How ready are we for personalized healthcare?

Shift HEALTH

Workshop Report

24 April 2020

On February 6th, 2020, Shift Health facilitated a half-day workshop with over 100 stakeholders, including patients, healthcare providers, government, industry and researchers.

The purpose of this session was to launch the development of a made-in-Canada Personalized Healthcare Readiness Index that catalogues the attributes of the personalized healthcare system to which we collectively aspire.

Data-driven personalized healthcare (PHC) represents one of the most exciting prospects—and pressing priorities—for our healthcare future. We know that the ability to collect, share and use diverse health data to drive innovation, generate insights, inform better decisions and reflect the uniqueness of individuals is the future of healthcare—but we are inconsistent in how we describe this future. The promise and urgency of personalized healthcare underscore the need for greater clarity: if we are to aspire toward a desired future state, we need to begin by describing it with certainty and conviction.

Personalized healthcare goes beyond 'precision medicine', capturing the more encompassing possibility of integrated wellness, prevention and treatment solutions that reflect individual circumstances and choices. With this possibility comes complexity: modernizing approaches to privacy, consent and data-sharing; re-engineering regulatory and reimbursement systems to accept and adapt to real-time, real-world evidence; empowering the public with the digital literacy essential to meaningful engagement and accountability.

The implications are multifaceted and daunting. Addressing these implications will require unprecedented collaboration and partnership across sectors, disciplines and stakeholders in defining the shared future we aim to create. If Canada is to be at the forefront of this transformation, we critically need to engage as a community in solutions-oriented dialogue that takes stock of where we stand today and helps us align on the features we expect to see in a resilient, responsible and impactful personalized healthcare system of the future.

This report captures the insights of our speakers and panelists:

Dr. Alan Bernstein, President & CEO, CIFAR; *Dr. Sacha Bhatia*, Chief Medical Innovation Officer, Women's College Hospital; *Kelly Butterworth,* Policy Strategy Leader for Personalized Healthcare, F. Hoffmann-La Roche Ltd; *Bogi Eliasen*, Knowledge Broker & Health Futurist, Copenhagen Institute for Futures Studies; *Aaron Leibtag*, Co-founder & CEO, Pentavere; *Alies Maybee*, Co-founder, Patient Advisors Network; *Carole Piovesan,* Partner & Co-founder, INQ Data Law; *Angela Power*, Director, Data Ethics & Privacy, Newfoundland and Labrador Centre for Health Information; *Dr. Michael Schull*, CEO, ICES; and *Dr. Elissa Strome*, AVP Research & Executive Director, Pan-Canadian AI Strategy, CIFAR

This workshop was generously sponsored by Roche, Amgen, Bitnobi and StrategyCorp.

#PHCready

A science mindset.

The case for change

THE DISEASE BURDEN ASSOCIATED WITH OUR AGING POPULATION THREATENS HEALTH SYSTEM SUSTAINABILITY.

While life expectancy in OECD countries has increased by around 10 years over the past three decades, so too has the disease burden, with approximately half of the additional years of life characterized by ill health. Globally, health spending is forecasted to increase until 2040 at a rate comparable to—or even faster than—the pace of the past 20 years. Around 75-80% of this cost will be driven by ~10% of the population: individuals with multiple chronic diseases, low quality of life and reduced, if any, ability to contribute to the labour market.

OUR ONE-SIZE FITS ALL APPROACH TO HEALTHCARE MEANS THAT INCREASED SPENDING IS NOT TRANSLATING INTO IMPROVED HEALTH OUTCOMES.

Despite public demand and political will to invest in healthcare, health outcomes are not improving. While there are multiple reasons, two stand out: (i) health systems tend to intervene at late stages of illness rather than investing in cost-saving health promotion and disease prevention approaches; and (ii) the medicines on which health systems spend the most money only work for a subset of patients.

WE NEED TO USE HEALTH DATA— INCLUDING REAL-WORLD DATA—TO ENABLE PERSONALIZED AND SUSTAINABLE APPROACHES TO HEALTHCARE.

Developing a viable PHC system is a 'wicked problem' that hinges on multi-stakeholder solutions. Stakeholders understand the value of data and evidence-based medicine—but unless all stakeholders move from an inertial focus on the legal and ethical issues that complicate data-sharing toward the development and implementation of solutions that enable the health data ecosystem, PHC will elude us.

PHC is about solving wicked problems that nobody can solve on their own—no institution, no doctor, no territory, no country.

