ratio between the medical and physio team varied from 1:1 in some trusts, compared to 1:8 in others. Data from best practice areas indicates that ratios of 1:3/4 are optimal.

A national survey of current clinical practice was carried out in 2019 to assess the types of roles being undertaken across rheumatology physiotherapy, which provided the platform for the development of the capabilities framework that was released in October. The document has proved to be an effective tool in enabling professional development and supporting business cases for the recruitment of new staff. Individual sections in the document align to the patient journey including MSK screening, investigations, physiotherapy interventions, condition management, medication management and non-clinical capabilities.

The framework forms part of broader efforts to assess current service provision, define key aspirations and share best practice on standards of care for rheumatology and axial SpA patients.

#### **7. Presentation from Mo Motion (Extended Scope Practitioner, Newcastle Hospitals NHS Foundation Trust)**

Mo Motion then shared an example of local best practice service provision in Newcastle, which began in August 2019 through the Aspiring to Excellence journey, and how this has helped to enable improvements in the assessment and treatment of axial SpA patients.

Mo then described the current state of play in axial SpA services in Newcastle and how a concerted effort has been made in recent years to improve the uptake of ASAS-informed screening. Recent audits have shown that compliance with this screening method is at 100% after a brief drop during the height of the pandemic. This has led to a major step forward in reducing the delay to diagnosis. Other key successes of the programme include the introduction of web-based physio, the restart of hydrotherapy services post Covid, and holding weekly axial SpA MDT meetings involving community physiotherapy staff. Recently there has been a shift towards ensuring that the full axial SpA self-referral programme is fully embedded into community physio practice.

The local team then set the goal of delivering 100% implementation of axial SpA physio pathways by March 2022. Progress towards this ambition has been underpinned by the identification of physios who will lead on rheumatology, facilitating clinical discussions about patients, providing education, compiling electronic patient records, agreeing clinical standards for physio assessment, and understanding the main drivers of variation.

Mo concluded by referencing how there is now a comprehensive management pathway for axial SpA patients in Newcastle, and how patients can expect to receive broadly the same quality of care across the region. This pathway will continue to be evaluated through a quality improvement project and the gathering of patient feedback.

## **7. Question and Answer Session**

Tom Randall MP thanked the speakers for their presentations and introduced Dr Dale Webb, the Chief Executive of NASS, to jointly facilitate the group discussion. Attendees were asked to consider four broad topic areas including: their own experience of the role of physiotherapy within axial SpA, the threats to rheumatology physiotherapy provision, how rheumatology physiotherapy can be placed on a stronger footing, and realistic aims for improving current practice over the next three years.

A summary of the group discussion has been included below:

### **Recognising the effectiveness of physiotherapy care**

- Dr Prior reflected on why we are in a situation where only 50% of rheumatology departments don't have specialist physiotherapists embedded within MDT teams. This is despite the significant body of evidence pointing to both the clinical and cost effectiveness of physiotherapy for axial SpA patients. There are particular issues around training and in the availability of clinical placements. These issues were put forward as part of the BSR's submission to the Health and Social Care Committee's inquiry into workforce shortages across the NHS.

### **Establishing required workforce levels**

- Rob Yeldham (Director of Strategy, Policy & Engagement, Chartered Society of Physiotherapy) referenced how these workforce challenges are shared across many other clinical areas, however there is cause for optimism in the popularity of physiotherapy from an educational perspective. One of the main issues relates to the lack of planning and assessment at national, regional, and local levels to determine how many physios are needed, and the lack of sustained funding to support clinicians to develop specialist expertise in areas such as rheumatology. This underpinned his call on members of the APPG to issue any encouragement they can to the Department of Health and Social Care, NHS leaders, and their local ICSs to develop comprehensive workforce plans and identify appropriate funding streams.

### **Addressing workforce challenges**

- Andy Bennet (National Clinical Director for MSK) described how physiotherapy has a wide variety of roles in MSK care including during triage, rehabilitation, and supportive self-management. The role of physiotherapy within axial SpA is mostly based in the rehabilitation and self-management spheres. He advised that workplace planning needs to be considered as a whole, rather than in specific polarised areas. The current capacity challenges across the physiotherapy workforce will take time to be addressed, so it is important to make use of other clinical specialities who can provide support such as health coaches, social prescribers, and other allied health professionals.
- Amanda Hensman-Crook provided an overview of HEE's progress with delivering on the recommendation from the BSR workforce report to develop a strategy that commits to training more physiotherapists. Currently there is more focus on the early parts of the pathway to improve early diagnosis and provide training to GPs so that they can spot the signs of axial SpA. In particular, this work has targeted professionals who have been in practice for several years to support them to develop advanced practitioner roles and specialisms.

