

# **CMDO Network: Deliberative Workshop**

The challenges and opportunities of Big Data to better tackle cardiometabolic diseases, diabetes and obesity.

Final Report 2019

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## Preface

The following report prepared for the CMDO Network membership is a summary of an invitational deliberative dialogue that took place over 1.5 days in Quebec City, Quebec on February 28 and March 1, 2019. To choose the 2019 workshop topic, a survey was conducted to CMDO membership and the selected topic was the most commonly cited as this year's hot topic to debate. Funding for this event was provided by the CMDO, which is a thematic network supported by the FRQS

The report contains a summary of the presentations from invited experts as well as a rigorous analysis of the discussions from all participants with conclusions and recommendations. The report has been prepared and submitted on behalf of the CMDO network by workshop the organizing and reporting committee:

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## Summary

A total of 22 researchers and practice partners came together to initiate a deliberative dialogue on the theme of Big Data and its role in the fight against cardiometabolic diseases, diabetes and obesity.

The existence and exploitation of Big Data represents a unique opportunity to improve diagnosis, optimize health care delivery and improve understanding of important health issues such as obesity, diabetes and cardiometabolic diseases. Like many new concepts, the challenges and opportunities of Big Data have only begun to be explored. The objective of this workshop was twofold: 1) to bring together experts and stakeholders to set priorities for the use of Big Data in Quebec; and 2) to promote the implementation of these priorities by laying the groundwork for a follow-up pilot study.

The workshop was organized by Dr. Gillian Bartlett, Deputy Director of the CMDO Network and Professor in the Department of Family Medicine at McGill University and her team. The first day's program began with a presentation by François-Pierre Gauvin entitled "Creating Rapidly Learning Health Systems: What Can be Learned from the Canadian Context?" Dr. Gauvin is the Senior Scientific Lead at the McMaster Health Forum where he leads the Forum's citizen participation initiative. He is also responsible for the development of Health Systems Evidence and Social Systems Evidence, the world's most comprehensive access points for evidence to support policy makers, stakeholders and researchers. He provided an overview of his work on learning health systems. Notably, in December 2018, the McMaster Health Forum released a report commissioned by the CIHR Institute of Health Services and Policy Research and the Health Services and Policy Research Alliance of Canada. The purpose of this report was to catalyze a discussion of how the 'learning health system' approach could be adapted and implemented in different Canadian jurisdictions. This presentation clearly identified how Big Data could contribute to the emergence of learning health systems. Subsequently, Benoît Lamarche presented the PULSAR project. Dr. Lamarche is responsible for the scientific architecture of PULSAR at the Laval University following the approach supported by Alliance Santé Québec. Dr. Lamarche is a professor at the School of Nutrition at Laval University, a researcher at the Institute on Nutrition and Functional Foods (INAF) and holder of the Chair of Nutrition. He has published more than 350 scientific articles in areas related to nutrition and health. He has written two books with the

famous Jean Soulard, including a very recent one entitled the DNA of the Quebec diet, which demystifies and presents the concept of health food in a Quebec context.

The participants then discussed these presentations over an informal dinner allowing attendees to easily mingle. The following day, four short presentations set the tone for the deliberative dialogue: Dr. Samira Rahimi discussed "Artificial Intelligence and its role in clinical contexts"; Dr. Mike Benigeri spoke about "Twinning of Medico-Administrative Data. Presentation of two major projects in Quebec "; Dr. Tibor Schuster presented "Machine Learning - Evolutionary perspectives and stimuli from the causal revolution"; and Dr. Lise Gauvin concluded with "Towards a Socially Responsible Digital Transition: Some Issues".

After these presentations, the participants were grouped at four tables where they discussed what they considered to be the best opportunities for Big Data in the context of cardiometabolic diseases, diabetes and obesity in Quebec. At each table, a note-taker trained in ethnographic participant observation recorded the discussions without guiding the debate. After the presentation of the themes from these discussions by the note takers, the groups were redistributed and then discussed the most appropriate governance structure to realize the opportunities presented by Big Data.

The debates have been transcribed and were subjected to a thematic analysis integrating the observations of the note-takers who made the ethnographic observation. This will result in three outputs: a public report for the CMDO network, a position paper to be published in a peer-reviewed journal, and a pilot project proposal to implement one of the priorities identified at the workshop.

The deliberative workshop, "The challenges and opportunities of Big Data to better tackle cardiometabolic diseases, diabetes and obesity" was a great success. Indeed, during the workshop, the enthusiasm of the participants was palpable. In addition, the positive feedback received during the workshop reflects the participants' satisfaction with the workshop and the feasibility of implementing a successful pilot project.

## Resumé

Au total, 22 chercheurs et partenaires des milieux de pratique se sont rassemblés pour amorcer un dialogue délibératif sur le thème des méga-données et leurs rôles dans la lutte aux maladies cardiométaboliques, au diabète et à l'obésité.

Les méga-données et leur exploitation représentent une occasion unique pour améliorer les diagnostics, la prestation des soins de santé et de mieux comprendre les problèmes de santé importants tels que l'obésité, le diabète et les maladies cardiométaboliques. Comme beaucoup de nouveaux concepts, les défis et les opportunités liés au méga-données n'ont pas été beaucoup explorés. L'objectif de cet atelier était de deux ordres : 1) réunir des experts et des intervenants afin d'établir des priorités pour l'exploitation des méga-données au Québec et 2) promouvoir la mise en œuvre des priorités en explorant les possibilités de réaliser une étude pilote.

L'atelier a été organisé par l'équipe de Dre Gillian Bartlett, directrice adjointe du Réseau CMDO et professeure titulaire dans le département de médecine familiale à l'université McGill. Le programme de la journée a débuté par une présentation de François-Pierre Gauvin intitulée "Créer des systèmes de santé apprenant rapidement : quelles leçons tirer du contexte canadien?". François-Pierre est responsable scientifique senior au McMaster Health Forum. Il dirige les initiatives de participation citoyenne du Forum. Il est également responsable du développement de Health Systems Evidence et de Social Systems Evidence, les points d'accès les plus complets au monde pour des données probantes afin de soutenir les responsables de politiques, les parties prenantes et les chercheurs. Il a dressé un portrait de ses travaux sur les systèmes de santé apprenants. Notamment, en décembre 2018, le McMaster Health Forum a publié un rapport mandaté par l'Institut des services et des politiques de la santé des IRSC et l'Alliance de recherche sur les services et les politiques de santé au Canada. Ce rapport avait pour objectif de catalyser une discussion sur la manière dont l'approche de « système de santé apprenant » pouvait être adaptée et mise en œuvre dans les différentes juridictions canadiennes. Cette présentation a bien cerné comment les méga-données pourraient contribuer à l'émergence de systèmes de santé apprenants. Par la suite, Benoît Lamarche a enchaîné en présentant l'expérience PULSAR. Le Dr Benoît Lamarche est responsable de l'architecture scientifique du projet PULSAR mis de l'avant par l'Université Laval suite à la démarche de l'Alliance Santé Québec. Benoît est professeur titulaire à l'École de nutrition de l'Université Laval, chercheur à l'Institut sur la nutrition et les aliments fonctionnels (INAF) et titulaire de la Chaire de nutrition de l'Université Laval. Il a publié

plus de 350 articles scientifiques dans des domaines liés à la nutrition et la santé. Il a rédigé deux livres avec le réputé Jean Soulard, dont un tout récent intitulé l'ADN de l'alimentation québécoise, qui démystifie et présente le concept d'alimentation santé dans un contexte québécois.

