



Call for an Ontario Health Data Ecosystem

Prepared by Ontario Genomics with support from the Data for Health Advisory
Group and the Ontario Personalized Medicine Network

Fall 2015

Acknowledgements

Ontario Genomics is thankful to the many individuals and organizations who have contributed to the information and recommendations in this report (please see Appendix I for a list of consultations). In particular we acknowledge the extended contributions of the Data for Health Advisory Group (please see Appendix II for a list of members) and the Ontario Personalized Medicine Network (please see Appendix III for a list of representatives).

Ontario Genomics is a non-profit organization that enables the genomics field in Ontario. Ontario Genomics' mandate is to spark, support and sustain genomics innovation as a key driver of Ontario's economy.

Ontario Genomics' efforts in constructing this report originated from a request from the Ministry of Research and Innovation (MRI) and the Ministry of Health and Long-Term Care (MOHLTC) to outline the challenges and opportunities presented by personalized medicine in Ontario. In response to this request, Ontario Genomics has struck an expert panel: the Ontario Personalized Medicine Network (OPMN; please see Appendix III for a list of representatives) who identified access to health-related data as an important opportunity. Due to the cross-cutting role of data in enhancing healthcare, research and policy within the health system in general, Ontario Genomics has engaged an additional group of experts with expertise in health data (the Data for Health Advisory Group; please see Appendix II for a list of members) and with their support the report's scope of information gathering was expanded to serve this broader purpose.

The Value Proposition

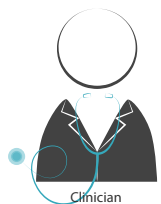
Ontario houses a large number of highly valuable health databases used for research, patient care and health system planning. Every time an Ontarian makes a visit to the doctor and with the launch of every new patient-oriented research study, the richness and magnitude of this asset grows. While these databases continue to evolve in isolation from one-another, there is a developing need for patient information from across the research and care continuum to be linked in order to inform better policy decision making, higher quality healthcare or more patient-focused research. In response to this need, we are beginning to see more and more programs where patient data collected from routine visits to the doctor are being linked to data collected through research and through Ministry of Health and Long-Term Care administrative databases. However, each time such an initiative is attempted, a complex maze of policy, privacy and security issues involving multiple stakeholders with differing interests and objectives must be deciphered. We propose the establishment of an enabling mechanism—an alliance of key data powerhouses across research and care with a professional secretariat—to develop some foundational data sharing policies aimed at accelerating and facilitating these opportunistic initiatives. This model is anticipated to not only enhance the objectives of the participating institutions but also to catalyze the emergence of a more interconnected health data ecosystem where Ontario and individual Ontarians can reap the everyday benefits of access to health information.

Background

Development of new technologies is leading to an exponential increase in the volume and types of data surrounding individuals, creating unprecedented possibilities for informing and transforming health research, health policy and healthcare.

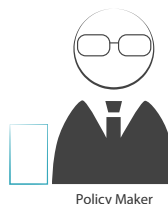
Expanding pools of data and the use of advanced analytics is slowly changing how healthcare is delivered. Patient information is now for the most part digitally recorded through Electronic Medical Records (EMRs), and over the last decade, our ability to quickly and inexpensively generate molecular information (such as genotypes) has dramatically improved. Availability of new and comprehensive data elements and advances in computing is allowing us to better understand disease determinants and comorbidities. For instance, since the initial sequencing of the human genome in the early 2000s, the number of rare diseases with an identified genetic culprit has risen from 160 to 3600.¹ New algorithms are also allowing for combined analysis of clinical and molecular data alongside social and environmental information to facilitate healthcare policy decision-making and to enable evidence-based health system planning. Better use of data and technology, as stated by the UK's National Information Board "has the power to transform the quality and reduce the cost of health and care services. It can give patients and citizens more control over their health and wellbeing, empower care givers, reduce the administrative burden for care professionals, and support the development of new medicines and treatments."²

Over the coming years, sophisticated use of data is expected to transform the health system. Below is a snapshot of what we might see:



Benefit for Clinicians

Through his patient management system, an endocrinologist gets an automated alert that one of his diabetic patients has recently converted to being at high risk of vision loss and is prompted to prescribe him laser therapy. The automated recommendation was based on computerized integration and interpretation of live information about the patient from the endocrinologist's records as well as from several external sources including a research study and a recent unrelated visit to the ER.



Benefit for Policy Makers

A public payer is faced with repeated humanitarian requests to fund an expensive and currently non-reimbursed depression therapy. Unsure of the population-level benefit of the drug in relation to its system-level cost, the payer decides to fund every request for a pilot period of two years. With access to detailed system usage data, the payer monitors how access to the therapy changes patients' use of government services over the pilot period and decides to systematically reimburse the drug for patients with a severe disease phenotype below the age of 30.



Benefits for Researchers

Looking at her 5000 patient research cohort, a diabetes researcher observes that obese women with diabetes may be more likely to develop breast cancer. By utilizing a centralized research portal that gives access to research-ready and de-identified patient records from the health system, she was able to identify a virtual cohort that matched her study criteria. Analysis of these records showed a statistical correlation between obesity, diabetes and breast cancer—within 6 months and with a budget of \$30,000.



Benefit for Patients

With their consent, a group of patients on a Health Canada-approved anti-inflammatory medication are enrolled in an "electronic clinical trial" to monitor their outcomes through their electronic health records. The trial reveals a statistically significant risk of cardiac failure that is immediately disseminated to all doctors with patients on the therapy. Within a few months, Jill, a patient with Rheumatoid Arthritis who is taking this anti-inflammatory drug is told by her doctor that there are developing safety concerns associated with the medication and is put on a different medication.

