



UPDATES ON THE FLORENCE PROJECT

OCTOBER 2018

Like most people – we are having trouble believing we are quite so far into 2018. In this newsletter, we will share what we have been up to, and also share some opportunities for being involved in research with the Florence Project and with other studies at the University of Queensland.

The Lived Experience Experts have been an important part of the research and analysis processes and have been involved in sharing the findings of the research. Ron and Dennis were both involved in presenting at the “Neuroscience and Society: Ethics, Law and Technology” Conference in Sydney in August. Along with Jacki, they presented (via videos) a presentation titled

“Considering Ethics as part of Co-Designing Technology with People Living with Dementia”

The presentation, and particularly their videos were well received by a mixed audience including neuroscientists, health

professionals, ethicists, social scientists and lawyers.

If you have a particular interest in being part of presenting research, the analysis and writing, or other aspects, please email Jacki and let her know. j.liddle@uq.edu.au



Dennis Frost's presentation video asked the hard questions about technology

Ron Beleno providing the care partner perspective from Canada in his video



Teaching and talking tech

One of the issues raised by members of the reference group and participants in our research is that more education is needed for health professionals and technology designers.

Members of the Florence team have been involved in education of University students as well as community groups, retirement villages and school students.

We also involve technology and health professional students in the research projects to support their learning about the research process, issues facing people living with dementia and their care partners, and technology design. When we orientate these students to the project, we have been sharing the Dementia Friends training from Dementia Australia, and also the Hello My Name Is series from Dementia Alliance International.



Florence Project brochures at a community event

Poster for working with school children



Rachel Sluis presenting at the Improving the Health of Older People Conference in Brisbane

If you are part of a community group that might appreciate a talk from a member of the Florence team please let us know!



Jacki speaking to the U3A in Townsville

.Understanding and creating the technology

The main focus for the Florence team is to understand where and how technology may help people, and to create this technology in collaboration with people living with dementia and their care partners.

At the moment the team is focused on two big issues – one is the “back end” or the hidden part of technology that stores information, keeps things secure and allows things to be retrieved at the right time.

As part of this work, we are working on:

- Finding out whether computers can detect when someone needs some communication help through what they are saying and their vocal patterns (and how this compares to what speech pathologists notice)
- Figuring out how best to store the information people would like to “bank” – and how best to let that information to be released to only the right people.

At the same time, we are working on the “front end” or the parts of technology that people interact with. We have been listening to people’s perspectives and experiences with technology and trying to understand how best technology should look, behave and fit in with people’s lives.

We have looked particularly at people’s ethical concerns, but also people’s hopes for technology.

Technology just for you

An exciting new project that is starting up for the team, is working with a person living with dementia and their families, to build a piece of personalised technology. This means that we will work with each household to:

- Identify a goal or issue where tech might help
- Get your ideas about what the tech should and shouldn’t do
- Make a few things to get feedback and get us on the right track
- Keep meeting up and improving the technology
- Leave it for you to try out and give some more feedback.

If people find the technology helpful and working well, they can keep it at the end of the project.

We are seeking people in Brisbane (or close by) to be involved. Please contact Jacki if you are interested:
j.liddle@uq.edu.au

Research projects currently seeking participants

The Florence Project has a number of active projects that are currently seeking people living with dementia and their care partners to participate. We also have one seeking professional (paid) carers. Please share this information with anyone who may be interested. Please also let us know if you are interested in being part of any of these studies. **Please email Jacki (j.liddle@uq.edu.au) or call the team on 07 33659765 to register your interest.**

Study 1: Communication changes and needs: This is a study exploring needs and experiences related to communication changes for people living with dementia and their communication partners, as well as their experiences with technology. It involves between 2 and 6 visits and would include conversations, language tasks and interviews. South East Queensland only.

Study 2: Professional caregiver perspectives: This is a study arising from suggestions that technology could help to skill paid carers up about people's needs, preferences and routines, as well as supporting their communication. We are seeking paid caregivers from Australia. Participation could be face to face or over Zoom/Skype or phone. Please email Amanda: a.gellatly@uq.edu.au

Study 3: Personalised technology: This study involves working with the team to create a

Other Projects at the University of Queensland

I have had a number of people ask to hear about other studies that they might be able to get involved in – so we will start highlighting some projects here.

The first is a clinical trial of the CarFreeMe program. This is an education and support program to help with adjustment when someone stops driving. Current trials are seeking people living with dementia in a number of locations in Australia. More details at: <http://carfreeme.com.au/carfreeme-launches-new-trials-for-people-living-with-dementia/> or email Donna Rooney: donna.rooney@uq.edu.au.

CarFreeMe

piece of technology to support a need or goal. We are seeking people living with dementia in the Brisbane region. (More details on previous page).

Study 4: Ethical and value-based considerations: This study will involve people living with dementia, family members, health professionals, technology designers and other interested people in exploring ethical concerns. Participation could be face to face (in Brisbane) or via phone/online.

Joining the lived experience experts
People with lived experience (people living with dementia and their conversation partners) are welcome to join the lived experience expert reference group at any time. Let people you know who may be interested about the group.
Email Jacki: j.liddle@uq.edu.au