

Supporting Dementia Care

Participant Information Sheet

What is the purpose of this pilot?

Thank you for your interest in taking part in our pilot. Please take your time to read this information and think about whether you would like to take part. If it's helpful, then please discuss the pilot with family, friends or other trusted people to help you make your decision.

The Helix Centre (part of Imperial College London), funded by the London Office of Technology and Innovation and the Mayor of London, are working with people with dementia, carers/family members, local authorities, charities and community groups to find new ways to help people with dementia and carers access support online and get connected.

We want to see if our ideas help people with dementia and carers improve their digital skills and ability to participate in social activities online. We will work out whether we have done this by asking people who take part in the pilot to fill out some short questionnaires.

What will happen if I take part?

We will ask you to answer a short questionnaire to help us find out whether the pilot is working later on. Someone from the team or a community lead can read it out to you and write down your answers if that works better for you.

A member of the team or community lead will get in touch to arrange a date and time to visit you at your home. Two members of the team (at least one DBS checked) will then visit together and show you how to use your tablet. Please do not worry if you forget the date or time of this visit: we will remind you closer to the time. If you do not

already have internet access at home, they will also install a router. This visit should take no longer than 1 hour.

The pilot will run for 4 weeks. You will get some training on how to use your tablet and will join an online activity once a week. Once a week, someone will also talk with you about how you have found using your tablet computer and kit by asking the questionnaire again and hearing your feedback. We won't be assessing you or your health or abilities - just whether using the tablet computer with our approach and equipment makes things easier for people and helps them to feel connected.

At the end of the pilot, you will be invited to participate in a final feedback session, to ask you about your experiences taking part.

What are the online activities?

We will ask you to join one online group activity a week, and have one individual online conversation with a project team member.

The online group activity will be an informal conversation based meeting themed around a different activity each week. We would like to see what people enjoy doing together online. We anticipate poetry, music, puzzles, and map based activities.

The individual conversation with the project team member will be using the tablet if you are happy to, or by phone if you would prefer. It is a short conversation to see how you are getting on with the tablet, and to see if you need any technical assistance.

For everyone's benefit and emotional comfort, we will have a strict zero tolerance policy towards extreme, overly political or anti-social comments (including anything that could be deemed sexist or racist) during a video call. Participants agree that any such comments during online meetings will result in them being removed from the meeting immediately. Online meetings will be moderated by a project team member and they will have the ability to remove people from meetings.

What devices will I receive ?

You will be provided with equipment to be able to join online video meetings. We have designed this to be as easy as possible, and we will show you how to use the equipment. This equipment consists of:

- **Tablet computer (iPad)**

You will be given an iPad, pre-configured with software applications (Apps) to make it easier to use.

- **iPad Stand**

To give the tablet a 'place in the home' and make it easier to use the tablet, especially with the "Zoom tickets"

- **"Zoom tickets"**

These are printed cards that will give you access to online video meetings (using a software application called Zoom). The ticket can be scanned by the camera on the iPad to join the meeting. This will be demonstrated to you.

- **Router & Data Sim card**

If you don't have a router at home, we will install one for you for the duration of the pilot so you can take part. The router allows the iPad to connect to the internet. The Sim card provides the internet connection for a period of about 5 weeks only.

The tablet computer, iPad stand, Zoom tickets and router and Data Sim Card will be provided by the project team at no cost to you.

We will provide you with a demonstration of the equipment, and easy to follow printed instructions, and answer any questions you may have about the kit when it is delivered to you.

If any of the devices provided are **lost, damaged or stolen**, then you will **not** be penalised in any way, or expected to replace them. However, it is also unlikely we

will be able to replace them within the time period of the pilot, and so this may result in you no longer being able to participate fully.

What will happen to the information I give?

Survey responses and other data will only be accessed by members of the team who are conducting surveys, analysing evaluation results and writing the final report. Responses will be anonymised by linking people's answers through a number and not their name.

We will use the information you give us to find out whether this pilot has helped people with dementia, family and friends to take part in activities online. We will also see whether the pilot has an impact on people's feelings of social connection.

We will use the results to write an evaluation report on the pilot and, if it works well for people, make the case for more people to try this approach.

Anonymised quotes and data from evaluation surveys and feedback may be included in the report and other project outputs.

