Trustworthy Evidence to Support Quality Digital Healthcare Policy for Underserved Communities: What Needs to Happen to Translate Evidence into Policy?

COMMENTARY

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ABSTRACT

In this paper, we explore what is needed to generate quality research to guide evidence-informed digital health policy and call the Canadian community of patients, clinicians, policy (decision) makers and researchers to action in setting digital health research priorities for supporting underserved communities. Using specific examples, we describe how evidence is produced and implemented to guide digital health policy. We study how research environments must change to reflect and include the communities for whom the policy is intended. Our goal is to guide how future evidence reaches policy makers to help them shape healthcare services and how these services are delivered to underserved communities in Canada. Understanding the pathways through which evidence can make a difference to equitable and sustainable digital health policy is vital for guiding the types of research that attract priority resources.

Introduction

Industry is investing billions in digital health (Duffy et al. 2022), and billions of people are downloading healthcare apps to their devices (Patrick et al. 2016). While the COVID-19 pandemic turbocharged public discussion about and demand for digital health services, digital health is not a new way of delivering healthcare (Bashshur and Armstrong 1976). Underserved communities have been at the forefront of developing and implementing digital healthcare (Bacon et al. 2023; Rothman 2023); through sheer necessity, they are pioneers of essential healthcare (Novak Lauscher et al. 2023).

Digital health research and policy must reflect the needs and experiences of underserved communities. Unfortunately, the foundational work required to develop digital health tools very often does not seek the input of the very people who are supposed to use the digital health solutions. Compounding the problem is the new technology developed in funded research projects that often does not integrate well with the existing healthcare systems.

Policy makers are recognizing the potential for digital health to help plug gaps in overstretched and understaffed health systems (BC Gov News 2022). The COVID-19 pandemic forced a rapid pivot in how healthcare services were prioritized and delivered –change can happen, and fast. Before policy makers start implementing a digital health solution, they need evidence to inform decisions that help them ensure that the digital health services they plan to implement work, that people can access what they need when they need it and that digital health services pair with existing systems.

In this paper, we explore what is needed to generate trustworthy evidence to inform policy about digital health for underserved communities. We call patients, clinicians, policy makers and researchers to action in conducting, disseminating and implementing digital health research.

Canadian (digital) health policy

Connecting health systems and their services to good health outcomes is the ideal state, yet it is difficult to achieve (Chen 2012). Generating trustworthy evidence and sharing the evidence to support health policy are priorities for improving health services (WHO 2012).

Canadian health policies are founded on the *Canada Health Act* (1985) and aspire to fairness and equity (Health Canada 2021). Policies can help address the needs of underserved communities by (1) identifying gaps in how services are delivered or inequities in health outcomes and (2) directing focus and funding to address priority issues. A joined-up care approach helps address underlying inequities (Pollack Porter et al. 2018; White et al. 2006).

In the early 2000s, the *Accord on Health Care Renewal* introduced information/digital health technology as part of a targeted health system reform to support timely access to quality care and sustainability (Health Canada 2021). Since then, reports have recommended how digital health can support the healthcare system; examples include using:

- *virtual care* to connect providers and people in rural and remote areas to services (Commission on the Future of Health Care in Canada and Romanow 2003);
- *electronic health records and telehealth* to improve access to services, enhance patient safety, and boost quality of care and productivity (Health Canada 2019); and
- *learning health systems*, supported by fully electronic and interoperable health systems, to aid in data access and sharing (Forest and Martin 2018).

> *Generating trustworthy evidence and sharing the evidence to support health policy are priorities for improving health services.*

What Is the Current Landscape of Digital Health Research in Canada?

Canada has been slow to adopt, disseminate and implement digital health solutions (Hamoni et al. 2021). The Pan-Canadian Health Data Strategy – the foundation to strengthen how health data are created, used and exchanged (Public Health Agency of Canada 2022) – provides national policy recommendations for virtual care (Falk 2021), and a virtual care framework outlines key policy levers to deliver sustainable digital healthcare (Health Canada 2021).