Ontario's Health Data Landscape

Ontario possesses a compelling set of health data assets including a wealth of databases, world-class expertise in analytics and robust digital infrastructure. There are also many public and private organizations working with these assets to deliver new value propositions in health. This landscape can be segmented into six distinct "Domains" spanning across the research and clinic continuum.



Patient Care Domain

Making integrated and reliable patient information available at the point of care to enable better and faster healthcare delivery.

Key Players: eHealth Ontario; hospitals, Local Health Integration Networks (LHINs), Community Care Access Centres, Cancer Care Ontario (CCO); the Ontario Medical Association (OMA) etc.

Data Assets: Patient information from Electronic Health Records (EHRs), Electronic Medical Records (EMRs), Laboratory Information Management System (LIMS), eHealth Ontario portals including CGTA and OLIS; computing capacity at hospitals, commercially and academically-developed clinical decision-making software etc.



Patient-Powered Research Domain

Enabling patient-focused medical discovery with robust individual-level clinical and molecular data.

Key Players: Ontario Institute for Cancer Research (OICR); Ontario Brain Institute (OBI); Compute Ontario; clinical trial hubs (e.g. NCIC Clinical Trials Group, Population Health Research Institute etc.); universities; hospital research institutes etc.

Data Assets: Research and clinical trial databases; research-focused computing infrastructure such as High Performance Computing Virtual Laboratory (HPCVL), HPC4Health; OICR facilities, SciNet and SHARCNET, the Southern Ontario Smart Computing Innovation Platform (SOSCIP); commercially- and academically-developed molecular data analysis tools, sequencing and analytics facilities (e.g. The Centre for Applied Genomics) etc.



Longitudinal Health Research Domain

Collecting vast amounts of long-term survey data to understand how social and environmental factors affect complex and chronic diseases.

Key Players: The Canadian Longitudinal Study on Aging (CLSA), the Ontario Health Study (OHS) etc.

Data Assets: Large-scale longitudinal cohort databases; algorithms, tools and portals for querying and access etc.



Performance Measurement Domain

Making better use of healthcare usage and patient outcomes data to enhance operational decision-making and performance in healthcare delivery.

Key Players: Ministry of Health and Long-Term Care (MOHLTC); Health Quality Ontario (HQO); Cancer Care Ontario (CCO); the Institute for Clinical Evaluative Sciences (ICES); Local Health Integration Networks (LHINs; e.g. The Hamilton Niagara Haldimant Brant LHIN); hospitals (e.g. The Ottawa Hospital, St. Michael's Hospital) etc.

Data Assets: MOHLTC administrative databases; disease registries; computing infrastructure and analytics capacity at ICES, CCO and HQO; Ministry-, LHIN- and institutional-level analytics tools and algorithms etc.



Population Health and Policy Research Domain

Employing large and comprehensive datasets surrounding individuals to conduct evidence-based population health and policy research.

Key Players: The Institute for Clinical Evaluative Sciences (ICES), Cancer Care Ontario (CCO), the Canadian Primary Care Sentinel Surveillance Network (CPCSSN), the Ontario Medical Association (OMA) etc.

Data Assets: MOHLTC administrative databases; CPCSSN database, Record Administrative Data Linked Database (EMRALD); computing capacity, security and linkage protocols and analytics expertise at ICES, CCO etc.



Patient-Centric Technology Development Domain

Developing interactive technologies to maximize participation of patients in their own health including generation and management of patient-generated health data.

Key Players: University Health Network's Centre for Global eHealth Innovation, hospitals with patient portals (e.g. Sunnybrook Health Sciences Centre and MyChart, Mount Sinai Hospital and VitalHub etc.), NexJ Connected Wellness, Telus Health etc.

Data Assets: Patient data from mobile devices, commercially- and academically-generated tools, apps and digital platforms for health management etc.

The Problem

Ontario's health data landscape is prolific but disorganized and poorly connected, with exchange of data between organizations (in particular ones residing in different Domains) being limited to *ad hoc* pilot initiatives.




Stakeholders in Ontario's health data landscape are generally not set up to exchange data, expertise, tools or hardware in a streamlined and efficient way. For instance:

- There is little consistency in the types and standards of data that are collected across various initiatives;
- People are often not consented for the use of their information beyond an initial primary purpose;
- There are multiple and lengthy ethics approval processes for obtaining data from more than one source;
- There are no easily accessible inventories to make existing data, samples and tools "discoverable";
- There are many different interpretations of laws pertaining to protection and exchange of health information;
- The same individual is often identified by different means in different health system settings;
- Each institution has devised a different set of privacy and security protocols for storage and transfer of information.


In spite of these barriers, there are many pilot projects underway to enable the exchange of data across institutions and quite a few have had success. For instance, patient data collected at multiple hospitals is now being harmonized and made available for research to OBI investigators and real-life outcomes information from ICES has been successfully linked to OBI data. Unfortunately, however, learnings from these success stories are not being disseminated or adopted across the landscape as best practices. As such it is unclear whether these pilots might, in fact, facilitate future systematic exchanges of information between the patient care and research Domains.

Implications for Stakeholders


The inefficient and suboptimal exchange of data assets is resulting in tangible disadvantages for individual patients, clinicians, researchers, for data-focused public organizations and businesses, as well as at a system level for government and the province of Ontario.




At the moment, most clinicians in Ontario do not have ready access to their patients' comprehensive healthcare data. Basic information such as name, age and bare minimum clinical history must be re-recorded every time a patient enters a new healthcare establishment and critical diagnostic information (e.g. from a family physician to a specialist) is either not shared or is transferred with great difficulty.




Emerging new evidence for better and more cost-effective healthcare is often poorly disseminated or not adopted in our clinical practices. For instance, when good evidence negates the effectiveness and safety of first line guidelines and medications, it may take years or even decades for the information to transform the care that is provided through the Ontario healthcare system.



