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Placing conditions on sharing general practice data for research: Recommendations from two community juries

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Abstract

Objective
There is increasing demand for access to general practice health records for secondary purposes, including research. However, the extent to which the public supports such use is unclear. We sought to explore informed Australians' perspectives on conditions under which the use of general practice data for research would be acceptable.

Methods
We conducted two community juries in July and August 2023 with 20 participants, selected for diversity, in each jury. Jurors worked for 36 hours, in a combination of online and face-to-face sessions, over 6 days. They listened to expert presentations, discussed, and challenged experts, deliberated, and developed their own recommendations.

Results
Both juries, in principle, supported sharing general practice data for research purposes. They made 24 (Sydney jury) and 19 (Melbourne jury) recommendations related to consent, information provision, public benefit, data security, governance and costs.

Conclusions
The outcomes of the deliberative process suggest that an informed group of Australian citizens are willing to share general practice data for research provided strict conditions are met.

Implications for Public Health
Adopting the recommendations from the juries will require a range of policy and regulatory responses including legislative changes.

Keywords
community jury; consent; data linkage; deliberation; general practice; general practice data; privacy

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Introduction

There is a strong demand in Australia and internationally for access to administrative health data for research. General practice data can be a rich resource for such purposes, particularly when combined with hospital and other health service data through data linkage [1]. Although there are now over 100 primary care datasets available in Australia, these datasets are not being used to their full potential [2]. Alongside technical reasons related to poor data quality and the lack of standardisation of and interoperability between clinical software tools, "fear, reticence and lack of trust" amongst GPs and patients is the most frequently cited reason [2]. In addition, the legal and policy frameworks in Australia are not well suited to support the use of general practice data for research [3].

A number of international studies suggest patients and the public hold similar views to people in Australia specifically about sharing the information in their general practice [12–30]. Many people recognise the benefits of using general practice data for research. They appreciate that using general practice information in research has the potential to advance medical knowledge and improve quality of care, support monitoring of disease outbreaks, enhance disease registries and benefit individual health service users [30, 31]. Some patients also believe that sharing their health information allows them to contribute to society and help other patients [32].

Patients and the public are also uncomfortable with sharing both identifiable and non-identifiable general practice data beyond the clinical encounter, particularly as their appreciation of the link with their own healthcare becomes less direct [16, 24]. For example, willingness to share with researchers varies, with some studies reporting over 60% willingness to share [24, 31] and others as low as 20% [19, 33]. Patient and public concerns about sharing general practice data are related to several factors, including: lack of control over their own health record [16, 35], data security [17, 32], misuse [17, 30, 32], profit motives [14], the level of trust in the data custodian [16, 17, 33] and, to a lesser degree, the impact of research involvement on GPs and practice staff [30].

There has been less research in Australia on patient and public views on sharing the information in general practice records for research. Our recent national survey and focus groups [33] demonstrated lower levels of public support for the secondary use of general practice data for research compared with other Australian studies on community views about secondary use of health data for research [34].

Exploring community views on sharing health data has challenges. Patients and publics have variable understanding of how data are collected, linked and shared, whether and how consent is sought and how privacy is protected. This variability in understanding has been noted as a limitation in effectively exploring community views in quantitative and qualitative research [16, 32, 35, 36]. We used community juries to explore what informed Australians considered justified uses for sharing general practice data for research. Community juries provide an opportunity for members of the public to give informed input into policy making about the secondary use of general practice data for research [37, 38]. The community jury process allows a diverse group of people to rapidly increase their knowledge and understanding of relevant evidence, and social and ethical factors, allowing them to engage effectively with complex policy questions in an informed manner [37]. To explore what informed Australians consider to be justified and legitimate uses of general practice data for research, we convened two community juries to consider the charge: Under what conditions, if any, should general practice data be used for research in Australia?

Methods

This project was approved by the (University of Wollongong) Human Research Ethics Committee (Ethics number: 2023/108). We ran two community juries in July and August 2023 in Sydney and Melbourne to explore the views of well-informed lay people regarding the secondary use of general practice data for research. Supplementary Appendix 1 provides our detailed methods reported via the CJCheck Stage 1 [39].

