

Advancing Community Engagement in Healthcare in Rural BC:

A gap analysis to improve community involvement in healthcare planning

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Final Report

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Message from the Project Team

In 2020, the Centre for Rural Health Research (CRHR) undertook a provincial survey to understand and document the healthcare priorities of rural communities across British Columbia (BC).^{*} Although the findings were as expected regarding health care concerns for rural communities (lack of access to primary care, support for aging in place and subsidized transport), the open-text boxes for additional comments yielded an unanticipated finding: general dissatisfaction over engagement with health care policymakers and planners and the consequential desire for better mechanisms of communication. At the same time, the BC Rural Health Network (BCRHN), a pan-provincial, community-based organization advocating for issues of concern to and identified by rural communities, was gaining traction due to their strategic approach of bringing community issues forward within a solutions-based framework. Through intensive outreach activities, the Network was also witnessing the growing disillusionment of rural communities who expressed the desire for connection with policy and decision-makers. The alignment of values and complementary approach of the two organizations – the former focused on creating a robust evidence base for rural health care planning and the latter working at a grass-roots community level to inform decision-making through the experiences of rural communities – led to a natural and productive relationship. The two organizations partnered to form the BCRHNs ‘Implementation Committee’, an open and virtual provincial group that meets regularly to focus on issues of concern to rural communities and, importantly, develop position statements to share with regional and provincial decision-makers, social service agencies and, where appropriate, the media.

It was based on this natural alignment of interests and productive confluence of weaving evidence with advocacy, that the two organizations committed to further understanding how to bridge the gap between rural community evidence-based advocacy and including these voices in policy and planning. Although the ‘end-game’ objective was to develop a provincial platform to allow such communication to flow, conversations with SPARC alerted us to a need for a preliminary step: to understand and document the organizational barriers faced by policy and decision-makers that made the inclusion of such experience-based data difficult. We recognized this to be a missing piece and a necessary antecedent to the proposed communications platform. That is, if we did not thoroughly understand the *cultural* challenges of the uptake of community solutions for health care planning, the *structural* solutions would be ineffective. Given this, we set out to work with regional and provincial policy and decision makers to understand the institutional, cultural, and practical realities of engaging with rural communities for the purpose of health care planning. A core value held by both organizations was the

^{*} Kornelsen, J., Carthew, C., Míguez, K. et al. [Rural citizen-patient priorities for healthcare in British Columbia, Canada: findings from a mixed methods study](https://doi.org/10.1186/s12913-021-06933-z). BMC Health Serv Res 21, 987 (2021). <https://doi.org/10.1186/s12913-021-06933-z>

recognition that those in public service had the best of intentions to actualize the provincial commitment to community-based planning but were constrained. That is, we clearly recognized the commitment of decision-makers to do the best job they could.

Through the initial stages of the project, however, we heard the assertion that there *was* successful and effective community outreach occurring in parts of the province and on discrete topic areas both by regional and provincial governments, but also through arms-length agencies that report back to the Health Authorities and Ministry. As this was not congruent with what CRHR had found through previous research and what the Network was learning through their outreach initiatives, we determined the emergent need for more robust data on community experience and quickly developed an online survey to gather these data. The survey was intended to provide context for the focus of the research, understanding and documenting the experience of municipal, regional, and provincial leaders. We had a solid response from across the province, slightly surprising given the niche topic of the survey. This led to a more fulsome process with leaders at all levels of governance and is a significant contribution to our understanding of community engagement in BC.

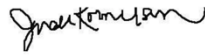
The efficacy of this study was based on the strength of the pre-existing relationship that has developed between the CRHR and BCRHN. The natural alignment seems obvious: robust evidence combined with grass-roots connection to ensure the practical utility of the data gathered and effective relationship-based knowledge translation *back to the communities*. This commitment to longitudinal engagement and returning data to the communities was a necessary starting point as it reflects the system-level commitment we are advocating for to actualize community-based planning.

We believe that the yield of this SPARC-funded work contributes meaningfully to building a culture of inclusivity and to the democratization of health policy and planning. However, it is still early days. We have already leveraged these findings to apply for and receive a small grant to do virtual regional engagement sessions with communities from across the province to take their direction on how the data should be used and what practical actions should be taken. This work will be occurring through the spring and will add to the initial findings presented in this report.

We – and the rural communities across BC that we have the privilege of working with – are profoundly grateful for the opportunity to better understand the issues at hand that the SPARC grant has afforded. We look forward to continuing to provide updates to SPARC and additional,

related projects enhance our understand and as we work with government to affect the evidence-based recommendation.

Sincerely,



Jude Kornelsen

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Project Overview

This project was borne out of the respective experiences of both co-collaborators through feedback received from rural communities regarding both the innovative ways in which they are solving health service delivery challenges at a local level and their desires for their innovation to be recognized and integrated into system-level planning. Although the intention was to move towards the development of a provincial communications platform, helpful feedback from SPARC alerted us to the importance of understanding the *culture* of decision-making as until the normative values, constraints and enablers were understood, any communications platform would remain dormant. That is, we needed to understand the antecedents to and characteristics of the communications *gap*.

To this end, our immediate goal became to understand and address the gap between the outputs of rural community-oriented voice in policy and decision-making and its uptake in health planning at regional and provincial levels. We decided to do this by endeavouring to understand the *cultural change* that needs to occur in increasing the receptivity of the output of community-oriented voices into policy and decision-making. This is a significant task as much 'cultural' behaviour is normalized and stays in the background. However, we felt that with meaningful discussion we could elucidate some of the main influences. This would necessarily need to build from an understanding of the experiences of those 'at the coal-face'. This was done through the pressing desire to understand how diverse voices – those not usually heard but in urgent need of responsive services – are or can be blended into the provincial discussions without losing their authenticity. Ultimately, both organizations have directly experienced the integrity and idealism that most healthcare planners have when they undertake their responsibilities, so beyond culture, framed any 'gaps' around resources available.

This work is based on evidence of the importance of pluralistic health planning in identifying local priorities and needs; this is particularly relevant across rural communities that often suffer the consequences of centralized, urban-based decision-making. It is further underscored by the

role of the community voice in promoting equity and increasing engagement and trust in health services, whether they be embedded in the health and social system or private models of care, and the assumed relationship between equity and trust in improved health outcomes. The long-term goals of the project are to improve health outcomes, equity, and access in rural BC, through decisions and policies that respond to community-identified needs and health services priorities. We feel these fit well under SPARC's priority area of '*Systems Perspective and Impacts.*' Additionally, SPARC's mission to make research more open, efficient, and accessible aligns well with the goals of this analysis. SPARC has a strong track record of funding and supporting initiatives that promote open access to research, increasing collaboration between researchers and institutions, and advancing the use of innovative technologies in research. This, alongside SPARC's experience and dedication to supporting rigorous research, makes them an ideal funding partner to not only provide financial resources but also valuable expertise and guidance to help ensure the success of the project.

Addition of Survey Data

As noted above, pushback early in the project implementation to the contention that rural residents are not engaged in meaningful outreach across levels of policy and decision-making posed a challenge for the research team. That is, if there is no consensus with our research partners that there *is* in fact a lack of community engagement, it is very difficult to derive evidence-based solutions. To this end, we recognized early on the need to rigorously collect evidence and document rural community's experiences of engagement, not only to create a foundation for discussion with research partners, but also to ensure that we were not relying on anecdotal information based on our respective organizations' frames of reference. In retrospect, this was a strong and validating approach which underscores both advocacy for amends but also contributes significantly to our understanding of systems-based community engagement, as the question itself had not been posed previously.



Alignment with SPARC's Mission and Goals

At its foundation, this work was underscored by a commitment to rural community inclusion in health care decision and policy-making to mitigate the current emphasis on urban-based planning and promote health equity for rural populations. Although from an ethical perspective, we appreciate the need to respond to the population concentration in urban and urban-adjacent communities, we juxtapose this with the federal imperative, through the Canada Health Act, to provide accessible health care to *all* Canadians. The lack of accessible health care for many rural communities is an issue of social justice, and there is evidence to suggest that addressing this, will lead to a more just and healthy society for all. In fact, in 2004, Nagarajan concluded “[I]f there is two-tiered medicine in Canada, it [is] not rich and poor, it [is] urban versus rural” (Nagarajan, 2004).

A strong case has been made in the research literature regarding the healthcare-related vulnerability of rural communities: they have limited or inadequate access to primary care, diagnostic and treatment services, health promotion resources and illness prevention services (Beiser & Stewart, 2005; O’Neil & Gilbert, 1990). Choices in types and models of care, for example, female physicians and women-centred care, are almost non-existent (Gaston, 2001). In response to the cumulative research on rural health, Ryan-Nicholls concludes that a “community’s health is inversely proportional to the remoteness of its location [and] rurality is internationally recognized as a risk factor towards progressive deterioration in health the greater the distance from urban areas.” (Kirby & Le Breton, 2002).

The implications of a lack of access are severe. Kirby observed that “in terms of the health status of the rural population, compared with urban areas, life expectancy in rural areas is shorter and infant death rates are higher. Overall, the health of rural residents is worse than their urban counterparts.” (Kirby & Le Breton, 2002). Likewise, research has shown that a lack of local maternity services is linked with increased incidence of perinatal deaths and premature births,⁹ and women forced to deliver away from home due to lack of local services were more likely to experience complications in birth (Grzybowski et al., 2011, 2015). Soon after regionalization in BC, a study by Koch noted that when a hospital closes and health care services are reduced, the costs associated with travel are downloaded to patients, families, and friends (Koch, 2003). Leipert, referring specifically to the impact of lack of local access to care on women’s health status suggests that the system-dissociated costs may lead to compromised health status (Leipert & Reutter, 2005).

Rurality has been correlated with compromised health outcomes when compared to the outcomes of urban residents (Mitura & Bollman, 2003; Pitblado et al., 1999; Shields & Tremblay, 2002). Rural and small-town populations are often characterized by higher rates of infant mortality, lower life expectancies, and higher rates of illness (Northern Secretariat of the BC Centre of Excellence for Women's Health, 2001). Accident rates, levels of disability, high levels of unemployment, low incomes, low education levels, and sub-standard housing are all highest in rural and small-town regions (Kilshaw, 2002). Globally, "the health status of people in rural areas is generally worse than in urban areas... despite the huge differences between developing and developed countries, access is the major issue in rural health around the world." (Strasser, 2003).

Consequences of the lack of access to care for rural residents are compounded by other vulnerabilities such as rates of chronic conditions (arthritis, back disorders, bursitis, and hearing and visual impairments) (Strasser, 2003), higher risks of dying from a motor vehicle accidents, poisoning, suicide, diabetes, and cancer, and higher risk of violence, economic insecurity, primary industry occupational hazards and problems associated with lack of confidentiality (Reimer, 2010) in comparison to their urban counterparts. These confounding vulnerabilities may be the result, in part, of differential determinants of health; rural residents tend to have less formal education than urban residents (Reimer, 2010) and have higher rates of smoking, heavy alcohol consumption, obesity and physical inactivity (Ryan-Nicholls, 2003). The combined effect of the confluence of these factors on health outcomes has been identified in the literature (Kilshaw, 2002; Reimer, 2010). The result of having access to health care dependent on such factors as income and finances is that residents who have low incomes, who are unemployed, or ill, may not have the resources, financial or social, to access non-local health care (Beiser & Stewart, 2005; Greig, 1990). Cultural inequities based on Aboriginal ethnicity have also been well-documented, leading to the further vulnerability of rural Aboriginal peoples due to the legacy of exclusion and discrimination they have faced since pre-Confederation times (*Report of the Royal Commission on Aboriginal Peoples. Volume 3: Gathering Strength.*, 1996).

It is also evident that addressing the health disparities in rural communities is a *systems issue*: that is, perturbations in one service delivery level (rural) will inevitably have consequences across other strata and addressing the challenges in one level of care without attending to the others will lead to further destabilization. To advance system-wide health equity, then, it is essential to focus attention on the most vulnerable populations to avoid unintended, downstream consequences. This aligns directly with SPARC's commitment to both *equity* and, at a systems level, *social inclusion*. Specifically in reference to the latter, our emphasis on the diversity *of* and *between* rural communities was a key guidepost for our approach to this work.

Finally, this work aligns closely with SPARCs commitment to *equality*: analysis of the project data confirms that a commitment to increasing equality “builds social cohesion, improves health, increases safety... and contributes to sustainable and vibrant communities” (Sparc BC, n.d.).



Background

Based on anecdotal information from rural residents across BC and previously published research, there is a lack of rural community engagement in healthcare planning in BC (Johnston et al., 2021). This gap is leading to centralized, urban-based decision-making, which is not always reflective of the needs and priorities of rural communities (Kornelsen et al., 2021). This scoping review of the literature aims to provide an understanding of and the mechanisms to address the gap between rural community-oriented voices and uptake into health policy and decision-making at regional and provincial levels. Please see Appendix A for a description of the search strategy.

Defining Community Engagement

There are a variety of terms for community engagement, including ‘lay participation’, ‘public participation’, ‘civic engagement’ and ‘citizen participation’ (Farmer et al., 2018). After considering the nuances of the various terms, we felt most congruence with the term “community engagement,” which Fagnan defines as, “communities collaborating with other [partners] in the planning, design, governance, and delivery of health services to tackle health related matters and promote wellbeing” (Fagnan & Dolor, 2015).

A Call for Community Engagement in Healthcare Planning

While rurality does not always translate into poorer health outcomes, there are certain health system problems specific to rural areas, including access to services and delayed treatment that leads to an increased prevalence of chronic diseases attributed to restricted access of primary care (K. B. Smith et al., 2008). Furthermore, rural areas typically have a lower socioeconomic status which affects health outcomes (Karly et al, 2008). Karly et al argue that healthcare policies should focus on health promotion, illness prevention and early interventions to improve rural health outcomes (K. B. Smith et al., 2008). This is in addition to the growing body of evidence which demonstrates positive outcomes in response to patient involvement in health planning (Kornelsen et al., 2022).

