

Appendix 7: Evaluation Survey Data

Understanding of sharing general practice data for research

	Very knowledgeable	Somewhat knowledgeable	A little knowledgeable	Not at all knowledgeable
How knowledgeable are you about sharing datasets for secondary purpose	15.8	52.6	23.7	7.9
How knowledgeable are you about linking datasets with other datasets	25	13.9	50	11.1

Juror support for sharing general practice data for research

	Strongly support	Support	Neither support nor oppose	Oppose
How much do you support or oppose sharing general practice data for research	45.9	48.6	2.7	2.7

Please tell us why you support or oppose sharing general practice information for research:

- It will provide insight across multiple practices to determine how best to treat patients.
- Assist general populations health future
- Assist with reaching outcomes of benefit to the community
- Because benefits of improvements to public health outweigh the costs
- Because I think it's important to be involved
- Cause I think it is a good learning skill
- Essential
- For better health outcomes
- Great benefits for medical advancement and clearer picture of population needs
- I prefer to think it is done for the common good and to improve results
- 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
- I support sharing GP info as there are many benefits to public health outcomes and understanding that could be achieved with a linked data set.
- I support this cause because if it can help have better treatment outcomes, better health care and quicker diagnosis, it will make life in general as a whole for the population better
- I think it could greatly improve the scale and speed of medical research, which could ultimately save lives/ or improve people s lives
- I think it will be great in developing treatment for chronic health conditions, but it needs to be shared correctly (i.e. mitigate as much risk as possible)
- I would like information to be shared for the common good of the population
- If done to improve health outcomes I am happy to share all data
- If used appropriately it can create outcomes to improve health and supports
- Improving health for the public
- 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.

- It can hugely support an improvement in public health outcomes
- It depends on who asks for it and for what purpose
- It is incredibly important to have population-wide statistics in order to know how and where and what to improve
- It's important for the health care advancement of everyone
- Progressing the health of the nation
- Research is important for future knowledge
- Seeing the impact of research and how it could help, its woken me up to benefits and risks
- Sharing data can often contribute to positive outcomes for planning and service availability as well as improve better overall medical practice
- Support from an improved clinical experience. Knowledge and understanding gained to help the community and provide medical expertise found through research. No support to private corporations for provide generation
- The Australian population will benefit from it
- The information/ potential to improve health services is too great to waste. It should be used to our benefit
- There is a positive outcome for health policy
- This data is important for ongoing health, media and pharmaceutical research
- To improve medical services and cures for diseases
- Whatever helps future health I support as I have a boring health record

Juror perspective of the community jury experience

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Participating in the jury changed my understanding of sharing general practice data for research	64.9	29.7	5.4	0	0
The jury has changed my awareness of different points of sharing general practice data for research	64.9	32.4	2.7	0	0
Enough time was provided for each aspect of the process	29.7	40.5	10.8	16.2	2.7
The participants represent a diverse and inclusive sample of Australians	35.1	45.9	5.4	13.5	0
The role the participants played was clear	45.9	51.4	2.7	0	0
The purpose of the event was clear	73	27	0	0	0
The issue to be discussed was clearly defined	59.5	40.5	0	0	0
It was clear how we were meant to arrive at a decision	55.6	41.6	2.7	0	0
It was clear how decisions were made within the jury	54.1	40.5	2.4	2.7	0
Enough financial assistance was provided for me to be able to engage in the event	62.2	29.7	5.4	2.7	0
The previous online session prepared me appropriately to participate in the deliberations	48.6	43.2	8.1	0	0

Any conflict that has arisen has been dealt with efficiently by the facilitator	61.1	36.1	0	2.8	0
I feel I was listened to by the facilitator	70.3	27	0	2.7	0
There were equal opportunities for all participants to express their views	64.9	29.7	2.7	2.7	0
All participants were treated with politeness and respect	70.3	27	0	2.7	0
Participants in the sessions were listening to each other and allowing each other to speak	56.8	35.1	8.1	0	0
I endorsed and adopted points of view that differed from my own	63.9	36.1	0	0	0
I felt that my opinions were respected by the group	62.2	35.1	2.7	0	0
I felt comfortable with the degree of disagreement during the deliberation	56.8	35.1	2.7	2.7	2.7
I was willing to abide by the groups final position, even if I personally had a different view	67.6	27	2.7	0	2.7
All requested information has been provided	44.4	44.4	8.3	2.8	0
The expert witness represent a broad range of perspectives on the issue	61.1	27.8	8.3	2.8	0
There were important issues that the evidence packages did not cover	14.7	29.4	20.6	32.4	2.9

‘Best thing’ about the community jury

What are the best things about the community jury?

