

Data Stewardship Committee

Annual Report 2018

Executive Summary

The Data Stewardship Committee (DSC) is required to report annually on their activities. This document details the nature of and changes to the membership of the DSC, requests for the disclosure of protected information for a health research purpose, collaborations, and policy development.

In 2018, the DSC continued to support researcher access to health data and updated DSC policies respecting the disclosure of health data for research. The maximum time required for adjudication of new health data requests has decreased over time (Table 1), and the number of requests for amendments to extant research agreements has increased over time (Figure 2). Student requests for health data access remain a priority for the DSC (Figure 3).

Requirement to Report

DSC reporting requirements originate in § 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.

2018 Data Stewardship Committee Activities

Membership and Meetings

In 2018, five members were reappointed to the Data Stewardship Committee and no new members were appointed. Dr. Colin Dormuth continued in his role as Chair. Currently, there are no unfilled positions on the DSC, with the Committee having a full complement of 12 members (see Appendix). The Committee met nine times during the reporting period; two of these meetings were full-day workshops to develop policy, in addition to the usual consideration of requests for data access.

Research Requests for PharmaNet or data from a Health Information Bank

During the reporting period from January 1st, 2018 to December 31st, 2018, the DSC received a total of 23 new data access requests for PharmaNet data and 147 amendment requests. Eight requests were made for amendments to student requests, but no new student requests were received. Three new data access requests for PharmaNet data were rejected by the Committee in 2018, and one was withdrawn by the applicant, leaving a total of 16 approved requests and three which had not been considered for approval by the end of the year.

Collaboration with the OIPC

The "Request to Contact" process framework was established through collaboration across the DSC, the Ministry of Health (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 received in 2018.

The Committee and the OIPC meet annually to discuss issues of mutual interest. The 2018 meeting between the Committee and the Information and Privacy Commissioner was held on April 18th.

Collaboration with Canadian Institute for Health Information (CIHI)

The majority of data access requests 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 2018, the Committee received and approved two such requests.

Data Stewardship Committee Policies and Protocols

During the reporting period, the Committee revised its Terms of Reference and updated its policies respecting the disclosure of health data for research. The updated policies, titled "Policies Respecting the Disclosure of Information" support alignment with the *Access to Data for Health Research* guidance document (January 2018) by the Office of the Information and Privacy Commissioner for British Columbia, and the Ministry's *Access to Health Data for Research* policy (September 2018).

Ministry of Health Agreements

The Ministry entered into research agreements or administrative information sharing agreements for all data access requests approved by the Committee in 2018.

Approval of Data Access Requests

Academic Requests

Since June 2012, the Committee has been responsible for approving research requests for PharmaNet data and, in cooperation with the Ministry, has continued to work towards improving the approval times for academic requests to PharmaNet data. Both new data access requests and amendments to existing research agreements must be approved by the Committee.

The details of new data access requests for PharmaNet data from 2010-2018 are shown in Table 1. Approval times do not include the time from initial submission by the researcher to the date by which it is considered ready for review by the DSC, or the time required to provision the data after an data access request is approved by the Committee. Both steps may add significantly to the total wait time experienced by the researcher. The DSC is continuing to work with the Ministry to address these issues.

Table 1 Data Stewardship Committee (DSC) Data Access Requests – New 2010-2018

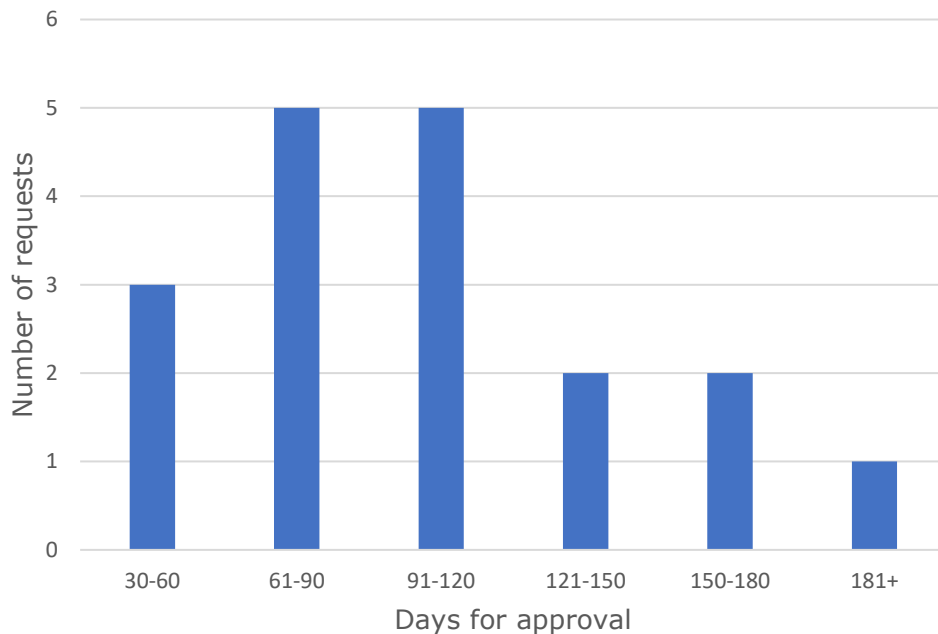
YEAR¹	Received (number)	Approved (number)	Min (days)	Max (days)
2010	20	20	31	746
2011	8	8	52	414
2012	7	6	36	125