The project team will preconfigure the devices with generic email accounts, so that no personal data will be stored on the device or associated accounts. We will not add any identifiable personal information to accounts created for participants.

The tablet computers (iPads) will have remote management software on them. This means that the project team can help solve problems with the device remotely if you need help. They can also see the location of the device on the map, and when it is used. The remote management software will also add restrictions to the device to keep you safe online. We will stop remotely managing the software when the pilot ends.

Participants agree not to enter any personal or sensitive data (including financial information) into the Tablet computer, for my own safety. If you have any concerns or questions about this you should contact the project team using the details below.

Do I have to take part?

No. You decide whether or not you want to take part in this pilot. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form saying that you agree to take part. Taking part is voluntary. It is separate from any health, social care or community support that you might get. If you decide not to take part, then this will in no way compromise your rights and affect the care or support you receive.

Can I change my mind?

Yes. You are free to withdraw your participation at any time without giving us a reason. If you choose to withdraw, your decision will not compromise your rights and the standard of care you receive. We will remind you of this.

Will my participation in this pilot be kept confidential?

Yes, we will not link your name or other identifiable information with your data. Instead, we will give you a unique identification (ID) number to help us keep track of your data without naming you. We will not store personally identifiable information such as your name or address with your questionnaire data so your answers cannot be linked back to you.

Who can see my personal information and the data you collected from me?

Members of the Supporting Dementia Care team (project team within Helix Centre only) will have access to your personal information (name, address, phone number and/or email address) so they can contact you about the pilot.

This will include arranging to visit you in your home, telephoning you to confirm that you still want to be part of this pilot, or contacting you if you have a problem with your tablet. Access to the database that holds this data will be restricted to members of the project team at the Helix Centre. The database will be held on OneDrive, which requires a password and username to access.

Printed surveys you complete will be securely stored at the Helix Centre, Imperial College London, where they will be analysed by the team. Only members of the team will have access to these cabinets.

If you take part in a feedback session, data from this will be transcribed and stored in locked filing cabinets in a central location (Helix Centre, Imperial College London) and on OneDrive and will be accessed only for translation purposes and/or data analysis by members of the project team.

What will you do with my personal information when the pilot stops?

We will delete your personal information (Name, address, phone number, email address) from our database 3 months after the completion of the pilot's final report. We will keep it for 3 months in case we need to contact you about anything that has come up over this period. Anonymised feedback, comments and insights that you have provided during the research will be kept and may be used in project reports and presentations.

What will you do with my personal information if I withdraw?

If you withdraw your consent after the session, or if we find we have any research data without any associated consent, we will delete your personal data and dispose of paper notes in confidential waste.

What happens at the end of the pilot?

At the end of the pilot the participant will have the opportunity to keep the tablet computer and/or router for their own use. (However, please note that if the equipment was lost, damaged or stolen during the pilot, it will not be replaced).

If you decide to keep the device:

- You will need to sign an agreement saying that you will take over all responsibility for use of the device.
- Imperial College London and its funders will not be able to provide ongoing support for the use of the device after the pilot.

- At the end of the pilot the remote management of the device will be ended, and the device will be erased and reset for you to use with your own account. This will result in any data on the device (e.g. photographs) being removed, and can be set up again as a new device.
- If you are using the router & Sim card (because you don't already have Wifi), the SIM card that provides the data allowance will automatically expire shortly after the pilot. You can continue to use the data allowance until it expires, but it will not be renewed further.

If you do not wish to keep the device(s) - we will arrange a collection from you at an agreeable time.

Once we have completed the project and produced the report (published by LOTI), we will be happy to share a copy with you, if it is of interest. The report will be primarily written for Local Authorities and Community Organisations to help them with their digital inclusion programmes.

What if I have more questions?

If you have any questions before you take part, please contact:

Cat Kilkenny

cat@helixcentre.com

07889191100 (between 09:30-17:30)

What if I am unhappy and wish to make a complaint?

In the first instance, please contact the project lead on:

Matthew Harrison

01865 600 444

matthew.jc.harrison@imperial.ac.uk

If you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this pilot then you should immediately inform the Principal Investigator:

Professor Ara Darzi

a.darzi@imperial.ac.uk