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RER

Rural Evidence Review

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

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About the Rural Evidence Review

The Rural Evidence Review (RER) project is a joint collaboration 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 most to them and their communities, (2) review the international evidence on what we hear, and (3) share what we learn with policy- and decision-makers and rural communities across the province.

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Key Terms

Citizen-Patient-Community (CPC)

For the purposes of the current scoping review, the term 'Citizen-Patient-Community' is used as a catchall to refer to patients, families, caregivers, citizens, communities, the public, lay persons, service users, and consumers.

Rural Health Council (RHC)

For the purposes of the current scoping review, the term 'Rural Health Council' is used as a catchall to refer to committees, boards and councils with rural health care planning, decision-making and/ or delivery functions.

Abstract

The importance to involve 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 hospitals 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 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. To this end, the current scoping study aimed to understand the value of CPC participation in health care planning, decision-making and delivery through rural health councils.

The scoping study asked: *'What is the structure, function and impact of rural health councils that include citizens-patients-communities in health care planning, decision-making and delivery activities?'*

The scoping study yielded evidence on the rationales for citizen-patient-community participation, the structure and function of rural health councils, including the role of CPCs on the councils, the importance of and how to support CPC participation, including through capacity-building and offering compensation, measures of effectiveness for participation activities, and barriers to CPC participation.

There is evidence that effective models of CPC involvement in health care planning and service delivery lead to care that reflects the needs of local communities. There is an opportunity and a mandate to integrate citizen-patient-community-led rural health councils (and CPC voices) within the emerging infrastructure of the Primary Care Networks in British Columbia, through the objectives of quality improvement and patient-centred care. The scoping review yielded evidence to support the following **recommendations**:

- (1) Rural health councils be struck in alignment with the Primary Care Networks to realize B.C.'s commitment to patient-centered care and to prioritize the value of citizen-patient-community voices in health care planning.
- (2) 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 CPC voices in health care planning;
- (3) An accountability framework parallel to the Primary Care Network accountabilities be clearly articulated with ultimate accountabilities for rural health councils reaching a provincial level (Ministry of Health, GPSC);
- (4) That an evaluation of the effectiveness of rural health councils be integrated into the larger evaluation metrics of the Primary Care Networks.

Executive Summary

Introduction & Context

The importance to involve 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 primarily 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 hospitals 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 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. To this end, the current scoping study aimed to understand the value of CPC participation in health care planning, decision-making and delivery through rural health councils.

Methods

The review asked:

What is the structure, function and impact of rural health councils that include citizens-patients-communities in health care planning, decision-making and delivery activities?

A scoping review methodology was used to understand the major concepts that underpin this topic of research to, ultimately, summarize and disseminate the research findings for their application to health care planning activities in British Columbia, Canada. Derivatives of the keywords 'rural', 'governing board' and 'community participation' were applied to five electronic databases: MEDLINE (Ovid), EMBASE (Ovid), CINAHL, PAIS Index and Web of Science. In addition, the reference lists of publications deemed highly relevant (n = 5) and their citing publications were searched for additional studies. In total, 2,530 records were identified. Following the removal of duplicate titles (n = 876) and the application of eligibility criteria to 1,654 citations and 233 full-text publications, 58 publications were selected for inclusion in the scoping study.

Findings

The scoping study yielded evidence on the rationales for citizen-patient-community participation, the structure and function of rural health councils, including the role of CPCs on the councils, the importance of and how to support CPC participation, including through capacity-building and offering compensation, measures of effectiveness for participation activities, and barriers to CPC participation. What follows is a more detailed description of the review findings.

- There are multiple rationales to involve citizens-patients-communities in health care planning, decision-making and delivery activities, including to improve decision-making and population health outcomes, to ensure public trust and accountability, and to promote inclusivity, community ownership and community empowerment.
- There is no 'one-size-fits-all' model (structure, function) for successful CPC participation in health care activities.
- As members of rural health councils, CPCs might be involved in identifying and defining issues and priorities; developing strategies to address identified priorities; implementation; resource management; and monitoring and evaluation.
- Successful CPC participation requires support in the form of capacity building (orientation and training) to ensure that CPCs feel adequately equipped to fulfill their council responsibilities, and compensation for their time dedicated to their role as council member.
- The literature included for review emphasized the importance of particular attributes (knowledge, skills, qualities and demographics) that are important for successful CPC participation, including leadership skills, trustworthiness, experience in and commitment to local matters, knowledge of the organization, health and health care (including local health needs), and diversity of ethnicity, age, gender, geography and occupation.
- It is important to evaluate the effectiveness of CPC participation activities to understand their success toward achieving their stated objectives.
- 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, outcomes for the community, and system-level outcomes.
- There is evidence that effective models of CPC involvement in health care planning and service delivery lead to care that reflects the needs of local communities.
- Barriers to successful CPC participation in health care activities include a lack of a clear definition of CPC participation with multiple (and perhaps, conflicting) objectives for involvement; their reluctance to participate; the challenging interface between CPCs and the health system; the complexity of health care issues; conflict of interest, especially within rural health councils; and the representativeness of CPC participants.
- In response to the challenges for participation, it is recommended to make clear for CPCs how their input will be included in health care activities and prioritized; to specify the objectives for CPC participation at the outset of an activity to ensure that the roles and responsibilities for CPCs are targeted appropriately; to address power imbalances between CPCs and health professionals; to establish clear and well-enforced conflict of interest policies; and to ensure appropriate funding to support CPC participation activities.

Discussion & Recommendations

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.

B.C.'s Primary and Community Care (PCC) initiative aims to improve the performance of the primary and community health care systems through multiple activities, including to connect key stakeholders for their input on the quality of clinical services, system efficiency and productivity; to engage patients in their own care; and to optimize engagement with, and the capability of, primary and community care providers to ensure that working conditions correspond to local needs, professional and patient. Within the PCC initiative, Primary Care Networks serve as the consolidation of the PCC activities, connecting primary care clinics, community health centres and where applicable, urgent primary care centres. The Networks are anticipated to enable more effective leveraging of locally available resources for local access to comprehensive primary care, as well as evaluation and quality improvement activities at the clinic-level. Therefore, the infrastructure of the Primary Care Networks provides an opportunity to integrate citizen-patient-community-driven health councils to represent and voice the needs and priorities of communities within a quality improvement, data-driven mechanism.

The scoping study yielded evidence to support the following **recommendations**:

- (1) Rural health councils be struck in alignment with the Primary Care Networks to realize B.C.'s commitment to patient-centered care and to prioritize the value of citizen-patient-community voices in health care planning. Based on the literature reviewed, 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 CPC 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 CPC 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.
- (2) 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 CPC voices in health care planning;
- (3) An accountability framework parallel to the Primary Care Network accountabilities be clearly articulated with ultimate accountabilities for rural health councils reaching a provincial level (Ministry of Health, GPSC);
- (4) That an evaluation of the effectiveness of rural health councils be integrated into the larger evaluation metrics of the Primary Care Networks.

Introduction & Context

Over the past decade, British Columbia has increasingly recognized the importance of patient involvement in health care, and, more recently, codified this as a strategic priority through 'The British Columbia Patient-Centred Care Framework' (B.C. Ministry of Health, 2015a). Although the framework is primarily focused on patient involvement in their own care, there is also an invitation for *"patients, families and caregivers ... to participate in: quality improvement and health care redesign"* (B.C. Ministry of Health, 2015a, p. 2). This mirrors similar initiatives in Ontario ('Patients First - A Proposal to Strengthen Patient-Centred Health in Ontario', 2015), Alberta ('Strategic Direction - Defining our Focus/ Measuring Our Progress', 2009 - 2012), Saskatchewan ('Patient First Review Update - The Journey So Far and the Path Forward', 2015) and other jurisdictions across Canada (New Brunswick, Manitoba, Northwest Territories, and Nova Scotia). Underscoring this direction is the pragmatic awareness of the need for productive relationships between researchers, health care professionals and policy-makers to *"ensure a patient-oriented approach that improves both practice and treatment"* (B.C. Ministry of Health, 2015a). It is a short - although conceptually essential - step to recognize "community", either by place or intent, as synonymous with patient and applicable to the larger patient-oriented frameworks driving health care improvement. This is particularly important where participation in health planning is understood through a rural lens and the characteristics of rural communities are recognized, including increased transparency in decision-making, the dual roles that many people hold, and the sometimes longitudinal relationships that exist. The questions that then arise include those of how we include citizen-patient-community (CPC) in health care planning and the question begged by the conceptual shift from the individual to the community of "who speaks for community". These questions of 'how' and 'who' plague rural health planners and have not seen resolution despite the growing imperative for patient-community-centered planning. To this end, this review was undertaken to explore historical and international models of effective ways to increase the role of CPC voice in health planning with applicability to rural British Columbia. Additionally, we recognize the reciprocal value of rural health councils in being a conduit for decision maker-community communication in a way that allows the clear expression of the rationale for decisions to be shared with those whom such decisions will affect.

The challenge of CPC inclusion in health system decision-making in British Columbia

predates the Patient-Centered Care Framework and can be traced back to the B.C. Royal Commission on Health Care and Costs (1991); the commission itself motivated by the need for increased system organization and thoughtful short- and long-term planning objectives. The author, Justice Peter Seaton, suggested that previous health care reforms focused on immediate need (usually at crisis point) and thus lacked a broader societal view (B.C. Royal Commission on Health Care and Costs, 1991). This was in part due to policy makers' alienation from CPC experiences, which, it was argued, could be addressed through administrative decentralization with the goal of health care "*closer to home*" (this became the familiar title of the Seaton report). Democratic CPC participation in health care as critical to local decision-making underscored the vision of how the recommendations would be actualized to reach the broader goal of increased CPC control over their health leading ostensibly to improved population health.

The New Democratic Party government of the day responded to the report by embracing decentralization and putting into action key recommendations, first through the creation of 82 Community Health Councils (CHCs) and 20 Regional Health Boards (RHBs) (B.C. Ministry of Health & Ministry Responsible for Seniors, 1993). The purpose of the restructuring was to ensure a mechanism for hearing and responding to local health concerns, which were understood to vary by regional geography; a key part of the new provincial model was CPC participation in both the CHCs and RHBs. However, this provincial infrastructure was soon deemed too cumbersome and constricted to 34 CHCs and 11 RHBs and a new structure, "Community Health Societies", for a total of 52 Health Authorities (B.C. Ministry of Health & Ministry Responsible for Seniors 1995). Local and regional accountability was to be ensured by public elections to health boards, although this later shifted to provincial appointment of health board members. Davidson (1999) reported that the shift from elected to appointed health boards signaled a sea-change in the intent of the province, namely from political accountability to managerial accountability. Kornelsen et al. (2005) noted that "*Appointees to the governing structures of the B.C. Liberal era were more likely than their predecessors to be drawn from business and professional ranks than previously, increasing the perception that fiscal and managerial accountability were their key mandates*" (p. 33).

Although there is dissent regarding the utility of health boards and concerns of, for example, the domination of special interest groups (Veenstra & Lomas, 1999), the vision of enhanced public participation in health system decision making expressed in

the Seaton report through participation in hospital boards remained into the 2000s, although under a renewed government commitment to reduce bureaucracy and increase accountability. This gave rise to further health care restructuring which resulted in the current five geographic Health Authorities, the Provincial Health Services Authority and what eventually became the First Nations Health Authority (B.C. Ministry of Health Planning, 2001). Along with this restructuring, however, came the disbandment of local hospital boards with the assurance that the new optimized regional structure of health service delivery would ensure local citizen engagement and involvement, although the precise mechanism of this engagement was not immediately evident. Most agree that a robust replacement to local hospital boards has not been achieved and, consequently, local community voice has been diminished. Despite this, other initiatives in British Columbia offer promise to actualize true CPC participation, namely B.C.'s Patient-Centered Care Framework, noted above.

One of the tacit challenges of citizen-patient-community participation in health care planning is definitional or, most importantly, the lack of consensus around the definition. British Columbia commonly uses the International Association for Public Participation's (IAP2) spectrum of engagement: inform, consult, involve, collaborate and empower (IAP2, 2018). This matrix explicitly states the goal of the engagement and the promise to the public attached to each level of engagement. Others have described the disparate stages of engagement as "traditional models" (geared toward information and servicing), "transitional stages" (geared toward consumer involvement to receive information and advice) and "idea type" (geared toward consumer involvement within an accountability framework) (McGrath & Grant 1992, c.f. Aronson, 1993). Regardless of the theoretical underpinnings of engagement, however, the question of purpose is essential to grapple with. The Australian Government Department of Health (2016) uses a comprehensive, high-level mandate for the Community Advisory Committee boards: "[to] provide a community perspective to the Primary Health Network Board to ensure that decisions, investments and innovations are appropriately patient-centred, cost-effective, locally relevant and aligned to local care experiences and expectations" (p. 46). From this vantage point, the boards are seen as a way for consumers to influence primary care planning and delivery (McClellan & Trigger, 2017; ACSQHC, 2008). Although other jurisdictions have nuanced definitions that best meet their mandate, the underscoring principle is recognizing the crucial role of local CPCs in providing input into local health care. As we will see below, the issue of method (how CPCs are optimally engaged) is

more variable and is generally in response to the specific needs of the community and the health planning responsibilities. British Columbia has formally adopted the 'Patients as Partners' initiative (B.C. Ministry of Health, 2007) to include and integrate patient voice into decision-making about health care. Canada's Strategy for Patient-Oriented Research (SPOR) Support for People and Patient-Oriented Research and Trials (SUPPORT) Units are well-placed to revise and refresh this existing approach.

Regardless of precise definitions and methods of citizen-patient-community engagement, however, the principles underscoring successful engagement rest in a tacit understanding that health services and policy evidence must be situated in a framework inclusive of the specialized knowledge yielded from science-based methodologies but extended also to recognition of individual knowledge, local and community knowledge, organizational knowledge and holistic knowledge (Brown, Harris & Russell, 2010). In this way, incorporating the citizen-patient-community voice is part of a paradigm shift away from normatively valuing scientific evidence (easily measurable) at the cost of alternate forms of knowledge (not easily measurable). CPC experience is at the core of this new paradigm and citizens-patients-communities are encouraged to be active participants in their own care and decisions about that care. For this vision to actualize, however, CPC involvement must be met by a system recognition of the value of such involvement and established mechanisms and accountabilities for including the yields of patient voice (either in real-time or through collected data) in decision-making. Actualizing these principles is essential to ensuring authentic CPC representation in policy development. There is an opportunity through our current focus on CPC engagement to enact this agenda through B.C.'s Primary and Community Care (PCC) initiative (B.C. Ministry of Health, 2015b).

The PCC initiative is currently in its second phase of integration (2018/19-2020/21) and one key activity to improve the performance of the primary and community health care systems is through the linkages of multiple key stakeholders for input on quality of clinical services delivered and overall system efficiency and productivity. There are also the parallel objectives of engaging patients in their own health care and optimizing the engagement with and capability of primary and community health care providers to ensure the working conditions correspond to local needs (both professional and patient); although it remains a question to see how (or if) these two disparate threads will be brought together. The objectives of the consolidation of this activity, Primary Care Networks, provide the glue to link together

primary care clinics, community health centres and, where applicable, urgent primary care centres. Through this linkage, health planners anticipate more effective leveraging of locally available resources for local access to comprehensive primary care. The B.C. Ministry of Health's Primary and Community Care plan further anticipates that within the rubric of the Primary Care Networks, individual clinics will engage in evaluation and quality improvement initiatives.

This emerging infrastructure provides opportunity to integrate local CPC-driven health councils to reflect the needs of the community within a quality improvement, data-driven mechanism. At a local level, this would require CPC-led councils to work alongside the operational leadership and implementation steering committees. These complimentary although distinct committees could ostensibly feed into Regional Health Authority leadership and, ultimately, provincial tables advising on implementation (e.g., GPSC). The exact mechanism of integration and accountability may be unclear due to the currently emerging PCN structures; the point, however, is that we currently have an opportunity to cement citizen-patient-community input for health service delivery into emerging structures.

We need, however, a framework conducive to making these linkages. This will involve developing accountabilities by answering the question, *'What culture change needs to occur to increase receptivity of the output of CPC-oriented voice into policy and decision making?'* The approach involves grappling, in close collaboration between communities and decision-makers, with questions, such as:

How do we weigh the desired or potential influence of citizen-patient-community voice (however it is represented) alongside other policy influences?

What are the 'lessons learned' from discrete location consultations that can be applied more broadly?

Addressing these questions will require the development of an approach to clearly understand the enablers and barriers in policy/ decision-making environments and expert panel discussions on how to address them. The current review considers best available international evidence through a rural lens to offer broad suggestions of how we can systematize and entrench CPC voices into health care planning as one way of meeting the mandate of B.C.'s Patient-Centered Care Strategy and of the Academic Health Sciences Network.

We recognize distinct protocols and mechanisms may be needed to actualize local input within Indigenous communities. Represented in this review are two published examples of case studies that, although helpful, underscore the need for more Indigenously-specific exploration of Indigenous voice in health care decision-making and planning. Again, however, this can align well with provincial commitments to advancing the resolutions of the 'Truth and Reconciliation Calls to Action' (Truth and Reconciliation Commission of Canada, 2012) and the 'United Nations Declaration on the Rights of Indigenous Peoples' (United Nations, 2007).

Finally, this report, like all reports done through the Rural Evidence Review project (Centre for Rural Health Research/ Rural Coordination Centre of B.C.), has prioritized the issue of citizen-patient-community involvement through a rural lens and to this end, sought out evidence and examples that would illuminate citizen-patient-community voice in rural B.C. The question of how this may be accomplished in larger centres with blurred population catchments has not been addressed and, although relevant, requires a different approach to the literature. Below we review relevant literature on the rationale for citizen-patient-community involvement, the structure and function of rural health councils, the issue of support for citizen participation, measures of effectiveness and challenges for participation, through a rural lens. We believe this literature provides value to system planning in British Columbia.

Methods

Research Objective & Question

The objective of this scoping review was to strengthen our understanding of the value of citizen-patient-community participation in health care planning, decision-making and delivery through rural health councils. The topic was identified through the Rural Evidence Review project's online survey to understand the health care priorities of rural residents across British Columbia (<http://bit.ly/ruralevidencereview>), and confirmed as a strategic provincial and regional priority for health care in B.C. by the RER project's Expert Advisory Panel, comprised of representatives from the B.C. Health Authorities, the B.C. Ministry of Health, and other key stakeholders engaged in rural health care in the province.

The research question was:

What is the structure, function and impact of rural health councils that include citizens-patients-communities in health care planning, decision-making and delivery activities?

Scoping Review Method

The present literature review employed a scoping methodology, informed by both Arksey and O'Malley's (2005) methodological framework and the Joanna Briggs Institute Reviewers' Manual (2015) for the conduct of scoping studies. In contrast to other review methodologies, the scoping study method is guided by a more broadly defined research question and objective, and the obligation to identify all relevant literature regardless of research design (Arksey & O'Malley, 2005; JBI, 2015). In the present case, a scoping review methodology allowed for the exploration of a broad topic of research where multiple research designs were applicable, to understand the major concepts underpinning the area of research as well as the nature and breadth of the relevant evidence (Arksey & O'Malley, 2005). The ultimate aim of the scoping study was to summarize and disseminate the research findings such that they may be applied to health planning activities in British Columbia.

