CALL TO ACTION
FOR RESPONSIBLE
INNOVATION IN
DIGITAL HEALTH

An initiative of the
Digital Health Consortium following up
on the International Symposium –
Responsible Innovation in Digital Health
January 29 and 30, 2020

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EXECUTIVE SUMMARY

This call to action is rooted in the reflections and exchanges that took place during the International Symposium: Responsible Innovation in Digital Health, Opportunities, Barriers and Avenues held in January 2020 at the Université de Montréal during the initiative of its Digital Health Consortium. These reflections and exchanges were subsequently used as an opportunity for complementary discussions among six groups of digital health stakeholders. Throughout this process, the objective was to identify concrete courses of action likely to responsibly accelerate the health sector's digital transformation.

The exchanges during the Symposium, as well as the subsequent discussions by the expert panels, led to a series of courses of action covering three major areas of digital health: technologies and infrastructure, governance and public policy, and the participation of citizens and users in the innovation process. Five priority areas for action have been identified:

1. Modernizing IT tools and equipment

2. Training health system professionals, workers and managers

3. Accessing and sharing health data

4. Creating organizational conditions for a learning health system

5. Valuing citizen and clinician practices as a basis for digital transformation

This call to action does not incorporate the entire wealth of ideas and exchanges that were expressed either at the symposium or during the expert group meetings. It does however convey the main courses of action on which consensus has been reached and thus invites us to act together to accelerate the pace of transformation and become a responsible model of digital health.

Digital health is a broad concept that encompasses the applications of information and communication technologies to support all health-related activities. It includes data sciences applied to health, the design and application of operations research and learning algorithms. Digital health also includes the study of the ethical, legal, political and societal implications of technological approaches.

Although the digital transformation of the public sector in health is occurring later than in other sectors of society, its development is now taking place exponentially and involves all stakeholders. Digital approaches in all sectors affecting health are at the heart of innovation, both for fundamental and clinical research and for patient management and support. The digital transformation in health would benefit from operating in accordance with ethical rules and standards of conduct, taking into consideration ecological and economic dimensions, while respecting the principles of equity, diversity and inclusion that will ensure a responsible transformation.

This **call to action** invites all stakeholders to act in a concerted manner in order to accelerate a responsible digital transformation in health.

A REFLECTION INCLUDING ALL STAKEHOLDERS

The reflection that led to the five priority areas for action identified here is based on the discussions and exchanges that took place during the International Symposium: Responsible Innovation in Digital Health, Opportunities, Barriers and Avenues at the Université de Montréal. The Proceedings of the Symposium were then deliberated by panels of experts, made up of scientists and decision makers from various sectors: academic, public, industry and citizen representatives. The result is this call to action, which aims to rally all stakeholders in innovation and digital transformation in health around concrete courses of action, thereby suggesting solutions for a responsible digital transformation.

A CALL TO ACTION FOR A RESPONSIBLE DIGITAL TRANSFORMATION IN HEALTH

The digital transformation in all spheres of health is now inevitable and has enormous potential for promotion, prevention of disease, diagnosis, treatment and organization of care and services in the health system. As long as the rules of equity, diversity and inclusion are respected, the use of connected objects for more efficient home monitoring, telehealth, and mobile applications to support taking charge of one's own physical and mental health are examples of the potential digital technologies offer.

Add to these examples the use of dynamic artificially intelligent (AI) algorithms applied to mega health data to speed up diagnoses, drug development and access to personalized healthcare. In mental health, for example, continuous monitoring of a patient's condition can help detect an episode in the early stages of development. In the case of public health, mega-data can be used to track population health indicators, understand the impact of public policies and optimize the performance of the health system. AI can also help identify the emergence of disease in both animal and human health and thus avoid preventive antibiotics.

