

Data Stewardship Committee

Annual Report for 2022

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 2022, the DSC continued to support researcher access to health data and updated DSC policies respecting the disclosure of health data for research. While all DSC meetings continue to facilitate online participation, September 2022 saw the DSC return to their first in-person/hybrid meeting in recent years.

The DSC received 34 requests for new projects in 2022. This marks a slight reduction from the peak of 35 requests received in 2021 and remains greater than the average number (26) of new requests received from 2016-2020.

Requirement to Report

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

2022 Data Stewardship Committee Activities

Membership and Meetings

The DSC was joined by newly appointed Members Mike Coss (Health Authority Member), Suzanne Malfair (College of Pharmacists Member), and Joseph Puyat (Health Research Member). Please see Appendix A for further details.

The Committee met twelve times in 2022: ten routine meetings, one meeting with the Office of the Information and Privacy Commissioner, and one extra-ordinary policy meeting.

Research Requests for PharmaNet or data from a Health Information Bank

Between January 1st, 2022, to December 31st, 2022, the DSC received a total of 34 new data access requests for PharmaNet data and approved 24 new data requests. Of the 34 new requests received by the Ministry of Health in 2022, 19 were adjudicated by the DSC within 2022 and 15 were carried forward to 2023. 6 new data requests carried forward from 2021 were approved in 2022.

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

The DSC and the OIPC have a practice of meeting annually to discuss issues of mutual interest. The 2022 joint meeting was held on the 15th of June.

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

¹ https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/08038_01#section16

Commissioner must approve all such requests in advance. No new Request to Contact were received or approved in 2022.

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. If a request includes BC's PharmaNet data, the request is adjudicated by the DSC. In 2022, the Committee approved one CIHI request.

Collaboration with the Data Innovation Program (DIP)

Some PharmaNet data are held by the Data Innovation Program (DIP), which is a program that 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. In 2022, the DSC received one DIP request.

Data Stewardship Committee Policies and Procedures

The DSC have cemented the acceptance of digital signatures and the elimination of witness signatures on Declarations of Research Independence.

The Committee stood down the standing sub-committee to address public health emergency related research while retaining the option to recall the sub-committee in the future.

The Committee continued to prepare to accept future requests using the Health Data Platform, including the normalization of a harmonized Data Access Request form for academic requests for either the HDP or PopData environments based on the 5-Safes framework.

Additionally, in 2022, the Committee discussed and refined policy positions on:

- Satisfactory Peer Review
- Documentation of indirect for-profit funds via non-profit society donors
- Building confidence in adjudicating requests using machine learning methods
- New requests continuing work of old requests
- Opportunities for streamlining adjudications (e.g., Consent Agenda eligibility)

Ministry of Health Agreements

All Data Access Requests approved by the Data Stewardship Committee become embedded as an Appendix to Research Agreements signed between the Principal Applicant, their Institution, and the Ministry of Health (represented by the Chief Data Steward).

Approval of Academic Data Access Requests

The Committee is responsible for approving research requests for PharmaNet 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 2010-2022 are shown in Figure 1. Approval times from years before 2020 are based on the date the Ministry received a request, whereas 2020-2022 timeframes are based on the date by which a request 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.

