

April 1, 2011  
Life Sciences British Columbia  
Draft Meeting Notes/Actions Required  
Updated April 8

**Attending**

LSBC: Don Enns; David Hall; Doug Janzen; Simon Pimstone

Ministry of Health: John Bethel; Bob Nakagawa; Woody Turnquist

**Summary of initial agenda topics**

Meeting began with agenda topics "Policy Landscape Review" (new Minister and Deputy Minister) and "Current Pharmaceutical Context" (drug review process and timelines and Canada-European Union patent and data protection issues). LSBC was updated on recent changes at Ministry of Health, and provincial considerations regarding federal Intellectual Property negotiations were discussed. No Action Items from these agenda topics.

**"PharmaNet – current and future use"**

This was an extension of a previous discussion regarding LSBC's assessment of the unique value of PharmaNet and BC's linked data bases in potentially establishing BC as a global centre for clinical research.

The Ministry has interest in discussing this topic further, provided that PharmaNet data is used only on an aggregate basis, with no disclosure of any personal or individual information.

LSBC believes there are two opportunities to drive revenue, without compromising privacy:

1. Gathering health outcomes data through post-marketing surveillance/patient studies in British Columbia;
2. Sale of aggregate data from BC's Health data bases

**Action Item**

Organization Responsible	Action
Ministry	Generate a high-level summary of the data fields available
Ministry	Include Elaine McKnight in next LSBC meeting

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**"Innovation Agenda"**

Two case studies were presented to illustrate obstacles that local innovative companies face when trying to get their new technology assessed and potentially utilized by the health system.

Ensuing discussion included overview of Leadership Council approach for a joint review/decision process for adopting new technology/systems among Health Authorities.

**Action Item**

Organization Responsible	Action
Ministry	At next LSBC/Ministry meeting, John Bethel to provide an update regarding provincial Health Authorities' Health Technology Assessment program.

**Next Meeting**

- Tentatively scheduled for Wednesday June 8; 8:00 – 11:00 am (Vancouver) to be confirmed

**Draft Agenda items**

**E-Health**

- Mobile (remote applications; home health monitoring)
- Government priorities
- Appropriate 'receptor' (i.e. mechanism or gateway)

**HTA update**

**PharmaNet/BC's Health Databases**

- Review of data fields summary

*Further agenda detail as determined/available*

June 8, 2011  
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Updated June 14

**Action Item**

<b>Organization Responsible</b>	<b>Action</b>
Ministry  Woody Turnquist	In conjunction with LSBC, organize a half-day meeting for discussion of topics related to potential receptor entity/mechanism for a Provincial Innovation Review/Assessment Process  <b>Date: Thursday July 14, 1:00 – 4:00 pm</b> <b>Location: Ministry of Health, Victoria</b>

Following a short break, there was further discussion on the HTA process as it now exists.

LSBC characterized the current HTA process as more relevant to technology than innovation and stressed that we still need to create an environment for innovation to be reviewed.

It was suggested that a meeting be set with LSBC, Elaine McKnight and Barry Rivelis (Chief Information Officer, Provincial Health Services Authority) and Philip Barker (VP, Information Management, Fraser Health Authority) for a more detailed review of current HTA process, including how it might be enhanced.

**Action Item**

<b>Organization Responsible</b>	<b>Action</b>
Ministry  Woody Turnquist	Set a two-hour meeting with LSBC; Elaine McKnight, Barry Rivelis and Philip Barker to discuss the HTA process and look at how the process might be enhanced.  <b>Thursday, July 7, 2:00 – 4:00 pm</b> <b>Meeting Room A, 7th floor, 1380 Burrard Street, Vancouver</b>

**BC's Health Databases**

Following April 1, 2011 meeting, a summary of BC's health databases was provided to LSBC. However, as there was no ability to link information from the various databases together, it was difficult to really assess the value of the data through the information provided.

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Bob Nakagawa indicated there have been external reviews conducted of BC Databases and offered to provide a list of 5 such reviews

**Action Item**

Organization Responsible	Action
Ministry/  Bob Nakagawa	Bob to provide a list for LSBC (with links if possible) of external reviews of BC Health Databases. Date: ASAP

**Global Approach to Innovation – June 22, 2011 luncheon**

LSBC confirmed they are sponsoring event and have sent luncheon invitations to Health Minister De Jong and Jobs, Tourism and Innovation Minister Bell.

John Bethel and Elaine McKnight indicated they would mention event to Minister De Jong and encourage him to attend if possible.

**Action Item**

Organization Responsible	Action
Ministry  John Bethel Elaine McKnight	Remind Minister De Jong of June 22 Global Approach to Innovation luncheon

**Canada-European Union Trade Agreement**

Ministry executive indicated that this issue falls under Federal authority and that the Province has not been asked for a position by Federal officials. They further noted there is significant pressure for endorsement from both sides of this debate and that BC will not be taking a position. Ministry did agree to include LSBC support in any briefing regarding the brand drug industry's position.

June 8, 2011  
Life Sciences British Columbia  
Draft Meeting Notes/Actions Required  
Updated June 14

**Attending**

LSBC: Don Enns; David Hall; Doug Janzen; Simon Pimstone

Ministry of Health: John Bethel; Bob Nakagawa; Elaine McKnight; Katelyn Ranger (job shadowing Elaine); Woody Turnquist

**Summary of Action Items from this Meeting**

Organization Responsible	Action
Ministry Woody Turnquist	In conjunction with LSBC, organize a half-day meeting for discussion of topics related to potential receptor entity/mechanism for a Provincial Innovation Review/Assessment Process  <b>Date: Thursday July 14, 1:00 – 4:00 pm</b> <b>Location: Ministry of Health, Victoria</b>
Ministry Woody Turnquist	Set a two-hour meeting with LSBC; Elaine McKnight, Barry Rivelis and Philip Barker to discuss the current HTA process and look at how the process might be enhanced.  <b>Thursday, July 7, 2:00 – 4:00 pm</b> <b>Meeting Room A, 7th floor, 1380 Burrard Street, Vancouver</b>
Ministry Bob Nakagawa	Bob to provide a list for LSBC (with links if possible) of external reviews of BC Health Databases.  <b>Date: ASAP – sent to Don Enns June 22</b>
Ministry John Bethel Elaine McKnight	Remind Minister De Jong of June 22 Global Approach to Innovation luncheon

**Summary of Agenda Topics**

**Provincial E-Health Strategy**

An overview of the Provincial E-Health Strategy was provided, including Provincial priorities (Chronic Obstructive Pulmonary Disease; Congestive Heart Failure; Diabetes) with description of several initiatives that lay the foundation for the Strategy (Provincial Laboratory Repository; Diagnostic Imaging; E-Prescribing).

