



Parent as a Participant Information Sheet/Consent Form

Title	Supporting players with T1D and their coaches in sport: developing resources to educate and empower
Protocol Number	V1.1 18.11.2020
Project Sponsor	Children's Diabetes Centre
Coordinating Principal Investigator Principal Investigator	Elizabeth Davis Vinutha Shetty (PCH)
Investigator(s)	Alison Roberts, Leanne Fried, Heather Roby
Location	Perth Children's Hospital

You are being invited to take part in this research project as a participant.

Why are we doing this study?

Our Type 1 Diabetes (T1D) community has said that one of the biggest challenges for young people participating in sport is the lack of knowledge and understanding in regards to T1D and its management in the community sport setting. Creating a resource/s for sports coaches was suggested as a possible solution to educate and upskill coaches on T1D. This project is aiming to develop these resources in partnership with adolescents and young adults with T1D, their parents and coaches from the community sport setting.

By listening to personal experiences of young people with diabetes and their parents, we hope to develop resources that are practical and useful and can help young people with T1D feel supported in the wider community. We would also like to explore ways in which we can support and empower young people with T1D to participate in sport.

Who is carrying out the study?

Researchers from the Children's Diabetes Centre at Perth Children's Hospital (PCH) and Telethon Kids Institute are conducting this study.

What does participation in this research involve?

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

Once this is done, the researcher will send you a link for you to complete a short online questionnaire using REDCap to find out about your child and their diabetes.

You will then be asked to participate in an online interview using Zoom with other parents of children with T1D. Due to the nature of online video platforms, there will be a maximum of three individuals attending each of the online interviews. This may include a spouse or someone you know or a parent you may not know. The interview will be approximately 45-60 mins in duration.

Interviews will explore whether and how you/your child talks about their diabetes to their coach, what information you would like your child's coach to know and whether you would direct your

child's coach to a resource if it was available. Questions such as 'What have your interactions with your child's coaches been regarding their diabetes?' and 'What do you think coaches need to know about players with diabetes?' are examples of what might be asked.

The interviews will be recorded and researchers will transcribe, or copy out what you say word for word so that the researchers can accurately interpret the information you provide. The recordings and transcripts will only be accessible by the research team. Following interviews, the main points and themes will be sent to participants to review and agree upon. You will receive a reimbursement for your time upon completion of the online interview. As there are no face to face visits, this will be done by electronic transfer and we will need your bank details to do this.

Do I have to take part?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your child's routine treatment, your relationship with those treating your child or your relationship with Perth Children's Hospital or Telethon Kids Institute.

Is there likely to be a benefit to me?

We cannot guarantee or promise that you will receive any benefits from this research. However, the expected outcome of this research is a print and/or media resource, for you and your child to take to your coach, so they can understand their condition and better support them in their sport.

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

We are developing this resource in the hopes that it will benefit coaches and T1D players alike. By educating and empowering coaches of players with T1D, will in turn help the T1D player to feel more comfortable and secure in their chosen sport. We will make this resource easily accessible and available to all T1D players and their coaches.

Where is my information kept?

All information collected for this research project will be treated as confidential and securely stored. Paper records collected during this project will be kept in a locked cabinet in a secure research office in Telethon Kids Institute. Electronic data will be stored on a password-protected secure server nothing will be stored on Zoom. Only the researchers on the project team will have access to both the paper and electronic records. At the completion of the study, de-identified files will be archived and stored for a minimum of 7 years; after which all documents for the study will be destroyed according to PCH guidelines.

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

What about my privacy?

Findings and research data will be securely stored in line with the National Statement on Ethical Conduct in Human Research (2007). Any publications will report the interview findings as a whole. No participant will be identified by name or in any other way in any published results.

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). The ethical aspects of this research project have been approved by the HREC of the Child and Adolescent Health Service.

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 any further information or would like to participate please contact:

Name	Rachel Lim
Position	Research Assistant
Telephone	6456 8024
Email	Rachel.Lim@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 RGS00000039000



Parent as a Participant Consent Form

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Protocol Number V1.1 18.11.2020

Project Sponsor Children's Diabetes Centre

**Coordinating Principal Investigator
Principal Investigator** Elizabeth Davis
Vinutha Shetty (PCH)

Associate Investigator(s) Alison Roberts, Leanne Fried, Heather Roby

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 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 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.

I agree not to repeat what is discussed during interviews/focus groups and to respect the privacy and confidentiality of other participants.

Name of Participant (please print) _____	
Signature _____	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 _____

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



Form for Withdrawal of Parent Participation

Title Supporting players with T1DM and their coaches in sport: developing resources to educate and empower

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**Coordinating Principal Investigator
Principal Investigator** Elizabeth Davis
Vinutha Shetty (PCH)

Associate Investigator(s) Alison Roberts, Leanne Fried, Heather Roby

Location Perth Children's Hospital

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with Perth Children's Hospital and Telethon Kids Institute.

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

Declaration by Study Doctor/ Researcher

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Study Doctor/ Researcher (please print) _____
Signature _____ Date _____

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