

Data Stewardship Committee

Annual Report for 2019

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 2019, the DSC continued to support researcher access to health data and engaged in policy revision and development.

Requirement to Report

DSC reporting requirements originate in § 16(1) of the *e-Health (Personal Health Information Access and Protection of Privacy) Act*¹:

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.

Data Stewardship Committee Activities in 2019

Membership and Meetings

Eight members of the DSC were re-appointed in 2019 (see Appendix). Professor Colin Dormuth continued in his role as Chair and Graeme Keirstead was designated Vice-Chair of the DSC on 19 November, 2019. Alison Wainwright was appointed as a new Member of the DSC representing the BC College of Nursing Professionals on 13 October, 2019, with her term to commence on 1 January, 2020.

The DSC met ten times during 2019. Additionally, the DSC held a joint workshop with the OIPC, an Extraordinary meeting, and three teleconferences with Ministry of Health representatives and researchers to discuss aspects of complex data access requests.

Research Requests for PharmaNet or data from a Health Information Bank

During the reporting period from January 1st, 2019 to December 31st, 2019, the DSC received a total of 23 new data access requests for PharmaNet data, 10 Student Data Access Requests, and 39 requests for extensions to current projects. One new data access request was withdrawn, and five had not yet been approved by the end of 2019.

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

¹ http://www.bclaws.ca/civix/document/id/complete/statreg/08038_01

Commissioner must approve all such requests in advance. No Request to Contact applications were received in 2019.

The Committee and the OIPC meet annually to discuss issues of mutual interest. The 2019 meeting between the Committee and the Information and Privacy Commissioner was held on the 18th of September in Victoria.

Collaboration with Canadian Institute for Health Information (CIHI)

Most 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 2019, the Committee received and approved two such requests.

Data Stewardship Committee Policies and Protocols

In 2019, the Data Stewardship Committee disseminated and fully implemented their Policies Respecting the Disclosure of Information for health research purposes, and updated their Terms of Reference. They also developed a Declaration of Research Independence, which provides a way for researchers to clarify potentially influential relationships so that a greater range of applications can be considered for approval.

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 2019.

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 2010-2019 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 a 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, and new status tracking mechanisms are in development.

Table 1 Data Stewardship Committee (DSC) Data Access Requests – New 2010-2019

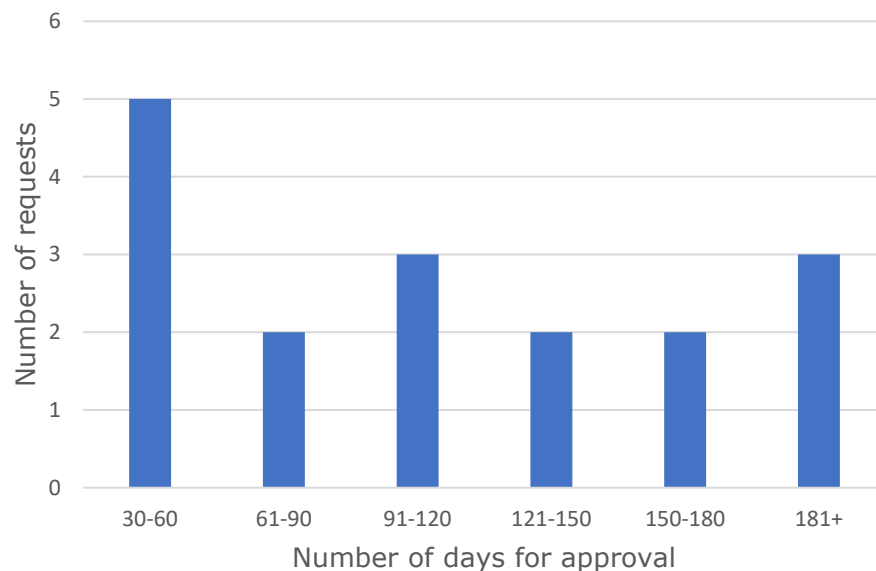
| Year² | Received (number) | Approved (number) | Min (days) | Max (days) |
|-------------------------|------------------------------|------------------------------|-----------------------|-----------------------|
| 2010 | 20 | 20 | 31 | 746 |

² 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.

| | | | | |
|-------------|----|----|----|-----|
| 2011 | 8 | 8 | 52 | 414 |
| 2012 | 7 | 6 | 36 | 125 |
| 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 |
| 2019 | 23 | 17 | 35 | 317 |

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.

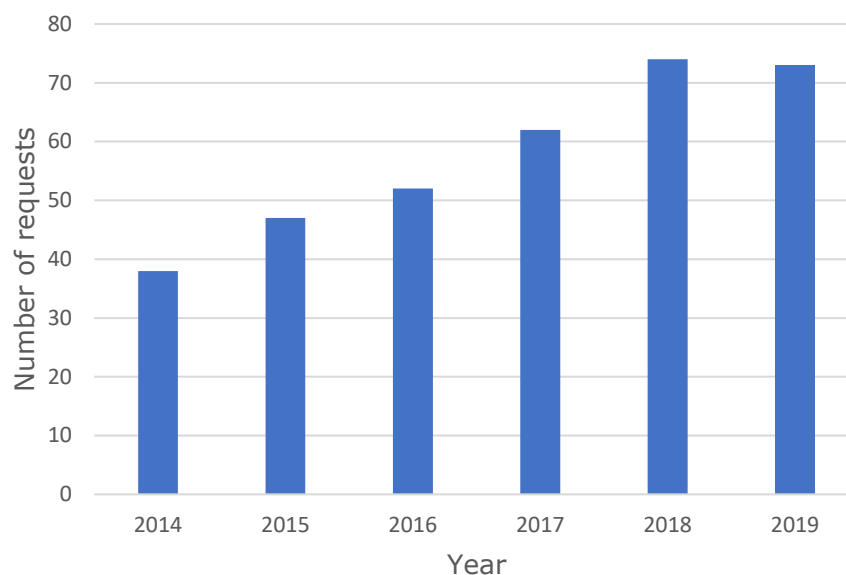
Figure 1 DSC Approval times for new PharmaNet Research Requests, 2019