LSBC members cautioned that while these initiatives are absolutely necessary, the “cubes of data” being gathered are only the foundation and that innovation will be in the applications created to help physicians actually use the data, not in the “data cubes” themselves.

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**BC Health Authorities Health Technology Assessment Process**

An overview of the BC Health Authorities Health Technology Assessment (HTA) Process was provided, including the steps that will be undertaken to review items brought forward. The following discussion touched a number of points, including:

- New HTA process focuses on medical equipment, processes and systems and specifically excludes pure Information Technology (IT) projects;
- The need still exists for a formalized entity for the review and dissemination of innovative IT-based projects
- LSBC stressed that if there was a process properly established and communicated, entrepreneurs would build application that would require BC data to validate
- Government should establish a fee schedule for such projects brought forward, including a project review cost and ongoing licensing fees

Further discussion narrowed the issue to the following concepts:

- How do we create systems that allow innovative technologies to be tested?
- How do we generate revenue from the platforms that may be created?
- How do we proactively communicate government priorities to potential innovators?

It was suggested that the next step may be to create a Working Group to fully think through a potential business model, including potential organizational and political challenges and a thorough risk assessment.

It was determined that, at this time, some more informal discussion would be appropriate. A half-day "no risk" session (i.e. confidential discussion, nothing binding, no external provision of information) was agreed upon that would focus on issues such as:

Clearly describing 'what it is' – the opportunity and the infrastructure required to access the opportunity

- The steps required to develop the needed infrastructure
- Who would be the potential customers of such an initiative
- Level of revenue that could be generated through such an initiative
- The challenges and risks associated with the project

Desired outcome from half-day discussion would be detail required to generate a short (5 pages?) Summary Concept Paper

## **Amos, Deanna M HLTH:EX**

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**From:** Amos, Deanna M HLTH:EX  
**Sent:** Wednesday, November 16, 2011 3:41 PM  
**To:** Campbell, Alana HLTH:EX  
**Cc:** Norman, Chris HLTH:EX; Murdock, Melissa HLTH:EX; Jennings, Phil CITZ:EX  
**Subject:** FW: Assistance Requested - Deputy Minister's Multilateral Stakeholder Session - December 1 (and December 5 follow up)  
**Attachments:** 904264 LSBC - Issue 3 Access to Database.pdf; LSBC June 8\_ Meeting Notes\_draft.docx; Meeting Notes\_July 14\_Ministry\_LSBC.docx

Further update: I'm checking with Carrie to see if there are any other meeting notes available from her area. Janet and I are having some difficulty locating the BN I mentioned but hopefully we'll locate it. From what I can gather on the matter, they're really pushing for access to BC's health data for Industry and are even proposing sale of aggregate data from BC's health databases. Please read the meeting notes that Woody provided in conjunction with the info Phil provided as background to Bob & Phil's meeting in April.

Thanks!

D.

**Deanna Amos**  
Sr. Research Methodology Analyst  
Ministry of Health  
250.952.1281

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**From:** Amos, Deanna M HLTH:EX  
**Sent:** Wednesday, November 16, 2011 2:49 PM  
**To:** Campbell, Alana HLTH:EX  
**Cc:** Jennings, Phil CITZ:EX; Norman, Chris HLTH:EX; Murdock, Melissa HLTH:EX  
**Subject:** RE: Assistance Requested - Deputy Minister's Multilateral Stakeholder Session - December 1 (and December 5 follow up)

Alana,

I was unable to locate any CeRTS file on this matter and the meeting w/Bob & Phil has been the only action re: Life Sciences BC by our area. I contacted Carrie Daniels who is organizing the BN's for the DM. Carrie provided the Issue 3 Access to Database pdf document to me (which I have included here). Woodie Turnquist is no longer involved in any discussions with LSBC but provided additional meeting notes (see attached Word docs). He suggests that if there have been any further discussions with LSBC, Nikki Sieben's group would have been involved.

Nonetheless, the issue here is that the DM will be meeting one on one with LSBC on December 1<sup>st</sup> and LSBC sent us the ministry a note (the PDF Carrie provided) and our area needs to be able to give the DM's response to LSBC's request: "To convene a 'blue ribbon' panel comprised of academia, industry, legal, privacy and other stakeholder groups to examine the possibility of permitting access to health linked databases and report back to the Ministry in the second quarter of 2012".

There is a BN re: Proposed Western Canada Life Sciences Partnership Fund from 2010 which is likely unrelated but Janet is trying to locate a copy of the BN.

Woodie is available for questions regarding what he's provided. Carrie is available as well. I haven't been in touch with Nikki but Carrie indicates that Nikki is also available if we have any questions.

Let me know if there're any next steps here.

D.

**Deanna Amos**  
Sr. Research Methodology Analyst  
Ministry of Health  
250.952.1281

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**From:** Campbell, Alana HLTH:EX  
**Sent:** Wednesday, November 16, 2011 8:16 AM  
**To:** Amos, Deanna M HLTH:EX  
**Subject:** FW: Assistance Requested - Deputy Minister's Multilateral Stakeholder Session - December 1 (and December 5 follow up)

Hi Deanna,

Will you please check in CERTS and see if you can find anything that may relate to the info below?  
Chris may end up asking for a BN, so the more info we can find the better.  
Thanks!

