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OF WOLLONGONG  
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**PHRN** Population  
Health  
Research  
Network



**MACQUARIE**  
University



Australian Government  
Department of Health, Disability and Ageing

# Using general practice data for research in Australia: Ethical and legal conundrums in relation to privacy and confidentiality



digital health crc

# Plan

1. Context  
Annette Braunack-Mayer
2. The current regulatory framework  
Carolyn Adams
3. Views of HREC chairs  
Yves Saint James Aquino
4. The general practitioner perspective  
Justin Beilby
5. Views of policy makers and regulators  
Carolyn Adams
6. A critical commentary  
Mark Taylor
7. Conclusions and discussion  
Annette Braunack-Mayer

# 1. The GP Data project and its context

**SEN PROF ANNETTE BRAUNACK-MAYER,  
UNIVERSITY OF WOLLONGONG**

# Health and illness data in Australia

- Limits to our understanding of patterns of health and illness across the lifespan
- For individuals:
  - health problems not addressed
  - health needs not met
  - Inappropriate health services



# Making more use of general practice data

General practice records can help us:

- Design better health services
- Provide more appropriate healthcare
- Avoid inappropriate care

80%

Australians visit a  
GP each year



# Community and general practitioner concerns about sharing health data

## NHS in England delays sharing of medical records

GP and patient groups hail decision to put launch of care.data back six months to evaluate opt-outs



NHS England has delayed the launch of care.data. Photograph: Dominic Lipinski/PA

The NHS delayed for at least six months the launch of care.data from people's medical records and patients' groups, acknowledging their concerns in the scheme.

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## Stealth plan to sell UK patient health data

The UK government just scrapped a plan to sell health data without patient consent. Now it's considering a similar new one.

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## Care.data: How did it go so wrong?

19 February 2014 • 354 Comments



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## Controversial mega-database of medical records scrapped over privacy concerns

Critics said the care.data scheme violated patients' privacy and contained unreliable and inaccurate records

Siobhan Fenton • Thursday 07 July 2016 11:09 BST • 0 Comments



# Collecting the evidence to build public confidence in using general practice data

National community focus groups. Four groups (N=22)

National community survey (N=2064)

Legal & policy analysis

Community juries. Two juries (N=39)

Training guide for health consumers

GP semi structured interviews (N=19)

GP Delphi survey (N=22)

Interviews: policy makers & regulators

Interviews: general practice managers & owners

Interviews: research ethics committees chairs

2021 / 2022

2023

2024

2025

# Collecting the evidence to build public confidence in using general practice data



## 2. The current regulatory framework for the use of GP data for research

**DR CAROLYN ADAMS, MACQUARIE  
UNIVERSITY**



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# Legal, Ethical and Policy Issues

C Adams, A Braunack-Mayer and F Flack, 'Access to General Practice Data for Research in Australia: The Need for Greater Clarity in Relation to Privacy and Confidentiality' (2025) 31(4) *Journal of Law and Medicine*

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## Research

Outcome: Current legal and policy framework does not provide a clear authorising framework for stakeholders

## Interviews

Asking regulators and policy makers what elements should be considered in developing a potential best practice model

# Existing Legal and Ethical Framework

GPs must  
comply  
with two  
bodies of  
law when  
releasing  
data to  
researchers

- Data protection (privacy) legislation
- Legal and ethical duties of confidentiality

# The *Privacy Act 1988* (Cth)

Releasing  
data to  
researchers



- Regulates health service providers, including general practitioners, in the private sector
- Allows the use of personal health information for research, including without consent where it is impracticable to obtain consent
- Requires approval from a Human Research Ethics Committee

# The Ethical Duty of Confidentiality

Underpins  
the doctor-  
patient  
relationship  
of trust



- Dates back to the Hippocratic Oath taken by medical students in ancient Greece
- Ensures that patients feel free to disclose the most sensitive personal information relevant to symptoms and treatment

# The Legal Duty of Confidentiality

Arises as a matter of course in the provision of health services



- The information has the quality of confidence
- The information is communicated in circumstances of confidence
- Almost all information confided by patients will attract the duty
- The duty also applies to any third party who knows the confidential nature of the communication eg researchers

# Legal Duty of Confidentiality: Exceptions

Not  
absolute  
but has very  
limited  
exceptions



- Disclosure with voluntary and fully informed consent of patients
- Disclosure required by law
- Disclosure is justified in the public interest: this has been interpreted narrowly by the courts

