

Participant Information Sheet – Family carers

UCL Research Ethics Committee Approval ID Number: 22357/002

Title of Study: Improving support services for family carers from the Pakistani ethnic group through social prescribing.

Department: Primary Care and Population Health, University College London (UCL)

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You are being invited to take part in our research project. Before you decide, it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. One of our team will also go through this information sheet with you and answer any questions you have. This should take about 10 minutes. Thank you for reading this.

Why is the study being done?

Informal care can have a significant impact on the physical and mental health of carers across all ethnic groups, but higher levels of social isolation exist among Pakistani carers. Community-based referrals (known as social prescribing) can help support people with caring responsibilities and to improve overall health and wellbeing. Social prescribing is a way for health professionals such as General Practitioners (GPs) or practice nurses to refer people to a range of local, non-clinical services social prescribing scheme can involve a range of activities that are typically provided by voluntary and community sector organisations. These activities aim to support individuals to take greater control of their own health.

We want to explore how support for carer health and wellbeing can be improved for Pakistani family carers. This will help us to better understand and identify, how culturally

sensitive social prescribing services can address the unmet health and wellbeing needs of Pakistani family carers.

Why have I been chosen?

We are speaking to adults who identify as being Pakistani and have current or recent experience (past 12 months) of caring for a family member who cannot cope without their care. You have contacted the research team and been identified to take part in the study. This means you are someone who has experience of being a carer for or looking after a family member such as a child or adult with a long-term health condition. We would really value the contribution you can make to this study.

Do I have to take part in the project?

Taking part in the project is entirely voluntary. If you do decide to take part, you will be given this information sheet to keep and will also be asked to provide written consent (we will give you a form to complete) to take part. If you do decide to take part, you are free to withdraw from the study up to 4 weeks after the interview by contacting the Principal Investigator or Research Assistant for this study (contact details can be found at the beginning of this document). You can withdraw without giving a reason. If you withdraw from the study, any care/support you receive will not be affected in any way. If you withdraw, any data you have provided up until that point may be included in the study and be retained as part of the study for a minimum of 10 years, unless you ask us not to. We will only retain data with your consent. The only personal data we keep will be your signed consent which will be stored securely, everything else will be anonymised and will not be used in any research outputs (conferences, publications) or in future studies.

What do I have to do if I participate?

If you agree to participate in the project, we will invite you take part in an interview with a researcher. The interview will take place in a location of your choice – this could be in your home or in a private room community venue (or over the phone/video call on zoom/Microsoft Teams depending on your preference). The interview will be an informal

conversation and should last no more than 90 minutes (including breaks if needed). In the interview, you will be asked some questions about your overall health and well-being, access to support services and how support services can be improved to better support Pakistani carers. You will be able to stop the interview at any time or choose not to answer questions that you are not comfortable with. We will also ask you to provide details for us to complete a short demographic form so that we can collect important information such as age, gender, ethnicity, relationship with the person you care for and their health condition/s, carer status.

Will I be recorded and how will the recorded data be used?

We are asking people who are being interviewed to be audio recorded. This helps us to accurately recall all the information you give us. These recordings will be transcribed (written out), with any names or identifying information removed. Interview transcripts will be used in our analysis and anonymised. They will inform our reports – which may be publicly available – as well as conference presentations, lectures and academic publications. Transcripts and original audio recordings will not be shared with anyone outside the project.

What are the possible disadvantage and risks of taking part?

We do not anticipate any risks or harm to you as a result of taking part in this project, though it is possible that the conversations may touch on some difficult subjects. We will ensure that if this is the case, we are able to signpost you to appropriate support if needed.

Some key contacts national support providers are listed below:

- **Mind:** Provider of advice and support for anyone experiencing a mental health problem. <https://www.mind.org.uk/information-support/local-minds/>, helpline: 0300 123 3393
- **Carers UK:** Offer expert information and advice specific to carers and their needs. <https://www.carersuk.org> , advice line: 0808 808 7777
- **Family Action:** Practical, emotional and financial support to those who are experiencing poverty, disadvantage and social isolation. <https://www.family->

[action.org.uk/](https://www.action.org.uk/), helpline: 0808 802 6666.

- **Samaritans:** Provides emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide. <https://www.samaritans.org/how-we-can-help/>, helpline 116 123.
- **Aawaz:** Provides counselling, support, guidance and signposting nationwide. Support can be provided in Urdu, Punjabi, Mirpuri, Gujrati, Bengali and English. Phone: 01254 398176 <https://www.aawaz.org.uk/>

What are the possible benefits of taking part?

We are hoping that the project will help us better understand carer health and wellbeing needs and how support services can be improved to meet the culturally sensitive needs of Pakistani carers. As a thank you for your time, you will receive a £50 voucher. In exceptional circumstances we are also able to cover additional carer costs for some participants.

What if something goes wrong?

If you have a concern about any aspect of this project, in the first instance you should ask to the Principal Investigator (abigail.woodward@ucl.ac.uk) who will do their best to answer your questions. However, if you feel your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

Will my taking part in this project be kept confidential?

All the information that we collect about you during the research will be kept strictly confidential. You will not be able to be identified in any reports or publications that we produce, and we will use pseudonyms (change your name).

Limits to confidentiality

Please note that confidentiality will be maintained as far as it is possible, unless if during our conversation I hear anything that makes me worried that someone might be in danger

of harm, I might have to inform relevant agencies of this. If this were the case, we would inform you of any decisions that might limit your confidentiality.

What will happen to the results of the research project?

The results gathered from you and other participants will help us better understand how support for carer health and wellbeing can be improved and how culturally sensitive support services can be implemented to address existing needs. The results will also be published in academic journals, at conferences and lectures. You will be advised where you can access a summary of the results.

Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

<https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>

If you are concerned about how your personal data is being processed, please contact the Chief Investigator Dr Abi Woodward in the first instance using the contact details provided at the top of this document. If you are still concerned you should contact UCL at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

The legal basis used to process your *personal data* will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavor to minimise the processing of personal data wherever possible. The project team will keep your name and contact details confidential and will not pass this information to any other organisation. We will only use this information to contact you about the project and to link your interviews. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. All information that identifies you will be deleted before the data is analysed.

All information collected during the project will be combined, and no individual will be identified in any report or publication.

Who is organising and funding the project?

This project has been funded by the National Institute for Health Research (NIHR). It is a collaborative project led through the Research Department of Primary Care and Population Health and the Centre for Ageing Population Studies (CAPS) at UCL.

Contact for further information

Dr Abi Woodward: abigail.woodward@ucl.ac.uk or Sarah McMullen:
s.mcmullen@ucl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research study. The information sheet is for you to keep.