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**Alana Campbell** | Senior Health Information Advisor  
Ministry of Health  
250.952.2317

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**From:** Jennings, Phil CITZ:EX  
**Sent:** Tuesday, November 15, 2011 12:45 PM  
**To:** Norman, Chris HLTH:EX; Murdock, Melissa HLTH:EX; Campbell, Alana HLTH:EX  
**Cc:** Fech, Toni-Lynn HLTH:EX  
**Subject:** RE: Assistance Requested - Deputy Minister's Multilateral Stakeholder Session - December 1 (and December 5 follow up)

This may be related to what Woodie Turnquist was doing some initial discussions with Bob and I back in April. See attached notes and attachments on the calendar notice. Bob may have a Certs number for this and possibly more information but I don't access Certs so someone else would need to check. The discussions with me were high level and no "promises" were being made according to Woodie at that time.

Shalom  
Phil Jennings  
Lead Director,  
Strategic Policy and Information Management,  
Strategic Policy, Information Management and Data Stewardship  
Health Sector Information Management and Technology Division  
Ministry of Health  
Suite 2-02 1515 Blanshard Street  
Victoria, BC  
V8W 3C8  
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cell (250) 588-0530

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**From:** Norman, Chris HLTH:EX  
**Sent:** Tuesday, November 15, 2011 9:09 AM  
**To:** Murdock, Melissa HLTH:EX; Campbell, Alana HLTH:EX; Jennings, Phil CITZ:EX  
**Cc:** Fech, Toni-Lynn HLTH:EX  
**Subject:** FW: Assistance Requested - Deputy Minister's Multilateral Stakeholder Session - December 1 (and December 5 follow up)  
**Importance:** High

Does anyone have any idea what the LSBC – Database Access topic is (for which we have to prepare a BN for next Tuesday)?

**Chris Norman**  
*Chief Data Steward and Executive Director,  
Strategic Policy and Information Management  
Health Sector IM/IT  
Ministry of Health  
Email: [chris.norman@gov.bc.ca](mailto:chris.norman@gov.bc.ca)  
Ph: (250) 952 1822  
Cell: s.17*

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**From:** Somner, Kurstie HLTH:EX  
**Sent:** Tuesday, November 15, 2011 8:56 AM  
**To:** Shrimpton, Paul HLTH:EX; Norman, Chris HLTH:EX  
**Cc:** Shields, Lindsay HLTH:EX; Kislock, Lindsay M HLTH:EX; Fech, Toni-Lynn HLTH:EX; Clifford, Katherine HLTH:EX  
**Subject:** Assistance Requested - Deputy Minister's Multilateral Stakeholder Session - December 1 (and December 5 follow up)  
**Importance:** High

Good morning,  
Heads up that formal assignments for the following will be coming your way shortly and will be due to our office by Friday. Thanks!

"In the interim, there are background BNs that the Deputy Minister will need for two issues for these bilateral meetings. Elaine suggested that your area is best prepared to develop these BNs.

Two official cliff requests are being sent your way. They are for:

- BCPhA – e-Health only (Issue #1 in the enclosed 3 Issues Note)
- LSBC – Database Access

In the interim, I wanted to send you this information as soon as possible so that your staff can begin preparing the required responses.

The deadline for these notes is November 22, 2011."

Kurstie Somner | Manager, Divisional Operations  
Health Sector IM/IT | Ministry of Health  
Ph: 250.952.2162 Fx: 250.952.2109 | 5-1, 1515 Blanshard St. Victoria BC V8W 3C8

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**From:** Daniels, Carrie HLTH:EX  
**Sent:** Mon, November 14, 2011 10:27 AM  
**To:** Kislock, Lindsay M HLTH:EX  
**Cc:** Somner, Kurstie HLTH:EX; Harapiak, Marcelle HLTH:EX; Partington, Nicole HLTH:EX  
**Subject:** Assistance Requested - Deputy Minister's Multilateral Stakeholder Session - December 1 (and December 5 follow up)  
**Importance:** High

Good morning Lindsay,

It was a pleasure speaking with you following the Deputy Minister's town hall meeting last Wednesday.

As discussed, Elaine McKnight would like you to attend a few meetings related to the Deputy Minister's Multilateral Stakeholder Session in Vancouver. They are as follows:

- November 30 – Dinner with the Deputy Minister and Key Note Guest Speaker Will Falk in Vancouver
- December 1 – 8:00 am – 2:00 pm – DM Multilateral Stakeholder Session at the Fairmont Hotel Vancouver – (optional)
- December 1 – 2:30 – 5:30 pm – DM Bilateral Meetings with Key Stakeholders at the Fairmont Hotel Vancouver – these are the meetings Elaine mentioned
- December 1 – 6:00 pm – Dinner to debrief Bilateral Meetings (optional)
- December 5 – 10:00 – 11:30 am – DM Bilateral Meeting with Life Sciences BC (this is the final PSD stakeholder meeting for this event)

These meeting notices have been sent to you and/or your administrative staff.

In the interim, there are background BNs that the Deputy Minister will need for two issues for these bilateral meetings. Elaine suggested that your area is best prepared to develop these BNs.

Two official cliff requests are being sent your way. They are for:

- BCPHA – e-Health only (Issue #1 in the enclosed 3 Issues Note)
- LSBC – Database Access

In the interim, I wanted to send you this information as soon as possible so that your staff can begin preparing the required responses.

The deadline for these notes is November 22, 2011.

If you have any questions whatsoever, please feel free to contact me directly. My Executive Director Nikki Sieben is also available for your questions.

