

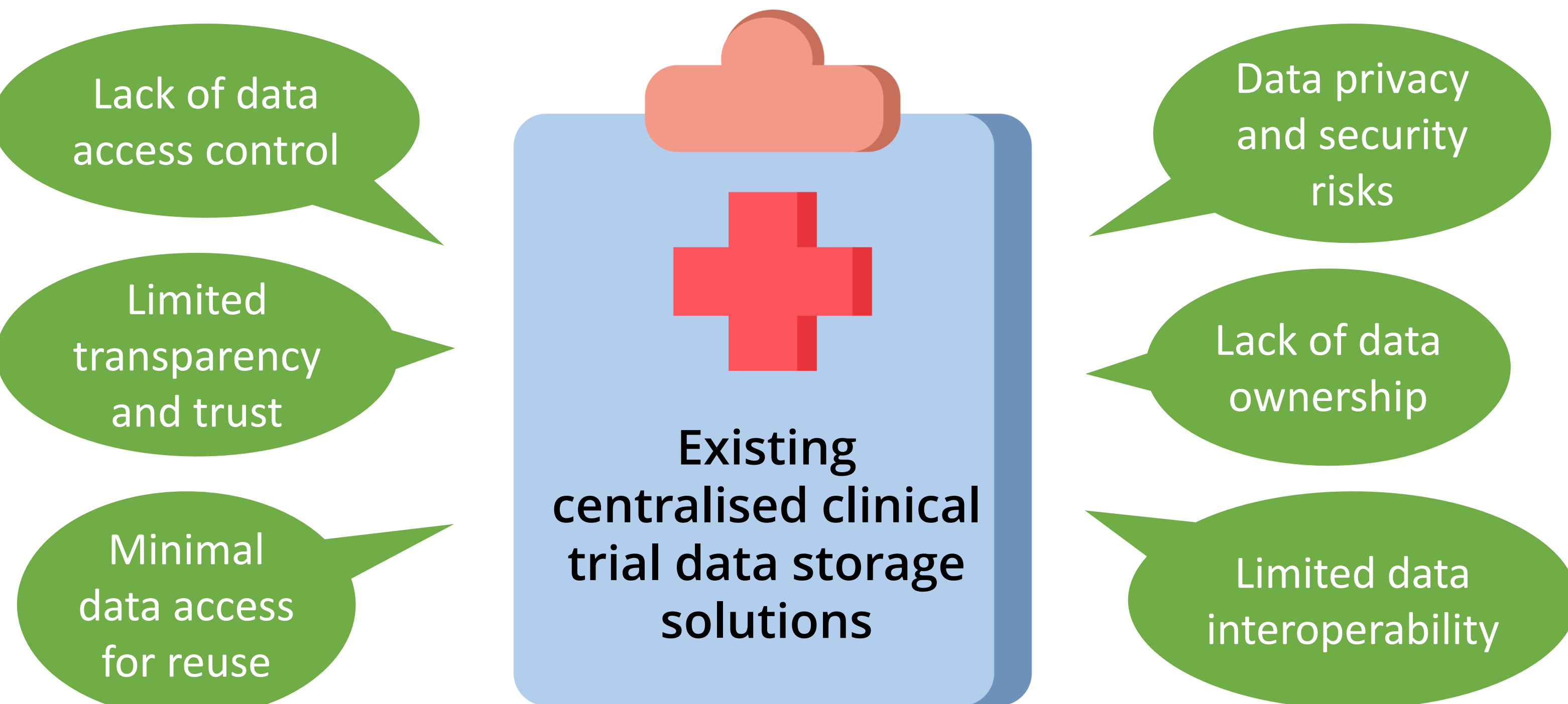
Rio: Federated Privacy-First Data Collection in Medical Research Clinical Trials using Personal Online Datastores

Sergio José Rodríguez-Méndez¹, Anushka Vidanage¹, Dawei Chen¹, Jess Moore¹, Yang Chen¹, Caley Sullivan², Graham Williams¹

