

Data Stewardship Committee Annual Report 2016

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.

2016 Data Stewardship Committee Activities

a. Membership and Meetings

In 2016, four members were reappointed to the Committee and five new members were appointed. In addition, the term for the member appointed at the pleasure of the Minister came to an end. Currently, there are no unfilled positions on the Committee.

The Committee met nine times during the reporting period.

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

During the reporting period, the Committee approved a total of 22 new project requests for PharmaNet data and 50 amendments for past projects. The Committee rejected one research request for PharmaNet data in 2016. One research project was withdrawn by the researcher before being submitted to the Committee for approval.

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 2016, no such research requests for PharmaNet data were 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. During the reporting period, the Committee approved one new project request for data from the Client Registry System.

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.

One Request to Contact application was submitted to the Office of the Information and Privacy Commissioner by the Committee in 2016. The request was approved by the Privacy Commissioner and subsequently by the Committee.

In 2016 there was one meeting between the Committee and the Privacy Commissioner.

d. Data Stewardship Committee Policies and Protocols

During the reporting period, the Committee established a new policy on the privacy and security framework.

e. Ministry of Health Agreements

The Ministry has entered into research agreements or administrative information sharing agreements for all academic research projects approved by the Committee in 2016 except two, which are in the process of being signed by the parties involved.

Approval Wait Times for Research Requests

a. Academic Requests

Since June 2012, when the Committee became responsible for approving research requests for PharmaNet, the Committee and the Ministry have continued to work towards improving the approval times for academic requests to PharmaNet data. Prior to June 2012, research requests for PharmaNet data were approved by the PharmaNet Stewardship Committee, which was dissolved in 2012 as a consequence of the *Pharmaceutical Services Act*.

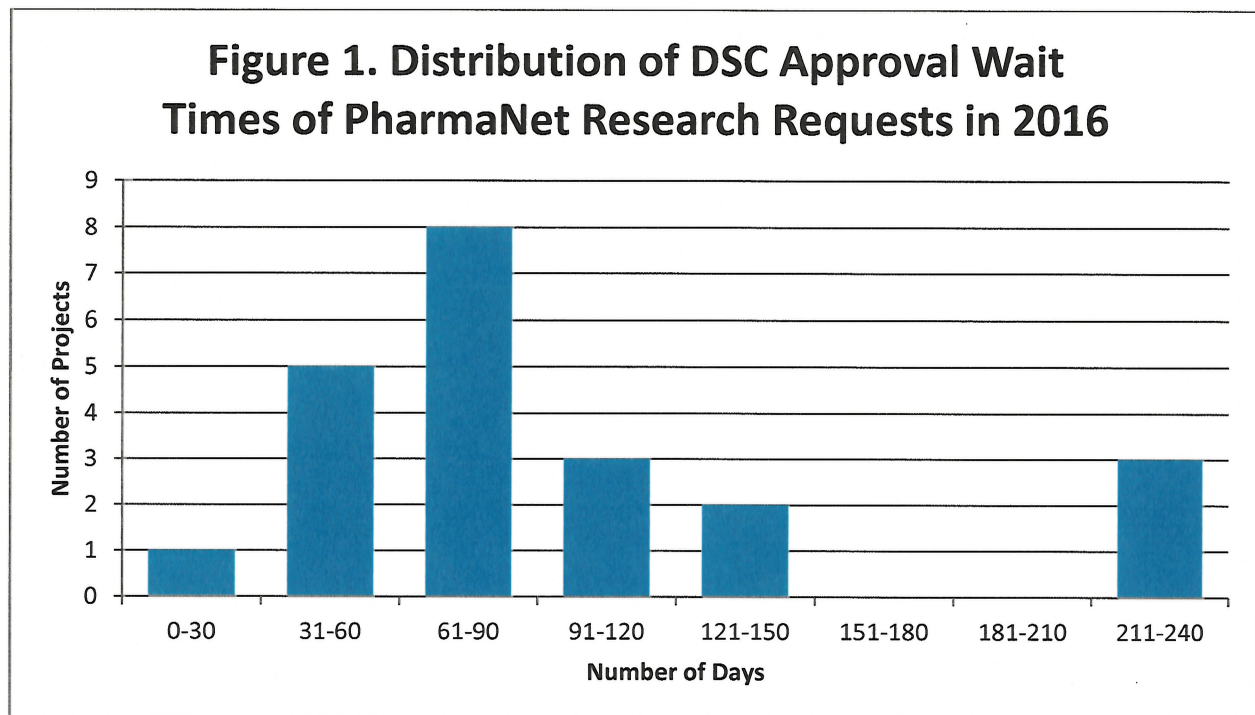
Table 1 below shows the median number of days for approval. This has been reduced from 316 days in 2010 to 79 days in 2016, while the maximum number of days for approval has been reduced from 746 days in 2010 to 224 days in 2016.

