IRAS ID: 319712

Culturally Competent Mental Health Services

PARTICIPANT INFORMATION SHEET (Interview)

Invitation and Brief Summary

You are being invited to take part in an interview as part of a study to understand your experiences when using mental health services, difficulties experienced and solutions proposed, and factors relating to quality of services that are acceptable to ethnic minorities.

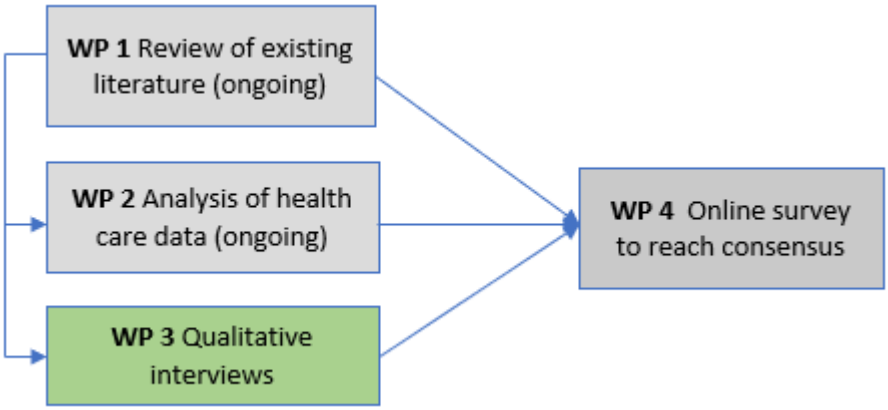
This sheet provides information about the purpose of the study, what you need to do if you decide to take part and how your data will be used. Please read it carefully before deciding whether or not you wish to take part. If you do decide to take part, you are free to withdraw from the interview at any time, without giving any reason and without any penalty.

What is the purpose of the research?

COVID has shown an unequal impact on ethnic minority populations in the UK. Recent research has reported that compared to White British, many ethnic minorities experienced higher levels of anxiety and depression across the pandemic, but they had less support from mental health services. These inequalities have been widened in several ways by the pandemic due to lockdowns, quarantine and closure of some supporting services.

Through working together with ethnic minority communities and care professionals, this overall project aims to establish culturally competent mental health services. It contains four work packages (WP). WP1 and WP2 are ongoing. This information sheet is specifically for WP3 (qualitative interviews) that will help understand your experiences when using mental health services, difficulties experienced and solutions proposed, and factors relating to quality of services that are acceptable to ethnic minorities. A separate information sheet will be provided for you for WP4, if you are interested in taking part.

This study has been developed with people with lived experience and representatives from two charities (Health equality for ethnically minoritised communities (Haref) and Ethnic Health Forum). A flexible public and patient involvement strategy have been co developed with them, who will continue to be consulted throughout this study to support future dissemination activities. They will not have access to personal data.



Why have I been invited to take part?

This study is taking place in both Newcastle and Manchester. You are invited to this study because you are over 18 years old and had your mental health conditions diagnosed pre COVID, and we would like to hear about your experience in seeking care before and during the pandemic to understand the changes that you have experienced. We have selected a sample of people to ensure we have a range of demographics, locations and experiences.

What does taking part involve?

We would like you to take part in a single interview which should take 45-60 minutes. The interview will be conducted either face to face, over Zoom or Microsoft Teams or by telephone according to your preference. We can also arrange a translator to help with the interview if needed.

If you are interested in taking part, please contact the researcher (information attached at the end of this sheet), who will then contact you and make arrangements for obtaining your informed consent and the interview.

The interview will cover your experiences of seeking care for your mental health problems, services provided and difficulties experienced and solutions proposed. You will also be asked questions about how you define a high quality of service and characteristics that enable culturally sensitive services.

What are the possible benefits and risks of taking part?

Benefits:

Taking part in this study will give you the opportunity for your views and experiences to be heard and the information may help improve future services. A summary of the findings collected from this study upon completion will be made available to you.

Risks:

Some of you may feel talking about your mental health upsetting. However, you will be made fully aware of the topic of discussion before deciding whether you would like to take part, and you are free to stop at any time. This will not affect your care in any way. Researcher also has an obligation to report any disclosures if a possible risk of harm is indicated.

The researchers have experience in talking about sensitive issues with patients and will ask questions in a thoughtful manner.If you become upset during the interview or raise any specific concerns, the researchers will stop the interview and ask you if you still want to continue. They will also point out links to support, such as Mental Health NHS https://www.nhs.uk/mental-health/; MindWell https://www.mindwell-leeds.org.uk/; Rethink Mental Illness https://www.rethink.org/ Information from these websites and free Mental Health Leaflets produced by the National Centre for Mental Health about support https://www.ncmh.info/leaflets/ will be made available in hard copies if participants do not have internet access or prefer paper versions.