- Facilitator was engaging and friendly
- Incentives- ethics involved
- The expert presenters
- Understanding different POVs
- Was a great opportunity to come together to review this topic. Facilitators were very engaging and put together an excellent couple of days activities. Matthew was a very engaging facilitator.
- 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.
- Able to listen and learn from different views and able to reach an agreement with strangers
- Accepting opinions from folks that you may not have had the chance to communicate with in the real world
- Being able to collaborate together and make recommendation that could change the future of health care system and how data research is being used. Learning more things about the experience.
- Being informed by experts on each topic and hearing about practical uses
- Being part of it
- Contributing to public policy
- Different views
- Enlightening, enjoyable, meeting new people, novel experience
- Fun and eventful

- Getting to know more information on data sharing from GPs
- Having different opinions on topics/ ideas/ recommendations and having respectful conversations about them. It was a safe and respectful environment and when anyone had difficulties the team and the jury did what they could to appropriately address it and find a solution to help
- Hearing about legal cases
- I think it is a great way to bring many perspectives and life experiences to an important topic
- I was incredibly impressed. Opened my eyes to a million aspects I's not hitherto considered
- Learning about data sharing and how data sharing is happening currently right now with a lot of the population not even knowing
- Listening to everyone's opinions allowed me to take a different perspective on things
- Lots of opinions, everyone was willing to give input and consider other perspectives
- Meeting and discussing diverse opinions
- Meeting everyone, learning, helping out with an important issue! Also getting to do an exciting project with a uni.
- Networking and fruitful, inclusive discussions
- Solving important issues
- The ability to engage with a diverse group of people and hear how each person's background informs their opinions. I have really enjoyed my time this weekend, it has given me the chance to chat with lots of people where I'm normally quite isolated.
- The community jury allowed a diverse group of participants to come together to hear and learn about many different considerations about a complex issue, discuss and dissect issues and come to a fairly shared view of the recommendations to be presented.
- The feeling that you have a say in how the research will be conducted and the gathering of data from GP practices
- The range of people and opinions. Everyone contributed and was listened to.
- Well run, great connection with jury
- Wide range of discussion and good varying viewpoints
- wide scope of thoughts and ideas provided by a diverse group of individuals in a safe and secure environment

Improvements to the community jury

Based on your experience so far, how could the community jury be improved?

- Extremely positive experience, well managed and controlled. Time may be the only factor for consideration with regards to improvement.
- Discussion re costs.
- I liked and appreciated how it was run and the care the team had for the jury members.
- It could use more time
- More discussion of why people don't want to share data- from a GP- from general public.
- More time for deliberation
- Needed more time
- Allowing more time for deliberation, food options to be given, perhaps a few more microphones.
- By giving more options about data breaches
- Day 2 on policy deliberation was most important- should spend more time in discussion
- Don't know
- 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 my opinion due to others bulldozing conversation or running out of time. Whether intentional or not, I often found

the facilitator to be really rude and condescending. Although this would have been fixed without time pressure.

- I feel we could have had a little less time listening to the expert witnesses on the Saturday and a little more time in discussions. By Sunday it felt like we rushed through some latter recommendations, and we were also a bit tired. Maybe the formation of the small groups could be 'constructed' a little rather than by general interest and some way of visiting each group before the whole groups discussion came to be.
- I'd like to know about all the best studies and outcomes that had happened from data sharing and also the largest breaches
- It seemed to flow nicely. I cannot think of anything specifically to improve it.
- Longer for decision making
- Make it clearer beforehand and reiterate throughout how each step will work. More time need to be given on deliberation day. Time was given for speakers but finishing earlier on the final day was not a good idea.
- More pre-work, reading and analysing the booklet and raising concerns
- More time- bit of a rush near closing time
- More time for Q&A with experts
- more time needed to refine recommendations
- Natural improvement the more that are done
- Not sure it could I thought it ran smoothly
- Probably more time
- Providing additional representation
- Seems like a good process already
- They needed a negative view on this topic as it was positive bias
- Was happy with outcome and interested in final outcome

A note to potential future jurors

If you were speaking to someone who was considering participating in a community jury, what would you say to them?

- Do it- fantastic opportunity to give back to community
- Do it if you can
- Do it, it is rewarding
- Do it. Invaluable. Increases knowledge and community respect.
- Encourage them to take part
- Get involved:)
- Go for it
- Go for it! It is very interesting and informative
- I can find out how personal information is being shared
- I highly recommend if only for the experience that connects you to a range of people and viewpoints.
- I would encourage them to participate as it is a great learning experience
- I would encourage them to participate, for the social experience as well as the opportunity to become well-informed about a given topic. ... that as an everyday citizen you get to hear from such a wide array of experts who are so passionate about their work.
- I would encourage absolutely someone to participate as it was an extremely interesting process, topic and project. It is also so important to have a voice and be able to contribute to such an important and impactful issue.
- I would recommend that they attend
- I would tell them to do it as it's a great experience and you learn things about it. You also have the opportunity to make a difference.

- it was a great experience and the range of topics it brings up was amazing and all aspects were covered.
- It's a chance to interact with people you may not have in real life and learn how to deliberate and process resolutions
- It's a great experience
- Just keep an open mind