

Gurriny ANU Solid Health PODs

Prof Graham Williams, ANU

Dr Jess Moore, ANU

Dr Anushka Vidanage, ANU

Anita Lee Hong, GYHSAC

Dr Jason King, GYHSAC

Nigel Hacker, GYHSAC

In Collaboration with the Yarrabah Aboriginal Community

Our Data Sources as a Strategic National Asset

9 March 2023



Australian
National
University

Software
Innovation
Institute

Personal Online Data Stores (PODs)

Data systems that work for data users

Individuals as Key Data Users

- **Individuals** - first and foremost
- Government providing Service to Individuals and Society
- Organisations supporting Individuals and Society
- Business provision of goods and services to Individuals and Organisations



Individuals First as the Data Users

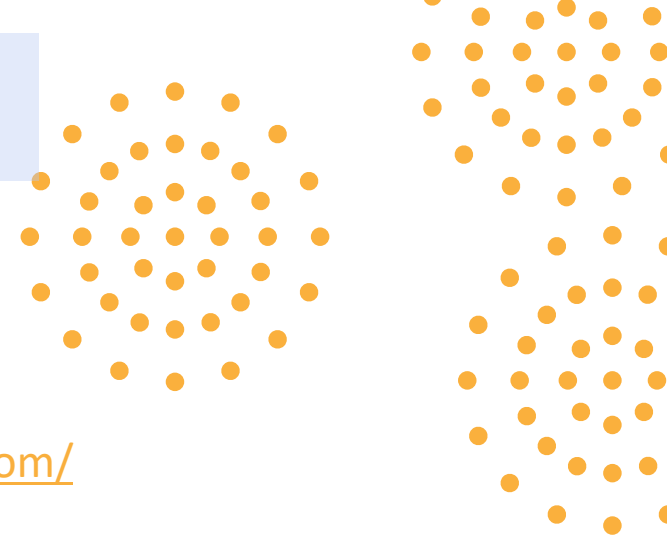
- Envisaging individuals owning their data
- Data managed in their own private, secure, protected PODs
- The only location for **most of** their (linked) data – financial, health, personal, ...
- Multiple Data Sources ingested into their own PODs hosted where they choose
- User decides what data to share with **other Data Users**
- Local Apps analyze user's data locally to give more complete advice – e.g., Tax Compliance

Infrastructure Supporting PODs

- **SOLID** (Social-Linked Data) Specification of Server API including **authentication** and **authorisation**
- Community Solid Server or Nextcloud Plugin <https://solidproject.org/self-hosting/css>

Solid Servers

An individual will access medical/health/++ data and AI analytics apps within their own POD.



A Common Server for All

Individual: <https://solid.ecosysl.net/>
Government: <https://bit.ly/3y4FIBu> (Flanders)

Community: <https://yarrabah.net>
Commercial: <https://start.inrupt.com/>

ANU Research and Development

- Trust No One (TNO): POD data is **encrypted**
- Standards: Data is stored in common data structures (RDF) for **interoperability**
- No Lock In: PODs can **migrate** between SOLID servers

Challenges

- Data is decrypted on-device and thus is susceptible to **back doors**
- Once shared we can stop sharing but data already shared cannot be unshared - **trust**

Gurriny Solid Health PODs



<https://www.peopleorienteddesign.com.au/>

Individuals have control over all their medical and health data.



ANU - Gurriny Collaboration

- Patients to share (or not) their data with Gurriny health care professionals
- Gurriny to share aggregate community data with individuals PODs
- Focus on whole of person health care
- Improved access to health information and services
- Deliver Indigenous sovereignty of data
- Utilizing Open Source specifications and software

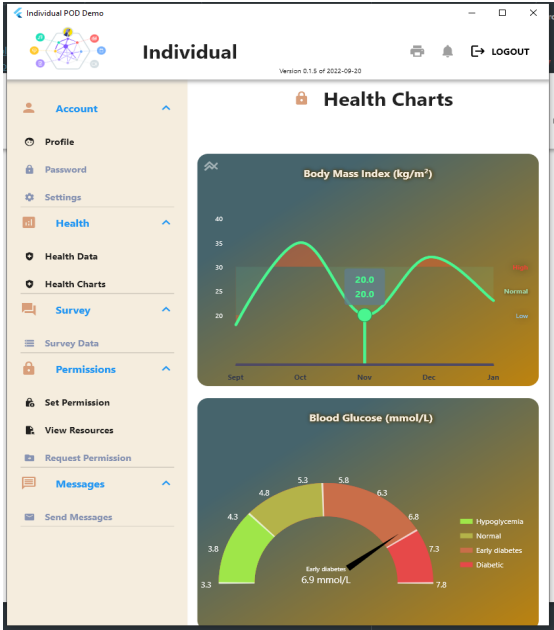
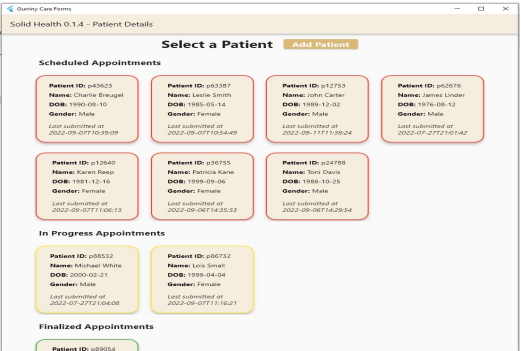
Status 2022-2023

- Conducting software trial for diabetic patients
- Patients each have a POD accessible from app on supplied device
- Data collection app used by health workers to collect and review
- Patient app to access, record and share data with doctors
- Aggregated analytics app for Gurriny.

Patient User Experience

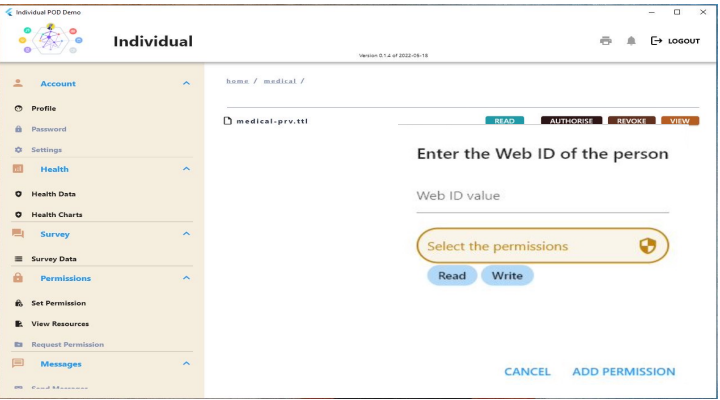
Phase 1 Health Worker App

Data collected on iPad Forms App by the **Health Worker** to visualise and populate Patient/Gurriny PODs/PIMS.



Phase 2 Patient App

Participants will be introduced to their POD by the **Patient App** during consultation with the Health Workers, populating the **Gurriny** PODs and Gurriny PIMS



Data



Medical Demographic Well being Social/Cultural

Thank you!

✧ Graham.Williams@anu.edu.au

✧ Jess.Moore@anu.edu.au

✧ Anushka.Vidanage@anu.edu.au

✧ Anita.LeeHong@gyhsac.org.au

✧ Jason.King@gyhsac.org.au

✧ Nigel.Hacker@gyhsac.org.au



Australian
National
University



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

<https://gyhsac.org.au>

On behalf of the ANU-Gurriny team