

The psychological and emotional experience of receiving a diagnosis and accessing care for individuals with Young Onset Dementia (YOD) from ethnic minorities

Study Overview

- This study aims to collect information from adults with a diagnosis of YOD, and their unpaid carers to understand the experience of the receiving a diagnosis and accessing care for individuals from ethnic minorities.
- We hope to use this information to help improve services for people with YOD from ethnic minorities.



Who can take part in this study?

You can take part in this study if you are:

- 1) A person who has received a diagnosis of YOD and is from an ethnic minority background.

OR

- 2) An unpaid carer for a person who a) has received a diagnosis of YOD and b) is from an ethnic minority background. Unpaid carers do not have to be from an ethnic minority background to take part in this study.

What will happen if I take part?

- You are being asked to take part in an interview about your experiences.
- This is a conversation with a researcher, where they will ask you some questions.
- The interview shouldn't take longer than an hour in total.
- They can take place online or face to face at a time and date that suits you.
- Taking part is your decision. 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 at any time you become upset during the interview, we will provide you with information on services and supports available to you.



How will we use information about you?

- We will keep all information about you safe and secure.
- Information you share in the interview will be audio recorded, typed up, and then kept in password protected computer files.
- Once we have finished the study, we will keep some of the data so we can check the results.
- We will write a report in a way that no-one can work out that you took part in the study.

Who can I contact if I have any questions or wish to take part?

- Fiona Lowe - filowe@liverpool.ac.uk
- Dr. Clarissa Giebel - clarissa.giebel@liverpool.ac.uk
- Dr. Kerry Hanna - k.hanna2@liverpool.ac.uk

