

Data Stewardship Committee Annual Report 2015

Requirement to Report

This report is submitted to fulfill 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 (the Committee);
 - (b) Information-sharing agreements entered into by an administrator under this Division; and,
 - (c) Any matter the Minister of Health (the Minister) requires.

2015 Data Stewardship Committee Activities

a. Membership and Meetings

In 2015, three members were reappointed to the Committee, three new members were appointed, and three members resigned from the Committee. Mr. William MacDonald was appointed the new Chair of the Committee in July 2015. Finally, the term for the member appointed at the pleasure of the Minister has come to an end. Currently, there is one unfilled position on the Committee, that of Ministry of Health (the Ministry) representative 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 48 amendments for past projects. The Committee rejected one research request for PharmaNet data in 2015. One research project was withdrawn by the researcher before being submitted to the Committee for adjudication.

In 2014, 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 (GHISA). 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 2015, one such research request for PharmaNet data was 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 were two request received for data from the Client Registry System; these requests have been approved in 2015 by the Committee.

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. The 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.

Two Requests to Contact applications were submitted to the Office of the Information and Privacy Commissioner by the Committee in 2015. The requests have been approved by the Privacy Commissioner and subsequently by the Committee.

In 2015 there were no meetings between the Committee and the Privacy Commissioner.

d. Data Stewardship Committee Policies and Protocols

No new policies or protocols were established by the Committee in 2015.

e. Ministry of Health Agreements

The Ministry has entered in research agreements or administrative information sharing agreements for all academic and health authority research projects approved by the Committee in 2015.

f. Other Activities

The Committee was engaged in 2015 by the Ministry and a Ministry service provider (Delaney & Associates) in a Stakeholder Engagement process for Developing a Health Information Management Policy Framework. All the members provided their personal input in the engagement process.

The Committee met in 2015 with representatives of Population Data BC (PopData) to discuss PopData's proposed Proportional Governance Framework.

Approval Wait Times for Research Requests

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. Prior to June 2012, research requests for PharmaNet data have been approved by the PharmaNet Stewardship Committee, which was dissolved in 2012 as a consequence of the *Pharmaceutical Services Act*.

Table 1 below shows the median number of days for approval. This has been reduced from 316 days in 2010 to 59 days in 2015, while the maximum number of days for approval has been reduced from 746 days in 2010 to 173 days in 2015. In 2015 project 15-024 was rejected 213 days after the request was submitted to the Committees' Secretariat.

YEAR ¹	# 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
2015	24	21 ³	26	173 ⁴	59

[1] The approval year was not necessarily the same as the submission year due to application date, review time, and DSC meeting times.

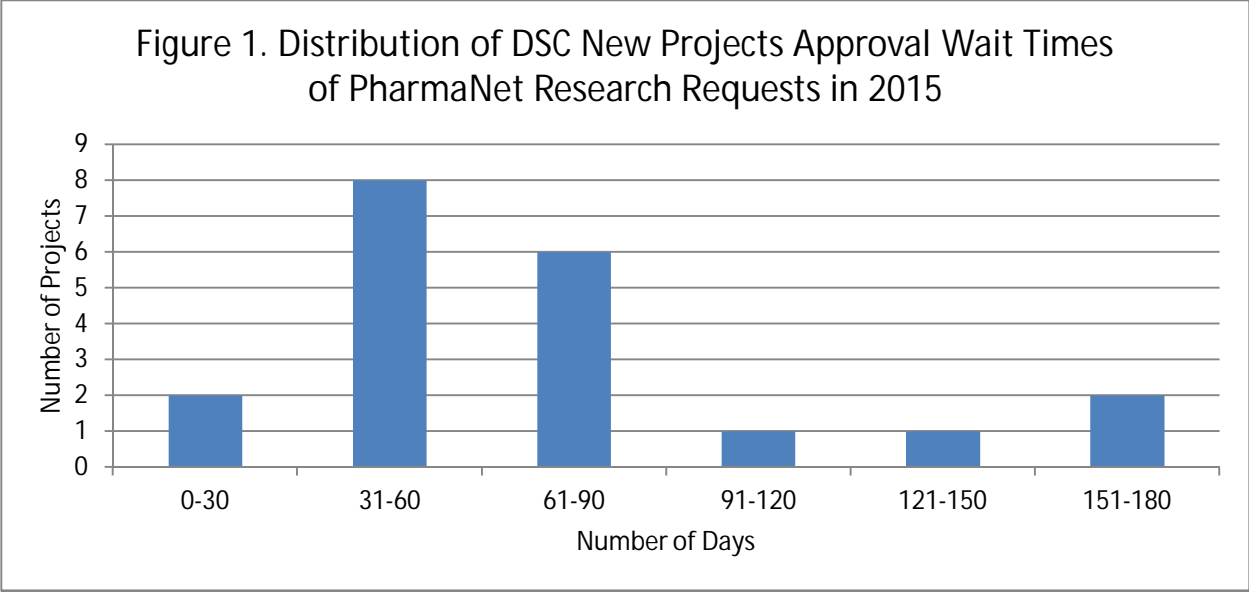
[2] Project 12-012 had a total approval wait time of 545 days out of which the project was on hold 357 days, making the active wait time 188 days long.