# The Legal Duty of Confidentiality

Disclosure  
with  
consent

- Consent may be express or implied
- Implied consent may extend, for example, to sharing with the treating team
- Implied consent does not extend to sharing for secondary purposes, such as research

# The Legal Duty of Confidentiality

Disclosure  
required by  
law



- Legislation may modify or set aside the legal duty of confidentiality
- Disclosure must be required, not simply allowed as under privacy legislation
- For example, mandatory notification of diseases and mandatory provision of information to Medicare and PBS

# The Legal Duty of Confidentiality

Disclosure  
in the  
public  
interest



- Not any public interest counts: the courts have interpreted this exception narrowly
- For example, where there is a serious and imminent threat to an individual or to public health
- Does not extend to the public interest in research

# Privacy v Confidentiality

They are not  
the same  
thing and  
do not  
mesh well



- Both regimes allow the disclosure of health information for research with consent or where required by law

BUT

- where information is disclosed without consent under the research exception in the Privacy Act this may place GPs in breach of their duty of confidence

# Interviews with Regulators and Policy Makers

Looking  
forward for  
solutions



- Explore views on the legal and policy barriers to sharing information for research
- Is reform needed?
- How to move forward while building public confidence so as not to undermine the relationship of trust between patients and GPs?

# Further Information

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C Adams, A Braunack-Mayer and F Flack, 'Access to General Practice Data for Research in Australia: The Need for Greater Clarity in Relation to Privacy and Confidentiality' (2025) 31(4) *Journal of Law and Medicine*

Thank You

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# 3. Research ethics and governance of secondary use

**DR YVES SAINT JAMES AQUINO**



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# Methodology

- Qualitative, semi-structured interview study with chairs of human research ethics committees (HREC) in Australia
- Purposive sampling of chairs from certified and registered committees
- 8 interviews completed (aiming for 15-20 or upon saturation)
- Aim: to explore HREC chairs' perspectives on what, how and why decisions are made about the secondary use of general practice data for research purposes in their committees.

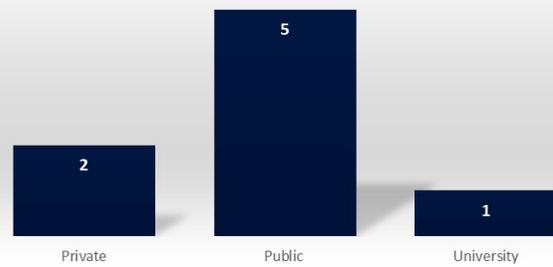
## **Case study:**

You have received an ethics application from a group of researchers. This is an 'umbrella application' that has a wide range of research objectives focused on building a comprehensive picture of patient pathways through the health system. The program of research is designed to improve patient outcomes, implement health prevention strategies, design health service improvements and analyse trends in certain chronic conditions.

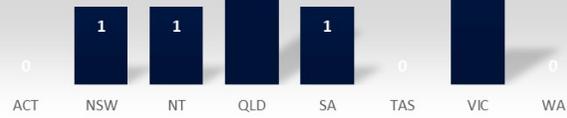
The study is a program of research that combines general practice data from 750,000 patients throughout NSW and links the data with other patient data