Les participants ont ensuite discuté des présentations dans le cadre d'un cocktail dinatoire. Le lendemain, 4 courtes présentations ont donné le ton aux dialogues délibératifs : Dre Samira Rahimi a discuté de « Artificial Intelligence and its role in clinical contexts »; Dr Mike Benigeri a parlé de « Jumelage des données médico-administratives. Présentation de 2 projets d'envergure au Québec »; Dr Tibor Schuster avec « Machine Learning – Evolutionary perspectives and stimuli from the causal revolution »; et Dre Lise Gauvin avec « Vers une transition numérique socialement responsable : quelques enjeux ».

Après ces présentations, les participants ont été regroupés dans quatre groupes où ils ont discuté de ce qu'ils considéraient être les meilleures opportunités pour les méga-données dans le contexte des maladies cardiométaboliques, du diabète et de l'obésité au Québec. À chaque table, un preneur de notes formé à l'observation ethnographique a enregistré les discussions sans susciter le débat. Après la présentation des thèmes, les groupes ont été répartis à nouveau et ont ensuite débattu de la structure de gouvernance la plus appropriée pour concrétiser les opportunités.

Les débats ont été transcrits et ont été soumis à une analyse thématique intégrant les observations des preneurs de notes ayant fait de l'observation ethnographique. Il en résultera trois produits : un rapport public pour le réseau CMDO, une prise de position à publier dans une revue à comité de lecture et une proposition de projet pilote visant à mettre en œuvre une des priorités identifiées lors de l'atelier.

# INTRODUCTION

## Big Data, Machine Learning and Artificial Intelligence

The amount of data being collected in the field of health is expanding rapidly. While this may represent an opportunity to improve health care services, it also represents a challenge regarding how to handle, implement and use “Big Data”.<sup>1</sup> The main elements that define Big Data are volume, variety, velocity, and value with value referring to the ability to stimulate transformation in health care.<sup>2,3</sup> Big data carry the potential for new knowledge and can also facilitate its dissemination. Further, it has been postulated that Big Data could have implications on health care at the grassroots level by fostering patients’ engagement within their own care. It is possible through machine or deep learning and artificial intelligence, which can be integrated with EHR data, that Big Data have the capacity to translate person-centred-care or individual health care into practice. Theoretically, daily use of Big Data has the ability to change clinical practice for improved and more effective care.<sup>1</sup> Big data supports both research (eg. pharmaceuticals, personalized medicine) and health care providers (eg. evidence-based care, disease prevention and management) while increasing efficiency, reducing in cost, and increasing patient empowerment.<sup>2</sup> Although there have been technological advancements that have allowed Big Data to reach a larger number of organizations, many healthcare institutions have been slow to adopt Big Data and therefore have little to no experience with its use and the associated concepts of machine learning and artificial intelligence. Big Data and its associated methodologies remain an esoteric concept in health care and health care research. With the continued advances in technology and analysis, data “lakes”, which are currently being described as Big Data, may no longer be considered as such with the passage of time.<sup>4</sup> Therefore, the definition of Big Data and what it is, is likely continuously evolving. Ethics and governance around Big Data also needs to be reflected on as current legislation is unlikely to be able to address the security and usage of all health-related Big Data.<sup>5</sup> This is particularly important for internet-based data (e.g. patient driven database) that are increasingly common with the strong focus on patient-oriented research and care.

Given the evidence gaps that currently exist in cardiometabolic conditions, diabetes and obesity focused care and research resulting in suboptimal health outcomes for patients and increased health care system burdens, the CMDO held an interactive workshop focused on the challenges and opportunities for the use of Big Data in improving management of these disease.



## Objective and Methods

To address the objective of exploring the challenges and opportunities for the use of Big Data in improving management of cardiometabolic, diabetes and obesity diseases, the workshop employed an adaptation of deliberative democratic methods that we labelled deliberative dialogues. Adapted from the methodology of deliberative stakeholder consultations,<sup>6,7</sup> the workshop was held over the course of one evening and a full day (see Appendix I for full agenda). Key stakeholders were invited to attend the workshop along with any interested members of the CMDO (see participant list in Appendix II). First, invited guest speakers presented on the topic of Big Data to help situate the participants in terms of current state of knowledge and definitions of key concepts. After the evening and morning presentations, the participants of the workshop were invited to debate the first question presented at the workshop. This was done in four small groups with a trained participant observer (notetaker) at each table to monitor the discussion. In addition to taking notes, the discussion was recorded with permission of all participants. The first question was “What are the challenges and opportunities you see that are associated with the use of Big Data in the context of cardiometabolic disease, diabetes and obesity?”. The notetakers at each table reported back the main points before the lunch break. Focusing on some of the issues raised in the morning session, the afternoon discussion, concentrated on what the vision, mission, scope, and governance should be for an initiative developed with the purpose of facilitating the utilization of Big Data. There was a change in small group membership between sessions, so it was not the same mixture of participants. Again, the main themes were reported back. The day ended with a summary of the discussions and proposal for next steps.

For this report, the recorded discussions were transcribed verbatim. For the morning and afternoon session respectively, analytic procedures included the following: first, the transcriptions were reviewed for accuracy by the lead analyst who read the transcripts and compared them against the recordings and the notes provided by each note taker. During the second reading, key ideas discussed in each transcript were identified and grouped based on their similarities, within and across transcripts. Each group was assigned a label representing either stakeholders’ own words or the core idea discussed. A preliminary coding system was created based on intuitive patterns identified across transcripts. A trained research assistant, external to the process and trained for the purposes of coding, coded one transcript. The coded segments were compared and discussed, and the preliminary coding system was adjusted. The coding system was then

uploaded to MAXQDA software (VERBI GmbH, Germany, version 2018) along with the four transcripts to facilitate data management. The transcripts were coded in MAXQDA using the coding system.

The notes taken by the participant observers were used to validate the coding system. The codes grouped under each theme and subtheme served to inspire the preparation of descriptive summaries. For the purposes of trustworthiness, the aforementioned research assistant coded a random transcript using this coding system.<sup>8</sup> Finally, the coding system was refined, revised, and readjusted based on exchanges between coders. The summary of the expert presentations and the results from the analysis of the discussions are presented in the next section of the report. The summary of discussion is supported by quotes in which the acronym AM or PM refer to whether the discussions were held in the morning (AM – Session I) or in the afternoon (PM – Session II), followed by a T to indicate the group membership (tables 1-4).

## CHALLENGES AND OPPORTUNITIES IN BIG DATA

The following is summary of the presentations given at the workshop. The slides are included in Appendix III with permission from the presenters. This was followed by the deliberative dialogue, the results of which are summarized after the presentation summaries.

