

INFORMATION SHEET FOR CARER PARTICIPANTS

Ethical Clearance Reference Number: HR/DP-20/21-21567



Title of project

Ethnic inequalities in mortality and service use in people with mental disorders and multi-morbidities during the COVID-19 pandemic (COV-EIMM study)

Invitation Paragraph

We would like to invite you to participate in this interview study which is being conducted online. It is part of a larger research project about ethnic inequalities in mortality and service use in people living with a serious mental condition and one or more long-term health conditions during the COVID-19 outbreak. King's College London is doing the research in partnership with the University of Sussex and Global Black Thrive, a south-London based organisation working with Black mental health service users locally and nationally. Our interviewers are from Black and Asian descent and some have experience of using mental health services.

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. 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 project?

This study aims to explore the experiences of service users from Black African, Black Caribbean, Indian, Pakistani and Bangladeshi descent (including those of dual heritage), living with multiple long-term conditions and mental health problems, as well as carer and healthcare provider perspectives, from three geographical places in England (Birmingham and Solihull, Manchester and South London). The study is being carried out in order to understand the reasons underlying ethnic inequalities in mortality and service use during the Covid-19 pandemic. This will include looking at access and barriers to care and discrimination within health services. Our aim is that recommendations resulting from the research will help to improve health care and make it safer.

To do this we will interview people in the community about their experiences:

- up to 30 people with multiple long-term health conditions who also have mental health problems.
- Up to 15 of these 30 interviews will be with people who have been supporting or caring for a mental health service user with multiple long-term health conditions.
- up to 10 healthcare providers.

Why have I been invited to take part?

You are being invited for an interview as a **carer** because you are:

- an adult (aged 18 or over)

and you are caring for:

- an adult (aged 18 or over)
- of Black African, Black Caribbean, Bangladeshi, Indian or Pakistani descent
- with one or more long-term physical health conditions as well as a current or previous diagnosis of depression, schizophrenia, bipolar disorder or other psychotic disorder.
- who has current contact, or a history of previous contact, with secondary mental health services in England.

The exclusion criteria mean that we will not be able to interview you if you are

- under 18 years old.

and if the person you are caring for:

- is under 18 years old, or
- is not of Black or Asian ethnicity, or
- does not have a diagnosis of a severe mental illness in addition to one or more long-term physical health conditions, or
- has not used secondary mental health services in England.

What will happen if I take part?

If you volunteer to take part in the project, we would first ask you to seek permission from the person you are caring for, for you to speak to us about their health and health service use. We will provide you with a consent form (Carer-Service-User consent form V1-11-06-21) for you to record their permission. Once you have their permission, we will ask some screening questions to check you are eligible for the study (e.g. not under 18). We would also ask you some questions about the person you support because it is our intention to include people:

- with a range of different mental and physical health diagnoses,
- from across all the target locations (Birmingham & Solihull, South London, Manchester)
- from every target background (Black African, Black Caribbean, Bangladeshi, Indian and Pakistani descent).

If we had several volunteers caring for people with identical diagnoses, from the same location and ethnic background, it is possible that you could be excluded as a result of your answers.

If you are selected for interview, we will arrange a date and time to suit both you and the interviewer. We will ask if you have somewhere you could do the interview in private, or, if you would like to be accompanied by a friend or family member.

On the day of the interview we will start by recording your consent to be interviewed and recorded.

If you consent, we will start the interview. It will cover a range of topics about experiences of health-service use during the COVID-19 outbreak of the person you care for. Questions such as:

- Do you consider the person you care for more vulnerable to COVID-19 because of any underlying health conditions?
- Has the COVID-19 outbreak affected the care of the person you support and was this care different to that provided previously?
- If they were not able to access their usual services, have you been able to get other types of health support for the person you are caring for?
- Given their experiences of using healthcare services during the COVID-19 outbreak, can you think of any actions that could be taken to improve experiences in the future?

If you are selected for interview and decide to take part, we will arrange a date and time to suit both you and the interviewer. We work Monday-Friday 09:00-17:00. We will ask if you have somewhere you could do the interview in private, or, if you would like to be accompanied by a friend or family member.

Because of the COVID-19 outbreak we will do all the interviews remotely. We will give you the choice of whether you would prefer to be interviewed via your computer/laptop on MS Teams or Zoom, or to call a freephone number to be interviewed by phone.

There will be either two or three people on the call, depending on whether a lived-experience or university researcher is conducting the interview. When a lived-experience researcher is conducting the interview, a university researcher/facilitator will record the interview securely.

If the interview is via video, the interviewer will have their camera on, but you could choose whether you want your camera on or off. The facilitator will introduce themselves but will go on mute and turn their camera off when the interview starts. We expect the interview will be about one hour long.

It will be necessary to collect some personal data. Our screening questions will be about the age category (18-24, 25-34, etc), ethnicity, gender and clinical condition of the person you are caring for.

The interview will start with some more background questions about the person you care for. For example:

- mental and physical health diagnoses and conditions
- what services they have used and what for
- who they live with
- which part of England they live in.

When the interview has finished, we will stop recording and ask you some demographic questions including about your gender identity and sexual orientation and whether you consider yourself to have a disability or impairment. All the demographic questions have the option: 'Prefer not to say'.

We collect personal data for two reasons:

- so we only interview people who are eligible for the study and do not waste the time of anyone whose data we would later have to exclude (e.g. because they were under 18 years of age);
- so we can describe the range of people included in the study and be clear about any groups not included. For example, we would say if all participants were heterosexual, or some were bi-sexual, gay, lesbian or asexual.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact us if you have any questions that would help you make a decision about taking part.