Eligibility Criteria

The eligibility criteria serve as the basis for which sources of information are considered for their inclusion in the scoping review (JBI, 2015). The inclusion and exclusion (i.e., eligibility) criteria were developed iteratively and finalized *onrsqnb*, based on increased familiarity with the literature (Arksey & O'Malley, 2005) and included the following:

Inclusion Criteria

- Publications focused on systemic and sustained mechanisms of citizen involvement or leadership in health care planning, decision-making or delivery through health councils
- All research designs were considered eligible.
- Publications were limited to high-income countries, as defined by the World Bank (2018).

Exclusion Criteria

- Publications that described *ac tgnb* or one-off initiatives for citizen involvement in health service planning, decision-making or delivery through health councils.
- Non-English language publications.
- Articles published before the year 1990*.

*This limit was not applied during citation searching activities.

Search Strategy

The literature search was conceptualized and conducted by one reviewer (CC) in consultation with the Principal Investigator (JK) and the University of British Columbia's Medical Liaison Librarian (KH). The following five databases were searched from inception until November, 2018: MEDLINE (Ovid), EMBASE (Ovid), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PAIS Index, and Web of Science. The literature search was not limited by research design, date or language of publication. However, non-English publications and materials published before 1990 were ultimately excluded due to limits on time and considerations of relevancy, respectively. The regionalization of health care in British Columbia was initiated in the 1990s, as articulated in the Seaton Commission (1991) and adopted in 1993 through the 'New Directions for a Healthy British Columbia' strategic plan, whereby 82 Community Health Councils were established. This real-world consideration guided our conceptualization of the appropriate time-frame to recover relevant literature. Note, the date limit was not applied during citation searching activities (see below), where foundational texts pertaining to citizen participation in health governance were retrieved and included for review (e.g., Arnstein, 1969).

The concepts underpinning the literature search were identified and defined by one reviewer (CC) in consultation with the Principal Investigator (JK) and the Medical Liaison Librarian (KH) (see below). The Medical Liaison Librarian (KH) offered support to identify the keywords and the databases most likely to return the appropriate citations to answer the research question. The final version of the search strategy was first employed in the MEDLINE (Ovid) database and then converted for all subsequent databases. The search strategy as employed in the MEDLINE (Ovid) database is included as Appendix A.

Table 1: Search Concepts

Citizen-Patient-Community Participation in Health Care Planning, Decision-Making and Delivery through Rural Health Councils		
<i>Concept</i>	<i>Keywords</i>	<i>Reasoning</i>
Rural	<p><u>Keywords:</u> Rural*</p> <p><u>MeSH:</u> Rural Health Rural Population Rural Health Services Hospitals, Rural</p>	<p>The objective of the scoping study is to understand the value of citizen-patient-community participation in health care planning, decision-making and delivery through rural health councils, specifically. For this reason, the following keywords and subject headings were applied to limit the search to publications that describe rural and remote populations and health contexts. Note, this concept was not applied during citation searching activities.</p>
Community Participation	<p><u>Keywords:</u> Communit*, Public*, Consumer*, Citizen*, Local, Patient*, User*, “Civil Society”</p> <p><u>MeSH:</u> Community Participation Community-Institutional Relations</p>	<p>The ‘Community Participation’ concept, together with the ‘Governing Board’ concept, aimed to capture the literature that addressed CPC involvement in health care activities and CPC relations with health service organizations.</p>
Governing Board	<p><u>Keywords:</u> “Foundation Trust*”, (Health* OR Hospital* OR Govern* OR District* OR Regional) ADJ3 (Authorit* OR Council* OR Board*)</p> <p><u>MeSH:</u> Governing Board Health Planning Organizations</p>	<p>This concept aimed to capture the literature that addressed rural health councils. The scope of the MeSH term ‘Governing Board’ captures the intent of the concept, described as: “The group in which legal authority is vested for the control of health-related institutions and organizations” (MeSH Browser, 1994).</p> <p>Note, all concept keywords were limited to the last five years in the MEDLINE database. This was due to the volume of retrieved titles in the absence of the limit and time constraints on behalf of the research team, and based on the assumption that articles published more than five years prior will be indexed appropriately in the database and will be captured through use of the targeted MeSH terms. The keywords were not limited in the Embase and CINAHL databases, due to the absence of targeted Subject Headings for this concept in the Embase database and due to the small volume of retrieved citations in the absence of this limit in the CINAHL database.</p>

Citation searching was employed by two reviewers (CC, ZY) using the Web of Science database; the reference lists of publications deemed highly relevant and their citing publications were searched for additional studies. The publications for which citation searching was used include: Guzy et al. (2017), Abelson et al. (1995), Pickard et al. (2002), Elder & Amundson (1991), and Kenny et al. (2017).

A total of 2508 records were identified through database searching. Following the removal of duplicate titles (n = 876), one reviewer (CC) applied the eligibility criteria to the titles and abstracts of the remaining records (n = 1632) to determine their relevance. 211 citations were deemed potentially relevant and their full-texts were assessed for eligibility for inclusion in the scoping review by two reviewers (CC, ZY). An additional 22 citations were retrieved through citation searching activities; the eligibility criteria were applied to their full-texts to determine their relevance. Following the review of the full-texts, 58 publications were selected for inclusion in the scoping review (Appendix B).

Type and Nature of Included Studies

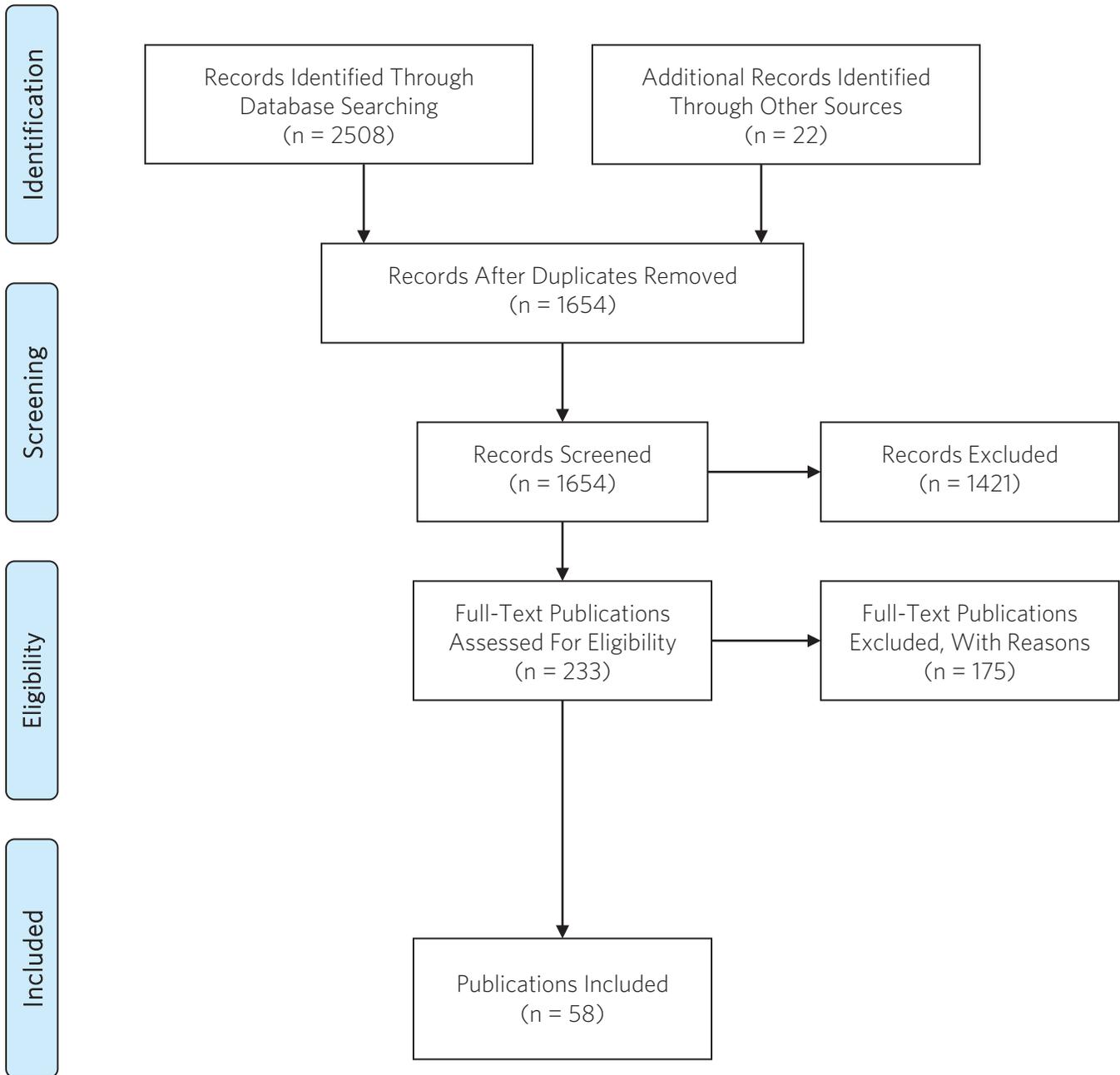
In accordance with the protocols of Arksey and O'Malley (2005) and the Joanna Briggs Institute (2015) for the conduct of scoping studies, all literature was eligible for review regardless of research design, methodology and sample size. A hierarchical ranking of evidence design was not employed.

58 publications were included for review. The types of evidence represented include case studies, qualitative interviews, surveys, discussion papers, conceptual frameworks, narrative descriptions, evaluations, literature reviews, a Delphi study, and a commissioned report. The jurisdictions from which the literature was derived included: Canada, Australia, the United States of America, Finland, New Zealand, and the United Kingdom. Two literature reviews include international evidence across multiple jurisdictions.

Data Extraction Process

The data extraction process - or 'charting the results', as it is referred to in scoping studies - is intended to produce a summary of the results of each included publication, guided by the question and the objective of the scoping study (JBI, 2015). In the present case, two reviewers (ZY, CC) performed data extraction alongside the appraisal of the quality of the included literature, using a combined data extraction and

PRISMA Flow Diagram



critical appraisal form (Appendix C). Our approach to quality appraisal was informed by the 'Meta-Tool for Quality Appraisal for Public Health Evidence' (Public Health Ontario, 2016). This tool is well-suited for appraising heterogeneous evidence, as it is both flexible and specific, with broad utility and the capacity to assess publication-specific factors in detail (PHO, 2016).

Limitations

A limitation of the present study includes applying the 'Rural' concept to the database search. Additional relevant citations might have been identified in the absence of this concept; however, it is the mandate of the Centre for Rural Health Research to conduct rigorous research through a rural lens, and the objective of the Rural Evidence Review project to produce high quality evidence that is relevant to rural communities, and therefore, this concept was deemed essential. Moreover, due to limits on time, citation searching was confined to those publications deemed highly relevant to answer the research question. Additional applicable citations might have been identified through comprehensive citation searching of all publications included for review. A final limitation of the scoping study includes considering only English language publications.

Findings

Rationale for Citizen-Patient-Community Participation

- The literature included for review offered multiple rationales to involve citizens-patients-communities in health care planning, decision-making and delivery activities, including to improve decision-making and population health outcomes, to ensure public trust and accountability, and to promote inclusivity, community ownership and community empowerment.
- 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.

The included literature offered multiple rationales for citizen-patient-community participation in health care planning, decision-making and delivery activities. Forty-one of the 66 publications included for review emphasized one or more reasons to include CPCs in health care activities, including to improve decision-making and health outcomes, ensure public trust and accountability, and promote inclusivity, community ownership and empowerment.

Improved Decision Making

The most commonly cited rationale for CPC participation in health care activities was improved decision making that considers and incorporates their needs and preferences (Abelson et al., 2002; Abelson et al., 1995; Anton et al., 2007; Aronson, 1993; Barnett & Barnett, 2001; Charles & DeMaio, 2017; Farmer et al., 2017; Hemingway & MacLeod, 2004; Hudson, 1996; Hurley et al., 1995; McClean & Trigger, 2017; Pagatpatan & Ward, 2017; Saleh et al., 2002; Nova Scotia Blueprint for Health System Reform, 1994).

Skinner et al. (2016) reported that involving CPCs in decision making processes provided a local voice to ward against perceived threats to local services (Skinner et al., 2016). Additionally, Australian Primary Health Networks (PHNs) include infrastructure for Community Advisory Committees (CACs) to ensure that decisions are patient-centered, cost-effective, locally relevant and aligned to local experiences of care (McClean & Trigger, 2017). Moreover, Saleh et al. (2002) observed that the involvement of community leaders on rural hospital governing boards in Iowa and Nebraska, U.S.A., aimed to support strategic decision making to enhance the public's trust and improve hospital performance. Finally, in Canada, the Nova Scotia Blueprint for Health System Reform (1994) reported that Nova Scotia residents wanted to have input into the decisions that affect their health, including decisions around access to, distribution and quality of health care.

Taken together, the rationale for citizen-patient-community involvement in health care decision making is rooted in an appreciation of the experience and wisdom of lay CPCs, which can be harnessed to increase the local relevance of health care planning and delivery activities (Hemingway & MacLeod, 2004; Hudson, 1996; Aronson, 1993; Humphreys, 1997; Merkens & Emmerson, 1995).

Inclusivity

'Inclusivity' was frequently cited as an imperative for CPC participation in health care activities, in particular to enable the participation of minority groups (Arnstein, 1969; Elder & Amundson, 1991; Hogg & Williamson, 2001; Simpson & Kirby, 2004). Arnstein (1969) described CPC participation as the redistribution of power to enable those who are presently excluded from political and economic processes (the "have-nots") to be included moving forward. The author elaborated that CPC participation serves to induce significant social reform, enabling the have-nots to contribute toward decisions around information sharing, priority setting, resource allocation, program operations and so on, and thereby to share in the benefits of affluent societies (Arnstein, 1969). Hogg and Williamson (2001) described the *Snublistrik r hm* approach, which aims to safeguard the public interest by appreciating the views of CPCs who have neither professional self-interest nor commercial links to the health care industry. Simpson and Kirby (2004) argued that inclusivity serves to "level off" the administrative bent of health care decision-making:

"... in this way, the interests of rural facilities and disadvantaged social groups are less likely to be lost in the re-writing of policy drafts at senior health professional and administrative levels where institutional politics may play out in nonconstructive ways" (Simpson & Kirby, 2004, p. 281).

Public Trust and Accountability

Several authors reported that CPC participation is primarily concerned with gaining the public's trust and ensuring accountability to the public for the processes within and the outcomes of the health care system (Charles & DeMaio, 2017; Hogg & Williamson, 2001; Hurley et al., 1995; Pagatpatan & Ward, 2017; Pickard et al., 2002; Singer, 1994; Tritter & McCallum, 2006; Wright, 2013; Abelson & Eyles, 2002). For instance, reform to the National Health Service in the 1990s placed emphasis on democratic accountability, rights of citizenship, partnership, empowerment and choice. The "New NHS" involved the establishment of district health authorities that included CPCs in setting priorities as a way to increase the public's confidence in the NHS (Singer, 1994; Pickard et al., 2002). Moreover, community health centre board members across fourteen U.S. states indicated that CPC representation on the board

was important to convey confidence in the organization; the CPC board members suggested to members of their communities that they believed in the organization, including the quality of care provided (Wright, 2013). Finally, Charles and DeMaio (2017) cited increased public accountability for decisions regarding health care resource allocation as a factor that has stimulated interest in Canada for CPC participation in health care decision-making. The authors suggested that increased public accountability is important to make providers more accountable to the communities that they serve (Charles & DeMaio, 2017).

Community Ownership and Empowerment

Lastly, the literature included for review described 'community ownership' and 'community empowerment' as key reasons for CPC involvement in health care activities (Barnett & Barnett, 2001; Elder & Amundson, 1991; Farmer et al., 2017; Hogg & Williamson, 2001; Kenny et al., 2017; Robinson et al., 2003; Rose et al., 2014; Wade & Radford, 2005). To exemplify, Kenny et al. (2017) reported that CPC participation creates self-determining, empowered communities, who then contribute to the provision of locally responsive health care leading to improved health outcomes. In addition, Elder and Amundson (1991) perceived participation as a mechanism to empower CPCs, thereby ensuring broad responsibility for the future of the health care system. Similarly, Farmer et al. (2017) suggested that participation enhances the responsibility of CPCs in health care activities by making them co-producers of health; their role in health care activities is expanded from consumer to producer-consumer. Finally, Robinson et al. (2003) described the Australian Aboriginal Coordinated Care Trials (CCTs) whereby Aboriginal Health Boards were established to develop Aboriginal participation in health care planning, allocation, management and coordination. The anticipated contribution of the Health Boards was to establish improved control of health services by the participating communities (Robinson et al., 2003). The authors reported that the creation of the CCTs and Health Boards established the potential for Aboriginal involvement in high-level health care decision-making of a kind previously unknown, through their participation in consultative processes and the creation of Aboriginal organizations with legitimacy and resources (Robinson et al., 2003).

Improved Health Outcomes

The literature included for review emphasized the importance of CPC participation in health care activities for improved health outcomes (Bismark & Studdert, 2014; Kidd et al., 2007; Robinson et al., 2003 ; Rose at al., 2014; Wright, 2013). For instance, Kidd et al. (2007) cited Jacobsen and Curtis (2000), who reported that CPC input into mental health services has the potential to shape and to improve treatments and models of service delivery. Moreover, Wright (2013) reported that the aspirations that underpin efforts to empower CPCs to make decisions about their health care are to improve access and quality of care, while simultaneously controlling costs. The author interviewed thirty community health centre board members from fourteen U.S. states to understand the role of consumers on the boards; respondents described the importance of CPC participation in governance activities to provide feedback about the quality of care during the clinical encounter (Wright, 2013).

Structure and Function of Rural Health Councils

- There is no 'one-size-fits-all' model (structure, function) for successful citizen-patient-community participation in health care activities.
- As members of rural health councils, citizens-patients-communities might be involved in governance, planning, resource allocation, evaluation, and quality improvement activities.
- The literature included for review emphasized the importance of particular attributes (knowledge, skills, qualities and demographics) that are important for successful CPC participation, including leadership skills, trustworthiness, experience in and commitment to local matters, knowledge of the organization, health and health care (including local health needs), and diversity of ethnicity, age, gender, geography and occupation.

Function

The literature included for review described the structure and activities of several council models from international jurisdictions where CPC participation was integral to their composition and operation (Blueprint for Health System Reform, 1994; Andrews et al., 2014; Bismark & Studdert, 2014; McClean & Trigger, 2017; Robinson et al., 2003; Weiner & Alexander, 1993; Greene, 2002; Knoble, 1993; Larson, 1999; Karash, 2016; Kralewski & Moscovice, 1992; Longley, 1999; Rosenthal et al., 1991; Wilson et al., 1993; Hemingway & MacLeod, 2004; Hurley et al., 1994; Riley & Elder, 1991; Hudson, 1996; Nelson & Gauss, 2016; Pickard et al., 2002; Tritter & McCallum, 2006; Veronesi & Keasey, 2012; Wright, 2013). As members of the councils, there were multiple health service activities in which CPCs might participate, including but not limited to: identifying and defining issues and priorities; developing strategies to address identified priorities; implementation; resource management; and monitoring and evaluation (Farmer et al., 2017; Abelson et al., 1995; Hogg & Williamson, 2001; Pickard et al., 2002; Robinson et al., 2003; Charles & DeMaio, 2017; Tritter & McCallum, 2006).