Kind regards,  
~Carrie

Carrie M. Daniels, MPA | Manager, Stakeholder Relations | Stakeholder Relations and Transformation Branch | Planning and Innovation Division | Ministry of Health | Ph: 250.952.3599 | BB: s.17 Fax: 250.952.2788

## **Amos, Deanna M HLTH:EX**

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**From:** Norman, Chris HLTH:EX  
**Sent:** Wednesday, November 16, 2011 8:56 PM  
**To:** Amos, Deanna M HLTH:EX  
**Cc:** Campbell, Alana HLTH:EX; Murdock, Melissa HLTH:EX; Jennings, Phil CITZ:EX; Fech, Toni-Lynn HLTH:EX  
**Subject:** BN

Hi Deanna

So we need you to start shelling out the BN – and get the key information into that note. And then you need to liaise with Phil to ensure that, from his perspective and with this additional information he might have, you have included the key information.

Alana, you need to supervise this and ensure that what I get by mid-afternoon is ready for me to begin the finalizing process.

I think there is mostly the information we need to cover the background and much of the discussion, and I will try to get more information to help to finalize the recommendations section during the day (from Lindsay, Danielle, and others). I have sent a note to Lindsay and have spoken with Danielle already late this afternoon so I think we have some if not most of what we need – just some key pieces of the puzzle to get yet and then we should be ok.

Thanks for making this a priority – this has to be finalized, formatted and to the ADM's office by Friday.

c

**Chris Norman**  
*Chief Data Steward and Executive Director,  
Strategic Policy and Information Management  
Health Sector IM/IT  
Ministry of Health  
Email: [chris.norman@gov.bc.ca](mailto:chris.norman@gov.bc.ca)  
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## **Meeting with Phil Jennings**

### Background

Over the past several months we have been meeting with a particular stakeholder group, Life Sciences British Columbia (LSBC) on a number of topics. LSBC is an association that represents the biopharmaceutical, medical device, and greater life sciences community of BC.

Recent discussion has been focused on innovation and health-related economic development opportunity, including LSBC's vision of BC as a global centre for health research. The value of BCs databases and the role that aggregate data can potentially play in generating such economic development has been part of these discussions.

In November 2010 these topics were brought forward in a bi-lateral meeting with the Deputy Minister. Current Ministry lead participants in these discussions are John Bethel and Bob Nakagawa. Elaine McKnight is confirmed to participate in our next meeting.

### Reason for meeting with Phil

At a meeting last week, LSBC was asked for more detail about their proposed approach to accessing and utilizing aggregate data – essentially how they might see things working.

In response they said they need a better understanding of what data is being captured and asked if they could be provided with a 'high level summary of data fields available'. John and Bob indicated we would try and provide them such a summary.

I've been tasked with looking into getting a summary of available data fields and have been referred to Phil by Darlene Therrien.

Hope this helps

## **Amos, Deanna M HLTH:EX**

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**From:** Campbell, Alana HLTH:EX  
**Sent:** Thursday, November 17, 2011 12:50 PM  
**To:** Norman, Chris HLTH:EX; Jennings, Phil CITZ:EX  
**Cc:** Amos, Deanna M HLTH:EX  
**Subject:** LSBC data disclosure

Chris and Phil,

I think you both hit a fundamental question when we spoke – is this research or evaluation or something else? Because ultimately the disclosure has to comply with *FIPPA*, *PODSA* etc, so there must be a clear determination of what the disclosure falls under.

If the disclosure is aggregate so that the data does not include “personal information”, then the disclosure could fall under Part 2 of *FIPPA*. However, disclosure under Part 2 is prohibited if it is harmful to the business interests of a third party. There are lots of decisions of commercial parties successfully opposing disclosure under this section by arguing that it would result in a financial loss (or competitive position) to them or a financial gain (or competitive position) to a competitor.

So it could lead to a situation of MoH having to deal with a bunch of reviews by the OIPC due to competing companies opposing disclosure to their market rivals.

If the data will contain “personal information” then we need to clearly determine what section the disclosure falls under – as you said Chris, evaluation (s. 33.1 or 33.2) or research (s. 35)?

If the disclosure is for research, there are decisions stating that there must be a system in place to ensure the disclosure is in the public interest, specifically that the disclosure is reasonable and proportionate to the possible public benefit. These decisions say that to ensure the disclosure is in the public interest, and therefore meets the requirements of s. 35(1)(b) of *FIPPA*, research proposals must be approved by an ethical review committee at a public post-secondary institution. The decisions suggest that if for some reason a public post-secondary ethical review committee is not available to approve (for example for disclosure to an entity not affiliated with a university or for disclosure to a government body) that the government should establish a similar, independent committee to perform this function.

I don't know the answer, but would LSBC and pharmaceutical companies have difficulty affiliating themselves with universities in order to get their ethical review committees to review and approve the research? If not, the government could end up in a situation of having to put in resources to establish an independent committee.

If PharmaNet data is included, *PODSA* specifically prohibits disclosure for market research. Regardless of the positive spin being presented, MoH should be prepared for challenges to the disclosures by interest groups because of the involvement of LSBC and pharmaceutical companies.

I know you want to keep things positive and supportive Chris, so you may decide that we shouldn't raise these issues in the BN, but I thought I should mention them as possible considerations.

Regardless of what specific considerations we include in the BN, I think we should suggest that government clearly articulate its position, even if the position is that the matter is being considered, to help avoid the situation of LSBC and private entities leading the agenda.

**MINISTRY OF HEALTH SERVICES  
INFORMATION BRIEFING NOTE**

**Cliff #904264**

**PREPARED FOR:** Graham Whitmarsh, Deputy Minister - **FOR INFORMATION**

**TITLE:** Bi-Lateral Meeting with Life Sciences BC (part of the Deputy Minister's Annual Multilateral Stakeholder Engagement Session on December 1, 2011)

**PURPOSE:** To provide information on Life Sciences BC Issue #3 – *Approaches to Access of Provincial Health Integrated Databases(s)*

**BACKGROUND:**

Life Sciences BC is an industry-funded association that supports and represents the life sciences community (from biopharmaceuticals and medical devices, to bioproducts and bioenergy, forest, agricultural and marine biotech). Life Sciences BC undertakes programs and projects in support of these sectors. In discussions with the Ministry of Health (the Ministry), Life Sciences BC has raised the value of BC's health data in supporting an innovation and change agenda that would produce health benefits and generate revenues. The issue of utilizing BC health data to support this agenda has been discussed at several meetings during 2011 with senior Ministry of Health staff, including April 1, June 8 and July 14 and is profiled in an Issue Note produced by Life Sciences BC for the Bi-Lateral stakeholder meeting.

