



Fraser Basin Council

Social well-being supported by a vibrant
economy and sustained by a healthy environment

April 30, 2014

Honourable Terry Lake, MLA, Kamloops-North Thompson
c/o Government Caucus
Parliament Buildings
Victoria, BC V8V 1X4

Dear Terry:

Ensuring the long-term vitality of BC's rural communities, tackling climate change, improving aboriginal/non-aboriginal relationships and responsibly developing the rich natural resources of this great province – you know that these and other issues and opportunities require creative ways to engage and inform people and the organizations and interests they represent. Providing those creative ways is what the Fraser Basin Council (FBC) has excelled in for the past 17 years.

We are going to be in Victoria on May 14th to deliver a presentation to caucus about the work of the Council and I hope you will join us. As an impartial, non-partisan, broad-based organization, the FBC has provided invaluable assistance over the years to several ministries of the provincial government, one of its founding partners.

Recently I was honoured to be appointed as Chair of FBC, succeeding Dr. Charles Jago. A registered charity established in 1997, the FBC is a unique partnership among all four orders of Canadian government (provincial, federal, First Nations, local), the private sector and the community. Its primary role is to catalyze and facilitate multi-interest collaboration throughout BC in support of strong communities, vibrant economies and healthy ecosystems.

Beyond the tangible and relevant outcomes of its work, what impresses me the most about the FBC – and a key factor in its ongoing success – is its effectiveness at bringing together a remarkable diversity of people and organizations to harness limited resources, find collaborative solutions, and reach agreement to take cooperative action on both tough issues and promising opportunities.

On May 14th, you'll hear about the FBC's wide-ranging accomplishments – from facilitating the deployment of over 400 electric vehicle charging stations throughout the province and improving the efficiency of BC's trucking fleets to helping BC communities partner with others to improve regional flood preparedness.

I believe that how you get to a decision can be more important than the decision itself, particularly if a tough decision demands broad-based support if it is to endure. In this respect, I believe the FBC offers a unique and timely approach to addressing the complex issues and opportunities that you encounter every day as an MLA. I hope you will join me on May 14th along with FBC Executive Director David Marshall and staff.

Melissa has slotted us for 10:30 am to 11:30 am. I look forward to seeing you then.

Sincerely,

Colin Hansen
Chair, Fraser Basin Council

MINISTER'S OFFICE HEALTH	
#	1009296
DRAFT <input type="checkbox"/>	REPLY <input type="checkbox"/>
REPLY <input type="checkbox"/>	FILE <input type="checkbox"/>
REMARKS	Meeting Request
<input type="checkbox"/> AA	<input type="checkbox"/> MA
<input type="checkbox"/> EA	<input type="checkbox"/> DM



Arthritis Research Centre of Canada
Arthrite-recherche Canada

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Leading research. Finding answers. Saving lives.	Orienter la recherche. Trouver des réponses. Sauver des vies.
DRAFT <input checked="" type="checkbox"/> REPLY <input checked="" type="checkbox"/> FYI <input type="checkbox"/>	1005611 MAR 03 2014 <input type="checkbox"/> REPLY DIRECT <input type="checkbox"/> FILE
REMARKS	
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Feb 26, 2014.

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arthritisresearch.ca

Terry I have received invitations from several health related not-for-profits to join their boards but this is the only one I have said "yes" to. I had three reasons: One, they are a national organization that is BC-based. Two, they are a young organization doing great work and, three, they are entirely focused on leading edge research.

I know that year-end funds are probably more scarce than ever but I encouraged them to put this proposal forward in hopes that there may be an opportunity.

- Alvin

Ps. We have also sent it to Mike deJong.



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Saving lives. Sauver des vies.

February 25, 2014

Honourable Terry Lake
Minister of Health
PO BOX 9050
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arthritisresearch.ca

Dear Terry,

With your support, we are actively pursuing our proposal for a one-time grant from the Government of BC for research to benefit BC's 600,000 arthritis patients. We know that arthritis is a major obstacle to achieving key goals for BC's future: healthy families, healthy communities and a healthy workforce.

As you know, the personal and economic burden of arthritis is increasing rapidly. One in ten doctor's visits is related to arthritis and it has become the leading cause of long-term disability. Health care costs and the numbers of employees disabled by arthritis will continue to rise unless a determined effort is made now to prevent and control its impact. Women in particular are affected, representing two-thirds of arthritis patients.

The only national clinical arthritis research centre, The Arthritis Research Centre of Canada, headquartered in BC, and located in Richmond, ARC has become a leader in BC's knowledge-based economy. Our partners include over 27,000 donors within the province of BC and include individuals, corporations, universities and research institutes. The BC Government's investment in ARC will yield dividends for patients, the health care system and the BC economy.

Enclosed is our proposal for you. Thank you for considering our request to support the advancement of arthritis research in BC.

Sincerely,


Colin Hansen,
Board Member



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arthritisresearch.ca

Dear Minister Lake,

Proposal for a BC Government Grant for a Partner to help reduce the cost of Arthritis and change the lives of Arthritis Patients

The Arthritis Research Centre of Canada (ARC) is seeking a one-time BC Government grant of \$3 million to accelerate research into arthritis, a group of chronic diseases that affects 600,000 British Columbians. The grant will enable ARC to make advances to prevent work disability, improve pain management, address the special needs of women and men with arthritis and reduce health care costs. Acclaimed for its ground breaking research, the Arthritis Research Centre of Canada is recognized as a global leader in efforts to conquer arthritis.

The chronic pain of arthritis affects more British Columbians than cancer, heart disease, diabetes or chronic lung disease. People disabled by arthritis have difficulty remaining in the work force, staying physically active and managing everyday tasks. Arthritis has also become the most costly disease, with drug costs increasing more rapidly than for any other disease group.

In BC, the public health costs of arthritis are \$1.6 billion per year. An additional \$2.7 billion annually is attributed to lost work productivity, incurred primarily by people aged 36-60. Two - thirds of those living with arthritis pain and disability are women.

The Arthritis Research Centre of Canada is making rapid advances in preventing and treating arthritis. From its beginnings in 2000 with a single scientist, one student and one part-time assistant, ARC has grown to a team of 60 investigators and staff funded by research grants from around the world. Our small administrative team of five ensures overhead costs are kept to a minimum. ARC's International partners include Harvard Medical School, Duke University, Boston University, and the University of California, as well as scientists in Scandinavia, England, France, Holland, Australia, and China.

ARC is finding answers and saving lives. In its first decade, ARC researchers:

- Discovered the cause and prevented the marked increase in heart attacks in patients with rheumatoid arthritis and lupus.
- Demonstrated that pharmacists can diagnose osteoarthritis of the knee a decade early and save health care costs.
- Provided scientific content for the development of the first program to reduce workplace disability for people with inflammatory arthritis.



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- Conducted the first study into the impact of arthritis on women with children.
- Provided feedback and co-leadership on the concept and content development of the world's most downloaded smartphone apps for arthritis patients and health care professionals with our partner, Arthritis Consumer Experts (ACE).
- Launched culturally-sensitive self-management programs in partnership with First Nations communities, where arthritis is more widespread and severe than in the general population.

