Implementing the Social Brain Toolkit

1. Summary of impact

The Social Brain Toolkit is a series of free, online communication training tools funded by iCare NSW and developed in collaboration with the University of Sydney, Brain Injury Australia and Changineers. It supports people with brain injury, their loved ones and carers to connect, communicate and interact successfully.

In this project, UTS PhD student and speech pathologist Melissa Miao is implementing the Toolkit through a series of dissemination strategies and design and technical improvements that were developed through user feedback. She's exploring how users want to hear about the Toolkit, what they do and don't like about the content and the interface, and how its features could be made more useful. The result is a series of programs that are richly embedded with living experience, making them more effective, more accessible and more impactful for future users.

2. The problem

Brain injuries including stroke and traumatic brain injury <u>affect over 135 million people</u> <u>globally</u> and can have a detrimental impact on communication ability. Speech pathology plays an important role in helping people with brain injury regain their capacity to communicate effectively, both in person and online. However, limited access to and implementation of resources to support communication means that many people with brain injury and those who care for them struggle to access the support they need. Connecting people to resources that can help them rebuild and maintain relationships after brain injury is crucial to both equitable healthcare access and our universal human right to communication.



3. Beneficiaries

Communication deficits that often result from brain injury don't just affect the individual: their friends, family, carers and communities may also struggle to interact with them in a way that works for both parties. The Social Brain Toolkit has been developed to support all these stakeholders; as such, its implementation has the potential to provide important benefits to countless people around the world.

4. Approach to impact

The Toolkit is comprised of three tools: convers-ABI-lity, which supports people with brain injury and their nominated 'communication partners' (friends, spouses, carers or family members) to improve the quality of their conversations; interact-ABI-lity, which helps family members, friends, carers and the general public learn to interact successfully with people with brain injury; and social-ABI-lity, which helps people with brain injury learn to navigate social media safety and successfully.

Melissa's work is focused on understanding the dissemination and user experience of each tool. She does this by examining web analytics and user feedback surveys and conducting a series of in-depth interviews with the Toolkit's intended users (described above). She then takes participant experiences and recommendations and translates them into changes that can be rapidly integrated into the tools.

Melissa has shared her research broadly, making it publicly available Open Access and disseminating it through national and international conferences and public videos. She was selected to receive an international fellowship to share her findings in the United States, and to represent UTS internationally in the Visualise Your Thesis and 3-Minute Thesis competitions.

5. What has changed as a result of this work?

The Toolkit is now richly embedded with the expert living experience of real users with brain injury, their families, friends and clinicians. The first tool, interact-ABI-lity, reached more than 1000 users from across 29 countries in its first year, with users improving knowledge and confidence communicating with people with brain injury, and reporting

20.09.2022

high levels of satisfaction with the tool. Interact-ABI-lity has also been embedded into speech pathology training at five American universities. social-ABI-lity is halfway through a 12-month study, and convers-ABI-lity will be launched in 2023.

The Social Brain Toolkit provides a much-needed resource for people with brain injuries and their communities who might otherwise miss out on evidence-based care. These are promising early-stage results, paving the way for significant impact as the Toolkit matures; Melissa's research provides an important evidence base that can now be used to inform future work in both implementation science and brain injury research.

6. What has helped you accomplish this work?

The crucial firsthand insights of people with brain injury, their families and clinicians helped researchers understand how the tools could be delivered in the real world. The grant enabled end users to be reimbursed in acknowledgement of their expert living experience, as well as Open Access sharing of Melissa's research methods.

7. Challenges

One of the key challenges of using interview and survey data to inform the iterative design process was the speed at which the changes needed to be made. User feedback and data was rapidly translated into design and dissemination changes to the tools — a challenging prospect given the time lags normally associated with academic research.

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External partners: Brain Injury Australia, iCare NSW, the University of Sydney Acquired Brain Injury Communication Lab, Changineers.

*Melissa is supported by an Australian National Health and Medical Research Council (NHMRC) Postgraduate (PhD) Grant [GNT1191284], an Australian Research Training Program (RTP) Scholarship.