Recruitment

22 Australians were recruited for each community jury, using a social market research company, CRNRStone Australia [40], from their opt-in online panel. We used purposive sampling to recruit a sample that was diverse with respect to gender, age, Aboriginal or Torres Strait Islander status, educational qualifications, employment, rurality and cultural background. This method was used to keep within the budget constraints of the juries. Only participants 18 years and older were invited and those with current or previous experience(s) working in a general practice setting were excluded. For each jury, two 'standby' jurors were recruited in the event of jurors dropping out.

Consenting jurors were asked to complete a short online survey to assess their knowledge of and views about sharing general practice information for research (see Supplementary Appendix 2). Before the jury, we provided jurors with the participant information booklet which contained background and information on the jury process and a summary of the expert witness material (see Supplementary Appendix 3).

Jury procedure

We convened the face-to-face juries over 2.5 consecutive days, beginning with a 90-minute online session, followed by a Friday evening, then two full days on Saturday and Sunday. Facilitation was led by an independent facilitator (MWS) with extensive experience in community engagement.

Both juries followed the same program over a total of 19.5 hours. Friday evening and Saturday morning were primarily information provision by experts, with time allocated for discussion and questions and answer sessions with the experts (see Table 1). Saturday afternoon and Sunday were spent in deliberation and development of recommendations, guided by a set of pre-determined questions that reflected key policy and governance issues (see Table 1).

Information was provided using a range of perspectives and the research team attempted to hold a neutral stance throughout the jury. Jurors were encouraged to clarify and challenge the evidence presented. The jurors alternated between plenary and small group activities, with small

Table 1: Jury content, process and guiding questions

Jury Content and Process
Day 1: Online (1.5 hours)
Information provision (55 min) and skill building (35 min) Research team introductions, brief overview of the jury process and two short activities to support juror critical thinking and information bias skills *(Matthew Wright-Simon, Engage Change).*
Day 2: Friday - In person (3 hours)
Relationship building (45 min) Two short activities to foster understanding of social styles and support group connection *(Matthew Wright-Simon, Engage Change).*
Information provision (20-min presentation and 10 min Q&A)
1. What is a Community Jury? (i) background to community juries, and (ii) role of the juror *(Annette Braunack-Mayer, University of Wollongong).* 2. General Practice in Australia: (i) an overview of the general practice context in Australia (ii) what is in a GP record, and (iii) how information is recorded in a GP record *(Justin Beilby, University of Wollongong & Torrens University).*
Day 3: Saturday - In person (8 hours)
Information provision (20 min presentation and 10 min Q&A)
3. Using the Data in General Practice Records: (i) who uses general practice data, and (ii) what general practice data is used for *(Joel Rhee, University of New South Wales).* 4. Linking Health Records: (i) what is data linkage (ii) how does data linkage happen (iii) what data can be shared, and (iv) examples of data linkage *(Kate Miller, Population Health Research Network).* 5. General Practice Data Sharing Example (Lumos): (i) what is Lumos (ii) what types of data does Lumos collect (iii) general practice participation in Lumos, and (iv) privacy and ethics in Lumos *(Patricia Correll, Lumos).* 6. Ethical Issues in Sharing General Practice Data: (i) ethical principles in sharing personal health information (ii) benefits and harms (iii) bias and fairness, and (iv) ethical clearance for research projects *(Professor Annette Braunack-Mayer, University of Wollongong - Sydney & Melbourne Juries) and (Carolyn Adams, Macquarie University - Melbourne Jury).* 7. Legal Considerations, Regulations and Consent: (i) confidentiality (ii) privacy legislation, and (iii) consent *(Carolyn Adams, Macquarie University).* 8. Community Views: (i) results from a national survey *(Professor Annette Braunack-Mayer, University of Wollongong).* 9. Community and Health Consumers Views on Sharing General Practice Data: (i) community and consumer concerns, and (ii) Consumer and Community Involvement (CCI) *(Carrie Hayter, Health Consumer NSW - Sydney Jury) & (Anthony Brown, Health Consumer NSW - Melbourne Jury).*
Deliberation Deliberation 1: Draft recommendations
Day 4: Sunday - In person (7 hours)
Deliberation Deliberation 2: Small group work to explore guiding questions Deliberation 3: Refine recommendations as a whole group Deliberation 4: Vote on recommendations as a whole group
Guiding Questions
1. Who should have direct access to general practice data when used for research? 2. Who should oversee and make decisions about sharing general practice data? 3. Do certain types of general practice data need more protection than others? 4. Should there be penalties applied if those who use general practice data break the rules or misuse the data? 5. Who should pay the costs associated with sharing general practice data? 6. How should general practice patients be told about the way in which their general practice data are collected and shared? And how much should they be told? 7. Should there be a requirement that research findings be released to general practice patients or to the Australian community?

groups randomly re-allocated to ensure cross-fertilisation of perspectives. In plenary sessions, the recommendations from each small group were presented by spokespersons and then revised by the whole group. Finally, the jurors voted on each recommendation. Votes and reasons for and against each recommendation were recorded.

