

# LIBERATING HEALTH DATA IN A DIGITAL WORLD

## Implications for Law, Technology, and Patient Outcomes

A solutions workshop report from  
the Schwartz Reisman Institute for  
Technology and Society at the  
University of Toronto in partnership  
with Diabetes Action Canada



UNIVERSITY OF  
TORONTO



SCHWARTZ REISMAN INSTITUTE  
FOR TECHNOLOGY AND SOCIETY



Diabetes Action Canada  
Preventing complications. Transforming lives.

# CONTENTS



- 1 INTRODUCTION**
- 2 THE PROTOTYPICAL CHALLENGE**
- 3 THE UNDERLYING PROBLEMS**
- 4 THE WORKSHOP'S APPROACH**
- 5 THE PARTICIPANTS**
- 6 THEMES AND PRELIMINARY INSIGHTS**
  - 7** Dominant themes
  - 8** Preliminary insights
- 9 SESSIONS**
  - 10** “Five Things”
  - 12** “Organizational Empathy”
  - 13** “How Might We...?”
- 16 INSIGHTS AND KEY TAKEAWAYS**
  - 17** What the Schwartz Reisman Institute learned
- 18 FUTURE DIRECTIONS**
- 19 ABOUT US**
  - 20** About the Schwartz Reisman Institute for Technology and Society
  - 20** About Diabetes Action Canada
  - 20** About Schwartz Reisman's Solutions Stream
  - 21** About workshop facilitator Dan Ryan

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Date of publication:  
July 31, 2020

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# INTRODUCTION

This is a **privacy protection story** about improved health outcomes rather than absolute principles.

Privacy legislation has been instrumental in protecting data rights and data privacy in an increasingly data-driven world. But privacy regulations have often been conceived of as fairly blunt instruments unable to account for the nuances of access to data for the public good and the ways in which emerging technologies like artificial intelligence (AI) use data.

Healthcare, for example, is a sector in which increased flexibility with and access to data could benefit patients, researchers, providers, and policy makers, while also meeting the goals of data privacy.

“Canada has some of the best and most comprehensive health data in the world and world-class expertise in advanced data technologies, including AI and **machine learning**,” says Schwartz

Reisman Director Gillian K. Hadfield, a scholar of law and economics who specializes in legal system design and the governance of AI.

“And yet, almost all of our data is effectively under lock and key due to an outdated approach to protecting privacy,” says Hadfield.

“There are easily achievable ways to simultaneously protect privacy and get the masses of data we have into

the hands of data scientists and public health officials. The problem is not that we value privacy too much; it’s that we protect it in the wrong way.”

To explore ways in which data can remain safe while also becoming more easily accessible to researchers who examine issues of public interest, Diabetes Action Canada and the Schwartz Reisman Institute for Technology and Society at the University of Toronto teamed up to host a collaborative, cross-disciplinary workshop to uncover insights about how health data could be liberated from the outdated mechanisms that ostensibly protect privacy, but actually act as obstacles to improved health outcomes for patients.

Participants came from a variety of policy sectors, academic disciplines, non-profit organizations, and healthcare institutions to bring their diverse perspectives and backgrounds to a common goal: improving the health and autonomy of those who live with diabetes in Ontario through better access to and analysis of data stored in the health system. The group aimed not only to address diabetes-specific data challenges, but to more generally think about how data liberation could improve health and save lives.

This report summarizes the problems for which participants tried to pinpoint root causes, the diversity of approaches that were brought to bear on those problems, and the unique perspectives and backgrounds of participants from a variety of sectors.

## What is machine learning?

Machine learning (ML) is a type of artificial intelligence (AI) in which algorithms learn to make predictions based on recognizing patterns—whether or not humans tell them what to look for. An ML tool scans large amounts of data about known cases, uncovers previously unknown connections, and “learns” to make predictions in other cases. A fundamental characteristic of ML tools is that the more data they have access to, the better they can learn.

**“The problem is not that we value privacy too much; it’s that we protect it in the wrong way.”**

# THE PROTOTYPICAL CHALLENGE

**Ontario could prevent thousands of cases of diabetes-related blindness every year if existing data could be analyzed by existing tools like machine learning.**

While eye disease currently occurs in over 60 per cent of individuals with diabetes, this number could be dramatically reduced with proper intervention at an early stage. Unfortunately, those who live with diabetes aren't being connected to timely screenings that can prevent diabetes-related blindness.

