

A B S T R A C T

This article describes partial results from a case study of community participation in “New Directions for a Healthy B.C.,” a now-abandoned health reform policy. For this study, focus groups were conducted to explore the perspectives of traditionally under-represented citizens in understanding reasons for nonparticipation and to identify strategies for fostering participation in the health reform process. The findings indicate that participating in traditional ways – committee meetings, public fora, completing surveys – was not relevant to the realities of these individuals. Yet, rather than merely refusing to be involved, focus group members extended an invitation for health planning group members to experience their daily lives; an idea that is referred to in the literature as ‘experiential participation.’ In order to foster broad-based participation in community health initiatives, the findings from this study argue for a new understanding of, and appreciation for what actually constitutes participation.

A B R É G É

Cet article décrit les résultats partiels d’une étude de cas impliquant la participation de la communauté sur «les nouvelles directives pour une Colombie-Britannique en bonne santé», programme de réforme sur la santé maintenant annulé. Pour cette étude, des groupes d’observation furent établis afin d’étudier le point de vue de citoyens habituellement sous-représentés et pour comprendre les raisons de leur manque de participation ainsi que pour identifier les stratégies qui inciteront leur participation au processus de réforme sur la santé. Les résultats indiquent qu’une participation de type traditionnel (réunions de comités, forum au public, sondages) ne s’accordait pas à la réalité quotidienne de ces individus. Cependant, plutôt que de simplement refuser de s’impliquer dans les recherches, les membres des groupes d’observation ont invité les autres participants à venir observer leur vie de tous les jours – un concept auquel on fait souvent référence sous le terme de «participation expérimentale.» Afin d’encourager une vaste participation aux initiatives sur la santé au niveau de la communauté, les résultats de cette étude montrent à la fois une nouvelle compréhension et une nouvelle appréciation des éléments constituant réellement la participation.

Closer to Home: The Case for Experiential Participation in Health Reform

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The concept of public participation, or citizen involvement, in planning and implementing health programs, has been articulated and supported in various national and international documents for many years¹⁻⁴ and is a core element of both health promotion and community development.⁵⁻⁷ The concept is considered to be the bedrock of practice,⁸ one that is integral to the “health” of a democratic community and is significant to governance and management issues in regionalized health services.⁹ Yet it is also a concept that has been realized only in a limited sense.¹⁰

The literature on citizen participation contains demographic and psychological profiles of participants, and accounts of their activities, most often committee or public meetings.¹⁰⁻¹⁴ Despite the eclectic assortment of research in the field,¹⁵⁻²⁴ the conclusions to be drawn are profoundly similar: the difficulty of enlisting participants from a broad base of citizens. Participants in community endeavours are characterized by their skill in public speaking, ability to understand policy and technical language, familiarity with meeting etiquette and by discretionary resources (education, income, previous experience) and professional status that motivates and enables them to become involved.²⁵⁻²⁹

Academics and professionals have criticized the design flaws of traditional participation techniques, including the economic and sociocultural barriers that make public fora inconvenient and inaccessible, citizen advisory meetings that require educational

and financial resources, and an over-reliance on superficial opinion surveys.^{14,30-32} The deficiency of such methods, then, is that they are exclusionary and fail to represent those who they are supposed to represent.^{25,33} These impediments are beyond the citizens’ control, yet contribute to keeping the traditionally voiceless silent.³⁴ Those unemployed, or who are stereotyped because of youth or old age, gender, physical or mental impairment, low income or ethnicity, are the politically and socially marginalized, and comprise the traditionally voiceless ranks of Canadian society.³⁵⁻⁴⁰

Why is it difficult for community initiatives seeking public participation to achieve inclusive, broad-based involvement? Are there alternatives to committee meetings and public fora that may be more accessible and inviting, particularly to and by under-represented segments of the community? Scholars of participation in community association and health promotion have called for research which would further identify feasible strategies for fostering broad-based participation.^{26,41-45} The purpose of this paper is to begin to address the gap between the promise and reality of participation. This article presents some of the findings from a case study documenting the community development experience of local health planning groups as they implemented the now-abandoned health reform initiative “New Directions for a Healthy B.C.”⁴⁶ (Appendix I). “New Directions” sought to decentralize the management, resource allocation and decision making for health care to the local level and included an ongoing commitment to improve public understanding of and participation in health and health services. Local health planning groups, comprised of volunteers, were expected to fos-

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ter community participation in developing a community health plan that reflected the health goals of their constituents. In doing so, health planning groups were expected to elicit, generate and document representative input from a broad base of community members. This article discusses the portion of the research that explored the perspective of the traditionally under-represented citizen so that better strategies for encouraging their participation might be identified.

