Learning Health Systems: A Paradigm Shift in What We Can Do about Digital Health Inequities

COMMENTARY

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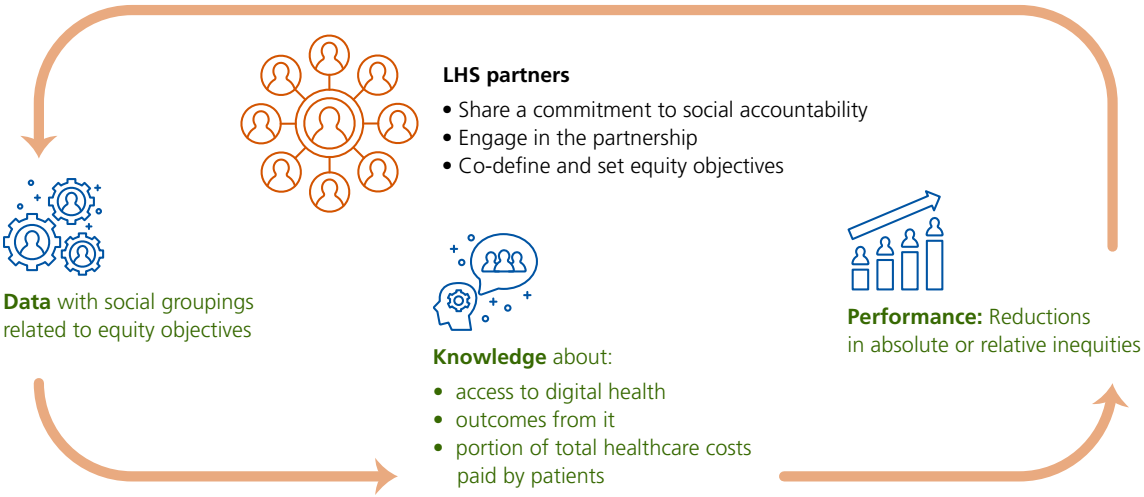
ABSTRACT

Learning health systems (LHSs) embed social accountability into everyday workflows and can inform how governments build bridges across the digital health divide. They shape partnerships using rapid cycles of data-driven learning to respond to patients' calls to action for equity from digital health. Adopting the LHS approach involves re-distributing power, which is likely to be met with resistance. We use the LHS example of British Columbia's 811 services to highlight how infrastructure was created to provide care and answer questions about access to digital health, outcomes from it and the financial impact passed on to patients. In the concluding section, we offer an accountability framework that facilitates partnerships in making digital health more equitable.

The Learning Health Systems Advantage

The Agency of Healthcare Research and Quality (AHRQ) defines a learning health system (LHS) as "... a health system in which internal data and experience are systematically integrated with external evidence, and that knowledge is put into practice ..." so as to result in high-quality, safer and, ultimately, more efficient care (AHRQ 2019). Germaine to the LHS approach is rapid access to data that can be meaningfully applied to inform cycles of feedback and learning, allowing system administrators to link data to knowledge to performance (D-K-P) (Figure 1). From an organizational perspective, it features performance metrics and a governance structure that holds all participants accountable for overall outcomes, including equity – one of the quintuple aims of healthcare administration (Reid and Greene 2023; Schoenthaler et al. 2023). Data are at the heart of the LHS approach, providing the capacity to rapidly address challenges in providing essential digital health – its measures (what metrics are relevant for capturing health [in]equities), its collection (disaggregated, inclusive and accurate and tracked regularly over time) and its application (analyses to identify and solve for equity gaps) through the rapid D-K-P cycles make LHSs especially well-suited for measuring progress on equity objectives.

Figure 1. Measuring progress on digital health equity objectives through the D-K-P cycles of LHSs



D-K-P = data to knowledge to performance; LHS = learning health system.

