

**Data Stewardship Committee
Annual Report, 2011/2012**

Requirement to Report

This report is submitted in fulfillment of the requirements of Section 16(1) of the *e-Health (Personal Health Information Access and Protection of Privacy) Act*:

16(1) At least once each year, the data stewardship committee must report to the minister respecting

- (a) The activities of the data stewardship committee,
- (b) Information-sharing agreements entered into by an administrator under this Division, and
- (c) Any matter the minister requires.

2011/2012 Data Stewardship Committee Activities

a. Membership and Meetings

Four members were reappointed to the Committee, and Lindsay Kislock, Assistant Deputy Minister, replaced Elaine McKnight as the ministry representative.

The Committee met seven times during the reporting period, with one meeting held as a joint session with the PharmaNet Stewardship Committee.

No Information-sharing agreements involving Health Information Banks were entered into during the reporting period.

b. PharmaNet and Data Stewardship Committee Amalgamation

A number of planning sessions were held regarding the anticipated amalgamation of the PharmaNet and Data Stewardship Committees. The *Pharmaceutical Services Act* came into effect May 31, 2012, at which time the Committee's role expanded to include PharmaNet research data and requests for personally identifiable research data.

c. Collaboration with the Office of the Information and Privacy Commissioner

A Request to Contact process framework was established in collaboration with the Committee, the Ministry of Health, and the Office of the Information and Privacy Commissioner perspectives.

Four "Request to Contact" applications were considered during the reporting period by the Committee, and successfully recommended for approval by the Information and Privacy Commissioner.

d. Advisory Work – Policy Recommendations

The Committee welcomed the Ministry's of Health's request for two separate policy recommendations. The expectation is that in future, select ministry policy issues will be brought to the attention of the Committee in order to provide recommendation on policy creation or revision to existing policy.

e. Strategic Work – Health Planning, Health Benefits

During the reporting period the Committee dedicated thoughtful discussion to the widely anticipated *Data Effect Conference*, held in Vancouver BC, June 05, 2012, for which the Chair of the Committee was invited by Colin Hansen, MLA, as Keynote Speaker. The conference explored the opportunity and benefits in expanding access to the Province's health and demographic research data, while ensuring the protection of personal privacy. Going forward, the Committee shall play a role by providing strategic and stewardship recommendations regarding how research data is used and accessed in BC.

Next Steps

As I mentioned during my comments at the *Data Effect Conference* in June, I would like the Ministry of Health and the Data Stewardship Committee to work towards implementing a rapid response process for health data requests.

For non-patient level data requests (also known as non-record level data requests) which can be used to formulate a more fulsome investigation of a particular health planning issue, I suggest approvals/rejections or clarifications be provided to requestors within two weeks. For patient-level requests, a timeline of no more than 30 days should be the goal.

This is likely to require redirected Ministry resources to facilitate these improvements in data access. The benefits of this are that we can begin to formulate health system improvements in BC much more quickly.

The data holdings in BC are immense and an important resource for improving the health of British Columbians. Harnessing these data and the academic expertise that exists among requestors will contribute significantly to improving and preserving our health system.

Sincerely,



Dr. Bruce Carleton
Director, Pharmaceutical Outcomes Programme
BC Children's Hospital
Professor of Paediatrics, Population & Public Health, Pharmaceutical Sciences, Medical Genetics and Co-Chair, Division of Translational Therapeutics, Department of Pediatrics, University of British Columbia
Senior Clinician Scientist, Child & Family Research Institute
Vancouver CANADA