

Public engagement in cancer control in Canada

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By informing the public about relevant and timely issues as well as facilitating public input in policy development, public engagement in cancer control – as with many areas of health care – can increase the fairness and legitimacy of decisions and policies made by public officials. Equally important, public engagement holds policy makers accountable to the wider public for their decisions that are supposed to serve the public's interests. In these ways it enhances accountability for reasonableness¹. While the ultimate goal of public engagement in health care is to keep citizens' values, preferences and priorities reflected in what is essentially 'their' healthcare system², engagement specifically in the area of cancer control fosters education on cancer prevention while simultaneously involving the public in processes of improving cancer care delivery³, research⁴ and policy⁵. One clear example where public engagement has impacted health care guidance, is regarding patient information and choice in screening technologies for the early detection of colorectal cancer in Ontario⁶.

Unfortunately, much of the literature published to date on public engagement relates to other domains of health care, and little is known about the Canadian public's values concerning cancer and its care, including those around different cancer interventions, outcomes from these interventions and how resources should be distributed among the population at need. In Canada, cancer affects approximately 45% of men and 39% of women, with about one in four individuals dying from the disease⁷. The recent paradigm shift in science and medicine towards personalized care, especially in regards to cancer treatment⁸, together with greater consumerism and patients wanting options around treatment⁹ brings new economic concerns to the sustainability of cancer care, as well as ethical concerns associated with biobanking and treatment allocation. For

example, many new pharmaceuticals and treatments are being developed for specific groups of patients and public funding limitations raise concerns about access to innovative and potentially beneficial treatments. Cancer drugs and biologics alone now occupy 30% of provincial cancer budgets, and "the annual growth rate of oncology drug sales is roughly double that of the overall pharmaceutical market."⁷ Recognizing that limited resources require hard choices to be made by authorities, public engagement could assist in the setting of difficult priorities¹⁰ for cancer control¹¹, thereby helping to legitimize the deliberation or decision process utilized for making fiscal decisions.

In order to reduce the burden of cancer on the Canadian population, cancer must be controlled at the intersection of public health and health policy. From prevention, treatment and the pursuit of a cure for cancer to survivorship, public engagement can contribute to better policy development. Regarding cancer prevention, an effective public engagement process that is broad and transparent in nature would not only increase the likelihood of public opinion influencing policy making, but would also support education of the public at large, equipping citizens with appropriate information to improve their collective health. Since there is often a chronicity to cancer that arises from several co-morbid conditions, such as heart disease and chronic obstructive pulmonary disease, an ideal strategy may be to take lessons learned from a public health-chronic disease perspective and apply them to public engagement in cancer prevention and control as more literature is generally available on public involvement in chronic disease. Moreover, although cancer is unique in many of its causal pathways, several risk factors overlap with other diseases, opening up opportunities for transfer of education, policy and public opinion across conditions. For instance, the genetic components of cancer prompt

important questions around newborn screening, adult predictive genetic testing¹², etc., which comprise more general policy issues that span across medical conditions. Public engagement would also act to elicit consumer and patient preferences in terms of the diagnosis and treatment of cancer, identifying technologies¹³, interventions and resource allocation models considered useful and appropriate by the public. This engagement could be employed to make similar prioritizations in cancer research and to plan the direction of future research agendas. Finally, with the goal of improving life with and after cancer, survivors should be included as active participants in the public engagement process. With a wealth of first-hand knowledge and insight into the cancer experience within the Canadian healthcare system, they have a unique opportunity to advise on health services that would be more responsive to the needs of future cancer patients.

Policy makers want to involve citizens in the decisions that affect them¹⁴, but often do not know how to do so effectively. The positive trend in public engagement towards the use of deliberative methods (e.g. citizens councils, Deliberative Polling®) and more dialogue with the public versus one-way elicitation of public views¹⁵, does not seem to be utilized in cancer control. If public engagement is primarily operating to improve the fairness and legitimacy of health care decision-making and policy, perhaps its effectiveness should be measured by the accountability for reasonableness framework¹. Furthermore, public engagement could advance public health education efforts in addition to ensuring health services embody the values, preferences and expectations of both consumers and patients.

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Author Profile

Recently, Michelle successfully defended her M.Sc. thesis at the Institute of Medical Science on public engagement in health policy under Dr. Ross Upshur's supervision. In her program, she also completed the Collaborative Program in Bioethics at the Joint Centre for Bioethics. She is currently working with Drs. Jennifer Gibson and Stuart Peacock at the Canadian Centre for Applied Research in Cancer Control on 'Setting research priorities for public engagement in cancer control: A national workshop' through a CIHR MPD grant.