With no ready access to existing healthcare, social and education databases, researchers are losing ground in the race to understand multifactorial disorders like heart disease, diabetes, and cancer. Other competitor jurisdictions make de-identified data from the public health system readily available to researchers. The Farr Institute in the UK for example has established regional data safe havens where de-identified patient records from the National Health Services' (NHS) databases are made available for authorized research.



Lack of access to multi-dimensional data is impeding accurate system performance measurement and policy decision making in particular as related to complex and chronic diseases. Targeting support toward programs that are most likely to reduce the burden of expensive diseases such as mental health is a particular challenge. This is primarily because many factors such as life style, economics and social status contribute to the patient and financial burden of these disorders.



Our current inability to pull multiple datasets and value-add processing and analytics services together under one business-ready platform is limiting our ability to attract industrial clientele as well as to serve homegrown innovation. In contrast to Ontario, commercial opportunities related to health and health-related data are being readily seized in the US and many institutions are successfully leveraging patient information within business models that have full and informed support from their patients. For example, Explorys was founded as a spinoff from Cleveland Clinic in 2009 and is now successfully commercializing a data platform with over 315 billion clinical, financial, and operational data elements, spanning 50 million unique patients, 360 hospitals, and over 317,000 providers. Explorys' secure cloud-computing platform is being used by 26 major integrated healthcare systems to identify patterns in diseases, treatments and outcomes.

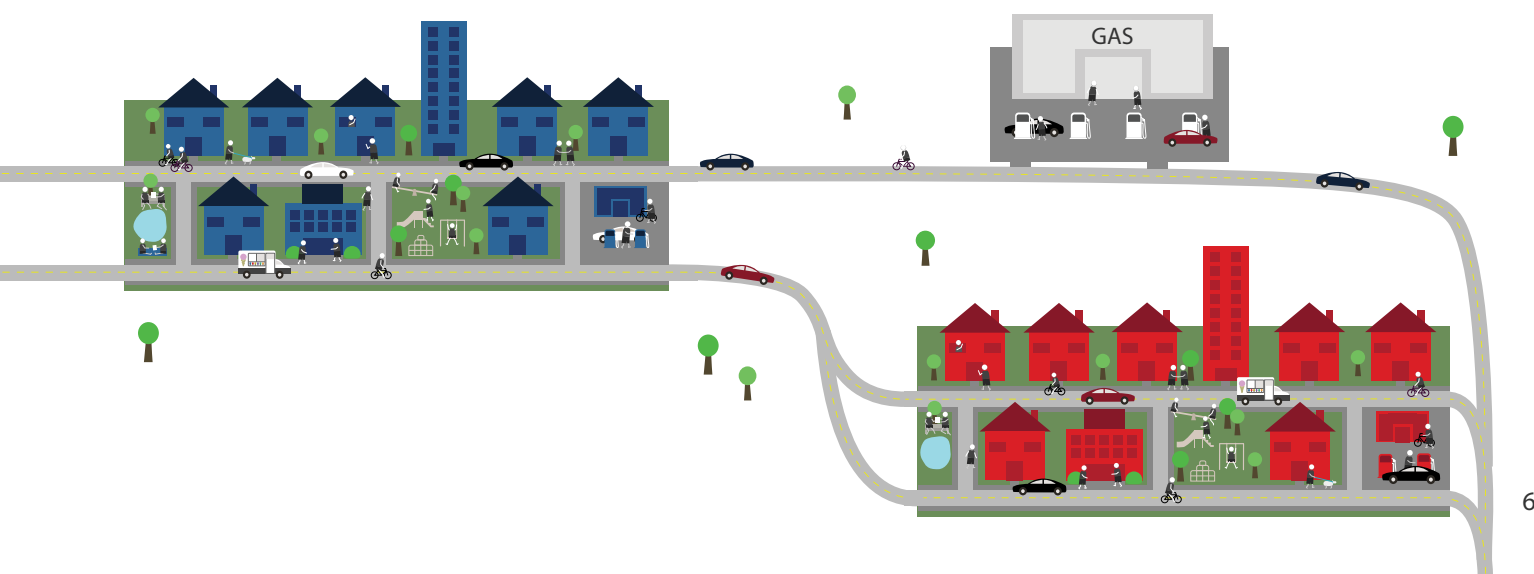
The Solution

Stakeholders point to the need to establish universal data policies and to designate broad-serving data infrastructure to enhance connectivity and synergy among health institutions in Ontario.

As part of this solution, common data policies such as universal ways of capturing basic patient information or mutually-agreed upon methods for transferring sensitive files would serve as robust roadways to facilitate systematic data exchange *between institutions in a given Domain*. At the same time, some algorithms, software, expert capacity and computing infrastructure might be designated (or created) as common amenities to serve collective and collaborative objectives for organizations in a particular Domain. Much of this work is already underway. For instance, in the Patient-Powered Research Domain, Compute Ontario has been established to help coordinate high performance computing usage and infrastructure upgrades, Clinical Trials Ontario (CTO) has launched a new system to streamline research ethics board approvals across multiple institutions and the Global Alliance for Genomics and Health (Global Alliance) has set out to create a common international framework for health and genomic data sharing. Similar initiatives are underway in the other Domains. For instance, within the Patient Care Domain, eHealth Ontario is already providing integrated data access among several LHINs and community care nodes through its ConnectingGTA portal.



Similar “policy highways” and broad-serving data infrastructure would facilitate and streamline the opportunistic exchange of data between *institutions residing in different functional Domains*.