There is not an industrial model (“one-size-fits-all”) for citizen-patient-community participation in health care activities. What follows are exemplar models from international jurisdictions to inform the range of possibilities for CPC participation in B.C.

New Mexico’s Community Health Councils, United States of America

New Mexico’s Community Health Councils were described as assessing, planning and coordinating bodies, with the goal to encourage the development of comprehensive, community-based and culturally appropriate health plans to meet the needs of the state’s CPCs (Andrews et al., 2014). The primary functions of the Health Councils included networking with community agencies, identifying health-related priorities and needs, conducting community health planning, educating the CPCs about health challenges, mobilizing and allocating resources, advocating for public policy objectives, and implementing and coordinating health programs and services (Andrews et al., 2014).

Public Health Services Boards, Victoria, Australia

Bismark and Studdert (2014) described the governing boards of public health services in Victoria, Australia. The statutory functions of the boards were to ensure the quality and effectiveness of health services through monitoring, quality improvement and issue management (Bismark & Studdert, 2014). This included setting priorities (including anticipating issues), measuring progress, ensuring accountability (i.e., holding staff accountable and engaging with consumers), and shaping culture. With regard to measuring progress, a rural board member explained: "I think outcomes, at the end of the day, are the yardstick by which you measure your governance progress. We have a good system of [quality indicators] in place to check and measure" (Bismark & Studdert, 2014, p. 477). Moreover, the chair of a regional quality committee offered the following impression of the board's role, and in particular, the citizen participants' involvement to ensure accountability:

"[There] should be a relatively short piece of string between the decisions we're making and the effect on the patient ... Community representatives have direct input in and get feedback out" (Bismark & Studdert, 2014, p. 477).

Community Advisory Committees, Primary Health Networks, Australia

Community Advisory Committees within Primary Health Networks in Australia are described as a structured mechanism for consumers to provide a community perspective on decision-making in primary care and to participate in planning health services (ACSQHC, 2008 c.f. McClean & Trigger, 2017). McClean and Trigger (2017) presented the experience of the Gold Coast Primary Health Network to establish and operate a Community Advisory Committee through use of the public deliberative model. This involves bringing together a representative group of community members, who are given balanced information on a topic and are supported to consider multiple, diverse perspectives, to learn from other members, as well as to reflect on their own impressions prior to finalizing their opinion (McClean & Trigger, 2017). A skilled facilitator is critical to the success of this process to encourage and ensure open and respectful discussion (McClean & Trigger, 2017). The authors emphasized the importance of a "closed feedback loop" to successful CPC engagement, whereby care was taken to ensure realistic expectations among Advisory Committee members and impact was assured by presenting only issues or topics for discussion that were

directly related to the activities of the Primary Health Network (McClellan & Trigger, 2017).

Aboriginal Health Boards, Aboriginal Coordinated Care Trials, Australia

The Aboriginal Health Boards were established to develop Aboriginal participation in health service planning, allocation, management and agency coordination within four Aboriginal Coordinated Care Trials (CCTs) in the Northern Territory, Western New South Wales and Western Australia (Robinson et al., 2003). The Aboriginal Health Boards were described as fund holders and purchasers of services for trial populations (Robinson et al., 2003). Robinson et al. (2003) reported that the establishment of the CCTs and the Health Boards afforded legitimacy and resources to participants to enable them to mobilize collaboration between community agencies, to engage with external agencies that provide services to the communities, and to develop their own health priorities and health programming.

Hospital Boards, International Jurisdictions

At a local level, CPCs have served as members of hospital boards since their inception (Stone, 1920 c.f. Hogg & Williamson, 2001). Weiner and Alexander (1993) reported that the function of hospital boards is both varied and complex, resulting from multiple competing pressures, including institutional and historical forces. Therefore, it is unsurprising that the literature included for review offered multiple accounts of the activities of hospital boards globally (Greene, 2002; Knoble, 1993; Larson, 1999; Karash, 2016; Kralewski & Moscovice, 1992; Longley, 1999; Rosenthal et al., 1991; Wilson et al., 1993; Weiner & Alexander, 1993; Riley & Elder, 1991). Strategic planning emerged as a critical “success factor” for hospital boards (Greene, 2002; Knoble, 1993; Larson, 1999). Also included among hospital trustees’ responsibilities were to assess and advocate for CPC needs (Larson, 1999; Karash, 2016; Greene, 2002); design programs to address CPC needs (Rosenthal et al., 1991); assure the quality and safety of care (Karash, 2016); oversee hospital administration (Greene, 2002; Rosenthal et al., 1991); and raise revenue and manage financial resources (Longley, 1999; Rosenthal et al., 1991), among other activities.

Structure

The organization and composition of the committees, councils and boards described in the literature were varied, with no single structure emerging as 'ideal' or as 'best'. For instance, Weiner and Alexander (1993) observed that, within hospital boards specifically, board form varied according to the organizational and environmental characteristics of hospitals. With regard to CPC representation on councils, lay individuals comprised a portion (Andrews et al., 2014; Bismark & Studdert, 2014; Hemingway & MacLeod, 2004; Hudson, 1996; Nova Scotia Blueprint for Health System Reform, 1994) or the entirety (McClellan & Trigger, 2017) of council members. For instance, within New Mexico's Community Health Councils, citizen participants contributed alongside health service providers and local policy-makers as council members (Andrews et al., 2014). In contrast, in the case of the Community Advisory Committee within the Gold Coast Primary Health Network, it was believed that the inclusion of health providers on the CAC would dilute the community voice and be an inauthentic representation of CPC interests and therefore, providers were intentionally excluded (McClellan & Trigger, 2017).

Additionally, in a review of public participation in Quebec, Godbout and Leduc (1987 c.f. Hurley et al., 1994) found that having a majority of CPCs on a board was a necessary condition for meaningful citizen participation and empowerment. However, Checkoway (1981 c.f. Hurley et al., 1994) reported that majority representation by CPC members on local decision-making bodies did not ensure that their voices dominated, nor that their voices were heard in decision-making. Hurley et al. (1994) cited Steckler and Herzog (1979), who suggested that experts can dominate discussion, intentionally or otherwise, by framing discussions technically. Aronson (1993) elaborated that it is critical to consider how CPCs' relative lack of power and resources hinder their ability to participate through the 'official' routes of consumer participation.

There were several instances wherein councils utilized committee structures to strengthen their functioning (Riley & Elder, 1991; Bismark & Studdert, 2014; Hemingway & MacLeod, 2004; Umbdenstock et al., 1990). Riley and Elder (1991) described an intervention to improve the financial expertise of rural hospital board members; as a consequence of the intervention, finance committees were formed in

three of four participating communities that did not previously have them. Moreover, Hemingway and MacLeod (2004) detailed the Prince George Community Advisory Committee, within the British Columbia Northern Interior Regional Health Board, which established multiple sub-committees, or 'task forces', to address sector-specific health challenges, including the Task Force on Seniors' Health.

Council members might be elected or appointed, and identified by volunteering themselves or being nominated (Bismark & Studdert, 2014; Hemingway & MacLeod, 2004; Hurley et al., 1994; McClean & Trigger, 2017; Hogg & Williamson, 2001; Abelson & Eyles, 2002; Nova Scotia Blueprint for Health System Reform, 1994). The literature included for review emphasized the importance to consider the experiences, skills and knowledge, as well as the demographics of candidates to assure a balanced and representative council (Nelson & Gauss, 2016; Bismark & Studdert, 2014; Guzys et al., 2017; McClean & Trigger, 2017). For instance, within Victoria's Public Health Service Boards, members were appointed by the Minister of Health (Bismark & Studdert, 2014). The authors reported that there was frustration among several of the board chairs of the participating health services with regard to the boards' inability to decide who to appoint (Bismark & Studdert, 2014). One chair explained:

That skill matrix issue which is so dominant in good boards is not present in the health sector. Because the Minister decides. Did I recently get a communication expert to put in an application? Yes, I did. Was he selected? No. What did I get? A third accountant. So how can I as Chair be held to account in the same way as I would if I was actively involved in ensuring that my board had the right matrix of skills? (Bismark & Studdert, 2014)

In response, it was suggested that the process to appoint board members should be merit-based to achieve a balanced matrix of skills (Bismark & Studdert, 2014) and the expertise to address the specific priorities of the board (Umbdenstock et al., 1990). Similarly, within the Prince George Community Advisory Committee and specifically, the Task Force on Seniors' Health, task force members were selected by the members of the CAC. or by the Task Force itself once formed, for their particular skill set (Hemingway & MacLeod, 2004). The authors cited as a challenge that, due to the selection process, there was no public avenue for seniors to request to become

members and therefore, the task force and the CAC did not represent the diversity of citizens living within the boundaries of the Health Authority (Hemingway & MacLeod, 2004). To address skill- and representativeness-related barriers to CPC involvement, McClean and Trigger (2017) described the use of a knowledge- and skills-based criterion and demographic requirements within the Gold Coast Primary Health Network's Community Advisory Committee. The authors argued that determining the membership of the CAC was critical for the success of the committee and that this selection process ensured that the membership was as representative of the local CPC as possible (McClean & Trigger, 2017). However, Guzys et al. (2017) cautioned that the use of skill matrices to influence board composition during recruitment will likely preference the inclusion of those with higher educational attainment, thereby increasing the influence of the "elite".

Moreover, Hurley et al. (1994) described B.C.'s Community Health Councils, whereby participants were both appointed by the Minister of Health and elected by the public. In this case, the authors spoke positively about the processes to determine council membership, suggesting that the election and appointment processes assured public accountability (Hurley et al., 1994). However, Abelson and Eyles (2002) warned against the electoral process, citing the experience of health boards in Saskatchewan and Quebec, whereby only those with concentrated interests stood for election.

McClean and Trigger (2017) reported the importance to maintain consistency in the format of committee meetings for the success of CPC participation. The authors suggested that this consistency establishes a stable environment where members are made to feel comfortable and know what to expect (McClean & Trigger, 2017).

Finally, Umbdenstock et al. (1990) suggested that the best source of guidance in determining the proper structure for a board is its mission, goals and objectives.

The Role of Citizen-Patient-Community Participants

The literature included for review outlined multiple health service activities in which CPCs might participate, including governance, priority setting, planning, provision, evaluation, quality improvement, resource management, research, information design and practitioner training (Farmer et al., 2017; Abelson et al., 1995; Hogg & Williamson,

2001; Pickard et al., 2002; Robinson et al., 2003; Charles & DeMaio, 2017; Tritter & McCallum, 2006).

Hogg and Williamson (2001) distinguished the activities of CPCs at national and local levels in the United Kingdom; at the national level, CPCs are involved in, for example, government advisory committees and professional regulatory bodies, whereas at the local level, CPCs serve as members of hospital boards and audit committees, and are appointed as chairs and non-executive directors of health authorities, trusts and primary care groups, among other activities. In addition, Charles and DeMaio (2017) discerned three decision-making contexts: treatment, service delivery (i.e., resource allocation decisions for a defined service region) and system-level decision-making (i.e., macro-level health care allocation and policy decisions for a jurisdiction).

Abelson et al. (1995) explored the suitability and willingness of five groups (including randomly selected citizens, attendees at town hall meetings, appointees to district health councils, elected officials and experts in health care and social services) to take on overall and specific decision-making functions. The authors reported that 72% of the people polled (n = 189) expressed a personal willingness to take on a role involving responsibility for overall decision-making, while far fewer (30%) believed that their group was well-suited to taking on such a responsibility. In addition, the majority of citizens polled indicated less interest in being involved in specific decision-making activities, with the exception of planning and priority setting, than in overall decision making: 9% (n = 24) of participants believed that their own group was suitable to raise revenue, 33% (n = 91) rated their own group as well-suited to distribute funds and 39% (n = 108) felt that their own group was suitable to manage services (Abelson et al., 1995).

Who participates?

The literature included for review emphasized the importance of particular participant attributes for the success of CPC participation, including leadership skills (Anton et al., 2007; Jaklevic, 2002; Larson, 1999; Pirani et al., 1993; Hart et al., 1991), trustworthiness (Anton et al., 2007; Larson, 1999), experience in and commitment to local matters (Anton et al., 2007; Ramstead, 1992), knowledge of the organization, health and health care (Anton et al., 2007; Karash, 2016) including knowledge of local health needs (Guzys et al., 2017; Wright, 2013), knowledge of and experience in business (Barnett & Barnett, 2001; Jaklevic, 2002), finance and law (Kralewski &

Moscovice, 1992), expertise in strategic planning (Kralewski & Moscovice, 1992; Pirani et al., 1993; Hart et al., 1991), and creativity where resources are scarce (Ramstead, 1992).

However, with regard to the selection of CPCs with experience in business, Guzys et al. (2017) cited Keevers et al. (2012) and Maier et al. (2016), who suggested that restructuring not-for-profit boards and committees to include “business-like” and professional members might reduce advocacy in favour of service provision, disempower grassroots activists and increase the influence of the elite. Similarly, Longley (1999) refuted the importance of council members with expertise in business and finance. Instead, the author suggested that what is needed are resources to communicate to council members complicated financial issues (Longley, 1999).

Through the deliberative polling of 280 individuals in Ontario, Canada, Abelson et al. (1995) explored the willingness and suitability of specific citizen groups for decision-making responsibilities. The author reported that elected officials were the most willing to take responsibility for overall decision-making (85% of respondents were personally willing and 50% believed that their group was suitable) and randomly selected citizens were the least willing (60% of participants were personally willing and 17% thought that their group was suitable) (Abelson et al., 1995). The individuals polled favoured a combination body, including several community groups, as the most suitable overall decision-making body, with representation from experts in health care and social services, town-hall meeting attendees (i.e., “interested citizens”), the provincial government and elected officials prioritized for the combined decision-making group (Abelson et al., 1995).

Finally, Pagatpatan and Ward (2017) reported the importance of ‘inclusiveness’ for successful CPC participation, which refers to the consideration of a broad range of perspectives in a public participation exercise, with a particular focus on the involvement of marginalized and hard-to-reach publics. Tritter and McCallum (2006) echoed this sentiment, suggesting that to build a successful user involvement system, diverse individuals and groups at local, organizational and national levels must be engaged. Similarly, Dunn (2007) described the importance of diversity for hospital boards, including considerations of ethnicity, age, gender, geography and occupation:

“Board decisions become more informed - and consequently better - when you have people of diverse opinions and backgrounds to frame a decision. It allows for better choices (p. 13).

Motivation for Participation

The literature included for review presented multiple reasons for participation by lay CPCs, including to achieve a specific outcome for their community or organization (Farmer et al., 2017), “having a say” or to be included in decision-making (Rose et al., 2014, p. 22), to affect service change (Farmer et al., 2017; Rose et al., 2014) or “the way things were done” (Abelson et al., 1995, p. 407), a perception that they could contribute useful information (Farmer et al., 2017), institutional credibility (Swapan, 2016 c.f. Farmer et al., 2017), and payment for their time (Abelson et al., 1995). Pallarito and Shinkman (1997) quoted a citizen-trustee, who explained:

“You do it ... [because] it’s part of your life (p. 26).

Supports for Citizen-Patient-Community Participation

Successful citizen-patient-community participation requires support in the form of capacity building (orientation and continuous education) to ensure that CPCs feel adequately equipped to fulfill their council responsibilities (i.e., to bridge any knowledge gaps), and compensation for their time dedicated to their role as council member.

The literature included for review highlighted the importance of offering support to CPC participants for the success of participation processes and effective functioning of rural health councils (McClellan & Trigger, 2017; Knoble, 1993; Karash, 2016; Ramstead, 1992; Umbdenstock et al., 1990; Charles & DeMaio, 2017; Bismark & Studdert, 2014). Two major forms of support were described: first, capacity-building to ensure the success of CPCs in health care activities, including through orientation and continuous education (McClellan & Trigger, 2017; Knoble, 1993; Karash, 2016; Ramstead, 1992; Umbdenstock et al., 1990; Wilson et al., 1993; Charles & DeMaio, 2017; Bismark & Studdert, 2014), and second, compensation for CPCs to participate

(Bismark & Studdert, 2014; Wilson et al., 1993; Kidd et al., 2017).

Orientation & Training

A review of the “place” of rural hospital boards to deliver public sector health services in Western Australia revealed that more than 90% of respondents (board members) perceived that they had insufficient skills to adequately discharge their board responsibilities (Wilson et al., 1993). Moreover, only 32% of respondents reported receiving orientation to prepare them for their role as board member and of those, approximately two-thirds of respondents felt that the induction was insufficient (Wilson et al., 1993). Similarly, Bismark and Studdert (2014), reported the impressions of board members and executives across 13 public health services in Victoria, Australia, who articulated that gaps in the skills and expertise of board members were a barrier to effective governance on quality issues. In response, the authors recommended board training on quality governance that is accessible, flexible and tailored (vs. a ‘one-size-fits-all’ approach) (Bismark & Studdert, 2014). In particular, participants identified a need for a basic introduction to quality, safety and risk; topic-specific training on issues such as patient-centred care; and ‘master classes’ pertaining to innovations in health care quality governance (Bismark & Studdert, 2014).

Additionally, McClean and Trigger (2017) described the approach taken by the Gold Coast Primary Health Network in Australia to support CPCs 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 (McClean & Trigger, 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 (McClean & Trigger, 2017).

Umbdenstock et al. (1990) underscored the importance of supporting the continuing educational needs of hospital board members to enable improved decision-making

toward the board's specified priorities. In addition, Knoble (1993) highlighted the need to educate boards on the importance of leadership principles and the values of an institution. Moreover, Karash (2016) reported that rural hospital trustees are faced with a steep learning curve, irrespective of their prior qualifications and emphasizes the importance to understand the educational needs of a board, and to establish a framework for meeting these needs (Karash, 2016). The author described a governance education certification program, designed and delivered by the Iowa Hospital Association in the U.S.A., which helps hospitals to use governance best practices, to improve the coordination of care, and to promote the best use of resources in both areas.

Charles and DeMaio (2017) reaffirmed the importance of education for CPCs, suggesting that providing CPCs with expert knowledge supports them to overcome information deficits and reduces knowledge imbalances between providers and CPCs, which ultimately affords them with higher levels of decision-making control.

Compensation

The literature included for review revealed that the importance of remuneration to support CPCs to participate in health care activities was contested (Bismark & Studdert, 2014; Ramstead, 1992; Barnett et al., 2001; Wilson et al., 1993; Kidd et al., 2007; Abelson et al., 1995; Nelson & Gauss, 2016).

