

The ATHENA COVID-19 Study

The Australians Together HEalth INitiAtive - Unlocking
Queensland's Potential

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Background

- Clinical Trials (CTs) are the primary mechanism of translational research
- Lead to societal access to new medicines, procedures and diagnostics.
- CTs drive the application of evidence-based medicines and include current best practice health care.



- Globally the CTs market is worth:
 - 2019: \$47 billion
 - 2027: \$70 billion
- Australia is ranked third globally behind the USA and Germany for CT density
- Mature health system, smart regulation and incentives

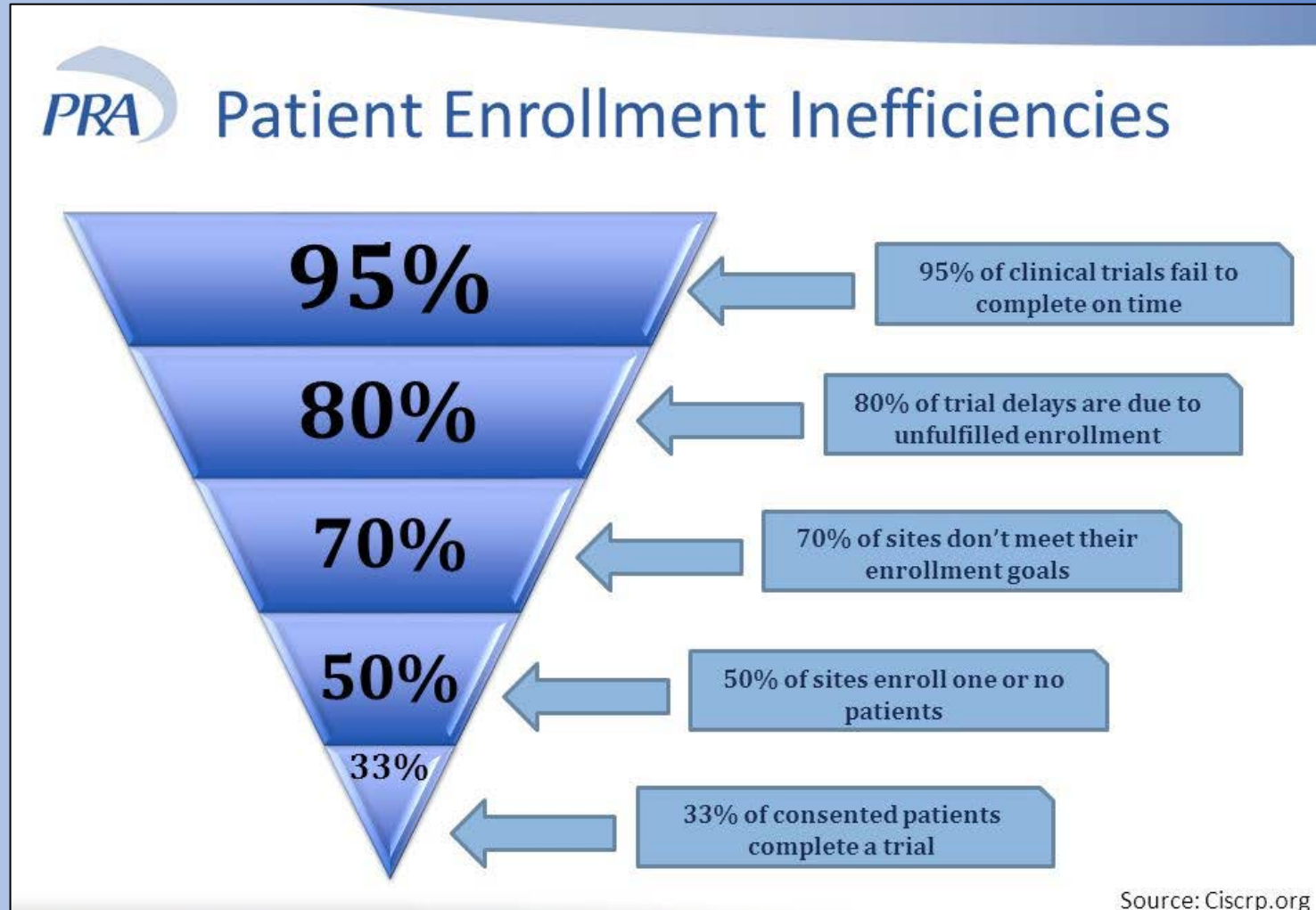


The Problem

- **Patient recruitment** is the largest **barrier** to CT timelines
- Greatest cause of trial failure.
- Participant recruitment is typically an intensive, manual and site-specific process.



Facts



Facts

- The cost of patient recruitment represents
 - 30% of overall CT costs
 - 30% of total CT time
- Improve patient recruitment numbers by 25%
- Sector value could increase from AU\$1.1Bn to AU\$ 2.5Bn p.a.