Community engagement is recognised as an important process to improve the responsiveness of the healthcare systems to address the needs and priorities of the communities accessing the health service (Boivin et al., 2014; Farmer et al., 2018; McClean & Trigger, 2018; Pagatpatan &

Ward, 2017; W. C. Smith & Benavot, 2019). It serves an essential role in policy planning and evaluation, providing community members opportunities to voice their unique needs and help shape local healthcare services that address their needs (W. C. Smith & Benavot, 2019). Mechanisms such as forums, committees, and surveys help facilitate meaningful dialogue and contribute to the design of services. The Alma Ata Declaration of 1978 acknowledges that “people have the right and duty to participate individually and collectively in the planning and implementation of their health care” (Johnston et al., 2021; Safaei, 2015). Despite the Declaration and growing recognition of the importance of community engagement (Johnston et al., 2021; Safaei, 2015), there remains a gap between community voices and implementation of healthcare services that represent local community needs (McClellan & Trigger, 2018; Pagatpatan & Ward, 2017; Safaei, 2015).

In Canada, the planning and delivery of healthcare services falls under the jurisdiction of provincial governments (Safaei, 2015). While BC has acknowledged the importance of patient-centred health care and has taken measures to include patient voices in health care planning (see ‘The British Columbia Patient-Centred Care Framework’), (British Columbia Ministry of Health, 2015)), this framework fails to address the inclusion of a *community* perspective, rather than solely patient perspective in addressing the collective health care needs and challenges of rural communities of BC.

In BC, the Ministerial Mandate for Honourable Adrian Dix, the Minister of Health, establishes the accountabilities of the Minister of Health to the Premier and the people of BC (BC Ministry of Health, 2022). One of the four priority areas include improvements to and the strengthening of the public health care system. Furthermore, the Mandate Letter for Jennifer Rice, the Parliamentary Secretary for Rural Health, “Work with rural, remote, and First Nations communities as well as stakeholders to identify gaps in health care services (BC Ministry of Health & Eby, 2023).” Mandate letters emphasize that the Ministry of Health has an obligation to “listen” and “respond” to the priorities of British Columbians—and in effect calls for community engagement in health (BC Ministry of Health, 2022). In addition to the Ministerial Mandate, in the 2024 Budget Consultation Report, the Select Standing Committee on Finance and Government Services of B.C. recommends “a shift towards community-driven planning” for rural and remote communities (Legislative Assembly of BC, 2023). Despite the Government’s recognition of the importance of community engagement in rural healthcare planning, there is limited information on how this is undertaken in BC.

The Rural Coordination Centre of BC, an arm’s length organization funded by the Joint Standing Committee on Rural Issues, has initiated a series of community visits (‘The Sites Visits Project’). The visits are predicated on bringing together rural physicians and other healthcare providers,

health administrators, municipal leadership, First Nation leadership, first responders, academics, and policy makers to better understand how to achieve sustainable, beneficial rural health system changes through community engagement processes in BC (Johnston et al., 2021). During the initial roll-out of the program, 107 communities were visited, and qualitative data was analysed from 185 meetings in 80 communities (Johnston et al., 2021). Significant findings include an understanding of the primacy of relationships built on communication, trust, transparency, and collaboration. While good communication helped build trust among healthcare providers, poor communication resulted in adverse relationships. Another finding was that autonomy for decisions to be made at the local level in response to the local context without approval from hierarchical, top-down systems. Furthermore, the authors suggest that healthcare systems need to adapt to changes in communities, such as demographic changes that can impact the need for resources, funding, patient access, staffing and infrastructure (Johnston et al., 2021). Although this program highlighted best practices in community engagement, it was not undertaken directly by policy and decision-makers.

Challenges and Best Practices

While the importance of community engagement in healthcare design, delivery, and evaluation is recognized internationally (Boivin et al., 2014; Kenny et al., 2018; McClean & Trigger, 2018; Pagatpatan & Ward, 2017), there is a lack of clarity on engagement processes, ambiguous expectations and roles for community members, insufficient evaluation, and inadequate adaptive strategies have prevented meaningful change (Abelson et al., 2004; Anton et al., 2007; Aronson, 1993; Charles & DeMaio, 1993; Farmer et al., 2018; Pagatpatan & Ward, 2017).

From the literature, it is apparent that there is a disconnect between the intent and execution of several government-led long-term healthcare initiatives. Initiatives focused on integrating community voices into healthcare planning often fall short of the promised democratizing potential. Many authors discuss how participants in community engagement initiatives feel like they lack the power to influence decision-making (Abelson et al., 2004; Anton et al., 2007; Montesanti et al., 2017). Community engagement initiatives should provide “consumers” a chance to express their needs and offer possible solutions. Aronson states that initiatives “elicit only particular kinds of information from consumers and do not live up to their democratizing promise” (Aronson, 1993). Well-defined goals and a vision for the inclusion of community voices into the decision-making process are crucial to the sustainability and effectiveness of community engagement initiatives (Abelson et al., 2004). Furthermore, information sharing with participants and the greater community should be transparent, accessible and include the how community voices will be incorporated into the policies and decision-making processes (Anton et al., 2007; Montesanti et al., 2017).

By giving a voice to communities, there is increased accountability and an opportunity to build ownership of policies and develop effective implementation strategies (W. C. Smith & Benavot, 2019). Furthermore, the inclusion of community members demonstrates transparency in decision-making, helps safeguard public interests, provides the perspective of service users, and brings diversity of experiences (Abelson et al., 2004; Anton et al., 2007; Hogg et al., 2001). These are all important elements of accountability in healthcare planning and decision-making, which is vital to increase trust in the healthcare system, transparency in decision-making, and improve policy ownership of services (Abelson et al., 2004; Kenny et al., 2018; W. C. Smith & Benavot, 2019).

Another underlying mechanism that influences the effectiveness of community engagement in health policy and planning is political commitment (Pagatpatan & Ward, 2017). Pagatpatan describes political commitment as the willingness of political leaders to commit to engagement exercises to actively engage and support public input. Political commitment entails a willingness to listen, dedicate resources to the engagement process, educate the public on healthcare choices and consequences, and provide feedback loops in the spirit of transparency and accountability to the public. The outcome of political commitment is increased understanding of and community influence on policy decisions (Pagatpatan & Ward, 2017).

Other challenges impact the success of community engagement in healthcare, including imbalances of resources between participants and decision-makers; inadequate training in community engagement; mitigating for vested interests; lack of diverse representation; varied public willingness and ability to participate; time pressures; disregard for public input due to the political climate; and the exclusion of disadvantaged and vulnerable populations (Safaei, 2015). These challenges often lead to dissatisfaction and a lack of trust in healthcare planning and by extension democratic systems (Safaei, 2015).

Diversity and Inclusion in Community Engagement

Inclusivity is an essential element of community engagement. Inclusivity can be achieved by involving a wide range of stakeholders, including marginalized groups and hard-to-reach groups. Inclusivity includes maintaining clear and regular communication when working with stakeholders to ensure their active and meaningful participation (Pagatpatan & Ward, 2017). On the flip-side, tokenistic involvement and siloed thinking restricts the potential of community engagement (Abelson et al., 2004; Kenny et al., 2018). Community engagement should include a diverse representation of community voices (Abelson et al., 2004; Kenny et al., 2018). Therefore, promoting inclusivity and diversity by dismantling barriers through strategic efforts are crucial for deliberative healthcare planning to reflect the diverse perspectives and needs of the community.

Effective community engagement approaches should proactively address barriers to participation, including but not limited to the social and economic circumstances leading to distrust, language barriers for marginalized populations, and economic barriers for new migrants (Montesanti et al., 2017). Strategies to address these barriers to participating include strengthening the capacities of marginalized people and building trusting relationships (Montesanti et al., 2017; Boivin et al., 2014). It is also important to address the power dynamics among stakeholders participating in deliberative processes and to legitimize the value of the individual and collective experience of community members to increase trust in the process (Boivin et al., 2014). It has been found that participants who have positive perceptions of community engagement processes have built relationships with decision makers over time (Abelson et al., 2004).

Conclusion

An overview of literature consulted revealed that there is a lack of *rural* community voices in healthcare planning and decision-making. The literature emphasized the importance for communities to be involved in the design, delivery, and evaluation of healthcare services. Communities need to see their diverse voices, priorities and needs represented in the design and implementation of healthcare systems, which not only helps build trust but also a sense of ownership in healthcare services. There also needs to be regular and transparent information sharing about healthcare planning processes and how community input will be incorporated into the final decisions and policies.



Research Methods

To understand the gaps between the inclusion of community voice and current healthcare planning practices in BC, Canada, the research team used mixed method approach including in-depth virtual interviews with policy and decision makers (n=8) at a regional and provincial level, rural community leaders (n=14) and an electronic survey for self-identify as rural community members (n=707). The triangulation of qualitative and quantitative data yielded a richness and validity to the findings presented. The study received ethical approval from the University of British Columbia's Behavioural Research Ethics Board (BREB). All participants consented to participate in the study. Participant confidentiality and anonymity was maintained throughout the study and survey and interview responses were analysed as an aggregate. Our interview and survey approaches are discussed in-depth below.



Rural Residents' Experiences of Engagement in Health Planning: Findings from a Pan-Provincial Survey in British Columbia

The Survey Story

At the outset of this project, we began engaging with regional and provincial policy and decision-makers to talk about what rural residents had told us, both in direct conversation and through previous research (Kornelsen et al., 2021): that they felt disengaged from health care decision-making and that locally derived health service solutions were not incorporated into strategy. 'Where is the logjam?', we wondered. 'What are the constraints of including community voices in health planning?' *were* there productive outreach opportunities with communities through a myriad of provincial agencies and whether communities took advantage of these opportunities was out of their purview. But that was not what we were hearing from communities. So, we set out to learn why there was a disconnect, going straight to the (rural) source, in the form of a pan-provincial survey (Appendix B).

We recognized early on that participants interested in a survey about engagement in health planning would be a niche group: 'health planning' generally ranks below environmental concerns, the current cost of living crisis, unstable housing, and the more immediate downstream effects of the *lack* of health care planning including constricted access to health care. Although this may be true for urban settings, the immediacy of – and lack of recourse for – access to health care is different for many rural communities. Distance to alternative options and lack of specialist care due to low population densities bump healthcare challenges to the top of

the list for many rural residents. It is one of the pillars of the urban-rural divide. Despite this, however, we did not anticipate the 707 responses that we captured. However, we know from research *about* surveys that there are sometimes systematic errors (“survey response bias”) that occur due to things like difficulty remembering past experiences (“recall bias”), cultural and language bias or the propensity of most respondents to provide answers that they believe are socially acceptable or favourable. Most important in this instance, however, is the potential for “nonresponse bias” (the attitudes and opinions of those who do *not* respond to the survey) and the potential that the responses that are tabulated do not correspond to the general population (“sampling bias”). This is where one of the benefits of the academic–community collaboration was most useful: through combined, multiple, and community-engaged recruitment, we were able to saturate recruitment opportunities through key stakeholders across the province, with effectiveness increased based on accrued trust and credibility of both organizations. This is not to say that we convinced potential respondents with no interest in health planning to participate, but we did present (and incent) the opportunity. However, we do acknowledge that those who responded to the survey would likely have had very positive or negative experiences, thus leading to over-representation of extreme views. It is with this understanding that we present the findings.

Our Approach

The research team developed a draft survey, which was presented to the BC Rural Health Network’s Implementation Committee for feedback. The revised version was posted and tested on UBC’s Qualtrics server. The survey asked 22 questions, including a combination of short answers, Likert scales, and multiple-choice questions. The survey consisted of 12 Likert scale or yes/no questions and 11 open-text responses for further explanation, if desired. The latter resulted in rich qualitative data and description to augment the quantitative data that was presented, allowing us to capture unanticipated insights and provide a context to interpret responses, thereby enhancing validity. Ultimately, the mixed-methods approach allowed the *flexibility* for us to explore themes and patterns that emerged from the data, leading to a more comprehensive understanding of rural community involvement in healthcare decision-making.

A poster invitation to participate in the survey was sent electronically through the community databases and communication channels at both the Centre for Rural Health Research and the BC Rural Health Network (see Appendix C). The BC Rural Health Network also issued a media release, prompting several provincial media outlets to write about the study and provide a link to the survey, expanding our reach to rural residents across BC. Please see Appendix F for a list of media coverage.

Survey participants self-identified as rural community members, and participants were not required to answer all questions. The survey was hosted on a UBC Qualtrics server. All responses were collected anonymously, and survey respondents were given the opportunity to enter a draw for one of three \$100 gift cards. Two reminder messages were sent after the first invitation. To increase response rates, we ensured that the purpose of the survey was clear, questions were plainly worded and there was a clear pathway to the utilization of the findings (to present to healthcare decision-makers as evidence for amending engagement strategies, if necessary).