Impact: Optimal Value Realization in a “Network of Networks” Ecosystem

With the establishment of policy highways and communal data amenities, each health data Domain will be transformed into a networked community and the entire landscape will be transformed into a symbiotic ecosystem where organizations maintain their distinctive assets and mandates but can deliver enhanced or new value.

Patient Care

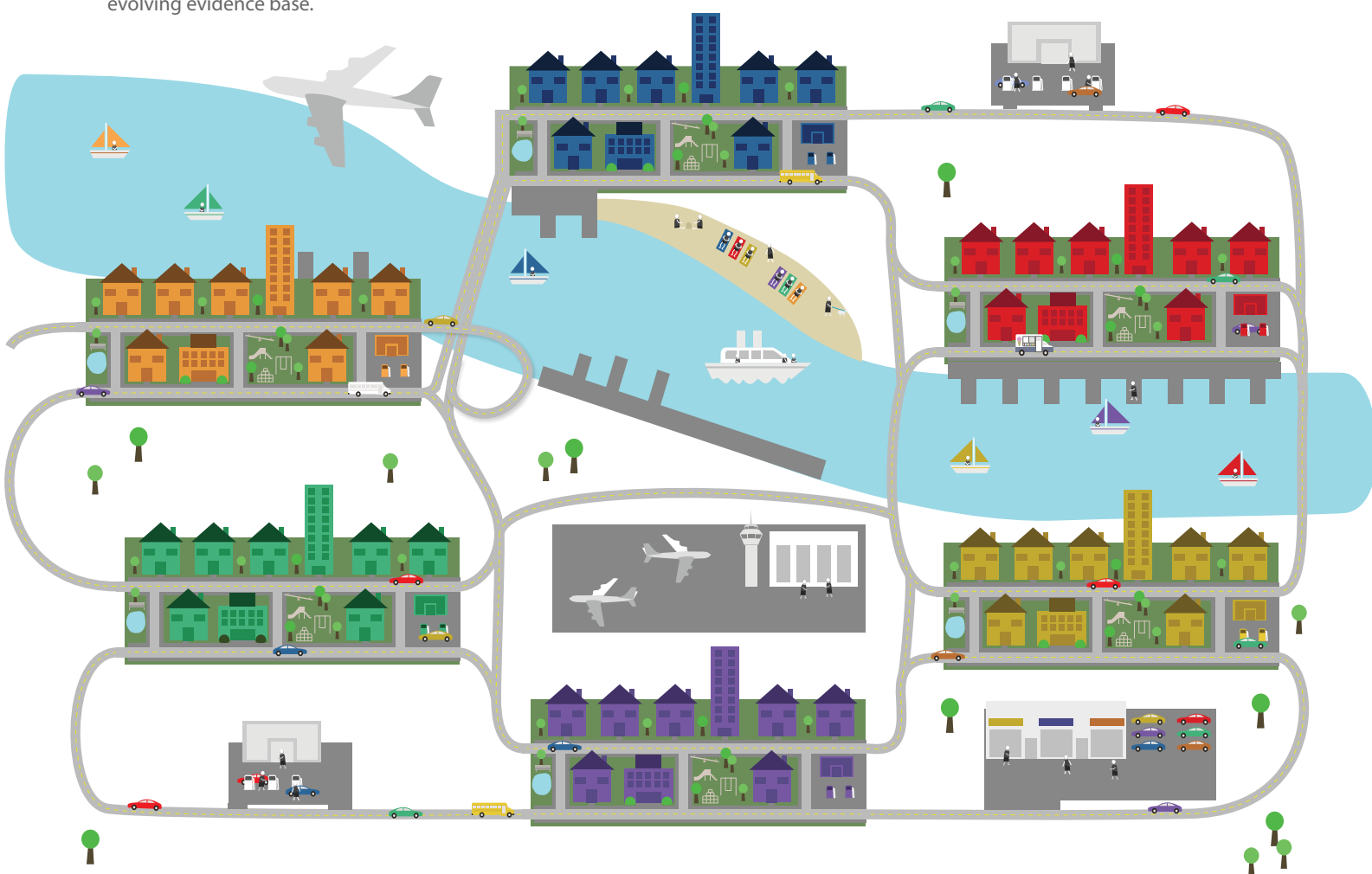
Up-to-date knowledge and decision support tools to sort through a complex and rapidly evolving evidence base.

Performance Measurement

Access to more real-time and comprehensive data for planning and reimbursement decisions.

Patient-Centric Technology Development

Access to business-ready and comprehensive data platforms to generate new economic value.



Patient-Powered Research, Population Health and Policy Research, Longitudinal Health Research

Greater access to more comprehensive and statistically meaningful patient information to deepen our understanding of disease, interventions and outcomes.

Implementation

We recommend that leading organizations from the six health data Domains (e.g. eHealth Ontario, ICES, HQO, CCO, OICR, OBI, 2-3 hospitals, OHS, CLSA, Compute Ontario etc.) as well as the Ministry of Research and Innovation and Ministry of Health and Long-Term Care strike a “Coalition” with a professional secretariat to accomplish the following goals:

1. Create and sign onto a data sharing charter consisting of minimal quality, privacy and security policies, to facilitate and accelerate the exchange of assets across the Domains when the desire for sharing of information, infrastructure, tools and expertise exists.
2. Provide an on-going mechanism for rationalization of investments to ensure utility and interoperability of existing and new infrastructure (hardware, software and people) across the entire ecosystem.