At the completion of the jury, jurors completed a post jury survey (see Supplementary Appendix 4) and evaluation survey (see Supplementary Appendix 5). Each juror received $AUD690 to cover their time and a $100 Visa gift card to cover travel to and from the venue. All meals for the face-to-face meeting were provided.

Data collection and analysis

A Hansard reporter was present to capture whole group jury proceedings on Day 1 and Day 2. Jurors explored the guiding questions in small group work using butchers' page, notepads and templates to capture their recommendations, reasoning and considerations. A member of the research team typed up the recommendations from each small group and these recommendations were presented back to the jury for deliberation. With support from the facilitator, the jury revised their recommendations and voted on each recommendation using red 'no', orange 'maybe' and green 'yes' cards. The Hansard reporter recorded all deliberation, including votes and reasons for and against each recommendation.

Quantitative data were captured through the pre- and post-jury survey and evaluation survey. We used NVivo [41] to code the qualitative data (transcription and template content) into themes, and Statistical Package for Social Sciences (SPSS) [42] to analyse the quantitative data descriptively (pre- and post-jury survey and evaluation survey). No statistical testing was performed on the quantitative data as the aims of the paper did not have a-priori set hypothesis to be tested. The descriptive summaries and results are shown to provide an indication of observed changes in the sample, not to infer that taking part in community juries would have changed scores at the population level.

Results

Juror demographics

In total 20 jurors attended each jury. One juror had to leave the Sydney jury before final voting took place, resulting in only 19 jurors voting on recommendations. Almost half the jurors identified as female (47.5%) or male (47.5%) with the remainder identifying as non-binary (5%). There was approximately equal representation of jurors across three age groups: 18-39, 40-59 and over 59 years. Around one third of jurors had a university or post graduate degree (35%) and three jurors identified as Aboriginal and Torres Strait Islander (15%). Juror demographics may be found in Table 2.

Jury recommendations

Both juries, in principle, supported sharing general practice data for research purposes, subject to certain conditions. Each jury produced a set of recommendations that described these conditions. The juries made similar and complementary recommendations related to consent, information and transparency, public interest, security and governance, with the Sydney jury also making recommendations about the costs of data sharing (see Table 3). Jury recommendations were unanimous unless otherwise indicated.

Each jury wrote an overarching statement for their recommendations. In the findings below, jurors are identified by an S for Sydney and M for Melbourne plus a unique identifying number. References to 'we' in the quotations reflect the views of small groups reporting back on discussions.

Jury reasoning

Overarching statement

Both juries wanted to ensure that the views and experiences of specific population groups were reflected in recommendations. The Sydney jurors were concerned that they did not adequately represent the views of people from more vulnerable backgrounds who might not be as supportive of data sharing.

> *S1: . . . we're worried that as a jury, as part of a jury, we're unable to make informed decisions for everybody in the Australian community, and I feel that there are groups that aren't represented here in this room, and I don't think that we can . . . make the decision for those people because we don't live in their shoes, so that's why we have done this.*

The Melbourne jury's overarching statement was developed in response to the perspectives of jurors whose past experiences of trauma and the systemic abuse of Aboriginal and Torres Strait Islander peoples had led to great distrust in government generally. Their fellow jurors recognised the impact of these experiences and the importance of acknowledging distrust when developing recommendations.

> *M1: . . . and I can't trust the government as far as I can throw them. So, yes, that's why every single thing that I say is just like, "The government can give you assurances, but there need to be independent bodies, there need to be things with teeth, because they are a power unto themselves." So, yes, I don't trust them either, but I feel like that's why we are here, to find a way to make them trustworthy.*

Consent

Both juries supported an opt-out model of consent because they believed it appropriately balanced concern for individual patient choice and access to care against ensuring datasets were comprehensive and representative of the whole population.

