# Will it make a difference if I show up and share? A citizens' perspective on improving public involvement processes for health system decision-making

# Julia Abelson<sup>1,2</sup>, Pierre-Gerlier Forest<sup>3</sup>, John Eyles<sup>1,4</sup>, Ann Casebeer<sup>5</sup>, Gail Mackean<sup>5</sup>, the Effective Public Consultation Project Team

<sup>1</sup>Centre for Health Economics and Policy Analysis, <sup>2</sup>Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton; <sup>3</sup>Department of Political Science, Laval University, Quebec; <sup>4</sup>Department of Geography, McMaster University, Hamilton; <sup>5</sup>Department of Community Health Sciences, University of Calgary, Calgary, Canada

Introduction: Health policy decision-makers are grappling with increasingly complex and ethically controversial decisions at a time when citizens are demanding more involvement in these decision processes.

*Objectives*: To assess and revise a set of guiding principles for the design of public involvement processes generated from a synthesis of public participation design and evaluation frameworks that can be used to inform the design and evaluation of future public participation processes in the health sector.

*Methods*: Six focus groups held in five Canadian provinces comprising citizens with considerable experience of public participation processes.

*Results and discussion*: Our findings suggest that citizen participants are highly critical of, and discerning about, their public participation experiences. Yet, they are optimistic and determined to contribute in meaningful ways to future public policy processes. They are clear about where improvements are needed and give top priority to what information is shared, and how, among participants and decision-makers. The views of experienced citizens mapped well onto most of the prior principles of public involvement with a few modifications. First, participants gave greater emphasis to the content and balance of information for the purposes of building trust and credibility between citizens and decision-makers. Second, participants viewed themselves, as well as decision-makers, as sources of information to be shared through the consultation process. Finally, participants stressed the importance of getting the information and communication principles right over addressing all other principles.

Journal of Health Services Research & Policy Vol 9 No 4, 2004: 205–212 © The Royal Society of Medicine Press Ltd 2004

#### Introduction

Health policy decision-makers are grappling with increasingly complex and ethically controversial decisions at a time when citizens are demanding more involvement in these decision processes – processes they

Correspondence to: JA.

perceive to be opaque and lacking public accountability. In response, policy decision-makers have established new institutional mechanisms for citizens to contribute to public policy decisions. In 2002, a Citizens' Council was established in the UK to advise National Institute of Clinical Excellence (NICE) decision-makers, with the purpose of providing a 'backdrop of public opinion'.<sup>1</sup> A vear later, the Commission for Patient and Public Involvement in Health was established in the UK National Health Service (NHS) with a mandate to 'champion and promote the involvement of the public in decisions that affect their health, putting them at the heart of decision-making in local NHS services'.<sup>2</sup> Underlying their official mandates to provide formal public involvement mechanisms, these structures are responses to sharp criticism of NHS decision-making in the wake of recent public inquiries into the medical care system.<sup>3</sup>

The Royal Commission on the Future of Health Care in Canada offers a case study of comprehensive efforts to consult citizens (through citizens' dialogues) about

Julia Abelson PhD, Professor, Centre for Health Economics and Policy Analysis and Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton L8N 3Z5, Canada. Pierre-Gerlier Forest PhD, Professor, Department of Political Science, Laval University, Quebec, Canada. John Eyles PhD, Prfoessor, Department of Geography, McMaster University, Hamilton, Canada. Ann Casebeer PhD, Associate Professor, Gail Mackean PhD, Research Associate, Department of Community Health Sciences, University of Calgary, Calgary, Canada. Members of the Effective Public Consultation Project Team include (in alphabetical order): Francois-Pierre Gauvin (Centre for Health Economics and Policy Analysis, McMaster University), Denise Kouri (Canadian Centre for the Analysis of Regionalization and Health), Elisabeth Martin (Department of Political Science, Laval University), Mike Pennock (Mental Health and Addiction Services, British Columbia Ministry of Health), Patricia Smith (Department of Anthropology, McMaster University).

health care reform options.<sup>4</sup> Like its UK counterparts, the commission recommended the establishment of a national health council (to include citizen representation) to explicitly address concerns regarding the health system's lack of transparency and public accountability.<sup>5</sup> At other levels of the health system, efforts continue to involve citizens more effectively in priority-setting and resource allocation decisions both regionally and centrally<sup>6–8</sup> while explorations of value conflicts underlying broad public health initiatives<sup>9</sup> and ethically controversial new technologies<sup>10</sup> proliferate.

