Community Ageing Research Across Ethnicities (CARE) Network - Exploring health and wellbeing across diverse ethnic communities and faith groups in the UK

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: 25/SC/0083

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Invitation paragraph

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully and discuss it with family or friends if you wish. We recognise that there is a lot of information contained within this document. If you have any further questions, please contact a member of the study team (details are at the end of this information sheet).

It is important that you understand that you do not have to take part in the study and that if you do take part, you are free to withdraw at any time. If you decide to take part, we will ask you to read and sign the declaration on the next page of the website.

Why are we doing the study?

There are currently 850,000 people living with dementia within the UK, with an estimation of 25,000 being from ethnic minority communities. Black, Asian, and minority ethnic populations are one of the fastest ageing communities, therefore being increasingly more susceptible to developing dementia. However, ethnic communities remain underrepresented and underserved in both research and clinical trials. It is imperative to enhance participation in research to adequately assess and tailor services required by these groups.

The UK has long been recognized as a multi-ethnic society and the diversity of the population continues to increase. Ethnicity is a multidimensional concept with numerous links to health.

With the current gap in information available to show how diverse ethnic communities and specific groups are supported in terms of dementia, the study aims to study their knowledge and awareness of dementia, whilst highlighting support and services that are employed by these groups. Moreover, it will provide validated key information to these groups. The research will focus on the needs of various ethnic communities and specific faith groups, with the goal of developing better strategies to meet their care requirements. The key questions that will be addressed during the study will include:

- To assess service use and support information available in relation to healthcare services.
- To assess research participation and awareness for ongoing local and nationwide opportunities.
- To assess barriers and facilitators for research participation and service use
- To assess dementia awareness and knowledge
- To assess health and wellbeing of ethnic communities and faith groups including quality of life, function, cognition and mental health.

We are inviting adults aged 40 and above across all ethnicities across the UK to take part in this study. Participants will need to use your own smartphones, tablets, or computers to complete online questionnaires.

What would taking part involve?

If you decide to take part, you will be required to complete a series of anonymised online questionnaires from the comfort of your own home using a smart device. The entire online questionnaire will take up to 20 minutes to complete. We are going to ask you to complete these every six months up to 10 years.

Survey questions will be based on the following topics:

- Dementia-research awareness
- Healthcare service use and knowledge related to dementia
- Key barriers to accessing mental health services
- Mental health including anxiety, depression and neuropsychiatric symptoms
- Memory function
- Functional abilities
- Loneliness
- Quality of life and well-being
- Lifestyle factors
- Caregiver burdens and Coping Strategies

- Use of medication and medical history
- Other key information such as study demographics include age, gender, marital status, education, language preferences and religious preferences.

Participants may also be invited to take part in optional assessments that include an assessment of daily living activities and a brief telephone-based memory test. These tests will ask simple questions to assess your cognition and function, such as the current day of the week, the season, and the name of the current Prime Minister.

Furthermore, a subset of participants may be invited to join focus group research activity in the future. These groups will discuss topics such as care needs, significant research gaps, and ways in which the study could potentially address some of the critical needs identified. Participation in these focus groups is voluntary and will provide deeper insights into the topics under study. Participation in these focus groups will be online on Microsoft Teams and these sessions will be recorded for research analysis purposes. Participation will be requested via email through our mailing list every six months.

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. The purpose of this information sheet is to describe the study in detail to help you make your decision. If you agree to take part, you will then need to read and sign a consent form on the website. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive through your own General Practitioner or local NHS services.

You can withdraw from the study at any time without giving a reason. You can do this by emailing the study team. If you withdraw from the study, you can tell us whether you want us to retain any personal information that could be used to identify you (email address, home address, phone number and full postcode) or whether you would like us to destroy that information. Please note: we will retain the full name, partial postcode and participant ID of any withdrawn participants to ensure we have a record of your consent when you registered. We will retain all anonymised data that we have collected up to the time you withdraw. This includes all anonymised data from assessments and questionnaires.

What will happen to the data I provide?

King's College London (KCL) and South London and Maudsley (SLaM) NHS Foundation Trust are the lead sponsors for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. KCL will keep identifiable information about you for 10 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible. Data will be collected using the Qualtrics and JISC platforms. JISC is a UK-based digital platform that provides secure online tools for data collection and analysis, specifically designed for education and research purposes. Qualtrics is an advanced online survey platform that allows for the creation, distribution, and analysis of surveys. Both platforms are available to King's researchers and are compliant with data protection regulations, ensuring that all information remains confidential and is not shared externally. Any group discussions conducted as part of the study will take place via Microsoft Teams. Participants will be asked for permission to record these sessions, and Microsoft Teams will also be used to transcribe the recorded discussions. Data collected through the survey platforms (JISC or Qualtrics) will be exportable in CSV format and accessible only to designated members of the CARE Research Team. Consent will be taken electronically via JISC and Qualtrics, where participants will be asked to review the Participant Information Sheet (PIS) and confirm their consent through e-signature before participating in the study. All personal information will be securely stored in password-protected systems.

