Facilitating Access to General Practice Data for Research in Australia

The Need for Legal Reform

Presenting
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Population Health Research Network
Health Consumers NSW
Department of Health, Disability & Ageing

digital health crc

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OF WOLLONGONG
AUSTRALIA

PHRN Population Health Research Network

MACQUARIE
University

HEALTH CONSUMERS NSW

Australian Government
Department of Health, Disability and Ageing

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digital health crc

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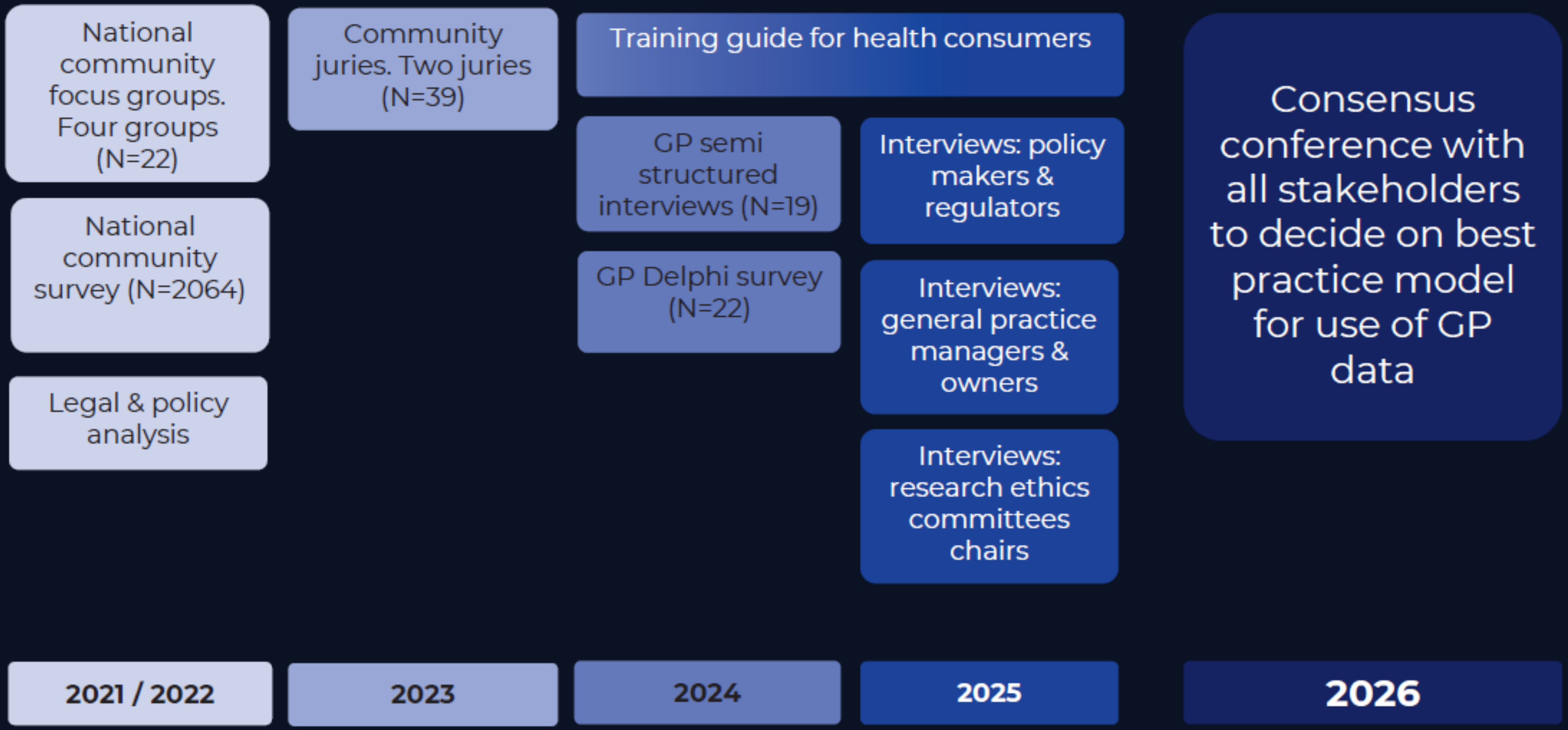
Collecting the evidence to build public confidence in using general practice data



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

Consensus conference with all stakeholders to decide on best practice model for use of GP data

2021 / 2022

2023

2024

2025

2026

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* 840

Research	Interviews
Outcome: Current legal and policy framework does not provide clear guidance for stakeholders	Ask regulators and policy makers about the legal and policy challenges, and what elements are needed in 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

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

- To 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?

Public Interests are in Tension

Public Interests

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

must be balanced with

- Public interest in facilitating research for the public good

What Data is Most Valuable for Research?

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 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 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
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

Further Information

Thank You