DUBLIN CITY UNIVERSITY

NEX ARC Trial – Plain Language Statement

Introduction This study is being carried out by a group of researchers from Dublin City University. The study is called NEX ARC Trial and this is the third part of a larger project which aims to explore how technology can support older adults to remain living independently at home in the community.

The purpose of the NEX ARC Trial is to assess the performance of the "NEX system" and to get participant feedback on the system regarding user experience. The "NEX system" was designed to provide support to older adults living independently at home. The design of this system was informed by prior research with older adults, family caregivers and health and social care professionals.

Participants who are eligible (older adults, who live in their own home and are aged 60 years and older) and willing to be involved in this research will have the NEX system technology installed in their home for a period of 12 weeks. The technology will be installed by a technical engineer and training will be provided. The NEX system consists of 5 different technology types:

1. **A voice activated assistant**
   A voice assistant is a device which can help with various day to day tasks. You can give your assistant a command by speaking and the assistant will carry out your command e.g. set reminders or ask for news or weather updates (examples of these devices include Alexa and Google Home).

2. **Ambient sensors**
   These are small devices that can detect movement, humidity, temperature, light and vibration. For example, they can detect if a door is open or closed. These devices can be placed at different points in your home – please note that these sensors do not consist

of microphones or video cameras so the users' privacy is respected at all times.

3. **Smart plugs**
   Smart plugs are simple plug in devices that convert ordinary appliances in your home into "smart" ones. They do this by allowing you to control and measure the power supply to the appliance through an app. For the purposes of this trial we are only interested in tracking the power consumption of some key appliances (e.g. kettle or coffee machine) in your home so that we can use this data to learn more about your daily routine.

4. **A wearable device**
   In most cases, these devices are worn on the wrist and they can track your movement or activity inside and outside of the home e.g. number of steps taken over a period of time or distance travelled (an example of these devices is the Fitbit). An additional wearable device will be available for a small number of participants who live in households with multiple people. The purpose of this wearable is to identify which household member is interacting with the NEX system.

5. **A tablet device**
   The tablet device will be used so that you can view some of the information collected from the ambient sensors and the wearable device e.g. how many steps taken over a period of time or temperature/ humidity information in your home environment.

What does participation in the study involve?

You are being invited to participate in Phase 3 of the project – the NEX ARC Trial. The purpose of this study is to assess the performance of the NEX system in identifying various activities in the home (e.g. eating, washing, moving around the home) and to get participant feedback on the system regarding user experience.

As a participant you will meet with the research team on 7 different occasions over a 12-week period, however 5 of these visits will take place online via Zoom and the remaining two visits will involve a researcher and technical engineer visiting you in your home. It is anticipated that the initial Zoom meeting and subsequent installation visit will take approx. 1.5 hours each. All other meetings should last approx. 30 mins. You will not be required to travel anywhere to take part in this study and the research

team and technical engineer will be fully vaccinated and will comply with social distancing guidelines during the visit to your home.

Some participants may wish to involve their informal caregivers in this trial e.g. son/daughter/friend/neighbour etc. As part of this involvement, participants will consent to share their NEX system data with their caregiver on ONE occasion. This will allow the caregiver to comment on the usefulness of having access to this data in the provision of support to you. This will help us inform the development of the system. This is not a compulsory aspect of participation and you can participate in the study without caregiver involvement.

Visit 1: At the start of the trial, a researcher will meet with you on Zoom (online) and record your formal consent to the trial. We will ask you some questions about you (e.g. age, health status, prior technology use), quality of life, cognition, frailty, your general wellbeing, activities that you participate in, your preference for routine and novelty and your belief that you can perform particular tasks. These will help us understand how people use the NEX system. We will repeat some of these questions at the end of the trial to see if using the NEX system has changed your answers to these questions.

Visit 2: The following week a researcher and a technical engineer will visit you in your home and identify the most appropriate locations to install the NEX system (see description above) in your home. Once the system has been installed, you will receive full training on how to use the system. We then ask you to use the system as often or as little as you wish over a 12-week period.

Visit 3, 4 and 5: For these visits a member of the research team will be in contact with you via Zoom. These visits will focus on how you are finding the trial and to show you some of your data.

Visit 6: On this occasion the researcher will also contact you via Zoom but the focus of this visit will be to discuss your overall experience of the trial and of using the NEX system. This will provide very valuable feedback to the project team about how we can adapt and improve the NEX system going forward.

Visit 7: At the final visit, the technology will be uninstalled from your home. After this is complete you will receive a €60 one4all voucher via post as compensation for your time and effort on this research project.

If at any point you are experiencing difficulties with the system or wish to have the system removed from your home, you can contact the research team on the research study mobile (number: 089 2653951) and the system will be removed from your home as soon as possible.

