MJA
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Supporting Information

Supplementary methods and results

This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.

Appendix to: Carter SM, Aquino YSJ, Carolan L, et al. How should artificial intelligence be used in Australian health care? Recommendations from a citizens' jury. *Med J Aust* 2024; doi: 10.5694/mja2.52283.

1. Our question for you

Artificial Intelligence (AI) refers to a set of computer-based technologies that can do things that previously required human thinking and action. Artificial Intelligence is widely used in everyday life.

Artificial intelligence systems are being developed to detect or diagnose diseases. Artificial intelligence systems can help healthcare workers to find disease, or in some cases, can find disease automatically, without help from healthcare workers.

In this jury, you will be asked to make recommendations on the following question:

Under what circumstances, if any, should artificial intelligence be used in Australian health systems to detect or diagnose disease?

In making your recommendations, please consider:

1) What are the most important issues that you have heard about during the expert sessions and your discussions?
2) How important are potential benefits of these artificial intelligence systems in our reasoning, and which potential benefits seem most important?
3) How important are potential harms or dangers of these artificial intelligence systems in our reasoning, and which harms or dangers seem most important?
4) What should be done about the potential for algorithmic bias and unfair outcomes from these artificial intelligence systems?

2. Deliberative democratic approaches and the Australian health AI citizens jury

Background

Deliberative democratic methods have been used to explore health-related questions in Australia and overseas[1, 2] (Box), but they are less well known than e.g., qualitative or observational methods. This is reflected in the lack of an EQUATOR reporting standard for deliberative democratic work.

Deliberative methods have much to offer health research. As consumer and community involvement becomes an imperative in both health services and health research,[3,4] deliberative methods offer practical strategies for high quality engagement, and relevant political grounding for this work.

Deliberative democratic methods are underpinned by theory from political science, and methods first developed in the 1970s in the USA and in Germany.[5] The methods have since spread internationally and have been refined.[6] Deliberative democratic methods are overtly political: they aim to improve the quality of democracy by including communities in development of the laws or policies that they are governed by.

Because deliberative democratic methods are built on a political, rather than an epidemiological, logic, their recruitment and sampling methods reflect this political logic. The aim in deliberative democratic approaches is to ensure, as much as possible, that all affected members of a community have an *equal opportunity to participate*, then to select from volunteers to ensure that the *diversity of the community* is represented as well as possible. The usual methods for achieving this are: 1) *invitation* by random ballot; and 2) stratified *selection* against demographic criteria. This creates what is referred to as a 'mini-public' – a diverse small group asked to make decisions on behalf of the broader public.

Deliberative processes have some other key features:

1. A clear charge, question or remit is crafted. The process focuses on delivering an answer to this statement or question.
2. The 'mini-public' is provided with balanced, high-quality information, and sufficient time, to understand the topic, the remit, and the trade-offs entailed in making a decision. This includes opportunities to hear from and interact with experts.
3. The group is supported, via expert facilitation, to deliberate together to reach a conclusion and make recommendations on the remit.
4. The jury output is intended to provide a direct input to policymaking.

Box: Further resources and examples

Reviews of deliberative democratic research in health

Degeling C, Carter SM, Rychetnik L. Which public and why deliberate? A scoping review of public deliberation in public health and health policy research. *Soc Sci Med*. 2015;131: 114-21.

Degeling C, Rychetnik L, Street J, et al. 'Influencing health policy through public deliberation: Lessons learned from two decades of citizens'/community juries'. *Soc Sci Med*; 179:166–171.

Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: a systematic review. *Soc Sci Med*. 2014;109:1-9.

Selected list of Australian deliberative democratic projects relevant to health

Moretto N, Kendall E, Whitty J, et al. Yes, the government should tax soft drinks: findings from a citizens' jury in Australia. *Int J Environ Res Public Health*. 2014; 11: 2456-2471.

Degeling C, Carter SM, Rychetnik L. All care, but whose responsibility? Community juries' reason about expert and patient responsibilities in prostate-specific antigen screening for prostate cancer. *Health* 2016; 20: 465–484.

Street J, Sisnowski, J, Tooher R, et al. Community perspectives on the use of regulation and law for obesity prevention in children: a citizens' jury. *Health Policy* 2017; s121: 566-573.

Scuffham PA, Krinks R, Chaulkidou K, et al. Recommendations from two citizens' juries on the surgical management of obesity. *Obes. Surg.* 2018; 28: 1745-1752.

Degeling C, Barratt A, Aranda S, et al. Should women aged 70–74 be invited to participate in screening mammography? A report on two Australian community juries. *BMJ Open* 2018; 8: e021174–e021174

Degeling C, Johnson J, Iredell J, et al. Assessing the public acceptability of proposed policy interventions to reduce the misuse of antibiotics in Australia: A report on two community juries. *Health Expect.* 2018; 21: 90–99.

Thomas R, Sims R, Beller E, et al. An Australian community jury to consider case-finding for dementia: Differences between informed community preferences and general practice guidelines. *Health* 2019; 22: 475–484.

Degeling C, Carter SM, van Oijen AM, et al. Community perspectives on the benefits and risks of technologically enhanced communicable disease surveillance systems: a report on four community juries. *BMC Medical Ethics* 2020; 21: 31.

Degeling C, Williams J, Carter SM, et al. Priority allocation of pandemic influenza vaccines in Australia – Recommendations of 3 community juries. *Vaccine* 2021; 39: 255–262.

Shih P, Nickel B, Degeling C, et al. Terminology change for small low-risk papillary thyroid cancer as a response to overtreatment: results from three Australian community juries. *Thyroid* 2021; 31: 1067-1075.

Street, J, Fabrianesi, B, Adams, C, et al. Sharing administrative health data with private industry: A report on two citizens' juries. *Health Expect* 2021; 24: 1337–1348.

Nicol D, Dryzek JS, Niemeyer S, et al. The Australian Citizens' Jury and Global Citizens' Assembly on Genome Editing. *AJOB* 2023; 23: 61-63.

Process design

This deliberative process was run by the Australian Centre for Health Engagement, Evidence and Values (ACHEEV), a leading specialist deliberative democratic health research group in Australia.[7] ACHEEV researchers have conducted scores of deliberative processes over more than a decade. These have often run on small budgets, so have been relatively short (e.g. 1 day of evidence followed by 1 day of deliberation), and have often involved researchers travelling to particular communities and running a process in those communities.

This process was different: we aimed to design something closer to the gold standard in non-health-related deliberative democratic work, and to test whether this was feasible within a grant-funded project. The elements that were less like what we had done in the past, and more like what is typically done in the deliberative democratic sphere included:

1. A more open remit, with jurors asked to work together to write recommendations from scratch rather than select from options and give reasons.
2. A larger jury (30, typically we had worked with groups half that size or less).
3. A national jury (rather than researchers travelling to demographically different local communities to run juries in those communities).
4. Rather than using a market research agency for recruitment as we had previously done, we used the Sortition Foundation, an independent agency specialising in recruitment for deliberative democratic processes. When we used market research agencies, they would advertise on social media, supplemented by targeted phone recruitment. The Sortition Foundation, instead, distributed 6000 printed invitations to households all over Australia, selected randomly from the Australia Post database, with distribution in proportion to population density in different locations. Thus the destination of the invitations was better understood, and planned with population demographics in mind. The Sortition Foundation then used a purpose-built algorithmic system designed to sample the best balance of participants from the respondent pool to match defined demographic criteria. Target proportions reflecting population demographics were defined for gender, age, ancestry, highest level of education, and location of residence (state/territory, and urban/regional/rural). This provided a more systematic way of constructing the most diverse final jury cohort possible.
5. A much longer time period for jury engagement – 3 weeks rather than 2-3 days.
6. Hybrid mode rather than face-to-face only (15 days online followed by 3 days face-to-face).
7. More evidence and more time to consider the evidence and engage with experts.
8. More activities that directly addressed the process (such as opportunities to consider cognitive bias and how to ask critical questions).
9. Flying jurors from across the country to one location to work together for 3 days to generate recommendations, a process which included time for skill building, socialisation, small group work and plenary work (see the process roadmap in Supplementary File 4).
10. Inclusion of observers from agencies that were potential partners for impact.
11. A much larger research team, required to support the size of the jury and the complexity of the process (rather than 2-3 hands-on researchers, 6 hands-on researchers).

The remit is a critical component of process design and takes considerable time and work to refine. Our remit was shaped by the grant funding the work (which was focused on diagnostic and screening AI). It was discussed widely within the research team, with the experts, and with the independent reference group for the overall project (of which the jury was a part) over several months. The remit and protocol were discussed with the reference group, which was independently chaired, and included representatives from the industry, regulation, consumer and clinical sectors. There is, however, always scope for more consultation, and in future juries we would aim to have a longer period for stakeholder input to the remit and framing. In our experience it is in the nature of jury processes to engage actively with the remit and to reset the agenda to some extent. In this case, the lead Facilitator chose to support the jury to express recommendations at a general level rather than for diagnostic/screening AI only.

Reflections on this process

Formal evaluation of the process is underway; the observations below are informal impressions of the strengths and weaknesses of the process as we designed it.

The process raised challenges:

1) Having a significantly more inclusive jury, and a more demanding process, means that far more accommodations and supports are needed for participants. This requires significant time and planning (e.g., to appropriately accommodate complex medical conditions), multiple team members on the ground, and highly responsive facilitation. We will develop a more detailed distress protocol for our next process: a more diverse jury plus a more interpersonally demanding process meant some jurors needed significant support at times.
2) After jurors viewed the expert videos, we allotted too much time to developing questions for the experts, leading to an overwhelming number of questions and answers, and creating a significant workflow problem for the research team and the experts. Next time we will screen the videos 'live' to the jury, provide a short period for small group discussion about pressing questions, and then move directly to a live exchange with the expert. This is closer to the format we have used in previous juries.
3) Consistent with usual practice for national juries, we ran only one process. Some reviewers/audience members have since raised questions about the trustworthiness of a single jury. This tension between repetition and the depth and quality of the process within available resources will always be a trade-off in deliberative design.
4) Doing more of the work in small groups is necessary when the cohort is larger but means that significant portions of the process are not directly available to the facilitators during the process. This gives the jurors themselves more agency to determine the final outcome but gives the lead facilitation team less immediate access to granular detail.
5) Despite having made the process much longer, we needed more time, particularly for wordsmithing. In very large-budget deliberative processes, jurors sometimes meet multiple times (e.g., 6x1-day meetings) over a longer period (e.g., 6-18 weeks). This could not be accommodated within our budget but may be preferable. A somewhat less open remit may also assist in addressing time pressure.

Despite these challenges, the process had significant strengths relative to our earlier projects. Broadly speaking, the process met its objectives: the jurors were able to generate a list of relevant and important recommendations in the available time. Particular strengths included:

1) A notably more diverse jury, with all our demographic targets met, and jurors from widely varied life experience present, actively participating and included. Using the Sortition Foundation was considerably more expensive, but a worthwhile investment.
2) Far greater engagement, with all jurors actively participating in online and face to face activities. In the previous shorter process, most work was done in plenary. In this process, far more work was done in small groups, so all jurors were directly engaged in information provision, skill development and deliberation stages; information provided by experts was often used by jurors in deliberations.

3) Benefits from the explicit skill development and other process-oriented activities, including a facilitated conversation about hopes and fears for the process, and a social event on the first evening. Jurors supported one another in practical ways and talked openly about what they had learned from the process activities.
4) Hybrid mode enabled a long period of engagement with manageable costs.
5) A high degree of responsiveness, with activities, ordering, timing and direction shifting to meet the requirements of the jurors and the process.

Overall, we are satisfied that this process delivered a high-quality deliberative engagement, and we will continue to build our national process to reflect gold standard methods in deliberative democracy.

References

1. Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: a systematic review. *Soc Sci Med*. 2014;109:1-9.
2. Degeling C, Carter SM, Rychetnik L. Which public and why deliberate? A scoping review of public deliberation in public health and health policy research. *Soc Sci Med*. 2015;131: 114-21.
3. Australian Health Reseach Alliance. Consumer and Community Involvement: Australian Health Research Alliance; 2023. https://ahra.org.au/our-work/consumer-and-community-involvement/ (viewed October 2023).
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5. Gastil J, Levine P. Preface. In: Gastil J, Levine P, Eds. The Deliberative Democracy Handbook: Strategies for Effective Civic Engagement in the Twenty-First Century. Jossey-Bass 2005.
6. Participedia; 2023. https://participedia.net/ (viewed Oct 2023).
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3 February 2023

3. Invitation

Dear Resident,

You could be one of 30 people selected to take part in the Community Jury on Artificial Intelligence in Health discussing the important question:

How do we use artificial intelligence to check for diseases and who should decide?

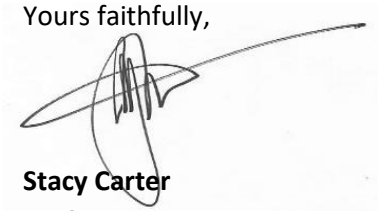
Artificial intelligence can now be used to detect or diagnose diseases. These systems have great potential. Imagine if artificial intelligence could automatically read all the medical records in a hospital and find people who might have dementia; scan breast screening images to look for cancer; or listen to the way you talk and spot the signs of depression. But there are also real worries about using artificial intelligence to look for disease. It can get things wrong; it often works well for the people who already get lots of healthcare, failing those who already miss out; and when artificial intelligence takes over a task, health workers tend to forget how to do that task, and can have trouble disagreeing with artificial intelligence when it is incorrect. There are big decisions to make in Australia about how these systems should be used. Your opinions are important to us and we will share recommendations from the event with decision-makers in healthcare.
The Jury will run across three online sessions from Thursday 16 to Sunday 26 March & a weekend face-to-face session in Sydney from Friday 31 March to Sunday 2 April and you need to attend all the sessions. If you take part we will give you $1015 and cover travel, accommodation and meal costs to thank you for your time.