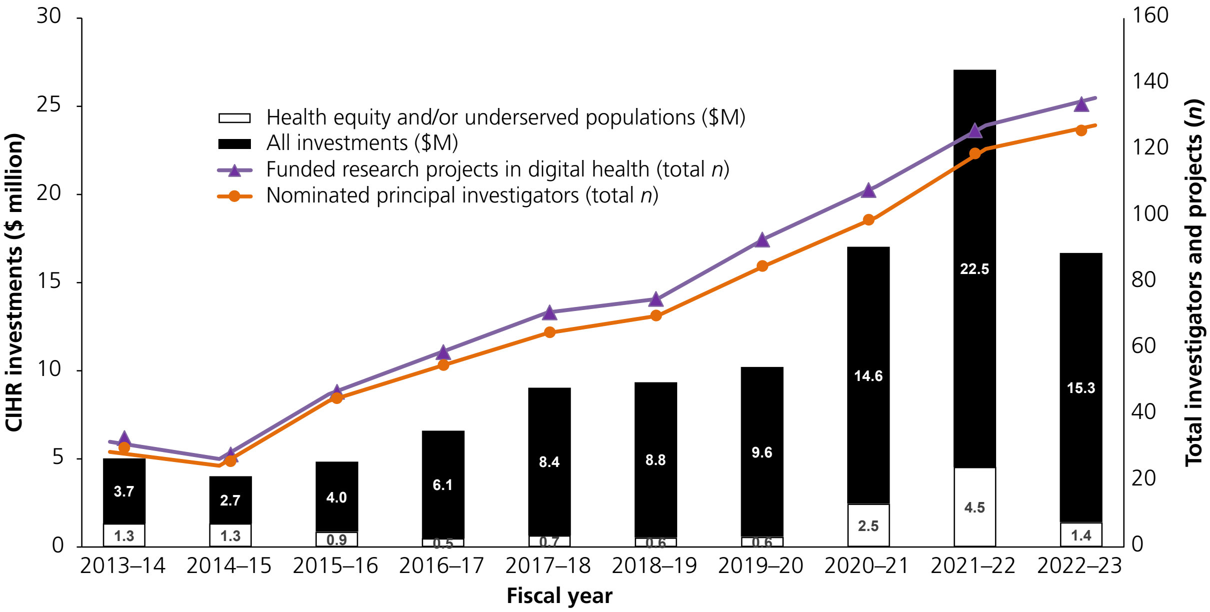
Federal research funding to underpin a sustainable health system

The Canadian Institutes of Health Research (CIHR) – Canada's federal health research funding agency – catalyzes and supports the digital health ecosystem. CIHR supports work that meets the needs of underserved communities and informs health policy and practice (CIHR 2021). CIHR funds often support co-designed research.

To illustrate CIHR's investment in digital health over the past decade, we identified the research projects funded in the themes of digital health, health equity and underserved communities (Indigenous Peoples and historically excluded, under-represented, marginalized and at-risk populations) between 2013 and 2023. Our keyword search identified 506 projects; each project was checked and validated for accuracy. Here, we describe 420 projects (Figure 1).

In the past decade, CIHR invested $95.6 million in digital health–related projects; $16.9 million (or 17.7%) was directed to 62 projects (out of 420 digital health projects) related to health equity and/or underserved populations. CIHR's attention to and investment in digital health has steadily increased. In 2021–22, total investment peaked, so did the number of funded projects and nominated principal investigators.
The proportion of funded projects that focused on health equity/underserved populations also rose, likely in response to major socio-cultural events, including the COVID-19 pandemic.

Figure 1. CIHR investments in digital health from 2013 to 2023



CIHR = Canadian Institutes of Health Research.

Source: Investment data provided by CIHR Funding Analytics in 2023.

As one of the many research funders in Canada, CIHR contributes a portion of the funding for Canadian digital health research. The remaining funding comes from a mix of public and private organizations (e.g., national funding agencies, provincial health research funding organizations, health charities, pan-Canadian organizations, ministries of health and local and regional health-related organizations).

