



OFFICE OF THE  
INFORMATION &  
PRIVACY  
COMMISSIONER  
*for British Columbia*



**BRITISH  
COLUMBIA**

## **REPORT OF THE HEALTH DATA RESEARCH FORUM**

**Office of the Information & Privacy Commissioner for B.C.  
and the B.C. Ministry of Health**

Held on December 9, 2013  
Victoria, B.C.

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DATE: January 31, 2014

## Letter from the Steering Committee

Health research plays a vital role, not only in finding new ways of saving lives and keeping people healthy, but also in finding and implementing new efficiencies and cost saving measures to keep our public healthcare system sustainable. We are blessed to have great data, some of the finest universities and health researchers in the world, and they are eager to work on a variety of healthcare issues.

It has been a difficult year for health research in B.C. High profile data breaches, such as the breaches investigated at the Ministry of Health in 2013, are an example of the type of event that shakes public confidence and trust and puts the future of health research in B.C. at risk. However, recent polls show that over 90% of British Columbians continue to support the use of health data for research provided that the data are anonymized and their privacy is protected. Data stewards, such as the Ministry of Health and health authorities, researchers, universities and research institutions all share the responsibility to protect the data they have in their care and in maintaining public trust in health research.

The steering committee for this Health Data Access Forum greatly appreciates the time and effort of all the forum participants in giving a day of their time to participate in this session. We recognize the importance of having the expertise, perspectives and insights of all stakeholders participating in a conversation on enhancing timely and appropriate health data access for research in British Columbia.

The outcome of this Health Data Research Forum will build upon the efforts of the first roundtable discussion on health research held in June 2012 as well as the ongoing efforts of the Ministry of Health to implement previous recommendations that improve privacy protections and security safeguards.

We understand that there are complex data flows between the Ministry of Health, health authorities, universities and research institutes and that there have been some tensions in these relationships. Moreover, the health data access system in B.C. can be expensive, inefficient, and not sufficiently organized, transparent and effective.

We see the need for a comprehensive and transparent cross-sector governance framework to add greater clarity and understanding not only of the data access processes, but also the roles, responsibilities and accountabilities in using health data for research. We hope that by bringing all the parties together to discuss the issues, identify challenges and opportunities, and to develop recommendations, we can collaboratively move forward with a principled framework that incorporates the needs of all the relevant stakeholders.

We are pleased that the outputs of the Health Data Research Forum provided in the attached report captured the voices of all the participants. As a group we have identified many opportunities and challenges and developed dozens of recommendations that will guide ongoing efforts to enhance timely access to and appropriate use of health data. These recommendations will be reported to established data access working groups. Moreover, the steering committee will work with willing participants to form additional working groups to focus efforts and implement recommendations throughout the coming years.

We are committed to continuing the conversation and plan on holding another Health Data Research Forum in the coming months to enhance and report on the progress being made and identify new issues, opportunities and concerns.

In the end, we have the commitment and the confidence that through our ongoing collaboration and efforts we can collectively improve timely and appropriate health data access in B.C. that is acceptable for all stakeholders.

Thank you again to all the forum participants for their input and effort.

Sincerely,



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Elizabeth Denham, Commissioner  
Office of the Information and Privacy  
Commissioner for British Columbia



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Lindsay Kislock, Assistant Deputy Minister  
Health Sector IM/IT Division  
Ministry of Health



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Howard Brunt, Vice President, Research  
University of Victoria



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Heather Cook, Chief Nursing Officer and  
Professional Practice Lead  
Interior Health Authority

**Table of Contents**

Purpose ..... 1

Background ..... 1

Structure of the Meeting ..... 4

Discussion..... 5

    A) Expectations for the Forum ..... 5

    B) Identifying the Ideal Future ..... 5

    C) Exploring the Possibilities – Roundtable Discussions ..... 7

        1) Determining Roles and Responsibilities of Data Stewards, Universities and Researchers..... 7

        2) Developing Robust Privacy and Security Frameworks..... 8

        3) Improving Data Access Approval Processes..... 9

        4) Conducting Audits and Ongoing Monitoring ..... 11

        5) Creating and/or Enhancing Avenues to Access Data..... 12

Conclusion..... 13

Next Steps ..... 13

Appendix A – List of Participants ..... 14

Appendix B – Forum Agenda..... 16

## Purpose

On December 9, 2013, the Office of the Information and Privacy Commissioner for British Columbia (OIPC) and the B.C. Ministry of Health (MoH) convened a meeting of 38 representatives from the health research community and its stakeholders in British Columbia. The attendees were invited to come together to discuss and seek solutions on timely access to, and appropriate use of, health data under the stewardship of the MoH and health authorities for research, evaluation, planning and quality improvement while maintaining academic independence and enhancing privacy protections and security safeguards. Discussion included, but was not limited to:

- The current state of health data access for research and health system innovation in B.C.;
- Best practices for improving access to health data for research purposes;
- Methods to ensure strong privacy protections and security safeguards; and
- Principles for an improved future state with identified priority action items for continuous improvement.