Immediate strategic and practical considerations for the coalition might include:

Development of some founding principles. For example:³

- **Decentralized data sharing:** The Coalition will work towards the creation of shared spaces for temporary and secure federation of data and/or standards and tools for leverage of data across the ecosystem through a distributed analysis model.
- **Participation not obligation:** Coalition members will have the ability to identify data assets of interest within the network and gain access to information (or link their own data with other information) under conditions that are acceptable to all the relevant participants.
- **Transparency and representation:** Coalition members will always have the opportunity to approve and release access to their data within what they deem to be acceptable privacy and security frameworks.
- **Mutual benefit:** Coalition members believe that by gaining access to data across the entire network, they will advance science, clinical care, public health and product development, generating wholly different and transformative value propositions that no single enterprise could achieve on its own.
- **Cost neutrality:** Participation in the network will be a cost-neutral venture, where any investments are off-set by value generated as a result of enhanced access to data from other sources.
- **Interoperability, not re-design:** The network will utilize a set of standardized “adaptor” data harmonization tools that maximize the accommodation of existing data collection mechanisms and policies within each enterprise while facilitating streamlined data exchange.

Creation of a clear action plan with short-, medium-, and long-term outcomes. For example:

Goal 1: Create and sign onto a data sharing charter consisting of minimal quality, privacy and security policies

	Anticipated Outcome		
	Short-Term (1-2 yrs)	Medium-Term (3-5 yrs)	Long-Term (5+ yrs)
I. Reach a common understanding of the legal liabilities around data protection and release		Policy finalized; members gain streamlined ability to access data and gain increased confidence to share data across the Domains	
II. Identify a minimal sharable dataset and mechanisms for quality control		Policy finalized; members gain streamlined ability to use information on the same individual within each Domain	Policy finalized; members gain streamlined ability to use information on the same individual across the ecosystem
III. Identify a mutually beneficial minimal consenting scheme and mutually-agreed upon ethical parameters		Policy finalized; existing information on individuals becomes more readily available within one Domain	Policy finalized; existing information on individuals becomes more readily available across the ecosystem
IV. Establish Standard Operating Procedures for data exchange		Policy finalized; harmonized transfer, storage and security protocols exist to streamline exchange and linkage of data within each Domain	Policy finalized; harmonized transfer, storage and security protocols exist to streamline exchange and linkage of data across the ecosystem

Goal 2: Provide an on-going mechanism for rationalization of investments in Ontario's health data infrastructure

	Anticipated Outcome		
	Short-Term (1-2 yrs)	Medium-Term (3-5 yrs)	Long-Term (5+ yrs)
I. Create and maintain a live web-based inventory to showcase health data assets across the entire ecosystem	Gain ability to discover what exists and initiate collaborations within and across the Domains		
II. Conduct an independent health IT needs review to outline additional (current and future) infrastructure needs for an integrated ecosystem (storage, analysis capacity, safe havens and portals, expertise, software etc.)	Gain unbiased information to coordinate capacity planning across the Domains		
III. Strategically identify and promote on-going small-scale infrastructure development projects that enable the exchange of data assets within and across Domains to advance recommendations from Objective II	Ensure small investments in hardware, tools and people enable community and ecosystem development; identify policy gaps to streamline sharing of information across the ecosystem		
IV. Develop a plan, secure funding and implement large-scale platforms for data exchange within and across the Domains based on recommendations from Objective II		Begin to deliver previously impossible value propositions with a new ability to link data and synergistically use assets within and across Domains	

Identification of a functional governance and operational model. For example:

A Steering Committee with senior representation from Coalition members, a neutral and charismatic Chair, various topic-specific task forces with relevant subject-matter experts, as well as a designated and funded Secretariat.

Maintaining national and international alignment. For example:

Establishing a continuous feed from organizations such as Canada Health Infoway; Canada Foundation for Innovation (CFI); Canadian Network for Observational Drug Effects Studies (CNODES); Canadian Partnership Against Cancer (CPAC); Canadian University Council of Chief Information Officers (CUCCIO); CANARIE; CIHR Institute of Health Services and Policy Research; CIHR SPOR; Council of Academic Hospitals of Ontario (CAHO); Compute Canada/Compute Ontario; Genome Canada; The Leadership Council for Digital Infrastructure; Manitoba Centre for Health Policy; ORION; PopData BC; Regie for l'assurance maladie Quebec; Research Data Canada, Statistics Canada, US National Institutes of Health.

Taking advantage of Industry capabilities. For example:

Early engagement of the technology development industry, in particular major investors with strategic interest in the ehealth space such as Blackberry, Google, IBM, SAS, TELUS Health, etc. is recommended.

Keeping the pulse of the public. For example:

Having citizen representation on the Steering Committee and/or Task Forces or holding episodic town halls to incorporate patient perspectives in the work of the Coalition.

Conclusion

Similar collaboration models are being successfully employed across the globe to bring additional and transformative value to the health sector while leveraging existing investments in data infrastructure. Initiatives such as Alliance for Clinical Research Excellence and Safety (ACRES), Patient-Centred Outcomes Research Institute (PCORI), and the FDA's Mini-Sentinel are prime examples where stakeholders have come together under a set of mutually agreed upon data sharing guidelines to exchange information across numerous clinical and research enterprises in complex and heterogeneous data environments. Ontario is primed to follow suit with many historically siloed organizations expressing genuine interest to share data, expertise and best practices to remain competitive in the global landscape. In this model, Ontario's data enterprises will be able to enhance their distinctive expertise, infrastructure and mandates but have in place the connective tissue that allows them to function as a system, delivering more value to the Province, the research community and ultimately to patients.