¹ The approval year may not match the submission year due to application date, review time, and DSC meeting dates. Approval numbers which are higher than the number received reflect requests from previous years.

2013	18	8	35	120
2014	13	21	35	232
2015	24	21	26	173
2016	22	22	17	224
2017	30	30	12	394
2018	23	16	40	186

Figure 1 below shows the distribution of new data access requests based on the number of days for approval. This is the time from which a data access request was received by the Ministry from the applicant directly or via Population Data BC, and the date the Committee approval letter was issued.

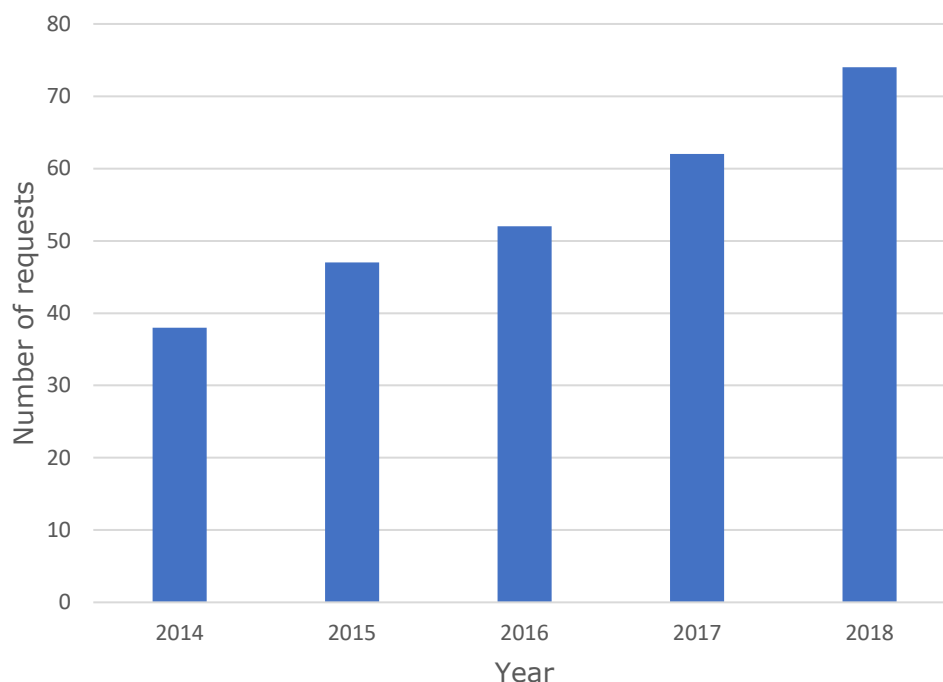
Figure 1 DSC Approval times for new PharmaNet Research Requests, 2018



In 2018, 50 per cent of the new academic approvals were adjudicated within 90 days and 31 per cent were adjudicated within 91 - 150 days. Longer timelines represent instances where required documents were not submitted, modifications and/or clarifications were required to support the review process, or negotiations between multiple data stewards and the requesting party were necessary.

In addition to considering new requests for data access approval, the DSC also considers requests for modifications and amendments to existing agreements, which have increased over time. Figure 2 shows the change over time in requests for amendments and extensions.