The initiatives described above signal a commitment to address concerns about lack of transparency and public accountability at all levels of government through the creation of new structures or the improvement of existing mechanisms to involve citizens in the governance of the health system. But the chequered history of previous efforts to involve citizens in health system decision-making<sup>11</sup> prompts questions about the ability of these new structures, on their own, to overcome the problems that have plagued past processes. Informed by the results of the first of three phases of a three-year comparative study of public involvement in regionalised health systems in Canada, we examine the prospects for success of these new participatory processes and offer recommendations to ensure that these institutional mechanisms build on the best available evidence, which includes the perspectives and attitudes of the citizens who are likely to be encouraged to take part in these initiatives.

# Lessons and challenges from the literature

Over the last few decades, public confidence and trust in representative democracy and traditional political institutions has declined, contributing to a frustrated public, dissatisfied with the status quo yet unable to find meaningful ways to participate in society.<sup>12</sup> While the sources of this decline are numerous and widely debated, it has led to a renewed interest in more direct interactions between citizens and their governors in a broad range of public policy processes, including those undertaken within the health system. Associated with this trend is a history of expert-driven public participation processes in the health system where citizens have been given largely symbolic positions on governing or planning bodies or asked to provide their views on a narrow range of issues usually determined by someone else.13

In the Canadian health system, as with many other publicly funded health systems, there are numerous ways in which citizens can participate outside the electoral process. The capacities for public involvement (e.g. citizen governor versus citizen consultant) tend to be the same at all levels of municipal/regional, provincial or federal government. However, the types of decisions to which citizens contribute align with the decision-making responsibilities of each level of government. In the predominantly regionalised health systems in Canada, the most visible and contentious decisions

are often taken regionally, hence the attention given in the literature to public involvement practices in this context.

Knowledge of what citizens expect from their public involvement experiences has improved over the past decade, but remains fairly superficial. Experimentation with public involvement methods in health planning, priority-setting and resource allocation processes has generated knowledge about: the health care decisionmaking roles that patients and citizens are willing to accept for themselves;<sup>7,14,15</sup> citizens' reluctance to take on the role of rationer;16 citizens' growing desire for 'accountable consultation' that guarantees that their contributions will be heard and that decisions taken following consultation will be explained;<sup>15</sup> and the requirement for a critical mass of patient and public representatives to be able to contribute to prioritysetting processes (e.g. decisions about which cancer drugs to recommend for public funding).<sup>6</sup>

Our understanding of which public involvement methods appeal to citizens (and under which conditions) has also improved,<sup>17–19</sup> based largely on participant assessments of short-term experiments with face-to-face deliberative processes where participants have the opportunity to develop more, rather than less, informed opinions about an issue. However, we are still in the early stages of producing knowledge about whether generic processes can be applied to a range of decision-making and cultural contexts and, if so, what these features might look like. For example, interactive face-to-face methods are increasingly favoured over passive methods, but for what types of issues and at which point in the decision-making process are they best suited?

Recent scholarly contributions (e.g. theoretically based evaluation frameworks and empirical studies) in this area offer instructive guidance for the design and/ or evaluation of a broad range of public involvement processes.<sup>20–23</sup> For example, the authors of a recent systematic review of 239 case studies of public participation in environmental decisions conclude that 'process matters', and point to the association between broad acceptance of the decision outcomes and 'processes in which agencies are responsive, participants are motivated, the quality of deliberation is high, and participants have at least a moderate degree of control over the process'.<sup>21</sup>

Although the integration of synthesised case study experiences with theoretical evaluative frameworks is instructive about issues in the design of public involvement processes, there is little knowledge about the consequences of citizens' aggregate public involvement experiences with respect to how these experiences shape their attitudes towards public involvement in health system decision-making and to political participation more broadly. Public opinion surveys have documented a decline in citizens' trust in and deference to public officials.<sup>24–27</sup> Yet more recent polling data suggest that citizens want to be involved in major public policy decisions (health system decisions in particular) and would feel more confident in government decisionmaking that 'regularly seeks informed input from average citizens'.<sup>27</sup> These findings, coupled with claims of 'democratic deficits' and increased calls for public accountability, prompt questions about citizens' current attitudes toward, and relationships with, existing political institutions that have implications for improving public involvement processes in the future.

