



Australian Research Data Commons



Towards a National Platform for Australian Health Research Data

Hugo Leroux, Lien Le, Kate LeMay, Adrian Burton, Lynne Cobiac, Jurgen Fripp, Liming Zhu
7 May 2019

HEALTH AND BIOSECURITY

www.csiro.au



Australian Research Data Commons



Problem statement

- Australia spends approx. \$1billion on clinical research annually (private & public funded)¹
- Once completed, data from studies remain dormant, inaccessible and isolated with significant untapped latent value¹
- Emerging opportunities exist for rethinking clinical research in a dynamic & networked data-driven world
 - Suggested that a **national** approach to **data storage, enhanced access, curation, provenance, standards, analysis, sharing** and **rewards** systems while *protecting IP* and **privacy** might *contribute positively* to **health research community**

¹MTPConnect. 2017. Clinical trials in Australia. The economic profile and competitive advantages of the sector.

Flying Blind (Digital Health CRC report)



- Commissioned by Digital Health CRC
- Key findings:
 - Australia health & medical research (HMR) world class & ranks top 10 OECD countries despite below average R&D expenditure
 - Underused HMR data can be **linked**, **de-identified** & **repurposed** to improve Australian healthcare and deliver *prevention-based, precision-personal medicine*
 - Help shift from a **curative** to a **preventive health model!**
 - Facilitating access to linked datasets is a matter of national urgency!
 - Identified core challenges and barriers to Australia's HMR
 - Complex process
 - Data governance
 - Legislation and policies regarding data usage/sharing

Flying Blind: Challenges and barriers



Figure 2: Researcher's Journey

Srinivasan, U. et al., 2018, *Flying Blind: Australian Researchers and Digital Health, Volume 2: Health Data Series*, Digital Health Cooperative Research Centre, Sydney.

Flying Blind: Challenges and barriers

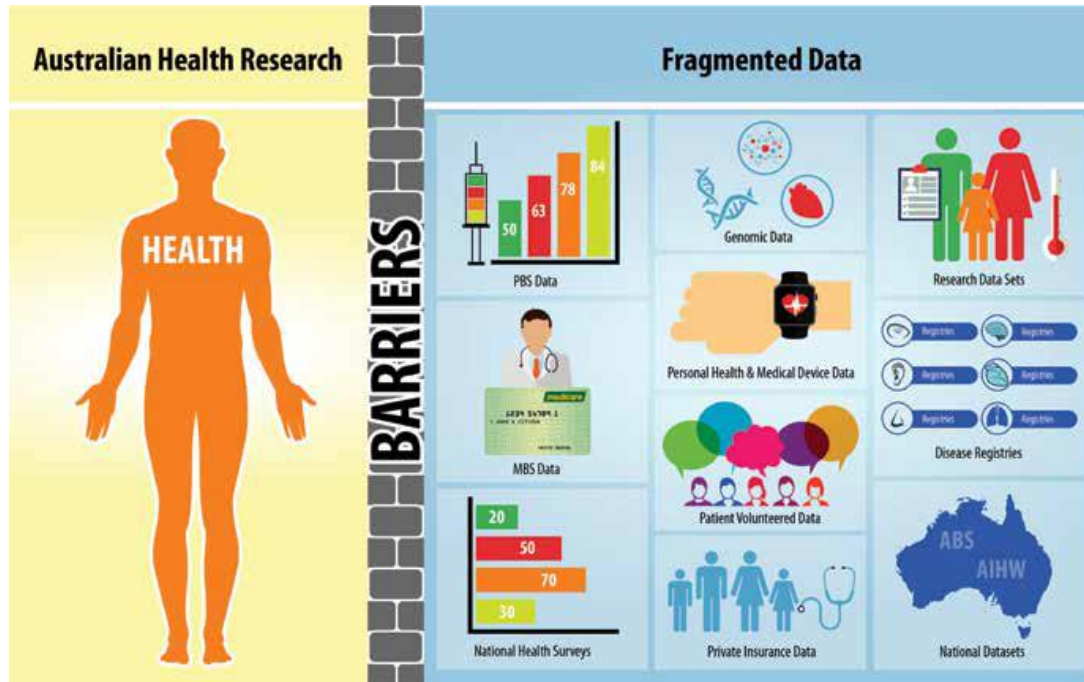


Figure 5: Structural Problems Facing Australian Research

Srinivasan, U. et al., 2018, *Flying Blind: Australian Researchers and Digital Health, Volume 2: Health Data Series*, Digital Health Cooperative Research Centre, Sydney.