While the benefits of digital technology are substantial, the responsible digital transformation in health faces many challenges, including tensions generated by a disconnect between the culture of innovation in health and the culture of digital technology. This tension is less exacerbated in other areas of life (e.g., transportation, finance). The rate at which digital innovations and solutions are invading the market is creating tensions with the health sector, where the integration of new technologies is highly regulated. The world of health faces a structural challenge arising from the model of health innovation which, by tradition and prudence, is regulated by a complex

set of regulatory frameworks and is usually the subject of centralized decisions, given our universal and public health system.

Some of the challenges raised include:

- ecosystem access to material and human resources to develop and maintain leading-edge infrastructure essential to digital transformation.

- the availability of a skilled and trained workforce capable of operating in a digital environment.

- increasing the digital literacy of individuals through an inclusive approach and mitigating the risk of increasing individual and social inequalities.

- citizen access and access for the clinical and scientific communities to administrative and clinical health data.

We can add to this list the notion of accountability for this transformation with respect for individuals and the confidentiality of personal information, ensuring an inclusive and equitable transformation. In this regard, the Montreal Declaration for the Responsible Development of AI offers a series of ethical principles to guide the development of technological innovations towards morally and socially desirable ends.

The COVID-19 health crisis experienced here and around the world has catalyzed the need to deploy digital health solutions. In Quebec, for example, the regulatory framework of the Régie de l'assurance-maladie du Québec (RAMQ) was quickly amended to allow teleconsultations. Artificial intelligence approaches were quickly leveraged in research

efforts to identify pharmaceutical interventions and tracking applications were quickly developed to identify contacts. Telepresence applications have helped alleviate the isolation of remote populations and more vulnerable individuals during a period of physical distancing from family and caregivers. The health crisis catalyzed the needs and accelerated the digital transformation applied to health.

The digital transformation in the health sector lags far behind other sectors of life while the needs are increasing. While there are very real risks of adverse effects related to the development and use of information technologies, such as increased social inequalities, the potential benefits of a successful digital transformation are numerous, both economically and in terms of the health of populations and the well-being of individuals. Such a transformation holds out the promise of significant breakthroughs for better healthcare and health systems, as well as for health promotion and disease prevention for the benefit of all. It is within this framework that the Fonds de recherche du Québec – Santé (FRQS) has issued an invitation to share data linked to research on COVID-19 while deploying a collaborative network in which digital technology plays a key role.

A COLLECTIVE REFLECTION BY EXPERTS

Sensing the urgency to act, Université de Montréal's Digital Health Consortium took the initiative to launch a call to action aimed at accelerating the integration of digital tools in health. The challenges to the full deployment of a responsible digital transformation

"Digital health ... it was possible because the crisis has broken down barriers ... huge barriers that existed. These barriers should not be allowed to go up again when the crisis is over."
[free translation] — Dr. Nathalie Caire Fon
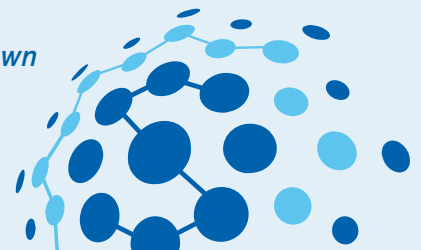
in health are significant and, at first glance, opinions seem to be divided on the priorities to be addressed. At the same time, Quebec is not alone in facing these challenges. Experts from outside Quebec, in Canada and internationally, can certainly help define the outline of a potential call to action. In order to draw on experiences from here and elsewhere, experts from various sectors were invited to discuss avenues likely to accelerate the digital transformation in health at the International Symposium on Responsible Innovation in Digital Health held on January 29 and 30, 2020 at the Université de Montréal.

Following this symposium, the Digital Health Consortium brought together six groups of experts, including public decision makers, in order to take the reflection further and identify a series of actions to be implemented. These groups included members of the academic community, government agencies and the private sector. The courses of action identified by this collective process are the result of an inclusive reflection process. Citizens took part in the Symposium's discussions to ensure that patient and user perspectives were integrated throughout the process.

