



Policy Brief

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Citizen-Patient-Community Participation in Health Care Planning, Decision-Making and Delivery through Rural Health Councils

To: British Columbia Ministry of Health & Health Authority Decision-Makers

From: Rural Evidence Review Project, Centre for Rural Health Research, UBC

Background

The importance of involving patients in health care activities is widely recognized and prioritized through British Columbia's Patient-Centred Care Framework. Although B.C.'s framework is focused on patient participation in their own care, the framework does recognize the role for patients, families and caregivers to participate in quality improvement and health care redesign.

The challenge of citizen-patient-community (CPC) involvement in health care activities in British Columbia predates the Patient-Centred Care Framework and can be traced to the B.C. Royal Commission on Health Care and Costs (1991) (i.e., the Seaton report), which highlighted the importance to include CPCs in health system decision-making. Despite multiple iterations of health care restructuring following the Commission, the vision of enhanced CPC involvement in health care activities as articulated in the Seaton report remained into the early 2000s through CPC participation on hospital boards. The disbandment of the hospital boards in the 2000s alongside further health care restructuring that resulted in the current Regional Health Authorities, the Provincial Health Services Authority and what became the First Nations Health Authority, was met with the promise that the new structure would ensure local CPC engagement and involvement. There is a widespread agreement, however, that a robust replacement to local hospital boards has not yet been achieved and consequently, CPC voices in health care activities have been diminished.

Problem Statement

There is a need for a robust infrastructure to hear and to integrate citizen-patient-community voices, and to support CPC participation in health care planning, decision-making and delivery activities in British Columbia. CPC engagement and involvement must be included within the larger health care decision-making framework.



Key Points from the Evidence

Citizen-patient-community participation in health care activities is rooted in an appreciation of the experience and wisdom of lay individuals, which can be harnessed to increase the local relevance of health care planning and delivery activities. There is evidence to suggest that CPC participation creates self-determining, empowered communities, who then contribute to the provision of locally responsive health care leading to improved health outcomes (A. Kenny N. H.-S., 2017).

The following are important considerations for well-functioning and successful rural health councils:

Clarify objectives. It is critical to specify the objectives for CPC participation at the outset to ensure that the roles and activities for CPCs are targeted appropriately (Farmer J, 2017).

Provide adequate training. It is critical to provide education for citizens-patients-communities to overcome information deficits and reduce knowledge imbalances between those who work in the health system and those who experience it (Charles C, 2017); (Umbdenstock et al., 1990). In addition, Bismark and Studdert (2014) recommended board training on quality governance that is accessible, flexible and tailored (versus a 'one-size-fits-all' approach). Moreover, Knoble (1993) highlighted the need to educate boards on the importance of leadership principles and the values of an institution.

The following program example can inform CPC orientation and training activities in British Columbia:

Gold Coast Primary Health Network

The Gold Coast Primary Health Network in Australia supported citizens-patients-communities to participate on a Community Advisory Council, through orientation and training. The orientation process involved creating hard copy introductory materials (including contact details for appropriate staff, a welcome letter, and overview details regarding the Primary Health Network, such as policies, and forms related to CPC participation, conflicts of interest, and remuneration) and developing an online member portal where CPCs could access resources at any time (J. McClean, 2017). With regard to training, a consumer health body ('Health Consumers Queensland') offered formal training to advisory committee members, focused on responsibilities of a health consumer, resources and support (J. McClean, 2017).

Provide remuneration. There is evidence to suggest that remunerating council members enables them to participate in a meaningful way, by devoting a significant portion of their professional work to the role (A. Jha, 2010). Kidd et al. (2007) elaborated that appropriate funding at both government and service levels is required to support the implementation of developed models and processes that support more than tokenistic consumer involvement, including support for remuneration.

Ensure Representativeness. There are difficulties in defining the "best" candidates or "legitimate" voices to serve as representatives on behalf of the public, and in finding a suitable mechanism to capture public representation (Anton S, 2007). To address the barriers to representative CPC participation, it is important to:

- Articulate a clear definition of "citizen-patient-community".
- Specify the appropriate participant type for effective participation.

With regard to participant type, Farmer et al. (2017) reported four conceptualizations of CPC participants: 'the public', including individuals with some or no relation to a particular service and inputs informed by a breadth of influences; 'consumers', defined as those using a particular service, including patients, carers and other support persons; 'community of place', inferring a connection between people and place; and 'community of interest', where some aspect of the shared interests of a group is relevant to a proposed activity.

