

ALL-PARTY PARLIAMENTARY GROUP ON AXIAL SPONDYLOARTHRITIS – WRITTEN EVIDENCE (PSR0080)

Lessons from Coronavirus House of Lords Select Committee on Public Services Consultation

1. About the APPG

1.1. The All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA) is a special interest group of cross-party MPs and Peers, jointly chaired by Derek Thomas MP and Lord Campbell-Savours. The primary aims of the APPG are to raise awareness of axial SpA (AS) within Parliament and to ensure the widespread and effective implementation of key NICE guidance, including the Quality Standard for Spondyloarthritis. The secretariat for the APPG is being provided by M&F Health, in association with the National Axial Spondyloarthritis Society (NASS).

2. Response Overview

2.1. The APPG on Axial Spondyloarthritis welcomes this consultation from the House of Lords Select Committee on Public Services and the opportunity to highlight lessons that can be learned from COVID-19 in respect of those living with axial SpA (AS). Our consultation response focuses on the axial SpA (AS) services and levels of care that were available during the outbreak, and the measures that we believe need to be put in place to mitigate potential harms resulting from a possible future outbreak.

3. What is axial SpA and why do we need to improve outcomes?

3.1. Axial SpA (AS) is a form of inflammatory arthritis that most commonly affects the spine. It is a painful and progressive long-term condition for which there is no cure.

3.2. Whilst arthritis is often associated with older people and the wear and tear that comes with ageing, axial SpA (AS) tends to present in late teens to early twenties, with an average age of onset being just 24. The overwhelming majority of people with axial SpA (AS) (90–95%) are aged less than 45 years at disease onset - a period when most people are at a crucial stage of their lives, looking to forge social relationships, start families and build careers. **There is currently an average delay of 8.5 years between the onset of axial SpA (AS) symptoms and diagnosis, during which time the condition can deteriorate considerably.**

3.3. Despite a widespread lack of awareness of the condition, axial SpA (AS) is not rare and affects an estimated 1 in 200 of the adult population in the UK (approximately 220,000) which is higher than the prevalence of multiple sclerosis and Parkinson's combined. The burden of musculoskeletal (MSK) conditions on the NHS and economy is well documented with 6-9% of people

presenting to general practice doing so with back pain - between 7-15% of these will show features of axial SpA (AS).

4. Consultation Question: How well did central and local government, and national and local services, work together to coordinate public services during the outbreak? For example, how effectively have national and local agencies shared data?

4.1. Disruption to axial SpA (AS) care

4.2. Despite the best efforts from those working to deliver clinical services, the outbreak of COVID-19 had a significant impact on people living with axial SpA (AS). As a result of prioritising system resources towards the response to COVID-19, which we recognise was entirely appropriate considering the severity of the situation, axial SpA (AS) services were severely disrupted, with significant variation across the UK in terms of the level of care that remained available for patients.

4.3. Despite *NICE COVID-19 rapid guideline: rheumatological autoimmune, inflammatory and metabolic bone disorders guideline [NG167]* advising that core services remain intact, the National Axial Spondyloarthritis Society (NASS) reported a >400% increase in helpline calls in the weeks following the COVID-19 outbreak. Many patients reported being unable to reach anyone from their local rheumatology unit to get advice on the risks associated with immunosuppressing drugs used to manage their axial SpA (AS) and how to maintain existing levels of care.

4.4. Considering that axial SpA (AS) is managed largely by physiotherapy combined with medication, an inability to access emergency physiotherapy and hydrotherapy services during lockdown has had a particularly negative impact on those who are suffering flare-ups of the condition, as has the inability to reach rheumatology for a medication review to help during flare.

4.5. Unfortunately, and as revealed by the first national inquiry into axial SpA (AS) services that was published by the APPG earlier this year, these developments have exacerbated existing inequalities in service provision. Before the start of the lockdown many people living with axial SpA (AS) did not have local access to key elements of NICE-recommended care:

- Only 21% of Clinical Commissioning Groups (CCGs) had a specific inflammatory back pain pathway in place
- More than half of services did not have a specialist axial SpA (AS) clinic in place
- Three-quarters of services did not have direct access to psychological services via secondary care for those who need it
- One-fifth of local services did not have access to a specialist rheumatology physiotherapist

- Almost 90% of services did not offer personalised flare care plans for patients

4.6. These worrying gaps in care for those with axial SpA (AS) are likely to have deteriorated further, and it is important that steps are taken to address these within local responses to achieving an appropriate balance between COVID-19 and 'ordinary' health and care demand. This is especially important considering the negative physical and mental health impacts that will have been caused by COVID-19 for those living with axial SpA (AS), whom as a cohort are more likely to experience poorer mental health and physical health outcomes than the wider population.

5. Learning lessons from COVID-19

5.1. It is of vital importance that lessons learned during this pandemic are embedded into service planning in the weeks and months ahead, to strengthen the resilience of the healthcare sector and its ability to maintain core levels of function in the event of future outbreaks, including for those living with axial SpA (AS).

- **Recognising the benefits of service redesign:** Feedback from services across the country for instance show that there have been numerous examples of innovative and rapid service redesign to facilitate maximum patient access and provision of care. In larger axial SpA (AS) units for example, where few staff have been redeployed, virtual appointments have been put in place and new methods of patient contact have been embedded, which has actually helped to increase appointment attendance in some groups (for example men in their 20s to 30s who work full time).
- **Investing in IT infrastructure:** However, reports have also emerged that efforts to innovate have been hampered in some areas due to limited IT infrastructure. Ensuring that robust IT systems are in place in rheumatology services in all parts of the country is essential, underpinned by effective coding that enables quick and accurate patient identification.
- **Developing effective triage protocols for those most in need:** As plans are put in place to support an easing of social distancing measures, it is vital that national and local decision-makers prioritise making urgent referrals available for axial SpA (AS) patients who are experiencing flare-ups of their condition, with triage systems in place to ensure that the most in need are seen first. Examples of innovative axial SpA (AS) practice that has emerged in recent weeks in response to the pandemic should also be capitalised on, so that learnings can be made more widely available and as many patients as possible can benefit from new ways of working.
- **Identifying appropriate minimum service specifications:** It is also important that steps are taken to safeguard service provision in the

event of any further outbreaks, with 'minimum service specifications' to be considered, the maintenance of which would help ensure an essential level of service function would continue to be available for those with axial SpA (AS), regardless of the reintroduction of social distancing measures.

- 5.2.** Working with other stakeholders, the APPG intends to support efforts to gather the positive and negative developments that have occurred in axial SpA (AS) since the start of the outbreak, which we hope can help to inform the development of 'minimum service specifications' in axial SpA (AS). If adopted, these specifications would help to build service provision and workforce resilience in the sector, and safeguard care delivery in the event of future outbreaks.

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