Bogi Eliasen
Copenhagen Institute for Futures Studies

Preparing individuals and providers for personalized healthcare

WHILE STAKEHOLDERS ACROSS THE HEALTHCARE SYSTEM—AND BEYOND—WILL NEED TO COLLABORATE TO MAKE PHC A REALITY, WE MUST PAY SPECIAL ATTENTION TO THOSE DELIVERING AND RECEIVING CARE.

PHC will dramatically impact how patients receive care and interact with healthcare providers. Patients looking to contribute to and benefit from personalized healthcare will need to become comfortable with sharing personal health data. Providers will need to rely more heavily on real-world evidence to make decisions. Both will need to familiarize themselves with increasingly digital means of patient-provider engagement. We must ensure that these stakeholders are prepared and empowered to maximize the health and broader benefits of PHC.

The public needs to be educated and involved in discussions related to PHC, and I urge all stakeholders to find ways in whatever work they're doing to do this.

Alies Maybee
Patient Advisors Network

PATIENTS, CAREGIVERS AND THE PUBLIC MUST BE ACTIVELY ENGAGED IN CREATING THE FUTURE OF PHC.

There must be patient/caregiver involvement in all initiatives, working groups and conversations focused on advancing PHC. Suitable mechanisms must be established to regularly gather input from the broader public. Engagement will ensure that the right problems are being solved, that the solutions being put forward are practical and impactful, and that ethical risks are identified and care is taken to mitigate them. There must be a cohesive discussion with the public that explains how the components of PHC that they may hear about through the media (e.g. AI, genomics) come together to enhance health—and we must be transparent about both the benefits and the risks. A public that is literate in these topics will be ready to shape, participate in and benefit from PHC.

WE MUST ARM PHYSICIANS WITH EVIDENCE TO SHIFT FROM A REACTIVE MODEL OF TREATMENT TO A PROACTIVE MODEL OF PREVENTION AND WELLNESS.

Providers are not completely clear on what PHC encompasses, nor do they fully appreciate that applications extend beyond treatment to encompass the full continuum of health promotion and wellness. We must develop and share data with providers that demonstrates the potential of PHC in all areas of health, including disease prevention. Providers should also be included in discussions to develop policies and strategies around using PHC in a way

that reflects the day-to-day realities of the Canadian healthcare system to ensure that our approach is feasible and sustainable.

Patients, the public and providers must be engaged in setting PHC priorities, creating new models of engagement, and developing PHC solutions that are relevant, impactful and sustainable.

We can talk about ethics or privacy or consent, but I choose to turn the conversation towards enablement and transparency.

Angela Power
Newfoundland and Labrador Centre for Health Information

Empowering Canada's health data ecosystem

CANADA MUST SEIZE THE OPPORTUNITY TO BUILD ON ITS HEALTH AND RELATED DATA TO DEVELOP A HOLISTIC VIEW OF INDIVIDUALS AND THE BROADER HEALTH SYSTEM.

Canada is home to a wealth of health-related data, including medical records and health statistics, research-based datasets, data on the broader social determinants of health and data from devices that sit with different stakeholders across the country. Canada can leverage its national health research infrastructure to integrate and enable movement of data from the siloed components of the healthcare system to establish a health data ecosystem that allows us to apply big data analytics to generate meaningful evidence (including real world evidence) and generate insights that improve health system efficiency and patient outcomes.

CANADA CAN APPLY ITS LEADERSHIP IN AI TO ANALYZE COMPLEX DATA AND DRAW INSIGHTS TO INFORM EQUITABLE HEALTH POLICY AND HEALTHCARE.

Canada is a recognized leader in the development and implementation of AI technology. By applying this strength to explore determinants of health across our diverse populations—including how communities utilize and benefit from our publicly-funded healthcare system—we have a unique opportunity to improve health equity through evidence. CIFAR has assembled a task force of leaders across Canada's AI and health innovation ecosystems to develop an *AI for Health* strategy. The strategy will enable the complex analyses of the diverse and disparate datasets to generate insights for the personalized healthcare of all Canadians.

My vision for the future of PHC is one in which the investments that we make and the strategies that we adopt actually truly result in a reduction in the inequities that we know are really apparent, not just in Canadian health outcomes but also social outcomes.

Dr. Michael Schull
ICES

How ready are we for personalized healthcare?

IT'S TIME TO FULLY LEVERAGE EXISTING TECHNOLOGIES TO PROTECT THE SECURITY AND PRIVACY OF OUR DATA.

