Patient Partners Respond to High-Level Findings on the Connectedness of Health and Social Services across Canada

Les patients partenaires réagissent aux constatations de haut niveau sur la connectivité des services de santé et des services sociaux au Canada

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Abstract

This short article captures input from patient partners on the dimensions of the research program that most resonated with them. They are passionate about wanting to see a better connection between health and social services, and they are also willing to be involved as advisors for policy directions in the same way as their involvement has become the norm in any patient-oriented research.

Résumé

Ce court article présente les commentaires de patients partenaires sur les aspects du programme de recherche qui les ont le plus interpellés. Ils sont avides de voir un meilleur lien entre la santé et les services sociaux, et ils sont également prêts à participer en tant que conseillers pour les orientations stratégiques comme ils le font déjà pour toute recherche axée sur le patient, où leur participation est désormais la norme.

Introduction

The College of Family Physicians of Canada outlined the Patient's Medical Home as its vision for ideal family practice in Canada (CFPC 2011). This is the health system hub where a patient receives person-centred, relational and longitudinal care that addresses most health problems and connects patients to services elsewhere in the system and the community. The 2019 update of the Patient's Medical Home recognizes connected care as a foundation of family practice and adds community adaptiveness and social accountability as a new pillar (CFPC 2019). In keeping with this perspective, it was appropriate to get the patient perspective on the research program to describe and compare initiatives across Canada that integrate services across health and social sectors for primary care patients with complex care needs (Haggerty et al. 2023). This article synthesizes the responses of a group of patient partners to the results of our program.

The involvement of patient partners in research brings the voice and lived experience of patients to every stage of the research process, but their role is particularly important and appreciated in the initial design and implementation of the study and in the interpretation of results. Training and inclusion of patient partners was one of the core principles of the Strategy for Patient-Oriented Research (SPOR), and it has now become the norm for all patient-oriented research in every SPOR project and network (Holmes et al. 2018). As part of our commitment to getting patient input, we presented the high-level findings to patient partners of the pan-Canadian Canadian Primary Care Research Network (CPCRN) (https://cpcrn-rcrsp.ca/about/patient-partners/). The responses of the patient partners were synthesized into key messages that they wanted to pass on to policy makers.

Methods

Between 2017 and 2020, our pan-Canadian team conducted a comparative policy and program analysis to take stock of progress toward the integration of primary care with health and social services needed by children and youth with high functional health needs and community-dwelling older adults experiencing functional decline (Haggerty et al. 2023). While two patient partners were members of our team, we mobilized additional patient partners as needed, especially, to help us identify the highest priority services to be linked to primary care for our two population groups. This set of services formed the foundation for the five projects within the research program.

In January 2021, the principal invesigator (JH) presented the high-level findings of our cross-provincial research program to eight CPCRN patient partners, including one member of our research team. The session was video recorded, and the patient partners' responses were summarized, with special weight attached to ideas that were endorsed verbally or nonverbally by several participants. Mentioned below are their key messages as close to their voice and words as possible.

Results

"We need this!"

The patient partners confirmed the need for greater integration between health and social services. Several of them mentioned specific grassroots projects that they were involved in that address this issue. The notion of dignity was underlined in the words of one who self-identified as having complex care needs:

> This is something [that] we have been wishing for a long time – the merge between social and health services (especially for our folk with mental health issues) – instead of telling our stories five times, which is what you have to do to get through doors that are closed unless you do this. One-stop shop is the way to go. You have to treat folks properly. (Patient partner, Nova Scotia)

"One size does not fit all. When rolling out provincial programs, keep them flexible at the local level."

The patient partners welcomed any policy initiatives to integrate health and social services, but they also drew our attention to their lived experience of our findings. For example, when some innovative programs spread or scale up – especially those targeted at older adults – they lose local front-line engagement in program design and implementation and patient-facing flexibility that was present in the initial version. Patient partners recognized the importance of high-level policy support and structure but wished for front-line and local flexibility. We found that programs to connect health and social services for children and youth with complex problems had very patient-centred, community and front-line supported beginnings but were often not sustained when the community momentum dissipated, or these local innovations were not spread to other contexts because there was insufficient policy and organizational support for disrupting existing practice patterns to formally adopt new ways of working. Patient partners made a plea to policy makers to plan in ways that combine provincial or regional support with community-based and patient-facing flexibility at the front line.

"Look to rural contexts and community organizations for innovations in integrated care."

