

APPG on Axial Spondyloarthritis: Submission to Major Conditions Strategy Consultation

27 June 2023

1. Tackling the risk factors for ill health

This response is submitted by the Axial Spondyloarthritis All-Party Parliamentary Group (APPG for Axial SpA), a cross-party Parliamentary group established in 2019, working to raise awareness of axial SpA within Parliament and support the widespread and effective implementation of key guidance and best practice. Reference sources used to inform this response are available upon request.

Axial SpA affects around 1 in 200 of the adult population in the UK (approximately 220,000 people), and as highlighted within the APPG's recent axial SpA 'State of the Nation' inquiries, there is a pressing need to improve care and outcomes for people affected by the condition. Beyond achieving earlier diagnosis of axial SpA – which is a key priority and covered in further detail in subsequent answers - opportunities for improving secondary prevention of axial SpA include:

- **Improving access to specialist physiotherapy:** Provision of specialist physiotherapy care is a crucial component of a high-quality axial SpA service and is recommended by NICE guidelines. The APPG's recent State of the Nation report however identified that almost 30% of services weren't able to offer this form of care for patients, meaning that individuals are missing out on important support to help maintain mobility and flexibility, and help keep them in work. Addressing this unwarranted variation should represent a key care priority.
- **Supporting provision of hydrotherapy care:** Alongside this, commissioners should also ensure that patients with rheumatic conditions such as axial SpA are able to access nearby hydrotherapy or aquatic physiotherapy, in recognition that some individuals with these conditions are not able to tolerate land-based therapy. The APPG has heard from many patients how access to hydrotherapy care has had a transformative impact on their symptoms and overall wellbeing, however the availability of these specialist pools has declined since Covid-19, and there are concerns around the future of pools which remain open.

Prioritising regular and effective patient monitoring: It is important to ensure that patients with axial SpA receive regular monitoring of their condition, to identify disease progression, and the need for specific interventions or changes in treatment plans. Ensuring that best-practice Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREM) are deployed in the management of axial SpA patients should be a key priority for local commissioners. These should also be reviewed regularly, and underpinned by referral pathways, facilitating access to wider multidisciplinary care in line with any specific patient needs that have been identified.

2. How can we better support local areas to diagnose more people at an earlier stage?

There is a particular need to improve the speed at which people affected by axial SpA are diagnosed. Within the UK it currently takes an average of 8.5 years to achieve axial SpA diagnosis, following onset of symptoms. Due to the progressive nature of axial SpA, the condition can deteriorate considerably during this period, with a worsening of symptoms and individuals at greater risk of facing irreversible disability. Delayed axial SpA diagnosis also has considerable costs for the wider healthcare system. Recent research undertaken by the University of East Anglia showed that an average 8.5 year axial SpA diagnosis delay causes an estimated £18.7 billion cost to the wider UK economy per year, and that by driving down the delay, cost savings of £167,000 per person could be achieved.

The APPG has been made aware of several important and tangible opportunities to improve axial SpA diagnosis:

- **Improved public awareness:** As the most common symptom of axial SpA is back pain, many people with the condition are likely to present in primary care. Evidence shows however that awareness of axial SpA is low, with over 90% of individuals not having heard of the condition, meaning it is often confused with mechanical back pain. Introducing public awareness initiatives can help to increase the visibility of axial SpA and support more proactive discussions around its symptoms, leading to earlier identification and diagnosis.
- **Scaling-up best practice:** Innovative approaches to accelerating axial SpA diagnosis have been developed in recent years. The National Axial Spondyloarthritis Society (NASS) have for instance developed a new time to diagnosis audit to help understand more clearly where delays in the diagnosis of axial SpA occur, and to monitor change over time. 39 NHS Trusts have signed up to the audit in the first 6 months, enrolling 400 patients and improving understanding of diagnosis journeys. Encouraging more Trusts to adopt the tool would strengthen data and support efforts to address key barriers to diagnosis.
- **Implementing the GIRFT axial SpA pathway:** In 2022 NASS and the Getting It Right First Time (GIRFT) team developed a new pathway to improve local identification and diagnosis of axial SpA. The pathway is designed to improve early recognition of the signs and symptoms of axial SpA, and its widespread implementation across the NHS would help to accelerate diagnosis journeys.