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arthritisresearch.ca

Strong partnerships have been central to ARC's success. Visionary donors Maureen and Milan Ilich have invested in our work, with a recent gift of \$4 million along with rent-free office space to sustain ARC's operations. ARC's goal is to use this donation to leverage funds to advance research results to the next level.

A BC Government grant of \$3 million will enable ARC to achieve its research targets in reducing work disability, improving pain management, minimizing health care costs, and meeting the special needs of men and women with arthritis.

Our goal is to ensure that people living with arthritis benefit first from leading edge research underway right now, right here in BC.

It's time for arthritis action. We invite the BC Government to join ARC in making BC the best place for people living with arthritis. We look forward to creating a customized recognition plan to acknowledge your commitment and will be pleased to feature the partnership in our communications with our 27,000 donors across British Columbia.

On behalf of the individuals, families, employers and communities affected by arthritis, thank you for considering our request to support the advancement of arthritis research in BC.

Respectfully submitted by:

John M. Esdaile, MD, MPH, FRCPC, FCAHS
Scientific Director
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604.207.4001

Shauneen Kellner
Executive Director
skellner@arthritisresearch.ca
604.207.4000

Tyson, Jo HLTH:EX

From: Manning, John HLTH:EX
Sent: Sunday, June 24, 2012 9:19 PM
To: Health, HLTH HLTH:EX
Cc: Miniaci, Mario HLTH:EX; Maksymetz, Richard HLTH:EX
Subject: FW: Data Effect Report
Attachments: Data Effect - Report June 19.pdf; Data Effect - Report June 19.doc

Please log as FYI.

John Manning | Executive Assistant
Office of the Honourable Michael de Jong, QC Minister of Health Province of British Columbia
T: 250.387.1247 | F: 250.356.9587

-----Original Message-----

From: Hansen, Colin [<mailto:C.Hansen@leg.bc.ca>]
Sent: Tue, June 19, 2012 8:22 AM
To: Kislock, Lindsay M HLTH:EX; Nikolejsin, Dave LCTZ:EX; Manning, John HLTH:EX
Subject: Data Effect Report

This is a final draft of a report coming out of our Data Effect conference.

We hope to circulate this Thursday.

- Colin.

“Data Effect” Conference Report

“Moving Forward for the Benefit of British Columbians”



June 2012

“Data Effect” Conference Report

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“Data itself is not valuable, rather what is done with it that brings value.”

1. Introduction

Over the last four decades British Columbia has collected detailed digital health and demographic records on everything from hospital admissions to doctor visits and prescriptions filled by every pharmacist in this province. It is one of the best collections of health data anywhere in the world. This longitudinal data is a unique analytical tool that can save lives, save our health care system billions of dollars and be a catalyst for research innovation in BC and Canada. Yet in BC there have been multiple challenges to access to this data for health research, preventing researchers from being able to derive the value inherent in this resource.

Purpose of the Conference

The “Data Effect” Conference, held in Vancouver on June 5, 2012 by CityAge Media Inc., began the process of addressing this problem. The Conference organizers, supported by key public sector sponsors, featured a wide range of speakers from researchers and government representatives to industry and politicians. It was well attended with over 200 people from a variety of sectors. The goal of the Conference was to create an open dialogue amongst those who are responsible for collecting and managing the data with those that need access to it for research purposes. In addition, it began a process that will continue over the next several months to fully understand the causes of the problem then identify and implement solutions. See Appendix A for a list of speakers and moderators.

The Purpose of this Report

This Report has been prepared by the office of Colin Hansen, MLA, with the purpose of continuing the conversation initiated at The Data Effect conference. It is not meant to be a detailed record of each speaker’s presentation rather it is meant to provide direction for solving the current problem. This Report gives a synopsis of the current legislation, opportunities, issues and problems in the data environment in British Columbia.* Based on the Conference dialogue it provides a Road Map in the form of a list of action items to be undertaken over the next several months that will change the data environment in British Columbia from one that is restrictive to one that proactively encourages the responsible use of the data by researchers.

* A full record of the speaker’s presentations and the discussion has been recorded both by video and in written format. The written format is available upon request.

2. Privacy and Legislation

British Columbia is already known globally for leading-edge health research. Recent breakthroughs in technology, software and information security can protect privacy and allow researchers to use public databases to discover better medical practices, drug treatments, healthcare and other societal trends. The research community adds hundreds of millions of dollars to the BC economy. But researchers' access to this data is limited or restricted, because of concerns about protecting privacy. The protection of individuals' privacy must be paramount. BC has the safeguards to guarantee privacy is protected.

Legislative Framework

Freedom of Information (FOI) and Protection of Privacy Act (FIPPA) (RSBC 1996 Chapter 165.

Purposes of this Act

2. (1) The purposes of this Act are to make public bodies more accountable to the public and to protect personal privacy by
 - (a) giving the public a right of access to records,
 - (b) giving individuals a right of access to, and a right to request correction of, personal information about themselves,
 - (c) specifying limited exceptions to the rights of access,
 - (d) preventing the unauthorized collection, use or disclosure of personal information by public bodies, and
 - (e) providing for an independent review of decisions made under this Act.
- (2) This Act does not replace other procedures for access to information or limit in any way access to information that is not personal information and is available to the public.

Health Data has specific legislation covered by the following Acts.

- E-Health Act – overseen by Data Stewardship Comte.
- Pharmaceutical services Act – overseen by Data Stewardship Comte.

In addition, FIPPA references how data is linked to public bodies and Research Ethics Board (REB) approvals are governed by the Tri-Council agreement.

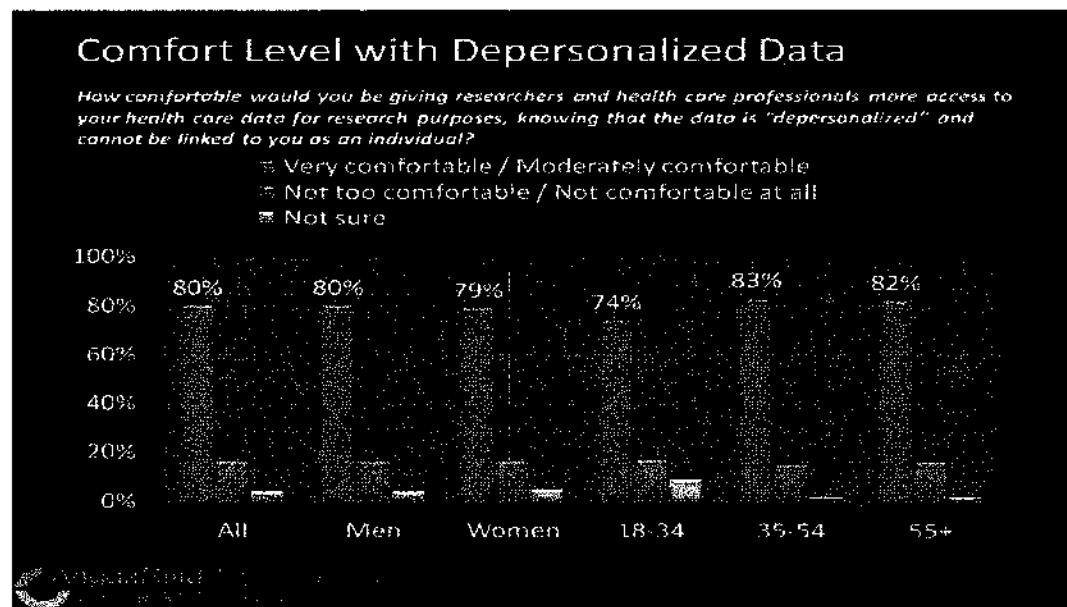
Based on the legislation elsewhere in Canada, BC is consistent with other provinces in its treatment of the FIPPA. However, the legislation around health research varies somewhat, although fundamentally there is consistency in terms of needing ethics review, that it is in the public interest, and that it is done by bona fide researchers. Essentially privacy and research is fundamental, but the public needs to feel confident as to how information is used and that their privacy is protected. More information on the Data Stewardship Committee and the current access processes are found in Appendix B.