Life Sciences BC contends that "academia has had access to the data rich environment on a selective basis but industry has not been granted any form of access largely because of real and perceived ethical issues". Life Sciences BC states that these ethical issues have been satisfactorily addressed in other Canadian jurisdictions and suggests that this puts BC at a collaborative disadvantage. Life Sciences BC has identified two opportunities to derive revenue from health data: 1) gathering health outcomes data through post-marketing surveillance and/or patient studies and 2) sale of aggregate data from BC's health databases. Life Sciences BC requests that we convene a 'blue ribbon' panel comprised of academia, industry, legal, privacy and other stakeholder groups to examine the possibility of permitting access to health linked databases and report back to the Ministry in the second quarter of 2012.

**DISCUSSION:**

Health data is a core resource that supports the primary purposes of direct health care delivery and health governance, including monitoring, planning and evaluation. However, it is seen by some stakeholders (such as Life Sciences BC) as having tremendous untapped potential in pursuing population and public health outcomes, and deriving unrealized market value. Other stakeholders, because of its unique sensitivity, view health data as needing special care and protections from secondary uses, especially by industry. In addition to supporting health care, health data is heavily valued and utilized for academic health research.

The collection (creation), use and disclosure of this data for health service and research is governed by a number of relevant statutes and associated policies, including but not limited to the *Freedom of Information and Protection of Privacy Act* (FOIPPA) and *Pharmacy Operations and Drug Scheduling Act* (PODS). These provisions provide the framework and rules for health data use and in some cases provide explicit direction, such as the current prohibition under PODS against direct access to PharmaNet data by industry for market research. The current legislative landscape for health data is complex and unique and therefore Life Sciences BC's reference to "solutions" in other jurisdictions would need careful analysis to determine their applicability.

The Ministry provides significant support to academic research, including recent partnerships with the University of British Columbia (through Population Data BC) to expedite research initiatives through more timely access to health sector data. The Ministry also sponsors evaluation and planning projects and initiatives (sponsored research) to support an innovation and change agenda for health. Furthermore, detailed discussion with Life Sciences BC would help to determine if the industry they represent has adequately utilized the existing data access opportunities available to them. Population Data BC's Secure Research Environment contains linked and linkable data sets (most of the major Ministry data holdings, with plans to include PharmaNet data) that are de-identified and accessible to external users, while protecting the security and privacy of these sensitive holdings. Academic research methodologies and ethics approvals could help to address some of the ethical and privacy issues raised in Life Sciences BC's Issues Note.

While Life Sciences BC identifies that their industry's primary interest is in aggregate data, their proposals speak to the value of data linking opportunities, which would not normally be contemplated with aggregate data. Further considerations of the Life Sciences BC proposals would need to include, at a minimum, a much clearer understanding of the kinds and purposes of the linkages contemplated, the levels of access actually needed by industry, and the intended short and longer term uses and disclosures. It is important to note that even if an industry's proposed access is to aggregated data only, once data linkages or data mining are involved, there is a high risk of re-identifying the data. This is especially true if the data is linked with other non-health personal data that may be available on the data purveyance market.

#### **RECOMMENDATION:**

Continue engagement with Life Sciences BC but focus on putting much more shape and detail to the broad ideas and concepts initially identified, and also including discussion of utilizing existing avenues and mechanisms for accessing data, such as that provided by the Ministry through Population Data BC. With respect to the "blue ribbon" panel, discussions could include utilizing existing forums for developing these ideas, such as the Data Stewardship Committee, chaired by Dr. Bruce Carleton, Director, BC Children's Hospital and Professor, UBC, and including representatives from the public, the health sector, health sector professions, and academia. Further discussions would also clarify more what the revenue-generating opportunities mentioned by Life Sciences BC.

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**Program ADM/Division:** Lindsay Kislock, Health Sector IM/IT

**Telephone:** 250 952-2791

**Program Contact (for content):** Chris Norman, SPIMDS

**Drafters:** Deanna Amos/Chris Norman, November 18, 2011



## **MINISTRY OF HEALTH PREPARATION NOTES**

**PREPARED FOR:** Chris Norman, Executive Director - **FOR INFORMATION**

**TITLE:** Blue Ribbon Panel proposal and the Data Stewardship Committee

**PURPOSE:** To inform the Chair of the Data Stewardship Committee (DSC) about the opportunity to align the Ministry's commitment to form a "Blue Ribbon Panel", with an enhanced role for the DSC

### **BACKGROUND:**

Life Sciences BC (LSBC) is an industry association that represents biopharmaceuticals and medical devices, bioproducts and bioenergy, forest, agricultural and marine biotech. The term "life sciences" began as a relabelling by Industry Canada in 1999, of what was previously known as "Biotech/Pharma".

LSBC undertakes activities in four strategic areas:

1. active facilitation of investment and partnering,
2. advocacy and public policy development,
3. industry marketing, and
4. programs around mentoring, education and networking.

LSBC contends that "academia has had access to the data rich environment on a selective basis but industry has not been granted any form of access largely because of real and perceived ethical issues". Life Sciences BC states that these ethical issues have been satisfactorily addressed in other Canadian jurisdictions and suggests that this puts BC at a collaborative disadvantage. Life Sciences BC has identified two opportunities to derive revenue from health data:

1. gathering health outcomes data through post-marketing surveillance and/or patient studies and
2. sale of aggregate data from BC's health databases.