### **Incorporating best practice within quality standards and service design**

- Responding to a question over how best practice can be incorporated into quality standards, Amanda stressed the importance of making the distinction between capabilities and standards. Capabilities refer to the level of practice that an individual is proven to be working at, whilst standards relate to operationalising these capabilities in practice. These standards need to ensure that people have sufficient capacity to train and develop their expertise and establish the right culture so that clinicians are allowed to develop skills outside of their specific role and job description.

- Responding to a question on the potential value of a consensus statement on a standard of care for axial SpA patients, which would incorporate specific recommendations on physiotherapy, Dale Webb referenced a future project to establish a gold standard of axial SpA treatment that would involve extensive engagement with professionals.

#### **Rheumatology Capabilities Framework**

- Will Gregory and Dr Carol McCrum (Consultant Physiotherapist, East Sussex Healthcare NHS Trust) reflected on the uptake and traction of the rheumatology capabilities framework and how this could help to improve the standard of physiotherapy service provision across the NHS. There was a recognition that this will take time, although in the short-term it has proved beneficial in terms of validating new and existing roles. This framework will also help to ensure that physiotherapy provision is incorporated within future clinical guidance and quality standards.

#### **Co-developing best practice**

- APPG Co-Chair Lord Campbell-Savours asked a specific question on the role of physiotherapy within local service delivery plans that have been implemented in Newcastle. Mo Motion described how these online bespoke plans are co-developed by physios and patients and have been extremely beneficial for axial SpA patients. In particular they have improved patients' ability to effectively self-manage their condition, whilst also enabling physios to monitor the uptake of specific exercises.

#### **Protecting time for staff training**

- Claire Jeffries (Physiotherapy Clinical Specialist, Solent NHS Trust) asked a question about how local physiotherapy services can ensure that there is protected time for the training of new staff through engagement with their MSK leadership team. In response, Will Gregory referenced the need for an accurate assessment of specialist rheumatology capacity and the numbers that are required to serve specific populations.

### **8. NASS Activity Update**

Dr Dale Webb then brought the discussion to a close reflecting on the pressing nature of the workforce challenges facing rheumatology and physiotherapy. He referenced an upcoming meeting with Health Minister Gillian Keegan as a potential avenue for exploring these issues further, as well as possible letters that could be addressed to the Department of Health and Social Care, NHS leaders, and local ICSs.

He then went on to provide an overview of wider key NASS priorities for 2022. This includes work to increasingly establish the 'gold standard' time to diagnosis of axial SpA, moving toward the target of achieving diagnosis within a year. Last summer this involved the first stage of a national awareness campaign to raise awareness around the symptoms of axial SpA and encourage swift action. A second iteration of this campaign will be launched later in the year. Meanwhile a two-year quality improvement and leadership development programme has been set up with a view to establishing axial SpA champions across primary care, whilst several national reviews are due to be carried out, covering the provision of axial SpA training for secondary care providers, referral pathways, and axial SpA training for radiologists. NASS will also be inviting expressions of interest in the development of an integrated pilot across the entire axial SpA pathway.

Dale then shared the results of newly delivered research carried out by the University of East Anglia on the cost of delayed diagnosis for individual axial SpA patients. The research showed that for a person whose symptoms start at the age of 26 and face the average 8.5 year delay to diagnosis, the cumulative cost is £196,000, per individual. Productivity losses amount to £122k per individual, whilst patients are estimated to be left £68k out of pocket, with direct healthcare costs to the NHS is £7k. The second and final part of this study will be presented later in the year, providing for the first time a comprehensive assessment of the overall cost of delayed axial SpA diagnosis for the UK economy.

NASS have also recently published their first report on the *Aspiring to Excellence* programme which demonstrated the value of a structured educational programme that teaches quality improvement tools and maintains engagement from clinicians. New resources have been rolled out as part of this programme including the 'Rheum for improvement' podcast series.

Hydrotherapy has also been an important part of NASS's work, who have supported the establishment of a multi-organisational alliance involving patient and professional bodies across a variety of conditions. The alliance is facilitating joint working to build the evidence base around the value of hydrotherapy and to take forward advocacy for ensuring that it increasingly becomes a core part of NHS service provision.

### **9. Meeting Close**

Dr 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 referenced the upcoming meeting with health Minister Gillian Keegan as an opportunity to raise some of the issues discussed during the session.

### **Further Information**

For any further information about this meeting or the APPG on Axial SpA, please contact [appgspa@mandfhealth.com](mailto:appgspa@mandfhealth.com)

*The work of the APPG in 2022 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](#).*