DEM-VW study: Evaluating virtual wards

Participant information sheet

You are being invited to take part in a research study. This information sheet is designed to explain why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. Please get in touch with a member of the research team if anything is not clear or you would like more information. **Thank you for reading this.**

If you have any questions, please contact our researcher:

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Queen Mary, University of London

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Why are we doing this research?

As a person with dementia becomes frailer, they are at an increased risk of falls and infections, often resulting in hospital admission. Most people with dementia would prefer to remain at home, which can be enabled through the use of virtual wards. Although such services have been delivered in some areas for many years, services are heterogeneous with no 'blueprint' to inform optimal care.

It is currently unclear how different models of virtual ward work with and for people with dementia, whether adaptations are required, or if they face barriers to access. Family carers are critical to supporting people with dementia while on a virtual ward, however little is known about how these services can support family carers without increasing carer burden.

The aim of this research is to investigate how virtual wards can best be adapted for people with dementia, as well as the family carers involved in supporting them to stay at home. Using the findings from this study, we hope to develop policy and practice recommendations for virtual wards caring for people with dementia.

Why have you been invited?

You have been invited to take part in this study because you are a clinical lead involved in the delivery of a virtual ward.

What are we asking you to do?

If you decide to participate:

- **You will be invited to complete an online survey**. This survey will ask questions about ways in which your virtual ward may have been adapted to support people with dementia, the resource requirements for supporting this population, as well as any barriers or facilitators you have encountered. The survey will also ask about the key conditions and reasons for admission to the virtual ward for people with dementia.
- The survey should take **10 minutes** to complete and will comprise open- and closed-ended questions.
- We hope to use this information to develop **policy and practice recommendations** on how virtual wards can work best for all people with dementia and their family carers.
- **All of your information will be stored securely and confidentially.**

What are the benefits of taking part?

Your involvement in this study will help us to understand how virtual wards can best be adapted to support people with dementia and their family carers. This will help us to develop policy and practice recommendations for the delivery of virtual wards for these individuals. We hope that this will lead to improved care.

What are the risks of taking part?

There are no known risks to taking part.

Do you have to take part?

No. It is up to you to decide whether or not to take part. If you choose to take part, you can withdraw from the study at any time without giving a reason by closing the browser window.

After the survey, a group of people with dementia, family carers and health and care professionals will help us develop policy and practice recommendations on running virtual wards for people with dementia. You can tell us whether you would be interested in participating in this phase of the study.

Will information be kept confidential?

Confidentiality will be subject to legal constraints and professional guidelines. This means that anything you share will be treated as confidential, unless you tell us something that suggests malpractice by staff, risk of harm to service users, a potential criminal offence, or serious concerns about someone's health and wellbeing.

The survey is produced using JISC online surveys which is a QMUL approved and licenced platform. All data will be stored securely.

How will we use information about you?

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

- Your name, if you provide this
- Your contact details, if you provide this
- The survey you complete

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.

You will be asked for your contact details should you wish to participate in other research projects or receive a summary of the findings. These will be stored securely and separately from your responses on a QMUL secure severs. Only authorised members of the study team will have access to these details, and these will be deleted at the end of the study. Your contact details will be stored separately from your survey responses.

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.

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

- Storing electronic data on an access-controlled, encrypted network.

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.

Please note, as the survey is anonymous, once survey responses have been submitted, we cannot delete responses.

Your data will not be shared outside of the UK.

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?

This research study has been reviewed and approved by the NHS Research Ethics Committee Wales REC7.

What if there is a problem?

If you have any concerns about any aspects of this research, please contact the Chief Investigator - Professor Nathan Davies.

Email: n.davies@qmul.ac.uk

What happens now?

If you are happy to participate, please proceed to the survey.