



Eich cyf/Your ref: WQ98669

Steve Bayliss MS
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16 June 2026

Dear Steve,

I am writing in response to your written question tabled on 27 May, where you asked:

'What assessment has the Government made of the reasons for the delay in publishing the NHS Wales primary care pathway for Ehlers-Danlos syndromes and Hypermobility Spectrum Disorders, and when does the Government expect the pathway to be published for use across Wales?'

A Community Health Pathway for Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD) has been developed through multidisciplinary collaboration, including clinical experts and patient representation. This forms part of wider work to improve care for people with rare and complex conditions in Wales, including through the [Wales Rare Disease Action Plan](#), and supports our intention to strengthen care closer to home.

All Community Health Pathways must be agreed through established national governance arrangements, including with primary care representatives, before publication. This ensures they reflect current practice and are safe, effective, and deliverable across the system. The EDS and HSD pathway is progressing through this process and has not yet secured the clinical agreement required for publication. Work is ongoing with relevant partners to address outstanding issues and support final agreement. As a result, I am not able to confirm a publication date at this stage.

Yours sincerely,

Mabon ap Gwynfor AS/MS

Gweinidog Cabinet dros Iechyd a Gofal
Cabinet Minister for Health and Care