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# The effects of helping and supporting an adult who experienced harm in the NHS and/or social care

## PARTICIPANT INFORMATION SHEET

## Central University Research Ethics Committee (CUREC) reference: MS IDREC 674605, version 1.0, 12 September 2025

You are invited to take part in a research study on understanding experiences of family or friends who help and support an adult with long term health conditions, disability or age-related needs, when that person has experienced harm when using NHS or Adult Social Care services.

Before you decide whether to take part, it is important for you to understand why the study is being conducted and what it involves.

Please take time to read this information sheet carefully, and to decide whether you wish to take part. Discuss it with family, friends or others if you wish. Ask us if anything is not clear or if you would like more information.

### What is this study about?

Adults with long-term physical and/or mental health conditions, disability or age-related needs sometimes cannot manage on their own. Often, family or friends, (sometimes called carers) give them help and support. The NHS and Adult Social Care services aim to keep people using their services safe. Unfortunately, some people experience physical and/or emotional harm as a result of the treatment or care given, or the lack of treatment or care. Whilst there is some understanding on how this harm affects people who use services, little is known about how the harm affects family or friends who act as carers.

The study aims to understand the experiences of family or friends, who help or support an adult with long-term health conditions, disability or age-related needs, when that person experienced harm from ***NHS*** or ***Adult Social Care*** services. The study will seek to include people with different backgrounds (e.g. age, ethnicity, disability) and experiences (e.g. where the harm happened, impact of the harm).

> ***NHS***, services include healthcare services like General Practitioners (GPs), inpatient or outpatient clinics, hospitals, pharmacies, physiotherapists, dieticians and/or other NHS services.
>
> ***Adult Social Care*** services include services for adults with care and support needs, aged 18 years or over. This includes home care (e.g. help with washing, dressing and everyday tasks), personal assistance or help from support workers, day centres, occupational therapy, advice or support from local authority adult social services, or residential or nursing care. These services could be partly or fully funded by local authority adult social services or privately purchased.

**Why have I been invited to take part?**

You have been invited because you have experience of supporting or caring for an adult with long-term health conditions, disability or age-related needs.

To be able to participate, you need to be:

- A family member or friend (sometimes called a carer), who provides or provided help or support to an adult who experienced harm in the NHS or Adult Social Care in the last five years
- Aged 18 years or older at the time of the harm
- Able to participate in an interview. Reasonable support and adaptations can be made (e.g. language or disability support)
- Able to give informed consent to participate in the study (Able to understand the study information and to agree to taking part in the study)
- Living in England

Unfortunately, you cannot take part if:

- The harm was experienced outside of England
- The harm was experienced in private healthcare settings, outside of NHS care.

If you are unsure whether you are eligible to take part and would like to discuss this further, please contact Dr Siabhainn Russell by Email: Siabhainn.Russell@ndph.ox.ac.uk or telephone: 01865 289792 or alternatively contact Dr Stacey Rand s.e.rand@kent.ac.uk or telephone: 01227 823877

**Do I have to take part?**

No. It is ***up to you to decide*** whether to take part. Your choice will not affect any care or support your family member or friend receives.

If you decide to take part, you can withdraw from the study, at any time, without giving a reason, and without consequences to the care that you and/or your family member or friend receives. You can do this by telling us about your decision, verbally or in writing (see contact details below). You can withdraw at any time within **two weeks of your interview**. Any data that has been collected about you will be securely destroyed, and it will not be included in any written reports or study outputs. After these two weeks, data will have been anonymised so we are no longer able to identify your contributions.

**What do I do if I am interested in taking part in the study?**

If you are interested in participating, a researcher will arrange a convenient time to speak with you, either online (via MS Teams) or telephone (as you prefer). During this 10–15 minute conversation, the researcher will explain the study and answer any questions you may have. The researcher will also check that you are eligible to take part in the study.

**What will happen if I take part in the study?**

If you are eligible, you will be given time to consider if you would like to participate. If you decide to take part, a researcher will arrange an interview online (via MS Teams), by telephone, or in-person (if you wish). The interview will last 60 to 90 minutes, but may be longer or shorter, depending on how much you wish to share. It will be like an informal conversation covering the following main questions:

- Information about you such as your age, gender, marital status, ethnicity.

- What was the harm, how and where it happened, and what consequences it had for you and your everyday activities?
- What effect it has had on you and your wellbeing, and the care or support you give?
- What, if any, actions (such as, seeking advice from a health professional or making a complaint) you have taken or considered taking, following the harm.
- What, if any, support you were offered or given by health or social care professionals in the following the harm; and how helpful you found this support

If you do not wish to answer a question, please just tell the researcher and they will move onto another question. It will be possible to take breaks, as and when you wish. You can pause or stop the interview at any time. Please just let the researcher know. At the end of the interview, you will have space to add anything else you think is important, and to explain why.