With data breaches making headlines, the public is understandably wary of the security and privacy of personal data. This concern is further exacerbated by the fact these two concepts are often unhelpfully conflated. Security refers to protection against unauthorized access to our data. Privacy relates to the right to control how our data is used within an ethical framework that respects personal identity. With proven technologies and approaches to enable both security and privacy, we cannot continue to allow these concerns to pose a major barrier to realizing the benefits of personalized healthcare. Canada can look to other jurisdictions that are leaders in curation, maintenance and growth of health data (e.g. UK Biobank and One Hundred Thousand Genomes Projects). We can do our diligence by putting new technologies into action through pilots to test technologies and to demonstrate the risk-benefit to the public. With time, ongoing dialogue and objective documentation of the benefits of PHC, public opinion will shift as it has in the past on other health-related ethical issues. We need to evolve from a rigid position that holds privacy as absolutely sacrosanct and come to appreciate that privacy risks can be curtailed—and that the benefits of sharing personal health data (and the risks of not doing so) far outweigh the negligible risks of error.

Canada has established technological strengths, a diversity of datasets and strong health research infrastructure that should be used to lay the foundation of an equitable PHC system.

We can't just put up the flag of privacy and say, sorry, can't do it. We can do a risk assessment, evaluate that risk and use appropriate technologies, document the process and demonstrate diligence to the public and other stakeholders.

Carole Piovesan
INQ Data Law

Co-creating Canada's Personalized Healthcare Readiness Index

The panel discussions set the stage for an interactive session focused on co-creating Canada's Personalized Healthcare Readiness Index. Workshop attendees were presented with six dimensions central to a fair, effective and sustainable PHC system:

- Access and Equity;

- Health and Social System Workforce;

- Technology and Digital Infrastructure;

- Policy and Regulatory Environment;

- Public/Patient Accountability and Engagement; and

- Research, Innovation and Evidence-generation.

Participants worked in small breakout groups to identify attributes (i.e. supporting features of our future PHC system) for each dimension. These attributes were compiled and synthesized in real-time and subjected to audience voting, generating an initial list of prioritized attributes that describe the healthcare future to which we collectively aspire (presented in the table below).

It's always the public that is the true driver of change—we need to have them see the opportunity of PHC and see the potential of what our technologies are capable of now and going forward. And we also have to let the public know that we don't have all of the answers and that we need their help.

Dr. Alan Bernstein
CIFAR

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	Trigger Question	Prioritized Attributes
Access and Equity	What are the attributes of a PHC system that ensures *equitable access* to health knowledge, services and innovations?	• Based on a holistic view of an individual (including social determinants of health) • Transparent, open and unbiased; rooted in trust among stakeholders • Universal and equitable access to understandable data • Dynamic and adaptive
Health and Social System Workforce	What are the attributes of a *workforce* with the knowledge, skills and resilience to enable PHC solutions?	• Capable of working in multidisciplinary, interprofessional, multisector, multicultural teams • Adaptable, agile and creative: lifelong learners • Knowledgeable about privacy, security, ethics and associated risks
Technology and Digital Infrastructure	What are the attributes of a health system whose *infrastructure* enables widespread adoption of PHC solutions and use of personal health data?	• Cohesive and interoperable on a national scale • Trustworthy, secure and traceable with transparent risk management • Enabled by tools that translate into insights and better care (not simply accumulation of data)
Policy and Regulatory Environment	What are the attributes of a *policy and regulatory environment* that enables appropriate use of data to guide better decision-making?	• Balanced risk-benefit approach • Transparency and clarity in both policy and application • Effective, consistent approaches to ethics, governance and consent
Public/Patient Accountability and Engagement	What are the attributes of a PHC system that both empowers and is *accountable to individuals, patients and the public*?	• Transparent, ethical and secure data sharing and reporting across the health system • Educated public and patients with health system and digital literacy • Mutual patient-system accountability and co-creation • Strong focus on public health, prevention and broader wellbeing
Research, Innovation and Evidence-generation	What are the attributes of a *research, innovation and evidence-generation ecosystem* that is fuelled by and unleashes the potential of PHC?	• Supportive of public-private partnerships and other collaborations • Focused on enabling a learning healthcare system • Focused on knowledge mobilization and implementation • Guided by patient partnership in co-designing research questions and sharing in the benefits

