

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 57

Ymateb gan: | Response from: **Uned Ymchwil Ysbyty Arch Noa i Blant Cymru | Noah's Ark Children's Hospital for Wales Research Unit**

Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrsgerbydol.

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.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?

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

Within paediatrics one of the main priorities is ensuring that children can access evidence-based innovation in health. Historically, children have faced challenges in accessing research to develop treatments essential for their healthcare needs. A team from the Noah's Ark Children's Hospital for Wales highlighted the Wales specific issues during the Children's Rights Inquiry held by the Children, Young People and Education Committee in 2019 - <https://business.senedd.wales/mglIssueHistoryHome.aspx?lId=25724>.



Although discussions have begun with Welsh Government officials because of the CYPE Committee Inquiry there is still a big disparity in the clinical research infrastructure available to adults in Wales and to children. Whilst some progress has been made, the early phase paediatric oncology infrastructure in Wales for example, is still funded by charity funding, whilst the adult services are able to access statutory funding to offer life prolonging trials to patients in one of three centres in Wales. For children, early phase trials are often the last treatment option available to them, they are life prolonging rather than curative, but children in Wales for the majority of studies, will need to leave Wales to participate.

Wales also lacks a young people's advisory group that is able to input into clinical research in Wales, opportunities available to children and young people in both England and Scotland ([Generation R](#)).

The pandemic has highlighted the importance of clinical research and the importance of having an infrastructure to support it ([Saving and Improving Lives: The Future of UK Clinical Research Delivery - GOV.UK \(www.gov.uk\)](#)). We ask the HSC committee to consider taking evidence on medical research in Wales with a particular focus on paediatric research, noting the findings of the CYPE committee in the last Senedd, and consider at that point whether further recommendations should be made to the Welsh Government and/or whether there should be a debate on this in the Senedd. We would ask that this happens early on in the Committee's agenda to ensure we do not lose the momentum built from the CYPE Inquiry