

**PARTICIPANT INFORMATION SHEET****CSU HREC Number: H20372****Perspectives and experiences of people with hypermobile Ehlers-Danlos Syndrome and hypermobility related conditions in relation to functioning, disability and management: A cross-sectional survey****Researchers**

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**Invitation to participate in research**

You have been invited to participate in an online survey to explore perspectives and experiences of people with Ehlers Danlos Syndrome (hypermobility subtype) and hypermobile spectrum disorders (HSDs). The study is being conducted by researchers from the School of Community Health at Charles Sturt University. Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. You also can contact the principal researcher for more information.

**What is the purpose of this study?**

This study aims to explore your perspectives and experiences of hEDS or HSD in terms of impact on functioning and disability, and different treatment and management approaches. The survey will ask you to describe your symptoms, activity and participation, and any factors that facilitate or impair your functioning. You also will be asked to describe different treatment and management approaches you have used or currently use, and to comment on your perceptions of their effectiveness and level of satisfaction.

This research will provide insight into the perceived impact of hEDS/HSD on functioning and disability and may assist in identifying treatment and management approaches that people with hEDS/HSD consider effective and valuable. Findings therefore may provide a nation-wide perspective of the perceived impact and burden of the hEDS/HSD in Australia, as well as inform treatment and management decision-making in clinical practice, and assist in design of research trials to explore and evaluate the efficacy of different interventions.

**Why have you been invited to participate in this study?**

You are eligible to complete this survey if you meet the following selection criteria:

1. You are between 18 and 65 years of age.

2. You have been diagnosed by a medical practitioner as having Ehlers Danlos Syndrome (hypermobility type/type III) or Hypermobility Spectrum Disorder.
3. You have access to a computer or other device that can access the internet.
4. You are proficient in reading, writing and comprehension in the English language.

### **What does this study involve?**

Once you have provided informed consent you will be able to access and complete the online survey. The survey will include multiple choice, multiple answer and short answer questions. The survey will take approximately 45-60 minutes to complete, but responses can be saved and the survey resumed at a later time if needed. You will have two options when completing the survey:

1. Complete the survey in one sitting by clicking on the first SurveyMonkey link provided. This will take approximately 45-60 minutes of your time to complete.
2. Complete the survey in multiple sittings by clicking on the individual parts of the survey that will be emailed to you. Each section of the survey will take approximately 12-15 minutes of your time to complete.

We recommend that you progress through the survey section by section and have breaks in between. If you do decide to have a break, please ensure you have finished the section of the survey you are on before you leave, then access the individual links to continue through the survey. This will prevent you having to re-type answers you have already completed. The survey will be open between February 2021 and approximately April 2021. You will be asked to complete the survey within 2 weeks of providing consent. No more than two reminders will be emailed to you to complete the survey if you haven't completed the survey within this time period.

### **What are the benefits and risks in taking part in this study?**

There is no payment or reward for completing this survey. The potential benefit of this survey, though, is that clinicians and researchers will be more informed regarding the current level of functioning, disability, and management of people with hEDS/HSD in Australia. This may result in greater understanding and empathy regarding the potential impact of hEDS/HSD on functioning and disability. Ideas for enhancing health care treatment and management may also be identified and trialed in the absence of higher level research evidence being available to direct clinical practice.

There are minimal risks associated with participating in this study. The time and energy taken to fill out the survey may be inconvenient and temporarily fatiguing for you. The survey contains in-depth health questions that may potentially cause you some distress as you reflect and report on the impact of the condition on your functioning or disability, and/or unpleasant treatment or management experiences. If you do become upset and distressed, please discontinue the survey and seek advice from your general practitioner or appropriate health care professional. Lifeline Australia is a crisis support counselling service and can be contacted via phone on 13 11 14 or their website at [www.lifeline.org.au](http://www.lifeline.org.au).

**What if I don't want to take part in this study?**

Participation in this research is completely voluntary. Participation in the study can be stopped at any time without consequence. Your data can be removed from the study if you decide to withdraw your consent during the data collection period.

**How will my confidentiality be protected?**

Your name and email address will only be used for collating screening and consent forms and for distributing the survey. Survey responses will be de-identified with the use of numerical codes. Identifying details will be removed prior to data analyses and will not be included in any reports, presentations or publications.

**What will happen to the information that I will give you?**

Personal information will be used only for survey administration purposes by the principal researcher. Survey responses will be de-identified before analyses and in any reports, publications, or presentations. Participant information and responses will be stored electronically on a password protected computer and a shared drive folder at Charles Sturt University for at least 5 years as per mandatory storage and legislation requirements. Participants may request to be provided with a copy of any published article or a copy of any presentations from the research team after completion of the project.

**Can I take breaks during the survey?**

Yes. If you would like to take a break please finish the section of the survey you are on before you leave, then access the individual links to continue through the survey. This will prevent you having to re-type answers, which you will be required to do if you go back to the full survey link. You will be emailed the individual links after providing consent.

**Is this project funded?**

This project has received no external funding.

**Will I be able to gain access to the results of this study?**

Once the results have been analysed and at the conclusion of the study, we will email all participants a plain language summary of the results of the survey. We will also indicate and provide a link to any published manuscripts either via university repositories or via open access journal websites that occur as a result of the survey.

**What should I do if I want to discuss this study further before I decide or if I have any concerns about the conduct of this study?**

If you have any questions or require any further information please contact the principal researcher - Rohan Toft via email on [csuedssurveyau@gmail.com](mailto:csuedssurveyau@gmail.com)

You may also contact the supervisors of this project if you have any further questions:

Dr Boris Budiono: [bbudiono@csu.edu.au](mailto:bbudiono@csu.edu.au)

Dr Ian Skinner: [iskinner@csu.edu.au](mailto:iskinner@csu.edu.au)

Dr Cherie Wells: [chwells@csu.edu.au](mailto:chwells@csu.edu.au)

Charles Sturt University's Human Research Ethics Committee has also approved this project (approval no. H20372). If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Ethics and Compliance Unit via the following contact details:

The Governance Officer  
Human Research Ethics Committee

Ethics and Compliance Unit  
Charles Sturt University  
Locked Bag 588  
Wagga Wagga NSW 2678  
Te: (02) 6933 4213  
Email: [ethics@csu.edu.au](mailto:ethics@csu.edu.au)

Any issues you raise will be treated in confidence and investigated fully. You will also be informed of the outcome.

**Thank you for considering participation in this survey.**

**Please retain a copy of this information for your records.**