> *M2: I think that it's pretty important to gain permission from patients, but also acknowledge that if certain groups of people weren't to give permission it could also create bias in the data potentially, which would be problematic.*

The juries' additional recommendations about consent also reflected their wish to both meet individual patient needs

Table 2: Juror demographic

Demographics	Jurors % (n)	Australian population %
Gender		
Man	47.5 (19)	49.3
Woman	47.5 (19)	50.7
Non-Binary	5 (2)	0.2
Age[2]		
15-19	2.5 (1)	6.0
20-24	5 (2)	6.5
25-39	30 (12)	21.9
40-59	27.5 (11)	24.8
60-74	27.5 (11)	15
75+	7.5 (3)	7.8
Country of birth[3]		
Australian born	85 (34)	70.5
Overseas born	15 (6)	29.5
Education[4]		
Secondary (up to year 12)	30 (12)	36.7
TAFE (Cert or Dip)	27.5 (11)	25.6
Bachelor's degree level and above	37.5 (15)	26.3
Unknown/ Not stated	2.5 (1)	8.2
Aboriginal and/or Torres Strait Islander[5]		
Yes	12.5 (5)	3.8
No	87.5 (35)	96.2

[1]https://www.abs.gov.au/statistics/people/population/population-census/2021.
[2]https://www.abs.gov.au/statistics/people/population/population-census/2021.
[3]https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/jun-2023#data-downloads-data-cubes.
[4]https://www.abs.gov.au/census/find-census-data/quickstats/2021/AUS.
[5]https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/30-june-2021.

and ensure research quality. Allowing patients to choose which components of their health record would be included, potentially restricting the use of free-text notes, and ensuring consent models reflected the needs of specific population groups were vehicles to demonstrate respect for patient choice. These strategies could also encourage patients not to opt-out, which would address potential bias in the dataset.

> *S2: We phrased it that way because a lot of people would opt out, say, if they were [from minority groups] – they would opt out. This way they could opt in but just prevent one particular item or more than one particular item from being presented to other outside sources. Better to join than not join.*

The jurors also recognised that an approach which completely waived consent would likely provide more data, of higher quality, and be easier to implement.

> *S3: Once upon a time, an opt out was just presumably a note up saying, 'We're doing this. Let us know if you don't want to', but suddenly it has now become a lot more complicated because you're going to have to spell out every single thing, tick a box. Who is responsible for that? Is it the poor doctor who has zero time in his life to do everything and is now stuck explaining ever single bit? That would be my concern.*

Nonetheless, they balanced these limitations against the needs of individual patients and recommended an opt-out model.

Information provision

The juries' support for opt-out consent was also contingent on the provision of accessible and appropriate information about data sharing. They wanted all patients, including those from diverse backgrounds, to understand how their data were being used, where, by whom and for what purposes. The jurors also noted that, as data sharing practices changed over time, patients would need to receive regular updates.

> *S4: So we were talking about the initial patients, so when they sign in they get the form with the information on it, but if legislation changes, this is how we get everyone else to know as well. So we communicate with them in other ways to say, "Legislation has changed . . ."*

Table 3: Community jury recommendations by location

Sydney (19 jurors)	Melbourne (20 jurors)
Overarching Statement	
We note that further research on community views should be undertaken to include a broader selection of opinions from the Australian community, for example vulnerable minority groups with complex and sensitive data including LBGTQI+, people affected by domestic violence, severe mental health and other groups for whom sharing sensitive information may be detrimental to their lives.	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, including but not exclusive to: • The LGBTIQ+ communities • People living with disabilities. • Asylum seekers and refugees If nothing changes, nothing changes.
Consent	
Patient consent be provided through an opt-out system.	Patient consent is sought using an opt-out model. *Yes 18, Not sure 2*
Patients can choose which components of their information are excluded. *Yes 15, Not sure 1, No 3*	Consent models be appropriate for the specific needs of research participants. *Yes 17, Not sure 3*
GPs should be able to choose not to provide patient free text notes.	Human research ethics committees require researchers to demonstrate that patients understand that they can opt out. *Yes 16, Not sure 4*
New patients be required, at initial consultation, to acknowledge that they are aware that they can opt out.	
Information	
Information be provided in language and with timing that patients can understand.	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.
The information be available in appropriate and accessible formats.	Patients can request access to information about how their data is being used for research purposes. *Yes 15, Not sure 5*
Existing patients be provided with communication through appropriate and accessible formats.	
Public Benefit	
Data only be provided for research related to improving health outcomes.	General practice data be shared with researchers solely with the intention of progressing medical practice and for the benefit of the public.
Data are not provided where the only benefit is likely to be private sector profit. *Yes 1, Not sure 13, No 5*	Researchers should demonstrate to the human research ethics committee how their research will benefit the public and/or medical practice.
	Access to high quality patient-centred care and doctor-patient relationships must not be put at risk by the collection of general practice data for research.
	General practice datasets used in the research are representative of the population being researched.
	All general practices should contribute data to improve the quality of their patient care. *Yes 15, Not sure 4, No 1*
Data Security	
Best practice in data security be investigated and used.	Data and cyber security practices (including data gathering, distribution, usage and storage) are audited every 6 months by an independent body. *Yes 18, Not sure 2*

