

Participant Information Sheet: Family Carers (Interview)

Study title: Pre-hospital care for older adults (REACH)

Researcher's name: Dr Abi Woodward, Abigail.woodward@qmul.ac.uk

Coordinating Investigator: Professor Simon Conroy

Study Sponsor: Queen Mary University of London

Research Ethics Committee Reference: 26/NW/0195

We are inviting you to take part in a research study. Before you decide whether you wish to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. The researcher 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.

What is the purpose of the study?

In this study, we want to understand how a pre-hospital support service, which is called the Remote Emergency Access Coordination Hub (REACH), is working for its patients and their family carers. REACH involves specialist doctors who provide advice to paramedics when they are called out to see patients in their homes. Specialist doctors can help patients access community services to provide care at home if the person does not need to or want to go to hospital.

We are interested in hearing from older adult patients (aged 65 years and over) and their family carers about their experiences of the REACH service. We plan to recruit up to 30 patient and family carer participants in total to take part in interviews for this part of the study.

We would like to find out what works well or not so well for older adults and why. By doing this, we hope to learn what helps staff to provide care that benefits patients in the best ways and what we might need to improve.

You do not need to be familiar with the name of the service (REACH) to take part – we are just interested in your experience.

What would taking part involve?

If you agree to participate in the study, we will invite you to take part in an interview where you will talk to a researcher about the person you look after/care for. The interview will take place alongside the person you care for (joint interview) or if you prefer, on your own.

During the interview we will ask questions about what happened when the person you care for was seen by a paramedic or ambulance crew (from the London Ambulance Service). We will ask you to talk us through what happened, how decisions were made about their care, and whether you felt involved in those decisions. We will ask how you felt about the decisions that were made, whether things were explained clearly (including any risks), and what happened afterwards (for example, whether the person you care for was taken to hospital, cared for at home or received any other type of care).

We would also like to find out what mattered most to you and the person you care for at the time, what you were hoping would happen, and whether things turned out as you expected. The interview will be an informal discussion and will last up to 90 minutes (1.5 hours), with breaks as required. You do not have to talk about or share anything that you are not comfortable with, and you can stop the interview at any time without giving a reason.

You can choose whether you would like the interview to be in person (e.g. at your home or at another location such as the university), online via Microsoft Teams video call, or by telephone. We will try to provide an interpreter if you need one.

Everything you tell us during the interview will be kept confidential. However, if you tell us that a member of staff has done something wrong (malpractice), someone is being harmed or treated badly, a crime may have been committed, or you are at serious risk of harm, we may need to share this with someone who can help.

Your participation in the study will end once you have completed the interview. After this, you will not need to do anything else for the study.

Do you have to take part?

No. It is up to you to decide whether or not to take part. If you choose to take part, you can withdraw from the study at any time without giving a reason. Withdrawing from the study will not affect your care or any services you receive.

If you would like to withdraw, please contact Dr Abi Woodward, the researcher, using the contact details provided at the end of this information sheet.

If you withdraw within 6 weeks of the interview, we will delete the recording and any other information we have collected from you. After 6 weeks, we will have started to analyse the interview, so we may not be able to remove information that has already been included in the analysis.

What are the possible benefits of taking part?

Potential benefits include the opportunity to talk about your personal experiences, and to contribute to research that aims to improve pre-hospital care for older people.

What are the possible disadvantages and risks of taking part?

We do not anticipate any risks or harm to you as a result of taking part in this study, though it is possible that the conversations may touch on some difficult subjects. You can refuse to answer questions that you do not want to answer and can stop taking part in the interview at any time without giving a reason. We will follow up with you after the interview to check you are okay. You can also contact your GP or another healthcare or support professional for advice and support. Where possible, we will signpost you to appropriate support if needed. Some key contacts and national support providers are listed below:

- Age UK: A free, confidential national phone service for older people, their families, friends, carers and professionals. <https://www.ageuk.org.uk>, advice line: 0800 055 6112

- Carers UK: Offer expert information and advice specific to carers and their needs. <https://www.carersuk.org>, advice line: 0808 808 7777
- Mind: Provider of advice and support for anyone experiencing a mental health problem. <https://www.mind.org.uk>, helpline: 0300 123 3393

In the unlikely event that you or the person you care for becomes very distressed during the study, a member of the research team will stop the interview and offer appropriate support. In rare circumstances, if we have serious concerns about your safety or the safety of others, we may need to share relevant information with appropriate professionals to help keep you safe. This could involve sharing information that would normally be kept confidential.

