CITYAGE DIGITAL ROUNDTABLE

THE DATA EFFECT: DATA-DRIVEN HEALTH CARE BREAKTHROUGHS

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BACKGROUND:

British Columbia's health care system doesn't have a data problem -- it has a data-*sharing* problem. How can we use all the health data that we collect all over the province to save lives, predict outbreaks, allow citizens access to their own records, and build a health research sector that competes on a global scale? The clear answer is to share it.

The deficit of data-sharing was the central issue at a recent roundtable that brought together a select group of leaders from B.C.'s health care data system to envision the future.

ABOUT THE TOPIC:

The BC Ministry of Health's data platform has set the stage for more health care data sharing. It's meant to be a convenient and secure way to bring data from different organizations into a central repository, linking and analyzing it and allowing researchers and health care workers to use it while protecting everyone's privacy. Still in its early stages, it's already being used. Issues like data integration, analysis, capacity and skill sets, public acceptance, government engagement, and ethical and legal matters are still on the table, though. As we slowly emerge from a pandemic that perfectly demonstrated the importance of sharing outbreak data inter-provincially, our roundtable members wondered aloud whether it's either right or efficient for B.C. to hoard its health data.

"Genomic data can do a lot of things, but it can do a lot more things when it's linked to health data. What would take us another 20 years to solve and unravel about the genome without health data can probably be done within the next five years by combining health and genomic data. Although we may be protecting the data, we are probably doing harm to humanity by not sharing."

PANELISTS INCLUDED:

FEDERICA DI PALMA

Chief Scientific Officer & Vice President of Sectors, Genome BC

RAYMOND NG

Director, Data Science Institute at UBC

RACHAEL RITCHIE

Director of Innovation, Vancouver Coastal Health

ALEXANDRA FLATT

Vice President Pandemic Response & Chief Data Officer, Provincial Health Services Authority

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Data Science Lead, Genome BC

MARTIN WRIGHT

ADM, Health Sector Information, Analysis and Reporting, BC Ministry of Health

JENNIFER DEPREZ

Director, Data Management, LifeLabs

JEANNETTE VAN DEN BULK

Deputy Commissioner, Office of the Information and Privacy Commissioner for British Columbia

BRIAN SIMMERS

CFO and VP, People and Health Informatics, Providence Health Care

ERIK SUTHERLAND

Executive Director, Pan-Canadian Health Data Strategy, Public Health Agency of Canada

WENDY HURLBURT

President & CEO, Life Sciences British Columbia

MARCO MARRA

Professor, Medical Genetics, UBC; Director, Canada's Michael Smith Genome Sciences Centre, BC Cancer

KIM MCGRAIL

Scientific Director, Health Data Research Network Canada and Population Data BC

VALERIE LUKAC

Director, Management Consulting, KPMG

BILL TAM

Co-Founder, Digital Technology Supercluster

PARVEEN BHATTI, PHD

Principal Investigator, Cancer Epidemiology & Prevention, Scientific Director, BC Generations Project, BC Cancer, UBC

PARTICIPANTS' KEY CONCLUSIONS:

Each organization in B.C.'s complex health care system has its own way of collecting, storing and sharing data, unconnected to the cloud or to state-of-the-art analyzation programs. Since privacy, consent, ethics and data governance practices vary between health regions, it's hard to connect and navigate between them. We need a space where we can safely share our health data and solve big problems.

Sharing health data would allow for broader perspectives, research projects and collaboration. One solution is a system that resembles matryoshka (Russian nesting) dolls -- data systems that can interoperate with the larger ecosystem in BC, across Canada and the world.

Further to that, let's develop Canada's health data strategy first and then introduce B.C. idiosyncrasies, as opposed to developing B.C.'s data-sharing system first and then trying to integrate it with other systems across the country.

We need a working group within B.C. to try and figure out how to move this along, perhaps by setting ourselves up with a vision for the next five-10 years in the same way that Genomics England and the National Health Service (NHS) have done.

"We need a Paris Agreement, except for health data. What are we working toward for the next five years, and how do we reverse-engineer tactics to meet those goals?"

1.

PEOPLE'S HEALTH ISSUES DON'T DISAPPEAR AT THE PROVINCIAL BORDER, SO WHY SHOULD OUR DATA?