Continued

Table 3: Continued

Sydney (19 jurors)	Melbourne (20 jurors)
Data be accessed only by authorised researchers. *Yes 14, Not sure 5*	Anyone working with data must have background checks and undertake regular best practice cyber-security training. *Yes 16, Not sure 4*
Stakeholders who misuse data be prosecuted under the law (fines, jail or whatever is applicable).	An independent body should investigate the root cause of data breaches. If found to be malicious or for personal gain, individuals should be heavily punished. If found to be a genuine mistake, the organisation should be fined to encourage better and more secure practices. *Yes 19, Not sure 1*
Non-stakeholders (such as hackers) be fined and face jail time.	A secure research environment be the preferred approach to access datasets. *Yes 17, Not sure 3*
Government departments are resourced to locate and prosecute those who misuse data.	Researchers and their organisations should follow standardised policies and procedures for the destruction of datasets at the conclusion of the research project and be responsible for their destruction. *Yes 19, Not sure 1*
The above data misuse recommendations be put into legislation.	
Stakeholders (data collection agencies, ethics committees, community groups, researchers) be held to the same confidentiality standards as GPs.	
Governance	
A governance body be established to oversee sharing general practice data for research purposes.	Access to general practice data may be granted only if approved by a human research ethics committee. *Yes 18, Not sure 2*
The governance body include representatives from the Department of Health, general practitioner associations, consumer interest groups, community leaders and elders, university research institutes, ethics committees and other relevant stakeholders.	A governance manual incorporating appropriate policies and procedures be documented for each research project using general practice data *Yes 18, Not sure 2*
This body operates under a transparent framework with clear terms of reference.	All research projects using general practice data must have relevant community involvement.
Data only be provided with unanimous ethics committee approval.	
Costs	
Government agencies should cover the cost for establishment, storage, access, retention and subsequent destruction of data. *Yes 17, Not sure 2*	
General practices which provide data should be remunerated.	
Private companies should pay for data collection, collation and associated access costs.	

Unless otherwise indicated, all votes were unanimous.

As with their deliberations on consent models, the jurors recognised that ensuring patients received and understood information about data sharing could be challenging, for example, if practice posters became hidden. They also appreciated that it could be difficult to commit the time and resources required to fully inform patients when their health information was being used.

Public benefit

Both juries recommended that the secondary use of general practice data for research be restricted to research which would benefit the public, focusing particularly on research that would improve health outcomes and medical practice.

> *S5: So I'm generally ecstatic about the fact that when data is shared for health purposes it can improve outcomes.*
>
> *M3: From a health perspective, we sort of saw that it would give the patient a better understanding and hopefully more effective treatment, a broader knowledge the community . . . the population, and hopefully direct improvements in the short term and long term, and better outcomes for the GP; for*

the practice, stronger patient relationships, some time saving and improved patient knowledge.

The jurors were also clear there were some uses of general practice data which would not be acceptable. The Sydney jury recommended that research that would benefit the private sector could only be undertaken for the public good - particularly if there would be financial benefits for the private sector.

S6: So we believe that by sharing data it should be for the greater good and not to profit from our data, so we don't want to have these types of data to be sold to pharmaceuticals or be sold for anything to be used for marketing purposes.

S7: . . . I feel like sometimes it can be hard to delineate whether something is purely for profit . . . while it is in the interest of improving health outcomes for people with a certain condition, they are also like, "Well, this actually makes us a lot more money because now we have identified how to get this medicine or treatment to people who need it in a more efficient way", so I think that can be difficult.

