Mature Minor Participant Information Sheet/Consent Form

Title	Developing an exercise intervention to support adolescents with T1D
Coordinating Principal Investigator **Principal Investigator**	Keely Bebbington Vinutha Shetty (PCH)
Associate Investigator(s)	Brendan Smith, Heather Roby, Eleanor Quested, Marlene Kritz
Location	Perth Children's Hospital

You are being invited to take part in this research project because you are aged between 14-17 years old and are living with Type 1 Diabetes.

Why are we doing this study?

After talking with young people with type 1 diabetes about the challenges they face being physically active, our team have been working with researchers to help us understand what would make physical activity more interesting and less challenging for young people with type 1 diabetes. In this study we aim to work with young people with type 1 diabetes to design a new intervention that aims to makes it easier for young people with type 1 diabetes to be active and make them more confident with their diabetes management.

Who is doing the study?

Researchers from the Children's Diabetes Centre at Perth Children's Hospital and Telethon Kids Institute and Curtin University are running this study.

What would I need to do?

A researcher will talk to you to go through the study and answer any questions you may have. If you decide to take part in this study, you will be asked to sign a consent form.

You child will then be asked to participate in two separate workshops with other young people with type 1 diabetes. There will be a maximum of 8 young people with type 1 diabetes attending each workshop, which will be facilitated by a member of the study team who is experienced working with young people. The workshops will go for approximately 2 hours each.

During the workshops you will be asked for your views on the types of activities that might be included in the intervention, as well as how the intervention might be delivered. For example, you might be asked about how long you think the intervention should be, where the intervention might be delivered and how best to engage young people who might be unsure about doing regular physical activity.

Study members will take notes regarding what is discussed in these sessions to make sure the views of young people involved in the workshops are accurately represented. This information will only be accessible by the research team.

We may seek input from you outside of these workshops, either via phone or email, to gain additional input on the intervention design. You are free to say no to these requests if you do not wish to provide further input on this study.

Do I have to take part?

No. It is your decision if you want to participate. If you do not wish to take part, you do not have to. You can talk about it with your parents before you decide. If you decide to take part and later change your mind that is ok.

Is there likely to be a benefit to me?

We cannot guarantee or promise that you will receive any benefits from this research. We hope that you enjoy participating in this research and you may enjoy meeting other poeple who have similar experiences.

Is there likely to be a benefit to people in the future?

We hope that this research will benefit young people with T1D to be more active and healthy. The information we collect during this study is being used to design an exercise program for adolescents with T1D. This will be trialled in another study and we hope this can move into the community in the future.

What are the possible risks or side effects?

This is a low risk study, meaning we do not anticipate any risks from being involved in this project. In the unlikely event that you become upset or distressed because of participation in the research, please tell your parents or carer, or the research team so that they can talk to you about this.

Confidentiality is important; therefore, when participating in this research, we will ask you not to discuss this information outside the focus group except with your parents or carer.

Where is my information kept?

Any information about you that is collected as part of this research will be kept private. The information will be stored in a locked cupboard or on a computer that only the research team can access. Any information that can identify you will be removed before the results of the research are shared with other people. At the end of the study, files without names will be kept and stored for a minimum of 5 years. Data will then be destroyed following hospital guidelines.

The results of this research may be presented at conferences or published in professional journals. Personal information will not be included in any results that are published or presented.

Who has approved the study?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). This study 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.

Further information and who to contact

If you want to know more, your parent can contact:

Name	Marlene Kritz
Position	Postdoctoral Researcher
Telephone	(08) 6456 4610
Email	Marlene.Kritz@telethonkids.org.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Position	Executive Director of Medical Services at Perth Children's Hospital
Telephone	(08) 6456 2222
Reference	Please quote the project number RGS0000004688

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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 study.
- I understand that the focus group audio will be recorded.
- I agree not to disclose any information discussed during the focus groups to other who were not involved.
- I was able to ask questions and I am happy with the answers I received.
- I understand that some of the staff working on this study are employed by the Telethon Kids Institute or Curtin University 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 study as described and understand that I can withdraw at any time without affecting my future care.

Name of Participant (please print) _____

Signature of Participant _____ Date_____

Declaration by Study Doctor/Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/
Researcher† (please print) _____

Signature _____ Date _____

† A member of the research team must provide the explanation of, and information concerning, the research project.