PATIENT INFORMATION SHEET

Qualitative study to explore alcohol, ethnicity and COVID-19.

IRAS Number: 273216

Exploring ethnic differences in alcohol trends, explanatory models, and attitudes to alcohol consumption and intervention in a British South Asian population during COVID-19.

Invitation

Thank you for taking the time to read this information. We would like to invite you to take part in our research study funded by Barts Charity, which will contribute towards a PhD qualification. Before you decide to take part, we would like you to understand why the research is being done and what it would involve for you. Please take the time to read this information carefully and, if you wish, discuss it with your friends, relatives or your GP. Deciding not to take part will not affect your healthcare. You will be given as much time as you want to make a decision so please take time to consider this information. Please ask if anything is not clear or if you would like any further information. This information sheet also gives you details of who to contact if you have any questions during the study**. If you would prefer to read this information sheet in a different language or have an audio version, please let the researcher know directly or ask your health/support team to request this.**

Introduction

We are conducting a study to explore attitudes to alcohol use and treatment for people with South Asian heritage living in the UK (often referred to as British South Asians). Previous research has shown that ethnic groups can differ in how they understand mental and physical health problems, and which treatments are preferred. As very little is known about the factors that influence alcohol use and treatment for British South Asian compared to other ethnic groups, we want to speak to people from South Asian and White British groups to compare experiences. Whilst South Asian and White British religious minorities are permitted; we will focus on the major religions of each ethnic group (e.g., Islam, Sikh, Hindu, Christianity). You will be asked to take part in a confidential interview with a researcher at a time of your convenience. The interview will include topics such as symptoms, causes, consequences and treatments for alcohol use and will last approximately 60 minutes.

What is the purpose of the study?

The purpose of this study is to explore attitudes to alcohol use and treatment to help improve alcohol services and health messages to better meet the needs of British South Asian people.

Why have I been invited to take part?

We are asking people to take part in the study if, according to our information, they:

- Have previously or are currently experiencing alcohol-related problems

- Have previously been referred to, received, or are currently receiving treatment or support for alcohol use

Do I have to take part?

No, you do not have to take part. Your participation is completely voluntary, and it is entirely your decision if you would like to take part in this study. Deciding not to take part will not affect your healthcare. If you do choose to take part, you will be asked to sign a consent form to confirm that you understand what is involved when taking part. You are still free to withdraw from the study at any time, without having to give a reason, and doing so will not affect the quality of any NHS care that you receive.

What will happen to me if I take part?

If you are happy to participate, our researcher would like to meet with you. Due to COVID-19, this can be via a telephone or video call. They will contact you to arrange a time and method suitable for you. If guidelines allow face to face meetings, we can schedule this at a time and place of your preference, e.g., before or after an existing healthcare appointment or at a location convenient for you. The meeting would involve going over the study details again and asking you to sign a consent form to show you have agreed to take part. This meeting will take approximately 1 hour and will be audio recorded. During this interview you will be asked some questions about:

- Your alcohol consumption (including how much and how often you drink, and problems you may have experienced because of alcohol use)
- Your mental health and wellbeing
- Your use of health, social and religious support for alcohol use
- Your perspectives on available and new alcohol treatment/support
- How COVID-19 has impacted any of the above

If you require an interpreter, we can arrange for professional interpreters via Language Line or NHS Bilingual Health Advocacy and Interpreting Services.

How much time will be involved at each stage of the study?

The interview will take approximately 60 minutes to complete.

Are there any expenses involved?

All participants will be offered a £10 Love2Shop voucher as a thank you for their time. Due to COVID-19, where possible, interviews will be scheduled to take place over the telephone or via video call to reduce any burden. However, if guidelines permit a face-to-face meeting, we can arrange for this to take place during a standard care visit or at a location convenient to you. Should you need to travel, expenses will be reimbursed up to the value of £12.

Will my data and participation in the study be kept confidential?

Yes. What is said in the interview is regarded as strictly confidential. Audio recordings will be typed into anonymised written transcripts by the researcher and original recordings permanently deleted immediately after transcription. Any information you provide will be held securely. If you disclose any information that may result in you or anyone else being put at risk of harm we may have to inform the appropriate authorities. If this situation arises we will discuss all possible options for ourselves and you before deciding whether or not to take any action. All data collected during this study will be processed in accordance with the GDPR and Data Protection Act 2018.

How will you use information about me?