3. Public Perception: Use of Data for Research

Studies indicate that patients will adopt behaviors to protect privacy if they feel this information may be compromised, such as less doctor visits and not disclosing information to their doctors. Therefore, protecting the patients' information is essential to their health and well being. Currently technology exists that is capable of de-identifying data.

First Nations want to be part of data analysis as long as they are consulted with why and how data about their people will be used. They support access to data for ethical uses, if it will lead to better health outcomes.

A recent poll by Angus Reid Public Opinion showed that 77% of those polled believed that researcher access to depersonalized health data can improve health care treatments. In terms of their comfort level of using depersonalized information for research purposes 80% were very comfortable or moderately comfortable. As long as privacy is guaranteed they are supportive. See other results from Opinion Poll in Appendix C.



It was concluded that the research community needs to increase public engagement and identify better ways to engage the public and identify how to bring them into the discussion.

4. Data and Research Opportunities

There are many opportunities to use data to decrease costs, increase safety and increase health care. The flow of data for effective research includes: collection of health data --- identifying the health question --- linking available data --- researchers answering health questions --- results to health professionals, health authorities and government --- creation of guidelines --- implementing guidelines --- leading to improvements in health of individuals and specific populations and reducing costs on the health care system.

Following are several examples of effective research using data that were presented during the Conference by Dr. Bruce Carleton and Ms Nancy Meagher.

- Repurpose data to save health care costs by using the existing guidelines that are not currently fully implemented for example, diabetes control. The major test used to monitor diabetes control is hemoglobin A1C. It measures glucose control by analyzing the amount of glucose in the red blood cells. The Canadian Diabetes Association (CDA) recommends testing every 3 months. No evidence that testing more than every 4 months is necessary. Data in BC shows the numbers of tests are increasing, and being used more frequently than every 90 days. It appears BC is doing a lot of retesting. Money to be saved includes \$3.5M 90 days; \$4.1M 230 days; \$8.7M 120 days. A working group within the BC Medical Association is following up to develop guidelines and key principles.
- Linking of data sets and collaboration with stakeholders. For example, improving care for patients by understanding how drugs interact and affect outcomes. Tamoxifen used in the treatment of breast cancer, patients experiencing hot flashes can be prescribed anti-depressants. Anti-depressants interact with Tamoxifen which could impact on survival of the patient.
- Building databases across Canada that are linked and then applying genetic information to increased understanding of treatment outcomes. For example, data can improve patient safety in preventing adverse drug reactions (ADR) which is the fifth leading cause of death in North America, 95% of ADRs are never reported. A specific example is anthracycline (doxorubicine chemotherapy) used to treat pediatric neuroblastoma. Some patients develop serious cardiac dysfunction and ultimately need heart transplants. Anthracycline is very effective in treating this type of cancer but for some patients it can be toxic and shorten life. Dr. Carleton's team identified key genes in the anthracycline transport pathway that indicated patients with these genes were at higher risk of heart failure and as a result they have been able to determine who will develop cardio- toxicity leading to clinical options for personalized anthracycline therapy. The low risk patients are followed-up as usual. Intermediate risk patients are provided intense echocardiogram follow-up; and high risk patients are provided alternative medication or dose; cardio-protectant medication; and treatment with ACE-inhibitors or beta-blockers to prevent further damage.
- A recent study by the Partnership for Work, Health and Safety at UBC's School of Population and Public Health, used linked data from WorkSafeBC workers' compensation claim data and British Columbia Cancer Agency (BCCA) Tumor Registry to learn how many mesothelioma cases in BC are compensated, and the factors that influence compensation. The results indicated that less than 50% of mesothelioma cases present for compensation from WorkSafeBC; these health care costs and

services are absorbed by the Ministry of Health. Compensation rates vary by region, suggesting that public knowledge in large industrial settings with known asbestos exposure influences awareness of compensation benefits. Based on the findings, the BCCA and WorkSafeBC began working together to increase awareness of compensation benefits among mesothelioma cases; this included a letter to physicians of patients to encourage them to seek WorkSafe BC compensation thus resulting in significant cost savings to the BC Ministry of Health.

5. Current Problems

The problems are:

- Slow review times by the Ministry of Health, resulting in limited access to the data.
- Overly complex processes for access, despite the fact that the technology and the systems to facilitate access and protect individual privacy are present.
- Lack of clarity about the specific processes to easily access data.

6. Potential Solutions

There were a number of discussion points and potential solutions put forward during the Conference. Each is presented below for consideration and further discussion.

Solution #1: Need to:

- Protect citizens and bring them into the discussion about the use of data.
- Determine what will be returned to the tax payer: attract talent, investment, jobs, etc.
- Determine who owns the data.
- Determine what are the next steps are in order to open the data.
- Determine “What is the question?” For example, what are the top five issues and how to make “outcomes” matter.

Solution #2: Create a rapid response mechanism to enable effective health planning and improve efficacy and care

- Step #1: No record level request – define problem and scope of data required
 - 14 day turnaround time
- Step #2: De identified record level request for deeper analysis
 - 30 – 60 day turnaround time
- Consider a “Trusted Researcher” concept (think of the Nexus card). So the researchers that have this status would get ease of access. But they are required to follow specific guidelines and as long as they do, they will have continued ease of access.

Solution #3: The key aspect of the data in BC is that it is longitudinal, but many data sets need to be linked in order to be useful. Here are six steps to make linking easier.

- Create a Harmonization Committee.
- Establish an ongoing process for leadership and management of issues.
- Create an inventory of data sets and determine how information is currently linked.
- Create an ongoing dialogue with everyone at the table including patients (collective effort).
- Look at the current and the future data and how it will work together.

Solution #4: Create a partnership and collaboration between academic, government, business, public, patients, health professionals in order to work closely together to achieve better results.

- Academics play a significant role as data is very important for research.
- Applied research: innovators developing new pharmaceutical could get new breakthrough products to market faster and cheaper.
- Government is the catalyst.
- Most important is the public and patients, therefore patient advocacy groups should be incorporated.
- There needs to be respect, trust, and professional responsibility.
- Need to have ongoing dialogue in order to find and maintain solutions.
- Use data and information system to design health care facilities in a more effective manner.
- Ministry of Health researchers, doing very similar work as academic researchers, are well positioned to look at a systems wide approach.

