

ACCESS TO DATA AND CONNECTIVITY IN HEALTHCARE – LESSONS FROM DENMARK

PREPARED BY THE TRADE COUNCIL OF DENMARK IN CANADA



TABLE OF CONTENTS

- **03** PURPOSE, KEYNOTE BY MR. KASPER LINDGAARD
- KEYNOTE BY MS. FREDRIKA SCARTH
- **05** KEY THEMES FROM DISCUSSION
- **17** NEXT STEPS, RESOURCES, AND SPONSORS





PURPOSE

The Royal Danish Consulate was delighted to host a roundtable discussion to help exchange ideas and best practices on how Ontario can develop a digital health strategy to help improve the speed and efficiency of care for Ontarians by using learnings from other successful jurisdictions, including Denmark. The discussions covered a range of thematic areas, including:

- The role of data and connectivity in the health system
- The importance of public-private sector collaboration in digital transformation
- Considerations for developing a digital health strategy

KEYNOTE BY MR. KASPER LINDGAARD

Mr. Kasper Lindgaard, Head of Division at Denmark's Ministry of Industry, Business and Financial Affairs, delivered the first keynote. He oversees the implementation and coordination of the National Life Sciences Growth Strategy, implemented by the Danish government in 2018 to strengthen an already flourishing life sciences sector. The focus of his presentation was on 'Digital Denmark', the underpinning of a strong life science sector.

Denmark is the most digitized country in Europe, and globally, based on the Digital Economy and Society Index. This is because Denmark has made digitalization a priority. The country has recognized that digital transformation in the life sciences sector leads to an increase in productivity and prosperity. Danish health data is unique because they collect high quality health data over long periods of time, with comprehensive health data registries and a unique personal identification number that makes it possible to link data across these different registries. They have a wealth of data that includes biological samples and digital information, and even collect data from ambulances. Denmark also uses its high-quality data for population health purposes. For example, the health and environmental systems can identify specific illnesses in certain regions by cross-referencing industrial pollution data and health information.

Regarding privacy issues, Denmark is unique in terms of citizen trust in public authorities. Society has a high degree of trust in its publically funded healthcare system and expects the system to be digital. As a result, citizens are comfortable sharing their healthcare data. The government views better data as a potential cost reduction to the system and is willing to invest in the infrastructure and strategy in order to implement digital solutions. Privacy is implemented according to the 'privacy by design' method, as well as by the General Data Protection Regulation (GDPR).

One major challenge identified by Denmark is that its health data is stored in silos. However, they have taken a proactive approach and created national strategies for precision medicine and digital health to overcome this challenge. Furthermore, they have created an initiative called Data Saves Lives, which looks into mapping 170+ registries. This initiative also provided recommendations to the government to have one point of entry to access data; a data land map to use in national and regional registries; as well as methods to analyze the data to try to test for and identify new correlations.



KEYNOTE BY MS. FREDRIKA SCARTH

Ms. Fredrika Scarth, Director of the Secretariat to the Premier's Council on Improving Healthcare and Ending Hallway Medicine in Ontario's Ministry of Health and Long Term Care, delivered the second keynote. In this role, she works with the provincial advisor on health quality to support their programs. She provides leadership and direction on a range of innovative funding programs and health service delivery models that aim to improve patient outcomes and experience while ensuring health system sustainability.



The mandate of the Council on Improving Healthcare and Ending Hallway Medicine is to make recommendations to the Premier and Minister of Health regarding ending hallway medicine and creating more value in our current healthcare system. On average, there are over 1,000 patients waiting in emergency wards in Ontario every day. The goal is to determine how patients can receive timely care, prevent hospitalization, and transition out of the hospital appropriately. The government wants to structure care around the patient in a way that they can navigate and understand. The new Government of Ontario plan includes the following actionable steps: organize health care providers as cohesive Ontario Health Teams based on geography, provide the public (patients, caregivers, families) with help navigating the healthcare system, integrate provincial oversight agencies, and improve access to digital tools.

Canada and Denmark are facing similar healthcare challenges in terms of a shortage of general practitioners and nurses and an aging population. This is creating a greater need for efficiency via the use of digital technology. In Canada specifically, health is less digitized than other sectors. One of the goals of the Ontario government is to have one record for each patient, not multiple disparate records across multiple institutions. The government has identified that there is a need for connectivity across the whole care spectrum in Ontario, specifically in terms of point of care tools, coordinated care tools, as well as patient and caregiver tools. There is a specific focus on making sure primary care is the backbone of our medical system in Ontario, and using that as a base to ensure a continuity of care and healthy aging in the community.

In Ontario, citizens are demanding digital health, however, patients do not want digital health in place of personal interactions. Ontario needs to get to a place where they are connected and share data across sectors. The Ontario Telemedicine Network (OTN) has resources to assist, but the utilization of OTN is mainly in remote regions. OTN's resources need to be utilized more broadly.



KEY THEMES FROM DISCUSSION

THEME 1: THE ROLE OF DATA AND CONNECTIVITY IN THE

HEALTH SYSTEM

One recurring discussion theme was the role of data and connectivity. An important factor in the success of data and connectivity in Denmark is social cohesion and trust. Patients trust the government and are willing to communicate and interact with the public sector and ultimately share their health data. The digital transformation in Denmark began in the 1980s, allowing citizens to share and adapt to the increasingly digital environment over time. In Denmark, there will now be a login function for patients to see who is accessing their data.