The Evolution of Evaluation

What does the LHS approach offer in the context of essential digital health that continuous quality improvement has not already? Evaluation and quality improvement are well-embedded in healthcare performance, so it is unsurprising that the LHS approach is not immediately associated with cutting-edge innovations toward bridging the digital divide. Starting with the quality improvement era in the late 1990s – with milestone systems-level achievements in accountability – the concept of socially accountable work through partnerships has steadily gained acceptance.

Noteworthy accomplishments include the Joint Commission in the US mandating the release of organization-specific performance reports (The Joint Commission 2022) and the seminal publication on healthcare quality and safety, *To Err Is Human,* by the Institute of Medicine (now known as the National Academy of Medicine) (Kohn et al. 2000). While the terminologies have evolved over time, the principles underlying the ongoing evaluation of health system performance have not.

The LHS concept naturally evolved from conversations in 2006 around the key components of quality care: clinically safe and effective, patient-centred and contextual (timely, efficient and equitable) (Institute of Medicine [US] Roundtable on Evidence-Based Medicine 2007). At the time, LHS was seen as a necessary and novel framework to advance the lagging goals of evidence-based medicine. It has since evolved in its understanding and methodological, practical and policy implications. The dynamic and recurrent learning cycles are anchored in the core LHS partnerships, forming a learning community with governance that can include social accountability as its mandate (Enticott et al. 2021).

Socially Accountable LHSs

Socially accountable LHSs assume that change is needed, and key partners will continuously work on the problem (Woods et al. 2023). Ideally, partnering organizations bring together policy makers, administrators, communities, patients and caregivers, health professionals, health researchers and linked sectors in a shared commitment to improve the status quo (McGinnis et al. 2021). Socially accountable LHSs will leverage these core partnerships to clarify what aspects of equity

they want to see improved. In co-defining the equity objectives, partners keep the outcomes of D-K-P cycles in constant reach – everyone can observe the progress and share ideas. The LHS approach has an advantage in addressing equity in that the model runs counter to cycles of blame and shame practised in healthcare organizations when a program does not work as intended or, inevitably, when systemic inequities are revealed (Markham et al. 2021).

A Necessary Shift in Thinking

Change is hard. People working in organizations prefer to stick to what they know; policy makers and health system administrators play a critical role in enabling policy frameworks guided by LHSs and channelling resources to support their implementation. Managing change starts from the top, and system leaders set the tone for cultivating a culture of ongoing learning with everyone who contributes to establishing the LHS, including governments, healthcare organizations and professionals. Healthcare leaders are responsible for culture change. Administrators can help by incentivizing organizations to learn and contribute externally, either by direct funding of such initiatives or by enabling some organizations with disadvantages (e.g., capacity constraints, lack of support staff) to contribute equally to LHSs. Within organizations, some may argue against change, claiming that LHSs are too expensive or at least that measuring change is expensive and the investment puts the administration at risk of poor optics and loss of reputation. It is hard to say that healthcare systems are doing badly and *failing forward* until another D-K-P cycle shows that something has been done that succeeds. Sometimes, it can take several D-K-P cycles/years to reduce the gap between discovering that an approach is failing and finding a solution that works.

LHSs Become the Time Equalizer

LHSs become an equalizer of the time needed to deliver results by balancing the slow process of generating evidence from research and the fast decisions needed to inform policy (Allen et al. 2021). The agility and responsiveness of the LHS approach have been experienced firsthand at the Institute for Better Health (IBH) in Ontario – the research and innovation division of Trillium Health Partners and the largest community-based hospital system in Canada (Glauser 2021). Scientists at IBH regularly meet with healthcare staff and administrators to learn about care delivery experiences and to understand what is working, what is not and why. In building these strong communication channels between the people in the LHS, IBH/Trillium also gained the trust of their people to implement incremental improvements in organizational policies and care plans that can improve patient programs and outcomes.

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Trillium rolled out their electronic health record (EHR) system three years ago. All patient data, including doctor's notes, reports and medications, are captured in the system; the entire patient journey is found in one location. In further LHS cycles, IBH studied the effects of implementing their LHS model on patient care coordination, adverse events and medication errors. Retaining and understanding digital information guide care improvements in further D-K-P cycles.