The data and resources to narrow this gap exist.

This shortfall is just one example of the ways in which existing privacy legislation prevents helping a patient in need of care. This is only one of the many ways the current data governance model impedes improved outcomes. More broadly, existing privacy law is generating significant delays and obstacles, both for conventional researchers and researchers working in the emerging field of machine learning for health.

## What is de-identified data?

Our current laws and regulations protect data by relying heavily on a concept developed before the rise of big data and powerful machine learning: “de-identification.” In simplest terms, de-identified data is data that has things like names and health card numbers removed. But researchers eventually showed that it's not difficult to “re-identify” data by cross-referencing it with other public data, thereby compromising privacy. So, privacy legislation like Ontario's Personal Health Information and Privacy Act defined de-identified data as data that has so much information removed from it that there is no “reasonably foreseeable” chance of re-identification. This effectively ignores recent advancements in data processing—like machine learning—which extract valuable insights from large data sets. Unfortunately, the outdated de-identification standard is almost impossible to meet without stripping data to a point where it is almost useless, or without the data custodians who could share data with researchers taking on excessive legal risk.





# THE UNDERLYING PROBLEMS

At the workshop, **five problem sets** were identified as areas in which the roots of the challenge lie:

1. Researchers find it difficult to access data due to complex and expensive data sharing and use negotiations with **data custodians**.
2. Machine learning (ML) specialists face a lack of understanding about their need for large quantities of data—a quantity erroneously seen as unnecessary.
3. Research Ethics Boards (REBs) have varying capacities, interpretations of risk, and timetables. When researchers have to consult multiple REBs, lengthy delays result.
4. Modern, responsive health systems (“learning health systems”) require up-to-date information. But integrating data from different levels (patient, clinical setting, institution, population) is challenging.
5. Canadian institutions struggle to retain top ML researchers because obstacles to accessing data are bigger than in other jurisdictions. The high-performance computing systems needed for ML are scarce and not well-integrated with conventional systems.

These five problems took the tensions within broad notions of “data” and “privacy” and put them into real-world situations to make them tangible. The reality is that enormous potential for solutions to these challenges is not being realized. Using exercises such as “excavating the why,” participants addressed the unique characteristics of a real-world problem, felt as though they were moving towards a possible solution, and empathized with other “players” in the problem.

The workshop brought together participants from a variety of sectors and disciplines who put aside their biases and individual approaches to identify—and dismantle—the barriers to data-driven health improvement. For example, some workshop participants were deeply committed to timely access to relevant data for the purpose of improving health outcomes, while others felt that the protection of privacy is paramount for the public interest.

This tension is at the heart of many health-related questions in Ontario, and many other jurisdictions around the world. This workshop was the first step in a long journey to resolve this tension, unlock data, and improve health outcomes—all while protecting patient privacy.

## What are data custodians?

Data custodians are people or organizations who have custody or control of people's personal health information. Examples of data custodians are: hospitals, physicians, laboratories, clinics, pharmacies, ambulance services, long-term care homes, or regional authorities that administer public healthcare in Ontario. In Ontario, the responsibilities of health data custodians are outlined in the Personal Health Information Privacy Act (PHIPA).



## THE WORKSHOP'S APPROACH

This workshop was the first to take place under the umbrella of **Schwartz Reisman's Solutions Stream**.

The Solutions Stream aims to meet the tremendous demand within industry, government, and civil society for innovative, actionable, high value, and globally appealing solutions to the challenge of building safe, responsible, and inclusive AI and other advanced technologies.

On March 6 and 7, 2020, collaborators worked to identify and investigate challenges that patient-oriented and population health researchers face today in accessing, integrating, and analyzing data, both for treatment and research purposes.

The workshop was led by Dan Ryan, professor at the University of Toronto's Faculty of Information and specialist in design thinking, collaboration in communities of organizations, and innovation in the legal and educational sectors.





## **THE PARTICIPANTS**

The **expertise convened at the workshop** comprised areas ranging from **medicine (and specifically diabetes) to machine learning, privacy law, policy, government, design thinking, and research.**

Our nearly 30 participants came from diverse bodies and institutions, including government, non-profit health informatics organizations, hospitals, law firms, research outfits (traditional and machine learning), the private sector, and more.

