

Building Equitable Patient Partnerships during the COVID-19 Pandemic: Challenges and Key Considerations for Research and Policy

Mise en place de partenariats équitables avec les patients pendant la pandémie de COVID-19 : défis et considérations pour la recherche et l'élaboration de politiques



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Abstract

The unequal social and economic burden of the COVID-19 pandemic is evident in racialized and low-income communities across Canada. Importantly, social inequities have not been adequately addressed and current public policies are not reflective of the needs of diverse populations. Public participation in decision-making is crucial and there is, therefore, a pressing need to increase diversity of representation in patient partnerships in order to prevent the further exclusion of socially marginalized groups from research and policy making. Deliberate effort and affirmative action are needed to meaningfully engage and nurture diverse patient partnerships by broadening the scope of the patient community to include excluded or underrepresented individuals or groups. This will help us co-develop ways to enhance access and equity in healthcare and prevent the systematic reproduction of structural inequalities that have already been heightened by the COVID-19 pandemic.

Résumé

Le fardeau socioéconomique inégal de la pandémie de COVID-19 est manifeste dans les communautés racialisées et à faible revenu du Canada. Il y a donc un besoin urgent d'accroître la diversité de la représentation dans les partenariats avec les patients afin d'éviter que les groupes socialement marginalisés se trouvent exclus de la recherche et de l'élaboration des politiques. Des efforts délibérés et une action positive sont nécessaires pour entretenir de manière significative les partenariats avec la diversité, et ce, en élargissant la communauté des patients pour y inclure des individus ou des groupes exclus ou sous-représentés. Cela aidera à développer conjointement des moyens pour améliorer l'équité et l'accès aux soins de santé. Cet engagement garantira que la réponse du système de santé canadien à la pandémie reflète une représentation inclusive et équitable des voix des patients, tout en empêchant la reproduction systématique des inégalités structurelles déjà exacerbées par la pandémie de COVID-19.

Background

The Canadian healthcare system has demonstrated agility and innovativeness in its response to the COVID-19 crisis (Bernardo et al. 2021; Brunet et al. 2020; Hall 2021). As we move into the next stage of preparedness planning and strategize on ways to deal with the massive backlog of chronic care cases created by the pandemic response, policy makers and researchers must ensure that the needs of patients, as identified by patients, are met. Prioritizing the needs of patients will be necessary in mitigating the long-term adverse effects of the COVID-19 pandemic and promoting equitable health outcomes across the population. To succeed at this, it will be important to deliberately include diverse patient communities in shaping research and influencing public policy in order to prevent a widening of health inequities that are rooted in social inequalities.

In this paper, we discuss how the first wave of COVID-19 brought efforts to actively engage patients in research and policy making to a near halt. We emphasize the need to integrate diverse patient voices into the health system's pandemic response and describe ways in

which policy makers and researchers can build inclusive patient partnerships by applying an equity lens (Nasser et al. 2013).

COVID-19's Impact on Patient Engagement and Its Implications for Health Services Research and Policy

The Canadian Strategy for Patient-Oriented Research (CIHR 2011) defines patient engagement (PE) as an active collaboration with patients to establish governance structures, identify research priorities and co-create knowledge in order to influence organizational structures and policy making. PE can improve health outcomes by promoting the use of quality-of-life metrics that match patient-identified needs, increasing access to the healthcare system and improving overall cost-effectiveness (Manafa et al. 2018). The spectrum of PE ranges from tokenistic consultation to active participation in the design and conduct of research (Manafa et al. 2018). Few initiatives have high levels of PE in which patients partner as co-leads and decision makers in organizational processes and policy making (Carman et al. 2013).

