

Cyflwynwyd yr ymateb hwn i ymgynghoriad y Pwyllgor Plant, Pobl Ifanc ac Addysg ar Flaenoriaethau'r Chwched Senedd

This response was submitted to the Children, Young People and Education Committee consultation on Sixth Senedd Priorities

CYPE SP 54

Ymateb gan: Rhian Thomas Turner, Ysbyty Plant Arch Noa yng Nghymru, Uned Ymchwil Plant ac Oedolion Ifanc.

Response from: Rhian Thomas Turner. Noah's Ark Children's Hospital for Wales, Children and Young Adults' Research Unit.

Beth yn eich barn chi yw'r prif flaenoriaethau neu'r materion y dylai'r Pwyllgor eu hystyried yn ystod y Chwched Senedd? Os oes modd, nodwch eich barn o ran sut y gallai'r Pwyllgor fynd i'r afael â hyn.

What do you consider to be the main priorities or issues that the Committee should consider during the Sixth Senedd? Where possible, please set out your view about how the Committee could address them.

Thema 1: Addysg oedran ysgol | Theme 1: School-age education

Thema 2: Addysg bellach ac addysg uwch | Theme 2: Further and higher education

Thema 3: Iechyd a lles, gan gynnwys gofal cymdeithasol (i'r graddau y maent yn ymwneud â phlant a phobl ifanc) | Theme 3: Health and well-being, including social care (as they relate to children and young people)

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 previous 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 would like to ask the CYPE Committee to undertake a one-day inquiry into paediatric research in Wales, as a piece of follow-up to the issues identified by its predecessor committee 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.

Thema 4: Plant a phobl Ifanc | Theme 4: Children and young people

