

## **FURTHER RESOURCES ON COMMUNITY ENGAGEMENT IN HEALTH PLANNING**

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Ontario is undertaking significant reforms of its health care system by implementing Local Health Integration Networks (LHINs) and developing a new overall health strategy. Community engagement is seen as a crucial element of these and other reforms. How can community members be involved in developing strategic priorities and planning? Below is a selection of articles and reports on approaches used throughout the world.

### **Selected Annotated Resource List**

Abelson, J. 2001. Understanding the role of contextual influences on local health-care decision making: case study results from Ontario, Canada. *Social Science and Medicine* 53, 777-793.

Abstract: Approaches to involving the public in local health care decision making processes (and analyses of these approaches) have tended to treat participation and publics uniformly in search of the ideal method of involving the public or providing the same opportunities for public participation regardless of differing socio-economic, cultural, institutional, or political contexts within which decisions are made. Less attention has been given to the potential for various contextual factors to influence both the methods employed and the outcomes of such community decision-making processes. The paper explores the role that context (three sets of contextual influences more specifically) plays in shaping community decision-making processes. Results from case studies of public participation in local health-care decision making in four geographic communities in Ontario are presented. During the study period, two of these communities were actively involved in health services restructuring processes while one had recently completed its process and the fourth had not yet engaged in one. Several themes emerge from the case studies regarding the identification and role of contextual influences in differentially shaping participation in local health care decision-making. These include the propensity for communities with different social

and structural attributes to engage in different “styles” of participation; the importance attached to “community values” in shaping both the qualitative and quantitative aspects of participation; the role of health councils, local government, and inter-organizational collaboration as participation “enablers”; and the politicization of participation that occurs around contentious issues such as hospital closures.

Annotation: This is one of the few articles of the ones reviewed here that focuses on contextual or structural facilitators and constraints on public participation in health care decision-making. It speaks to the differences in the “publics” and their social contexts that mediate if participation will happen, what it will look like, and whether it works. Still, while it begins to look at how particular “community” characteristics impact upon participation efforts it fails to adequately discuss how historically unheard and/or ignored communities can participate in setting health care decisions.

Abelson, J., et al. 2003. Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science and Medicine* 57, 239-251.

Abstract: A common thread weaving through the current public participation debate is the need for new approaches that emphasize two-way interaction between decision makers and the public as well as deliberation among participants. Increasingly complex decision making processes require a more informed citizenry that has weighed the evidence on the issue, discussed and debated potential decision options and arrived at a mutually agreed upon decision or at least one by which all parties can abide. We explore the recent fascination with deliberative methods for public involvement first by examining their origins within democratic theory, and then by focusing on the experiences with deliberative methods within the health sector. In doing so, we answer the following questions “What are deliberative methods and why have they become so popular? What are their potential contributions to the health sector?” We use this critical review of the literature as the basis for developing general principles that can be used to guide the design and evaluation of public involvement processes for the health-care sector in particular.

Annotation: This is a good overview of public participation approaches used, including their theoretical underpinnings and practical implications.

Abelson, J., et al. 2002. Obtaining public input for health-systems decision-making: past experiences and future prospects. *Canadian Public Administration* 45, no. 1:70-97.

Abstract: Interest in finding more effective methods for public involvement in decision-making about health systems is more widespread than ever in

Canada since significant aspects of health-care decision-making were devolved from provincial governments to regional health authorities. Involving the public can be risky business, however, as the accountability and legitimacy of decisions made by governing authorities are often assessed against the nature and degree of interaction that occurs with the public. Consequently, decision-makers in a variety of policy domains routinely struggle with questions about when it is appropriate to involve the public, what the most effective means are for doing this, and how to measure their success. The authors analyzed these issues by documenting the experiences of health-systems decision-makers in two Canadian provinces (Ontario and Quebec) with public consultation and participation over the past decade. Their findings illustrate that despite the different roles and responsibilities held by Ontario and Quebec decision-makers, decisions to consult with their communities are driven by the same basic set of objectives: to obtain information from and to provide information to the community; to ensure fair, transparent and legitimate decision-making processes; and to garner support for their outcomes. Decision-makers also acknowledged the need to rethink approaches for involving the public in decision-making processes in response to the perceived failure of past public participation and consultation processes. While these experiences have clearly left some participation practitioners feeling beleaguered, many are approaching future community consultation processes optimistically with plans for more focused, purposeful consultations that have clear objectives and more formal evaluation tinged with a healthy dose of pragmatism.

Annotation: This is a decent, though academic, overview of public participation efforts in Ontario since the 1990s.

Abelson, Julia, et al. February 2004. *Toward more meaningful, informed, and effective public consultation*. Ottawa: Canadian Health Services Research Foundation.

