

## Participant Information Sheet (Parents/carer Interview)

**Study title:** Improving Support for Physical Activity in Adolescents with Type 1 Diabetes (ISPA-T1D): Understanding needs and preferences for supporting young people with type one diabetes with physical activity

**Chief Investigator:** Dr Emma Cockcroft [e.j.cockcroft@exeter.ac.uk](mailto:e.j.cockcroft@exeter.ac.uk). Telephone 01392 722764 or 07476 943278

We would like to invite you to take part in research being undertaken at the University of Exeter. This leaflet will explain the aims of the study and what this would involve for you.

### What is the study about?

Type 1 Diabetes (T1D) is one of the most common chronic diseases in adolescents with around 29,000 people under the age of 17 living with T1D in the UK. Adolescents with T1D may have twice the risk of developing heart and blood vessel disease, compared to those without diabetes. Regular physical activity is an important aspect of the management of T1D. Physical activity can improve blood sugar control, wellbeing, and reduce the risk of heart and blood vessel disease. Because of these benefits, adolescents with T1D are recommended to do 60 minutes of physical activity per day. But lots of adolescents with T1D are not meeting this target. This might be because they worry about low blood sugar levels and are not sure how to manage changes to diet and insulin while being physically active. Thank you for showing an interest in this project. There are currently no specific programmes for adolescents with T1D that provide support for physical activity

This research aims to develop the UK's first programme for adolescents with T1D to support and encourage physical activity. It will provide education on how to manage glucose levels before, during and after physical activity, and help encourage adolescents with T1D to be physically active.

### Why have I been approached to take part?

You have been approached to take part because we would like to hear from parents/carers of adolescents with T1D.

### What would taking part involve?

You will be invited to agree a date and time to take part in an interview with a member of the research team. The interview will take place over the telephone, or using a secure video-conference application such as Zoom or Teams.

The interviewer will ask some questions about your experiences of supporting an adolescent with T1D, with a focus on management around physical activity. The interview will be audio recorded and will last for about 45-60 minutes.

We would like you to join the interview from a quiet and private space, so that you are free to talk to us without interruptions and can concentrate on the interview.

### **What are the possible benefits of taking part?**

By taking part, you will help us gather valuable information which will be used to help develop a programme to support adolescents with T1D to be physically active.

### **What are the possible disadvantages and risks of taking part?**

We do not think that there are any risks or disadvantages to taking part. However, in the unlikely event that you find talking about any of these topics to be uncomfortable or upsetting, you can decide not to answer a question, or to stop the interview.

Sources of support are listed at the end of this information sheet.

### **What if there is a problem?**

If you have any questions or concerns about our project, either now or in the future, please

contact the project lead

Dr Emma Cockcroft, Research fellow, University of Exeter Medical School. Tel: 01392 722764 or 07476 943278

Email: [e.j.cockcroft@exeter.ac.uk](mailto:e.j.cockcroft@exeter.ac.uk)

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School Research Ethics Committee:

Mark Tarrant, PhD

Chair of the UEMS Research Ethics Committee

Email: [uemsethics@exeter.ac.uk](mailto:uemsethics@exeter.ac.uk)

### **Do I need to take part and what will happen if I don't want to carry on with the study?**

No you do not need to take part. It is entirely up to you to decide. This information sheet has been written to help you decide if you would like to take part or not. If you do decide to take part you are also free to change your mind at any time, without giving a reason. A decision not to take part, or to withdraw from the study will not affect the care you or your family receive in any way. If you wish to withdraw please contact the project lead.

### **How will my information be kept confidential?**

All information collected in this study will be kept strictly confidential and stored on an encrypted password protected computers, which can only be accessed by the research team. You will be allocated a unique participant number, to ensure your information will be protected and cannot be identified outside of the research team. Any personally identifiable information will only be kept for a limited time (up to five years) and securely destroyed at the end of the project. The only exception to this would be if you disclose something that presents a safeguarding risk, either concerning yourself or another person. At that point, for safety reasons, we would share this information with appropriate services.

