

Version Number 2 07/08/2018

INFORMATION SHEET FOR PARTICIPANTS

REC Reference Number: *HR-17/18-7535*



YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study

Improving the Health of Young People – Evaluation & Intervention Project (The HYPE Project)

Project Lead Dr Stephani Hatch

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

You have been asked to participate in this original research project organised by King's College London and funded by the South London and Maudsley NHS Trust and King's College London National Institute of Health Research Biomedical Research Centre.

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 wish to know more.

You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve.

Improving the Health of Young People – Evaluation & Intervention Project (The HYPE Project)

We invite you to participate in an online research project investigating social experiences together with psychological and biological factors impact health and health service use. This information will help us understand how to prevent health problems from developing, understand what types of resources are needed to promote health and well-being in the community and improve access to health and social services.

What is the purpose of the study?

The primary aims of this project are:

1. (a) To develop an online survey to investigate biological, psychological and social factors; mental and physical health conditions and health service use among young people starting at 16 years
(b) To improve access to health and social resources through the delivery of guided online interventions to promote health and well-being in the community.
2. To obtain permission for the donation of biological samples which will be stored and used for future genetic analysis.
3. To obtain permission for the linkage of survey and biological sample data with electronic health records.

Version Number 2 07/08/2018

Why have I been invited to take part?

We are asking residents of England aged 16 years and older to help us by taking part in this project.

Do I have to take part?

Participation in the project is entirely optional. If you decide to take part you are still free to withdraw at any time and without giving a reason. Withdrawal from the study will not affect the treatment you receive from the NHS or legal rights in any way. Participants can withdraw from The HYPE Project at any given time and ask for their survey data (with the exception of anonymised transcribed interview data) to be deleted, until the end of the project (31st March 2021). In order to withdraw, please contact either Dr Gunasinghe or the HYPE study team whose details are listed below.

What will happen to me if I take part?

If you agree to take part, you will be asked to complete a consent form. You will then be asked to:

- **Fill in a short questionnaire** about your physical and mental health and some events that you may or may not have experienced in your life. This will take about 40 minutes.
- **You will be re-contacted** about our follow-up and evaluation study and provided with information about health and social care resources as well as local events and activities. We also may ask you to answer some questions about your experience of using the online research and resource platform together with recent health service use. This will between 30 and 60 minutes.

What are the possible benefits and risks of taking part?

There are no other direct benefits from participating in this study. However, we believe that by participating, this will allow us to explore the needs of young people. This will aid future policies and improvements to health services that will help people in the community.

We hope that the information you provide us with can help us to provide appropriate guided online resources to promote health and well-being. These will be revised based on the feedback from our participants. Your anonymised data may be archived for use by other researchers in other research studies.

You can also receive a copy of our final report describing the main findings from this study. However, this is optional and you do not have to be sent any additional information regarding this study in the future if you do not want to.

There are no major risks involved in taking part in this study. We will ask you a range of questions regarding your health and various stresses and life experiences. Some of these questions touch on sensitive areas. If you feel uncomfortable with any of the questions you do not have to answer them. If you want to stop the survey you can do so at any time without giving us a reason. In addition, you may also withdraw any information you provide us with, within one month after completing the study. This can be done over the telephone, contact details of the research team can be found at the bottom of this letter.

Version Number 2 07/08/2018

The saliva sample is a pain-free, less intrusive method of providing a biological sample for genetic research.

Will my taking part be kept confidential?

We take confidentiality very seriously. All personal identifiable information about you is regarded as strictly confidential and it will be stored separately to the information you provide as part of the study. All participants will be given an anonymous identification number which will be used as an identifier throughout the study. Only the researchers directly involved in this study will be able to trace the information you have given to your personal details.

Information provided during the survey will be completely confidential. Confidentiality might be breached only when your life is considered to be at risk, for example in cases where suicidal thought and plans are disclosed. If this is to happen, our aim will be to make sure you get all the help and support you may need. We can provide you with some support by facilitating an appointment with your GP or putting you in touch with an expert from the study team.

Personal details will not be recorded on the biological samples (saliva) provided by you for this study. All samples will be labelled with the anonymous identification number. Researchers involved in the analyses will only have access to the anonymised samples. In addition, you will not be identifiable in any publications that result from this study. All information collected during the study will be securely held in King's College London, in agreement with the Data Protection Act 1998 and the European Union General Data Protection Regulation 2018 (Please see the HYPE Project website for full details of our Privacy Notice - <https://hypekcl.com/privacy-notice>)

If you agree to take part in this project you will be asked whether you are happy to be re-contacted about participation in our online resources, future research projects and community-based events. This is entirely optional and you do not have to agree to this. This decision will not affect your participation in the current survey.

How is the project being funded?

This study is funded by the National Institute for Health Research Maudsley Biomedical Research Centre Nucleus.

What will happen to the results of the study?

We would like to discuss findings from completed studies in public meetings which we will inform our volunteers via The HYPE Project website and a regular newsletter. Results will also be disseminated through scientific publication, conference/workshop presentations and user/carers groups.

The volunteers' names will not be mentioned in any report or publication, and data published will be presented at the group level to minimise risks of tracing to any individual. We anticipate that these samples will contribute to research for many years to come. Future research involving the information volunteers supplied may involve other research groups seeking to understand diseases. These could be

Version Number 2 07/08/2018

our collaborators or independent researchers from other academic and/or industry groups. Anonymised information would be made available only to valid research groups with full ethical approval for the research undertaken.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details: Dr. Cerisse Gunasinghe - email: cerisse.gunasinghe@kcl.ac.uk, Tel: 0203 8480462, Address: Department of Psychological Medicine, Institute of Psychiatry, Psychology & Neuroscience, King's College London, Weston Education Centre, 10 Cutcombe Rd, London SE5 9RJ

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, **Psychiatry, Nursing & Midwifery Research Ethics** rec@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.