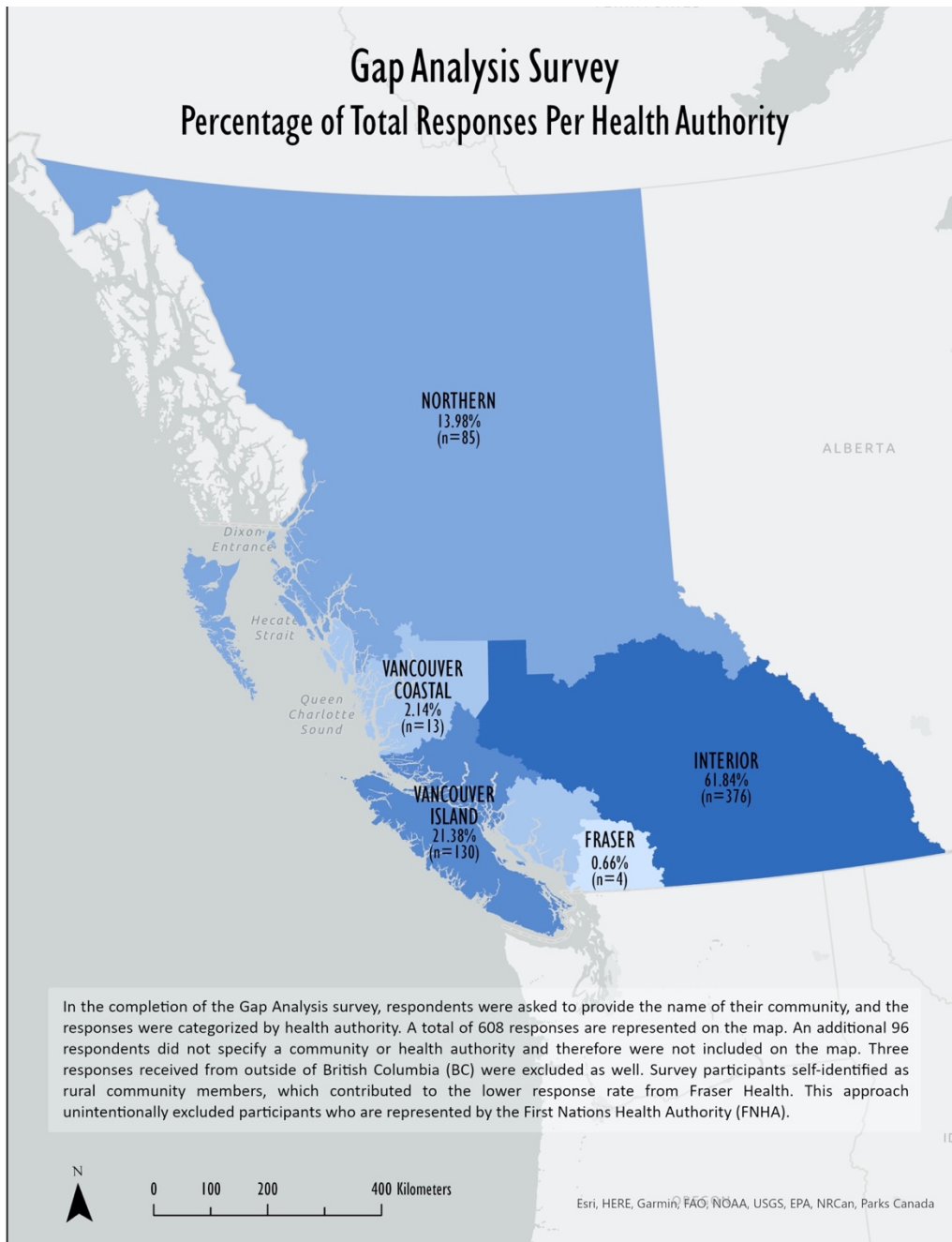
The survey was open for four months from June 20 to October 20, 2023. During that period, 707 participants started the survey, 699 participants submitted the survey, and 413 participants completed the entire survey.

The survey response data was put into Excel, cleaned, and analysed. Multiple choice and Likert scale responses were analysed by the frequency, percentage, and medians for each item. Short answer survey responses were coded and thematically analyzed. The shorter responses were amenable to clustering. Findings from the complete survey are presented below.

Findings

707 people responded to the survey, each filling in at least one question. The majority of respondents came from the Interior Health Authority, with the rest coming from Vancouver Island Health Authority, Northern Health Authority, and Vancouver Coastal Health Authority respectively, with 4 responses from Fraser Health. 3 respondents were from outside of BC and 96 respondents did not specify a community. See the map below for the complete breakdown.

Figure 1: Respondent Map



Open-text responses in the survey explicated, in most instances, the quantitative findings. Quantitative and qualitative findings are thus presented below, sequentially.

Do you feel that your community's healthcare needs are adequately represented in the planning process?

The first question was binary and asked whether respondents felt their community's healthcare needs were adequately represented in the planning process. 90% of respondents said they were not adequately represented, with the remaining 10% replying affirmatively. None of the respondents who felt their needs were adequately represented left open-text responses and the responses of those who felt they were *not* represented were aligned with three themes: a lack of mechanisms for engagement, the urban orientation of health planning and lack of accountability to rural communities. Each is explicated below.

Lack of mechanisms for engagement

Most respondents reflected simply that there was “absolutely no input into the health planning process”, that “the community is not included in any aspect of local health care planning” and there is “not much opportunity to work together with the health authority”. One respondent summarized the feelings of many when they said,

“Most of us feel completely left out of any decision-making processes that affect the state of our local healthcare. There is very little contact or community involvement on the part of [the] Health Authority who own and operate our facility.”

Others asked, “What planning process? How/where are citizens [able] to find out? Who is involved?” Others were definitive that members of the community had “never been contacted by [the] Health Authority” to either gather or provide information despite, in some cases, a letter writing campaign, resident surveys and the intervention of their area director. This led many to feel an “unacceptable disrespect of [the] community”.

Many others, however, spoke directly to the lack of *structure* for such engagements (“the public lacks a mechanism for interface with Health Care Planners for our community”; “there is no way of communicating problems when they arise”). For most, this meant a disconnect between the planning process and the needs of the community. As one person noted:

“Often the planning process for health initiatives is carried out by individuals with limited knowledge [of our community]. Health policies/programs are sometimes implemented by individuals who do not permanently reside in the community or are new to the community. With no opportunity for interface, healthcare needs identified by the community are not met.”

Others focused on the way the community was engaged, namely the lack of representation from those ‘on the ground’:

“There are volunteer groups that could be consulted, instead of limiting discussions with village council and the Health and Wellness Society... community forums are few and far between.”

The experience of selective engagement was endemic across respondents, with others emphasizing that although community-level professions may understand the health needs of the community, lay community members also had much to offer based on their lived and living experiences of receiving care. This selectivity was sometimes described as “so-called consultations” that were, ultimately, “really not at all helpful or effective”.

Urban orientation of health planning

Most respondents felt that rural communities were “an afterthought” in health planning and that consequently, programs were not targeted to meet the specific needs of rural settings, due to the centralist tendency of health planning. As one respondent said:

“Health planning at the provincial level is very urban-oriented and there is little understanding about the difficulties experienced by rural communities. The attitude is often, “Well, they chose to live there”.”

Another noted, “We are rural, not urban and it seems to me that IHA has no interest in a flexible model for rural Healthcare”. This led to the observation by many of urban-centric planning (“a lot of planning decisions are based on what is happening in Vancouver”), one consequence being a lack of appreciation for rural community needs (“decision makers in urban areas have no concept of rural needs”). One respondent summarized the corollary to this being the need for policymakers “to listen to the needs of rural communities and enact their recommendations”. An additional consequence of urban-based health care planning noted by many was the lack of

capacity to address local issues in a timely, efficient way due to lack of local autonomy. As one respondent noted.

“Decisions are made at larger facilities that affect the daily routines of our local hospital. We are not the same as large facilities and have to be able to manage our own daily routines and problems that may arise. Some situations have to be dealt with immediately, but we are faced with having to await decisions made at another facility that has very little understanding of our local situation.”

For some respondents, consequent to the need for rural-specific planning, or perhaps as an antecedent to it, was the need for rural-specific data that addressed the challenge of registering the needs of low population density outcomes. As one respondent clearly described,

“The data about the needs of our residents routinely gets subsumed into the data generated by our larger neighbour. Making decisions based on statistics is tricky in a population of under 1,000 but being lumped into the data of a nearby town of 10,000 doesn't always tell our story.”

Lack of accountability

Many respondents observed that not only is there no mechanism of accountability by the RHA or the province to act on the direction of local communities (“The system seems too fractured and unstable to have any accountability”), but there is also no provincial standard for engagement. This has led to “a disconnect...between the everyday resident and their healthcare system”. This same lack of accountability led, for some, to a “top-down approach” by the Health Authorities (“I have not been asked what I need; I feel I must take what they provide and have no voice”). Interestingly, many respondents deemed their health authority as being particularly inadequate in working with local communities, despite respondents being from different health authorities.

Others saw accountability as resting in action, particularly in instances when health planners acknowledged and seemed to understand what was required but did not follow through. As one participant succinctly said, “They need to act on recommendations” (made by the community). Many saw the lack of action being due to the lack of political oversight of the engagement process.

Do you agree that your community's needs are met through the health planning process?

When asked about needs being met through the planning process, 76% of respondents disagreed that their community needs were met, 13% neither agreed or disagreed and 11% agreed.

Have you been engaged in healthcare planning in BC?

When asked if they had been engaged in health care planning in BC through community meetings, special interest groups or participating in surveys, 54% responded negatively while 46% said they had been engaged. The level of engagement ranged from “inadequately informed” (42%) to “collaborating” (3%). 23% of respondents felt they were “informed” (provided with balanced and objective information to understand the problem, alternatives, opportunities, and solutions) (International Association for Public Participation, n.d.); 17% felt they were “involved” (asked to actively participate in the process, with concerns and aspirations being understood and considered) (International Association for Public Participation, n.d.); 10% felt they were “consulted” (asked to provide feedback on analysis, alternatives, and decisions) (International Association for Public Participation, n.d.); and 5% felt they were “empowered” (asked to be part of the decision-making itself) (International Association for Public Participation, n.d.).

Open-text responses detailing *how* respondents were engaged ranged from participation in public meetings, workshops and forums and letter writing to advocate for community needs, to participation as elected officials on community health boards or town councils. Although some respondents reflected a performative engagement (“When asked to plan, we hear of that which is already planned”), others reported a more community-driven process where local residents met with the Health Authority and “set the agenda”.

When asked what could have been done to improve the engagement process, many participants recurred back to the fact that currently there is *no* engagement process, so the first step is to establish one that includes local, regional, and provincial participation.

There was a thematic awareness of the need to approach engagement through a diversity lens. According to respondents, this begins with recognizing the contribution equivalence of all involved: “Treat everyone as equals, for example, don’t [treat] MLAs, mayors or those with more status as being more informed or having better lived experiences”. This need to correct power imbalance was noted by others, specifically regarding the lack of recourse of community members when faced with decision-makers who “appear to have all of the clout”. Respondents

also noted the importance of creating forms for participation that *everyone* could participate in, including face-to-face encounters to avoid disadvantaging those without access to a computer for virtual engagement opportunities. Others specifically identified the need to be aware of creating opportunities for including those of different ages, cultures, languages, and educational levels to ensure engagement truly represents the needs of the whole community.

Additionally, many respondents identified the need for authenticity in engagement, demonstrated through active listening, repeated engagement and responsive actions based on the engagement. Ideally for many, was decision-maker exposure to small towns (“[Have]... some of them live in a small community when they have medical issues, especially in the winter”). Others identified the need for an alignment of values between communities and decision-makers:

“[Decision-makers] main purpose it seems is a business model in which “the bottom line” or providing the cheapest service is their priority, not what will meet the health needs of the members of each community.”

For some, authenticity included the involvement of regional planners, while for others it was contingent on decision-makers truly listening to and acting on the direction of communities, as opposed to having a pre-determined agenda:

“I have found there is often already a plan in place before the consultation, they are using the consultation to validate the plan rather than listen to the needs of the community to inform the development of a plan or service.”

Many respondents expressed frustration with time being wasted in meetings that did not lead to change and suggested a clear articulation of “when we are getting help and how”.

Solutions offered by respondents ranged from system solutions to cultural ones, the former being largely pragmatic and including suggestions of increasing community meetings and forums to bring people together “to share stories and ideas”, and having decision-makers offer solutions to problems (“I feel that there are lots of surveys and studies done, but nothing is being done to fix the problems of health care for rural residents”) and involving local leaders and “less from those leaders located on the other side of the province”. Summatively, participants recognized the need to “open the doors to the inclusion of rural communities as part of the health care system”. As above, accessibility and inclusivity of disparate voices were highly regarded, as one respondent suggested the need to

“Create more accessible ways for community members to be part of the feedback process. Maybe using simple language and paper/pen methods with a few questions. Other surveys, or public meetings, are often presented above the capacity of the most vulnerable community members.”

Practical solutions also involved restructuring services to allow local governments to oversee and deliver health services which would allow for “more local knowledge of care needed and delivered” which would most importantly, allow for an iterative approach to system-wide improvements. Finally, practical adjustments suggested by several participants included extending engagement to include an effective communication process “for the two-way flow of information”. For many, this necessitated reciprocal information flow sharing policy development and capturing community feedback. As one respondent noted, “Provincial policy has a tremendous impact locally, yet a mechanism to provide feedback is not apparent”.

Other participants alluded to the need for a change in culture in how healthcare challenges are handled, including a

“...more proactive approach to issues rather than responsive. Many of our issues are likely preventable with forward thinking and prioritizing provincial funding, projects, and training.”

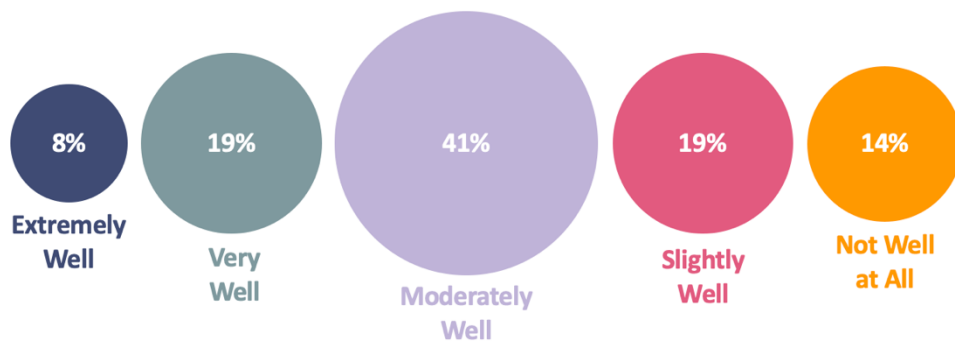
Culture changes also extended to reversing the lack of transparency of health authority decision-making that many respondents identified (“stop the closed-door policy”) and resisting the ‘tick box’ exercise that many experienced.

Some respondents described examples of productive engagement with decision-makers, but offered additional suggestions for improvement, such as ensuring diversity of opinions was captured and having follow-up mechanisms to ensure that the engagement led to actual change in rural health planning.

How well-equipped are you to engage in healthcare decision-making about issues that concern your community?

Most respondents to this survey reported they felt at least moderately well-equipped to engage in health care decision-making, while more felt slightly/not well equipped to engage (33%) than those who reported feeling well/extremely well equipped to engage (27%).

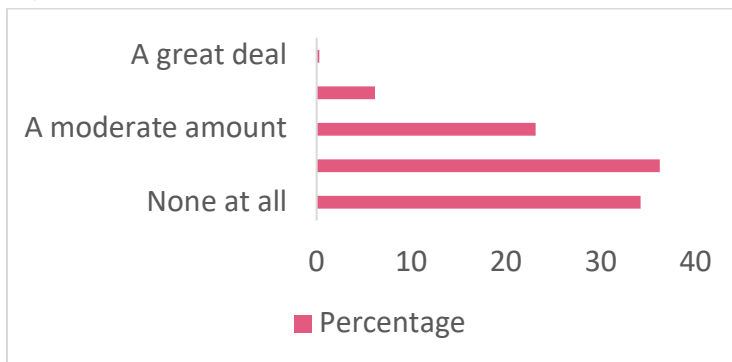
Figure 2



How much confidence do you have in healthcare decision-makers making decisions that will be best for your community?