METHODS

As part of the larger case study, data collection methods included participant observation in four health planning groups over 11 months, interviews with participants (n=12) and documentary review. From these sources, the author was able to identify groups of citizens who were under-represented in, or completely absent from the health planning groups. As a result, focus groups (N=50) were organized and conducted with members of First Nations bands on and off reserve, street youths, youths, single parents, persons with physical disabilities, and persons with mental illness. Following an overview of "New Directions," focus group discussions explored citizens' perceptions of health, levels of awareness about, and perspectives about participation in, "New Directions" (see Appendix II). Discussions were audio-taped and transcribed. An editing analysis⁴⁷ of the transcripts was facilitated by MARTIN software,⁴⁸ a program that aids the coding and retrieval of data and acts as a code-based theory builder. The analysis was guided by a orientational approach to interpretation.⁴⁹ Orientational inquiry uses a specific theoretical framework to interpret the findings. The use of social marketing concepts of understanding the consumer perspective, exchange, marketing mix and segmentation provided the perspective from which these data were analyzed and interpreted. From the analysis, a number of themes emerged, including two which are discussed below as they pertain to this article: "Closer to Home" and "Participate in Our Reality". The analysis process is described in more detail elsewhere.⁵⁰

APPENDIX I A Summary of "New Directions"

British Columbia's now abandoned health reform policy, "New Directions," evolved from a 1990 Royal Commission on Health Care and Costs. The Commission's 1991 report *Closer to Home* suggested that the centralized structure for decision-making and resource allocation resulted in poorly planned, poorly managed and uncoordinated health care at the local level. "New Directions for a Healthy British Columbia" was the response to the Commission's report, and outlined five 'new directions' to guide the implementation of health reform:

1. All determinants of health were to be addressed in order to achieve "better health" for British Columbians in a holistic sense.
2. "Greater public participation and responsibility" was thought to be necessary to ensure the delivery of appropriate services to meet health needs, and to assist individuals to make informed decisions about their health care. In order to achieve this second direction, opportunities for citizens to participate in local decision-making were to be made available.
3. Local communities and regions were to assume control over planning, resource allocation, management and delivery of health care services in order to "bring health closer to home."
4. "Respecting the care provider" by strengthening the support for volunteers and family caregivers, involving paid and volunteer care providers in planning services, providing respite options and appropriate training and safe working environments were to be critical to health reform.
5. Finally, "effective management of the new health system" was deemed necessary to ensure ethical and financial accountability at every level of the new decentralized system, including professional organizations.

N.B. In 1996 "New Directions" was replaced by "Better Teamwork, Better Care" which was designed to streamline the approach to regionalization in British Columbia. Members of regional health boards and community health councils are still responsible for local decision-making and governance of health care, however, members are appointed by the Minister of Health rather than elected from their constituency.

APPENDIX II Semi-Structured Focus Group Interview Schedule

Each focus group began with an introduction/overview of "New Directions" and the work being done by the health planning groups. The following questions were posed as a means of generating a dialogue about participating in "New Directions."

1. What does the word 'health' mean to you?
2. What has been your awareness or experience with or participation in "New Directions" up to now?
3. If you have not participated fully, or at all, in "New Directions" so far, what do you think are the reasons why you have not?
4. What do you see as some of the questions, concerns or issues that you may have about "New Directions" or participating in "New Directions"?
5. What can be done to encourage or make it easier for you to participate in "New Directions"?
6. What are the most affordable, convenient and "citizen-friendly" ways to participate in the health reform process?

Basic demographic data were also gathered from each focus group member in order to assemble a general profile of focus group respondents, including age, number of children/dependents and marital, employment, occupational and educational status.

