**Version 1.2 07/04/2022.**

**INFORMATION SHEET FOR PARTICIPANTS**

**Title of study:** What are families understanding, expectations and experiences of inpatient mental health care for people with dementia?

We would like to invite you to take part in our research. Before you decide if you want to take part, we would like you to understand why the research is being carried out and what taking part will involve. Please read the following information carefully and discuss it with others if you wish, before you decide.

If anything is not clear or you would like more information, please email Emma Wolverson (contact details are at the end of this information sheet).

**What is the purpose of the study?**

Inpatient mental health care for people with dementia is considered when a person poses a significant risk of harm to himself, herself, or someone else. As such, an admission can be a very distressing time for the person and their family. There is very little publically available information about the role of mental health care for people with dementia and so families do not always know what to expect. The majority of people with dementia admitted to these mental health wards under a section of the mental health act as they may be unable to consent to an admission, which brings with it legal terms and requirements that can feel alien and frightening for families. Many people with dementia are then discharged to residential care and so an admission often reflects a significant transition in a family’s journey with dementia.

There is very limited research about an admission to a mental health care facility for people with dementia and to date there have been no studies exploring the experiences of families during this time.

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

You are being invited to take part because you have supported someone living with dementia who was admitted and cared for in a mental health ward in the last 5 years.

**Do I have to take part?**

No. It is up to you if you wish to take part. If you find the discussion too upsetting then you can just stop the interview without giving a reason. You can ask us to delete the recording (up to two weeks after the interview) if you change your mind about taking part.

**What will I have to do?**

If you decided you want to take part, please contact Emma to arrange a time for you to speak with either her or Karen, his can be an online meeting or over the phone. The meeting will last about an hour and will be recorded.

**What are the possible risks of taking part?**

We will be thinking about your experiences and this might be upsetting. If you think it will be too difficult you don’t have to take part. If you need a break at any point during the interview or it gets too much you can tell Emma or Karen and you can either pause or stop the interview.

**What are the possible benefits of taking part?**

We hope to share our findings to raise awareness of family’s experiences and their needs leading up to and during an admission. We will write up our findings in academic journals and in a blog.

**How will we use information about you?**

Each interview will be recorded and transcribed. The written transcript of the discussion will be stored on a safe University of Hull approved secure storage service and will follow all privacy rules. It will not include your name or any other identifiable information. The data will only be used for this study and will be safely stored for 10 years on secure network drives at the University of Hull.

Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018. We can provide you with more detailed information about how we will look after your data if you wish.

The only time we may need to share information is during the conversation we become concerned about your safety or the safety of the person with dementia you support, or if you share serious concerns about the care that your relative received. If we had concerns, we would talk with you about these before sharing them with the relevant authority such as a local safeguarding team or the police.

**Who has reviewed this study?**

This study has been reviewed and been given a favourable opinion by the Faculty of Health Sciences Ethics Committee at the University of Hull.

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact:

**Emma Wolverson:** [E.Wolverson@hull.ac.uk](mailto:E.Wolverson@hull.ac.uk)

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull by emailing [coo@hull.ac.uk](mailto:coo@hull.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research.**