

Participant Information Sheet

Informal carers' views on the support available to them from Adult Social Care: A qualitative interview study

Invitation summary

I would like to invite you to take part in a short interview for this research project.

It is up to you to decide whether you wish to take part in the project.

Before you decide, please read this sheet carefully. Talk to others about the study if you wish. Please ask me questions if anything is unclear, my contact details are at the end.

What is the purpose of the project?

This study aims to:

1. Explore the views of informal carers on the support available to them through Adult Social Care and carers support organisations
2. Find out what further support carers would appreciate to help them continue to care for their friend or family member.

Why have I been invited to participate?

We want to hear the views and experiences of carers who have had support or advice from local authorities or carers support organisations during the period July-Sept 2024.

Do I have to take part?

It is up to you to decide whether you want to take part. Whatever you decide, it will not affect the services you receive in any way.

If you agree to take part, you will be asked to give written or verbal consent at the start of the interview.

You are free to decide which questions to answer during the interview, and you can change your mind

What will I have to do if I agree to take part?

If you agree to take part, I will arrange a day and time to interview you by email or phone, depending on your preference. You can decide whether you would prefer to be interviewed in person, or on the phone (mobile or landline), or by online video call (teams or zoom).

The interviews will be audio recorded using an encrypted audio recorder, which means that only I and other members of the research team will have access to the recordings.

What are the possible disadvantages and risks involved in taking part in the project?

There are no anticipated risks involved in taking part. It will take 30-40 minutes of your time.

What are the possible benefits of taking part?

You will receive a £20 voucher as a thank you for taking part. You may welcome the opportunity to share your views about what it is like to be a carer and the support you think carers need.

The main benefit of the research will be to help us to build a picture of the support available to carers, what they value and what improvements are needed. We will write a report about our findings to share with Adult Social Care departments and carer support organisations. This might lead to improvements in service delivery to carers.

Will what I say be kept confidential?

Everything you say will be confidential, unless you tell us something that indicates that you or someone else is at risk of harm. If that happens, we will need to share this information with others, for example local safeguarding teams. We would discuss this with you before telling anyone else.

How will we use the information about you?

We will need to use information that you provide about yourself for this research project, including your name and contact details and what you tell us during the interview. 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 transcripts of the interviews with no names or other identifying details so we can check the results. Once the data has been analysed, we will seek to share our findings through publication, presentation and the media. All reports will be written in a way that ensures 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 – during or after the interview - without giving a reason. We can delete any data we have already collected from you if you ask us to do this no later than two weeks after the date of your interview. After this time it will not be possible to delete it because it will have been anonymised.

If you agree to take part in this study, your anonymised data saved from this study may be used for future research.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at <http://www.bristol.ac.uk/secretary/data-protection/policy/research-participant-fair-processing-notice/>
- by asking one of the research team
- by sending an email to data-protection@bristol.ac.uk, or
- by calling the University's Data Protection Officer on (0117) 3941824.

What will happen to the results of the research project?

Findings will be presented to the local authorities and carers' support services in Bristol, North Somerset and South Gloucestershire. A summary report will be sent to all participants. A scientific paper will be submitted for publication in a peer reviewed journal. No-one we interview will be identified or identifiable in any presentation or written report of the findings.

Who is organising and funding the research?

This research is being led by Professor Geraldine Macdonald and Dr Christie Cabral at the University of Bristol.

The research is funded by the National Institute of Health and Social Care Research (NIHR), which is part of the Department for Health and Social Care. It is part of the ConnectED project (<https://tinyurl.com/ConnectED-ASC>) (grant reference number 131345).

Who has reviewed the study?

This research project has been reviewed by the Research Ethics Committee of the School for Policy Studies at the University of Bristol.

Further information and contact details:

If you have any questions about this study please contact:

The lead researcher: Geraldine.Macdonald@bristol.ac.uk

The study team: Connect-ED@bristol.ac.uk Please put 'Carers' in the title line- or phone: 0117 456 0540.

If participants have any concerns about this study, please contact the University of Bristol Research Governance Team, research-governance@bristol.ac.uk