Citizen Participation and Public Petitions Committee
Wednesday 10 December 2025
19th Meeting, 2025 (Session 6)

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

Introduction

Petitioner	The Ehlers-Danlos Support UK
Petition summary	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.
Webpage	https://petitions.parliament.scot/petitions/PE2038

1. The Committee last considered this petition at its meeting on 9 October 2024. At that meeting, the Committee agreed to write to the Scottish Government and NHS Wales.

2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.

3. The Committee has received new written submissions from the Scottish Government, NHS Wales and the Petitioner which are set out in **Annexe C**.

4. Written submissions received prior to the Committee's last consideration can be found on the petition's webpage.

5. Further background information about this petition can be found in the SPICe briefing for this petition.

6. The Scottish Government gave its initial response to the petition on 6 September 2023.

7. Every petition collects signatures while it remains under consideration. At the time of writing, 2,405 signatures have been received on this petition.

8. At its meeting on 24 September 2025, the Committee took evidence on thematic healthcare issues that have been raised in multiple petitions, including this petition.

Action

9. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee

CPPP/S4/25/19/7

December 2025

Annexe A: Summary of petition

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

Petitioner

The Ehlers-Danlos Support UK

Date Lodged

24 July 2023

Petition summary

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.

Previous action

Volunteers and members from The Ehlers-Danlos Support UK have met with Bob Doris MSP as a result of interactions via the Rare, Genetic and Undiagnosed Conditions Cross Party Group. Constituents have met with Mairi McAllan MSP, Angela Constance MSP, Bill Kidd MSP, Pauline McNeill MSP, Emma Roddick MSP and Daniel Johnson MSP.

Motions on behalf of constituents have been raised in the chamber of the Scottish Parliament by Martin Whitfield MSP and Michelle Thomson MSP.

A meeting with Emma Roddick MSP on 4 November 2022 resulted in Ms Roddick publicly calling for a pain pathway for those with EDS and others. She also agreed to speak to then Cabinet Secretary for Health Humza Yousaf about the issues and to raise a question in the Parliament about a care pathway for people with EDS.

Background information

hEDS is a connective tissue disorder with body-wide symptoms which can be disabling, affecting all aspects of life. Symptoms include musculoskeletal problems, chronic pain and fatigue, gastrointestinal disturbance, pelvic and bladder problems, anxiety and more. There is no single test, which makes diagnosis challenging. HSD presents many of the same symptoms and shares the same diagnostic challenge. Together, hEDS and HSD are thought to affect 1 in 500 people.

Historically, those showing symptoms have been referred to local rheumatology departments where service access is known to be inconsistent.

While there is a commissioned diagnostic service in England for rarer types of EDS (which can be accessed by people in Scotland), diagnosis and management has relied on the personal interest and knowledge of a small number of clinicians rather than formally commissioned services.

The situation described has resulted in inequalities in access to healthcare, causing anxiety, distress, and unnecessary pain and suffering for those waiting for diagnosis, those on inappropriate treatment pathways, and their families.

Annexe B: Extract from Official Report of last consideration of PE2038 on 9 October 2024

The Convener: PE2038 calls on the Scottish Parliament to urge the Scottish Government to commission suitable NHS services for people with hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders and to consult patients on their design and delivery. For consideration of the petition, we have been joined by our MSP colleague Michael Marra, who has taken an interest in the petition. Good morning, Mr Marra.

Michael Marra (North East Scotland) (Lab): Good morning, convener.

The Convener: We previously considered the petition on 4 October last year, when we agreed to write to the Scottish Government and the national services division. The Scottish Government's response provides information about its engagement work with individuals living with Ehlers-Danlos syndrome and hypermobility spectrum disorders. The submission highlights the Government's work on the rare disease action plan and states that officials would be happy to meet the petitioner to discuss that work further.

The national services division's submission explains that a short-life working group that it facilitated found that

"there was a need for specific specialist expertise in Scotland to improve patient care"

but one of the reasons why that work has not progressed is that the national specialist services committee determined 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."

The response from the petitioner—Ehlers-Danlos Support UK—states:

"This is exactly what we are trying to achieve",

but it has been informed by Healthcare Improvement Scotland that there is "not enough evidence" to support the creation of guidelines from the Scottish intercollegiate guidelines network. The petitioner has shared that NHS Wales has now

"committed to co-creating a hypermobility pathway for primary care to help GPs diagnose and manage these conditions."