# Participants

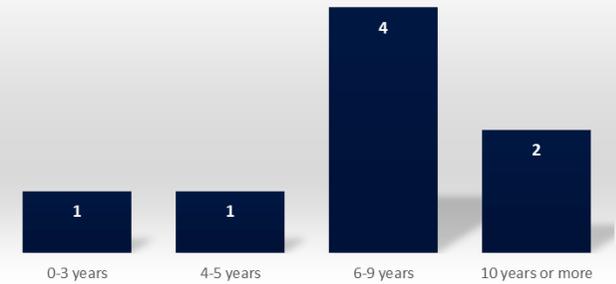
Sector



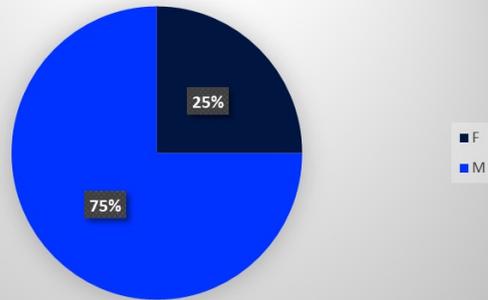
State



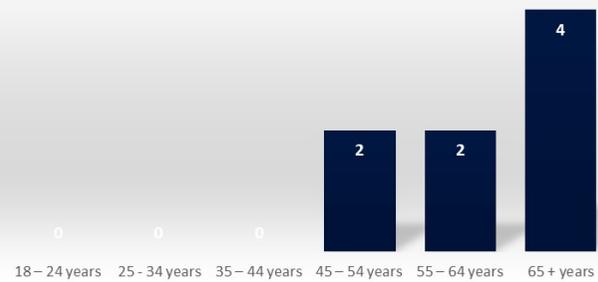
Experience as chair



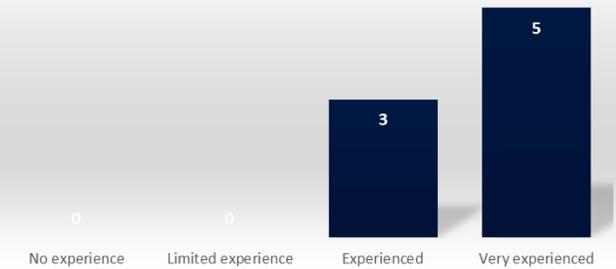
Sex



Age group



Experience with waiver of consent



# 1. Approach to consent compliance

- Broad ranging views
- Disagreement about whether waiver of consent is ethically appropriate
- Opt-in approach: university clinics or clinics that accept student placements to ask patients to agree to their data being used for purposes outside clinical care
- Recommendations: clarify which parties should give consent (GPs?)

*“Under the current circumstances, maybe you asked me about 10 years ago, I'd probably say you can try for a waiver of consent, but right now I'll have to say the minimum would be an opt out consent.” – P8*



## 2. GP data exceptionalism

### Non-exceptionalist view

- GP data are similar to other health information

*“I think, you know, when we're talking about health data, it's sensitive data. Full stop. Whether it's primary, acute, quaternary, tertiary, take your pick, it's health data. Full stop. I don't see the difference.” – P04*

### Exceptionalist view

- GP data are different from other health information

Risk-based exceptionalism

Data-based exceptionalism

Governance-based exceptionalism

### 3. Governance of commercial research

- Will the ethics review process differ if the applicants are from a for-profit organisation?
- Disagreement about impracticability and public benefit

*"The rules should be the same and I think for the [for-profit organisations], the penalties should be higher for breachers." –P08*

*"The commercial enterprise are a definite no go [for waiver]. I can't. I cannot honestly hand on heart say that I have ever received an application where there's been a waiver of consent." –P04*



# Thank you

Dr Yves Saint James Aquino

University of Wollongong

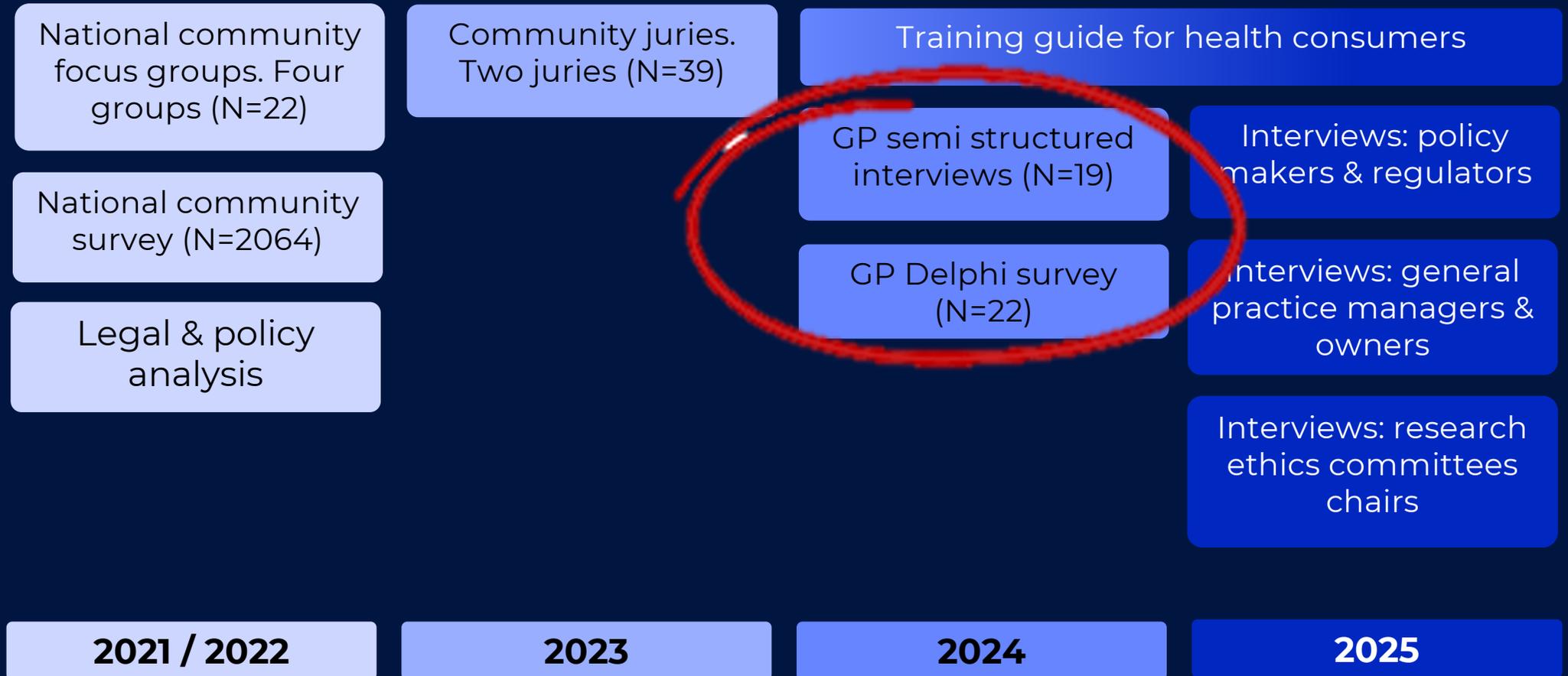
[yaquino@uow.edu.au](mailto:yaquino@uow.edu.au)