Moreover, this forum built upon previous efforts to enhance timely and appropriate access to health data by identifying opportunities, barriers and solutions to health data access discussed in the OIPC's *Report of the Roundtable Discussion on Access to Data for Health Research* – held on June 25, 2012 and the efforts of the MoH to implement recommendations following three recent health data breaches and the associated investigations. This report serves as the record of the discussions of the Health Data Research Forum held on December 9, 2013.

## Background

The personal health data of British Columbians is regarded as some of the most robust health data available for research purposes. The responsible and appropriate use of this data are essential to improving the innovation, productivity and efficiency in the delivery of health services to British Columbians and abroad. There is a great demand for access to these data resources to conduct research, program evaluations, health surveillance and/or policy development. This health data, under the stewardship of the MoH and health authorities, is invaluable as it covers the entire population of the province and can be linked to pharmaceutical, education, vital statistics and/or other data sets.

There have been a number of barriers to timely and appropriate access to health data in B.C. Consequently, the OIPC, MoH and other collaborating stakeholders have undertaken efforts to address those barriers.

Prior to the Health Data Research Forum on December 9, 2013, the OIPC hosted a Roundtable Discussion on Access to Data for Health Research on June 25, 2012.<sup>1</sup> This roundtable discussion was in response to conferences, reports and editorials in the media stating that privacy concerns and the requirements of the *Freedom of Information and Protection of Privacy Act* (FIPPA) were impeding health

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<sup>1</sup> For the full report, please see: <http://www.oipc.bc.ca/special-reports/1483>

research. Moreover, that meeting sought to “discuss the opportunities, barriers and possible solutions to improving access to data for health research” (p 3). This roundtable discussion came to the following conclusions:

- Health research in B.C. is suffering because researchers cannot get timely access to health data;
- Privacy laws in B.C. are not a barrier to health research, but rather the interpretation of the laws by data stewards in their application of administrative policies and practices and overall capacity creates the barriers; and
- There are numerous possible solutions to remove or reduce the identified barriers to timely and appropriate health data access for research.

Moreover, in early 2012 the MoH received allegations of inappropriate and unauthorized access to health data for research purposes. The internal investigation into these allegations led to the discovery of three health data breach incidents.<sup>2</sup> In addition to the internal investigation, the MoH:

- Accepted and began implementing the OIPC’s recommendations in response to the three breaches<sup>3</sup>;
- Hired Deloitte to consult and recommend enhancements to security and privacy protections of the Ministry’s data systems and policies; and
- Undertook a LEAN business process improvement exercise for various data access processes.

Throughout 2013 the MoH has made significant progress in implementing the Deloitte and OIPC recommendations, including the development of a Governance Operations Committee to oversee the implementation of improvements. By the end of 2013 the MoH has delivered over 29 projects, with approximately 150 deliverables, on information governance, policies & procedures, education & awareness and technology, and work is underway for 2014.

The MoH continues to maintain its 90-day review time commitment for all eligible researcher data access requests (DARs) through Population Data BC. In addition, the MoH has eliminated the backlog of DARs and the median waiting time for DAR approvals has decreased significantly from 342 days in 2010 to 83 days in 2013. Also, the number of new academic research data requests has also increased from 18 in 2011 to 22 in 2013. Metrics from other avenues of data access, for example from data requests from the health authorities, was not readily available at the time of writing.

Additionally, on December 5, 2013, the Minister of Health announced the establishment of a joint ministry working group to identify innovative ways to improve access to data for research purposes. This inter-ministry working group is co-sponsored by the MoH and the Ministry of Technology, Innovation and Citizens’ Services (MTIC). This working group will:

- Review the current state of research in BC and identify gaps or unmet needs;
- Review various research models in BC and around the world; and

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<sup>2</sup> For more details, please see: <http://www.health.gov.bc.ca/cpa/mediasite/healthdata.html>

<sup>3</sup> For full report on *OIPC Investigation Report F13-02 Ministry of Health*, please see: <http://www.oipc.bc.ca/investigation-reports/1546>

- Make recommendations for best practices in data accumulation, privacy, security and access.

