Participant Information Sheet

Understanding Nutritional Challenges in hEDS/HSD Survey

Tēnā koe,

We are a group of researchers from the Nutrition Department in the Faculty of Medical and Health Sciences at the University of Auckland. We are interested in understanding the unique nutritional needs and experiences of people with hEDS/HSD in New Zealand, and identify perspectives on future nutrition research priorities according to the hEDS/HSD community.

You are receiving this information to help you 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 will not disadvantage you in any way, including future research opportunities, or the healthcare you receive now or in the future. If you want to take part now, but change your 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 your GP/health provider.

Our contact details are listed at the end of this document, and we are available to talk about the study and answer any questions you have.

What is the purpose of this study?

There has been limited research with people with hEDS/HSD in New Zealand. International research tells us that people with hEDS/HSD face nutrition-related challenges, but we do not know what this looks like for people in New Zealand. This research will help to identify and understand what the nutritional needs, barriers and priorities are from the hEDS/HSD community in New Zealand. These findings will help to guide the direction and priorities of our team's future research related to nutrition care and hEDS/HSD. we hope that this research will also serve to increase the understanding and recognition of hEDS/HSD in Aotearoa

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 musculoskeletal specialists. We have also worked with EDS-NZ in the design of this survey. This study is part of a Master of Nutrition and Dietetics research project being undertaken by Amara Dawson. Dr Nicola Gillies is Amara's supervisor and the lead researcher of the study. Dr David Musson and Dr Leigh O'Brien are also researchers on this project. The study is funded through the Health research council (HRC 24/1343), who have not influenced the study design.

Who can take part in the study?

We are aiming to include 100-200 adults across Aotearoa New Zealand with hEDS/HSD, including those with diagnosed hEDS/HSD, or suspected hEDS/HSD.

You are able to take part in the survey if you meet the following criteria;

- Aged 16+ years.
- Live in New Zealand.
- Either diagnosed or suspected hEDS/HSD (may have received a diagnosis from health professional or awaiting diagnosis). At this stage, we are focusing on hEDS/HSD specifically and are not able to include people with other EDS subtypes into this particular survey.
- Have access to a device that enables questionnaire completion.
- Able to provide own informed consent.

Please be in contact with a member of the research team if you are not sure whether you meet these inclusion criteria or not. Our details are at the end of this document.

What will taking part in the survey involve?

All study processes will take place online, and can be completed from a smartphone, tablet, or computer connected to the internet. The study will take approximately 20 minutes of your time – you are able to stop at any time if you need a break, and clicking on the link again will take you back to where you last were in the survey.

Consent

You will be directed to the consent information page, which summarises the key ethical aspects of this research. Here you will be able to tick the check box "yes, I consent to participate in this study" indicates your consent to take part in this study, and you will be directed through to the main survey.

Background Questionnaire

After gaining consent we will ask you to provide some background information about yourself, including gender, ethnicity, geographic location, urban or rural area, diagnosis of hEDS or HSD, and other medical conditions. We use this information to describe the characteristics of the group of participants who have completed the survey.

Understanding Nutritional Challenges in hEDS/HSD survey

You will then be directed to the "Understanding Nutritional Challenges in hEDS/HSD" survey which includes rating scale and open-text format questions. You will be asked about how you access nutrition information, dietary restrictions or challenges, interactions with healthcare professionals regarding nutrition support and priorities in nutrition-related research. You can discuss the questions with whānau, friends, or carers if you wish. This will take approximately 20 minutes to complete. This survey is anonymous.

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

This is an opportunity for you to share your views, experiences, and unique perspectives to shape our team's future research. It provides an opportunity for your voice to be heard in research. Additionally, to acknowledge and thank you for your time and knowledge shared, upon completion of the survey you can go in the draw to win one of 20 $50 Prezzy card vouchers.

This study is not expected to cause physical, emotional, social, or spiritual harm to you. We aim to gather as much information related to your unique nutritional needs and experiences. If answering any of these questions causes any discomfort or emotional distress during the study (either related to the study or not), you can find a list of community-based support services at the end of this document and the survey itself. You can also leave the survey at any point if you find the questions uncomfortable to answer.

What are my rights as a participant if I take part?