¹The Australian National University (ANU), Canberra, ACT, Australia

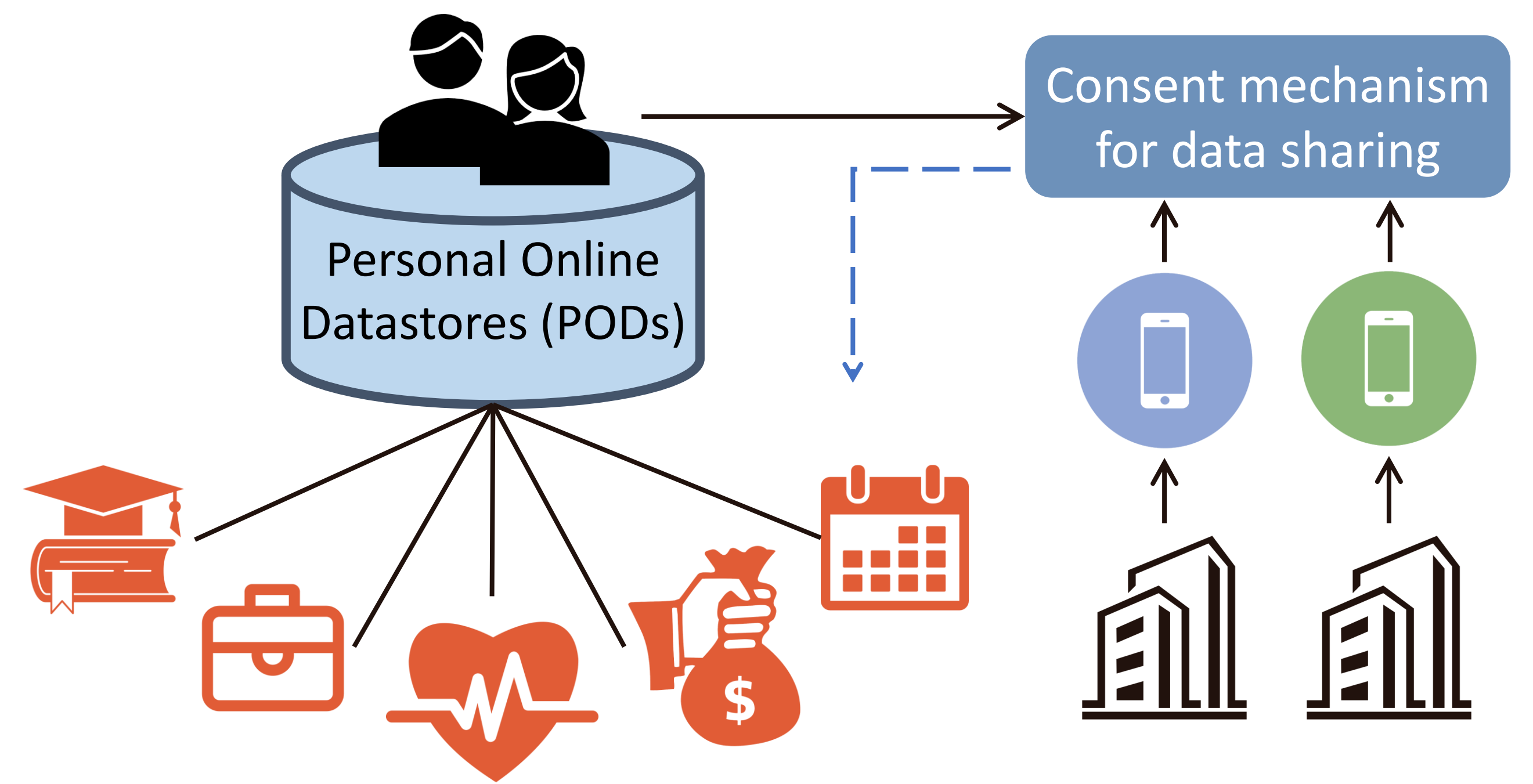
²ANT Neuro Australia, Blackburn, VIC, Australia