RESULTS

In keeping with the purpose of this paper, the bulk of the results presented here refer to focus group discussions about participating in "New Directions" (Table I). Across the discussions a key finding revealed that strategies utilized for citizen involvement in "New Directions" – committee meetings, public forum/meetings, and surveys – were not part of the realities of the focus group members. These citizens defined participation as an activity that would reflect, and be closer to, their daily lives and experiences. They recommended that opportunities to participate be "Closer to Home": at daycare centres, the Aboriginal Friendship Centre or Street

Community Association, via internet 'chat rooms,' or during art therapy sessions. High school youth expressed interest in dialoguing with health planning group members during class time. "Closer to Home" not only embodies the notion of geographical convenience, but of a comfort level as well. One focus group member with a physical disability feared he lacked the qualifications to become involved in "New Directions." *"I would love to participate in some way, but my problem is not having the skills and tools ... how smart do you have to be to be on a board?"*

Rather than merely refusing the invitation to participate in committee meetings or public fora, focus group members invited members of the health planning groups

TABLE I
Profile of Nonparticipants and Their Comments About Participation

Group	Demographics	Comments Concerning Opportunities to Participate
Street Youth (n=9)	Aged 15-25 Single No children Some part-time, irregular work Completion of grades 8-10	"Come join us, walk with us. If you want a real insight into how we are, go put your grubbier clothes on, grab yourself a backpack and spend maybe a day on the streets . . . it would give them [health planning group] a better idea of what we're going through to sit with us and pan one day and see how many people step over you and look at you and go Ugghh. People don't understand how bad it is."
High-school Youth (n=6)	Aged 15-18 Single No children Part-time retail and restaurant work Completion of grades 9-12	"Have them [health planning group] be in person [at the school]. It is the only way to do it. It is not like writing a letter that they are never going to read. Or they give you one back that they never even wrote. You are actually knowing that they [health planning group] are hearing them [youths' ideas]. You have to make interactive. You can't just have someone standing up there going blah, blah, blah."
Single Parents (n=6)	Aged 25-54 Divorced or never married 1-3 children Part-time, irregular retail and volunteer work Completion of grades 9-12	"The opportunity to provide input, make decisions, and receive information should see in at you from different places...places where people go anyway...places like day care centres, drugstores, grocery stores, at the worksite, community centres/organizations, in addition to using existing organizations' bulletins and newsletters."
First Nations (n=17)	Aged 22-54 Married, single and divorced 0-5 children Full and part-time, skilled and unskilled labour, off and on reserve Completion of grades 8-12	"We would have gatherings and feasts in our communities that are conducted by Aboriginal facilitators, and attended by elders. We need to give voice to our unique identity, culture and needs."
Persons with a Physical Disability (n=6)	Aged 36-65 Married and single 0-2 children Not employed Completion of grades 10-12 and post-secondary	"It has got to be more involved - where they come and spend a bit of time. If they are in the position, if they are spending the money, if they want to be on that health board, then they have got to experience it. Participation for them so they can see what is going on and at the same time consumers will be able to give some immediate feedback. Someone coming in and saying it in front of the board, is [not] going to be the same thing. They don't really see what happens."
Persons with a Mental Illness (n=6)	Aged 27-52 Single and divorced No children Not employed Completion of high school and post-secondary	"Somebody share with us. Give him [health council member] his \$529.00 and say - ok, get out. Live for a month. Get out there and find out what you can have and what you can do. And also here's your symptoms and see what you can find out in the way of getting help for those."

to "Participate in Our Reality": to experience the lives of those the participants represented; in other words, "to spend more time learning how the community is organized and less time trying to organize it."⁵¹ The voices of focus group members speak to the need for understanding the realities of those we hope to reach.⁵² This suggests, in the absence of inclusive and broad-based participation, an alternative may be to 'walk in the shoes' of those who lack the necessary skills, resources and confidence to become involved in traditional techniques.

DISCUSSION

Lomas and Veenstra²⁷ caution community organizers against pretending that traditional methods of involving citizens "really attract the general public." Indeed, participation rates in the health planning groups' meetings, fora and surveys averaged 0.003% of the region's population.