### Expert Presentations

#### Créer des systèmes de santé apprenant rapidement: quelles leçons tirer du contexte canadien?

##### François-Pierre Gauvin

This presentation explored the lessons from current efforts to develop rapid-learning health systems in Canada. It was suggested that this can be done by answering questions regarding the consolidation of data and research evidence infrastructures (along with a better alignment of governance, financial and delivery arrangements), as well as by leveraging the assets (and addressing the gaps) within each jurisdiction. Dr. Gauvin believes that rapid-learning systems must rely on robust “health system” and “research system”. It must be defined by targeting the needs, perspectives and goals of the patients while also using data and research evidence. Having adequate decision support tools in place will facilitate the decision-making process and foster a favourable learning environment. In addition, data regarding patient experiences must be made available. Second, this improvement must diminish doubts and misunderstandings that make certain health professionals hesitant in supporting this system. Dr. Gauvin states that there is no “magic recipe”, but rather individual studies that provide evidence for the success of a rapid-learning system approach. These studies are focused on major components, such as the involvement of clinicians and the importance of creating interdependence between all players involved. There are many positive assets within each jurisdiction that could be leveraged, but also common gaps such as the lack of reliable and easy access to data and the failure to promote collaboration between different levels (micro, meso and macro levels). There is also a hesitation to share data within and across jurisdictions, as well as a limited capacity of some organizations to adequately analyze the data and optimally package the data to be used. Dr. Gauvin believes there are ‘windows of opportunities’ to develop a rapid-learning health system approach. These include leveraging Pan-Canadian efforts by the Canadian Health Services and Policy Research Alliance and the Canadian Institutes for Health Research to promote the rapid-learning health system approach, various initiatives in several provinces (including British Alberta, Ontario and New

Brunswick) to adopt a rapid-learning health system approach, as well as technological developments that could support such approach like artificial intelligence and Big Data. Dr. Gauvin asserts that who you involve and how you name the approach will need to be adaptable to optimize success: this makes it more tangible and understandable to a wider audience.

### Étudier la santé durable dans toute sa complexité: l'expérience PULSAR

#### **Benoît Lamarche**

The main goal of the presentation was to demonstrate the value of the collaboration between Laval University through PULSAR and the City of Quebec to study sustainable health and all of its dimension for the benefit of the population. Sustainable health is the equal access to resources of good quality used responsibly. All improvements to this system are to benefit present and future generations. This is done by exploiting a large array of data reflecting many dimensions of health using sophisticated and novel methods based on IA capacity. The goal is to intervene at the population level to implement strategies that will allow the exploitation and release of this large amount of data. Dr. Lamarche insists that by collaborating and making data available to researchers from many horizons, we can better intervene and improve sustainable health at the population level. In addition, he postulated that we must combine collaborative work with analytical tools, virtual workspaces, and structured databases to create an efficient and self-learning system addressing the complex nature of sustainable health. One of several challenges is addressing the social inequalities of health and this is at the core of PULSAR's philosophy and activities.

### Jumelage des données medico-administratives: Présentation de 2 projets d'envergure au Québec

#### **Mike Benigeri**

The goal of the project highlighted in this presentation was to facilitate access to researchers to an enriched data cohort representative of the population of Quebec. More specifically, the Health Trajectories - Enriched Data Cohort (TorSaDE) was created to identify the most effective and efficient care trajectories for people with chronic diseases, to help decision-makers, stakeholders, and clinicians in the planning and organization of healthcare services. The specific objectives of this cohort are twofold: Describing healthcare trajectories of people with chronic health

conditions and measuring the impact of healthcare trajectories on health service utilization and health.

TorSaDE includes all Québec (Canada) residents who participated in 4 cycles (2007-2008, 2009-2010, 2011-2012 and 2013-2014) of the Canadian Community Health Survey (CCHS). TorSaDE is representative of the population aged 12 and over in Quebec and each of its health regions. In total, there are 81,093 distinct participants. For each participant, the data contains all the information available in the CCHS questionnaire to which the participant responded. The CCHS included sections on health status and reported health problems, lifestyle, prevention, use and access to health services and socio-demographic characteristics. In addition, these responses to the CCHS questionnaires are linked with the participants health-administrative data over a period of more than 20 years (1996 to 2016). Researchers are welcome to use the cohort data, and to do so they must submit their project for approval to the TorSaDE Working Group and obtain the necessary authorizations.

### Artificial Intelligence and its role in clinical contexts

#### Samira Rahimi

This presentation explored the uses of Artificial Intelligence (AI), what has been done in the past, as well as its potential uses in the health care system. AI has traditionally been used in robotics, game playing, speech recognition, logistic planning, scheduling, and more. In clinical contexts such as nursing, it can improve productivity up to 30-50%, and increase GDP savings by 2%.<sup>1</sup> In addition, AI could address the health and wellbeing gap, improve the quality of training as well as patient-doctor relationships by freeing up time. It can also improve accuracy in diagnosis such as diagnosis of skin cancer, rheumatoid arthritis. Dr. Rahimi emphasized the importance of cross-disciplinary collaboration, data sharing and data quality, and patient and public engagement in AI research and development for the successful implementation of AI in health care. It is also essential to improve the education, training, and awareness building around AI among medical communities to promote a culture of learning as well as support current and future HCPs.

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<sup>1</sup> McKinsey Global Institute Report, 2017

<https://www.mckinsey.com/~/media/McKinsey/Industries/Advanced%20Electronics/Our%20Insights/How%20artificial%20intelligence%20can%20deliver%20real%20value%20to%20companies/MGI-Artificial-Intelligence-Discussion-paper.ashx>

## Evolutionary perspectives and stimuli from the causal (inference) revolution

### Tibor Schuster

This presentation explored the caveats of implementing AI in the current health care system and stressing the importance that current AI approaches are mostly drawing on associational statistics and do not enable causal inference. AI includes any technique that enables computers to mirror human intelligence, using logic, if-then rules, decision-making, and machine learning. Machine Learning is a subset of AI that uses algorithms to learn from and make predictions about data without being explicitly programmed. With the implementation of AI, there is increasing potential of learning about reality: however, questions we can answer are currently limited to 'what is' and not 'what if' (unless explicit causal inference paradigms are implemented: no causality in → no causality out). Notions of preventive medicine, e.g. learning about costs truly attributed to obesity and the health problems linked with it, are counterfactual i.e. causal in nature and cannot be answered by observed data and AI alone. The aim of causal inference is to infer aspects of the data generation process and understand the dynamics of events under changing conditions (changes that may not have been observed before, i.e. changing policies on the population level). Finally, humans possess the ability to use their imagination to generate mental representations and manipulation of their environment, without the need for costly trial and error optimisation exercise (the key element of modern AI). Dr. Schuster stresses that in order for AI to be useful in the health care sector, it should also possess this quality

## Vers une transition numérique socialement responsable : quelques enjeux

### Lise Gauvin

The aim of Dr. Gauvin's presentation was to highlight the importance of finding ways around the challenges of adopting and integrating rapid-learning systems and AI while continuing to promote the interdependence of rapid-learning systems and AI. Some of the goals specific to rapid-learning systems are to reduce waste (unused collected data), increase added value, use the virtuous cycle: science, evidence, and care to promote harmony between communities, patients and clinicians, and promote collaboration between universities, health care organizations, non-profit organizations, private health care corporations, patients, and the public. Some possible uses of AI in the future include using it for tumour radiation, decision-making, and automatic data collection. Patients, however, have certain reservations regarding sharing their data, most notably because

of their right to privacy. Thus, there is a need for structure and governance to control access to data, as well as a need to identify the most pressing research areas in which the data would be used to optimize knowledge advancement. It is necessary for both patients and the population as a whole to be involved, as well as for them to share common goals and interests in order to establish collaboration and trust between clinicians and patients. It is also important to reduce social inequalities by avoiding unequal access to resources stemming from the sharing of the data. To ensure successful collaboration between rapid-learning systems and AI, it is important to ascertain the roles of both “Big Data” and “small data”. Promotion of learning, innovation, and collaboration is also essential. This can be done by using data and conclusions from research and combining them with the developing interactions between humans and machines, conducting more studies on the implementation of this collaboration and what it would look like in action, and finally promoting “systemic and logical thinking/reasoning”. It is also crucial to ensure the ethical integration of AI in health care system by encouraging discussions and questions between all stakeholders.

