

Information about our study

Experiences of ethnic minority carers of persons living with dementia in navigating the benefit system.

About this research

This research is a part of some exploratory work that seeks to better understand the experiences of carers of people living with dementia from ethnic minority groups in navigating the benefit system. We want to understand the factors that influence decisions or ability to make claims for certain benefits (Carers Allowance, Disability Living Allowance, Personal Independence Payment or Attendance Allowance). We also want to explore the factors that influence experiences with the application process, identify any specific challenges, understand the impacts benefits received have on carers and/or the person with dementia they provide support to, and identify what needs to be improved. We hope this exploratory work can help support development of future research in this area.

About the researcher

This research is being conducted by Jayeeta Rajagopalan from the Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science (LSE) as part of a Career Development Award funded by the NIHR Three Schools' Dementia Research Programme.

Who can take part

We are inviting people over the age of 18 that support a family member or friend living with dementia and are/were receiving Carers Allowance (CA) or the person they provide care to is/was receiving Disability Living Allowance, Personal Independence Payment or Attendance Allowance post their dementia diagnosis to take part in an interview conducted in English.

What are you asking me to do?

We are inviting you to take part in a research interview. During the interview, topics discussed will include your caring responsibilities, how you initially heard about the benefits you are claiming, what prompted you or the person you support to apply for the relevant benefit, experiences with the application process including any challenges experienced, how the benefit received helps you or the person you are supporting, and what do you think needs to be improved. You do not have to answer any questions you do not want to. You can also pause or end the conversation at any time.

The interview will take around 60-90 minutes and can take place in-person in a quiet place that is convenient to you (e.g., in your own home or somewhere nearby), or online using Zoom if you prefer. We will also arrange this at a time best suited to you.

The interviews will be audio-recorded, if you give us permission to do so, and will later be transcribed using a professional transcription service. As part of the presentation of results, your own words may be used in text form and this will be anonymised, so that you cannot be identified from what you said.

As a thank you for taking part we would like to offer you a £50 e-voucher or cash. Your benefits may be affected by this payment. This depends on the type of benefits you receive. If requested, we can offer a lower amount than the above because of your earnings limits. Please contact Citizens Advice if you would like benefits advice at 0800 144 8848.

Will my participation in the project remain confidential?

Yes. We will not use your name and anything you say will not identify you or your family. The only time when we will need to share any information, is if we are concerned for your safety, or the safety of someone in your family. We will aim to let you know first if this is the case. This is our safeguarding duty.

Will the discussion be confidential?

Yes, as far as is possible. All the researchers will keep the information they hear confidential. No names will be mentioned in any reports that are written as a result of the research. Your answers will not affect the services, support or benefits that you or your family receives.

Do I have to take part in the study?

No, your participation in this project is entirely voluntary. It is up to you whether to take part or not. If you decide not to take part, it will not affect any services or benefits you receive. If you do decide to take part you are still free to withdraw at any time without giving a reason, including during the interview. If, after taking part, you decide you do not want us to use your comments you would need to let us know by one week after the interview, and we will delete your information from the study. If you decide to take part, you will be asked to give consent before attending the interview.

What will happen to the information I give?

Everyone's answers will be put together and used in a paper/report on the experiences of ethnic minority carers of persons with dementia in navigating the benefit system. We store your contact details for up to two years after the end of the study in order to contact you about any future research, unless you request otherwise. You can request that your contact details are changed or removed from our system and destroyed at any point by contacting us using the details below. You can read more about LSE's data protection procedures and research privacy policy here:

<https://info.lse.ac.uk/staff/divisions/Secretarys-Division/Assets/Documents/Information-Records-Management/Privacy-Notice-for-Research-v1.1.pdf>. To request a copy of the data held about you, you can contact: glpd.info.rights@lse.ac.uk

What if I have a question or complaint?

If you have any questions regarding this study please contact Jayeeta, using the contact details below. If you have any concerns or complaints regarding the conduct of this research, please contact the LSE Research Governance Manager via research.ethics@lse.ac.uk.

This study has been approved by LSE Research Ethics Committee.

If you are interested in taking part or want to find out more

Please contact Jayeeta Rajagopalan, email: j.rajagopalan@lse.ac.uk

Thank you for reading this information sheet