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

Axial SpA APPG

Assessing the impact of COVID-19 on Axial SpA - Patient & Clinical Survey Results Summary

Introduction

This document has been produced to provide a high-level overview of findings from two surveys that have been carried out in recent weeks to help strengthen understanding of the impact that COVID-19 has had on both those living with axial spondyloarthritis (axial SpA), as well as on axial SpA services. These survey results will be discussed in further detail at the fourth meeting of the All-Party Parliamentary Group on Axial SpA, which is taking place virtually on Wednesday 15th July, 17:00-18:30 (further meeting details set out in accompanying briefing paper).

Patient Survey Summary

The COVID-19 and axial SpA patient survey ran from 26 May 2020 to 7 July 2020. It was advertised via the NASS website, Facebook, Twitter, e-news and targeted emails to NASS subscribers. Following qualifying questions, 838 valid responses were received. The aim of the survey was to understand the experiences of people with axial SpA in lockdown, specifically in relation to how it had affected their lives and access to services. It was also an opportunity to get initial reaction to any future changes to service delivery.

Key Patient Survey Findings

- **Impact on medication:** 8% of respondents stopped taking their medication, but only 15% of those were told to do so by their health professional. 32% worried they were more at risk of infection while 27% were worried they were more at risk of serious symptoms if they were to develop COVID-19.
- **Deterioration in outcomes:** 9% found their axial SpA (AS) had improved during lockdown, for 44% it had not changed but for 47% it had got worse. Almost half of respondents said that their general health and mental health had also deteriorated in recent weeks.
- **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.

Respondent Profile Summary

Respondents were asked a series of questions relating to their demographics. 89% of respondents were in England, 3% in Wales, 7% in Scotland and 1% in Northern Ireland.

- **Diagnosis status:** 12% were diagnosed with axial spondyloarthritis, 7% with non-radiographic axial spondyloarthritis and 80% with ankylosing spondylitis. The remaining 1% had a different diagnosis which was not disclosed.
- **Length of diagnosis:** 4% had been diagnosed less than a year, 22% 1 to 5 years, 16% 6 to 10 years and 58% more than 10 years.
- **Age and sex:** 47% of respondents were male, 52% were female while 1% preferred not to say. 25% of respondents were under 45.

Life in Lockdown

Respondents were asked questions relating to their employment status, medication and whether they had been shielding or isolating to help build a picture of experiences of, and attitudes to, the pandemic.

- **Employment impact:** 6% of people has lost their jobs while 16% were shielding and claiming sick pay. 4% had reduced their hours. Most people who had been asked to return to work had been offered a different position or way of working if requested. 8% had requested such an arrangement but had not been offered this.
- **Medication:** 8% of respondents stopped taking their medication, but only 15% of those were told to do so by their health professional. 32% worried they were more at risk of infection while 27% were worried they were more at risk of serious symptoms if they were to develop COVID-19. Biologic drugs were most commonly stopped.

- **Shielding:** 49% of respondents had been advised to shield by a health professional or NHS. 13% were not advised to do so but chose to themselves.
- **Self-isolation/distancing:** A further 13% were advised to self-isolate or practice enhanced social distancing, and 14% more chose to do so themselves.

Access to services during the pandemic

- **Ability to access services:** 31% of respondents had needed to access services during the pandemic, and 75% of those had been able to do so.
- **Blood monitoring tests:** 37% were not able to access blood monitoring tests; for those that were able, 10% had visited the hospital, 17% had visited the GP, 3% had accessed another community service while 2% had a home visit.
- **Engagement satisfaction:** 20% of people were not satisfied with the level of engagement from their health care teams during the pandemic. More positively 50% were very or fairly satisfied.
    - Those that were unsatisfied generally felt that there was a lack of communication at the start of the pandemic regarding cancelled /rearranging appointments and advice on shielding. Some telephone appointments that had been arranged also did not go ahead as planned. There were also those that had been contacted at the beginning of the pandemic but had not been able to reach anyone since.
    - There were also those who found there was always someone available to speak to on the telephone if needed and this was helpful.
- **Kyphosis:** Some people with kyphosis had received no advice regarding their level of risk.
- **Access methods:** 8% were able to have face to face appointments whilst 38% were able to access a rheumatology helpline and 16% submit an email enquiry. 45% were able to access telephone appointments and 9% online appointments. 32% were not aware of what services were available while 6% had not been able to get in touch with anyone from their healthcare team.
- **Virtual appointments:** Of those that had been offered a virtual appointment, 37% had attended and 63% had not. Only 3% did not find their virtual appointment to be satisfactory.
    - **Respondent quote:** *"It was easy to communicate to the healthcare provider, and apart from physical examination and measurements I was able to relay all the information that the healthcare provider needed to complete a routine check on me."*
- **Biologic prescribing:** 12% of people were in the process of being prescribed a biologic before lockdown; 44% had found this had been delayed.