### Themes from Session I: Big data, the New Kid on the Block?

The question discussed across groups was: “What are the challenges and opportunities for Big Data to better understand and manage cardio-metabolic diseases, diabetes, and obesity?” Three main subthemes related to Big Data were identified in the discussions, namely: challenges and limitations, benefits and opportunities, and priorities and needs.

#### Challenges and Limitations

Stakeholders discussed certain challenges related to knowledge and data that could limit the impact of Big Data if not properly addressed.

Knowledge. For two reasons, ‘Big Data management’ represents a knowledge challenge. First, according to the stakeholders, Big Data has to be handled from a different healthcare paradigm, one that the stakeholders might not be familiar with, either because they have received no training or because they do not implement such interventions in their daily practice. Big Data requires dealing with abstract data related to large populations, collected by different research teams, and stored under different formats. To benefit from this data, professionals involved in the process of using Big Data need to undergo a new and innovative type of training. Second, stakeholders raised the fact that they were uncertain about whether they, and their colleagues,

truly understood the way in which Big Data could address healthcare related needs; i.e., the immediate application of data to a specific health problem and/or research. For instance, these stakeholders: (a) shared their own limitations regarding how to define a research that could be answered with the already available Big Data, (b) they questioned their own ability to analyze and interpret Big Data, (c) debated about the potential use of Big Data to answer research questions or specific health care problems, and (d) questioned their own ability to communicate evidence resulting from Big Data. Along these lines, stakeholders believed that the scope of Big Data could actually be broader than what they could even imagine; moreover, it would require a totally new training to be able to understand the extent, the quality, and the potential application of the information, as well as being able to use it as shown by these exemplary quotes:

What standards would we want as a community of researchers and clinicians, to apply for bio banking, genomics and all those things that are relevant? (AMT4)

It's kind of the history of abandoning and moving on to the next paradigm, as opposed to maybe let's see what we can take from both, and to have a more rigorous approach, and at least attempt to overcome some of the drawbacks of each. Like, the idea of... there is no such thing as rapidity when designing a randomized control trial. You can't do that fast. [laugh] Like, you can't do that in a month or in two months, you know what I mean? Even with the pragmatic randomized control trial; still, the time delays you hit, right? (AM T1)

It limits the questions we are thinking of. The questions we are thinking about are limited by the training we have, but we have to change that because the scope is actually broader. (AM T1)

Je pense qu'on a encore un grand espace à faire, à définir c'est quoi le point de valeur qu'on va entraîner nos algorithmes pour qu'ils disent dans les mil-cinq-cents barrières qui se promènent pis qu'ils déterminent exactement. (AM T2)

- I think some questions are more enabled to some techniques than others. That was my connection to... we were taught to think in a certain way, in a traditional... how we are taught to think about causality and such questions, how to formulate and how to collect data and such questions. But it could be also that some questions, we have not even thought about, because of our in-box thinking strategy, right? So, some of those questions we have not even started to meet. (AM T1)

Data. Stakeholders agreed that there was tension between Big Data and healthcare. This tension, crystallized in five issues, was especially tangible in regard to handling data to respond to health care needs. The first issue had to do with *governance* of data and was related to who managed and controlled what; and more specifically, who stored and provided access to data. According to these stakeholders, some institutions tended to be territorial about the data they generated and restrained access to researchers. This led to a second issue: *accessibility and availability*. Stakeholders agreed that a major challenge to those who seek to use Big Data in their research



was accessing already available data. Sharing data has not yet been regulated in Quebec, an issue that stakeholders referred to as a waste of time and money. This position, however, entailed some ethical challenges, around whether Big Data should be accessible to the public such that arrangement of standards that should be discussed and agreed concerning the use of population information. As well, *consent, confidentiality, and anonymity*, along with the importance of sharing data were preoccupations discussed in which potential benefits and harms were compared. There were some debates as to the different ways public and private data managers tend to use data with sensitive information, as well as the different motivations behind the use of information: while public institutions were perceived as seeking to benefit citizens' lives (e.g., identifying key dangerous features of a given neighbourhood), the private sector was perceived as solely profit-oriented (e.g., having the information to sell certain products). Another challenge was *data management*. Discussions around this issue included both practical and organizational matters. Practical matters related to using and reusing available data, identifying conceptual models to guide the analysis, developing algorithms to generate specific data, and making data accessible to researchers; whereas organizational matters had to do with not having clear guidelines on how data could be used. Finally, Big Data was not without *limitations*. The stakeholders agreed that data produced and collected could sometimes have internal (e.g., biased data collection, inaccurate documentation) or external limitations (e.g., inappropriate for a given population); suggesting that Big Data is not perfectly reliable. The following quotes illustrate the ideas discussed:

Because if we could establish these principles at all levels, and say, for instance, Big Data will be used in certain ways for detecting problems and making diagnostic... It will not go as far as making decisions on behalf of the patients or the professional... (AM T1)

There are value judgements and all sorts of considerations, but... yes. Because I feel... it's always going to stumble on, "Oh, there are ethical issues." We can't move forward unless we clarify... (AM T1)

À « merger » les données qui viennent de partout pis c'est pas sans défi mais c'est possible de le faire. Ça demande du travail, c'est sûr. Mais les outils, je pense, vont nous permettre de faire ça. (AM T2)

### Benefits and Opportunities

Two benefits and opportunities were identified: integration of data and the possibility of targeted interventions.

Integrating data. The integration of the massive amounts of diverse data referring to individuals and environments would allow for the possibility of making grounded health-related predictions and decisions and for an entire population. This represents an invaluable opportunity because it does not necessarily require the collection of new data since potentially useful data collected across different research initiatives are already available; thus, integrating data allows for saving time and money. Integrating data also allows the researchers to learn about the best way to collect data by comparing the articulation of data collected across different time points. Of note, this is important as Big Data combines not only large amounts of data, but also varied data coming from different venues, as highlighted in the following excerpts:

But you can use that data to predict, based on algorithms, what will happen in ten, twenty years, or something like that. So, that's something that is a possibility.... Because if we could establish these principles at all levels, and say, for instance, Big Data will be used in certain ways for detecting problems and making diagnostic... It will not go as far as making decisions on behalf of the patients or the professional... (AM T1)

That is what is happening in health. We have so much data that we can link, that we don't need to collect new data. There is almost no need to collect new data with this many question – like, specifically for one research could find data, and some research questions could be answered. (AM T1)

Targeted Interventions. Accessing information that comes from different venues notably facilitates the design of interventions. In healthcare, it could be possible to both offer more accurate feedback to a given individual and to design population-level interventions. While individual- and population- represent different levels of interventions, the effects may be intertwined and complementary. As well, having patterns that represent the views of the individuals and the needs of a population would allow the physician to avoid repeating redundant messages to the patient, by simply referring him or her to more generalized messages created for these purposes and based on large amounts of data. In sum, it could enhance the possibility of achieving a public health goal, through tailored strategies based on stronger models. Thus, properly used, it could be an important tool to facilitate the diagnosis made by the physician as noted in these quotes:

From my perspective, what potentially Big Data and AI could possible provide is better targeting of clinical interventions for different types of complications. Because the way it works right now is that often, you'll get these large ministerial decrees about: "This is how you should treat diabetic patients. You need to be seen three times a year; you need to do this text, this test, this test. They should be quizzed on this food intake; they should be lectured on physical health," and so long and so forth. And it's like, this is what you have to do with every patient. So, the question of, if you have for example combinations of

genome related inflammation, plus environmental determinants that can be applied at a local level... So, you have a clinic that is seeing patients in this neighbourhood versus that neighbourhood; and ways that that data could translate into more targeted, on the ground treatment recommendations for actual patients... AM T1)

Ma compréhension, c'est que ça a viré plus projet de recherche, alors qu'au départ c'était un très grand outil populationnel. Un discours qui ressemble à ce qu'on entend là, justement, pour l'intelligence artificielle. Ça devait être un outil pour connaître la structure génétique de notre population, par région. Où sont les gens, où il y a plus de mutations monogéniques avec des interventions qui pourraient être ciblées... C'était comme ça; mais ça a viré plutôt en projet de recherche. (AM T3)

### Priorities and Needs

Three priorities and needs were brought up by the stakeholders: legislation and guiding documents; optimization of the process; and informing patients and stakeholders.