For instance, Bismark and Studdert (2014) reported the impression of board chairs from four public health services in Victoria, Australia, who spoke to the difficulty of identifying strong candidates who were willing and able to serve on their boards, particularly in rural and regional areas where board members are not remunerated for their role. A board chair explained:

"It's a huge ask for someone that's employed full-time. So there's an imbalance of [too many] retired people on the board." (Bismark & Studdert, 2014, p. 5)

In response, Bismark and Studdert (2014) cited Jha and Epstein (2013) who recommended remunerating all board members such that they can participate in a meaningful way by devoting a significant portion of their professional work to the role.

Similarly, Wilson et al. (2013) reported that while only 5% of board members in rural Western Australia believed that they should be paid for their role, 84% of participants believed that they should be reimbursed for out-of-pocket expenses (Wilson et al., 2013).

In contrast, Kidd et al. (2007) reported that, while remuneration is important to consider in the development of processes for CPC participation, a clinician within a mental health service in rural Victoria, Australia, perceived that remuneration could impact negatively on CPC participation. A clinician explained:

"If you do go down the line of paying consumers that can have a negative effect anyway, not having a true consumer perspective." (Kidd et al., 2007, p. 218)

However, this view was contrasted by a CPC advocate within a mental health service in rural Victoria, Australia, who disregarded financial gain as a rationale for their involvement:

"It's not something you get a lot of money for. But you get a lot of personal satisfaction seeing how you can have your ideas taken on board." (Kidd et al., 2007, p. 218)

Measures of Effectiveness

- It is important to evaluate the effectiveness of citizen-patient-community participation activities to understand their success toward achieving their stated objectives (e.g., improved decision-making and population health outcomes, and community empowerment).
- The most useful indicators to measure the impact of citizen-patient-community participation will vary according to the objective of the participation activity.
- The literature included for review revealed mixed findings regarding the impact of CPC participation activities. However, 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.

The literature included for review described the importance of evaluating citizen-patient-community participation activities to understand their success toward achieving one or more of the multiple objectives for participation: improved decision-making and health outcomes, community ownership and empowerment, public trust and accountability, and inclusivity. Several authors offered theoretical discussions of useful indicators for successful CPC participation (Abelson & Eyles, 2002; Charles & DeMaio, 2017; Farmer et al., 2017; Hudson, 1996; Tritter & McCallum, 2006; Kenny et al., 2013), while others discussed the findings of relevant evaluation studies or spoke to the impact of participation activities (Andrews et al., 2014; Anton et al., 2007; Aronson, 1993; Barnett & Barnett, 2001; Elder & Amundson, 1991; Hemingway & MacLeod, 2004; Peck et al., 2002; Robinson et al., 2003; Strenger, 1995; Rose et al., 2014; Wright, 2013).

Farmer et al. (2017) emphasized the importance of developing outcome indicators for rural health councils to understand the impact of CPC participation. The authors elaborated that indicators should, ideally, be tangible concepts for which assessment is possible through use of existing scales or customized local data collection methods (Farmer et al., 2017). The literature included for review offered the following key indicators to consider for measuring the impact of CPC participation on rural health councils: efficiency of the health care system, including for example, efficiency of allocated resources (Abelson & Eyles, 2002); access to quality care (Andrews et al., 2014); sustainability of health services (Barnett & Barnett, 2001); public commitment to the health care system (Abelson & Eyles, 2002; Anton et al., 2007); community ownership, leadership and empowerment (Elder & Amundson, 1991; Hemingway & MacLeod, 2004; Peck et al., 2002; Kenny et al., 2013); and local economic development (Arnstein, 1969).

Moreover, Kenny et al. (2013) reported several indicators of “higher-level” community participation, as conceptualized by Arnstein (1969) to refer to ‘partnership’, ‘delegated power’ and ‘citizen control’. The indicators included awareness of health services provided (Johns et al., 2007, c.f. Kenny et al., 2013); improved self-efficacy, social capital and accountability; benefits to CPCs, including for example, learning new skills, meeting facilitation (Johns et al., 2007, c.f. Kenny et al., 2013), grant submission (Broussard et al., 2003, c.f. Kenny et al., 2013) and leadership; and outcomes for the broader community, including for example, implementation of new public policy

(Coady, 2009, c.f. Kenny et al., 2013), new infrastructure and health services; and increased local employment positions (Kenny et al., 2013).

The evaluation studies included for review reported mixed findings regarding the impact of CPC participation. For example, Barnett and Barnett (2001) reported that community ownership and control of health services through community health trusts in New Zealand has resulted in both costs and gains, including a strong sense of control over destiny and services that are more secure and more appropriate than before, but also administrative “burdens”.

“... we have local control but that is a two-edged sword since we now have all the responsibility” (Barnett & Barnett, 2001, p. 234).

Moreover, the authors reported that within the participating trusts, there are no longer surgical services and for several trusts, no longer maternity services (the latter attributed to inappropriate facilities) (Barnett & Barnett, 2001). However, the pattern of available services is described as more varied and more accessible than prior to trust formation and the majority of respondents (trust representatives, including the chairs or “key persons”) reported that the services are “better” than before and satisfy a wider range of needs.

Additionally, Strenger (1995) reported the achievements of a hospital board chair and other hospital board members (described as “community leaders”) in Pennsylvania, U.S. toward developing local solutions to ensure that hospital services reflect local health care needs. For instance, the board was successful in establishing a prenatal clinic that lowered the number of premature babies born in their county, and they had initiated a community health program that brought together the county’s leaders, including business owners, educators, and representatives from social service agencies, to learn how to better work together to meet the needs of residents.

Elder and Amundson (1991) reported improvements in the community leadership and organizational processes (e.g., strategic planning and organizational development) of six rural hospitals in the northwest of the United States, through implementation of the WAMI Rural Hospital Project (RHP). By way of the project, CPCs were deliberately involved in hospital and health system planning to enhance community leadership and to ensure a broad base of responsibility for the future of the health system (Elder & Amundson, 1991). Prior to the implementation of the project, none of

the respondents (board members, top administrative staff and physicians) rated their community's hospital involvement as being effective, while post-project, 38% of respondents rated their community involvement as effective.

In contrast, Aronson (1993) explored the degree to which consumer participation initiatives succeed as opportunities for CPC groups to voice their interpretations of their needs and influence how their needs might be met. The study observed that participatory processes (in this case, consultation meetings) fail to give people control over policies and practices that impact on their lives. This was accomplished through an illustrative case study of the development of long-term care policies for elderly persons in Ontario, Canada (Aronson, 1993). The author reported that, rather than "tapping" elderly people's priorities and experiences, the consultation meetings confined participants to speak of services and solutions in terms of professional and administrative structures, through use of a fixed agenda and by placing emphasis on making suggestions and proposals, thereby putting the onus on participants to translate their experiences into actionable, bureaucratic vocabulary (Aronson, 1993). In addition, the author contended that the overarching direction for policy development was established prior to the consultation meetings and therefore, some areas for discussion were closed (Aronson, 1993). This resulted in skepticism and a lack of confidence in the value of the consultations by participants:

"So the government's saying to us: 'You talk, and I'll do what I want to do!' (Aronson, 1993, p. 373).

Anton et al. (2007) spoke to the difficulty of evaluating the impact of CPC participation. In a mixed-methods study involving key informant interviews with fourteen Scottish NHS policy makers, planners, voluntary sector and CPC representatives, and academic experts, they discovered that the informants held different opinions as to why assessing public involvement was important (Anton et al., 2007). The authors elaborated that there is both uncertainty and a lack of consensus about how assessment of CPC involvement should be undertaken (Anton et al., 2007). To exemplify, one informant suggested using "hard" data (i.e., measurable, quantitative data) to establish a link with service performance (e.g., improved waiting times), while others emphasized the importance of an assessment framework to facilitate discussions among all relevant stakeholders and to initiate organizational

learning and a cultural shift toward setting and reaching shared goals in health services activities (Anton et al., 2007). Notwithstanding the inherent complexities involved in evaluating the success of CPC involvement, interviewees embraced the idea of assessing public involvement and were supportive of efforts to develop an assessment framework for Scotland (Anton et al., 2007). A policy maker explained:

“Public involvement can improve planning, but we have not got the evidence yet that [public involvement] is the right thing to do; also we don’t know exactly how it does it. We need to demonstrate what impact [public involvement] has” (Anton et al., 2007, p. 7).

In response to the complexities inherent to the evaluation of CPC participation in health care activities, Tritter and McCallum (2006) noted that CPC involvement in health care serves a myriad of purposes and therefore, evaluators must not fail to recognize where participation itself is the end goal.

Challenges for Citizen-Patient-Community Participation

- Barriers to successful citizen-patient-community participation in health care activities include a lack of a clear definition of CPC participation with multiple (and perhaps, conflicting) objectives for involvement; their reluctance to participate; the challenging interface between CPCs and the health system; the complexity of health care issues; conflict of interest, especially within rural health councils; and the representativeness of CPC participants.
- In response, it is recommended to make clear for CPCs how their input will be included in health care activities and prioritized; to specify the objectives for CPC participation at the outset of an activity to ensure that the roles and responsibilities for CPCs are targeted appropriately; to address power imbalances between CPCs and health professionals; to establish clear and well-enforced conflict of interest policies; and to ensure appropriate funding to support CPC participation activities.

The literature included for review revealed several barriers to successful participation by CPCs, including the public's reluctance to participate ; a lack of a clear definition of CPC participation with multiple, conflicting objectives for involvement; the challenging interface between CPCs and the health system; the complexity of issues and volume of information in health care decision-making; conflict of interest, especially within rural health councils; and the representativeness of CPCs. Special care must be paid to address these challenges to promote successful CPC participation and each will be discussed in detail below.

A critical challenge for CPC participation in health system governance (i.e., decision-making and planning) pertains to whether CPCs consider it worthwhile and are willing to participate (Aronson, 1993; Arnstein, 1969; Abelson & Eyles, 2002; Abelson et al., 1995; Anton et al., 2007). Arnstein (1969) reported the difficulty in arranging representative and accountable CPC involvement when confronted with public experiences of futility, alienation and distrust. Abelson and Eyles (2002) described the public as increasingly cynical toward and weary of pre-determined, illegitimate public consultation processes. Moreover, Abelson et al. (1995) explained that CPCs' willingness to participate is reduced as the time required for participation increases, while Anton et al. (2007) suggested that a lack of confidence is, in part, to blame for CPCs not wanting to be involved.

Aronson (1993) cited Beresford (1988), who emphasized the importance of making clear for CPCs how their input will be included and taken seriously:

"... assure people it is actually worth getting involved in the first place and that their views will not just be taken away to be filed and reinterpreted" (p. 44).

Kidd et al. (2007) reported the impression of a clinician in a mental health service in rural Victoria, Australia that CPC participation must be taken seriously and prioritized, including through respecting experience as expertise and incorporating this knowledge into recovery-focused treatment:

"It's actually about much more than just having a consumer consultant ... and some sort of consumer reference group. It's about having the capacity to take the input of those people, to take that to

the next level, and actually to make sure that it is incorporated into clinician's practice. That's the next level that we have to get to."

A lack of a clear definition of CPC participation was frequently cited as a barrier to CPC participation in health governance (Pickard et al., 2002; Kidd et al., 2007; Kenny et al., 2017; Abelson & Eyles, 2002; Farmer et al., 2017; Hogg & Williamson, 2001). Kidd et al. (2007) reported that this ambiguity led to difficulties in establishing CPCs within two mental health services in rural Victoria, Australia. In response, the authors offered the following recommendation: *"At a policy and service level, it is imperative that all key stakeholders develop a shared understanding of the role, scope and purpose of consumer initiatives in mental health services"* (p. 220). Kenny et al. (2017) cited the challenge of conceptualizing CPC participation in primary health care design and implementation, namely articulating the purpose of the involvement and intended outcomes. The authors described a spectrum with, at one end, the promotion of CPC participation as a panacea to the challenges of primary health care delivery and, at the other, the perspective that CPC participation involves a transfer of responsibility to CPCs who are expected to have both the capacity and the willingness to participate (Kenny et al., 2017). Similarly, Abelson and Eyles (2002) reported that the multiple and, at times, conflicting objectives of participation, including for instance, to improve decision-making and health system performance, and to foster a more active, engaged citizenry, present a significant barrier to CPC governance in the health system. Farmer et al. (2017) elaborated that, although there is potential to achieve multiple outcomes from participation activities, the conflation of reasons for undertaking participation might lead to confused outcome evaluation downstream. In response, the authors note the importance of specifying the objectives for CPC participation at the outset to ensure that the roles and activities for CPCs are targeted appropriately (Farmer et al., 2017).

The interface between those who work in the health system and those who experience it was commonly cited as a challenge for CPC in health governance (Tritter & McCallum, 2006; Pickard et al., 2002; Kidd et al., 2007; Abelson & Eyles, 2002; Kenny et al., 2017; Aronson, 1993; Arnstein, 1969; Abelson et al., 1995; Hurley et al., 1994). Abelson and Eyles (2002) described the experience of CPC participation in the governance of the Canadian health system as being characterized by "citizen domination by powerful groups", who are interested in involving the public only when

it suits their purpose. Similarly, Abelson et al. (1995) reported the public's perception of being manipulated by decision makers as an impediment to CPC participation. Tritter and McCallum (2006) cited Blaauwbroek (2002), who reported that hostility from health care professionals was in part to blame for the slow pace at which CPC involvement in policymaking had developed in the Netherlands. In addition, Pickard et al. (2002) reported tensions around professional accountability (i.e., between professional control of clinical quality and lay participation) as a barrier to CPC in clinical governance. The authors described the challenge of reconciling antagonistic or clashing viewpoints and perspectives (differences between lay and professional viewpoints). It was suggested that the culture of the medical profession needs to change:

"The doctors themselves are scared of public opinion ... they think the public are going to complain all the time" (Pickard et al., 2002, p. 196).

Kidd et al. (2007) offered the following recommendation to address the interface between CPCs and health professionals, and to facilitate CPC participation:

"Development of plans to address the power imbalances between consumers and health professionals. Partly this could be encouraged by supporting clinicians to recognize the value in the consumer perspective rather than viewing consumers merely as individuals afflicted with illness" (p. 220).

Similarly, Aronson (1993) contended that professionals and administrators in health service and planning organizations will need to share power and control with CPCs, if CPC participation processes are to realize objectives of empowering CPCs. Moreover, Kenny et al. (2017) suggested that successful CPC participation will only be achieved when the siloes that exist between those who work in the health system and those who experience it are removed.

"... participation without redistribution of power is an empty and frustrating process for the powerless" (Arnstein, 1969, p. 216).

An additional challenge for CPC involvement in health governance pertains to the complexity of clinical issues and information used in health care decision making (Pickard et al., 2002; Abelson et al., 1995). Pickard et al. (2002) explained that this

leads to inhibition on the part of lay members in terms of their ability to contribute:

"I know damn well I don't know too much about CHD, other than what I see or what I read in the papers, so you find the people who are not clinicians do tend to defer to the doctors and health visitors and the nurses ... how can you have a proper opinion, when you don't even understand the drugs people are being given, you don't understand the regimes at all?" (lay board member, p. 195-6)

Conflict of interest between a hospital board trustee and the health care organization was cited as a challenge to governance accountability, especially for hospital boards in rural communities where there are fewer qualified persons and where community leaders are more likely to hold other positions in conflict with their role on the board (Larson, 2001; Orlikoff & Totten, 2004). To address and mitigate against conflicts of interest, Larson (2001) and Orlikoff and Totten (2004) recommended to establish clear and well-enforced policies. Orlikoff and Totten (2004) elaborated that a strong conflict of interest policy will describe the purpose of the policy, specify what constitutes a conflict of interest, specify what is required to adhere to the policy, establish procedures for disclosing a conflict of interest, establish a mechanism for impartial decision making where conflict or the appearance of a conflict exist, establish a governance mechanism to investigate policy violations, and establish protocols and repercussions for board members found to have violated the policy.

Impediments to CPC participation that were less frequently cited included the timing and irregularity of council meetings (Kidd et al., 2007), and for rural and remote seniors in particular, distance and climate-related challenges (Hemingway & MacLeod, 2004). Finally, a lack of adequate funding to support CPC participation was reported as a barrier to participation in health governance (Kidd et al., 2007; Humphreys, 1997). Kidd et al. (2007) cited the experience of a clinician in a mental health service in rural Victoria, Australia pertaining to policy makers promoting CPC participation but not funding it:

"At that sort of level they know, you talk about it a lot and suppose, produce a lot of documents about consumer participation. But if as I say to get to that point there has to be a real commitment to actually, to ensure we are funding towards positions, like the consumer consultant

position. Or a component of funding we are going to provide this amount of training to the staff" (p. 218).

In response, Kidd et al. (2007) offered the following recommendation: *"Appropriate funding at both government and service levels to support the implementation of developed models and processes that support more than tokenistic consumer involvement"* (p. 220).

Who speaks for community? (i.e., Representativeness)

A commonly cited challenge for CPC participation in health governance through rural health councils pertains to the representativeness of CPCs (Anton et al., 2007; Pickard et al., 2002; Tritter & McCallum, 2006; Abelson & Eyles, 2002; Kidd et al., 2007; Abelson et al., 1995; Hurley et al., 1995). That is, 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 et al., 2007). In fact, Pickard et al. (2002) suggested that the search for the elusive 'typical user' has paralyzed activity in the area of CPC involvement within Primary Care Trusts and Groups in England's National Health Service.

The difficulties observed to impede representative CPC participation include a scarcity of opportunities (i.e., board positions) available to users, which limits the ability of health organizations to engage the spectrum of users (Tritter & McCallum, 2006), as well as a limited pool of candidates, referred to as the "usual suspects" (Anton et al., 2007). Hurley et al. (1994) cited Morone and Marmor (1981) who suggested that typically, only those with vested interests (e.g., narrow advocacy groups) have an ongoing and powerful incentive to participate regularly.

In addition, Abelson and Eyles (2002) suggested that CPC participation in health governance in Canada has been characterized by the ability for only the most highly educated and arguably, the most unrepresentative and biased "publics" to participate as CPC representatives. Pickard et al. (2002) echoed this sentiment, criticizing CPC involvement within English Primary Care Trusts and Groups for being unrepresentative of voices other than those of white, educated, able-bodied, and middle-class individuals with sufficient leisure time to participate. This was heightened by the application process for lay members, as one lay board member explained:

"I was annoyed that they said this was meant for normal people in the queue at

Tesco to fill in and you needed a Masters' degree to fill that application form in" (Pickard et al., 2002, p. 192-3).

Hurley et al. (1995) cited March and Olsen (1989), who suggested that the advantages to individuals with greater intellectual and economic resources may be reduced by simplifying administrative and deliberative processes within organizations.

Moreover, a lack of a clearly articulated definition of "community" was cited as a barrier to CPC participation (Abelson et al., 1995; Kidd et al., 2007). Kidd et al. (2007) recounted the challenge of articulating what a consumer is within two mental health services in rural Victoria, Australia:

"The federal government demands that we have consumer representation on all our committees and we really struggled with 'what's a consumer in this [service]?' Is a consumer one of the people working in the field... or is a consumer someone who represents someone who suffers from the disease or carer?" (clinician, p. 216)

Farmer et al. (2017) emphasized the importance of specifying participant type for effective participation. The authors 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, families, 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 (Farmer et al., 2017). Based on these conceptualizations, Farmer et al. (2017) recommended involving CPCs in discussions regarding improvements to existing health services and the public in strategic decision-making and priority setting.