Motivation



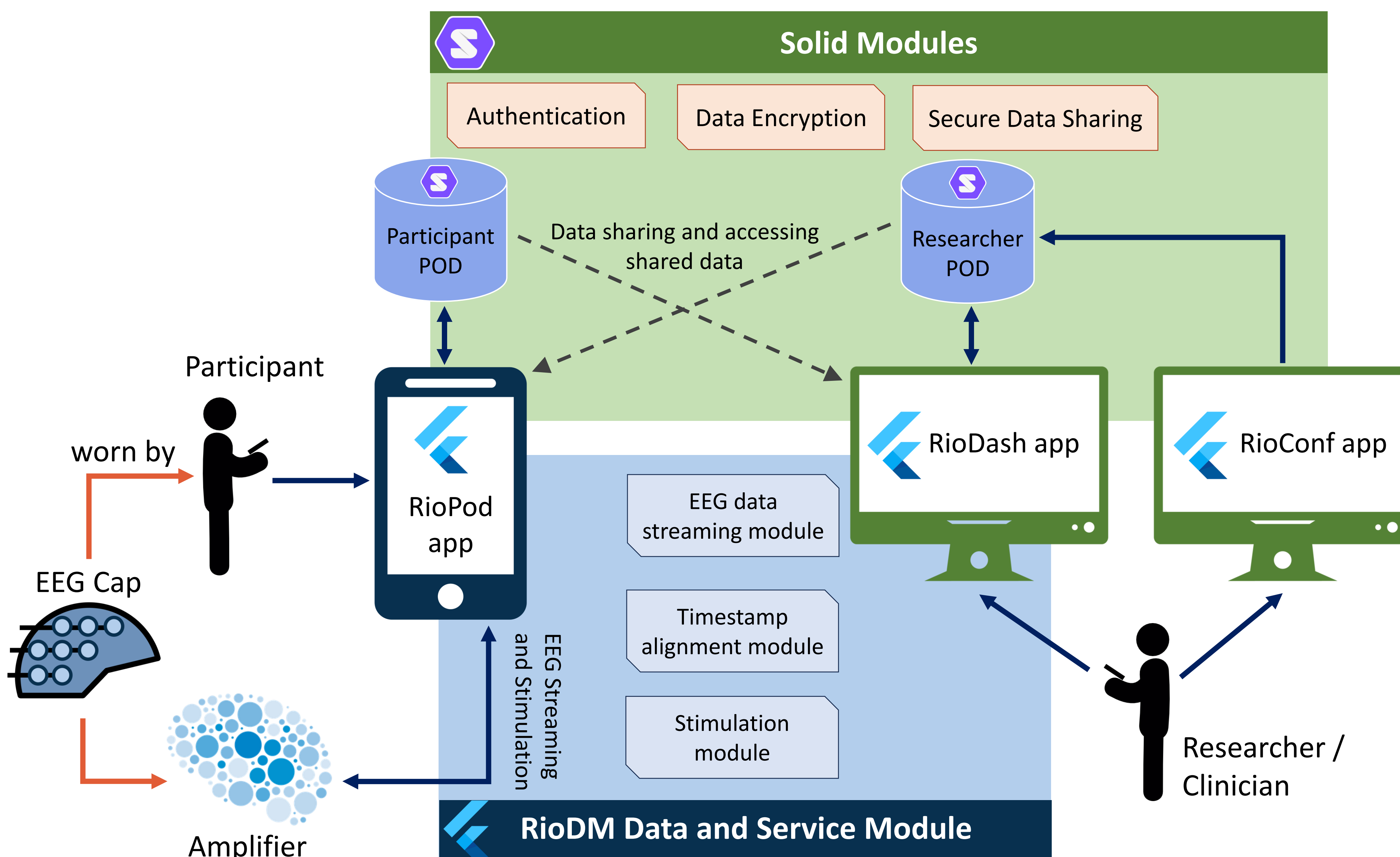
- Clinical trial data is typically collected, hosted and managed by researchers (or their institutions), usually with minimal control or access given to the participants in the trial.
- Such centralised data collection can lead to issues such as unknown privacy and security risks, lack of proper consent mechanisms, and limited transparency and trust.

Personal Online Datastores



- **Personal Online Datastores (PODs)** is a place where you can store your personal data. With PODs, data is separated from applications, allowing individuals to retain full ownership and control over their own data.
- PODs allow individuals to control their data, enabling them to be smarter about sharing and accessing data to participate in society and innovate in the data economy.