We will need to use information from you and your care team (where applicable) for this research project. This information will include your name and contact details. Our research team at Queen Mary University London will use this information in order to do the research or to check your records to make sure that the research is being done properly and will act as the data controller for this study. This means that we are responsible for looking after this information and using it properly. Only the research team at QMUL will be able to see your name or contact details. Your data will have a code number instead. We always store and process information that identifies you (e.g., name, date of birth) separately to any other information we collect about you. 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 my choices about how my 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. If you do not want this to happen, tell us and we can remove your information from the study. A decision to withdraw from the study will not affect the quality of NHS care you receive. 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 I find out more about how my information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our privacy leaflet available from [www.insertstudywebsite.com]
- by contacting the research team at Stacey.jennings6@nhs.net, or 07841833442.
- By contacting the QMUL data protection officer (Jonathan Morgan) at data-protection@qmul.ac.uk or to: Data Protection Officer, Queens' Building, Mile End Road, London, E1 4NS.

If I decide to participate, will my GP be notified?

With your consent, we will write and inform your GP that you are taking part in this study. Also, if we find anything unexpected of clinical significance, we will inform your GP who may follow this up.

What are the possible benefits of taking part?

We cannot promise that this study will help you, however we hope that your contribution will help improve the future treatment of people who consume excessive amounts of alcohol by creating effective health messages and tailoring interventions. At the end of the study, you will be offered a £10 voucher to thank you for your participation in the study.

What are the possible disadvantages and risks of taking part?

We do not expect there to be any disadvantages to taking part in the study. If you agree to participate, you will be asked some questions that some may find embarrassing or uncomfortable. For example, we will ask about your mental health and the impact of alcohol on your wellbeing. The researcher will not expect you to answer any questions you are uncomfortable with.

What will happen if I change my mind and don't want to carry on with the study?

You are free to withdraw from the study at any time and you do not have to give a reason if you wish not to. If you do withdraw, we would like to continue to use your data, in a confidential manner, up to the point of withdrawal as this will help us with our analysis. However, if you would prefer us not to use your data then you can request for your data to be removed from the study. A decision to withdraw from the study will not affect the quality of NHS care you receive.

What if there is a problem?

If you have a concern about any aspect of the study, please feel free to speak with the researcher who will be happy to answer your question. Whilst we do not anticipate any major problems, in the event that something does go wrong, and you are harmed during the research you may have grounds for legal action for compensation against QMUL and Barts Health Trust but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you. If you have cause to complain about any aspect of the way you have been approached or treated during the course of this study, you can do this through the NHS Complaints Procedure for which details can be obtained from the hospital. If you wish to make a complaint about the conduct of the study you can contact QMUL using the details below for further advice and information: Stacey Jennings, Stacey.jennings6@nhs.net, 07841833442.

What happens if I have a complaint?

If you have complaints or concerns, please contact the study CI: Stacey Jennings, [insert study tel number]. Alternatively, you can contact the Patient Advisory and Liaison Service (PALS). The PALS is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. However, PALS is unable to provide information about this research study.

Barts Health NHS Trust

Royal London & Mile End Hospitals- Email: RLHpals.bartshealth@nhs.net, Tel: 0203 594 2040

Whipps Cross Hospital- Email: WXpals.bartshealth@nhs.net Tel: 0208 535 6438

Newham University Hospital- Email: nuhpals.bartshealth@nhs.net Tel: 0207 363 9292

Homerton University Hospital Trust

Email: huh-tr.pals.service@nhs.net, Tel: 020 8510 7315
Write: PALS, Homerton University Hospital NHS Foundation Trust, Homerton Row, London E9 6SR
Textphone: 07584 445 400

Barking, Havering & Redbridge Trust
King George Hospital: Tel: 0208 970 8234
Queen's Hospital: Tel: 01708 435 454

What will happen to the results of the research study?

At the end of the study, the results of this research will be reported to Barts Charity and disseminated through publications in scientific journals and conferences. All data used will remain confidential and anonymous meaning there is no chance of you being identified by the study. The researcher will ask you at your meeting if you would like a summary of the findings which we can send you when the study is finished.

Who is organising and funding the research?

This study is being organized by QMUL and is being funded by The Barts Charity.

Who has reviewed the study?

The research has been reviewed and approved by an independent NHS Research Ethics Committee to ensure that participants will not be negatively impacted by being involved in this research project. This is a standard procedure to protect your safety, rights, wellbeing and dignity. This study has been reviewed and was given a favourable opinion by Camden & Kings Cross Research Ethics Committee, an independent Ethics Committee.

Contact details:

If you want to find out more information about the study, or for answers to questions relating to this research study, please feel free to contact the Chief Investigator of the study:

Stacey Jennings
Wolfson Institute for Population Health, Charterhouse Square, London EC1M 6BQ
07841833442
Stacey.jennings6@nhs.net

Thank you for considering participating in this study