The group included “patient partners” (people who live with diabetes), whose lived experience with the health system is crucial to patient-oriented research.

With the diverse group, the workshop was structured to support the construction of relationships and ideas that wouldn't have otherwise existed. The workshop demonstrated capabilities that could lead to future solutions for problems in health data, particularly in light of the ongoing COVID-19 crisis. The event not only added value to the conversation about diabetes, but it also set the stage for future and potentially broader projects that will facilitate access to data for machine learning tools in healthcare.



# THEMES AND PRELIMINARY INSIGHTS



Only when there is equivalency between releasing and not releasing data can the public interest truly be served.



# DOMINANT THEMES

Some notably consistent themes emerged from all groups of participants.

First, it was noted that along the complex chain of research, data, privacy, and health care, there are necessarily multiple players involved. While participants appreciated the inclusive nature of that system, they often reported feeling frustrated by the multitude of voices, perspectives, and conflicting mandates that such a system inevitably involves.

A second and very prominent theme was a recognition that the people and institutions involved in this system are dedicated and committed to better results for the public good. Despite frustration in their work, our participants were adamant that malicious intentions were not the cause.

Finally, the bureaucratic nature of decision-making led to a waste of money, time, and effort. There is a belief, particularly amongst researchers, that those organizations with the most influence (government, government agencies, hospitals, etc.) are the ones with the lowest risk tolerance.

This leaves researchers, and particularly machine learning specialists, in an impossible position: they require data to deliver results, but risk-averse organizations often require projected results or estimated impacts before granting access to data. Understandably, organizations want reassurance about the purpose of data, but their lack of flexibility precludes the application of innovative tools that require data before understanding projected outcomes.



# PRELIMINARY INSIGHTS

In the course of the two-day workshop, a deeper understanding of *why* problems persisted in the way they do emerged.

Participants began to hypothesize how we might better tackle these problems, with a particular focus on how we might better understand and communicate the benefits of improved data-sharing between stakeholders for the improvement of patient outcomes.

Recommendations included:

- Develop better risk assessment measurements and provide more nuanced risk assessment outputs than simply “yes” or “no.” One suggestion envisioned a “sliding scale” model of risk according to which some data could be released. Alternatively, various aspects of data could be released but with conditions that mitigate the projected risks of releasing each aspect.
- Better inform data custodians about the risks of not providing access to data, including responsibilities and liabilities. Only when there is equivalency between releasing and not releasing data can the public interest truly be served.

- Find ways for subject matter specialists from all stakeholder groups to coherently determine and communicate about the balance between risks and benefits of data use.
- Develop a standardized framework of regulatory practices that applies more broadly across regulatory and data custodian bodies.
- Adopt best practices, initiatives, and strategies from other countries or other domains of practice. A key example presented was Denmark’s suite of initiatives to digitize, manage, and protect public health information while granting researchers access to crucial information—such as, for example, the Danish National BioBank.<sup>1</sup>

1. The Danish National BioBank is a coordinated set of registries containing more than 25 million biological samples from residents of Denmark. Its goal is to grant scientists from Denmark and abroad easy access to these samples for biomedical research while maintaining strict security oversight by the Danish Health Data Authority. See [danishnationalbiobank.com](http://danishnationalbiobank.com).





# SESSIONS

There were a number of thought-provoking and productive sessions over the course of our two days together.

In this report, we focus on three of the most productive sessions:

“Five Things,” “Organizational Empathy,” and “How Might We...?”





# FIVE THINGS

Each group of participants was asked to come up with five suggestions or ideas that could help inform solutions.

While participants were previously seated with others from a variety of fields of expertise, the “Five Things” session had participants seated with their peers in the same area of specialization. After having spent time seated next to people from different fields and with different perspectives, the newly-formed groups engaged with renewed energy when participants were surrounded by others with similar expertise.

Tables were asked to discuss the five “problems” at hand and come up with five suggestions or ideas that could help inform solutions. The most salient points are listed below:

## Table 1: Legal Specialists

- It's important to keep in mind that acquiring consent is only one of six factors that constitute “reasonable grounds” for sharing personal health information. What role do the other five play, and how can they inform solutions to data access?
- The structure of legislation on privacy and confidentiality is extremely complex because a lot of reasonability standards can be interpreted differently. There are no specific instructions that apply across the board, so competing interpretations are at play.

