NOURISH-EDS Study - Participant Information Sheet

Tēnā koe,

We are a group of researchers interested in improving nutrition-related outcomes for people with hypermobile Ehlers-Danlos Syndrome (hEDS) and Hypermobility Spectrum Disorder (HSD). For this study, we are interested in understanding the dietary intake of people with hEDS/HSD, the presence and severity of gut symptoms, and the relationship between diet and gut symptoms.

You are receiving this information to help your decide if you want to take part in our research or not. If you don't want to take part, you don't have to give a reason. Choosing not to take part won't affect you in any way, and won't have any impact on your future involvement in research or health services. If you want to take part now, but you change their mind, you can pull out of the study at any time.

Please take some time to read the following information to help you decide if you want to take part. It tells you why we are doing the study, what you will need to do if you choose to take part, what the benefits and risks might be, and what happens after the study ends. Before you decide, you may want to talk about the study with other people such as whānau, friends, or a healthcare provider.

Please make sure you have read and understood all of the pages before agreeing to take part. Our contact details are at the end of this document, and we are always available to talk about the study and answer any questions you have.

What is the purpose of the study?

International research tells us that people with hEDS/HSD face nutrition-related challenges and gut symptoms are very common. However, we do not know what this looks like for people in New Zealand, and there is limited in-depth information about actual dietary intake. This research will address that gap by comprehensively measuring dietary intake, including eating patterns and nutrient intake. We will also look at the relationship between dietary intake and gut symptoms.

This research has the potential to inform updates to both local and international clinical guidelines, and we hope that this research will also serve to increase the understanding and recognition of hEDS/HSD in Aotearoa New Zealand.

Who are the researchers?

The study has been designed by a team of researchers from the University of Auckland, including Dietitians who have experience in working with people with hEDS/HSD, and lived experience researchers. This study is part of a Master of Nutrition and Dietetics research project being undertaken by Aeson Chappell. Dr Nicola Gillies (Dietitian/Lecturer, lead researcher) and Dr Leigh O'Brien (Dietitian) are Aeson's supervisors.

The research team work closely with EDS-NZ to ensure that our research is appropriate and can lead to meaningful outcomes for the EDS community. This study has not received external research funding.

Who can take part in this study?

We are aiming to recruit 50 people with hEDS/HSD across Aotearoa, New Zealand to take part in this study.

You are eligible to take part if you;

- Are aged 16 years or older
- Have been **diagnosed** with hEDS/HSD by a healthcare professional like your GP, a medical specialist like a rheumatologist, or a physiotherapist etc.

You are **not eligible** to take part in this study if you;

- Are currently pregnant or breastfeeding, as this would impact your dietary intake and symptoms.
- Completely rely on artificial nutrition (either enteral feeding like a nasogastric tube or parenteral nutrition) for **all** of your nutritional needs at this point in time, as we are primarily interested in food intake and eating patterns for this study
- Are unable to understand written English, as this would prevent you from completing the questionnaires used in the survey

You will complete an online screening questionnaire before starting the study to make sure you meet the criteria stated above. Please be in contact with the lead researcher (Dr Nicola Gillies) if you are not sure whether you meet these inclusion criteria or not. Nicola's contact details are at the end of this document

What will taking part in the study involve?

This study will be conducted 'virtually', and you can complete all study processes from home. If you decide to take part in the study, there are two phases involved. Both phases should be completed within one month of signing up for the study.

Phase 1 – Online survey

You will be asked to complete the following series of questionnaires;

1. **Participant information** – capturing information about you (age, gender, ethnicity, geographic location), your diagnostic and medical history, and your supplements and medications.
2. **Gastrointestinal symptoms** – the type and severity of different gastrointestinal symptoms, and gastrointestinal-specific anxiety.
3. **Eating behaviours** – risk for avoidant restrictive food intake disorder (ARFID) and disordered eating.
4. **Whole-body symptoms** – the type and impact of symptoms across 8 different domains that people with hEDS/HSD commonly report.
5. **Health-related quality of life** – quality of life across five different health-related domains

The background information questionnaire is purpose-designed for this study, all other questionnaires are validated tools which have previously been used with people with hEDS/HSD or related conditions.

The surveys will be completed through an online data collection tool called REDCap. This will take approximately 30minutes of your time, and if you need a break you can exit the survey and start again where you left off.

Phase 2 – Food and symptom record

You will be asked to complete a **three-day** food and symptom record. This involves recording all the foods/beverages you consumed across three days, including details like the time of consumption, ingredients, brand names, portion sizes and so on – as much information as possible! Each day you will also be asked to record **gastrointestinal symptoms**, including the time they occurred, the type of symptom, and their severity.

We will give you a template and detailed instructions to help you complete the food and symptom record.

Please note that if you report a high score in the questionnaire which screens for disordered eating risk, you will not be asked to complete this phase of the research.

What will happen with my data?

