

Artificial intelligence in health care: nothing about me without me

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The adoption of digital health has accelerated markedly in response to global health care challenges. One transformative technology is artificial intelligence (AI), particularly generative AI, such as ChatGPT. This step change suggests that we are experiencing a new industrial revolution, the data revolution.¹ Unlike the coal-powered industrial revolution, the resources for this revolution are the health-related data generated by patients and clinicians.¹ This disruption is understandably causing some anxiety. Our experiences of earlier major disruptive change will hopefully facilitate a more mature and thoughtful approach to this data-driven revolution, including amplifying the voice of people who receive health care, who have both the most to gain and the most to lose in this revolution.

In this issue of the *MJA*, Carter and colleagues² have taken a novel approach to this disruption, asking a citizens' jury to provide some guidance on the use of AI in health care. A citizens' jury attempts to improve the two most frequent approaches to policy change: top down, with little community consultation, and bottom up, with community special interest group consultation.³ The jury is assumed to represent the general population, but an acknowledged limitation is that its composition will be biased toward those willing to devote time to the activity, and it will exclude people who do not feel comfortable participating.

Another acknowledged challenge is the significant time, expense, and planning involved in convening a large, nationally representative citizens' jury. However, this effort could be considered an investment that achieves robust engagement and informed recommendations. A citizens' jury is much more empowering than traditional brief consultations, and even brief (single day) citizens' juries can deliver quality outcomes for policy and practice if the research question is appropriately defined.^{4,5}

Carter and colleagues² report that gathering the opinions of thirty Australians on this important topic resulted in a consensus statement including fifteen recommendations in ten categories. Perhaps surprisingly, they found that this diverse group welcomed the advent of AI in health care as a tool for overcoming the health system problems we are all experiencing. But this support comes with some important conditions. The jury recommended an independent national charter for AI in health. Other recommendations emphasised rigorous evaluation, fairness, and patient rights, clinical governance and training, technical and data requirements, and community education and involvement.²

The findings by Carter and colleagues² indicate that the public understand that doing nothing with regard to AI in health care is not an option and that we should proceed to accept it with

important caveats regarding governance and privacy. Enabling appropriate use of health care-derived data is important for improving outcomes, but so is maintaining privacy and ensuring that people retain control of their personal data. The essential components of doing so are:

- informed consent and transparency: clear and concise information about data use is provided each time data are accessed, and explicit and informed consent is obtained before collecting or sharing data;⁶
- granular consent and data sharing controls: allow people to specify the level of detail in their consent and enable them to control with whom their data can be shared (dynamic consent);⁷
- access and portability: ensure that people have easy access to their health data, and facilitate data portability between their health care providers;⁸
- data de-identification and anonymisation: robust de-identification techniques that protect privacy,⁹ including using synthetic data in appropriate cases;¹⁰
- education and empowerment: educate people about the importance of controlling their health care data, and empower them to make informed decisions about data sharing;¹¹
- regulatory compliance: ensure compliance with existing regulations, and advocate stronger privacy protection laws and regulations that allow safe sharing.¹²

In an ideal world, we would undertake these steps immediately, but it is not yet technically possible to do so beyond dedicated cohort studies. But we cannot wait. Balancing the risks and benefits of data-driven improvement in health care has been difficult without a clear understanding of public perceptions.

The findings of the citizens' jury reported by Carter and colleagues² are consistent with opinions expressed by the Australian Medical Association¹³ and NSW Health;¹⁴ in the United States, a presidential executive order has addressed the responsible use of AI in health care.¹⁵ The advent of AI in health care is here, and we need to proceed with both enthusiasm and caution.

Although the citizens' jury in the study by Carter and colleagues² was helpful, real value to the health system and the Australian public will require the timely and systematic implementation of its recommendations, which in turn will require ongoing, systematised input by the public. The technology is artificial intelligence, but the engagement of human beings must be genuine. As people and their data are the basis on which the AI revolution is built, it is critical that they help lead the change, and that we are guided by the principle: nothing about me without me.

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