## Table 2: Diabetes Specialists

- Diabetes is immense in scope, impact, and sheer volume of people affected in Ontario, underlining the urgency with which innovative patient assessment and treatment are needed.<sup>2</sup>
- The ability to self-manage care is critical for persons with diabetes; it's frustrating when systems do not support this self-management. Access to a patient's own health data is paramount to successful self-management.
- There is a major issue with lack of access to community-based and/or specialist diabetes care, such as home care or the oversight of diabetes specialists.
- The lived experience of persons with diabetes is crucial in informing solutions. The diabetes community is extremely engaged in patient advocacy, systems, and resources.
- There is enormous potential for solutions that is not being realized. The inability to use data prevents potential advancements in areas such as clinical interventions, public health research, academic research on population health, machine learning development, and more.

2. “Ontario has more people living with diabetes than anywhere else in the country. Rates of type 1 and type 2 diabetes have increased by 42 per cent since 2009. There are now 4,424,000 million people with diabetes or prediabetes in the province.” [www.diabetes.ca/media-room/press-releases/new-data-shows-diabetes-rates-and-economic-burden-on-families-continue-to-rise-in-ontario--](http://www.diabetes.ca/media-room/press-releases/new-data-shows-diabetes-rates-and-economic-burden-on-families-continue-to-rise-in-ontario--)

**Table 3: Health Systems Specialists**

- We need to advance a more holistic perspective on the risk vs. opportunity divide. What are the costs of not accessing data that could improve patient wellbeing?
- We need to advance integrated system thinking, in which a productively-functioning ecosystem reduces conflict between various silos and data custodians. Deeper integration between different partners in the system is paramount.
- A deeply informed and detailed sweep of the landscape will be crucial for highlighting key “wins,” however small. Many seemingly small changes can add up to help improve decisions and processes. There are a variety of little things we can do to create incremental but meaningful change.
- A sense of citizen as patient and researcher is crucial and should always be top of mind. The focus on designing patient-centered policy needs to thrive and grow.

**Table 4: Machine Learning (ML) Specialists**

- ML researchers and developers need as much data as possible in order to train an impactful ML model. The model’s performance scales with the amount of data made available to it.
- Many ML researchers in non-health sectors are working in roughly four-month cycles. ML researchers in healthcare can’t compete with their peers if it takes them four months to simply acquire the approvals necessary to access data. ML researchers in Ontario in particular are hit hard with obstacles.
- Incentives for data stewards like ICES are not aligned with factors that foster innovation. Data stewardship organizations default to privacy protection over innovation, patient outcomes, and overall health system improvement.
- No data is completely “de-identified.” While this may sound distressing, it should in fact be reassuring: despite the fact that completely de-identifying data is impossible, there is extremely minimal risk for a certified ML professional to accidentally re-identify any information. ML researchers want to provide clarity about what de-identifying data really means in order to inform non-specialists and provide important context about their work.
- Without data housed in strong computational resources, we are not able to train and retain top ML talents in Toronto and Canada more broadly. This jump-starts a potential chain reaction: we lose or cannot recruit talent, quality work is not conducted, and Canada does not see the benefits.

# ORGANIZATIONAL EMPATHY

Participants strove to **improve empathetic understandings** of what various actors in the network are trying to achieve.

Participants and organizers both perceived the “Organizational Empathy” session as one of our more impactful and insight-generating sessions. It will be key to how we proceed with further work on this and related topics. The sessions provided a necessary deeper understanding of

other organizations’ goals and motivations—particularly those who are competitors or sometimes seen as “blockers” to what others want to achieve.

In this session, the tables again comprised participants from a variety of sectors and specializations. Each participant spoke to their group about the five “problems” at hand from their own perspectives, encouraging others to walk a mile in their shoes, to think about the incentives and pressures that other actors face, and to recognize the key players on each problem. For example, ML researchers started to understand what data stewards are up against—and vice versa.

An improved and empathetic understanding of what each of

the “adversaries” in this complex system are trying to achieve, how they operate, and what they can contribute to their partners will be paramount to making advances.

Participants at the table concerned with data sharing negotiation and delays attempted to improve each other’s understandings of the various parties involved in facilitating data sharing, including the office of the Information and Privacy Commissioner of Ontario (IPC), the IT systems being used to house and manage data, the vendors who provide

and maintain these IT systems, and the various levels and actors in the senior leadership ranks of these organizations.

