Dear

[INSERT YOUR NAME, ADDRESS and POSTCODE HERE]

As a member of your constituency I am writing to let you know about an important new set of recommendations that was recently published by the APPG for Axial Spondyloarthritis.

As you may be aware, 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 that affects approximately 1 in 200 adults in the UK and has an average age of onset of just 24 years of age. A quarter of patients with axial SpA (AS) will develop complete fusion of the spine, while 50 per cent experience inflammation and damage to other parts of their body, particularly the skin, eyes and gut.

I was diagnosed X years ago [INSERT PERSONAL STORY, APPROX 50 WORDS]

The new recommendations are a set of minimum service specifications for axial SpA, which can be adopted by rheumatology departments to ensure that patients are able to receive the care they need in the event of future Covid-19 outbreaks.

The recommendations have been developed with input from leading national axial SpA (AS) experts and are endorsed by the National Axial Spondylarthritis Society (NASS) and the British Society for Spondyloarthritis. The measures can be adopted without the need for significant additional investment or disruptive service reorganisation.

**Summary of Minimum Service Specifications**

* Patients should be **accurately coded** in local databases to ensure those at risk can be identified.
* Some **face to face capacity** should be maintained for new diagnosis and those in flare.
* Core services should be able to be **delivered digitally** and health professionals should have **adequate training** to be able to do this.
* **Clinical supervision** is vital for junior staff in the event of senior staff redeployment.
* Provisions should be in place **for those not able to access services remotely**.
* Patients should feel **supported to self-manage** as well as have access to **uninterrupted physiotherapy**.

**Recommendations for NHS System-Leaders**

1. **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.
2. **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.
3. **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.

I have attached a full copy of the recommendations. **As a next step, I would be extremely grateful if you were able to help raise awareness of these important recommendations in the following ways:**

* **Write to our local NHS Trust** and ask about the steps that they plan to take to adopt the minimum service specifications.
* **Make representations in Parliament** encouraging the Government to work with NHS system-leaders to implement the three recommendations identified by the APPG.

Further information is available by emailing [jill@nass.co.uk](mailto:jill@nass.co.uk) or the Simon Whalley of the APPG secretariat on [appgspa@mandfhealth.com](mailto:appgspa@mandfhealth.com).

Yours sincerely