> *"…there are ethical charters and the law, they [AI developers] don't always manage to understand how this applies to their situation in practice… The need to bridge this gap is an important request so that we don't lose these people's interest in the responsible development movement."*
> [free translation] — Catherine Régis
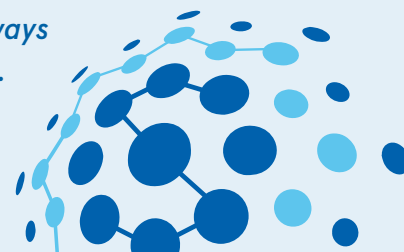
FIVE COURSES OF ACTION TO ACCELERATE RESPONSIBLE DIGITAL HEALTH TRANSFORMATION

The five prioritized courses of action can be grouped under three main areas: technologies and infrastructure, governance and public policies, and citizens and users. Grouping the suggested actions into three areas could prove useful to decision makers at all levels and promote the successful integration of digital tools in health.

Technologies and infrastructures

→ **Modernize digital tools and computer equipment in health and social services institutions** and make them accessible to professionals, workers and managers **(TRACK 1)**

→ **Train health system professionals, workers and managers** in consultation with the professional orders to ensure that they meet tomorrow's training requirements **(TRACK 2)**

Governance and public policies

→ **Ensure sharing and access to health data while protecting personal information (TRACK 3)**

→ **Create the organizational conditions to implement a learning, flexible and innovative health system (TRACK 4)**

Citizens and users

→ **Use citizen and clinician practices as a basis for digital transformation (TRACK 5)**

"A solution must not be just sector-specific, but rather cooperative and multi-level." [free translation] − Denis Roy
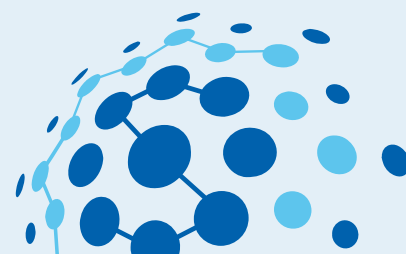
MODERNIZE DIGITAL TOOLS AND COMPUTER EQUIPMENT IN HEALTH AND SOCIAL SERVICES INSTITUTIONS

The digital transformation in healthcare requires that clinical data, notes, examinations and other information that should enrich patient medical records be recorded in digital form and organized. This objective requires both access to adequate computer equipment and the use of processes that will generate digital data that can be used for clinical, management and research activities.

Renew obsolete equipment in the public health sector's computer and software stock to allow for the use of the latest applications

Update IT tools on a regular basis to ensure cyber security and maintain secure data and information exchanges

Ensure the sharing and retrieval of data in electronic health records (patient records), namely through the adoption of clinical data acquisition software and the development of interoperable databases

Abandon exchanges by fax in favour of technologies and procedures that allow real-time and secure exchanges.

Accelerate the deployment of a single digital health record for each citizen

Despite the progress made, Quebec is lagging behind in terms of a single health record. Several other Canadian provinces such as Alberta or other countries such as Japan and the United Kingdom are moving closer to a single record. To accelerate deployment, it would be crucial to implement interoperable and reusable information systems that will be able to integrate data from different records. This requires the description and indexing of data and metadata and the use of a perennial identifier. The information and data integrated in this unique file must allow access to information such as, but not limited to: medical history (diseases, surgeries), possible allergies, medication, hospitalization and consultation reports, test results (imaging, biological analyses, etc.).

