Aphasia Fit: Supporting and Motivating People with Aphasia to Manage their own Aphasia Treatment

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A research centre of the STARS Education and Research Alliance
CREATING KNOWLEDGE | TRANSFORMING CARE

Medical Research Future Fund

Australian Aphasia Association

The University Of Queensland AUSTRALIA
CREATE CHANGE

Metro North Health

Queensland Government

Acknowledgement of Country

The University of Queensland (UQ) acknowledges the Traditional Owners and their custodianship of the lands on which we meet.

We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

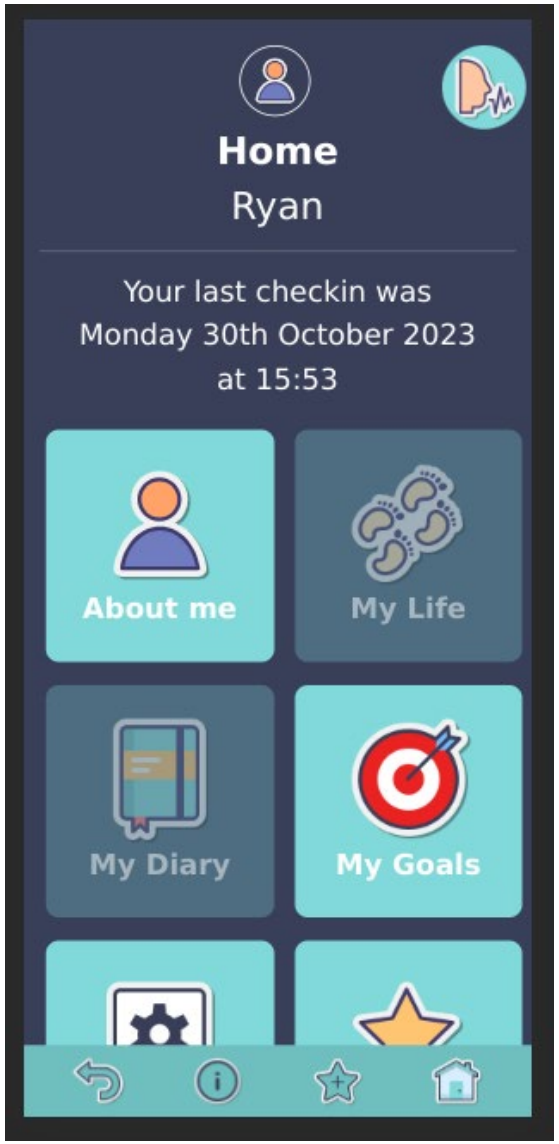
We recognise their valuable contributions to Australian and global society.

Sarah

Gopal

AphasiaFit

1. Why we did this research.
2. What we did and the results and outcomes.
3. What the experience has been like.
4. What is next.