The inter-ministry working group will make recommendations that will take into account broader research needs across government; however, the group's initial focus will be on health data and the requirements associated with access to health data. In considering these requirements, the working group will leverage the extensive consultations conducted by the Michael Smith Foundation for Health Research (MSFHR) with the health sector and health research community that informed the Strategy for Patient Oriented Research and the provincial health research strategy.

The inter-ministry working group will report its findings to the Minister of Health and the Minister of Technology, Innovation and Citizens' Services in the spring of 2014.

The Strategy for Patient Oriented Research (SPOR)<sup>4</sup> was developed by the Canadian Institutes of Health Research (CIHR) "to foster evidence-informed health care by bringing innovative diagnostic and therapeutic approaches to the point of care." SPOR is a unique grant program intended to improve health outcomes and enhance patients' health care experience by integrating research evidence at all levels in the health system.

Central to SPOR are the regional SUPPORT (Support for People and Patient-Orientated Research Trials) Units "that will function as research service centres to provide specialized expertise and infrastructure for patient-orientated research" and "enable researchers, healthcare providers and healthcare decision-makers to conduct and implement patient-orientated research. The Michael Smith Foundation for Health Research (MSFHR) and the MoH are coordinating the planning of the SPOR SUPPORT Unit for BC. A business plan for B.C.'s SUPPORT unit is currently under development. It is anticipated that financial framework for B.C.'s SPOR SUPPORT unit will be between \$2 million and \$10 million annually, with CIHR matching financial commitments invested by the jurisdictions.

Overall, efforts are well underway to improve the timely and appropriate access to health data for research while enhancing the privacy protections and security measures. Through the spirit of continuous improvement, the Health Data Research Forum held on December 9, 2013 strives to build upon the current successes and further collaborative efforts among stakeholders to reduce the barriers to data access for vital health data research.

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<sup>4</sup> For more details, please see: <http://www.msfhr.org/our-work/activities/strategy-patient-oriented-research>

## Structure of the Meeting

The Health Data Research Forum was organized by a steering committee consisting of:

- Elizabeth Denham, Information and Privacy Commissioner for BC;
- Lindsay Kislock, Assistant Deputy Minister, Health Sector IM/IT Division, MoH;
- Heather Cook, Chief Nursing Officer and Professional Practice Lead, Interior Health; and
- Howard Brunt, Vice-President, Research, University of Victoria.

In November 2013, the planning committee developed a representative stakeholder group and sent out invitations in November 2013. In total, 38 invitees participated in the forum, representing privacy experts, the OIPC, the MoH, the Ministry for Technology, Innovation and Citizens' Services, health authorities, universities, research ethics boards and research institutions and stakeholders, such as the Michael Smith Foundation for Health Research, Population Data BC, the Centre for Health Services and Policy Research, the BC Cancer Agency, and the Canadian Institute for Health Information. Regrettably none of the invitees representing patient advocacy groups could participate on December 9<sup>th</sup>. Please refer to appendix A for a complete list of all the participants. Prior to the forum, participants were asked to identify three desired outcomes from this meeting.

The forum was held at the OIPC offices at 947 Fort St. in Victoria B.C. and James T. Bretzlaff, from Berlin Eaton management consultants, moderated the forum. All notes from the forum were collated and not attributed to any individual and/or organization.

The forum was separated into two parts. In the morning, attendees were provided an opportunity to discuss and confirm their expectations for the day and identify and share their vision for an ideal future for access to health data in British Columbia. In the afternoon portion of the forum the participants were asked to identify challenges, opportunities and recommendations in three 30 minute roundtable discussions of the five discussion theme topics:

1. Determining roles and responsibilities of data stewards, universities and researchers;
2. Developing robust privacy and security frameworks;
3. Improving data access approval processes;
4. Conducting audits and ongoing monitoring; and
5. Creating and/or enhancing avenues to access data.

The forum concluded with the five roundtable discussion hosts reporting the identified recommendations for each theme. This was followed by a confirmation of next steps and a commitment to share the draft of this report with all the participants at the beginning of January 2014.

The content of the discussions on the participants' expectations, ideal future and the challenges, opportunities and recommendations of the five roundtable discussions is in the Discussion section below.

All participants had an opportunity to review a draft of this report.