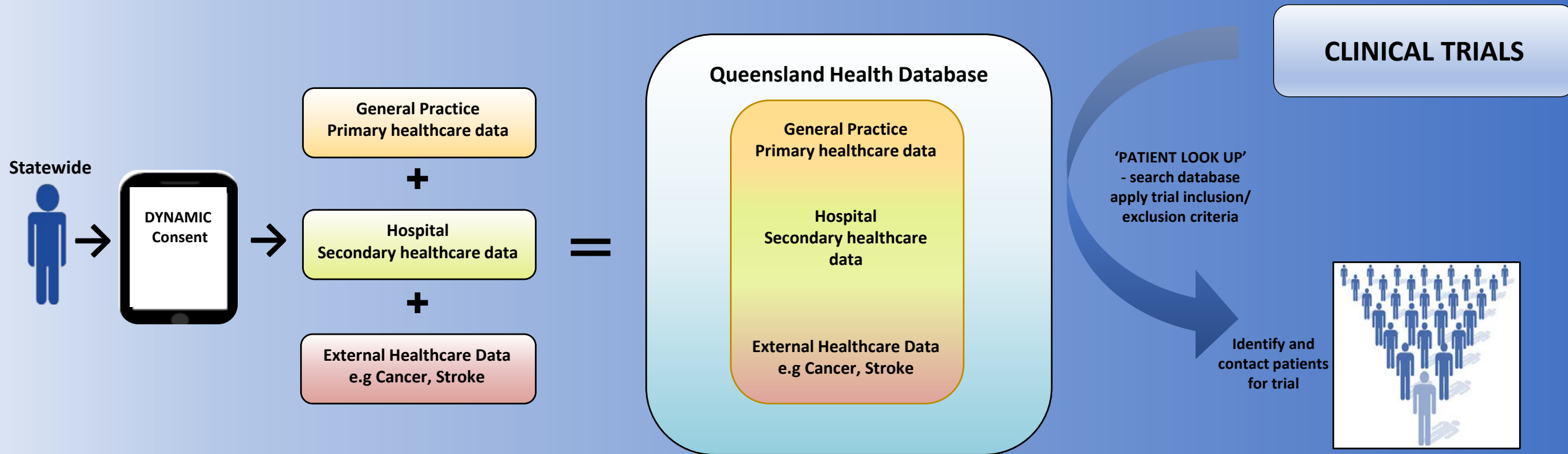


The Solution

ATHENA Program Vision

“The vision of the ATHENA Program is to deliver a **state-wide registry** containing the healthcare information and biospecimens of several million Australians across Queensland using **dynamic consent** to **connect** patients, researchers and the **Clinical Trial industry**. The result will be to deliver unprecedented growth in cutting edge commercial & non-profit health research, for health and economic benefits across Queensland.”

The ATHENA Program



- ✓ Patients consent primary, secondary and external registry data linked and stored by QH for research
- ✓ Patients consent to allow *future re-contact* to discuss participation in clinical trials or research studies

ATHENA

- ✓ Rapidly finding
- ✓ Right patients
- ✓ Large numbers
- ✓ For Clinical Trials

ATHENA PROGRAM BENEFITS

-  Growth of our AU\$1.1B clinical trial market by **accelerating participant recruitment**,
-  Enable pharmaceutical industry to undertake **rapid feasibility assessments**
-  Enable pharmaceutical industry to **improve their trial design**.
-  Greater support for local **investigator-led research**
-  Increased access to CTs for patients living **rural, regional and remote areas**
-  Increased access to CTs translates to **improved health outcomes** for Queenslanders
-  Promotes **health literacy, education** by involvement of patients
-  The ATHENA program and Dynamic Consent supports the **Queensland Biobank** initiative.

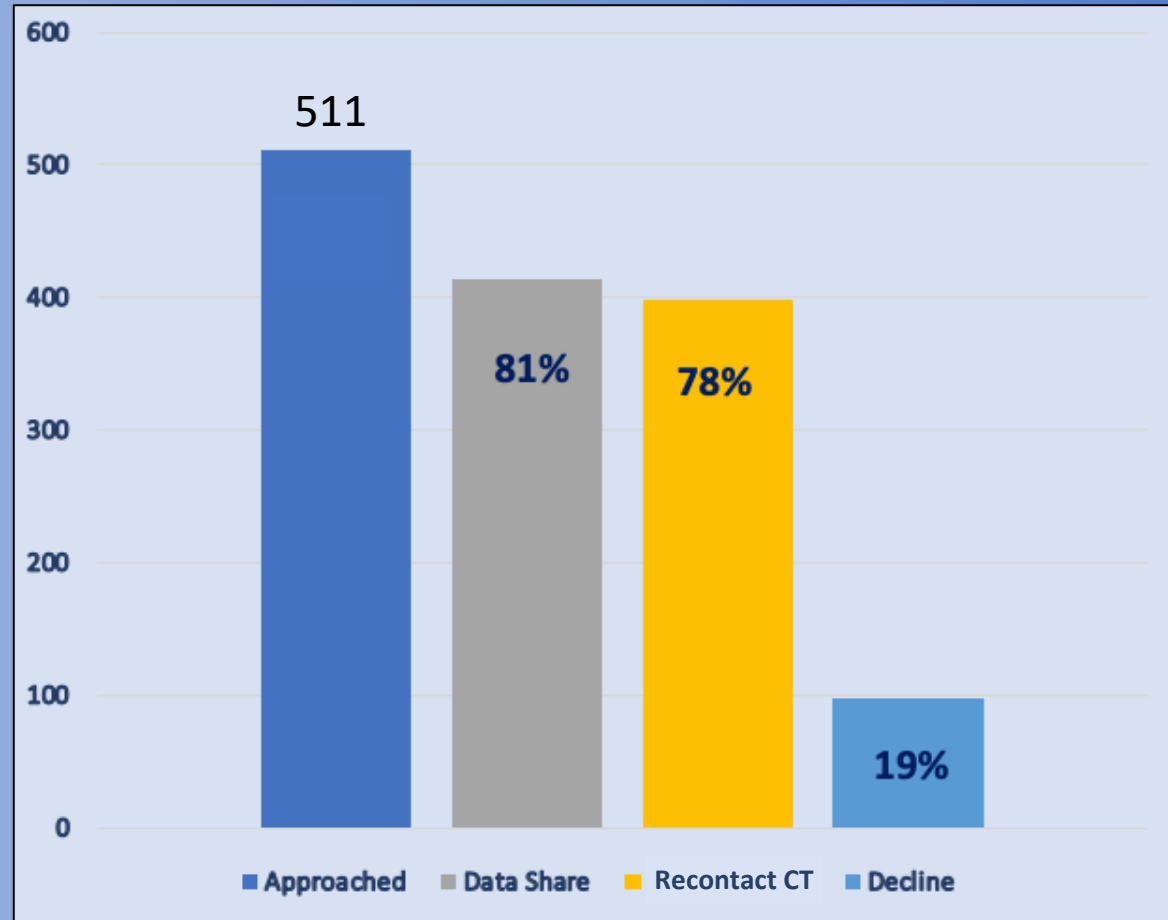
Our progress.....