Solution #5: Need more than incremental change – significant changes are required so all parties are beneficiaries.

- Link data sets that are safe for patients, safety is very important.
- Need to have a separation of data from individual information.
- Needs to be more education of what data is and who the owner of it.
- Access to data needs to be intentional especially with patient access and control of the data.

7. Road Map Forward: Who are the Drivers and What Will They Do?

Individual	Position	Ongoing Role and Activities
Bruce Carleton	Chair Data Steward Committee	Spokesperson for researchers. Participation in discussions and provide direction.
Minister Mike De Jong	Ministry of Health	Working to enable his Ministry to provide access to health data within a two month time period.
Elizabeth Denham	Information and Privacy Commissioner for BC	Roundtable Meeting of Stakeholders on June 25, 2012 for discussion of the problem and potential solutions. What are the specific barriers and what evidence is provided? Closed door meeting. Will report out on the results of the meeting. Also her office is working on a White Paper regarding "High Water" marks for privacy and security. Action items from the Roundtable Meeting, to be determined.
Don Enns	President, Life Sciences BC	Participation in discussion. Leadership with industry and communication of progress.
Diane Finegood	President MSFHR	Spokesperson for researchers. Participation in discussions and provide direction. Further activities to be determined.
Colin Hansen	MLA Former Minister of Health and Finance	Continue his role as Champion both within Government and the Research Community.
Lindsay Kislock	ADM, MOH	Overall responsible for the Office of the Data Steward
Minister Margaret MacDiarmid	Ministry of Labour, Citizens' Services & Open Government	Mandate of Ministry is Open Government therefore spokesperson within government for change. Liaison with researchers and provide direction and advice.
Mary McBride	Distinguished Scientist BC Cancer Agency, UBC Clinical Associate Professor, School of Population & Public Health	Long history of data stewardship and research in BC therefore leader for change. Consulting with researchers for input into E. Denham meeting on June 25 th . Attending meeting. Preparing "Background Statement" to present to Minister De Jong, Minister MacDiarmid and Colin Hansen.
Nancy Meagher	Executive Director Population Data BC University of British Columbia	Population Data BC's core business is to provide researcher access to data. Also, has extensive knowledge of the privacy-related issues. Represents the research community, further activities to be determined.
Dave Nikolesjin	Chief Information Officer BC Ministry of Labour, Citizen's Service and Open Government	Ongoing dialogue with Research Community re: changing the paradigm.

8. Conclusion

This Report provides a road map of action items to be undertaken over the next several months. It is expected that the result of these activities will change the data environment in British Columbia thus enabling millions of new research dollars and human talent, discoveries that will save more lives, improve quality of life and cement British Columbia as a centre of excellence for bringing efficient and effective health care solutions to Canada and the world.

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Appendix A: Speakers and Moderators

Colin Hansen, MLA, Former Health and Finance Minister

Bill Barrable, CEO, Rick Hansen Institute

Dr. Evan Adams, Deputy Provincial Health Officer with responsibility for Aboriginal health.

Christer Johnson, Leader, Business Intelligence and Advanced Analytics, IBM

Mario Canseco, Vice President, Angus Reid Public Opinion

Dianne Doyle, President and Chief Executive Officer of Providence Health Care

Bruce McManus, Director, James Hogg Research Centre

Dr. Diane Finegood, President and CEO, Michael Smith Foundation for Health Research

Harry Kim, Senior Director, Enterprise Services WW Healthcare Strategy and Portfolio HP

Madhu Pawar, Partner, McKinsey & Company

Mo Amin, Director, Health Economics, Amgen

Martin Ester, Professor of Computer Science and Data Analytics, Simon Fraser University

Brian Bot, Senior Scientist, Sage Bionetworks

Michael Guerriere, Vice President and Chief Medical Officer, Telus Health Solutions

Gerry Salembier, ADM, Western Economic Diversification, Government of Canada (Panel Moderator)

Fazil Mihar, Editorial Page Editor, Vancouver Sun (Conference Moderator)

Dr. Khaled El Emam, Canada Research Chair in E-Health Information, University of Ottawa

Elizabeth Denham, Information and Privacy Commissioner for British Columbia

Nancy Meagher, Executive Director, Population Data BC

Hon. Mike De Jong, Minister of Health, Province of British Columbia

Karimah Es Sabar, Senior Vice President, The Centre for Drug Research and Development

Brad Popovich, Chief Scientific Officer, GenomeBC

Dave Nikolejsin, Chief Information Officer, Province of British Columbia

Dr. Patricia Martens, Director, Manitoba Centre for Health Policy

Dr. Julio Montaner, Director, BC Center for Excellence in HIV/AIDS (by video)

Dr. Bruce Carleton, BC Children's Hospital, Chair of Provincial Data Stewardship Committee

Don Enns, President, Life Sciences British Columbia

Joe Greenwood, Program Director, Data, MaRS Discovery District

Appendix B: Health Data Environment in BC: Who Does What?

The BC Ministry of Health provides the following online services to authorized partners in the health care system who require ongoing access to specific health systems and data.

The Office of the Chief Data Steward and Strategic Policy, Information Management and Data Stewardship includes Strategic IM/IT Policy, the Data Stewardship Committee Secretariat, Data Access, Research and Stewardship, Information Management, and Strategic Health Data Warehousing. The Chief Data Steward also administers all Ministry of Health – Health Information Banks established under the *eHealth Act*. www.health.gov.bc.ca/chiefdatasteward/

PharmaNet is the province-wide network that links all B.C. pharmacies to a central set of data systems. Every prescription dispensed in BC is entered into PharmaNet. It is administered by the Ministry of Health and the College of Pharmacists of BC and was developed in consultation with health professionals and the public to improve prescription safety and support prescription claim processing. Users include community pharmacies, hospital pharmacies, emergency departments, medical practices, the College of Pharmacists of B.C. and the College of Physicians & Surgeons of B.C.

PharmaNet Stewardship Committee (PSC) is established under section 14 of the *Pharmacy Operations and Drug Scheduling Act*. Committee members are appointed by the Minister of Health, and are responsible for making decisions on disclosure of data from the provincial PharmaNet database for research, evaluation, planning and other specified uses. The PSC also reviews requests to use PharmaNet data to contact individuals to request participation in health research. Researchers considering an application are asked to contact the Secretariat to discuss their project and request the latest version of the application form. www.health.gov.bc.ca/chiefdatasteward/pharmanet-stewardship-committee.html

Medical Services Plan (MSP) insures medically-required services provided by physicians and supplementary health care practitioners, laboratory services and diagnostic procedures. It maintains extensive data on medical and supplementary health care claims and payments for current and past years. A number of publications regarding MSP fee-for-service payment statistics are available. <http://www.health.gov.bc.ca/msp/paystats/index.html>

Provincial Lab Information Solution or PLIS is the centralized computerized record-keeping system for storing and accessing all lab tests results done in BC. Health care providers, system administrators and others with lawful authority across BC have access to the records on PLIS. PLIS will also enable the collection, use and disclosure of laboratory information for the purpose of analyzing and managing chronic diseases in BC. www.health.gov.bc.ca/ehealth/plis.html

BC Vital Statistics Agency maintains an extensive research database of current year and historical files extracted from the Vital Statistics Information System (VISION). Research projects and publications of the Branch covering a wide range of birth and mortality-related topics are reproduced including Annual Reports, Quarterly Reports, Supplemental Reports, Health Status Registry Reports, Status Indian Reports, Feature Reports, and The Physicians and Coroners Handbook 2004 Revision. www.vs.gov.bc.ca/stats/

Acute Myocardial Infarction (AMI) & Stroke BC administrative databases; Discharge Abstract Database / Hospital Morbidity database (CIHI); POI database, Vital Statistics files, and life tables (Statistics Canada).