When asked about their level of confidence that decisions made would reflect what is best for their community, most respondents reported they had ‘a little’ confidence (36%), while 34% reported no confidence at all. However, 34% also reported having a moderate amount of confidence while 6% reported “a lot of confidence. One respondent said that had “a great deal” of confidence.

Figure 3



As reported above, most respondents (86%) felt that their needs and concerns were not genuinely acted upon, with 14% reporting that they were. In open-text explanations, several respondents attributed this to the “multiple layers of rotating-door infrastructure” in the health authorities while others noted an abject lack of opportunity to *express* their needs and concerns. Most respondents, however, reflected on the lack of opportunities for engagement (“How can my needs and concerns be acted upon if I wasn’t asked for input?”) or lack of visible

consequence to input given (“[We] have been giving input for years, and nothing is getting better”, “It’s a lot of talk, but actions say otherwise”).

Several respondents expressed difficulties with engagement, mostly in the form of either lack of an engagement process (“There is no transparency in any consultation or planning process. How would one even get involved?”), or lack of acknowledgement for communication when it occurs (“To the best of my knowledge, the current Health Minister, nor anyone in his office has *ever* answered a call or responded to a letter”). These experiences precipitated, for many, a sense of cynicism in health planning.

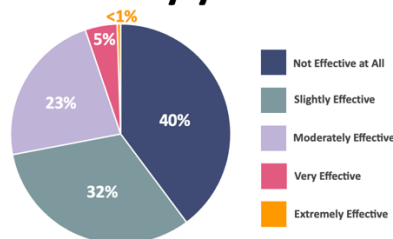
Others acknowledged that although people on the “front lines” of health care were doing their best to attend to the needs of the population, they were constricted due to infrastructure challenges such as lack of government funding. A minority of respondents conveyed positive experiences with engagement, as noted in the quantitative findings above. A few participants felt validated and appreciated in their role as those with lived and living experiences while others observed more generally that there was “excellent” work being done. As one participant noted:

“I think all my engagements have taken my opinions into consideration as most on the committees our business people and not lived experience so I have that to offer as being with chronic pain for 44 years gives me an advantage to what would serve the patient to its fullest but as far as being involved with my community of Vernon there is definitely more work to be done.”

When asked how effectively policies were communicated to respondents, most felt they were “not effective at all” (40%), while 32% felt they were “slightly effective”. 23% reported moderate effectiveness while only 6% reported they were “very” or “extremely” effective (5% and <1%, respectively).

Figure 4

How effectively are policies communicated to you in a way you understand?



Most respondents (89%) felt there were no language or cultural barriers impeding effectiveness and 85% of respondents felt that communication with communities regarding health policies was not effective. Many respondents who elaborated on their responses through open text felt there was “no experience of open communication” with their Health Authority, or if there was, they were not aware of it. Others saw communication as being unidirectional from decision-makers, almost always when reduction in local services was being communicated. Still, others lamented the loss of communication channels that previously existed, such as “Health News” websites that were rescinded due to lack of funding.

Many of those who responded that there was adequate communication from health planners further explained that the communication usually occurred after policies were made, prompting one participant to say “This is too late. We need more transparency and communication”. Another respondent noted, “I don’t think they have trouble communicating policy, it’s more [about] being responsive to community in the creation of policy”. For others, the *way* information is communicated was a top concern, recognizing that, for example, online communication will disadvantage those without computer access or proficiency. This underscored the contention of one respondent who noted, “The community is too diverse [for one form of communication]; those most in need are too often also those least able to access or interpret the information”.

Others recurred back to the theme of “action”, suggesting that communication in and of itself will not provide solutions to health care challenges (“The communication provided does not rectify anything”). Several respondents expressed skepticism about *what* was being communicated with some contending that it was all “political in nature” and not fact-based. One respondent noted that it should not be the communities’ responsibility to facilitate communication with decision-makers, but instead that communication to constituents is part of their governance responsibility, while others observed the difficulty of effective communication due to “information overload”.

Several respondents reported positive instances of communication, expressed that there were “advised as needed”, and that the health authority kept the community “well informed”.

When participants were asked, through an open-text question, if they **knew of any effective structures or organizations that engage their community in healthcare planning**, the majority replied they did not. Of those who did identify structures or organizations, approximately half

were community-based while the others were pan-provincial and included the BC Rural Health Network (through which recruitment for the survey occurred), Divisions of Family Practice, Health Data Coalition, and the Rural Coordination Centre of BC. Others alluded to informal groups that knew of but that lacked transparency so “unless you are in the loop, you would not know about [them] at all”.

The final question was, “Is there anything you would like to add?”, which elicited responses from 157 of the survey respondents, some expressing opinions in detail. The main themes reflected opinions on the *political structure of health care* (including regionalization and associated reflections on Regional Health Authorities, privatization, and system-level accountability), *models of care* (health centres) and *geographically specific comments* (care in the North and perceptions of an urban bias in health care). Each are described in more detail below.

Political structure of Health Care

Most of the open-text responses focused on the system of regionalized health care that BC implemented in the early 2000s, like other jurisdictions across Canada (Church & Barker, 1998),[†] with most respondents offering critical commentary. Some felt regionalization was the antecedent to current challenges with the health care system:

“The centralization/regionalization policies of the last 20 years have been a complete and total failure and are largely responsible for bringing about the state of healthcare not only in rural BC but now it has spilled over into urban centres as well.”

Several respondents noted the centralizing tendencies brought by regionalization and the need to course-correct with a distributed model of health services, while others focused more on the impact of regionalization on local communities, namely a top-down organization that does not allow for regional variation in response to local conditions (“Regionalization has taken away local decision-making regarding health and does not allow for differences, especially in rural communities, each of which are unique”). Others noted that regionalization appears to privilege

[†] Church and Barker (1998) defined regionalization as the creation of a new organizational structure that involves the introduction of an additional layer of governance that assumes responsibility for devolved functions. Typically, programs that were formerly directed by a single body are decentralized as they are taken over by new, regionally defined governing bodies. Regionalization in the Canadian context has typically involved transferring a measure of authority from a ministry of health to a local governing authority. The area administered by this governing authority is usually determined by factors including geography, population distribution and patient flows.

urban settings over rural or, at the least, not understand the realities of rural health care needs (“[RHAs] see, so disconnected from the reality that is rural living”).

Closely related to comments on regionalized health care were observations on the nature of regional health authorities themselves including their urban-focus and the attendant loss of structures of communication that existed prior to their implementation. Some felt that the regional structure expunged mechanisms of communication, including local hospital boards with many suggesting their reinstatement. Others focused more on their observations of the urban-centric nature of RHAs (“We are a rural /remote community with unique health needs located in a health authority designed to delivery to an urban population”), while still others were skeptical about the corporate influence (“I believe that the health authorities should be managed by the province, not by corporations whose primary concern is profit”).

Alongside concerns about the system structure of health care delivery within a regionalized context were comments reflecting concerns about privatization (“It comes down to dollars. Privatization scares me in that we would simply duplicate the American system”). A key theme among respondents was concern regarding the prioritization of “profit rather than good care”.

Comments on accountability, as noted above, focused on the disconnect between input given and actions taken, from both a contextual and system perspective. This coalesced around issues of transparency (in decision-making and resource allocation), as well as the lack of governance and oversight structures. Several respondents also alluded to political decisions trumping evidenced-based health planning that meets community needs. As one respondent noted,

“If you ask for input listen to that input. So many different branches of government ask and then do the complete opposite of what had been suggested.”

Models of Care

The championing of Primary Care Networks[‡] by the provincial government gave rise to optimism for meaningful community engagement for several respondents. However, experiences did not match expectations as respondents reported a lack of overall engagement and the engagement that did occur was “slow and fraught with uncertainty”. As one respondent succinctly noted, “There is no Primary Care Network collaboration per se”.

[‡] A PCN is a clinical network of local primary care service providers located in a geographical area, with [patient medical homes](#) (PMHs) as the foundation. A PCN is enabled by a partnership between the local division of family practice and health authority, along with local First Nations and Indigenous partners (Family Practice Services Committee, n.d.).

A few respondents referenced the desire for community health centres, a model of care based on principles of team-based care, health equity and community-driven services (BCACHC, n.d.). As one respondent said, “I just know [services] could be provided in a better way using an effective healthcare centre [model]”. Others saw the potential for Community Health Centres to gain the trust of rural community members through responsiveness to local needs.

Geography

Several respondents provided comments on local conditions (mostly the North) and the perception, as noted above, of an urban bias in health care planning and delivery. In the first instances, survey participants conveyed observations of the North being overlooked in healthcare planning, a harbinger of the more general devaluation of rural healthcare compared to urban health. Examples such as disadvantaged access to cell phones or internet services, resulting in constricted access to virtual care was cited as evidence of a lack of understanding or prioritization of rural health care. Likewise, the example of challenges associated with accessing rural public transportation to access care was also presented as evidence of an urban-centric planning bias.

Some respondents linked urban-centered healthcare funding to further disadvantaging rural communities while others saw the urban focus as the root of health system failure. As one respondent said:

“The entire model of centralized healthcare, relying on an expensive hierarchy of bureaucratic managers, mini-managers, and micro-managers, has proven itself an abject failure. Time and again, local medical needs are forced to fit into a one-size-fits-all, primarily urban mentality that has no clue how rural communities work or what their needs are, nor do they seem to care.”

Several respondents saw the best recourse being a reset of the perceived urban planning bias lying in consulting rural community members when designing and implementing health policies.

Despite the majority of comments focusing on critical aspects of health service planning and engagement, some respondents did acknowledge that “[t]here are some good things happening within the healthcare system and money being spent”, the same respondent also suggesting that although criticism is generally focused on the current government, it was the *previous* governments that “derailed progress”. Many others expressed a desire to be more involved, with one respondent noting:

“Great topic! This leads to the next question regarding the 'how' and 'when' to genuinely engage communities in health services planning and the actual impact/influence such input will have on decision and policy-making, i.e., not just token input. This is more than patient voices; it's community voices.”

Others expressed appreciation for the opportunity to voice their concerns through the survey while a handful of participants expressed the need for action over discourse:

“Please stop engaging in planning studies, engagement exercises, etc. etc. The problem of access to primary care in the interior of this province is not new. There are models of primary care, physician recruitment that have been shown to succeed. Act now.”

The experiences of engagement in health planning for survey respondents were largely focused on the lack of engagement opportunities and structural barriers to health system improvement. To understand the complete picture of community engagement more fulsomely in rural health planning, however, we needed to understand the experiences of community leaders in the process and, ultimately, the experience of decision-makers. Results from the interviews with each group, respectively, are detailed in the next two sections.



Rural Community Leaders' Experiences of Engagement in Health Planning in British Columbia

The Importance of Local Leadership in Community Engagement and Development

The effectiveness of 'community voices' is enhanced when there is an organizing structure to consolidate otherwise disparate contributions. From this vantage point, however, it is essential to recognize the heterogeneity of communities and the tendency for voices expressing the views of socially marginalized communities to be silent. With good leadership, however, these voices can not only be amplified, but also used to an advantage to understand the composite needs of communities. Understanding and meeting the needs of vulnerable populations is critical not only to improve population-level health outcomes, but also as a way of refining system responsiveness for *all* citizens. Effective leadership is key to this endeavour, both through formal and informal means.

Formal community leadership positions are those that typically occur within community structures, namely elected positions, or organizations with pan-community responsibilities (e.g., director of a local Food Bank). In contrast, *informal* leaders emerge based on their accrued influence in the community, usually over a period of sustained contribution (e.g., members of Hospital Foundations). The differences between the two are mainly in the areas of authority and accountability; that is, formal leaders are vested with the power to make decisions, such as the allocation of resources or the creation of local policies, whereas informal leaders rely on *relational* influence and the attendant capacity to inspire the community around specific causes (Pielstick, 2000; Van De Mieroop et al., 2019). As a corollary, formal leaders are held accountable by higher authorities (or the constituents that elected them) while informal leaders may not have defined accountability structures (although often feel a strong sense of responsibility).

Regardless of the level of formality of a leadership designation – whether by intention or de facto - they play an essential role in community advocacy due to their clear understanding of local needs, the relational trust they have developed over time, their capacity to facilitate productive discussion and participation, and their potential to mobilize resources. It is also often the case that the community leaders are the interface between community dialogue and external partners who can action community intention. For these reasons, and to explicate further the findings from the pan-provincial survey of rural residents, we interviewed community leaders.

Our approach

Policy and decision-makers at regional and provincial levels received an invitation (Appendix G) to participate in the study through email and direct contact. The research team reached out directly to 30 policy and decision-makers: 17 regional and 13 provincial. Snowball sampling was employed to identify additional participants involved in rural health planning, including a participant distributing an email about the study to the Ministry of Health employees. Participants representing either the Ministry of Health, Health Authorities, or other provincial agencies.

Rural community leaders were recruited by distributing posters (Appendix D) and a one-pager (Appendix E) through the BC Rural Health Network communication channels, including newsletters, their website, social media, and a media release. Snowball sampling was used to recruit other rural community leaders to participate in the study. 14 rural community leaders contacted the research team to participate in the study. Participants were included based on their self-identified leadership role in their community, either municipal leaders or directors of community-based organizations. No one who responded to the request for participation was excluded from the study.

Once recruited, policy leaders and rural community leaders participated in in-depth virtual interviews with Dr. Jude Kornelsen (PhD) and Kate Wills, lasting approximately 60 minutes. The interviews were structured around questions such as:

Do you see a role for community voices in health planning? How valuable is this input, from a practical perspective?

Are there preferred frameworks for hearing this voice (e.g., existing health and social service agencies)?

Do you face barriers to including community voices in decision-making? What are they?

Do you see any downside to community-informed health planning?

Do you have established ways of reaching out to communities?

How does the yield of community consultation influence decision-making?

How do you weigh community perspectives with other policy-making influences?