Legislation and Guiding Documents. In light of previous discussions, stakeholders brought up the fact that legislation and written guidelines to frame and support the use of Big Data represented a priority. The need for legislation mainly relied on the fact that the use of individuals' information should be regulated to both avoid unnecessary disclosure and protect confidentiality. Stemming from legislation, written guidelines should be developed to optimize the generation, use, and management of data; including the management of ethical issues. Stakeholders highlighted the importance of developing written guidance by explaining that even information that was currently available was not being used due to a lack of clear rules and instructions. This discussion was crucial to concluding that Big Data was not a new phenomenon; but rather, an unused or misused phenomenon. This issue led to the subsequent point related to optimization of process emphasized by these quotes:

Un cadre de gestion pour l'accès et pour l'utilisation des données... (AM T3)

Donc il faudrait qu'on se donne des règles pas sur des chiffres, mais sur est-ce qu'il y a une possibilité de retrouver la personne ou d'éventuellement de ré-identifier des choses. (AM T2)

Mais je pense qu'il y a un besoin pour le règlement dans le gouvernement du Québec pour dire « Ok, si on met ce critère, ça va être correct pour la cette étude ». Pour avoir un accès plus rapide. Parce que je crois qu'il n'y a pas de règles très définies pour l'intelligence artificielle, qui commence à être utilisée davantage récemment à travers le monde. Donc je pense que c'est important que le gouvernement prenne [inaudible, un mot à 21:20] et définisse le règlement pour l'accès, pour la rapidité de l'accès aux données. (AM T2)

Optimization of Process. As part of the utilization of data, it is important to launch and optimize different actions and strategies that have to do with generating data from different perspectives. The many actions that could be involved in the optimization of the process include: prioritizing needs, learning to think out-of-the-box, defining casual frameworks and standards to compare and share data, identifying potential venues for integration of data could be some of them, identifying places where to store data, identifying ways to store and retrieve data (e.g., data catalogues), and discussing potential governing structures as summarized in these quotes:

... after that, you can federate your data with all their data, and they can talk to each other.... without human intervention, because it's all built in.... So, standardization can... Should we try to set goals? (AM T4)

... the causal structure could be highly beneficial from the use of the frame reference we have used until now. We don't have to throw away all this knowledge we created, right? So, that could go in support machines to actually have a starting point. The machine doesn't have to start from square one. (AM T1)

Informing and Training Patients and Stakeholders. A final priority identified by stakeholders was to properly inform, prepare, and train the patients and stakeholders in the process of moving towards health supported by Big Data. All people involved need to understand the value, the impact, the possibility, and the procedures related to Big Data. While many discussions revolved around the need of education for the practitioners, health care professionals, and health care decision makers, stakeholders agreed that the patient need to understand what Big Data is, how it works, and why health care professionals would make decision and suggestions even when personal information from the patient had not been collected as noted in these quotes:

You see, so different stakeholders have different processes to optimize too. (AM T1)

I know very few clinics who have gotten as far as we have in the last year and a half, in terms of creating or incorporating analytics into our strategic priority, and communicating that information with not just physicians, but nurses and administrators. Like, what do you do during the day? How much of your time is taken up by responding to these kinds of acts, versus booking physicians, and try to change the culture to one that looks... that sees feedback and data as important to how we run our clinic and how we take care of our patients. (AM T1)

## **Themes from Session II: Consortium, or the War of Roses?**

The following question was discussed across groups to address this topic: what should be the vision, the mission, the scope, and an appropriate governing structure of a consortium created to utilize Big Data? After analyzing data, the discussions were organized around two main sub-themes: mission and vision of the consortium. In face of the fact that stakeholders

interchangeably used ‘mission’ and ‘vision,’ for the purposes of coding, we regrouped stakeholders’ comments following the definitions provided by the Merriam-Webster Dictionary.<sup>9</sup>

### Mission of the Consortium

Under the ‘mission of the consortium’ we grouped the predicated purpose (i.e., what does it do?) and the objectives (i.e., what has to be done?) of a consortium created to manage Big Data. In addition, we included two topics that came up consistently when the mission was discussed.

A Consortium, What is it for? The overarching purposes of such a consortium, as agreed by all stakeholders, should be to both prevent health risks and improve individual and population health. To do so, the objectives of a consortium should be to: (a) monitor and control health-related trends and outcomes (e.g., raising epidemics such as obesity); (b) promote health through different actions (e.g., education, training); (c) inform health-related actions (e.g., redesign of a given neighbourhood), integrate data of interest coming from different venues, and implement specific strategies to enhance individual and population health (e.g., vaccination campaigns, develop tailored interventions, prescribe medication).

Whenever the mission was discussed, stakeholders brought up two other notions into the table: the importance of who should be involved in the consortium and the fact that objectives and activities should be accomplished and carried out with the utmost social responsibility. Responsibilities included developing partnerships with a larger and varied membership community, allowing a strong and committed representation of different stakeholders based on honest collaboration and trust. Through discussion, the stakeholders realized that the mission of such a consortium, could overlap, to some extent, with the CMDO’s own mission; however, the mission of the former would reach a larger audience, representing, therefore, different societal interests as illustrated by these selected quotes:

La mission, c’est d’améliorer la qualité de vie qui est liée aux maladies cardiométaboliques. (PM T2)

Bien, ça revient à la mission du CMDO : prévenir, mieux traiter, mieux comprendre, je ne sais pas... (PMT2).

Donc dans la mission, il y a tout l’aspect training, et l’aspect communication du potentiel des données. Je pense que ça serait peut-être une des missions du consortium. (PM T2)

Recherche, éducation, transmission – bien éducation, ça peut rentrer dans transmission... éducation, communication... (PM T2)

I would say to create new partnerships with you know, between researchers, clinicians, patients, you know other stakeholders. So, we have an enhanced engagement. I'm not expressing it very well so that we are all in partnership focused on enhancing health research and health care for healthcare delivery ultimately. (PM T1).

Ça pourrait être dans la mission de développer des collaborations académiques, un peu, autant avec... (PM T2)

The trust component is huge. The whole business model is monetizing data, and that's just what every giant tech company has done in the last 25 years, is figure out different angles on monetizing voluntarily, user-submitted data. So, the question would be why would you want industry involved in a consortium? What would they be able to offer that would be missing? (PM T3).

I think building awareness connecting to all this is a really important component and should come in the early phases. There should be enough resources allocated for that, because there are a lot of worries [and] a lot of misconceptions [around] that. (PM T3).