We addressed this knowledge gap by probing the views of experienced citizen participants who had participated in numerous public involvement processes in both health and non-health sectors in five Canadian provinces. Our specific study objective was to assess and refine, based on the views of experienced citizen participants, a set of guiding principles for the design of public involvement processes, generated from a synthesis of public participation design and evaluation frameworks, to inform future public participation processes in the health sector. While efforts have been undertaken to use citizen participants to influence the design of public participation strategies in local government studies,<sup>28,29</sup> this subject has gone largely unexplored within the health sector.

## Methods

Focus groups were held in five Canadian provinces as part of a larger comparative study of public participation in regional health authorities designed to improve the effectiveness of public involvement processes as tools for communicating with the public on complex health and health care issues and obtaining the public's views to inform and improve future decisions about health and health care.

Focus group recruitment was guided by our interest in gaining rich and representative depictions of public involvement experiences that would inform the assessment and refinement of a set of generic public involvement design principles. Recruitment, therefore, centred on the identification of current or recently active public participants in one or more regional health authority decision-making processes (who may have also been involved in non-health-related public involvement processes) who could share views based on aggregate rather than one-time experiences and exposure to different methods and approaches.

At each site, regional health authority decision-makers (in their role as research team partners) assisted in identifying potential focus group participants who met these criteria. Participant lists from recently completed public involvement processes in each regional health authority were provided to the research team, as were former volunteer members of the regional health authority or community health board advisory body. With respect to their constituencies and interests, we describe these focus group participants as formal (i.e. identified and selected through institutionalised mechanisms) and substantive (i.e. reflecting different population characteristics, health needs, etc.) representatives.<sup>30</sup> A double consent process was used to recruit participants where the regional health authority mailed a letter to each prospective focus group participant to obtain consent to have their name released to the research team. A member of the research team then contacted potential focus group recruits directly to obtain their written informed consent.

A common set of focus group questions was used to ensure consistency across provincial jurisdictions and to explore the following topics:

- General and process-specific participant experiences with public consultation processes.
- Citizen impressions of the barriers and facilitators to participation.
- Depictions of the role that information and information sources play in the consultation process.
- Perceived effects of public consultation on participant views about policy issues.
- Impacts of public consultation on decision-makers and decision-making.
- Elements of successful consultation.

In two sites, local research teams tailored the focus group guide to their context but retained a common set of questions (see list above).

Focus group transcripts were entered into the qualitative analysis programme QSR Nvivo. The lead investigator (JA) and a research assistant read all transcripts and developed a coding scheme broadly informed by focus group questions (e.g. What are the elements or features of successful consultation?) and specifically informed by themes arising from the discussions of participants' experiences with public consultation processes (e.g. the importance of information sharing, a neutral facilitator, etc.). A preliminary set of findings was circulated to all focus group participants which provided them with the opportunity to comment on the study findings.

## Results

Six focus groups were held between October 2001 and April 2002 in five Canadian provinces. Focus groups varied in size from four to ten participants, giving a total of 43 participants across five sites. Participants were active citizens within their communities; all were members of one or more community-based volunteer organisation in addition to being involved in at least one (and often several) regional health authority decisionmaking processes. The range of health system decisions for which their input had been sought included health care facility siting, relocation and closure decisions, and programme and service planning for specific population groups (e.g. mentally ill, disabled, children with special needs, multicultural, youth, addictions).

Our findings are reported in relation to six themes. The first focuses on participants' general attitudes to public consultations. Subsequent sections address participants' views regarding the different public participation design elements, followed by their general reflections on the future prospects for public consultation in democratic societies. The findings are assessed against a set of proposed guiding principles for the design and evaluation of public involvement processes generated from prior synthesis work and empirical studies of decision-maker experiences with public involvement processes.<sup>20</sup> In the Table, we summarise the principles generated from our prior synthesis work against the results obtained from our focus group discussions.