Similarly, Hogg and Williamson (2001) offered three categorizations of CPC participants that are important to consider for appointment to rural health councils: 'supporters of dominant (professional) interests', 'supporters of challenging (managerial) interests', and 'supporters of repressed (patient) interests'. The authors suggested that those with little experience in health care tend to support dominant interests, describing this categorization as the 'default position' for CPCs, while those with backgrounds in business, management, health economics and policy analysis and

with interests in the rational and cost effective use of resources tend to support challenging or managerial interests (Hogg & Williamson, 2001). The supporters of repressed interests were described as individuals with an acute sense of patients' disadvantage in health care, formed through close attention to consumer groups, familiarity with research into patients' views and through abstraction from their own and other patients' experiences, and include patients and carers, consumer groups, and patient advocates (Hogg & Williamson, 2001). The appointment to governance bodies will depend on the purposes of the body; however, the authors emphasized that the expertise of the supporters of repressed interests must be acknowledged.

In response to the challenge of representativeness, Tritter and McCallum (2006) countered that central to the utility of involving CPC participants is the applicability of their personal experiences and their non-medical frames of reference, which are distinct from those of health professionals:

"... it is asking questions that health professionals have not considered" (p. 164).

Discussion & Recommendations

Effective models of citizen-patient-community involvement in health care planning and service delivery are seen in the international literature to lead to decisions that most aptly reflect the needs of local communities, with some studies showing improved population health outcomes (Barnett & Barnett, 2001; Strenger, 1995; Rose et al., 2014). Although B.C. had an historical model of community hospital boards, the administrative burden, associated inefficiencies and shifting political agendas lead to its dissolution. Currently, however, there is not only an opportunity to revisit the role of rural community health councils, but a mandate through the objectives of the Primary Care Networks that includes local community quality improvement and a provincial commitment to patient-centered care. The **key assumptions** that underscore the following recommendations include:

- Rural communities are not only different from larger urban centres with regard to economies of scale and local access to resources. Significant differences exist

between rural communities, differences that must be accounted for to avoid the industrialization of health planning across diverse geographies;

- Within the context of Canada's resource economy, well-functioning and sustainable rural communities are essential to economic stability.
- There is a heightened need for the expression of authentic community voices as a structural imperative of sustainable rural health care;
- Community voice must be facilitated by system structures that allow organization at a community-level and the conveyance of community insights through all levels of primary care redesign to the highest provincial levels;
- Given the realities of regionalization and how health economies are structured, the role of the CPC-engaged structures will not involve funding and resource decisions, but will focus on monitoring outcomes through a quality of care framework to ensure local needs are met and recommendations can be made based on data-driven population needs.

Recommendations

(1) Rural health councils be struck in alignment with the Primary Care Networks to realize B.C.'s commitment to patient-centered care and to prioritize the value of citizen-patient-community voices in health care planning. Based on the literature reviewed, 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 CPC 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 CPC 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 (Carcasson & Sprain, 2016; Carman et al., 2014);
- 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.

(2) 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 CPC voices in health care planning;

(3) An accountability framework parallel to the Primary Care Network accountabilities be clearly articulated with ultimate accountabilities for rural health councils reaching a provincial level (Ministry of Health, GPSC);

(4) That an evaluation of the effectiveness of rural health councils be integrated into the larger evaluation metrics of the Primary Care Networks.

Although as noted by Wilson (2001), "Community control should not be a rhetorical device that allows governments to shirk their responsibilities toward indigenous citizens in remote areas, including the provision of basic human services and citizenship entitlements such as affordable, reliable and safe essential services and affordable quality housing."

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Appendix A: MEDLINE (Ovid) Search Strategy

1	(communit* or public or consumer* or citizen* or "civil society" or local or patient* or user*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
2	exp Community Participation/
3	exp Community-Institutional Relations/
4	rural*.mp.
5	exp Rural Health Services/
6	exp Rural Population/
7	remote*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
8	1 or 2 or 3
9	4 or 5 or 6 or 7
10	exp Governing Board/
11	exp Health Planning Organizations/
12	((health* or hospital* or govern* or regional or district*) adj3 (authorit* or council* or board*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
13	"NHS board*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
14	"foundation trust*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
15	((health* or hospital* or govern* or regional or district*) adj2 (authorit* or council* or board*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
16	10 or 11 or 12 or 13 or 14
17	8 and 9 and 16
18	4 or 5 or 6
19	10 or 11 or 13 or 14 or 15
20	8 and 18 and 19
21	limit 15 to last 5 years
22	limit 14 to last 5 years
23	limit 13 to last 5 years
24	limit 12 to last 5 years
25	10 or 11 or 21 or 22 or 23
26	8 and 18 and 25

Appendix B: Citations Table

	Bibliographic Reference	Jurisdiction	Research Question	Context	Evidence Type	Main Findings
1	Abelson J, Eyles J. Public participation and citizen governance in the Canadian health system. Commission on the Future of Health Care in Canada 2002;(7):1-36.	Canada	<ul style="list-style-type: none"> • What can public participation and democratic processes, more broadly, contribute to the health system, its governance and the values held by Canadians toward and in the health system? • What has public participation in the Canadian health system contributed toward: (a) the efficient functioning of organizations in the health sector, (b) strengthening citizen commitment toward health programs and policies, and (c) encouraging the expression of democratic values in Canadian society? • What are reasonable objectives for public participation in the future governance of the Canadian health system and how can more effective, legitimate processes be created to achieve these objectives? 	<ul style="list-style-type: none"> • After establishing a universal, publicly administered health system in Canada, citizens have participated in the health system as 'consultants', resource allocators, health system governors, and 'protectors of the public interest'. • Given the multitude of distinct and overlapping roles for the public, and goals for its participation, public participation in the Canadian health system can, in many ways, facilitate the expression of democratic values held in Canadian society and enhance the performance of the health system. 	Discussion Paper	<ul style="list-style-type: none"> • The authors permit that public participation may never contribute to a more efficient health system and might at times, lead to the inefficient allocation of resources. However, through legitimate and accountable participation, there is potential for participation to strengthen citizen commitment to health programs and policies, and to encourage the expression of democratic values.
2	Abelson J, Lomas J, Eyles J, Birch S, Veenstra G. Does the community want devolved authority? Results of deliberative polling in Ontario. CMAJ 1995;153(4):403-412.	Ontario, Canada	<ul style="list-style-type: none"> • To understand and contrast the informed opinions of citizens from five potential decision-making groups - randomly selected citizens, attendees at town hall meetings, appointees to district health councils, elected officials, and experts in health care and social services - 	<ul style="list-style-type: none"> • Provincial governments across Canada are instituting reforms to their health care systems, primarily through changes to the governance structures to devolve authority for decision making from the provincial governments to regional, district or local bodies. 	Deliberative Polling (Qualitative Research)	<ul style="list-style-type: none"> • Participants, especially randomly selected citizens favored consulting roles over taking responsibility for overall decision making and were less willing to accept decision making responsibilities for specific functions such as raising revenue. • Preferred information for decision making was ranked in the

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			<p>regarding their personal willingness and their group's suitability to be involved in devolved decision making; their desired type of involvement; their information preferences; their preferred areas of decision-making involvement; and their preferred composition of decision-making bodies.</p> <ul style="list-style-type: none"> The authors sought to answer the following questions: Q1. How willing are community members to participate in local health-care and social-service decision making? Q2. For which types of health-care and social-service decisions do local community members wish to be responsible? Q3. What type of information would local community members want if they participated in local decision making on health care and social services? Q4. (A) What type of local body would be suited to taking on all health care and social service decision making? (B) What type of local body or bodies would be suited to taking on decision making in specific areas of health care and social services? 	<ul style="list-style-type: none"> The common objectives for reform include the improved management of health care resources, increased flexibility and responsiveness to the needs and preferences of communities and populations, and enhanced integration and coordination of service provision. <p>Rationale</p> <ul style="list-style-type: none"> The stated rationale for establishing community-based governance structures is to give citizens decision-making authority. There is sparse empiric evidence regarding public participation in health care decision making. Impediments to participation that have been cited in the literature include the perceived costs of participation; feelings of being manipulated by decision makers; the complexity of information used in health care and social service decision making; and a lack of a clearly articulated definition of "community". 		<p>order of highest to lowest as health care needs, benefits, costs and preferences. Only elected officials thought costs ranked higher, immediately below needs. Participants thought cost and need required the most precision when making decisions about health care and social services and they were generally pessimistic about the level of precision in the information their group would use to make decisions.</p> <ul style="list-style-type: none"> A form of combined group was deemed the most suitable for decision making followed by experts on health care and social services. In a combined group, participants thought provincial government, elected officials and experts required constant representation in these groups although if a single group were to be assigned, participants thought experts followed by town hall meeting attendees i.e. interested citizens, followed by provincial government and elected officials would be considered suitable.
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3	Andrews ML, Sanchez V, Carrillo C, Allen-Ananins B, Cruz YB. Using a participatory evaluation design to create an online data collection and monitoring system for New Mexico's Community Health Councils. <i>Eval Program Plann</i> 2014;42:32-42	New Mexico, U.S.	To present the collaborative development of an online reporting system to represent the collective experience of thirty-two county health councils in New Mexico.	The focus of research on the effectiveness of health coalitions and partnerships has shifted toward defining intermediate outcomes, which can be linked to longer-term population health changes through use of logic models. In creating a model that is focused on system-level changes, coalitions can strategically identify, engage and mobilize constituencies to produce changes that may directly improve health status or access to care.	Evaluation	<ul style="list-style-type: none"> • The online system accomplished the creation of common outcomes and a tracking system across health councils, and the development of a flexible system to capture the unique contributions of the councils. • The iterative process to develop the system revealed insights into council processes and functions (e.g., varying internal decision-making processes, varying levels of influence by state agencies, etc.).
4	Anton S, McKee L, Harrison S, Farrar S. Involving the public in NHS service planning. <i>J Health Organ Manag</i> 2007;21(4-5):470-483.	Scotland	<ul style="list-style-type: none"> • To inform discussions about the development of a framework for assessing public involvement in the NHS in Scotland. • To identify potential criteria and methods for assessing public involvement in the planning and delivery of health services; and; • To consider the suitability of the identified criteria and methods for assessing public involvement for the particular case of Health Boards' efforts to involve their publics in decisions about the planning and delivery of services. 	The NHS Boards have a statutory requirement to involve patients and the public in all levels of individual care and major health service design as per the Patient Focus and Public Involvement (PFPI) policy initiative.	Case Study, Interviews	<ul style="list-style-type: none"> • Generally, there was consensus on the importance of assessing public involvement. • There were varying opinions as to why assessment was important and a lack of consensus on how assessment should be undertaken. For instance, some participants thought that it was important to demonstrate NHS Boards' accountability to the public, while others thought that it was important to show measurable evidence of impact of public involvement (e.g., improved waiting times). • Three tension areas on patient and public involvement were identified in the interviews: (1)

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						informing versus consulting, (2) the legitimacy of “representative” and “direct” voices, and (3) prescriptive versus flexible assessment processes.
5	Arnstein SR. A ladder of citizen participation. Journal of the American Institute of Planners 1969;35(4):216-224.	United States of America	<ul style="list-style-type: none"> • What is citizen participation and what is its relationship to the social imperatives of our time? • To present a typology of citizen participation using examples from three federal social programs: urban renewal, anti-poverty, and Model Cities. 	The concept of citizen participation is described as being "a little like eating spinach" as "no one is against it in principle because it is good for you" (p. 216). Participation of the governed in their government is, in theory, the cornerstone of democracy - and this idea is widely celebrated. Yet, enthusiasm is reduced where this principle is advocated for by the "have-nots", and there is opposition when the "have-nots" define participation as a redistribution of power.	Framework	<ul style="list-style-type: none"> • Citizen participation is citizen power; it should result in the redistribution of power that enables the “have-nots” (or, the powerless) to be included in decision making regarding how resources are allocated. • Citizen participation is conceptualized to include eight types, arranged in a ladder pattern with each rung corresponding to the extent of citizens’ power. The bottom rungs are ‘manipulation’ and ‘therapy’, described as non-participation; the middle rungs, ‘informing’, ‘consultation’ and ‘placation’, are described as levels of tokenism; and the highest rungs, ‘partnership’, ‘delegated power’ and ‘citizen control’ pertain to levels of citizen participation with increasing degrees of decision-making power.
6	Aronson J. Giving consumers a say in policy development: influencing policy or just being heard? Canadian Public Policy 1993;19(4):367-378.	Ontario, Canada	<ul style="list-style-type: none"> • To explore the trend to involve consumers in public policy-making and implementation. • Through illustrative case example, to explore the 	• As of 1993, there is a trend toward seeking the input of citizens for public policy-making, to attend more closely than before to those using or affected by government policies and	Illustrative Case Review	<ul style="list-style-type: none"> • There is a disparity between the democratizing rhetoric of consumer participation and the actual limitation of the process • These limitations come from consumers not being able to

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			<p>purposes and accomplishments of public participation initiatives.</p>	<p>program and to close the gap between those who plan and provide services and those targeted by them (Hambleton, 1998).</p> <ul style="list-style-type: none"> • It is suggested that consumers' input can contribute to ensuring that policies and programs are more closely attuned to their needs and imperatives. • However, this view does not consider the differences in power between those planning, providing and using public services, nor recognize the political significance of "needs talk" in late capitalist societies. 		<p>provide actionable solutions to the problems they face to government undervaluing the input from consumers.</p> <ul style="list-style-type: none"> • This may cause disenchantment and lack of optimism for consumers who approach this with great expectations.
7	<p>Barnett P, Barnett JR. Community ventures in rural health: the establishment of community health trusts in Southern New Zealand. Aust J Rural Health 2001;9(5):229-234.</p>	<p>New Zealand</p>	<p>To extend the existing literature on solutions by examining one specific strategy, community trusts, used in New Zealand to retain essential health services for rural communities.</p>	<ul style="list-style-type: none"> • Market reforms in the 90s in New Zealand threatened health services in rural areas as their economy was not large enough to contribute to the profit required by the government. • Community health trusts were created in response to these threats in order to preserve the viability of health services in rural communities. • The paper surveys the community trusts to assess the factors that led to their success. 	<p>Survey</p>	<ul style="list-style-type: none"> • Trusts expanded the range of services provided, from GP to specialist consultations and even home care. Some have provided practice facilities, actively recruited and employed locums directly. • Factors that were critical to the success of trusts include: involvement of capable local leadership with skills to accomplish tasks including health professionals; getting locals to commit to the vision of the trust and to put in the time required; learning from the experience of other trusts; and reducing their costs of operations by eliminating bureaucracy.

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8	Bismark MM, Studdert DM. Governance of quality of care: a qualitative study of health service boards in Victoria, Australia. <i>BMJ Qual Saf</i> 2014;23:474-82.	Victoria, Australia	To identify the tools that boards use to oversee and improve quality of care and to better understand the key influences of board activity in this area.	<ul style="list-style-type: none"> • It is increasingly recognized that effective governance is pivotal to improvements in health care quality (e.g., patient experiences of, and the safety and effectiveness of care), yet the real-world factors that stimulate and retard board activities in this area are not well understood. • There is evidence to suggest that hospitals overseen by boards that are actively engaged in the institution's quality agenda are more likely to have quality improvement programs in place and superior performance on a variety of indicators (e.g., risk-adjusted mortality rates). • Despite the promulgation of several guidance documents to assist boards to understand what they should be doing in this area, the movement toward 'best practice' is uneven; there is recent evidence that has shown substantial inter-board variation in the intensity of board engagement and the attitudes of board members to quality issues. 	Individual and Group Interviews	<ul style="list-style-type: none"> • Public health service boards can and should establish the leadership, accountability and organizational culture necessary for staff to deliver safe and effective services. • Despite a perceived array of opportunities to oversee and support improvements in quality of care, interviewees articulated four main barriers to exploiting such opportunities, including insufficient resources, lack of skills and expertise among board members, inadequate information on performance, and unhelpful forms of regulatory control. • To overcome the challenges, interviewees identified four enablers of more effective quality governance, including stronger regional collaborations, tailored board training on quality issues, smarter use of reporting and accreditation requirements, and better access to data that was reliable, longitudinal and allowed for benchmarking against peer organizations.
9	Charles C, DeMaio S. Lay participation in health care decision making: a conceptual framework. <i>CUAJ</i> 2017;11(1-2).	Canada	To present an analytic framework to describe different dimensions of lay participation in health care decision-making, including to define lay	<ul style="list-style-type: none"> • There is increasing interest in Canada regarding lay participation in health care decision making. 	Framework	<ul style="list-style-type: none"> • A framework for conceptualizing lay participation in health care decision-making is presented, including three frameworks variables: 'decision-making

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			<p>participation, to facilitate greater understanding of the content and the merits of specific recommendations for participation, to provide guidance in designing implementation strategies, and to assist in identifying and anticipating potential problems in achieving stated goals.</p>	<ul style="list-style-type: none"> • There is little consensus about what lay participation actually means and a lack of a common framework for describing the key dimensions of lay participation in different health care decision-making contexts. 		<p>domains', 'role perspectives' and 'level of participation'.</p> <ul style="list-style-type: none"> ○ 'Decision-making domains' refers to the types of health care decision-making contexts. Three subdomains are specified, including treatment, service delivery and system-level decision-making contexts. ○ 'Role perspectives' defines two different role perspectives that individuals can adopt in health care decision-making: (1) user of health services, and (2) public policy perspective. ○ 'Level of participation' distinguishes the extent to which individuals have control over the decision-making process.
10	Dunn P. Diversity on the rural hospital board: challenges for today and beyond. <i>Trustee</i> 2007;60(6):16.	North Carolina, U.S.	To discuss the importance of diversity on rural hospital boards, including challenges and strategies for diversification.	<ul style="list-style-type: none"> • The community seeks to have individuals that look like them in leadership positions within the hospital. • Individuals will be attracted to hospitals where they see a commitment to diversity. 	Narrative Description	<ul style="list-style-type: none"> • Strategies to diversify the rural hospital board include: <ul style="list-style-type: none"> ○ Talking to people you don't know. ○ Looking for balance: Bring in non-traditional board members. ○ Maintain a permanent recruitment campaign. ○ Educate and integrate.
11	Elder WG, Amundson BA. The WAMI Rural Hospital Project. Part 3: Building health care leadership in rural communities. <i>J Rural Health</i> 1991;7(5):511-525.	United States of America	To evaluate the impact of the WAMI Rural Hospital Project (RHP) intervention toward improving the leadership of six Northwest rural hospitals.	The WAMI Rural Hospital Project aimed to improve the financial stability and the functioning of rural hospitals, as well as community leadership and organizational effectiveness in six Northwest communities in the U.S. The project combined	Qualitative Survey	<ul style="list-style-type: none"> • The greatest improvement noted among participating hospitals pertained to the effectiveness of their governing boards; all boards had adopted some or all of the project's model governance plan and had successfully completed considerable portions of their