You don't need any prior knowledge to take part in the Jury; all we require from you is a willingness to listen to the information presented and share your opinions with us and your fellow participants. We want to hear from a real cross-section of people from across Australia, so if your household has received this letter then you are the right person to take part!

Everyone aged 18 and over who lives at this address can register their interest by visiting **www.sortitionfoundation.org/healthAI** or by calling Freephone **1800 [phone number]**. The deadline to register is **Sunday 26 February**. Participants will then be chosen by lottery from everyone who applied. More details are available overleaf.

This is a fantastic opportunity to help to shape the future of disease diagnosis and health management. We hope that you will be interested in joining the Jury and we look forward to hearing from you.

Yours faithfully,



Stacy Carter
Professor, Empirical Ethics in Health
Director, Australian Centre for Health Engagement Evidence and Values (ACHEEV)

Frequently asked questions (FAQs)

What is a Community Jury?

A community jury is a form of an innovative democratic tool used all over the world. It brings together a randomly selected group of people who broadly represent the entire community. The people who attend learn about issues, discuss them with one another, and then make recommendations about what should happen and how things should change.

What is artificial intelligence?

"Artificial intelligence" (AI) refers to widely-used computer-based systems that can assist or replace humans. It is an artificial intelligence that automatically suggests what TV show to watch next on a streaming service, alerts your bank to unusual transactions in your account, or automatically touches up a photo you've taken with your phone.

Artificial intelligence can help healthcare workers to find disease, or in some cases, can find disease without help from healthcare workers. Artificial intelligence systems already exist to identify conditions like cancers, eye problems, mental health conditions and dementia. Artificial intelligence systems can work in health services like hospitals, or at home on your devices.

Who is running the event?

The Australian Centre for Health Engagement, Evidence and Values (ACHEEV) specialises in connecting health decision-makers to the Australian public via processes like community juries. Our mission is to make health systems more inclusive and democratic. We identify real-world problems faced by health systems, and support Australians to learn about these problems and provide advice to decision-makers.

The Sortition Foundation is a not-for-profit organisation that specialises in recruiting and selecting people by lottery to take part in these kinds of events, in a way that is broadly representative of the wider population.
www.sortitionfoundation.org

How much of my time will the jury take, and when are the sessions?

There are two parts, Part 1 is online, Part 2 is in person in Sydney:

Part 1

A total of 8 hours spread over 2 weeks, from Thursday 16th March to Sunday 26th February. You will participate in three online sessions with other jurors (evening Thursday March 16th, afternoon Sunday March 19th and afternoon Sunday March 26th) – in between you will access online information provided by experts

Part 2

A weekend session, approximately 14 ½ hours, from Friday 31 March to Sunday 2 April, held at the Mercure Hotel, next to Central Station in Sydney. Travel time to and from Sydney will be extra time and could take between 7-17 hours return depending where you live. If you cannot fly back to your home state on Sunday afternoon, you will receive an extra night's accommodation and fly home on Monday morning.

What will taking part involve?

If you are selected to take part you will have the opportunity to meet with individuals from all walks of life from across Australia. You will hear from engaging speakers, and discuss the issues involved in small groups, with facilitators to make sure everyone has their voice heard. You don't have to know anything about artificial intelligence to participate – all the information you need will be provided.

Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Wollongong. If you decide to take part in the study and then change your mind later, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will have no consequences for you. Withdrawal from the study can be organised by contacting the lead Chief Investigator Prof. Stacy Carter (*contact details*). If you decide to withdraw from the study, we will not collect any more information from you, and will remove as much information as we can that we have already collected. However, some of your information will remain in our study records and

may be included in the study results: this is because we will be recording group conversations, which may include contributions from you.

How will you ensure that the event is accessible?

Each participant will get a $415 digital gift card to compensate them for their time at the end of Part One. Each participant will get a $600 gift card to compensate them for their time at the end of Part Two.

The in-person meeting will be held at an accessible venue and you will be given accommodation and transport expenses. Afternoon tea and a welcome reception will be provided on Friday evening, breakfast, lunch and morning and afternoon tea will be provided on Saturday and Sunday, and there will be meal vouchers for dinner on Friday and Saturday. If you have any needs in relation to the venue, meals, or travel, just let us know if you are selected.

We can provide internet-enabled digital devices and an internet connection for use during the online meetings to those who do not have access to a suitable device or internet connection. We can support you to learn the IT skills needed to take part in the Community Jury, including one-to-one phone calls and online introductory sessions.

Who can apply?

Anyone aged 18 and over by the close of registrations, who is normally resident in the area and who lives full or part time at an address that has received this invitation can apply, with a few exceptions set out below. Please note that a maximum of one person from any single household will be selected to participate.

People who have worked with artificial intelligence and clinicians who are directly involved in patient care are not able to apply.

How was I selected to receive this invitation?

Your household was one of 6,000 addresses that was randomly selected from the Australia Post address database.

After I register my interest, what happens next?

Once registration has closed, 30 people will be randomly selected from those who registered their interest, to take part in the event.

This random selection will be weighted to make sure that there are people from all across the community attending.

If you are selected, we will contact you by phone and email on or around 27 February to let you know. We will then arrange a call with you to confirm that you can attend, discuss any requirements you may have to make it possible for you to attend, and explain what happens next.

What will happen after the event?

ACHEEV works with organisations that educate health professionals, regulate the healthcare industry, and connect health researchers to health services. Some of these organisations will observe the jury. The jury's recommendations will be shared with decision makers in these organisations to guide decision-making about the use of Artificial Intelligence in Australia. We will also provide you with a copy of the jury's recommendations.

Where can I get more information?

If you would like to talk to someone about the Community Jury before registering, please call the Freephone number below. More information about the event will also be available at https://uow.info/TAWSYN_JURY.

To register your interest visit: **www.sortitionfoundation.org/healthAI**

or call Freephone **1800 phone number** (during office hours), by 26 February 2023

Chief Investigator
Prof Stacy Carter

[contact details]

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Participant information statement

Using Artificial Intelligence technology to check for diseases in Australia: a Community Jury

(1) What is this study about?

You are invited to take part in a research study investigating community attitudes or evaluations of the future use of artificial intelligence (AI) for disease diagnosis and screening in Australia. This project is part of a larger study examining ways to and to explore policy options that a well-informed citizenry will find ethically justifiable and acceptable.

You have been invited to participate in this study because the perspectives of members of the public on these issues are critically important. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary. It's up to you whether you wish to take part or not. By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read
- ✓ Agree to take part in the research study as outlined below
- ✓ Agree to the use of your personal information as described.

(2) Who is running the study?

This project is administered through the University of Wollongong. The Chief Investigators are:

Name	Affiliation	Email
Prof Stacy Carter	University of Wollongong	email address
Dr Chris Degeling	University of Wollongong	email address
Prof Annette Braunack-Mayer	University of Wollongong	email address
Dr Yves Saint James Aquino	University of Wollongong	email address

The research staff are:

Emma Frost	University of Wollongong	email address
Ms Julie Hall	University of Wollongong	email address
Ms Lucy Carolan	University of Wollongong	email address
Ms Tory Haywood	University of Wollongong	email address

This project is funded by the National Health and Medical Research Council (NHMRC APP1181960)

(3) What will the study involve for me?

If you agree to participate in the Community Jury, you will be required to participate in two parts over an approximate two-week period. Part 1 is an online discussion using Visions Live and Zoom (both online meeting tools) and Part 2 is a face-to-face community jury over a long weekend (Friday April 1st to Sunday April 3rd, 2023), held at the Mercure Hotel Sydney CBD, near Central Station.

Part 1 (online), over a 14-day period, you will hear video evidence and information from experts about AI in healthcare and related issues, be able to question the experts, and discuss with other community members (a total of 35 participants), and share your thoughts on how we should handle these issues. You will also be asked to complete a short survey before you hear the evidence and again at the end of the evidence provision. The survey is anonymous, and your answers will be collated and included in the data set. You will be asked to participate in two small group discussions and a whole group information session via Zoom.

Part 2 will be held in person (face to face) over a long weekend where participants will be given the opportunity to discuss the evidence already presented and to ask any questions of the experts. Day 1 is set aside for travel to Sydney, introductions and ground rules, as well as an opportunity to ask questions of the experts. Day 2 is for deliberation and day 3 participants will be asked to come to a consensus about hypothetical recommendations for how best to address the use of AI in healthcare in Australia. Discussion and debates amongst the participants during these sessions will be digitally recorded. At the end of the proceedings, you will be asked to complete a final short survey and evaluation survey. The survey is anonymous, and your answers will be collated and included in the data set.

(4) How much of my time will the study take?

Participants in the Community Jury will be required to participate in a two-part process over an approximate two-week period. We have estimated that part 1 - online component will take approximately 8 ¼ hrs. (across a two-week period). Part 2 - the face-to-face jury component will take approximately 14 ½ hrs. (held over a long weekend).

However, this does not include travel time to and from the venue in Sydney, NSW. Please view the table below with travel time estimates. Please note we have allowed a minimum of 30 mins and a maximum of 2 hours travel time from your home to the airport in our calculations, you will need to add more time if you live more than 2 hours from an airport.

FROM Your home, via Airport	**RETURN trip** Estimated travel time in hours
Adelaide, SA	Approx. 9 to 12 hours
Alice Springs, NT	Approx. 13 to 15 hours
Ballina, QLD	Approx. 8 to 11 hours
Broken Hill, NSW	Approx. 10 to 13 hours
Brisbane, QLD	Approx. 8 to 11 hours
Broom, WA	Approx. 13 to 16 hours
Canberra, ACT	Approx. 7 to 10 hours
Cairns, QLD	Approx. 11 to 14 hours
Coffs Harbour, NSW	Approx. 8 to 11 hours
Darwin, NT	Approx. 14 to 17 hours
Dubbo, NSW	Approx. 7 ½ to 10 ½ hours
Gold Coast, QLD	Approx. 8 to 11 hours
Griffith, NSW	Approx. 8 to 11 hours
Hobart, TAS	Approx. 9 to 12 hours
Launceston, TAS	Approx. 9 to 12 hours
Melbourne, VIC	Approx. 8 to 11 hours
Merimbula, NSW	Approx. 7 ½ to 10 ½ hours
Orange, NSW	Approx. 7 to 10 hours
Perth, WA	Approx. 13 ½ to 16 ½ hours
Sunshine Coast, QLD	Approx. 8 to 11 hours
Tamworth, NSW	Approx. 7 ½ to 10 ½ hours
Toowoomba, QLD	Approx. 8 ½ to 11 ½ hours
Townsville, QLD	Approx. 10 ½ to 13 ½ hours
Wagga Wagga, NSW	Approx. 7 ½ to 10 ½ hours

Jurors will also be asked to fill in an anonymous evaluation form at the end of jury proceedings.

In acknowledgment of the time taken and to thank you for participating, community jury participants will be offered a $415 gift voucher for the online component, as well they will be offered food and refreshments during the face-to-face community jury sessions and will be offered a $600 gift voucher for their participation as well as any accommodation and travel expenses reimbursed.

(5) Who can take part in the study?

Anyone can apply to be on a community jury. The panel of community representatives (jurors) will meet both online and face to face, in a number of sessions to carefully examine an issue of public significance. This jury will meet online using VisionsLive for Bulletin Boards, Zoom for small group meetings, and face to face for deliberation. The panel of community jurors, consisting of 35 individuals from around Australia, serves as a microcosm of the broader public. We will be selecting participants to try and ensure that a diversity of social and cultural backgrounds is represented in the jury.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Wollongong.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will have no consequences for you. Withdrawal from the study can be organised by contacting the lead Chief Investigator Prof. Stacy Carter (contact details).

If you decide to withdraw from the study, we will not collect any more information from you. Any information that we have already collected, however, will be kept in our study records and may be included in the study results. This is because we will be recording the entire jury as a group and will often not be able to identify exactly who is speaking at any given time in the discussion.

(7) Are there any risks or costs associated with being in the study?

This is a low-risk project. The most significant risk is unwanted identification in reporting. To minimise this risk, we will remove any details that might reveal your identity. Digital audio files will be kept on password protected servers at all times. Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

(8) Are there any benefits associated with being in the study?

While we intend that this research study furthers knowledge about attitudes to AI in healthcare, it may not be of direct or immediate benefit to you. It will provide you with opportunities to contribute your thoughts and experiences which will culminate in the development of tools to guide future policy and practice. You will be provided with $415 gift voucher for participating in part 1 – the online component and a $200 gift voucher for each day you attend in person (part 2 – face to face component), as a thank you for your time.

(9) What will happen to information about me that is collected during the study?

The online line group sessions using Zoom will conducted with video cameras turned on and will be recorded. Please note that the video-recording will be deleted immediately after the group and only the audio-recording will be retained as described below.

