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Advancing Equity-Oriented, Person- and People-Centred Care in Alberta

Healthcare systems are social systems in which values constitute a key determinant of system transformation. Currently, the values that prevail in our healthcare systems do not align with the values of people who are served by these systems. Increasingly, the development of a person- and people-centred (PPCC) healthcare system is seen as a strategy for addressing this problem.

PPCC is about respecting the values of people ‘who are sometimes patients’ and putting people in the context of their families and communities at the centre of care. If people are truly at the centre, then their knowledge and expertise about their own health and well-being – what matters most to them in the context of their lives – is more likely to be valued in health policy decisions and improvements in the delivery of health services. An approach centered on persons and people requires that the healthcare system adopt a health equity and social justice lens, and work in true partnership with people and communities to design and deliver care in ways that are responsive to a diversity of needs, preferences, and goals.



Description of the problem

The importance of involving patients and the public in transforming the Canadian healthcare system has grown significantly in recent decades [1,2]. These developments have been linked to a growing recognition of the benefits of involving patients and the public in contributing to health policy decision-making and health services re-design [3].

In Alberta, existing structures, mechanisms, and infrastructure support for patient and public engagement in health policy decision-making and system improvement exist within Alberta Health Services (AHS) and across other health organizations. However, these opportunities for engagement are designed based upon a narrow definition of “patients” that often ignores the reality that individuals’ economic, political, cultural, subjective, and experiential lives intersect in intricate and multifaceted ways that shape their experience and interaction with the healthcare system, as well as their willingness to participate in health policy decision-making and system improvement opportunities [4]. It also excludes the involvement of individuals who may not identify as patients for a myriad of reasons — people who are unable to access the healthcare system because of geography and/or systemic barriers (including racism, colonialism, sexism, classism, ableism and heterosexism); individuals living with mental health or substance use issues who may be hesitant in taking up the identity of patient because of the associated stigma attached to such a label; and people who refuse to engage because of experience with healthcare trauma including unresponsive or disrespectful care [4].

To have a more inclusive and meaningful approach to engagement that does not reiterate existing health inequities, it is important to re-conceptualize patient engagement through a health equity and social justice lens. This re-conceptualization will facilitate the disruption of the identity of “patient”.

An important, but commonly challenging, aspect of patient and public engagement is to include a spectrum of voices to prevent tokenism and/or the exclusion of individuals from diverse communities whose voices have been typically left out of decision-making processes. Moreover, there are no strategic directions or policy statements by the Alberta Ministry of Health on how patients and their carers can be involved in health policy decision-making, and there is minimal guidance for provincial health organizations on equity-oriented approaches with which to engage people in health policy decision-making or health system improvement. The Alberta-based IMAGINE Citizens Network (ICN) has begun to do some of this work, but there are no clear mechanisms for involving patient-citizen organizations/networks, such as the ICN, in the health policy decision-making process in Alberta.

Background

Evolution of person- and people-centred care in the western world

Globally, the concept of person- and people-centred care (PPCC) has been advocated for as a strategy for acknowledging each person's diversity, and for putting people – in the context of their families and communities – at the centre of care [5]. Person-centred care is the evolution of patient-centred care, a shift that signals the importance of being treated as a person first, and as a patient second. Whereas patient-centred care is commonly understood as focusing on the individual seeking care, person-centred care encompasses these clinical encounters, paying particular attention to the health of people in their social and cultural context. The discourse on person-centredness has influenced national guidelines and policy in various countries and organizations, including the U.S., Canada, the U.K., Australia, New Zealand, Norway, and Sweden, as well as the EU and World Health Organization (WHO) [6-9].

Living and managing illness is part of life but is usually not seen as being the focus of our lives. Health is viewed as a more holistic concept, and much more than the absence of disease and/or even living with illness and, when seen through a health promotion lens, as a resource for everyday living.

Patients identify the social determinants of health (SDOH), such as housing, food security, income and social relationships, as important aspects of their lives and well-being (things they value). The SDOH also play a critical role in determining outcomes such as healthcare utilization and health outcomes (e.g., morbidity and mortality) [10-12]. Thus, removing the “patient” label serves to remind us that health and well-being in the context of peoples' lives transcend what happens in the context of the healthcare system.