A more thorough understanding of how this element of the system works helped those who are outsiders to the data stewardship landscape understand some explanations for why access to data is difficult to acquire.

The table assigned to discuss Research Ethics Board (REB) delays highlighted the fact that someone needs to represent the interests of the institutions providing funds for great ideas to be realized. That’s where REBs come in, and why they are crucial to the process. Improved communications channels and processes could speed up coordination between research institutions, community representatives, research coordinators, and legal representatives.

The table assigned to discuss learning health systems had similar observations and recommendations about improving communications and information flow between actors. For example, in the case of the diabetes health system, actors include Diabetes Action Canada, the government’s data stewards, Research Ethics Boards, and the three-way interaction between principal investigators, device vendors, and clinicians/institutional custodians.

Because a learning health system relies on the consistent, continual, and speedy capture of new knowledge generated during daily practice, the communication of this knowledge in a cohesive and timely manner is crucial to the continual improvement of care by and within the system.

**An improved and empathetic understanding of what each of the “adversaries” in this complex system are trying to achieve, how they operate, and what they can contribute to their partners will be paramount to making advances.**

# HOW MIGHT WE...?

In this very **practically-oriented session**, participants attempted to scope the larger problem and began to outline what might be done.

The guiding question of this session was: “If we want to achieve x, what has to be true?”

## Table 1: Data-sharing negotiation delays

How might we communicate with the Information Privacy Commissioner (IPC) in terms of improved overall outcomes rather than absolute privacy protection principles? Potential suggestions for communicating better with the IPC included:

- Conducting increased reporting about public input on data use
- Getting citizens engaged in this topic
- Demonstrating a serious return on investment
- Creating a data research sandbox with a “low rules” environment—one in which trust is paramount to compensate for decreased regulation
- Demonstrating improved care through improved data access
- Administration oversight on privacy and data access
- Anticipating a worthwhile value proposition

How might we change the laws on privacy, specifically on access to lab data? Currently, the provincial Ministry of Health controls the data. We could:

- Improve data management capacity
- Address liability concerns
- Create a data commissioner
- Create a new framework for central data governance and data authenticity

## Table 2: ML access to Ontario health data

How might we find ways for groups to coherently determine the risks and benefits of data use?

Suggestions for ML researchers and gatekeepers:

- Create regulatory standards for trusted ML research that evolve privacy practices
- Change the incentive paradigm in research (e.g. publication volume) to capture societal benefit or research interests
- Change the culture of key organizers to solve problems that serve an overarching shared goal or commitment
- Demonstrate the benefits of ML research to non-specialists in an accessible, easy-to-understand manner
- Demonstrate that access to data for ML will lead to “paradise rather than Pandora’s box,” as one participant stated
- Determine a socially acceptable risk vs. benefit profile
- Improve data access resources and methodologies including security and privacy, such as the incorporation of “privacy by design” principles in ML tool development
- Engage researchers across disciplines to bridge silos in the innovation value chain and thereby demonstrate and accelerate all parties’ shared goals

### Table 3: Research Ethics Board (REB) delays

How might we decrease or mitigate the effects of REB delays?

- Separate specific risks from other responsibilities or liabilities
- Give a more nuanced risk rating rather than simple binary Y/N feedback
- Redefine the role of REBs; whose interests do they currently prioritize, and whose should they prioritize?
- Improve efficiencies at the local level
- Coordinate for simplified process
- Optimize the sharing of risks between actors via:
  - The creation of a board group
  - Risk ratings
  - A centralized precedent

### Table 4: Learning health systems

How might we become a true learning health system, one of constant improvement?

Individuals could:

- Amplify the voices of individual people; do they care what happens to their data?
- Provide people the autonomy to “opt in”

Clinicians could:

- Get more of their colleagues to participate in contributing health data

Providers could:

- Encourage their peers and colleagues to see the value of data
- Encourage their peers and colleagues to make use of the existing research to help individual patients
- Make it easy for their peers and colleagues to get insights when they need it

Legislation could:

- Standardize formats for governance frameworks
- Create certainty in another form
- Motivate political change and action

The system could:

- Ensure commercial interests do not override public good
- Protect privacy principles without blocking data use for legitimate purposes
- Change the perception of the privacy risk vs. benefits balance
- Provide additional staffing
- Create a central system





### Tables 5+6: ML researcher recruitment/retention and computing resources

How might we change our system to increase our ability to recruit and retain global talent, while also increasing our computing capacity?

