INNOVATIVE APPROACHES TO THE USE OF HEALTH DATA: BEST PRACTICE SHARING BETWEEN DENMARK, CANADA AND QUEBEC

OUTCOMES REPORT

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OVERVIEW

The modernization of healthcare continues to evolve and expand across jurisdictions worldwide. In Denmark, Canada, and its provinces, including Quebec, their respective life science strategies are leading them to focus heavily on the use of health data as a means to ensure citizens have access to high quality healthcare. Denmark and Canada differ in their current health data practices, yet they are equal in their desire and potential to precipitate significant positive impact on population health.

On June 9 and 10, 2022, the Trade Council of Denmark in North America, the Royal Danish Embassy, and the Danish Life Sciences Forum (Novo Nordisk Canada, LEO Pharma Canada, Lundbeck, and ALK-Abelló) hosted two virtual roundtables with a federal and provincial focus, respectively. In the separate sessions, stakeholders from Denmark, Canada, and Quebec gathered to discuss innovative approaches in the collection, storage and secondary uses of health data— and share best practices therein.

Experts (see next page) lent their insights as they collectively considered a range of topics, including: the importance of a health data strategy, how to leverage sources of existing health data, the role of public-private partnerships, as well as privacy and creating societal trust in the use of health data.

The roundtables revealed that despite differences in health data infrastructure and adoption, Denmark, and Canada, including Quebec, share common challenges: collecting holistic health data, scaling healthcare digitalization and data centralization, and improving public trust and data literacy. To that end, they are also aligned in their visions for the future: enabling public-private partnerships to improve healthcare, leveraging health innovation for economic and social growth, and international cooperation in setting standards and sharing best practices. The following sections of this report describe the main outcomes of the roundtable discussions.

EXPERT INSIGHTS

Representatives from the following institutions participated in the roundtable discussions:

- Sundhed.dk
- Danish Medicines Agency
- Novo Nordisk A/S
- Health Canada
- Public Health Agency of Canada (PHAC)
- Office of the Chief Science Advisor of Canada
- Canadian Institutes of Health Research (CIHR)
- Canadian Institute for Health Information (CIHI)
- Canadian Agency for Drugs and Technologies in Health (CADTH)
- Ministry of Health and Social Services of Quebec
- Ministry of Economic Innovation of Quebec
- Canada Health Infoway
- Life Sciences Ontario (LSO)
- Fonds de Recherche Québec Santé
- University of Montreal Health Centre
- McGill University Hospital Centre
- TECHNATION
- BIOTECanada
- Bio International
- Quebec International
- Montreal InVivo

CONTEXT

Denmark, Canada, and Quebec are simultaneously developing strategies and launching initiatives to digitalize healthcare and support strong life sciences sectors. See below for a summary of the current status in each jurisdiction.

Denmark

Denmark's history of collecting and storing electronic health data dates back more than 40 years. There are over 170 clinical databases, and due to Denmark's unique patient identifiers, it has been made possible to combine patient data for research.

Denmark has several initiatives in its Digital Health Strategy (2018-2022) and new Life Science Strategy (2021-2023) dedicated to further improving health data in the country.

Canada

The Government of Canada, along with provinces and territories, is in the process of creating the first Pan-Canadian Health Data Strategy (PCHDS). This strategy will specifically focus on modernizing data collection, approaches to privacy and sharing data between provincial and territorial governments.

An Expert Advisory Group has been working on providing the government with feedback and advice on the strategy, which aims to overcome critical barriers to data collection, sharing, and utilization. To date, key factors include trust and accountability, risk aversion, and incentives.

Quebec

Health data are a central part of Quebec's recent life sciences and innovation strategies, i.e. stratégie québécoise de recherche et d'investissement (2022-2027) and stratégie des sciences de la vie (2022-2025). The province sees data as a key component of aligning population health and the economy. They are on a mission to develop platforms that enable the mobility of health data and to support projects that enable experimentation within the parameters of ethical and responsible use of health data.