1. Pilot study 'GP Data Linkage Study'
2. ATHENA COVID-19 Study
3. High level architectural design for the ATHENA Program
4. Dynamic Consent Platform pilot study



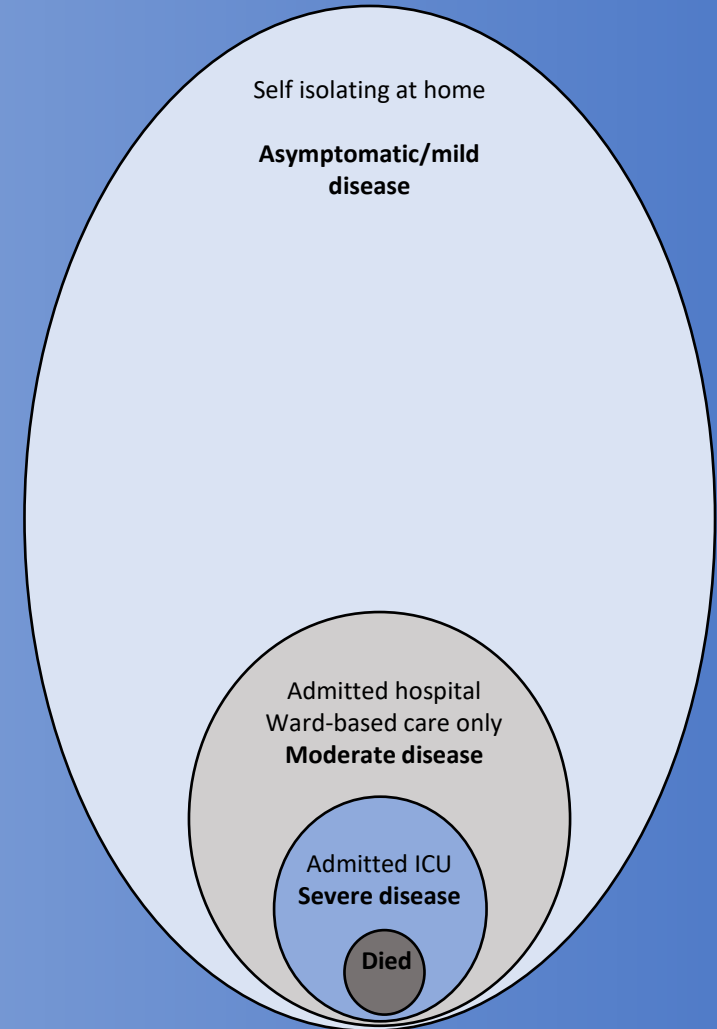
GP Data Linkage Study

- Majority agreeable to having data linked and used for health services analysis and research
- Majority agreeable to being contacted to discussing participation in clinical trials



ATHENA COVID-19 study aims

- To create a cohort of all people diagnosed with COVID-19 in Queensland
- With linked primary, secondary and registry data.
- To investigate predictors of outcomes
- To provide an ongoing resource for future clinical trial recruitment



Part 1

- Notifiable Conditions System for all people tested positive CV19
- Linked to Emergency Department Collection
- Queensland Health Admitted Patient Data Collection
- Deaths Registration
- No consent

Part 2

- Part 1 data
- + GP data
- + Consent
 - To extract GP data and use health information including biospecimens for CV19 related research
 - To consent to recontact patients to discuss participation in clinical trials

COMMUNICABLE
DISEASES
INTELLIGENCE

2021 Volume 45

<https://doi.org/10.33321/>

**The ATHENA COVID-19 Study: Cohort profile and
first findings for people diagnosed with COVID-19
in Queensland, 1 January to 31 December 2020**

Jennifer Welsh, Rosemary J Korda, Ellie Paige, Mark A Morgan, Hsei-Di Law, Tony Stanton, Zoltan MJ Bourne, M Ximena Tolosa, Kim Greaves, for the ATHENA (Australians Together Health Initiative) COVID-19 Project Team

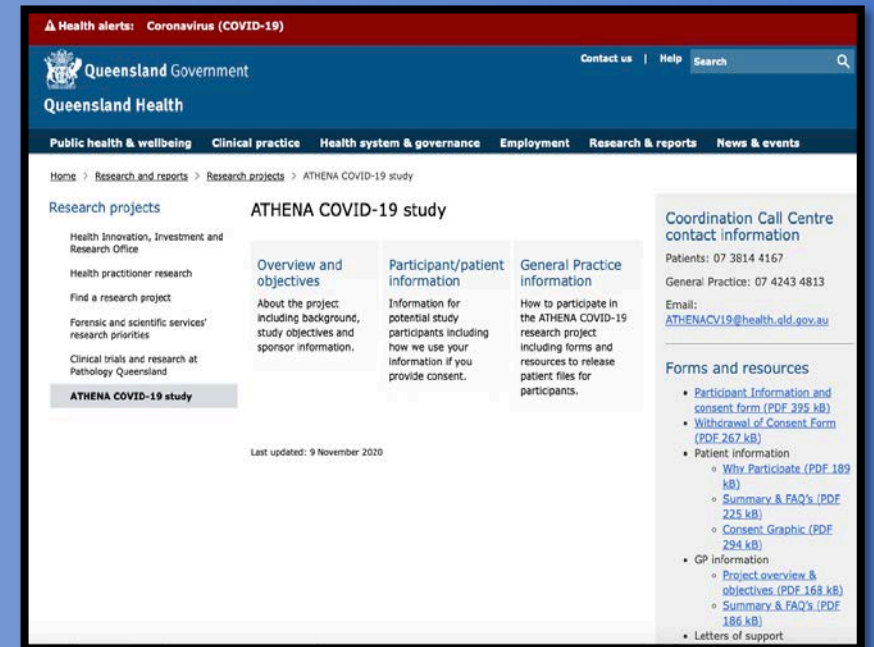
Part 1: Key results

- Time from symptom onset date to admission 4 days
- 21% hospitalizations: median stay 11 days
- 1.4% admitted to ICU (80% required ventilation)