How is Health Data accessed through the Office of the Chief Steward?

There are three separate streams of activity supporting requests for access to health data through the Office of the Chief Data Steward: Data Access and Research Stewardship; Data Stewardship Secretariat; and Health Data Access Services.

MOH Data Access, Research and Stewardship (DARS) administers requests for access to Ministry of Health databases through Population Data BC at the University of British Columbia (excluding those that are health information banks, prescribed under the e-Health Act and PharmaNet), providing administrative, technical, strategic, policy and decision support to the Office of the Chief Data Steward. The Research Agreements section handles requests from academic researchers for access to data held at Population Data BC at the University of B.C., throughout the application, review, and ongoing monitoring processes. www.health.gov.bc.ca/das/

Data Stewardship Secretariat in the Office of the Chief Data Steward the Secretariat provides administrative, technical, strategic, policy and decision support to the Data Stewardship and PharmaNet Stewardship Committees, and is the point of contact with the Committees and the Office of the Information and Privacy Commissioner on requests to contact for participation in health research. www.health.gov.bc.ca/chiefdatasteward/secretariat.html

Data Stewardship Committee (DSC) is established under section 12 of the E-Health (Personal Health Information Access and Protection of Privacy) Act. DSC members are appointed by the Minister of Health, and are responsible for managing the disclosure of information contained in a Health Information Bank (HIB) or prescribed Ministry of Health database. Anyone seeking data contained in a HIB or prescribed ministry database for planning or research purposes must submit a request to the DSC through the Data Stewardship Secretariat. If the DSC approves the request, the HIB administrator may disclose the requested information, subject to any conditions that the DSC or the administrator set. The DSC has the authority to exempt HIBs from providing an otherwise-mandatory disclosure directives service. Disclosure directives are written instructions by individual patients to block access to their own personal health information contained in a HIB. www.health.gov.bc.ca/chiefdatasteward/data-stewardship-committee.html

Requests to Contact Individuals to Request Participation in Health Research All requests to use data for the purposes of contacting individuals to request their participation in health research must be reviewed and approved by the Information and Privacy Commissioner. If the contact will be made using data from the Ministry of Health or a health authority, applications for this review are to be submitted through the Data Stewardship Secretariat. Researchers considering an application are asked to contact the Secretariat to discuss their project and request the application and/or request to contact forms.

Other Ways to Access BC Health Data

HealthIdeas is a range of information products and services designed by the Ministry of Health to support decision making. It contains information about health services to British Columbians including hospital services and physician services. It also contains population and other reference data.

www.healthideas.hnet.bc.ca/portal/page/portal/HealthIdeas

Population Data BC is a multi-university, data and education resource facilitating interdisciplinary research on the determinants of human health, well-being and development. It supports research access to individual-level, de-identified longitudinal data on British Columbia's four million residents. These data are linkable to each other and to external data sets, where approved by the data provider. Linkage of data across sectors, such as health, education, early childhood development, workplace and the environment, facilitates advances in understanding the complex interplay of influences on human health, well-being and development. Such research informs health related policy-making and investment decisions for healthier communities. Researcher access to data will be approved by the Data Steward for a holding using a harmonized Research Agreement process through Population Data BC. See list of data sets below. Location: UBC www.popdata.bc.ca

Hospital Discharge Abstract Database (Hospital Separations File) Data on discharges, transfers and deaths of in-patients and day surgery patients from acute care hospitals in BC. The database contains demographic, administrative and clinical data for hospital discharges (inpatient acute, chronic, rehabilitation) and day surgeries. www.popdata.bc.ca

Home and Community Care provides information on transactions for individuals receiving services paid by the Continuing Care Division, BC Ministry of Health Services. Transactions relate to clients who are publicly-funded residents of long-term care facilities, assisted living facilities, family care homes and group homes, clients in adult daycare programs, and clients receiving home care and home support services. www.popdata.bc.ca

Medical Services Plan (MSP) Payment Information File Data on medically necessary services provided by fee-for-service practitioners to individuals covered by the Medical Services Plan, BC's universal insurance program. Practitioners are separated into: physicians, supplementary benefit practitioners (physiotherapists, massage practitioners, naturopathic physicians, etc.), and out-of-province practitioners. www.popdata.bc.ca

Discharge Abstract Database (Hospital Separations) Data on discharges, transfers and deaths of in-patients and day surgery patients from acute care hospitals in BC. www.popdata.bc.ca

Home & Community Care (Continuing Care) Information on transactions for individuals receiving services paid by the Continuing Care Division, BC Ministry of Health Services. Transactions relate to clients who are publicly-funded residents of long-term care facilities, assisted living facilities, family care homes and group homes, clients in adult daycare programs, and clients receiving home care and home support services. www.popdata.bc.ca

Mental Health The Mental Health data set contains administrative data in several files that were created using tables in the Mental Health Data Warehouse (MHDW). The mental health data we have are the Minimum Reporting Requirement (MRR) tables from the MHDW at the Ministry of Health Services. The MRR is now the requirement for all HAs in reporting on all patient/clients receiving mental health services in the community. The mental health data are a snapshot from a continuously updated relational database system with files such as client, care episodes, and service events.

Consolidation File (MSP Registration & Premium Billing) Population Data BC's central demographics file for research requests. It contains basic demographics such as age and sex, geo-codes indicating location of residence, and registration data.

WorkSafeBC Claims and Firm Level Files Information on reports of injury to WorkSafeBC (Workers' Compensation Board), and injuries accepted for compensation, including disability time periods, injury information and compensation amounts.