How do you build and maintain trust with communities?

Although the questions reflected an open-ended approach, we followed the participants in the direction they felt most important. This approach was used as there is a breadth of knowledge

on this topic and we wanted to ensure comprehensiveness in our understanding of participants' experiences. The interviews were recorded and transcribed with the participant's permission.

The research team thematically analyzed the transcripts by cohort (policy leader and rural community leaders) and transcripts were inductively coded (Fereday & Muir-Cochrane, 2006). Three research team members independently reviewed three transcripts from each cohort respectively, developing codes and grouping ideas and trends in the data relevant to the research questions. The codebooks were compared to determine the level of congruence. There was a high level of congruence between the codes and minimal adjustment was needed. The research team reconciled their codes and developed a codebook to ensure consistency with coding the rest of the transcripts, which was done using a qualitative coding software program, NVivo14. The themes identified in the policymaker and community leader interviews were closely aligned.

Findings

We interviewed 14 participants from across BC and analyzed 12 transcripts, with representation from Interior, Northern, and Vancouver Coastal Health Authorities along with two participants occupying a more pan-provincial role. Participants were included based on their self-identified leadership role in their community, either municipal leaders or directors of community-based organizations. Those involved at a provincial level were engaged in programming that had relevance to rural communities locally or pan-provincially. Our interviews with community leaders revealed the following main themes: *the need for accountability, community advocacy, engagement, and experiences of urban-centric planning*. Each is described in more detail, below.

Accountability

For most respondents, 'accountability' was the cornerstone of a well-functioning healthcare system and referred to a series of "checks and balances" that ensure the capacity for course correction, should new or contradictory planning information arise. It does not eliminate the potential for errors in decision making, but instead encourages addressing such errors. As one participant said,

"Hold people accountable. Let them make the decisions they think [are] right. [A]re they gonna make mistakes? Of course, we all make mistakes and there's nothing wrong with making a mistake as long as you learn from them. And as long as we have checks and balances in there through the health authority, say, 'okay, well, you know, you don't get too far down the road, you know, making a mistake,

but you get it... How do we fix it?"

Others were more terse, observing the current *lack* of accountability: "We have no mechanisms of accountability for the decision makers" or "[t]here's no follow-up". For many, the discussion of accountability necessarily involved the involvement of communities to "offset the negligence at the federal, provincial and ministry level". But some also suggested that accountability also involved compensation to local communities when they fill the service gap that the province is responsible for, in terms of remuneration for costs incurred. One participant provided the following example:

"[T]here is specific downloading that can be accounted for by your fire departments to say 'we responded to say a hundred calls, and 90 of those calls should have been and ought to have been paramedics'. So, there's a cost to that, to the municipality, so therefore that cost now should be allocated [from] the province."

Others focused more on the challenges of accountability due to the bureaucratic organization of healthcare decision-making that resulted in those who engaged with communities being unable to make decisions until they talked with "somebody else higher up". For many participants, an additional consequence of engaging with a large bureaucracy was the lack of consistency in the individuals occupying the positions, with many observing high turnover ("When they do come, it's different people each time"). This made enforcing accountability difficult.

This was closely related to the observation by others that bureaucratic norms are aligned with protocols like attention to seniority ("Once you get in the big bureaucracy and you are needing to hire the person who's got the most seniority even though they don't like the job and they don't wanna be there...") which made accountability very difficult due to the inherent dysfunction of the position. Others pointed to the larger challenge of health authorities as institutions noting the inefficiencies of bureaucratization itself, in this case with the example of middle managers ("Get rid of about four layers of [Health Authority] managers or, at the very least, redeploy more of them to a site level"). This contrasts with what some saw as the recourse of Health Authorities in response to system challenges: to create new positions ("Their solution is to create a new position and make them a vice president... I can't understand what the job must entail. It's just it's gotten ridiculous").

Relatedly, several other participants noted that the very nature of a large institution makes clear communication (this accountability) difficult. As one participant commented:

"I feel like the structure itself is probably the biggest [challenge], the many layers and the

disjointedness of the layers of [the] health authority have probably led to a lot of that... I haven't talked to people at any one level that really knew what the other level was doing and could answer any questions.... That's not helpful, right? ... [I]t doesn't address issues and find solutions. So, I think more it's the structure being as fractured as it is that makes it hard for anybody... even people who really want to make it different..."

Others were more pointed in identifying the importance of an antecedent to system accountability, which was ensuring a good fit between the local community and regional and provincial planners and the consequent challenges when this didn't occur:

"...the regional or local managers they've hired have just been absolutely terrible at being involved with the community, communicating with the community. Any, *any* involvement with the community has either been none or not very pleasant. Health authorities... have been viewed by communities at the local management level as a barrier to any constructive solutions moving up the food chain."

When the needs of local communities cannot be communicated effectively to those who can effect change, there is no potential for responsiveness (thus, accountability) to local needs.

Several participants expressed their ideas of the underlying causes of system accountability beyond the bureaucratic hurdles, such as the need for institutional control and ownership of the process. This was seen to be motivated in part by fear of loss of control and the consequent need to take responsibility for decisions that were not entirely theirs, and also due to the lack of solutions. In this way, the health system was seen as being accountable primarily to its governance mandate, to the detriment of innovation. As one participant said,

"I think it's control. I think it's ownership. I think that they want to control the situation from their end, but also, I honestly think that they don't have solutions."

Like the survey respondents above, several participants identified the system shift to regionalized health care as being a central challenge of accountability to rural communities. Some recalled that prior to regionalization, many parts of the health care system worked to advantage for rural BC but "they threw the baby out with the bathwater." This led to the contention that to increase accountability as a foundation to solving the current health care crisis, a structural overhaul is required. Several participants described a "broken" health care system", with some noting that this is not limited to rural health care, but urban health care as well.

Others noted that although there were less direct lines of accountability within regionalized health care, there were structural advantages to regionalization due to economies of scale (and appropriate distribution of resources) that need to be considered in juxtaposition to the diminished communication:

“In these really tiny communities...yes, they have hospital infrastructure and yes, they’re trying to attract doctors and nurses to come and live in their communities. [T]hey are not close to the nearest regional hospital. At what point is it unrealistic to duplicate all of these services and have all of these specialists – maybe not even specialists...? ... So, I think there’s a conversation that needs to be had.”

Others specifically recognized the emergence of Primary Care Networks (PCNs) in their geographies as initial cause for optimism that structures of engagement, leading to accountability, would be put in place, but very few saw this come to fruition. Many noted they were not sure what the PCN engagement process or mandate was, because they didn’t “think they involve[d] rural communities... because [they] never hear anything”. Another said, “I know very little about it, but it shouldn’t be like that, right?” However, the theme of project-focused engagement was conveyed by other participants and seen as a conduit to more fulsome relationships between communities and health authorities. One participant, involved in the development of a health centre, noted that the project forced channels of communication with the health authority and observed how the shared focus forged relationships that had not existed previously, with relationship development being a key component of accountability.

Strategies to enforce accountability

Some participants recounted using media channels to garner the attention of and response from policy and decision-makers, most to positive effect (although one respondent noted that “[I]t’s been protest, not communication”). Another participant observed that their media strategy was to reflect “all of the Ministry’s own statements about community-based decision-making, patient-centred care” as a public accounting of policy directions. Still another participant, when faced with a lack of response from their Health Authority, reported “There is no recourse, but we do keep nagging. We don’t give up. And so, we tend to write a lot of letters.” Letter-writing was cited by many as a key strategy in their attempts to precipitate communication.

Several respondents acknowledged the value of uniting the voices of rural communities to create a stronger position of advocacy, some referencing the importance of the BC Rural Health Network in filling this vacuum. This was seen as a necessary step to gaining a rural health strategy or, as others referred to it, “a master planning process” as a step to enforcing accountability. These strategies contrasted with existing provincial mechanisms, such as the annual Union of BC Municipalities meeting, which some respondents deemed ineffectual and

lacking accountability (“You make a bunch of recommendations, you put your hand up, you vote on a motion and then it’s kind of... stalls there...”).

Some local leaders reported progress in engaging with decision-makers, demonstrated for example through regularly scheduled meetings, amendments to Memorandums of Understanding, and adjustments to local budgets ahead of fiscal year-end deadlines. This led to one respondent to observe, “We’re not just a rubber stamp”. Others acknowledged the value of “informal round tables” that occurred while others recalled participation in regional panels to argue their positions. Even despite these concrete directions, however, most participants acknowledged uncertainty in outcome and impact. As one study participant said:

“I don’t know how successful it was. Like, people were certainly there and interested and engaged. But I don’t know if there’s any measurable outcomes from that session that we could point to and say, you know, yeah. They took us seriously. I’m not saying that it’s not. I just don’t know.”

Larger Solutions

Solutions addressing the lack of system accountability offered by many of the participants started with a complete system overhaul starting “at the top” with funding for adjustments to the health system. In this way, participants felt that accountability markers could be built in, including engagement mandates that could be set to establish an expected standard, leaving the health authorities to determine the nuances of the engagement in the context of local communities. Underscoring the system refresh for many was the need for robust evidence to inform planning. Other participants suggested accountability for engagement with rural communities should be included in mandate letters from the Premier to the Ministers and the Health Authorities. This would necessarily be accompanied by resource allocation to build infrastructure and enable meaningful activities.

Others saw the value of increasing the role of municipalities in health service planning and delivery to ensure local responsiveness to need (as one participant said, “I think it starts at a community level to take action and [provide] a coordinating role”) while still, others referenced returning to the pre-regionalization model of health boards and councils. This direct pathway from communities to decision-makers was seen to be the most effective:

“I think I’m probably filling the gap that if [we had] the old board model, [we] would have been the representative from that community. And [the representative] would have presented her information to the board and then the board makes decisions from there.”

Some advocated for municipally directed health policy (“... they take ownership of it”) including the development of a specific health coordination role responsible for liaising local activities with provincial priorities. This would involve bringing forward community-derived solutions to other layers of government, while the municipalities maintain the agency to set direction. More pragmatically, several participants recognized that for municipalities to have a voice, they needed to work through locally elected officials as “[t]hose are who the health authorities and Health Ministry listen to”.

Community Advocacy

Many interview participants who participated in this study took on the role of community leaders based on their recognition of the need for *community advocacy*, to take advantage of the wealth of local knowledge that could contribute to solving health system challenges in a way that responds to local conditions. Similarly, to observations made by rural survey respondents, several community leaders observed the reciprocal need for decision-makers to have local knowledge of the community they are making decisions on behalf of. This was closely associated, for some, with the value of the lived and living experience of rural residents:

“You know what the community is. You’re living it. Like nobody can tell my story like I can tell my story, you know, and so you are living that you have a relationship with the people...”

Several respondents expressed exasperation that locally derived solutions had not been listened to in the past, but some sensed the potential for a change:

“I am [optimistic]. I am, because deep down, they know it’s not working. They have to do something and they’re willing to listen to... well-organized groups like [The BC Rural Health Network] with evidence-based solutions. A lot of these solutions have been arrived at rurally for the last 20 years but haven’t been listened to and now they know they’ve got to listen.”

At the heart of effective community advocacy was the need for widespread community involvement in planning and decision-making, alongside established linkages between sectors. One participant noted the advantage of being a member of a local community social service agency board and transitioning to chairing the regional district, a position which allowed them to engage with government staff. Others emphasized the value of inclusivity and the importance of “bringing everyone into the discussion”. As one participant summarized: “So it was really about bringing business, government, our cultures together, our not-for-profits...”. The importance of inclusivity was noted mostly by those participants who reported successful community-level

engagement.

Some participants recognize their effectiveness in advocating for their community would be increased if they were elected representatives (“We can’t be just one person going to the media slugging our health authority... you need a united community”). Others emphasized the need for self/community education about the issues of concern. Several respondents opined that rural residents have become used to expecting less access to health care than their urban counterparts, with some groups feeling “embarrassed” to advocate for better care. As one participant, referring to seniors, noted, “They don’t have that voice, they don’t have the social confidence, the vocabulary”. The communicative marginalization extended to a lack of digital literacy, which in some instances leads to isolation and the ensuing system of “invisibility”.

Other community advocates espoused, after many years with no engagement, the need to be “confrontational” to gain attention, with the hopes that this would quickly change to constructive work with policy and decision-makers. As one participant said, “But most of us... have come from a protest base. Because it’s the only step we had left”. Although the “unite and fight” approach was evoked by several participants, many also observed that there is a “fine line” with confrontation and that it is essential to maintain the willingness to collaborate:

“Unite and fight. That’s the first step. But it doesn’t always have to be that way. Your ultimate goal should be to finally get the respect of the health authority you’re dealing with and the health ministry. Get them to come to the table.”

Others described it as “a constant fight”. Interestingly, some noted that protest and confrontation were not in their nature personally, but they were spurred on by their commitment to advocating for health services in their community. Ultimately for some, local advocacy-based change was clearly a recourse to the lack of change initiated by others in the health care system: “Something has to change, and the change is not coming from the province, it’s not coming from the health authority so it’s going to come from within us. And so that’s what keeps me going”.

For others, community advocacy was more productive, as some observed the value of Health Authority participation in regular meetings, signifying a “direct line” to decision-making. Building on this, one participant described playing a coordinating role to bring others to the table as well. As they described:

“[W]e invite [the health authority], our local MLA, a representative from Emergency Health Services and our local CRD representative to discuss a variety of things, mainly around transportation of people in emergency situations. And so, we do initiate those

connections”. “

However, despite the coordinated engagement, the participant went on to note that *action* arising from the engagement has been slow. This was endorsed by several other participants, many of whom provided discrete examples, one noting “[the engagement] just goes into a vacuum somewhere... it falls by the wayside, and I firmly believe that they are just waiting for all of us with skin in the game to retire”. Still, others described what one person referred to as “that walk of death” where, after a meeting, appreciation is expressed and “you never hear from them again”.

