

**Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)**

**This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)**

**HSC PSS 115**

**Ymateb gan: | Response from: Cymru vs Arthritis**

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## Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

### Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

This submission has been prepared by Cymru Versus Arthritis. We are part of Versus Arthritis, the charity formed when Arthritis Research UK and Arthritis Care merged in 2018. We work alongside volunteers, healthcare professionals, researchers and people with arthritis to do everything we can to push back against arthritis. Together, we develop breakthrough treatments, campaign for arthritis to be a priority and provide support. Our remit covers all musculoskeletal conditions which affect the joints, bones and muscles including osteoarthritis, rheumatoid arthritis, back pain and osteoporosis.<sup>i</sup>

We are grateful for the opportunity to respond to the Health and Social Care Committee consultation regarding its priorities for the Sixth Senedd.

Cymru Versus Arthritis welcomes the current proposed list of priorities. We have provided detail at Question 2 regarding an additional priority – addressing the waiting list backlog that has developed through the pandemic – that we would urge the Committee to consider adding to its priorities list.

We are particularly pleased to see the inclusion of the priority on ‘Access to services for long term conditions, including musculoskeletal (MSK) conditions.’ The priority provides the Committee with the opportunity to scrutinise the delivery and development of key services impacting on individuals and communities across Wales. The number of people living with MSK conditions alone in Wales is 970,000.<sup>ii</sup>

The prioritisation of this work would also fit well with other work streams at the national level, with the Welsh Government’s recent consultation on its ‘Arthritis and Long Term Musculoskeletal Conditions Framework’.<sup>iii</sup>

Access to the right services at the right time for people with chronic long-term arthritis and MSK conditions is vital to minimise the impact of these conditions in terms of physical and mental health, disability, persistent pain, mobility, dexterity, independence and employment. Ensuring access to high quality services is of even greater significance following the disruption to services caused by the Covid pandemic.

- Many people with MSK conditions have experienced significant delays and cancellations in relation to access to services during the pandemic. The pausing of elective orthopaedic services during the pandemic has resulted in many tens of thousands of people with arthritis and musculoskeletal (MSK) conditions waiting significantly longer for life-changing procedures such as joint replacements. Many are waiting in severe and worsening persistent pain, with significant consequences for their physical and mental health, mobility and independence.
- Rebuilding services such as elective orthopaedic surgery to provide pre-pandemic levels of access will take a significant amount of time to achieve. It is vitally important therefore that coordinated proactive communications, signposting and support is available to people waiting longer for services such as orthopaedic surgery to help them retain their activity levels, mobility and independence and to help them manage the physical and mental health challenges of their longer wait.
- Many issues relation to timely access to services for people with MSK conditions are long standing and were impacting on people with these conditions before the pandemic.

Example issues include:

- The need for early and clear diagnosis. Delayed diagnosis can have a significant impact on physical and mental health, leading to permanent, irreversible damage and disability. This is a significant issue for a number of MSK conditions, for example in axial SpA (AS) there is an 8.5 year average delay to diagnosis.<sup>iv</sup>
- The need for proactive early intervention to promote and support the individual with an MSK condition to develop self-management knowledge and skills. Many people with MSK conditions are not aware of the effectiveness of self-management and need to be supported to overcome barriers to utilise such approaches, e.g. lack of knowledge of the benefits of safe exercise and fears of damaging already painful joints. There are successful, well evidenced programmes to achieve this aim, such as ESCAPE pain.<sup>v</sup> There is considerable variance between regions in the provision ESCAPE pain programmes.
- The need for speedy early access to specialist services. For certain MSK conditions, such as rheumatoid arthritis, suspected cases need to be referred into rheumatology services for assessment and early intervention as soon as possible – within a timeframe of weeks to meet NICE guidance – to reduce long term joint damage and disability.
- Ongoing access as required to services to support self-management and activity levels. The symptoms of MSK conditions change and develop over time and the support needed by individuals also changes.
- Timely access to orthopaedic services as required. Orthopaedic services in Wales were struggling to meet demand and waiting times targets before the pandemic.

Work is needed to ensure that orthopaedic services in Wales are rebuilt to address future demands and meet pre-pandemic waiting times targets.

- Lack of dedicated multidisciplinary rheumatology services in many areas.
- Difficulty accessing specialist pain management services in many areas.
- The lack of clear pathways of care for some MSK conditions, such as Fibromyalgia.
- The need to better integrate support available from the third sector into care pathways to ensure people have access to information, peer support, and supported self-management. For example, third sector organisations such as Cymru Versus Arthritis provide a range of quality services to people living with MSK conditions that can help them understand their condition, their treatment and self-management options including safe exercise, and provide peer support to reduce isolation and to facilitate opportunities for people to build community and learn from others with similar experiences. Such services in the third sector can also provide signposting to wider support services and networks that can help someone with an MSK condition in relation to employment, finance and access to assessments for aids and adaptations that can support independence.

## Question 2: Key priorities for the Sixth Senedd

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) **health services;**
- b) **social care and carers;**
- c) **COVID recovery?**

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

a) Health services

We are concerned that tackling the backlog / reducing waiting times that have grown to record levels during the pandemic and supporting people on those waiting lists has not been referenced explicitly within the set of priorities proposed by the Committee.

It is clear that the backlog of patients for services such as orthopaedic surgery is one of the most significant health challenges that NHS Wales has faced.

We believe reducing the backlog and supporting people on the waiting lists needs to be among the highest policy and service priorities in Wales. We would like to see this priority added to the priority list of the Health and Social Care Committee.