### **DISCUSSION:**

In a letter to the Deputy Minister dated November 9, 2010, LSBC first proposed the creation of an "independent entity distinct from any political ideology whose mandate would be to generate objective economic evidence associated with health related innovation that would then lead to better health policy and reform". LSBC held a bi-lateral meeting with John Dyble on November 24, 2010, which led to several meetings during 2011 with senior Ministry of Health staff, including April 1, June 8 and July 14 with the progress made profiled in an undated Issue Note (November 2011) produced by LSBC for the Bi-Lateral stakeholder meeting.

Among the proposals brought forward by LSBC for Graham Whitmarsh's bilateral meeting held on December 1, 2011, the request that the ministry convene a 'blue ribbon' panel comprised of academia, industry, legal, privacy and other stakeholder groups to examine the possibility of permitting access to health linked databases and report back to

the Ministry in the second quarter of 2012” was favourably received. The deputy brought forward the suggestion that an option to explore would include utilizing existing forums for developing these ideas, rather than to create something from scratch. An example would be expanding the role of the Data Stewardship Committee.

While LSBC identifies that their industry’s primary interest is in aggregate data, their proposals speak to the value of data linking opportunities, which would not normally be contemplated with aggregate data. Further considerations of the proposals would need to include, at a minimum, a much clearer understanding of the kinds and purposes of the linkages contemplated, the levels of access actually needed by industry, and the intended short and longer term uses and disclosures. It is important to note that even if an industry’s proposed access is to aggregated data only, once data linkages or data mining are involved, there is a high risk of re-identifying the data. This is especially true if the data is linked with other non-health personal data that may be available on the data purveyance market.

**RECOMMENDATION:**

Chris Norman and Melissa Murdock have a teleconference scheduled with Dr. Bruce Carleton, Chair of the DSC, scheduled for December 13, 2011 to discuss proposed revisions to the DSC Terms of Reference, and matters relating to the upcoming DSC meeting in late January.

As part of the discussion with Bruce Carleton, this is a timely opportunity to inform him about the ministry’s commitment to convene the “blue ribbon panel”, and ask for his feedback on whether he can see this as a mutually beneficial alignment opportunity and enhancement of the DSC, and whether it would be the best place for the ongoing discussion to occur beginning at the January meeting.

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**Drafters:** Roger McGuire, December 12, 2011

# Data Stewardship Committee

## DRAFT Meeting Agenda

January 25, 2012  
11:00AM to 3:00PM  
Child and Family Research Institute  
A3 – 204  
950 West 28<sup>th</sup> Ave  
Vancouver, BC

Contact: Roger McGuire (250) 952-2465  
<mailto:Roger.McGuire@gov.bc.ca>  
Restricted SharePoint Site: <https://hlth004.gov.bc.ca/DSC/default.aspx>

Conference Call Number: 1-877-353-9184 Participant ID: 1121002

TIME	TOPIC	PRESENTER	Share Point Folder	ACTION ITEM
11:00-11:05	A. Introduction - Adoption of the Agenda	Bruce Carleton	A	Adopt
11:05-11:10	B. Conflict of Interest Declarations	Melissa Murdock	N/A	Document, if any
11:10-11:15	C. Approval of Minutes – October 26, 2011	Bruce Carleton	C	Approve
11:15-12:15	D. Data Stewardship Committee Role	Bruce Carleton	D	
	1. Life Sciences BC (Chris Norman - 5 mins)			
	2. Future role for DSC			Discuss, identify next steps
	a. Amalgamation (PSC/DSC)			
	b. Expanded DSC Scope			
12:15 – 12:45	LUNCH (PROVIDED)			
	E. Request To Contact Files	Melissa Murdock/ Cornel Lencar		

s.13, s.17

# Data Stewardship Committee

## DRAFT Meeting Agenda

TIME	TOPIC	PRESENTER	SHARE POINT FOLDER	ACTION ITEM
2:30- 2:50	F. Updates	Chris Norman	N/A	Update only
	1. Office of the Chief Data Steward			
	2. PharmaNet Stewardship Committee			
2:55	G. Next Meeting & Adjournment	Bruce Carleton	N/A	Confirm

**Next Meeting: March 8, 2012 (to be confirmed)**

**Minutes**  
**Data Stewardship Committee**  
January 25, 2012  
11:00 AM – 3:00 PM  
Room A3-205, Child & Family Research Institute  
Children's and Women's Health Centre of BC  
950 West 28<sup>th</sup> Avenue, Vancouver BC

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**In Attendance:**

**DSC Members**

Linda Boon	Member representing Nursing (by phone)
Bruce Carleton (Chair)	Health Researcher
Cam Egli	College of Pharmacists Member
Michael Epp	College of Physicians and Surgeons member
Lindsay Kislock	Ministry of Health Services Member
Bill MacDonald	Public Member

**Ex-Officio**

Chris Norman	Chief Data Steward, Ministry of Health
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**Data Stewardship Secretariat**

Cornel Lencar	Secretariat Support (by phone)
Roger McGuire	Secretariat Support (by phone)
Melissa Murdock	A/Director, Research Data

**Regrets:**

Colin Bennett	Member
Marc Pelletier	Health Authority Member
Robin Saunders	Member
Ted Taylor	Public Member

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Meeting called to order at 11:10am

**A. Adoption of the Agenda, Introductions**

- Agenda - Adopted
- Introductions – Cornel Lencar is the new Senior Health Data Request Officer in the Data Stewardship Secretariat, MoH.

**B. Conflict of Interest**

- Bruce Carleton declared that he knows Dr. Shiefele, but has no working relationship. No concerns of conflict expressed by members.
- No additional conflict of interest matters with other committee members
- Future conflicts, if any, to be disclosed to Secretariat one week in advance of meeting

- o Mitigation strategy to be determined in advance (i.e. excuse member from room during the planned discussion/decision, or restrict view of material etc.)