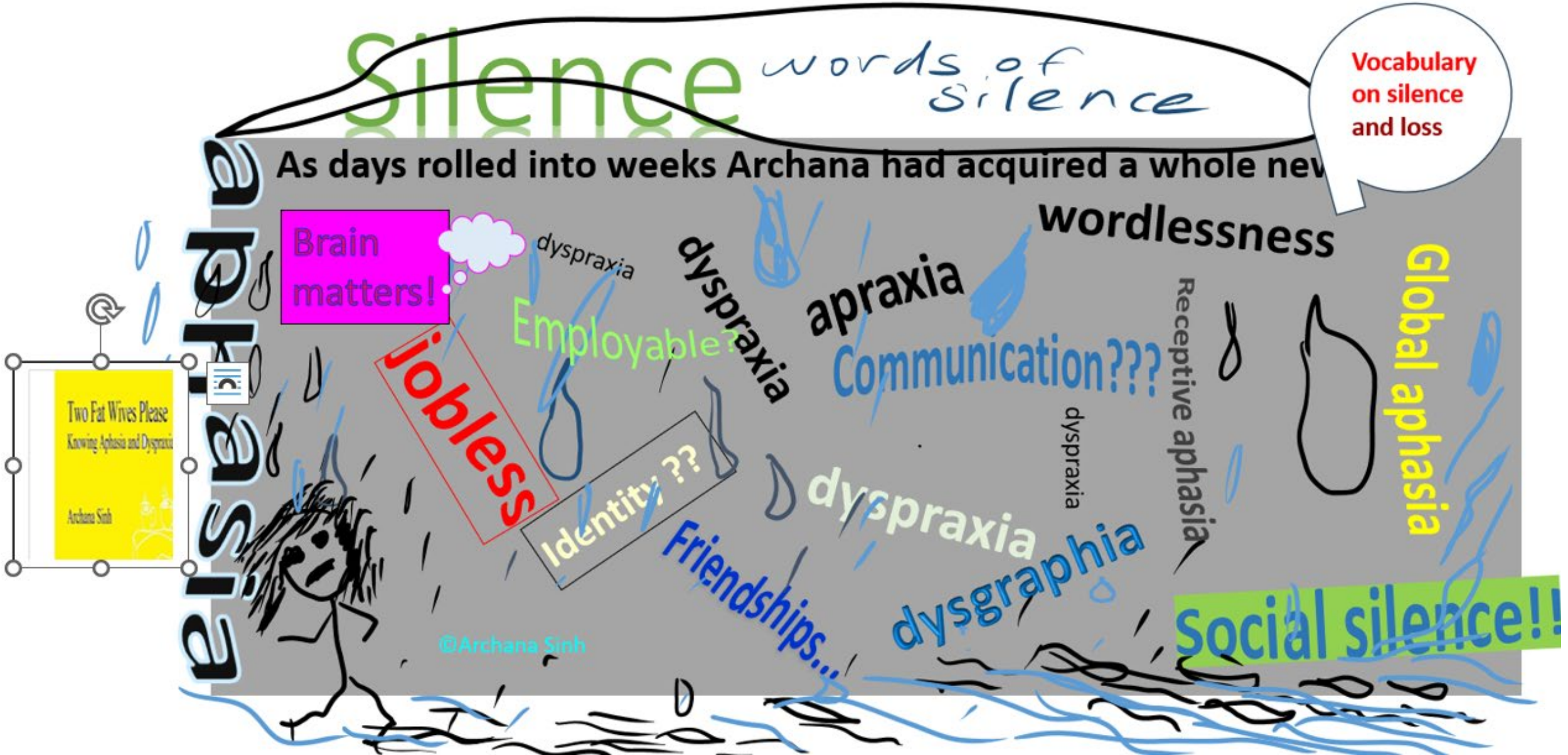


The Research Team

The Team (n=95 and counting)

Why?

You can see how far you've walked... but language is hard to see.


Silence
words of silence
Vocabulary on silence and loss
As days rolled into weeks Archana had acquired a whole nev
aphasia
Brain matters!
dyspraxia
Employable?
dyspraxia
apraxia
wordlessness
Global aphasia
jobless
Communication???
Receptive aphasia
dyspraxia
Identity ??
dyspraxia
Friendships...
dysgraphia
Social silence!!
©Archana Sinh
Two Fat Wives Please
Knowing Aphasia and Dyspraxia
Archana Sinh

If you can’t see progress, are you going to be motivated to do therapy?

And how do you really track progress when someone is back at home?

What do we know?

- We know people with aphasia have **long-term unmet needs and poor quality of life**. **Wray et al. 2017, Lam et al. 2010**
- We know aphasia therapy is **effective in the short-term**, however **access to treatment is insufficient** and **gains are often not maintained**. **Brady et al. 2016**
- We know **self-management can provide an effective and sustainable alternative** to traditional care. **Fryer et al. 2016**
- We know that people with aphasia need a "**personalised communication infrastructure"** to self-manage and this includes technology. **Nichol et al. 2021, 2021, 2022, 2022.**

What do we know?

- We know that lived experience tells us **aphasia recovery is hard to 'see'** and that effects motivation. **Gopal et al.**
- We know **technology can support access and adherence** to therapy and that **mHealth or mobile health** has been used in other areas to **motivate** people through monitoring and tracking of progress. **Hamine, 2015**

Tech Map – There's a lot happening!

Aphasia Tech Map: Aphasia Rehabilitation Research Technology Mapping Project (robcavanaugh.com)

Aphasia Rehabilitation Research Technology Mapping Project

The Aphasia Tech Map is a product of the Collaboration of Aphasia Trialists Working Group 4, sponsored by the Centre for Research Excellence in Aphasia Recovery and Rehabilitation.

Florence and Aphasia in the Wild– Measuring Language

Aims to produce a software resource that makes Natural Language Processing relevant to aphasia available to researchers and clinicians.