If people are truly at the centre, then their knowledge and expertise about their own lives, what matters most to them in the context of their lives, and what will work best, with respect to integrating the management of any illness, is likely to be highly valued in health policy decisions and in improvements in the delivery of health services. Moreover, a person-centred approach requires the healthcare system to work in partnership with people and communities to design and deliver care that is responsive to needs, abilities, preferences, lifestyles, and goals [7].

The WHO recently took this evolution a step further, by conceptualizing what person-centred care is at a systems level using an equity lens, through the development of a global strategy on *people-centred and integrated health services* ([5], see fig. 1). This strategy proposes five interdependent strategic directions to move health service to become more people-centred and integrated. The first of these is “the empowering and engaging of people (communities and individuals) through providing opportunities, skills and resources” [13]. People and communities are seen as assets.

Accreditation Canada assesses health and social services organizations against standards developed by the Health Standards Organization (HSO). HSO has recently developed a foundational standard on integrated people-centred health systems, which is a national Canadian standard [14]. This means that across Canada, healthcare organizations are becoming increasingly aware of this approach to care and the work that's required to design, implement, and evaluate people-centred health and social service systems. Moreover,

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different healthcare system stakeholders – patient organizations, professional groups, and policymakers – have different perspectives on which values play a prominent role in shaping person-and people-centred healthcare.

