Gurriny ANU Solid Health PODs

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In Collaboration with the Yarrabah Aboriginal Community

Our Data Sources as a Strategic National Asset

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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](https://solidproject.org/self-hosting/css)
Solid Servers

A Common Server for All

Individual: https://solid.ecosysl.net/
Community: https://yarrabah.net
Government: https://bit.ly/3y4FlBu (Flanders)
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

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.

Individuals have control over all their medical and health data.

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!

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On behalf of the ANU-Gurriny team

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