Outcomes

Software library with measures relevant to aphasia research and clinical practice including:

1. Tokenization and pre-processing
2. Utterance length
3. Turns (length and duration)
4. Pause length
5. Removal of auxiliary verbs
6. Grammar correction

On github and PyPI soon!

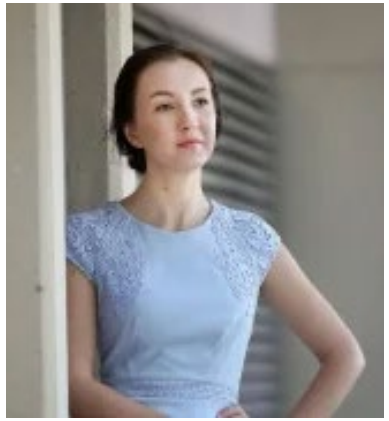
Current Goals

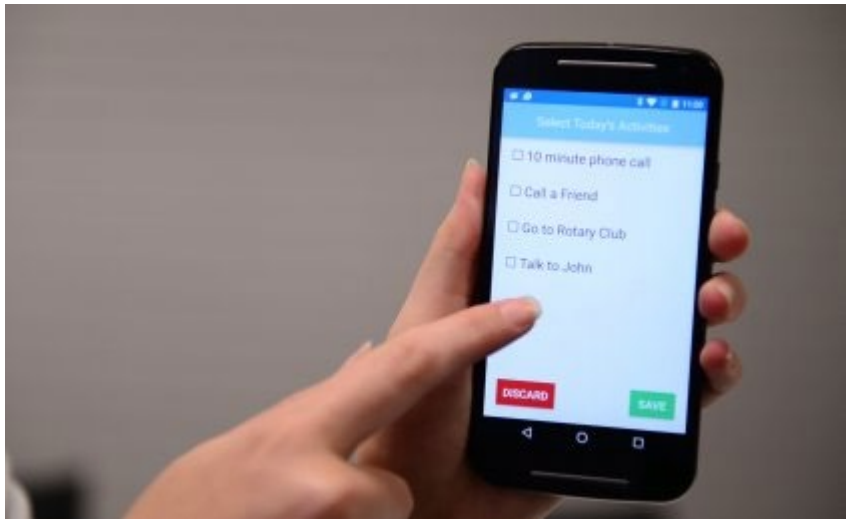
1. Add to the available analysis functions
2. Develop a same graphical user interface to be used by researchers and clinicians
3. Build an API to allow connection of apps to the analysis functions
4. Extend the guide on how to use the system

This research was conducted with support from the ARC Centre of Excellence for the Dynamics of Language (Project ID: CE140100041). ARTHub funded by the Australian Government Research Support Program.

CommFit – Measuring Communication and Participation

- COMMFIT– Brandenburg et al.
- Personalised communication tasks
- Measures of talk time
- Bone conduction microphone





Communication Connect – Measuring Mood

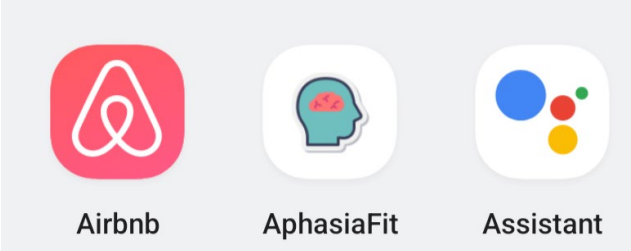
- D-VAMS (Burrows et al)
- Brief non-verbal mood assessment
- To be integrated as a component of Communication Connect (Rose et al).

Paul Burrows
https://www.nottingham.ac.uk/medicine/documents/published-assessments/dvams-user-guide.pdf

We wanted….