Discussion and debates amongst the participants during these sessions will be audio recorded. All the information collected from you for the study will be treated confidentially. The digital audio file will

only be accessible to members of the research team. It will be kept on a password protected server. The study results will be presented at conference and in scientific publications. However, any observations and quotations in the material presented will be de-identified. The data will be securely retained, then destroyed 5 years after the project ceases.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

If you choose to participate, this will generate:

- An audio file recording your consent* to participate
- Data from a short survey that you will take at three time points: before you start, at the end of the part 1 – online activities, and at the end of part 2 – face to face activities
- Data from an evaluation survey
- Bulletin Board posts, comments and responses that will be used as research data
- A audio file recording of the whole group and small group discussions generated by Zoom

*A member of the research team will contact you prior to the research taking place to ask if you have any questions regarding this information sheet or the study process and to ask you to give a verbal consent. A sample of the verbal consent script is below.

All the information collected from you for the study will be treated confidentially. The data will only be accessible to members of the research team. It will be kept in a secure data storage system provided by the University of Wollongong.

The research platform, VisionsLive have signed a legal agreement with the University of Wollongong which includes a commitment to ensure security and confidentiality of all data; their systems have been assessed by the University of Wollongong's data specialists. All of your data will remain in Australia throughout the project. As soon as the Bulletin Board is finished, we will download all of the data from the VisionsLive system into the secure University system, and the VisionsLive team will securely destroy the data from their system. All data will be retained in the University of Wollongong secure data system then will be destroyed 5 years after the project ends.

The study results will be presented at conferences and in scientific publications, but we will never use your name in any of these publications or presentations.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

(10) Can I tell other people about the study?

Please note that your household has been randomly selected to be invited to participate. Only invited households can express an interest in participation. However, if you choose to participate you are welcome to discuss the experience with friends and family in a way that protects the privacy of other participants.

(11) What if I would like further information about the study?

When you have read this information, Prof Stacy Carter or another investigator on the project will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Prof Stacy Carter (contact details).

(12) Will I be told the results of the study?

When analysis of the Community Jury data is complete, researchers will provide participants with a summary of the findings. This will likely occur late in 2023. If you would like to be contacted with results, please provide your email address on the Evaluation Form (given to participants at the end of the community jury).

(13)**If you would like to talk to someone** about any issues that have arisen from participating in this survey, about how you have been feeling, or if you have any concerns about your mental health, please seek support from one of the services listed below:

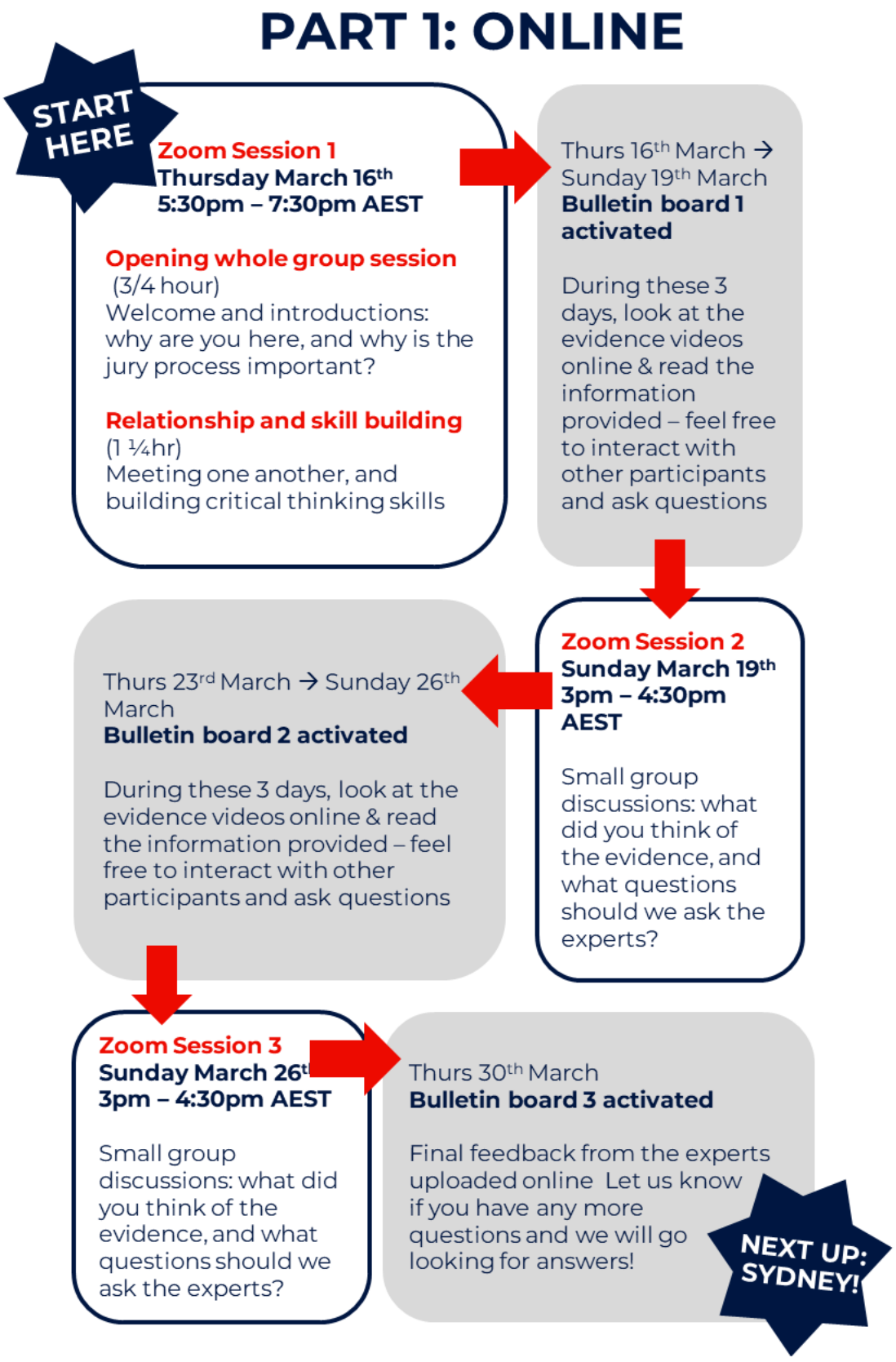
beyondblue	www.beyondblue.org.au
Phone:	1300 22 4636
Lifeline	www.lifeline.org.au
Phone:	13 11 14

(14) What if I have a complaint or any concerns about the study?

This study has been reviewed by the Medical Human Research Ethics Committee at the University of Wollongong (Reference Number) In the event of any concerns/complaints regarding how the research is conducted, please contact the UOW Ethics Officer, by phone on (phone number) or email via (email).

This information sheet is for you to keep.

4. Process road map



PART 2: FACE-TO-FACE

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3pm – 6pm

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Check in with the experts: reviewing what we've learned, and any questions

5pm – Introduction
Get to know each other and the process

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9am – 5pm

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(1½ hrs)
What matters to us?

10:30am – Break
(1/2 hr)

11am – Discussion 2
(1½ hrs)
Understanding the range of perspectives in the room

12:30pm – Break
(1 hr)

1:30pm – Deliberation 1
(1½ hrs)
What needs attention?
Narrowing our focus to key areas

3pm – Break
(1/2hr)

3:30pm – Deliberation 2
(1 ½ hrs)
Documenting agreement and talking about areas of disagreement

DAY 3: Sunday April 2nd
9am – 3pm

9am – Deliberation 3
(1 ½ hrs)
Producing our final list of recommendations and clarifying reasons

10:30am – Break
(1/2 hr)

11am – Deliberation 4
(1 ½ hrs)
Final drafting and preparing to present

12:30pm – Break
(1 hr)

1:30pm – Final session
(1 ½ hrs)
Presentation to supporting organisations
Feedback on the jury process and we say goodbye

6. Community jury on artificial intelligence in health: information booklet

UNIVERSITY
OF WOLLONGONG
AUSTRALIA

Australian Centre for
Health Engagement,
Evidence & Values

Community Jury on Artificial Intelligence in Health

INFORMATION BOOKLET

ACKNOWLEDGMENTS

Our thanks to the organisations supporting this community jury process: the Royal Australian and New Zealand College of Radiologists, Monash Partners Academic Health Science Centre, Maridulu Budyari Gumal, the Sydney Partnership for Health, Education, Research and Enterprise (SPHERE), and the Western Australian Health Translation Network.

Our thanks to the experts: Professor Farah Magrabi, Associate Professor Katy Bell, Professor Ian Scott and Distinguished Professor Wendy Rogers, who reviewed the contents of this booklet and will act as witnesses for the jury.

Thanks also to Professor Mike Burgess, Professor Annette Braunack-Mayer and Belinda Fabrianesi, who generously shared materials that have informed the design of this booklet, and MosaicLab, whose leadership in deliberative methods has informed our process.

This document was prepared by Lucy Carolan, Emma Frost, Dr Yves Saint James Aquino and Professor Stacy Carter from the Australian Centre for Health Engagement, Evidence and Values. Professor Stacy Carter is the guarantor and takes final responsibility for the contents.

FOREWORD

Welcome to the Australian Community Jury on Artificial Intelligence in Health. We are grateful that you have accepted our invitation to be part of this national event. To help you prepare for the event, we have put together this information booklet. It contains an overview of what to expect in a community jury and a brief introduction to some of the basics of artificial intelligence in health, to help you prepare for the discussions you will have with other participants about this important topic. You can use the booklet before, during and after the event.

You don't need any prior knowledge to take part in the jury. Just read the contents and start to think about what we are asking you to consider. You or your fellow participants are not expected to be experts on this topic, and you will most likely have further questions after reading this booklet. We encourage you to bring these questions to the community jury process, along with your insights and perspectives. These are all critical to the deliberation. A list of key terms can be found on the last pages of this booklet.

The booklet also includes information about our COVID-Safe plan and information you will need during your stay in Sydney. Please take some time to familiarise yourself with this information.

We look forward to welcoming you online on March 16th, and in person on March 31st, 2023.

CONTENTS

1. THE COMMUNITY JURY

1.1. WHAT IS A COMMUNITY JURY?

A community jury is an innovative democratic process used all over the world. It brings together a randomly selected group of people who broadly represent the entire community. The people who attend learn about issues, discuss them with one another, and then make recommendations about what should happen and how things should change. The group's conclusions are reported to people and organizations that can make decisions about the topic, and publicised to the wider community.

1.2. COMMUNITY JURY KEY TERMS

A list of key terms can be found on the last pages of this booklet.

1.3. YOUR ROLE AS A JUROR

This project is an opportunity for members of the community to be directly involved in democratic decision-making. Potential outcomes include providing evidence about community acceptability of healthcare tools that use artificial intelligence, and ways of implementing these tools.

Your role as a juror is to represent your fellow Australians, and work with your fellow jurors, to provide recommendations to decision-makers about the use of artificial intelligence in health services. You and your fellow participants each bring different life experiences and perspectives. Understanding these differences will ensure that the recommendations you make together are sensitive to the range of views in the Australian population. It is also important that your discussion and recommendations are well-informed. This booklet and the

experts you will hear from online and at the event will provide you with the information you need to understand the issues and make decisions. The recommendations that you make as a group will provide advice to people who design, implement and use artificial intelligence in health systems.

1.4. OUR QUESTION FOR YOU

Artificial Intelligence (AI) refers to a set of computer-based technologies that can do things that previously required human thinking and action. Artificial Intelligence is widely used in everyday life.

Artificial intelligence systems are being developed to detect or diagnose diseases. Artificial intelligence systems can help healthcare workers to find disease, or in some cases, can find disease automatically, without help from healthcare workers.

In this jury, you will be asked to make recommendations on the following question:

Under what circumstances, if any, should artificial intelligence be used in Australian health systems to detect or diagnose disease?

In making your recommendations, please consider:

1) What are the most important issues that you have heard about during the expert sessions and your discussions?
2) How important are potential benefits of these artificial intelligence systems in our reasoning, and which potential benefits seem most important?

3) How important are potential harms or dangers of these artificial intelligence systems in our reasoning, and which harms or dangers seem most important?
4) What should be done about the potential for algorithmic bias and unfair outcomes from these artificial intelligence systems?

1.5. THE PROCESS: A ROADMAP

This jury process is in two parts. Part 1 is online, Part 2 is in person in Sydney.

Part 1 A total of 8 hours spread over 2 weeks, from Thursday 16th March to Thursday 30th March. You will participate in three online sessions with other jurors (evening Thursday March 16th, afternoon Sunday March 19th and afternoon Sunday March 26th). In between you will access online information provided by experts, and you can interact with your fellow jurors on a message board.

Part 2 A weekend session, approximately 14½ hours, from Friday 31st March to Sunday 2nd April, held at the Mercure Hotel, next to Central Station in Sydney. Travel time to and from Sydney will be extra time and could take between 7-17 hours return depending on where you live. If you cannot fly back to your home state on Sunday afternoon, you will receive an extra night's accommodation and fly home on Monday morning.

PART 1: ONLINE

START HERE

Zoom Session 1
Thursday March 16th
5:30pm – 7:30pm AEST

Opening whole group session
(3/4 hour)
Welcome and introductions: why are you here, and why is the jury process important?

Relationship and skill building
(1 ¼hr)
Meeting one another, and building critical thinking skills

Thurs 16th March → Sunday 19th March
Bulletin board 1 activated

During these 3 days, look at the evidence videos online & read the information provided – feel free to interact with other participants and ask questions

Zoom Session 2
Sunday March 19th
3pm – 4:30pm AEST

Small group discussions: what did you think of the evidence, and what questions should we ask the experts?

Thurs 23rd March → Sunday 26th March
Bulletin board 2 activated

During these 3 days, look at the evidence videos online & read the information provided – feel free to interact with other participants and ask questions

Zoom Session 3
Sunday March 26th
3pm – 4:30pm AEST

Small group discussions: what did you think of the evidence, and what questions should we ask the experts?

