

PARTICIPANT INFORMATION SHEET

PUPS: Understanding the psychological impact of living through the COVID-19 Pandemic

Chief investigator: Anna Heinen, Oxford Health NHS Foundation Trust

Co-Investigators: Sherin Varghese, Andrew Molodynski and Shayda Khoshnaw

Thank you for taking the time to read this!

This information sheet explains why the research is being done and what would happen if you decided to take part. Please take as much time as you need to read this information. If there is anything you think doesn't make sense, or if you would like more information, please don't hesitate to contact us at pupsresearchstudy@oxfordhealth.nhs.uk

What is the purpose of the study?

We want to understand the psychological consequences of living through a pandemic. Many people have made sudden changes to their day to day lives due to the imposed self-isolating and social distancing measures. Many people may also have worries about elderly relatives or relatives with underlying health conditions, as well as fears about developing the illness themselves. We are interested to understand whether the pandemic is affecting people's wellbeing, particularly feelings of hopelessness, anxiety, health anxiety, loneliness, phobias, quality of life, uncertainty, obsessive compulsive behaviours and panic.

The results of this study will:

- Help to understand the psychological impact of living through a pandemic
- Help to understand what sort of support people might require

Why have I been invited to take part in this study?

Participation is completely voluntary. We are looking for people living or working in Oxfordshire or Buckinghamshire to take part in the study.

What happens if I take part?

We are asking participants to complete some online questionnaires about their wellbeing. We will also collect some demographic information.

We are also asking all participants to complete a follow up set of questions 3 months after they completed the initial set of questionnaires. This is to assess if there has been any change over time.

All the online questionnaires will be completed through an online platform called 'Qualtrics'. You will not need to create an account with Qualtrics, you just need to click on the link to complete the questionnaire. If you complete the questionnaire, in 3 months' time we will send you another link to complete the 3 months follow up questionnaires.

We will also ask participants if they would like to complete an optional telephone interview with a researcher. This is because we are interested to find out about individual people's experiences during the COVID-19 pandemic. We are particularly interested in studying people's resilience to stressful situations and understanding a bit more about how they think about the situation. The telephone interview will take approximately 30 minutes and if you agree to be contacted we will contact you within one week of you completing the online questionnaire. Please note, we do not plan to contact everyone who volunteers to take part in the telephone interview as we only require 12-16 participants, so even if you do volunteer to be contacted we may not contact you. We will only contact participants who have consented to be contacted and have provided a contact telephone number.

Do I have to take part?

No, you don't have to take part, your involvement with this research is voluntary.

How many people will take part?

We are looking to recruit 1000 participants for the online survey and 12 participants for the optional telephone interview.

Are there any possible disadvantages or risks from taking part?

We do not anticipate that there are any significant risks involved in participating in the study. If you do find completing the questionnaire tiring, we recommend taking regular breaks. Your wellbeing is a priority! If at any point you find the questionnaire disturbing, please stop. If you would like to discuss your participation in the study, please contact us at pupsresearchstudy@oxfordhealth.nhs.uk

What are the possible benefits of taking part?

We are looking for people to volunteer their time to support research and there are not any direct benefits to individuals. However, the information that you share can help us understand the psychological

impact of living through a pandemic. This will help us understand what support the population might need.

Will my General Practitioner/family doctor (GP) be informed of my participation?

No.

We will not be informing any third party about the information collected and only researchers in the study will have access to the data collected.

Will my taking part in the study be kept confidential?

The research team will ensure that the participants' anonymity is maintained. All documents will be stored securely and only accessible by study staff and authorised personnel. The study will comply with the General Data Protection Regulation (GDPR) and Data Protection Act 2018, which require data to be de-identified as soon as it is practical to do so. Moreover, we will also be following Oxford Health NHS Foundation Trust's information governance requirements and guidelines on patient confidentiality. Direct access will be granted to authorised representatives from the Sponsor or host institution for monitoring and/or audit of the study to ensure compliance with regulations.

