

# Data Stewardship Committee

## Annual Report 2017

### Requirement to Report

This report fulfills 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.

### 2017 Data Stewardship Committee Activities

#### a. Membership and Meetings

In 2017, four members were reappointed to the Committee and two new members were appointed. A new Chair, Dr. Colin Dormuth, was also appointed. Currently, there are no unfilled positions on the Committee, with the Committee having a full complement of 12 members (see Appendix for membership list).

The Committee met ten times during the reporting period.

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

During the reporting period, between January 1<sup>st</sup>, 2017 and December 31<sup>st</sup>, 2017, the Committee received a total of 30 net new research applications for PharmaNet data and 63 amendment requests.

During the reporting period, the Committee approved a total of 30 new requests for PharmaNet data and 65 amendments to existing projects. No new research requests for PharmaNet data were rejected by the Committee in 2017, while one project was withdrawn by the applicant.

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* (PSA), such requests for PharmaNet data must be approved by the Committee. In 2016, four such research requests for PharmaNet data were approved by the Committee. In addition, another research project funded by the Ministry of Health via a grant<sup>1</sup> was also been approved by the Committee in 2017.

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<sup>1</sup> 16-045 "Towards the Development of a Treatment as Prevention for HCV Strategy in British Columbia" with BC Centre for Excellence.

Two 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, no new project requests for data from the Client Registry System or the Provider Registry were approved by the Committee.

c. Collaboration with the Office of the Information and Privacy Commissioner (OIPC)

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 existing legislation and established protocols, the Information and Privacy Commissioner must approve all such requests in advance.

No Request to Contact applications were submitted to the Office of the Information and Privacy Commissioner by the Committee in 2017.

Traditionally, the Committee and the OIPC meet annually to discuss issues of mutual interest. In 2017 no meeting between the Committee and the Information and Privacy Commissioner was held. It is anticipated that the Committee and the OIPC will meet in 2018 following the appointment of a new Information and Privacy Commissioner.

d. Collaboration with Canadian Institute for Health Information (CIHI)

The majority of research applications submitted to the Committee requesting access to PharmaNet data are developed and processed through Population Data BC. However, CIHI, as a custodian of the National Prescription Drug Utilization Information System (NPDUIS), accepts data access requests and discloses data to third parties for research purposes. Such disclosures, if involving BC data, must be approved by the Committee in accordance with the PSA. In 2017, the Committee received and approved two such requests.

e. Data Stewardship Committee Policies and Protocols

During the reporting period, the Committee established no new policies.

f. 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 2017 except two, which are currently 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* coming into force.



Table 1, below, shows the median number of days for approval. This has been reduced from 316 days in 2010 to 66 days in 2017, while the maximum number of days for approval has been reduced from 746 days in 2010 to 394 days in 2017. **It is important to note the time estimates below do not include the time between when the application is submitted by the researcher to when it is considered ready to be reviewed by the DSC, or the time required to provision the data after an application is approved. Both of the aforementioned steps can add significantly to the wait time experienced by the researcher.** The DSC is working with the MOH to better understand and address these issues, which may result in revised methodology being used for future reports.

Table 1. Data Stewardship Committee (DSC) Data Access Requests – New Projects					
YEAR <sup>1</sup>	# 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 <sup>2</sup>	68
2015	24	21 <sup>3</sup>	26	173 <sup>4</sup>	59
2016	22	22	17	224 <sup>5</sup>	79
2017	30	30 <sup>6</sup>	12	394 <sup>7</sup>	66

[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 within the # approved of statistic (21). 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.