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				community development, strategic planning and organizational development to accomplish this aim.		strategic plans. <ul style="list-style-type: none"> • Despite improvement being made toward effective community involvement in hospital and health system planning, this factor was rated lowest in both the pre- and post-project periods.
12	Farmer J, Taylor J, Stewart E, Kenny A. Citizen participation in health service co-production: a roadmap for navigating participation types and outcomes. Aust J Prim Health 2017; 23(6):509-515.	Australia	<ul style="list-style-type: none"> • To delineate key categories and concepts within participation, and align participants, activities, outcomes and measures, to provide a framework for consistency in future planning and evaluation of citizen participation. • The overview is intended to help managers to understand, and perhaps discuss and probe, the policy directions they receive, and then to plan activities appropriately. 	<ul style="list-style-type: none"> • Within Australia and internationally, health care managers responsible for providing primary care services are required to facilitate the participation of consumers and community representatives in all aspects of service design and delivery. • Studies spanning over a decade conducted in different countries and cultures have so far been unable to delineate what lay participation is for and how it should be done. 	Framework	<ul style="list-style-type: none"> • Health care managers need to take into consideration certain factors in deciding who will participate in decision-making, how they would participate and what roles they would play if public participation is to be effective in achieving its goals. These considerations include: <ul style="list-style-type: none"> ○ Defining the kinds of people to participate either consumers themselves, the public at large or the community of place or interest; ○ Outcomes for public participation should be defined from the onset to ensure that their roles and activities are targeted appropriately. These outcomes may be service improvement, responsabilisation, health improvement, citizen influence or community capacity and democratic participation; ○ Quantifiable indicators should be in place pre and post participation to measure improvement; ○ Contextual factors that influence

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						the effectiveness of public participation should also be considered which include: participant motivations, sponsorship, method of participation the topic for participation and the characteristic of participation facilitators.
13	Greene J. Saving the small, rural hospital. <i>Trustee</i> 2002;55(7):20-23.	United States of America	To discuss the Critical Access Hospital (CAH) program, including the role of hospital trustees in deciding whether to convert and subsequently, managing a CAH hospital post-conversion.	<ul style="list-style-type: none"> The Critical Access Program allows rural hospitals to get cost-based reimbursement for inpatient and outpatient Medicare services in exchange for maintaining 15 or fewer beds, keeping patients an average of four days or less, and establishing a relationship with a larger hospital. 	Discussion Paper	<p>Important considerations for conversion:</p> <ul style="list-style-type: none"> Hospital boards must be given all relevant information. There are issues pertaining to operations and financing that must be understood. A comprehensive financial feasibility study should be conducted to determine whether conversion is a “smart move”. The board should use its ties to the community to educate people about what a critical access conversion means and post-conversion, to determine the hospital’s place in the community.
14	Guzys D, Threlkeld G, Dickson-Swift V, Kenny A. Rural and regional community health service boards: perceptions of community health - a delphi study. <i>Aust J Prim Health</i> 2017;23(6):543-548.	Victoria, Australia	To identify how those engaged in determining the strategic direction of local regional or rural community health services in Victoria, Australia, perceived the health and health improvement needs of their community.	It is well known that health service boards need to consist of people skilled enough for the role even though board members have traditionally been altruistic members of their communities. Oftentimes, governance training are given to health board members to assist them in their governance responsibilities.	Delphi Study	<ul style="list-style-type: none"> Health board members prioritize community health indicators that do not align with standard measures that are not typically used by government in planning for, funding for and reporting on health.

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				However, the way in which this knowledge is dispensed really depends on the board members' perception of health in their community.		
15	Hart LG, Pirani MJ, Rosenblatt RA. Causes and consequences of rural small hospital closures from the perspectives of mayors. J Rural Health 1991;7(3):222-245.	United States of America	The purpose of this study is to examine the causes and consequences of rural hospital closures from the perspectives of the mayors of towns that lost their only small rural general hospitals between 1980 and 1988.	Rural hospitals are extremely viable components of rural communities. Not only do they ensure basic healthcare services, they contribute to the town's economic vitality by being among the top employers of labor. Yet, in the 1980s, a large proportion of rural hospitals were closing down. While most research have focused on why the hospitals closed, there is a paucity of research on the consequences of the closures in rural communities.	Cross Sectional Survey	Perceived causes of hospital closure: <ul style="list-style-type: none"> • Among others, lack of community support was listed as one of the perceived reasons for hospital closures; • Inadequate hospital board leadership/planning was ranked as very or somewhat important among the selected factors that resulted in closure.
16	Hemingway D, MacLeod T. Living north of 65 years: a community-based process to hear the voices of northern seniors. International Rural Human Services Conference - Beyond Geographical and Disciplinary Boundaries. Rural Soc Work 2004;9:137-146.	British Columbia, Canada	<ul style="list-style-type: none"> • What are the successes and limitations of the community based process to encourage senior citizen involvement in health care planning undertaken in BC? • What implications does this have for policy development, service delivery and social work practice with older adults in smaller northern and rural communities? 	Budget cuts have had negative effects on health service delivery especially in the area of home and adult care. In order to bring issues about seniors to the forefront, older adults have been encouraged to become involved in health planning within various health regions in British Columbia.	Program Overview	<ul style="list-style-type: none"> • The community advisory councils (CAC) and task force on seniors health ensured a successful participatory process which positively impacted the lives of project volunteers and seniors throughout the region but it was not without its limitations. • Its achievements has potential implications for other aspects of policy development, service delivery and social work practice among older adults in other northern and rural communities.

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17	Hogg C, Williamson C. Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees. Health Expectations 2001;4:2-9.	United Kingdom	To attempt to distinguish between the different sorts of people who may be appointed to health service bodies as 'lay' people, and so to put forward a model for understanding lay involvement that can provide the basis for future research. To describe lay attitudes that have developed as a result of socialization as they relate to the three main interest groups within health care: consumers (i.e., patients, carers and user/patient/ consumer groups), corporate rationalizers (i.e., executive managers, civil servants, public health doctors), and health professionals, especially doctors in clinical practice.	<ul style="list-style-type: none"> • There is lay participation in health service decision making at both the national and local levels in the United Kingdom, yet there is little empirical research on their role and no thought-out strategy about how lay people will be recruited, what skills they need nor how they should be held accountable. 	Discussion Paper	<ul style="list-style-type: none"> • The authors contend that lay people fall into three broad categories: supporters of dominant (professional) interests, supporters of challenging (managerial) interests and supporters of repressed (patient) interests; these alignments should be taken into consideration in appointments to health service boards.
18	Hudson T. Make no little plans. Community health planning is an antidote to a world in which the strong survive and the weak usually don't. But in an era of scaling back, does it have a future? Hosp Health Netw 1996;70(9):47-48.	United States of America	<ul style="list-style-type: none"> • To highlight the importance of community health planning in small and remote communities. 	<ul style="list-style-type: none"> • Health planning is critical to ensure that all communities, and in particular geographically isolated and medically indigent communities, are provided with the necessary resources to address their health needs. • Independent planning agencies are described as being "on the endangered species list", and among the few states where these agencies still existed, 	Discussion Paper	County health departments have served as alternatives to independent planning agencies. The health departments have formed councils, comprised of representatives from hospitals, medical groups, schools, law enforcement and senior citizens, to identify local health needs. Using community input and data, the departments produce a health assessment and a plan to address the identified needs.

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				several were discontinuing funding.		
19	Humphreys JS. Reflections on national rural health policy: the 'big picture' framework. Aust J Rural Health 1997;5(1):48-52.	Australia	To maintain an awareness of the “big picture’ of rural health if interventions designed to bring about improved health status are to tackle the underlying causes of the problems, minimize problems associated with lack of co-ordination between health authorities, and avoid duplication of activity. Given the communality of rural health problems across Australia, close co-operation and collaboration among rural health groups is vital in developing appropriate national rural health policy. At the same time rural communities must continue to participate actively in the policy formulation and implementation process.	§ The occasional contradictory and rapidly changing nature of rural health policies cause distrust among rural community members on their intentions § As such, it becomes important to gain effective community participation in policy formulation and implementation processes.	Reflection	<ul style="list-style-type: none"> • Residents of rural communities are the most knowledgeable on rural community issues and can help determine whether rural health policies are effective or not • However, time constraints and limited resources occasionally leads to an exclusion of community participation in rural health policies.
20	Hurley J, Birch S, Eyles J. Geographically-decentralized planning and management in health care: some informational issues and their implications for efficiency. Soc Sci Med 1995;41(1):3-11.	Canada	To apply concepts drawn from organizational theory and the economics of information to assess how informational considerations affect the potential for geographically based decentralized planning and management structures within health care to improve system efficiency compared to centralized structures.	Amongst the Organization for Economic Cooperation and Development (OECD) countries, a new agenda is emerging on decentralized planning and management in all areas of government services including health care. In advocating for decentralization, there are calls for greater authority to be given to local decision-making bodies to	Discussion Paper	<ul style="list-style-type: none"> • Based on informational considerations, decentralized structures have better potential than centralized structures for improving efficiency. • In a static, classical decision-making context both the nature of the information required by decision makers and the nature of the context in which decisions are made suggest that decentralized

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				improve the efficiency of health care systems.		structures offer greater potential for incorporating all relevant information while in a dynamic context decentralized structures offer greater potential for generating new information, learning, and adapting the information regarding the organization and delivery of health care services.
21	Hurley J, Lomas J, Bhatia V. When tinkering is not enough: provincial reform to manage health care resources. CPA Journal 1994;37(3):490-514.	Canada	The objective of the paper is to review the reports of independent commissions in seven Canadian provinces with mandates to review the health care sector; to outline how each of the provincial governments have translated the findings of the commissions into reform plans; and finally, to comparatively analyze the reforms.	A number of Canadian provinces are restructuring their health care systems to improve resource management either due to cost containment or recommendations from provincial review boards. These new health care plans include varieties of decentralized approaches to management through devolution of management structures. It is important to look at the effectiveness of these different approaches in organizing health care through the reports of the independent commissions set up to review the health sector.	Discussion Paper	<ul style="list-style-type: none"> Health care governance structures and management processes across different Canadian provinces have evolved based on new knowledge, new demands, new fiscal realities and the natural evolution of power among the various interests in the health care system - Saskatchewan, British Columbia and Nova Scotia transfer substantial decision making power to local bodies representing as few as 10,000 people whose responsibilities will be to plan and coordinate health service delivery and identify local health needs - In Quebec however, there are no local health decision-making bodies. The regional boards which represent on average more than 250,000 citizens each have consolidated in their authority to set regional health and welfare

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						<p>priorities based on the need of the region and plan, manage and coordinate the delivery of services to meet those needs</p> <ul style="list-style-type: none">- In Manitoba and to some extent New Brunswick authority has been centralized reducing the authority of local level institutions.• All provinces but Manitoba use boards and other governance authorities to give voice to elected citizens, appointed representatives, professionals, and other designated sectors of society. Manitoba deliberately strengthens the role of bureaucrats, professionals, and the research community as adjuncts to the provincially elected politicians. Quebec appears to be creating a balance between strong regional bureaucrats and the regional boards, whose members are both elected and appointed.• None of the provinces seem to dedicate enough attention to the informational requirements for improved decision-making. Those that opt for devolved approaches appear to give insufficient attention to how regional and local bodies are provided with good scientific evidence and the skills required to interpret information for decision making. At the same time, those
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						that opt for a centralized approach emphasize expert advice and technical information neglecting the other types of information.
22	Jaklevic MC. 2002 trustees of the year. Missouri lawyer brings a hospital to hometown. Mod Healthc 2002;32(6):33.	Missouri, U.S.	To highlight the achievements of a hospital trustee in Missouri, U.S.		Narrative Description	<ul style="list-style-type: none"> • The hospital trustee “led the charge” to make a case for the construction of a local hospital, and has served on the hospital’s board ever since.
23	Karash JA. Today's rural trustees: ready for anything (and everything!). Hosp Health Netw 2016;90(1):24-28.	United States of America	To describe the role of rural hospital trustees in the U.S. amid a “dizzying” array of challenges, including value-based reimbursement, declining populations, aging infrastructure and difficulties in recruiting and retaining medical staff to rural communities.	<ul style="list-style-type: none"> • Rural hospitals, the primary care providers for some of the most vulnerable populations in America, face difficult challenges as they struggle to maintain their viability and deliver on their objectives. • Hospital executives and trustees are faced with making difficult decisions regarding which services to maintain, which to drop and whether to affiliate with a larger hospital. 	Discussion Paper	<ul style="list-style-type: none"> • Individuals that make up a hospital board of trustees must possess certain characteristics in order to enable them to carry out their functions effectively: <ul style="list-style-type: none"> > Trustees must be knowledgeable about the hospital and its finances and various health policies that affect operations (e.g., Medicaid); > Be willing to go through educational training on focus areas that are required for best governance practices despite the qualifications they already possess; > Prioritize community need when considering mergers or affiliations instead of brands and job titles.
24	Kenny A, Hyett N, Dickson-Swift V. Reconceptualising community participation in primary health. Aust J Prim Health 2017;23(6):i.	Not Applicable	To introduce a special issue of the Australian Journal of Primary Health, where the advantages, challenges, and issues of community participation are discussed.	Not Applicable	Editorial	Not Applicable
25	Kenny A, Hyett N, Sawtell J, Dickson-Swift V, Farmer J, O’Meara P.	International Evidence	<ul style="list-style-type: none"> • The objective of the study was to identify examples in the 	<ul style="list-style-type: none"> • International policy is increasingly identifying a role for 	Scoping Review	Not specified

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	Community participation in rural health: a scoping review. BMC Health Services Research. 2013;13:64.		international literature of higher-level community participation in rural healthcare, utilizing Arnstein's (1969) categories of partnership, delegated power and citizen control (commonly clustered as 'citizen power'). <ul style="list-style-type: none"> • The scoping study asked: What examples of higher-level community participation in rural healthcare exist in the international literature? 	communities in healthcare planning, design, delivery and evaluation to avoid a 'one size fits all' (i.e., industrial) approach. <ul style="list-style-type: none"> • However, consistently, a lack of knowledge on how to build effective community-policy maker partnerships that empower communities and encourage citizen control and responsibility in local decision-making is identified. > Researchers continue to debate models, approaches, motivations, definitions and operational challenges. • In light of international imperatives to develop locally responsive services and to build sustainable empowered communities, research that investigates process and outcomes of community participation is of central importance for policy and practice. 		
26	Kidd S, Kenny A, Endacott R. Consumer advocate and clinician perceptions of consumer participation in two rural mental health services. Int J Ment Health Nurs 2007;16(3):214-222.	Rural Victoria, Australia	<ul style="list-style-type: none"> • First, the study aimed to explore the perceptions of consumer advocates and clinicians regarding consumer participation in two new regional mental health services • Second, the study aimed to explore how broad policy 	<ul style="list-style-type: none"> • Over the years, there's been allegations of inhuman practices which deny social justice and human rights to customers within the mental health system by their providers • Consumer participation which requires health professionals and 	Qualitative Interviews	<ul style="list-style-type: none"> • There were contradicting views among clinicians and consumer advocates on what consumer participation entailed and what role consumers should have within an organization. This meant that they had no clear processes to support the implementation of consumer

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			initiatives, related to consumer participation, are enacted at a service delivery level.	health services to value the lived experience of people who have managed a mental illness, is an important strategy which has been deemed essential by the Australian government to address social injustice and improve the quality of mental health service delivery <ul style="list-style-type: none"> • Yet despite this acknowledgement, little has been done to ensure effective consumer participation at a service delivery level. 		<p>participation.</p> <ul style="list-style-type: none"> • Meanwhile, both consumer advocates and clinicians acknowledged the value of consumer experience in contributing to the development of services yet more barriers to enacting a policy were identified including: consumer advocates of mental health still having the lasting effects of the illness, bias that may ensue with their remuneration and lack of dedicated funds for the process.
27	Knoble JK. Breaking rural health care paradigms leads to collaboration. Interview by Donald E. Johnson. Health Care Strateg Manage 1993;11(5):7-9.	New Mexico, U.S.	The author interviewed the president and chief executive officer of a U.S. medical centre to discuss the challenges of federal health care reforms and rural health care administration in the U.S.	Not Applicable	Narrative Description	<ul style="list-style-type: none"> • Success factors for rural hospital boards: <ul style="list-style-type: none"> > Members see the ‘whole picture’ of a future state of the institution; > Time is spent to educate the board on the importance of leadership and values within an institution. > To establish a strategic plan, together with the CEO, with meaningful and measurable objectives.
28	Kralewski JE, Moscovice I. Rural health care: an American perspective. Leadersh Health Serv 1992;1(6):12-15.	United States of America	To discuss the difficulties encountered by rural hospitals in attempting to maintain reasonable access to health services in rural areas, and the way forward to ensure their viability.	In the context of increasingly limited resources and a rapidly changing health care delivery system, rural hospitals encounter the following challenges: <ul style="list-style-type: none"> • A high turnover of hospital administrators and a consequent lack of long-term planning; 	Discussion Paper	To remain viable, rural hospitals need to restructure their programs and develop a coordinated network of health services. Management, boards and physicians will need to re-think their roles and develop mutual relationships in order to

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				<ul style="list-style-type: none"> • Inadequate involvement by physicians and hospital trustees in strategic planning and program development; • Politically motivated board appointments that weaken hospital governance; • Undue competition among health care providers in rural communities; and • A lack of good health insurance coverage. 		effectively deliver health care services.
29	Larson L. How many hats are too many? <i>Trustee</i> 2001;54(2):10.	United States of America	Where leaders are few and overlapping, how can trustees represent their community and remain true to their fiduciary and ethical duties in a rural setting?	<ul style="list-style-type: none"> • Conflicts of interest tend to arise when creating health boards in rural communities as small towns have very few qualified persons who may hold positions that may be conflict with their role on the board • As the health care environment is more regulated nowadays, these conflicts can no longer be ignored. 	Case Example	<ul style="list-style-type: none"> • In small rural communities, conflicts of interests on health boards are unavoidable and boards need to spell out clearly in written policy statements what needs to be done in disclosing conflicts and how decisions can be taken when conflicts arise. • A good conflict of interest by-law should enforce the following: <ul style="list-style-type: none"> - Enforce the submission of annual disclosure statements of any relationships that may pose a conflict of interest; - State how decisions should be taken when conflicts arise e.g. decide whether to refrain from voting or exiting the room during discussions on conflicting issues; - Encourage board members to speak up, in a non-confrontational manner, when they have conflict

