

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC52: Ymateb gan: | Response from: National Axial Spondyloarthritis Society.



Submission details

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[REDACTED]

[REDACTED]

I am submitting on behalf of the National Axial Spondyloarthritis Society.

I am happy for my name to be published.

General information

Axial spondyloarthritis (axial SpA) is a form of inflammatory arthritis which most commonly affects the spine but can also affect other joints, tendons and organs. The average age of onset is 26, with most people first displaying symptoms in their late teens to early twenties. There is a current 8.5 average delay to diagnosis in the UK from symptom onset.

NHS and social care services

The readiness of local NHS and social care services to treat people with chronic conditions within the community.

- *Although axial SpA is generally managed within rheumatology services in secondary care, there will be a cohort of people with the condition who will access certain community services such as physiotherapy, mental health and pain management.*

Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.

- *Rheumatology services in Wales are under extreme pressure which is making it difficult for people to access services. A look at workforce issues and how to best optimise the workforce currently in place would be welcome.*

Support available to enable effective self-management where appropriate, including mental health support.

- *Self management is a vital component of living with axial SpA. In particular coping with fatigue, pain and flare up of the condition can leave people debilitated. As a recent piece of research by NASS pointed out, self-management is life with axial SpA between appointments, which are often once a year or less.*
- *In addition to this, it is reported that up to 59% of people with axial SpA will have mental health issues at some point, compared to 25% of people with musculoskeletal conditions, and 20% of the general population.*

Multiple conditions

The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.

- *This is an extremely important area for people with axial SpA. Those with axial SpA will often also have extra musculoskeletal manifestations (EMM), most prominently uveitis (affecting 25% of people with axial SpA), psoriasis (affecting approximately 7% of people with axial SpA) and inflammatory bowel disease (affecting approximately 5% of people with axial SpA).*

The interaction between mental health conditions and long-term physical health conditions.

- *As mentioned earlier up to 59% of people with axial SpA will have ill mental health at some stage. There needs to be consideration about the link between ability to work and financial pressures with ill mental health.*

Impact of additional factors

The impact of the pandemic on quality of care across chronic conditions.

- *No comment*

The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.

- *No comment*

The extent to which services will have the capacity to meet future demand with an ageing population.

- *No comment*

Prevention and lifestyle

Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).

- *Early intervention should also be about swift diagnosis. Too often people with conditions like axial SpA are left in pain, unable to carry out day to day tasks, with long term and irreversible damage taking place whilst waiting for a diagnosis.*

Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.

- *No comment*

Suggested additional areas to cover

- *Economic impact of chronic conditions.*
- *Work / occupational therapy/health*
- *Diagnosis – where should people be diagnosed?*
- *Workforce optimisation*
- *Patient initiated follow up (PIFU)*