- Living in a regional/remote are more likely to be admitted to hospital
- Living in a less disadvantaged area, less likely to be admitted to hospital
- Increasing age more likely to be admitted to hospital
- Smoking like to be admitted to hospital

Part 2: ATHENA COVID-19 Study

- Contacted all patients who have had COVID-19 In Queensland
- Consent to release GP data access to biospecimens, for COVID-19 related research
- Consent to recontact to discuss participation in clinical trials
- Used e-consent



The screenshot shows the Queensland Health website page for the ATHENA COVID-19 study. The page is titled "ATHENA COVID-19 study" and is part of the "Research projects" section. The page layout includes a navigation bar at the top with "Health alerts: Coronavirus (COVID-19)", "Queensland Government", and "Queensland Health" logos. Below the navigation bar, there are links for "Public health & wellbeing", "Clinical practice", "Health system & governance", "Employment", "Research & reports", and "News & events". The main content area is divided into three columns: "Research projects", "ATHENA COVID-19 study", and "Forms and resources". The "ATHENA COVID-19 study" column contains three sub-sections: "Overview and objectives", "Participant/patient information", and "General Practice information". The "Forms and resources" column contains a list of links for "Participant Information and consent form", "Withdrawal of Consent Form", "Patient information", and "GP information".

Health alerts: Coronavirus (COVID-19)

Queensland Government

Queensland Health

Public health & wellbeing Clinical practice Health system & governance Employment Research & reports News & events

Home > Research and reports > Research projects > ATHENA COVID-19 study

Research projects

- Health Innovation, Investment and Research Office
- Health practitioner research
- Find a research project
- Forensic and scientific services' research priorities
- Clinical trials and research at Pathology Queensland

ATHENA COVID-19 study

Overview and objectives

About the project including background, study objectives and sponsor information.

Participant/patient information

Information for potential study participants including how we use your information if you provide consent.

General Practice information

How to participate in the ATHENA COVID-19 research project including forms and resources to release patient files for participants.

Coordination Call Centre contact information

Patients: 07 3814 4167

General Practice: 07 4243 4813

Email: ATHENACV19@health.qld.gov.au

Forms and resources

- Participant Information and consent form (PDF 395 kB)
- Withdrawal of Consent Form (PDF 267 kB)
- Patient information
 - Why Participate (PDF 189 kB)
 - Summary & FAQ's (PDF 225 kB)
 - Consent Graphic (PDF 294 kB)
- GP information
 - Project overview & objectives (PDF 168 kB)
 - Summary & FAQ's (PDF 186 kB)
 - Letters of support

Last updated: 9 November 2020

Part 2: ATHENA COVID-19 Study

69% of
respondents

consented to share full clinical data

73% of
respondents

consented to be contacted for future research

83% of
respondents

willing to consent via a digital platform

499

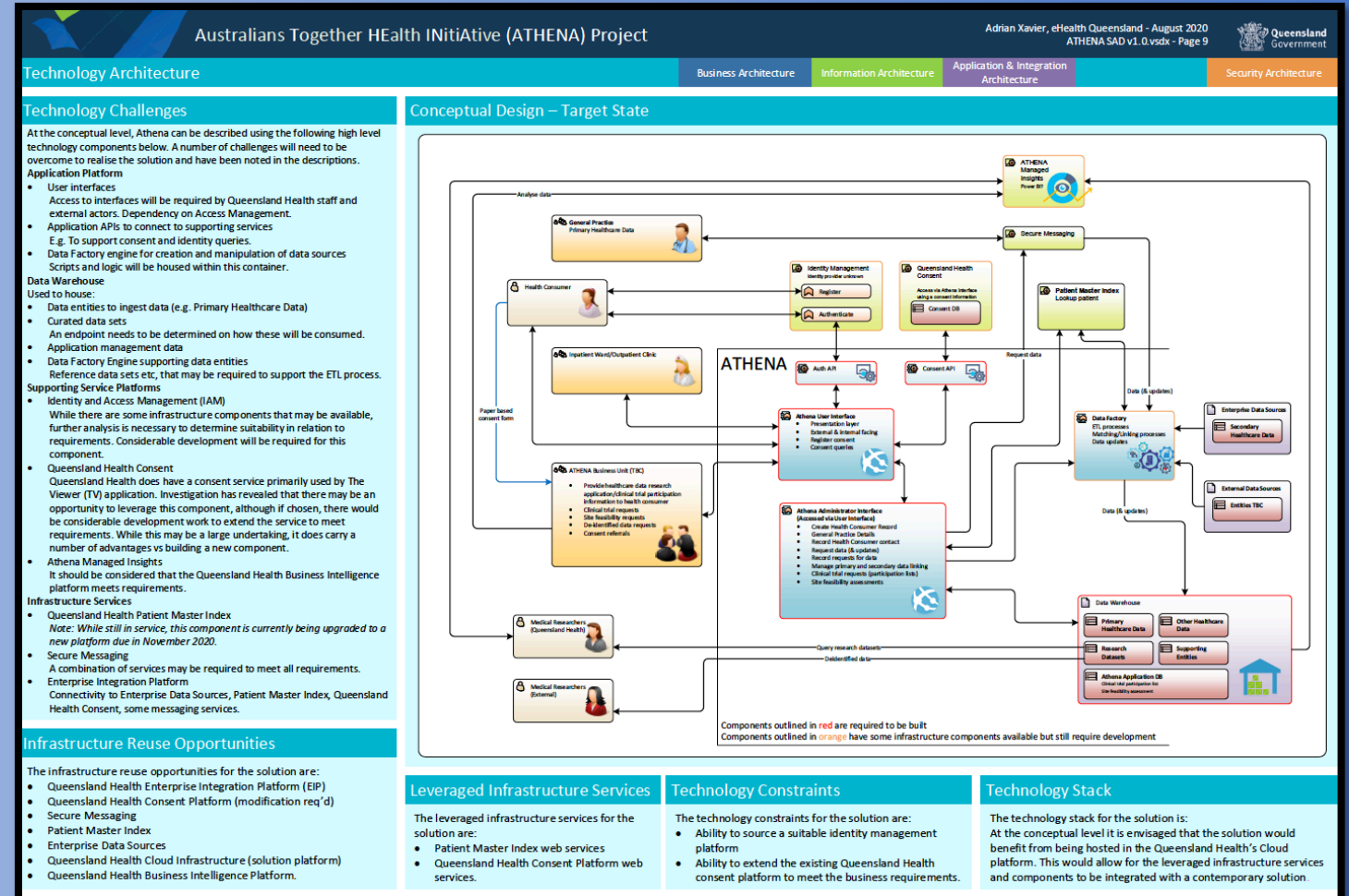
participants' GP health records collected