Patient partners wanted to sensitize policy makers to two settings that have high levels of innovation and resourcefulness but often experience fragile resourcing: (1) rural areas and (2) community organizations and associations. Rural areas often do not have the resources at their disposal to implement a one-size-fits-all provincial-level program, such as for chronic pain management or youth mental health. However, people who work and live in rural areas are very adept at using existing resources to address a broad scope of needs. They would like policy makers to demonstrate regulatory and operational flexibility to recognize the resources that rural communities do have.

In rural areas, primary care is the main health service and innovating to achieve comprehensive integrated care has been a long-term reality. Enhancing and supporting formal involvement and recognition of community associations and patient associations will strengthen programs that integrate health, social and community services. The COVID-19 pandemic demonstrated the capacity for community associations to mobilize themselves rapidly to address the needs of shut-in older adults or to get mental health resources on websites to address this need. Unfortunately, our scan of programs highlighted that community organizations were rarely explicitly acknowledged as part of the program descriptions. A lack of recognition of the experience and capacity of community associations to provide timely resources and response is a loss to policy makers and to formal health and social services, but mostly to patients and families.

"We can help. It's time to engage patient and citizen partners in policy making."

The robust role of patient partners in the CPCRN is not an anomaly. In less than a decade, it has become the norm that any patient-oriented research actively engage patients as partners at all stages of the research, preferably as full-fledged members of the research team. Patient partners have experiential expertise that formal care providers, researchers and decision makers do not have. To make valued contributions, they acknowledge the importance of receiving training in order to effectively communicate their own and others' viewpoints in the service of the research project.

Patient partners also advocated for more policy stability. As they saw it, politicians are highly reactive to "noise" or news bites and think in terms of four-year political terms. Patient partners suggested it would be better to have a 10-year health policy plan that is less reactive.

> In a few years, the government will not be able to impose any decisions without having patient and citizen partners involved in the decision making and policies. It is critical to engage [at] the grassroots. (Patient partner, Quebec)

There was strong agreement among the patient partners that the time had come to make it the norm to include patients and citizens as partners in policy processes as exemplified in processes that have been used in the Quebec Commissaire à la santé et bien-être and the Romanow Commission's approach to consulting citizens.

> We need trusting relationships not only between the patient and the doctor but also between patients and policy makers. (Patient partner, Saskatchewan)

Conclusion

As a federated state, policy decision making about the structure and administration of healthcare in Canada rests jointly with the federal and provincial/territorial governments. Recent calls from provincial and territorial governments for the federal government to add more money to healthcare have the potential to perpetuate the status quo. The policy recommendations put forward from the different projects are based on the research team's understanding that fundamental governance structures will not change and that the changes that are required will take years to achieve, but we have to start somewhere. Patient partners believe that change begins with engaging them in policy making.

Engaging citizens as partners in policy making is not a new idea. Canada has two notable examples that bear recall: the National Forum on Health (1998) and the Romanow Commission (Romanow 2002). The National Forum on Health was launched by the prime minister in 1994, and it engaged Canadian citizens to advise the federal government on innovative ways to improve the health system and face the (predominantly economic) crisis that the health system faced. In 2000, the first ministers authorized Commissioner Romanow to undertake broad data-gathering and dialogue with Canadians to recommend policies to ensure the long-term sustainability of Canada's public health system. Both reports demonstrated that intentional consultation and deliberations uncovered very strong support for the publicly funded system, and they yielded recommendations that were very different from public opinion polls (Abelson et al. 2003; Ham 2001; National Forum on Health 1998). Canadian citizens can truly be partners in policy making.

Perhaps we could start with a dialogue with Canadian citizens and patient partners to understand the expectations for comprehensive care, starting with the current narrow definition in the *Canada Health Act* (1985), which covers only medically necessary services. As more and more Canadians are living with complex chronic health conditions, action is needed if we are going to address the gaps that these patient partners have identified. The time has come for first ministers across Canada to listen to patient partners and design federal or national policies that can help Canadians feel secure that they will receive the comprehensive care that they require regardless of where they live in Canada.

We have learned through the COVID-19 pandemic that policy making can be nimble when the incentives exist. We suggest that there is a clear recognition of the need for change and substantial evidence indicating some of the fundamental changes that are needed. The current crisis of healthcare across Canada demonstrates the urgency for change.

As Katharine Smart, president of the Canadian Medical Association, said recently, "Let's stop with the finger pointing and winning the political points. Even just a willingness to move away from the politics and more to the action-oriented, and solution-oriented, would go a long way" (Woo and Cook 2022).

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