# **PARTICIPANT INFORMATION (for health professionals)**

# **REC reference number ETH2122-0279**

# **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 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?**

Children and adolescents with long-term conditions have significantly higher rates of mental health problems compared to children without physical health concerns. Little is known about the potential for digital technology to support good mental health for young people with a long-term condition.

The purpose of the study is to identify and prioritise key mental health themes to be addressed in a digital intervention and to identify the most appropriate digital technology to be used.

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

You have been invited because you work with children/ young people who have a long-term physical health condition. We wish to recruit a total of twelve people from the following professions: clinical psychologist, paediatrician, paediatric nurse, psychiatrist, school teacher, social worker, youth worker

Please note, if lots of professionals 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 do decide to take part you can follow the link at the end of the document to complete the survey. If you decide to take part you are still free to withdraw at any time, questionnaires already submitted cannot be retracted as questionnaires are submitted without name.

**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 for your views about the main challenges young people (10-18 years old) face in living with a long-term physical health condition, as well as prioritise common themes we have found in the literature. 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 reported by all participants in round one should be prioritised and what digital intervention form we need to prioritise.

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 phase questionnaires 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 concern, you are free to stop or withdraw at any time.

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

Whilst there are no immediate benefits for people participating in this study, it is hoped that this work will contribute to improving psychological 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.

# **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 take 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 (principal investigator) and Dr Jennie Brown (research fellow). City will keep identifiable information about you from this study for 10 years after the study has finished. Anonymised data will be stored in an open access repository for future researchers to access and benefit from.

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 course of 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.

# **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 appropriate 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 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. 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 Dr Angeliki Bogosian at [Angeliki.Bogosian.1@city.ac.uk](mailto:Angeliki.Bogosian.1@city.ac.uk) or Dr Jennie Brown Jennie.Brown.2@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.