Part 2: ATHENA COVID-19 Study

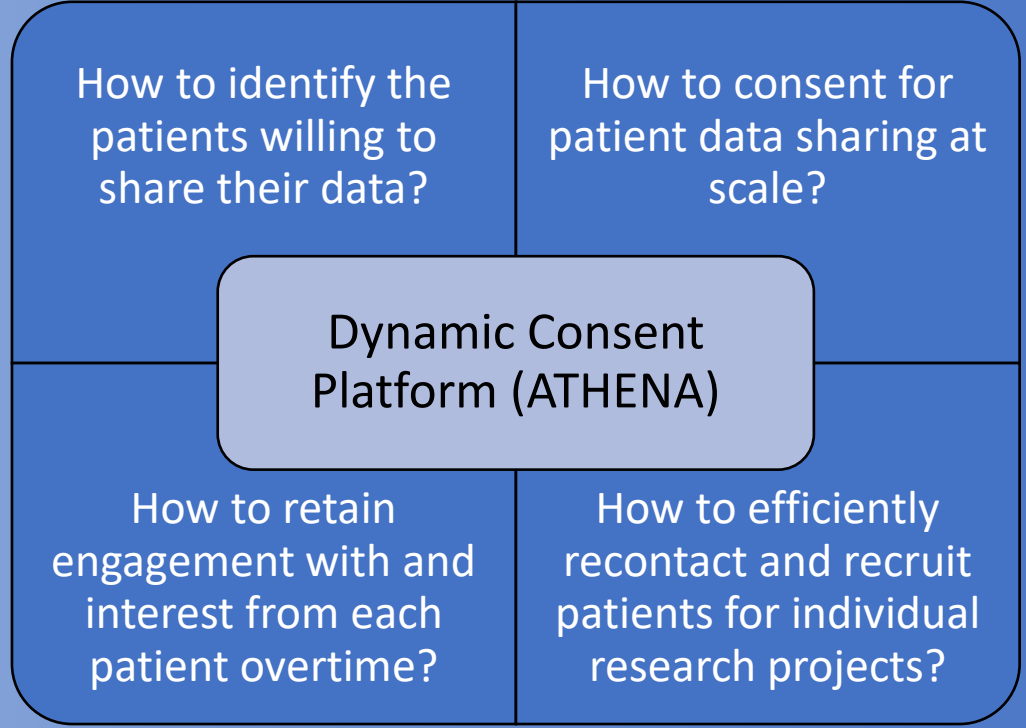
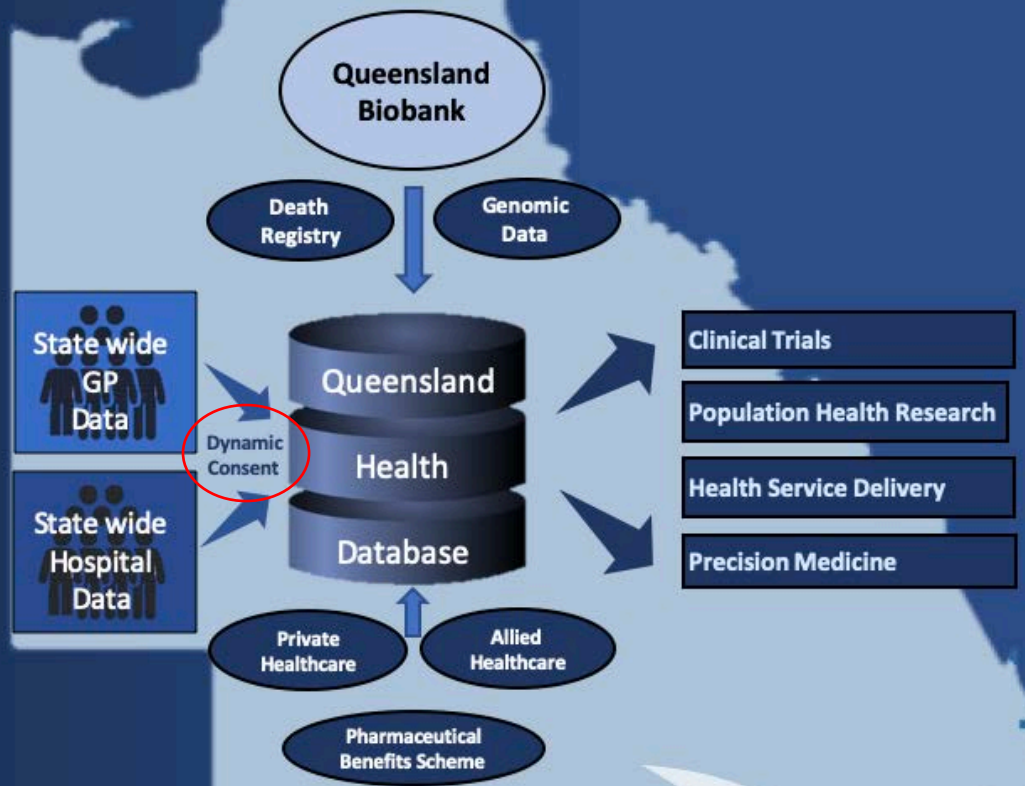
- Demonstrates that the public are willing to share their health information for research
- Prepared to form part of a pre-consented registry of willing participants ready to discuss CT participation
- Valuable information
 - Patient and GP attitudes towards to sharing of patient health information
 - Complexities of linking health information