Engagement

Although there were exceptions, the general tone of participants’ description of engaging with decision-makers was one of lack of satisfaction, leading to frustration. This is in part due to the lack of availability of decision-making colleagues but also when they were available, the likelihood that they would be new to the position (“revolving door” was a common phrase) in addition to, as noted above, that lack of consequent action. Engagement, for most, was both regional and provincial in focus, with a clear delineation between those who were advocating for changes to local services (the former) and those more focused on policy solutions (the latter). For some, the challenge lay in their process of responding to community need at a practical level, and the lag-time they experienced waiting for policy to catch up. As one respondent said,

“We did reach out to Ministry of Health four years ago to [ask] ‘what is your funding tied to? ...how closely do we need to line up with this?’ And nobody knew. We talked to quite a few people, and they said, oh, we’re just writing those policy papers, we’re not sure.”

Several participants cited the lack of any standards for engagement that would provide a benchmark from which to evaluate the success of their activities. For some, this was seen as a provincial role:

“And there also... needs to be that provincial expectation and mandate that there’s a minimum level of engagement happening and maybe set that standard. But then leave it to health authorities to figure out how that engagement is going to work based on the context of those communities.”

Other reflections on engagement were more directed toward mechanisms – and challenges – of engagement, particularly with health authorities. One participant noted that the only way to meet with the CEO of their health authority was at the Union of BC Municipalities (UBCM) annual meeting. Interestingly, others relayed experiences of sending resolutions to UBCM and requests

for meetings with the MoH but reported only having success meeting with staff, not the Minister himself. Another participant noted that they

“Don’t even go to UBCM anymore because it’s... a total waste of time... we have these heartbreaking stories, and we share them with the premier and minister after minister and nothing would change.”

They went on to note that although there is meant to be access to their Health Authority board, this is only possible if they meet in the local community which, for many, happened infrequently. Others did express more access to their RHA boards, however. When another participant was asked if there was cynicism regarding engagement with the health authority, they replied, “I would say that was an understatement”.

Some participants specifically spoke to assumptions of Health Authority knowledge of the history and conditions of health care within their community that were misplaced. These assumptions of inherent knowledge and understanding led to significant challenges, for some, in enacting community-based planning.

Other participants turned the lens towards upskilling local elected officials to optimize relationships with the Health Authorities. They observed:

“I think a lot of times, local government people get elected, and they go in and... they don’t understand their job. They have no idea what they’re doing, and so they think their job is to be mad at government for not providing the services that they need. I think educating a bunch of politicians when they come in the door that they do have tools that are more effective than, just being upset, like a master planning process, like the hospital district, like the primary care network, like all of these community groups that are doing work, I think is really important. So, education.”

Others reported attending Health Authority board meetings as a municipal elected official, mostly in their capacity as a member of the local Division of Family Practice which created the need for an interface, “... because you are meant to be analyzing data and... developing plans that are all going to interface with the [Health Authority].

Reciprocally, however, other community leader respondents detailed how they reached out to their *communities*, emphasizing the need for this same kind of engagement upstream. The outreach described was based on an understanding of the importance of public engagement (one participant described this as “one of our strategic priorities”) fulfilling the commitment to

“listen to our community and hear the inputs they have”. This participant went on to note that substantial engagement occurs informally, in social settings (“on the ski hill and the soccer field”) but also through more deliberately organized chats over coffee. The capacity to do this hinged on the characteristics of the (small) town and advantage of previous interactions with community members.

Others noted deliberate efforts to create connections between activities at a municipal, regional, and provincial level through cross appointments in leadership positions:

“We appoint 2 members to that board, and so that [Community Leader] and myself are both on the hospital district and both on the regional district, and so connecting the dots for people. And then I think maybe one of the biggest ones is what [others]] did for our community, which is educate people, educate politicians, educate municipal staff, help people understand what’s going on.”

Despite this, others noted the inherent challenges of engagement due simply to the expansive geography that many health regions cover (“...we’re disconnected from decision makers because *we’re disconnected from decision makers*. Like, they live in different places than we do”). Another participant pointed out that “... our staffing is done in [a regional referral centre]” and that this made responsiveness to the conditions of the local community difficult.

Others suggested mitigators to challenging geography, like tools that facilitate virtual communication, such as Zoom. Despite this, many participants noted geographical distance as an impediment to relationship-building.

Other participants articulated the challenge of community representation in engagement, summarized best by the question, ‘Who represents community?’. Several people pointed out that it is “the loudest voices that get heard” and strategies were needed to ensure more stratified representation, starting with an awareness of “who we’re missing”. For others just starting down the path of engagement, “listening and learning and understanding” was the kind of community engagement already underway which was crucial.

For upstream regional and provincial communication, some participants noted the advantage of structures put in place during the COVID-19 pandemic, such as regular virtual meetings with communities, that were subsequently rescinded. Others described the silver lining to the COVID-19 pandemic more extensively, noting the pandemic was “a tremendous benefit to us” in that it was the first time that there was coordinated activity between the municipality and the Health Authority (“those relationships through COVID were very strong, and it became sort of a natural

advocacy point that we were able to make”). The participant went on to note that the need for communication during the pandemic allowed them to

“... talk to [the decision-maker] whenever I wanted. I was talking to the Minister of Health... it was a very different time. [We] were in regular touch with decision makers and staffers at all levels.”

As with comments on engagement, above, several participants identified the lack of action emanating from engagement, not just with policy and decision-makers, but with other agencies and academics. Lack of follow-through from engagement also extended to a lack of follow-through for decisions made at a provincial or regional level that impacted local communities. As one participant said, “I would expect more from the government in terms of decision making and assessing... the impact of their decisions”.

Vulnerable populations

Some participants observed the need – and inherent wisdom – of tailoring services to meet the needs of vulnerable communities, as through this we “create something that meets everyone’s needs.” Several respondents emphasized the importance of different modes of engagement with those parts of the community whose voices are less heard. One participant summarized the challenge this way:

“And then how do you get those very important voices to the table? And I use bunny ears because that’s the problem, I think in itself, is saying to the table. We often want to engage those voices on our terms in our way and that isn’t safe. We’ve done harm. So, I think there’s lots that we need to do differently to engage those voices, those communities. And part of what we need to do is get out and away from our tables and get into the community and connect to organizations and associations and groups and community services that have relationships with those folks and have trust there. And start trying to meet them where they’re at, where they do feel safe, in a way that feels safe. So that’s a big thing that we need to do there.”

Urban Centric Health Planning

Many community leaders observed an “urban centric” tendency to health planning, congruent with the findings from the pan-provincial survey. At the core, this was thought to be due to the disconnect between rural communities and decision-makers, as noted above, but also due to the lack of engagement with rural communities and entrenched evaluation of policies for decisions impacting local care. As discussed above, the disconnect was in part seen simply as a lack of

familiarity with the realities of health services in rural communities, including a lack of understanding of context and multiple roles that individuals may have.

There was a further disconnect between what some rural community members described as ‘engagement’ and how they believed policy and decision makers saw community engagement, with the former prioritizing *relationship building*. As one respondent said, “[they should not] come in with all of the reasons why they haven't or can't or shouldn't or all these answers that don't work, because yes, they were developed for a city system and it's not going to work here.” There was overwhelming consensus that “you have to live rural to know rural,” with this participant further stating, “We do know what we're talking about. We do have some good solutions”. In addition, several participants emphasized the need to ensure an iterative method of system improvement.

“...so we can continue to learn and understand and then improve what we’re doing. Because I think in some context... some of those structures need to look different, and I think we have to create flexibility in being able to adapt.”



Health Care Decision and Policy-Makers Experiences of System Change in British Columbia

The Role of Health Policy and Decision Makers in a High-Functioning Health Care System

Policy and decision-makers play a pivotal role in shaping, implementing, and overseeing the strategic direction of health care. They do this through a myriad of activities from goal and priority setting, allocating resources and providing oversight. They also attend to integration of various health care sectors, partner engagement and monitoring and evaluation, ideally through a lens that promotes health care equity and accessibility thereby reducing health disparities (Mitton & Donaldson, 2002). Their role is critical in ensuring effectiveness (quality and safety in patient outcomes), efficiency, equity, and sustainability (Brinkerhoff, 2004).

The decision-making process, however, is multifaceted and involves a range of partners and municipal, regional, and provincial layers of decision-making. The provincial Ministry of Health is the agency responsible for oversight, on the direction of the Minister of Health (BC Ministry of

Health, 2022). Ministry employees are the “stewards of BC’s health system”, setting the direction and providing a legislative and regulatory framework for decision-making (Province of BC, n.d.). Activities are funded through regional health authorities, who are responsible for the *delivery* of health care (Province of BC, n.d.). Health Authorities in BC have their own decision-making structure, budgets, and responsibilities, although aligned with provincial priorities (Pauly et al., 2013), leading to regional variation. The province is mandated to engage in consultation and collaboration with partners, from healthcare providers and social service organizations to communities and patients (Légaré et al., 2022) alongside a system-wide commitment to evidence-based decision-making. Public engagement ensures that healthcare policies reflect the needs and preferences of the population, although accountabilities for meaningful engagement, as noted by community members and leaders above, are lacking (Berland, 2019).

This multifaceted governance and decision-making system creates challenges for patients and communities wishing to engage: the system itself is also constrained by *how* and *when* engagement with communities occurs and, perhaps most importantly, by resources facilitating engagement. To better understand the real-world challenges of (rural) community engagement in health care decision-making, we interviewed 14 regional and provincial policy and decision-makers to better understand the constraints they face and to document their views on community participation in health care decision-making. The main themes arising from the interviews include *decision-making during a health care crisis*, *the use of data in decision-making*, *the importance of leadership*, *the challenge of rural health service planning* and *the impact of the electoral process on health care reform*. Each is explicated further, below.

Decision-making during a healthcare crisis

All policy leader participants in this study discussed the challenges facing the BC healthcare system. As one described, “We do know the health care system is in full-blown crisis at the moment.” Policy leaders commented on the challenges faced by the Ministry of Health including, for example, emergency transportation and transfer and stabilizing maternity and primary care. In the face of increasing challenges, all policy leaders had a desire to make a meaningful change to improve the healthcare system. As one described:

“We don't want to continually be fighting fires. Right now, we are being very reactionary to the immediate needs or the service interruptions that are happening across our system.”

In the face of service delivery challenges, policy leaders described a complicated process involved in making creating the conditions for meaningful changes within the healthcare system. Participants spoke of using evidence-based data and community engagement in their work. One policy leader explained the process of presenting relevant and comprehensive evidence to the Minister and Ministry, emphasizing that the Ministry takes the lead on health care reform. However, several participants noted that ultimately, “decisions are [made by] elected officials.”

Participants explained that healthcare reform is often shaped by the “health mandates” set forward by the Minister, following which, the rest of the system aligns with the mandate. One participant explained, “[T]he government sets the path for a lot of our initiatives... We have guardrails on what we need to deliver based on the current government, our mandate, and what our board says.” Despite this seemingly simple top-down approach in decision-making, participants in this study often commented on the challenges when implementing healthcare changes due to the many diverse opinions and desires of different groups present in the healthcare system. One participant noted:

“There is this constant tension between what the minister wants based on the political party, what the ministry needs to have done as the inner workings of the health system, and what the health care providers want to do.”

Many participants described BC’s healthcare systems as highly fragmented, highlighting the importance of building relationships to improve system function:

“There are diatribes in this culture: Us and them, community versus provider, or provider versus health authority, health authority versus ministry, or anywhere in between. We are trying to find those alignments and allegiances and build a better system where we understand one another, we have shared values, shared goals, and shared accountability.”

Policy leaders often spoke of making a change from both a systems perspective, which includes understanding service needs of a population, and from a health human resources perspective, which is more pragmatically and fiscally oriented. One participant described the challenges that must be considered when advocating for healthcare:

“How are we going to navigate, negotiate, or even advocate for the services that people need? We aren't a service provider. So, I can't say we now need a birthing center in Masset. Let's go put it there. We're really negotiating or advocating for the entire system based on the needs of our members who are serving the patients.”

Another participant provided an example in maternity service planning by explaining how their decisions are shaped not only by the demand for services within communities, but also by consideration of issues of potential litigation for providers. They explained:

“In some [rural] communities, do they need c section services? Not in every community. They might want a birthing service and they're happy to move out of community if they want to [have a c-section], but it's patient choice and informed decision making. That is also a risk model where patients may be willing to take on more risk in their care, whereas providers are not.”

All participants in this study spoke about an overwhelming desire to improve the current healthcare system. However, policy leaders also acknowledged that in addition to challenges in gathering endorsement from the Minister to implement these changes, there is also limited funding and constrained resources. One participant summarized the fiscal limitations constraining meaningful change:

“The discretionary funding that is available on an annual basis is relatively slim... Even when their budget increases, it's for wage increases and for other kinds of things or other expenses that just keep going up. Reconceptualizing [our healthcare system] seems incredibly difficult.”

Some participants described examples of systemic changes within the healthcare system that are currently taking place. However, they explained that these changes require a lot of planning, data collection, and timing where “alignment in political will/interest aligns.” The next section will outline the types of evidence and data policy leaders who participated in this study use to plan healthcare services, design the healthcare system, and bring to the Health Minister.

The use of Data in healthcare decision-making

Many participants described the use of quantitative data to evaluate the current state of service delivery and to identify service and resource needs. In other words, they often use quantitative data to identify what *is going on and what is needed*. Most talked about the process of data

gathering as essential in their work. One participant explained that “data-informed decision making is a key point” in their work. Many talked about jurisdictional scans, assessing population data, and working with economists to identify operational impact to the system. Participants in this study talked about the importance of quantitative data in their work, as one participant explained:

“We look at policy, population demographics, a variety of inputs to shape up some considerations for health service delivery, both in refinement, making it better, and what are we missing. And then truly new services, big gaps in the system where population over time is needing those services.”

Another participant noted that using existing data trends allows them to identify resource needs, develop a service-delivery plan, and justify the request for additional funding. The participant elaborated:

“The team is looking at call volume, acuity, and patient demographics, like age. Is there a community that has [a higher] proportion of elderly patients compared to a younger population? We're looking at common diseases in those areas, to try and get a better handle on what kind of resources do we need in those communities. That's helping populate the information that we're giving back to government...”

At the same time, participants acknowledged the limitations of using quantitative data in developing service delivery plans. One participant explained, “you have health service models, social service models that are very technocratically designed and created in a bureaucracy. They may have been evidence and data informing in their creation, but they can't very effectively absorb the reality of humans in their delivery.”