The Melbourne jury was concerned that the time and resources that would be devoted to collecting and making available general practice data could be at the expense of patient care, and they wanted to emphasise that the doctor-patient relationship should always take priority. They prefaced their recommendation on this matter with an explanatory statement:

M4 The provision of GP data to be used for research purposes must not place undue burden that directly or indirectly leads to a reduction in patient care, including accessibility parameters such as cost, availability of bulk billing services and length of consultations. While the collection of GP data will be a rich source of quality information, it is important to recognise and ensure that patient-GP relationships are critical to safe and quality medical care. Where these two benefits are in conflict, patient-centred care should be prioritised.

Data security

Both juries made recommendations on the need for systems and practices that would maintain the security of general practice data, in whatever settings they are held and used. They trusted GPs, governments and researchers to hold data securely, but they also recognised that data misuse does occur.

S3: . . . a big chunk of the general population out there. . . generally trust the GP, they probably trust all the government mechanisms that were in place to keep that data safe, but they know full well that there is a hacker out there . . . really at the end of the day there is no guarantee that data will be safe and there is no guarantee that you can't be identified in the future.

The jurors argued that robust security systems were essential to maintain trust and they made a range of recommendations to enhance data security. Both juries recommended strong penalties for data misuse. These penalties were intended to punish those who misused data and to act as a deterrent.

S2: . . . I think the only way you can trust people is if there are huge penalties for mistrust or misuse or selling the information, and I suggested that a person who misuses the information be fined $100,000; a company that misuses information be fined $1 million; and that anybody who sells the information for profit be gaoled.

M5: . . . if something goes wrong, it's not so much that we're going to punish people for having done the wrong thing; you want to deter people, not to allow themselves to get into a situation where something is going to go wrong.

Both juries also recommended standardised systems to manage data and independent agencies to audit security practices and investigate breaches. In part, these recommendations reflected the jurors' belief that independent, well-resourced "experts" were needed to investigate breaches and to ensure that best practice measures for the collection, storage and disposal of data were used.

M5: We recommend that datasets may only be accessed via secure research environments.

M6: Yes. That way you know that it is going to be deleted and that they have the standardised process to begin with. It's an extra safeguard.

Governance

The juries recommended that independent bodies oversee data sharing, and both juries recognised that ethics committees had an important role to play. The Sydney jury wanted broader involvement from key stakeholders in decision-making and required that decisions to allow research to go ahead had unanimous support from an ethics committee. The Melbourne jury recommended that community members be involved in these decisions.

S8: . . . there are lots of different stakeholders with lots of different varying interests that they represent, but there doesn't seem to be an overall framework of looking at it all together at the moment, where everybody can actually have their say. Also, if things go wrong, there's no one oversight point at all, so someone to look over to make sure the integrity of all of this is going in the right direction and the best interests of the general public . . .

Both juries also recommended transparency in the governance of research projects, with clarity around the operations of governance bodies (Sydney) and a governance manual for each project (Melbourne).

M3: . . . for everyone, from project to project to project, we [should] have a clear understanding of what the expectations are and the ability to follow up, knowing that these are the guidelines they should be following, so for consistency.

Costs

The Sydney jury made recommendations about how the use of general practice data for research should be funded, with their primary concern being that the resources, time and training to engage GPs should not be a disincentive to their involvement.

> *S9: We also want this type of program to have incentive programs for GPs, especially because they are putting so much time and effort into participating in sharing data for research purposes, especially knowing that GPs are actually operating on such a lean-margin business model, they should be compensated for their time.*

Pre- and post-jury survey

Overall, there were changes in responses to the juror surveys before and after the juries, which reflected, to some degree, the information jurors had received during the juries. After the jury, a higher percentage of jurors were willing to share general practice data for research with all organisations and for all purposes (see Table 4). The largest percentage changes were observed for sharing with individuals and organisations outside of the practice and for purposes beyond individual care.

The percentage of jurors willing to allow their general practice data to be linked to other health service data rose very slightly after the jury (94.9% pre, 97.4% post). By contrast, the percentage willing to allow their general practice data to be linked to education department (61.5% pre, 51.3% post), social service (66.7% pre, 59.0% post) and criminal justice records (46.2% pre, 38.5% post) was slightly lower following the jury. There was a slight increase in the percentage of jurors willing to let their GP decide who could see the information in their record (38.5% pre, 51.3% post). However, this was counterbalanced by a lower percentage of jurors after the jury who were confident that their GP could take care of the information in their general practice record (100% pre, 89.7% post). Finally, there was also a slight increase after the jury in the percentage of jurors who required their names, addresses and dates of birth to be removed before their information could be shared (82.1% pre, 92.3% post). All pre and post survey results may be found in Supplementary Appendix 6.