# 4. The general practitioner perspective

**PROF JUSTIN BEILBY**



# Collecting the evidence to build public confidence in using general practice data



# Making more use of general practice data



## Using patient data is vital to improve health and care for everyone

There is huge potential to make better use of information from people's patient records. Data is vital for your individual care, and to improve health, care and services across the NHS. The information can be used to help understand more about disease, develop new treatments, monitor safety, plan NHS services and evaluate policies.

### Examples:

#### Individual care

- Making sure your whole care team, from GP to hospital to care home, has up-to-date information to help give the best and safest care
- Helping people to manage their condition, from psychosis to asthma, using smart phone apps

#### Understanding disease

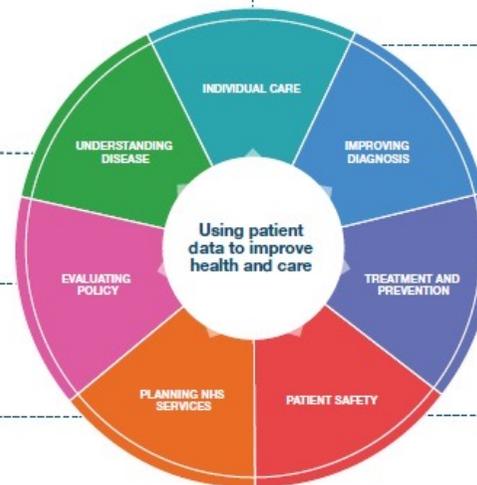
- Exploring why diabetes rates vary between ethnic groups
- Finding out about the biological changes involved in Parkinson's

#### Evaluating policy

- Comparing cancer survival rates between countries
- Showing the impact of a smoking ban on reducing premature births

#### Planning NHS services

- Finding out how many people have arthritis to inform planning
- Improving the delivery of kidney dialysis services



#### Diagnosis

- Demonstrating that bowel cancer screening is effective
- Finding new ways to identify early warning signs of dementia

#### Treatment and prevention

- Testing a treatment for lung disease in the real world
- Investigating the benefits of giving statins to men who haven't had a heart attack

#### Patient safety

- Monitoring the safety of whooping cough vaccination during pregnancy
- Checking the safety of hip replacements

# Method

## Community Juries

Two community juries (Sydney & Melbourne) with 39 jurors (F=19, M=19, non-binary=1)

Under what circumstances, if any, should general practice data be shared for research purposes

Phase 1



Recommendations from the community juries

## GP Interviews

19 GPs (F=14, M=5) with self-reported limited expertise with data sharing participated in qualitative interviews

## GP Delphi Survey

22 GPs (F=11, M=11) with experience and interest in data sharing for research participated in a Delphi study

Phase 2

# Results



## GP Interviews

- Broad support for using general practice data in research but emphasised the **centrality of trust in the doctor–patient relationship**.
- Concerns were raised about privacy breaches, re-identification risks, and the ethical implications of remuneration.
- Organisational constraints, such as time pressures and limited decision-making authority within practices, were identified as barriers to implementing ethical data-sharing practices.