References

1. International Rare Diseases Research Consortium. <http://www.irdirc.org/>.
2. “Personalized Health and Care 2020” report for the UK National Information Board, November 2014
3. “Federalist Principles for Healthcare Data Networks” by Kenneth D. Mandl and Isaac S Kohane. Nature Biotechnology. April 2015

Appendix I: Stakeholders Consulted by Ontario Genomics

First Name	Last Name	Title	Affiliation
Monique	Albert	Director	Ontario Tumour Bank
Don	Aldridge	Former Industry Executive, Research & Life Science	IBM Canada
Shiva	Amiri	Former Manager, Informatics & Analytics	Ontario Brain Institute
Sandy	Aronson	Executive Director of IT	Partners Personalized Medicine
Philip	Awadalla	OICR Senior Investigator and Scientific Director, CARTaGENE	OICR and CARTaGENE
Gary	Bader	Assistant Professor, Computational Biology	University of Toronto
David	Barber	Kingston lead, CPCSNN	Queens University
Allison	Barr	Director	Ministry of Research and Innovation
John	Bartlett	Principal investigator	Ontario Tumour Bank
Erika	Basile	Ethics Officer - Health Sciences REB Full Board	Western University
Angela	Behboodi	Director, Government Relations and Health Policy	Roche
Robert	Bell	Deputy Minister	Ministry of Health and Long-Term Care
Ayse	Bener	Director, Data Science Laboratory	Ryerson University
Richard	Birtwhistle	Director, Studies in Primary Care	Queens University
Sandra	Black	Scientist and Director Brain Sciences program	Sunnybrook Research Institute
David	Bogart	Director, Research Programs and Industry Relations	Ontario Brain Institute
Yvonne	Bombard	Scientist, Li Ka Shing Knowledge Institute	St. Michael's Hospital
Katherine	Bonter	Director of Innovation	Centre of Excellence in Personalized Medicine
Richard	Borrelli	Principal	IMS Consulting
Kym	Boycott	Co-Chair, International Rare Disease Research Consortium, Diagnostics Committee	Children's Hospital of Eastern Ontario (CHEO)
Michael	Brudno	Director, Centre for Computational Medicine, Genetics & Genome Biology	Hospital for Sick Children
Alison	Buchan	Vice-Dean, Research and International Relations	University of Toronto
James	Calvin	Chair/Chief, Department of Medicine, Schulich School of Medicine & Dentistry	Western University
Pearl	Campbell	Director, StemCore Laboratories	Ottawa Hospital Research Institute
Chris	Carew	Director of Strategy, Centre for Genetic Medicine	Hospital for Sick Children
June	Carroll	Principal Investigator, Family Medicine Genetics Program	Mount Sinai Hospital
Ron	Carter	Director, Molecular Genetics Laboratory	LifeLabs
Ann	Cavoukian	Executive Director, The Privacy and Big Data Institute	Ryerson University
Yolande	Chan	Associate Vice-Principal (Research)	Queens University

Kathy	Chun	Head, Cytogenetics Lab	North York General Hospital
John	Clarkson	Senior Vice President	Ontario Brain Institute
Ronni	Cohn	Chief, Division of Clinical and Metabolic Genetics	The Hospital for Sick Children
Neil	Corner	Director Innovative Solutions (Real World Evidence Lead)	IMS Health
Pieter	Cullis	Director, Life Sciences Institute	University of British Columbia
Janet	Dancey	Program Director, High Impact Clinical Trials	Ontario Institute for Cancer Research (OICR)
Jill	Davies	Director, Genetics Program	Medcan
Sheree	Davis	Former Director, Community and Population Health Branch	Ministry of Health and Long-Term Care
Irfan	Dhalla	Interim Vice President, Evidence, Development & Standards	Health Quality Ontario
Mark	Dobrow	Acting Vice-President of Health System Performance	Health Quality Ontario
Craig	Earle	Program Leader, Health Services Research	OICR
Elizabeth	Eisenhauer	Co-Chair, Canadian Cancer Research Alliance	Queens University
Khaled	El Emam	Associate Professor and Canada Research Chair, School of Electrical Engineering and Computer Science	University of Ottawa
Ken	Evans	President and CEO	InDoc Research
Harriet	Feilotter	Associate Professor, Pathology and Molecular Medicine, Queen's University	Queens University
Vincent	Ferretti	Associate Director, Bioinformatics	OICR
Alan	Forster	Chief Quality and Performance Officer	Ottawa Hospital
Rob	Fraser	Principal Consultant	Rob D. Fraser & Associates
Brenda	Gallie	Senior Scientist, Ontario Cancer Institute	University Health Network
Jason	Garay	Vice President, Analytics and Informatics	Cancer Care Ontario
Jack	Gauldie	Director, Institute for Molecular Medicine and Health	McMaster University
Richard	Glazier	Senior Scientist & Lead, Primary Care and Population Health Program	Institute for Clinical Evaluative Sciences
Sholom	Glouberman	President and CEO	Patients Canada
Peter	Goodhand	Executive Lead, International Partnerships	The Global Alliance for Genomics and Health
Mary	Gospodarowicz	Medical Director, Cancer Program	Princess Margaret Hospital and University Health Network
Anna	Greenberg	Director - Community and Population Health Branch	Ministry of Health and Long-Term Care
Michelle	Greiver	Ontario lead, CPCSN	North York General Hospital
Jill	Hagenkord	Chief Medical Officer	23andMe
David	Henry	Professor and Senior Advisor to the Dean	Dalla Lana School of Public Health, University of Toronto
Michael	Hillmer	Director, Planning, Research and Analysis Branch	Ministry of Health and Long-Term Care
Rafi	Hofstein	President and CEO	MaRS Innovation
Thomas	Hudson	President and Scientific Director	Ontario Institute for Cancer Research
Karey	Iron	Director, Data Partnerships and Development	Institute for Clinical Evaluative Sciences
Franny	Jewett	CEO	Impact Genetics
Michael	Julius	Vice President, Research	Sunnybrook Health Sciences Centre
Suzanne	Kamel-Reid	Head, Laboratory Genetics & Director, Molecular Diagnostics	University Health Network
Jim	Kennedy	Director, Neuroscience Research Department	Centre for Addiction and Mental Health
Saba	Khan	Lead Epidemiologist, Aboriginal health partnerships	Institute for Clinical Evaluative Sciences
Zayna	Khayat	Lead, MaRS Health and Director, MaRS EXCITE	MaRS
Richard	Kim	Director, Centre for Clinical Investigation & Therapeutics	Western University
Jack	Kitts	President and CEO	Ottawa Hospital
Bartha	Knoppers	Director, Centre of Genomics and Policy	University of Montreal
Darren	Larsen	Chief Medical Information Officer	Ontario Medical Association
Lydia	Lee	Senior Vice President & CIO	University Health Network
Jordan	Lerner-Ellis	Director and Head, Advanced Molecular Diagnostics	Mount Sinai Hospital
Leslie	Levin	CSO	MaRS EXCITE
Peter	Lewis	Vice President, Research and Innovation	University of Toronto
Samantha	Liscio	Senior VP, Enterprise Planning & Reporting	eHealth Ontario
Alex	MacKenzie	Director, CHEO Research Institute	Children's Hospital of Eastern Ontario (CHEO)
Muhammad	Mamdani	Director, Applied Health Research Centre	St. Michael's Hospital
Bill	Mantel	Assistant Deputy Minister	Ministry of Research and Innovation Ministry of Economic Development, Trade and Employment
Susan	Marlin	Executive Director	Clinical Trials Ontario
Rebecca	McClure	Molecular Pathologist	Health Sciences North