Kaiser Permanente in Washington, US, is another organization that has an established LHS with dedicated program funding, which

indicates that the organization is serious about adopting LHS. The Kaiser Permanente LHS program has research at its core, supporting strong relationships among researchers, clinical leaders, quality improvement, operations and strategy. The Kaiser Permanente LHS also actively embeds research into healthcare practice (Allen et al. 2021). During the COVID-19 pandemic, the LHS program consulted with the Washington governor's office to develop care models for hospitals and intensive care units. The LHS conducts biweekly rapid evidence reviews for health system leaders – continuing the cycle of embedding evidence into practice and supporting health system leaders to make informed decisions quickly. Another advantage that LHS offers is that in developing these close ties with research, core datasets with indicators of systems efficiency are retained in-house, contributing to the organization's "digital assets," or data sources, that will be available for future generations and predictive models to learn from.

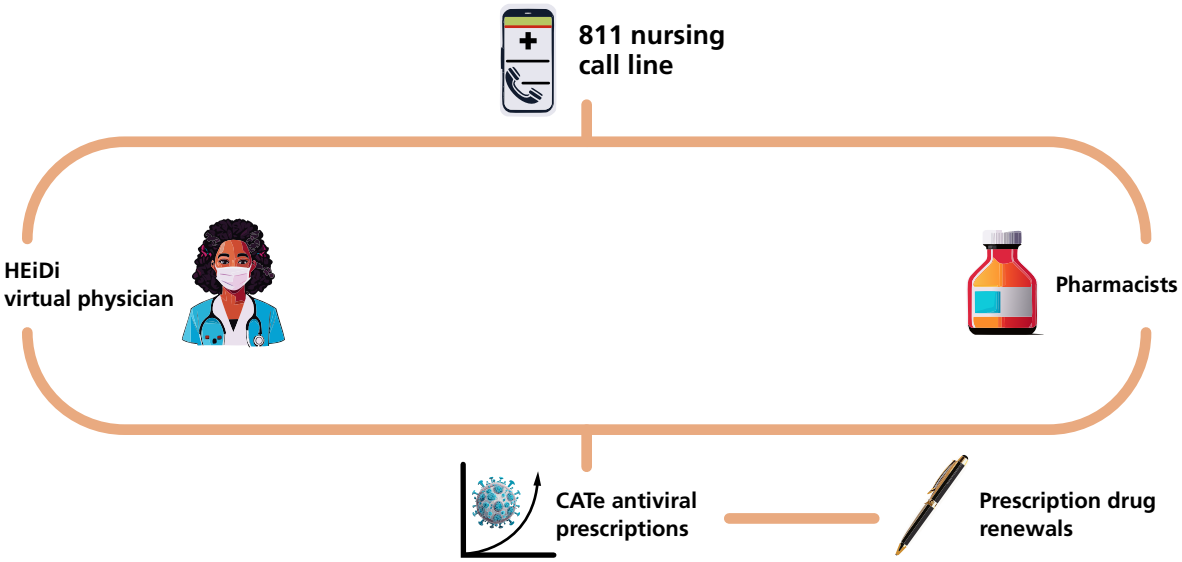
HealthLink BC's 811 LHS: Creating a digital footprint

The British Columbia 811 nursing telephone line is grounded in an LHS with partnerships between health policy makers and health professionals, researchers and patients that operationalizes rapid data capturing to inform practice. The 811 LHS rapidly responded to the risks associated with the COVID-19 pandemic by offering alternatives to making in-person trips to emergency departments (EDs). Within a month of the provincial lockdown orders, the program launched a virtual physician service to partner with 811 nurses, creating the first such 811 program in Canada called HealthLink BC Emergency iDoctor-in-assistance (HEiDi) (https://emergencycarebc.ca/rtvs/heidi/). Publicly funded, HEiDi offered widespread, on-demand physician services for patients with urgent health concerns. The service reached more than 30,000 patients in its first year of operation.

