

Data Stewardship Committee Annual Report 2014

Requirement to Report

This report is submitted in fulfillment of the requirements of Section 16(1) of the *eHealth (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 (the Committee);
 - (b) Information-sharing agreements entered into by an administrator under this Division; and,
 - (c) Any matter the Minister requires.

2014 Data Stewardship Committee Activities

a. Membership and Meetings

During 2014, two members were reappointed to the Committee, two new members were appointed, and two members resigned from the Committee. Currently, there is one unfilled position on the Committee, that of Health Researcher for which the recruitment process is underway.

The Committee met ten times during the reporting period.

b. Research Requests for PharmaNet or a Health Information Bank data.

During the reporting period, the Committee approved a total of 21 new project requests for PharmaNet data and 44 amendments for past projects. The Committee rejected one research request for PharmaNet data in 2014.

In 2014, the Ministry of Health (the Ministry) and the Health Authorities agreed to consider requests from Health Authorities for research purposes using administrative data, under the framework established in the General Health Information Sharing Agreement. In accordance with the requirements of Section 26(1) of the *Pharmaceutical Services Act*, such requests for PharmaNet must be approved by the Committee. In 2014, five such research requests for PharmaNet data were received from the Health Authorities and approved by the Committee.

Two new Health Information Banks were established in 2014 by the Health Minister: the Client Registry System/Enterprise Master Patient Index and the Provider Registry. In accordance with the *eHealth Act*, access to these Health Information Banks must be approved through the Committee. In 2014, there was one request received for data from the Client Registry System; this request is currently under review.

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 and the Office of the Information and Privacy Commissioner. This framework is used to support research where direct contact with patients is required. Per the existing legislation and the established protocols, the Privacy Commissioner must approve all such requests in advance.

One Request to Contact application was considered during the reporting period by the Committee. The requestor was advised to modify the request before the Committee recommended it for approval to the Information and Privacy Commissioner.

In 2014 the Information and Privacy Commissioner met with the Committee to continue the dialog started in 2012 as well as to address several specific issues, including:

- Interest from the Committee in more participation in any future Health Data Research Roundtables
- Input from the Committee into the Office of the Information and Privacy Commissioner Special Report on Prescription for Legislative Reform and the Commissioners

d. Data Stewardship Committee Policies and Protocols

In order to ensure a consistent and transparent review process, the Committee adopted two new protocols in 2014 for addressing research requests for data from PharmaNet and/or Health Information Banks:

- Adjudication Process Protocol
- PharmaNet Review Process Protocol

e. Ministry of Health Agreements

The Ministry has entered into research agreements or administrative information sharing agreements for all academic and health authority research projects approved by the Committee in 2014.

Approval Wait Times

a. Academic Requests

Since June 2012, when the Committee became responsible for approving research requests for PharmaNet, work has continued by both the Committee and the Ministry towards improving the approval times for academic requests to PharmaNet data.

As it can be seen in Table 1 below, the median number of days for approval has been reduced from 316 days in 2010 to 68 days in 2014, and the maximum number of days for approval has been reduced from 746 days in 2010 to 232 days in 2014.

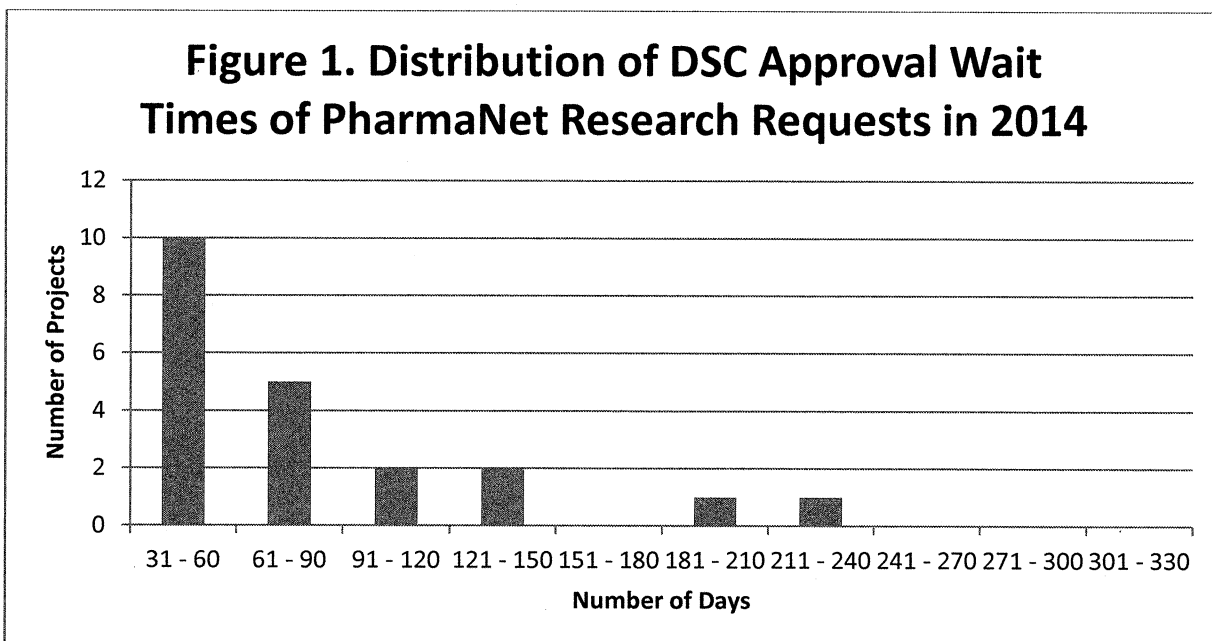
YEAR¹	# Received	# Approved	Min (days)	Max (days)	Median (days)
2010	20	20	31	746	316
2011	8	8	52	414	205
2012	7	6	36	125	56
2013	18	8	35	120	70
2014	13	21	35	232 ²	68

[1] The approval year was not necessarily the same as the submission year.

[2] Project 12-012 had a total approval wait time of 545 days out of which the project was on hold 357 days, making the active wait time 188 days long.

A more detailed picture of the approval times is depicted in Figure 1, which shows the distribution of projects based on the number of days to approve. The number of days to approval was calculated as the difference between the date when the Committee approval letter was issued and the day the application was received by the Ministry from Population Data BC.

In 2014, 48 percent of the approvals were adjudicated between 31 and 60 days and 24 percent were adjudicated between 61 and 90 days. The remaining projects represent those where modifications/clarification were needed to support the review process and/or where the Committee had specific issues that needed to be addressed prior to approval.



b. Health Authorities Requests

The Committee has received and approved five research requests submitted by Health Authorities. Procedures on how to streamline requests are still under development; the initial requestors did experience delays as the new program was launched. The Ministry will be working with Health Authorities in 2015 to ensure this new line of research is supported and data is provided in a timely manner.

The Committee looks forward to continuing to provide leadership and support for researcher access to health data and supports continuous improvement to make access as efficient as possible.

Sincerely,

A handwritten signature in black ink, appearing to read 'KM', with a long horizontal flourish extending to the right.

On behalf of the Data Stewardship Committee
Kelly Moran, Executive Director
Information Management and Knowledge Services Branch
Health Sector IM/IT Division
Ministry of Health