Thurs 30th March
Bulletin board 3 activated

Final feedback from the experts uploaded online Let us know if you have any more questions and we will go looking for answers!

NEXT UP: SYDNEY!

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What matters to us?

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3pm – Break
(1/2hr)

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(1 ½ hrs)
Documenting agreement and talking about areas of disagreement

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9am – 3pm

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(1 ½ hrs)
Producing our final list of recommendations and clarifying reasons

10:30am – Break
(1/2 hr)

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(1 ½ hrs)
Final drafting and preparing to present

12:30pm – Break
(1 hr)

1:30pm – Final session
(1 ½ hrs)
Presentation to supporting organisations
Feedback on the jury process and we say goodbye

1.6. ABOUT THE EVENT

ONLINE SPACES FOR PART 1

For Part 1 you will need to access **'Zoom'**, a video conferencing platform that can be used through a computer desktop or a tablet, and allows users to participate in group discussions and live chat. There are short videos on the Zoom website which show you how to join a Zoom meeting and how to use the functions in Zoom (https://support.zoom.us/hc). Please let the research team know in advance if you haven't used Zoom before, so we can make time to talk you through it if needed. Please see the separate 'How to Zoom guide' enclosed in the information booklet pack.

For Part 1 you will also need to use **'VisionsLive'**, an online research platform. On VisionsLive you can watch videos, read information, post your reactions, comments and questions, and interact with other participants. To access VisionsLive you will need a computer or a tablet. You will receive email messages and links to access the Bulletin Board activities. You will simply need to clink on this link to join – there is no need to download any programs or apps – the links will take will take you straight to VisionsLive.

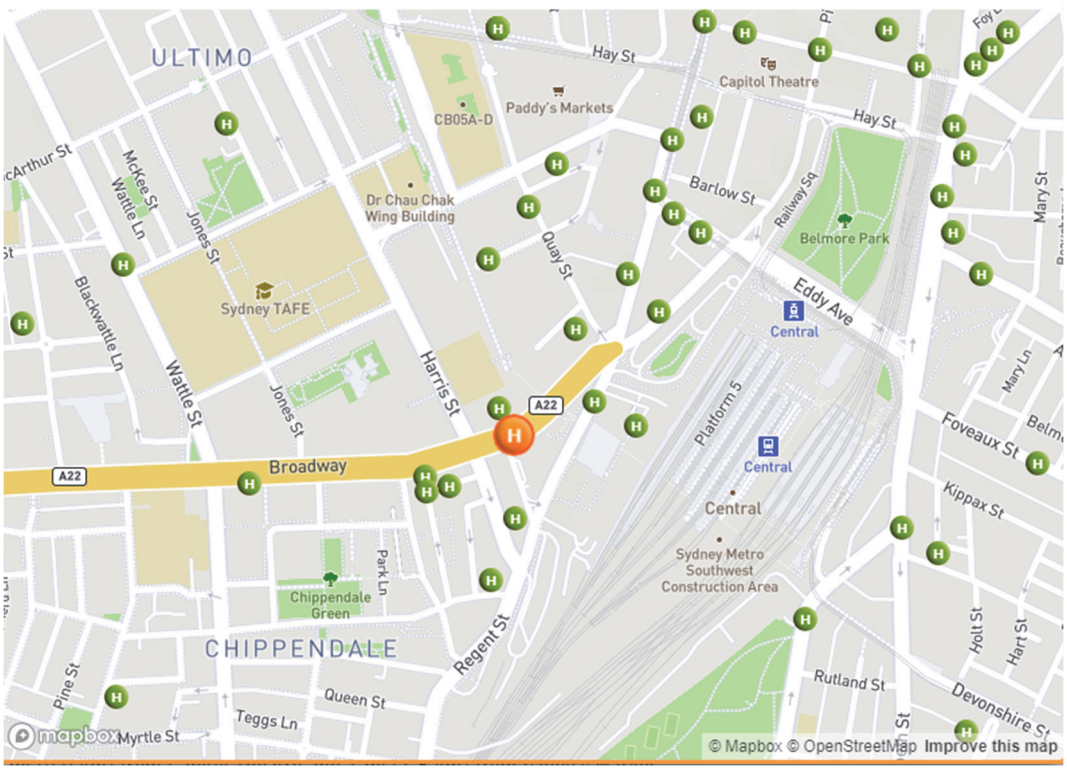
VENUE FOR PART 2

For Part 2, the face to face meeting, you will travel to Sydney to meet with the other jurors, the researchers, the experts and representatives of the organisations supporting the process.

ACCOMMODATION

All participants will stay at the Mercure Sydney Hotel, which is located at 818-820 George Street, Sydney, NSW, 2000. (See the map below). There is 24-hour reception which may be reached

by phone on (02) 9217 6666. Mercure Sydney Hotel is an eight-minute walk from Sydney Central Railway Station, and one-minute walk to Sydney Central Bus stop. All the participants will have their own queen room with a private bathroom.



At the hotel you should check in to your room and acquaint yourself with the hotel before our event starts. The jury starts at 3.00pm in the afternoon of Friday 31st March in the Town Hall Room on Level 2. A member of the UOW research team will be at the hotel reception to greet you from 2:30pm.

A buffet breakfast is provided to all hotel guests with no need for vouchers. Breakfast is available from 6.30am. On the Friday an afternoon tea will be served on arrival, with a light supper served at the end. Morning tea, lunch and afternoon teas will be provided on Saturday and Sunday. When you arrive at the hotel, you will receive a VISA gift card with funds to cover dinner for Friday and Saturday nights ($80 in total, $40 per night).

When you arrive at the first jury meeting on Friday afternoon, we will provide you with another VISA gift card. This will contain payment for your participation in the online process ($415). If you have any questions about how to use the VISA gift cards just ask someone from the research team.

COVID SAFETY

In this booklet pack, we have included a Rapid Antigen Test (RAT). Please use this RAT on the day you plan to travel (before you travel). If the test is positive, please do not travel. Contact us and we will discuss options with you.

We will supply Rapid Antigen Tests each day of the jury and will ask you to do the test in your room before you attend each day. If you need help to do the test, or if you test positive, or if you develop symptoms while you are in Sydney, please let someone from the research team know immediately.
You must not travel to the event if you are unwell, or if you have been a close contact with a known active case of COVID-19 in the 7 days before. If you are unsure, please call the research team to discuss.

The room for the event is large and well-ventilated. Hand sanitiser will be available. You can ask a member of the research team for a mask if you need one. We support and welcome anyone who wants to wear a mask. You do not have to wear a mask to participate.

If you are unable to travel or experience delays, please notify the project coordinator, Lucy Carolan M: 0448 746 163 or email lengland@uow.edu.au

1.7. TRANSPORT TO THE MERCURE SYDNEY HOTEL

BY PLANE

When you arrive in Sydney Airport, you will need to make your own way to the venue (once you have collected your luggage). The best way to get to the Mercure Sydney Hotel is by a direct train from Sydney Domestic Airport Station to Central Station. Trains leave approximately every 10 minutes and take approximately 10 minutes to get to Central Station. Exit Central Station towards Railway Square. From Central Station there will be an eight-minute walk to the Hotel (600 metres).

Later this month we will post you a $100 VISA gift card to cover any taxi fares or other travel between your home and the airport, and train travel between the airport and the hotel on Friday and Sunday. If you think your travel will cost more than $100 in total, please keep your receipts and show them to the research team so we can organise reimbursement.

BY TRAIN

When you arrive in Central Station, Sydney, you will need to make your own way to the venue. Exit Central Station towards Railway Square. From Central Station there will be an eight-minute walk to the Hotel (600 metres). Later this month we will post you a $100 VISA gift card to cover any taxi fares or other travel between your home and the train, and train travel between home and the hotel on Friday and Sunday. If you think your travel will cost more than $100 in total, please keep your receipts and show them to the research team so we can organise reimbursement.

BY BUS/COACH

When you arrive in the Bus Terminal Central Station, Sydney, you will need to make your own way to the venue. Exit Central Station towards Railway Square. From Central Station there will be an eight-minute walk to the Hotel (600 metres). Later this month we will post you a $100 VISA gift card to cover your bus fare (e.g. Sydney buses or long distance bus / coach). If you think your travel will cost more than $100 in total, please keep your receipts and show them to the research team so we can organise reimbursement.

2. SUPPORTING ORGANISATIONS, EXPERT WITNESSES AND RESEARCH TEAM

2.1. ORGANISATIONS SUPPORTING THE PROCESS

THE ROYAL AUSTRALIAN AND NEW ZEALAND COLLEGE OF RADIOLOGISTS

*The Royal Australian and New Zealand College of Radiologists, or RANZCR, is supporting the community jury. RANZCR is one of 25 specialist medical colleges accredited by the Australian Medical Council. These colleges train and certify medical specialists, set standards, and support and promote research in their fields. RANZCR is the college for radiologists: the specialists who i*nterpret and analyse images produced by diagnostic imaging technologies (like CT-scans or MRI scans). *RANZCR has provided the statement below.*

RANZCR is committed to improving health outcomes for all, by educating and supporting clinical radiologists and radiation oncologists. RANZCR is dedicated to setting standards, professional training, assessment and accreditation, and advocating access to quality care in both professions to create healthier communities. Our members are critical to health services: clinical radiology is central to the diagnosis and treatment of disease and injury and radiation oncology is a vital component in the treatment of cancer. RANZCR creates a positive impact by driving change, focusing on the professional development of its members and advancing best practice health policy and advocacy, to enable better patient outcomes.

RANZCR has been at the forefront of policy on medical artificial intelligence in the region, and is committed to engaging with members of the public and understanding their perspective on using AI for diagnosis and screening. RANZCR will make an opening statement at the meeting of the jury in Sydney, will join the final day of the meeting to hear the jury's recommendations, will consider the recommendations made by the jury, and will provide a public response to the recommendations which will be forwarded to all members of the jury.

MONASH PARTNERS ACADEMIC HEALTH SCIENCE CENTRE
MARIDULU BUDYARI GUMAL, THE SYDNEY PARTNERSHIP FOR HEALTH, EDUCATION, RESEARCH AND ENTERPRISE (SPHERE)
WESTERN AUSTRALIAN HEALTH TRANSLATION NETWORK

Three Australian Health Research Translation Centres from Victoria, New South Wales and Western Australia respectively, are jointly supporting the community jury. The three Centres have provided the statement below.

monashpartners.org.au thesphere.com.au wahtn.org

Monash Partners Academic Health Science Centre; Maridulu Budyari Gumal, the Sydney Partnership for Health, Education, Research and Enterprise (SPHERE); and the Western Australian Health Translation Network are delighted to be non-financial sponsors and observers of the "Community Jury on Artificial Intelligence" in Health, to be held in Sydney, 31st March to the 2nd April, 2023.

Our three Research Translation Centres consist of partnerships between leading health service, research and teaching organisations focused on innovating for better health and wellbeing. Each are accredited by the National Health and Medical Research Council (NHMRC).

These centres, along with seven others, make up the Australian Health Research Alliance (AHRA) whose priorities are the systematic embedding of research in Australian health care; better alignment of research capacity with clinical priorities and more, better and faster research translation to deliver patient, public and economic benefit.

While we recognise the uptake of Artificial intelligence (AI) in the world is moving rapidly, the use of AI in Australian healthcare is still in its infancy.

The use of AI in healthcare for disease detection and diagnosis aligns closely with two of AHRA's top priorities: consumer and community involvement and data driven healthcare improvement.

AI has the potential to change the health landscape – to be able to recognise symptoms and provide the ability to access healthcare sooner than is humanly possible within current systems.

It presents an exciting opportunity in the future of healthcare and community input into its application is crucial.

Your contribution, thoughts and recommendations presented during this community jury will aid in the introduction and use

of AI in healthcare for disease detection and diagnosis when being presented to and considered by health organisations.

2.2. THE EXPERT WITNESSES

In the online process, you will hear important background information from a range of experts. This will include experts with different talents and training, including in medical informatics and data science, medical ethics, and healthcare practice. If you have questions for the experts at any time let us know and we will do our best to get you an answer! Four experts will be presenting evidence to you.

WHO ARE THE EXPERTS FOR THIS COMMUNITY JURY?

PROFESSOR FARAH MAGRABI

Farah is a Professor of Biomedical and Health Informatics at the Australian Institute of Health Innovation, Macquarie University. She has a background in Electrical and Biomedical Engineering and is an expert in the design and evaluation of digital health and Artificial Intelligence (AI) technologies for clinicians and consumers. She leads the NHMRC Centre of Research Excellence in Digital Health's Safety research stream and is co-chair of the Australian AI Alliance's Working Group on safety, quality and ethics. **Farah will provide expert evidence on the question "What is Artificial Intelligence and how does it work in healthcare?".** Farah will also be our 'Expert in the room' for the Community Jury.