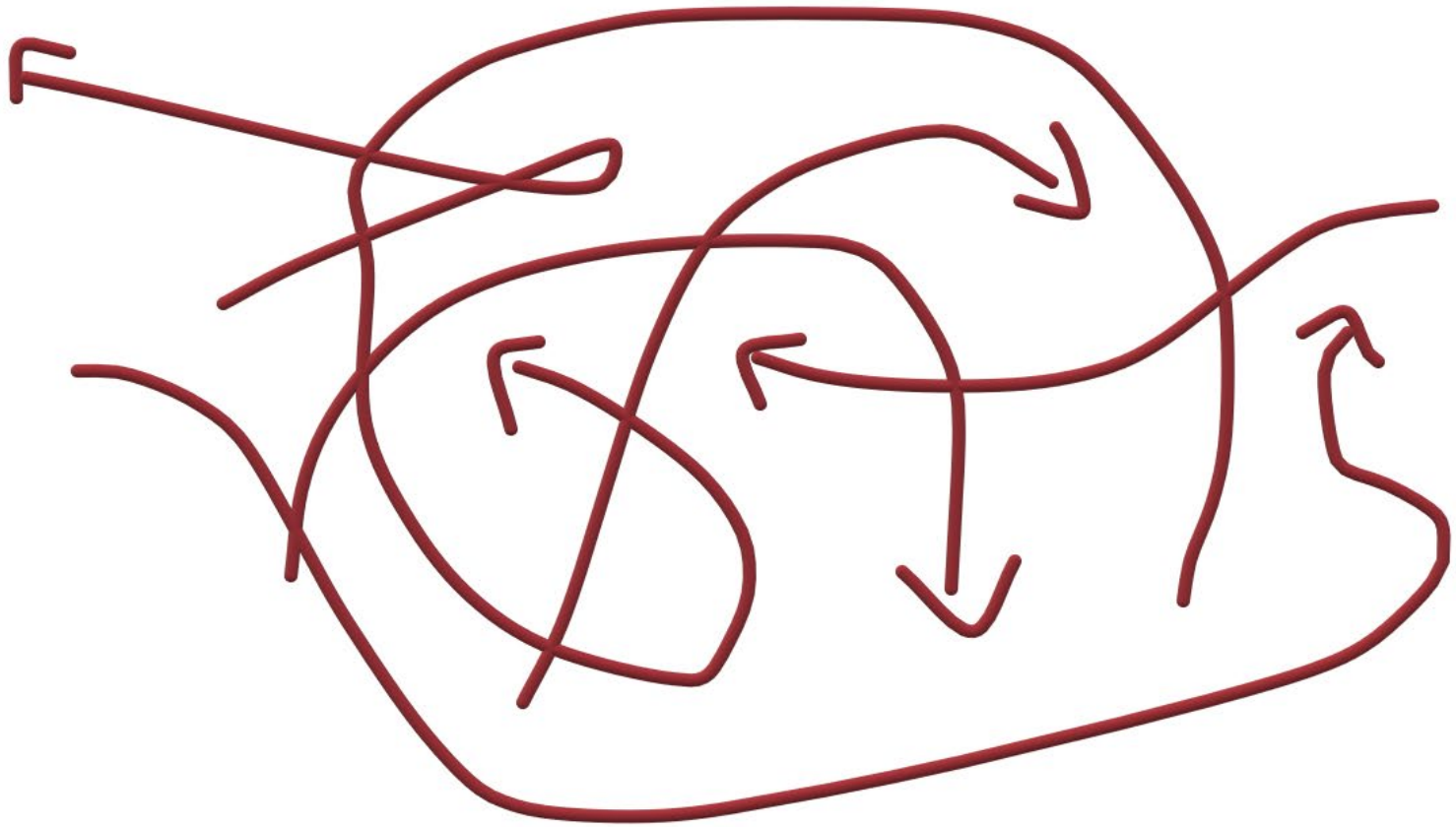
to support **access** to therapy from home.

to **motivate** people with aphasia to do more therapy.