The study is funded under the Government of Ireland Disruptive Technologies Innovation fund. The person leading the research is Dr Catriona Murphy at the Centre for eIntegrated Care (CeIC), School of Nursing Psychotherapy and Community Health, Dublin City University. If you would like any further information about the study you can contact her at Catriona.murphy@dcu.ie or by phone at (01) 700 8956.

Am I eligible to take part? Older adults aged 60 years and over, who are fully vaccinated against Covid-19 and are living in their own home and who pass a mini cognition assessment are eligible to take part in this research. However, in light of current HSE recommendations relating to COVID-19, individuals who meet any of the criteria below will not be eligible to take part in the interest of their own personal health.

•have cancer and are being treated with radiotherapy/ chemotherapy or similar drugs other than hormone therapy
•are on dialysis or have end-stage kidney disease and an eGFR less than 15
•have a condition affecting the brains or nerves that has significantly affected your ability to breathe, meaning you require non-invasive ventilation (such as motor neurone disease or spinal muscular atrophy)
•have unstable or severe cystic fibrosis, including people waiting for a transplant
•have severe respiratory conditions including Alpha-1 antitrypsin deficiency, severe asthma, pulmonary fibrosis, lung fibrosis, interstitial lung disease and severe COPD
•have Down Syndrome
•have uncontrolled diabetes
•have had an organ transplant or are waiting for a transplant
•have had a bone marrow or stem cell transplant in the last 12 months, or are waiting for a transplant
•have a rare condition that means you have a very high risk of getting infections (such as APECED or errors in the interferon pathway)
•sickle cell disease
•have been treated with drugs such as Rituximab, Cyclophosphamide, Alemtuzumab, Cladribine or Ocrelizumab in the last 6 months
•have certain inherited metabolic disorders (such as Maple Syrup Urine Disease)

Are there risks associated with the study? There are no perceived or anticipated risks associated with this study and all visits to your home by the research team will be completed in accordance with the relevant government guidelines for COVID-19 e.g. social distancing etc.

Are there benefits (direct or indirect) to my involvement in the study? Your participation will provide a valuable contribution to research by testing the NEX system in your home and providing the research team with valuable feedback regarding your experience. In addition, you will receive a €60 one4all voucher as compensation for your time and effort on this research project.

Privacy Notice: The Data Controller is Dublin City University. In regard to any queries regarding the use of personal data please contact Dr Catriona Murphy (catriona.murphy@dcu.ie Ph: 700 8956 / 700 6811). Alternatively, please contact the DCU Data Protection Officer, Mr. Martin Ward (data.protection@dcu.ie Ph: 7005118 / 7008257).

Personal contact information will be collected for administrative purposes and for your consent to take part in the study. The legal basis invoked for the processing of any personal data you provide to the project is consent. You have the right to revoke your consent at any stage and ask for your perosnal data to be deleted. This will be done where your data is still identifiable. Other categories of information that we will collect include a brief outline of your participant profile, information relating to your health, video and audio recordings of the interview relating to your experience of the trial and of using the NEX system and de-identified transcripts of those audio recordings.

Deidentified audio recordings of the interview you participate in will be sent to a transcription provider. The data collected from the NEX system technologies will be securely stored by the project partner Davra. Any paper documents will be shredded immediately after the data has been entered into an electronic database. Electronic information will be stored on a limited access folder on DCU Google Drive account and on a password encrypted USB device as a backup measure. Only the DCU research project team will have access to the study information.

Anonymised datasets will be retained indefinitely. Your data will remain confidential within the limits of the law. Confidentiality of information provided can only be protected within the limitations of the law. It is

possible for data to be subject to subpoena, freedom of information claim or mandated reporting by some professions.

This data will be shared with project partner Danalto for data verification and to 8West for visual display. The information collected as part of this study will be retained for 3 years after the completion of this study for continued analysis.

You have the right to access a copy of your personal data and if you wish to invoke this right please contact Dr Catriona Murphy or the DCU Data Protection Unit. You have the right to lodge a complaint with the contact the *Irish Data Protection Commission* if you are unsatisfied with any aspect of the processing of your personal data in this project.

The research study is voluntary Participation in this study is entirely voluntary. You can withdraw at any point in time. There will be no penalty for withdrawing from the study. If you withdraw your data can be deleted if you wish unless it has been included anonymously as part of a published piece of work.

What should I do now? If you are interested in taking part in the study, please contact a member of the research team at the email or phone numbers below. If possible, please provide us with a contact number and the research team will contact you as soon as possible to discuss your participation.

Dr Emma Heffernan (trial researcher) or Dr Claire Timon (project manager) email NEX@dcu.ie phone 089 2653951

If participants have concerns about this study and wish to contact an independent person, please contact: The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie

Thank you for your consideration.