"What struck me most at the symposium was that in many places in Europe there is one patient, one file, which doesn't mean that they all have the same system. They have several systems, like us, but they put emphasis on interoperability."
— Rick Glazier
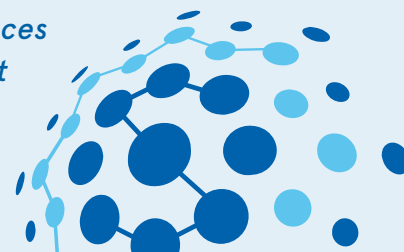
TRAIN HEALTH SYSTEM PROFESSIONALS, WORKERS AND MANAGERS AND ENSURE THAT THEY MEET TOMORROW'S TRAINING REQUIREMENTS

Train practising healthcare professionals and workers in digital approaches and technologies, and include all the digital dimensions of health (tools, processes, responsible approach, cyber security) in the training of tomorrow's clinicians, health system managers and those responsible for purchasing policies in hospitals and Integrated University Health and Social Services Centres (CIUSSS).

Financially support the development by universities, in partnership with health institutions and professional orders, of digital health training offers for professionals and managers, both for those in practice and for cohorts in training.

Promote the integration of Quebec players in Canadian organizations dedicated to digital health.

Quebec has little presence on the Canadian scene, particularly among the main think tanks on digital health tools in Canada (e.g., Digital Health Canada). The implementation of incentives for Quebec researchers and clinicians to join Canadian initiatives would allow Quebec to contribute to development strategies and learn from experiences elsewhere in the country. The various players would thus be encouraged to join these national organizations and increase the sharing of tools and information, as well as access to inspiring examples.

Continue the collaboration between Quebec and Canada in international research initiatives and assume a greater leadership role by launching our own initiatives

The frantic pace of the digital transformation in health requires established links for the reciprocal sharing of experiences and approaches. In this respect, Quebec has carved out a leadership position in terms of being responsible when it comes to digital transformation in health. Beyond collaborating on international research initiatives, it is time to encourage and support digital health stakeholders and organizations so that they are actively involved with major international groups working in the field of digital health.

"It's not just the digital infrastructure, it's the whole organization around it that needs to be built. It's a new organization of care."
[free translation] — Sylvie Grosjean

ENSURE SHARING AND ACCESS TO HEALTH DATA WHILE PROTECTING PERSONAL INFORMATION
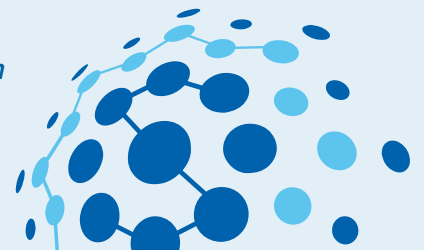
Identify a leader at the provincial level whose role will be to coordinate the key players for a responsible and integrated digital transformation in health in order for the digital transformation in health to continue with true cohesion between stakeholders and a sharing of experiences and expertise developed by all. A visible leader with certain discretionary powers, recognized by both the clinical and academic communities, could set up a short-term action plan involving all stakeholders in the sector, such as the INESSS and the Ministère de la Santé et des Services sociaux (MSSS), the clinical and management communities, the academic community, patients and citizens. This leadership would be based primarily on moral authority and, with the exception of its own coordination office, would work with the bodies already in place.

Implement regulatory and ethical frameworks that will ensure consistent and transparent management of healthcare data

Experts agree that a review of the rules, standards and processes for sharing and accessing health administrative and clinical data is needed to foster a culture of sharing for future research and other purposes (e.g. education, innovation, transparency and replication of science). Such a culture is only possible if it is based on public trust and, therefore, if it flows from clear rules and a coherent and transparent governance framework.

Ensure the confidentiality of personal data

More generally, there is the question of respecting the confidentiality of personal information in relation to the collection of health data and its more or less controlled use for prevention, treatment, research or public health. An ethical governance framework, as put forward in the Declaration of Montreal, must be implemented to ensure that any research or application using personal data has social acceptability.