The petitioner also outlines statistics to support its view that Ehlers-Danlos syndrome and hypermobility spectrum disorders are not necessarily rare disorders, as they often go undiagnosed.

We have received a written submission from our colleague Emma Roddick, who is unable to attend the meeting. Her submission, which is available on the committee's website, touches on her experience of living with chronic pain and the value of

meeting other people who have similar experiences to her own. She acknowledges that doctors

“cannot be expected to know everything”,

but she believes that there should be

“a nationally agreed standard for pain pathways to ensure that people do not fall through the cracks”.

Before we consider what we might do next, I invite Michael Marra to speak to the committee.

09:45

Michael Marra: I greatly appreciate being afforded the opportunity to address the committee. This is the first time that I have spoken to the committee about the petition, and I would like to provide an update on some of the developments from my involvement with the petition.

My involvement relates to constituents who are living with such conditions and have faced challenges in accessing treatment and support. That includes some who have waited 20 years for a diagnosis. I have lodged a motion for a members’ business debate on the subject, which has gained cross-party support, for which I am grateful. I look forward to having that debate in the chamber when it is scheduled.

Last month, I was pleased to host a round-table meeting in the Parliament with Ehlers-Danlos Support UK and researchers from the University of Edinburgh, Kathryn Berg and Dervil Dockrell, who shared the findings of their recent research into EDS, which revealed that people are waiting decades for a diagnosis, with a large proportion of those people either leaving Scotland to access healthcare in England or paying for private treatment. That demonstrates that there is a clear gap, as that research testifies, in the services that are available in Scotland for people living with HEDS and HSD. For that reason alone, I urge the committee to keep the petition open for further consideration, and I will come on to suggest some potential actions.

Ehlers-Danlos syndromes are a group of 13 heritable connective tissue disorders that are caused by genetic changes that affect connective tissues. Each type of EDS has its own set of features, but common features of various types of EDS include joint hypermobility, skin hyperextensibility and tissue fragility. That can cause a person’s joints to dislocate and their skin to be stretchy. They bruise easily and their wounds can take a long time to heal.

I have heard powerful testimony from constituents on living with such conditions. They have talked about being in constant pain, living with reduced mobility and having a limited quality of life, as well as the impacts on their mental health.

The most common type of EDS is hypermobile EDS, which accounts for about 90 per cent of the cases that are being considered today. There are various statistics on the prevalence of such conditions. The convener referenced some of them in his opening remarks. As he did and as colleagues from EDS UK have done, I point out

that there is a crucial distinction between rare and rarely diagnosed. One study found that one in 500 people had a diagnosis of HEDS and HSD, so the matter certainly requires more investigation.

The Scottish Government's submission on 12 October 2023 stated that the Government was

"considering what additional stakeholder engagement activities may be required throughout 2024."

It also talked about

"the Rare Disease Implementation Boards's intention to hold a number of 'involvement meetings' early in 2024".

However, as it states in its latest submission, EDS UK does not feel that those meetings are an appropriate avenue for developing a specific care pathway for EDS, as they cover a range of rare diseases.

The response from the national services division on 13 October 2023 stated:

"The ongoing diagnostic, treatment, and care needs of hEDS and HSD patients are the responsibility of individual Health Boards".

However, given the experiences of my constituents that I have highlighted and those that have been highlighted through research and the work of EDS UK, that system is simply not working at the moment.

The petitioner's most recent submission calls for

"A pathway for NHS diagnosis and care for hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders ... NICE/SIGN guidelines for Ehlers-Danlos syndromes and hypermobility spectrum disorders ... A coordinated, multidisciplinary approach to diagnosis and care for people with hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders"

and, crucially,

"Support and training for healthcare professionals to deliver this."

I commend the staff and volunteers at EDS UK for their continued determination on the issue.

I note that progress has been achieved in other United Kingdom nations to date. For example, in May, as the convener said, NHS Wales committed to co-creating a hypermobility pathway for primary care to help GPs to diagnose and manage the conditions. Colleagues at EDS UK have met community health pathway teams in Wales, which has helped to progress work on that pathway. Research and lived experience have shown that GPs are often not aware of such conditions or the potential treatment options that are available. Publishing a pathway would give clearer guidance to GPs and lead to improved patient experiences. At the round-table meeting that was held in the Parliament, there was a clear desire from the general practitioner workforce to have such information available to them.

