

The Capacity for Patient Engagement: What Patient Experiences Tell Us About What's Ahead

Capacité en matière d'engagement du patient : ce que l'expérience du patient nous laisse entrevoir de l'avenir

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Abstract

Although great achievements in patient engagement merit celebration, many patient collaborators recognize growing gaps are straining the promise of seamless partnership. Recruitment is failing to keep pace with demands for diversity and expertise. Attempts to sustain enthusiasm face volunteer burnout and dropout. The investment in professional capacity to partner with patients contrasts sharply with the missing equivalent for patients asked to meet ever more demanding roles. While peer-led initiatives attempt self-help, more is needed to support patients to fulfill the potential for fully diverse, competent and fulfilling collaboration across all facets of healthcare.

Résumé

Bien que de grandes réalisations en matière d'engagement du patient méritent d'être soulignées, de nombreux patients collaborateurs reconnaissent que des écarts croissants pèsent sur la promesse d'un partenariat homogène. Le recrutement n'arrive pas à suivre le rythme des revendications en matière de diversité et d'expertise. Toute tentative de préserver l'enthousiasme est confrontée à l'épuisement et au décrochage des bénévoles. L'investissement dans la capacité professionnelle de partenariat avec les patients contraste vivement avec l'équivalent absent pour le patient appelé à remplir ce rôle de plus en plus exigeant. Tandis que les initiatives dirigées par des pairs misent sur l'entraide, il faut faire davantage pour aider les patients à réaliser le potentiel d'une pleine collaboration diversifiée, avérée et épanouissante dans tous les aspects des soins de santé.

KEY MESSAGES

1. Canada has a wealth of motivated and seasoned patient and family partners drawn largely from a limited fraction of the Canadian population because recruitment filters and engagement requirements have been constructed so narrowly.
2. The expanding appetite of healthcare for greater breadth and depth of lived experience and partnership skills already exceeds current recruitment, which is not surprising given the lack of structural support for capacity development on the patient side of collaboration.
3. The Patient Advisors Network is a national peer community of practice that responds to this capacity gap by addressing two urgent needs: (1) a personal supportive introduction to collaboration for individuals and communities through trust-based peer relationships and (2) experienced assistance with needed skills, information exchange and continual support for the increasingly specialized partnerships expected by healthcare partners.

Over the past decade, I've been privileged to join a revolution in patient participation in multiple facets of healthcare. Following my husband's 2008 avoidable death just days after successful surgery, I sought answers for common-sense questions and was dumbfounded by inadequate answers. Soon I observed patients constructively seeking sensible improvement. While following their lead, I probed for opportunities to influence thinking about patient harm, practitioner safety, systems resilience, research priorities and distributive leadership. As an independent "citizen-patient," I've now contributed across Canada and five continents without formal training, prior knowledge or ongoing sponsorship.

This Special Issue's inspiring account of rapid achievement in patient engagement also exposes critical gaps in attempting to truly "democratize healthcare" (Coney and New Zealand Guidelines Group 2004; Staniszewska et al. 2008). How does self-selection bias the patient voice? What hidden barriers block participation? What do patients need to sustain their development as partners? Could investing in patient capacity reap rewards as effectively as with healthcare providers? Confronting difficult issues, as in this commentary, will help realize the shared ambitions of patient partners and healthcare providers for system transformation.

The Lay of the Land

Generations of community volunteers have contributed endless hours to "engage" with sick and recovering people for individual support. Clinicians ask their patients to "engage" in their own care to manage conditions for better quality of life. By contrast, the present patient-engagement movement sees recruits as agents for change in system-level improvement.

Patients are invited into professional settings to destabilize the status quo, introduce fresh perspectives and catalyze innovation. They address not only the safety and quality of care but also improved professional training, research, governance, policy, regulation and integrated social services for individual and community well-being.

In Canada, leaders such as Kingston General Hospital (n.d.), the Canadian Foundation for Healthcare Improvement (CFHI n.d.) and BC's Patient Voices Network (n.d.) created partnership roles far beyond the familiar patient and family advisory bodies. Citizen-patients are panelists hiring staff,

improvement coaches, policy advisors, funding adjudicators, peer mentors, research co-investigators, patient safety instructors, accreditation surveyors, inspirational speakers, workshop facilitators, manuscript reviewers, awards judges, advisors on endless committees and more. We touch every healthcare sector. For the most part, these volunteer skills garner no compensation or support beyond expenses for an individual assignment.