SHARED CHALLENGES

Challenge #1: Collecting Holistic Health Data

Generally, when we think of health data we think of disease incidence, rates of hospitalization and complications, medication prescriptions, and treatment counts, among other measures. Although Denmark, Canada, and Quebec currently track such information efficiently, this type of data lends itself better to economic analysis than the assessment of overall population health. In Canada, hospitals generate the majority of this data— there is a gap of information from primary and community care, a critical patient-clinician interaction point in the healthcare system. In both Canada and Denmark, the realm of mental health is poorly quantified, nor is data shared widely with public authorities. This represents a significant missed opportunity to capture upstream and downstream consequences of treatment protocols and resource allocation.

Biology and care account for only half the story of a person's health. Environmental influences play a vital role, too. The World Health Organization's definition of health refers to a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Yet, our traditional conceptualization of health data does not include social determinants of health or nuances of psycho-emotional elements of wellness. To generate holistic health data, parallel government ministries must cooperate with each other, as well as private businesses, to integrate information from their respective sectors. This is easier to achieve in more digitalized societies such as Denmark, where each citizen has a social security number (called a CPR number) that is widely used when interacting with public authorities, health authorities, libraries, banks, and so on.

Disjointed data sets from various sources are difficult to integrate for analysis and decision-making. However, interoperability across sectors should not be the end game. Instead, we should leverage artificial intelligence (AI) to incrementally process and collate disparate data. Under a unifying framework, the resulting information can be applied to upgrade clinical practices and broader policies to improve the health of our populations.

Challenge #2: Digitalization, Centralization & Scaling

The first step in maximizing health data for positive impact is to execute a digital healthcare strategy and ensure that the appropriate infrastructure is in place. In that regard, Denmark is more evolved than Canada. It is understood that the digitalization of Canadian healthcare will be the result of a multi-year transformation process, likely to take about 10 years. Given that healthcare in Canada is primarily a provincial responsibility, the trajectory of this timeline is complicated by misalignment of asynchronous democratic cycles. We cannot risk the inertia that comes from changing political stripes through elections. As such, an integral project like this—one that has the capacity to benefit and empower every citizen— needs to be broken up into smaller meaningful milestones that can be accomplished within shorter timeframes.

Under the Danish model of connected e-health, they build components and networks rather than large systems. Institutions are free to choose which programs and tools to implement, the data from which is aggregated by public entities. Dedicated organizations are positioned to liaise between various stakeholders in the ecosystem and galvanize them toward consensus-based end goals.

While standardization is important to generate insights from health data efficiently, over-standardization can be as bad as full anarchy. Experts therefore recommend achieving harmonization between data sets by standardizing semantics of tests, diagnoses, and demographics over time as opposed to data collection processes. Denmark has the ability to review their ecosystem's pooled data from various sources to identify opportunities for quality improvement. They subsequently build modular solutions to address gaps moving forward and do not bother retrofitting old data. Meanwhile, Quebec is implementing a data lake approach, whereby it will centrally store raw data from various sources for ad-hoc analysis. Governments are challenged with striking a fine balance to enable data sharing without breaking innovation capacity.

Experience shows that the best, most sustainable initiatives grow incrementally from mutual agreements and collaboration. A simultaneous bottom-up approach is also valuable; once health databases gather more users, gain maturity, and display judicious handling, the practice will eventually be adopted and integrated into governance models.

Challenge #3: Public Trust & Data Literacy

No health data strategy can succeed without the participation of citizens. All related activities should be grounded in user-driven design and operate under the guiding principle that citizens are partners, not subjects, and their data should always be returned to them.