# The roots of the cynical citizen

Citizens in all focus groups described their frustration with 'corruptible' consultations that are used to 'mask' hidden agendas, specifically those of decision-makers 'looking for public support for predetermined agendas and outcomes'. They spoke disparagingly of 'windowdressing' consultations where challenging stakeholders, labelled 'troublemakers', were excluded to protect tightly controlled agendas. These negative experiences led one citizen to suggest that poor consultation practices are partly responsible for broader societal trends of declining citizen participation and a more disengaged citizenry.

We are becoming an apathetic society, but I think a lot of it has to do with the way we were treated last time.

While these general depictions of public consultation were shared across all focus groups, certain themes were given greater or less emphasis in different jurisdictions. For example, in one province that has passed legislation mandating formal processes for incorporating citizen input into the health authorities' business plans, citizens view this as 'government putting something in place to share blame'. In another jurisdiction, citizens emphasised their lack of power to influence decisions as a major source of cynicism. In another, the need to push beyond the 'hidden agendas' was seen as critical to breaking through the cynicism surrounding many public consultation efforts.

More positive portrayals of public consultation experiences came from parents of children with special needs who had developed close links with regional decisionmakers over time. These citizen participants were more optimistic and felt that their views were welcomed and listened to.

... but overall the whole group was very welcoming.... they would be arguing an issue that really affected patient care and they'd say, 'Well, what do you think?'

To minimise future disappointments, public participants had become more selective about their involvement.

## Paying attention to design and process

Public participation evaluation frameworks<sup>20</sup> suggest that those designing and executing public participation processes need to pay careful attention to the following

dimensions: communication; procedural rules; representation; and information. With respect to communication, focus group participants were looking for clarity about the purpose of the consultation and about 'where...it all fit[s] in the larger decision-making process'. Another critical feature was the presence of someone in a position to act on the input provided to link the consultation to the decision(s) taken.

Who is there on the hosting side? Is it [someone] who will write a report and pass it on or are the big shots there?

Participants stressed the importance of ensuring that the right mix of people was brought together (i.e. 'who's talking' and 'who's listening') so that that 'the group that [comes] together is going to be a useful group for the decision that has to be made'. This was viewed as an improvement on past experiences where 'sometimes there is a whole group of people who are missing'.

To ensure fair process (i.e. procedural rules), several focus group participants stressed the importance of an impartial facilitator, 'to keep [it] from becoming a circus', 'to control the audience, but also the decision-makers...to make sure they listen' while building in a flexible enough structure to allow participants to contribute meaningfully 'so that if an idea comes up it can be pursued'.

# The centrality of information and information exchange

Information is a central component of any well-designed consultation process, particularly those that emphasise discussion and deliberation. Most critiques of the information component of public consultation processes have been directed at the need for care in the selection, synthesis and presentation of written, oral or electronic information that can often overwhelm and bias participants who may know little about a subject. Information also has the potential to manipulate or coopt participant views.<sup>20</sup> Focus group participants appeared less concerned with the amount or specificity of the information than with seeking assurances that information would be presented honestly in 'nonmanipulative' ways and with a 'sense of ethics'.

One way a host could help is by saying, 'Here is our information. Here is a list of other sources of information for you to go to that are independent of us.' That shows that the host is secure enough in their sources that they can encourage you to go elsewhere.

The need for information sharing was forcefully communicated as a key element of meaningful and legitimate public involvement:

... if you are going to meaningfully involve people, then you have to share the information. ... if you can't share it then how can the public legitimately go through a consultation process? You've got to be able to share the information. And that serves two purposes: that means the public can think as creatively as the planners, and also then people have a better sense of how complex the issue is and then maybe, whatever the decision is, there is less chance of them getting mad about it, because at least they have a full understanding of what's involved.

Participants conveyed an equally important message about the need to ensure that citizen views and expertise were incorporated into the consultation process, as a means for levelling the playing field between participants and decision-makers. Simply recognising the value of citizen expertise was considered a partial solution. Deciding when to incorporate lay and technical expertise into a decision process and recognising the limits of each type of expertise were also highlighted, framed as a 'who has the information and who needs it' issue.

The best available information, however, does not guarantee its understanding or acceptance by citizen participants. Contentious issues such as proposed hospital closures are dominated by strong vested interests with a citizenry vulnerable to these interests who may be impervious to information exchange.

