

## Information Sheet for Service User Participants

### UCLP-PRIMROSE: Qualitative Study

Version 4.0, 06/05/22

(IRAS Project ID 285554)

You are being invited to participate in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information.

#### Who is carrying out the study?

Research teams based at University College London (led by Professor David Osborn with Dr Philippa Shaw) and Bradford Institute for Health (led by Dr Kristian Hudson with Dr Zuneera Khurshid), in collaboration with staff in Camden and Islington NHS Foundation Trust and Bradford Teaching Hospital NHS Foundation Trust.

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

This study is investigating the support you received over the last six months relating to your physical health, this support falls under the service UCLP-PRIMROSE. UCLP-PRIMROSE aims to improve physical and mental health of people with severe mental illness through nurse- and peer-coach led support. It helps the development of relapse prevention strategies through behavioural strategies, such as goal setting. We aim to gather the views and experiences of service users, practice nurses and peer coaches, and people involved in setting up the service.

#### Why have I been asked to take part?

You have been invited to take part because you have been supported through the UCLP-PRIMROSE service.

#### Do I have to take part?

It is completely up to you to decide whether or not you would like to take part. If you decide to take part you will be asked to provide verbal consent. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the care you receive now or in the future. If you withdraw from the study, we will include your data collected up to that point unless you ask us to remove it.

#### What will happen to me if I take part?

You will be invited to complete one interview lasting up to 60 minutes with a researcher either by video call, on the telephone, or face-to-face (which would comply with the current COVID-19 guidelines at the setting the interview takes place, or following additional measures to make you feel comfortable and safe). In the interview the researcher will ask about your experience of implementing the UCLP-PRIMROSE service, and recommendations to improve the services.

The interviews will be audio-recorded, and recordings will be typed up after the interview to help with the analysis of what was said. The recording will be sent to a professional transcription company to be typed up, but no identifying details will be included, and the company adheres to a strict data protection policy.

### **What are the possible benefits of my participation?**

People often enjoy talking about their own experiences. The information gained from the study will be used to inform the development of UCLP-PRIMROSE, hopefully improving the service offered to people in the future. You will be offered a £20 gift (you may select either a bank transfer or receive a gift voucher) as a thank you for taking part.

### **What are the possible disadvantages of my participation?**

Many people feel it is helpful to talk about their experiences; however sometimes this can also raise issues that are distressing. If you find any topic upsetting and you wish to stop the interview at any point you are of course free to do so. The researcher will provide immediate emotional support, offer to pause or postpone the interview, and offer to contact someone else for you (e.g. a health professional, a friend, or family member). You can tell us in advance who this person would be.

### **Confidentiality and Consent**

Staff from your GP surgery will know that you have been approached about this study, but not whether you agreed to take part. Any information that is collected from you during the course of the research will be kept strictly confidential.

If you disclose information that makes the researcher concerned about your safety or someone else's, then they will talk with you about what you feel should happen. If they are still concerned they may contact your GP or another appropriate professional.

UCL is the sponsor and data controller for this study. Data will be stored in accordance with the Data Protection Act 2018. Electronic data will be stored in password protected files on UCL's secure servers and the Bradford Institute for Health Research. Data (including audio recordings) will be archived one year after the end of the study, and then kept in UCL's secure archive for 20 years. When we report on the research, it will not be in any way possible to identify you from the report, as all information will be anonymised.

The information collected for this study may be used to support other research in the future and may be shared anonymously with other researchers. For example in funding applications for further work, student research, or to evaluate other aspects of the UCLP-PRIMROSE service.

### **Local Data Protection Privacy Notice**

The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice [here](https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies) (https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies)

The categories of personal data used in this study include: Name, Address, Phone number, Email address, Age, Gender, Ethnicity. Your personal data will be processed so long as it is required for the research project. We will anonymise or pseudonymise the personal data you provide where possible.

### Where can I get further information?

If you require any further information or have any questions not answered by this information sheet, or if you have any comments or concerns, please do not hesitate to contact a member of the research team.

#### London:

**Professor David Osborn**  
Chief Investigator

[d.osborn@ucl.ac.uk](mailto:d.osborn@ucl.ac.uk)

**Dr Philippa Shaw**  
Research Fellow

[philippa.shaw@ucl.ac.uk](mailto:philippa.shaw@ucl.ac.uk)

#### Bradford:

**Dr Kristian Hudson**  
Implementation Specialist

[kristian.hudson@yhia.nhs.uk](mailto:kristian.hudson@yhia.nhs.uk)

**Dr Zuneera Khurshid**  
Research Fellow

[zuneera.khurshid@yhia.nhs.uk](mailto:zuneera.khurshid@yhia.nhs.uk)

### What if I am unhappy with the study?

If you have any problems during the study or would like to discuss the study, you can contact any of the research investigators. In the unlikely event that you come to harm as a result of you taking part in the study, then please speak with your doctor and make a claim in writing to Professor David Osborn. If you wish to complain, or have any unresolved concerns about any aspect of the way you have been approached or treated during the course of this survey, you can contact your local NHS advice and complaints service or Research & Development Office:

Advice and Complaints Service  
Camden and Islington NHS Foundation Trust  
FREEPOST 1st Class (LON 12613)  
London  
NW1 0YT  
Phone number: 020 3317 7102  
Email address: [feedback@candi.nhs.uk](mailto:feedback@candi.nhs.uk)

### What happens to the results of the research study?

The information collected will be made anonymous and written up in a report. The report will be shared with GP practices that offer the UCLP-PRIMROSE service, and to Camden and Islington NHS Foundation Trust and Bradford Teaching Hospital NHS Foundation Trust managers who organise the service. The report will not contain any personal information from which you could be identified. The results are likely also to be published in scientific journals and publications. Anonymised quotations may be included in conference presentations and published documents. If you indicate on the consent form that you are interested in the results, a copy of the report will be made available to you.

**Who is funding the study?**

It is funded by the ARC North Thames, a research unit based in the UCL Department of Applied Health Research, and ARC East Midlands which receives funding from the National Institute of Health Research.

**Who has reviewed the study?**

The study has been reviewed favourably by researchers in the UK with considerable research experience, by West of Scotland Research Ethics Committee 3 (reference 20/WS/0153).

*Thank you for reading this information sheet*