Information for patients about an interview study

You are being invited to take part in a research study. We would be very grateful for your help. This information sheet explains why the research is being done and what it would involve. Please read this information carefully. You may want to discuss it with a family member, friend or healthcare professional to help you decide.

Thank you for reading this.

If you have any questions, please contact our researcher:

Emily Spencer — Telephone: 07502 872305

Queen Mary, University of London — Email: emily.spencer@qmul.ac.uk

This information sheet has two parts:

- **Part 1** provides an overview of the study
- **Part 2** gives more detail about certain aspects of the study

Part 1: Overview of the study

Why are we doing this research?

People with dementia or problems with memory and thinking often prefer to be treated at home instead of in hospital. Hospitals can be distressing for some patients and their family carers.

The National Health Service (NHS) is now investing money in **virtual wards**. Virtual wards provide care, monitoring and treatment for patients who would otherwise be in hospital. This can be through face-to-face treatment, as well as using technology. Through virtual wards, patients can be supported to stay at home.

The benefits of virtual wards include being in a familiar environment, keeping your usual routines, and avoiding the need to travel for treatment. This may be particularly helpful for people with dementia or problems with memory and thinking. However, at the moment we don't know whether virtual wards work well for these people.

We would like to know how virtual wards can work best for people with dementia, as well as the family members and friends who are involved in supporting them to stay at home.

Why have you been invited?

We are working with your local virtual ward to see how they care for people with dementia, memory or thinking difficulties. You have been identified as someone who has been cared for as part of the virtual ward in the last year, and who may want to take part.

What are we asking you to do?

If you decide to take part:



You will be invited to take part in an interview. The interview can be in person, by video call, or by phone – whichever you prefer. You will be asked about your experience of being treated at home on a virtual ward. This will include what went well, what didn't go well, and how virtual wards can best meet your needs.

The interview will last **up to one hour**. You will be able to take a break or stop completely at any time.



If you agree, **the interview will be audio recorded**. The interviewer may also take notes to help them remember what you said. The recording will be typed out (a 'transcript') by a professional company. After we check that the transcript is accurate, the recording will be deleted. We will remove any information that could identify you, such as names or locations, from the transcript.

We hope to use this information to develop **guidance and information** on how professionals can ensure virtual wards work best for all people with dementia.



We will ask you to **complete a short questionnaire** with us so that we can collect important information such as your age, gender, ethnicity and living situation. This will take no more than five minutes. It helps us to understand how people's experiences might differ depending on their background.

All of your information, including audio recordings, will be stored securely and confidentially.

What are the benefits of taking part?

By sharing your experiences, you will help us understand how virtual wards can best work for people with dementia, memory and thinking difficulties, and their family carers. This will help us to develop guidance and information for the health and care professionals involved in running virtual wards. We hope that this will lead to improved care.

As a thank you for your time, you will also be offered a £20 high street voucher.

What are the risks of taking part?

We do not believe taking part will cause you any harm, and your treatment will not change in any way. However, we will ask you about your good and bad experiences of being cared for on a virtual ward. Some of these questions could be upsetting for some people. If at any stage you feel uncomfortable, you can take a break or stop the interview altogether. If this happens, we can stop the recording.

Do you have to take part?

No. Taking part is your choice. It will not affect your medical care in any way if you decide not to take part.

If you choose to take part, you can change your mind without giving a reason. If you change your mind within 6 weeks of the interview, we will delete the recording and any other information that we have about you. After 6 weeks, we will start to analyse the recording.

After the interview study, a group of people with dementia, family carers and health and care professionals will help us develop some guidance on running virtual wards. You can tell us whether this is something you might like to help with. **You do not have to take part.**

Part 2: Further information

How will researchers use information about you?

We will use information you give us to complete this research project. This will include:

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

This information will help us do this research, answer the questions we have, and make sure the research is done properly.

Only members of the research team will be able to see your name and contact details.

A professional company that is approved by the university will listen to the recording of your interview and type it out to make a transcript. This company will follow strict rules to keep your information safe. They will not know who you are or see any other information about you. After the transcript has been made, the recording of your interview will be deleted.

When the research is finished, we will keep some of the information so we can check our findings. The findings of the study will be written up in scientific journals and presented at professional conferences. We will never use your name or anything that could identify you in any of our reports.

Will information be kept confidential?



All your information will be kept in a secure location at Queen Mary, University of London. Electronic data will be stored on an access-controlled, encrypted network. Paper documents will be kept in a locked filing cabinet.

To make research easier, we would like to keep the interview transcript and other information you give us so that it can be used by other researchers in future ethically approved studies. Things that could identify you, like names or places, would be removed. **You have the choice to say no to your information being used in future research.** You can still take part in the study if you say no.

Everything you tell us during the interview will be kept confidential. However, if you tell us that a member of staff is doing 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.

We will send you a copy of the findings when the study has finished if you would like this.

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

- At www.hra.nhs.uk/information-about-patients/
- By looking at the Health Research Authority's leaflet, available at www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team
- Or by sending an email to data-protection@qmul.ac.uk

Your data will not be shared outside the UK.

The data custodian for this study is Professor Nathan Davies.

Who is organising and funding this study?

This research is funded by the Alzheimer's Society (project grant 667). The study is being led by Professor Nathan Davies. Queen Mary, University of London are the sponsor for the study.

Has the research been reviewed by an appropriate research ethics committee?

All research in health and social care is looked at by an independent group of people – a Research Ethics Committee – to protect participants' safety, rights, wellbeing and dignity. This research study has been reviewed and approved by the NHS Research Ethics Committee Wales REC7.

What if there is a problem?

If you feel worried about anything to do with the research, please contact the principal investigator, Professor Nathan Davies.

Email: n.davies@qmul.ac.uk

You can also complain formally through the NHS Complaints Procedure. You can contact the NHS Patient Advice and Liaison Service (PALS) on 020 3594 2040 or by emailing bartshealth.familycontact@nhs.net.

What happens now?

You can get in touch with the lead researcher to say whether or not you would like to take part, or to ask for more information:

Researcher: Emily Spencer

Email: emily.spencer@qmul.ac.uk

Telephone: 07502 872305

Thank you for taking the time to read this.