Data collected outside the traditional academic setting

Non-academic data, including those gathered and analyzed by health authorities, are important because they:

- provide a real-world insight into the challenges and opportunities in the local context and
- help decision makers design policies that meet the community's needs and deliver services that work in their environment/context.

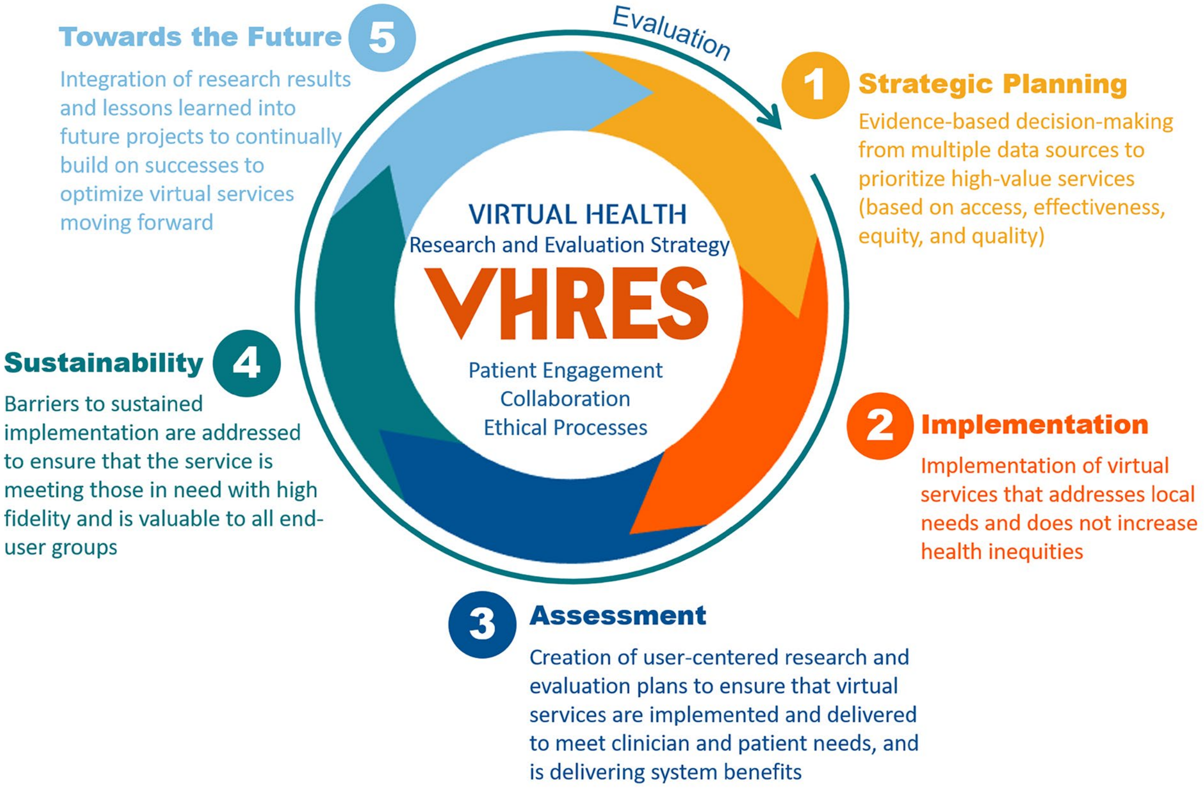
Here, we share an example of how data from a non-academic setting play a central role in guiding digital health policy. The Fraser Health Authority, which is the largest health authority in British Columbia, collects and uses data for digital health research, evaluation and quality improvement projects.

Fraser Health delivers hospital and community-based health services to over 1.9 million people in 20 diverse communities within the traditional, ancestral and unceded territories of the Coast Salish and Nlaka'pamux Nations and is home to six Métis Chartered Communities. The diverse patient demographic includes 62,000 Indigenous Peoples and almost 250,000 South Asian community members (https://www.fraserhealth.ca/about-us/about-fraser-health).

