

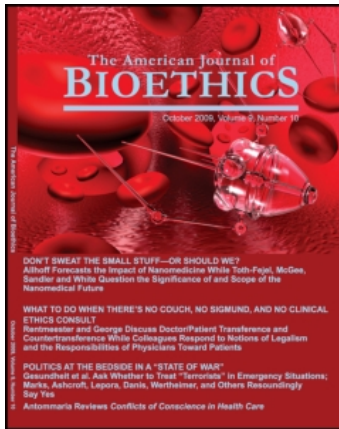
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Public Engagement on Social Distancing in a Pandemic: A Canadian Perspective

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Open Peer Commentaries

Public Engagement on Social Distancing in a Pandemic: A Canadian Perspective

Joint Centre for Bioethics Pandemic Ethics Working Group, University of Toronto

We concur with Baum and colleagues (2009) on the importance of pandemic planners taking explicit steps to employ public engagement methodologies. Thus far, as Baum and colleagues note, there have been few published reports of such engagement. Most public engagement has been carried out by academic researchers. Our group at the University of Toronto Joint Centre for Bioethics (JCB) is conducting similar research to Baum and colleagues, engaging the Canadian public in regard to their perceptions of the ethics of pandemic planning and response, through various methodologies including a national telephone survey, town hall forums and qualitative interviews with stakeholders. In our preliminary results, our data closely aligns with Baum and colleagues' findings; however, differences in the political and health care traditions between the United States and Canada may account for key differences in the trust the public has for its government's pandemic planning and response strategies.

WHY ENGAGE THE PUBLIC?

There may be many good reasons to engage the public on policy issues within a democracy. Some reasons will be intrinsic to democratic institutions and procedures, trusting the wisdom of the public and maintaining that engaging their views is an important part of attaining substantively just outcomes. Other reasons will be instrumental, in which public engagement is means to obtaining independently valuable outcomes, e.g., compliance, relationship building, affirmation of citizen perspectives, etc.

One important instrumental reason for public engagement on pandemic preparedness and response planning is public justification legitimacy. It is a form of legitimacy that,

according to Trotter (2007), "results from a process in which proposed interventions and their rationale are properly discussed, articulated, marketed, explained, or otherwise brought to life before the general public" (30). The prospect of a pandemic presents significant ethical challenges for policy-makers, clinicians, and the public in Canada and elsewhere. The values that underpin the decisions taken in preparing for and responding to a pandemic require political justification and engaging the public on these values will form one component of ensuring the measures undertaken to protect public health are legitimate.

The University of Toronto JCB (2005) produced a report building, in part, on the experiences of employing restrictive measures during severe acute respiratory syndrome (SARS), which outlined a framework of values for inclusion in pandemic plans. The framework itself was derived by expert reflection and, at the time of development, it was unknown to what extent the proposed values identified in the framework would be endorsed by the Canadian public. Public engagement was considered an important next step in further refining and testing this framework. Research has indicated that the public can, under the right conditions and using appropriate methodologies, make coherent and sophisticated contributions relevant to the policy-making process. Public engagement also has the potential feature of enhancing accountability, especially in government decision-making and has been argued extensively to improve the legitimacy of decisions taken. Furthermore, this type of engagement offers opportunities to elicit perspectives from First Nations and spiritual communities by participating in communication within diverse populations (Faust et al. 2009).

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PUBLIC ENGAGEMENT ON RESTRICTIVE MEASURES

In what follows, we present results from our research involving public engagement undertaken in order to evaluate the conclusions derived from the framework and how it compared with the results presented by Baum and colleagues (2009).

Town Hall

In order to engage the public in pandemic planning processes, the University of Toronto JCB organized pandemic town hall forums in Vancouver, Winnipeg, and Saint John; three geographically distinct areas of Canada. These day-long town halls were similar to the focus groups carried out by Baum and colleagues (2009). The goal of these forums was to assemble members of the general public and facilitate a discussion of their perspectives on pandemic preparedness. Participants split into small breakout groups and were presented with scenarios related to ethical issues that could arise in an influenza pandemic. In the restrictive measures group, participants were asked to consider a case study that detailed a recently immigrated family's struggle to adhere to social-distancing recommendations.

Many of the key themes that emerged from these discussions are similar to those described in Baum and colleagues (2009). Participants in both studies shared concerns about the threats posed by restrictive measures to job security and economic stability. They emphasized that those in quarantine must be assured that they will not be unnecessarily penalized—e.g., losing a job—for following quarantine orders. Furthermore, participants generally agreed that society as a whole has the obligation to provide social and material support to persons subjected to restrictive measures (e.g., providing essential goods and services). One participant noted, "For me this raises a question of interactive societal responsibility, so if society deems it necessary for [a person] to stay at home to protect society from the spread of infection by advising him of quarantine, then society must, in turn, be responsible to [that person] to ensure he is well provided for and will not suffer the results of his patriotic duty" (personal communication, town hall forum participant, 14). This supports arguments such as those advanced by Holm (2009) on the justification for compensating those who are subject to detention.