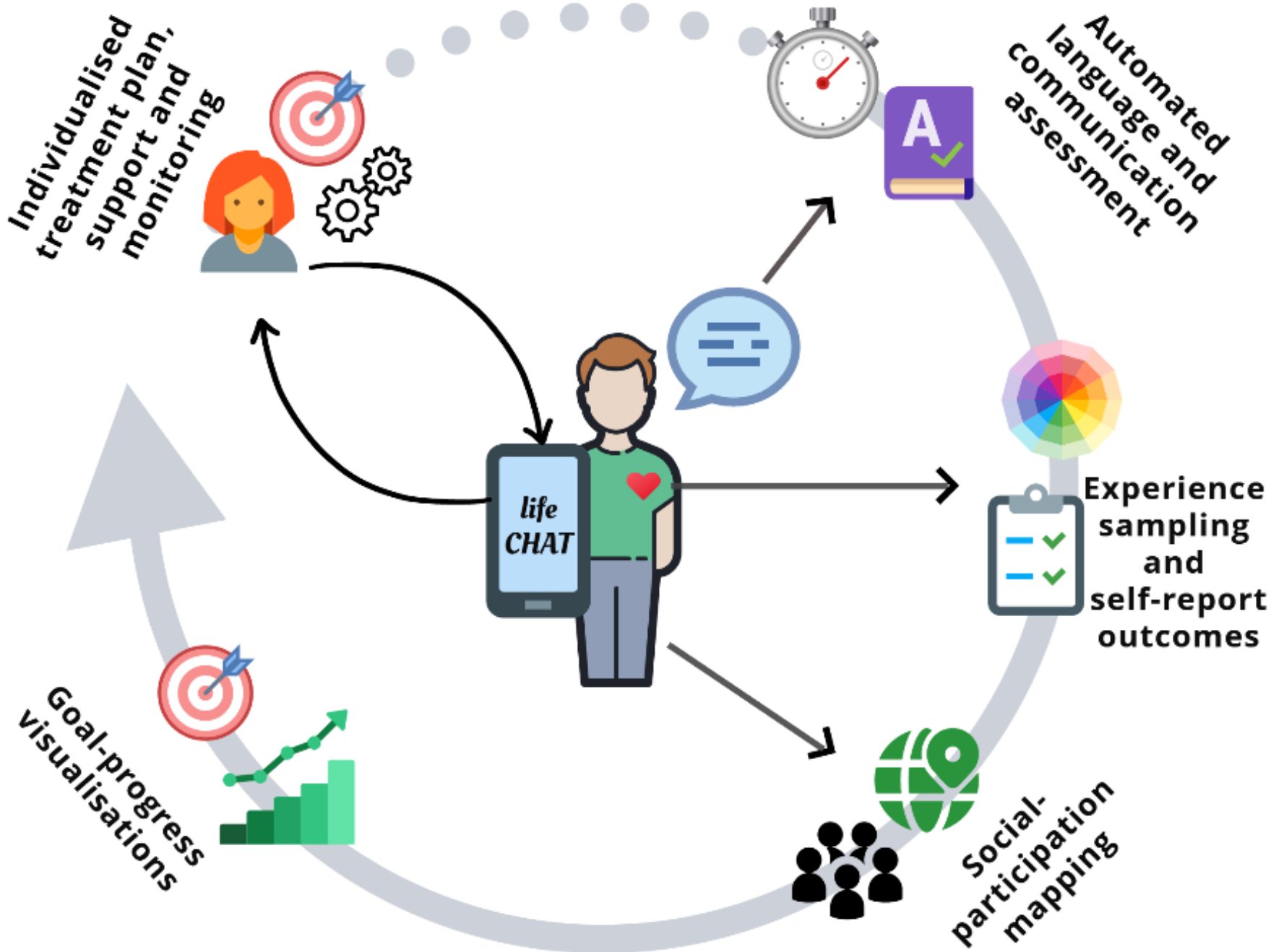


…by developing **an App** that can measure aphasia progress.

Initial design based on existing research



Review and celebration event


Individualised treatment plan, support and monitoring
Automated language and communication assessment
life CHAT
Experience sampling and self-report outcomes
Goal-progress visualisations
Social-participation mapping

Stage 1: Experience Gathering

Online focus groups using a nominal group technique:

- 13 people with aphasia
- 8 family members
- 10 health professionals

"What would help you do more aphasia therapy at home?"

Positive and Negative experiences

113 ideas for supporting and motivating self-managed aphasia treatment.

(1) Therapy opportunities and therapy support

- Ongoing therapy/support from **speech pathologist**
- Ongoing treatment and support from **other professionals** and through **community activities**
- **Peer** supported therapy
- **Everyday opportunities** for therapy
- Support to **access and manage** therapy

"Chat Roulette…But not as scary - available at any time, trusted people, prompts to get people talking - group of people can form - short quick chats."

(2) Information and resources for aphasia therapy

- Aphasia **therapy resources**
- **Information** about **aphasia therapy**
- **Information** about **aphasia**

"It would be helpful to receive information about aphasia services and support groups (including where/how to access them) in a discharge kit."