[3] Project 14-072 was a Health Authority research project and was included as a count. However, the timelines were not included since the review process involved a different approach from the regular academic requests. The approval time for this project was 213 days.

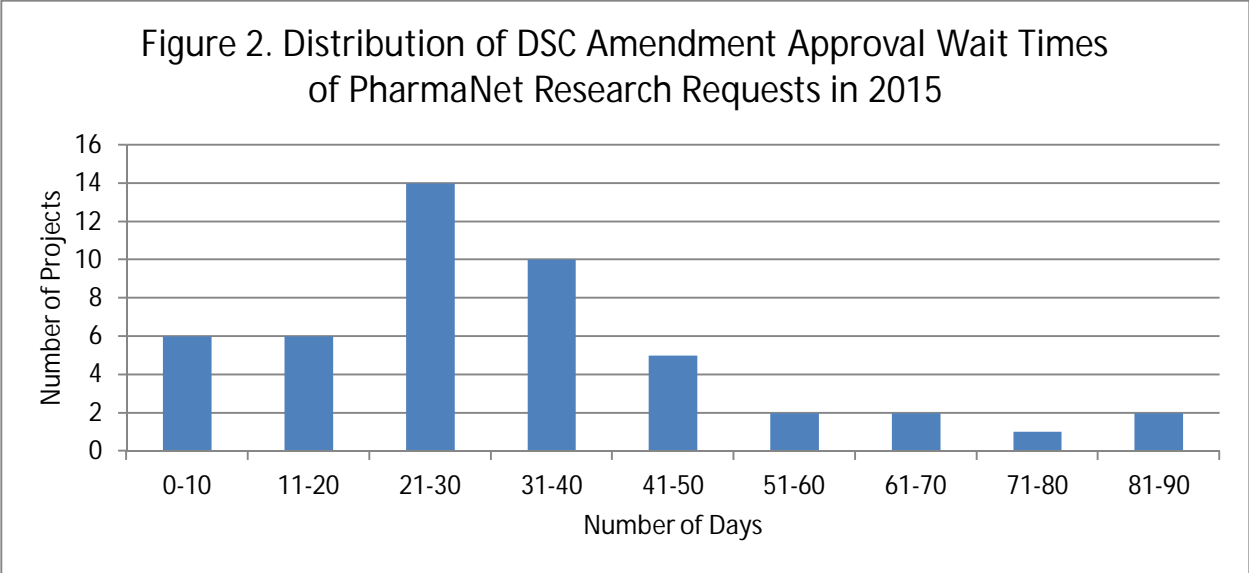
[4] Projects 14-113 and 14-131 also involved approval by the OIPC Privacy Commissioner for Requests to Contact, which increased the approval time to 173 and 167 days respectively and carried them into 2015.

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 PopData BC.

In 2015, 50 per cent of the new academic approvals were adjudicated between 0 and 60 days and 30 per cent were adjudicated between 61 and 90 days. The remaining projects represent projects where modifications/clarification was needed to support the review process, or where the Committee had specific issues that needed to be addressed prior to approval, or required the Office of the Information and Privacy Commissioner approval.



As depicted in Figure 2, in 2015 there were a total of 48 amendments for existing projects that were approved by the Committee. The median approval time for the amendments was 28 days, while the minimum number of days was 2 and the maximum number of days for an amendment approval was 86. In 2015, 55 per cent of the amendment approvals were adjudicated between 0 and 30 days and 35 per cent were adjudicated between 31 and 60 days. The remaining 10 percent of amendment requests with approval times between 61 and 90 days represent requests where modifications/clarifications were needed to support the review process.



b. Health Authorities Requests

The Committee has received and approved one research request submitted by Health Authorities. The approval time for this project was 213 days. Procedures were still under development and the requestor did experience delays as the program was being fine-tuned. Presently, the Ministry has finalized the

development of this process and has provided a clear and transparent process for Health Authorities applicants to follow on the following BC Government public site:
<http://www2.gov.bc.ca/gov/content/health/conducting-health-research-evaluation/data-access-health-data-central/health-authorities>

The Ministry will continue to work with Health Authorities in 2016 to ensure this new line of research applications 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 blue ink, appearing to read 'W. MacDonald', written in a cursive style.

William MacDonald, Chair
Data Stewardship Committee