## Discussion

Included herein are the discussion notes captured during the Health Data Research Forum on December 9, 2013. The discussion is separated into the following sections:

### A) Expectations for the Forum

Participants responded to the question: “What is one expectation that you have for today’s meeting?” The responses include, but are not limited to:

- A collaborative environment where all voices are heard and recorded,
- Greater clarity on the roles of all the stakeholders, the data request and access processes, and navigational tools,
- Better understanding of the barriers, problems and operational challenges faced by the entire health research sector, and
- Development of a structured, principle-based, specific action plan that takes significant steps to address the problems through pragmatic solutions and best practices with timely accountabilities.

### B) Identifying the Ideal Future

The participants were divided into six groups representing their respective sectors to identify and confirm the ideal future for health data research in British Columbia by answering the question “What are the key characteristics of the ideal future, with respect to research data?” The six groups included: two groups for universities, one for the OIPC, one for health authorities, one for the MoH and one for agencies, councils and other privacy professionals.

#### The University Groups

The first of the two groups representing the universities sought to have a data centre that could be a one-stop-shop for requests not only for health data, but for data requests and linkages from multiple sectors. This data centre would have clear policies and procedures and offer multiple forms of data access and related services, including warehousing, linking, training and a virtual environment in which to work with the data.

The second group representing the universities also sought a data centre as a long-term solution that builds on the existing infrastructure, engenders trust and includes avenues for knowledge translation. In the short-term (proposed as one year) the group identified a need to focus on clarity of roles for each of the entities reviewing research and data requests, including research ethics boards, data stewards and peer review panels. Moreover, the group desires greater clarity on health data governance and centralized adjudication on matters of health data policy making and decisions regarding the future of Big Data.

#### The Office of the Information and Privacy Commissioner for British Columbia’s Group

The group representing the participants from the OIPC seeks an approach with clear accountabilities for all parties that maintain public trust and confidence through independent and comprehensive oversight of data linking initiatives by the OIPC. The ideal future would have consistent data access rules and

appropriate mechanisms for data linking with a comprehensive data platform that is run by an entity, prescribed by law and at arms' length from government and universities.

### **The Health Authorities Group**

The group representing the health authorities seek an ideal future with a tactical, clarified, integrated and shared governance framework. This governance framework needs to define the roles of the health authority and the MoH in managing data and provide guidance tools and a risk framework to help develop greater understanding of appropriate access, use, storage and disclosure of data. Moreover, the health authorities desire a future with standardized and transparent data access systems, processes and platforms among the health authorities and their respective domains with centralized support and governance without creating further bureaucracy and still maintaining decentralized access to the health authorities' real time data.

### **The Ministry of Health Group**

The MoH wants confidence in the system being created with a clear timeframe for the vision. The ideal future includes a single data source for all data types (linked clinical, administrative and patient reported data) and a transparent and clear framework on data governance, access and platform with respect to information security, privacy, legislation and standards. This group hopes for a future that is technology agnostic wherein technology is based on function not organization, for examples: pattern recognition versus hypothesis driven, single versus multiple databases, and/or traditional hosting or cloud computing.

### **The Agencies, Councils and Other Privacy Professionals Group**

The sixth group consisting of participants from various agencies, councils and other privacy professional organizations felt that there is no need to re-invent the wheel and seeks an ideal future when there is strong support in the community to have a one-stop-shop to request and retrieve the data. This group notes that the eHealth (Personal Health Information Access and Protection of Privacy) Act tried to achieve this but has not necessarily achieved its promised vision. This group spent time considering why the current system does not necessarily work or need to be changed. They also make the point that from a perspective of solely maintaining privacy, it makes sense to maintain an approach where information is separated into silos.

Overall, common themes that arose from the ideal future exercise amongst the various groups include:

- Greater clarity of process;
- Stronger governance;
- More capacity for data linkage;
- A “one-stop-shop” to request and access data;
- Maintaining public trust;
- Generating value; and
- Independent oversight by the OIPC.

### **C) Exploring the Possibilities – Roundtable Discussions**

In the afternoon of the Health Data Research Forum, the participants attended three of the five roundtable discussions on the predetermined theme topics:

1. Determining roles and responsibilities of data stewards, universities and researchers;
2. Developing robust privacy and security frameworks;
3. Improving data access approval processes;
4. Conducting audits and ongoing monitoring; and
5. Creating and/or enhancing avenues to access data.

During the 30 minute roundtable discussions participants strived to address the following questions:

1. What is currently working well with respect to this topic?
2. What challenges are you currently facing with respect to this topic?
3. What are the possible opportunities you have moving forward?
4. What are the possible threats?
5. What are key recommendations for the next 12 months?
6. What are Key recommendations for the longer term (> 12 months)?