Consistent with most of Canada's provincial telephone triage systems, Healthlink BC's 811 also contributes to equitable access by offering its services in multiple languages and uses a variety of modes to communicate electronically (Young et al. 2023). The 811's LHS is well-suited to measure progress on its equity objectives featuring rich, structured demographic data and an LHS partnership grounded in a commitment to social accountability. In April 2020, when the service initially launched, HEiDi expanded both telephone- and video-based virtual care access for patients in social isolation due to the pandemic, responding simultaneously to inequitable circumstances determined by their age, mobility and/or comorbidities when patients were seeking care.

In February 2022, when COVID-19 antiviral agents such as Paxlovid became available, HEiDi expanded to a COVID Anti-Viral Therapeutics e-Team (CATe) (https://covidtreatments.gov.bc.ca) to assess patients at high risk of hospitalization if they contracted COVID-19 and provided prescriptions and access to Paxlovid (Figure 2). In January 2023, the 811 virtual care team also launched the Provincial Prescription Renewal Support Services (PPRSS) in partnership with community pharmacies to assist patients without family doctors to get prescription renewals without having to go to urgent care clinics or EDs. Employing the D-K-P cycles of LHSs, virtual team-based care models were established on data from health services need (data to knowledge), then knowledge of how to deploy the virtual care models to address the need (knowledge to performance) and then by implementing the services while monitoring outcomes to inform next steps (performance to data).

Figure 2. Expanding access to care via the 811 LHS



CATe: COVID Anti-Viral Therapeutics e-Team; HEiDi = HealthLink BC Emergency iDoctor-in-assistance; LHS = learning health system.

The HEiDi LHS has closely engaged with researchers in multiple D-K-P cycles. In the first D-K-P cycle, data were generated to ensure that the HEiDi service was safe, feasible and acceptable to patients (Ho et al. 2021). In the second cycle, researchers showed that 60% of the calls were for low-acuity health concerns that could be safely diverted for non-urgent follow-up with a family physician or self-managed at home (Ho et al. 2023). Patients without a vehicle, such as many of the elderly, could call 811 before visiting the ED, potentially saving costly or unsafe travel as well as their own time. In the most recent cycle, LHS-embedded researchers uncovered clues about why a patient would not follow the HEiDi-physician's advice (i.e., lack of attachment with a family physician and rural limitations on available services), offering program planners valuable information about how to target or tailor their goals to improve care coordination (Duncan et al. 2023). These examples demonstrate the ability to learn from the digital footprint in the data created by the 811 LHS, and the opportunity to leverage these as *digital assets* for future research aimed at making 811 services more equitable. Predictive models hold enormous potential to make an impact in this area. By creating and then following the digital footprint created today as training data, we can predict ways to improve access to care and outcomes from it in the future.

The "Wobbly Stool" Problem

Patient engagement within an LHS has been aptly described as a "wobbly stool" – a metaphor for the current state of how and to what extent the LHS is demonstrated as driving or informing actions in health equity that has not been paid significant attention. The contribution of patients, caregivers and those with lived/living experience of the healthcare system and of the communities to which they belong is critical to understanding how health systems should be improved. While on the one hand, an LHS provides a framework and opportunity for structuring and repurposing this input to enhance system performance, on the other hand, meaningful participation is often absent or falls short of what is needed (Lee-Foon et al. 2023). The wobbly stool