What will happen to my data?

We are using a secure online platform called 'Qualtrics' for the questionnaires. If you choose to participate in the study, your data will be initially stored on the Qualtrics platform. It will later be downloaded and stored in a password protected documents on Oxford Health NHS Foundation Trust computers. To protect your data, several measures are in place. Data will only be accessed by delegated members of the Psychological Impact of Pandemics Research Team. We will use your email address to send you a reminder email to complete the 3 months follow up questionnaires. We will also use your email address to link your baseline and 3 months follow up questionnaires. We will delete your email address once we have used it to match your baseline and 3 months follow up questionnaires. Once deleted, your data will be completely anonymous. Anonymous research data will be stored for 10 years after the study.

If you would like to hear the results of the study, we will keep your email address. This will be kept separately to your answers to the questionnaires. The log will be password protected. We will delete this information once the results have been disseminated.

If you provide permission to be contacted about the optional telephone interview, we will collect additional personal data (your first name and telephone number). This information is only needed to compete the telephone interview and will be deleted after the telephone interview has been completed. Data provided from the questionnaire will not be linked to your telephone interview.

If you choose to take part in an optional telephone interview, we will record the interviews on an encrypted recording device. The recordings will be transcribed by a member of the Psychological Impact of Pandemics research team. During transcription, identifiable information will not be included. A

pseudonym will be used in place of your name. The transcriptions will be stored in a password protected document.

If you would like to hear the results of the study, we will keep your email address. This will be kept separately to your answers to the questionnaires. The log will be password protected. We will delete this information once the results have been disseminated.

If you provide permission to be contacted about the optional telephone interview, we will collect additional personal data (your first name and telephone number). This information is only needed to complete the telephone interview and will be deleted after the telephone interview has been completed.

If you choose to take part in an optional telephone interview, we will record the interviews on an encrypted recording device. The recordings will be transcribed by a member of the Psychological Impact of Pandemics research team. During transcription, identifiable information will not be included. A pseudonym will be used in place of your name. The transcriptions will be stored in a password protected document.

Who has reviewed the study?

The study has been given a favourable ethical opinion by the Research Ethics Committee (REC) 2 and permission has also been obtained from Oxford Health NHS Foundation Trust to carry out the study.

Who should I contact if I have a question about the study?

Please contact us at pupsresearchstudy@oxfordhealth.nhs.uk

What if there is a problem?

Please contact Chief Investigator (Anna Heinen) on 01865901000 or on pupsresearchstudy@oxfordhealth.nhs.uk and we will aim to get back to you as soon as possible.

In case of complaints, please, contact the Patient Advice and Liaison Services (PALS) on 0800 3287971 or PALS@oxfordhealth.nhs.uk

Anna Heinen– Chief Investigator

Senior Research Assistant
Mental Health Research Team
Research Delivery Team
Oxford Health NHS Foundation Trust
Warneford Hospital
Headington
Oxford
OX3 7JX
Tel: 01865 901000
Email: pupsresearchstudy@oxfordhealth.nhs.uk

Sherin Varghese– Principal Investigator

Clinical Research Assistant
Mental Health Research Team
Research Delivery Team
Oxford Health NHS Foundation Trust
Warneford Hospital
Headington
Oxford
OX3 7JX

Andrew Molodynski -Principal Investigator

Consultant Psychiatrist, Oxford Health NHS Foundation Trust
Honorary Senior Clinical Lecturer, Oxford University
99 Wantage Road
Didcot
OX11 0AF

Shayda Khoshnaw -Principal Investigator

Locum Consultant Psychiatrist
Oak Team
Warneford Hospital
Headington
Oxford
OX3 7JX

How can I find out the results of this study?

It is our intention to publish the results of this study in academic journals and present findings at conferences. If you are personally interested to find out the results of this study, please provide your email address (you will be prompted when you complete the online consent form or alternatively you can email us at pupsresearchstudy@oxfordhealth.nhs.uk). We will contact you in due course with information about the results of the research study