# **PARTICIPANT INFORMATION SHEET (for young people)**

# **REC reference number [Insert number]**

# **03rd February 2022**

# **Version 1.0**

# **Title of study:** Developing digital tools to support young people with a long-term health condition

# **Name of principal investigator:** Dr Angeliki Bogosian [Angeliki.Bogosian.1@city.ac.uk](mailto:Angeliki.Bogosian.1@city.ac.uk)

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You will be given a copy of this information sheet to keep.

# **What is the purpose of the study?**

We understand that living with a long-term physical health condition can be difficult. We are doing this study to find out which aspects of living with a long-term condition young people would most like support with. We would also like to ask what type of digital technology they would find most useful to support their wellbeing.

# **Why have I been invited to take part?**

If you are between 10-18 years of age and have asthma, diabetes, or epilepsy we would like to invite you to take part in a survey for this research. A total of nine children will take part. This study has been advertised to young people via schools and relevant charities.

Please note, if lots of young people are interested in taking part, we may not be able to include everyone. We will let you know as soon as possible after you contact us.

# **Do I have to take part?**

Participation in the project is voluntary, and you can choose not to participate in part or all of the project. You can withdraw at any stage of the project without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time without giving a reason. You can take part whether or not your parent would also like to take part.

**What will happen if I take part?**

If you decide to take part, you will be asked to complete (without using your name) an online survey in three rounds. The first round will ask you to prioritise common themes we have found in the literature as well as ask for your views about the main difficulties you face. The research team will then summarise the views of all participants in the first round. In the next two rounds, you will be asked to select which of the needs in round one should be prioritised in a digital support tool.

Each stage of the survey will take approximately 10 minutes to complete. The survey rounds will take place approximately 2 weeks apart. You will complete all parts of the study within 4 weeks. Each survey round will be open for 2 weeks so you can complete them at a time that suits you during that period.

The link to the first phase survey is at the end of this information sheet. Once your mum or dad agree for you to take part, you can complete the survey. We will email you and your parent the links to the next two phases over the following 4 weeks.

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

It is unlikely that you will experience any harm by taking part in the study. If you do find that taking part causes you any discomfort, distress or concern you are free to stop or withdraw at any time.

*If the research has raised concerns for you, please visit* [*Young Minds*](https://www.youngminds.org.uk/) *or call* [*Samaritans*](https://www.samaritans.org/) *for free on 116 123 further* mental health support. Please, do talk to your parents or any other adult you are close to if you are experiencing mental health difficulties.

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

Whilst there are no immediate benefits participating in this study, it is hoped that this work will contribute to improving support for young people with long-term physical health conditions. We also hope that you will find it interesting to take part and learn of the results.

# **Expenses and Payments**

To thank you for your participation, you will receive a £10 voucher for each completed survey, which will be emailed to you. You will get £30 if you complete all 3 surveys.

# **How is the project being funded?**

The project is being funded by a grant from eNurture [www.enurture.org.uk](http://www.enurture.org.uk)

**What should I do if I want to take part?**If you would like to take part, please click on the link at the end of this information sheet, which will bring you to the consent form and survey.

# **Data privacy statement**

City, University of London is responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City’s public task.

City will use your name and contact details to contact you about the research study as necessary. If you wish to receive the results of the study, your contact details will also be kept for this purpose. The only people at City who will know your name and email address are: Dr Angeliki Bogosian (the lead of this research project) and Dr Jennie Brown (research fellow). The questionnaire responses without your name will be saved in a database, future researchers could use.

# **Will my taking part in the study be kept confidential?**

Apart from Angeliki and Jennie, no one else will know you have taken part in this study.

However, if you tell us something that gives us concern about your safety or the safety of another person, we may have to pass that information on to your parent, GP or social services, depending on the nature of the disclosure.

# **What will happen to the results?**

The data collected will be written up for publication in academic journals and reported at health conferences. You will not be named in any study report.

The findings from this study will be used to inform the future development of a digital intervention to support the mental health of young people with long-term physical health conditions subject to funding.

# **Who has reviewed the study?**

This study has been approved by City, University of London, School of Health Sciences Research Ethics Committee, reference number [insert ethics number].

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

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team or ask your parent to help you complain formally.

# **Further information and contact details**

If you are interested in taking part in this study but would like some more information before you decide, please contact:

**Jennie** [**Jennie.Brown.2@city.ac.uk**](mailto:Jennie.Brown.2@city.ac.uk) **or**

**Angeliki Angeliki.bogosian.1@city.ac.uk**.

**Thank you for taking the time to read this information sheet.**

Please click HERE if you wish to continue to the first-round survey and ask your mum or dad to consent before you begin. We can also call you and you can complete the survey over the phone.