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						<p>concerns about each other.</p> <ul style="list-style-type: none"> • However, despite the knowledge of conflict of interest, the community itself benefits from the connections held by members of the hospital board as they may work to promote local businesses.
30	Larson L. Rural rescue - a vision in time. Trustee 1999;52(10):13-17.	United States of America	To describe the contributions of the hospital board of a small town community hospital in keeping the hospital afloat and helping it prosper.	Health care budget cuts make it difficult for small rural hospitals to stay open and provide services to the communities they serve. Yet a small town hospital in rural America credits its board for keeping it afloat by providing the leadership required to maintain its autonomy, garnering resources to stay functional and obtaining information from the community on how best to serve them.	Discussion Paper	<ul style="list-style-type: none"> • In deciding how to save a rural hospital in financial straights from going under, the hospital board entered a partnership with a hospital management firm. The benefits of this partnership include: <ul style="list-style-type: none"> > Opportunity to maintain their autonomy as health management firms have no interest in buying them out of their business; > Gaining recent health care knowledge and broader health system connections from the management professionals; > Gaining legal, financial and other economic resources usually lacking in small rural hospitals. • Key features that have ensured the success of the board include: <ul style="list-style-type: none"> > Defining their vision and goals and how to achieve them; > Reviewing goals frequently to ensure they are on track for success; > Investing revenue back into hospital services; > Implementing strategies to recruit

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						and retain physicians which ensures the provision of health services; > Receiving community support in the form of fundraising and patronage of hospital services; > Networking with local health leaders to ascertain local health care concerns; > Working with neighboring rural hospitals to resolve their shared challenges.
31	Longley R. View from the boardroom. Interview by Sarah F. Zarbock. Home Care Provid 1999;4(1):17-18.	Northwestern Connecticut, U.S.	To explore board functioning, including their roles, and strategies to enhance communication, connection and cooperation between board members and home care agency staff.	Home care providers and the board members of home care agencies are focused on different issues, yet they share a common goal: to provide the best possible care to patients. It is critical to explore how to improve the relationship between both groups to achieve this shared goal.	Narrative Description	<ul style="list-style-type: none"> • The relationship between board members and nursing staff is improved if board members keep in touch with nursing staff either through formal or informal meetings to enable them to feel supported in their work. • The major role of board members is ensuring financial stability of the organization through fundraising, public relations, advertising and marketing. • Effective board members do not have to be subject matter experts but they need to be willing to learn about key issues that home care agencies face.
32	McClellan J, Trigger K. Not just tea and biscuits: the Gold Coast Primary Health Network process of designing, implementing and operating a	Australia	To contribute to a practical primary care account of designing, implementing and operating a CAC (Community Advisory Committee) by outlining	<ul style="list-style-type: none"> • Federal health reforms in Australia have directed the formal involvement of communities in primary care through advisory committees in 	Case Study	<ul style="list-style-type: none"> • The Gold Coast Primary Health Network's Community Advisory Committee supports citizen participation in health care decision making in the following ways:

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	Community Advisory Council. Aust J Prim Health 2017;23(6):504.		the process undertaken by Gold Coast Primary Health Network (GCPHN).	the newly established Primary Health Networks <ul style="list-style-type: none"> • Despite consensus in the literature regarding the merits of engaging consumers, conceptualizations remain inconsistent and evidence on effective tools and strategies for specific settings is limited. 		<ul style="list-style-type: none"> > Providing orientation and training for lay participants to reduce knowledge gaps; > Ensuring a closed feedback loop, by establishing realistic expectations and assure impact by presenting issues or topics for discussion that were related to the activities of the Primary Health Network; > Establishing a consistent structure and format to CAC meetings, to create a stable environment where members feel comfortable and know what to expect.
33	Merkens BJ, Emmerson RG. Local healthcare planning in rural southwestern Ontario. Leadersh Health Serv 1995;4(4):12-16.	Palmerston, Ontario	To describe how health and social services programs came into being in a rural community in Ontario; to examine the strengths and weaknesses of this informal process; and to make recommendations for improving governance and support.	<ul style="list-style-type: none"> • The cohesiveness of small rural communities is emphasized when planning for health and social services. • A lot of the planning is done by informal combinations of hospitals, community agencies and volunteers. 	Case Study	<ul style="list-style-type: none"> • Local partnerships between hospitals, community agencies and volunteers are very instrumental in solving the local health needs of rural communities. • Three main programs in Palmerston, Ontario have been formed through this means. They include: North Wellington Advisory Group, Palliative care support group and community based program advisory community of the PDH board. • Their major advantage is in their ability to clearly detect community concerns for health needs and work to raise projects that would solve those needs. • This set up is however challenged

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						by poor follow through due to the informality of the programs and their limited pool of skills and talent from which to draw from to manage such programs.
34	Nelson B, Gauss J. For rural boards, an imperative to change. Trustee 2016;69(1):4.	United States of America	To highlight steps that rural boards need to take to adopt an integrated governance model required for them to change with the times.	As changes in health systems occur with increased focus on population health and a continuum-of-care model, rural health boards need to evolve in a similar manner from the mindset of a traditional, acute care model of health care. Adopting integrated governance models is a critical step in sustained transformation to improved rural health care system Integrated governance system is the creation of new coalitions that foster collaboration, improve regional expertise and sharing of practices in lieu of organization consolidation.	Discussion Paper	<ul style="list-style-type: none"> • Rural boards need to adopt an integrated governance model to improve their composition and roles and prepare to adapt with the times. • The steps involved in achieving this include: <ul style="list-style-type: none"> > Carrying out regular succession planning for board management; > Considering skills and competency when selecting board members; > Managing turnover of board members through fixed term limits and new member onboarding plans; > Maintaining the right size for a health board; > Including out of community members to complement board member skill sets; > Compensating board members for their time; > Improving working relationships between board members and CEOs through frequent engagement for strategic decision making.
35	Nova Scotia's Blueprint for Health System Reform. As recommended by	Nova Scotia, Canada	To address the problems in our [Nova Scotia] health care system and improve efficiency and cost	The health system needs significant renovations as health care costs are extremely high	Commission Report	<ul style="list-style-type: none"> • Input from Nova Scotians regarding ways to improve of health care highlights citizen

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	The Minister's Action Committee on Health System Reform. April 1994.		effectiveness through a health system reform.	when compared to the health results being achieved. The system is currently riddled with waste and duplication as there is a lack of evaluation and funding is not based on outcomes.		participation as one of the major requirements <ul style="list-style-type: none"> • Decentralization of health care ensures that decisions regarding health care allocation and spending are taken at the local level with participation of the community. • To ensure decentralization, health boards are constituted with public participation on these boards.
36	Orlikoff JE, Totten MK. Conflict of interest and governance: new approaches for a new environment. <i>Trustee</i> 2004;57(4):15-18.	United States of America	To present case examples on the importance of a conflict of interest policy in health care boards.	Conflict of interest is an important aspect of governance accountability and a major issue among rural boards due to the limited pool of qualified board members that small communities may have. Conflict of interest policies must therefore be included in the requirements for rural hospital boards compositions.	Case Examples	<ul style="list-style-type: none"> • Health care organizations must hold their boards to the highest standards by taking steps to eliminate conflict of interest within their ranks. This maintains an ethical standpoint and builds the trust of the community in the health boards.
37	Pagatpatan CP, Ward PR. Understanding the factors that make public participation effective in health. <i>Aust J Prim Health</i> 2017; 23(6):516-530.	Australia	This paper presents a realist synthesis, which identifies and explains the underlying mechanisms and specific contextual factors that lead to effective public participation in health policy and planning.	Researchers have for a long time argued the importance of involving the public in developing health policy, there has been little focus on key questions on the mechanisms of public participation such as; what techniques of public participation work, in what circumstances and why.	Realist Literature Review	<ul style="list-style-type: none"> • A synthesis of the health policy and planning literature and its comparison with the broader literature shows that political commitment is the major impetus for effective public participation. Political commitment ensures public influence, increased understanding and reached consensus. • Broader literature however, suggests three other possible mechanisms of partnership

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						<p>synergy, inclusiveness and deliberativeness that could be relevant to the field of health policy and planning. These generate effectiveness such as increased understanding, consensus and improved quality of decisions.</p> <ul style="list-style-type: none"> • Of note is that this synthesis was unable to show the specific mechanism that generates specific effectiveness criteria, such as increased trust.
38	Pallarito K, Shinkman R. 1997 Trustees of Year. Mod Healthc 1997;27(3):26-28.	United States of America	To discuss the accomplishments of long-time hospital board trustees.	To recognize the contributions and leadership of two hospital board trustees.	Narrative Description	<ul style="list-style-type: none"> • The authors contend that the featured trustees were instrumental to health system development in their home communities. • As a hospital trustee in Binghamton, New York, William Rincker offered guidance, leadership and support toward the development of United Health Services, a network of three acute-care hospitals, several primary care clinics, a long term care facility, a home health nursing service, a medical equipment company, a physician services firm, a multispecialty group practice and an independent practice association. • J. Patrick McGillis, a hospital trustee in western Montana, was touted to have "revived" the local hospital, by

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						<p>offering "good ideas and management philosophy", and through establishing a strong rapport with the hospital's CEO.</p> <ul style="list-style-type: none"> • Despite their communities facing vastly different challenges, the featured trustees share many attributes, including dedication to and knowledge of their communities; easy-going and soft spoken natures; modesty; diplomacy; a willingness to learn and to pitch in; and quiet leadership.
39	<p>Peck E, Gulliver P, Towell D. Governance of partnership between health and social services: the experience in Somerset. Health & social care in the community 2002;10(5):331-338.</p>	<p>Somerset, England</p>	<p>To explore the role of the Joint Commissioning Board in the governance arrangements for health and social partnership in Somerset, UK.</p>	<p>Partnerships in governance boards for health and social planning has been shown to lead to problems and the role of non-executive directors and councilors has been marginalized and often overlooked.</p>	<p>Evaluation</p>	<ul style="list-style-type: none"> • The Joint commissioning board brings together health executives, local health authorities, councilors, health care users and carers together in decision making for health and social services. • The board is distinct from the National Health services (NHS) trust with the latter focusing more on funding related issues. • Decision making at the JCB is mostly dominated by health authority representatives and health executives with local councilors and health care users contributing little as they lack understanding of the major issues. • The impact of the JCB is queried at being only a visual tool for

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						partnership with little known achievements.
40	Pickard S, Marshall M, Rogers A, Sheaff R, Sibbald B, Campbell S, et al. User involvement in clinical governance. HEALTH EXPECTATIONS 2002;5(3):187-198.	England	<ul style="list-style-type: none"> • To investigate the involvement of users in clinical governance activities within Primary Care Groups (PCGs) and Trusts (PCTs). • To investigate how clinical governance strategies differ in involving service users and the public in clinical governance. 	<ul style="list-style-type: none"> • There have been calls, since policy initiatives in 1997, for the involvement of lay stakeholders in clinical governance in the British NHS. This lay involvement was to restore public confidence in the system, improve accountability and ensure cost effectiveness through better outcomes for individual patients and appropriate use of health services. • Despite this, public involvement has mostly been ad hoc with little consistency and uniformity among participant groups and this varieties affect how well represented patients on groups such as this. • PCGs and PCTs (Primary Care Groups/Trust) where then introduced to involve users of the health system in strategic planning, communication and clinical governance to strengthen public participation in the system. 	Qualitative Interviews	<ul style="list-style-type: none"> • Lay involvement in health care decision making is heavily advocated for in theory, but in practice very little is done to implement it and ensure its success. • Lay involvement remains low due to several challenges that have not been carefully addressed including: lack of clarity of their roles, the complexity of clinical issues, methodological problems around how to do user involvement, tensions around professional accountability (that is, between professional control of clinical quality and the policy of lay participation) and the prerequisite for a cultural change to take place organizationally.
41	Pirani MJ, Hart LG, Rosenblatt RA. Physician perspectives on the causes of rural hospital closure, 1980-1988. J Am Board Fam Pract 1993;6(6):556-562.	United States of America	To examine the reasons for sole community general hospital closures from the perspective of the physicians and to compare these reasons with the perspectives of the local mayors.	<ul style="list-style-type: none"> • A significant number of rural hospitals in the US closed in the 1980s. While some think that this is an indication of low utilization of health services in the rural axis, the impact of these closures in 	Qualitative Survey	<ul style="list-style-type: none"> • The main reason for hospital closure was government reimbursement policies and this was consistent among both physicians and the local mayors. • Bad board leadership was also

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				<p>towns where they are the sole health providers would be extremely detrimental.</p> <ul style="list-style-type: none"> • It is therefore necessary to understand why this closures happen in order to prevent future occurrences. As numerous studies have reported perspectives of mayors on this issue, we can better solidify our understanding by comparing physician perspectives with those of the mayors. 		<p>sighted as a secondary reason for hospital closure.</p>
42	<p>Ramstead O. Rural trustees brave the health care funding crisis. Interview by Matthew D. Pavelich. Leadersh Health Serv 1992;1(3):26-28.</p>	<p>Saskatchewan, Canada</p>	<p>To discuss potential changes in Canadian health care directions- such as the amalgamation of hospital governing boards and administrations - and their special impact on rural facilities.</p>	<p>In helping rural hospitals weather the funding crises, trustees and health care professionals must be willing to adjust traditional conventions and practices. A seasoned hospital board trustee from Saskatchewan discusses what extra mile board chairs may have to go to make this possible.</p>	<p>Narrative Description</p>	<p>A long term board trustee shares tidbits that would make trustees more successful:</p> <ul style="list-style-type: none"> • Trustees should be willing to go the extra mile to ensure the best services for the board such as paying for required professional development if necessary which the community may not be able to reimburse; • Trustees first and foremost role is one of duty and commitment to the community and health care.
43	<p>Riley KK, Elder WG. The WAMI Rural Hospital Project. Part 4: Improving the financial health of rural hospitals. The Journal of rural health : official journal of the American Rural Health Association and the National Rural Health Care Association 1991;7(5):526-541.</p>	<p>Washington, U.S.</p>	<ul style="list-style-type: none"> • To increase the level of financial expertise of the management and hospital board and to strengthen the financial practices of rural facilities. • To measure whether key financial indicators were affected 	<ul style="list-style-type: none"> • High rates of rural hospital closure in the 1980s are largely attributed to financial challenges faced by these hospitals due to negligible no profits, low cash reserves and declining market share. • The Rural Hospital Project (RHP) 	<p>Survey, Secondary Data Analysis</p>	<ul style="list-style-type: none"> • The intervention of the Rural hospital projects strengthened financial expertise of hospital leadership and hospital boards which led to substantial improvement in financial practices across all sites.

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			in a positive direction by the intervention.	was implemented in six northwestern communities to support their hospitals with interventions to help address these financial problems.		
44	Robinson G, d'Abbs P, Togni S, Bailie R. Aboriginal participation in health service delivery: Coordinated care trials in the Northern Territory of Australia. Int J Healthcare Technol Manage 2003;5(1-2):45-62.	Australia	To outline general Coordinated Care Trial (CCT) outcomes according to the findings of the commissioned evaluation studies, and examines the possibilities and constraints encountered in improving Aboriginal participation in complex health service developments.	<ul style="list-style-type: none"> • Australian Aborigines have lower life expectancy than the Australian population as a whole as they have been disenfranchised from access to quality primary care through the health care disparities that in rural and remote regions • Coordinated Care Trials (CCT) were established in the late 90s to address this inequality; the aim was to improve Aboriginal participation in health service delivery through the establishment of Aboriginal community Health Boards to act as funds managers and providers of health services to the trial populations. 	Case Study, Evaluation	<ul style="list-style-type: none"> • Overall, involving Aboriginals in health care decision making showed no apparent change in the level of service delivery in both coordinated care trial groups, in the three-year period of the pilot, but data management and use of IT infrastructure improved during the study period. • On user involvement in clinical care decision making, varied experience was noted across both care trials as self-responsibility and compliance improved with some patients being passive recipients of both Aboriginal and non-Aboriginal health worker demands.
45	Rose D, Barnes M, Crawford M, Omeni E, MacDonald D, Wilson A. How do managers and leaders in the National Health Service and social care respond to service user involvement in mental health services in both its traditional and emergent forms? The ENSUE study. NIHR Journals Library 2014.	United Kingdom	To explore the impact of service user involvement in mental health on shaping policy agendas and delivery specifically in terms of their impact on key decision-makers: 1. What have been the impacts of user involvement in mental health in terms of service development, delivery,	Mental health services pioneered user involvement in decision making before other medical specialties and yet the impact this has on care quality is not yet known. This study presents how user involvement is currently fairing and its impact on mental health services in the UK.	Quantitative Survey, Qualitative Interview	<ul style="list-style-type: none"> • Service users have a positive impact on service planning and delivery and they are supported by both front-line and senior staff. This has led to new opportunities opening up for user involvement, including becoming members and governors of NHS Foundation Trusts • User led organizations however,

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			<p>commissioning and personal benefit to users? We have the same research question for front-line staff.</p> <p>2. How do managers and other key decision-makers respond when user-led organizations (ULOs) approach them, seeking change?</p> <p>3. Moving to a more individual level of user involvement, what is the role played by user governors on trust boards and how do key decision-makers on the boards respond to them?</p> <p>4. What are the implications of the move to 'personalization' in both health and social care, specifically in terms of the role of ULOs in brokerage and care planning?</p> <p>5. What are the underlying assumptions, beliefs and values held by senior managers about the benefits and drawbacks of user involvement in mental health, and how do they individually and collectively respond to, facilitate or impede this?</p>			<p>have abandoned traditional styles of operations through confrontations and campaigns for more corporate and professional modes as a means to adapt to complexity of the climate in which they work in.</p>
46	Rosenthal TC, Doemland M, Parisella JS. An assessment of rural hospital trustees' health care knowledge base. J Rural Health 1991;7(1):13-22.	New York, U.S.	To better understand the demographics of rural hospital trustees, their knowledge base	The role of hospital trustees is important in defining health care quality in rural areas through administration, financial	Survey	<ul style="list-style-type: none"> • Most board members receive instructional materials regarding their roles as trustees, as part of continuing education/orientation to

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			regarding the hospital, and their roles as trustees.	management, fundraising, regulatory oversight etc. However, most rural trustees are volunteers without a health care background and their knowledge on hospital issues is limited. To be effective therefore, they must learn the complexities of running a hospital.		help them carry out their roles more effectively. <ul style="list-style-type: none"> • Less than half of the participants offered correct responses to questions about average hospital census, length of stay, payer type and hospital services. • Most trustees were aware that recent quality assurance guidelines increased their liability and half believed it was their most important activity.
47	Saleh SS, Vaughn T, Rohrer JE. The effect of governing board composition on rural hospitals' involvement in provider-sponsored managed care organizations. J Healthc Manag 2002;47(5):321-333.	United States of America	To examine the effect of the governing board's composition on rural hospitals' involvement in provider-sponsored managed care organizations (PSOs).	Changing health care environment is seeing more rural hospitals get more involved in provider-sponsored managed care organizations which enhance public trust and improve the performance of the hospitals. The competence and composition of the hospital boards is said to be influential on the hospitals' decision to take on such a strategic and organizational change.	Secondary Data Analysis	<ul style="list-style-type: none"> • Hospitals that owned PSOs had on average, more community leaders, business leaders, health professionals and other types of member groups on their boards.
48	Simpson C, Kirby J. Organizational ethics and social justice in practice: choices and challenges in a rural-urban health region. HEC Forum 2004 Dec;16(4):274-283.	Nova Scotia, Canada	The paper describes organizational ethics and social justice in action in the Capital District Health Authority (Capital Health for short) in Nova Scotia, Canada.	Ethical and social justice needs of community and rural health care facilities may differ from those of tertiary facilities and health authorities managing health facilities of either or both types need to be aware of these differences. The paper looks at one health	Case Study, Discussion	<ul style="list-style-type: none"> • Health care policies were developed through ad hoc policy working groups which included participants from rural facilities/programs and disadvantaged social groups that are anticipated to be directly impacted by the policy change.