The following are the outputs of these roundtable discussions and constitute the comments, thoughts and opinions of the forum participants.

#### **1) Determining Roles and Responsibilities of Data Stewards, Universities and Researchers**

Regarding the roles and responsibilities of data stewards, universities and researchers, the participants noted that the existing common data access framework – with established authorization models through Population Data BC, data stewards and the OIPC – and the General Health Information Sharing Agreement (GHISA) framework between the MoH and the health authorities – are working well. Moreover, there exists subject matter expertise, knowledge assets, and support and trust from citizens for health research, and clear expectations for maintaining privacy protections.

However, the degree of transparency on data agreements, lack of clarity in legislation and policy regarding the governance, care, custody, roles and responsibility across sectors, and lack of standardization on how to exercise discretion can make it challenging to determine the roles and responsibilities of data stewards, universities and researchers. Furthermore, there exists pressure to complete work within time limits and deadlines without relying on workarounds.

Identified opportunities to determine the roles and responsibilities of data stewards, universities and researchers include, but are not limited to:

- Training opportunities for all parties;
- Documented and transparent operational principles, standards of practice, common language and data governance structures for data stewards, universities and researchers;

- Clear penalties for non-compliance identified in agreements; and
- Decision support tools to help all parties better understand and follow principles, practices and processes.

Participants noted, however, that insufficient resources (funds, staff and time) to make the necessary changes, a lack of consensus among data stewards, universities, researchers and other stakeholders and people trying to circumvent the systems and processes due to time restraints threaten the successful implementation of these opportunities. In addition, efforts to try to centralize governance structures may create even more bureaucratic barriers.

The **key recommendations for the next 12 months** to determine the roles and responsibilities of data stewards, universities and researchers include:

- Consistent and common contracts and data access agreements;
- Training programs for data users;
- Integrated, global tool sets for using data;
- Review of governance models for data access, use and storage;
- Explore designating more health information banks;
- Health Authorities (private and residential) to agree on common language and definitions;
- Clear guidance documents on data access, use, storage and disclosure; and
- Three year legal responsibility for researchers using health information.

The **key long-term recommendations** to determine the roles and responsibilities of data stewards, universities and researchers include:

- Governance framework with clearly identified roles and responsibilities, including standards of practice and clearly defined penalties for non-compliance;
- Common language and definitions for the roles and responsibilities of all involved parties; and
- Alignment of provincial government data initiatives.

## 2) Developing Robust Privacy and Security Frameworks

The development of the MoH's HealthIdeas data warehouse, existing policy framework for university research access through Population Data BC, and the GHISA framework between the MoH and the health authorities are working well in B.C. The participants identified some challenges to developing robust and enabling privacy and security frameworks, which include, but are not limited to:

- Developing agreements with the researchers and not just institutions;
- Developing and applying fair and consistent recourse and penalties for noncompliance with requirements of the framework and agreements;
- Lengthy review and approval processes and risk aversion for data access requests may encourage people to develop workarounds;

- Aligning data retention periods; and
- The implementation and subjective interpretation of related policies.

Collaborative solutions from the health research community, such as this Health Data Research Forum and the Canadian Institutes for Health Research funding of the Strategy for Patient Oriented Research (SPOR), are good opportunities to develop robust and enabling privacy and security frameworks. Other identified opportunities for developing privacy and security frameworks include leveraging the BC Health Research Strategy, government’s innovation agenda and open data initiatives, developing OIPC guidelines regarding accountability and expanding the Population Data BC model, and the wide array of available data sets. Insufficient resources (funds, staff and time) to make the necessary changes, a lack of consensus among data stewards, universities, researchers and other stakeholders and frameworks that unduly impede timely access to health data may impede or threaten the successful implementation of these opportunities.

The **key recommendations for the next 12 months** to develop robust and enabling privacy and security frameworks include:

- Reviewing the role of the Data Stewardship Committee (DSC);
- Designing proportionate and tailored privacy and security framework;
- Articulated and common principles within the GHISA and training for the principles and framework developed in the GHISA;
- Standardized data request, review and approval process within health authorities;
- Clearly identified roles and responsibilities for all parties involved;
- Clarification on the “use for contact purposes” in the FIPPA S.35 (1)(a)(i);
- Acceptable alternatives to encryption;
- Workshops to review existing privacy and security frameworks and work towards a harmonized approach; and
- Develop a library of Privacy Impact Assessments (PIAs).