Abstract: Approaches to public involvement can yield productive, long-term, trusting relationships between citizens and decision makers if they satisfy the following criteria: 1) clear communication about the purpose of the consultation and its relationship to the larger decision-making process; 2) identifiable links between the consultation and the decision outcome; 3) information presented clearly, honestly, and with integrity; 4) procedural rules that promote power and information sharing among and between participants and decision makers; and 5) processes that are viewed as legitimate by citizens and decision makers. Substantial organizational commitment and resources are required to successfully integrate the above criteria into public involvement processes. Public involvement approaches that emphasize the principles of deliberation are more effectively applied when a range of concrete decision-making options is being considered;

when there are clear links between the consultation and the decision it is designed to inform; and when the time period between the consultation and the decision it is to inform is relatively short. Challenges to the process and outcomes of informed, effective, and meaningful public involvement within regional health authorities include: provincial and local experiences with past public consultations; organizational environment and receptivity to public involvement approaches; and characteristics of the consultation issue and decision-making context. Credible, neutral, third-party facilitators, in conjunction with content experts, should be used as much as possible to build trust among participants and decision makers. Three key “information obstacles” must be overcome by citizens and decision makers to achieve more informed, effective, and meaningful public participation: 1) address citizen concerns about the adequacy and quality of information; 2) address decision makers’ concerns about sharing information and the constraints that apply to this process; and 3) recognize public participants’ experiential knowledge as an information source.

Annotation: This report provides empirically-grounded guidelines for developing public participation approaches. The case studies that informed the guidelines are Canadian, including one in Ontario (Hamilton DHC).

Calgary Health Region. March 2002. *Public Participation Framework*. Calgary: Calgary Health Region.

Abstract: In 1998, the Board, through the former Community Affairs Committee, called for the development of a framework that would outline the values, operating principles and opportunities for public participation, subsequently defined as “the process by which public concerns, needs and values are incorporated into governmental decision making”. The framework was developed over the next year and was validated through a broadly consultative process over 2000-2001 fiscal year. The Calgary Health Region actively engages in information exchange with the citizens it serves, the purpose of which falls along a continuum of involvement; from informing the public of decisions taken (one way messaging with no involvement) through consultation (an interactive exchange of information which informs decision making) to partnership, and potentially limited delegation of decision making (very high involvement). The Framework focuses on the higher levels of involvement and provides a statement of values and guiding principles to support engagement of the public. It is expected that adoption of the Public Participation Framework will support the CHR in achieving a number of aims, including: informing and educating participants; incorporating public values, assumptions and preferences into decision making; increasing the substantive value of decisions; fostering trust in the CHR; reducing conflict among stakeholders; and enhancing cost-effective decision making. Opportunities for participation are listed for the critical functions of the Board,

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Senior Management, operating divisions and direct care providers. Finally, four steps are suggested for the use of the framework, supported by questions to guide the way: 1) Determine if the issue is consistent with the framework; 2) Determine if a public participation process is warranted; 3) Develop a detailed plan; 4) Seek approval.

Annotation: This framework used by the Calgary Health Region has been implemented and provides a concrete example of a regionally-based public engagement strategy.

Frankish, C. J., et al. 2002. Challenges of citizen participation in regional health authorities. *Social Science and Medicine* 54, 1471-1480.

Abstract: Citizen participation has been included as part of health reform, often in the form of lay health authorities. In Canada, these authorities are variously known as regional health boards or councils. A set of challenges is associated with citizen participation in regional health authorities. These challenges relate to: differences in opinion about whether there should be citizen participation at all; differences in perception of the levels and processes of participation; differences in opinion with respect to the roles and responsibilities of health authority members; differences in opinion about the appropriate composition of the authorities; differences in opinion about the requisite skills and attributes of health authority members; having a good support base (staff, good information, board development); understanding and operationalizing various roles of the board (governance and policy setting) versus the board staff (management and administration); difficulties in ensuring the accountability of the health authorities; and measuring the results of the work and decisions of the health authorities. Despite these challenges, regional health authorities are gaining support as both theoretically sound and pragmatically based approaches to health-system reform. This review of the above challenges suggests that each of the concerns remains a significant threat to meaningful public participation.

Annotation: These are the standard challenges presented in several articles and reports, though they do not address issues pertaining to the participation of marginalized communities.

Kashefi, E., and M. Mort. 2004. Grounded citizens' juries: a tool for health activism? *Health Expectations* 7, 290-302.

Abstract: Involving the public in decision-making has become a bureaucratic pre-occupation for every health agency in the UK. In this paper we offer an innovative approach for local participation in health decision-making through the development of a 'grounded' citizens' jury. We describe the process of one such jury commissioned by a Primary Care Group in the north-west of England, which was located in an area suffering intractable health

inequalities. Twelve local people aged between 17 and 70 were recruited to come together for a week to hear evidence, ask questions and debate what they felt would improve the health and well-being of people living in the area. The jury process acted effectively as a grass-roots health needs assessment and amongst other outcomes, resulted in the setting up of a community health centre run by a board consisting of members of the community (including two jurors) together with local agencies. The methodology described here contrasts with that practiced by what we term 'the consultation industry', which is primarily interested in the use of fixed models to generate the public view as a standardized output, a product, developed to serve the needs of an established policy process, with little interest in effecting change. We outline four principles underpinning our approach: deliberation, integration, sustainability and accountability. We argue that citizen's juries and other consultation initiatives need to be reclaimed from that which merely serves the policy process and become 'grounded', a tool for activism, in which local people are agents in the development of policies affecting their lives.