Fraser Health's virtual health evaluation and strategy team

The following four guiding principles underpin the research and evaluation projects coordinated by Fraser Health (Figure 2):

Figure 2. Fraser Health's virtual health research and evaluation strategy



1 Strategic Planning
Evidence-based decision-making from multiple data sources to prioritize high-value services (based on access, effectiveness, equity, and quality)

2 Implementation
Implementation of virtual services that addresses local needs and does not increase health inequities

3 Assessment
Creation of user-centered research and evaluation plans to ensure that virtual services are implemented and delivered to meet clinician and patient needs, and is delivering system benefits

4 Sustainability
Barriers to sustained implementation are addressed to ensure that the service is meeting those in need with high fidelity and is valuable to all end-user groups

5 Towards the Future
Integration of research results and lessons learned into future projects to continually build on successes to optimize virtual services moving forward

Source: Reproduced with permission from Fraser Health.

- *Engage with patients:* Patient and family advisory councils actively participate using tools such as patient journey maps to identify opportunities to implement digital health services, visualize how digital health can integrate with existing health systems and enhance digital health strategy planning at a policy level (Borycki et al. 2020; McCarthy et al. 2020).
- *Collaborate:* The virtual health team collaborates with clinical leaders and other dedicated teams to embed virtual health solutions into clinical programs. An interdisciplinary approach embeds virtual health solutions into clinical care.
- *Meet the community's needs:* Internal data inform digital care services and promote accessibility and equity. By examining usage patterns among different demographic groups, policy makers can identify where interventions may fall short, and tailor policies accordingly.
- *Evaluate:* Ongoing evaluation and quality improvement projects are integral. The iterative process relies on data to refine and improve services.

Between September 2022 and September 2023, three in every 10 patient visits occurred online. Collecting data helps Fraser Health decision makers understand how technology helps the community access care and the outcomes of care. Guided by the data it collects and analyzes, Fraser Health's virtual health service follows a patient-centred care model to connect patients, families and providers.

How Evidence Can Inform Digital Health Policy and Shape Healthcare Services

In this section, we guide the reader to concepts of justice for people who seek healthcare. Before identifying and recommending appropriate next steps, we ask readers to consider how systems of producing and evaluating evidence are related to a society's power structures, which can erode equity and entrench disadvantage.

Epistemic injustice describes how systems and societies value different forms of knowledge, based on how they are produced and by whom (Fricker 2007). There are two types of epistemic injustice: testimonial injustice and hermeneutical injustice.

Testimonial injustice (Fricker 2007) occurs when those who are marginalized are perceived as having less capacity to understand and communicate the way they experience the world – they are perceived as having less capacity to know. *Hermeneutical injustice* (Hänel 2020) occurs when the experiences of marginalized people are not accurately perceived, interpreted or communicated because society has ignored or suppressed the language and frameworks that are needed to attach meaning to them.

Testimonial and hermeneutical injustice often reinforce one another (Medina 2012). People, whose capacity to know is devalued, are excluded from contributing to collective knowledge. Marginalized people, whose accounts of their experiences challenge what is already accepted as known, are perceived as being unreliable sources of knowledge (Byskov 2021).

What is evidence?

The paradigm of evidence-based medicine advocates for classifying evidence (Burns et al. 2011). Clinicians and policy makers are expected to make decisions using the highest level of evidence available to them. When evidence and decisions are framed in this way, it implies that evidence is high quality (i.e., trustworthy and *valid*) when it is obtained through large, highly controlled experiments and analyses; at the bottom of the evidence *pyramid* are individual experiences' data and preferences (Blease et al. 2017; Bueter 2023; Heggen and Berg 2021; Michaels 2021; Pozzi 2023).

Who is an expert?

More than three decades ago, the Evidence-Based Medicine Working Group asserted that their new approach to teaching the practice of medicine would flatten the hierarchy in how medical knowledge is produced, disseminated and used (Guyatt et al. 1992). Yet hierarchy and authority are omnipresent in the *expertise* of evidence-based practice and policy.

