# Study participants needed

**Great Ormond Institute of Child Health** 

**Ellen Ewer and Jane Simmonds** 



## What is this project about?

A group of researchers have designed a new questionnaire 'The Spider'. The Spider is designed for people with symptomatic hypermobility and looks at the the common symptoms that people may have, and how this affects their life. Once the questionnaire is completed, a 'Spider's web' is drawn making it easy to see what is affecting the person's life. We hope to use this one tool to look at the eight most common symptoms to make sure each person's care considers all these important aspects. You may have already seen other studies looking at whether the Spider questions ask the right information, but now we need to check whether we can use the Spider to measure change in symptoms over time.

### What would you have to do?

We will ask you to complete three surveys which will each take under 20 minutes and can be done at home. We will ask you to do survey 1, survey 2 a week later, and survey 3 after 3 months. We will ask you to share your email address so we can send you email reminders for each survey.

The surveys will ask about your pain, energy levels, mental health, digestion and bowel, bladder symptoms, light-headedness/dizziness and about your muscles, joints and nerves. We will ask about your quality of life and whether your symptoms are getting better or worse.

#### Contact details:

Ellen Ewer – <u>ellen.ewer.20@ucl.ac.uk</u> Prof. Jane Simmonds – <u>jane.simmonds@ucl.ac.uk</u>

Ethical approval: UCL REC (project ID: 19629/002 Email: ethics@ucl.ac.uk, phone: 02076798717

#### Are you eligible?

Do you meet the following criteria?

Aged between 13 and 65 either:

With symptomatic hypermobility (without neurological conditions, rheumatological/ inflammatory conditions or joint/muscle problems unrelated to HSD/hEDS – please see the survey link for more details)

Able to understand and communicate in English