Some Key Health Data Sets in BC

BC Cardiac Registry and Evaluation Service (BCCR) contains information such as demographics, nature of cardiac surgeries, as well as diagnostic and interventional catheterization procedures. This is one of the most comprehensive medical databases in Canada; it records over 30,000 diagnostic procedures per year. The data is gathered from all hospitals with cardiac catheterization labs in British Columbia. Location: PHSA www.phsa.ca

HIV Drug Treatment Program (DTP) is a research and treatment program designed to ensure that all medically eligible persons living with HIV in British Columbia have access to free antiretroviral therapy. Established in 1992, the DTP currently provides nearly 5,500 patients with access to life-saving drugs. Information from all participants is entered into a database, providing data for clinical and virological outcome studies of patients receiving antiretroviral therapy. This database acts as a registry of all HIV-treating physicians in the province, as well as an "early warning system" to alert government about the trajectory of the disease. Location: St. Paul's Hospital www.cfenet.ubc.ca/our-work/initiatives/drug-treatment-program

The Rick Hansen Spinal Cord Injury Registry (RHSCIR) is part of the Translational Research Program of the Rick Hansen Institute. Launched in 2004, the RHSCIR is a nation-wide SCI patient registry that has been implemented in 14 cities located in 9 provinces. Currently there are over 1500 individuals who have sustained an acute traumatic spinal cord injury who are registered. Location: Rick Hansen Institute

British Columbia Diabetes Registry includes those patients who meet specific criteria. It is modelled after the National Diabetes Surveillance Strategy's registry whose goal is to implement a standardized model for the surveillance of certain 'core' data to provide comparable information on the incidence and prevalence of diabetes, mortality, diabetes-associated diseases, and health-care utilization rates for Canadians with and without diabetes. Location: Population Health Surveillance and Epidemiology Branch, MSP Economic Analysis Branch. www.healthservices.gov.bc.ca/cdm/practitioners/diabetesreg.html

BC Provincial Renal Agency Patient Record and Outcome Management Information System (PROMIS) is a database used to capture information on all BC patients known to nephrology teams. It provides the only information tool linking hospitals providing direct renal patient care, the University of BC (UBC), research organizations, financial groups and other organizations. It also enables improvements in clinical care, provides caregivers access to indicators of care, and supports research into both disease processes and evaluation of various treatment strategies. Currently, PROMIS collects data from over 30 renal units throughout BC. www.bcrenalagency.ca/HelathPro/PROMIS/

BC Cancer Registry was started in 1969. It collects data and generates BC population cancer data for the purpose of monitoring cancer in the province. It provides ongoing information on the scope of the cancer problem, information to plan programs to reduce mortality and morbidity from cancer, monitors the effectiveness of such programs, and provides information on the size of the cancer problem to aid in future planning. It serves as a source of information for research. It contains personal and demographic information as well as diagnosis and death information on all cases

of cancer diagnosed in BC residents. Location: BCCA Surveillance and Outcomes Unit - Population & Preventive Oncology www.datareq@bccancer.bc.ca

PharmaNet is the province-wide network that links all B.C. pharmacies to a central set of data systems. Every prescription dispensed in B.C. is entered into PharmaNet. It is administered by the Ministry of Health and the College of Pharmacists of BC. (See page 1 for more details.)

Medical Services Plan (MSP) insures medically-required services provided by physicians and supplementary health care practitioners, laboratory services and diagnostic procedures. It maintains extensive data on medical and supplementary health care claims and payments for current and past years. (See page 1 for more details.)

Canadian Health Data Organizations

Canada Health Infoway was created as a strategic response to needs expressed by Canada's First Ministers when they agreed in September 2000 to work together to strengthen a Canada-wide health infostructure to improve quality, access and timeliness of health care for Canadians. Infoway's mission is to foster and accelerate the development and adoption of compatible electronic health information systems and the electronic health record (EHR). <https://www.infoway-inforoute.ca/>

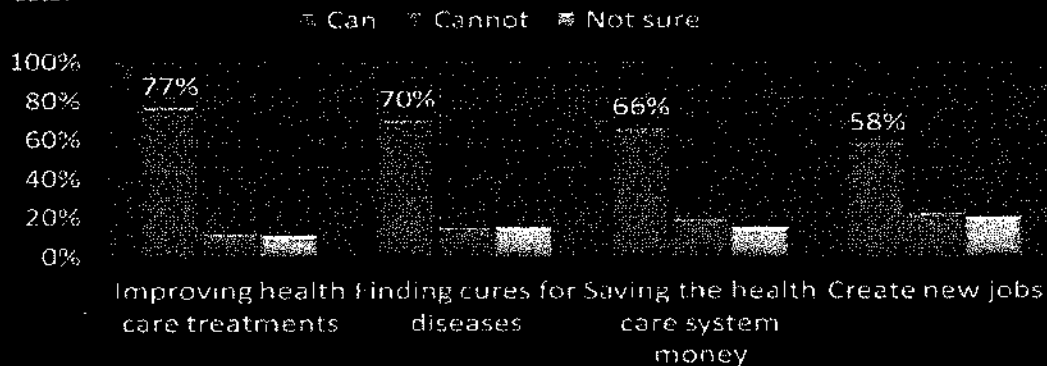
Canadian Institute for Health Information (CIHI) is an independent, pan-Canadian, not-for-profit organization whose mandate is to improve the health of Canadians and the health care system by providing quality, reliable and timely health information. CIHI is responsible for data definitions, content standards and classification systems which are core to CIHI's business. <http://www.cihi.ca/CIHI-ext-portal/internet/EN/Home/home/cihi000001>

Canada Health Infoway and the **Canadian Institute for Health Information** have a formalized relationship to develop and maintain the standards required to support the EHR data definitions and standards. Infoway leads the development of EHR Solution standards and acts as the overall program manager for EHR standards-related work. CIHI acts in the capacity of Preferred Partner to Infoway in the development of standards.

Appendix C: Public Perception: Angus Reid Poll

Benefits of a Database of Depersonalized Data

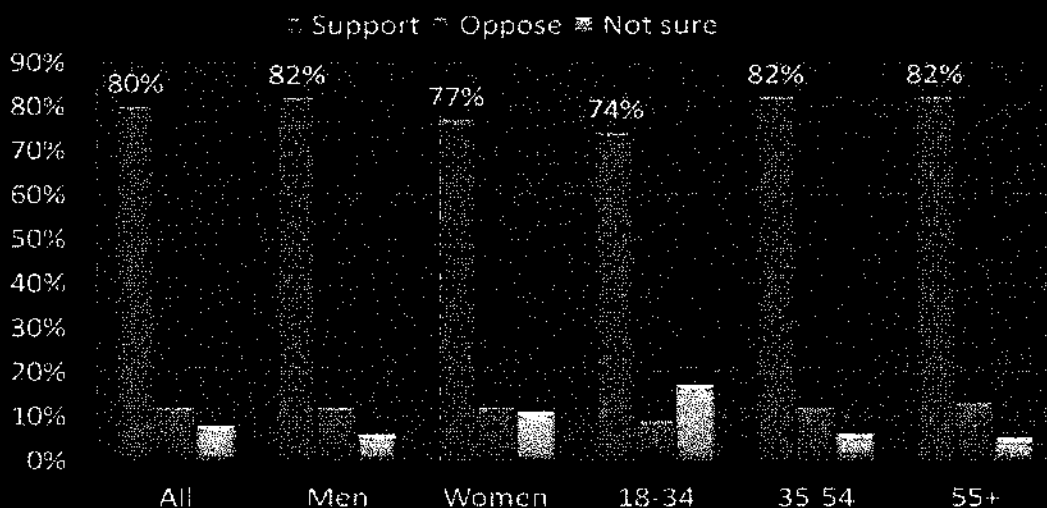
As you may know, British Columbia has built one of the world's best databases of "depersonalized" health care and demographic records. Regulations and technologies are in place to safeguard individual privacy. All data is "depersonalized" by removing any links to individuals before it is given to researchers and health care professionals under controlled circumstances. Thinking about this, do you think each of these goals can be achieved if researchers and health care professionals can have access to "depersonalized" health care data?