- Instead of a Y/N decision, developing a risk rating system to enhance the interaction during the evaluation process could be crucially beneficial. How might this be done?
- Instead of a Y/N decision, develop a risk rating system to enhance information flow and increase interactions between researchers and data custodians throughout the process
- Shorten the approval process
- Shorten the assessment process for ML researchers; self-assessment could be conducted under limited parameters and as appropriate
- Negotiate from an angle of genuine interest, not position
- Maintain literacy, particularly about ML, for stakeholders in process
- Borrow from other legal frameworks like pensions and loans
- Build a safe shield to find common ground on outcomes
- Ensure regulators are making scoped decisions to get to approvals
- Change the relationship between gatekeepers and researchers to one of mindful partnership
- Create models to compare cost of expected failure to cost of lost innovation
- Leverage private cloud providers, to abdicate to them
- Allow for analysis/results without needing to get the data
- Design shared systems with more flexibility
- Certify local infrastructure



# INSIGHTS AND KEY TAKEAWAYS





# WHAT THE SCHWARTZ REISMAN INSTITUTE LEARNED

**We learned that we can play a key role as a safe nexus at which the expertise of stakeholders with divergent interests can solve complex problems.**

What do we bring to the table?

**Audience curation:** High-level creative problem-solving requires the right people to be in the room including both strange bedfellows and difficult to convene mixtures. When inviting stakeholders and subject matter experts, we have at our disposal the convening powers of the Schwartz Reisman Institute and the University of Toronto.

**Multiple tools and methods:** Our interdisciplinary and cross-sectoral approach is unique and different, but grounded in research and pragmatism. It helps people think in new ways about intractable problems.

**Design thinking:** We combine a fundamental respect for scientific, policy, and humanistic expertise and a commitment to engaging with topics at a high level, with tools borrowed from human-centred design thinking: a solutions-orientation built on empathy, outside-the-box brainstorming, and iterative prototyping and testing.

**Problem articulation:** We can lend guidance to those in the field to better scope and articulate the problems at hand. For example, what is experienced as a “privacy” problem could mean a slow process, a conservative legal interpretation, dated legislation, a misunderstanding of the concept between parties, or misaligned incentives. By acting as a safe nexus without a “dog in the fight,” Schwartz Reisman can lead its partners to find the heart of problems.

**Expertise:** Schwartz Reisman has expertise in process and law/infrastructure. That makes us trusted and non-threatening to those with specific subject matter expertise. And, we can unlock over \$1B in academic research at the University of Toronto and bring in world-leading academics who want to use their research in an applied way in the real world. Plus, we’re fixing the university model while we are at it!

# FUTURE DIRECTIONS

There were **three main takeaways** and **directions** taken at the conclusion of our solutions workshop.

First, Diabetes Action Canada was able to create new pathways and relationships, and develop new approaches to problems that are starting to bear fruit. Our hope is that solutions are generated that can help improve the lives of diabetic patients. Second, the workshop brought together key players from the health sector, the Ministry of Health, regulators, data providers, and leaders at Schwartz Reisman for the first time. Immediate trust and respect was developed across the board, leading to the creation of a health data platform group in the early days of COVID-19 that holds real promise for data and machine learning researchers. Finally, the success of this inaugural workshop has inspired us at Schwartz Reisman to pursue our Solutions Stream as a viable and needed enterprise in our policy and academic community.

With this workshop, we've generated the framework and blueprint for a path forward in using powerful new technologies to solve critical healthcare issues, and we're proud to have highlighted the extent to which relationship-building in these pursuits is key.





# ABOUT US

got together and shared data system  
Developed a governance framework?

br sys

HMW Standardize formats?

lack of resource

\$

Lack of interoperability

Diffe Data formats

risk exposure

HMW create certainty in another form?

Complex Data Sharing and Contracts

Commercial interests

Killing Commercial interests kills innovation

HMW ensure commercial interests don't override public good? (LHS goals)

What if MOH held consultations on new personal health data framework w/ stakeholders?

