

Who owns your medical data?

Rio: Federated Privacy-First Data Collection in Medical Research Clinical Trials

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Australian
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Motivation

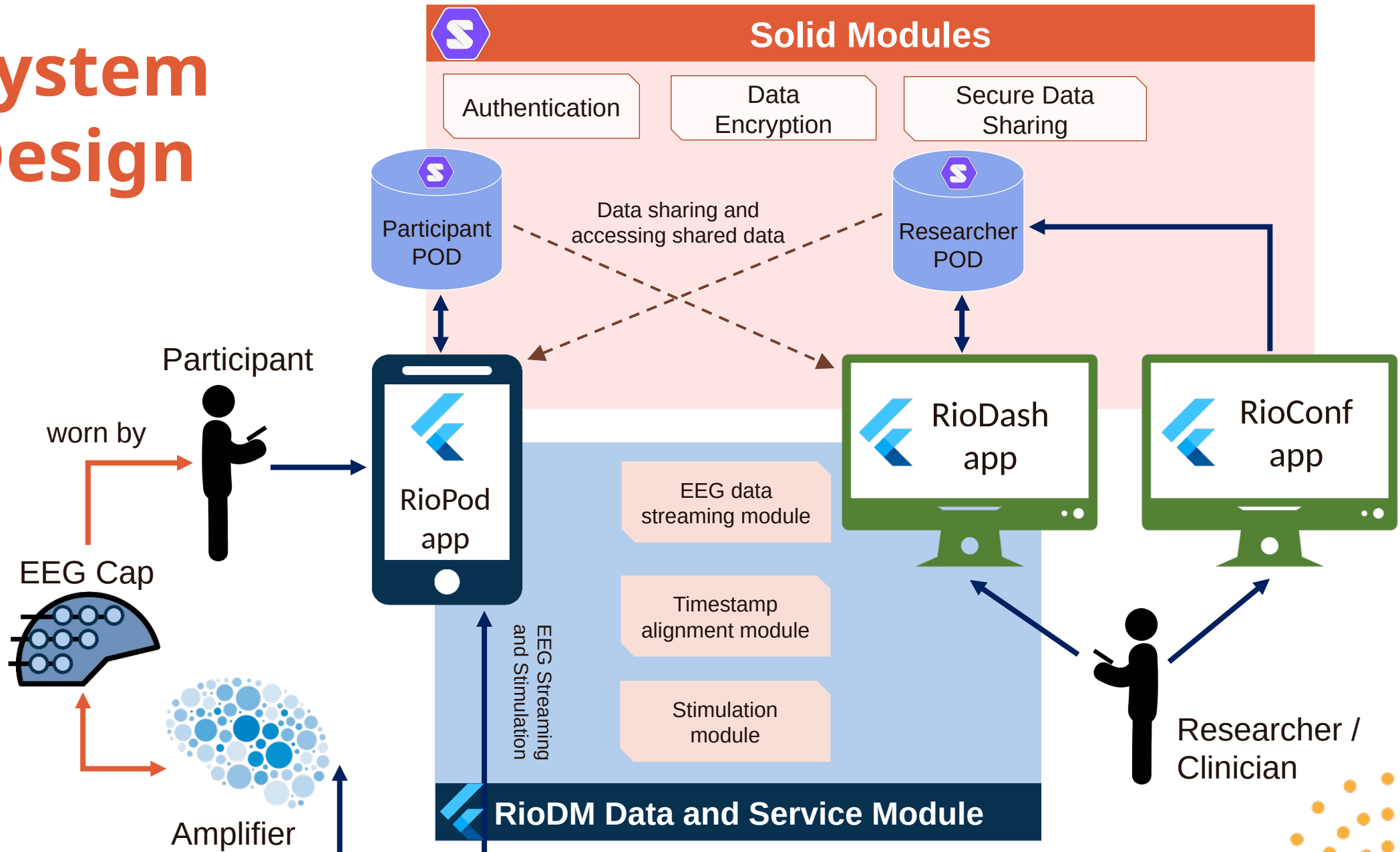
- ❖ Current clinical trials are heavily regulated but still rely on centralised architectures
- ❖ This create issues related to data privacy and ownership
- ❖ And even with strict governance, participants have minimal real control over their data once collected

Rio reframes this model by treating participants as the primary data owners, not just data sources