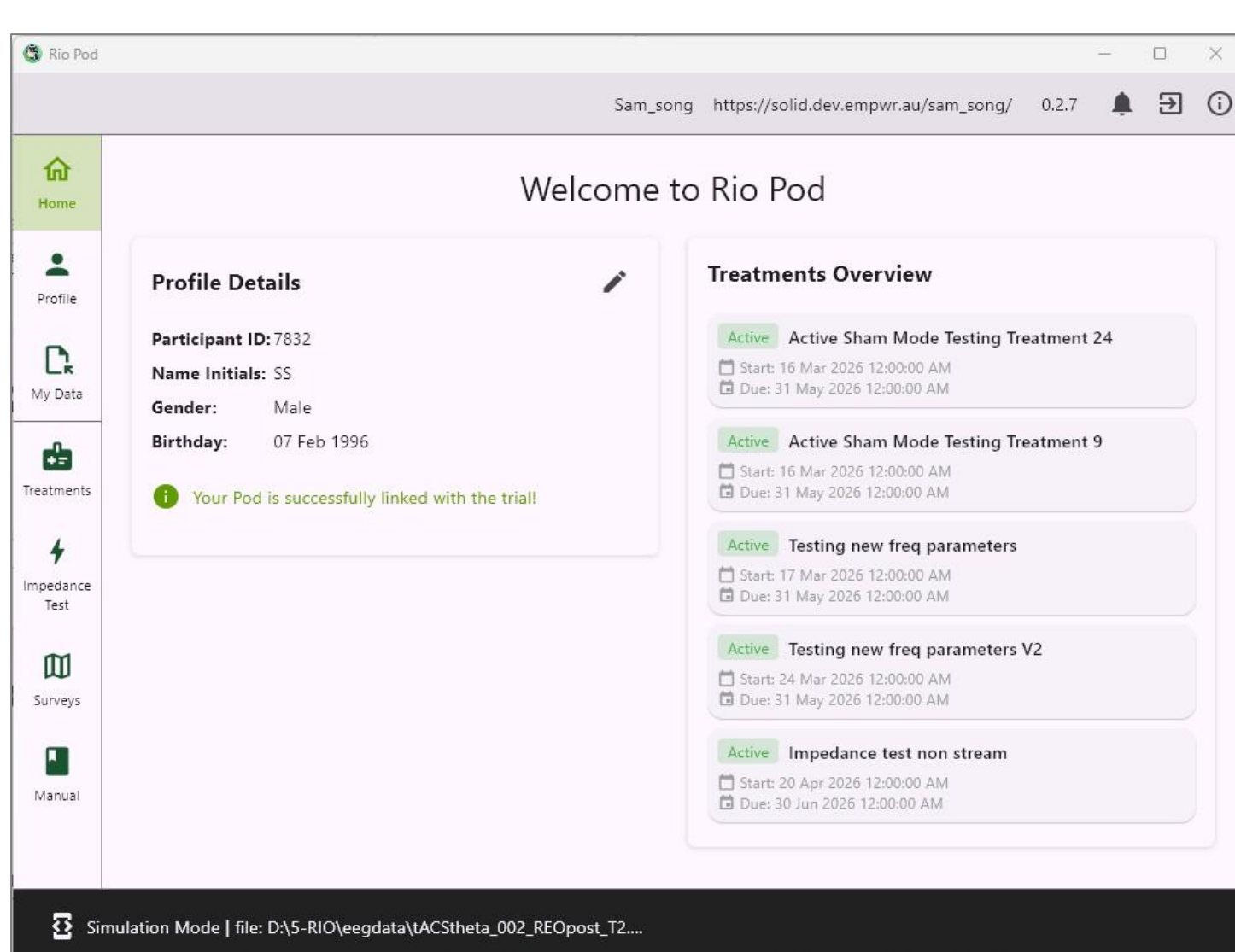
Rio: Engineering Decentralised Clinical Trial Data Storage Solution



Solid (Social Linked Data) is a decentralised data management platform that lets people store their data in PODs and control how applications access and use that data.

- **ANU Software Innovation Institute (SII)** is collaborating on a project led by the **ANU School of Medicine and Psychology** to reinvent how we undertake ethical clinical trial research.
- Through Solid (<https://solidproject.org/>) PODs, we have implemented a participant-centred framework for data collection and ownership for a clinical trial of a home-based therapeutic system for depression treatment.
- For the trial, we have developed three software applications and a data model to enable secure collection, storage, and sharing of trial data.