We need to create a system that protects patient privacy but contributes to a national body of knowledge.

The pandemic showed us that B.C.'s health data systems are massively fragmented. We should take a pan-Canadian approach to health data, knowing that it's our most precious asset in this digital age.

Data stewards encourage the sharing of effective, trusted, timely data; data privacy officers protect the privacy of personal data. These two roles both need to exist because each contributes to the public interest in a different way.

We need to be able to de-identify the patient while preserving and sharing their data.

Over the next 10 years, we must adopt the idea of a learning health system, where data from every encounter are used to continuously improve the health system. Not only can this data-gathering affect personal health outcomes, it gives providers and clinicians the information they need to care for entire communities.

2. HOW DO WE START CREATING STANDARDIZED, COHESIVE PLATFORMS FOR SHARING?

For a comprehensive view of community health, data-sharing platforms need input from outside the health care sector.

Health is not an island. We depend on data when it comes to education, social services, census, finance -- so let's really take a look at our health care ecosystem. Let's establish a vision for making data available in an appropriate way, so we can improve the performance and quality of health systems.

If our goal is to follow the patient through the health care system to see them in a three-dimensional fashion, we need well-understood common data keys.

We should allow researchers and other organizations and government sectors to bring in their own data and link it to the Ministry's federated health data. That way, we can uncover the social and economic determinants of health.

There's also synthetic data, where we're not trying to share real data but we're using real data to synthesize results based on certain properties, and then we're going to share those results.

3. HOW CAN WE USE TECH SAFEGUARDS TO ENSURE THE PRIVACY OF HEALTH DATA?

Ensuring widespread data literacy will give people more confidence in how their data will be used.

You never want a situation where somebody doesn't seek health care because they don't know where their data are going.

There are no technology roadblocks to data integration, analysis, capacity, skill sets, public acceptance or government engagement – there are just ethical and legal issues.

We need to use data literacy to win the public's trust. That's how we'll get enthusiastic advocates for the types of change that we want to save the health care system.

"We need to be able to track who has accessed the data and for what purpose -- was there a commercial intent? -- as a way to create a repeatable process. That's what we're calling, loosely, a data lab."

4. WHAT ARE THE PARTICULAR ISSUES OF GENOME RESEARCHERS WHEN IT COMES TO DATA?

Genome researchers need more generous, longer-term funding and access to Canada-wide sharing so data collected through biobanking contributes to big picture analysis.

Genome researchers often collect specimens that then sit for a long time in the bio repository, awaiting attention. If we could apply the latest amazing technologies to these samples, we could do whole genome sequencing and epigenetics work and unlock that data.

Because there are obstacles to sharing data across provinces, never mind the world, we find it difficult to contribute to international projects. Other countries have cohorts that are contributing by country and we're just contributing provincially.

If we wish to increase diversity, inclusion, public engagement and trust in genomic research, we need an injection of private sector resources and different types of funding models. If we want to uncover the etiology of diseases, for example, we need long-term funding, not just five-year commitments.

There's a constant fight between academia, research, industry, and global pharma when it comes to health data. We really need to envision what we're trying to do with it, and we must set aside some of the old barriers, both real and perceived.

5. HOW CAN WE IMPROVE B.C.'S HEALTH DATA PLATFORMS RIGHT AWAY?

The data is fragmented and often difficult to access.

We have a lot of really important research data that sits in different places and is in no way integrated with our clinical information systems. Some information is still on paper and it's hard to make that accessible. And while we can integrate it from an analytics perspective, we also need to make sure that it actually becomes part of the patient record.

Health authorities should be active partners – they're generating massive amounts of data on a daily basis. It's not research data, but there's a real opportunity to connect those two things.

Health authorities have limited capacity. That's a big barrier for data-sharing and health research.

A lot of the resistance to sharing has to do with data shame -- it's not "good enough" or "clean enough" or "curated," or "I wish I had more metadata." We've got to get over the shame. Let's start the sharing and have the courage to change.

"A good health strategy establishes the environment of policy, of governance, of standards, of trust, that enables the data to be shared most effectively in order to achieve the outcomes that we want."