Phase 1 Participant Information Sheet – Parent as Participant

Perth Children's Hospital

Title	Using co-design to understand and enhance the experiences of emerging adults with type 1 diabetes and their parents as they transition from paediatric to adult care in metropolitan and regional Western Australia.
Short Title	Co-designing transition support
Principal Investigator	Kelly West
Location	Telethon Kids Institute

1. Introduction

You are invited to take part in a research project. This project aims to document how young people with Type 1 Diabetes and their families experience health care transition from paediatric to adult services and determine what they need when they are going through this transition.

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

2. Who is carrying out the research?

The researchers from the Children's Diabetes Centre at Perth Children's Hospital (PCH) and Telethon Kids Institute are working together to do this research.

3. Why are we doing the research?

For young people with Type 1 Diabetes (T1D), growing up means moving from child to adult health care, which is known as 'transition'. When young people transition, they commonly move from familiar environments and well-known health care professionals to unfamiliar adult clinics with health care professionals they don't know. Transition often requires young people with T1D to suddenly take on much more responsibility for their diabetes management. This transition often happens at the same time as many other changes, such as leaving school, gaining independence, and changing relationships with parents and friends. For all of these reasons, transition can be challenging, and many young people with T1D report struggles with mental and physical health both during and after this transition.

In this project, we want to understand how young people with T1D and their families experience this transition, and what they feel is needed to make transition easier. The researchers believe that to improve services for young adults with T1D in Western Australia, we must start by understanding the experiences of young adults who have recently moved to adult health care.

4. Who can be involved in this study?

We are inviting the parents of young people aged 18-25 years who live in Western Australia, have had T1D for at least a year and transitioned to adult service in the last 5 years.

5. What will the study involve?

The study is divided into 5 phases. This information sheet relates to **phase 1**.

You will be asked to take part in a focus group with other parents of young people with T1D. This focus group will occur face-to-face at Telethon Kids Institute in Subiaco (100 Roberts Road, Subiaco) and will run for approximately 60 minutes. The focus group will involve a group discussion about your own experience with your child's transition and what you think a successful transition looks like. We will also discuss what young people with T1D and their families need to successfully navigate this transition.

The focus group will be voice recorded so we can transcribe them word for word to accurately record the details of the conversations and interpret the information you provide. The transcription of the audio recording will not include any identifying information about you.

You will be reimbursed $40 for your time and travel/parking fees.

6. Do I have to take part in this research?

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

7. Is there likely to be a benefit to me?

We cannot promise that you will benefit from being part of the research. You may benefit from being able to share your experiences and feedback about current transition practices. You are also providing essential information to help us improve future transitions for young people with T1D and their families.

8. What are the possible risks or side effects?

As this is a low risk study with no intervention, there are no known risks. It is possible that the experience of talking about your child's transition experiences may cause some discomfort. If this happens, we will be able to supply you with details of where you can access support.

During the focus group, you are not required to contribute to the discussion if you do not wish to do so. If at any point during the focus group you are uncomfortable and wish to stop, you are not required to continue and will be free to go.

9. What will happen to my information?

All information collected for this project will be treated as private and securely stored. Your name, your child's name, and any identifying information will be removed before the results of the research are shared with other people.

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 Telethon Kids Institute.

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 for at least fifteen years.

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 (2007)*. 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 an independent person, the Executive Director Medical Services at Perth Children's Hospital (Telephone No: 6456 2222). Your concerns will be drawn to the attention of 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.

12. 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
Position	Coordinating Principal Investigator
Telephone	(08) 6319 1766
Email	keely.bebbington@telethonkids.org.au

Phase 1 Consent Form – Parent as Participant

Perth Children's Hospital

Title	Using co-design to understand and enhance the experiences of emerging adults with type 1 diabetes and their parents as they transition from paediatric to adult care in metropolitan and regional Western Australia.
Short Title	Co-designing transition support
Protocol Number	RGS0000004599
Principal Investigator	Kelly West
Location	Telethon Kids Institute

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 purposes, 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 understand that the focus group will be audio recorded.

I understand that some of the staff working on this study are employed by 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 child's future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by 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 Researcher (please print) _____

Signature _____ Date _____

Note: All parties signing the consent section must date their own signature.