Table 1. Data Stewardship Committee (DSC) Data Access Requests – New Projects					
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
2016	22	22	17	224 ⁵	79

[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.
- [5] Projects 16-114 was submitted as a third party request via CIHI and the extended timeline involved clarifications on the legal mandate of the Committee in respect to such projects.

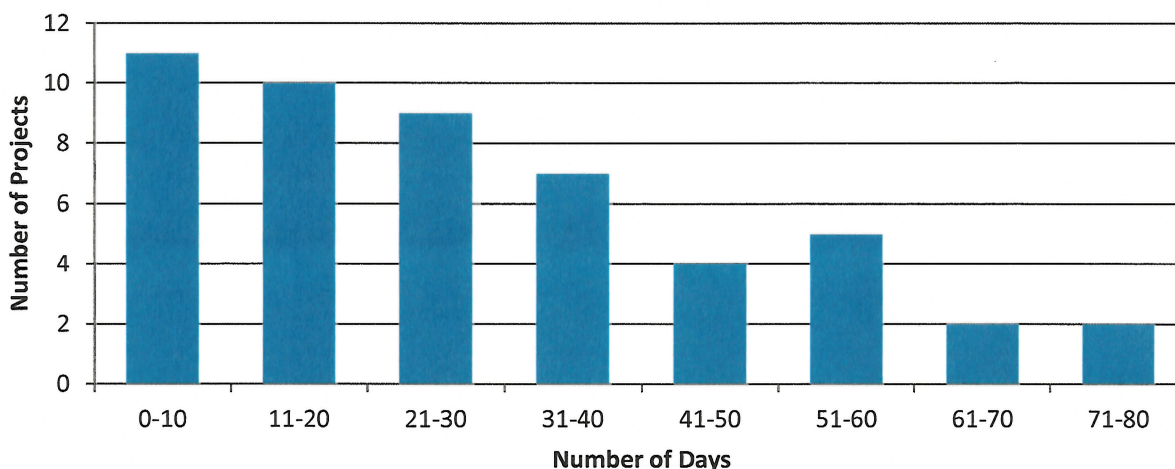
A more detailed picture of the approval times is depicted in Figure 1, which shows the distribution of projects based on the number of days to approve. The number of days to approval was calculated as the difference between the date when the Committee approval letter was issued and the day the application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



In 2016, 65 per cent of the new academic approvals were adjudicated within zero and 90 days and 23 per cent were adjudicated within 91 and 150 days. The remaining projects represent projects where modifications/clarification were 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 2016 there were a total of 50 amendments for existing projects that were approved by the Committee. The median approval time for the amendments was 25 days, while the minimum number of days was zero and the maximum number of days for an amendment approval was 77. In 2016, 60 per cent of the amendment approvals were adjudicated within zero and 30 days and 32 per cent were adjudicated within 31 and 60 days. The remaining 8 percent of amendment requests with approval times between 61 and 80 days represent requests where modifications/clarifications were needed to support the review process.

Figure 2. Distribution of DSC Amendment Approval Wait Times of PharmaNet Research Requests in 2016



Ten of the amendments approved by the Committee referred to student projects associated with the original projects data and/or objectives.

b. Health Authorities Requests

The Committee did not receive or approve any new research request submitted by Health Authorities in 2016. However, there were three amendments involving health authority research projects approved by the Committee in 2016, two of which concerning student projects.

The Ministry will continue to work with Health Authorities in 2017 to explore whether this line of research applications will be supported.

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

Sincerely,

William MacDonald, Chair
Data Stewardship Committee