Participation in this research is entirely voluntary (your choice), and your decision to take part will not disadvantage you in any way, including your relationship with the University of Auckland or opportunity to participant 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. This is an anonymous survey, and clinicians responsible for your healthcare will not have any way of knowing whether you have participated or not.

If you do choose take part, as a participant you have the right to;

- Leave the survey at any stage to withdraw your participation in the study, without giving reason and with no consequence. If you leave the survey before submitting it, your answers will not be used in data analysis. Please note that if you do submit your survey, you will not be able to edit or withdraw your data after this point as the survey is anonymous.
- Ask any questions about the study at any point in time during participation in the study – our contact details are available at the end of this document and in the survey itself.
- Receive a summary of findings from this research project
- Refuse to answer any survey questions.

How will my confidentiality be protected?

The research team takes confidentiality very seriously. The survey is entirely anonymous. There is no risk that you will be able to be identified by anyone other than the research team. If you choose to receive a summary of the findings, or to go in the draw to win the gift voucher, you will be required to leave your name and email. However, this information is stored in a separate database to your survey response, so there is no chance the two will be linked at any point. Only the research team members specified in this document will have access to the information you provide

How will data be stored, retained, and destroyed?

The data and information collected through the questionnaires and surveys will be collected using Qualtrics software for the duration of the study. This is a secure online software, which is hosted by the University of Auckland and protected by passwords and two-factor authentication. Once data collection is complete, all data will be exported to secure password protected servers at the University of Auckland. Data will be permanently deleted from the Qualtrics software after data analysis has been finalised.

Only the research team will have access to the data during and after the study. According to our ethical approval, all data will be kept for 6 years after the study is complete then deleted or destroyed. The lead investigator (Dr Nicola Gillies) is responsible for safekeeping data. Your data will not be used for any purpose other than what is specified in the information sheet, and individuals outside of the research team will not have access to the data you have provided for this study.

What happens to the results?

The results will be published as part of the student researcher's thesis project. The findings may also be further published in academic journals, presented at conferences or other meetings. We may use quotes from the survey to illustrate our research findings, however, there is no chance you can be identified from these. No information that could identify you will be used in any research outputs.

A summary of the research findings can be sent to you on request, which you can select at the end of survey completion. If you choose to do so, your contact information will be stored on a separate database to survey responses, and the two will not be linked at any time. 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 researcher Amara Dawson, adaw739@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 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 Nutrition Department Andrea Braakhuis a.braakhuis@auckland.ac.nz

This research has been approved by the Auckland Health Research Ethics Committee on 09/07/2025 for three years. Reference Number AH29681.

Contact details for further support

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

- **Need to talk? Free text 1737** if you are feeling stressed, down, or overwhelmed and need someone to talk to. This service is available 24 hours a day, and you will talk to (or text with) a trained counsellor or peer support worker. Website: https://1737.org.nz/
- **Youthline Aotearoa Helpline** is staffed by qualified counsellors and trained volunteers who can provide support on a range of different issues, such as psychological and emotional distress, work issues, family problems, and experiences of abuse. The helpline is available 24/7. Freephone: Call 0800 376 633 or Free text to 234. Website: https://www.youthline.co.nz/
- **Smallsteps** is an Aotearoa New Zealand created suite of tools that you can pick and choose from depending on your needs. Website: https://www.smallsteps.org.nz/
- **Headspace App** is a meditation and mindfulness app to help with stress. Website: www.headspace.com.
- **SPARX** is designed by researchers in Aotearoa | New Zealand. It is created to be used on a mobile phone and a computer. It has been designed with
- Tamariki/Rangatahi in mind. It uses computer gaming approaches to help. https://www.sparx.org.nz/for-young-people
- **Calm website** provides techniques and information to help with managing stress, anxiety, depression and more. Website: www.calm.auckland.ac.nz
- **The Low Down** provides support for rangatahi for hauora, identity, culture, and mental health. Website: https://ww.thelowdown.co.nz
- **Outline** is a confidential, free, all-ages support-line for people who want to speak to a trained volunteer from the rainbow (LGBTIQ+) community. Freephone: Call 0200 5463 between 6pm-9pm. Website: https://outline.org.nz/ Further information and free support can be found athttps://www.depression.org.nz/ and https://www.depression.org.nz/. This includes information for Māori, Pasifika, and LGBTI groups.

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**. If you have a medical emergency and require urgent assistance please call 111.**