I can think of a good example of that with the closing down of the hospital. All the information was there, but people didn't absorb that. And I was one of them. I just didn't absorb all the pros and cons of why we had to have one hospital. And that's why I ran for the health board. I thought there must be something we can do about that.

While there was an understanding that information will always be subject to the problems described above, there were clear views about how the process of opinion change is facilitated.

It helps if the information is well presented, coherent, understandable to the lay person (because a lot of this stuff has technical information), so there is an educational process in the information sharing by the host. Also, you have to be able to believe that the people you are talking to have some integrity, some honesty, in the sense of ethics. If they seem shady or that you can't trust them, then that undermines whether you can trust the information. And how do you do that? The only way to do that is if you are honest.

## The effects of consultation on participants

A central tenet of most deliberative participation methods is that an informed citizenry, given the chance to discuss and debate with one another in a mutually respectful manner, will ultimately come to a more informed judgement about an issue and change its opinions.<sup>31</sup> Our focus group participants discussed the effects of their respective consultation experiences and seemed to agree that a well-designed and well-implemented process could encourage mutual understanding with the potential for reaching common ground among participants.

Sometimes people feed off one another. And it's important to hear the other side. Maybe I haven't completely changed, nor has he, but we meet somewhere in the middle.

I'm too stubborn, so often the best to hope for is that I appreciate the nuances more and don't see things in such

black-and-white ways. That's what I would call a success, if I come out seeing things not so black and white, and being able to understand the decision-makers' perspective a bit better.

Consensus is often cited as an intended goal of public participation processes but is rarely explicitly defined. Seasoned citizen participants recommend that, if consensus is a goal of the process, it should be defined, and they suggest that it be defined not as 'everybody agrees' but that 'everybody's comfortable with a decision'.

There will be parts of it that you'd rather have seen it this way or you'd rather have seen it that way but as a whole we can live with it.

#### Trust, accountability and democracy

Despite their criticisms, focus group participants were reasonably optimistic about future public consultations. They identified the importance of public consultations as 'a valuable tool in a democratic society' and were committed to making improvements through incremental change.

Public consultation is here to stay, even if it is frustrating at times. So the thing is to make it better. That is my sense of optimism.

You continue to do it because you believe the process will work, that changes will be made to help everybody.... That is why you do it...a little bit at a time.

Throughout their discussions, participants made numerous suggestions for improving future public consultations. An area requiring remedial action was the need to establish or re-establish trust between citizens and decision-makers so that people 'really believe that their input is wanted and is going to be needed, [and] not abused'. To achieve this, according to one citizen participant, 'the key word now is accountability', expressed in calls for more transparent links between the input provided and the final decision outcomes.

So being able to track and just be comfortable that your views were heard and not just heard but actually communicated in reports that come out of these processes in a legitimate way.

In several of our study jurisdictions, community advisory councils have been established to provide the types of links described above. For the most part, these councils have loose accountability requirements to regional health authorities or to the communities they serve. Recent changes to legislation in one Canadian province require health authorities to demonstrate how input provided by community health boards (composed of local citizens) has been used in the health authority's business plan development process. Although these accountability mechanisms have not been evaluated, citizens are paying close attention to these accountability requirements and looking to see how the community health plans are used in the health authority's business plan.

After doing the community health plan [we] never received any feedback. [We] would have liked to know how it was received by the 'higher ups'.

# Public consultations and the democratic process

Despite strong endorsements for continued, albeit strengthened, public consultation processes, some participants were careful not to give more emphasis to the role of public consultations than they deserved and expressed the need for public consultations to be integrated into rather than to substitute for existing democratic institutions.

Whether there is a public consultation or not, I expect my elected official to be out there talking to people, including me, about what's going on. I don't think public consultations are a substitute for elections, it's not a substitute for my elected official, doing whatever they need...you know, returning my phone calls, because that's all a part of getting public input.

...elected officials are hired to make decisions with public input. It's not a situation of saying 'well, I think I'll go and let the public do a little of my job'. No. My job is to find out what they want.

In the Canadian health policy decision-making context, this integration is difficult to achieve as the bulk of health system decision-making, for which public consultations are routinely sought, occurs at the regional level whereas the electoral accountability for health care decisions resides at the provincial level.

