



PARTICIPANT INFORMATION

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title: *The social understanding of mental health crisis in dementia.*

Researcher/Student: *Alessandro Bosco, Alessandro.bosco@nottingham.ac.uk*

Supervisor/Chief Investigator: *Professor Martin Orrell, m.orrell@nottingham.ac.uk*

Ethics Reference Number: *0259*

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you if necessary and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of this study?

The study is looking at crisis care for people with dementia. In particular, we want to hear from people with dementia aged 50 years old and above, living at home. If you have experienced such critical situations, we would like to explore the quality of care you received. This study will help us to better understand how to support people with dementia in crises. We hope that, by hearing about the experience of people with dementia through their own voices, we can identify improvements to the process of care.

Why have I been invited?

You are being invited to take part because you are a user of this online blog. We assume that you are over 50 years old and have a diagnosis of dementia but if that is not true, please do not participate in this study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, on the forum page, you will see a link to an information sheet describing the study. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will I be asked to do?

As this is an open forum, you will be able to post your answers any time you want and for as long as the thread is on. This is not a private forum and your replies may be read by other members of the forum. If you accept to take part in the study, you will take part in a discussion along with other people with dementia. The researcher (AB) will ask questions to the group around the quality of



care for their mental health crisis and around their experience of receiving help from health professionals.

Will the research be of any personal benefit to me?

There are no benefits to taking part in the study, however you may enjoy sharing your experience. The findings of this study may help us better understand the experiences of people who have had a crisis and so improve the care they receive.

Are there any possible disadvantages or risks in taking part?

We do not anticipate any risks or disadvantages for the participants in the study. However, if you find that any of the topics/questions make you feel upset or distressed during or after the study, please raise your concern with the co-ordinator of the forum or the researcher and/or the study supervisors.

What will happen to the information I provide?

During your participation, you will not be asked to provide any personal information (e.g. name, address, email, phone number). Once you have submitted an anonymous response it is not possible to withdraw the data because we won't know who you are.

Results from this study will be part of the doctoral dissertation of the researcher and will also be disseminated through publications in relevant journals and at conferences at the national and international level. This will ensure that the findings of the study get the attention of the research community, healthcare professionals and policy makers on the experience of mental health crisis for people with dementia. During the development of the materials for dissemination, your data will always be kept anonymous and your responses will be rephrased. This means that we will keep the integrity of your responses, but we will use different words. You will be able to access the dissemination materials upon request. If you are interested in receiving these materials, please contact the research team through one of the contact details you were provided with this information sheet.

We will follow ethical and legal practice and all information will be handled in confidence.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

<https://www.nottingham.ac.uk/utilities/privacy.aspx>.

The data collected for the study (your responses to the forum) will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may



also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

At the end of the project, all raw data will be kept securely by the University under the terms of its data protection policy after which it will be disposed of securely. The data will not be kept elsewhere.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons at the Talking Point Forum (Alzheimer's Society). Should reporting be needed, you will be told by the Principal Investigator.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the email addresses above.

What if there is a problem?

If you have any queries or complaints, please contact the Alzheimer's Society and or coordinator of the Talking Point. Alternatively, you may contact the student's supervisor/chief investigator. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee adrian.pantry1@nottingham.ac.uk who will pass your query to the Chair of the Committee.

We believe there are no known risks associated with this research study; however, as with any online activity the risk of a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous.

Further information and contact details

If you have any queries or concern you may wish to discuss, you can contact the study investigator, who will be able to assist. The contact details of the study investigator are as follows:

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The contact details of the Chief investigator are as follows:

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