Building awareness and the importance of transparency in terms of what are the objectives and how is it going to be used. (PM T3)

... we want to look at problem-solving from a much more comprehensive level... (PM T3)

I think the consortium also has a responsibility [regarding] data evidence [and data] implementation... It's to be dynamic....a dynamic system.... if the consortium doesn't go forward and not stop at creating evidence, but go further, and then we facilitate and implement that. (PM T3).

Yeah, that's a good question. Is our mission any different from the mission of CMDO? (PM T3)

The understanding of the underlying mechanisms to be added to the mission... (PM T4)

### **Vision of the Consortium**

Discussion of the 'vision of the consortium' consisted of the actions needed to accomplish the mission (i.e., how is the mission going to be achieved?).

Defining the Scope of the Consortium. When the scope the consortium was at stake, the approach and the view were discussed. The approach referred to whether the consortium should be thought as a local (i.e., Quebec), Canadian, or even global initiative; whereas when discussing the view, stakeholders reflected about whether the consortium should target personalized or population care. These perspectives related to the scope brought up questions regarding who should be included in such an organization and what the governing structure would look like.

Stakeholders agreed that all people affected, in any manner, by Big Data should be part of the consortium. Potential participants included people: generating data (i.e., researchers); manipulating data (i.e., technicians); using data (i.e., physicians), and benefiting from data-related

information (i.e., patients). Interaction among different stakeholders would warrant that the whole community's interests and motivations are represented and taken into account. The diversity of people meant to participate in such a consortium created room to discuss the roles members should play and the training they should receive to optimize their contribute. For these stakeholders, clear profiles and actions should be defined to enhance potential collaborations, conflicts of interests, and confidentiality. This process should be accompanied by the provision of training and education opportunities for all participants involved. The stakeholders debated whether industry should participate in such a consortium. In this regard, two issues were identified. First, the stakeholders highlighted the importance of distinguishing between sharing data (i.e., raw, unorganized evidence) and sharing information (i.e., processed, organized, and structured evidence), as sharing data related to patients, with industry, could raise some ethical constraints. Second, while the industry could contribute economically to support Big Data-related endeavours, this could open the door to conflicts of interest.

Regarding the governing structure, stakeholders agreed that available examples of structures developed at a local level could be used as a starting point for designing the structure of a population approach. Participants noted that if the scope of the consortium is patient-centered; then, patients should be present and be decision makers, rather than merely being consulted. Another point related to the governing structure was whether the information available would be open science (i.e., dissemination accessible to all levels of an inquiring society) or would have restricted access, and in the former scenario, would economically support and ethically control such an endeavour.

A final item related to the vision is the use of data. Decision makers should decide, initially, how Big Data would be used to respond to health care needs (e.g., prevention, treatment). Also, a decision has to be made regarding how and when Big Data could be used (and/or reused).

For governance of those things, including consents and other things. Because we can bring in other people who deal with issues of consent and ethics and policy and data governance and regulation. People who are not around the table right now and are not in the room. That really is what a consortium can do. Is to bring in others who – you know, all the stakeholders that can participate in things like that. Because otherwise, we're just perpetuating the same things that has been going on for years. (PM T1)

And it has to be patient based and patient centered. (PM T1)

I think for me, the question "Who will do it?" is a question to be answered by the consortium itself. It's up to the consortium to decide how you are going to use the data. But then you're going to have to report to those who are paying taxes, who vote. I think

that's why we need a consortium. I think that that's a big part of the responsibility of the consortium that makes sure that happens. Do you want industry in the consortium? I would want. (PM T3)

But we live in an era where people or patients want to have ownership of their data and also want to share their data. (PM T1)

Who would be in the consortium? .... It was great because we, actually, had a lot of different levels of stakeholders. We had people who were very specifically focused on the technical manipulation of Big Data and AI.... so at the public health level and the clinical level and individual level. At least, from a membership perspective, it would seem that you would really need people who understand the actual technical details of doing the work, and then the representation at all the different potential outcome models, including patients. (PM T3)

Well, I guess it's the same as in any other field, is to get a better scope or better understanding of the determinants of cardiometabolic health. We tend to assess everybody in the last 50 years, we've used a very singular approach. (PM T4)

Because we can bring in other people who deal with issues of consent and ethics and policy and data governance and regulation. People who are not around the table right now and are not in the room. That really is what a consortium can do. Is to bring in others who – you know, all the stakeholders that can participate in those things like that. Because otherwise, we're just perpetuating the same things that has been going on for years. (PM T1)

Yes, that currently would not be possible if everything would be patient-centered because right now, this data is not in the hands of the patient. So, lots of survey or other data are collected by our governments and we actually have a big obstacle right now because we cannot link and use this information to. (PM T1)



## CONCLUSION

### Big Data and the CMDO

As confirmed by the stakeholders, although initiatives based on Big Data and artificial intelligence have been in the field for several years now, discussions seemed to indicate these topics were somehow novel or less familiar to the stakeholders, especially regarding implementation. An important issue that can be gleaned from these discussions is that even when several challenges on implementing the use of Big Data exist, stakeholders are willing to move into that direction. Moreover, even though the final format of a consortium that needs to be created to manage health-related Big Data has yet to be determined, the stakeholders provided a roadmap for to make real progress in this area.

We identified five patterns that cut across all discussions. The first had to do with the fact that, repeatedly, stakeholders *appeared unsure of the appropriateness of their contributions*, probably due to the vocabulary used (e.g., mission vs vision) or the fact that they are still not familiar enough with the specific features associated to the topic. Second, even while the stakeholders proposed strategies to take advantage of Big Data in the health sector, they often referred to the notion of an *unknown future*. Third, when sharing their viewpoints, the stakeholders' self-reflections were anchored in their own present or past experience while acknowledging, at the same time, that working with Big Data required *thinking outside the box*. A barrier shared across groups and topics was that stakeholders reported having a *limited understanding of the current healthcare system*. Therefore, as observed in their discussions, the stakeholders had difficulty imagining potential changes to a system they do not fully understand, to meet the requirements of Big Data, which utilizes techniques they do not fully understand. A final pattern observed was that during the discussions, the stakeholders repeatedly *referred to extremes* when making their points. These extremes were: (a) the public vs the private system, (b) the individual vs the population information, (c) the epidemiologist vs the Big Data/artificial intelligence researcher, and (d) the researcher vs the practitioner. As expected, the discussions revolved around ways to transect different agendas and interests these polarized positions represented. Findings from this deliberative dialogue suggested that despite not being fully prepared, from a knowledge and training perspective, these stakeholders are not only willing to engage in initiatives related to the creation of a consortium to manage Big Data, but also now have the foundation make this a reality.

The findings of from this report have a few caveats. First, the stakeholders invited to discuss were all professionals who were either members of CMDO or working in the field of cardiometabolic, diabetes, and obesity from the province of Quebec. Due to the very exploratory nature of the topic, no patients or citizens had been invited to participate in the discussions and therefore their perspective is not present. Third, unlike group interviews and other deliberative methods, the moderators at each table did not participate, guide, or question what was being discussed around the table. This is consistent with deliberative stakeholder consultations. The goal was to engage stakeholders in an open conversation and observe. This strategy allowed us to take a first step in understanding stakeholders' readiness and understanding of Big Data as a new working platform.

In sum, evidence from this report offers a roadmap to both continue future steps of inquiry in order to better comprehend challenges, needs, and priorities related to Big Data; and to also start building the foundation on which to develop the necessary structure and launch a new working programme that can optimize the potential contributions of Big Data to the field of health.

