



Parent Information Sheet/Consent Form

Perth Children's Hospital

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)
Associate Investigator(s)	Alison Roberts, Leanne Fried, Heather Roby
Location	Perth Children's Hospital

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

Why are we doing this study?

Our Type 1 Diabetes (T1D) community, has said one of the biggest challenges for young people participating in sport is a 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 T1DM. This project is aiming to develop these resources in partnership with adolescents and young adults with T1DM, their parents and coaches in 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 T1DM to participate in sport.

Who is carrying out the study?

The researchers from the Children's Diabetes Centre at Perth Children's Hospital and Telethon Kids Institute are conducting this study.

What does participation in this research involve?

If your child decides 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 both 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.

Participation in this research involves your child completing an online interview for approximately 45-60 mins in duration. The interview will be on Zoom and may be with other children who have T1D. Due to the nature of online video platforms, there will be a maximum of three participants attending each of the online interviews. This may include a spouse or someone you know or a parent you may not know.

Interviews will explore whether and how your child talks about their diabetes to their coach, what information they would like their coach to know and whether they would direct their coach to a resource if it was available. Questions such as 'What do you think coaches need to know about players with diabetes?' might be asked.

Interviews will be recorded and researchers will transcribe, or copy out what your child says word for word so that the researchers can accurately interpret the information your child provides.. 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. Participants will receive reimbursement for their 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.

Does my child have to take part?

Participation in any research project is voluntary. If you do not wish for your child to take part, they do not have to. If they decide to take part and later change their mind, you are free to withdraw your child from the project at any stage.

If your child does 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 my child?

We cannot guarantee or promise that your child 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 child's 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 saved 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 child's 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



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Coordinating Principal Investigator Elizabeth Davis
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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 and to respect the privacy and confidentiality of other participants.

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

Name of Child (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 Participation

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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 Telethon Kids Institute.

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

Name of Child (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.