Attn: Mr. James Wolfe
Department of Work and Pensions
April 2025

Dear Mr Wolfe,

We write collectively on behalf of those living with Ehlers-Danlos Syndromes (EDS), Hypermobility Spectrum Disorders (HSD), and associated conditions, to express deep concern over the proposed changes to the Personal Independence Payment (PIP) system in the UK.

We understand that the key change is that at least one domain must score a 4 or more for a person to be eligible for PIP. Many of the community we represent record scores of 2 across multiple domains which collectively in an individual represents a significant burden on activities of daily living. Under the new scheme these individuals would not be eligible unless at least one of their concerns scored a 4. How can that be justified?

These changes risk disproportionately disadvantaging our community - individuals already burdened by chronic pain, fatigue, joint instability, and multisystemic complications that are often invisible, poorly understood, and devastatingly life-altering. EDS and HSD are complex and lifelong conditions that frequently go unrecognized, misdiagnosed, or dismissed altogether by healthcare professionals and benefits assessors alike. The impact of this systemic misunderstanding has been significant: delays in diagnosis, lack of access to appropriate care and treatment, and insufficient recognition in disability support frameworks such as PIP.

Many with EDS and HSD rely on PIP to meet basic daily living and mobility needs. This support is not a luxury; it is a lifeline that enables independence, dignity, and participation in society. Any move to restrict access, tighten criteria, or overlook fluctuating and invisible disabilities will compound the barriers this community already faces. It will push more people into crisis - physically, emotionally, and financially.

We urge policymakers to recognise the unique challenges posed by EDS, HSD, and related conditions. Assessments must be informed, compassionate, and rooted in an understanding of the lived experience of those affected. Now is the time to amplify their voices—not silence them further through exclusionary reforms.

We stand united in calling for a benefits system that upholds equality, justice, and dignity for all disabled people in the UK.

**Signed:**

**Professor Lara Bloom**
**The Ehlers-Danlos Society**

**Susan Booth**
**The Ehlers-Danlos Support UK**

**Lisa Bone**
**The Hypermobility Syndromes Association (HMSA)**