Architecture for ATHENA program

Supported by QH Architecture and Standards Committee

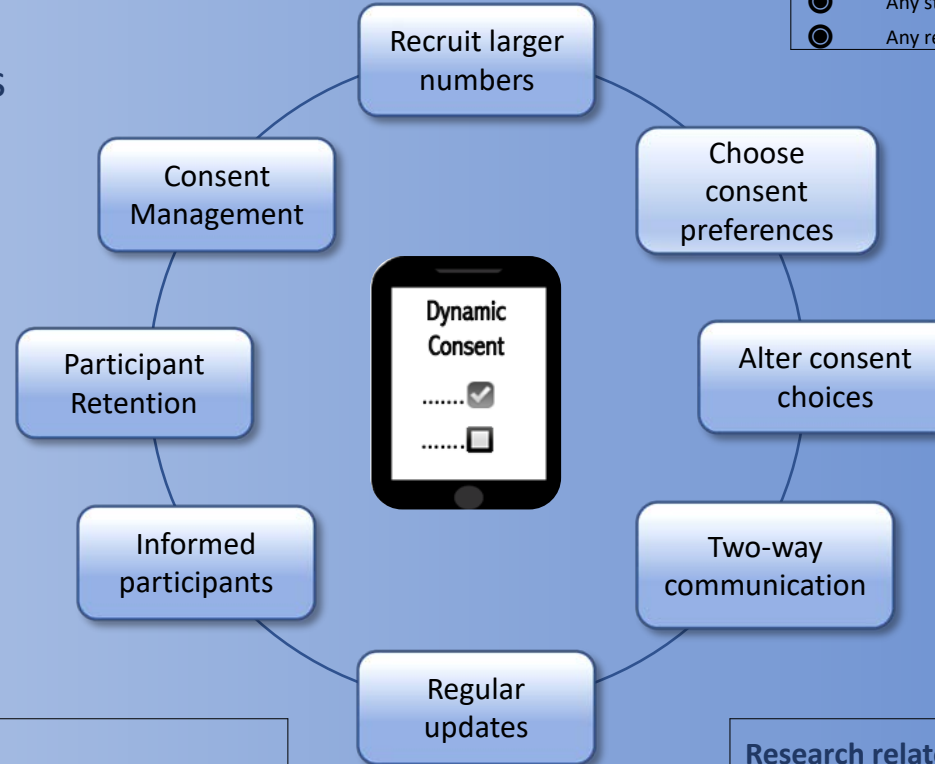


"A statewide asset where the participants are partners"



What is Dynamic Consent?

- Web-based consent platform
- Desktop or hand-held Devices



My Consent Choices

My clinical data may be used by

- Research institutes that are members of the original study
- Any study in the same research field as the original study
- Any research field

When and why have my electronic patient records been used

Start Date	Research Institutions	Research Area	Ongoing
July 2017	University of Queensland	Osteoporosis	N
March 2018	Heart Foundation, Australia	Cardiovascular	Y
January 2020	Australian National University	COVID-19	Y
June 2020	Imperial College London	Mental Health	Y