The very structure of the participation techniques themselves influenced who participated and who did not. Membership in the health planning groups was dominated by health professionals, planners and administrators and local civil workers. Meetings and surveys represented a comfortable and familiar part of what they know and do. As with other experiences in the literature,^{10-14,53} the opportunities to participate in "New Directions" were simply unable to accommodate and reflect how focus group members' view and understand their lives and so discouraged them from participating. This argues against a one-size-fits-all notion of participation and for opportunities that are developed in, and tailored to specific contexts and persons.^{25,26,54}

As is so often seen, participants in "New Directions" were well educated, well spoken and well off, and hence did not represent the diversity of the community. In fact, those who go to public meetings tend

to be "... a pretty unrepresentative bunch!"⁵⁵ In addition to being a comfortable and convenient venue, citizens must be able to see some reflection of themselves in the participatory endeavour in order to trust the process and participate.¹¹ The images visible in the health planning group membership failed to mirror the diversity of the communities they represented. It can be argued, however, that it was not necessary for health planning groups to be representative of their constituency if they understood the needs and experiences of those they represented.¹⁰ Yet such 'active representation' required an ongoing relationship between the participants and the citizens in the differing municipalities; a relationship health planning groups failed to establish. As the chair of one health planning group acknowledged, "*to really involve the community, we have to get out and spend the time and listen to them. And, that's something that we haven't done enough of. We really expected everybody to come to us.*"

Acknowledging that other domains for participation exist does not discount the contribution of health planning group members nor their conventional structures for participation. What experiential participation would bring is the understanding, experience, attitudes and views of citizens, gained in the social life of communities, to the health planning groups. Such participation constitutes a new kind of active (as opposed to passive) representation based on an experiential relationship.¹⁰ Electoral representation is limited because there is no guarantee that those who represent citizens share similar constituent gender, ethnic or socioeconomic status, let alone understand their needs or experiences.⁵⁵ Needs are best identified and appreciated by sharing in the lives of others. Representation, based on shared experiences where needs are actively and subjectively assessed, enhances the legitimacy of representation when economy of time and problems of scale restrict participation by all.

CONCLUSION

In the absence of broad-based public participation, experiential participation may be a step toward achieving better representation of diverse perspectives. The implications from this study for practitioners and policy makers designing and conducting participation initiatives include:

1. Start where people are at:¹⁵ visit work-sites, community centres, malls, coffee houses, streetcorners and churches. Abandon the meeting mindset and spend time in neighbourhoods with citizens, observing, listening and learning first-hand.⁵⁶ Be proactive and seek out those whose involvement is desired. This will demand extending the time commitment of participation endeavours.
2. Engage community members in activities that reflect their life experience. As one focus group member stated, "if the community health board comes, spends some time and looks to see what is going on [in mental health services] you get this feeling that they are not a faceless board. Perhaps, then, more people will start saying, 'I would like to be

on that board' or 'I am more interested in participating.'"

3. Acknowledge and respect the diverse and nontraditional contributions and strengths of citizens to participatory endeavours.⁵⁷⁻⁵⁸ A select few have the ability to chair meetings, digest reports and write briefs. Yet, focus group members possessed the 'insider' knowledge about the delivery and appropriateness of health care services that health planning group members lacked yet sought. Meaningful participation may constitute sharing experiences as recipients of services, providing input and feedback about the quality of health care, as well as identifying needs in the planning of programs. This may be in the form of citizen panels, discussion groups or innovative methods such as at religious gatherings⁵⁹ and as display structures in malls.⁶⁰

It may be that citizens *are* interested in health and do wish to influence the quality of health in the community, but do not feel they really can,⁶¹ or have not had the chance⁶² in contexts that are meaningful to their lives.^{63,64} Thus, the invitations extended to health planning group members to understand and appreciate the health experiences and needs of physically disabled or mentally ill persons, displaced youth, Aboriginal persons or single parents, represent a point at which we can begin. Experiential participation may set the stage for inclusive participation as trust is built and citizens discover how they can make a contribution. Clearly, new ways of thinking about,⁶⁵ and designing access to, participation are required, "particularly [for] members of the community who have been traditionally denied access to decision-making processes."⁶⁶ Experiential participation appears to offer an alternative means for regionalized health boards to achieve an appropriate and confident representation of the health needs and issues of those who are unable to participate in conventional ways.

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