Randy	McIntosh	VP, Research & Director, Rotman Research Institute	Baycrest Research
Nancy	Meagher	Executive Director	Population Data BC
Karen	Menard	Former Chief Planning and Administrative Officer	Ontario Health Study
Fiona	Miller	Associate Professor	University of Toronto
Michelle	Mujoomdar	Assistant Chief Scientist	Canadian Agency for Drugs and Technologies in Health
Ben	Neel	Former Director of Research	Princess Margaret Cancer Centre
Stuart	Nicholls	Post-Doctoral Fellow, Epidemiology and Community Medicine	University of Ottawa
Amit	Oza	Senior Staff Physician & Prof of Medicine at Princess Margaret	Princess Margaret Hospital
Alison	Paprica	Director, Strategic Partnerships	ICES
Laurence	Pelletier	Senior Investigator, Centre for Systems Biology	Lunenfeld-Tanenbaum Research Institute
Bruce	Pollock	Vice President of Research	Centre for Addiction and Mental Health
Brad	Popovich	Chief Scientific Officer	Genome British Columbia
Caroline	Popper	Co-Founder and President	Popper and Company LLC
Conrad	Pow	Project Manager, Data Partnerships and Development	Institute for Clinical Evaluative Sciences
Konrad	Powell-Jones	Commercialization Consultant	The Hospital for Sick Children
Ken	Pritzker	President	RNA Diagnostics
Mark	Purdue	Former CEO	Ontario Health Study
Wei	Qiu	Chief Medical Informatics Officer	eHealth Ontario
Parminder	Raina	Principal Investigator, Canadian Longitudinal Study on Aging (CLSA)	McMaster University
Ruth	Rennicks White	Acting Scientific Manager	BORN Ontario
Richard	Reznick	Dean, Faculty of Health Sciences and Director, School of Medicine	Queens University
Jared	Rhines	Former VP, Scientific and Strategic Affairs	Rx&D
Etienne	Richer	Assistant Director, CIHR signature initiative in Personalized Med	Canadian Institutes of Health Research
Beni	Rovinski	Managing Director	Lumira Capital
Amy	Sayani	Director, R&D Alliances	GSK
Stephen	Scherer	Senior Scientist, Genetics and Genome Biology	The Hospital for Sick Children
Michael	Schull	President and CEO	ICES
Michael	Sherar	President and CEO	Cancer Care Ontario
Katherine	Siminovitch	Director, Genomic Medicine Program, Lunenfeld-Tanenbaum Research Institute	Mount Sinai Hospital
Dan	Sinai	Associate Vice-President (Research)	Western University
Lillian	Siu	Senior Staff Physician, Princess Margaret Hospital	University Health Network
Arthur	Slutsky	VP Research	St. Michael's Hospital
Ann	Sprague	Acting Director	BORN Ontario
Vasanthi	Srinivasan	Executive Director	SPOR SUPPORT Unit, Ontario
Lincoln	Stein	Platform Leader, Informatics and Bio-computing	Ontario Institute for Cancer Research (OICR)
Duncan	Stewart	CEO, Ottawa Hospital Research Institute & VP Research	Ottawa Health Research Institute (OHRI)
Michael	Strong	Dean, Schulich School of Medicine & Dentistry	Western University
Donald	Stuss	President & Scientific Director	Ontario Brain Institute
Frank	Sullivan	Director	University of Toronto Practice-Based Research Network (UTOPIAN)
Jeff	Sumner	Senior Vice President, Innovation Clinical Affairs & Business Development	LifeLabs
Robyn	Tamblyn	Scientific Director	Clinical and Health Informatics Research Group, McGill
Victor	Tron	Chief of Department of Laboratory Medicine	St. Michael's Hospital
Karen	Tu	Senior Scientist, Primary Care and Population Health Research Program	Institute for Clinical Evaluative Sciences
Ron	Van Holst	Director, Research for High Performance Computing	Ontario Centres of Excellence
Belinda	Vandersluis	Director of Implementation	Canadian Clinical Trials Coordinating Centre
Carl	Virtanen	Bioinformatics Manager	Princess Margaret Genomics Centre
Mima	Vulovic	Sr. Policy Advisor	Ministry of Research and Innovation Ministry of Economic Development, Trade and Employment