Clinical Trials in Australia



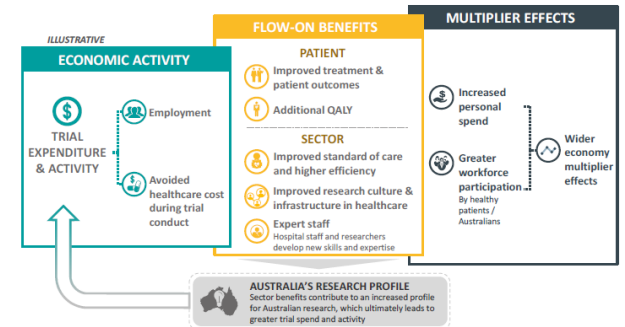
- Report by MTPConnect and L.E.K Consulting
- Key findings/recommendations:
 - Optimise efficiency in CT conduct through governance improvements
 - Improve patient recruitment & retention
 - Invest in deeper capabilities in innovative & novel CT types
 - Enhance transparency & track CT volume & economic contribution

Figure 1 Australia's clinical trial sector at a glance



MTPConnect. 2017. Clinical trials in Australia. The economic profile and competitive advantages of the sector

Figure 2 The value of clinical trials in Australia



Healthy Australians, Healthy Economy



- Statement from Research Australia identifying key policy settings enabling Australia's HMR to respond to future challenges and opportunities
- Key recommendations:
 1. Long-term, stable funding
 2. Fully-funded, transparent Medical Research Future Fund
 3. Standardised national approach to clinical trials
 4. Digitisation and open access of health data for research
 5. Promoting Australian health innovation
 6. Consistent approach to rare disease

Establishing a national approach

- The CSIRO and the Australian Research Data Commons (ARDC) have partnered to gauge the community's appetite for an exercise towards establishing a national framework for health research data.
- Through a consultative and staged approach, we aim to develop a national approach to capture maximum value from publicly funded health and clinical research data to provide greater national benefits.

Establishing a national approach (Cont)

- Our aims are:
 - Increased **integrity** of research through **transparency** of data underpinning **health research conclusions**
 - Increased **efficiency** of research through **quicker** access to existing studies and **avoidance** of **duplicative research**
 - Increased *Findability, Accessibility, Interoperability* and *Reusability* (FAIR) of data
 - Increased **innovation** through new **data-driven research** built on a **long term national data asset** designed for *re-use, re-purposing, linkage, meta analysis, machine learning*.

Summary of outcome from March workshop

- Workshop on *Unlocking the value from publicly funded clinical research data* (March 6th 2019)
- Brought together the stakeholders
- Scoping work and goal was to ascertain whether there is value
- Discussion around clinical research landscape
- Afternoon focus on requirements and enablers and barriers
- Definitely see value but more consultation need to happen

Key objectives

- Implementation of a national framework enabling data sharing
- Ensuring that systems, data and metadata are interoperable
- Providing *best practice* infrastructure => *best practice* in research protocols
- Allowing metadata and processes from previous studies to be compared
- Standardising clinical research design to expedite reuse of data and introduce efficiencies in curation leading to improved sharing

WEP: Value in Healthcare Report



- Commissioned by World Economic Forum
- Key recommendations and learnings:
 - To realise full potential of value-based healthcare:
 - New models for multistakeholder cooperation
 - E.g Atlanta Heart Failure Pilot
 - New standards for health informatics
 - Standards for data capture (Data and metadata)
 - Standards for data mapping (semantic and data models)
 - Standards for data access (security, privacy, transparency)
 - New directions for leadership
 - Industry leadership
 - Government leadership
 - Global leadership

Key lessons from Atlanta Pilot

1. Build a **clear case** for **change** and an **ambitious vision statement**
2. Enlist **strong** and **visible *public-sector* leadership**
3. Focus on **system-wide transformation** – beyond individual initiatives
4. Take **time** to **design a *detailed* roadmap**
5. Aim for **broad multistakeholder representation**
6. Create an ***active* working group** with ***extensive* engagement**
7. Dedicate **onsite resources** to **project management**
8. Build ***strategic* commitment** to **implementation**

Take home message ...

- Workshop and engagement with the community
- Value in national initiative confirmed
- Next steps are transparent consultations with key stakeholders

Thank you

CSIRO Health and Biosecurity

Hugo Leroux
Senior Research Scientist

t +61 7 3253 3614
e hugo.leroux@csiro.au
w www.csiro.au

Australian Research Data Commons

Lien Le
Associate Director

t +61 7 3346 4301
e lien.le@ardc.edu.au
w ardc.edu.au

HEALTH AND BIOSECURITY

www.csiro.au

