Nothing about us without us

This issue of the *MJA* includes several articles that raise what it looks like to meaningfully involve consumers in health care discussions. The first is a research article (https://doi.org/10.5694/mja2.52283) that brings together two fascinating and topical issues in health care: artificial intelligence (AI) in health care and the involvement of the community in health care, in this case via a citizens' jury. In their article, Carter and colleagues describe the process and the outcome of citizen jury recommendations after being asked to consider this question "Under which circumstances, if any, should [AI] be used in Australian health systems to detect or diagnose disease?" As the authors note, "The aim of deliberative democratic methods, developed in political science and government, is to enhance democracy by involving communities in developing the laws or policies that affect them". The approach, however, is not without challenge — notably the inevitability of selection bias to the jury despite the best efforts of the researchers in recruiting jurors. The jury was larger than court juries, with 28 jurors participating in the process and final deliberations. Their deliberations produced a set of recommendations that included processes of evaluation, fairness, patients' rights, and technical requirements for AI in health care. These recommendations have relevance to a diverse group of people across the health system, from individual clinicians to health care organisations and service providers and patient representatives. As the authors note, the article shows it is possible to get meaningful public engagement: "Our study illustrates the feasibility of robust public engagement and deliberation for guiding AI development and implementation".

In their editorial on this research article (https://doi.org/10.5694/mja2.52282), Sullivan and Pointon note that this article provides evidence 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". They conclude that next steps "require the timely and systematic implementation of [the jury's] recommendations, which in turn will require ongoing, systematised input by the public" and that "the engagement of human beings must be genuine". This is a good reminder for everyone involved in health care innovation; we must be "guided by the principle: nothing about me without me".

In their ethics and law article (https://doi.org/10.5694/mja2.52254), Cormack and colleagues discuss the individual ramifications that can arise if consumer experiences and understanding are not at the forefront of patient care and counselling — specifically, how genomic testing is used and the need for counselling associated with it. They describe the challenges for a family in receiving information about, and then managing, the potential wide implications of the genetic cause of their child's seizures.

In their perspective article (https://doi.org/10.5694/mja2.52261), Rogers and colleagues ask if we are ready for Medicare-funded reproductive genetic carrier screening in Australia, noting that there are "no provisions in the Medicare rebate for pre- or post-test counselling". They highlight the importance of pre-test counselling, as in Cormack and colleagues' article, so that "Individuals should be given the opportunity to prepare for a clinically significant result, which may lead to complex decision making in a current or future pregnancy".

As genomic medicine becomes more widespread and complex innovations such as AI spread, these issues will become more common. All these articles reinforce that there are no shortcuts, nor should there be, to meaningful engagement of both individuals and whole communities in health care decisions. ■

Virginia Barbour

Editor-in-Chief, the *Medical Journal of Australia*,
Sydney, NSW.

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