# Discussion

The citizen participants we spoke to offered numerous recommendations for health policy decision-makers and system managers who are wrestling with the design and implementation of new participatory mechanisms. Participants flagged concerns about: how information is used in public involvement processes; the extent to which decision outcomes are predetermined versus negotiable; the unbalanced power relationships between participants and consultation organisers; and the exclusivity of processes with respect both to the selection of participants (i.e. who is invited/who is not invited) and the degree of content knowledge necessary to be able to participate meaningfully.

Meeting the conditions for continued public involvement

# A clear purpose with built-in accountability mechanisms

With respect to the design of future processes, focus group participants expressed an interest in maintaining their involvement provided that specific conditions were met. These included the need for more clearly articulated purposes for public consultation processes, and accountability mechanisms that establish a clear relationship between the input provided and the decision outcome. Participants were realistic about what they could expect in terms of their input directly influencing policy decisions; however, they were adamant about the need for decision-makers to clarify at the outset of a process why their input was being sought and how it would be used in the decision-making process.

# A central role for information

Information was seen to play a crucial role in the following ways:

- It needs to be shared between decision-makers and the public.
- It needs to be presented clearly, honestly and with integrity (preferably by neutral facilitators).
- It needs to be considerable to ensure participants' comfort with the topic and to build the confidence they need for meaningful participation.
- It needs to value and include the views that participants bring with them.

When assessed against the design principles presented in the Table, the empirical results map closely onto most of the principles, with a few exceptions. First, participants gave more emphasis to the content and balance of information for the purposes of building trust and credibility between decision-makers and participants than for the purposes of reducing uncertainty and promoting understanding of the issues. Second, participants viewed themselves as well as decision-makers as sources of information to be shared through the consultation process. This is a much more technical view of public input than has traditionally been considered in the health field. Notions of citizens as information sources need further consideration as well as the prospects for applying our increased understanding of knowledge exchange practices between decision-makers and researchers, for example, to knowledge exchange relationships between decision-makers and citizens. Finally, although the empirical data addressed each of the design principles to some degree, participants stressed the importance of getting the information and communication principles right over other principles such as the mix of participants or the procedural rules.

# Challenges to meeting these conditions

Meeting the conditions laid out by these participants is no small task. A better understanding is needed of what constitutes 'trusted, credible and honest information', how this is to be delivered and with what resources. Recognition is also needed of decision-makers' apprehensions about entering into reciprocal relationships with citizens, especially those requiring them to open their decision-making processes to greater scrutiny and

#### Table Comparison of public consultation design principles with citizens' views about public involvement

Public consultation design principles (from previous synthesis work)

- Clearly communicate:
- the purpose of the consultation
- its procedural rules

• the relationship between the consultation and the decisions taken

Represent views, interests and constituencies:

- by carefully considering whose input should be considered
- by providing opportunities for all participants to contribute fairly

Develop procedural rules:

- that promote power-sharing and mutual respect among participants and between participants and decision-makers
- that allow for adequate time for questions, clarification, listening and understanding
- that promote trust, credibility and legitimacy

Provide information:

- that is accessible (e.g. understandable, appropriate amount)
- presented in a way that informs discussion
- that can be discussed and interpreted
- from credible and trusted sources

Citizens' views about public involvement (from focus groups results)

- clear communication about the purpose of the consultation, and its relationship to the larger decision-making process
- identifiable links between the consultation and the decision outcome (through the presence of someone in a decision-making role)

#### People

careful recruitment of the appropriate mix of people for the issue being discussed

#### Process

- promote power-sharing and mutual respect among participants and between participants and decision-makers through neutral, impartial facilitation
- use a flexible structure to allow for meaningful contributions

Information exchange

- information sharing in a context of trust
- information to be presented clearly, honestly and with integrity (by neutral facilitators)
- needs to ensure participants' comfort with the topic and to build the confidence for meaningful participation
- lay views and experiential expertise should be listened to and considered

to share control over the inputs to a decision process with no guarantees about the outcome that will be obtained at the end of the process. There are signs that some decision-makers are re-orienting their work toward more purposeful, accountable and evidence-based consultation.<sup>12</sup> However, decision-makers will always be cautious of sharing power with others and as a result need to be convinced of the desirability or the consequences of not doing so. The experimental research currently underway in the final phase of our comparative public consultation research project aims to inform these issues.