Figure 1 Data Stewardship Committee (DSC) Data Access Requests – New 2010-2022²

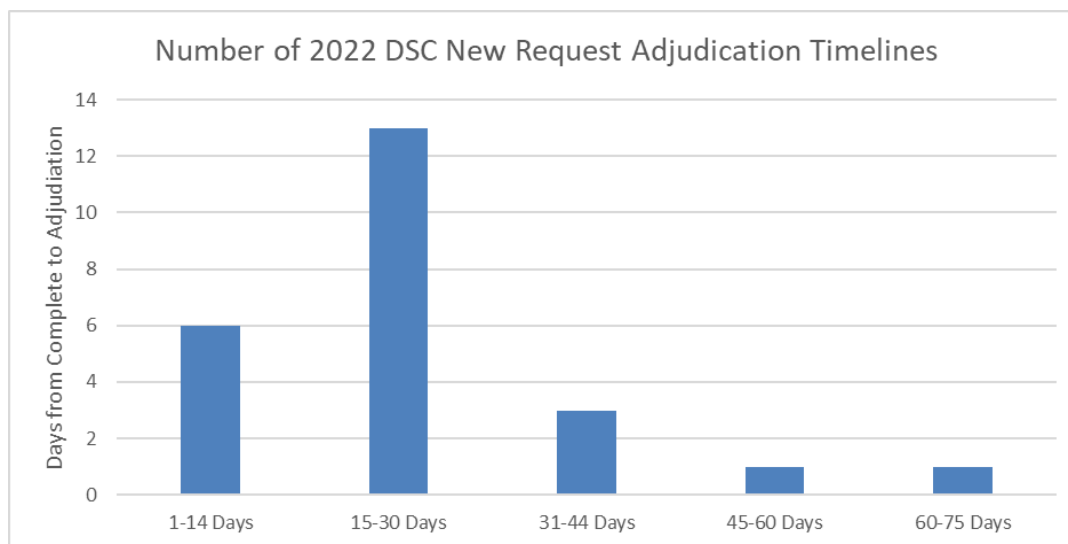
YEAR³	Received (number)	Adjudicated (number)	Min (days)	Max (days)
2010	20	20	31	746
2011	8	8	52	414
2012	7	6	36	125
2013	18	8	35	120
2014	13	21	35	232
2015	24	21	26	173
2016	22	22	17	224
2017	30	30	12	394
2018	23	16	40	186
2019	23	17	35	317
2020	31	30	1	133
2021	35	28	1	56
2022	34	24	5	61

² Metrics from Population Data BC Quarterly Reports and Ministry of Health; Approval times from years before 2020 are based on the date the Ministry initially received the request, from 2020-forward are based on the date by which the request was complete and ready for DSC adjudication.

³ The approval year may not match the submission year due to application date, review/response time, and DSC meeting dates. Approval numbers which are higher than the number received reflect requests awaiting adjudication from the year prior.

Figure 2 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.

Figure 2 DSC Adjudication timelines for new PharmaNet Research Requests, 2022



Of the approved new requests for access to PharmaNet data, 80% were adjudicated within 30 days of a fully 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, resourcing challenges or negotiations between multiple data stewards and the requesting party.

In addition to the 34 new data access requests reflected above, the Committee also received and adjudicated requests for nested Student DAR amendments, extension amendments, and other amendments (primarily data-related). A related summary is found below in figure 3.

Figure 3 DSC Receipt and Adjudication of Amendment-Type Requests, 2022

	Received (number)	Adjudicated (number)
Student DAR amendment	15	17
Extension request	19	18
Data related & other	34	29

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

Sincerely,

Colin Dormuth

Chair of the Data Stewardship Committee

Appendix A - DSC Members, 2022

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
Coss, Michael	Vancouver	Health Authority Rep.	MO 484 December 31, 2021 MO 396 December 31, 2022	December 31, 2024
Dormuth, Colin	Victoria	Chair	MO 449, December 31, 2017 MO 363, December 31, 2019 MO 391 December 31, 2022	December 31, 2024
Elderfield, Andrew	Victoria	Chief Data Steward	MO 525, December 22, 2016	At Pleasure
Keirstead, Graeme	North Vancouver	Vice Chair College of Physicians and Surgeons Rep.	MO 453, December 31, 2017 MO 366, October 13, 2019 MO 392 December 31, 2022	December 31, 2023
Malfair, Suzanne	Vancouver	College of Pharmacists Rep.	MO 482 December 31, 2021 MO 395 December 31, 2022	December 31, 2024
Moraes, Karen	Surrey	Pharmaceutical Research Rep.	MO 206, May 13, 2021 MO 393 December 31, 2022	December 31, 2023
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
Puyat, Joseph	Vancouver	Health Research Rep.	MO 483 December 31, 2021 MO 394 December 31, 2022	December 31, 2024
Wong, Shirley Mei-Ling	Victoria	Ministry Rep.	MO 122, April 1, 2019 MO 111, March 31, 2021	March 31, 2023