Citizens must be able to recognize the direct personal and societal benefits of consenting to the collection and sharing of their data. They must also trust that those handling the information will protect its security and act according to person-centred guidelines with integrity. Denmark has benefitted from a historic culture of trust as it has collected various data about its citizens for decades. Now, Danish citizens expect digital solutions and understand that data sharing is necessary. Importantly, authorities are very cognizant about how to consistently work to maintain and protect that inherent trust. One of the main mechanisms to accomplish that is fierce transparency: Denmark's digitalization policy hinges on the notion of giving data back to users and being upfront in cases of data misuse. Danish health data consists of an open model, whereby any treating physician can access a patient's full data set, and includes automatic safeguards to reduce risk of misuse. Patients can log onto the national e-health portal at any time and see who has accessed their data; the system will send a notification to the patient when a person outside of the normal pattern accesses their profile. Furthermore, Denmark publicly flags data breaches or mishandling, and swiftly terminates and/or prosecutes liable actors.

When we talk about trust in Canada, the literature states it is often based on personal experience. Canadians trust what they see and whom they know. For instance, while trust in general practitioners has traditionally been high, there was a large uptick in trust in pharmacists as a result of increased interactions throughout the COVID-19 pandemic to access vaccines and tests. In Quebec, patients are more inclined to share data for scientific research as they anticipate an improvement in their care, especially if they suffer from a rare disease. The Health Data Research Network has undertaken deliberative consultation with patients across Canada on their expectations around their health data. Preliminary findings indicate that Canadians are willing to share their data by default amongst their circle of care, with academic researchers to improve health outcomes for specific diseases, and to improve safety and effectiveness of the public system.

Respondents also underscored that those who collect and use the data have the duty to protect it, and this should be governed by relevant laws. It is important to note here that concerns about privacy do not automatically equate to a lack of support for these activities.

Unlike Denmark, the expectation to share personal data routinely does not yet exist in Canada—a cultural circumstance that challenges the digitalization process. More active resistance to sharing data also poses a threat. Citizens may not be willing to share their data because they lack a fulsome understanding of the ways in which their information will be accessed and the consequences of it. Meanwhile, some subsets of the population may be extremely reluctant to give their data due to historic prejudice and mistreatment. Unfortunately, these same citizens may also be at higher risk of complications from poor health promotion, prevention, and treatment. We need to engage these reluctant populations better and earlier. We need to work with them to determine their needs and desires, which should subsequently be evaluated and integrated into the development of process and systems. A more in-depth education and communication campaign is needed. Otherwise, they will refuse to participate.

COMMON GOALS

Vision #1: Improve Healthcare Systems Through Public-Private Partnerships

The future of medicine lies in precision treatments and evidence-based approaches, both of which require health data. Experts from Denmark, Canada, and Quebec envision home-grown life sciences ecosystems through which there are multidirectional flows of raw data. Working together with industry partners, such as pharmaceutical, medical device, and service provider companies, can generate synergies to address major health challenges.

About 90% of the Danish public is willing to share personal data for scientific research as long as a public partner is the driving force of the initiative. To date, Danish pharmaceutical companies can request access to data if they have a collaboration with an academic entity. Yet, public authorities do not have access to the company's post-marketing trial data. To create balance, the Danish Medicines Agency has begun working with the European Medicines Agency to collect raw data from pharmaceutical companies, with which they conduct their own analyses. In this scenario, both sectors are dependent on each other and this sets the foundation for resource sharing.

If private entities can make use of public data, then they should extend the same courtesy back to the government. Imagine the value if real-world Phase IV data could be compared with the daily basic health data gathered across the nation: we would gain exceptional insight into the efficacy of various treatments and leverage it to improve standards of care and negotiate optimal reimbursement prices. Both Danish and Canadian experts agree that public authorities and private companies should be jointly responsible for real-world data, using transparent databases of raw data as part of risk mitigation.

Denmark is working to “decriminalize” private companies in the court of public opinion to pave the way for greater collaboration. In Canada, the healthcare system’s response to pandemic demands was successful where there were business interests, highlighting the value of public-private partnerships to meet societal challenges. Looking to the future, there is untapped opportunity for public health authorities to leverage insights from data collected by consumer wearables for secondary use. Although it comes with its complexities owing to limited standardization or ability to validate, the power remains with users to consent to the sharing and analysis of their data.