The interview will be audio recorded to produce an accurate record of what you said. What you share will be kept confidential. The researcher would only ever reveal who you are if they have a concern that you or someone else are at risk of harm. In the rare event that this happens, the researcher may need to share your contact details with emergency services or your local social services. Usually, the researcher will discuss this with you and seek advice from the study lead researcher, Dr Michele Peters, first.

**How might taking part affect you?**

Some people find it helpful to reflect on their experiences and speak about them. However, you may find it upsetting to share your experience of supporting a family member or friend who experienced harm. The researchers will check with you on occasion if you wish to take a break. You can stop or pause the interview at any time.

If you feel distressed or upset at the end of the interview, the researcher will speak to you and you may wish to speak with your GP, family or friends, or other sources of support. At the end of the interview, you will be provided with information about sources of support, should you need them at any point following the interview.

**Are there any benefits in taking part?**

There are no immediate benefits to you in taking part. However, it is hoped that this study will lead to improvements to health and social care policy, guidance and practice. This will benefit people in the future. The study team are working closely with national policy-makers, health and care organisations, and others involved in supporting people after harm, to ensure the study findings are shared with those able to improve health and care services.

**Expenses and payments**

You will receive a £30 voucher as a thank you for your participation following an interview.

**What information (or data) will be collected and why?**

The study will collect information about you, which will be stored securely in a password-protected file on the University of Oxford's computer systems and will only be accessible to the research team (based at the Universities of Oxford and Kent) and people who check that research is being done properly.

The study will collect the following information:

- Your **personal data:** ***Name and contact details*** will be recorded, so a researcher can contact you about the study, to send you a thank you voucher for taking part in an interview, and (if you wish) a summary of study findings. You will be assigned a unique code, which will link your personal information to your research data. The unique code will be stored in a separate password-protected file. This information will only be available to the study team.
- Your ***consent form:*** This will be completed before the interview begins to record your consent (agreement) to take part in the study.
- Your **research data:** What you say in the interview. To make sure what you say is accurate, the interview will be recorded. The audio recording will be made on a secure encrypted device. After the interview, the recording will be transferred at the earliest opportunity to the University of Oxford's computer system and deleted from the encrypted device. It will be shared with a professional transcriber. The transcriber will have a contract with the University of Oxford to ensure they treat the data confidentially. The transcriber will type a word-for-word text version of what you said. This text version will be checked by a researcher and, once the researcher is sure it is accurate, the audio file will be destroyed securely. Personal and/or place names, or other identifiable information, will be removed from the text version. It will not refer to you by name, but will use your unique code.

Your contact details will be kept until the publication of the study findings, when they will be securely destroyed. Research data (the typed interviews, that will not contain any personal data) and the completed consent form will be stored for 5 years after publication of the findings. The researchers will store the consent form so there is a record that you agreed to take part in the study. The researchers will store the anonymised research data so it may be used in future studies, or may be shared with other researchers, upon request. For access to this study data, a request will need to be made to the lead researcher, Dr Michele Peters (or her representative), who will review the request. A decision whether to share information, or not, will be based on the proposed study's aims and objectives, to make sure the research aligns with similar aims and purposes to those explained in this document. Data sharing with other researchers will be subject to data sharing agreements, which will specify how the data will be shared and can be used. The study team would only share information directly relevant to the proposed study to further limit risk of identification.

**Will the research be published? Could I be identified from any publications or other research outputs?**

The study will be written up in reports and other formats to share the findings, like blog posts, videos and presentations. These will be publicly available on websites or in print or online publications. The study will use your words, as direct quotations, in the reports and other ways of sharing the study findings. Your quotations and any other information about you will be presented in a way that you will not be personally identifiable.

**Data Protection**

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. Research data may also be accessed by authorised personnel of the University of Oxford for monitoring or audit purposes. The University will process your personal data for the purpose of the study outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from:

https://compliance.admin.ox.ac.uk/individual-rights

**Who is funding the research?**

This project is funded by the National Institute of Health and care Research (NIHR) through the Quality, Safety and Outcomes of Health and Social Care Policy Research Unit (QSO-PRU) (Ref: NIHR206117). https://www.qso.ac.uk/

**Who has reviewed this research?**

This study has received favourable opinion from a subcommittee of the University of Oxford Central University Research Ethics Committee. (Ethics reference: **MS IDREC 674605**).

**Who do I contact if I have a concern about the research or I wish to complain?**

If you have a concern about any aspect of the study, please contact Dr Michele Peters on 01865 289428 (telephone) or at michele.peters@dph.ox.ac.uk.

She will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with.

If you remain unhappy or wish to make a formal complaint, please contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) team on 01865 616480 or at rgea.complaints@admin.ox.ac.uk.

**Further Information and Contact Details**

If you would like to discuss the research before you take part, or if you have any questions afterwards, please contact:

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