

FAIR, CARE & CALD

Community views on inclusive
approaches to data governance

Presenting

Prof Annette Braunack-Mayer

Other Project Partners

Macquarie University

Population Health Research
Network

Health Consumers NSW

Department of Health & Aged
Care



digital health crc



UNIVERSITY
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AUSTRALIA



PHRN Population
Health
Research
Network



MACQUARIE
University



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Professor Annette Braunack-Mayer
University of Wollongong

Dr Felicity Flack
Population Health Research Network

Dr Carolyn Adams
Macquarie University

Dr Anthony Brown
Health Consumers NSW

Dr Christian Jung and Dr Allison Clarke
Department of Health & Aged Care

Professor Alberto Nettel Aguirre
University of Wollongong

Professor Justin Beilby
Torrens University

Dr Heidi Green
University of Wollongong

Ms Lucy Carolan
University of Wollongong

Ms Belinda Fabrianesi
University of Wollongong

Acknowledgement of Country

I acknowledge the traditional owners of the lands on which we are meeting, the Gadigal people of the Eora Nation. I pay my respects to Elders past, present and emerging. I acknowledge the devastating impact of colonisation and commit myself to truth-telling, healing and education.

Why are there problems?

Upstream barriers

CALD communities are underrepresented in
data-intensive activities

Downstream
barriers

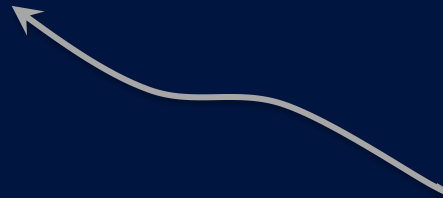
Why are there problems?

Upstream barriers

- Inaccurate data collection on marginalised groups
- Technical language
- Resources only in English language
- Mistrust in health systems
- Mistrust in government

Why are there problems?

- Sociocultural factors that may discourage people from taking in programs or strategies even when needs are recognised
- Material obstacles



Downstream
barriers

Background

GP Data 2.0

To develop best practice framework to enhance public confidence in the use of general practice data for research purposes

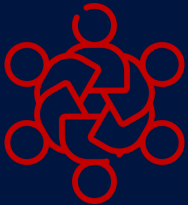
Explore the perceptions of key stakeholders including community members, GPs and policy makers regarding acceptable policies and practices



Jurors attending the Sydney Community Jury

Recommendations

Under what circumstances, if any, should we share general practice data for research purposes?



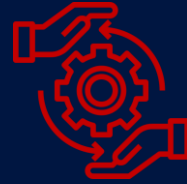
Consultation & consideration of vulnerable populations



Consent



Communication & Transparency



Governance



Public Benefit



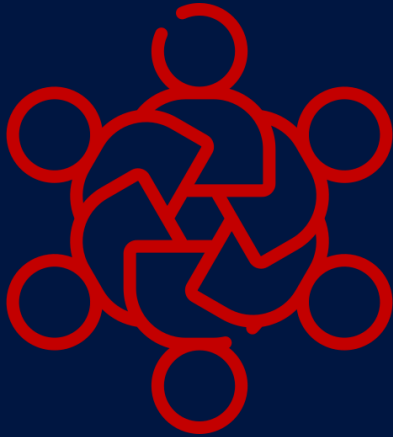
Security



Costs

How can we appropriately consider the needs of CALD communities?

Recognise our differences



...Further research on community views ... to include a broader selection of opinions from the Australian community, for example vulnerable minority groups with complex and sensitive data including LBGTQI+, gender reassignment, people affected by domestic violence, severe mental health and other groups for whom sharing sensitive information may be detrimental to their lives.

Sydney Jury

How can we appropriately consider the needs of CALD communities?

Understand others' experiences

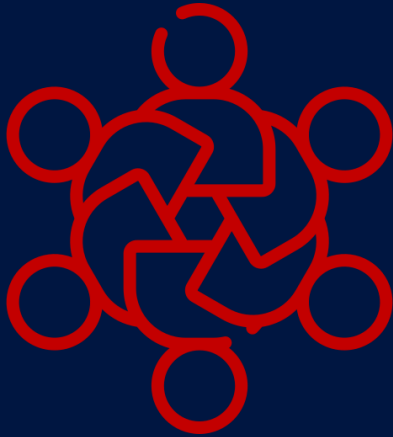
This jury needs to make clear that Aboriginal and Torres Strait Islander peoples have experienced and continue to experience abuses of power, breaches of trust and, in many cases, targeted discrimination.

These abuses continue to happen.

It also needs to be taken into consideration that these experiences are shared by others...

If nothing changes, nothing changes.

Melbourne Jury



How can we appropriately consider the needs of CALD communities?

Communicate appropriately

Information be provided in language and with timing that patients can understand.

Sydney Jury



People should be well informed. They should have access to clear, concise, accessible and up-to-date information (understandable by a community member) about the consent model, current and past studies, how data is de-identified and how, where, by whom and why it is used.

Melbourne Jury

Community views on inclusive approaches to data governance

Messages from GPData 2.0

- Transparency
- Work with minority populations to collect, store and use data in culturally safe ways
- Offer clear public benefits:
 - Conduct research that matters to communities
 - Prioritise CALD community questions
- Include community members as researchers



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GP Data 2.0

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[Macquarie University](#)

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[Population Health Research
Network](#)

Dr Anthony Brown
[Health Consumers NSW](#)

Ms Belinda Fabrianesi
[University of Wollongong](#)

Ms Lucy Carolan
[University of Wollongong](#)

Dr Kate Miller
[Population Health Research
Network](#)

Professor Alberto Nettel
Aguirre
[University of Wollongong](#)
