Everybody's talking about equity, but is anyone really listening?: The case for better data-driven learning in health systems

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Abstract

Data collection, analysis, and data driven action cycles have been viewed as vital components of healthcare for decades. Throughout the COVID-19 pandemic, case incidence and mortality data have consistently been used by various levels of governments and health institutions to inform pandemic strategies and service distribution. However, these responses are often inequitable, underscoring pre-existing healthcare disparities faced by marginalized populations. This has prompted governments to finally face these disparities and find ways to quickly deliver more equitable pandemic support. These rapid data informed supports proved that learning health systems (LHS) could be quickly mobilized and effectively used to develop healthcare actions that delivered healthcare interventions that matched diverse populations' needs in equitable and affordable ways. Within LHS, data are viewed as a starting point researchers can use to inform practice and subsequent research. Despite this innovative approach, the quality and depth of data collection and robust analyses varies throughout healthcare, with data lacking across the quadruple aims. Often, large data gaps pertaining to community socio-demographics, patient perceptions of healthcare quality and the social determinants of health exist. This prevents a robust understanding of the healthcare landscape, leaving marginalized populations uncounted and at the sidelines of improvement efforts. These gaps are often viewed by researchers as indication that more data is needed rather than an opportunity to critically analyze and iteratively learn from multiple sources of pre-existing data. This continued cycle of data collection and analysis leaves one to wonder if healthcare has a data problem or a learning problem.

In this commentary, we discuss ways healthcare data are often used and how LHS disrupts this cycle, turning data into learning opportunities that inform healthcare practice and future research in real time. We conclude by proposing several ways to make learning from data just as important as the data itself.

Keywords
learning health systems; population health data; healthcare practice

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Introduction

Data collection, analysis, and data driven-action cycles have been touted as integral parts of healthcare for decades. Its importance have become more pronounced during the COVID-19 pandemic, where case incidence and mortality data have frequently been iteratively used by governments, public health agencies, and healthcare institutions to inform evolving healthcare resource and service distribution in real time. Unfortunately, these real time responses have often been inequitable, forcing some of the most marginalized healthcare users to have to fend for themselves. Although the pandemic brought healthcare inequities to the forefront of public consciousness, years of data have consistently shown that, for example, racialized populations, and those experiencing low socio-economic status and housing insecurity are more likely to experience poorer health outcomes. COVID-19 data finally forced many institutions and governments to confront these pre-existing disparities and identify ways to provide more equitable pandemic support. This data prompted the province of Ontario—the most populous province in Canada [1]—to redistribute resources to support pandemic responses in hard hit areas and investigate sociodemographic data collection for vaccine distribution at the end of 2020. The federal government also created a pandemic equity model and called for a national socio-demographic data collection initiative [2]. Although the operationalization of these initiatives varied across Canada and within provinces, it answered years of calls for more granular and systematic data collection from community advocates, clinicians, scholars and community health centres.

What are learning health systems?

Rapid data informed responses to care proved that learning health systems (LHS) could be quickly mobilized and findings from routinely collected data used to support short and mid-term healthcare actions to reform how we deliver healthcare interventions that match people's needs in equitable, responsive, timely and affordable ways. Learning health systems prompts researchers and health focused institutions to not just seek out data but also simultaneously consider multiple factors during data analysis and in the ensuing policy or programmatic response. Researchers are required to take the time to assess what data-informed actions work, to what effect, in which contexts and populations. Although definitions of LHS abound, here, we define it as "the combination of a health system and a research system that at all levels is: 1) anchored on patient needs, perspectives and aspirations; 2) driven by timely data and evidence; 3) supported by appropriate decision supports and aligned governance, financial and delivery arrangements; and 4) enabled with a culture of and competencies for rapid learning and improvement [3]." Learning health systems may be a relatively new concept within the Canadian health landscape, but aspects of research with real-time impact have been around for several years. Within LHS, data are viewed as a starting point researchers can use to inform practice and subsequent research questions.

Healthcare and data gaps

Despite this innovative view, the quality and depth of data collection and robust analyses continues to vary from one healthcare institution to the next, with data often lacking across the quadruple aims. These data gaps often lead to imbalances in institutions' level of attention to improving healthcare across the aims and actions informed by the data. Additionally, they infrequently capture the full diversity of the populations that institutions support. Even with this fragmented data, health institutions are often slow to respond to and incorporate data findings into their preexisting healthcare policies and practices in meaningful and impactful ways. They often want additional studies done to bolster or counter these findings before committing to any changes. By the time additional research have been conducted, frequently requiring primary data collection, years have passed and with it, the impact of proposed interventions.

