

# Data Stewardship Committee

## Annual Report for 2020

### Executive Summary

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

In 2020, the DSC continued to support researcher access to health data and updated DSC policies respecting the disclosure of health data for research. This commitment may be most clearly demonstrated in the adoption of extraordinary measures in March to ensure that routine adjudication would continue and COVID-19 related requests for data access would be prioritized for review and adjudication. These measures included moving all DSC business and meetings online, adopting digital signatures, striking a panel to consider COVID-19 requests<sup>1</sup>, and holding two extraordinary meetings solely for the purpose of COVID-19 request adjudication.

These changes, along with improvements to request timeline tracking, resulted in an overall decrease in waiting times for adjudication despite an overall increase in the number of new requests. More than half of these were adjudicated within 30 days of a complete application being received, with one COVID-19 request adjudicated within 1 day. Amendment approval timelines also improved from 2019, with all student requests and extension requests adjudicated within 60 days. Only one data-related amendment required longer than 60 days for adjudication.

### 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.

### 2020 Data Stewardship Committee Activities

#### Membership and Meetings

In 2020, Alison Wainwright was appointed as the representative for the College of Registered Nurses (now the BC College of Nurses and Midwives) for a single-year term. Professor Colin Dormuth continued as the Chair of the Committee, with Graeme Keirstead continuing in the role of Vice-Chair. Members Mary De Vera (Member involved in Pharmaceutical Research) and Ognjenka Djurdjev (Member representing the PHSA) completed their final appointments to the Committee on December 31, 2020, with Constadina Panagiotopolous (Public Member) re-appointed to continue to 2022 (please see Appendix).

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<sup>1</sup> As per the E-Health Act, s. 13.1(b) [https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/00\\_08038\\_01#section13](https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/00_08038_01#section13)

The Committee met a total of 13 times in 2020: 10 routine meetings, two extraordinary sessions for the adjudication of COVID-19 related requests, and one meeting with the Office of the Information and Privacy Commissioner.

### COVID-19 Related Research Requests

The Committee received seven COVID-19 related research requests for data access, including one student request. All of these were adjudicated within 13 total days of the DSC Secretariat receiving a complete application.

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

During the reporting period from January 1<sup>st</sup>, 2020 to December 31<sup>st</sup>, 2020, the DSC received a total of 31 new data access requests for PharmaNet data and 112 amendment requests, including 60 authorized user additions. One new data access request for PharmaNet data was rejected by the Committee in 2020, with none withdrawn by applicants. A total of 30 new requests (including some received in late 2019) were approved, with one awaiting adjudication in 2021 and 8 not yet sufficiently complete for adjudication.

### 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 Committee and the Information and Privacy Commissioner must approve all such requests in advance. No new Requests to Contact were received in 2020.

The DSC and the OIPC meet annually to discuss issues of mutual interest. The 2020 joint meeting was held on the 17<sup>th</sup> of June.

### 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 since PharmaNet data are included in NPDUIS. In 2020, the Committee received and approved 5 such requests.

### Data Stewardship Committee Policies and Procedures

In addition to moving all DSC business online, procedural modifications were implemented to ensure that applications for Public Health Emergency related research purposes were adjudicated rapidly and barriers to research were minimised. These included the prioritization of Public Health Emergency related requests for adjudication, including requests received through the Michael Smith Foundation funding call for COVID-19 related research. The Committee convened a special panel, which met twice to review, discuss, and adjudicate Public Health Emergency related requests. Finally, all approvals were shifted to digital signatures only, with a temporary suspension of the requirement for witness signatures on Declarations of Research Independence.

The Committee also provided input on guidance for student applications<sup>2</sup> and laid the groundwork for developments to accommodate additional sources of requests for data access in the future. These include the Health Data Platform, the Data Innovation Program, and requests approved by the First Nations Health Authority Data and Information Planning Committee.