(3) Tailored technology

- **Personalised** to support communication and therapy
- Apps with **customisable** presentation
- Apps that **support independent therapy practice**

"Journalling and reflections"
"Realistic voices"
"Simple presentation"
"Culturally appropriate voices and language"

(4) Psychosocial support

- **Psychological support** for people with aphasia and families
- **Peer support** for people with aphasia and families
- **HP support** for families

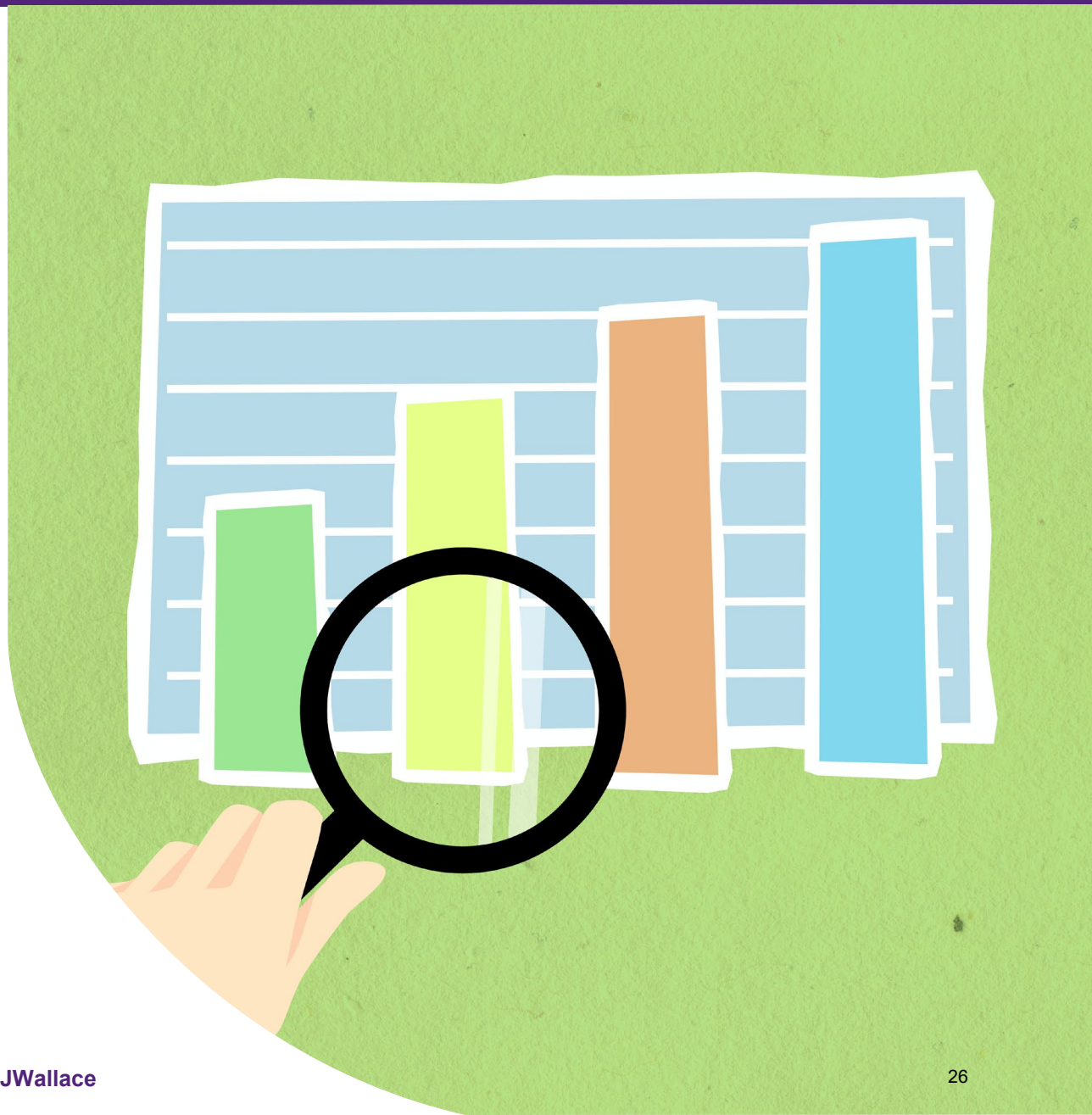
"It would be helpful to **recognise** the **impacts** that aphasia may have on **getting** back into the **community** and **adapting** to a new way of being yourself."

Aphasia Buddy
Connecting with people who have similar experience (commonality) and ability to support that connection.