General health during the pandemic

Respondents were asked to reflect on how their general health, axial SpA and mental health had been affected, as well as describe in their own words how they were managing their condition.

- **Deterioration in general health:** 13% found their general health had improved during lockdown, for 42% it had not changed but for 45% it had got worse.
- **Worsening of axial SpA:** 9% found their axial SpA (AS) had improved during lockdown, for 44% it had not changed but for 47% it had got worse.
- **Mental health experience:** 6% found their mental health had improved during lockdown, for 47% it had not changed but for 47% it had got worse.
- **New routines:** The vast majority of respondents had undertaken a daily stretching routine to self-manage their axial SpA (AS) during lockdown. Many also took up new hobbies and undertook some home improvement to help with their general well-being.
    - **Respondent quote:** *"The pandemic has been a great chance to reset my self-management and explore other ways to help myself"*
- **Homecare:** When asked if there were other areas related to their axial SpA A(S) services during the pandemic they would like to highlight, homecare medicine delivery teams were highly praised.

Future care priorities

Most were happy to continue social distancing I it meant keeping themselves and others safe, even if this meant that they were not able to attend face to face appointments. The main concerns highlighted were around physiotherapy and more specifically, hydrotherapy.

- **Rheumatology access:** 79% of respondents would consider online appointments with their rheumatologist, and 75% telephone appointments. 85% would still like to be given the option of a face to face appointment.
- **Physiotherapist access** 42% of respondents would consider online appointments with their physiotherapist, and 36% telephone appointments. 61% would still like to be given the option of a face to face appointment.
- **Nurse access:** 63% of respondents would consider online appointments with their nurse specialist, and 70% telephone appointments. 47% would still like to be given the option of a face to face appointment.
- **Helplines:** Email and helpline queries also scored highly for rheumatologists and nurse specialists. However fewer would seek advice from their physiotherapist via email or a helpline.
    - **Respondent quote:** *"I think regardless of social distancing and the pandemic, it would be useful to utilise technology more (for those who can use it comfortably) and don't require a face to face assessment."*
    - **Respondent quote:** *"I would like to have 'someone' to contact if I have a question, or the facility to send an email. My only contact with the Rheumatology department is a 10 minutesappointment every 18 months or longer."*
    - **Respondent quote:** *"Maintain hydrotherapy at all costs"*

Clinical Survey Summary

To help gather clinical perspective and insights from those involved in the delivery of axial SpA (AS) care during the outbreak of COVID-19, a parallel clinical survey was circulated via NASS and BRITSpA to relevant healthcare professionals. Questions sought to identify the impact that the pandemic was having on local service delivery, patient engagement and priorities for the months ahead. Key findings from the survey are outlined below.

Key Clinical Survey Findings

- 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.
- Three-quarters of respondents felt that developing some form of **minimum service specifications** for axial SpA would be helpful, and would help to mitigate against the impact of potential future outbreaks.

Respondent Profile Summary

The survey received 80 responses, from healthcare professionals working across the United Kingdom. The majority of respondents were based in England (91%), with 6 respondents from Scotland and 1 respondent from Wales. Almost half (49%) of respondents were physiotherapists, around a third (34%) were consultant rheumatologists, with the remainder of responses coming from a range of professional backgrounds, including rheumatology nurses, pharmacists, radiologists and primary care practitioners.

Current Access & Provision of Clinical Areas

- **Operational sites:** There was a 52% reduction in the proportion of operational sites providing axial SpA care after the outbreak of COVID-19.
- **Access:** Whilst the majority of respondents were able to provide **telephone appointments** (95%) and **access to a rheumatology helpline** (82%), there were – as expected – significantly less were able to provide **face to face care for new patients** (43%). 44% of services weren't able to provide **face to face care for those in flare** and almost 4 in 10 (38%) couldn't maintain specialist physiotherapy services.
- **Clinical care:** The majority of areas were able to maintain a form of flare management (80%), although this suggested that 1 in 5 patients in flare had no support at all. Almost four-fifths of services (78%) provided medication review and 62% maintained an infusion therapy service. Only 15% of services were able to maintain some form of psychological support service.