When expertise was invoked in evidence-based medicine, it was equated with the professional knowledge and qualifications of clinicians. Patients were not considered experts (Sackett et al. 1996; Wieten 2018). Since the late 1990s, proponents of evidence-based medicine have advocated for including patient preferences as a central tenet of evidence-based decision making (Sackett et al. 1996; Wieten 2018). Yet patient perspectives are framed as beliefs, not evidence or knowledge.

What counts as "valid" evidence?

Evidence-based medicine relies on statistical data about a group of patients to guide decisions for the individual – a situation some have labelled a fallacy (Anjum et al. 2015; Grotenhuis et al. 2011). For population-level trends to reliably predict an individual outcome, the individual must be *the same* as the study group, which is unlikely, given the complexity of the human body and pathophysiological mechanisms. Because underserved groups are under-represented in *traditional* research, the fallacy is perpetuated (Ellison et al. 2007).

The evidence-based medicine framework is challenged in clinical scenarios where little research evidence exists, including multimorbidity, rare, perceived-rare, under-researched and poorly understood conditions (Abrahamyan et al. 2016; Boyd and Kent 2014; Campbell-Scherer 2010; Goldenberg 2006; Greenhalgh et al. 2014; Kruer and Steiner 2008). These are scenarios in which patients from underserved social groups are over-represented (Moin et al. 2018).

Actions to Deliver Trustworthy Evidence for Excellent Policy in Digital Health for the Underserved

To move digital health research and policy forward in a way that makes a difference for underserved communities, the priorities of funders, people who do the research, the organizations that support the research and government agencies must align. We suggest four areas of focus.

Patients as research co-leaders

Our vision is for a research environment where patients contribute as full-fledged researchers with full access to the support of research institutions and infrastructure (e.g., academic libraries). Patients direct research priorities, design studies, lead analyses and disseminate the results. People, as experts in their own experiences and communities and in the care systems with which they interact, bring expert insights to the research and policy-making tables. Their personal encounters with health systems, access challenges and health outcomes provide a perspective that policy makers cannot ignore.

Meaningful collaboration between professional and lived-experience experts requires people to consider questions, such as what are the distinct bodies of knowledge and communities of practice to which clinical and patient researchers have access? Which elements of these communities are open and which are resistant to outsiders? What is needed to foster interdisciplinary and cross-cultural collaboration among groups?

Support for patient-oriented research

We call for targeted funds and grants that accommodate the specific needs and ways of engaging underserved communities. We are pleased to see tangible support for community-led research projects (The University of British Columbia 2023) and the success of CIHR's Strategy for Patient-Oriented Research (SPOR). In an impact assessment of CIHR's eHealth Initiative (CIHR 2023) – a $17.8 million digital health funding program – researchers reported that strong partnerships with patients and providers were key to the success of their project and to generating evidence for policy decisions. The co-designed digital health interventions better met the needs of the community and contributed to improving health equity and experiences of care, research and policy.

Lead investigators are expected to have an institutional affiliation or an affiliated partner who can support their funding application. The expectation excludes patient researchers who may have difficulty undertaking the kind of networking and social capital–building work required to get a foot in the door to support their research interests (Chenoweth and Stehlik 2004; Potts 2005; Sanders and Rogers 2007; Tankink 2023). We would like to see infrastructure that supports patient researchers to apply for funding and to connect with appropriate and interested co-investigators and institutional support as part of the funding process.

Interdisciplinary, critical and qualitative frameworks are essential for transformative research, including in digital health. Unfortunately, design research and interdisciplinary projects often fall through the cracks of existing tri-agency opportunities. We call for creative funding opportunities that bring people together from across disciplines to solve shared problems. The New Frontiers in Research Fund (Canada Research Coordinating Committee 2023) is a good start; we call for more support in this vein.

A "stepped evidence" model of valuing knowledge

In lieu of hierarchies of evidence, we advocate for a stepped evidence framework. Informed by stepped care approaches to mental health and chronic illness (Cornish 2020; Davison 2000; Von Korff and Tiemens 2000), a stepped evidence model (Figure 3) recognizes healthcare options that vary in intensity and patient autonomy. Rather than elevating a *gold-standard*, stepped evidence prioritizes a flexible approach that is tailored to the context of the person who seeks healthcare.

