

# Participant Information Sheet for Adults

## With Severe Mental Distress

IRAS ID: 289598

**Study Title:** Exploring **M**ultilevel barriers and facilitators **O**f **O**ral and **D**ental care utilisation amongst adults with severe mental distress: **the MOOD study**

### **Invitation and brief summary**

We (Queen Mary University of London) would like to invite you to participate in the MOOD research study. Before you decide whether you want to take part, it is important for you to understand why this research is being done and what your participation will involve. 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?**

Having good oral health and visiting the dentist regularly are important for you. Yet, many people with severe mental distress might find it difficult to have regular visits to the dentist. We would like to find out more about your views on your oral health. We also want to understand the reasons that either help or make it difficult for you to visit the dentist regularly and receive dental care.



### **What would taking part involve?**

You are invited to take part in a 1-hour informal 1-to-1 interview via telephone or Microsoft Teams to explore your experiences, views and suggestions about the issues that make it easy or difficult for you to visit the dentist regularly and receive dental care.

Discussions and interviews will be audio-recorded and transcribed using a confidential service.

You will also be asked to complete a short questionnaire, which includes questions about your age, gender, ethnicity, education, employment and when was the last time you saw your dentist. The questionnaire will take approximately 5 minutes of your time to complete.



### **Incentives**

You will receive a £20 voucher to thank you for your participation in this research.



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

This study could give you an opportunity to reflect on your dental care. If you need help in registering with a dentist we will provide the required support. We hope all participants will benefit from knowing they have contributed to new knowledge that will support people with severe mental distress and their oral health needs.



### **What are the possible disadvantages and risks of taking part?**

We do not anticipate any specific risks to anyone who participates in this study, however some people with severe mental distress may have had previously traumatic experience with dental care and could find talking about their experiences upsetting or distressing. If this does occur, the interviewer will follow a safety protocol and signposting procedures including:

- Offering you to skip the question
- Pause the interview, take a short break, and only continue if you are happy to do so
- Reconvene the interview on another day
- Or withdraw from the study
- You will be supported to seek help through your GP and existing carers
- Professor Frank Rohricht (who is the lead researcher at East London Foundation Trust) or Dr Derek Tracy (who is the lead researcher at West London NHS Trust) will be contacted to provide immediate advice and support to ensure your safety and wellbeing.



### **What will happen if I don't want to carry on with the study?**

Your participation is voluntary and you are free to withdraw at any time prior, and up to two weeks after the interview without giving any reason, and without your medical care or legal rights being affected.



### **Who is funding this study?**

QMUL NIHR Clinical Lecturer Small Grant scheme is the funder for this study.



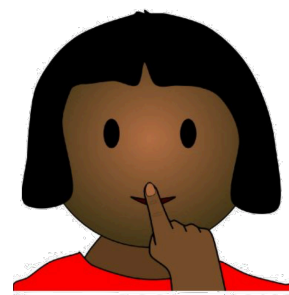
### **Who has reviewed the study?**

This study has been internally reviewed by Queen Mary University of London. It has also been independently, externally reviewed by the Wales Research Ethics Committee 5.



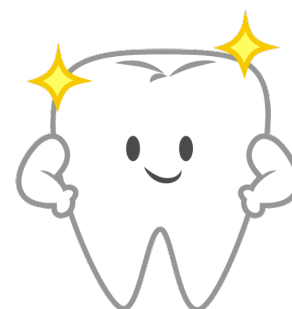
### **Will my taking part be kept confidential?**

- We will protect your privacy by abiding by the Data Protection Act 2018, and the rights you have under this Act.
- We may use direct quotes from your tape-recorded interview in the questionnaire and in publications but we will anonymise any quotes. No one will be able to identify you.
- We will keep the digital recorder and questionnaire data in a secure location at Queen Mary University of London. We will remove all personal information from the data and analyse it on university password-protected computers.
- In accordance with university policies, we will keep the data for 5 years.



### **What will happen to the results of the study?**

- We will use results from the study to develop an intervention to help people with severe mental distress receive dental care.
- As a participant you will receive a copy of the research project results if you request it.
- The findings will be presented in conferences and published as a manuscript in a peer-reviewed journal.



### **How will we use information about you?**

- We will need to use information from you for this research project.
- This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.
- People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.
- We will keep all information about you safe and secure.
- Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

### **What are your choices about how your information is used?**

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information

- At [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- By asking one of the research team: Dr Easter Joury ([e.joury@qmul.ac.uk](mailto:e.joury@qmul.ac.uk))
- By sending an email to [data-protection@qmul.ac.uk](mailto:data-protection@qmul.ac.uk), or
- By ringing us on (the study mobile number will be added).

### **What happens if there is a problem?**

- Queen Mary University of London has agreed that if you are harmed as a result of your participation in the study, you will be compensated, provided that, on the balance of probabilities, an injury was caused as a direct result of the intervention or procedures you received during the course of the study.
- These special compensation arrangements apply where an injury is caused to you that would not have occurred if you were not in the study. These arrangements do not affect your right to pursue a claim through legal action.
- If you have a complaint, please contact: The Complaints Officer, C/O: Chief Operating Officer for the Barts and The London, School of Medicine and Dentistry, Queen University of London, Wardens Office, 32 Newark Street, London E1 2AA.

### **Who do I contact if there is a problem or for further information?**

If you have a problem or have any questions about this study, please contact:

**Dr Easter Joury, Dental Public Health and Primary Care  
Centre, Barts and The London School of Medicine and  
Dentistry,  
Institute of Dentistry, 4th Floor, Office 2,  
Turner Street, London E1 2AD.  
Telephone: (the study mobile number will be added)  
Email: [e.joury@qmul.ac.uk](mailto:e.joury@qmul.ac.uk)**



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**University of London**  
**Barts and The London**