New research opportunities you may be interested in

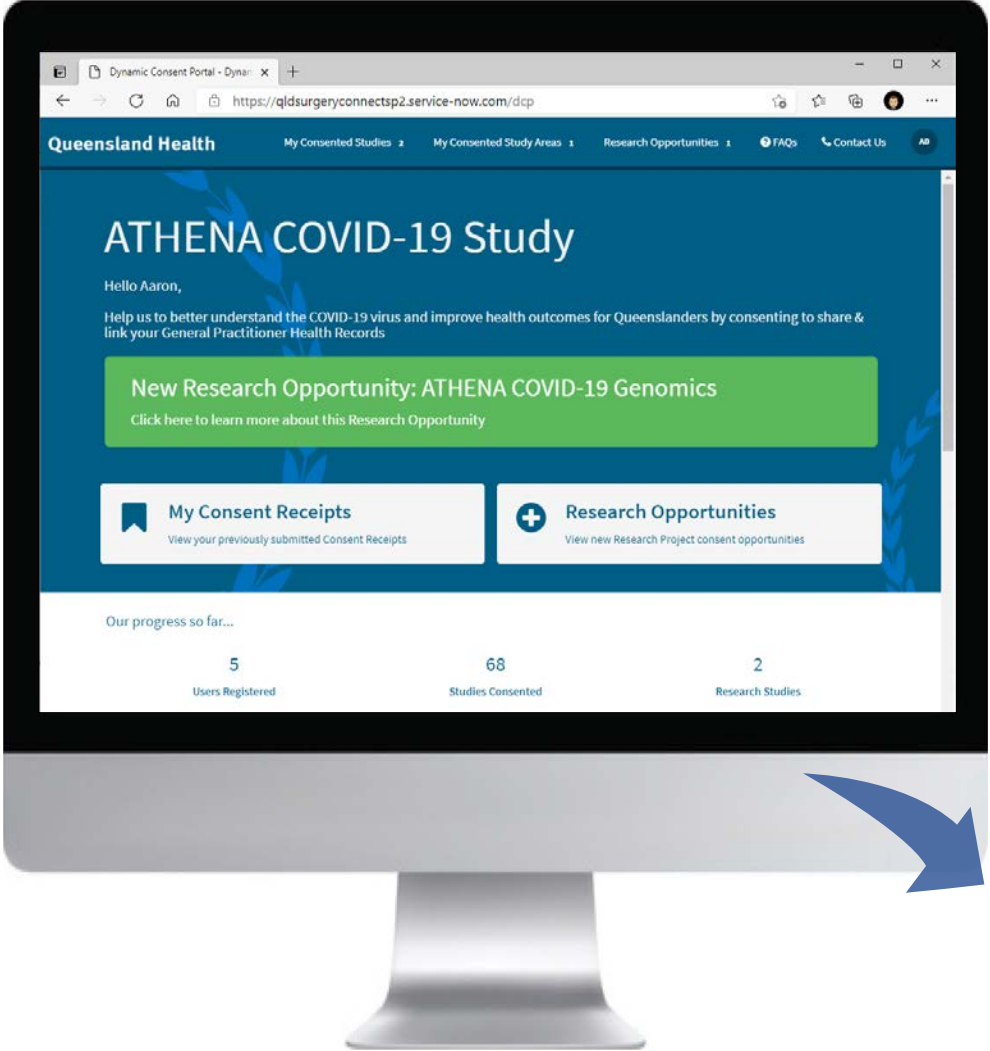
Study ID	Study Title	Who to contact for more information	website
0001	Understanding Long COVID	Professor Colin Orona c.orona@health.qld.gov.au	www.longcov.edu.au
0002	A new vaccine that may prevent heart attacks and strokes	Dr Andrew Theroma a.theroma@Griffith.edu.au	www.stopathero.hhs.au

Research related to my clinical data

Thank you for allowing you electronic patient record to be used in this research. This is how they are making a positive impact

Sample ID	Sample Type	Donation Date	Research results
0001	Blood	11.11.2017	Published paper – ‘Nature Genetics’
0002	Tissue	14.06.1019	Published Paper – ‘BMJ Open’


Dynamic Consent Platform MVP





powered by **servicenow**



✓ MVP developed and in testing

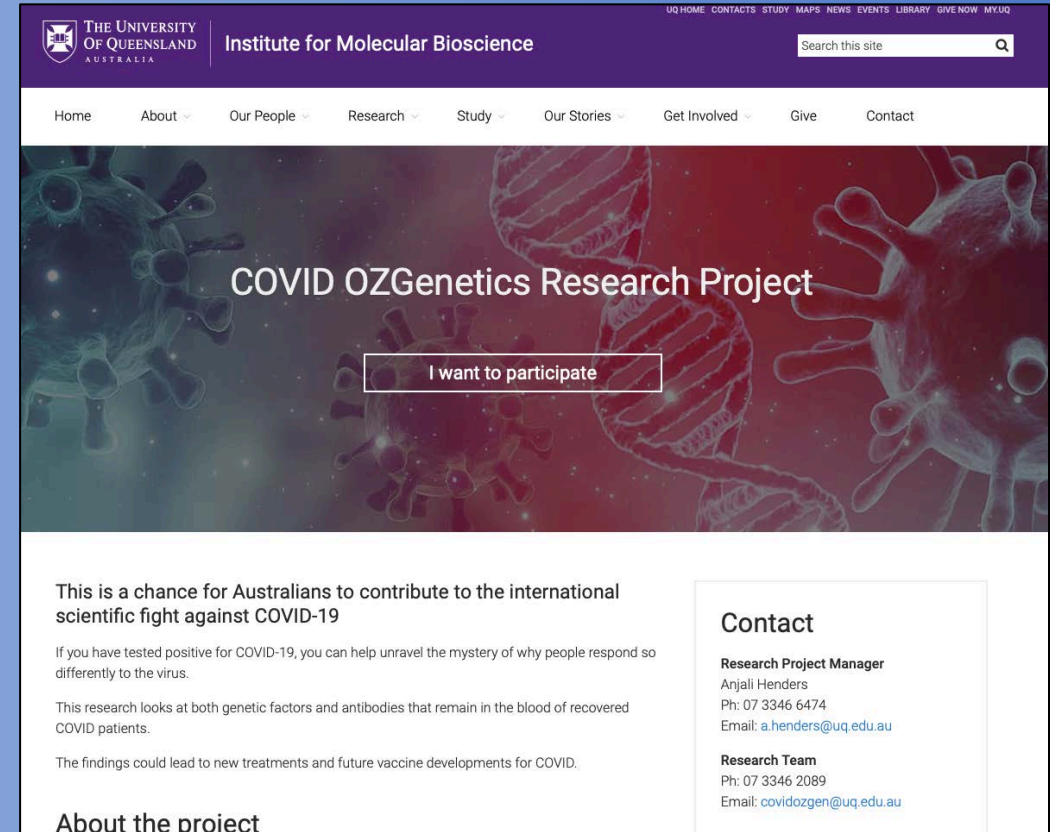
 Built on established platform

 Scalable

 Designed for consumers

Dynamic Consent Platform MVP

- Testing begins shortly
- Recontacting patients who have had COVID-19
- Agreed to recontact
- Participation in UQ 'COVID OzGenetics'
- Research Project
- Learn, refine and improve the MVP



THE UNIVERSITY OF QUEENSLAND AUSTRALIA | Institute for Molecular Bioscience

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COVID OzGenetics Research Project

I want to participate

This is a chance for Australians to contribute to the international scientific fight against COVID-19

If you have tested positive for COVID-19, you can help unravel the mystery of why people respond so differently to the virus.