Fig 1. Conceptual framework for people-centred and integrated health services

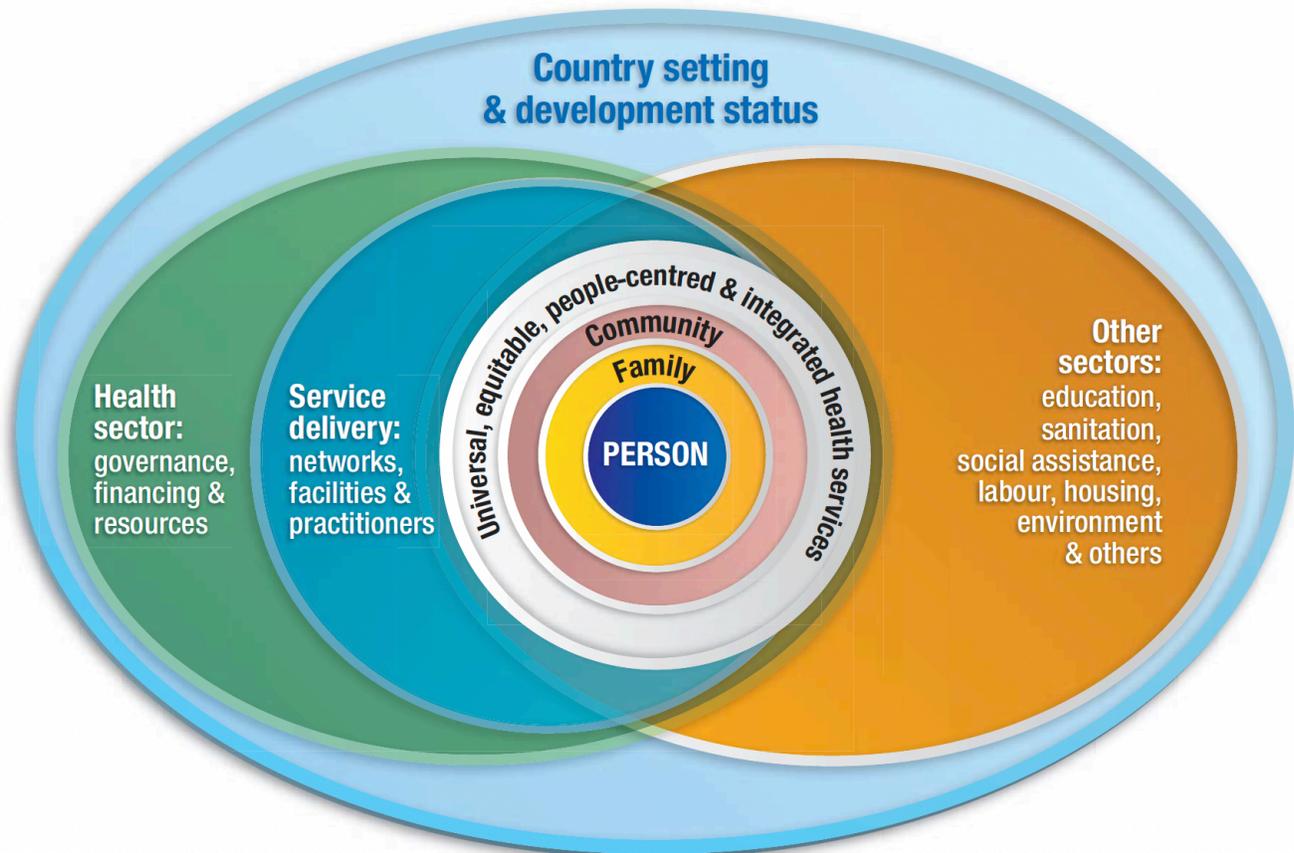


Fig. 1. World Health Organization. (2015). WHO global strategy on people-centred and integrated health services: interim report. World Health Organization. <https://apps.who.int/iris/handle/10665/155002>. p.13.

Support for person- and people-centred engagement in health policy and systems change



A public engagement event in Edmonton, sponsored by the Institute for Public Health in 2016, as a function of informing and shaping health care.

A component of this ongoing commitment to person- and people-centred engagement is infrastructure support and accountability structures to support the involvement of a diversity of people (including their family and caregivers) in health policy decisions for healthcare improvement. Arms' length and independent bodies for patient and public involvement in health – with their responsibilities for representing patients, their families, and communities, supporting healthcare organizations to involve people, and in some cases assuring that the involvement takes place – are key actors in supporting person- and people-centred engagement in policy and systems change across western countries.

Arms-length entities “can be a force for *more* democratic approaches to policy-making, defending the interest of publics” [15]. The boundary status of arms' length patient and public involvement bodies is central to their effectiveness. As boundary workers, they coordinate the action of government and non-government actors (e.g., professional associations, non-profit organizations, and patient groups), while preserving the authority and autonomy of relevant expert spheres [15].

An example of an arms-length and independent body on patient involvement is the European Patients' Forum [16] — a network of 74 patient organizations (referred to as the 'patient community') in Europe that acts as an intermediary between the patient community and EU policymakers, by advocating on issues that have a direct impact on people's lives in a national and regional context. It has been the leading voice of patient organizations in Europe and fosters trust and alliances among patient organizations across the

continent. It also acts as a single accountability structure for promoting patient and public engagement in health policy decisions for healthcare improvement.

The Alberta context

The ICN – (<https://imaginecitizens.ca/>) is an Alberta-based, independent citizen-led organization that brings together a network of people- and community-oriented partners who amplify the voice of Albertans in healthcare system reform and envision a healthcare culture where people and their families come first. ICN was established in 2015 with an interest in addressing the apparent gaps in existing strategies for engaging people across Alberta in health policy decision-making and system improvement. A discussion paper written by ICN – entitled: *“Are patient-centred care and integration achievable goals?”* [17] – argued for investment and infrastructure support for patient and citizen involvement in health policy decision-making:

“Canadian healthcare systems need to move past the notion that citizen-patients are advisors, and nice to engage, and begin to realize that the thinking they bring is critical to the health care services and system redesign efforts; that they are true partners in these efforts. The phrase “nothing about me without me”, which has become a tag line for patient-centred care, needs to transcend involving patients in their own care, and underpin all the work on healthcare innovation. The challenge is how properly constituted citizen-patient groups are organized and funded so they can be true partners at the table.” (p. 10)

ICN contributes to health policy and decision-making as members of stakeholder advisory groups in Alberta, and provincial and national government public consultations. They also translate complex information – whether scientific or policy-related – into readily understandable, relevant, and accessible resources for Albertans to support patient-citizen advocacy and build health literacy. As a leading patient-citizen organization in Alberta, ICN is a trusted and involved partner with government, AHS, healthcare organizations and community-based groups in the province on projects of shared interest. The process of policy formulation is a complex and lengthy process that requires coordinated input and guidance from all relevant stakeholder groups.