There is great potential for public and private stakeholders to co-create solutions and co-value projects to improve the healthcare system. For appropriate impact, these initiatives must employ person-centred design from the outset. It should be noted, however, that while health data can improve what already exists, it may not surmount fundamental issues like the fact that not every citizen in Canada has access to a general practitioner. Healthcare digitalization and associated data programs must be responsive to the larger context.

Vision #2: Leverage Health Innovation to Stimulate Social and Economic Growth

Denmark, Canada, and Quebec are alike in their intention to invest in sustainable and inclusive research and innovation to stimulate knowledge development. They aim to promote excellence within strong life science sectors, with the ultimate goal of creating economic and social growth. To achieve that, the guiding principles should be modularity and shared frameworks. The rationale is that when you get enough of the right building blocks in place, innovation takes off on its own. Moreover, systems are able to respond more quickly and efficiently to patient and social needs (i.e. pivoting to virtual clinical consulting during the COVID-19 pandemic). Under the Danish national strategy, stakeholder organizations and service providers have the freedom to make choices that suit them best (*e.g.* implementing specific electronic medical record software) while still working together across the country on strategic initiatives.

Canada needs to have collaboration across the health and life sciences sector to use data efficiently. The Pan-Canadian Health Data Strategy aims to create a roadmap to build infrastructure for interconnected health data. Canadian experts recommend a data stewardship model, allowing for health data to be as open as possible and as private as needed. They envision this fitting into a person-centred and self-learning health system in which stakeholders adopt common principles and use data insights to empower communities and drive equitable outcomes, the impact of which is consistently measured.

Vision #3: International Collaboration

More and more, countries will be required to respond quickly to the demands of their growing and aging populations. Given the rate of technological innovation as well as ever-changing environmental and societal pressures, bureaucratic inertia poses a significant roadblock. To expedite efforts, experts from Denmark, Canada, and Quebec see immense value in international knowledge and resource sharing, subsequently adapting key learnings and best practices to local settings. With global cooperation, like-minded nations can co-develop approaches to solve universal challenges. It is important that we continuously seek inspiration from other jurisdictions and usher in standards that transcend culture and geography.

TAKEAWAYS

Although Denmark and Canada are unique in their healthcare system infrastructure, the countries are aligned in their governing principles and objectives. Best practice sharing between these nations is invaluable. Canada can learn from Denmark regarding the notion of building health data infrastructure incrementally using modular digital solutions, actively protecting public trust via extreme transparency and constant involvement of citizens, and facilitating public-private partnerships to advance health matters. Denmark can take cues from Canada regarding scaling, handling regional strategies under a national framework, and consulting with vulnerable population groups.

The roundtable participants agree that health data is a precious resource that needs to actually be used, not just collected. As each jurisdiction continues to evolve its e-health strategy, the experts stress that the following best practices are kept in mind:

- Grow data and digital literacy amongst the public, workforce, and decision-makers—it is crucial for buy-in.
- Always give health data back to the patients. When individuals have tangible experiences with it, it drives trust and understanding, and, over time, quells concerns about data privacy.
- Prioritize transparency, as it is paramount in protecting citizens' data and sustaining public support.
- Create policies and processes that are person-centric.
- Ensure equity by soliciting feedback from marginalized population groups.
- Generate holistic health data that reflects the various factors that influence individuals' wellbeing.
- Leverage AI to collate and analyze disparate sources of data.
- Do not over-standardize health data collection such that innovation capacity is stifled.
- Expand incrementally to avoid bureaucratic inertia and maintain adaptability.

It is clear that barriers to healthcare digitalization and data expansion primarily relate to culture, policy, process, and governance—NOT technology. Locally, legislation is required to ensure easy, unified, transparent, accountable and secure access to health data. Internationally, we can work together to harmonize data policies across borders.

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