Expenses and payments

As a thank you for your time, we offer you a £30 voucher for taking part in the interview. Vouchers will be paid after you have taken part in the interview.

What information about me will you be collecting?

We are asking people who take part to agree to the interview being audio recorded using a password protected dictaphone. This helps us to accurately recall all the information you give us and make sure we do not miss anything important.

Audio recordings will be sent securely to a UK-based professional transcription company approved by Queen Mary University of London. The company will transcribe (write out) the recording to create a transcript. During transcription any identifiable details such as names and places will be removed. A member of the research team will then check the transcript against the audio recording for accuracy and to ensure any remaining identifying details are removed. Once the transcript has been finalised and checked, the transcription company will securely delete/destroy any copies of the audio recording and transcript held on their systems, in line with their data processing agreement.

Audio recordings will be retained by the research team only until the transcript has been checked for accuracy, after which they will be securely deleted.

We will also ask you for some basic demographic information (for example age, gender, education, job, living arrangements, and ethnic background). During the

interview, we will ask you questions about what happened when the person you care for was seen by a paramedic or ambulance crew and the care they received.

How will we use information about you?

We will need to use information from you for this research project.

This information will include:

- Your name
- Your contact details
- The demographics questionnaire you complete
- The recording and transcript of the interview

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.

Queen Mary University of London (QMUL) is the sponsor of this research.

QMUL is responsible for looking after your information. We will not share your information related to this research project with any other organisations.

We will keep all information about you safe and secure by:

- Keeping all your information in a secure location at QMUL.
- Electronic data, including audio recordings, will be stored on an access-controlled, encrypted network.
- Paper documents will be kept in a locked filing cabinet at QMUL.

How will we use information about you after the study ends?

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.

We will keep your study data for a maximum of 5 of years. The study data will then be fully anonymised and securely archived or destroyed.

Your data will not be shared outside of the UK.

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 information about you that we already have.
- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

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

You can find out more about how we use your information:

- by looking at the Health Research Authority's leaflet:
www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team, or
- by sending an email to data-protection@qmul.ac.uk

Who is organising and funding this study?

This research is funded by Barts Charity (grant reference G-003152). The study is being led by Professor Simon Conroy.

What will happen if I want to withdraw from this study?

You can withdraw from the study at any time and without providing a reason. After 6 weeks, data from the interview will have been combined with other participant data, and we will not be able to remove and delete it. If you withdraw before this final stage, we will remove all of the information you have given us and securely destroy it. Withdrawing will not affect your rights.

If you withdraw after participating in an interview you will still receive vouchers as compensation for your time.

What if something goes wrong?

- If you have a concern about any aspect of this study, you should first ask to speak to a researcher who will do their best to answer your questions (Dr Abi Woodward, abigail.woodward@qmul.ac.uk 07920450863).
- If you have a complaint which you feel you cannot discuss with the researcher then you should contact the Coordinating Investigator – Professor Simon Conroy, simon.conroy@nhs.net
- If you remain unhappy and wish to complain formally, you can do this by contacting NHS PALS services: **The Royal London Hospital**: 020 3594 2040 RLHpals.bartshealth@nhs.net

This study is sponsored by Queen Mary University of London. The University has insurance in place to cover research activities carried out by its staff.

If you are harmed as a result of taking part in this research study, there are arrangements in place for compensation. This includes cover even if no one is at fault (known as “no-fault compensation”).

How can I find out about the results of this study?

We can share a summary of the study findings with you via email (or post if you prefer) once we have analysed the results.

Who can I contact if I have any questions about this study?

Please contact Dr Abi Woodward (Research Associate) if you have any questions or would like to discuss the study further: Abigail.woodward@qmul.ac.uk, 07920450863.