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				authority's attempt to institute an ethical support framework through an "engaged participation" approach.		
49	Singer MA. Public Participation in Setting Health-Care Priorities: Should It Be Done and Can It Be Done? <i>Ann R Coll Physicians Surg Can</i> 1994 (27):275-278.	International	To review initiatives involving public participation in health care decision-making in Oregon (U.S.) and an inner London health district (U.K), and to determine what role communities should play in allocation discussions for health care.	Limited resources exist to meet health care needs and government makes decisions on what limits there are to health care spending. However, in a publicly funded system like Canada, what role should the communities play in decision making for the allocation of these resources?	Discussion Paper, Case Example	<ul style="list-style-type: none"> • Community meetings in Oregon were used to facilitate dialogue and reach a consensus on a list of values that define the importance of health care as a common goal. • In the London health district, public ranking of health services was compared to the priorities ranked by general practitioners in the district to determine allocation methods for resources. • Both these approaches were flawed in some way underscoring the need to define a suitable methodology to accurately sample public views and values.
50	Skinner MW, Joseph AE, Herron RV. Voluntarism, defensive localism and spaces of resistance to health care restructuring. <i>Geoforum</i> 2016 JUN;72:67-75.	Ontario, Canada	To supplement the limited stock of case studies probing voluntarism as a space of resistance to structural change by examining the role of the voluntary sector in shaping local responses to the re-organization of health care services into region-based health authorities in Ontario, Canada.	<ul style="list-style-type: none"> • Voluntarism occurs in a variety of spaces including those resistant to modern day restructuring initiatives such as regionalization. But little is known about the local dynamics involved in voluntarism as it has become a target for government devolution, divesting agendas and a space for resistance for individuals and communities coping with systemic challenges • With this gap in understanding, there is a risk of over-theorizing 	Case Study	<ul style="list-style-type: none"> • The media findings reveal a suite of public concerns and related activities, with the voluntary sector called upon in various ways to defend the autonomy of the community against the perceived threats to local services, employment and vulnerable populations. • However, the stance taken by such representatives and the nature of the advocacy for local health care priorities could not be examined from the media stories.

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				the contribution of voluntarism by researchers on one hand while exalting the role of voluntarism and voluntary organization in public discourse.		
51	Strenger EW. Taking care of their own. In western Pennsylvania, hospital leaders are taking a local approach to health care reform. <i>Trustee</i> 1995;48(7):16-19.	Pennsylvania, U.S.	To highlight one hospital's efforts to transform the health care system of their rural community.	Community leaders are dedicated to developing local solutions to suit health care needs.	Discussion Paper, Case Example	<ul style="list-style-type: none"> • A local hospital board leads community health initiatives to bring community leaders together in figuring out the health needs of the community and how to solve them.
52	Tritter JQ, McCallum A. The snakes and ladders of user involvement: Moving beyond Arnstein. <i>Health policy</i> 2006;76(2):156-168.	Finland	To explore the relevance of Arnstein's typology of user involvement to current development in healthcare, particularly within the English National Health Service (NHS), and draw on comparisons from the Nordic countries (Finland, Sweden), the Netherlands and Canada.	<ul style="list-style-type: none"> • Health services in Western countries are beginning to emphasize public and patient involvement in decision making on treatment, service development and health care evaluation. • In 1969, Arnstein developed a theoretical framework for citizen participation called "A ladder of Citizen Participation" which till this day continues to shape our thinking on the issue of citizen participation. • In the years since this model was put forward, progress has been made in the understanding of factors that drive user engagement yet its principles are still applied uncritically by policy makers and practitioners promoting user involvement. 	Discussion Paper	<ul style="list-style-type: none"> • Arnstein's model of citizen participation is limited by solely emphasizing power as an outcome; it does not provide effective responses to the challenge of involving users in services and undermines the potential of the user involvement process. It assumes that power is the same for users, provider and policy makers and ignores different forms of knowledge and expertise. • In addition, it fails to recognize that for some users, participation may simply be the end goal. • To mitigate this, a new model of citizen participation is proposed that argues for user involvement to improve health services while acknowledging the value of the process and the diversity of knowledge and experience of both health professionals and lay people.

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53	Umbdenstock RJ, Hageman WM, Amundson B. The five critical areas for effective governance of not-for-profit hospitals. Hospital & health services administration 1990;35(4):481.	United States of America	To explore the importance of five factors that impact on the governance of not-for-profit hospitals, and to suggest how to link a board's activity to its strategic plan.	<ul style="list-style-type: none"> • There are mounting pressures on hospitals and as a result, voluntary board members are increasingly nervous, making management's task to guide the board and build their confidence in management's approach to critical issues more difficult. • Traditionally, community hospitals have had voluntary boards comprised of trustees with mixed organizational and management experiences, and often, generally low level of first-hand experience in health care policy and practices. ○ This results in a "catch-22" for governance: time spent "educating" the board means less time for the board to carry out its work, but less time educating the board means increased risk for the executive who moves forward without them. 	Discussion Paper	<ul style="list-style-type: none"> • Five factors have been identified which account for board effectiveness. These factors aid effectiveness helping the board organize its work to address hospital priorities. They are: <ul style="list-style-type: none"> > A common definition of governance and what it means for their roles, responsibilities and relationships with the organization; > Clearly defined mission with specific goals and objectives; > A decision – making process that is well planned and based on the priorities of the organization; > A board structure that is tailored to suit the priorities of the organization; > An adequate information, reporting and communication system that helps the board ascertain its progress towards the accomplishment of its goals.
54	Veronesi G, Keasey K. A (new) model of board of directors: evidence from the National Health Service. International Journal of Public Sector Management 2012 May 25,;25(4):272-286.	United Kingdom	<ul style="list-style-type: none"> • To investigate the collective behaviour of boards of directors in 22 English National Health Service trusts and how this impacts on the exercise of their role and functions. • To understand the governance model characterizing boards of health sector organizations. 	<ul style="list-style-type: none"> • Reforms to the public sector, categorized by new public management (NPM), introduced mechanisms for administration and governance imported from the private sector; the ultimate aim: greater efficiency. • In response to criticism against NPM reforms, the English National Health Service 	Multiple Case Study	<ul style="list-style-type: none"> • Health care boards are characterized by different internal dynamics, processes and levels of engagement in the exercise of their tasks, owing to the existence of overlapping governance ideologies. ○ NPM-driven boards were primarily focused toward ensuring organizational financial stewardship. As a consequence,

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				<p>introduced the Foundation Trust (FT), a new organizational form, with greater decision making autonomy to facilitate the involvement of local communities.</p> <ul style="list-style-type: none"> • There is a lack of knowledge of the governance model that boards of public sector organizations have adopted and the behavioural characteristics of boards. 		<p>and facilitated through ambiguous accountability to local stakeholder, stakeholder participation in decision making seemed to be more as a form of conformance to the policy directive rather than a strategic goal.</p> <ul style="list-style-type: none"> ○ Post-NPM-driven boards, with an internal culture more favourably oriented toward power sharing and participation, appeared strategically more committed to redressing the balance between national priorities and local needs and as a result, decision-making was defined by a willingness to provide a relevant service for the local community. • FT boards (in comparison with other NHS boards) appeared as the highest performers in terms of organizational performance and behavioural measures of effectiveness. ○ FT boards largely shared post-NPM driven behavioural traits: enhanced influence of stakeholder voice in decision-making processes and a greater willingness to redress the balance between national and local priorities.
55	Wade TL, Radford AD. North Carolina state government and the healthcare safety net: building the nation's most extensive network of rural health	North Carolina, U.S.	Not specified.	<ul style="list-style-type: none"> • The North Carolina Office of Research, Demonstrations and Rural Health Development aims to transform government into a 	Commentary	<ul style="list-style-type: none"> • To help rural communities to address a critical shortage of primary health care services in their communities, the Office promoted

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	<p>centers. N C Med J 2005;66(2):125-126.</p>			<p>catalyst for improving access to quality and cost-effective health care services for underserved residents of North Carolina.</p> <ul style="list-style-type: none"> ○ Community investment is the cornerstone of the Office’s improvement strategy. ○ The Office adopted a state-local partnership approach, guided by five key principles: <ul style="list-style-type: none"> - Ownership is vested with community participants. - Roles and responsibilities of all participants, both community and governmental, are clearly defined. - In-depth technical assistance is provided on a continuous basis. - Accountability is clear and measured. - Meeting patient and community needs remains the focus of all activities. 		<p>the development and use of community nonprofit boards, comprising local residents as the owners and operators of their community’s health care program.</p> <ul style="list-style-type: none"> • The Office developed a comprehensive set of support services, including technical expertise to support interested communities to establish nonprofit corporations, organize fundraising campaigns, design and build facilities, recruit and hire staff, and oversee medical operations. • Together, community leadership and the technical assistance delivered by the Office were highly effective in making medical care available to rural communities. • A second structural change to support increased access to health care in rural communities in North Carolina was reliance on non-physician primary care providers (family nurse practitioners and physician assistants) to provide needed medical services. <p>○ Major changes in medical practice and reimbursement rules and regulations were initiated to allow non-physician primary care providers to practice in medical offices geographically removed from a supervising physician.</p>
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56	Weiner BJ, Alexander JA. Corporate and philanthropic models of hospital governance: a taxonomic evaluation. Health Serv Res 1993 Aug;28(3):325-355.	United States of America	<p>To assess the theoretical integrity of corporate and philanthropic governance models in the context of nonprofit hospitals operating in increasingly competitive health care environments.</p> <p>(1) What are the dominant forms of hospital governance? (2) To what extent do these dominant forms conform to the theoretical archetypes: corporate or philanthropic? (3) Are certain forms of governance more or less prevalent among hospitals operating under particular organizational and environmental conditions?</p>	<ul style="list-style-type: none"> • Hospital boards are being compelled to adopt more active roles in strategy formulation, environmental adaptation, and internal control of hospital management in light of increasing market pressures and regulatory changes. ○ Uncertainty remains about the form of hospital governance most appropriate for the changes in board functioning. • The philanthropic (volunteer) board model emphasizes asset preservation and constituent representation. • The corporate model of governance emphasizes streamlined decision-making and strategy development. 	Secondary Data Analysis	<ul style="list-style-type: none"> • Neither the corporate nor philanthropic models in their pure forms are found to be prevailing governance configurations; in fact, hospital governance configurations are characterized by a mix of corporate and philanthropic attributes. • A substantial degree of variation exists in hospital governance forms. • The findings of the study support the thesis that board form varies systematically by specific organizational and environmental characteristics of hospitals. ○ Hospitals exhibiting more corporate-type governance configurations are more likely to be large, privately owned, located in urban environments, and operating in competitive markets than are hospitals exhibiting more philanthropic governance configurations.
57	Wilson R, Boldy D, Denton L. A review of hospital boards of management in rural Western Australia. Aust Health Rev 1993;16(3):218-230.	Australia	<p>To review the place of country hospital boards in the delivery of public sector health services in rural Western Australia. In particular, this study explored the demographic characteristics of country hospital boards, board roles and functions, and strategies to evaluate performance.</p>	<ul style="list-style-type: none"> • There are 44 hospital boards, constituted under the Hospitals Act, within the seven designated Health Department of Western Australia (HDWA) country regions as of August 1989. • Nowhere within the Hospitals Act are the roles, responsibilities or authorities of hospitals boards 	Survey	<ul style="list-style-type: none"> • Boards tend to be predominantly comprised of males, aged more than 40 years, Australian by birth, with the occupational status of administrator, manager or farmer. • There is general consensus that boards have two major functions: management and representing the community. It is suggested that the latter function would be better

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				<p>clearly and comprehensively defined.</p> <ul style="list-style-type: none"> • There have been no serious attempts to define the functions and responsibilities of country hospital boards in Western Australia, or to establish mechanisms to develop and evaluate board members. • However, amendments to the Hospitals Act in 1985 include a requirement that the effectiveness of public hospital boards be assessed every five years. 		<p>served if there was closer alignment between age, gender, occupational status and country of birth of the board and of the community.</p> <ul style="list-style-type: none"> • The data gathered revealed a strong commitment by board members to their roles in terms of hours per month devoted to board activities, board attendance and preparedness to fulfill their roles without payment. However, there was also a strong feeling that members should be reimbursed for out-of-pocket expenses. • With regard to board member preparation for their role, only 32% of participants reported receiving induction or orientation when first appointed to their board, and roughly two-thirds of these individuals felt that the induction was insufficient. • Board members appeared to assign high priority to functions with a more operational focus and low priority to those concerned with more strategic aspects of management. • Members do not have a high level of understanding or, or interest in, processes for evaluating the quality of hospital services or the performance of hospital staff.
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58	Wright B. Rural-Urban Differences in Consumer Governance at Community Health Centers. <i>Journal of Rural Health</i> 2013;29(2):125-131.	United States of America	To identify differences in the structure and function of consumer governance at Community Health Centers in rural and urban areas.	<ul style="list-style-type: none"> • Community health centers (CHCs) are federally-funded primary care clinics that serve primarily low-income patients. • CHCs seek patient input through consumer governance. In fact, federal law requires that at least 51% of CHC board members be patients at the center that they govern. • CHCs face challenges including dominance by social elites, low levels of consumer participation, disparities in working knowledge between consumers and non-consumers and unanswered questions about the effect of consumer governance on measurable outcomes. • There may be differences in board structure and function associated with centers' degree of rurality. 	Interviews	<ul style="list-style-type: none"> • Consumer governance functions differently in rural versus urban CHCs. In particular, rural CHCs are more likely to have representative boards (i.e., that look like the community that they serve), boards that convey confidence in the CHC to community members, and boards that are more aware of community needs. • Conversely, urban CHCs are more likely to achieve objective decision making and have greater means for objectively evaluating the quality of care due to increased patient board member anonymity.
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Appendix C: Data Extraction and Quality Appraisal Form

Reviewer Name:

Date:

Data Extraction Form

Part 1

Bibliographic Reference (Vancouver Style):

Research Question(s)/ Objective(s):

Study Rationale/ Context:

Study Design/ Publication Type:

Jurisdiction:

Study Population:

Methods

Inclusion Criteria (for Participants, Studies, Data):

Exclusion Criteria (for Participants, Studies, Data):

Sources of Information:

Study Conduct (e.g., Interview Protocol, Survey Design and Distribution, Outcome Measurement):

Analysis (e.g., Statistical):

Part 2

Results

Main Findings (*for Annotated Bibliography – 2 to 3 points*):

-

What is the rationale for community or citizen-patient representation or involvement?

Structure:

What is the structure of the health board or council? (i.e., How is the board organized?)

What is the composition of the health board or council?

How are communities or citizen-patients represented on the health board or council?

Other relevant information.

Function:

What is the function (e.g., the mandate, the activities, the responsibilities etc.) of the health board or council?

What are important considerations with regard to the effective functioning of the health board or council?

How does the health board or council make decisions?

Describe the accountability relationship of the health board or council (i.e., Who is the health board or council accountable to? Who is accountable to the health board or council?)

How are communities or citizen-patients involved in the health board or council?

Other relevant information.

Impact:

What is the impact of the health board or council (as a whole), or individual board members, on health services planning, decision making or delivery? (i.e., What has been their influence? What has the board accomplished? Has the board (or individual board member) been successful/effective?)

How have communities or citizen-patients influenced the effectiveness of the health board or council?

What are advantages to community or citizen-patient representation on the health board or council?

What are challenges or barriers to community or citizen-patient representation on the health board or council?

Other relevant information.

Other Relevant/ Important Findings:

Quality Appraisal Form

Record your answer to each bolded question, using the prompting questions (in blue) to assist you as necessary and applicable.

An overall judgment is required for each domain (relevancy, reliability, validity and applicability) and overall. This judgment should be transparent based on your domain assessments.

Relevancy

Q1. Does the study address a topic(s) relevant to the issue under investigation?

YES NO NOT SURE

Is the rationale for the study clearly stated? (For example, does it address a gap in the existing literature?)

How similar or different is the study population or setting to ours? Is a difference likely to matter for the issue at hand?

Please provide further explanation if necessary.

Reliability

Reliability refers to the elements required so that one could reproduce the research. The main elements being assessed are the transparency of the research and the reporting quality.

Q2. Is the study presented clearly? YES NO NOT SURE NOT APPLICABLE

Is the rationale for study clearly stated? (For example, does it address a gap in the existing literature?)

Does the study focus on a clearly defined issue?

Is the conduct of the study clearly described and easy to follow?

Can you identify a research design?

Is there a conflict of interest statement?

Please provide further explanation if necessary.

Q3. Are the research methodology and results clearly described?

YES NO NOT SURE NOT APPLICABLE

Can the methodology be reproduced based on the information provided?

Does the methodology describe the population studied, the intervention given, and the outcomes?

Are all sources of information clearly identified?

Are inclusion and exclusion criteria defined?

Are the analytical methods described?

Please provide further explanation if necessary.

Q4. Are ethics procedures described?

YES NO NOT SURE NOT APPLICABLE

Was appropriate informed consent obtained?

Was the study approved by an ethics review board?

Please provide further explanation if necessary.

Validity

This section refers to the likelihood and magnitude of error or bias in the study.

Q5. Is the study methodology appropriate for the scope of research?

YES NO NOT SURE NOT APPLICABLE

Is the research question congruent with the study design?

Does the methodology match the theory or the conceptual model?

Are appropriate controls considered, if applicable?

Are the analytical methods appropriate for the design and or question?

Please provide further explanation if necessary.

Q6. Is the research methodology free from major sources of bias?

YES NO NOT SURE NOT APPLICABLE

Were there major sources of bias with respect to: study design, study participants inclusion or exclusion, measurement of exposure or outcome or important cofounders or predictors, data sources, analysis, or selection of studies?

Were potential sources of bias addressed and or discussed?

Please provide further explanation if necessary.

Q7. Are the authors' conclusions explicit and transparent?

YES NO NOT SURE NOT APPLICABLE

Are the results conclusive?

Are the authors' conclusions clearly derived from the results (i.e., transparent)?

Are potential discrepancies discussed?

Please provide further explanation if necessary.

Q8. Am I confident about the findings?

YES NO NOT SURE NOT APPLICABLE

Are there any major methodological flaws that limit the validity of the findings?

Are the study's results similar to those of the existing body of literature? If not, are the reasons for the difference clearly explained?

Please provide further explanation if necessary.

Applicability

Q9. Does this paper make a valuable contribution to our understanding of community or citizen-patient involvement (i.e., the structure, function and impact) on health boards or councils?

YES NO NOT SURE

Consider whether the authors discuss the contribution the article makes to existing knowledge or understanding (e.g., Do they consider the findings in relation to current practice or policy, or relevant research-based literature?).

Consider if the authors have discussed whether and how the findings can be transferred to other populations or other ways that the research may be used.

Does the information presented strengthen a current position? (i.e., Is the information presented aligned with relevant research-based literature?)

Consider the relevancy of the information presented.

Please provide further explanation if necessary.



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