PE is an area of increasing interest and research investments in Canada (Manafa et al. 2018). Prior to the COVID-19 pandemic, patient partnerships were rapidly growing across all areas of research, although almost exclusively by invitation from academic institutions. The result was a unidirectional approach to PE in which patient partners (PPs) at the table were those most accessible to research teams and often reflective of their own social identity: white, well-educated and well-resourced. As the pandemic pushed the health system into an emergency-response mode, PE came to a near halt similar to other health services considered “non-essential.” The health system, thereafter, was operating in a crisis mode with no regard for patient-identified priorities; this was despite the fact that patients suffering from chronic illnesses were the most impacted by a disruption to their routine of care (Immonen 2020), and socially marginalized patients were the most negatively impacted by the pandemic and the resulting health and social system responses. Since then, efforts have been made to reintegrate PE into research, policy and practice. However, representation at research and policy tables continues to be by invitation only, with participation almost exclusive to PPs who are most easily accessible.

Seldom-Heard Patient Voices and the Need for Inclusive Representation

An important, but commonly challenging, aspect of PE is to include a spectrum of patient voices to prevent tokenism and/or the exclusion of individuals from diverse communities whose voices have been typically left out of decision-making processes. Increasing the diversity of representation in patient partnerships is an essential step in preventing future exclusion of groups who experience marginalizing societal conditions that have been created through historical and systematic discrimination (i.e., low income, gender, sexual orientation, racialization, Indigenous identity and ancestry, disability and housing insecurity or homelessness). PE with seldom-heard and hard-to-reach patient communities is rarely carried out in a meaningful way due to a lack of material resources, exclusionary institutional practices

(Ní Shé et al. 2019) and engagement processes that are not inclusive in design and implementation (Brackertz 2007).

During a global pandemic in which the disproportionate social, economic and health burden experienced by racialized and low-income communities is heightened, it is important to acknowledge how our traditional methods of PE are likely to further exclude communities unless deliberate action is taken. For example, the life cycles of research funding and expected deliverables frequently do not allow for meaningful partnerships to be nurtured with seldom-heard populations for whom stigma, disenfranchisement, differences in lived experience or mistrust of the health system amplify the need for prolonged engagement. In such instances, it is important to initiate PE and build patient partnerships on solid foundations of pre-existing long-term relationships with individuals, advocacy groups and community-led organizations. This outreach outside of research can facilitate the identification of common stakeholder goals prior to the commencement of research and considerations for policy design.

Effective Engagement of Diverse and Inclusive Patient Communities for Equitable Patient Partnerships

Critical self-reflection and conscientious decision making are central to the work of a patient-oriented practitioner who is defined as someone who carries out patient-oriented research (POR) or patient-oriented policy development and who is engaged with groups experiencing social marginalization. Denzin and Lincoln (2011) described this as “telos,” or the “willingness to disassemble self, to deconstruct one’s world ... [in order] to avoid construction of power over individuals or groups” (p. 87). This process is needed in order to challenge personal assumptions, consider issues of representation and envision broader ways to engage diverse groups. For POR, this implies a reflexive examination of one’s own beliefs, judgments and actions (Macbeth 2001). Ultimately, researchers must explore the inclusiveness of their own work and be willing to critically reflect upon it as part of the reported study process and/or scope.

The same principles for POR could be meaningfully used to include patient voices in public policy development – where long-term partnerships should be formed with communities with clear goals explicitly stated and where policy makers are willing to critically reflect on who is left at the margins of existing and planned public policies. The exclusion of patient voices, particularly of those who experience marginalization, likely plays a role in some of the policy failures we have seen in the COVID-19 pandemic response, such as the neglect of long-term care homes, the lack of protections for essential low-wage workers and the delay in or resistance to collecting race-based data.

To prevent tokenism, to centre the voices of socially marginalised groups whose perspectives are often excluded and to recognize the reality of the current COVID-19 challenges in Canada, we offer five key considerations for putting “telos” into action and building inclusive and diverse patient partnerships:

1. USE AN EQUITY-ORIENTED APPROACH TO PATIENT ENGAGEMENT.

An equity-oriented approach (EOA) recognizes that health inequities have been created by the historical and systematic disempowerment of communities through interlocking structures of sexism, colonialism and racism. This has resulted in the unjust and unfair distribution of power, privilege and prestige, which determine health outcomes and access to healthcare (Sayani 2019). An EOA, therefore, 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 if the policy or intervention is enacted. These groups must then be the priority when it comes to partnering for knowledge co-creation, which will likely mean outreach and engagement with those communities.

