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

COVID-19 & Axial SpA (AS): Government Recommendation Paper

SUBMITTED BY THE APPG ON AXIAL SPONDYLOARTHRITIS

Introduction

This document has been developed by the All-Party Parliamentary Group on Axial Spondyloarthritis. It sets out a series of recommendations for the Government and senior NHS stakeholders to encourage the adoption of measures that can help to safeguard vital NHS services for axial spondyloarthritis (axial SpA (AS)) in the event of future disruption caused by further COVID-19 outbreaks or the emergence of other pandemics.

These recommendations have been informed by close engagement with the National Axial Spondyloarthritis Society (NASS), the broader patient community and leading clinical experts. They represent measures that can be adopted without the need for significant additional investment or disruptive service reorganisation. They are endorsed by NASS and the British Society for Spondyloarthritis (BRITSpA).

This document has been produced by M&F Health, who are funded to provide Secretariat services for the APPG. M&F Health work closely with the National Axial Spondyloarthritis Society (NASS) in the running of the APPG Secretariat. Further information on the APPG is available on the NASS website: <https://nass.co.uk/get-involved/campaign-with-us/appg/>

About Axial SpA (AS)

Axial spondyloarthritis (axial SpA) including ankylosing spondylitis (AS) is a form of inflammatory arthritis that most commonly affects the spine. It is a painful and progressive long-term condition affecting approximately 220,000 adults in the UK¹ (1 in 200), for which there is currently no cure. Symptoms typically begin in early adulthood² when people are trying to establish careers, start relationships and families.

A key challenge in axial SpA (AS) is achieving early diagnosis. In the UK, it currently takes on average 8 ½ years for someone living with axial SpA (AS) to be diagnosed. During this time people can experience significant amounts of pain and anxiety and they often pay a heavy physical and psychological price for this delay.^{3,4} The impact of axial SpA (AS) has been traditionally under-recognised within many healthcare systems, however in 2017 NICE produced the first clinical guidelines in England and Wales for the diagnosis and management of spondyloarthritis⁵ and in 2018 produced an accompanying Quality Standard⁶, to guide NHS commissioners and providers in several key improvement areas.

Whilst some progress is being made, many challenges remain, as demonstrated by the findings from a national inquiry undertaken by the APPG into the provision of key axial SpA (AS) services across the country.⁷ Published in January this year, the inquiry found considerable gaps and variation in the provision of core axial SpA (AS) service areas, which are having a detrimental impact on the experience and outcomes of patients.

Axial SpA (AS) & COVID-19

As set out above, there was already fragility within axial SpA (AS) services at the start of the COVID-19 pandemic. To help understand how services and those living with axial SpA (AS) have been further impacted by COVID-19, the APPG and NASS carried out surveys of the patient and clinical community to build an improved evidence base. Running from May to July, the patient survey generated 838 responses, and the clinical survey generated 80 responses (with respondents representing the majority of services across the country). These results were then discussed at a virtual inquiry meeting held by the APPG in July, featuring contributions from leading stakeholders working in the area, including the British Society for Spondyloarthritis (BritSpA), the Arthritis and Musculoskeletal Alliance (ARMA) and Andrew Bennet, National Clinical Director for Musculoskeletal Services, NHS England/Improvement. Key findings from the surveys are set out below:

Key findings on the impact of COVID-19 for axial SpA (AS) patients

- **Variation in accessing services:** A quarter of patients who needed to access services during the pandemic were unable to do so. Almost a third (32%) were not aware of what services were available
- **Deterioration in outcomes:** 9% of those living with axial SpA (AS) found their axial SpA (AS) had improved during lockdown, however 47% found it had got worse (for 44% it had not changed). Almost half of respondents said that their general health and mental health had also deteriorated during that time.
- **Importance of face to face care:** Whilst many respondents welcomed the positive impact of digital services, 85% highlighted the importance of face to face care for rheumatologist appointments, and 60% said likewise for physiotherapist care.

Key findings on the impact of COVID-19 for axial SpA (AS) services

- COVID-19 caused **significant disruption to essential care provision** – almost half of services (44%) weren't able to provide face to face care for those in flare and nearly 4 in 10 (38%) weren't able to maintain specialist physiotherapy support.
- **Considerable variation in digital care provision** – two-thirds of services provided virtual flare management and half of services were able to provide remote identification and diagnosis, resulting in postcode lottery for patients across the country.
- **Identifying high-risk patients:** There was significant variation in the ease at which services were able to identify high-risk patients under their care. 54% of respondents reported being able to identify this cohort within 2 weeks or less, 13% said it took 3-4 weeks and 6% said it took between 4-6 weeks. Almost 1 in 10 (9%) said that they still had not been able to identify all high-risk patients by July, largely as a result of coding challenges.

Recommendations

Based on the evidence generated from these surveys, the consensus that was reached at the APPG inquiry meeting and from extensive wider engagement undertaken with the patient and clinical community, a set of recommendations have been put forward by the APPG and NASS.