To ensure their plans are easily implemented, policy leaders explained the importance of engaging with the community and service providers. Gathering information mostly involves gathering qualitative data to understand context in identifying *how* services should be delivered. However, this process is not always straightforward. One policy leader expressed their frustration in integrating qualitative data and experiences to bureaucratic processes, for example when applied to emergency transport:

“I am trying to convince the government - why would I have ambulances driving for 4 or 5 hours on the road? If I break my hip and I'm in Dease Lake, I want a helicopter to swoop in, package me up and get me somewhere. I want to be comfortable, and I don't want to be rumbling around in the back of an ambulance. Plus, when that ambulance leaves the

community, that leaves that community unsupported because sometimes there's only 1 ambulance or sometimes there's 2, but a lot of communities only have 1 ambulance. I want to get to a policy where we wouldn't leave a community for more than 2 hours. That air [strategy is] based on what other countries are doing around the world. **But we have used some metric to actually drive the data.**" [Emphasis added]"

Many participants discussed the importance of community engagement from the perspective of healthcare providers. However, many noted they often hear about (rural) community planning second-hand from service providers. Several went on to express limited interest in engaging with community (healthcare recipients) to identify service gaps, explaining that they are concerned about hearing directly from the community who may "have a laundry list of things they would like to see done," and fear that engagement would open the "floodgates such that there are so many expectations created that could absolutely never be met." Despite this hesitation, most policy leaders acknowledged the importance of patient engagement. Specifically, policy leaders talked about the desire to ensure that all patients receive high quality care. One explained:

"We have [a] patient centered measurement [group], which conducts patient surveys of patients who have had an experience of care within various facilities in the province. The purpose of that is to have information on patient reported outcome measures and patient reported experience measures. We collect and use [that] kind of information. I would absolutely consider it a factor that goes into policymaking, but I don't know that I would consider it as evidence."

Participants talked about several engagement strategies used to engage within communities to identify local needs, including patient surveys and patient advisory committees. Challenges noted included identifying how to determine the appropriate standard and quality of care and how to create policies and standards to enforce them. They policy leader explained:

"I think [patient engagement] has to be a huge influence, because those are the folks that are receiving the care. If we are not listening or understanding what the needs are, how do you know you're delivering the best appropriate care, [that encompass] all the dimensions of quality. It's so important. But it's been challenging to understand or to translate what those needs are and how to translate that into those policy decisions. I think most of the decisions that are made in health care are clinician driven. What do providers need to deliver safe, appropriate care? But, again, what do people need on the ground?"

Although several respondents discussed patient engagement, fewer identified the importance of and mechanisms of community engagement.

The importance of leadership

One of the themes consistently noted by participants in this study was the importance of leadership within the Ministry, specifically the passion and desire of policy leaders to improve the healthcare system. Several participants expressed a keen desire to advocate for and contribute to policy change, one describing their experiences:

“In quiet corners, I pushed for physician's assistants. They [have] announced they're going to bring them. Now do I think that was cause and effect? No. By no means. There was a bunch of other work that was happening, but I get to have quiet nudging conversations with ministers or deputy ministers that most people don't.”

The policy leader further described the type of work they put in over a long period of time to push for a policy change:

“...lot of personal blood, sweat, and tears for a couple years.... I hadn't had been involved and done the follow-up and the pre-meetings with the associate deputy and the assistant deputy to say, ‘you guys need to show up’. These are some of the things the committee needs to hear.”

As alluded to by the experience of the policy leader above, participants in this study often demonstrate long-term thinking, especially in the preparatory work they do to lay the foundation for change. This long-term thinking is best described by a policy leader who continued to share a dataset developed 10 years ago with various colleagues:

“10 years ago, we did target population definitions for women in childbirth and pregnancy and people with chronic illness and mental health and substance use and, people with frailty... I send that document 10 years later, at least once every 6 months to somebody who's talking about something evaluating mental health [saying that] we don't have actually a provincial definition for mental health. Actually, we do. Here it is... I do think that was good work that's thoughtful and well done, is not exactly timeless because things can change, but it still is really important. **However, it does depend on someone**

remembering that it was done, or figuring out ways to make sure that it can be accessible to people who look for it. [Emphasis added]”

As highlighted by the participant above, the continuation of evidence over the years “depends on [organizational] memory. Somebody's got to remember.” Having a long-term organisational memory is important to not only prevent the duplication or replication of work, but to also build on existing work to gather evidence to determine healthcare need. In addition, sharing data and building relationships is central to the role of policy leaders. Another participant explicated this when they noted:

“The Ministry of Health, although being big, is very small. People know people. I do have colleagues, friends, tables of similar roles... in other health authorities that are responsible for clinical care. We meet regularly. Text each other problems. We try to kind of learn from each other. So that's kind of just part of my role and necessity to learn.”

Participants in this study noted the need to negotiate a space where they learn about and advocate for the needs of Health Authorities who administer healthcare as well as the Ministers who hold decision-making power for policy changes and resource allocation. Participants reported often finding themselves negotiating the immediate needs of the healthcare crisis and the desire to make long-term lasting change. One illustrated the challenge of negotiating both short-term resource needs from Ministers and long-term healthcare planning:

“I think there's just too many barriers. I just think there's too many levels, and I think squeaky wheel always gets the grease (funding) in health care. I've been part of that, trying to get my share as well, to be honest. But I do think we've got to get rid of all of that and start from the basics. Let's start with our rural and remote because that's where our least resources are.”

As alluded to by this Policy leader, there is a desire to redesign the healthcare system starting with rural healthcare. The next section will further discuss some of the challenges participants in this study articulated in working with the current health system.

The challenge of rural health service planning

One of the challenges participants alluded to was the different needs of rural and urban health services. The low volume of patients characteristic of rural sites meant that health centers or hospitals often lacked health human resources, expertise, and technology to support comprehensive healthcare services, recognizing that providing higher levels of care was not prudent, based on low population density. Consequently, the resources are often clustered in larger centers. As one participant explained:

“Hospitals have set up their centers of excellence based on recruiting the smartest [physicians] from across the world, and they want to set up their program, which is great, but is it in the right place? Is it in the right hospital? Let's look at what the population is.”

The same policy leader contended that healthcare expertise in certain specializations, such as for paramedics, should be concentrated in rural centers, noting, “the highest trained paramedics were put in the urban centers, and the lesser trained paramedics were put in the rural remote. It makes no sense. It should be the other way around.” They further explain, ‘Do we need an IV in Golden? Yes. Do we need paramedics that know how to intubate? Yes. That's the kind of stuff. So, we're trying to flip [the system] on its head.’

Challenges replicating success in rural settings

Given the size of BC, different population needs, and unique geography, many participants remarked that there is no “one size fits all” approach. One participant noted the need for a flexible approach, recognizing they are planning across a wide geography. Another elaborated on what variations in policy can look like, noting “I think it starts with... saying, you know, a policy that we're going to look at for Burnaby, may not be a policy that works in [a rural community]. So how do we allow for there to be some flexibility?”

Participants described situations where rural communities “may stretch the boundaries of a policy or procedure somewhere down or up the chain because it's the right thing for [the] patients.” One participant explained that success from such initiatives can receive:

“... some accolades, some attention, and some resources to scale it up, but then we need to share it with other people who didn't create it but want to be a part of it. And so, there's an inherent sneakiness initially and then humility when you get to share it.”

In this way, participants describe how successful initiatives are implemented and replicated across BC. Another cited the success from Haida Gwaii in maintaining a birthing center. However, despite success in maintaining the birthing center, the policy leader continued to puzzle over how to re-create the success in other rural sites. They explained:

“I think that a whole study should be done on Haida Gwaii. Because, they are a remarkable community and a remarkable site [to have] maintained low risk birthing for a decade, if not more now. And the physician partners, they don't do the birthing there, but they are completely supportive, and they work in a team-based model. They all learn together frequently, to support the community. And there's mutual respect and team-based care and all the things that happen, and all their nurses are trained...**What is it just the secret sauce of the people that that came around and rallied and worked together?** I'd like to know that, what the secret sauce is to be able to replicate that in other places. [Emphasis added]”

The impact of the electoral process on healthcare reform

As mentioned in the first section, the Minister of Health sets the policy mandate that the rest of the system aligns with. Participants noted there is a “lack of appetite” from Ministers to implement changes to the healthcare system to be “an inevitable product of our politics.” One participant described their ability to continue with their initiative due to their capacity to demonstrate it “does not produce any political risks.” Another explained this constraint in the context of the electoral cycle:

“The 4-year political calendar creates the conditions where decision makers... are inevitably focused on their own political well-being and to that often will dispense (omit) long term investments or the willingness to make the kinds of changes that are necessary. “

Most policy leaders in this study described a general feeling of frustration as policymaking often “collides with politics, where the politics wins.” The four-year political calendar means that Ministers/politicians favour solutions that appeals to the public for the next election cycle. As this requires the minister/politicians to respond to public sentiments, one participant explained that considering the healthcare crisis, there is the pressure to respond to individually expressed needs, noted that system change must be based on aggregate need. They further explained:

“[People will write in to say] ‘...my mom did not have transportation to her health service. Therefore, we need transportation for our health services’. When I do the analysis, and

it's 1 person in 10 weeks that need it, it doesn't make sense to start that [service]. People are trying to move from personal experience to a system view, which is hard. It's not their role. That's not what they do every day. It's their personal lives... The health system can't be everywhere for everyone. You have to have some rules in what's available.”

Participants alluded to a variety of situations where the public/constituents advocate for policy and healthcare changes. Politicians’ decisions are often impacted by these voices. Despite the best practices noted above, in some instances, these pressures can cause decision-makers to ignore data-driven evidence in favour of the political realities of a situation:

“Governments are choosing to ignore good evidence, data, the coroner, the public health bodies, in what they indicate... to reduce the impact of a health crisis and choose instead kind of a nonevidence based, non-data-informed, and probably more expensive [course], which is an ironic approach to addressing a problem, because that's more politically...feasible for them.”

Another Policy Leader explained in detail how the political cycle leads to a general reluctance to make extensive changes to the healthcare system, which has led to a shift in the relationship between the elected government and the healthcare bureaucracy. The policy leader explains:

“We have a lack of a real sense of the role of a minister in a government. A minister is there as the representation of the public and the public interest. On the other hand, you've got this government machinery that operates all along. It doesn't matter what government [the] political party is in, but that machine is going. Your job as the minister is to be relentless, you are pulling that machinery to be oriented towards public interest... What I think we see more of is that the ministers have become spokespeople for the machinery.”

They go on to note:

“And the irony of this is that we get these political changeovers in BC, and it doesn't matter which [party] is on either side of the house, the language is the same. So as soon as one party is in government, they are there defending how great the whole government machinery is and what a superior job they're doing delivering it... And I think that we don't have a kind of political willingness to wrestle with what is the role of

elected people and elected ministers in this government machinery. We've fallen more and more to where Ministers become spokespeople on behalf of the of the machinery.”

Despite referring to rigorous governance structures and parliamentary processes, this policy leader alluded to a breakdown in the political process where elected politicians are not taking steps to change the healthcare system, based on evidence. The participant further explains the lack of willingness to stems partially from the complexity of dismantling the system:

“I don't pretend to think that this is an easy thing to address, but I worry that as the machinery, the bureaucracies and the health authorities has become so dense, it's very hard to unravel the ways in which its operating, and it doesn't really matter which government is in place. We see decade over decade, the outcomes have not been terrific on the health delivery and the social services delivery. **We have a somewhat unsophisticated kind of way of, like, pointing at one individual or saying, this party is responsible for all these things.**”

Policy Leaders are placed in a precarious position as individuals advocating for change within limited and somewhat static healthcare resources. However, as non-elected officials, their capacity to advocate for change remains limited. Building relationships across the healthcare system and with elected officials remains crucial. As one policy leader pointed out, “I have no qualms about whether you're a liberal, conservative, or NDP, but he (the Premier/Prime Minister) is the most powerful person in the country when it comes to resource allocation.” As such, policy leaders must identify health service needs, gather financial resources, and build relationships to the implement change they advocate for. Another participant summarized their approach to making meaningful healthcare changes within this disparate system:

“My answer is going to be courage. This is what it takes to have a different system: courage and graciousness concurrently. I'm going to have to call people out in the ministry to say that this is the going on. Be tough on issues, and still again soft on people so I am able to look them in the eye the next day.”



Project Audience

By setting out to understand and address the gaps in the consideration and inclusion of rural community voices in health care policy and decision-making, this project serves residents and

leaders of rural communities, health care providers, as well as regional health authorities and the ministry of health.

Residents of rural communities in BC have unique healthcare needs and challenges compared to their urban counterparts and a lack of community engagement has led to the perception of urban-centric healthcare planning and decision making, resulting in feelings of alienation and distrust towards policy leaders and a lack of ownership in health care decision making.

Rural community leaders, including those working in health or social services, elected officials, and rural healthcare providers are able to observe and acknowledge how current healthcare systems and policies fail to address the needs of rural communities. Thus, engagement with these leaders, as well as rural residents, is vital in developing solutions that respond to these needs through services, policies, and programs. By more fully understanding the perceived gap between community members and decision-makers, this study impacts and informs the potential to strengthen communication and process between the partners. Ultimately, this will lead to improved access to health care services and consequently, improved health outcomes.

Findings from this initiative provides tentative first steps to understand the lack of information flow between planners and community members, with the potential of using it to improve health planning processes. As this study analyzes the existing gaps in the use of rural community output in policy, it will help inform what resources and actions are needed from policy leaders, at both the provincial/ministerial level and the regional level through health authorities. If findings are taken up, they could lead to the development of mechanisms for engagement with rural communities and the implementation of rural community-driven solutions through policy and decision-making.

Limitations

The efficacy of this work rested in the willingness of regional and provincial policy and decision-makers to participate in interviews and share their experiences. However, our interview numbers in this category are low. Although we were persistent in our recruitment strategies, leaned on third-party contacts to assist and employed multiple avenues of contact, regional health authority representatives did not take up the opportunity. We acknowledge that this is a difficult time in healthcare operations with health human resource shortages, transportation challenges and inadequate physical infrastructure to meet the growing needs of the population, we also believe lack of uptake validates the issue at hand of challenging engagement. We do, however,

feel confident in the veracity and insight of the data collected, analyzed, and presented, and believe we have taken tentative first steps to understand the gap in community evidence to policy in BC.