#### Limitations of the results

Our findings are limited to the experience of active citizen participants selected on the basis of their prior involvement in regional health system decision-making processes and to the experiences of citizens interacting with governance structures within the Canadian health system. Although often critical of past experiences, many of these participants were reasonably optimistic about future public involvement processes – attitudes that may reflect the 'civic leadership' positions they hold in their communities. These views may not reflect those of less traditional or marginalised participant groups.

Participants reflected on a fairly generic set of public consultations, some of which (i.e. priority-setting, resource allocation and health planning decisions) are typical of those routinely addressed at all levels of the health system and by some of the newly proposed participatory structures. Although some tailoring will be needed in the design of any public consultation process, concerns about generalising these findings to different decision-making contexts should be tempered by the conclusion from experience in other policy sectors that 'good processes appear to overcome some of the most challenging and conflicted contexts'.<sup>21</sup>

### The call for new approaches to citizen involvement

Our findings provide empirical support for proposals to revise traditional models of public consultation and participation<sup>26</sup> and mirror lessons recounted by health system decision-makers themselves.<sup>11</sup> They also reinforce previous calls for more 'accountable consultation'15 and further unpack how consultation processes might meet these accountability requirements (e.g. through a clearly articulated purpose for the consultation, information sharing between decision-makers and citizen participants, and sustained vehicles for ongoing consultation). Although the importance of devising explicit accountability mechanisms should not be discounted, widespread calls for these mechanisms may be more reflective of feelings of mistrust based on past experiences than their centrality in participatory processes. As suggested by others, with more solid, trusting relationships in place, calls for accountability mechanisms might not have been so loud.<sup>32</sup>

## Conclusions

Our findings reflect on citizens' current mood with respect to interactions with their political institutions. Citizens have clearly experienced feelings of apathy toward democratic participation based on the 'way they have been treated in the past', but they also want to make a difference to their own lives and to the lives of their communities, partly in response to the weaknesses of their existing democratic institutions.

Recent experience with the public consultation component of the Commission on the Future of Health Care in Canada appears to support this assertion. Since the release of its final report in November 2002, pressure has mounted for policy-makers to 'get it right' when it comes to establishing mechanisms for linking citizens with decision-makers. The findings from this study and others before it suggest that simply establishing another mechanism for 'giving citizens a say' without paying attention to issues of purpose and process has a good chance of failing to establish or re-establish trust between citizens and their governors.

Predicting the consequences of failing to do things differently is beyond the scope of this paper. Our research offers both a note of warning and some cautious hope and potential for meaningful public involvement in the future. The warning is that status quo models of consultation as top-down, paternalistic efforts to extract information from participants need revision. The hope lies in the emerging evidence that the cycle of enthusiasm, disappointment, cynicism and apathy that has characterised public consultations over the last two decades may be coming full circle, but only under the right conditions. Our empirical findings suggest that we are closer than ever to understanding what these conditions are. Future studies will assess their feasibility and desirability.

### References

- 1. National Health Service. UK's first citizens' council being established by NICE. Press release. www.nice.org.uk. 19 August, 2002
- 2. Department of Health. Strengthening accountability: involving patients and the public. Section 11 of the Health and Social Care Act. London: Department of Health, 2003
- 3. The Bristol Royal Infirmary Inquiry. Learning from Bristol. The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995. London: HMSO, 2001
- 4. Maxwell J, Rosell S, Forest P-G. Giving citizens a voice in healthcare policy in Canada. BMJ 2003; 326: 1031–1033
- Maxwell J, Jackson K, Legowski B, Rosell S, Yankelovich D with Forest P-G, Lozowchuk L. Report on citizens' dialogue on the future of health care in Canada. Ottawa: Commission on the Future of Health Care in Canada, 2002
- Martin D, Abelson J, Singer P. Participation in health care priority setting through the eyes of the participants. Journal of Health Services Research & Policy 2002; 7: 222–229
- Wiseman V, Mooney G, Berry G, Tang KC. Involving the general public in priority setting: experiences from Australia. Social Science & Medicine 2003; 56: 1001–1012
- 8. Mitton C, Donaldson C, Dean S, West B. Setting priorities and allocating resources in health regions: lessons from a project evaluating program budgeting and marginal analysis. Health Policy 2003; 64: 335–348
- 9. Staley K. Voices, values and health: involving the public in moral decisions. London: King's Fund, 2001
- Einsiedel E. Assessing a controversial medical technology: Canadian public consultations on xenotransplantation. Public Understanding of Science 2002; 11: 315–331
- Abelson J, Forest P-G, Eyles J, Smith P, Martin E, Gauvin F-P. Obtaining public input for health-systems decision making: past experiences and future prospects. Canadian Public Administration 2002; 45: 70–97