(5) Visualising progress

- **Visual representation** of progress that links goals and outcomes
- **Automated** language analysis with metrics
- **Feedback** based on monitoring

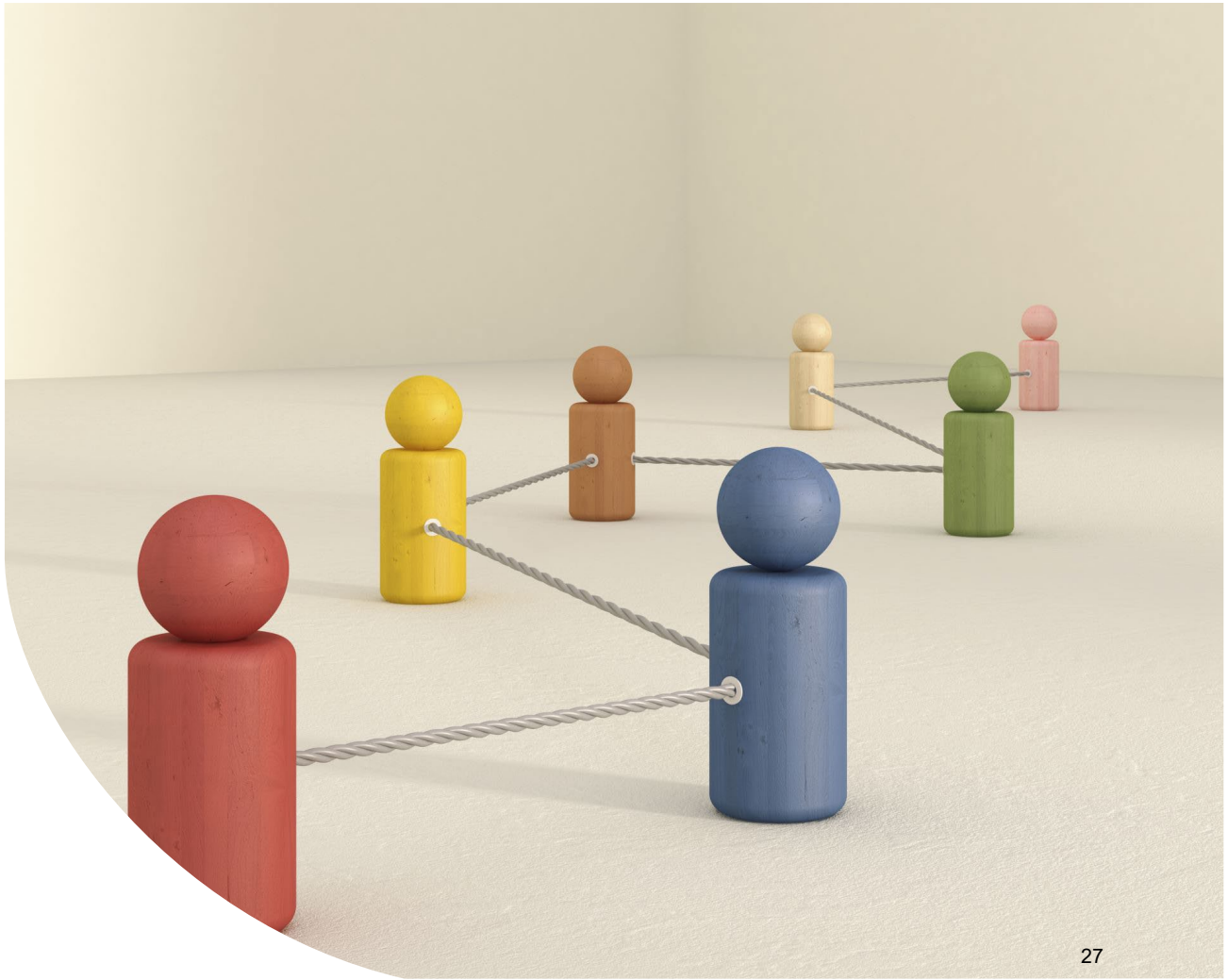
"Own goals linked to progress, with celebration of progress"



(6) Communication partner training

- Communication Partner Training **for medical and health professionals**
- Communication Partner Training **for families**
- **Practical and interactive**

"More than just reading (group, video presentation, etc). Demonstrating effectiveness of using different strategies. Providing practical strategies and examples."



(7) Motivating therapy & feedback

- **Motivating** therapy
- **Age and culturally appropriate** encouragement

“Need for therapy to be inspiring - an inspiring "virtual" therapist who makes you want to "have a go".

