DEM-VW study:
Evaluating virtual wards

Information for family carers about a workshop 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 872 305

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 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.

We have been learning from patients, family carers, and health and care professionals to find out about their experiences of being part of a virtual ward. We now want to develop some guidance and information on how professionals can ensure virtual wards work well for all 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 inviting people who support a family member or friend with dementia to take part in this study. We are looking for people who have supported a person with dementia while they have been cared for on a virtual ward, and who would like to help develop the guidance and information.

What are we asking you to do?

If you decide to take part:



You will be invited to attend up to three workshops. These workshops will include other people who have cared for a family member or friend with dementia, as well as health and care professionals involved with running virtual wards. Workshops will be interactive, with different activities in smaller and larger groups.

You will be asked to **share your thoughts** on the information and guidance being developed. What is discussed in the workshops will be used to shape and refine this guidance, to make sure that virtual wards meet the needs of people with dementia and their family carers.



Workshops will last **up to 90 minutes**, and will be held face-to-face. Refreshments will be provided. If for any reason we cannot conduct the workshops face-to-face, they may be held over videoconferencing software (Teams). **Workshops will be audio recorded**.

If attending a group workshop would be difficult for you, an **individual meeting** can be organised to make it possible for you to take part.



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?

Your involvement 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 for people with dementia.

As a thank you for your time, you will also be offered a £20 high street voucher. We will also reimburse your travel expenses for face-to-face workshops.

What are the risks of taking part?

We do not believe taking part will cause you any harm. However, you may find talking about your experiences of providing care for someone with dementia to be upsetting or tiring. You can take a break during the workshops or stop completely at any time. An experienced member of the research team will be available to listen to you and provide support.

Do you have to take part?

No. Taking part is your choice. It will not affect your family member or friend's medical care in any way if you decide not to take part. If you decide to take part, you can stop being part of the workshop at any time, without giving a reason.

Part 2: Further information

Will information be kept confidential?

Everything you tell us during the workshops 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.

How will we use information about you?

We will need to use information from you for this research project. This information will include:

- Your name
- Your contact details
- The questionnaire you complete
- The recordings of the workshops

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Queen Mary, University of London (QMUL) is the sponsor of this research. QMUL is responsible for looking after your information. We will not share your information related to this research project with any other organisations.

Your data will not be shared outside of the UK.

We will keep all information about you safe and secure by:



- Keeping all your information in a secure location at QMUL.
- Electronic data, including audio recordings, will be stored on an access-controlled, encrypted network.
- Paper documents will be kept in a locked filing cabinet.

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.

We will keep your study data for a maximum of five years. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

Where can you find out more about how your information is used?

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

- by looking at the Health Research Authority's leaflet: www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team, or
- by sending an email to data-protection@qmul.ac.uk

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.

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 872 305

Thank you for taking the time to read this.