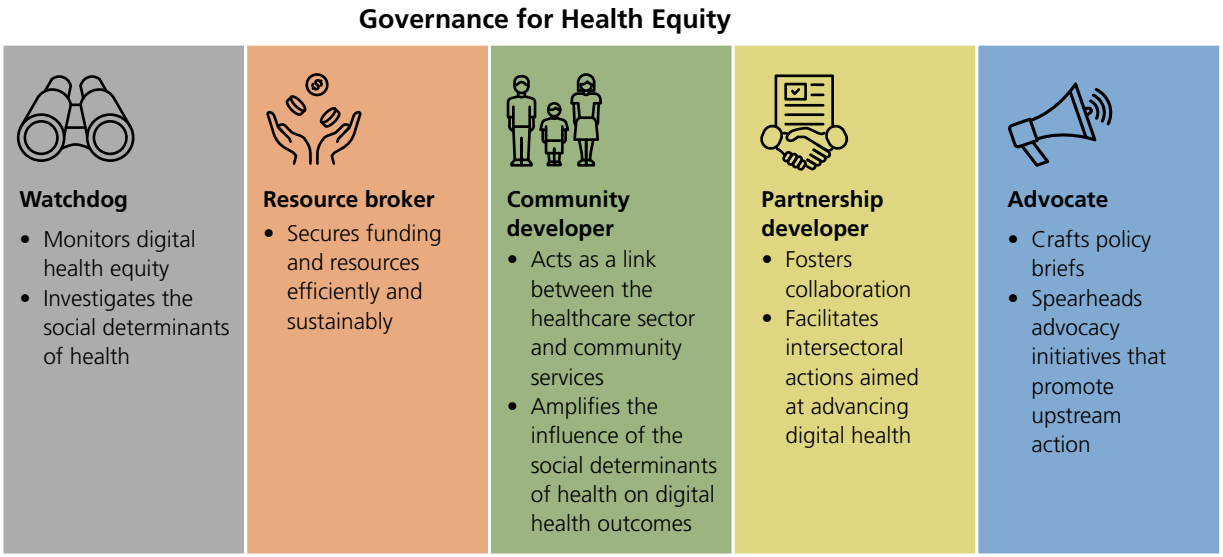
problem posits that although patient engagement is widely accepted and efforts have been made to include patient groups in LHS, the voices of people from structurally marginalized groups may still not be heard.

How Will Patients Know that They Have Been Heard?

Representing patient groups and community members is an essential step toward ensuring that social accountability is built into the LHS (Menear et al. 2019; Selby et al. 2012). Having representatives from communities that are experiencing inequities actively and are authentically involved in LHS governance aligns healthcare interventions and community-specific needs and preferences. An LHS approach could be fuelled by strong external partnerships that are inclusive and, therefore, generate pressure for change, while addressing the wobbly stool problem currently faced by LHSs that need to engage deeper with communities to bolster a response to their equity objectives.

Impactful patient engagement supports diversity in the patient and community representatives who participate in LHS governance (Sayani et al. 2021). Including First Nations, Inuit and Métis communities in governance structures, for example, is required to respond to calls to action on health inequities, specifically to problems associated with anti-Indigenous racism in healthcare (Rice et al. 2024; Turpel-Lafond 2020). A governance and accountability framework suggests five essential roles to support productive engagement and amplification of community perspectives toward the goal of improving health equity (Figure 3) (Labonté 2010; Sayani 2019). The accountability framework is responsive in essential digital health in that LHS partners who have lived experience or knowledge about digital health inequities would not just be in the room but will have their perspectives listened to and actioned upon.

Figure 3. Accountability framework for promoting digital health equity with communities



Source: Concept adapted with permission from Ambreen Sayani.

Conclusion

The pursuit of digital health equity is an ongoing process working against a backdrop of rapid technological innovation. Patient engagement, metrics, governance and inclusivity in socially accountable LHSs are pivotal components of this journey. To embed LHSs in Canada's healthcare systems, a cultural shift toward innovation and continuous learning that celebrates successes and learns from failures is essential. As the healthcare industry becomes increasingly data-driven, strong data governance, interoperability and efficient data-sharing mechanisms are paramount. An LHS is not only a method but a movement in healthcare, heralding a future where data, collaboration and continuous learning are at the heart of every healthcare decision.

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