Figure 2 Number of Requests for Amendments to extant agreements, 2014-2018



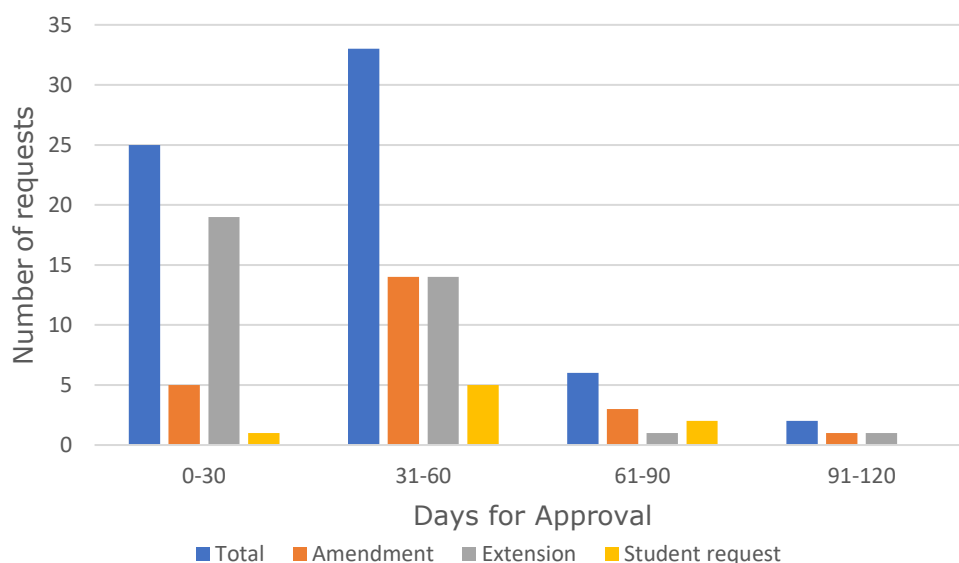
As depicted in Table 2 below, a total of 74 amendments for existing research agreements were considered by the Committee in 2018, in addition to 73 amendment requests to add members to research teams requiring data access.

Table 2 Data Stewardship Committee (DSC) Data Access Requests – Amendments to Extant research agreements in 2018

2018	Received (number)	Approved (number)	Min (days)	Max (days)
Amendment	26	23	14	91
Extension	40	36	1	91
Student request	8	7	30	70
Total	74	66		

The minimum approval time for an amendment was one day, with a maximum approval time of 91 days. In 2018, 37 per cent of the amendment approvals were adjudicated within 30 days, and 50 per cent were adjudicated within 31-60 days. Requests with longer timelines represent instances where supporting documents, modifications, or clarifications were necessary to support the review process. Figure 3 shows the approval time for all types of amendments to existing requests (excluding those which add research team members).

Figure 3 DSC Approval times for Amendments to PharmaNet Research Agreements



Student requests have a shorter approval time than other types of amendments to extant research agreements because they are prioritised for consideration by the DSC.

The Data Stewardship Committee looks forward to supporting ongoing improvements to make access to health data for research as timely and efficient as possible while safeguarding individual privacy.

Sincerely,

Colin Dormuth

Chair of the Data Stewardship Committee

Appendix - DSC Members, 2018

Name:	Location:	Position:	By order:	Expiry:
Chang, Ernest	Victoria	Public Member	MO 262, July 7, 2016 MO 473, December 31 2018*	December 31, 2019
Collins, Teresa	Victoria	Ministry Repr.	MO 451, December 31, 2017	December 31, 2019
De Vera, Mary	Vancouver	Pharmaceutical Research Repr.	MO 401, December 31, 2016	December 31, 2019
Djurdjev, Ognjenka	Vancouver	Health Authority Repr.	MO 396, December 31, 2015 MO 474, December 31, 2018*	December 31, 2019
Dormuth, Colin	Victoria	Chair	MO 449, December 31, 2017	December 31, 2019
Elderfield, Andrew	Victoria	Chief Data Steward	MO 525, December 22, 2016	At Pleasure
Elliot, Elizabeth	Coquitlam	College of Registered Nurses Repr.	MO 452, December 31, 2017	December 31, 2019
Keirstead, Graeme	North Vancouver	College of Physicians and Surgeons Repr.	MO 453, December 31, 2017	December 31, 2019
Koehoorn, Mieke	Vancouver	Health Research Repr.	MO 262, September 1, 2016 MO 475, December 31, 2018*	December 31, 2019
Nakagawa, Robert	Port Moody	College of Pharmacists Repr.	MO 454, December 31, 2017	December 31, 2019
Nam, Daniel	Surrey	Public Member	MO 401, December 31, 2016 MO 476, December 31, 2018*	December 31, 2019
Panagiotopoulos, Dina	Vancouver	Public Member	MO 450, December 31, 2017 MO 472, December 31, 2018*	December 31, 2020

* Re-appointed to the Committee in 2018