The **key long-term recommendations** to develop robust and enabling privacy and security frameworks include:

- Mechanisms to keep the framework current;
- Clear guidelines to researchers for safe storage of personal health and/or sensitive information;
- Consistent standards for data linking regarding identification;
- Data Stewardship Committee guidance on sensitivity of data;
- Population Data BC to have access to HealthIdeas; and
- Defined criteria for low-risk data regarding the potential identification of subjects.

### 3) Improving Data Access Approval Processes

The data access approval process through Population Data BC is regarded as working well as it is standardized, well vetted, transparent, not specific to any institution, province-wide, includes time

commitments for certain categories of data access requests, and there have been no breaches to date. Moreover there is greater cooperation between DSC and Population Data BC now and a move towards a common application process. The deployment of the MoH's HealthIdeas is also thought to be working well.

Managing approvals with multiple data stewards, separate governance frameworks for different working groups, a lack of awareness of what data are available from whom, and differing interpretations of legislation, different cultures and risk aversion among data stewards and health authorities represent challenges to improving the data access approval process. Participants also cautioned that defining the research community too narrowly, for example not including clinical research physicians who undertake different, consent-based approaches, may hinder successful improvement of the approval processes. Despite recent improvements to review times for approval, some participants feel the approval process is still not fast enough and too cumbersome as there is lots of duplication with related processes, for examples: ethics, privacy impact assessment (PIA), and grant application/funding. Moreover, the DSC meets only 10 times per year, thereby limiting the timeframe for data access requests going to that committee.

Identified **opportunities** to improve data access approval processes include, but are not limited to:

- HealthIdeas directly feeding into databases and Population Data BC for high quality and real time data;
- Canadian Institutes for Health Research funding of the BC SPOR SUPPORT unit;
- Development of a standardized risk matrix for data requests that is transparently applied across all avenues of data access including health authorities;
- Utilizing grant funds to pay for data access costs;
- Modernizing legislation;
- Training and education of processes; and
- Integration of the data access approval and research ethics board processes.

Participants cautioned that researchers are not applying for data access due to losing grant opportunities given the reputation of lengthy data access processes in B.C. Further deterrents include the lack of coordination across different associated processes (ethics, grant funds and data access) and the cost of the DAR process through Population Data BC. Technologies and data being developed without consideration for research applications may also threaten the successful and timely implementation of efforts to improve data access approval processes.

The **key recommendations for the next 12 months** to improve data access approval processes include:

- Integrated cross-sector working group to target specific deliverables;
- Data access and use risk management matrix;
- User group needs assessment;

- Alignment of the recommendations coming out of this Health Data Research Forum with the work of the SPOR working unit and the two ministry working group;
- Service standards tracked and reported across all data access processes; and
- Acknowledgement that research is more than academic user groups and also includes clinical research, evaluation, surveillance and policy planning.

The **key long-term recommendation** to improve data access approval processes is the development of enabling and harmonized health information legislation that reflects public opinion on and general support for the appropriate use of health information for research purposes.

#### 4) Conducting Audits and Ongoing Monitoring

When it comes to conducting audits and ongoing monitoring of health data use, participants felt that publishers auditing the researchers, the functions of the research ethics boards, and the auditing efforts of Health Canada and other research funders are working well. Population Data BC's Secure Research Environment (SRE) is also regarded as working well. The SRE is a technology solution that uses a central server accessible only via an encrypted Virtual Private Network (VPN) that was specifically designed to maintain data integrity and uses active monitoring technologies to mitigate data misuse and breaches. The health authorities' internal structures to conduct audits are also regarded as working well.

The lack of clarity on roles and accountabilities and lack of transparent communication about accountability processes among researchers, MoH, health authorities and other stakeholders present challenges to conducting audits and ongoing monitoring. Other identified challenges to conducting audits and ongoing monitoring include:

- Principles of academic freedom allegedly acting as a barrier to conducting audits and verifying compliance;
- Limited resources (funds, staff and time) to conduct audits and monitoring; and
- Lack of detailed controls in some large research entities and universities with complex governance regimes.

Demonstrating existing assurance processes and common accountabilities to data stewards, expanding the role of the ethics board and using financial industry accountability requirements as model for appropriate data use at universities were mentioned as opportunities to conduct audits and ongoing monitoring of health data use. Furthermore, audit findings could also be used for other positive purposes, such as developing good practice guides. Some participants cautioned, however, that the lack of clarity on accountabilities and data governance can threaten the successful auditing and monitoring of health data use.

