

PE2038/H: Commission suitable NHS services for people with hypermobile Ehlers-Danlos syndrome and hyper mobility spectrum disorders

NHS Wales written submission, 17 January 2025

There is a newly formed strategic clinical network for musculoskeletal (MSK) health under the NHS Executive in Wales.

That network has been reviewing condition specific pathways of care and methods to improve the quality of care and MSK health across Wales.

Hypermobility spectrum disorders (HSD) and Hypermobile EDS (hEDS) were highlighted by several patient, charity and clinical forums as an area which lacks guidance and consistency in delivery.

The Network understands that there are currently no recognised clinical guidelines and that NICE and the British Society for Rheumatology feel that research is not at a place to produce them as yet.

There is a GP toolkit that was developed by EDS UK charity that represents current best practice.

The MSK strategic network and its Rheumatology Implementation Network have worked with the national community health pathways provider to adapt an international pathway in co production between clinical and 3rd sector subject matter experts.

The pathway will be published on the community health pathways website and will offer advice on diagnosis and treatment for primary care clinicians, direct access to therapies services for primary and community care rehab and supported self-management interventions, and clear referral guidance for those with suspicion of the rarer forms of EDS that require genetic testing and specialty involvement.

We expect this to offer a level of consistency across Wales that can be updated when more formal and appropriate guidance is available.