## Next Steps

Following the ratification and publication of this report, the main findings will be published as a working group proceeding on behalf of the participants at the workshop. Some of the issues identified in this report will be further explored in a pilot project using Big Data for Type II Diabetes Management to address the questions of whether access to Big Data could change clinical practice. This pilot project will address (1) *challenge* issues: What is the necessary expertise to work with Big Data? What is the process for access to Big Data and how much time will this take? What are the data management needs?; (2) potential *benefits*: Will this Big Data change clinical practice? How much 'other' data is there? Is anything missing or data that needs to be linked?; (3) *translation*: How do we move ahead with the agenda around Big Data? How does it benefit traditional health research? What are the education gaps? What would the AI tools look like? The results from this pilot project will be presented at the 2020 CMDO Workshop on "Big Data: Moving from Theory to Practice" which will broaden the stakeholder participation including patient partners. This report represents an important first step in facilitating the inclusion of Big Data into the research programs and agenda for cardiometabolic health, diabetes and obesity.

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## APPENDIX I

### Deliberative Workshop Schedule



LE BONNE ENTENTE  
HÔTEL CONTEMPORAIN

# Atelier Délibératif

Les défis et les  
opportunités des méga-  
données pour mieux lutter  
contre les maladies  
cardiométaboliques, le  
diabète et l'obésité

Les 28 février et 1er mars 2019



**CMDO**  
Réseau de recherche en  
santé cardiométabolique,  
diabète et obésité

Jeudi le 28 février 2019

Salle Garneau

16h00.....Accueil et enregistrement.....

16h30.....André Carpentier.....

Directeur du Réseau de recherche CMDO, CHUS, Université de Sherbrooke

Mot de bienvenue : L'importance de positionner le CMDO vis-à-vis les méga-données

16h35.....Gillian Bartlett.....

Directrice Adjointe du CMDO, Université McGill

Présentation des objectifs de l'atelier

16h45.....Plénière.....

François-Pierre Gauvin

**Créer des systèmes de santé apprenant rapidement : quelles leçons tirer du contexte canadien?**

Les systèmes de santé au Canada mettent de plus en plus les patients, l'apprentissage rapide et l'amélioration au centre de leurs préoccupations. En décembre 2018, le McMaster Health Forum publia un rapport commandé par l'Institut des services et des politiques de la santé des IRSC et l'Alliance de recherche sur les services et les politiques de santé au Canada. Ce rapport avait pour objectif de lancer une discussion sur la manière dont l'approche de « système de santé apprenant » pouvait être adaptée et mise en œuvre dans les différentes juridictions canadiennes. Ce rapport était le fruit d'une analyse détaillée de la situation dans chacune des juridictions et d'entrevues auprès de 50 informateurs clés de partout au pays. La présentation explorera les principales leçons tirées de ce projet.

François-Pierre est responsable scientifique senior au McMaster Health Forum. Il dirige les initiatives de participation citoyenne du Forum. Il est également responsable du développement de Health Systems Evidence et de Social Systems Evidence, les points d'accès les plus complets au monde pour des données probantes afin de soutenir les responsables de politiques, les parties prenantes et les chercheurs. Les recherches de François-Pierre sont axées sur l'élaboration de politiques reposant sur des données probantes et la participation citoyenne. Il s'intéresse également au potentiel des forums de délibération pour trouver des solutions innovantes aux problèmes collectifs. François-Pierre est titulaire d'un doctorat en méthodologie de la recherche en santé de l'Université McMaster, ainsi que d'un baccalauréat et d'une maîtrise en sciences politiques de l'Université Laval.



Jeudi le 28 février 2019

17h35.....Plénière.....

**Benoît Lamarche**

### **Étudier la Santé Durable dans Toute sa Complexité : l'Expérience PULSAR**

La prise de conscience qui s'est effectuée au cours des dernières années au regard des coûts énormes engendrés par les maladies chroniques et le fardeau de ces coûts a facilité le passage d'une médecine axée sur le traitement des maladies à une médecine orientée vers la santé des individus et des communautés, dans un souci d'agir de manière préventive sur divers facteurs associés à la « bonne santé » au bénéfice des générations actuelles et futures. À cet effet, le nouvel espace collaboratif de recherche et d'innovation nommé PULSAR et développée par l'Université Laval sous l'impulsion de l'Alliance Santé Québec, vise à suivre, de



façon dynamique et sur plusieurs décennies, la santé de la population de la grande région de Québec et de tester en milieu de vie et en milieu clinique les nouvelles façons de faire. Alimentée par de multiples sources de données, elle aidera à documenter et à comprendre les contextes dans lesquels les citoyens vivent afin de mieux les soutenir dans la prise en charge de leur santé et de leur bien-être et d'apporter les améliorations requises. Par des exemples concrets, le conférencier illustrera comment tous les acteurs-clés de la communauté- les citoyens, les chercheurs, les cliniciens et les décideurs- peuvent collaborer et se questionner autrement afin d'influencer de façon durable la trajectoire de la santé individuelle et collective en s'appuyant sur une utilisation responsable des données et sur les perspectives de développement du numérique.

Le Dr Benoît Lamarche est responsable de l'architecture scientifique du projet PULSAR mis de l'avant par l'Alliance santé Québec et développé par l'Université Laval. Il est professeur à l'École de nutrition de l'Université Laval, chercheur à l'Institut sur la nutrition et les aliments fonctionnels (INAF) et titulaire de la Chaire de nutrition de l'Université Laval. Il a

publié plus de 350 articles scientifiques dans des domaines liés à la nutrition et la santé. Il a rédigé deux livres avec le chef réputé Jean Soulard, dont un tout récent intitulé l'ADN de l'alimentation québécoise, qui démystifie et présente le concept d'alimentation santé dans un contexte québécois. Benoît Lamarche a participé à deux occasions aux Jeux olympiques d'hiver en patinage de vitesse longue piste dans les années 1980.

18h25.....Échange et discussion.....

Foyer

19h00.....Cocktail dinatoire.....

*\*Les consommations sont aux frais des participants*

*\*Beverages available for purchase by participants*

*Jeudi le 28 février 2019*



Vendredi le 1<sup>er</sup> mars 2019

## MC Lounge

7h00 Déjeuner

## Salle Garneau

8h30 Mini conférences sur les topos essentiels

### Samira Abbasgholizadeh-Rahimi

#### *Artificial Intelligence and its role in clinical contexts*

Research in Artificial Intelligence (AI) has drastically increased around the world and AI tools are increasingly being applied in various industries including health care, in different countries. AI is being used to harness and analyze big data to improve efficiency and personalization in health care. It can improve equality of access to care; increase the speed of care; increase the quality of care; enable more patient centred care, and so more undiscovered potentials and benefits. This presentation gives a brief introduction on AI, some of its applications in clinical contexts, along with some suggestions for better integration of AI in Quebec and Canadian health care system.



Dr Samira Rahimi is an Assistant Professor in the Department of Family Medicine at McGill University. With an interdisciplinary background, Dr. Rahimi's research includes medical decision making and integration of technologies such as Artificial Intelligence in community based primary health care. She has been developed decision support tools in different contexts, and her recent patient decision aid for prenatal screening is being considered by the Quebec's Ministry of Health for its prenatal screening program. Dr. Rahimi has worked on several AI-related projects in different contexts (e.g. clinical, manufacturing). She is currently co-leading an international CIHR-funded project on use of AI in community-based primary health care. She completed her postdoctoral training in Shared Decision Making and Knowledge Translation at Family and Emergency Medicine Department of Université Laval, and her doctorate studies in Industrial and System Engineering (with focus on health care systems) at Mechanical Engineering Department of Université Laval.