Codify privacy rights + values

HMW protect privacy principles without blocking data use for legitimate purposes?

Privacy legislation (PHIPA)

Can we use a data trust model to help?

How do we give the people not at the table a voice?

Choose one or the other

Unstable political climate

What if individuals put pressure on govt?

new political climate every 4 years.

Lack of political, financial, social commitment

Decentralized system

Priority on clinical

# ABOUT US



## About the Schwartz Reisman Institute for Technology and Society

Established through a generous gift from Gerald Schwartz and Heather Reisman in 2019, the Schwartz Reisman Institute for Technology and Society is a research and solutions hub dedicated to ensuring that powerful technologies like artificial intelligence are safe, fair, ethical, and make the world better—for everyone. We're developing new modes of thinking in order to understand the social implications of technologies in the present age, and we're reinventing laws, institutions, and social values to ensure technology is designed, governed, and deployed to deliver a more just and inclusive world. Our researchers range in fields from law to computer science, engineering, philosophy, political science, and beyond. We draw on world-class expertise across universities, government, industry, and community organizations to unite fundamental research on emerging technologies with actionable solutions for public policy, law, the private sector, and citizens alike.

## About Diabetes Action Canada

Diabetes Action Canada is a pan-Canadian research organization that was launched in 2016 and is funded jointly by the Canadian Institutes of Health Research's (CIHR) Strategic Patient-Oriented Research (SPOR) program, non-profit organizations (e.g. Diabetes Canada, JDRF), and private sponsors. The Diabetes Action Canada network consists of a diverse team of patient partners, researchers, diabetes specialists, primary care practitioners, nurses, pharmacists, data specialists, and health policy experts committed to improving the lives of persons living with diabetes. Diabetes Action Canada focuses on bringing patients, their caregivers, and researchers together to identify the health concerns of those living with diabetes and to co-create research projects that address these concerns. Partnering and collaborating with university research teams across Canada, non-profit organizations, and provincial governments, Diabetes Action Canada plans, executes, and evaluates these research projects to improve patient outcomes and experiences.





### **About Schwartz Reisman's Solutions Stream**

Schwartz Reisman's Solutions Stream aims to move beyond current conversations that focus on principles, ethics, and guidelines for emerging technologies in order to develop real-world solutions. We believe that new models are needed to ensure the safe, efficient, and responsible deployment of emerging technologies. These models will likely reimagine the relationship between citizens, government, and the private sector. Our Solutions Stream works with a cross-section of researchers, together with stakeholders in industry, government, and civil society to develop distinctive methods of generating novel and practical solutions to problems posed by emerging technologies.

The goal of Schwartz Reisman's Solutions Stream is to incorporate innovative approaches like design thinking—an emerging cross-disciplinary approach that centres human experience to create processes, institutions, and frameworks that provide people-centric solutions to real world problems—into solutions-oriented methods and workflows.

We envision moving rapidly from problem analysis to idea generation to prototyping to proposed solutions available for implementation by industry, government, and civil society. Led by Schwartz Reisman Director Gillian Hadfield, our Solutions Stream strives to be a respected and trusted place where smart, novel, and concrete ideas can be generated and evaluated, with attention to the practicalities of implementation. We take our deep knowledge of design process and combine it with Hadfield's world-leading expertise in institutions, legislation, and regulation to help break up logjams and unleash the possibilities of emerging technology—with safety and human wellbeing as key components.

### **About workshop facilitator Dan Ryan**

Professor Dan Ryan of the University of Toronto's Faculty of Information curated our conversations for this particular solutions workshop. An educator with deep knowledge of design thinking and collaboration, Ryan proposed a variety of tools and techniques to help our participants feel open to new ideas and to each other: the two-day session combined creative thinking exercises and games, deep dives into particular problem sets, sessions designed to elicit empathy, and new solutions for old foes and old problems.

Ryan earned his PhD at Yale in sociology and a BA in mathematical, physical, and computer sciences at New College of Florida. He comes to the University of Toronto from the University of Southern California where he was professor of teaching of Arts, Technology, and the Business of Innovation and Law at the Lovine and Young Academy. Prior to USC he was professor of sociology at Mills College in Oakland, CA and held the Lokey Chair in Ethics and was founder of the Innovation Lab at Mills. He has written on the sociology of information, collaboration in communities of organizations, and time.

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