ASSOCIATE PROFESSOR KATY BELL

Associate Professor Katy Bell is a clinical epidemiologist in the University of Sydney's School of Public Health, specialising in the evaluation of medical tests used for screening, diagnosis, and monitoring. She is a member of the Evaluation Subcommittee for the Australian Government's Medical Services Advisory Committee (MSAC) which considers funding for new tests on the Medicare Benefits Scheme (MBS). She holds an NHMRC Investigator Grant supporting research into how early detection tests can be used to benefit health and not cause harm, and is a Chief Investigator for the NHMRC funded Wiser Healthcare collaboration that aims to support better value care for all Australians. **Katy will provide expert information on the questions "How do screening and diagnosis work now? What is evidence-based medicine?"**

PROFESSOR IAN SCOTT

Ian Scott is the Director of Internal Medicine and Clinical Epidemiology and a Professor with the Faculty of Medicine, University of Queensland. He is a consultant general physician with research interests in healthcare Artificial Intelligence,

clinical decision making, and quality and safety improvement issues in clinical practice, among others. He currently chairs the Queensland Clinical Networks Executive, is the inaugural chair of the Australian Deprescribing Network, Metro South Clinical AI Working Group, and Queensland Health Sepsis AI Working Group and is a founding member of the Australian and New Zealand Affiliate of the US Society to Improve Diagnosis in Medicine. **Ian will provide expert evidence on the potential and proven benefits of healthcare AI**

DISTINGUISHED PROFESSOR WENDY ROGERS

Wendy is a Distinguished Professor in the Philosophy Department and the School of Medicine at Macquarie University. She has wide ranging research interests including the ethics of AI and other new technologies in healthcare, the ethics of synthetic biology, organ transplant abuse and feminist bioethics. She is Co-Director of the Macquarie University Research Centre for Agency, Values and Ethics and a chief investigator on a number of ARC and NHMRC grants. Her recent publications include the co-edited 2023 Routledge Handbook of Feminist Bioethics. **Wendy will provide expert evidence on the potential risks or harms of healthcare Artificial Intelligence.**

2.3. WHO IS RUNNING THE EVENT?

The Australian Centre for Health Engagement, Evidence and Values (ACHEEV) specialises in connecting health decision-makers to the Australian public via processes like community juries. Our mission is to make health systems more inclusive and democratic. We identify real-world problems faced by health systems, and support Australians to learn about these problems and provide advice to decision-makers.

WHO WE ARE (THE RESEARCH TEAM)

PROFESSOR STACY CARTER

Professor Stacy Carter is the Director at ACHEEV. Stacy's training is in public health, and her expertise is in qualitative and deliberative methodologies, public health ethics, feminist bioethics and empirical ethics. Her research program focuses on artificial intelligence and big data in health, reducing harm and waste in healthcare, screening and diagnosis, and including consumers and citizens in healthcare decision making.

DR YVES SAINT JAMES AQUNO

Yves is a clinician and philosopher working as a research fellow at the Australian Centre for Health Engagement, Evidence and Values at the University of Wollongong. His research expertise

includes medical ethics, ethics of cosmetic surgery and ethics of artificial intelligence in healthcare.

ASSOCIATE PROFESSOR CHRIS DEGELING

Chris Degeling is an Associate Professor at ACHEEV. As a social scientist with a background in veterinary medicine, Chris' research focuses on the intersection of public health ethics, public health policy and emerging issues at the human-animal-ecosystem interface. Chris is a specialist in qualitative research and deliberative methodologies like community juries.

EMMA FROST

Emma is doing her PhD at the Australian Centre for Health Engagement, Evidence and Values at the University of Wollongong. She is from Jervis Bay (Yuin Country). Emma's research focuses on Australians' views on the use of Artificial Intelligence in healthcare.

LUCY CAROLAN

Lucy is a research assistant at ACHEEV working on a range of health-related projects. Her current research focuses on understanding the values of the Australian public regarding the implementation of Artificial Intelligence in diagnosis and screening.

3. THE BASICS OF ARTIFICIAL INTELLIGENCE IN HEALTH

3.1. WHAT IS ARTIFICIAL INTELLIGENCE

"Artificial Intelligence" (AI) refers to **widely used computer-based systems that can assist or replace humans.** Artificial intelligence systems do everyday things: they can automatically suggest what TV show to watch next on a streaming service, alert your bank to unusual transactions in your account, or automatically touch up a photo you've taken with your phone.

We will focus on applications of artificial intelligence that are designed to check for diseases. Artificial intelligence can help healthcare workers to find disease, or in some cases, can find disease without help from healthcare workers. Artificial Intelligence systems already exist to identify conditions like cancers, eye problems, mental health conditions and dementia. Artificial Intelligence systems can work in health services like hospitals, or at home on your devices. There are many kinds of health-related artificial intelligence systems, but we will focus on systems for disease detection and diagnosis.

3.2. HOW IS ARTIFICIAL INTELLIGENCE BEING USED TO DETECT AND DIAGNOSE DISEASES?

In healthcare, artificial intelligence is already being used for some tasks. Most applications of artificial intelligence for detecting and diagnosing diseases are in a sub-category of artificial intelligence called Machine Learning. **Machine learning technologies use large amounts of data to learn patterns, and the patterns can then be applied to predict an outcome in real life.** For example, researchers could use a

dataset to train a machine learning algorithm to “learn” how factors like age, sex, and family history influence a person’s likelihood of developing a cancer. Then, healthcare workers could use the patterns that the machine learning algorithm found to help them decide whether patients were at-risk of developing cancer.

Some examples of how Artificial Intelligence is currently being used to detect and diagnose diseases include:

- Assisting healthcare workers in analysing x-rays and other images used to diagnose medical conditions
- Using patients’ health records to determine whether they are at risk of developing a disease
- Analysing images of people’s retinas to look for diseases of the eye
- Collecting and analysing people’s health data from wearable devices such as Fitbit

Artificial Intelligence technologies are progressing quickly, and new Artificial Intelligence research is happening all the time. There are many new healthcare Artificial Intelligence technologies that are in development, being tested, or waiting to be approved for use by patients or healthcare workers in hospitals and clinics.

3.3. FAQS ABOUT ARTIFICIAL INTELLIGENCE

(FAQ = Frequently Asked Question)

DO ARTIFICIAL INTELLIGENCE TECHNOLOGIES HAVE A 'BRAIN' OR A 'MIND'?

No, artificial intelligence technologies do not have a brain or a mind. Artificial intelligence algorithms are far less complex than brains or minds. They can only use maths and statistics methods to find patterns in data. Most artificial intelligence systems can only do a small number of specific tasks.

DO ARTIFICIAL INTELLIGENCE TECHNOLOGIES MAKE MISTAKES?

Yes. Artificial intelligence technologies learn from health data, and health data can be biased, inaccurate and sometimes incomplete. The performance of artificial intelligence systems also relies on the way they are developed by human coders. **As a result of problems in data or problems with coding, artificial intelligence technologies will sometimes make mistakes.**

IS ARTIFICIAL INTELLIGENCE AS GOOD AS HUMAN DOCTORS AT DETECTING AND DIAGNOSING DISEASES?

At the moment, artificial intelligence systems mainly help healthcare workers who can combine AI advice with information about patients to make diagnoses.

There is a lot of variation in the accuracy of artificial intelligence technologies. **The accuracy of an artificial intelligence technology depends on many things, such as the data used for developing and training the technology and the disease that the technology is supposed to detect.** Research studies have found that some artificial intelligence technologies are about as accurate as human doctors when detecting or

diagnosing diseases. But these technologies might not be as accurate as human doctors when they are used in real life settings. Sometimes research shows that they work less well in the real world.

As researchers develop new ways to use artificial intelligence in healthcare, the hope is that technologies may become more accurate and begin to make fewer mistakes than human doctors.

IS ARTIFICIAL INTELLIGENCE ALREADY BEING USED IN AUSTRALIA FOR DETECTING AND DIAGNOSING DISEASES?

Artificial intelligence that is built into medical devices needs to be checked and approved by the Therapeutic Goods Administration, which is the regulatory agency for medical products such as drugs and medical devices.

You may use artificial intelligence-enabled apps on your smartphone, such as the HealthDirect app[1] for checking symptoms, or you may use an AI-enabled wearable device such as a Fitbit or Apple Watch to track your health. In some cases, artificial intelligence technologies might be used to assist your doctor in making a decision about your symptoms or analysing a scan, but **they cannot be used on their own to make decisions about your health.** At least in Australia, in 2023, your health care worker still needs to make the final decision.

3.4. DIAGNOSIS AND SCREENING

During the jury process you will hear a lot about diagnosis and screening. **Diagnosis is the process of identifying the disease or condition a patient has**. Diagnosis can involve taking a

[1] https://www.healthdirect.gov.au/health-app

medical history, examination of the patient, and doing tests. The diagnostic process starts when a person seeks healthcare because something is wrong – usually because they have symptoms. For example, you might go to a doctor with pain. Through the diagnostic process, the doctor tries to work out what condition is causing the pain.

Screening is different. **Screening is checking to see whether disease *might* be present, in people who don't have symptoms of that condition**. Usually a screening test is offered to those people who are at higher risk of a condition than the general population. For example, women 50-74 years old are offered breast cancer screening because they are at higher risk of developing breast cancer. Or people who have diabetes are offered regular eye examinations because they are at higher risk of eye disease than people without diabetes. The screening process might not deliver a definitive diagnosis: people with a positive screening result are often advised to have more tests to find out whether they actually have the disease. **You will hear more about diagnosis and screening from the expert witnesses.**

3.5. THINKING ABOUT EVIDENCE

In healthcare, there are strict rules about what counts as evidence. This is important, because health workers need to know whether a test or treatment works. Rules about what studies provide good evidence for tests or treatments make it possible to combine research from all over the world to ask, for example, 'is this a reliable test to detect this disease, and will it improve patients' health (for example, directing appropriate treatment)?'

But it's not that simple. **Generating evidence is time consuming and expensive, and the evidence doesn't always provide the answers health workers need**. Often research is from rich countries in the northern hemisphere, with members of marginalised groups being underrepresented. Not all evidence is published, and sometimes when studies are critically analysed, they aren't quite as good as their authors suggest. While the question of whether tests work is critically important, there are other important questions that have to be answered with different kinds of methods – for example, questions about the patient experience.

The health and medical research community continues to build knowledge about the effectiveness of tests and treatments. At the same time, there are always uncertainties and gaps. In the expert presentations and our activities, you will be invited to think critically about the evidence for AI in healthcare and to take that evidence seriously in your decision-making.

3.6. WHY ARE WE TALKING ABOUT THIS TOPIC?

Using Artificial Intelligence for detecting and diagnosing diseases has the potential to improve aspects of healthcare. However, it also introduces some risks, including risks of harm. Experts in artificial intelligence are debating whether the benefits are greater than the risks, and how we should decide.

POTENTIAL BENEFITS OF AI IN HEALTHCARE

AI may make speed up the process of detecting diseases by helping healthcare workers make faster decisions about a diagnosis for their patients.

AI may free up time for healthcare workers. Artificial intelligence may be able to complete some tasks that healthcare workers previously had to do. This could mean that health care workers have more time to spend with patients.

AI diagnosis may become more accurate than human diagnosis. As the technology develops, artificial intelligence may become a more accurate way to detect some diseases in patients.

AI may reduce the cost of healthcare. If artificial intelligence is faster or more accurate than human health care workers, and if the cost of implementing AI is not too high, it might reduce the cost of health care for the government and even for patients.

AI may be helpful in remote areas. Artificial Intelligence may allow people in remote areas to access health care in their GP's office that would normally need a specialist.

POTENTIAL HARMS OR DANGERS OF AI IN HEALTHCARE

AI may work better for some patients than others. Artificial intelligence technologies can be biased, meaning they work better for some types of people compared to others. AI has been found to sometimes copy human biases, meaning that AI might make more mistakes for people in already-disadvantaged groups.

AI may cause health care workers to lose skills. If Artificial Intelligence does things that human healthcare workers used to do, the healthcare workers may begin to lose skills they used to have.

AI may be less accurate than human healthcare workers at detecting diseases. Artificial Intelligence technologies may be less accurate than human doctors at detecting a disease. Early claims that AI is highly accurate are not always verified in real world studies. The accuracy of artificial intelligence technologies may vary depending on the place where it is used (e.g., a technology developed in the US may not work as well in Australia)

Healthcare workers may rely on AI over their expert knowledge. Even when Artificial Intelligence technologies are supposed to assist human healthcare workers rather than replace them, some healthcare workers may put trust AI technologies over their expert knowledge and not question the decisions made by AI, even when they disagree.

Some health AI technologies might not have human healthcare workers to check for mistakes. Some health AI technologies are designed to be used at home, where there is no healthcare worker to make sure that the technology is accurate.

4. EXAMPLES OF ARTIFICIAL INTELLIGENCE DESIGNED TO BE USED IN HEALTH

4.1. CASE 1: SYBIL, ARTIFICIAL INTELLIGENCE FOR LUNG CANCER SCREENING

WHY THIS CASE?

Lung cancer is an abnormal growth (tumour) in the tissue of one or both lungs.[2] Over time, lung cancer can progressively increase in size and affect breathing, causing pain and symptoms. Without intervention, the tumour could spread throughout the body.

Doctors can check for lung cancer, or the risk that someone has lung cancer, by taking images of the chest with x-rays or CT scans. A specific type of CT scan can be used to screen healthy people for lung cancer. The specialist doctors who read these images are called radiologists. Radiologists can interpret or "read" images to look for signs of lung cancer.

Sybil™ is an Artificial Intelligence algorithm designed to analyse images from CT scans. Sybil™ works without help from a radiologist. **Sybil™ predicts the risk of a patient developing lung cancer within six years.**

[2] https://lungfoundation.com.au/patients-carers/conditions/lung-cancer/overview/

WHAT IS IT?

Sybil™ is a software product that uses an advanced type of Artificial Intelligence called deep learning.[3] **Sybil™ was developed in the US and is not yet approved for use in Australia**. Developers of the software claim that it can predict lung cancer risk up for to 6 years. The software can work automatically as soon as the CT scan image is available. The software's prediction of risk is based on the analysis of a single CT scan image without the need for other patient information, and without input from a radiologist.