As far as I am aware, we do not have community health pathways in Scotland, but there is the possibility for some collaborative work across the two nations of Scotland and Wales in that regard. I suggest that the committee might want to contact NHS Wales to find out more detail on the progress of that work to date and how it might be applicable to Scotland.

The Convener: Thank you very much. There were a couple of good suggestions in there.

Foysol Choudhury: We should keep the petition open and, as well as doing what Mr Marra suggested, write to the Scottish Government to ask whether it accepts the petitioner's view that Ehlers-Danlos syndrome and hypermobility spectrum disorders are not necessarily rare diseases, as they are often undiagnosed. In the light of that, we should ask what action is being taken, beyond the rare disease action plan, to improve diagnostic services. We should also highlight the commitment by NHS Wales to co-produce a hypermobility pathway for primary care and ask whether a similar exercise could be undertaken in Scotland.

The Convener: I note that, in addition to Mr Marra and Emma Roddick, a number of our colleagues—Bob Doris, Angela Constance, Bill Kidd, Pauline McNeill, Màiri McAllan, Daniel Johnson, Martin Whitfield and Michelle Thomson—have all been engaged on the issue, so it has attracted a considerable amount of attention and concern among parliamentary colleagues.

I am happy to take forward all the suggestions that have been made. We might also want to ask about the view that the current way of moving forward might not be the best model to achieve the end result. It would be useful to put that point to the Scottish Government to see what its reaction is, because that view is obviously very clearly felt.

We will keep the petition open. There are a number of ways in which we can continue to pursue the issue. I thank the petitioner for lodging the petition and Michael Marra for joining us this morning.

Annexe C: Written submissions

Scottish Government submission of 15 November 2024

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

I refer you to your email of 18 October asking for the Scottish Government's views on the actions called for in petition PE2038, following its consideration at the Petitions Committee meeting of 9 October 2024. I have addressed the Committee's requests contained in the bullet points below.

- **The Committee is interested to know whether the Scottish Government accepts the Petitioner's view that Ehlers-Danlos syndrome and hypermobility spectrum disorders are not necessarily rare diseases as they often go undiagnosed and, in light of that, is keen to understand what action is being taken to improve diagnostic services beyond the Rare Disease Action Plan.**

- **The Committee heard that NHS Wales has now committed to co-creating a hypermobility pathway for primary care to help GPs diagnose and manage these conditions. The Committee is interested to know whether a similar exercise could be undertaken in Scotland.**

The Scottish Government recognises that rare conditions may be individually rare to greater or lesser degrees, but collectively more common, and the number of individual conditions under the umbrella of Ehlers-Danlos syndrome, as well as the spectrum of hypermobility disorders, make them collectively more common than some of the rarest conditions. We recognise, and have noted several times in the process of our engagement with the rare community, that delayed and missed diagnoses are a fundamental concern, and that awareness raising is key to addressing this.

As set out in our Progress Report on Scotland's Action Plan for Rare Diseases, published in August 2024, we have worked to understand in the first instance what level of knowledge healthcare professionals currently have of rare conditions, where they would access supportive resources, and identify what they would need to help them improve the care they give to people with rare conditions. This work was conducted in the form of a survey by Genetic Alliance UK and the Office for Rare Conditions, Glasgow. We are using the results of this survey to shape our approach to awareness raising going forward.

We are also developing awareness raising videos, in conjunction with NHS Education for Scotland, to encourage healthcare professionals to 'think rare'. The petitioner's website notes that healthcare professionals can often be trained to 'think horses not zebras when you hear hooves' (i.e. consider the most common diagnosis), and we recognise that a different approach is required when presented with a set of symptoms that, together, can indicate a rare condition. This will be a core message within the professional-facing videos we are developing, and will be

complemented by videos intended for families experiencing a rare condition. We have made faster diagnosis and awareness raising our key priorities for the coming year.

Our work to improve the lives of people with all rare conditions will remain an important commitment. In this instance however, the petitioner has specifically asked what action is being taken outwith our work for rare conditions to improve diagnostic services.

