

AN OVERVIEW OF LIVED EXPERIENCE EXPERT REFERENCE GROUP ACTIVITIES IN 2017

JANUARY 2018

A busy year in 2017

The Florence Project had a busy year in 2017. It marked the start of the Lived Experience Reference Group, two public showcases were held and a number of studies started.

The Lived Experience Experts have provided essential guidance to the project, with highlights for the year including:

- First round of consultation including guidance on overall focus, research method acceptability, feedback on ideas and generation of a wishlist.
- Development, trialling and feedback on prototype technology including: Simple games (*Proverbial, Grammar Game*), Apps for communication and sharing with family/friends and practicing names (*Postcards, Photo Album*)

Prof Helen Chenery
Speech Pathologist

Prof David Copland
Speech Pathologist

Peter Worthy
Interaction Design

Dr Brooke-Mai Whelan
Speech Pathologist

Dr Andrew Back
Machine Learning

Dr Paul Vrbik
Computer Scientist

Tariq Segal
Business &
Nanotechnology

Dr Anthony Angwin
Speech Pathologist

Prof Janet Wiles
Computer Scientist

Dr Jacki Liddle
Occupational Therapist

**The Florence Lived
Experience Expert
Reference Group**

Dr Daniel Angus
Computer Scientist

Ben Foley
Designer and Developer

Dr Yvonne Yu
Engineer in Signal
Processing

Florence project team of 2017

- Involvement in showcases
- Sharing perspectives of reference group in lectures to public, interest groups and students

What we learned from the Lived Experience Experts in 2017

Some key directions provided to the Florence Project by Lived Experience Experts in the past year included:

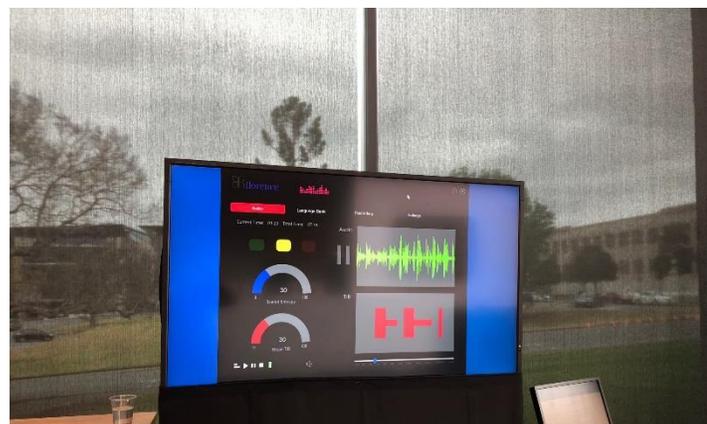
- Accessibility of the reference group and research is important – a range of options in terms of time of day, location and media (face to face or technology) should be offered and a flexible approach taken.
- Should be able to be involved when it suits and not at other times without being excluded
- Offering payment for time and consultation is important
- Invitations to events is welcome, even if people are not always keen to speak/present.
- A flexible approach to data collection is important and limit formal cognitive assessment to only absolutely essential.
- Audio recording is generally acceptable but it is important to check each time.
- **Technology should**
 - **Make the day go better**
 - **Use current strengths and skills**
 - **Help people to connect and share**
 - **Recognise everyone is different and changing over time**
- A language bank to store memories and individual use of language was interesting.
- Games that reflect individual interests and abilities, and that can involve

others in making and adjusting them are of interest.

- A “one size fits all” approach will not be successful.
- Start with what is familiar and working.
- People might use the same technology differently – everyone has great ideas.
- Screen size is important.
- Many different ideas about what the technology should look like.



A display at the showcase exploring what Florence technology should look like



A display at the showcase showing the “back end” of Florence detecting trouble in communication and indicating when help might be needed.

Research projects currently seeking participants

The Florence Project has two active projects that are currently seeking people living with dementia and their care partners to participate. Please let us know if you are interested in being part of either of these studies and pass on to others who may be interested. **Please email Jacki (j.liddle@uq.edu.au)**

or call Beck (07 3365 3988) to register your interest.

Study 1: Communication and technology:

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 a single interview and can be done at home for people in South East Queensland or remotely via phone or Skype/Zoom.

Study 2: Developing a language bank: This is a study exploring whether it is possible to develop and store meaningful language and memories to form a personalised bank of information for people living with dementia. Participants would need to live in and around Brisbane, have mild to moderate dementia or be a family member/communication partner. This study involves up to six home visits by a health professional and is very flexible.

Next steps for the Lived Experience Experts Reference Group

In 2018, there will be more ongoing projects and information will be forwarded to the Lived Experience Experts.

Our initial focus will be:

1. Exploring ethical issues
We will be exploring the ethical issues that need to be considered when developing technology with people living with dementia.
2. Trialling prototypes
For people living in Brisbane, we will be inviting people to try out and give feedback on some early versions of the technology
3. Events and presentations
An important part of the centre is sharing the work we are doing. We would love lived experience experts to be part of presentations or attend events and will send out information to the group.

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