Information for patients about an observation study

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1. About this study

We are doing a research study.

We want to learn about **virtual wards** and how they work for people with **dementia or memory problems**.



A virtual ward is where:

- A person stays at **home** instead of going to hospital
- Doctors and nurses still visit the person's house to **check on** them
- Care may happen **in person or using technology**

You may have also heard a virtual ward be called **hospital at home**.

We want to understand:

✓ How your local virtual ward cares for people with dementia or memory difficulties

✓ How virtual wards can work best for family members and friends who support people to stay in their home

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2. Why have I been asked?

You are invited because:

- You may have dementia or memory difficulties
- You are someone who is currently being cared for on the **virtual ward**
- Your experience is important.

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3. What will happen if I take part?

If you decide to take part:

A researcher will visit you at home to observe how you are cared for as part of a virtual ward. This will include:



- Observing any care of treatment provided by doctors or nurses in your home.
- Observing how your family or friends may help you with your care.
- The researcher taking written notes and asking some questions.

The researcher will not write down any information that could identify you.

With your agreement, we would like to visit **up to five times over the next year** to see how the support given varies on different days.



We will **only visit to observe and make notes** if everyone has agreed to take part. This means that any family members, friends, and health or care professionals involved in supporting you would also need to agree.

We will ask a few short questions, such as:



- Your age
- Your gender
- Your ethnicity
- Who you live with

This takes about **5 minutes**.

We would also like to access your medical notes to see how the virtual ward and your GP have been supporting you with your health care. All of your information, including your medical information and the notes written about your care, will be **stored safely and securely.**

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4. What are the benefits?

By allowing us to observe your care experiences, you will help us understand how virtual wards best work for people with dementia and their family carers.

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.

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5. Are there any risks?

Being observed may make you feel slightly self-conscious. If you feel uncomfortable at any stage, you can:

- Pause the observation
- Skip any questions you may be asked
- Stop the observation

You are always in control.

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6. Do I have to take part?

No.

Taking part is **your choice**.

Your care will **not change** if you say no or yes to taking part.

If you say yes but change your mind later:

- You can let us know within **6 weeks**
- We will delete your information if you ask

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7. How will my information be kept safe?

In this research study we **will use information from you and your medical records**. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study **will keep your data safe and secure**. We will also follow all **privacy rules.**

At the end of the study, we will save some of the data in case we need to check it and/or use it for future research.

We will make sure no-one can work out who you are from the reports we write.

The study results may be shared in:

- Research journals or conferences

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8. Can my information be used in future research?

We may ask if we can use anonymous information in future studies.

Anonymous means:

- Your name and personal details are removed.
- You can **say no** and still take part in this study.

9. Who is running the study?

The study is led by **Professor Nathan Davies**.

Email: n.davies@qmul.ac.uk

The research is run by **Queen Mary University of London**.

The study is funded by the **Alzheimer's Society**.

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10. Has the study been checked?

✓ Yes.

An independent **Research Ethics Committee** has checked and approved this research.

This helps make sure research is **safe and fair**.

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11. Who can I contact?

📞 If you would like to take part or ask questions, please contact:

Emily Spencer – Researcher

Phone: 07502 872305 Email: emily.spencer@qmul.ac.uk

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12. Thank you

Thank you for reading this information. Your experience can help improve care for people with dementia.