## Delphi Survey

- Supported ethical approval, transparency, protection of the doctor–patient relationship, and remuneration for practices contributing data.
- An opt-out approach to consent was endorsed under strict conditions, with clear distinctions made between vulnerable and non-vulnerable populations

# Conclusion

- Trust, transparency, and consent are central to ethical data-sharing models.
- System-level support are needed to align ethical ideals with practical realities in general practice.
- Need for legal and policy reform to provide a clear authorising environment to share data.

**There is broad conditional support for sharing general practice data. Building trust through transparency, safeguards, and inclusive governance is essential**





Thank You

Professor Justin Beilby  
Torrens University

# 5. Views of policy makers and regulators

**DR CAROLYN ADAMS**



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## Research

Outcome: Current legal and policy framework does not provide clear guidance for stakeholders

## Interviews

Ask regulators and policy makers about the legal and policy challenges, and what elements are needed in a potential best practice model

# Qualitative Research Methodology

Recruitment

- Eleven organisations and agencies were invited to participate
- Institutional approval was sought where necessary
- Institutions were asked to nominate a liaison officer to assist with circulating PICF to staff with relevant expertise and experience

# Qualitative Research Methodology

Participants

- To minimise the risk of coercion, individuals who wished to participate contacted me directly
- Nine interviews have been conducted to date
- Participants were drawn from two private sector and three public sector institutions

# Qualitative Research Methodology

Semi-structured interviews of one hour conducted online



- Benefits and risks
- Legal and policy challenges
- How might these be addressed?
- Elements needed in a best practice regulatory framework
- How to build greater awareness and confidence
- How to introduce greater transparency and accountability

# Benefits and Risks

## Theme 1: Benefits

- Filling a gap in the available data in the primary care setting
- Being able to identify trends earlier – very current data
- Improving models of care
- Improving management of the health system eg access

# Public Interests are in Tension

Theme 3:  
Public  
Interests



- Public interest in maintaining trust in GPs and the health system

must be balanced with

- Public interest in facilitating research in the public interest

# What Data is Most Valuable for Research?

Theme 4:  
Not all GP  
data  
needed for  
research



- Data minimisation principle reduces risk
- Need to define what data are most valuable for research
- Minimise burden on GPs who should be able to focus on providing health care

# Consent Model

Theme 5

Consent:

Waiver of  
consent

- Privacy legislation provides an avenue to access data for research without consent
- Facilitates research in the public interest BUT
- Does not support the public interest in maintaining trust in GPs and the health system
- Most participants did not support waiver of consent for GP data

# Consent Model

Theme 5  
Consent:

Opt-in  
consent  
model

- Some participants supported a requirement for fully informed, voluntary and express consent for use of GP data
- Consistent with GPs duty of confidentiality
- Supports the public interest in maintaining trust in GPs
- Does not support a wide range of research in the public interest

# Consent Model

Theme 5  
Consent:

Opt-out  
model

- Some participants supported the use of an opt-out model for use of GP data
- Supports the public interest in maintaining trust in GPs and the health system
- Facilitates a wider range of research in the public interest

# Response to Barriers and Challenges

Theme 6:

Improved  
systemic  
approaches

- A more even-handed approach to risk including the risk of the research not going ahead
- Develop acceptable guardrails for research that are pre-approved

# Raising Awareness and Confidence

Theme 7:

Closing the  
information  
loop



- Need to close the loop by sending information about the research back to GPs, patients and the community
- Move from producing reports to using dashboards that can be regularly refreshed in real time
- Need to tell the good news stories about the results of the research to build social licence

# Raising Transparency and Accountability

Theme 8:

Decision  
making

- 
- Parliament is one of our main institutions of accountability
  - Includes committee structures and community consultation
  - Well resourced, accountable, transparent
  - Governance and oversight body may be necessary on an ongoing basis

Thank You



# A Critical Commentary



**PROF MARK TAYLOR**  
**UNIVERSITY OF MELBOURNE**

**DIRECTOR, COLLABORATIVE FOR BETTER HEALTH AND  
REGULATION**  
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Australian Government  
Department of Health, Disability and Ageing

# Using General Practice Data in Research (GP Data)



# Thank you

Professor Annette Braunack-Mayer

Professor Alberto Nettel Aguirre

Dr Heidi Green

Ms Lucy Carolan

Ms Belinda Fabrianesi

University of Wollongong

Professor Justin Beilby

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