KCL will keep any identifiable information about you from this study for 10 years after the study has finished.

What are the possible benefits and risks of taking part?

This is an 'observational' study, meaning we only wish to observe your situation. There is a small risk that some people may find certain questions difficult to answer or distressing. For example, some of the memory tests are designed to be very challenging, which may cause increased stress. In addition, some of the questionnaires include questions about mental health, which may be distressing for some participants. Please contact your general practitioner (GP) or if you are worried about your mental health, please contact Samaritans at www.samaritans.org. You can also call the Samaritans day or night if you need someone to talk to without judgement on 116 123. Mind’s website at www.mind.org.uk has useful resources to help you cope if you are feeling anxious, worried or isolated.

Advantages for participation include:

The main advantage of this research is that participants will be taking part in an important research study that could provide valuable new knowledge about research preferences across diverse communities. The main benefit of participating in this research is the opportunity to contribute to vital investigations assessing support systems and coping strategies within diverse ethnic communities, with a particular focus on mental health and dementia awareness. Interaction with our team of qualified researchers, who will provide insights into the advantages of service use and offer updates on the latest research findings and information. By participating, individuals will not only gain valuable knowledge and resources but will also play a crucial role in shaping the future of research and support for their communities.

The Research Ethics Committee has approved this research (Reference Number: 25/SC/0083) and the research will be covered by normal insurance policies at the King’s College London.

What happens if I develop memory problems during the study?

There is a small chance that participants may develop significant memory problems or dementia over the 10-year study period. If we detect a noticeable decline in your performance on the study questionnaire, we will contact you by email to share our concerns and offer the opportunity to discuss this with a member of our study team. Should they have any concerns, we will recommend that you contact your GP, who can arrange further tests if needed. Your participation in the study will not be affected by this, and it remains your choice whether to continue.

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions: Dr Zunera Khan, zunera.2.khan@kcl.ac.uk. If you remain unhappy and wish to complain formally, you can do this through the SLaM Patient Advice and Liaison Service (PALS) on 0800 731 2864, pals@slam.nhs.uk. 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 King’s College London and/or SLaM NHS Foundation Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

How will we use information about you?

We will need to use information from you in this research project. This information will include your initials/NHS number/name/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 the 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/patientdataandresearch

Additionally, you can request our informational leaflet by contacting the CARE Network research team via email at carenetwork@kcl.ac.uk, or by reaching out to Dr Zunera Khan at 0207 848 0626.

Will my taking part in this study be kept confidential?

Research data, such as your answers to the questionnaires, will be collected online through the study. The study database will not include your name, just a study number. These data may be used by other researchers of our team in the future; however, they will be completely anonymised before they are shared with other researchers, and it will not be possible to identify you. Authorised members of the study team may contact you to invite you to additional studies, but they will not see your study results.

All study data will be stored securely according to Data Protection Laws* and the security procedures in place at the King’s College London.

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

Personally, identifiable information (PII) will be stored for 10 years after the study has ended.

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

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [carenetwork@kcl.ac.uk, 02078480549; 02078488199].

In the event that something does go wrong, and you are harmed during the research then you may have grounds for legal action for compensation against King’s College London, but you may have to pay your legal costs. King’s College London maintains adequate insurance to cover any liabilities arising from the study.

What will happen to the results of the project?

At the end of the study period, you will complete your final assessments. We will contact you to inform you that the study has ended and to thank you for your contribution. The results of the study will be published in peer-reviewed scientific journals, as well as shared through an internal report and conference presentations. Additionally, the findings will be made available on the study website and published on KCL and SLaM communication channels, including the SLaM Recovery Club. If you wish, we will also provide you with a lay summary of our findings in the form of a newsletter. Please be assured that all the information collected is completely confidential, and no individuals will be identified in any reports, publications, or presentations.

Further Information

Thank you for taking the time to read the information about this study. If you would like more information about the study before you decide whether to take part, you can contact a member of the study team via an email (carenetwork@kcl.ac.uk) or by calling the study helpline on 02078480549; 02078488199.

Please note that this helpdesk is for general information and support for the study. It will connect you to a member of the study team who will be able to talk about the study but will not be able to provide medical advice. Please also note that we are not able to give out information about your personal performance or progress in the study as your data are collected for research purposes only.

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