Participant Information Sheet: Informal family carers experiences following their relative with dementia's admission to an acute hospital.

You are being invited to take part in research on the experiences of family-carers following their relatives with dementia's admission to an acute hospital. Thomas Hadden (Trainee Clinical Psychologist) at Coventry University is leading this research. Before you decide to take part, it is important you understand why the research is being conducted and what it will involve. Please take the time to read the following information carefully.

What is the purpose of this research?

The purpose of the research is to gain a better understanding of informal carers experiences. It is hoped that the findings from this research will help to develop the knowledge of informal carers experiences following their relative with dementia is admitted to hospital.

Who is organising and funding the research?

The research is being organised and funded by Coventry University. The research was granted ethical approval by Coventry University's Research Ethics Committee [Ethics reference number: P173230].

Do you have to take part?

No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. Please note down your participant number and provide this to the lead researcher if you wish to withdraw from the research at a later date. You are free to withdraw your information from the research at any time until the data is fully anonymised in our records on 31st December 2024. You do not need to provide a reason for withdrawing. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

You will be asked to take part in a one-to-one individual interview with the researcher to discuss your experiences of being a family carer. The interview can take place either face-to-face or through MS Teams depending on your preference and we would like to audio record your responses. Before the interview begins, I will go through the study with you and answer any questions you might have, and I will do the same afterwards. You will be asked to provide your consent to participate before you start the interview (both verbally and written). It is predicted that the interview should take around 60 minutes.

At the end of the interview, you will be asked to indicate whether you would be happy for me to make a brief follow-up contact with you to provide feedback on a summary of the study's findings.

Why have you been invited to take part?

You have been invited to participate in this research because you have expressed an interest, and you meet the necessary criteria.

- You are over the age of 18.

- You are the spouse, partner, or child to a relative with dementia.
- You provide or have provided an informal unpaid caring role for your relative with dementia.
- Your relative with dementia is over the age of 65.
- Your relative with dementia has had an admission to an acute hospital which lasted at least 2 weeks.
- This admission occurred within last 12-months.

What are the benefits and potential risks and benefits in taking part?
By taking part, you will be helping Thomas and Coventry University to better understand the experiences of informal family carers following their relative's admission to an acute hospital. It is additionally hoped that the current study will be able to offer some clinical recommendations into supporting family-carers for a relative with dementia.

The study will include discussions around your relative with dementia, and your experiences following their hospitalisation, which can understandably be quite upsetting. If at any point you feel distressed, the study can be paused or ended, and you are not required to finish the interview.

Although every effort will be made to ensure you feel comfortable and at ease, due to the nature of the topic, sometimes you may be emotionally affected by discussing your experiences. Should you feel affected by the study, you can seek support from the following mental health charities:

- Samaritans - 116 123, www.samaritans.org
- MIND - 0300 123 3393, www.mind.org.uk.
- Dementia UK's Admiral Nurse Dementia Helpline - 08008 886 678,

What information is being collected in the research?
The researcher will collect information around your experiences of being a family carer following your relative's admission to an acute hospital, this may include questions around you experience of patient care, staff interactions and the hospital environment. The information you provide will be confidential, however the researcher may need to break confidentiality if you disclose any risks to yourself or others.

Lawful basis of processing

Under the UK General Data Protection Regulation (UK GDPR) 2016 we must have a lawful basis to process your personal data and for the purpose of this research, our lawful basis is that of Consent. Although we do obtain your consent, this is not for data protection purposes.

This research will require us to process your sensitive data (referred to by GDPR as 'special category data'). We will only process this on the basis of your consent, where you have previously published the information, for medical purposes or in certain circumstances where it is necessary for archiving, scientific or historical research purposes, or statistics purposes.

What will happen to the results of the research?
The results of this research may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Who will have access to the information?
Your data will only be accessed by the researcher/research team.

Where will the information be stored and how long will it be kept for?
Your data will be processed in accordance with the UK General Data Protection Regulation 2016 (UK GDPR) and the Data Protection Act 2018 (DPA). All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed.

All electronic data will be stored within a password encrypted computer file which will only be accessible by the research team. All paper records will be stored in a locked filing cabinet within Richard Crossman building at Coventry University. Your consent information will be kept separately from your responses. The researcher will take responsibility for data destruction, and all collected data will be destroyed on or before 30th September 2028.

For further information about how Coventry University will handle your personal data, please read our Privacy Notice for Research Participants.

What will happen next?
If you would like to take part, please contact the lead researcher. You will be asked to complete a consent form before taking part, and the research team will work with you to find a suitable for you to participate in an interview, this can be done face-to-face or remotely through MS Teams.

Research Team Contact Details:

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Who do I contact if I have any questions or concerns about this research?
If you have any questions, or concerns about this research, please contact the researcher, or their supervisor. If you still have concerns and wish to make a complaint, please contact the University's Research Ethics and Integrity Manager by e-mailing ethics.uni@coventry.ac.uk. Please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

Thank you for taking time to read this information sheet and for considering participating in this research.