Taking part in this study will also take some time for participants, we will also provide a £10 voucher to thank your time and contribution.

What will happen to my data?

Depending on where you are based, your interview will be carried out by researchers from either Newcastle University (study sponsor) or Manchester University (study collaborator). To ensure participant confidentiality, your data will be stored securely on the server of Newcastle University or Manchester University during the data collection and analysis stages, accessed by password-protected computers. Interviews will be recorded with the participant's consent. The interview recording will be transcribed by a professional transcription service approved by Newcastle University and the University of Manchester with a confidentiality agreement in place. Once data analysis has been completed at local sites, a password-protected file on the Newcastle University server will be set up for data transfer. The link to the file will be sent by email and the password will be provided by telephone for researchers at Manchester. All electronic data collected and analysed by Manchester University will be transferred to Newcastle University. Once the Newcastle researcher has confirmed the safe reception of all data, data will be stored and integrated with other project files on the server. The file for data transfer will be deleted from the University server and data will be deleted from the Manchester University server. This arrangement has been checked and approved by the University IT service. All paper documents including consent to contact and consent forms will be posted by the Manchester research to the researcher at Newcastle using Royal Mail 1st Class tracking and signature services. All data from this study will be stored on Newcastle University servers after the interview study has ended.

The interview data and transcripts will be downloaded as soon as possible after the interview on a password-protected University computer. Participants will be given a code number linked with name and contact detail and no reference to personally identifiable data will be made, only

researchers involved in the study will be able to identify them from their code number. The code link will be generated by the researcher only on a password-protected University computer. Once the researcher has confirmed the accuracy of the transcripts the original audio data files and the code link will be destroyed to minimise the amount of identifiable data held.

All signed consent forms and transcripts will be kept for five years after completion of recruitment when they will then be destroyed, as there is great potential that the research team will plan other relevant studies in the next five years. All data collected for this study will be anonymised and stored confidentially. This anonymised code number will be used when using any of their words (as illustrative quotes) in the report of findings. No identifying information will be reported. The data handling procedures will be managed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation (GDPR). Data will not be exported outside the UK.

Only the researchers directly involved in the project will have access to transcripts during the analysis of data. Quotes from transcripts may be used in reports, papers and other outputs, but you will not be identified personally. Should you wish to withdraw your data, this may be possible before analysis.

If you would like to hear what we find out from this study, your name and contact details will be stored securely until the end of this study. If you would like to hear about future research studies in this area that we do and agree to be contacted about possible participation in future projects, your name and contact details will be stored (with your consent) on secure networks only accessed by project researchers, to a maximum of five years.

How will you use information about me?

We will need to use information from you for this research project. This information will include your contact details held by sponsor for the research. People will use this information to do the research or to check your records to make sure that the research is being done properly. 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.

Where can I find out more about how my information is used?

You can find out more about how we use your information at at www.hra.nhs.uk/information-about-patients/ or by asking one of the research team.

Who is the sponsor and data controller for this research?

Newcastle University is the sponsor for this study, which is based in the UK. Newcastle University will be using information from you in order to undertake this study and will act as the data controller. This means that Newcastle University is responsible for looking after your information and using it properly. We will only use any personal information you provide such as email address, for the sole purpose of contacting you about the project.

Who is funding this research?

This study is funded by the National Institute for Health and Care Research (NIHR) Three School Mental Health Research Programme (reference MH027).

Has this study received ethical approval?

Ethical approval has been granted by the Health Research Authority (REC reference xxx, Date xxx).

What if I have concerns about this study?

If you have any concerns or in the case of any complaint, or for independent advice about taking part in this study, you can contact Kay Howes, the Head of Faculty Research at Newcastle University.

Address: Faculty of Medical Sciences, Medical School, University of Newcastle, Framlington Place, Newcastle upon Tyne, NE2 4HH

Email: kay.howes@ncl.ac.uk

Who should I contact for further information relating to the research?

Key members of the research team are:

Dr Evgenia Stepanova, Population Health Sciences Institute, Newcastle University. Email: Evgenia.Stepanova2@newcastle.ac.uk

Dr Sarah Croke, Centre for Primary Care and Health Services Research, University of Manchester. Email: sarah.croke@manchester.ac.uk

Dr Maria Panagioti, Centre for Primary Care and Health Services Research, University of Manchester. Email: maria.panagioti@manchester.ac.uk

The chief investigator for the project is:

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