3. How can we better support and provide treatment for people after a diagnosis?

Ensuring timely access to treatment for individuals living with axial SpA should represent a key healthcare priority. Considerable advances in the availability and effectiveness of treatments have been achieved in recent years, enabling people to manage symptoms much better and helping to slow overall disease progression. However, the effectiveness of available treatments is reduced when their access is delayed and evidence shows that many people are still waiting too long to receive the right medicines. Opportunities to address variation include:

- **Local improvement plans:** Commissioners should be encouraged to develop specific plans for improving delivery of care and treatment for individuals with axial SpA. Plans should be co-developed with clinical and patient voice input, and should be informed by best practice and existing resources, including for instance the GIRFT axial SpA pathway and NASS and BRITSpA's *Aspiring to Excellence* programme.
- **Improved delivery of regular reviews:** Regular reviews, on an at least annual basis, provide a key opportunity for reviewing disease progression and ensuring that current treatment plans are effective. Many patients are not receiving these reviews when they should be however, meaning that they are missing out on specialist care and opportunities to improve the management of their disease. Commissioners should be encouraged to ensure that all axial SpA patients receive regular reviews, which can be delivered by a member of the wider multidisciplinary team, such as a physiotherapist. Reviews should draw on existing best practice and template resources.

Supporting shared decision-making: Shared decision-making between patients and healthcare professionals to inform personalised treatment plans is a key principle of recommended axial SpA management guidelines. Data suggests however that there are significant numbers of axial SpA patients who feel that their views are not taken into account in treatment planning, particularly in the context of switching decisions. Addressing this can help ensure that an individual's views and circumstances can inform the most appropriate treatment plan, supporting optimum and person-centred care.

4. How can we better enable health and social care teams to deliver person-centred and joined-up services?

People affected by axial SpA require joined-up and holistic care in order to manage symptoms effectively and achieve the best possible outcomes. Integrated Care Boards across the country should be encouraged to develop specific plans that set out how people living with conditions such as axial SpA can be supported to access multidisciplinary care at a local level. This is particularly important considering the current variation in provision of dedicated axial SpA clinics, which are able to facilitate multidisciplinary care support. The APPG's 2022 inquiry report found that 53% of local areas were not able to offer dedicated axial SpA clinics, an increase from 42% in 2019, indicating that many patients are therefore not accessing the right levels of specialist care, putting them at risk of sub-optimal management and poorer outcomes.

In addition to putting in place specific ICB-level plans, services should also be encouraged to adopt available best practice tools and resources. These include for instance a toolkit developed by NASS to support healthcare professionals in engaging with patients effectively, covering appointment preparation, management plans and follow-up communication. Services should also seek to deliver care that meets the priorities of patients. Recently generated NASS research for instance demonstrated that patients wanted their care plans to be co-developed, and that interactions with healthcare professionals incorporated the following criteria:

- Listened to, heard and taken seriously.
- Any investigations to be carried out in a timely manner.

- Symptom management when waiting for a referral.
- Opportunity to discuss all symptoms.
- Diagnosis face to face or online, not in writing.
- Referral to physiotherapy
- Active involvement in discussions about medication options.
- Access to a flare helpline.
- Time to discuss the impact of axial SpA, such as fears of the future, sex life, fertility, pregnancy, menopause, relationships, home life, medication side effects, emotional wellbeing, work, and social life.

Time to discuss flares and symptoms and their impact.

5. How can we better support those with mental ill health?

There is a well-evidenced link between poorer mental health outcomes and individuals living with long term, chronic conditions. The APPG has heard from many individuals living with axial SpA who have highlighted how their symptoms contribute to poorer mental health and difficulty in engaging with everyday activities. This is supported by data, which shows that around 60% of people with axial SpA will experience mental health problems, with 4 in 10 reporting symptoms of depression. Opportunities to improve mental health support for those living with axial SpA include:

- **Improved HCP awareness and training:** Evidence shows that some healthcare professionals find it difficult to raise mental health care needs with individuals living with long-term, chronic conditions such as axial SpA. Improving mental health training for healthcare professionals can support improved identification of the signs of poor mental health, and can also empower the workforce to feel better equipped in engaging with patients.
- **Direct referral routes and MDT integration:** In addition to improved healthcare professional awareness of mental health, pathways should also be in place that enable secondary care teams to refer individuals directly into psychological services, when appropriate care needs are identified. The APPG's 2022 State of the Nation report found that only a fifth of rheumatology teams across England are currently able to refer directly for psychological support, demonstrating the need to address variation as a priority. Alongside this, multidisciplinary teams caring for individuals with axial SpA should also ensure that occupational therapist support is available to patients, to help a person manage their symptoms as effectively as possible, and to support them to adapt routines to remain engaged in work and other meaningful activities.