

# Engaging patients and the public with health care evidence

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At a time when public health agencies and health care providers are striving to make health care and health policy decisions on the basis of evidence, it is important for patients and the public to engage with the production, consumption and evaluation of evidence too. But such engagement is challenging, write Hastings Center scholars in the April issue of *Health Affairs*, because "evidence alone is never definitive." People will prioritize different values, and weigh risks and benefits differently.

The article, "The Ethical Imperative and Moral Challenge of Engaging Patients and the Public with Evidence," recommends ways to manage such conflicts. It is written by Mildred Z. Solomon, president of The Hastings Center, and research scholars Michael K. Gusmano and Karen J. Maschke.

They offer five ethical reasons for there to be transparent [public](#) dialogue about [evidence](#): to respect persons and provide for meaningful informed consent, to achieve better [health](#) outcomes, to support effective stewardship of public resources, to enhance the just distribution of the benefits gained from health care and health research, and to build public trust.

But accepting the ethical reasons for patient and public engagement with evidence "is only the first step," the authors write. "The moral landscape is far more complicated. Public engagement with evidence may fail to be an important route to sound public policy unless those complexities are anticipated and managed."

They outline value conflicts likely to emerge in five settings: clinical care, [health care organizations](#), public health, regulation, and among payers.

In clinical care, for example, along with evidence about effectiveness and risk, treatment choice is, and should be, influenced by a patient's values and preferences, including which benefits are deemed

worthy of the potential risks. In [public health](#), value conflicts often involve "tension between the desire to maximize personal choice and the desire to maximize community well-being," the article states. "Examples include campaigns to reduce the sale of sugary drinks and helmet laws that infringe on motorcyclists' liberty but save lives and reduce community [health care](#) costs."

The article proposes strategies for managing values conflicts in each of the five settings and concludes with three cross-cutting recommendations for navigating moral challenges that can arise from patient and [public engagement](#) with evidence:

- Advance community-based participatory research. With this kind of research, patients, family members, and community representatives would help identify worthy research and work with investigators in collecting, analyzing, and interpreting findings. "This is an ideal way to engage the public, helps ensure that research meets community priorities, and builds trustworthy research that communities can believe in."
- Facilitate patient and community involvement in the governance of learning health systems. Learning health systems collect data at the point of care to learn how to improve the value of their services. Patient and community involvement could include "decisions about which issues should be studied, what kind of oversight is needed, and how soon to put findings into practice."
- Gather and use evidence about cost as well as quality. The authors acknowledge that there is little support for considering costs in reimbursement decisions. "Indeed, the strong focus on a patient-centered ethic often obscures the consequences of spending money on high cost technologies that may not provide high value," they write.

One way they suggest to get public buy-in for the importance of considering costs is to involve patients and the public in technology assessment activities, including considering the impact of adopting unproven or marginally beneficial technologies on community resources and community wellbeing.

Provided by The Hastings Center

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