Young People and Parents Talking about Type 1 Diabetes

Parent/Guardian Information Sheet – Survey

What is this research about?

We are doing this research to find out more about you and your child's experiences of living with type 1 diabetes. We are interested in how adolescents (aged 11-17 years) learn to manage their type 1 diabetes and how parents and adolescents talk about and negotiate responsibilities for type 1 diabetes management.

Who is conducting this research?

Led by Dr. Veronica Lambert, this research is being carried out by a team of researchers from the School of Nursing and Human Sciences at Dublin City University (DCU) in collaboration with Prof. Nuala Murphy and her team at Temple Street Children's University Hospital (TSCUH) and Diabetes Ireland. Two researchers at DCU are working on this research project. Caroline Rawdon is a post-doctoral researcher and Ella Tuohy is a PhD student. This research project is funded by the Health Research Board. Ethical approval for this project has been obtained from the DCU Research Ethics Committee and the TSCUH Ethics Research Committee.

If I give consent to take part what will my child and I be asked to do?

- The team of researchers has created two questionnaires, one for adolescents (11-17 years) living with type 1 diabetes and one for their parents to complete. We would like you to complete the parent questionnaire, either online or in paper form, about being the parent or guardian of an adolescent living with type 1 diabetes.
- You will also have received an information sheet for your child and an adolescent questionnaire for your child to complete about their type 1 diabetes. The adolescent information sheet will contain all of the information your child needs to complete their questionnaire. We would encourage you to discuss the information sheet with your child.
- If you complete the parent questionnaire in paper form, we would ask you to kindly return the questionnaire using the enclosed stamped addressed envelope. We have provided two envelopes so that your child can return their questionnaire separately.

How long will the process take?

The questionnaire will take approximately 30 minutes to complete.

What if my child and I decide not to take part?

We understand that not all families will have the time to take part in our research, and some families may not be interested. If you choose not to take part in the survey, this will in *no way* affect your child's treatment in TSCUH, nor will it prevent you from being a part of any support groups/ activities organised by Diabetes Ireland in the future.

What will be done with the information collected from my child and I?

All the information you and your child provides will be anonymous (i.e. no one will be able to tell what you specifically answered).

- As we will not be able to identify your data, once you have submitted the questionnaires (by post *or* online) you will not be able to withdraw from the research as we will not be able to identify which questionnaire is yours.
- Only the research team and possibly the examiners of the PhD thesis will have access to the anonymised data and these will be treated in the strictest of confidence at all times.
- All information will be stored in locked filing cabinets and/or on password-protected computers in DCU.
- The information we collect from all the completed questionnaires will be used to write a report on the findings. The Health Research Board who are funding this project will receive annual reports and the findings from this research may be published in journals.
- Data gathered from the survey with adolescents will also be published in a PhD thesis completed by Ms. Ella Tuohy and submitted to the School of Nursing and Human Sciences at DCU.

How will this study be of benefit to me and my child?

While there may be no immediate benefits to you and your child from taking part in the study, the researchers hope that the findings of this study will help to inform current practices and develop new services to support adolescents living with type 1 diabetes and their parents, such as an intervention or educational material to support parent-adolescent communication as adolescents take on the responsibility of managing their type 1 diabetes themselves.

Are there any risks or downsides to taking part?

There should be no risks involved in taking part, however if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (e.g. your Diabetes Ireland representative) who can advise you on next steps. We have included an additional sheet in your survey pack with the contact details of some useful services should you need additional support.

Is there anything else I need to know?

If you would like to talk informally with a member of the research team and discuss any questions or queries you may have in relation to this research we would be happy to speak with you, our contact details are provided below.

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Additionally, you can contact the Principal Investigator, Dr. Veronica Lambert, at veronica.lambert@dcu.ie

Thank you for taking an interest in this research and completing this questionnaire!

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