2. CO-BUILD SUSTAINABLE SAFE SPACES.

A respectful partnership with communities that have experienced structural oppression requires a sustainable engagement plan beyond the life cycle of any single healthcare project or research study. A trauma-informed (Government of Canada 2018) way to PE recognizes that cumulative disadvantages over the life course have shaped opportunities to seek and benefit from healthcare and that these cannot be solved by shifting the responsibility for change onto individuals. Rather, an authentic commitment to listen and learn from diverse patient communities on what works for them for the PE process, and how they wish to be engaged and for which goals, is needed. This will enable the creation of a culturally safe (Williams 1999) space where PPs can feel comfortable speaking up and expressing views that challenge the status quo and persons in position of power and authority.

3. CONSIDER ISSUES OF ACCESSIBILITY.

PPs experiencing social marginalization may need to overcome multiple barriers to participation. For individuals living on low incomes, financial honoraria upfront can promote participation and reduce attrition over the course of a project (Gross and Bettencourt 2019). A patient-oriented project is emergent by design; however, patient partnerships in the middle of a pandemic require an even greater degree of flexibility and agility in order to engage with marginalized populations. This may require researchers and policy makers to arrange additional resources such as tablets (as well as arranging internet access) or digital recorders to promote virtual and physically distanced group participation from individuals who may not have regular access to the internet and other online tools. Ethical considerations must be given to privacy issues during online interactions, and care must be taken to protect the confidentiality of PPs who may already be facing issues of stigma and social isolation. Consideration of additional barriers to participation, such as working conditions and home and child care responsibilities, will enable researchers to remain dynamic and responsive to the needs of patients in a way that will facilitate diverse participation.

4. BUILD CAPACITY ONE RELATIONSHIP AT A TIME.

In order to meaningfully conduct PE and develop capacity for a robust patient partnership (CIHR 2015), patient-oriented practitioners must prioritize community engagement and relationship building. At a policy level, this means that all projects that seek to engage patients must receive adequate resources (sufficient funds, appropriate time allocation and human capital). Sustainable funding in particular may require innovative methods to support PE, such as a designated institutional fund or bridge funding between projects. It is important that sufficient opportunities exist for practitioners and PPs to learn from each other and to conduct collaborative exercises that help identify real-world problems and seek plausible solutions. Furthermore, inclusive capacity building will require a communication plan that includes details of the proposed work, time commitments required by PPs, expected deliverables, reimbursement for expenses and financial compensation for time. This plan must be clearly laid out and revisited regularly throughout the project. Ethically, it is the responsibility of the researcher or policy maker to set clear expectations about the anticipated timelines and possible outcomes in order to avoid disappointment, loss of interest and a general mistrust of the process.

5. DO NO HARM.

Of all of the strategies listed above, “do no harm” is the most important consideration when engaging with diverse patient communities. This includes the use of language that can convey judgment and elicit power. A variety of vague terminologies are used in the literature to describe individuals experiencing social marginalization. Examples of these terms include the following: vulnerable, disadvantaged, oppressed, excluded and underserved (Katz et al. 2020). Researchers and policy makers must not simply seek “vulnerable” PPs but must go beyond the vagueness of these terms when defining with precision who the PPs are that should be at the table. Also, the terminology used for any identified group must ultimately be decided by PPs who should be able to define for themselves the attributes and labels used in the dissemination of findings. This will prevent token involvement of patients, avoid mistrust of PE and prevent the production of knowledge and policies that are acritical of the systemic and structural inequities that underpin differences in risk and disease profile.

Conclusion

The COVID-19 pandemic has laid bare gross health and social inequities that current public policies have not yet adequately addressed. PE in both research and policy creation has proven itself to be crucial, and innovative ways are needed to meaningfully engage and nurture relationships for successful long-term patient partnerships with populations experiencing social marginalization and for whom these issues are intensified. As health systems continue to shape their response to the COVID-19 pandemic, it will be important to include patient-identified priorities in the research and policies that guide the redesign and restructuring of healthcare services. In addition, greater effort must be taken by everyone involved in health

services research and public health policy to take steps to include a diverse representation of patient voices through equity-focused PE.

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