A closer look at the type of equity-related data that are routinely collected, how they are analyzed and used within Canadian healthcare systems reveals that this is habitually done in a piecemeal, disjointed and time limited fashion. This leaves large gaps in information about participant and community socio-demographics, meaningful experiences and person-centered outcomes, perceived healthcare service quality and delivery as well as areas for improvement. Additionally, data capturing the social determinants of health are rarely equitably collected and/or analyzed, leaving many experiencing social and structural disparities uncounted and at the margins of improvement efforts. These gaps are often perceived by many researchers as an indication that more data is needed instead of an opportunity to take time to critically analyze and iteratively learn from various sources of well-organized and routinely collected data. This perpetual cycle of data collection and analysis leaves one to wonder whether healthcare has a data problem or a learning problem. In this commentary, we discuss the ways healthcare data are often used and how learning health systems disrupts this cycle, turning data into learning opportunities that inform healthcare practice and future research in real time.

Often, population research centered on data collection and analysis alone does not change much in the everyday lives of healthcare users. Take for instance the United States, which first used mortality data over a century ago to study its populations' health conditions and inform public health measures [4]. Data from a landmark 1985 report from the Secretary's Task Force on Black and Minority Health found Black and other minority populations in the U.S. experienced persistent health disparities compared to their White counterparts. The report found infant mortality, death from diabetes and cardiovascular disease and stroke were higher among Black and other minorities [5]. More than 30 years after this report was released and recommendations on how to address these issues were made, 2018 health data showed Black-Americans had 2.3 times the infant mortality rate [6], were 2 times more likely to die from diabetes and nearly twice as likely to die from a stroke compared to their White counterparts [7]. Researchers continue to explore the reasons behind and propose interventions to address these rates just like their predecessors in 1985.

Although these aforesaid rates might be surprising to some, for those working to support the health of racialized populations, data alone merely reconfirms what they already know. For instance, prior to the COVID-19 pandemic, researchers and community stakeholders could point to research that noted racialized populations and those experiencing low socioeconomic status faced heightened risks of illness as well as poor mental and physical health outcomes [8]. Data have also consistently shown that individuals from racialized populations face poor healthcare experiences and barriers to beneficial interventions.

Despite this knowledge, early provincial and municipal COVID-19 strategies equally distributed services and resources without critically examining and tailoring distribution to populations that have faced worse health outcomes in past pandemics [9]. It was not until more granular data was collected and analysed that various institutions realized they had to shift their resources and foci to ensure those most at risk could access healthcare and resources that reflected their level of need. This granular approach forced institutions to finally recognize that the proverbial 'we're all in this together' phase repeated by many Canadian politicians during the pandemic was incorrect. Granular data analysis also prompted many institutions to consider the ways that the social determinants of health impacted COVID-19 disparities and identify ways to address them. Unfortunately, this consideration is not commonplace.

Data are often viewed in a vacuum. Although data collection and analysis are frequently triggered by well-developed research questions, data are often analyzed in an objective and positivist fashion, disconnected from the socio-structural contexts from which they emerge. Without this contextual layer, granular COVID-19 data might lead some Ontario researchers to speculate, for instance, if there is a genetic component to Black communities' heightened rates of viral infection [10]. However, data combined with context would allow researchers to note that many racialized populations work in front facing positions [11] and live in multi-generational households in high-rise buildings that greatly increase their risk of exposure to COVID-19.

Conclusions

Learning health systems can disrupt this vacuum and foster context driven data collection and analysis. The cyclical nature of LHS ensures learning is always a vital component of healthcare with data playing a supporting role. Institutions that have embedded LHS into their work highlight several approaches to ensure learning from research takes centre stage. In considering this work and healthcare in the Canadian context, we propose several ways to make learning from data just as important as the data itself. First, learning must be seen as a vital part of data collection and analysis at the research planning phase. Researchers must move beyond merely framing data collection and analysis as ways to answer study questions. They must consider whether additional data is needed or if sufficient learning have been gleamed from pre-existing data. If more data are needed, researchers must critically reflect on how they will learn from and act upon these findings in direct partnership with healthcare institutions, its

users and communities. It is not enough to report research findings with the hope that someday, institutions will find, review and convert the results into practice. Second, these partnerships must be thoughtful, interdisciplinary and ensure that healthcare users' and community members' perspectives tangibly contribute to rapid, healthcare responses. Third, researchers must also include the collection of information that cannot be easily numerated. Greater emphasis must be placed on collecting qualitative data directly from healthcare service users, service providers and communities. These rich data will help add context to quantitative research findings and could shed light on issues not visible by numbers alone.

Finally, accountability must be embedded into learning practice. Public health institutions and all levels of government must actively agree to address data findings in concrete and actionable ways. These commitments must be bolstered with financing, human resources and key milestones that must be achieved. Milestone attainment must be assessed by proven performance metrics and/or funding incentives from an Auditor General with failure leading to demotions or removal from office in a subsequent election. Failure to hold those in power to account will likely lead to the continued cycle of data collection and analysis with the same findings of pre-existing health disparities and the same recommendations to address them. Combined, these approaches may help us solve the data problem.

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Statement of conflicts of interest

None declared.

Ethics statement

Ethics approval was not required for this article.

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