## 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 2020.

## 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 2010-2020 are shown in Table 1. Approval times from years before 2020 are based on the date the Ministry received the request, whereas 2020 timeframes are based on the date by which it is sufficiently complete for adjudication. The time required to provision the data after a data access request is approved by the Committee is not included for any year. Both application completion and data provisioning 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 2010-2020<sup>3</sup>**

<b>YEAR<sup>4</sup></b>	<b>Received (number)</b>	<b>Adjudicated (number)</b>	<b>Min (days)</b>	<b>Max (days)</b>
<b>2010</b>	20	20	31	746
<b>2011</b>	8	8	52	414
<b>2012</b>	7	6	36	125
<b>2013</b>	18	8	35	120
<b>2014</b>	13	21	35	232
<b>2015</b>	24	21	26	173
<b>2016</b>	22	22	17	224
<b>2017</b>	30	30	12	394
<b>2018</b>	23	16	40	186
<b>2019</b>	23	17	35	317
<b>2020</b>	31	30	1	133

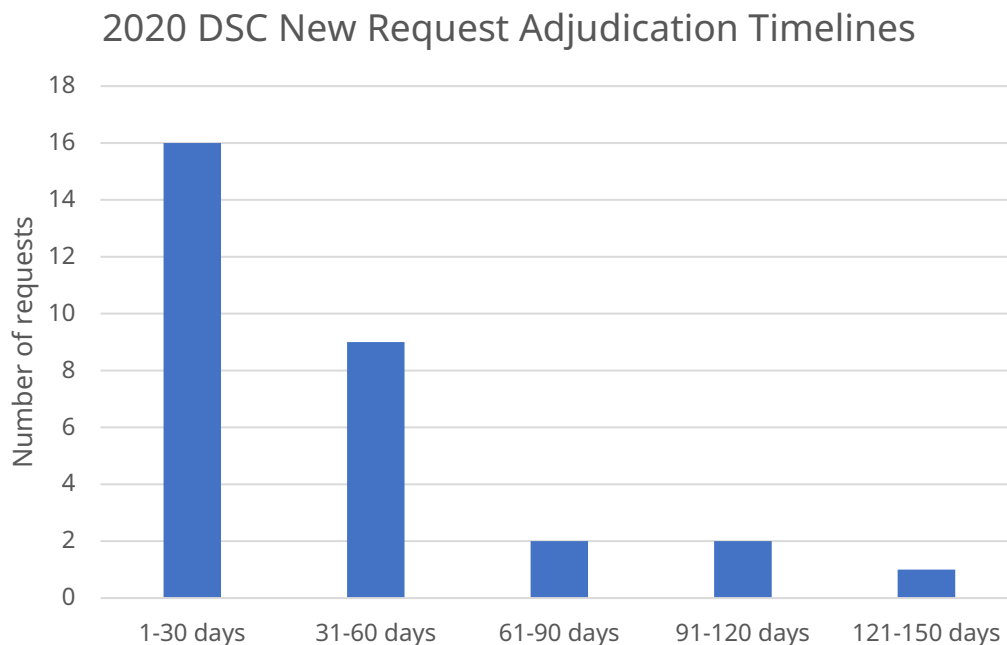
<sup>2</sup> [https://www2.gov.bc.ca/assets/gov/health/conducting-health-research/data-access/student\\_dar\\_guidelines\\_v14.pdf](https://www2.gov.bc.ca/assets/gov/health/conducting-health-research/data-access/student_dar_guidelines_v14.pdf)

<sup>3</sup> Metrics from Population Data BC Quarterly Reports; 2020 metrics as of January 21, 2021. Approval times from years before 2020 are based on the date the Ministry or DSC initially received the request, whereas 2020 timeframes are based on the date by which the request was complete and ready for adjudication.

<sup>4</sup> 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.

Figure 1 below shows new data access request adjudication timelines. This is measured from the day a data access request was complete enough to adjudicate to the date the Committee approved the request. Due to the DSC’s commitment to rapid adjudication of COVID-19 related requests, these timelines are greatly reduced from previous years.

**Figure 1 DSC Adjudication timelines for new PharmaNet Research Requests, 2020**



More than half of the new requests for access to PharmaNet data were adjudicated within 30 days of a complete application being received by the Data Stewardship Committee Secretariat. Longer timelines represent delays in receiving documents or information requested at the time of adjudication, modifications and/or clarifications being required to support the review process, or negotiations between multiple data stewards and the requesting party.

Table 2 shows the 52 amendments for existing research agreements received by the DSC in 2020, of which 48 were adjudicated. 60 amendment requests to add members to research teams were also received, which were approved through a delegated review and are not reflected below.