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Support for Database of Depersonalized Data

Would you support or oppose allowing researchers and health care professionals to have access to your "depersonalized" health care data, knowing that your privacy is guaranteed?

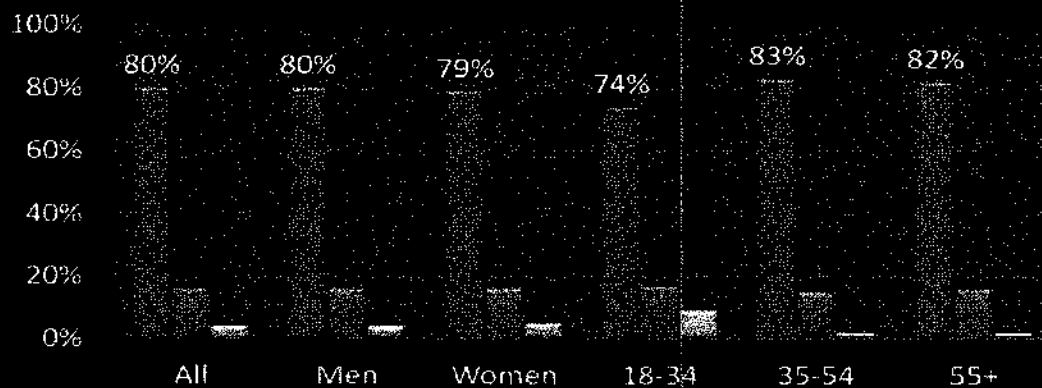


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Comfort Level with Depersonalized Data

How comfortable would you be giving researchers and health care professionals more access to your health care data for research purposes, knowing that the data is “depersonalized” and cannot be linked to you as an individual?

- Very comfortable / Moderately comfortable
- Not too comfortable / Not comfortable at all
- Not sure



August 2012
 Angus Reid Group

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Who Can Access “Depersonalized” Data?

Do you agree or disagree with these statements?

- Agree
- Disagree
- Not sure



The provincial government should allow researchers and health care professionals to have access to “depersonalized” health care data

Researchers working for private companies to seek better drugs and treatments should be given controlled access to “depersonalized” health care data

August 2012
 Angus Reid Group

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Appendix D: Health Data Acronyms and Health Data Terminology

Health Data Acronyms

CDM	Chronic Disease Management
CIHR	Canadian Institutes of Health Research
EHR	Electronic Health Record
EDAP	Emergency Department Access to PharmaNet
EPIDs	Enterprise Provider Identifiers
HAP	Hospital Access to PharmaNet
HIA	Health Information Act
HIB	Health Information Bank.
HPPA	Health Protection and Promotion Act
MPAP	Medical Practice Access to PharmaNet
MSP	Medical Services Plan, the BC health insurance plan
MSP Direct	Medical Services Plan: Group Plan Administrator Access
PHI	Personal Health Information
PHIA	Personal Health Information Act
PHIPA	Personal Health Information Protection Act
PI	Personal Information
REB	Research Ethics Board
RHAA	Regional Health Authority Act
THIPA	The Health Information Protection Act

Health Data Terminology

Ambulatory Electronic Medical Record (aEMR) is a computer-based medical record specific to a clinician, practice or organization. It is the record a clinician maintains on patients attending a specialty clinic and details patient and provider demographics, medical and drug history, and diagnostic information such as laboratory results and findings from diagnostic imaging. It is often integrated with other software that manages activities such as billing and scheduling. Ambulatory EMRs are deployed in community and hospital outpatient settings.

Client Registry is a directory that lists all patients and their relevant personal information (names, addresses, etc.) A component of an electronic health record (EHR) system, a client registry supports the centralized storage and retrieval of client (i.e. patient) identification data and enterprise client identifiers (ECIDs).

Consent means agreement. There are two types of consent: Express Consent and Implied or Implicit Consent. Express Consent means that an individual have expressed his/her consent either in writing or by giving verbal instructions. Implied or Implicit Consent means that it is assumed that an individual agrees, because in the situation it is obvious why his/her personal health information is collected, used or disclosed.

Consumer Health Application is an electronic solution that enables the consumer to collect, retrieve, manage, use and share personal information and other health-related data. A consumer health application could include applications

commonly known as personal health records and patient portals.

De-identifying Personal Health Information There are many different techniques for de-identifying personal health information, including randomization / masking / obfuscation / coding / pseudonymization / heuristics / analytics. www.ehealthinformation.ca/documents/DeidTechniques.pdf

Diagnostic Imaging Solution maintains and manages information about orders and results for DI tests, which constitute a vital part of a client electronic health record (EHR).

Disclosure means to give out or allow information to be seen by a person or organization.

Disclosure Directive is an instruction by an individual about whether or not personal information can be disclosed, or to whom, or for what purpose, which is attached to a personal EHR file in a particular health information bank.

Drug Information System is a tool that enables authorized health care providers to access, manage, share and safeguard patients' medication histories. A component of an electronic health record (EHR) system, a drug information system supports the storage and retrieval of patient prescription and medication information, and may provide application services supporting dispensing activities such as drug-usage evaluation.

Drug Information System: is made up of two certification classes: **Category I** serves only as a medication information repository, and does not provide any clinical application functionality, such as Drug Usage Evaluation or interaction checking. It does not support storage and retrieval of allergies or adverse reactions. **Category II** serves as a medication information repository, provides clinical application functionality, such as Drug Usage Evaluation or interaction checking, and supports storage and retrieval of allergies or adverse reactions.

Electronic Health Record (EHR) that refers to records of health information that are held in large databases and computer systems which are connected to other computer systems, so that the Electronic Health Record is made up of information from more than one computer system. Also a complete health record under the custodianship of a health care provider(s) that holds all relevant health information about a person over their lifetime. This is often described as a person-centric health record, which can be used by many approved health care providers or health care organizations.

Electronic Medical Record: (EMR) is a computer-based medical record specific to one clinician's (e.g. physician) practice or organization. It is the record clinicians maintain on their own patients, and which detail demographics, medical and drug history, and diagnostic information such as laboratory results and findings from diagnostic imaging. It is often integrated with other software that manages activities such as billing and scheduling.

Health Record is a general term that covers all types of records of health information, both written on paper or held in computers.

Health Care Provider includes all providers of health care, whether or not they work for a hospital or health authority or care centre or other government agency, or in a private practice or business.

Health Information Bank is a computer database containing personal health information which has been specifically designated by the Minister of Health, under the B.C. *E-Health Act*, as a "health information bank." A database can be designated as a health information bank only if certain requirements of the *E-Health Act* are met.

Independent Health Care Provider is a health care provider that is in private practice or business and is not working for a hospital or health authority or care centre or other public body.

Personal Health Information means information about an identifiable individual's health and includes information about the individual's health care providers, health numbers (such as care card number) and insurance.

Personal Health Record is a complete or partial health record under the custodianship of a person(s) (e.g. a patient or family member) that holds all or a portion of the relevant health information about that person over their lifetime. This is also a person-centric health record.