"In countries that are advanced in computer science, there is generally a national public agency that manages standards and semantic interoperability, especially, in an open access mode, where researchers are mobilized to develop the tools and then make sure they are integrated into the system." [free translation] — Aude Motulsky

CREATE THE ORGANIZATIONAL CONDITIONS TO IMPLEMENT A LEARNING, FLEXIBLE AND INNOVATIVE HEALTH SYSTEM

Allow local innovation in digital health

Centralized planning of the directions that digital health innovation should take is not seen as an optimal approach. It is critical to allow room for local innovation to target priorities specific to local issues that vary from place to place. Such an approach, however, needs to be framed by a number of standards and benchmarks, both provincially and nationally (e.g., cyber security, respect for rights, ethical principles), and closer ties with scientific experts. In this context, pilot projects developed and evaluated at the local level should be encouraged and the results shared throughout the network through dedicated exchange forums.

Foster digital health innovation in public procurement processes.

Processes for acquiring technology or digital solutions in healthcare are unique opportunities for adapted and creative development. Therefore, instead of a public procurement process based on existing digital solutions, an innovative procurement process could be implemented, following the example of other jurisdictions (e.g., Innovative Procurement – Healthcare in Ontario). In this context, the public procurement process becomes an additional opportunity to develop, together with experts and suppliers, state-of-the-art digital solutions that are fully adapted to the new realities.

Ensure access and sharing of data for research purposes

In the current situation, most health data recorded in digital format is accessible for clinical use. However, in the spirit of a learning society, and with a view to constantly improving healthcare and services, it is crucial that this data be available for research and public health, while respecting the rules of confidentiality and scientific integrity.

"In public calls for tenders or solutions, partnering with teams that are working on innovative solutions, applying them and learning from their experiences can be a way to integrate innovation into the government system." [free translation] — Marie-Josée Blais

USE CITIZEN AND CLINICIAN PRACTICES AS A BASIS FOR DIGITAL TRANSFORMATION

Put citizens at the centre of the development plan for technological tools

One of the objectives of digital tools is to make health services accessible despite the distance between the place of care and the living environment, whether for healthy and active individuals or those living with disabilities, or for those with limited access to technology due to their level of digital literacy. In order to mitigate risks and discrimination bias, an inclusive digital transformation cannot take place without taking into account the diversity of user profiles and the involvement of citizens and patient partners in all stages of the research and innovation process, from the earliest stages of reflection.

Use current population practices and clinical processes as a starting point

Too often, the digital transformation in health is approached from a top-down perspective. However, it seems critical to first observe the digital practices of patients, healthcare professionals and, more broadly, all citizens, and to use the evolution of these practices as a basis for a real digital transformation. One way to increase adherence to innovative digital health practices is to support the emergence of these practices in communities of practice for healthcare professionals and other virtual communities of patients and citizens.

Take the necessary steps to ensure that technology is used to disseminate information

The implementation of measures to support the population in this digital transformation is essential for it to take place naturally among citizens. More and more citizens, with or without a patient experience, are using the Internet and connected objects to better understand their health situation, anticipate possible treatments, or find out more about health. These practices, which are now well established, highlight the need to direct citizens towards technological solutions and reliable sources of information. An organization such as INESSS could be mandated to work with experts from the academic community, professional organizations and patient-partner groups to recommend valid and reliable applications that meet recognized quality standards.

"Let's not start with a system logic but a user logic... Let's observe from a reflective perspective the changes in the practices of all users (including patients and their relatives) and change the policies from there, rather than the other way around." [free translation] — Vincent Dumez

CONCLUSION

This call to action is part of a broader reflection taking place in Quebec, elsewhere in Canada and around the world. A reflection that foremost concerns citizens and civil society, but also a large number of stakeholders and decision makers. Both the public and private sectors are getting organized and considerable efforts are being made by our governments to meet the challenges of a responsible digital transformation in the health field. This *call to action* does not claim to be an action plan, but rather an opportunity for the players in this transformation to act on targets deemed to be priorities. Together, we will be able to plan concerted actions to accelerate a responsible digital transformation in health. The challenges are many, but the mobilization around the preparation of this *call to action* shows that our society is ready to support such a responsible digital transformation in health. The Digital Health Consortium will continue to mobilize the academic world to this end and to create links between all the partners.

THANKS

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