Recommendations

The recommendations below are aimed at improving community involvement and engagement in health care planning, particularly in rural and remote areas of BC. They are derived from the wisdom of the participants in this study and address the challenges of entrenched bureaucracy, political influences, and the need for effective communication with diverse communities, as reported. These recommendations are directed towards the Ministry of Health (MoH) and Regional Health Authorities (RHAs) but must also involve the direct collaboration and cooperation of rural communities. *They are loosely presented under four thematic areas: community engagement and transparency, Inter-RHA collaboration and knowledge sharing, overcoming political and bureaucratic challenges and effective communication with rural and remote communities.

The recommendations are purposively underdeveloped out of the recognition of the importance of co-creation with policy and decision-makers. That is, although we present tentative directions, we need engagement of all key partners to create an effective path forward. Regional and provincial working groups will be held in the spring (2024) to actualize this agenda.

1. Community Engagement and Transparency

1.1 Establishing Community Engagement Units (CEUs):** Each RHA should create a Community Engagement Unit to facilitate dialogue between the RHA and its communities. These CEUs should be staffed with existing senior executive management within each RHA and should include representation from RHA governance.

1.2 Implementing Transparent Reporting Systems: Develop publicly accessible platforms for updating and receiving feedback on healthcare initiatives.

1.3 Forming Community Advisory Boards (CABs): Create boards with diverse community members to regularly meet with RHA CEU officials. These boards could be created to include communities within a focused geographic area to ensure that small communities voices are not lost in the process.

1.4 Organizing Annual Community Health Forums: Facilitate direct interaction between community members, healthcare policymakers, and service providers.

1.5 Implementing Feedback Loops and Storytelling: Ensure community suggestions are acknowledged, reviewed, and responded to in a transparent manner.

2. Inter-RHA Collaboration and Knowledge Sharing

- 2.1 Inter-RHA Knowledge Exchange Portal:** (1) Develop a digital platform for RHAs to share and access information on successful healthcare strategies. (2) Provide a public access point to this platform that shows and tracks the information being exchanged and allows the public to see that their concerns and solutions are being addressed at the RHA level.
- 2.2 Regular Inter-RHA Conferences and Workshops:** Organize events for RHAs to present and learn from each other's initiatives and challenges. Ensure that stakeholders can also interact and attend these events to network and inform their own groups on the information provided to the RHA representatives.
- 2.3 Transparent Implementation Roadmaps:** Publish detailed plans for the adoption of strategies from other RHAs, including customization for local contexts. Provide these plans to all communities engaged and disseminate them broadly within the communities through known and reliable channels.

3. Overcoming Political and Bureaucratic Challenges

- 3.1 Policy Sandbox Approach:** Test innovative healthcare solutions in controlled environments, free from usual bureaucratic constraints.
- 3.2 Independent Health System Review Board:** Set up a board to periodically review the healthcare system's effectiveness and political neutrality.
- 3.3 Public Accountability Measures:** Implement regular public reporting, community feedback sessions, and performance audits.

4. Effective Communication with Rural and Remote Communities

- 4.1 Dedicated Rural Outreach Teams:** (1) Establish teams within RHAs focused on maintaining communication channels with rural and remote communities (CEUs). (2) Appoint local health communication representatives in rural and remote areas. These individuals or organizations, from the communities themselves, can act as liaisons between the RHAs/MoH and the community, ensuring that communication is relevant and culturally sensitive.
- 4.2 Utilization of Local Media and Community Channels:** Disseminate health-related information and gather feedback through local media channels and non-profit organizations.
- 4.3 Regular Community Consultation Tours:** Have healthcare officials visit rural and remote communities for open forums and discussions.

4.4 Enhanced Digital Infrastructure: Improve digital access in rural areas to facilitate telehealth services and online health resources. Covid-19 has created awareness and the ability to use video platforms for communication. In-person exchanges are important and should be enhanced but digital infrastructure is essential to ensure that everyone can participate in a better public system that is inclusive and accountable to the people it should serve (everyone.) The technology now exists to ensure every community has high speed internet access in at least one location.

Conclusion

The implementation of these recommendations requires a collaborative effort from the MoH, RHAs, and community stakeholders. By adopting these strategies, we aim to create a more inclusive, transparent, and responsive healthcare system that addresses the unique needs of rural and remote communities in BC.

* Rural communities are not limited to Rural Subsidy Agreement communities (RSAs) and must include organized unincorporated communities, Indigenous communities, and any group or community within a community.

** An example of a Community Engagement Unit model is being used in North Dakota with success and more information can be viewed [here](#).



Leveraged Funding

A further intersection of values between CRHR, BCRHN and SPARC is the commitment to engagement integrity. For the project team, this demanded our accountability through attention to sharing findings with communities not only with integrity (non-partisan transparency), but also with the intent to co-develop an implementation plan for the findings. We were determined to not contribute to the post-engagement ‘vacuum’ identified by so many of the research participants. To this end, we sought and have received (UBC, \$9953.84) additional resources to build on the SPARC-funded knowledge translation plan to actualize a virtual space for rural and marginalized voices to participate in guided discussion regarding how we can utilize the data for further rural health engagement. Again, we will work, through synergistic advantage, through both organizations to establish key rural community partners in each health authority to participate in regional consultations based on the findings from this project.

Beyond community members, however, the target audience also includes municipal, regional, and provincial policy and decision-makers. The rural vulnerabilities noted above emphasize the need for those affected by health planning decisions to be involved in creating solutions. Our

mechanism of research mobilization will be based on a framework for Integrated Knowledge Translation (iKT), which refers to the process of early onset collaboration of knowledge users to ensure the product yields resources of use to the decision-making process, as described above. We anticipate the success of this approach due to the relationships we (re)established during the data collection for this project and the keen interest participants had in follow-up.

Knowledge mobilization will occur through the process of virtual workshops involving the regional and provincial decision makers; that is, they will participate in the development of a framework for community-to-decision-maker knowledge transfer by providing feedback on feasibility (desirability has already been determined through stated policy objectives). The primary knowledge mobilization audience, therefore, are policy and decision-makers positioned to effect change. The secondary audience will be rural communities across BC and to this end, we will develop community-facing reports summarizing the combined output of each workshop and the provincial workshop. To increase the credibility of the findings, we will also develop a manuscript to submit for peer-reviewed publication. **Ultimately, however, our prioritized output will be a community-generated strategic plan for addressing the 'gaps' in community-to-decision-maker knowledge uptake to influence policy and planning.**

Additional funding applied for again by CRHR and BCRHN to build on the SPARC-funded activities which is still under adjudication (UBC \$25,000) will, if we are successful, be applied to developing a 'Rural Community Bill of Rights.' This initiative will enable rural voices to articulate their unique health needs and values, ensuring more responsive and accountable health planning. Building on our past successful collaboration, we'll work closely with rural communities to define engagement standards, accountability mechanisms, and practical applications within BC's healthcare framework. This partnership seeks to restore agency to rural communities, fostering improved health outcomes through genuine engagement and tailored health strategies. Through this approach, we will address the alienation rural communities have experienced from healthcare decision-making and planning. Ownership of the co-created product will be shared with participating communities and available through both organizations' websites. We will also use "snowball-sampling" to regionally identify marginalized communities that may require separate engagement sessions. In this way, we actualize our openness to learn from the wisdom of communities. Channels of knowledge translation will include regional and provincial meetings, a peer-reviewed publication, and, if appropriate media engagement.

The primary social benefit of this project, if funded, will be in the area of public and civic engagement as we actualize our collective responsibility to contribute to the needs of the wider community. That is, through a rigorous approach to engagement, data gathering, and report writing, we anticipate a product with a high degree of utility for rural communities currently

advocating for improved access to health services. This is due in part to the level of collaboration shared between the applicant organizations. The strength of the relationship between CRHR and BCRHN further emphasises best practices of engagement with communities in healthcare planning and in research more broadly.

In this project, *knowledge exchange* is not an end product but instead, a determining process characteristic that embeds community feedback into the development of the Bill of Rights. In this way, we are integrating knowledge exchange throughout the proposed work, culminating in the engagement with regional and provincial decision-makers. Based on our experience of the SPARC-funded Gap Analysis Project, we are confident that the relationship have been built will allow this approach.



Appendices

Appendix A: Search Strategy

We took a systematic approach to searching the literature. A search strategy was developed in consultation with a research librarian to optimize search term relevance, using both primary and secondary sources. The search query was run using MEDLINE (Ovid) using four search terms, including *health policy, decision-making, rural, and community voice*, with associated concepts. The geographic focus was refined to include developed countries with similar healthcare systems. The search and review of literature was done between June and September 2023. In the initial search, 2370 articles were identified. The researchers narrowed down the results and reviewed 30 articles discussing the role of community engagement in healthcare planning. There was limited literature on rural community engagement in healthcare planning in British Columbia and in other developed countries. Additionally, the research team reviewed current British Columbian policies and mandates relevant to the research to provide a region-specific understanding of current approaches and attitudes in the province. To ensure academic rigour, the reviewers used an adapted version of the PRISMA 2020 Checklist (Page et al., 2021)

Appendix B: Pan-Provincial Survey

Qualtrics Survey Software

<https://ubc.yu11.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPri...>

Gap Analysis Survey

Study team

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Sponsor

The Social Planning and Research Council of British Columbia (SPARC BC).

Survey purpose

The purpose of this survey is to understand and document rural residents' and communities' experiences of input into or engagement with health care decision-making.

Your voice will help us understand what we hear from policy makers and rural community leaders. This research project is the first step to bridge the gap between centralized, urban-based health planning and the needs and priorities of rural communities in BC. Understanding and addressing this disconnect is a step towards fostering a more inclusive, representative, and effective health policy-making process in BC.

Your perspective as a rural resident is essential and will contribute to more equitable healthcare policies and practices across BC's diverse communities.

Risks and Benefits

We do not anticipate any harm will be caused to you by completing the survey. You do not have to answer a question in the survey if you do not want to. There will be no direct benefits from participating in the survey; however, we anticipate system level benefits, which include gaining a clearer understanding of the constraints to including community voice in healthcare planning. Participation in

this survey cannot be withdrawn after submission since responses will be anonymous and unidentifiable. You are encouraged to review your responses prior to submission to ensure accuracy and confidentiality.

Privacy and Confidentiality

Your privacy and confidentiality will be respected at all times. You will not be able to be identified by your survey responses. All analyses of survey responses will be reported together to ensure participant confidentiality.

Data Access and Storage

The platform used to collect survey data are fully compliant with the BC Freedom of Information and Protection to Privacy Act (FIPPA). The survey data is kept secure and is stored and backed up in Canada. The survey data will be safely stored within the secure computer network at UBC. After survey data is downloaded, it will be encrypted to protect the information. Access to survey data will be strictly limited to the research team.

Study Results

The results of this study will be shared in various ways including journal articles, reports, oral presentations, and posters. A summary will be provided to participants. If you would like to receive information about the study results, please provide your email. At the end of the survey, you will be prompted to click on a link where you can opt to receive a study summary.

In current best practices in research, electronic data is to be preserved for future use in open access initiatives. Open access initiatives allow researchers from different universities to share their data upon completion of studies, in an effort to stimulate further use and exploration of existing data sets. Data from this study will be uploaded to an online repository and these files will be stripped of any information that could identify participants (e.g., names, email addresses), to ensure confidentiality.

Remuneration/compensation

Survey participants can enter a draw to win one of three \$100 gift cards. At the end of the survey, there will be a link that will take you to another page where you will be asked to provide your email to enter the draw. This is to preserve survey response anonymity.

Contact for information about the study

If you have any questions or would like more information about this survey, you may contact Kate Wills at Kate.Wills@ubc.ca.

Contact for information about the rights of research participants

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this survey contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598. The Ethics ID for this study is # H23-01773.

Consent

Participating in this survey is optional. By completing the survey, you agree that consent has been given.

Click on the right arrow to continue.

Default Question Block

Which community do you live in?

Do you feel that your community's healthcare needs are adequately represented in the planning process?

- Yes
- No

Please elaborate on why you feel your needs are not adequately represented.

Do you agree that your community's needs are met through the health planning process?

- Strongly Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Have you been engaged in healthcare planning in BC (i.e., through community meetings with your Health Authority, participation on special interest groups, participating in surveys)?

- Yes
- No

Please specify how you were engaged: surveys, public meetings or workshops, forums, etc.

Please, indicate the level at which you were engaged:

- Inform: Provided with balanced and objective information to understand the problem, alternatives, opportunities, and solutions.
- Inadequately informed: Provided with information but not adequately to understand the problem, alternatives, opportunities, and solutions.
- Consult: Asked to provide feedback on analysis, alternatives, and decisions.
- Involve: Asked to actively participate in the process, with concerns and aspirations being understood and considered.
- Collaborate: Asked to be a partner in each aspect of the decision-making process, including the development of alternatives and identification of the preferred solution.
- Empower: Asked to be part of the decision-making itself.

Which healthcare-related topics were you engaged in?

What aspects of this engagement process worked well?

In your opinion, what could have been done differently to improve the engagement process?

How well-equipped are you to engage in health care decision-making about issues that concern your community?

- Not well at all
- Slightly well
- Moderately well
- Very well
- Extremely well

How much confidence do you have in health care decision-makers making decisions that will be best for your community?

- None at all
- A little
- A moderate amount
- A lot
- A great deal

Do you feel that your needs and concerns are genuinely considered and acted upon?

- No
- Yes

Please explain.

How aware are you of provincial or regional policies that directly affect health care in your community?

- Very aware
- Somewhat aware
- Neither aware nor unaware
- Somewhat unaware
- Very unaware

How effectively are policies communicated to you in a way you understand?

- Not effective at all
- Slightly effective
- Moderately effective
- Very effective
- Extremely effective

Are there any language or cultural barriers that might hinder this communication?

- Yes
- No

Please explain.

Do you think communication to the community about these policies is effective?

- Yes
- No

Please explain.

Do you know of any effective structures or organizations that engage your community in healthcare planning (e.g., govTogetherBC)? If so, what are they?

Is there anything else you would like to add?

Block 2

Thank you for taking the time to respond to this survey.

To enter the draw to win one of three \$100 gift cards, complete this [form](#)

The link will bring you to another page where you can enter your email for the draw and/ or opt-in to receive information about the study results. This is to maintain survey response anonymity.

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