We will use professional transcribers to change the recording of your interview into written text. They will be asked to sign a Non-Disclosure or Confidentiality Agreement. This means your information will be kept safe.

All data will be identified only by a code, with personal details kept separately in a secure computer with access only by the immediate research team. The only exception to this will be if you tell us something that suggests a serious risk to any person (including yourself). At that point, for safety reasons, we will share this information with appropriate services, but if possible, we will try to let you know we will do this first.

These interviews are being led by the University of Exeter. The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will try to be clear about using your personal data and this information sheet should explain this. If you have any questions, please speak to the researchers.

Your rights to access, to change, or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study prior to your interview, any personal data can be withdrawn. After taking part in the interview, you will be given 14 days to indicate if you want to withdraw your research data (i.e., interview data). If withdrawal of this research data is requested, this data will be permanently deleted and not used in data analysis. If withdrawal of this research data is not requested, we will keep this data and you will not be able to withdraw it. Published data will be anonymous. However, you can request withdrawal of personal data at any time point by contacting the Principal Investigator.

You can also find more information about how the University uses personal data here and what to do if you are unhappy with how your data are being handled:

<https://www.exeter.ac.uk/privacy/research/>

### **Taking part in further research**

After reading this participant information sheet, you will be asked if you might also be interested in taking part in future research. If you are willing to be contacted again about taking part in future research, please indicate this on the study consent form by ticking the appropriate box. This does not mean you consent to participate in future research but only that you are willing for us to contact you to invite you. If you do not want to be invited to take part in this future research, you can indicate this on the form and the team will ensure you are not contacted again.

### **What will happen to the results of this study?**

We will be publishing our results from this project in 2024/2025. We may publish studies in journals and present our findings on the project website, in media, and at conferences. However, anything you say will be anonymised.

If you would like a copy of our findings, you will be able to get these from the project website ([www.ISPA-T1D.com/](http://www.ISPA-T1D.com/)). You can also request to be sent a link to any major findings from the project by ticking the relevant boxes on your consent form.

### **Who is organising and funding this study?**

This study is funded by National Institute for Health Research (NIHR) School for Primary Care Research as part of a postdoctoral fellowship award. The study Sponsor is the University of Exeter. The research is being led by Dr Emma Cockcroft

### **How have patients and the public been involved in this study?**

This research has been developed as a result of requests made by people with T1D. The study team includes a young adult with T1D who will help to ensure the research is sensitive and relevant. The research will be guided by a group of advisers made up of young people with T1D and their parents.

### **Who has reviewed the study?**

This study has been reviewed by the University of Exeter University of Exeter College of Medicine and Health Research Ethics Committee and received a favourable review. The review reference is [717231].

### **General Data Protection Regulation (GDPR)**

In 2018 regulatory changes in the way that data is processed came into force, with the EU General Data Protection Regulation 2018 (GDPR) and the Data Protection Act 2018 (DPA 2018). Since the UK left the EU, the key principles of EU GDPR have been adopted in the UK GDPR (a 'UK-only' version) and the DPA 2018 still applies.

The University of Exeter terms its lawful basis to process personal data for the purposes of carrying out research as being in the 'public interest'. The University continues to be transparent about its processing of your personal data and the participant information sheet should provide a clear explanation of how your data will be collected, processed, stored, and destroyed. If you have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information can be obtained from the University of Exeter's Data Protection Officer by emailing [dataprotection@exeter.ac.uk](mailto:dataprotection@exeter.ac.uk) or at [www.exeter.ac.uk/dataprotection](http://www.exeter.ac.uk/dataprotection)

### **Further information and contact details**

If you have any questions about the study or would like a printed version of this information sheet, please contact the research lead, Dr Emma Cockcroft. Telephone 01392 722764. Email [e.j.cockcroft@exeter.ac.uk](mailto:e.j.cockcroft@exeter.ac.uk)



### **Sources of support**

Further support and information for people with T1D



<https://www.diabetes.org.uk/>

<https://jdrf.org.uk/>

Thank you for taking the time to read this information sheet and to consider this study.