Our research team takes data storage and confidentiality seriously

Confidentiality: Any identifiable information provided (e.g., name, email) will only be collected during the screening and consent process. From that point onwards, you will be assigned a unique study code which will be used for all data collection processes. This means that your identifiable information and study data will be stored in separate databases and will not be linked. The research team will keep a list linking your code with your name, so that you can be identified by your coded data if needed. Only the research team will have acecss to the information you provide, including identifiable information (during consent processes) and de-identified information (data collected with your unique study ID).

Data storage: All data collected during the study will be stored on a password-protected computer using University of Auckland research drives, which only the research team will have access to. Any hard-copy documents (e.g., paper copies of food and symptom records) will be stored in a locked filing cabinet in a secure swipe-access area in the Nutrition Department at the University of Auckland. Data will be kept for 6 years and then deleted or destroyed. The lead investigator (Dr Nicola Gillies) is responsible for safekeeping the data.

What are my rights if I take part in this study?

It is your choice to participate in this study. Whether you take part in this study or not will not affect any your relationship with the University of Auckland or opportunity to participate in future research studies. If a clinician involved in your care has shared this research opportunity with you, you have their assurance that participation or non-participation will not affect the healthcare that you receive now, or in the future.

If you choose to participate, you have the right to withdraw from the study at any time. If you decide to pull out of the study, information contributed (survey responses, food and symptom record) can be used in study analysis, or if you prefer you can withdraw any information you have provided by letting the research team know.

You have the right to access and correct any information about yourself that we have collected as part of the research. No material that could personally identify you will be used in any reports.

What are the possible benefits or risks from taking part in this study?

Your participation in this project will help us in our mission towards improving nutrition-related healthcare for people with hEDS/HSD in Aotearoa New Zealand. This research will provide the first high-quality evidence describing dietary intake and gut symptoms in people with hEDS/HSD. This research has the potential to improve clinical practice by guiding targeted, nutrition-focused care – ultimately improving health outcomes for people with hEDS/HSD in the future. We recognise the taonga (treasure) of the knowledge and experiences you share with us. You will be offered a koha in the form a $40 gift voucher at the end of the study to acknowledge your time and knowledge shared. You can receive a summary of the research once the project is complete, and we will keep you up to date about our plans and opportunities for future research too.

The study is not expected to cause physical, emotional, social, or spiritual harm to you. We understand that recording dietary intake and completing the symptom questionnaires can be uncomfortable for some people. If anything difficult arises, the researchers can help you engage with appropriate support services if needed. You can also find a list of community-based support services at the end of this document.

Some of the questionnaires we are using in this study include scoring thresholds with indicate increased risk for avoidant restrictive food intake disorder (ARFID), other forms of disordered eating, or mental health concerns like depression and anxiety. The questionnaires do not diagnose these conditions, however a high score indicates that further investigation or management may be needed. If you report a score above the thresholds, we will inform you through a letter. With your additional consent, we can also inform your GP or usual healthcare provider through a letter.

Who pays for the study?

This study has not received any external funding, and there is no cost to your being part of this study.

What happens after the study?

The findings from this study can be shared with you in the form of an infographic, and will also published in a research thesis. Findings will also be shared through reports to stakeholders like EDS-NZ, scientific/professional conference presentations, and in peer-reviewed journal publications. You will not be identifiable in any of these reports. You are also able to get a written copy of the findings of this project once they are published, and there is space on the Consent Form for you to say whether you would like a copy. There may be a delay between the end of the study and you getting the final results.

Who do I contact for more information or if I have concerns?

If you have questions about the study or would like to participate, please contact the research team	**Principle investigator** Dr Nicola Gillies, n.gillies@auckland.ac.nz **Student investigator** Aeson Chappell, mcha769@aucklanduni.ac.nz
For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee	ahrec@auckland.ac.nz, or at 373 7599 ext 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland, 1142
For Māori cultural support	In the first instance, talk to your whānau. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by phoning 09 486 8624 x 2324
If you wish to talk to someone who isn't involved with the study	**Head of Department** Dr Andrea Braakhuis, a.braakhuis@auckland.ac.nz

This research has been approved by the Auckland Health Research Ethics Committee on 26/02/2026 for three years. Reference Number AH30932.

Contact details for mental health support

If you are experiencing feelings of stress or anxiety that you think you need more help with you should **make an appointment to see your family doctor** and talk about these feelings with them so that they can discuss support options with you.

The following websites or help numbers can be helpful for people experiencing mental health concerns and needing further support. They have skilled people you can contact to help:

- **1737:** Free call or text 1737 for support from a trained counsellor or peer support worker, this service is available 24 hours a day. Website: https://1737.org.nz/
- **Lifeline Aotearoa Helpline:** Free call 0800 543 354 or text 4357 (HELP) for confidential support, this service is available from 7am – midnight. Website: https://www.lifeline.org.nz/
- **Samaritans**: Free call 0800 726 666 for support for anyone who is lonely or in distress, this service is available 24 hours a day. Website: https://www.samaritans.org.nz/
- Further information and free support can be found at https://www.depression.org.nz/. This includes information for Māori, Pasifika, and LGBTI groups.

If this is an **emergency** and you **require urgent assistance** then please call **111**, or go to your nearest hospital emergency department (ED), or phone your local Mental Health Crisis Team (CATT Team)