Most new requests for data access were approved by the DSC within 120 days. The illustrated approval times include applications which were not complete at the time they were received. 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, 2014-2019



As depicted in Table 2 below, 73 amendments for existing research agreements were considered by the Committee in 2019, in addition to 61 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 2019

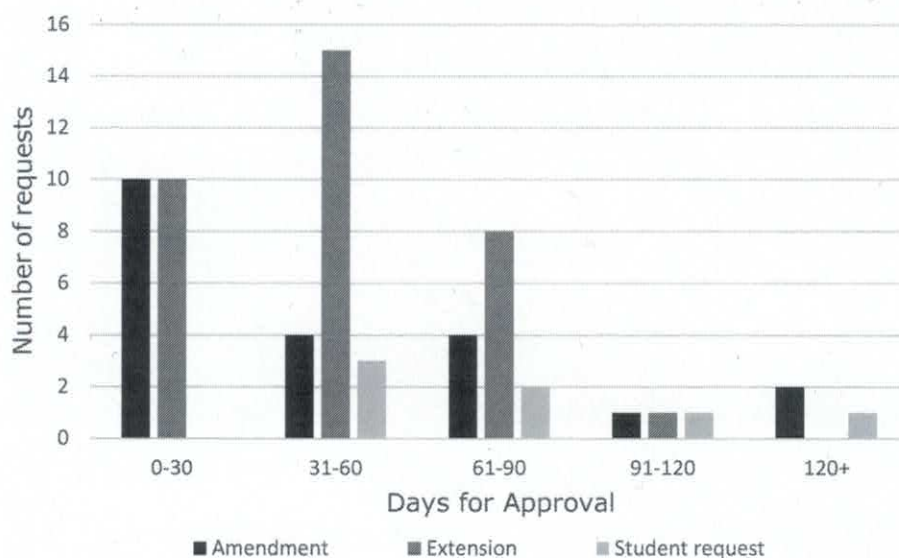
| 2019 Amendment Requests | Received (number) | Approved (number) | Min (days) | Max (days) |
|------------------------------------|------------------------------|------------------------------|-----------------------|-----------------------|
| Amendment | 24 | 21 | 1 | 233 |
| Student (new) | 10 | 7 | 37 | 141 |
| Extension | 39 | 34 | 1 | 117 |
| Total | 73 | 62 | N/A | N/A |

In 2019, 57 per cent of all amendment approvals were adjudicated within 60 days. The minimum approval time for an amendment was 1 day, with a maximum approval time of 233 days. Likewise, extensions were approved within a minimum of 1 day, and a maximum of 117 days. Although student requests are classed as amendments, they often require the same evaluation as a new data access request, and the complexity of these requests can contribute to these timelines. Student requests were approved in a minimum of 37 days and a maximum of 141 days.

The illustrated approval times show all requests, including applications which were not complete at the time they were received.

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



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 as of 31 December, 2019

| Name: | Location: | Position: | By order: | Expiry: |
|------------------------------------|------------------|--------------------------------------|--|-------------------|
| Chang, Ernest Jen-Hao | Victoria | Public Member | MO 262, July 7, 2016 MO 473, December 31 2018 MO 365, October 13, 2019 | December 31, 2022 |
| De Vera, Mary | Vancouver | Pharmaceutical Research Rep. | MO 401, December 31, 2016 MO 367, October 13, 2019 | December 31, 2020 |
| Djurdjev, Ognjenka | Vancouver | Health Authority Representative | MO 396, December 31, 2015 MO 474, December 31, 2018 MO 368, October 13, 2019 | December 31, 2020 |
| Dormuth, Colin | Victoria | Chair | MO 449, December 31, 2017 MO 363, October 13, 2019 | December 31, 2022 |
| Elderfield, Andrew | Victoria | Chief Data Steward | MO 525, December 22, 2016 | At Pleasure |
| Keirstead, Graeme Vernon | North Vancouver | Vice Chair | MO 453, December 31, 2017 MO 366, October 13, 2019 | December 31, 2022 |
| Koehoorn, Mieke Wilma | Vancouver | Health Research Rep. | MO 262, September 1, 2016 MO 475, December 31, 2018 MO 362, October 13, 2019 | December 31, 2021 |
| Nakagawa, Robert Sadayuki (Bob) | Port Moody | College of Pharmacists Rep. | MO 454, December 31, 2017 MO 370, October 13, 2019 | December 31, 2021 |
| Nam, Daniel | Surrey | Public Member | MO 401, December 31, 2016 MO 476, December 31, 2018 MO 369, October 13, 2019 | December 31, 2021 |
| Panagiotopoulos, Constadina (Dina) | Vancouver | Public Member | MO 450, December 31, 2017 MO 472, December 31, 2018 | December 31, 2020 |
| Wong, Shirley Mei-Ling | Victoria | Ministry Representative | MO 122, April 1, 2019 | March 31, 2021 |
| Vacant ³ | N/A | College of Registered Nurses (BCCNP) | N/A | N/A |

³ Filled by Alison Wainwright on 1 January, 2020 (MO 364/19, December 31, 2019)