Evaluation survey

Findings from the anonymous evaluation survey found almost all (94.5%) jurors supported sharing general practice data for research. Here jurors cited benefits to healthcare and health outcomes.

> *I strongly support de-identified data being available for use in research that will contribute to improving general health and wellbeing of all Australians and to further scientific knowledge and advance medicine for the entire world.*

The one participant who opposed sharing referenced the need to respect individual patient preferences when sharing general practice records.

> *In principle it is valuable, but it is not a one size fits all scenario - some research I do want to support / others not. I'd want choice, and I don't want my personal health data ending up in someone else's narrative, where it was collected on me for me.*

The evaluation survey found more than two thirds of jurors (68.4%) believed they were now knowledgeable on sharing datasets for secondary purposes, yet only half (50%) of the jurors believed they understood how datasets could be linked. The impact of the jury on knowledge and understanding was recognised by jurors, with most broadly agreeing the jury changed their understanding (94.6%) and awareness (97.3%) of the different viewpoints of sharing general practice data for research.

The evaluation survey captured high levels of juror satisfaction in the jury proceedings. Most jurors indicated processes within the jury were clear, comprehensive, engaging, respectful and constructive. Two-thirds (70.2%) of the jurors broadly agreed there was enough time provided for each aspect of the process. One of those who disagreed suggested that they would have been better able to express their views with more time, but their quotation suggests that the issue might equally have been dominant participants. Inadequate time is a common challenge for many juries with the public.

> *I believe the timetabling and structuring of the days could be improved. I often felt talked over and rushed. I often missed the opportunity to express*

Table 4: Combined community juries pre and post-jury survey findings (N = 39)

	Pre jury survey n (%)	Post jury survey n (%)
Broad agreement to share general practice data with different organisations:		
Health administrators and planners in government	9 (23.1)	29 (74.3)
Researchers in a university	12 (30.7)	35 (89.7)
Researchers in government departments	9 (23.1)	33 (84.6)
Researchers in private industry	5 (12.8)	18 (46.1)
Broad agreement to share general practice data for different purposes:		
To directly support my personal care	38 (97.4)	39 (100.0)
For my GP to improve the health services they provide	36 (92.3)	39 (100.0)
For the government to improve health services generally	28 (71.8)	36 (92.4)
For research in universities, hospitals or publicly funded research organisations	23 (59.0)	34 (87.2)

> *my opinion due to others bulldozing conversation or running out of time ... Although this would have been fixed without time pressure.*

In addition, nearly one third (32.4%) believed there were important issues the evidence packages did not cover, and several jurors indicated the need to hear more about the risks and benefits attached to sharing the information from general practice records.

> *I'd like to know about all the best studies and outcomes that had happened from data sharing and also the largest breaches.*

Many jurors cited the experience to connect, hear different viewpoints, explore their own perspectives and contribute towards positive changes to the healthcare system as personal and altruistic benefits to participating in a jury.

> *A diverse group of people with differing views and backgrounds that connected over a common goal and were for the most part respectful of each other.*
>
> *Being able to collaborate together and make recommendations that could change the future of health care system and how data research is being used. Learning more things about the experience.*

All evaluation survey responses can be found in Supplementary Appendix 7.

Discussion

To our knowledge, this is the first Australian deliberative process to focus specifically on the secondary use of general practice data for research. Both juries broadly supported the use of general practice data for research and made similar and complementary recommendations about the conditions under which sharing would be acceptable. Their recommendations align with other studies of community views on sharing administrative health data, which have also found broad public support for sharing personal health data for secondary purposes, provided a range of conditions are met [9, 11, 44].

Some of the juries' recommendations are reflected in existing legal and regulatory instruments, for example, the *National Statement on Ethical Conduct in Human Research* (2023) and the *Privacy Act 1988* (Cth). The National Statement, for example, requires researchers to develop comprehensive data management plans addressing storage and security and retention and disposal of data. The National Statement also requires researchers to demonstrate that their research is in the public interest before a Human Research Ethics Committee can approve the use of an opt-out approach [45]. In addition, the Office of the Australian Information Commissioner (OAIC) plays a central role in policy development and regulation of the use of data in Australia, including by the private sector. The Australian Information Commissioner, for example, already has power to investigate data breaches, either in response to complaints or on the Commissioner's initiative and has done so in relation to the secondary use of health data for research.