The **key recommendations for the next 12 months** to conducting audits and ongoing monitoring include:

- Implementing a risk-based approach with self-reporting requirements and risk-based audits;

- Investment in infrastructure and training to conduct audits and monitoring and demonstrate accountability and earn trust;
- Communicate among stakeholders to broker knowledge and share lessons learned, such as from the recent MoH internal review and the OIPC's breach investigation; and
- Explore the potential for researchers to conduct spot audits of peers with requirements and incentives built into grant requirements – researchers could be certified as “auditing researchers”.

The **key long-term recommendations** to conducting audits and ongoing monitoring include:

- A community of practice for accountability frameworks and minimum standards that can be adopted through entire health research community;
- A database of existing accountabilities and resources that allows research bodies to develop or improve upon their existing accountability mechanisms;
- Consolidate overlapping accountabilities; and
- Incentives for certified research organizations that establish and maintain accountability frameworks.

### 5) Creating and/or Enhancing Avenues to Access Data.

The forum participants regarded the current avenues to access data through HealthIdeas and Population Data BC, including reduced timelines for certain categories of DAR, and the data stewardship framework including the health authorities and the MoH as a solid foundation to build and improve upon. It is important to note that participants were not always clear on which avenue(s) of data access (for examples: Population Data BC, from a health authority or directly from MoH through HealthIdeas) they were commenting on. Any future discussions on avenues of data access should clearly delineate on the various avenues of data access.

Challenges to creating and/or enhancing avenues to access data identified by the participants include, but are not limited to:

- The diversity of data sources;
- Determining who has access to which data and for what purposes;
- Insufficient resources (funds, staff and time) to make the necessary changes; and
- A lack of awareness on current avenues of data access.

The forum participants stated that the Michael Smith Foundation for Health Research's support for the development of a data platform, developing a governance framework, and capitalizing on resourcing opportunities such as the SPOR initiative are all potential opportunities to create and/or enhance avenues of access to data. However, the development or enhancement of avenues of data access may diminish or threaten the potential to have one overarching avenue of data access. “Turfism” and data stewards and owners wanting to protect individual data sets may also threaten the creation and/or



enhancement of avenues to data access. Participants cautioned that for any avenue of data access to be successful, there needs to be sufficient and ongoing capacity to conduct data linkage.

The **key recommendations for the next 12 months** to creating and/or enhancing avenues of data access include:

- Conducting case studies on existing data access avenues, including Population Data BC and HealthIdeas, to better understand how to move forward;
- Efforts to enhance avenues of data access must be considered in the planning of any health information technology solutions; and
- Determine who should be involved in aligning avenues of data access.

The **key long-term recommendations** to creating and/or enhancing avenues of data access include:

- A working group to develop the governance structure, report out on an approach and, subsequently,
- Develop one robust data platform with multiple datasets from various sectors, including health and education.

## Conclusion

Participants agreed that progress has been made since the first Health Research Roundtable was held in 2012. Most significantly, there is engagement and willingness among many stakeholders to collaborate on a governance framework(s) to facilitate access to data and maintain public trust in the research enterprise. There is also agreement that practical short-term fixes are needed to enhance timely, accurate and privacy-positive research.

The stakeholders assembled for this meeting expressed a desire to provide input or commentary to the government's recently announced internal working group on innovative ways to improve access to data for research purposes (MoH and MTIC) on options under consideration, at the appropriate juncture in their work.

## Next Steps

All the participants have had an opportunity to review and comment on the proposed recommendations and volunteer to collaborate in the implementation of the recommendations. The recommendations provided herein will be provided to the working group developing the SPOR business plan to garner additional funds and resource to implement the recommendations. The recommendations will also be provided to the Ministry for Technology, Innovation and Citizens' Services and Ministry of Health's inter-ministry working group so these recommendations can be incorporated into ongoing government efforts to enhance timely and appropriate data access. Furthermore, specific smaller working groups will be established to guide and oversee the implementation of certain recommendations.

