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COVID-19 in axial spondyloarthritis care provision: helping to straighten the long and winding road



As the world handles the inevitable second wave of the COVID-19 pandemic, health-care systems are still struggling to fully implement the planned recovery phase after the devastating first wave. Existing inequities in health care globally have been deepened as a result of the pandemic, with substantial impact on individuals affected by lesser known, or rarer diseases, for which service provision was already deficient.

Axial spondyloarthritis (axSpA, also referred to as axial SpA), which includes ankylosing spondylitis and non-radiographic axSpA, is a chronic inflammatory arthritis that most commonly affects the spine, causing pain and disability from a young age. Symptoms of axSpA, primarily back pain, begin in early adulthood, a time when people are trying to establish careers and start families. Worldwide, key challenges include the low awareness and a paucity of diagnostic biomarkers of axSpA, leading to an unacceptable average delay in diagnosis of 8–10 years from symptom onset.¹ As a result of this delay, affected individuals have recurrent pain and fatigue, with substantial physical and psychological impact and work instability.^{2,3} Biological immunosuppressant therapies can be used to control disease symptoms but are not curative, leading to a substantial cost and economic burden associated with life-long treatment. Yet, the clinical impact of axSpA has traditionally been under-recognised in many health-care systems across the world. In the UK, where an estimated 220 000 people are living with axSpA,⁴ the first clinical guidelines for the diagnosis and management of spondyloarthritis⁵ were published by the National Institute for Care and Excellence (NICE) in 2017, followed shortly thereafter by an accompanying Quality Standard⁶ to guide National Health Service (NHS) commissioners and providers in several key improvement areas. To date, substantial gaps and variation in the provision of core axSpA service areas exist with detrimental effects on patients' experience and outcomes.⁷

To help better understand the effect of COVID-19 on patients with axSpA and their health-care services in the UK, two electronic surveys were done by the National axial Spondyloarthritis Society (NASS), with one aimed at patient groups and the other at health-care professionals working in axSpA (appendix pp 1–23). The surveys ran from

May to July, 2020, during the period of lockdown and early recovery phase in the UK. The patient survey generated 873 responses, and the health-care professionals survey generated 80 responses (with a completion rate of 75% and respondents representing most services across the country). Not all respondents answered all questions in the surveys. Key findings on the impact of COVID-19 for patients with axSpA were the variation in accessing services, deterioration in outcomes, and the importance individuals placed on face-to-face consultations (appendix pp 1–4). 60 (25%) of 237 patients who needed to access services during the pandemic were unable to do so and 241 (32%) of 753 were not aware of what services were available. Only 70 (10%) of 733 patients found their symptoms improved during lockdown, whereas 343 (47%) of 733 found their symptoms got worse and 320 (44%) of 733 reported no change. Nearly half of respondents said that their general health and mental health had also deteriorated during lockdown (appendix p 3). Although many respondents welcomed the positive effect of digital services, 562 (86%) of 657 highlighted the importance of face-to-face rheumatology appointments, and 404 (61%) said the same for physiotherapy access, the main stay of treatment in axSpA.⁸

The results of the survey among health-care professionals showed that COVID-19 caused substantial disruption to essential care provision in axSpA services, with a 31% reduction in the overall number of operational sites providing care for axSpA since the first national lockdown (appendix p 5). 27 (44%) of 61 services were unable to provide face-to-face care for patients with flare, and 23 (38%) of 60 services could not maintain specialist physiotherapy support. Crucially, considerable variation in the provision of digital care was identified, with 38 (66%) of 58 services providing virtual flare management and 27 (47%) of 58 providing remote identification and diagnosis, resulting in a lottery for patients that is entirely dependent on where they live. However, the widest variation was seen in the time taken to identify high-risk patients under their care, with 30 (58%) of 52 respondents reporting being able to identify this cohort within 2 weeks or less, seven (13%) saying it took 3–4 weeks, and three (6%) saying it took 4–6 weeks. Five (10%) respondents

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See Online for appendix

reported that they still had not been able to identify all high-risk patients by July, 2020, 4 months after shielding guidance was issued by the UK Government, largely as a result of coding challenges. When asked to consider a possible second wave, there was considerable concern among health professionals around the level of face-to-face capacity in the months ahead as a result of physical distancing, with 55 (92%) of 60 predicting having less than 50% normal capacity. 35 (69%) of 51 services said there were no plans in place (at the time of the survey) to reopen hydrotherapy services, which are an integral part of physical therapy in axSpA. 37 (73%) of 51 respondents believed that establishing a so-called minimum service specification would be helpful, to outline a set of core care standards for axSpA to be maintained in the event of future COVID-19 or other possible pandemic outbreaks that could enforce physical distancing measures for axSpA.

These data give important insight from both patients and physicians on the impact of the COVID-19 pandemic on service delivery for axSpA in the UK, which are likely to resonate in other health conditions and care systems globally. Importantly, these data highlight some key issues that require urgent attention, such as the upskilling of digital provision in the NHS, which should embed good digital practice as widely as possible, and ensuring that gaps in digital infrastructure and staff skills are addressed. Furthermore, improved patient coding is essential to allow for the identification of those at risk and should be addressed promptly, not only in the event of further outbreaks, but also to allow for overall improvement of service provision. Managing the clinical backlog created by the wider reorganisation of services in the wake of the pandemic requires that resources are in place to mitigate the potential for deterioration in outcomes, particularly for newly diagnosed patients. In a combined effort, the main stakeholders—patients and their representatives together with clinicians—have now produced a set of minimum axSpA service specifications⁹ to be put forward by the All-Party Parliamentary Group (APPG) for axSpA and NASS to inform commissioners across the country. These specifications are produced to assess the resilience of local services and adopt minimum service specifications to support the continued provision of core elements in the event of future outbreaks. Further liaison with national agencies including NHS Digital, which has responsibility for overseeing the development

of patient coding, should ensure that existing diagnosis and risk coding is fit for purpose and well understood by those delivering services not only for axSpA but every health condition.

In summary, the COVID-19 pandemic has highlighted existing gaps in service provision for people with axSpA. However, it has accelerated change, bringing virtual and remote consultations, including care for flares, to the forefront with rapid adaptation of patients and clinicians to new ways of working. As we move through the second wave of the COVID-19 pandemic and beyond, close collaboration with policy makers is crucial to help ensure that essential areas of care are safeguarded in the event of future outbreaks, and to strengthen care more broadly, supporting those with axSpA in the UK and all others in need of health care, and to avoid storing up avoidable pressures for the system at a later date.

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For more on the All-Party Parliamentary Group for Axial Spondyloarthritis see <https://nass.co.uk/get-involved/campaign-with-us/appg/>

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