

Insight and ACTION



PUBLIC ENGAGEMENT (PART I):* – ENGAGING THE PUBLIC IN HEALTHCARE POLICY: WHY DO IT? AND WHAT ARE THE CHALLENGES?

KEY MESSAGES

- The opinions and perspectives of the public play a valuable role in developing high-quality, evidence-informed policy guidance.
- Engaging the public in health policy decisions can increase the public's trust and confidence in their healthcare system.
- The public holds important health knowledge, but this knowledge should be applied carefully and appropriately, in line with the context and purpose of the decision in question.

"The legitimacy and sustainability of any major policy decision increasingly depends on how well it reflects the underlying values of the public."ⁱ

The development of evidence-informed healthcare policies relies heavily on the hierarchies of research and the technical know-how of experts. However, the experiences, opinions, and value preferences of patients, the general public and consumer advocates also play a legitimate and useful role,ⁱⁱ especially when difficult, value-laden decisions must be made.ⁱ

Why involve the public?

Health policy decisions are not cut and dried; they often go beyond weighing options of varying efficiency, effectiveness and other factors that may be demonstrated through research. These decisions sometimes involve trade-offs for which there is no research base, and may lead to different outcomes for different populations. One well-known example is the Oregon Health Plan. Two decades ago, in an effort to expand Medicaid enrolment, the state of Oregon began a process of rationing treatments for its Medicaid recipients. The process of defining what would be covered under Medicaid took place in the public eye, with various expert and community consultations, carried out by an 11-member health services commission comprised of professional and lay people.ⁱⁱⁱ Although the Oregon process has been criticized (for example, for being overly ambitious),^{iv} it was also considered a leading edge experiment, one that has sown the seeds for further public engagement in healthcare today.

Recently, researchers representing the *University of Toronto Priority Setting in Health Care Research Group* presented four reasons why engaging the public in setting healthcare priorities, in particular, has value: (1) the public is the most important stakeholder in the healthcare system; (2) engaging the public is in keeping with the principles of a democracy; (3) members of the public can provide insights on the values and priorities of their communities; and (4) engaging the public can lead to improved public trust and confidence in the healthcare system.^v The experiences of the 2001 Romanow Commission on the Future of Health Care in Canada demonstrate this value. Motivated by its mandate to reframe the healthcare contract, the Commission held 12 day-long dialogue sessions across the country, each with about 40 citizens representing cross-sections of the Canadian population (patients, taxpayers, and members of the community). For the participants, the consultations led to increased awareness of issues, which in turn led to greater acceptance of change. Participants' support for raising taxes to add more health resources, for example, increased from 48% to 61% overall.ⁱ For the Commission, the public dialogue substantially influenced its November 2002 report, aptly titled *Building on Values: the Future of Health Care*.

One area that has started to increase its use of public engagement is that of health technology assessments. HTAs – research that assesses the effectiveness of different healthcare treatments – are beginning to expand beyond a narrow interpretation of clinical effectiveness to include not only considerations of a technology's efficiency and safety, but also the impact on quality of life and patient satisfaction.^{vi} As the scope of this research grows, there is an increasing need to engage the public, particularly seeking their values, as these play a fundamental role in informing coverage recommendations.^{vii} In the United Kingdom, the *National Institute for Health and Clinical Excellence* allows members of public and stakeholder groups to become involved in reviewing specific technologies.^{viii} This initiative is designed to ensure that citizen perspectives are heard as part of the review process, while also allowing citizens to identify gaps in the available evidence or flaws in its interpretation.ⁱⁱ

Challenges and solutions

Researchers have mitigated a number of barriers to pursuing greater public involvement.^v One of the difficulties in incorporating the perspectives of the public is that the term “perspectives” covers a wide range of views – from a single person's claim that a treatment works, to more substantial exercises that engage a patient or the public and include the views of many people. Rather than relying solely on the testimony of one person or a small group, which can potentially introduce bias, preference should be given to approaches that systematically incorporate the perspectives of many people. Another concern is that participants' knowledge could inappropriately outweigh other types of evidence such as clinical trial and research data.^{ix} To help allay these concerns and those related to bias, systematic reviews of evidence should include high-quality qualitative research studies, as they allow for a more rigorous analysis of patient experiences.^x

Yet another challenge comes in choosing between the methods available for engaging the public - surveys and polls, interviews, focus groups, open houses, and public meetings are all well-known strategies for engaging members of the public. One strategy that is increasingly relied on in the health sector is deliberative processes.* Each of these methods has a different financial cost; the total bill for the

Romanow Commission's consultations, for example, was an estimated \$1.3 million.ⁱ Although more costly than polling, engaging the public in dialogue is essential when decisions require value-laden judgments. Regardless of the strategy used, however, it is important to establish guidelines at the beginning of the exercise for how personal testimonies and other forms of participant knowledge are to be included.

Conclusion

Any policy question can be answered without input from the general public or patients, but the idea behind seeking this kind of input is that the way in which the question is addressed can lead to more sound and considered policy. That said, the perspectives of the public must be incorporated in a way that does not undermine the original intent, which is to provide policy guidance based on consideration of all the relevant evidence. In the same way, public opinion should be sought in ways that are appropriate to the context and purpose of the decision in question.

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Further Reading

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