Digital Care Access

- **Variation in provision:** Access to key service areas through digital means was variable. Around half of services reported offering virtual identification and diagnosis, with two-thirds providing flare management. 56% of services were able to prescribe new medication via digital means.
- **Plans to improve availability:** Around 1 in 10 services weren't currently able to offer these areas of care digitally, but were planning to introduce them shortly.
- **Gaps in training:** A third of respondents reported that gaps in skills and training were having a detrimental impact on their ability to provide digital services. 22% of respondents highlighted that these skills weren't originally in place as lockdown started, but worked quickly to address them.

Quality of Patient Engagement

- **Engagement levels:** Despite the pressures and complications of COVID-19, the majority of respondents (79%) felt they were having 'good' or 'excellent' levels of engagement with their patients, largely as a result of improvements in digital outreach. The remainder (1 in 5) felt that overall engagement was 'poor' or 'very poor'.
    - **Respondent quote***: "Most patients are wishing to wait for face to face but this is not going to be available for likely months. We cannot offer the classes that would normally be majorly beneficial for this patient group."*
- **Identifying high-risk patients:** There was significant variation in the ease at which services were able to identify high-risk patients under their care. Whilst 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, with coding challenges widely seen to be behind this.
    - **Respondent quote: "***Coding needed at national level, as "horror" of shielding policy has shown. Lots of issues created by government's texting, creating confusion with people being told wrong message (i.e., not needing to shield and told to and vice versa). This should be done as a matter of urgency. we need a safe and effective system to identify patients."*

Future capacity

- **Estimated face to face capacity:** More than 9 in 10 respondents indicated that their service would have less than 50% capacity whilst employing social distancing measures in the coming months. Almost four in ten estimated that their service would have less than 20% of normal capacity, with 15% estimating they would have less than 10% capacity.
- **Hydrotherapy service access:** Respondents highlighted real concern around the closure of hydrotherapy services and the impact this was likely to have on patients. Two-thirds (67%) said there were no plans in place to reopen hydrotherapy services at the time of responding in June, with only 1 in 10 saying that plans were being put in place to facilitate limited reopening of these services.
    - **Respondent quote: "***Not been able to progress to far on these. But desperately keen to re-open in some form or another. Our self-management hydro service usually has 200 people per week attending, this is a big provision to be missing."*

Key identified priorities for recovery phase

Survey respondents highlighted a broad range of priorities they felt were needed for the coming months, with the main themes including:

- **Upskilling digital provision:** Emphasis was placed on the importance of embedding good digital practice that had emerged during the pandemic as widely as possible, ensuring that gaps in IT infrastructure and staff skills were addressed.
- **Increasing access to face to face care:** Despite the benefits of digital care, respondents highlighted the importance of ensuring that face to face care was increased, particularly for those at high-risk and/or unable to make use of digital alternatives.
- **Clearer shielding guidance and improved coding:** Many respondents described the confusion created by contradictory shielding advice, and the anxiety this created for many patients. Challenges in identifying those at-risk because of coding shortcoming were also identified as something that should be addressed as soon as possible, in the event of further outbreaks.

Minimum service specification and identified longer-term priorities

- **Minimum service specifications:** Almost three-quarters (73%) felt that establishing minimum service specifications for axial SpA would be helpful. 24% were unsure, with only 4% saying they wouldn't be helpful. Supportive comments suggested these could help to build on existing NICE Quality Standards, and would help to raise the visibility of axial SpA within rheumatology departments.
- **Longer-term priorities:** Respondents identified a number of axial SpA themes that they felt should be prioritised at a national level beyond the immediate pressures of the pandemic, including:
  - **Managing the clinical backlog:** Ensure sufficient resources are in place to help manage the significant axial SpA clinical backlog that has been building, to mitigate the potential for deterioration in outcomes, particularly for those with a new diagnosis.
  - **Improving screening pathways:** Ensuring that clear pathways for new patient referral are embedded across the system, with a particular focus on primary care
  - **Working to reduce delay to diagnosis:** Continue to drive forward efforts that could help to reduce the current 8.5-year average delay in axial SpA diagnosis.

Further Information

For any further information on this document, please contact appgspa@mandfhealth.com

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