



Mature Minor Participation Information Sheet

Perth Children's Hospital

Title	What do children and adolescents with Type 1 and Type 2 Diabetes in Western Australia eat?
Short Title	Dietary Audit: Children with T1D and T2D
HREC Number	RGS0000003979
Coordinating Principal Investigator	Dr. Amelia Harray
Location	Perth Children's Hospital

1 Introduction

You are being invited to take part in a research project. The research is for young people diagnosed with type 1 diabetes or type 2 diabetes. The aim of the research is to find out what children and adolescents with type 1 diabetes and type 2 diabetes are eating. This information will allow dietitians working within the Diabetes clinics at Perth Children's Hospital to look at what and how they teach families with diabetes about food and nutrition.

This information sheet tells you about the research. It explains what you will be asked to do. Please read this information. Then ask questions about anything you want to know about the research.

2 Why are we doing the research?

Taking care of yourself and eating well is very important and helps to manage your diabetes and reduce the risk of complications. Internationally, food recommendations for children and adolescents with T1D and T2D are based on healthy eating guidelines that are suitable for all children. In Australia these are based on the Australian Guidelines to Healthy Eating for Children and Adolescents.

Following dietary advice has been reported to be one of the more difficult areas of diabetes management. There are lots of places to get information about the types of foods that are good for you and even though you see a dietitian in clinic regularly, we don't have a clear picture of what children and adolescents with diabetes in Western Australia eat. Knowing this information will help us to teach you how to manage the foods you eat and your diabetes.

We hope that by doing this research we can look to see if children and adolescents with diabetes in WA are meeting current recommendations. If we find that people are finding it challenging, we may need to change the way we teach in clinic to help support you. This will also provide researchers with knowledge to help guide future research studies.

3 What will I be asked to do if I choose to take part in the research?

If you decide to participate after reading this information sheet, you will be asked to provide electronic consent. When this is done, we will add your name and your email address in the Australian Eating Survey® website, which will allow us to email you a link to complete the



Australian Child and Adolescent Eating Survey Food Frequency Questionnaire (ACAES-FFQ) online.

You will need to fill in the questionnaire and may need help from your parent or guardian. The survey responses are confidential and all information will not be shared or sold. The questionnaire will take approximately 20 minutes to complete. Once you have completed the survey, an individual summary of your responses is emailed to you. This report will also be available to the research team.

We are also asking your permission to access information about you and your diabetes management from the Western Australian Children's Diabetes Database. Each time you attend clinic the information that is collected such as age, diabetes duration, insulin regimen, total insulin requirements, HbA1c, height and weight, and any other diagnosis is recorded into this database. We would like to look at this information to see if there are any similarities in the types of foods children eat and their clinical characteristics and diabetes management. The information we are interested in listed above, would be copied from the database and linked with your questionnaire responses by a code given to you once you or your parent sign a consent. This code is used so that your name is not recorded on the data sheets and remains private.

4 Who is carrying out the research?

The researchers from the Children's Diabetes Centre at Perth Children's Hospital and Telethon Kids Institute are working together to do this research. Funding for the research has been provided by the Children's Diabetes Centre.

5 Do I have to take part in this research?

You do not have to take part in this research. If you decide you want to take part and then change your mind, you are free to pull out at any time. If you decide you don't want to be part of the research anymore then please let us know. If you withdraw, the information we have collected will be included in the study unless you ask for it to be removed. If you decide not to be part of the research, then it will not affect how you are looked after by your clinic diabetes team.

6 Is there likely to be a benefit to me?

The summary of your questionnaire answers will outline all the different types of foods you eat and compare it to the current Australian guidelines.

We cannot promise that you will benefit from being part of the research. However, if there are changes to what and how the clinical teaches families in the clinic due to this study, you may receive some benefit in the future.

7 What are the possible risks or side effects?

Because we are not changing any of your treatments, or giving you any new treatments for this study there are no known or likely risks, harm or discomforts by participating in this study.

We are using a questionnaire that has been used by other groups previously without any problems. If any of the questions asked, worries or upsets you tell your parent or guardian and they can contact the research team to help you.



8 What will happen to my information?

At consent, you will be given a code that we will use on study documents in place of your name. Any paper documents will be stored in a locked cupboard. Electronic files will be password protected and stored on a computer that only the research team can access. You have the right to ask to see the information that has been collected about you as part of this research.

At the end of the study, the study files will be stored for at least fifteen years. It will then be disposed of following hospital guidelines.

The results of this research may be presented at conferences or published in professional journals. Your name will not be used in any presentations or publications.

9 Who has approved the study?

All research in Australia that involves humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). This research project has been approved by the Child and Adolescent Health Service Human Research Ethics Committee. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

10 Who to contact if you have any complaints about the project or the way it is being conducted

If you have any concerns about how you are treated in this study or you have a complaint about how the research is carried out, you or your parent/guardian can contact an independent person, the Executive Director Medical Services at Perth Children's Hospital (Telephone No: 6456 2222). Your concerns will go to the Ethics Committee who is monitoring the study.

If you suffer any injuries or complications because of this research project, you should contact the study team as soon as possible and we will help arrange medical treatment.

11 Who to contact for more information about this study

If you would like any more information about this study, please do not hesitate to contact the research team. They are very happy to answer your questions.

Contact person for the research team

Name	Dr Sabrina Binkowski
Position	Research Officer
Telephone	(08) 6456 4617
Email	Sabrina.Binkowski@health.wa.gov.au



Mature Minor Electronic Consent Form

Perth Children's Hospital

Title	What do children and adolescents with Type 1 and Type 2 Diabetes in Western Australia eat?
Short Title	Dietary Audit: Children with T1D and T2D
Protocol Number	RGS0000003797
Coordinating Principal Investigator	Dr. Amelia Harray
Location	Perth Children's Hospital

Declaration by Participant

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.

I understand the purpose, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I provide permission to exchange personal identifiable information (my name and email address) with the Australian Eating Survey® website for participation in this study.

I understand that some of the staff working on this study are employed by the Diabetes Research Team which is part of the telethon Kids Institute and are not employed by the government of Western Australia. These staff are working with the approval of the Child and Adolescent Health Service (CAHS) and will follow all the required policies and procedures and will safeguard the confidentiality of the participant information.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

Name of Participant	_____
Signature _____	Date _____

Name of Parent (please print)	_____
Signature _____	Date _____

I certify that all the information in the document above is correct, and I understand that signing this form electronically is the equivalent of signing a physical document.