

Participation Information Sheet - Parent

Perth Children's Hospital

Title	Talking about type 1 diabetes: Understanding adolescents' needs to have confident conversations.
Short Title	Talking about T1D
Protocol Number	RGS0000007042
Principal Investigator	Keely Bebbington
Location	The Kids Research Institute Australia

1. Introduction

Your child is invited to take part in a research project. This project aims to explore the experiences of young people with Type 1 Diabetes (T1D) talking to others about their diagnosis and management of T1D.

This information sheet tells you about the research and what your child will be asked to do. Please read this information carefully. **Then ask questions about anything you want to know about the research. You can contact the research team on the email listed at the end of this document.**

2. Who is carrying out the research?

The researchers from The Rio Tinto Children's Diabetes Centre at Perth Children's Hospital, The Kids Research Institute Australia and the University of Western Australia are working together to do this research.

3. Why are we doing the research?

Living with T1D as a young person can be challenging, and many young people report that the tasks required to manage their diabetes interferes with everyday life activities like school or catching up with friends. When this happens, young people may have to choose whether or not to share or disclose information about their T1D to other people such as friends, classmates, or teachers. When people choose to share information such as their diabetes diagnosis, their treatment plan, their glucose levels, or how T1D impacts them, this is called disclosure.

Experiences and choices around disclosing T1D to others are unique to each young person. Some young people may wish not to disclose or may choose to hide their diabetes or delay management tasks so that other people will not know they have T1D. Other young people may wish to disclose but find it difficult to know when to share information about their diabetes, who to share this information with, and how to share it. While it can be stressful to disclose to others, research suggests that sharing this information can also promote social support and wellbeing for young people with T1D. Currently, there are no available supports to help young people with T1D talk with others about their condition.

In this project, we want to understand young peoples' concerns, perspectives, and experiences of disclosing their T1D diagnosis and management to other people. We also want to learn what supports young people would like to help them share information with

others about living with T1D. The researchers believe that by understanding the experiences of young adults with T1D, we will be able to develop appropriate and respectful supports to help young people with T1D talk about their condition with others.

4. Who can be involved in this study?

We are inviting young people aged 13-17 years old, who have lived with T1D for at least 6 months, and who are living in Australia.

5. What will the study involve?

Participation involves your child completing a short survey and taking part in a one-on-one interview.

If your child decides they would like to take part in this study, you will first be asked to complete an online consent form to provide consent for your child to participate. After your consent, your child will also need to consent and complete a similar form, and we will ask you to provide an email address to send this form to.

Following consent from both and your child:

- Your child will be asked to complete a short survey with a few questions about them.
- An email will be sent to the email address you elect (either yours or your child's) within 24-48 hours to schedule a time for an interview.
- The interview will be with a researcher from The Kids Research Institute Australia. This interview will occur online at a mutually convenient time and should take between 45 and 60 minutes. The interview will be audio recorded so that we can write down and analyse the information your child provides. The written version of their interview will not include any information that could identify you or your child.

In the interview, we will ask your child some questions about their experiences sharing information about their T1D with others, how they decide what information to share, any concerns they have about disclosing, and what information they think other young people would find helpful to make decisions about disclosure. Your child does not have to answer all the questions and can share as much or as little information as they wish.

Your child will receive an honorarium of \$40 for participating in an interview.

6. Does my child have to take part in this research?

Your child does not have to take part in this research. They can also stop at any time if they say yes and then change their mind. Your child's current and future medical care will not be impacted by their decision to participate or to withdraw.

7. Is there likely to be a benefit to my child?

There may be no benefit to your child from being part of the research. Your child may benefit from being able to share their experiences and thoughts about disclosure. They are also providing important information that will be used to help other young people with T1D in the future.

8. What are the possible risks or side effects?

As this is a low risk study with no changes to your child's diabetes care, there are no known risks. It is possible that the experience of talking about times they have told others about their T1D may cause your child to feel some discomfort. If this happens, we will be able to supply you and your child with details of where they can access support.

During the interview, your child is not required to answer any questions that they do not wish to answer. If at any point during the interview your child is uncomfortable and wishes to stop, they can tell their interviewer. They are not required to continue and will be free to go.

9. What will happen to my child's information?

All information collected for this project will be treated as private and securely stored. Any information identifying you or your child will be removed before the results of the research are shared with other people.

Audio recording of interviews will be stored on a secure network drive until data analysis is completed, then deleted. All electronic records will be stored on password protected computers and will be accessible only by the research team. All written data will be kept in a locked cabinet in a restricted access area within the The Kids Research Institute Australia.

The project team intends to publish the research findings. No identifiable participant information will be included in the manuscript. At the completion of the study, de-identified files will be archived and retained indefinitely and potentially used for future research purposes, subject to ethical approval.

10. 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 (2023)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

11. 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 the research has been carried out, you can contact the following:

Site contact:

Name	CAHS Research Ethics & Governance Office
Position	Manager
Telephone	(08) 6456 8639
Email	CAHS.RGO@health.wa.gov.au

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 a member of the research team. They are very happy to answer your questions.

Contact person for the research team

Name	Dr Keely Bebbington
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