One major challenge in Ontario is our privacy legislation and policies, creating a hesitancy to share health data for social good. We historically have been institution-focused rather than patient-focused. However, there is a readiness amongst Ontarians to share data, provided we get the right infrastructure in place. One of the barriers to implementing this infrastructure is the funding silos that exist across the various parts of the health system in the province. This creates the feasibility challenge of moving data between these separate systems and silos. There is a need for interoperability standards so the disparate systems can work together. Data needs to be well described in order to be exchanged between the separate systems. Denmark enforces standards of interoperability and there is an opportunity for the Ontario government to learn from these standards.

THEME 2: THE IMPORTANCE OF PUBLIC-PRIVATE SECTOR COLLABORATION IN DIGITAL TRANSFORMATION

Public –private partnerships were essential in the success of Denmark's digital transformation. In order to make pathways smooth and accelerated you need patients, providers, government and industry to work together. In Ontario and Canada at-large, there is a lack of trust on the side of government with industry, which is preventing these types of partnerships. Innovation occurs within the private sector, thus they need to be a trusted partner in finding solutions. Industry can aid government in filling in budget gaps when implementing new strategies and methods. When accelerating innovation into the system, this requires investment. Ideally, the patient should benefit by having better healthcare at a lower cost, which requires upfront investment and government collaboration with the private sector.

One example from Denmark is ambulances, which are privately owned. They collect patient data and this data is subsequently shared with the public sector. There is a mentality in government that 'health is wealth', whereby the life science industry creates wealth and revenue. Partnership and collaboration between government and industry is a given, as the government is open to the value that industry provides. The private sector is provided a seat at the table, and as a result they have a strong role in decision-making. The Danish healthcare system has proven that it is more efficient to co-develop strategies with private sector and implement them together. A recent initiative is looking into measuring the societal benefit of implementing a new initiative compared to the actual cost. In Europe at large, there is recognition that you need automation and push incentives in order to see success in the digital health space.

KEY THEMES FROM DISCUSSION

In Ontario, procurement rules are a barrier to public-private collaboration and the implementation of digital health. Hospitals are open to using co-design methods with industry. However, our procurement governance has centralized organizations assessing value and these solutions often do not have the opportunities to be purchased into these organizations. Value based procurement and co-design approaches offer Ontario an opportunity to work with industry to implement more innovative digital health solutions.

Both Denmark and Ontario face challenges with data standardization. There are no requirements for what to capture or how much. Providers need to have guidelines and data capture at the point of care with standardization of common data elements. International health outcome measures will then lead to data flow.

To accelerate digital health pathways, both industry and the public need to be in the room to demonstrate value. Currently, industry does not have a seat at the Ontario strategy table in both the life science and digital health sectors, which would be valuable in order to transition from the 'land of the pilots' to large scale digital health implementation.

THEME 3: CONSIDERATIONS FOR DEVELOPING A DIGITAL HEALTH

STRATEGY

One major consideration identified in the development of a digital health strategy is that there needs to be a mentality shift in Ontario: the individual holds the data, not the system. We need to consider whether we are doing as much as possible with the data. If we are bold and take on privacy challenges, it may be less overwhelming to take on multiple systems. It is better to take our time in developing a robust digital health strategy in order to develop a strategy that is accurate rather than try to make large, ineffective changes.

BARRIERS IN ONTARIO

Several barriers preventing access to data and connectivity in Ontario were discussed at the roundtable. First were privacy rules, which are restrictive in terms of sharing patient data.



Second is that there is a lack of public trust in government, which results in an unwillingness to share data. Third is that portals and databases are organization-based, leading to disparate data sources that are not interoperable. Finally, government policies, such as the governance of procurement, are restrictive. We develop technologies but we cannot ultimately procure them, as there are 'no dollars at the end of the rainbow'.



NEXT STEPS

This roundtable provided an opportunity for private and public sector to come together to share and discuss best practices in both Denmark and Ontario to improve access to data and connectivity in our healthcare systems.

Take-aways for Ontario include the need for a whole-of-government approach, where the separate ministries work together to help improve access to data, connectivity and digital health. Some considerations would be the standardization of data sets (ICHOM standards[1], for example). We can use a banana model and start from the corners, whereby we implement smaller changes. Incremental changes can be highly effective, rather than implementing a new system.

We can build trust and collaboration by giving industry a seat at the table. Furthermore, in Ontario there is a need to move beyond the land of pilots by adopting innovative procurement methods and value-based healthcare, all of which includes generating data. We can use directives – not just policies and guidelines – to be more efficient. In terms of addressing privacy issues, there is an opportunity to leverage the current move to reduce 'Red Tape' in order to improve our access to data and connectivity in healthcare.

Both Ontario and Denmark recognize the need for access to data and connectivity in healthcare, and how this ultimately benefits the patient and infuses value into our healthcare system. The Royal Danish Consulate will continue to organize similar forums in order to further explore some of the key themes that emerged during this roundtable.

RESOURCES

- 1. Danish Life Sciences Forum website
 - Danish life sciences growth strategy
 - Keynote presentation by Mr. Kasper Lindgaard
- 2. Danish Digital Health Strategy 2018-2022
- 3. Data Saves Lives Initiative

SPONSORS