Participants in the University of Toronto JCB's town halls and in Baum and colleagues' focus groups both recognized the public's right to have its health protected by use of appropriate restrictive measures when necessary. Town hall participants were broadly supportive of quarantine, provided it is applied equitably and there are support mechanisms in place. It was also mentioned in a town hall that instead of employing a punitive model for quarantine non-compliance, compliance should be encouraged and addressed proactively. Furthermore, in both studies, participants showed strong support for public input in pandemic planning. The theme of communication also emerged in both studies as many participants stressed the fact that

clear communication of vital information is critical for compliance and trust. Additionally, town hall participants emphasized that communication ought to be delivered through various channels and in multiple languages.

National Telephone Survey

Results from our telephone survey indicate consensus on several key ethical challenges, with strong support for the legitimacy of restrictive measures providing that restricted individuals receive support.

We found that a strong majority of respondents favored governmental power to order quarantines and suspend rights of individuals (e.g., travel, assembly) during outbreaks (85%), providing those quarantined had basic needs (e.g., food, shelter, social support) adequately met (95%) and support services after the quarantine ended (79%). This advocacy of governmental power extended to international authorities advising against travel to outbreak areas to stop a pandemic spread, even when the consequences included serious economic loss (97%). These results are indicative of an enhanced public trust in government that is lacking in Baum and colleagues' results. This may reflect the political culture of Canada, rooted in the concepts of peace, order, and good government.

Respondents were of the view that violating a quarantine order was a serious offence, with 50% reporting it equivalent to manslaughter. These results indicate that Canadians regard restrictive measures as important and legitimate means to address a pandemic threat.

PUBLIC ENGAGEMENT AND TRUST

The findings from our research and that of Baum and colleagues reinforce the importance of reciprocity as an important value in pandemic response (Viens et al. 2009). The research findings also point out significant willingness of citizens to play active roles in pandemic planning, and an appreciation of the value of community mindedness in response to a collective threat.

Much work remains for public engagement to become integrated into pandemic response. Currently it seems to be an academic enterprise with little traction in government or policy sectors. The sense of distrust of government identified by Baum and colleagues could perhaps be mitigated if pandemic planners more fully engaged and incorporated the findings of public engagement on ethically charged issues, such as the use of restrictive measures into pandemic plans.

Our research team plans to continue research into optimal models and methods of public engagement. There are many unanswered questions regarding the methodology of public engagement and how best to weigh qualitative, quantitative and normative considerations. One of the key goals of the Canadian Program of Research on Ethics in a Pandemic (available at: www.CanPREP.ca) has been to determine the aims, benefits and outcomes of public engagement. Of particular salience in comparing the data between the United States and Canadian studies is public

engagement's influence on policy—especially with respect to reflecting or supporting the values held by the public, and how the reactions of public health authorities and policy-makers bears on the public's trust. We hope public engagement in pandemic preparedness and response moves out of the academic realm and is embraced by planners. With the H1N1 pandemic upon us, the window of opportunity for engagement is surely limited, and thus a high priority. ■

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Listen! The Value of Public Engagement in Pandemic Ethics

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We commend Baum and colleagues (2009) for undertaking a much-needed exploratory examination of public opinion concerning social distancing during a pandemic. We concur with Baum and colleagues and Gostin (2009) that ethical issues in preparing for and responding to pandemic influenza are ripe for public deliberation.

Compared to the robust literature on clinical and research ethics generally, the body of ethics literature on infectious diseases and public health disasters is smaller and less developed, though growing rapidly. Ethical issues in planning for and responding to an influenza pandemic are at the intersection of these less explored topics in the literature. Few pandemic plans in this country explicitly offer robust ethical guidance (Prehn and Vawter 2008). Among those that do, the wide range of guidance should not be surprising, for the simple fact that pandemics—especially

severe ones—raise weighty and unusual questions of public health ethics, the answers to which are not obvious.

While some common themes—such as commitments to openness and transparency—are emerging, there are important substantive differences in ethical guidance to date. As the substance of ethical guidance varies, so has the method by which that guidance has been developed. Some jurisdictions have offered guidance based on what could be called an “expert” model, in which one or two ethicists are consulted on the ethical propriety of draft guidance. In contrast, others have employed public engagement to varying degrees and with different purposes and methods (Prehn and Vawter 2008).

The range of possible public engagement activities can be thought of on a continuum. Some seek simply to educate and inform the public about a particular policy issue, while

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