- Many tens of thousands of people with MSK conditions are on waiting lists that have hit record levels in recent months. Many are waiting for surgery in severe and worsening pain with no clear idea of when their operation will take place. Worsening pain and other symptoms can impact significantly on mobility, dexterity, independence, physical and mental health and ability to remain in employment. As a charity with supporter services for people living with MSK, we are hearing from people on the waiting list who express how desperate they feel and how much their lives have effectively been put on hold as they wait for an indefinite period for life-changing surgery.
- The Trauma and Orthopaedics (T&O) waiting list has grown to record levels during the pandemic. As at the end of June 2021 (latest figures), the total number of people waiting for T&O treatment in Wales was 92,150, a further 2% increase since May 2021 and 33% higher (+30,032) than the average for 2019 (62,118). 62,379 (68%) were waiting longer than 26 weeks compared to 15,323 people (25%) on average in 2019 and 54,394 (59%) waiting longer than 36 weeks, compared to 6,570 people (11%) on average in 2019. The number waiting over a year<sup>vi</sup> had grown to 43,491, a little under half (47%) of the waiting

list, compared to 2,472 people (4%) on average in 2019. 4,485 people were waiting over 105 weeks (over 2 years) as at the end of June 2021, an increase of 772 people (17%) since last month.

- The current backlog is likely to take a number of years to clear. The slower the pace of progress clearing the backlog, the longer many people will wait and the wider and deeper the potential impacts of the waits in terms of health and social care costs, interventions becoming more complex and less effective, impacts on employment, mental health and the development of comorbidities. It is vital that reducing the backlog through safely rebuilding capacity at pace is prioritised to reduce long term harm for individuals and greater future demands on health and social care services.
- Versus Arthritis recently surveyed people waiting for joint replacement surgery and found: (Wales figures in brackets)<sup>vii</sup>:
  - 52% said their pain levels had significantly worsened (60% Wales).
  - 40% said their independence has significantly reduced (39% Wales).
  - 81% said their physical health had either worsened or significantly worsened (88% Wales).
  - 72% said their mental health had either worsened or significantly worsened (80% Wales)
- Evidence shows that delaying surgery can lead to worse outcomes for people who have been referred for hip and knee joint replacement, particularly waiting times beyond 6 months.<sup>viii</sup> Interventions such as hip and knee replacement surgery can be transformative, significantly reducing or eliminating severe persistent pain and restoring mobility and independence.
- The pace of progress rebuilding capacity in many parts of Wales during recovery periods since the beginning of the pandemic has been inconsistent and, we would argue slower than it needs to be. We are concerned that there appears to be a lack of timeframes for restoring elective orthopaedic throughput to pre-pandemic levels and for meeting pre-pandemic waiting times targets.
- There is a lack of monthly published granular data regarding elective orthopaedic activity levels (number of operations by type), providing a barrier to developing an accurate assessment of progress rebuilding capacity to pre-pandemic levels. CVA has been calling for the monthly publication of the number of elective hip and knee replacement operations undertaken in each Health Board (and under contract to HBs by private healthcare providers.) The Committee has an opportunity to make recommendations regarding data requirements to make the recovery process far more transparent. Such transparency is needed to evaluate progress but also to provide reassurance and greater clarity for service-users regarding timeframes to surgery.
- It is clear from recent pausing of services in some Health Board areas that current measure to protect elective orthopaedic surgery services have not been sufficiently robust. The pausing of services due to admissions pressures is not a new development during the pandemic. It is vitally important that robust plans are in place to protect progress in rebuilding elective orthopaedic services going forward.
- It will take a considerable amount of time to bring waiting times back down to pre-pandemic levels. As detailed above, the long waits for surgery poses significant

challenges to individuals on the waiting list as they wait, challenges that can become more difficult over time.

- It is vitally important therefore that coordinated proactive communications, signposting and support is made available to people waiting longer for services such as orthopaedic surgery to help them retain their activity and independence levels, develop self-management skills, reduce isolation and to help them manage the physical and mental health and financial challenges of their wait for surgery.
- We believe that the provision of communications, signposting and support for people on the longer waiting lists should be a part of a backlog priority enquiry for the Committee.
- Cymru Versus Arthritis has been calling for a 'National Orthopaedic Recovery and Transformation Strategy'. Firstly, to develop guidance to support rebuilding at pace capacity and protection of elective services from Covid and winter pressures. Secondly, to plan the reconfiguration of orthopaedic services to build an efficient, robust service, fit to meet future demands and meet pre-pandemic waiting times targets. The Royal College of Surgeons of England in Wales has developed an Action Plan for the Recovery of Surgical Services in Wales that offers a valuable contribution to the development of such a plan.<sup>ix</sup>
- In England, the Health and Social Care Select Committee has announced an inquiry into the backlog caused by the pandemic.<sup>x</sup>
- We would welcome the Committee considering adding the waiting list backlog caused by the pandemic to its forward work programme, with consideration given for:
  - Data needs to monitor progress rebuilding services.
  - Current modelling provision for the scale of the current backlog, future demands and the timeframe and activity levels required to return to pre-pandemic levels.
  - Communications, signposting and support available for people on waiting lists to help them manage the physical and mental health challenges of their wait.
  - Scrutiny of current investment and service capacity plans.
  - Measures and planning to protect continued provision of elective services from future Covid, winter and other pressures.

b) Social care and carers

c) COVID recovery