- Clarify for CPCs how their input will be included and taken seriously (Beresford P, 1988).
- Simplify administrative and deliberative processes within organisations, to reduce advantages to individuals with greater economic and intellectual resources (March J G O. J. P., 1989).
- Consider the use of demographic targets for participation (J. McClean, 2017).

Share power and control. The interface between those who work in the health system and those who experience it is a challenge for citizen-patient-community participation in health governance. Professionals and administrators in health service and planning organizations must share power and control with CPCs if participation processes are to realize objectives of empowering users (Aronson, 1993). To address the interface between CPCs and health care professionals and to facilitate participation processes, Kidd et al. (2007) recommended the development of plans to address the power imbalances between consumers and health professionals. The authors elaborated that this could be encouraged by supporting clinicians to recognize the value in the consumer perspective, to respect experience as expertise.

Evaluate the effectiveness of participation activities. It is important to evaluate the effectiveness of citizen-patient-community participation activities to understand their success toward achieving the stated objectives, including improved decision-making and health outcomes, community ownership and empowerment, public trust and accountability, and inclusivity. The most useful indicators to measure the impact of CPC participation will vary according to the objective of the participation activity. These might include benefits to CPC participants, including learning new skills and leadership (Kenny A, 2013); outcomes for the community, including new infrastructure and health services, and implementation of a new public policy (Kenny A, 2013); and system-level outcomes, including public commitment to the health care system (Abelson J E. J., 2002); (Anton S, 2007), efficiency of the health care system (Abelson J E. J., 2002), accountability and increased local employment positions (Kenny A, 2013).

Recommendations

There is evidence that effective models of citizen-patient-community involvement in health care planning and service delivery lead to care that reflects the needs of local communities (P. Barnett, 2001); (D. Rose, 2014). There is an opportunity and a mandate to integrate citizen-patient-community-led rural health councils (and thereby, citizen-patient-community voices) within the emerging infrastructure of the Primary Care Networks in British Columbia, through the objectives of quality improvement and patient-centred care. In light of the evidence presented here, we recommend the following:

- I. Rural health councils be established in alignment with B.C.'s Primary Care Networks to realize the provincial commitment to patient-centered care and to prioritize the value of citizen-patient-community voices in health care planning. These boards should:
 - a. Have the mandate of planning for local services be based on best available local data, in conjunction with the Divisions of Family Practice and other local infrastructure to mobilize collaboration between community agencies and institutions;
 - b. Be resourced with skilled facilitators trained to manage CPC participation and input;
 - c. Be made of a collaboratively-determined ratio of appointed and elected local citizen-patient-community representatives based on knowledge, skills and demographic stratification to ensure representation;
 - d. Adhere to a province-wide framework for health council development including a shared mandate and scope of responsibilities, but also allow flexibility to respond to local community needs;
 - e. Make stipends available to all citizens-patients-community members for their participation;
 - f. Create realistic expectations among council members, delimiting the scope of influence of the council;
 - g. Be provided with current and relevant data regarding both local health issues and how the local community fits into the larger provincial context;

- h. Synthesize and utilize the health system data routinely collected through, for example, facilities, MSP billings and Pharmanet, alongside data on comprehensive costs to gain a clear and realistic understanding of system utilization by region and the associated outcomes. This data must be understood alongside CPC voices.
- II. Indigenous community leadership consider the needs of Indigenous-specific rural health councils, which may mirror existing band and health council structures or may require modification to meet the renewed mandate of citizen-patient-community voices in health care planning;
- III. An accountability framework parallel to the Primary Care Network accountabilities be clearly articulated with ultimate accountabilities for rural health councils reaching a provincial level (i.e., Ministry of Health, GPSC);
- IV. An evaluation of the effectiveness of rural health councils be integrated into the larger evaluation metrics of the Primary Care Networks.

About the Rural Evidence Review

The Rural Evidence Review (RER) project is a joint initiative between the Centre for Rural Health Research (Department of Family Practice, University of British Columbia) and the Rural Coordination Centre of British Columbia. The RER is funded under Canada's Strategy for Patient-Oriented Research (Canadian Institutes for Health Research). The goal of the project is to work with rural citizens-patients-communities to provide high quality and useful evidence for rural health services planning in British Columbia, Canada. To do this, we: (1) ask rural citizens-patients-communities about the health care priorities that matter the most to them and their communities, (2) review the international evidence to learn about best practices from other jurisdictions, and (3) share what we learn with policy- and decision-makers and rural communities across the province.

To learn more:

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