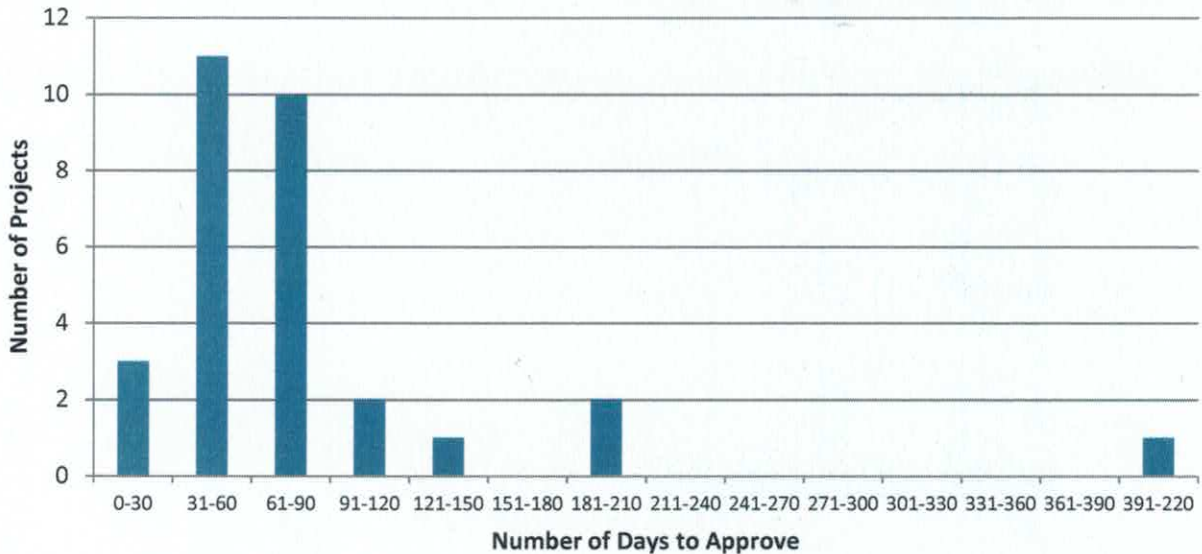
[5] Project 16-114 was submitted as a third party request via CIHI and the extended timeline involved clarifications on the legal mandate of the Committee in respect to such projects.

[6] All projects' approval time has been included in the calculation, regardless of the applicant's institution..

[7] Project 16-045 was a research project based on an MoH grant to BC CFE involving multiple data stewards and extended negotiations and clarifications. DSC has reviewed and approved only after all negotiations and clarifications raised by all parties were resolved.

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 the applicant directly or via Population Data BC.

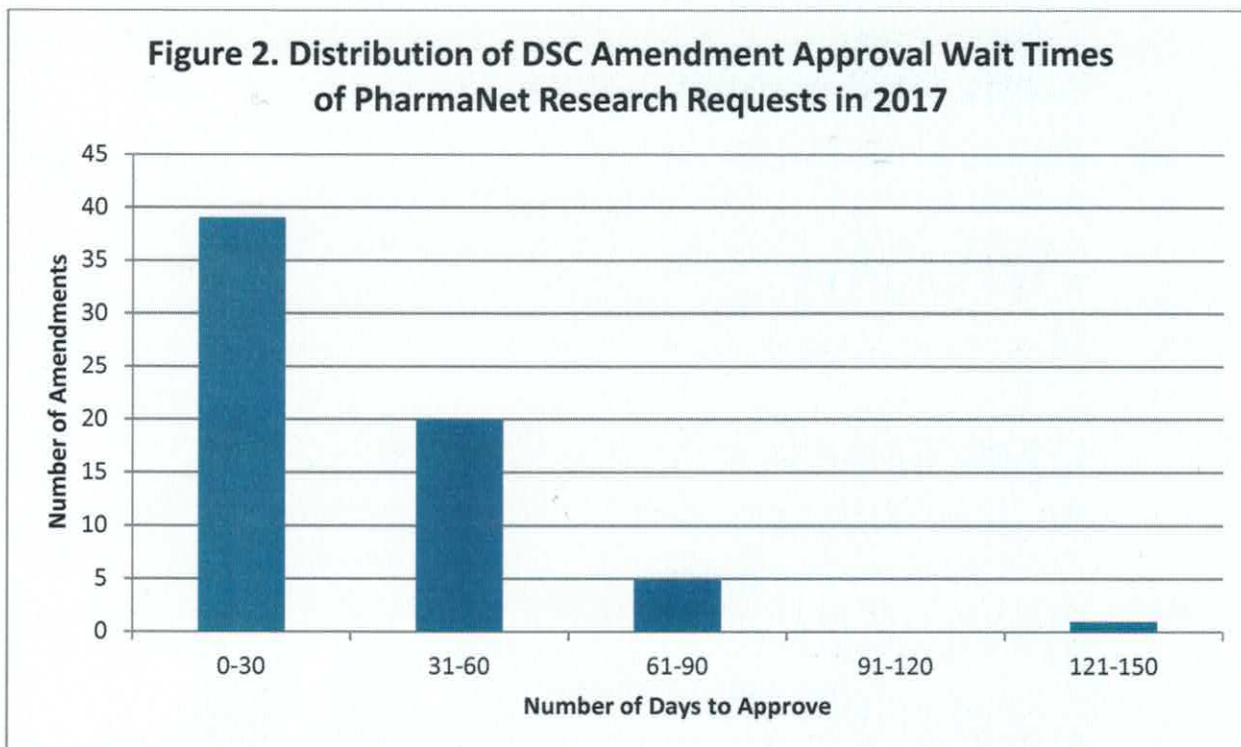
**Figure 1. Distribution of DSC Approval Wait Times of New PharmaNet Research Requests in 2017**