The software was developed by researchers from the Massachusetts General Cancer Center and the Massachusetts Institute of Technology. The researchers used lung CT scans of participants from the US National Lung Cancer Screening Trial.[4]

HOW MIGHT IT CHANGE HEALTHCARE FOR AUSTRALIANS?

Cancer Australia is actively looking into developing a nationwide Lung Cancer Screening program that will leverage the use of Artificial Intelligence and computer-assisted diagnostics.[5] A 2021-22 Federal Budget Measure tasked the Department of Health and Cancer Australia to work together to establish the feasibility of implementing a national program.[6]

In Australia, lung cancer is the leading cause of cancer death, and is **often detected at such an advanced stage that treatment options are already very limited**. A screening

[3] https://ascopubs.org/doi/full/10.1200/JCO.22.01345

[4] https://ascopubs.org/doi/full/10.1200/JCO.22.01345

[5] https://www.canceraustralia.gov.au/about-us/lung-cancer-screening

[6] http://www.msac.gov.au/internet/msac/publishing.nsf/Content/1699-public

program to detect high-risk people or early-stage cancer could save lives and reduce lung cancer mortality. It is estimated that in 10 years, a screening program in Australia could prevent over 12,000 deaths.

The proposed national screening program aims to incorporate Artificial Intelligence technologies similar to Sybil™. Nationwide screening programs entail a high number of images that must be read by radiologists, so require large workforces. Technologies like Sybil™ could work independently and provide support to radiologists.

WHAT IS PROMISING ABOUT IT?

- The system promises to **improve accuracy in identifying signs of potential lung cancer nodules** in CT scans even if these signs are too small for human eyes to see.[7]
- For patients and health consumers, **increased accuracy would mean that doctors could intervene early** and provide appropriate management to improve survival.
- Increased accuracy would also **decrease errors**, such as saying there is cancer present when there is none. This would prevent unnecessary use of extra diagnostic tests or treatment.

WHAT MIGHT BE PROBLEMATIC ABOUT IT?

- Like any technology that helps with decision making, when artificial intelligence systems are used, **clinicians tend to favour or rely too much on the recommendations or interpretations generated by the AI**. At times, this tendency

[7] https://news.mit.edu/2023/ai-model-can-detect-future-lung-cancer-0120

to favour or rely on the technology means that clinicians become less critical, which could then lead to errors.

- Many artificial intelligence systems are developed overseas using data from overseas populations that are different from the Australian population. There are currently **no clinical trials that demonstrate that Artificial Intelligence technologies developed overseas will perform properly on patients and health consumers in Australia.**
- As with other screening programs, using artificial intelligence may **increase risk of people being diagnosed who may not benefit from the diagnosis** (for example, because they cannot be treated), and may experience harm (for example, increased anxiety).[8]

[8] https://doi.org/10.17061/phrp2731722

4.2. CASE 2: CANARY™, A MOBILE APP FOR MENTAL HEALTH SCREENING

Image from https://canaryspeech.com/blog/canary-speech-launches-on-microsoft-azure-marketplace/

WHY THIS CASE?

Mental health conditions such as anxiety or depression can affect the way a person feels, thinks or behaves. In some cases, these symptoms lead to emotional and physical problems that are hard to cope with.[9] Screening and diagnosis of mental health conditions involve an appointment with a healthcare professional, who gathers detailed information about a person's thoughts, moods, behaviours, and medical history.

Canary™ mobile app offers a mental health service directly to consumers who have mobile phones and access to the internet.[10] The screening is fully automated, with the AI system processing information and providing evaluation without the help of a professional.

[9] https://www.healthdirect.gov.au/mental-illness

[10] https://doi.org/10.48550/arXiv.1910.10082

WHAT IS IT?

Developed by US-based company Canary Speech, Inc., Canary™ is a free mobile application with Artificial Intelligence capabilities. **The app is designed to screen for mental health conditions, including mood and anxiety disorders**. It does this based on analysing a person's speech. The app can be downloaded via Google App or Apple App stores.

How the app works:

- The Canary app instructs the user to speak freely for 20 seconds.
- The 20-second recording is processed by an Artificial Intelligence algorithm, which analyses features in the speech, such as volume, tone of voice, and presence of pauses.
- The app then provides a Vocal score, with higher scores indicating increased risk of the presence of a mental health condition.

The mobile app manufacturer claims that the app *"provides only information, is not medical or treatment advice and may not be treated as such by the user. As such, this App may not be relied upon for the purposes of medical diagnosis or as a recommendation for medical care or treatment. The information on this App is not a substitute for professional medical advice, diagnosis or treatment."*[11]

[11] https://canaryspeech.com/

HOW MIGHT IT CHANGE HEALTHCARE FOR AUSTRALIANS?

A 2022 survey showed that over 2 in 5 Australians aged 16 to 85 have experienced a mental health disorder during their lifetime, and 1 in 10 Australians reported having been diagnosed with a mental health condition.[12]

Despite the high number of Australians experiencing a mental health disorder, mental health services in Australia are not meeting the needs of patients.[13] The majority of Australians access mental health care through private service providers, with Medicare partly subsidising fees. Recently, the Australian government has decreased the number of subsidised Medicare sessions.[14] Those who cannot afford private services must rely on the public health system, which is also under-resourced.

As a free mobile app, Canary promises to provide a form of mental health screening for people who cannot access services in the public or private healthcare system.

WHAT IS PROMISING ABOUT IT?

- The company behind the mobile app claims that its technology is **more accurate than existing mental health screening methods,** and that it could detect mental health problems even before onset of observable symptoms.
- If it is accurate, the technology has the potential to **fill gaps in mental health assessment services**.

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[12] https://www.aihw.gov.au/reports/mental-health-services/mental-health

[13] https://napp.org.au/2021/04/the-australian-mental-health-crisis-a-system-failure-in-need-of-treatment/

[14] https://www.news.com.au/lifestyle/health/mental-health/medicare-subsidies-for-mental-health-care-to-be-reduced-to-10-sessions/news-story/88779e899756f2b4bb7099fec1d325a5

WHAT MIGHT BE PROBLEMATIC ABOUT IT?

- The app is subject to Australia's National Safety and Quality Digital Mental Health Standards,[15] which ensures the quality of digital mental health service provision. However, there is **no evidence that the mobile app has applied the recommended quality and safety standards**.
- Artificial Intelligence systems designed to analyse voice and speech tend to be **less accurate for people with accents** or dialects that are not well-represented in the data used to develop the technology.[16]
- Studies have shown that most mobile phone apps have **not been scientifically evaluated for their effectiveness in improving care or patient outcomes**.[17] Apps can lead to harm when they offer incorrect or misleading information.[18] For example, an app might offer advice not to consult a health worker when a user actually requires professional help.
- The app is designed for screening, but not treatment. **It may be unhelpful for a person to learn that they are at a higher risk of having a mental health condition if they cannot access mental health treatment services**.

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[15] https://www.safetyandquality.gov.au/standards/national-safety-and-quality-digital-mental-health-standards

[16] https://facctconference.org/static/pdfs_2022/facct22-43.pdf

[17] https://doi.org/10.1371/journal.pdig.0000002

[18] https://www.smh.com.au/lifestyle/health-and-wellness/wellness-and-mental-health-apps-are-they-worth-it-20190312-p513if.html

4.3. CASE 3: IDX-DR, ARTIFICIAL INTELLIGENCE TO SCREEN FOR DIABETES COMPLICATIONS

WHY THIS CASE?

About 1.3m Australians have diabetes.[19] **Diabetic retinopathy is a common complication of diabetes**. It is a condition of the retina, which is on the inside back surface of the eye. Diabetic retinopathy can cause blindness in people with diabetes.

About 4 in 10 adults with diabetes have retinopathy, and about 1 in 10 have reduced vision.[20] People can start to develop diabetic retinopathy without realising it, so it is recommended that people with diabetes have eye checks at least every two years.[21] But - especially in remote communities - this often doesn't happen. The checks are done by optometrists or ophthalmologists (eye specialists). **Early treatment can slow down or stop people with diabetes losing their vision.**

IDx-DR is an AI-enabled medical device for checking the health of the retina in people with diabetes. IDx-DR tells the operator whether a person has signs of diabetic retinopathy, so they can seek early treatment. Previously, only human clinicians could look for diabetic retinopathy in images of the retina. This is skilled work, but can be repetitive. In 3/10 cases, a person needs eye drops to dilate their pupils, and these take hours to wear off. Some specialists examine people's eyes directly, which can mean being in close proximity to the doctor and feeling uncomfortable.

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[19] https://www.aihw.gov.au/reports/diabetes/diabetes/contents/how-common-is-diabetes/all-diabetes

[20] https://pubmed.ncbi.nlm.nih.gov/28318640/

[21] https://www.healthdirect.gov.au/diabetic-retinopathy

IDx-DR automates this process, and does not require eye drops or direct examination of the eye by a health worker.

WHAT IS THIS CASE?

IDx-DR is an autonomous AI system inside a purpose-built machine. You can see pictures of IDx-DR here:

https://www.digitaldiagnostics.com/products/eye-disease/idx-dr/

There are two algorithms in IDx-DR. One is for quality control. IDx-DR takes pictures of the patient's retina, and the quality control algorithm checks that those pictures are good enough. If they are, a second machine learning algorithm analyses those pictures to check for signs of 'more than mild' diabetic retinopathy. **IDx-DR tells the operator within a minute whether the patient has 'more than mild' changes in their retina.**

HOW MIGHT IT CHANGE HEALTHCARE FOR AUSTRALIANS?

IDx-DR is designed to be used by healthcare workers in the community. The developers goal is for IDx-DR to be used by trained health workers so that **people with diabetes can have their eyes checked more easily and regularly, with less cost and inconvenience**.

People whose eyes are fine could then avoid unnecessary specialist appointments. And people who are developing retinopathy might be detected earlier, so they can be referred for specialist eye care. The Australian and New Zealand College of Ophthalmology has supported using AI to screen for retinopathy in New Zealand communities

where there are low levels of screening and treatment.[22]

IS PROMISING ABOUT IT?

- The company behind the system claims that a **clinician can be trained to operate the machine in 4 hours.**
- IDx-DR was **trained to look for the same changes that a human specialist would look for**, so specialists can understand how the system works.
- The early studies supporting IDx-DR were independently managed.
- These studies suggest that when a human specialist says an image *does not* show retinopathy, IDx-DR agrees 91% of the time. When a human specialist says an image *does* show retinopathy, IDx-DR agrees 87% of the time.
- The company claims that the system works for **people from all ancestries.**
- A fully autonomous system could make a difference in **remote Australian communities**, where people have less access to specialists but a higher need for services.
- **IDx-DR has regulatory approval in the US and EU**,[23] and was the first medical device to receive regulatory approval in the US that is considered ”autonomous”, which means it can work on its own without a health worker present.
- IDx-DR is being used in the US.
- **The company takes legal responsibility** for the accuracy of the system.

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[22] https://ranzco.edu/wp-content/uploads/2022/08/RANZCO-Position-Statement-Diabetic-Retinopathy-and-diabetic-retinal-screening-in-NZ_2022.pdf

[23] In Australia, the TGA has approved several software products for automated analysis of pictures of the retina, but IDx-DR has not yet been approved.

WHAT MIGHT BE PROBLEMATIC ABOUT IT?

- **IDx-DR only looks for diabetic retinopathy**, so it won't pick up other changes or eye diseases that a human eye specialist would identify.
- **The system is commercially protected**: the source codes are not publicly available and are patented.
- **The research about IDx-DR is mostly funded and/or authored by the company** or people with an interest in the company.
- In Australia, IDx-DR **does not have regulatory approval**, **uptake** of approved AI systems for eye screening is low.
- **It's not clear what happens to the data collected by the system.**
- The developers say IDx-DR can detect retinopathy in real-world settings, but **there is no evidence yet whether this will prevent vision loss**, save costs or improve access to care.

4.4. CASE 4: COGSTACK AND NATURAL LANGUAGE PROCESSING TO SCREEN FOR UNDIAGNOSED DEMENTIA IN MEDICAL RECORDS

WHY THIS CASE?

'Dementia' is used to describe a group of conditions where brain function gradually gets worse. This can lead to changes in people's memory, speech, thinking, personality, behaviour, and ability to walk and move.[24] There are between 400,000 and 500,000 people in Australia with dementia, and this number is going up.[20] As a person's dementia gets worse, they need more and more help to do things. Dementia can seriously affect the person's health and quality of life, and that of their family and friends. People with dementia usually need healthcare and

[24] Australian Institute of Health and Welfare. Dementia in Australia. Canberra: AIHW; 2022.

aged care services for care and support. There is currently no cure: the goal is to help the person maintain independence and quality of life for as long as possible.[20]

Dementia diagnosis requires face-to-face assessment by a specialist doctor.[25] Australians with dementia are often diagnosed late, so may miss out on relevant support. **If dementia could be detected earlier and more accurately, people with dementia might get services and support at an earlier stage** of their illness, and live a better life for longer.

WHAT IS THIS CASE?

This case uses a platform called CogStack to look for dementia based on the digital data in people's existing medical records.[26] It uses a machine learning technique called Natural Language Processing (NLP). **Natural language processing systems can process large amounts of text**. Think, for example, of all of the words written in all of the records in a hospital. A human couldn't think about all of that text at once, but a natural language processing system can process it quickly. It can catalogue and sort the information and look for patterns. This means natural language processing systems are particularly useful for dealing with large amounts of text data.