It is our hope that these recommendations can act as ‘**minimum axial SpA (AS) service specifications**’ that all commissioners across the country should be encouraged to adopt. In doing so, they will help to ensure that essential areas of axial SpA (AS) care are safeguarded in the event of future outbreaks, as well as helping to strengthen care more broadly, thereby supporting the 1 in 200 adults that live with the condition in this country to manage their axial SpA (AS) as best as possible and to avoid storing up avoidable pressures for the system at a later date.

Minimum Service Specification Recommendation Area 1: Risk Identification

- **Commissioners** should work with **service providers** to ensure that all axial SpA (AS) patients are accurately coded within local databases, in order that those at-risk can be identified and contacted rapidly with guidance in the event of future outbreaks.

Minimum Service Specification Recommendation Area 2: Diagnosis

- **Commissioners and providers** should ensure that capacity for some face to face axial SpA (AS) care is maintained in the event of future lockdowns, with priority given to appointments for referral of those with suspected symptoms of axial SpA (AS) and for patients with more complex needs.

Minimum Service Specification Recommendation Area 3: Care Services

- **Commissioners and providers** should ensure that the following core axial SpA (AS) services are able to be delivered digitally:
 - Follow-up identification and diagnosis appointments (initial appointments should be delivered face to face)
 - Flare management
 - Prescribing of medication
 - Consultant/nurse reviews (*use of outcome measures required for disease monitoring or initiation of treatment*)
- **Commissioners and providers** should work together to ensure that healthcare practitioners involved in the delivery of axial SpA (AS) services have the right skills and training in place to be able to effectively deliver virtual care in the event of a future pandemic.
- **Commissioners and providers** should ensure that any face to face axial SpA (AS) care is delivered with sufficient levels of specialist clinical supervision, to help mitigate against the impact of potential senior staffing reallocation.
- **Commissioners and providers** should ensure that pathways are in place to enable patients to switch onto new medication when needed, even in the event of reduced clinic capacity and social distancing.

Minimum Service Specification Recommendation Area 4: Optimal Management

- **Commissioners and providers** should ensure that axial SpA (AS) telephone/digital services are tailored to the needs of patients, including those with vulnerabilities and/or who may be less able to access services remotely.
- **Commissioners and providers** should take active steps to ensure that axial SpA (AS) patients are supported to self-manage their condition, particularly if they are not able to access services in-person.
- **Commissioners and providers** should ensure that access to physiotherapy (either in-person or virtual) is available for axial SpA (AS) patients on an uninterrupted basis, as it represents a key component of managing the condition effectively.

Recommendations for System-Leaders

- **National agencies (including NHS Digital)** with responsibility for overseeing the development of axial SpA (AS) patient coding should work to ensure that existing diagnosis and risk coding is fit for purpose and well-understood by those delivering services.
- **National agencies** should encourage commissioners to assess the resilience of local axial SpA (AS) services and adopt minimum service specifications to support the continued provision of core elements in the event of future outbreaks.
- **Stakeholders** should ensure that clear, up-to-date shielding guidance is made available for those with axial SpA (AS), tailored to patient cohorts depending on individual levels of risk.

Further Information

For further information on this recommendation paper, please contact appgspa@mandfhealth.com

¹ Hamilton L, Macgregor A, Toms A, Warmington V, Pinch E, Gaffney K. The prevalence of axial spondyloarthritis in the UK: a cross-sectional cohort study. *BMC Musculoskelet Disord* [Internet]. 2015;16. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4687290/>

² Feldtkeller E, Khan M, van der Heijde D, van der Linden S, Braun J. Age at disease onset and diagnosis delay in HLA-B27 negative vs. positive patients with ankylosing spondylitis. *Rheumatol Int*. 2003 Mar;23(2):61–6.

³ Martindale J, Goodacre L. The Journey to Diagnosis in AS/Axial SpA (AS): The Impact of Delay: The Journey to Diagnosis in AS/Axial SpA (AS). *Musculoskeletal Care*. 2014 Dec;12(4):221–31.

⁴ Martindale J, Shukla R, Goodacre J. The impact of ankylosing spondylitis/axial spondyloarthritis on work productivity. *Best Pract Res Clin Rheumatol*. 2015 Jun 1;29(3):512–23.

⁵ NICE. Spondyloarthritis in over 16s: diagnosis and management. NICE Guideline 65. February 2017. Available online at: <https://www.nice.org.uk/guidance/ng65>

⁶ NICE. Spondyloarthritis Quality Standard (QS 170). June 2018. Available online at: <https://www.nice.org.uk/guidance/qs170>

⁷ APPG on Axial Spondyloarthritis, NASS. Axial Spondyloarthritis Services in England: A National Inquiry. January 2020. Available online here: <https://nass.co.uk/wp-content/uploads/2020/01/Axial-Spondyloarthritis-Services-in-England-FINAL.pdf>