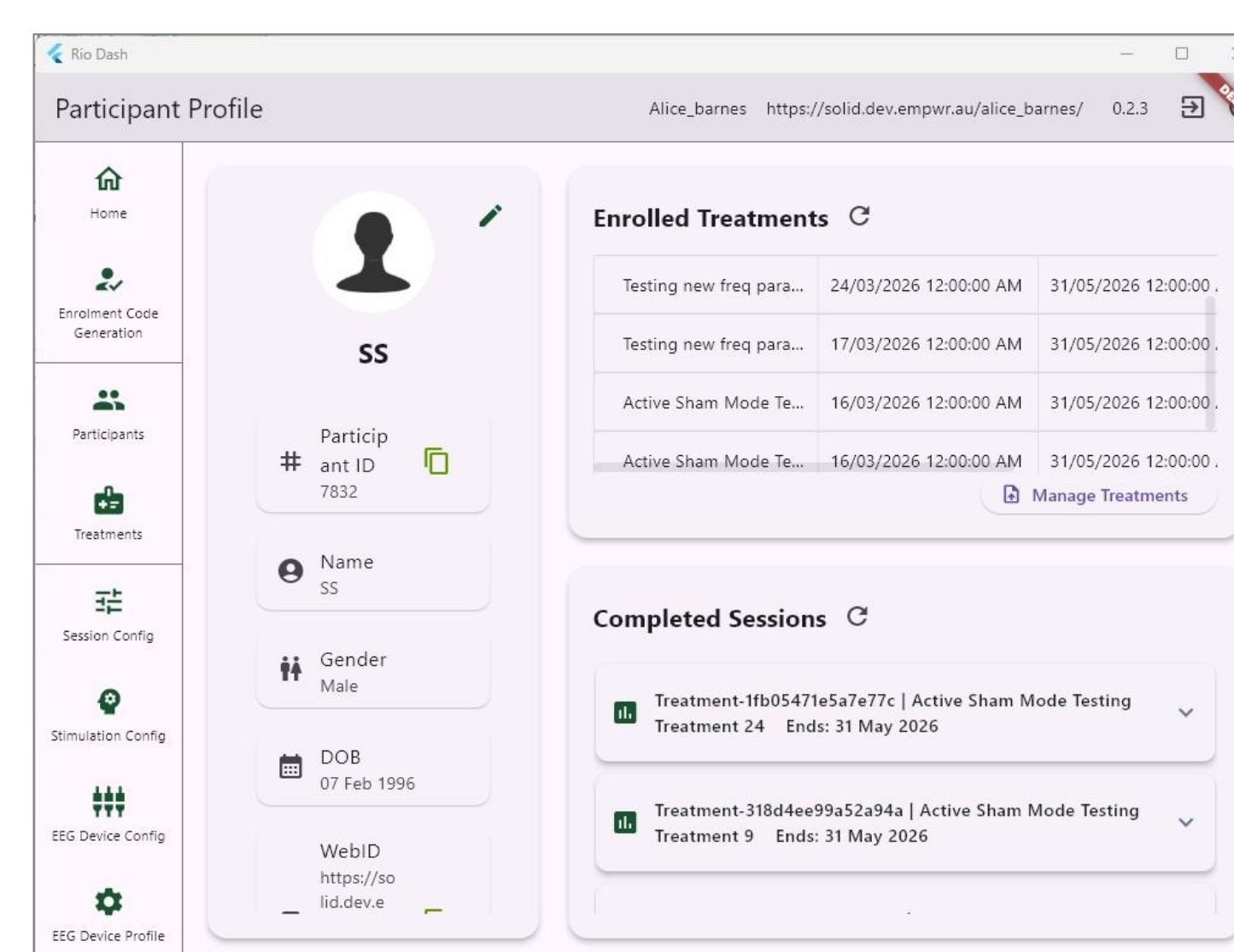
User Interfaces



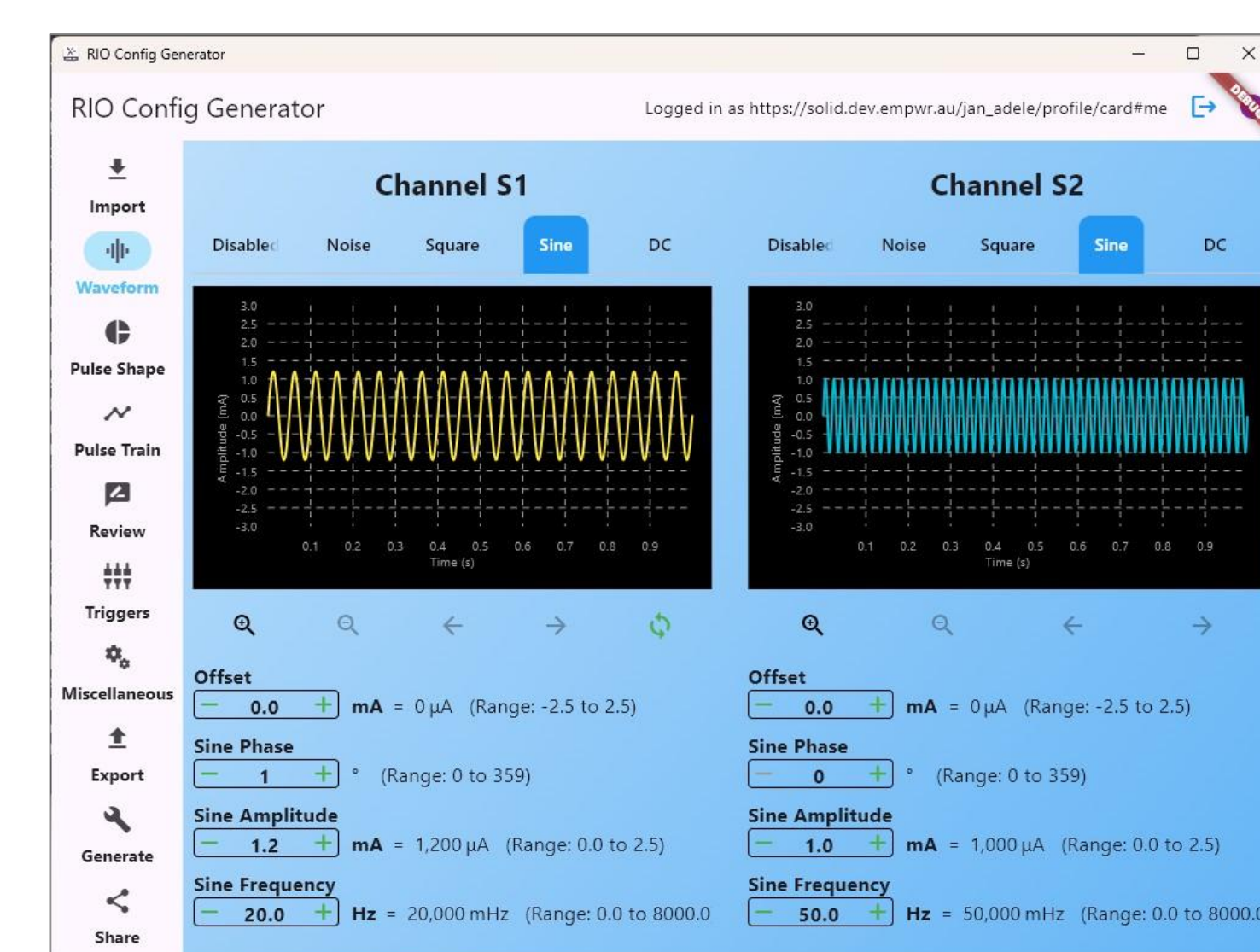
RioPod - Participant facing app to conduct trial treatments which can be run either on a desktop or a mobile device



RioPod – Flanker working memory task while streaming and recording EEG data



RioDash – Researcher facing app used to configure trial treatments and assign each treatment to the trial participants



RioConf – App used by the researcher to configure the EEG amplifier device parameters for a stimulation session

Acknowledgements: This work has been undertaken in collaboration with **ANU School of Medicine and Psychology** and **ANT Neuro** with support from the Australian Government's Medical Research Future Fund National Critical Infrastructure Initiative Grant. The developed apps used SII's open-source Solid based flutter packages - *solidui*, *solidpod*, *solid_auth* - for managing of clinical trial data.



Australian National University

Software Innovation Institute

ant neuro
inspiring technology

ANU Software Innovation Institute • School of Computing
Australian National University • Canberra • Australia
sii.anu.edu.au | Prof Graham Williams | graham.williams@anu.edu.au