

National Services Division submission of 13 October 2023

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

Thank-you for your recent correspondence from the Citizen Participation and Public Petitions Committee regarding a petition calling on the Scottish Parliament to urge the Scottish Government to commission suitable NHS services for those with hypermobile EDS (hEDS) and hypermobility spectrum disorders (HSD), and to consult with patients on their design and delivery.

We were sorry to hear that those with symptoms suggestive of hEDS and HSD as well as those with a diagnosis of these conditions continue to describe difficulties in obtaining timely, equitable, person-centered diagnosis, treatment, and ongoing support to meet their needs.

National Services Division (NSD) previously facilitated a Short Life Working Group (SLWG) bringing together several clinical staff from across Scotland and the UK as well as representatives of the patient advocacy group with a view to understanding the needs of this group of patients and scoping how services could be delivered.

Although patients from Scotland can access NHS England highly specialist diagnostic EDS services located in Sheffield or London via NSD's close working relationship with the English commissioners, such services have a very specific remit and patient referral criteria and are not commissioned to provide ongoing support or treatment following diagnosis. It was therefore the recommendation of the SLWG that there was a need for specific specialist expertise in Scotland to improve patient care.

An NHS Lothian application led by Professor Ralston to develop a national specialist service to deliver care for this group of patients based upon the recommendations of the SLWG was however not supported back in 2019 by the National Specialist Services Committee and therefore the application did not progress to designation.

The reasons for non-progression included the lack of support for the proposal from the Scottish Society of Rheumatology, the need for initial assessment and treatment by local rheumatology services prior to referral to the national service and that care might be better delivered through the development of a set of clinical guidelines, a patient pathway of care or a networked community of practice.

On this basis the recommendation of the National Specialist Services Committee (NSSC) was that this need should be passed back to the clinical community for further development.

The ongoing diagnostic, treatment, and care needs of hEDS and HSD patients are the responsibility of individual Health Boards across Scotland who commission and/or provide rheumatology, clinical genetic, cardiology, gastroenterology, pain management, physiotherapy, and occupational therapy services which these individuals often require.

The responsibilities of NSD do not extend to the performance management, planning, operational delivery, or scrutiny of such services and therefore it is not possible for NSD to undertake a needs or service gap analysis nor monitor service developments.

The option remains open to the clinical community to formally register a new application for consideration of designation of a national specialist service or managed clinical network however such an application would require the endorsement of the Chief Executive of the Health Board where the clinician is in clinical practice. The designation process now follows an annualized cycle with registration for the next cycle closing on 31 March 2024 for consideration during year 2024/2025.

We hope that this information is helpful to you however should you have any further queries please do not hesitate to contact us.