

Testing ‘the Spider’, a new screening tool to assess the impact of hypermobility in adults

*Professor Jane Simmonds & Ellen Ewer, UCL Great Ormond Street Institute of Child Health.
UCL Research Ethics Committee Approval ID Number: 19629/002*

Are you a person aged between 18 and 65 years who has been diagnosed with symptomatic hypermobility, hypermobile Ehlers-Danlos syndrome (hEDS) or hypermobility spectrum disorder (HSD)?

A team of specialist clinicians and researchers has developed a new patient questionnaire called ‘The Spider’. The Spider has been designed to assess the impact of various symptoms (or problems) experienced by people with HSD and hEDS. This questionnaire aims to help identify the impact these symptoms have on a person’s daily life, guide treatment pathways and monitor the impact of treatment for people with HSD and hEDS.

Before The Spider can be used in clinical practice and in research it is important that we know that it can accurately identify the specific symptoms (problems) and measure the impact of these symptoms on a person’s life. The team behind the Spider have validated this questionnaire with young people, which you may have seen advertised. We now hope to validate this tool with adults. This is the reason why they are asking for your help by completing these surveys. This will be done in a series of stages, with several questionnaires asking about different symptoms you may experience. Below you will find a link to the first 3 stages – each survey will take around 10 minutes, and we would be grateful if you could complete all 3. You don’t have to do this all in one go, you can do any of the surveys at any time.

Who can participate?

We need 300 adults with and without HSD/ hEDS to complete the questionnaire. We are looking for participants between 18 and 65, with and without HSD/hEDS and who do not have conditions such as:

Neurological conditions unrelated to HSD/hEDS such as stroke, multiple sclerosis, cerebral palsy and acquired or traumatic brain injury. Please note, people with co-existing neurodivergence (Autism Spectrum Disorder/Attention Deficit Hyperactivity Disorder/ Developmental Coordination Disorder) are NOT excluded and are encouraged to participate.

Rheumatological/inflammatory conditions unrelated to HSD/hEDS such as rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis.

Unrelated joint/muscle problems: post-surgery, traumatic injury. Please note people with co-existing POTS or orthostatic intolerances and age related osteoarthritis are NOT excluded.

What can be expected from participating?

This surveys will take around 10 to 15 minutes to complete, but should you need to, you can save your answers and return later. The first survey will ask you to share your experiences with your digestion and bowel habits, your energy levels and sleep and

'neuromusculoskeletal' symptoms involving your nerves, muscles and joints through a series of questions. The second survey will ask about your mental health and bladder concerns. The third survey will ask about your pain and feelings of light headedness and dizziness. We would be so grateful if you completed all three surveys.

We will not collect any personally identifying information and all survey answers will be anonymous and confidential. The decision to take part in this study or to stop participation is entirely up to you. This decision will not affect your medical care in any way. Upon submission of the questionnaire, the answers will be put into a database and analysed, but as these answers are anonymous we will be unable to remove data once submitted. By responding to this survey, you agree to have your anonymous responses included in the research analysis and results summaries. The results of this research will likely be presented at conferences and in scientific journals.

If you have any further questions to clarify regarding the research or the questionnaire, please contact Ellen Ewer via email: ellen.ewer.20@ucl.ac.uk or Professor Jane Simmonds at: jane.simmonds@ucl.ac.uk

Here is are the links to the questionnaires for you to complete. Once you open the link you will find further information about the study and will be required to consent to participating before you can access the survey.

Survey 1: <https://redcap.slms.ucl.ac.uk/surveys/?s=JEMDLR8FAEW44HDH>

Survey 2: <https://redcap.slms.ucl.ac.uk/surveys/?s=KJNPY337L7Y9W93T>

Survey 3: <https://redcap.slms.ucl.ac.uk/surveys/?s=9AH7ED7ECNATAPP7>

The researchers need hypermobile and non-hypermobile people aged between 18 and 65 to complete this so please send to friends and relatives. Large numbers are needed for the best research and we greatly value your input!