This research looks at both genetic factors and antibodies that remain in the blood of recovered COVID patients.

The findings could lead to new treatments and future vaccine developments for COVID.

About the project

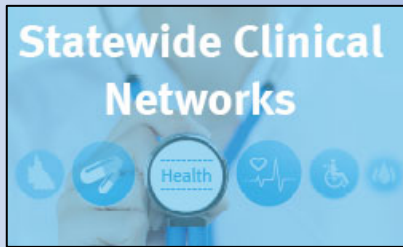
Contact

Research Project Manager
Anjali Henders
Ph: 07 3346 6474
Email: a.henders@uq.edu.au

Research Team
Ph: 07 3346 2089
Email: covidozgen@uq.edu.au

ATHENA Program

Widespread Support



“The Queensland Clinical Networks Executive strongly supports the ATHENA program”.... “It has the potential to transform healthcare and improve patient outcomes.”

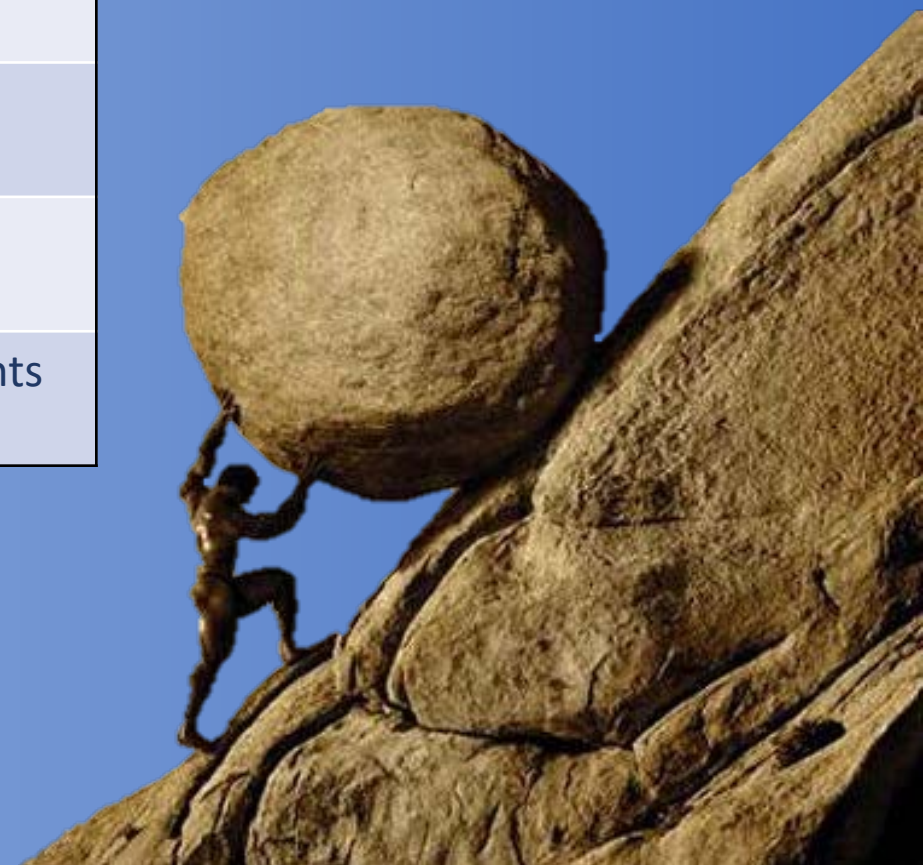
The 2021 ATHENA MRFF Frontiers bid received support from:

BDHP, AMA-Q, RDAQ, ARCS, UQ, AuSHI, QUT Centre for Healthcare Transformation, Menzies Health Institute Queensland, OQCE, ADHA, Medicines Australia, IQVIA, VIC Health, SA Health, WA Health, CSIRO,

+++++

Next steps.....

Component	
Dynamic Consent Platform	Further development of Dynamic Consent Platform (DCP)
	Pilot DCP at large hospital
Healthcare and GP Data linkage	Develop automated solution for retrieval of GP Information
	Setup store for GP information and linkage with QH Health Information
Data analytics	Develop analytics platform for identification of patients for research



ATHENA Program and ATHENA COVID-19 Study team

Dr. Zoltan Bourne: GP, Medicine on Maple, GP clinic

Aaron Davies: Health Innovation Investment and Research Office

Professor Kim Greaves: Cardiologist, Sunshine Coast Hospital and Health Services

Melissa Hagan: Health Innovation Investment and Research Office

Helen Horton: Health Innovation Investment and Research Office

Amanda King: Sunshine Coast Hospital and Health Services

Professor Mark Morgan: GP, Bond University

A/Prof. Rosemary Korda: Research School Population Health, Australia National University.

Karen Thompson: Health Innovation Investment and Research Office

Funding

Health Innovation Investment and Research Office, Queensland Health

Health Improvement Unit, Queensland Health

Central Queensland Sunshine Coast and Wide Bay Primary Health Network

Thank you

Any
questions?