So our app needs to…

Connect you with speech pathologist and peers and community

Link goals-therapy-outcomes

Show **progress visually**. In a way that is **appropriate and motivating**

Help you **find information** and **share information**

Be **customisable and accessible**

Funding

Medical Research Future Fund

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Australian Government
National Health and Medical Research Council

NHMRC

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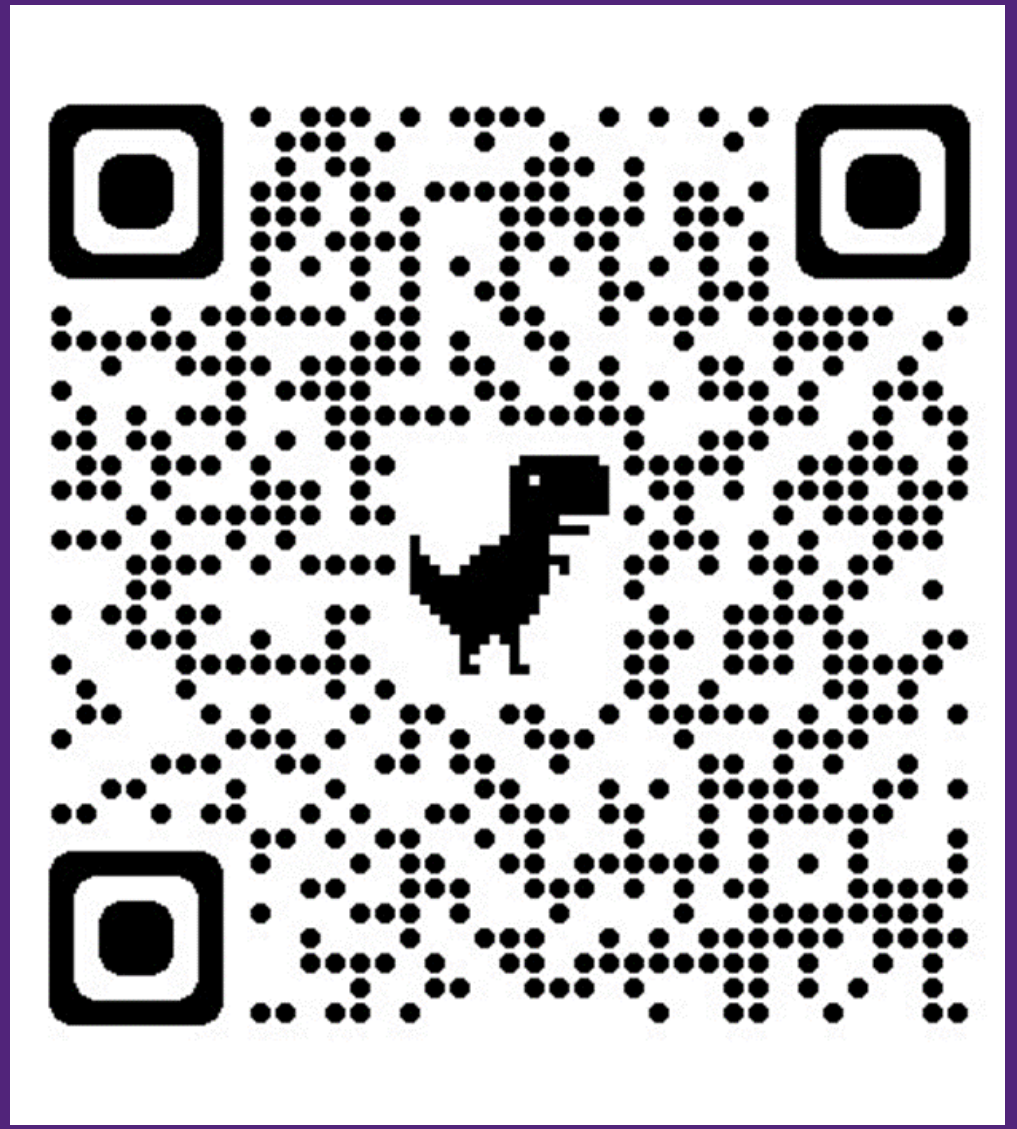
An acknowledgement

Dr Jessica Campbell
Chief Investigator

Questions?



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Queensland Aphasia Research Centre

Thank you

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