CogStack can find and extract information from any kind of digital record. It can use structured information (for example, a form that only allows people to tick boxes) or unstructured

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[25] Diagnostic and statistical manual of mental disorders : DSM-5. American Psychiatric Association, editor. Arlington, VA: American Psychiatric Association; 2013.

[26] Enticott J, Johnson A, Teede H. Learning health systems using data to drive healthcare improvement and impact: a systematic review. BMC Health Services Research. 2021;21(1):200.

information (for example, freehand notes). It can use a scanned document or image. It can use notes typed by a healthcare worker. It can analyse for patterns across all of these different types of data. It can also display patterns in a visual form that people can understand.[27,28]

Monash Partners Academic Health Science Centre (MP) received a grant from the Medical Research Future Fund (MRFF). The funds were used to **adapt CogStack for the Australian context and deploy this across health service partners**. One of three case studies occurred at the National Centre for Healthy Ageing (NCHA),[29] a partnership between Peninsula Health and Monash University, and complemented an existing NHMRC dementia grant. The aim of the study was to develop algorithms, using electronic medical record data, to detect the probability of a person having diagnosed or undiagnosed dementia.

HOW MIGHT IT CHANGE HEALTHCARE FOR AUSTRALIANS?

The project is focused on the Mornington Peninsula in Victoria. The National Centre for Healthy Ageing hope, through this project, to estimate how many people actually have dementia on the Mornington Peninsula. They also want to identify which suburbs people with dementia are living in, to improve services and supports available to those people, closer to where they live.

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[27] Jackson R, Kartoglu I, Stringer C, Gorrell G, Roberts A, Song X, et al. CogStack - experiences of deploying integrated information retrieval and extraction services in a large National Health Service Foundation Trust hospital. BMC Med Inform Decis Mak. 2018;18(1):47.

[28] Noor K, Roguski L, Bai X, Handy A, Klapaukh R, Folarin A, et al. Deployment of a Free-Text Analytics Platform at a UK National Health Service Research Hospital: CogStack at University College London Hospitals. JMIR Med Inform. 2022;10(8):e38122.

[29] https://www.monash.edu/medicine/national-centre-for-healthy-ageing

Results will also be used to provide State and National estimates of how many people are living with diagnosed and undiagnosed dementia.

WHAT IS PROMISING ABOUT IT?

- Right now, this system is **only being used to estimate how many cases of dementia there are** in specific areas or populations. But in future, algorithms supported by CogStack might be used **in the clinic** to find individuals with a high chance of undiagnosed dementia.
- If the system could be used to screen for dementia in individual patients, they could be **referred to a memory clinic for a formal specialist diagnosis**, or their General Practitioner (GP) could be notified.
- **Early detection could facilitate early tests and diagnosis** (or getting an all clear).
- If people were diagnosed through a screening process, **they could receive support and treatment earlier** than occurs now.
- The team involved in this project are observing our Community Jury and are keen to **include your views**—and the views of the broader community—to guide future uses of AI in this field.

WHAT MIGHT BE PROBLEMATIC ABOUT IT?

- It is not always clear how these types of AI fit into Australian **regulation** requirements
- There are no proven treatments to cure or delay progression of dementia. So **early identification can't stop the disease, it can only provide earlier support.**
- Algorithms are never 100% accurate, and screening tests always result in some false positives. This would mean **people**

being told they might have dementia, and then, after diagnostic tests, being told they don't have dementia. This could be very confronting for the person and their family.

- Because there is no cure, and because screening tests are sometimes wrong, **some people may not want to be told that they have a high chance of having dementia**.
- Deciding whether or not someone has early/mild dementia is not clear cut. **Some cases of 'mild dementia' may not progress to more severe disease**. People labelled with dementia may experience stigma and negative psychosocial effects from the disease label.

5. Key Terms

Adaptive algorithm	Algorithms designed to create models that develop and change continuously based on new data. Opposite of locked algorithm.
Algorithm	A set of rules, equations or instructions to solve a problem, perform calculations, process data or automate reasoning.
Algorithmic bias	Systematic errors in AI systems that result in unfair or unequal outcomes that privilege a group or an individual over others.
Artificial Intelligence	A set of computer-based technologies that can do things that previously required human thinking and action.
Assistive AI	AI systems that assist humans to make decisions, but use human inputs as well as existing data to provide the answers
Augmentative AI	AI systems that support humans to do tasks – for example by providing information when it is needed
Autonomous AI	AI systems that can complete tasks independent of human decision-making and action
Bias	See algorithmic bias
Big data	Large and often complex data sets that can be used to develop AI technologies.
Clinical data	Detailed information about specific aspects of people, or health conditions (e.g., blood pressure, weight, lab results).
Computer vision	A subset of AI applications that enable computers to analyse images.
Consent	Permission for something to happen or agreement to do something.

Deep learning	A type of machine learning approach that uses very complex algorithms called *multi-layered neural networks*. These algorithms require large amounts of data and create models that are too complex for humans to interpret.
Deliberation	Long and careful consideration or discussion. A citizens' jury aims for informed deliberation i.e. the participants have enough information and time to consider all the relevant issues in the case under discussion.
Diagnosis	The process of determining whether or not a person has a particular medical condition through taking a patient history, examination, and testing.
Direct-to-consumer healthcare	Healthcare and medical functions that are marketed to consumers (the public) rather than healthcare workers.
Expert	A person who is knowledgeable in a certain area. In a community jury, the experts are the ones who give information to the jurors.
Facilitator	A person who helps to guide a group through a process of discussion or deliberation.
Generalisability	When an AI technology is generalisable, that means that it can detect health conditions accurately when used in a different context or population to where the AI technology was developed.
Locked algorithm	Algorithm that produces a model that does not change over the course of its use. Opposite of adaptive algorithm.
Machine learning	A series of techniques that enable computers to learn from data without explicit instructions from a human.
Model	The output of a machine learning algorithm after the algorithm is run on data.

Natural language processing	A subset of AI applications that enable computers to analyse written and spoken language.
Observer	Observers are not part of the research team, but are interested in the jury process. Observers attend some jury sessions, but are not active participants.
Public interest	The public interest is the well-being and welfare of the general public and society.
Screening	Screening involves actively offering a test to a defined group in the population who do not have signs or symptoms to see whether they might be at risk of having a disease.
Supervised learning	A machine learning approach which uses data associated with a known outcome to create an algorithm that can then be used. For example, an AI technology that uses your symptoms to tell you if you have a disease or not (the expected outcome) is based on supervised learning.
Wearables	Any technology designed to be worn, such as smart watch.

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7. The expert witnesses: video presentations

Part 6 - THE EXPERT WITNESS - Video Presentations

Professor Farah Magrabi expert presentation: **What is AI and how does it work?**

Associate Professor Katy Bell
Expert Presentation: **Screening and Diagnosis**

Q&A Videos

1. **Q&A Part 1**
2. **Q&A Part 2**
3. **Q&A Part 3**
4. **Q&A Part 4**
5. **Q&A Part 5**

Professor Ian Scott
Expert Presentation: **Benefits of AI in healthcare**

Q&A Videos

1. **Q&A Part 1**
2. **Q&A Part 2**
3. **Q&A Part 3**
4. **Q&A Part 4**
5. **Q&A Part 5**

Professor Wendy Rogers
Expert Presentation: **Potential harms and wrongs of using AI healthcare tools**

Q&A videos

1. **Q&A Part 1**
2. **Q&A Part 2**
3. **Q&A Part 3**
4. **Q&A Part 4**

8. Community jury on artificial intelligence in health: questions from the jury

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Australian Centre for
Health Engagement,
Evidence & Values

Community Jury on Artificial Intelligence in Health

QUESTIONS FROM THE JURY

Contents

1. Jury questions for Prof Farah Magrabi

1.1. EXAMPLES, COMPARISONS, STRENGTHS, WEAKNESSES

1. Are some countries already using AI for diagnosis and screening? What can we learn from them? Is AI currently being used in diagnosis and screening (here or overseas)? If so, for what tasks? Are there any diagnostic AI systems that we can see in use in real time?
2. The jury is very interested in the differences between assistive and autonomous AI. Could you provide key positive and negative (or beneficial and harmful) examples of assistive and autonomous AI? What evidence do we have for their impact (here or in other countries)?
3. Is AI always a product? (like Canary or IDx-DR) Diagnosis is a process: is AI sometimes implemented as a process? Are there any key examples of AI as a process rather than a product in diagnosis and screening? Is it incorporated into a system? The jury has seen examples of AI as products with names/brands.

1.2. DIAGNOSTIC AND SCREENING AI IN PRACTICE

4. Has diagnostic AI been used with diverse populations (not just one ethnicity, but the possibility of mixed ethnicity), or Populations or groups that are historically underserved? Does AI learn the variety of differences in a population and account for this as a factor? Should we be concerned that AI will consolidate or 'average out' what health is and what health ought to be. Will humanity lose health diversity?
5. When AI is used to diagnose or screen someone, would they be told? Are there currently people who know that AI has been used in their care
6. How do assistive systems affect expert attention and decision making? Could they become de facto autonomous if an operator comes to trust the system?
7. Might value judgements by clinicians distort valid AI results?

1.3. AI LEARNING AND DEVELOPMENT

8. The jury is very interested in what it means to say that AI learns? How does it 'learn'? How does it become more accurate? Are there limits to its ability to learn? How long does it take to train an AI to do something as complex as medical diagnosis?
9. How is healthcare AI developed? Do developers (or others) influence how AI systems learn, or their outcomes? Can humans fix errors made by AI systems?
10. Is it correct to say that AI *cannot* make the kinds of judgements that humans might make based on experience or intuition (e.g. recognising that something is not important)?

11. Are neural networks a reliable analogue for brain activity?
12. Especially for autonomous AI systems, what is the risk of establishing a feedback loop within or between AI systems that will lead to an "average-bias"? Once a neural network has been established, with the rules that are guiding it, does have the capacity to become autonomous?

1.4. PERFORMANCE

13. Can AI keep becoming more accurate after it is released, or do some systems not need any more training?
14. If an AI system made decisions based on probabilities, and there were two possible diagnoses with similar probabilities, how would it handle this?
15. If AI is only looking for a specific thing, what happens if it doesn't find another condition so doesn't alert healthcare workers? What kinds of backup systems would be in place for when AI makes an error?
16. Can algorithms predict uncertainty? And can AI predict uncertainty, especially in populations? Does it apply or work in different ethnicities or social groups? Can it make decisions differently in different populations?
17. What is the unit of analysis for diagnostic AI --) e.g. the molecular level of disease? Some other aggregate?

1.5. OVERSIGHT AND INTERESTS

18. Who makes the decision to implement a particular AI product in healthcare?
19. How is oversight, regulation, control and security of healthcare AI systems managed in Australia? Are there any lessons from other countries for how we oversee AI in Australia? How is the potential risk for bias overseen?
20. Who would be responsible for errors or misuse if AI is implemented?
21. What companies are behind healthcare AI? Are they trustworthy? (Especially with our data). Where is the investment coming from?

1.6. ACCESS

22. Could AI increase access to healthcare e.g. in rural and remote Australia? Can everyone access AI in healthcare? If not, why not?

1.7. DATA

23. How do we know that the data being used to develop health AI are good quality? (How are they validated, checked, who signs off, is there a governance panel that reviews the data?) Are health data like MyHealthRecord, vaccination records, myGov data and data from health apps currently being used to develop AI?

24. How safe are the personal data used to develop AI systems? Are there controls on its use? Could increased use of AI reduce our privacy (e.g. increase on-selling of data, data breaches, access by health insurance companies with effects on individuals' premiums)
25. Is medical imaging data of high enough quality for AI to provide a diagnosis? Could AI misunderstand an image? If so, how would misdiagnosis be prevented? Could a good AI machine learning system make mistakes because it is working with poor quality data? (if so, what would happen then?)

1.8. COST

26. How expensive will it be to rollout AI systems for diagnosis and screening? What are the costs? (Is it just the equipment – or also healthcare workers?) Could screening using an autonomous AI be cheaper than the status quo?

2. Jury questions for Prof Katy Bell

2.1. SCREENING AND DIAGNOSIS IN PRACTICE

1. Could you explain what is meant by disease detection?
2. Can you say a little more about 'doing nothing' or 'doing little' as an alternative to screening in populations?
3. We hear on a daily basis of patients going undiagnosed due to medical practitioners not listening to their patients and not undertaking necessary testing to identify the cause of the signs and symptoms. Does research suggest screening might decrease mortality due to missed disease? Is there potential for AI-based screening process to miss more signs of a medical condition?

2.2. EVALUATING SCREENING

4. What criteria are used to evaluate screening programs and diagnostic tests? How consistent are these between countries? Will they also apply for screening using AI?
5. How are benefits, harms and cost-effectiveness defined and measured in evaluation? (would this be similar for AI-based systems?)
6. Can we trust research about screening and diagnosis (e.g. is the interpretation independent and unbiased)?
7. There is a lot of variation in screening and diagnosis practices in the real world – how do researchers remove this variation to create good quality evidence?
8. There is pressure to make tests available quickly. But generating evidence about screening programs seems to require a long time. How can these be reconciled?

9. How do screening researchers make sure their findings are used in practice?

2.3. PATIENT CENTRED SCREENING AND DIAGNOSIS

10. Do you think patient values and circumstances are considered in the application of evidence-based practice? Do you think using AI could change this?
11. Does current screening/diagnostic research apply to patients from all geographical locations, ages, sex, financial backgrounds etc? Does the evaluation of screening consider intersectionality and marginalised populations? Would research about AI in screening/diagnosis include marginalised populations? How would we make sure that all kinds of patients and all kinds of settings and all kinds of clinical practice are represented in data and in decision making?
12. Some people may have all the indicators for a diagnosis but do not want to have a label. Can this 'not knowingness' be honoured?

