

# Data Stewardship Committee

## Annual Report for 2021

### Executive Summary

The Data Stewardship Committee (“DSC”, the “Committee”) is required to report at least 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 2021, the DSC continued to support researcher access to health data and updated DSC policies respecting the disclosure of health data for research. This commitment is demonstrated in the adoption of extraordinary measures in 2020 to ensure that disruption to routine adjudication would be minimized throughout the COVID-19 pandemic. Public Health Emergency related requests for data access are prioritized for review and adjudication. All DSC meetings continue to take place online, and other adjustments such as the shift to digital signatures and creation of the standing committee to consider COVID-19 requests<sup>1</sup> remain in place.

These changes, along with improvements to request timeline tracking, resulted in an overall decrease in waiting times for adjudication despite continuing increases in the number and complexity of new requests. Of these, 82% were adjudicated within 30 days of a complete application being received, with all COVID-19 requests adjudicated within eight calendar days or less. Similarly, 63% of amendment requests were adjudicated within 30 days. Only two data-related amendments 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.

### 2021 Data Stewardship Committee Activities

#### Membership and Meetings

In 2021, Elaine Goh was appointed to represent the BC College of Nurses and Midwives; Ali Mussavi was appointed as Member representing the PHSA; and Karen Moraes was appointed Member involved in Pharmaceutical Research. Shirley Wong, representative for the Ministry, was re-appointed to that role (please see Appendix).

The Committee met 11 times in 2020: 10 routine meetings and one meeting with the Office of the Information and Privacy Commissioner. One sub-committee meeting was held to address issues specific to an individual request.

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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)

## COVID-19 Related Research Requests

The Committee received six COVID-19 related research requests for data access in 2021. All of these were adjudicated within eight calendar 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>, 2021 to December 31<sup>st</sup>, 2021, the DSC received a total of 35 new data access requests for PharmaNet data and 145 amendment requests, including 78 authorized user additions. Of the 35 new requests received, one was withdrawn prior to adjudication. Of the remaining 34, 28 were adjudicated, two requests were awaiting adjudication at the end of 2021 and four were not sufficiently complete for adjudication.

## Collaboration with the Office of the Information and Privacy Commissioner (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. One new Request to Contact was received and approved in 2021.

The DSC and the OIPC meet annually to discuss issues of mutual interest. The 2021 joint meeting was held on the 15<sup>th</sup> of September.

## Collaboration with Canadian Institute for Health Information (CIHI)

As a custodian of the National Prescription Drug Utilization Information System (NPDUIS), CIHI 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 2021, the Committee received and approved two such requests.

## Collaboration with the Data Innovation Program (DIP)

As with NPDUIS, some PharmaNet data are held by the Data Innovation Program (DIP), which exists to support population-level analysis of data held by multiple ministries and agencies across government. The DIP accepts applications for data access for research purposes. The Committee adjudicated two new research data access requests and one amendment to an existing request for access to PharmaNet data in the DIP.

## 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 has convened a standing sub-committee to adjudicate Public Health Emergency related requests which could face unreasonable delay. The shift to digital signatures and suspension of the requirement for witness signatures on Declarations of Research Independence have continued.

In 2021, the Committee initiated development of position letters on for-profit funding and peer-review and continued to lay the groundwork to accommodate additional sources of requests for data access in the future, including the Health Data Platform.

## 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 2021, with the exception of one request involving data from the First Nations Client File. That request was approved by both the Data and Information Planning Committee and the Data Stewardship Committee, but agreement development is pending.

## 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 2010-2021 are shown in Table 1. Approval times from years before 2020 are based on the date the Ministry received the request, whereas 2021 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 maintain and improve current timelines.

**Table 1 Data Stewardship Committee (DSC) Data Access Requests – New 2010-2021<sup>2</sup>**

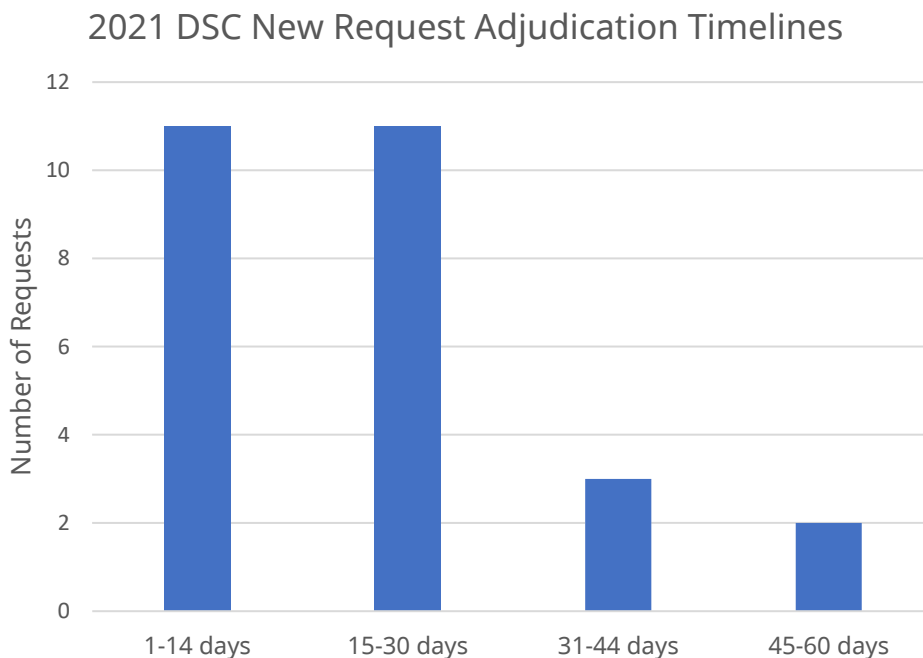
<b>YEAR<sup>3</sup></b>	<b>Received (number)</b>	<b>Adjudicated (number)</b>	<b>Min (days)</b>	<b>Max (days)</b>
<b>2010</b>	20	20	31	746
<b>2011</b>	8	8	52	414
<b>2012</b>	7	6	36	125
<b>2013</b>	18	8	35	120
<b>2014</b>	13	21	35	232
<b>2015</b>	24	21	26	173
<b>2016</b>	22	22	17	224
<b>2017</b>	30	30	12	394
<b>2018</b>	23	16	40	186
<b>2019</b>	23	17	35	317
<b>2020</b>	31	30	1	133
<b>2021</b>	35	28	1	56