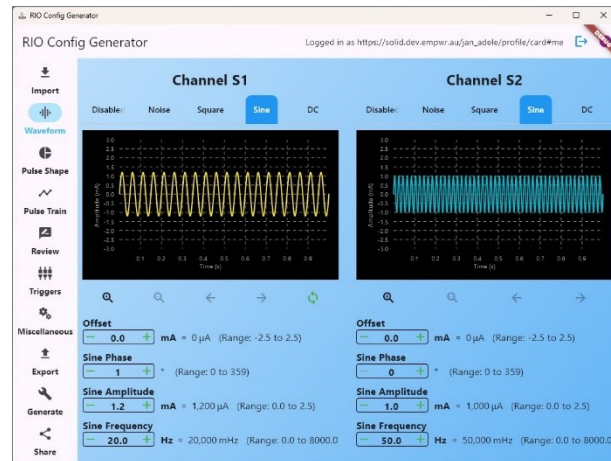
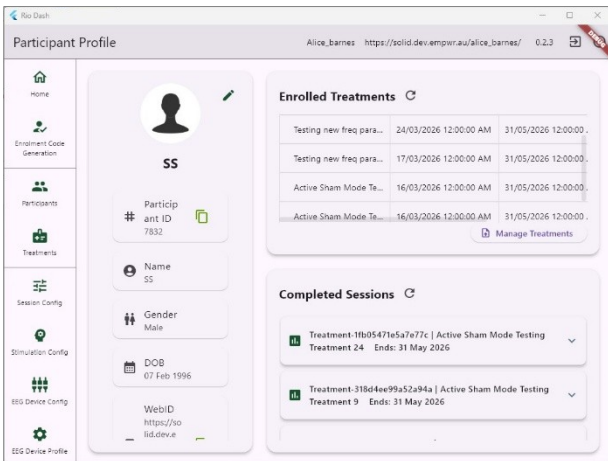
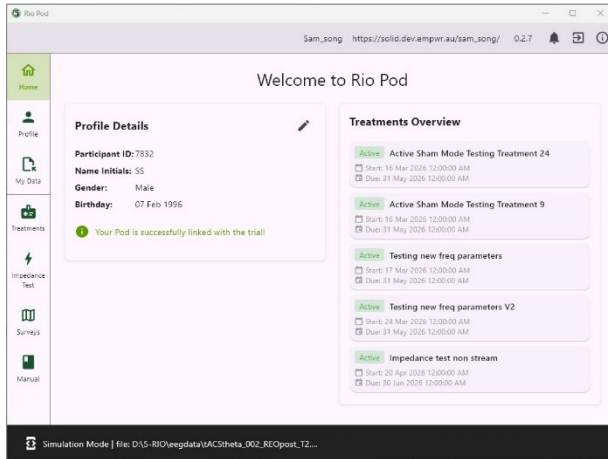
Key Idea

- ❖ Collaboration between *ANU Software Innovation Institute, ANU School of Medicine and Psychology, and ANT Neuro (Australia & Germany)*
- ❖ Rio is built on top of Solid Personal Online Datastores (POD)
- ❖ Each participant of the trial gets their own secure POD
- ❖ Through a mobile app connected to a cap, we collect EEG data of participants and store them in their PODs
- ❖ Participants then share their collected data with clinician at the end of each treatment session

System Design



Actual System



Why It Matters

- ❖ **The interesting part isn't just privacy. It is what this enables**
- ❖ **True data sovereignty:** participants retain ongoing control, not just initial consent
- ❖ **Data reuse:** participants can share their data across multiple trials without duplication
- ❖ **Interoperability:** the data model we developed supports querying across studies and that can be easily extended to other types of medical trials

Thank you!

Appreciate your feedback!

Get in touch with us to know more about our work

Contact:

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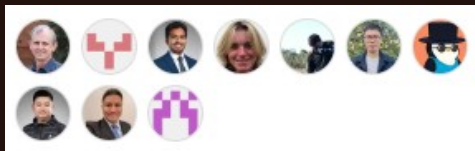
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SolidCommunity@togaware.com

Where to start:

<https://github.com/anusii/solidui>

ANU Solid team



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Explore further:

- <https://github.com/anusii/solidpod>
- <https://solidproject.au>
- <https://solidproject.org>

Get involved:

- <https://solidcommunity.au>
- <https://sii.anu.edu.au>