# **PARTICIPANT INFORMATION SHEET (for parents/guardians)**

# **REC reference number [ethics number code]**

# **3rd 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 and your child 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.

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

We understand that living with a long-term health condition can be difficult. The purpose of the study is to explore how to develop digital technology to support the mental health of young people. 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 would be most useful for accessing support.

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

You have been invited because you are the parent/guardian of a young person who has a long-term health condition. This study has been advertised to parents/guardians via schools and relevant charity websites.

If your child is aged 10-18 years and has asthma, diabetes, epilepsy, we would like to invite you to take part in a survey for this research. A total of nine parents will take part.

Please note, if lots of parents/guardians 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 take part whether or not your child is also taking part. 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 and without giving a reason. However, questionnaires already submitted cannot be withdrawn as the questionnaires do not have any names and we will not be able to find yours.

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

If you decide to take part, you will be asked to complete 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 challenges you feel your child facing in living with a long-term physical health condition. 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 themes 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 so your participation in the study will last approximately 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. The research team will email you the links to the next two phases over the following 4 weeks.

Your child will also be provided with the same link and you will be asked to consent to their participation before they are able to complete the survey. We can also arrange a phone call with you or your child to complete the survey.

# **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 or call* [*Samaritans*](https://www.samaritans.org/) *for free on 116 123 further* mental health support. Please, do contact your GP 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. 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, £30 total 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 the sponsor and the data controller of this study based in the United Kingdom. This means that we areresponsible for looking after your information and using it properly. The legal basis under which your data will be processed is City’s public task.

Your right to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personal-identifiable information possible (for further information please see [https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/?q=privacy+notice)).

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 have access to your identifiable information will be 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 and future researchers could have access to use in future research.

You can find out more about how City handles data by visiting <https://www.city.ac.uk/about/governance/legal>. If you are concerned about how we have processed your personal data, you can contact the Information Commissioner’s Office (IOC) <https://ico.org.uk/>.

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

All the information you provide during the research will be kept strictly confidential. We will use a unique number on all records, rather than your own name. Study information will be securely stored on a secure computer database at City, University of London. Only authorized individuals directly involved with the study will have access to the data. We will comply with the University’s policies to ensure confidentially of the data throughout the process.

Your survey responses will be submitted without your name. 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 the University safeguarding team. If your child tells us something that gives us concern for their safety or the safety of another person, we will advise the 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 psychology and medical 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 securing further 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 [add 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. If you remain unhappy and wish to complain formally, you can do this through City’s complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is *Developing digital tools to support young people with a long-term health condition*.

You can also write to the Secretary at:

Anna Ramberg  
Research Integrity Manager

City, University of London, Northampton Square  
London, EC1V 0HB

Email: [Anna.Ramberg.1@city.ac.uk](mailto:Anna.Ramberg.1@city.ac.uk)

# **Insurance**

City University London holds insurance policies which apply to this study, subject to the terms and conditions of the policy. If you feel you have been harmed or injured by taking part in this study, you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone’s negligence, then you may have grounds for legal action.

# **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. You will be asked to complete a consent form before starting the survey.