Initial workshop output

The following illustration captures the key elements and insights from the workshop discussion, including prioritized attributes of the PHC system to which we collectively aspire.
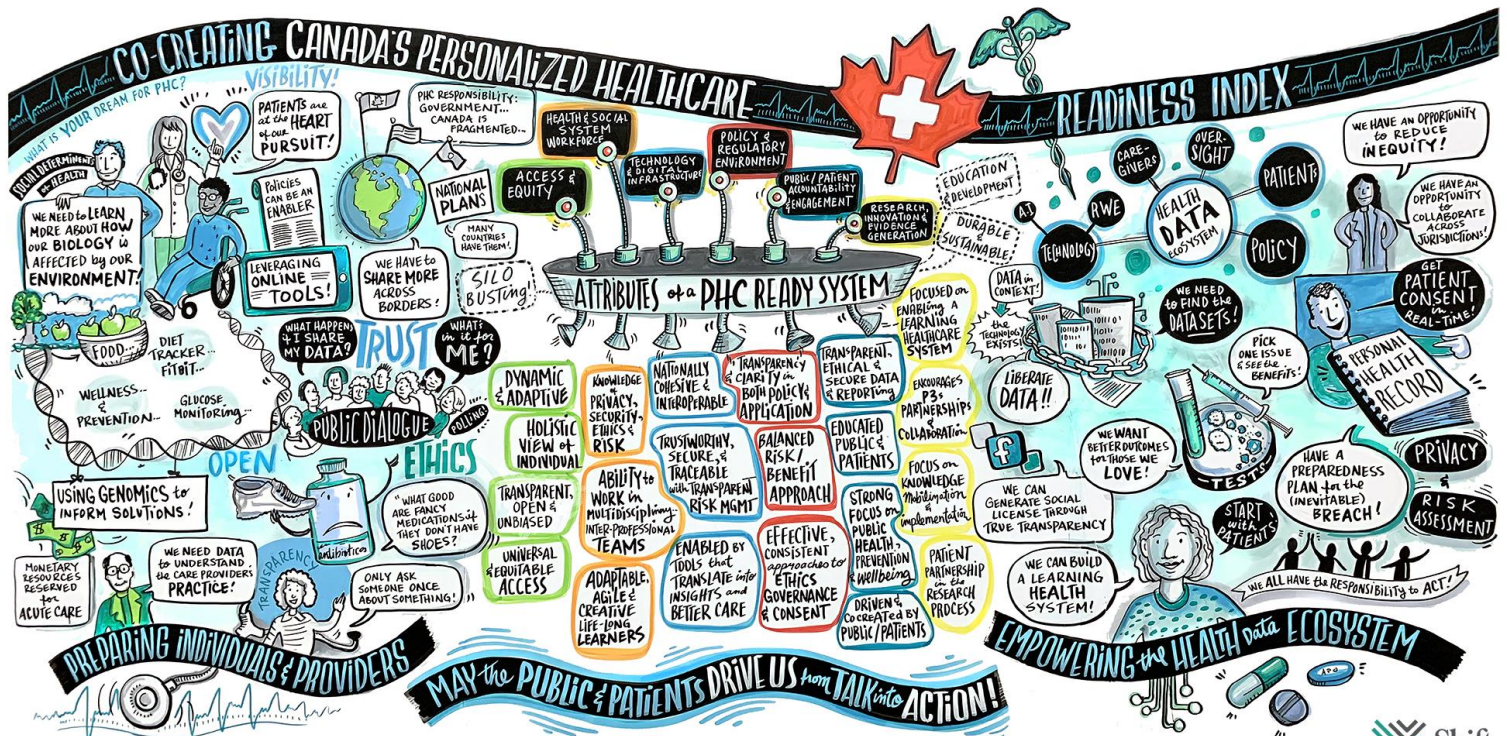
Call to action and next steps

Achieving our vision for PHC in Canada will require us to:

1. **Collaborate.** Building on the momentum of the 6 February workshop to continue to work together to identify challenges, develop solutions and formalize a plan to bring PHC to life in Canada. *As a first step, Shift Health plans to reconvene workshop participants via webinar to discuss and finalize the draft Personalized Healthcare Readiness Index.*

2. **Advocate.** Engaging patients, the public and decision-makers in discussions on the path forward to promote a shared understanding on the path forward and drive action.

3. **Evaluate.** Implementing key initiatives and studying outputs and impact to continue to refine and improve a learning healthcare system that ensures personalized healthcare for all Canadians.

For more information or to share ideas, please contact us at **phcready@shifthealth.com**