In 2017, 80 per cent of the new academic approvals were adjudicated within 0 - 90 days and 10 per cent were adjudicated within 91 - 150 days. The remaining projects represent projects where modifications/clarifications were needed to support the review process, or there were negotiations between the multiple data stewards involved in the request and the requesting party.

As depicted in Figure 2, in 2017 there were a total of 65 amendments for existing projects that were approved by the Committee. The median approval time for the amendments was 26 days, while the minimum number of days was zero and the maximum number of days for an amendment approval was 131. In 2017, 60 per cent of the amendment approvals were adjudicated within 0 - 30 days and 31 per cent were adjudicated within 31 - 60 days. The remaining 8 percent of amendment requests with approval times between 61 - 90 days represent requests where modifications/clarifications were needed to support the review process.

Six 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 received and approved four new research requests submitted by Health Authorities in 2017. Additionally, there were two amendments involving health authority research projects approved by the Committee in 2017.

The Ministry will continue to work with Health Authorities in 2018 to explore whether this line of research applications will continue to 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 timely and efficient as possible.

Sincerely,

Dr. Colin Dormuth, Chair  
Data Stewardship Committee



## Appendix

Current Members				
Name:	Location:	Position:	By order:	Expiry:
Chang, Ernest	Victoria	Public Member	MO 262/16, July 7, 2016	December 31, 2018
Collins, Teresa	Victoria	Ministry Repr.	MO 451/17, December 31, 2017	December 31, 2019
De Vera, Mary	Vancouver	Pharmaceutical Research Repr.	MO 401/16, December 31, 2016	December 31, 2019
Djurdjev, Ognjenka	Vancouver	Health Authority Repr.	MO 396/15, December 31, 2015	December 31, 2018
Dormuth, Colin	Victoria	Chair	MO 449/17, December 31, 2017	December 31, 2019
Elderfield, Andrew	Victoria	Chief Data Steward	MO 525/16, December 22, 2016	At Pleasure
Elliot, Elizabeth	Coquitlam	College of Registered Nurses Repr.	MO 452/17, December 31, 2017	December 31, 2019
Keirstead, Graeme	North Vancouver	College of Physicians and Surgeons Repr.	MO 453/17, December 31, 2017	December 31, 2019
KoeHoorn, Mieke	Vancouver	Health Research Repr.	MO 262/16, September 1, 2016	December 31, 2018
Nakagawa, Robert	Port Moody	College of Pharmacists Repr.	MO 454/17, December 31, 2017	December 31, 2019
Nam, Daniel	Surrey	Public Member	MO 401/16, December 31, 2016	December 31, 2018
Panagiotopoulos, Dina	Vancouver	Public Member	MO 450/17, December 31, 2017	December 31, 2018