3. Jury questions for Distinguished Professor Rogers

1.1. TRANSPARENCY, PATIENT INFORMATION AND PRIVACY

1. Is there an existing policy informing patients that AI will be utilised in detecting their diagnosis? Is there any information given to patients in relation to the privacy/confidentiality of any data collected? Is there going to be a detailed information package developed to allow patients to agree to or disagree to AI being used in their case? Can patients have the right to choose whether AI will be used? Do you think patients should be able to opt out of having their data used for AI analysis? Why or why not?
2. If AI was being used on someone within the scope of the people that the AI correctly analysed the data, do patients need to be made aware that it may not be as effective on someone else with a different skin colour or ethnicity?

3.1. GOVERNANCE, REGULATION, LEGAL IMPLICATIONS AND EVALUATION

3. Should the claims of developers of software/algorithms be accepted and adopted or should they be subject to rigorous appraisal, if so who/what should be responsible to conduct this?
4. What do you think about human oversight, to quality check AI, do you think there is a need/no need or varying degrees depending on various factors: previous/no past experience of algorithm/s? That oversight is reduced/removed only after problem free observation period, or never removed?

5. Is there any studies undertaken to understand and protect doctors and clinicians from any ethical or legal consequences of using AI

3.2. RISKS AND HARMS FROM USING AI AND PREVENTING HARM

6. Are you confident that the potential risks or harms of healthcare Artificial Intelligence can eventually be eliminated or at least diminished to a degree that is acceptable to all stakeholders or do you believe that attainment of a very high standard across all areas of health screening, diagnostics and care/treatment is not on the horizon yet? How likely is it that the harms will be addressed?
7. If an AI application is causing bias due to not having sufficient dataset for minority populations, is it a matter of inputting in more or have equal datasets across all population groups? If there was a requirement in place for AI companies and programmers to have the same amount of data for groups based on gender, age, race and ethnicity etc., would this eliminate or reduce the under-representation or equality in the datasets that are used to train AI systems?
8. Is there any further evidence about the performance of AI trained in diverse data sets on terms of the outcomes for patient satisfaction, as well as accuracy and efficiency?
9. Could you provide (if available) the demographics of those that build the AI? Is this predominately cishet white, able bodied men?
10. You have mentioned the problems that can result from bad algorithms, (Robo-debt), what can be done to prevent these seeing the light of day, can they be identified before being released/unleashed on the public, (lab rats)? Should there be a system of reviewing new algorithms before implementation and before ongoing development/modifications?
11. Is there a decision making framework for patients and clinicians about minimising the harm or risk of the use of AI?
12. What are some of the factors underpinning common and specific risks in the use of AI for health diagnosis and detection?
13. We have heard discussions of both potential benefit and potential harms. How are these being weighed? A potential harm to a patient is likely to be considered to the patient as far more heavily weighted than a potential benefit to a field of research by a researcher.

3.3. IMPLEMENTING AI FOR DIAGNOSIS AND SCREENING

14. Do you consider that some health domains are less suitable to AI involvement and are probably best left to be Natural Intelligence, at least in the short term, if so elaborate please?
15. What do you believe needs to happen to ensure best practice in the delivery of health services, AI v Natural Intelligence?

16. If you could design your ideal healthcare Artificial Intelligence system, what things would you consider essential requirements?

4. Questions for Professor Ian Scott

4.1. EVIDENCE FOR AI, BENEFITS AND COSTS

1. Why have there been so few studies undertaken and does that mean we are relying on the developers for accuracy of their AI? Are there enough Australian studies – or are we relying on international evidence that might be less relevant to our setting? Is there a plan to increase the Australian evidence base?
2. Are there any plans to undertake a rigorous set of studies on the benefits of using AI, the potential for cost saving, and greater efficiency from using AI? Do you think there will be randomised control trial evidence generated? Who would do this? Would they compare human performance with AI performance? Would this be on the same patients?
3. What is/will be the process of engaging a necessarily large cohort of clinicians and consumers required for the design, testing and implementation of AI?
4. How would data quality and inclusion of data from diverse participants be managed for such studies?
5. What about diagnosis where different clinicians have different views on what is 'right' and what is 'wrong'. Who will decide the programmers for AI? Will they provide a balanced input into diagnosing conditions or will they be from only 'one camp' so to speak. I see this as a different kind of bias other than just race and gender. In short, who decides the input data?
6. The jury are interested in the benefits and costs of implementing AI, including different types of AI:
   - A lot of AI developments are quite expensive to use – won't AI in healthcare be exposed to the same costs?
   - Are the benefits and costs of AI used to screen for disease different to those for AI used for diagnosis?
   - Are the benefits and costs of assistive AI different to those for autonomous AI?
   - How long would it take for AI products to break even on costs?
7. We have heard discussions of both potential benefit and potential harms. How are these being weighed? A potential harm to a patient is likely to be considered to the patient as far more heavily weighted than a potential benefit to a field of research by a researcher.

4.2. REGULATION AND GOVERNANCE

8. What stage is AI at in regard to a "Regulatory Framework"? Is there a blueprint or roadmap or trajectory for such a framework? How is it being approached? I am interested in the level of involvement of government, clinicians, consumer advocates. Would regulation include investigative powers and punitive powers? Would regulation include a process to handle complaints from injured members of the public? Are there any other features you deem necessary?
9. Are there any alternatives to regulation such as training healthcare professionals towards self-regulation and providing the necessary checks and balances within the practice of medicine itself?
10. What are the current AI regulatory bodies in other countries and how do they operate and give feedback about potential harm done by the use of AI in disease detection and diagnosis, as well as the accuracy of AI? What is happening at international levels through for example UN, EU etc to set international benchmarks and regulatory approaches for AI?

4.3. QUALITY ASSURANCE AND PERFORMANCE

11. Could the performance of an AI that analyses medical record data be affected by the quality of clinical notes? Who will be held responsible for undertaking updates and maintaining the AI functionality?
12. Is there potential for greater error and bias due to AI implementation compared to the status quo? Who would check that an AI-informed diagnosis was correct? Who would be liable if it was incorrect?
13. What measures do you think should be taken to ensure that AI is used in a fair and unbiased way in healthcare?
14. What might happen if the technology does not function or breaks down for a period of time, is there back up support readily available or contingency plans in place for remote clinics? Would there be staff to take over this role if the AI technology breaks down?

4.4. IMPLEMENTATION AND APPLICATIONS OF AI

15. We have been given four examples of AI in use – would AI be used to check only for those diseases (anxiety/depression, lung cancer, dementia, diabetic retinopathy) or could it be used in a wide range of diseases?
16. How are clinicians and consumers engaged in the early stages of implementation. You have discussed functionality on a busy clinical environment and I am wondering how engagement might impact on clinical performance. To me, I can foresee clinician time constraints and busy work environments hindering this process of engagement.

17. How might there be more engagement of clinicians and consumers right from the start with designing, testing and implementing AI application? It seems like the big overseas companies create these AI technologies privately, and it is being taken up in Australia after it is already in use in other countries, so how might consumer engagement occur here?
18. Will AI implementation change the skill requirements of health workers?
19. How has AI been implemented for diagnosis so far. For example, have there been new Medicare numbers introduced? Have there been any other change management strategies in place for this implementation?
20. They promote that this will improve access for rural/remote patients. However, services such as CT/MRI type scans are not always available in rural/remote locations so how is access improved for them? They still need to travel hundreds of kms to get to the scanning centres at which time they are located with the relevant clinicians in that area. The devices still need to be purchased, operated, and interpreted- who is referring these patients and who is assisting them after diagnosis? The issue in rural areas is about access to healthcare, not the quality of the few existing professionals.

4.5. PATIENT/CONSUMER PROTECTION AND ADVOCACY

21. Do you think patients will benefit from the use of AI? Is the use of AI better than current best practice for patient's experience of care?
22. Do you think patients should be able to opt out of having their data used for AI analysis? Why or why not?
23. The jury are very interested in the idea of a patient checklist or patient charter. Are there currently any advocacy organisations in Australia (or internationally) who could assist with making the AI consumer checklist more accessible? Are patient advocates dedicated health consumer not for profit advocacy groups – and how are they funded to ensure they can compete with the multinationals involved in marketing these tests and tools?
24. How have other countries increased the digital health literacy of patients and clinicians? In particular who is responsible and accountable for the digital health information provided (the patient, the clinician and/or the AI specialist?) How accessible is this information? How can digital health literacy be supported for a range of demographics and, in particular, a range of patient needs? Will this be the responsibility of clinicians? If we are discussing health literacy for any informed consent considerations, does this

include considerations of child participation in decision-making of health outcomes? How would this be addressed for those lacking capacity for autonomous decision-making of health outcomes?

5. Extra questions

5.1. UPGRADES, UPDATES, MAINTENANCE, INFRASTRUCTURE

1. Issue around the development of systems. We replace iphones etc. once every three years. The AI systems will need to be upgraded constantly. How will this impact on the AI. Given how much effort goes into approving the AI in the first place. System will need to cope with the updates and upgrades.
2. Post implementation phase, more neglected than the ideation, marketing phase. Needs to be a bit of balance. Few experts suggest more needs to be done more quickly or sooner post implementation to ensure things are working as intended. And not waiting too long for a review to identify that the AI is not working
3. If AI is not reliable/high performance, should it ever be autonomous?
4. Do we have the IT infrastructure to support implementation?

5.2. IMPACTS

5. Problem of loss of clinical skills – more about deskilling?

5.3. REGULATION AND OVERSIGHT

6. Are we really clear where the oversight is at a regulatory level. What organisations, establishments are we taking lead from. Who is policing. Who makes decision to pull an AI from the market.
7. Governance and regulation – is there anything in the regulatory frameworks that could overcome the challenges?
8. The group is seeking information about regulation of AI in Australia, what kind of regulation is needed in Australia, international organisation or cooperation ongoing? Use of AI and protection and safety of health data. What oversight is mandatory or voluntary?
9. Who should roll out these systems? The grand plan does not need to be 'Big Brother' – just need to ensure the investment going in drives home the needs of the community at a public health level. Ensure the benefits are available to everyone. Government supported by many organisations?
10. What control mechanisms will be placed around it to ensure it is development effective? Decentralisations of all AI – AI systems for specific tasks.

11. Still greyness around the governance – e.g. in finance you have a finance governing board that is responsible – e.g. to review data quality, if we're using third party is it safe and credible
12. Software legality – touches access, quality, whether a system helps or not
13. Would it be possible to make all diagnostic and screening AI open source with a public license? Would this address current problems with diagnostic and screening AI?
14. Who decides to implement in a given setting? Will this be based on developer data only?

5.4. SECURITY, PRIVACY, ETHICS

15. Cyber security systems may be an important area which as not been discussed as yet. What are the data security issues.
16. What are the major privacy and ethics issues?

5.5. MARKETS AND INTERESTS

17. Initial implementation. Appears technology is driven by big overseas companies. Will adopting overseas AI further bias use in Australia. Will there be any rules or regulations using data sets from other countries which may not be applicable to Australia
18. Who decides what we prioritise, what we should focus on, how we should proceed. Companies work on things that suit them. Creating solutions that suit their company needs. Where is the umbrella addressing of need – underserved groups, remote communities. In Australia we are adopters – just reacting, we should be proactive. Hopefully in the regulatory space there is a 'grand plan' for Australia's approach to AI.
19. Who is going to be benefited from all of these dollars?
20. The group is seeking information about whether there is one AI system being used by everyone, or each country or each company will be developing their own AI system.

5.6. ACCESS AND FAIRNESS

21. What part of the population will the AI be available too. Will the majority be able to afford, have access too. Is everyone going to have the chance to use these systems. Biggest concern about all AI systems.
22. Is there any research to suggest that AI has actually benefited marginalised groups?
23. Will recommendations be relevant to private healthcare or only public healthcare? How would public vs private work?
24. Performance – insight from someone who might have experienced AI directly

5.7. PATIENT INTERESTS

25. Is there a patient charter of rights?

5.8. RESEARCH

26. More information about the studies. Were they carried out in Australia. Who will be conducting them. Who will be in the studies. Will we have more studies conducted in Australia.
27. Barney – wants to know more about data – who decides what data exists and who decides what data is used?
28. Is the research all developers or is it independent and how is it being disseminated – how can an app be used if its performance is poor?
29. The group is seeking information about the presence of international bodies or standards that could collect data from all cultures or backgrounds; or any databank that contains information from different parts of the world that can be shared to AI developers to avoid bias.

5.9. RELEVANCE AND LOCAL APPLICABILITY

30. Can we have Australian technology for Australians.
31. What work is being done to ensure Australian AI research, development, implementation. And how can we support that.

5.10. PERSPECTIVES & COMPARISONS

32. Is there an example of end to end development and implementation in Australia that is documented and available?
33. Would like to see a SWOT analysis on AI, ranking risks – how to weigh up different risks and opportunities
34. What are the trade offs – who decides the trade offs – when are they dealt with – does the jury have to decide what trade offs are important? – to whom are these trade-offs put up? Will be a problem for performing the task in the jury without understanding the tradeoffs. Structure, conduct and performance of AI. Trade offs different at different levels/for different actors: patient, clinicians, health process, health management.
35. The group is seeking information about perspectives of clinicians and how they feel about the use or implementation of AI.
36. The group is seeking information about whether AI development and implementation takes into account the rural versus metropolitan context of population and health priorities.

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