## Appendix A – List of Participants

<b>PARTICIPANT</b>	<b>TITLE</b>	<b>ORGANIZATION</b>
Agata Stefanowicz	Faculty Liaison	Human Early Learning Partnership, UBC
Barbara Walman	Assistant Deputy Minister	Medical Beneficiary & Pharmaceutical Services Ministry of Health
Bill MacDonald		Data Stewardship Committee
Cara McGregor	Director of Communications	OIPC
Cathy Yaskow	Director	Information Stewardship, Access & Privacy VIHA
Charmaine Lowe	Executive Director	Ministry of Technology, Innovation & Citizens' Services
Dr. Beverly Holmes		Michael Smith Foundation for Health Research
Dr. Colin Bennett	Professor	Department of Political Science, Uvic
Dr. David Flaherty	Former Commissioner	Professor Emeritus, University of Western Ontario
Dr. Howard Brunt	Vice-President, Research	UVic
Dr. Julian Somers	Associate Professor	SFU Faculty of Health Sciences
Dr. Kendall Ho	Director and Professor	UBC FoM eHealth Strategy Office
Dr. Kimberlyn McGrail	Assistant Professor and Associate Director	Centre for Health Services and Policy Research
Dr. Kuo-Hsing Kuo	Vice-President, Research	UNBC
Dr. Stu Callaghan	Professor	UNBC
Dr. Michael Hayes	Director	Health Education Research Council and Acting Director, School of Public Health and Social Policy. University of Victoria
Elizabeth Denham	Commissioner	OIPC
Ellen Chesney	Chief Admin Officer	Research, Provincial Health Services Authority
Greg Tonn	Project Coordinator	Information Management & Knowledge Services, Ministry of Health
Heather Cook	Executive Director of Acute Services & Chief Nursing Officer and Professional Practice Lead	Interior Health
Heather Davidson	Assistant Deputy Minister	Planning & Innovation Division, Ministry of Health
Helen Morrison	Senior Policy Analyst	OIPC

Jamie Ross	Senior Manager	Enterprise Risk Services, Deloitte
John Jacobson	Deputy Minister	Technology, Innovation and Citizens' services
John Martin	Director	Information Management Services Fraser Health
Joseph Mendez	Vice President, innovation and Information Management Services, CIO	First Nations Health Authority
Ken Armour	Director, Policy & Research	Research Universities' Council of British Columbia
Laurel Evans	Director	Office of Research Ethics, UBC
Lindsay Kislock	Assistant Deputy Minister	Ministry of Health
Mary McBride	Distinguished Scientist	BC Cancer Agency
Michael McEvoy	Deputy Commissioner	OIPC
Michele Weins	Senior Manager	Human Early Learning Partnership, UBC
Nancy Gault	Manager, Client Affairs, BC and Yukon	Canadian Institute for Health Information
Nancy Meagher	Executive Director	Population Data BC
Nancy Paris	Director	Product and Process Applied Research Team BCIT
Shirley Wong	Director, Health Data Governance, Policy Strategy	Ministry of Health
Steven Tam	General Legal Counsel and Chief Privacy Officer	Vancouver Coastal Health Authority Research Institute
Susan Chunick	Director	Fraser Health Authority, Research & Evaluation Department
Victoria Schuckel	Director	Research, Knowledge Translation & Library Services Branch   Health System Planning and Innovation Division   Ministry of Health
Wendy Taylor	Executive Director	C&E Committee Secretariat, M

## Appendix B – Forum Agenda

### Health Data Access Forum Workshop

#### Participant Agenda

<b>Date</b>	Monday, December 9 <sup>th</sup> , 2013
<b>Time</b>	10:00am to 4:00pm
<b>Location</b>	OIPC Offices, 947 Fort Street 2 <sup>nd</sup> Floor Boardroom

#### Objective

- To seek solutions on how access to, use of and storage of MoH data\* for university researchers could be enhanced while retaining respect for independent academic research.

*\* focusing on the safety and security and privacy enhancing strategies for this information*

#### Agenda Timing and Elements

10:00am	<b>Welcome, Opening Remarks and Context for the Day – Why We Are Here</b> Elizabeth Denham, Commissioner, OIPC Lindsay Kislock, ADM Ministry of Health Howard Brunt, VP Research, UVIC
10:30am	<b>Agenda Review, Participant Check-in, Introductions and Expectations</b>
11:00am	<b>Identifying / Confirming The Ideal Future</b>
12:00 noon	<b>Lunch</b>
1:00pm	<b>Challenges and Opportunities - Roundtable Discussions</b>  Discussion Theme Areas: <ol style="list-style-type: none"> <li>Roles and responsibilities of data stewards, universities and researchers</li> <li>Developing robust privacy and security frameworks</li> <li>Improvements to data access approval processes</li> <li>Conduct of audits and ongoing monitoring</li> <li>Creating/enhancing avenues to access data.</li> </ol>
3:00pm	<b>Break</b>
3:15pm	<b>Solutions and Recommendations</b>
3:45pm	<b>Next Steps, Communications, and Closing Activities</b>
4:00pm	<b>Adjourn</b>