One asset carried by all patient collaborators is how to define "care" as spanning the silos of specialties and jurisdictions. Patient perspectives transcend scopes of practice, job descriptions, terms of reference, career stages, funding envelopes and hierarchies. Patients readily distinguish "work as imagined" from "work as done" (Hollnagel 2014). Healthcare is not what planners, managers, clinicians and regulators *believe* happens or what *should* happen. In patients' eyes, healthcare is what *actually* happens, for better or worse.

Not all Canadians feel the force of civic empowerment nor access to mechanisms for change.

Self-Selection: Altruism Is the First Screen

Those of us who step forward as engagement partners do so after encountering care just like every other patient. Some of us wish to ensure that a particular care failure never happens to another person. Others want to encourage others to know just how good care can be. What distinguishes us is our confidence in taking action.

In this altruistic act, stepping forward deliberately asserts the right to co-create the society in which we wish to live. Not all Canadians feel the force of civic empowerment nor access to mechanisms for change. So altruism may seem to be unevenly distributed.

Self-selected volunteers are clearly not "patient representatives." Health experiences are specific and unique. UK patient leader David Gilbert suggests that our best contributions may be in posing the right questions, not in making definitive statements (Gilbert 2015). Humility, generosity, trust, vulnerability, curiosity, commitment and kindness characterize those who step forward for change. Spite and militancy are rare.

Getting Through the Door: Who's Left Out?

Nearly 50 years ago, Julian Tudor Hart proposed his Inverse Care Law, observing that better delivery of medical advances offers the most to those who least need care (Hart 1971). As a corollary for patient engagement, those who most need their voices heard within the system seem least likely to gain entry. Conversely, those with no immediate need for care, like me, tend to have the greatest access and capacity to pursue engagement opportunities. In other words, the privileged become even more privileged.

Let's examine a few dimensions of this passive but brutally effective recruitment screen to see how it plays out from a patient perspective. Here is who's let in, but consider who's left out:

Self-selection

We believe we can act, that people will notice us and listen and that we can affect the status quo. We are confident in new challenges and environments where we know no one. As change agents, we can dispassionately outwait institutional inertia before expecting an impact.

Power

We confront social norms of medical authority without fear of rejection as troublemakers. Elites, education, wealth and life-and-death control do not intimidate us. We tolerate disrespect as unintended, not allowing past harm to impose mistrust of the powerful.

Availability

We can predict scheduled availability in advance, free of constraints of health, household, schooling, work and exhaustion. Others will cover for us during what's nearly always office hours during the workweek. If we need assistance, our attendant's schedule is available too. Instant contact is guaranteed by cell and e-mail connectivity wherever we are.

Stamina

Our spare energy for altruism exceeds demands for ourselves and those for whom we are responsible. We will prevail over obstacles of travel, mobility, vision, hearing, mental focus, medications, hydration, pain, fatigue, diet, toileting and treatment.

Voice

We can explain our ideas vividly and forcefully, confident of those absent persons for whom we also can speak. Recalling our own experiences does not mean reliving them. When confronted by unfamiliar people, information and settings, we fluently adopt the jargon, at ease with speaking and listening in groups, write expressively and clearly and address large and small audiences comfortably, if not at the podium then from the floor.

Setting

We find it easy to ask our way through the labyrinth of offices and boardrooms. We are familiar with agendas, facilitators, project teams, minutes, focus groups, PowerPoint presentations, meeting rules, budgets, strategic plans, confidentiality, webinars and survey questionnaires. Entering medical facilities does not trigger debilitating post-traumatic stress and anxiety. We wade effortlessly into large crowds of unfamiliar people, rest comfortably in hotels when away from home and thrive in noisy conferences with no quiet refuge. We are confident always, even when entirely on our own.

Appearance

We know how to dress "for business," with more than one costume and seasonal adaptability. Our style sense will not betray our outsider status and missing wardrobe budget.

Finances

Our excess savings can cover the costs of engagement, the unaddressed overhead for transportation, computers, software, Internet bandwidth, cell service, missed meals and incidental expenses. We can also bridge any promised expense reimbursement for many months or indefinitely when Accounting can't process a non-employee non-contractor. We accept that we will almost never be paid for our time but gratefully hear we are greatly valued (Twitter n.d.).