The Scottish Government recognises that demand for diagnostics has been growing progressively, and that reform is necessary to ensure that we have sustainable diagnostics that are able to deliver the best possible services for patients. The Scottish Strategic Network for Diagnostics is currently supporting work to strategically plan this reform across Scotland.

We have also been considering other resources that could be promoted for use by healthcare professionals to diagnose more effectively. One such resource, mentioned in the Progress Report on Scotland's Action Plan for Rare Diseases, is the Right Decision Service (RDS) hosted by Healthcare Improvement Scotland. RDS is a suite of digital tools that enable convenient and quick decision-making, and also hosts useful information for healthcare professionals, including information developed by NHS Boards. As the petitioner may already be aware, assessment and referral guidance for hypermobile Ehlers Danlos syndrome was developed by NHS Dumfries & Galloway last year, and is hosted on the RDS website. We will continue to look for ways to promote such guidance among healthcare professionals.

The Scottish Government is also engaging with clinicians, stakeholders, and those with lived experience, to develop an integrated strategy on long term conditions. This will include a consultation in the new year, to ensure a wide capture of views.

Scottish Government officials engage regularly with our counterparts in the UK government and the other devolved nations in order to share knowledge and progress in our work to improve the lives of people living with rare conditions. We will certainly be interested in learning more about the hypermobility pathway for primary care that NHS Wales will be developing. We will speak to our Welsh counterparts about their project plan, funding practicalities and resourcing required, and consider if it is feasible, within current resources, for a similar exercise to be taken forward in Scotland and by what means.

I hope this response is helpful to the petitioner.

Rare Diseases, Genomics, Diagnostics and Participation Unit

NHS Wales written submission, 17 January 2025

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

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.

Petitioner written submission, 20 February 2025

PE2038/I: Commission suitable NHS services for people with hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders

We would like to challenge the response from the Rare Diseases, Genomics, Diagnostics and Participation Unit of 15 November 2024. As previously detailed in our evidence there are 13 types of Ehlers Danlos Syndrome (EDS), 12 of which are rare and one which is far more common. That is hypermobile EDS (hEDS) and hypermobility spectrum disorders (HSD). We need to be clear that given the published studies and growing body of evidence that the prevalence of this condition is common, not rare; with studies suggesting a prevalence of between 1 in 227 and 1 in 500; and respectfully that perhaps this is outwith the Rare Diseases, Genomics, Diagnostics and Participation Unit’s remit. This petition is focused on hEDS and HSD which do not have a known genetic basis, which prevents these conditions from being identified by genetic testing. Therefore, our community is faced with incredible barriers to accessing diagnosis and care equitably.

We were pleased to hear that the Rare Disease Unit is producing awareness videos for the rare types of EDS and looking to reform diagnostics.

While we are pleased that guidance on the assessment and diagnosis for hEDS is available on the RDS website, we believe that this guidance would benefit from revision by a knowledgeable multidisciplinary team, should include information on

HSD, and could make use of the EDS UK GP Toolkit which has been based on the relevant evidence base. We would be pleased to see this advice readily available on RefHelp pages for each Health Board to ensure that all healthcare professionals in Scotland have access to the same guidance, while we await a national care pathway.

We would like to understand how the information provided on RDS is used by primary care across all Health Boards and if it is being accessed then why are our members still reporting problems in getting the diagnosis and care that they desperately need?

The response from NHS Wales states that '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.' As a result of our petition in Wales, we were invited to join the working group as subject matter experts to co-create a pathway for '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 speciality involvement.' We used our GP toolkit https://gptoolkit.ehlers-danlos.org/ as a basis for the work and we are pleased to report that the final draft has now gone out to wider consultation in NHS Wales. We are hopeful that this will be in use in the coming months and that we will start to see improvements in equitable access to healthcare in Wales.

Our questions for the Scottish Government are as follows:

How is the Right Decision Service used by healthcare professionals in NHS Scotland? Are there any statistics to show the use and impact of the hypermobility/hypermobile Ehlers Danlos syndrome guidance? Is the guidance widely used in primary care? If not, what systems are used, like the Community Pathways system, that could be adapted with the right information on current best practice?

Given the work that NHS Wales has done in collaboration with us, would NHS Scotland be prepared to commit to a similar project? Would the Scottish Government also support the development of SIGN guidance given recent evidence?