Privacy Officer is a job title for the position in an organization that is responsible for ensuring that the organization is compliant with the privacy laws that apply to the organization.

Provider Registry is a comprehensive directory of participating authorized health care providers; each authorized health care provider will be authenticated to ensure that he/she is authorized to access electronic health records. A component of an electronic health record (EHR) system, a provider registry supports the centralized storage and retrieval of provider (i.e. clinician) identification data, and enterprise provider identifiers (EPIDs).

Stewardship Purpose is defined in the Ministry of Health Act to mean any of the following purposes: (a) to develop, operate, monitor or evaluate a program or activity authorized under a health enactment; (b) to exercise powers or perform duties of the minister under an enactment; (c) to engage in health systems planning, maintenance or improvement; (d) to conduct or facilitate research into health issues; (e) to monitor or evaluate a health care body; or (f) a prescribed purpose.

Colin Hansen, M.L.A.
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Province of British Columbia
Legislative Assembly



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January 30th, 2012

Honourable Michael de Jong
Minister of Health
PO Box 9050, Stn Prov Govt
Victoria, British Columbia
V8W 9E2

MINISTER'S OFFICE HEALTH		
#	917057	
DRAFT REPLY <input checked="" type="checkbox"/>	FILED U 1 2012	
FILE <input type="checkbox"/>	REPLY DIRECT <input type="checkbox"/> FILE <input type="checkbox"/>	
REMARKS		
<input type="checkbox"/> AA	<input type="checkbox"/> MA	<input type="checkbox"/> SA
<input type="checkbox"/> EA	<input type="checkbox"/> CC	<input type="checkbox"/> CH

Dear Minister:

Re: By-laws of the College of Dental Surgeons of BC

Dr. K.K. Wan has brought to my attention issues that have the effect of preventing British Columbia dentists from treating their spouses. This strikes me as an unintended effect of well-intentioned rules.

I urge your ministry to take a look at it.

Sincerely;

Colin Hansen,
M.L.A. for Vancouver-Quilchena

cc. Dr. K.K. Wan

BRITISH
COLUMBIA

FEB 10 2012

Mr. Colin Hansen
MLA, Vancouver - Quilchena
5640 Dunbar St
Vancouver BC V6N 1W7

919180

DRAFT ☐ REPLY ☐ FEB 10 2012

REMARKS *Ref 917057*

☐ AA ☐ MA ☐ CA ☐ TA

917057

Dear Mr. Hansen:

The Honourable Michael de Jong, QC, Minister of Health, has asked me to thank you and respond to your letter of January 30, 2012, regarding treatment by dentists of their spouses.

Under the Dentists Regulation, the College is designated for the purposes of section 16 (2) (f) of the *Health Professions Act* (the Act). Section 16 (2) (f) provides that the mandate of a designated college includes "to ... establish a patient relations program to seek to prevent professional misconduct of a sexual nature". With one current exception, all colleges under the Act are designated for the purposes of section 16 (2) (f).

Section 13.03 of the College bylaws requires that the board of the College must establish a patient relations program to seek to prevent professional misconduct, including professional misconduct of a sexual nature. The term "professional misconduct of a sexual nature" is defined in section 13.03 and expressly includes sexual intercourse, or other forms of sexual relations, between dentists and their patients.

Section 13.03 represents the current Ministry-required standard that has been in place for several years. When dentistry became regulated under the Act in April 2009, section 13.03 was included in the College bylaws at the direction of the Ministry. Equivalent provisions have been included in the bylaws of a majority of colleges under the Act. In particular, the definition of "professional misconduct of a sexual nature" in the College bylaws is the same as that now in the bylaws of the College of Physicians and Surgeons of BC, the College of Optometrists of BC, the College of Chiropractors of BC, the College of Naturopathic Physicians of BC, the College of Podiatric Surgeons of BC and the College of Registered Nurses of BC.

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As a fundamental policy principle, the Ministry believes it is unacceptable for regulated health professionals to engage in sexual relationships with their patients. This policy has been in place for many years and is based in part on pre-existing Ontario policy and legislation. The definition of "professional misconduct of a sexual nature" which the Ministry requires in college bylaws is essentially identical to the definition of "sexual abuse" found in the Ontario legislation. As in Ontario, the Ministry does not mandate a definition of "patient".

The key difference between the two provinces is that BC has not adopted Ontario's legislated penalty for this type of misconduct, which is automatic cancellation of the individual's entitlement to practice for a minimum of five years. In BC, the colleges retain discretion in the imposition of penalties. Ontario is reviewing the minimum penalty only; it is not considering a spousal exemption to the ban on sex with patients.

The well-established position of the Ministry reflects the fact that times have changed and societal attitudes have evolved. The public now rightly expects both government and self-governing health professional regulatory colleges to set and enforce very high standards of professionalism when it comes to sexual misconduct by doctors – all doctors, regardless of the profession to which they belong. Concerns about college transparency and accountability in regard to sexual misconduct contributed significantly to major legislation in 2008 that strengthened BC's requirements in this area.

The Ministry applies the same policy to all colleges – no member of any college should have their spouse as a patient. The Ministry does not believe that dentistry should be treated differently from any other regulated health profession in this regard. The College of Physicians and Surgeons of BC has published informative statements that succinctly highlight the universal problems inherent in treating family members and failing to maintain sexual boundaries with patients, including the following points: 1) there is a power imbalance in the doctor-patient relationship; 2) sexualized behavior in the doctor-patient relationship is never acceptable; 3) a doctor cannot provide objective care when a sexualized relationship exists; 4) the fiduciary nature of the doctor-patient relationship makes a consensual sexual relationship between doctor and patient impossible.

The Ministry has only taken the position that spouses must not be patients, not that professionals are prohibited from treating their spouses regardless of circumstances. It is the responsibility of the college for each profession to provide guidance for its registrants as to what constitutes the establishment of a professional-patient relationship. In this case, the Ministry understands that the College has consistently communicated to its members that it is not the case that dentists may never treat their spouses. Instead, the real issue is whether or not there is a professional doctor-patient relationship established. The College advises it is approaching this issue from the perspective that every encounter with a patient is expected to be professional in nature, and has commenced a dialogue within the profession about what that means. It is up to each dentist to decide whether he or she can meet these expectations with each person that he or she treats, including family members.

... 3

The Ministry believes this approach is consistent with BC's health profession legislation, Ministry policy and College bylaws. The Ministry has no plans to change or allow exceptions to its current policy, which provides the College with limited but adequate discretion to give guidance to dentists about the circumstances in which dentists may treat their spouses. Similarly, the Ministry has no plans to interfere with the process the College is following to develop and promulgate a modern standard for defining the doctor-patient relationship within the profession of dentistry.

All colleges established or continued under the Act must comply with all applicable provisions of the legislation, and there is no exception or special consideration for dentistry in this regard.

Sincerely,



Christine Massey
Executive Director

pc: Honourable Michael de Jong, QC
Minister of Health

Dr. Bob Coles
President
College of Dental Surgeons of British Columbia

Dr. Hank Klein
President
British Columbia Dental Association

Page 34 to/à Page 35

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