**Table 2 Data Stewardship Committee (DSC) Data Access Requests – Amendments to Extant research agreements in 2020**

2020	Received (number)	Adjudicated (number)	Min (days)	Max (days)
<b>Data Related Amendment</b>	25	25	7	70
<b>Extension</b>	12	8	1	29
<b>Student request</b>	15	15	5	48
<b>Total</b>	<b>52</b>	<b>48</b>	N/A	N/A

The minimum approval time for any amendment was one day, with a maximum approval time of 70 days. In 2020, 71 per cent of the amendment approvals were adjudicated within 30 days, and 27 per cent were adjudicated within 31-60 days. The request with a longer timeline represents an instance where supporting documents and clarifications were necessary to support the adjudication process. Figure 2 shows the approval time for all types of amendments to existing requests (excluding those to add research team members).

**Figure 2 DSC Approval times for Amendments to PharmaNet Research Agreements**

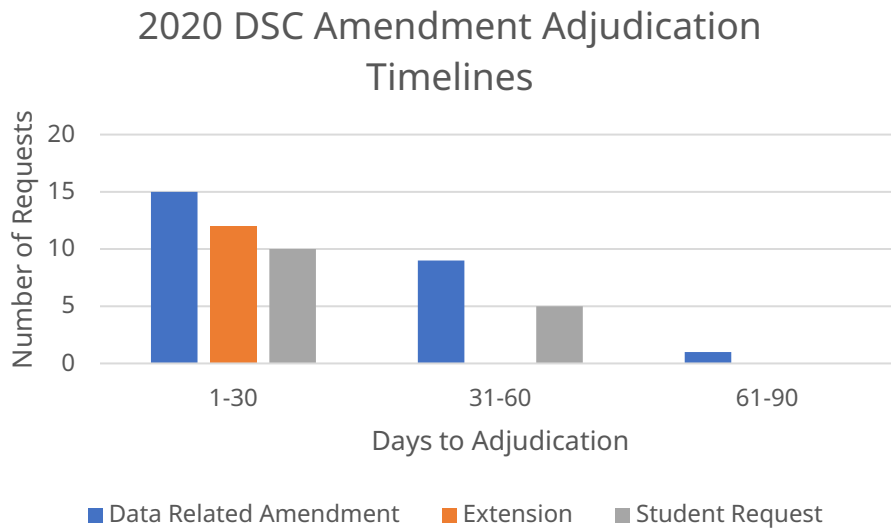


Figure 2 above includes a Student request which was adjudicated under the COVID-19 rapid processing framework adopted by the Committee.

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 privacy.

Sincerely,

Colin Dormuth  
 Chair of the Data Stewardship Committee

## Appendix - DSC Members, 2020

<b>Name:</b>	<b>Location:</b>	<b>Position:</b>	<b>By order:</b>	<b>Expiry:</b>
Chang, Ernest	Victoria	Public Member	MO 262, July 7, 2016 MO 473, December 31, 2018 MO 365, October 13, 2019	December 31, 2022
De Vera, Mary <sup>5</sup>	Vancouver	Pharmaceutical Research Rep.	MO 401, December 31, 2016 MO 367, October 13, 2019	December 31, 2020
Djordjev, Ognjenka <sup>6</sup>	Vancouver	Health Authority Rep.	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, December 31, 2019	December 31, 2022
Elderfield, Andrew	Victoria	Chief Data Steward	MO 525, December 22, 2016	At Pleasure
Keirstead, Graeme	North Vancouver	College of Physicians and Surgeons Rep.	MO 453, December 31, 2017 MO 366, October 13, 2019	December 31, 2022
Koehoorn, Mieke	Vancouver	Health Research Rep.	MO 262, September 1, 2016 MO 475, December 31, 2018 MO 362, October 13, 2019	December 31, 2021
Nakagawa, Robert	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	Vancouver	Public Member	MO 450, December 31, 2017 MO 472, December 31, 2018 MO 464, December 31, 2020	December 31, 2022
Wainwright, Alison <sup>7</sup>	Port Moody	BC College of Nurses and Midwives Rep.	MO 364, December 31, 2019	December 31, 2020
Wong, Shirley Mei-Ling	Victoria	Ministry Rep.	MO 122, April 1, 2019	March 31, 2021

<sup>5</sup> Appointment in process at the time of reporting

<sup>6</sup> Succeeded by Sayed Ali Mussavi Rizi, MO 484, December 31, 2020

<sup>7</sup> Succeeded by Elaine Mei Yee Goh, MO 483, December 31, 2020