Once we have made a decision about your participation in the study, we will send you a copy of the Carer Consent form V1 11-06-21 to read and keep. On the day of the interview we will start by recording your responses to the question on the consent form. We need a record to confirm that you have understood the purpose of the interview and how the information you give us would be used, and that your participation is voluntary.

Incentives

If you complete an interview, we will give you £20 or a shopping voucher for this amount as a thank you. As the interviews are by video or telephone, we will have to arrange a transfer to your bank account or email you an electronic retail voucher. We will ask you which you would prefer.

What are the possible risks of taking part?

The interviews will explore experiences of managing the mental and physical health of the person you are caring for during the COVID-19 outbreak. We are aware that if you have had experiences that were distressing it is possible that recollecting them during the interview would be sensitive and might bring up difficult feelings. As a way of managing possible upset we will:

- ask, in advance of the interview, if you would like to nominate someone we could call to support you if you became upset;
- ask, in advance of the interview, if you would prefer to have a close friend or family member present with you during the interview;
- remind you that you do not have to answer any questions if you do not wish to;
- remind you that you could take your time in answering, take a short break, complete the interview at another time, or terminate the interview;
- suggest that we could discuss concerns at the end of the interview when recording has stopped;
- ask if you would like to give us the contact details of your GP, case worker, or another professional involved in your care, so we could ask for support on your behalf;
- provide you with information about support organisations you could contact.

If the interviewer is concerned about a risk to you, they could contact a senior member of the research team. Dr Josephine Ocloo has considerable experience of conducting sensitive research with people with mental health conditions or experience of medical harm. Dr Jayati Das-Munshi is a consultant psychiatrist.

What are the possible benefits of taking part?

We cannot promise that the study will help you personally, but your input will inform work to improve services for people of Black African, Black Caribbean, Indian, Pakistani and Bangladeshi descent and will inform the work of the Patient and Carer Race Equality Framework (PCREF) which seeks to directly tackle race inequalities in mental health. There are four PCREF pilot sites in England and this study is working with three of them in Birmingham & Solihull, South London, and Manchester.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

- All the information you provide for this study will be kept confidential. The only exception to this is if you told us information which suggested a risk of serious danger to yourself or others. If this happened, we would talk to you first. We would then speak to clinical colleagues in the research team (e.g. Dr Jayati Das-Munshi) who might then need to inform your GP or other professional.
- Personal data you provide in answer to the screening and demographic questions will be entered onto a spreadsheet. Personal data of anyone screened but subsequently not interviewed will be deleted. When we write about the study, the data of people who were interviewed will be aggregated. For example, we might say that 5 people were Mixed-White and Black African, or 12 people were from Manchester, or 2 people considered themselves to be disabled with a hearing impairment. It will not be possible to identify any individual from these figures.
- Recordings of the interviews will be transcribed [typed up] and then pseudonymised. For example, your name will be replaced with 'Respondent', if you mention your local hospital, the name will be replaced with 'local hospital', if you refer to a health worker by name it will be replaced with 'psychiatrist' or 'community mental health nurse'.
- All data collected, recordings and transcripts, will be kept on a dedicated and confidential King's College London SharePoint site accessible only to the study team and no-one else. The researchers working on this project will not save the data anywhere else.
- We will base our analysis on the pseudonymised transcripts of all the interviews and when we write about the study, even if we quote something you said, it will not be possible to identify you.
- When the study has been written up, the interview recordings and any copy of a transcript before it was pseudonymised will be destroyed. The spreadsheet of personal data, consent recordings and pseudonymised transcripts will be retained until 31 December 2027.

- The Interview recording will be transcribed [typed up] by a transcription company who has a contract with King's College London not to disclose any information while doing the transcription work or any time after. One of the questions on the Consent form asks if you agree to your interview being transcribed by the transcription company. The Consent recording will not be transcribed.

Data Protection Statement

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). If you would like more information about how your data will be processed in accordance with GDPR please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

We can also post this information to you if you do not have internet access.

What if I change my mind about taking part?

You are free to withdraw at any point of the project, without having to give a reason. Withdrawing from the project will not affect you in any way. If you choose to withdraw from the project, we will not retain the information you have given.

Following the interview, you will be able to withdraw your data from the project up until two weeks (14 days) following the interview date. If you decided to do this, you would still receive £20. After 14 days, withdrawal of your data will no longer be possible because it will have been included in the analysis.

How is the project being funded?

The Health Foundation is an independent charity focussed on improving health and healthcare in the United Kingdom. This study is one of ten projects funded by grants from The Health Foundation as part of their COVID-19 research programme. The programme aims to explore:

- how health and social care service delivery has changed in light of COVID-19.
- the impact of COVID-19 on health inequalities and the wider determinants of health.

<https://www.health.org.uk/about-the-health-foundation>

What will happen to the results of the project?

The Study Research Team will write up the findings of the project for publication in a peer-reviewed, open-access journal. It is our intention to produce actionable recommendations for improving services. When we record your consent we will ask if you wish to receive a copy of the article when it is published, or a summary of it.

The research will be also presented to relevant people at The Health Foundation, Global Black Thrive and NHS England Mental Health Equalities Taskforce and NHS England Patient and Carer Race Equality (PCREF) Committee.

Who should I contact for further information?

Since the COVID-19 outbreak, the study team has been working from home. If you have any questions or require more information about this project, please email us at:

COV-EIMMstudy@kcl.ac.uk

We are based at:

King's College London
Institute of Psychiatry, Psychology & Neuroscience (IoPPN)
East Wing E3.10
Department of Psychological Medicine
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United Kingdom

Dr Jayati Das-Munshi, Principal Investigator.

Dr Josephine Ocloo, Senior Researcher and Co-Investigator for the qualitative interviews

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

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

The Chair

Psychiatry, Nursing & Midwifery Research Ethics Panel (PNM RESC)

rec@kcl.ac.uk

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