The need for public engagement in choosing health priorities

Arguably the biggest threat to our public health care system is not our ability to pay for the increasing cost of care, but rather a loss of public confidence. In Canada, numerous government reports and royal commissions dating back to the early 1970s have called for increased public engagement as a way to rejuvenate health reform and restore confidence.

Unfortunately, quite the opposite has occurred. Successful examples of public engagement in Canada’s health system are few. Political leaders too often appear to base decisions on the views of special interest groups aligned with their political interests or ideology. At the federal level, government departments cannot even conduct the least effective forms of public engagement—public opinion polls and focus groups—without ministerial approval. Despite extensive stakeholder engagement frameworks, few strategies for public input have been implemented at major agencies that award funds for research, recommend expensive drugs and vaccines, or set major health priorities.

Worse yet, there is evidence of neglect of public input. For instance, the Royal Commission led by Romanow held extensive public consultations only to have its report mothballed.1 There has even been political interference in peer review processes involving public or expert input. As federal Minister of Health, Tony Clement completely disregarded a panel’s advice in appointing the Board of Assisted Human Reproduction Canada, a government body dealing with morally sensitive issues that should be open to public debate rather than secret deliberations.2 Similarly, federal Finance Minister Jim Flaherty bypassed peer review to award moneys to specific research institutes.3

Public engagement does not mean running health care systems by opinion polls or focus groups. It does not mean making decisions based solely on lobby efforts of self-interested individuals who want privileged access to expensive procedures or medications. It does mean carefully choosing committed and broadly representative members of the general public, providing them with all essential evidence, finding ways to adequately represent marginalized citizens, eliciting values and expectations from participants and receiving clear guidance from them. Committees formed in this manner, such as citizen councils and public advisory bodies, not only weigh evidence but also contextualize its merits.

There are some positive examples of public engagement at the provincial and regional levels. The Government of Alberta has just completed four months of public consultations on what should be included in a new Alberta Health Act. These deliberations are serving as the basis of the provincial government’s new strategic plan for revamping its health care system. Politicians in Quebec are holding public hearings to clarify the public’s view on the morally difficult question of what options should be available to patients at the end of life. Some regional health authorities have actively engaged communities in strategic planning and prioritizing services. Still, there are opportunities for much more to be done, even at the local level.

One might legitimately ask why leaders have failed to act despite repeated public demands for greater involvement. Reasons offered will invariably include poor or negative experiences with public consultations, the belief that the lay public cannot grasp complex issues, the perceived loss of influence in decision-making, and the time and costs needed for effective public engagement. There is also a lack of rigorous evaluations demonstrating that public participation exercises lead to better decisions. Despite excuses and real barriers, there are numerous examples—such as the public’s involvement with the National Institute for Health and Clinical Excellence (NICE) in England—that show that the public can contribute to making difficult health care decisions.4 Institutions that have chosen to implement engagement strategies talk about improved relationships with the communities they serve.

If we are to embrace substantial public involvement, a genuine commitment is needed from our health leadership. Federal, provincial and territorial health ministers should articulate expectations for public engagement throughout the system and be prepared to allocate sufficient resources to sustain engagement activities.

As a start, greater public engagement should be introduced into federal–provincial–territorial committees, particularly around issues relating to the funding of and limits on our health care system. At a minimum, agencies like the Canadian Institutes of Health Research and the Canadian Agency for Drugs and Technologies in Health should have standing citizen councils and public voices on peer review panels.

At a time when the sustainability of our health care system is often debated, increasing the transparency and perceived legitimacy of funding and major priority decisions at all levels should be a foremost concern for our health care leaders. Providing more opportunities for public involvement and clearly reporting how input is used would reduce public cynicism. More important, we would add a legitimate new voice—that of the public—to aid in making difficult choices.

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