There are also points of difference between our juries' recommendations and those of other studies concerning secondary use of personal health data. First, both juries emphasised the unique experiences of specific population groups, particularly with respect to trust. The issue of trust in GPs will be especially salient for these minority groups who continue to experience breaches of trust and discrimination in their daily lives. Ongoing consultation with these groups will be required to build the social licence – acceptance and trust based on legitimacy, ethical standards and social responsibility - to share data [46].

Second, both juries recommended an opt-out model of consent with additional conditions to ensure that patients were fully aware of their right to opt-out. Recent Australian studies, using opinion polls, surveys, focus groups and deliberation, on sharing personal health data for health and medical research suggest that there is broad support for sharing data *without* consent, including sharing data with the private sector [33, 36, 47]. The preference in our study for opt-out, rather than waiver of consent reflected a perception that general practice is unlike other healthcare settings. Many GPs develop close relationships with their patients, recording aspects of their patients' personal and work lives that other healthcare practitioners may not and maintaining these records over long periods of time. This is likely to amplify the public's sensitivity about sharing their data in general practice settings.

In recent years, initiatives to harness the data held in general practice records have exploded, in concert with a recognition that better use of data and more robust research are key enablers for high quality, value-based primary care [48–51]. The findings in this study show that there is public support for sharing general practice data. However, that support is contingent on assuring the public that general practice data will only be shared when data are held securely, privacy is protected, information about data sharing is accessible and patients' wishes with respect to their data are respected. Adopting the recommendations from these juries would require a range of policy and regulatory responses, including:

- a data sharing framework that places the diversity and vulnerabilities of Australia's patients at the centre of its considerations;
- changes to legislation which support robust notice and (potentially opt-out) consent requirements for the use of general practice data;
- an independent body to provide oversight and governance of secondary use of general practice data; and
- a broad and deep program using a wide range of media to inform the Australian public about the secondary use of general practice data.

Limitations

Our participants were selected from a panel of 100,000 volunteer members available to participate in research making them perhaps more familiar with research than the general population and raising the possibility of selection bias. However, we purposively selected a diverse sample and

all jurors contributed to deliberation and recommendations. The Melbourne jury was conducted following the world's longest COVID-19 lock-down, which may have shaped the jurors' views about trust in government and access to health care. However, findings from the two juries were very similar, suggesting that the recommendations from the juries are indicative of broader community views. It is also important to acknowledge the methodological limitations of community juries in that they are not representative and require substantial resources to run.

Most jurors reported that they had been provided with opposing views. However, despite our efforts to minimise any potential information bias, a few jurors commented on needing to hear more negative viewpoints. The comments in the post-jury evaluation on the need to understand better the risks and potential benefits of sharing general practice data for research also highlight the importance of the general practice context.

Conclusion

The outcomes of the deliberative process suggest that an informed group of Australian citizens are willing to share general practice data provided strict conditions are met. The juries recommended opt-out consent, strict privacy protections, data use only in the public interest, and robust and independent oversight. The findings of this study provide guidance to ensure that any future use of general practice data for research is consistent with public expectations.

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Conflict of interest statement

The authors wish to declare a relationship with the following institutions and organisations: Digital Health Cooperative Research Centre (ABM, HG, LC, BF, CA, FF, AB), South Australian Department of Health and Wellbeing (ABM), Australian Medical Council (ABM), National Health and Medical Council (ABM), Australian Research Council (ABM), Bellberry Ltd (ABM, HG, ANA), NSW Ministry of Health (ABM), South Australian Health and Medical Research Institute (JB), Central Adelaide Local Health Network (JB), Australian Government National Collaborative Infrastructure Strategy (FF), Cambridge University Press (FF), Macquarie University (CA), Australian Government National Collaborative Infrastructure Strategy (KM), Westmead Applied Research Centre (CH), Royal Australian College of General Practitioners (JR) and Australian Medical Council (JR), PEN-CS (JR). In addition, authors (JB, JR) are practising general practitioners.

Ethics statement

This project was approved by the (University of Wollongong) Human Research Ethics Committee (Ethics number: 2023/108). Jurors provided audio recorded and written consent before participating.

Data availability statement

The participants of this study did not give written consent for their data to be shared publicly. Due to the sensitive nature of the research supporting data are not available.

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