Within a stepped evidence framework, researchers and funders evaluate the appropriateness of research methods (including traditional clinical research methods and sociological, user research and service co-design methods) for the specific parameters of a research project and population and balance the weighting of evidence gathered from clinical settings, people with lived experience and the community.

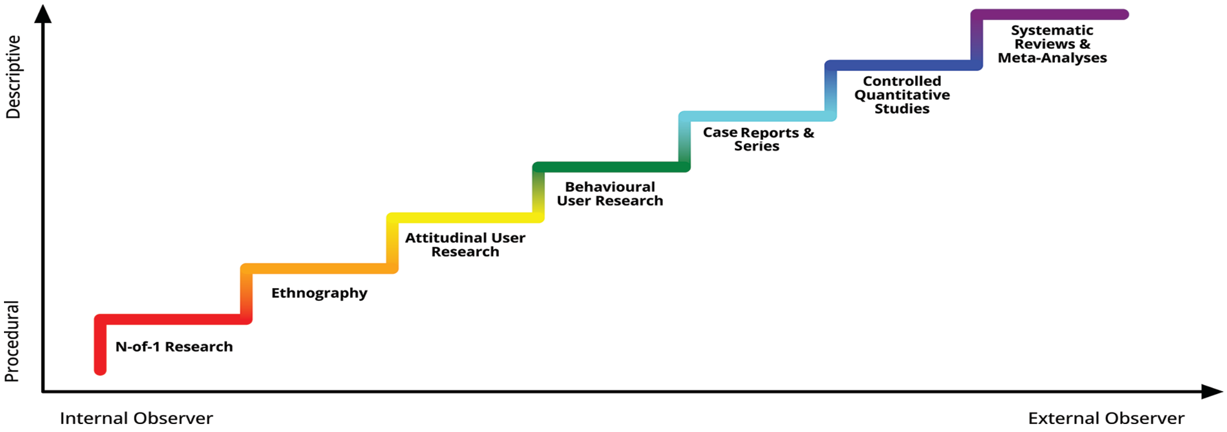
Inclusive design

Designing from the margins meets the needs of *extra-ordinary users* rather than designing for groups of normative users (Andrews 2016; Pullin and Newell 2007). Embedding inclusion principles in design – embracing user needs and behaviours – rather than treating inclusion as an after-thought produces solutions that work for more people (Andrews 2016; Conradie et al. 2014; Pullin and Newell 2007). A well-known example is the *curb cut phenomenon* (Newell and Gregor 1997; Reid 2022) where dropped curbs, built to create accessibility for wheelchair and other mobility device users, have improved access for others (e.g., parents pushing strollers and travellers pulling rolling luggage). Designing from the margins recognizes that marginalized users are experts on the design flaws within the existing systems and services because they have lived experience of the flaws.

Summary

Underserved communities deserve trustworthy evidence to support decisions about digital health policies that affect them. We encourage researchers and policy makers to bring a curious and creative open mind when producing and evaluating evidence. We suggest that the organizations and people who are funding, producing and interpreting evidence find ways to authentically involve and represent the

Figure 3. A stepped evidence model of valuing knowledge



lived experiences of non-researchers, including patients and caregivers from underserved communities. Involving patients and caregivers as co-leaders and incorporating principles of inclusive design into research are steps in the right direction.

Recommendations

To move digital health research and policy forward in a way that impacts underserved communities, the priorities of funders, people who do the research, the organizations that support the research and government agencies must align.

To generate quality research that guides quality, evidence-informed digital health policy, we call for:

- research teams to include patients as research co-leaders;
- funders to support targeted grants that support the specific needs and ways of engaging underserved communities;
- decision makers to embrace a stepped evidence framework when weighting evidence gathered from different sources; and
- designers to embrace inclusive ways of working that centre the needs of the "extra-ordinary" users rather than normative users.

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