<sup>2</sup> Metrics from Population Data BC Quarterly Reports; 2021 metrics as of January 19<sup>th</sup>, 2022. Approval times from years before 2020 are based on the date the Ministry or DSC initially received the request, whereas 2021 timeframes are based on the date by which the request was complete and ready for adjudication.

<sup>3</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 awaiting adjudication from the year prior.

Figure 1 below shows new data access request adjudication timelines, 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, 2021**



Of the approved new requests for access to PharmaNet data, 82% 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 requests for amendments to existing research agreements received by the DSC in 2021, of which 54 were adjudicated, 11 were incomplete or received after the final adjudication of the year, and two were withdrawn. 78 amendment requests to add members to research teams were also received, which were approved through a delegated review and are not reflected below.

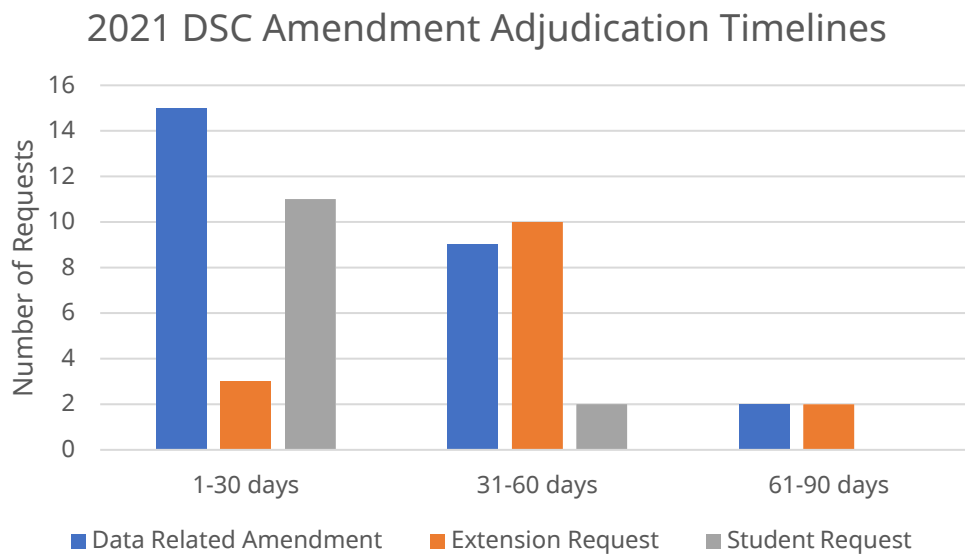
**Table 2 Data Stewardship Committee (DSC) Data Access Requests – Amendments to Extant research agreements in 2021**

2021	Received (number)	Adjudicated (number)	Min (days)	Max (days)
<b>Data Related Amendment</b>	33	26	1	83
<b>Extension request</b>	19	15	1	71

<b>Student request</b>	15	13	10	54
<b>Total</b>	<b>67</b>	<b>54</b>	N/A	N/A

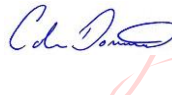
The minimum approval time for any amendment was one day, with a maximum approval time of 83 days. In 2021, 53% of the amendment approvals were adjudicated within 30 days, and 38% were adjudicated within 31-60 days. Amendment requests with a longer timeline represent instances where supporting documents 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**



The Data Stewardship Committee is committed to supporting ongoing improvements to health data access for research in the public interest while safeguarding privacy.

Sincerely,

 Digitally signed by Colin Dormuth  
 DN: cn=Colin Dormuth,  
 o=UBC, ou,  
 email=colin.dormuth@ubc.  
 ca, c=CA  
 Date: 2022.02.16 09:32:49  
 -08'00'

Colin Dormuth

Chair of the Data Stewardship Committee

## Appendix - DSC Members, 2021

Name:	Location:	Position:	By order:	Expiry:
Chang, Ernest	Victoria	Public Member	MO 262, July 7, 2016 MO 473, December 31, 2018 MO 365, October 13, 2019	December 31, 2022
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
Goh, Elaine	Vancouver	College of Nurses and Midwives	MO 483, December 31, 2020 MO 485, December 31, 2021	December 31, 2022
Keirstead, Graeme, Q.C.	Vancouver	Vice-Chair, 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
Moraes, Karen	Surrey	Pharmaceutical Research Rep.	MO 206, May 13, 2021	December 31, 2022
Mussavi, Ali	North Vancouver	Health Authority Rep.	MO 484, December 31, 2020	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 MO 486, December 31, 2021	December 31, 2022
Panagiotopoulos, Dina	Vancouver	Public Member	MO 450, December 31, 2017 MO 472, December 31, 2018 MO 464, December 16, 2020	December 31, 2022
Wong, Shirley Mei-Ling	Victoria	Ministry Representative	MO 122, April 1, 2019 MO 111, March 31, 2021	March 31, 2023