Annotation: This article describes a specific case of public engagement with a marginalized community. It suggests measures to ensure that the engagement is genuine and grounded in the needs of the community itself.

Maloff, B., D. Bilan, and W. Thurston. 2000. Enhancing public input into decision making: development of the Calgary Regional Health Authority Public Participation Framework. *Family and Community Health* 23, no. 1:66-78.

Abstract: Public participation in shaping policy and decision that affect health is receiving increased attention. In the health sector, an imbalance exists between theory and practice. This article describes the development of a framework to promote public and community participation in one urban health authority, including the components of the public participation framework of purpose, values, guiding principles, and expected outcomes. A list of participation activities within the authority was obtained by survey. These activities are presented in relation to the conceptual framework. The article concludes with a series of recommended steps for applying the framework.

Annotation: This is the scholarly supplement to the Calgary Health Region Public Participation Framework piece above.

Martin, D., J. Abelson, and P. Singer. 2002. Participation in health care priority-setting through the eyes of the participants. *Journal of Health Services Research & Policy* 7, no. 4:222-229.

Abstract: *Objectives:* The literature on participation in priority-setting has three key gaps: it focuses on techniques for obtaining public input into

priority-setting that are consultative mechanisms and do not involve the public directly in decision-making; it focuses primarily on the public's role in priority-setting, not on all potential participants; and the range of roles that various participants play in a group making priority decisions has not been described. To begin addressing these gaps, we interviewed individuals who participated on two priority-setting committees to identify key insights from participants about participation. *Methods:* A qualitative study consisting of interviews with decision-makers, including patients and members of the public. *Results:* members of the public can contribute directly to important aspects of priority-setting. The participants described six specific priority-setting roles: committee chair, administrator, medical specialist, medical generalist, public representative and patient representative. They also described the contributions of each role to priority-setting. *Conclusions:* Using the insights from decision-makers, we have described lessons related to direct involvement of members of the public and patients in priority-setting, and have identified six roles and the contribution of each role.

Annotation: This article attempts to provide insights on public participation processes from the perspectives of process participants. While it is relatively unique in this regard, it fails to discuss two important questions: whose perspectives are we missing and why?

Quantz, D., and W. E. Thurston. 2006. Representation strategies in public participation in health policy: The Aboriginal Community Health Council. *Health Policy* 75, 243-250.

Abstract: Within Canada's Aboriginal population, an ongoing health promotion strategy has been the facilitation of community participation in the development and application of health policy. The Calgary Health Region's Aboriginal Community Health Council has provided a setting for involving the local Aboriginal population in health policy and program development for over a decade. This paper represents the results of a case study to identify the Council's strategies for this work. Data sources included documents, such as meeting minutes and other reports; key informant interviews with past and present Council members and health region representatives; and participant observation of Council functions. Although direct membership in the Council provided a cores approach for representing the community, other strategies were actively utilized to involve the public. These included building links and partnerships with community organizations, networking, consultation activities and the identification of special needs groups.

Annotation: This is an example of a relatively longstanding public participation mechanism involving a traditionally marginalized community in Canada. The article documents the challenges faced in the process and the strategies used to attempt to overcome them. All this is within the context of a regional health authority.

Thurston, W., et al. 2005. Public participation in regional health policy: a theoretical framework. *Health Policy* 73, 237-252.

Abstract: How best to involve the public in local health policy development and decision-making is an ongoing challenge for health systems. In the current literature on this topic, there is discussion of the lack of rigorous evaluations upon which to draw generalizable conclusions about what public participation methods work best and for what kinds of outcomes. We believe that for evaluation research on public participation to build generalizable claims, some consistency in theoretical framework is needed. A major objective of the research reported on here was to develop such a theoretical framework for understanding public participation in the context of regionalized health governance. The overall research design followed the grounded theory tradition, and included five case studies of public participation initiatives in an urban regional health authority in Canada, as well as a postal survey of community organizations. This particular article describes the theoretical framework developed, with an emphasis on explaining the following major components of the framework: public participation initiatives as a process; policy making processes with a health region; social context as symbolic and political institutions; policy communities; and health of the population as the ultimate outcome of public participation. We believe that this framework is a good beginning to making more explicit the factors that may be considered when evaluating both the processes and outcomes of public participation in health policy development.

Annotation: Thurston offers a theoretical framework for public participation that incorporates the social context.