### Mike Benigeri

#### *Jumelage des données médico-administratives. Présentation de 2 projets d'envergure au Québec*

La présentation présentera brièvement le projet de cohorte Torsade mis en place par la composante Accès aux données de l'Unité de soutien SRAP du Québec. Ce projet basé sur les répondants québécois aux enquêtes sur la santé dans les collectivités canadiennes (ESCC) regroupe un peu plus de 100 000 participants pour lesquels les données médico-administratives ont été jumelées sur une période de 20 ans. On présentera également l'Entente avec le Ministère de la Santé et des Services sociaux (MSSS) et la Régie de l'assurance maladie du Québec (RAMQ) qui permet à l'Institut national d'excellence en santé et services sociaux (INESSS) d'exploiter l'ensemble des banques de données médico-administratives québécoises, afin de réaliser son mandat.



Mike Benigeri agit à titre de consultant dans le domaine de la gestion et de l'exploitation des banques de données médico-administratives, auprès d'organisations du réseau de la santé et d'universités. Il a une connaissance approfondie des banques de données en santé du Québec et plus de 20 ans d'expérience dans les domaines de l'évaluation, des indicateurs de santé et des systèmes d'information. Mike Benigeri détient un Ph. D. en santé publique de l'Université de Montréal. Il est professeur associé à l'école de santé publique de l'Université de Montréal.

Vendredi le 1<sup>er</sup> mars 2019

**Tibor Schuster**

**Machine Learning – Evolutionary perspectives and stimuli from the causal revolution**



*In this presentation I will talk about current rapid developments in the broader domain of artificial intelligence (AI) and machine learning (AI) by drawing parallels to evolutionary processes through a Darwinian lens. Incompatibilities of ML and AI with regard to the requirements of true causal inference i.e. how we can learn about reality using data and not just learn about data, will be discussed.*

*Dr. Schuster is biostatistician and Assistant Professor at the Department of Family Medicine, McGill University. He is holder of a Canada Research Chair in Biostatistical Methods for Primary Health Care Research and is the current acting Director of the Methods Development Component of the Quebec SPOR - SUPPORT Unit (Strategy for Patient-Oriented Research Support for People and Patient-Oriented Research and Trials). His main methodological interests are in the development and application of causal inference methods for the design and analysis of cluster randomized controlled trials and observational research studies based on administrative or electronic medical / health record data.*

**9h30..... Introduction aux débats.....**

**Lise Gauvin**

**Vers une transition numérique socialement responsable : quelques enjeux**

*Nous assistons actuellement à l'émergence de la 4e révolution industrielle. Les développements en intelligence artificielle, tant au niveau des algorithmes que des technologies, se multiplient à un rythme accéléré. Les acteurs des milieux de la santé et de la santé publique sont interpellés pour intégrer les nouvelles technologies et algorithmes et exploiter les mégadonnées qui ont été*



*créées et qui continueront à croître et se diversifier. Depuis maintenant environ 18 mois, un groupe de travail du Laboratoire d'innovation de l'Université de Montréal « Des données à l'action en santé » (<https://laboinnovation.umontreal.ca/quatre-grands-projets/des-donnees-a-laction-en-sante/>) se penche sur les enjeux soulevés par l'intégration des systèmes de santé apprenants et de l'intelligence artificielle. Les membres du groupe s'affairent actuellement à la rédaction d'un livre blanc sur ces enjeux. L'objectif de cette présentation sera de partager les réflexions du groupe de travail relativement aux enjeux identifiés pour assurer une transition numérique socialement responsable dans les systèmes de santé et de santé publique.*

*Lise Gauvin est vice-doyenne à la recherche de l'École de santé publique de l'Université de Montréal et directrice adjointe scientifique en santé des populations au Centre de recherche du Centre hospitalier de l'Université de Montréal (CRCHUM). En septembre 2015, elle a été nommée membre de l'Académie canadienne des sciences de la santé. Ses recherches portent sur les déterminants socio-environnementaux de la pratique régulière de l'activité physique, sur la portée, l'acceptabilité et l'impact d'interventions visant la promotion de l'activité physique et la prévention des troubles de l'alimentation et sur les inégalités sociales de santé. Dre Gauvin est engagée activement dans le partage et l'utilisation de connaissances. Ces activités de recherche et d'échange de connaissances sont développées en partenariat avec des chercheurs, décideurs et intervenants œuvrant dans les systèmes de santé et de santé publique*

**9h50..... Session de questions et réponses.....**

**Animation: Gillian Bartlett**

**Foyer**

**10h15..... Pause-café.....**

**Vendredi le 1<sup>er</sup> mars 2019**



## Salle Garneau

**10h30** ..... **Activité 1 : Débats en petits groupes** .....  
*Les défis et les besoins en lien avec les méga-données*

**12h00** ..... **Dîner** .....

**13h15** ..... **Retour sur le travail délibératif** .....  
Présentation des points saillants (accord et désaccord) par les secrétaires de chaque groupe

**14h00** ..... **Présentation du second sujet à délibérer** .....  
**Gillian Bartlett**

**14h05** ..... **Activité 2 : Débats en petits groupes** .....  
*Elaboration sur les sujets mis en focus lors du 1<sup>er</sup> débat*

## Foyer

**15h15** ..... **Pause** .....

## Salle Garneau

**15h30** ..... **Retour sur le travail délibératif** .....  
Présentation des points saillants (accord et désaccord) par les secrétaires de chaque groupe

**16h00** ..... **Gillian Bartlett** .....  
*Prochaines étapes et conclusion*

**16h15** ..... **André Carpentier** .....  
*Mot de fin*

**16h30** ..... **Clôture de l'atelier** .....

*Vendredi le 1<sup>er</sup> mars 2019*

## APPENDIX II

### Participant List

Nom de famille	Prénom	Position
Abbasgholizadeh-Rahimi	Samira	McGill University
Aboushawareb	Sarah	Université McGill
Arekunnath	Sreenath	McGill University
Artault-Noury	Carole	Université Laval / Équipe PULSAR
Barnett	Tracie	INRS
Bartlett	Gillian	Université McGill
Beaudry	Annick	Coordonatrice
Benigeri	Mike	Université de Montréal / INESSS
Bergeron	Lucien Jr	Université de Sherbrooke / CMDO
Bilodeau	Jean-François	Membre régulier du CMDO
Carpentier	André	Université de Sherbrooke
Després	Philippe	Université Laval / Équipe PULSAR
Després	Jean-Pierre	Université Laval
Fradet	Vincent	Université Laval
Gagnon	Justin	Équipe de l'atelier
Gauvin	François-Pierre	Université McMaster
Gauvin	Lise	Équipe de l'atelier
Ghachem	Ahmed	Université de Sherbrooke
Issa	Amalia Mary	McGill University
Lamarche	Benoît	Université Laval
Lavigne	Maxime	McGill University
Marc	Isabelle	Université Laval
Nicolau	Belinda	McGill University
Pelaez	Sandra	Université de Montréal
Pérusse	Louis	Université Laval
Salman	Ayat	McGill University
Schuster	Tibor	McGill University
Shulha	Michael	CCOMTL
Smargiassi	Audrey	ESPUM
Tremblay	Bénédicte	université Laval
Vohl	Marie-Claude	Université Laval

## APPENDIX III

Presentations included with Permission from Speakers