Not only do these filters discriminate harshly, but the learning curve once "inside" can be far steeper than even the most adept can sustain. The recruiting criteria predetermine a preponderance of people like me: white, retired with an income, adept with technology and office skills, with their own transportation and comfortable as the "dominant culture." When professionals identify me as one of "the usual suspects" or "already loud voices," such disrespect cuts deeply.

Filling the Capacity Gap

To many of us, the rising frenzy for patient partners seems to be outstripping supply. We are overwhelmed by quick response invitations to cryptic solo assignments. Are expectations so intimidating that they discourage new recruits? Are requirements presuming too much prior knowledge, skills or commitment? Or is it that experienced patient partners are dropping out, feeling disappointed, isolated, ineffective or unsupported? Perhaps a bit of each.

Ten years ago when I began my questioning, almost all learning was accessible only to medical professionals. With a neighbour's loaned professorial identity, I tapped a university's vast treasury of online health journals. My bedtime reading of choice became *BMJ Quality and Safety*. Soon, I talked the Institute for Healthcare Improvement into free access to its

online Open School, completing the full curriculum in only a few days. While I didn't expect to plot a PDSA run chart, I wanted to know what it meant. Citizen volunteers should not have to work so hard to become informed. I imagined a citizens' Virtual Institute for Patient Leadership and Capacity Development, free to all, independent and funded by enough sources to withstand electoral swings.

That dream is emerging now through the Patient Advisors Network (PAN), a unique peer-founded and -led bilingual community of practice across Canada with the proud tagline "Independent, Informed, Connected" (PAN 2016). As our membership grows, it is becoming clearer that peer-to-peer, cross-cultural connections to support this social movement will enable us to mature and flourish together. Our ambition is to lower barriers to involvement through accessible knowledge and friendly, human connections with those sharing their patient volunteer experience. This national "network of networks" reaches deeply through our personal connections to more diverse patient populations, demographic sectors and communities. Who better to identify recruiting, access, support and capacity needs than those who are scrambling to fill gaps in the field? As always, "strength in diversity" and collective creativity will enable healthcare to connect patients, families and communities without limit.

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Emerging Frameworks

Three paradigm-shifting ideas to advance a future of "patient-driven" healthcare systems have attracted much interest for their staying power and integrative thinking. First, the "Value Equation" places accountability firmly within the patient perspective: value is defined as the outcomes of care that are meaningful to patients, relative to the full costs of an episode of care, again defined by patients (Porter and Lee 2013). Secondly, "Learning Health Systems" propose high-level innovation with disciplines beyond healthcare fuelling a practice of continuous learning (Friedman et al. 2017). And thirdly, a community-anchored approach to recasting healthcare is the Indigenous ways of knowing with respect to health and well-being (First Nations Health Authority 2012). All three frameworks for transformation draw upon robust and inclusive citizen-patient involvement to gain legitimacy.

In Canada, urgency is returning to our perennial national challenge to engage the public in reform of the *Canada Health Act*. Perhaps we will finally update the scope, size and interoperability of our 13 insured and 6 direct healthcare systems, to clarify coverage for pharmacare, home care, residential care,

dental health and mental health. The movement for patient, public and community engagement in health systems is equipping an unprecedented number of citizens as adept healthcare "knowledge translators." What could more effectively mobilize public dialogue than collaborations already under way?

As a natural evolution, some experienced citizen-patients are taking up the challenge to acquire greater knowledge for specialized contribution. No longer casual volunteers, these skilled-up and motivated colleagues to professionals must have their efforts compensated as a matter of ethics and equity. To respect personal circumstance and wishes, volunteers could donate or divert their earnings to underwrite a fund for capacity development, such as conference attendance. There should be no debate that such workers deserve financial recognition for sophisticated and essential labour in Canada's health infrastructure (Richards et al. 2018).

Where today we have a national Strategy for Patient-Oriented Research (CIHR 2011), tomorrow innovative patient-led models, such as the Patient and Community Engagement Research (PaCER, n.d.), will train legions of patient investigators. Where today's Health Mentors offer students at the University of British Columbia (n.d.) experience with living with chronic conditions, new pedagogic innovation will enable more communities to lead learning throughout healthcare careers. Where today professional bodies have patient advisors, soon patient directors will invigorate governance and accountability. Where today patients join improvement teams, tomorrow teams of people and communities will track their own cycles of improvement for transformation. Where today expert patients inform health redesign, tomorrow system users will co-create revolutionary models of care.

Actually, tomorrow has arrived. Let's open the door to let it in. **HQ**

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