Mark	Walker	Clinical Epidemiology, Ottawa Hospital Research Institute, Director of BORN	BORN Ontario
Doug	Watt	Director, OLIS	eHealth Ontario
Jeffrey	Weitz	Director of Juravinski Hospital and Cancer Centre	Hamilton Health Sciences Centre
Catharine	Whiteside	Former Dean, Faculty of Medicine & Vice-Provost, Relations with Healthcare Institutions	University of Toronto
Donald	Willison	Associate Professor, Dalla Lana School of Public Health	University of Toronto
Arlene	Yee	Director, Industry Partnerships and Commercialization	The Hospital for Sick Children
Rae	Yeung	Senior Scientist, Cell Biology Research	The Hospital for Sick Children
Trevor	Young	Dean, Faculty of Medicine and Vice-Provost, Relations with Healthcare Institutions	University of Toronto
Salim	Yusuf	Director, Population Health Research Institute	McMaster University
Catherine	Zahn	President & CEO	Centre for Addiction and Mental Health
Nick	Zamora	Former Chief Clinical Advisor	Telus Health Solutions

Appendix II: Data for Health Advisory Group Members

Name	Title	Affiliation
Don Aldridge	Former Industry Executive, Research & Life Science	IBM Canada
Philip Awadalla	OICR Senior Investigator and Scientific Director, CARTaGENE	OICR and CARTaGENE
Alison Buchan	Vice-Dean, Research and International Relations	University of Toronto
Yolande Chan	Associate Vice-Principal (Research)	Queens University
John Clarkson	Senior Vice President	Ontario Brain Institute
Ronni Cohn	Chief, Division of Clinical and Metabolic Genetics	The Hospital for Sick Children
Khaled El Emam	Associate Professor and Canada Research Chair, School of Electrical Engineering and Computer Science	University of Ottawa
Ken Evans	President and CEO	Indoc Research
Harriet Feilotter	Associate Professor, Pathology and Molecular Medicine, Queen's University	Queens University
Alan Forster	Chief Quality and Performance Officer	Ottawa Hospital
Jason Garay	Vice President, Analytics and Informatics	Cancer Care Ontario
Sholom Glouberman	President and CEO	Patients Canada
David Henry	Professor and Senior Advisor to the Dean	Dalla Lana School of Public Health, University of Toronto
Suzanne Kamel-Reid	Head, Laboratory Genetics & Director, Molecular Diagnostics	University Health Network
Darren Larsen	Chief Medical Information Officer	Ontario Medical Association
Lydia Lee	Senior Vice President & CIO	University Health Network
Jordan Lerner-Ellis	Head of Advanced Molecular Diagnostics	Mount Sinai Hospital
Samantha Liscio	Senior VP, Enterprise Planning & Reporting	eHealth Ontario
Muhammad Mamdani	Director, Applied Health Research Centre	St. Michael's Hospital
Alison Paprica	Director, Strategic Partnerships	ICES
Wei Qiu	Chief Medical Informatics Officer	eHealth Ontario
Parminder Raina	Principal Investigator, Canadian Longitudinal Study on Aging	McMaster University
Michael Schull	President and CEO	ICES
Dan Sinai	Former Associate Vice-President (Research)	Western University
Frank Sullivan	Director	University of Toronto Practice-Based Research Network (UTOPIAN)
Carl Virtanen	Bioinformatics Manager	Princess Margaret Genomics Centre

Appendix III: OPMN Representatives

Name	Title	Affiliation
Mark Poznansky (Co-Chair)	President and CEO	Ontario Genomics
Kathryn Deuchars	Director, Ontario Personalized Medicine Network & Senior Manager, Business Development & Research	Ontario Genomics
Allison Barr	Director, Research Branch	Ontario Ministry of Research and Innovation
June Carroll	Sydney G. Frankfort Chair in Family Medicine and Associate Professor, Department of Family & Community Medicine	Mount Sinai Hospital, University of Toronto
Ron Carter	Director, Molecular Genetics Laboratory	LifeLabs
Jill Davies	Director, Genetics Program	Medcan Clinic
Ross Feldman	Chair of Medicine	Memorial University
Brenda Gallie	Senior Scientist, Division of Applied Molecular Oncology	Ontario Cancer Institute
Jack Gaudie	Distinguished University Professor, Department of Pathology and Molecular Medicine; Director, Institute for Molecular Medicine and Health	McMaster University
Tom Hudson	President and Scientific Director	Ontario Institute for Cancer Research
Suzanne Kamel-Reid	Head, Laboratory Genetics and Director, Molecular Diagnostics	University Health Network
Bartha Knoppers	Director, the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics	McGill University
Mark Lievonon	President	Sanofi Pasteur Ltd.
Fiona Miller	Associate Professor, Institute of Health Policy, Management and Evaluation	University of Toronto
Amit Oza	Senior Staff Physician, Professor of Medicine	Princess Margaret Hospital
Margaret Piper	Director, Genomics Resources	Blue Cross and Blue Shield Technology Evaluation Center
Caroline Popper	Founder and President	Popper and Company LLC
Beni Rovinski	Managing Director	Lumira Capital
Stephen Scherer	Director, The Centre for Applied Genomics	The Hospital for Sick Children
Katherine Siminovitch	Senior Investigator, Samuel Lunenfeld Research Institute	Mount Sinai Hospital
Vasanthi Srinivasan	Executive Director	SPOR SUPPORT Unit, Ontario
Rhonda Tannenbaum	Vice President, Business Development	Ontario Genomics
Jeffrey Weitz	Professor of Medicine and Biochemistry, McMaster University; Director, Juravinski Hospital and Cancer Center	McMaster University

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