#### **C. Approval of Minutes dated October 26, 2011**

- Motion to Approve as distributed – Bill McDonald
- Seconded - Linda Boon.
- Carried.

**ACTION: Secretariat to modify Minute format, per Chair's instructions.**

#### **D. Future Role of the DSC**

##### Life Sciences BC:

- Chris Norman introduced this topic by providing first an overview of the Ministry's engagement with Life Sciences BC and their proposals for use of health data.
- Also raised were discussions between the Chair and the Ministry on the enhanced advisory role for the DSC.;
- Bruce Carleton emphasized the focus of Life Sciences discussions should be "What is the value to British Columbians?"
- Chair led discussion and invited feedback from DSC members;
- Lindsay Kislock - Data is an asset that we are not leveraging, MoH interested in outcomes, maybe the same, maybe different than Life Sciences;
- DSC Consensus - Invite Life Sciences to provide a 15 minute presentation at March 08, 2012 DSC meeting, followed by 45 minute open discussion.
- Secretariat to allot time in agenda for internal discussion post-Life Sciences item

#### **ACTION:**

- (1) Secretariat to draft the invitation letter for Chair's consideration.
- (2) Lindsay Kislock to review draft letter
- (3) Chair to send final invitation letter to LifeSciences BC.

#### **E. Request to Contact Files**

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s.13, s.17

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#### **ACTION:**

1. Final consent package will be provided to DSC for its records;
2. Final consent package will be provided to OIPC for its records.

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**DECISION:** The DSC approves the request to contact to a maximum of ten attempts to contact, and one successful contact. This ratio to be considered as a benchmark for future, similar requests.

**ACTION:**

1. Chair to Issue DSC approval letter to the researcher, **stating conditions of approval (i.e. OIPC, etc)**
2. Secretariat to forward package to the OIPC for final approval of this request to contact
3. MoH to administer data transfer

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**DECISION:**

The Data Stewardship Committee approves the request to contact subject to the following conditions:

- (1) the research team obtains updates from Vital Statistics prior to subsequent contacts of study participants;

- (2) yearly updates on the research team competence and ethics certificates;
- (3) data obtained from MoH and other data stewards pertaining to the request to contact and further linkages must not leave BC, and

s.13, s.17

**ACTION:**

1. Chair to issue DSC approval letter to the researcher, stating conditions of approval (i.e. OIPC, etc);
2. Secretariat to forward package to the OIPC for final approval of this request to contact;
3. MoH to administer data transfer

4

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s.13, s.17

**DECISION: Tabled.**

**F. Updates**

**Office of the Chief Data Steward**

- MOH and OIPC meetings to discuss process of administering requests to contact ongoing;
- OIPC in discussions with Population Data BC (UBC) on "Intake" (administrative) role for request to contact applications
- MOH to keep DSC apprised of these discussions

**G. Next Meeting**

- The next meeting of the Data Stewardship Committee will be held on March 8, 2012 at the Children's and Women's Health Centre.
- Meeting adjourned at 3:00pm.





Where ideas work

January 31, 2012

91958

Don Enns, President  
LifeSciences British Columbia  
Suite 900 – 1188 West Georgia St  
Vancouver, BC V6E 4A2

Dear Mr. Enns:

The Ministry of Health is interested in pursuing innovative ways to utilize the Province's health data for the benefit of all British Columbians. As Chair of the Data Stewardship Committee, I would like to invite you as a representative of LifeSciences British Columbia to meet with the Data Stewardship Committee on March 8, 2012 in Vancouver, BC to discuss further your ideas for maximizing the potential of the provincial data asset.

The Data Stewardship Committee is a public committee, providing a venue for engagement with a number of health sector stakeholders, including health care professionals, researchers, health authorities, and the general public. The Committee promotes transparency and accountability for various data access requests and decisions affecting health data stewardship in BC. The Committee looks forward to exploring future opportunities intended to advance patient outcomes and also to leverage new and existing data assets through innovation, technology, and research.

I would be pleased to discuss this invitation with you further. Please contact my administrative coordinator, Gabriella Groeneweg, at (604) 875-3609 to arrange a time to discuss at your convenience. Thank you in advance for consideration of this request, and I look forward to hearing from you.

Best Regards,

Dr. Bruce Carleton  
Chair, Data Stewardship Committee

# Data Stewardship Committee Meeting Agenda

Wednesday, April 25, 2012  
11AM to 3:30PM  
Child & Family Research Institute  
Room A3-205  
950 West 28<sup>th</sup> Avenue  
Vancouver, BC

Contact: Roger McGuire (250) 952-2465  
mailto:Roger.McGuire@gov.bc.ca  
Restricted SharePoint Site: <https://hlth004.gov.bc.ca/DSC/default.aspx>

Conference Call Number: 1-877-353-9184 Participant ID: 1121002

TIME	TOPIC	PRESENTER	Share Point Folder	ACTION ITEM
11:00-11:05	A. Introduction - Adoption of the Agenda	Bruce Carleton	A	Adopt
11:05-11:10	B. Conflict of Interest Declarations	Melissa Murdock	N/A	Document, if any
11:10-11:15	C. Approval of Minutes – January 25, 2012	Bruce Carleton	C	Approve
11:15-12:15	D. LifeSciences BC	Don Enns	N/A	Presentation
12:15 – 12:45	LUNCH (PROVIDED)			
12:45-1:30	LifeSciences BC (Con'd)	Bruce Carleton		Internal Discussion and Next Steps
1:30-1:40	E.			
		s.13, s.17		
1:40-2:40	F.			
		s.13, s.17		
2:40-3:10	G.			
		s.13, s.17		
3:10-3:25	H. Updates	Deb McGinnis	N/A	Update
	1. Office of the Chief Data Steward			
	2. PharmaNet Stewardship Committee			
3:25	I. Next Meeting & Adjournment	Bruce Carleton	N/A	Confirm