- 12. Nevitte N. The decline of deference: Canadian value change in cross-national perspective. Peterborough, ON: Broadview Press, 1996
- Abelson J, Eyles J. Public participation and citizen governance in the Canadian health system. In: Forest P-G, McIntosh T, Marchildon G, eds. Changing health care in Canada: the Romanow papers, vol 2. Toronto: University of Toronto Press, 2004: 279–311
- Abelson J, Lomas J, Eyles J, Birch S, Veenstra G. Does the community want devolved authority? Canadian Medical Association Journal 1995; 153: 3–12
- Litva A, Coast J, Donovan J, Eyles J, Shepherd M, Tacchi J et al. 'The public is too subjective': public involvement at different levels of health-care decision making. Social Science & Medicine 2002; 54: 1825–1837
- Lomas J. Reluctant rationers: public input to health care priorities. Journal of Health Services Research & Policy 1997; 2: 103–111
- McIver S. Healthy debate? An independent evaluation of citizens' juries in health settings. London: King's Fund Publishing, 1998
- Coote A, Lenaghan J. Citizens' juries: theory into practice. London: Institute for Public Policy Research, 1997
- Lenaghan J. Involving the public in rationing decisions. The experience of citizens' juries. Health Policy 1999; 49: 45–61
- 20. Abelson J, Forest P-G, Eyles J, Smith P, Martin E, Gauvin F-P. Deliberations about deliberation: issues in the design and evaluation of public consultation processes. Social Science & Medicine 2003; 57: 239–251
- 21. Beierle TC, Cayford J. Democracy in practice: public participation in environmental decisions. Washington, DC: Resources for the Future, 2002
- 22. Webler T. 'Right' discourse in citizen participation: an evaluative yardstick. In: Renn O, Webler T, Wiedelmann P, eds. Fairness and competence in citizen participation: evaluating models for environmental discourse. Boston, MA: Kluwer Academic Press, 1995: 35–86
- Webler T. What is a good public participation process? Five perspectives from the public. Environmental Management 2001; 27: 435–450
- 24. O'Hara K. Securing the social union. Ottawa: Canadian Policy Research Networks, 1998: 77–110
- 25. Maxwell J. Toward a common citizenship: Canada's social and economic choices. Ottawa: Canadian Policy Research Networks, 2001
- 26. Graham KA, Phillips SD. Making public participation more effective: issues for local government. In: Graham KA, Phillips SD, eds. Citizen engagement: lessons in participation from local government. Monographs on Canadian public administration no. 22. Toronto: Institute of Public Administration of Canada, 1998: 1–24
- 27. EKOS Research Associates. Private voices, private choices. Online poll sponsored by the Charles E Frosst Foundation 2002. http://www.fondationfrosst.ca
- Lowndes V, Pratchett L, Stoker G. Trends in public participation: part 2. Citizens' perspectives. Public Administration 2001; 79: 445–455
- 29. Seargeant J, Steele J. Who asked you? The citizen's perspective on participation. London: Improvement and Development Agency, 1999
- Marmor T, Morone J. Representing consumer interests: imbalanced political markets, health planning, and the HSAs. Milbank Memorial Fund Quarterly 1980; 58: 125– 165
- 31. Yankelovich D. Coming to public judgement: making democracy work in a complex world. Syracuse, NY: Syracuse University Press, 1991
- 32. O'Neill O. Trust with accountability? Journal of Health Services Research & Policy 2003; 8: 3–4

Copyright of Journal of Health Services Research & Policy is the property of Royal Society of Medicine Press Limited and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.