In February 2020, ICN, in partnership with the Health Quality Council of Alberta (HQCA) and the Alberta SPOR Patient Engagement Platform (AbSPOR), held a workshop to explore health outcomes that matter most to Albertans. Underlying preferences for specific health outcomes were values such as equity, wholistic approaches to health and wellness, people co-designing or shaping the healthcare system, and care that is delivered compassionately [18]. It was noted by workshop participants that the adoption of person- and people-centred care comes with challenges, and entails a critical culture change, particularly with respect to how care is delivered and how patients and their healthcare providers interact.

Key direction for advancing equity-oriented and PPCC in Alberta

Establishing an equity, diversity and inclusion council for the advancement of PPCC

The role and focus of this Council



An IMAGINE Citizens Network event in February 2020, co-hosted with the Health Quality Council of Alberta (HQCA), to explore what health outcomes matter most to Albertans. Those in attendance include people with lived experience with illness.

The primary purpose of this Council would be to support people who are sometimes patients, their families, and communities to develop the confidence and skills to be involved in health policy decision-making and health system improvement. This is a central strategy for advancing PPCC, in that individuals and communities must shape what PPCC looks and feels like. The Council would act as an intermediary between people (individuals, families, communities), and policy- and decision-makers. Individuals, communities, and other groups with aligned interests, would be welcomed to become members of this Council.

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A major focus of this Council would be on equity-oriented approaches to people-centred engagement. To date, patient and public organizations and groups in Alberta have struggled to engage individuals and communities who are most likely to face racism and discrimination in our healthcare system and less likely to experience good quality care. An equity-oriented approach considers the systems of oppression that are at play and aims to understand which specific patient population groups are most likely to experience that oppression. This approach also considers the impact of systems and processes of oppression and domination (e.g., racism, colonialism, classism, sexism, ableism, homophobia) that exclude the involvement of individuals who often carry the greatest burden of illness — the very voices traditionally less heard in health policy and system decision-making.

The Council would work with diverse people and communities to co-build safe spaces for engagement by listening and learning from them on how they wish to be engaged and for which goals. This approach would enable the creation of a safe space where people and communities can feel comfortable speaking up and expressing views that challenge the status quo, and persons in position of power and authority.

A secondary purpose of this Council would be to support professional associations and healthcare organizations to develop their institutional capacity for equitable and inclusive engagement strategies. It would support training for person- and people-centred engagement (including patients, family/caregivers and the public) in healthcare policy development and system design, in partnership with academic institutions.

The creation of this Council and initial steps

The ICN is well positioned to lead the development of this Council, given: its constitution as a community-based, citizen-patient led entity; its experience to date (i.e. track record of working on this topic for seven years); its priorities; and, its relationships with people, communities, health organizations, and government. The ICN is currently a registered society with a community board. An important initial piece of work for this Council would be to lead the development of a framework that supports a shift to a person- and people-centred healthcare system in Alberta, drawing on the WHO framework on people-centred health systems as a foundational document along with the HSO Canadian national standard on integrated people-centred health systems.

It is essential that the people (who are sometimes patients) and communities lead the development of such a framework, inviting health organizations to join them in this process. Working on the development of this framework would enable the Council to learn together and model equitable, inclusive engagement strategies. This framework would address issues such as:

- a) Removing barriers for people to participate in policy development and health services improvement
- b) Recognizing different ways of knowing and guiding the inclusion of multiple sources of knowledge and expertise, including people's stories
- c) Building institutional capacity to embed equity and PPCC into the policy space; and,

d) Developing transparency in reporting on health outcomes that matter to Albertans (health equity, improved quality of life – as defined by individuals and communities, improved interactions with healthcare system).

The Alberta government would provide grant funding to ICN to lead the development of a framework for PPCC in Alberta, that would be co-designed with people and communities. An ongoing operational funding model would also be establishment in collaboration with community partners, and could include funding from the private sector, donations, and other grants.

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