Next Meeting: May 30, 2012

**Minutes**  
**Data Stewardship Committee**  
April 25, 2012  
11:00 AM – 3:30 PM  
Children's and Women's Health Centre of BC  
Room A3-205, Child & Family Research Institute  
938 West 28<sup>th</sup> Avenue  
Vancouver BC

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**In Attendance:**

**DSC Members**

Colin Bennett	Member
Bruce Carleton (Chair)	Health Researcher
Cam Egli*	College of Pharmacists Member
Michael Epp	College of Physicians and Surgeons member
Lindsay Kislock	Ministry of Health Services Member
Bill MacDonald	Public Member
Marc Pelletier*	Health Authority Member

**Ex-Officio**

Deb McGinnis	Chief Data Steward, Ministry of Health
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**Data Stewardship Secretariat**

Cornel Lencar*	Secretariat Support
Roger McGuire	Secretariat Support
Melissa Murdock	A/Director, Research Data

**Regrets:**

Linda Boon	Member representing Nursing
Robin Saunders	Member
Ted Taylor	Public Member

\*By phone

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Meeting called to order at 11:10am

**A. Adoption of the Agenda, Introductions**

- BM approve the agenda, subject to additional item requested by the Chair. CB seconded – approved.
- Introductions – Deb McGinnis, new Acting Chief Data Steward.

**B. Conflict of Interest**

- None

**C. Approval of Previous Minutes**

- ME motioned to approve the January 25, 2012 minutes as distributed. Seconded by BM.

**DECISION: Carried.**

**D. LifeSciences BC**

- Don Enns provided an overview presentation on Industry access.
- Discussion ensued.

**ACTION:**

1. RM to draft 'Thank You' letter, and suggest specific data requests at future meeting.
2. MM will review previously rejected 'industry' applications and discuss with BC; will compile materials for future DSC meetings
3. CL will prepare review materials to inform DSC members accordingly

**E. Request to Contact Files**

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s.13, s.17

**DECISION:**

s.13, s.17

**F.**

s.13, s.17

**ACTION:**

1. MM/CL to prepare complete review package containing:
  - a. Legislative/policy background
  - b. Complete s.22 materials (consent forms, etc)
  - c. Province by Province table
2. Health Sector policy to be treated separately.

**G.**

s.13, s.17

**G.**

## **H. Updates**

### **Office of the Chief Data Steward**

- DM reported that the academic request queue is now down to its lowest level since 2003. The Ministry is committed to a 3 month review period.

### **PharmaNet Stewardship Committee**

- The new legislation comes into effect upon Royal Assent.
- The new DSC is expected to have a membership of 12, including the Chief Data Steward, who is a non-voting member.
- DM will keep members of the DSC informed re: membership

## **I. Next Meeting**

- May 30, 2012 at the Children's and Women's Health Centre.
- CB moved to adjourn. Seconded by BC. Carried.
- Meeting adjourned at 3:32pm.



Where ideas work

May 9, 2012

File Number: 928220

Mr. Don Enns, President  
LifeSciences British Columbia  
Suite 900 – 1188 West Georgia St  
Vancouver, BC V6E 4A2

Dear Mr. Enns:

Thank you for meeting with the Data Stewardship Committee and for your presentation on April 25<sup>th</sup>, 2012.

The Committee is exploring future opportunities that advance patient outcomes through the use of BC health data. As a next step it would be helpful to discuss more specific questions regarding industry access to health data. Is it possible for you to bring forward a specific proposal for data access to the Committee? A single proposal or up to three proposals would allow us to begin a more focused discussion on the issues surrounding industry access.

Please let me know if you can provide such example requests. I know there have been previous requests in the past that have been made to the Ministry; perhaps these could be a first step.

Thank you again for your engagement with the Committee, and we look forward to hearing from you.

Best Regards,

Dr. Bruce Carleton  
Chair

## REQUEST FOR MEETING ADVICE FOR DEPUTY MINISTER

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**CLIFF #:** 999840

**MEETING REQUEST DETAILS:** Life Sciences British Columbia

**Requestor:** Jason Lesage, Manager, Communications

**Location:** 900 – 1188 W Georgia St, Vancouver

**Proposed Timeline:** January 2014

### BACKGROUND:

1. Access to health care data for researchers
  - Data requests are administered by PopData. Fact sheet attached.
  - Data requests that include access to Pharmanet, Health Information Banks as per *eHealth Act* and requests for contact are adjudicated by the Data Stewardship Committee. Fact sheet attached.
  - All other data requests are adjudicated by the Ministry of Health. Fact sheet attached.
2. Life Sciences British Columbia's participation in BIO (the big international biotech conference held every year in the United States)
  - The BIO International Convention is the largest global event for the biotechnology industry and attracts the biggest names in biotech, offers key networking and partnering opportunities, and provides insights and inspiration on the major trends affecting the industry.
  - British Columbia Ministries have in the past participated in this conference (previous Minister of Health Michael de Jong in 2012).
  - The 2014 BIO International Convention is in San Diego, California: June 23-26, 2014
3. IT Innovation
  - The Ministry of Technology, Innovation and Citizens Services (MTICS) has the lead on IT Innovation for the Province.
  - MTICS is currently looking at ways to capitalize on information technology trends within the BC Public Sector that could facilitate increased commercialization activity within BC's High Tech Sector.

### ADM RESPONSIBLE:

Lindsay Kislock, ADM, Health Sector IM/IT

**RECOMMENDATION:** Yes

**IF YES - SHOULD MINISTRY STAFF ALSO ATTEND, AND IF SO, WHO?**

Lindsay Kislock, ADM and Kelly Moran, Executive Director, Health Sector IM/IT Division  
Heather Davidson, ADM, Planning and Innovation Division

**IF YES - WHAT MATERIALS WILL BE PREPARED?**

Data Stewardship Committee Fact Sheet, PopData Fact Sheet, Access to Health Data  
Fact Sheet

**APPROVED BY:**

**DATE:**