

# Data Stewardship Committee Annual Report for 2023

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## Requirement to Report

As per § 16(1) of the *e-Health (Personal Health Information Access and Protection of Privacy) Act*<sup>1</sup>, the Data Stewardship Committee (DSC) is required to report annually on their activities.

This document covers membership and meetings of the DSC, data access requests brought forward for adjudication by DSC as well as collaborations and policy work in 2023.

## 2023 Data Stewardship Committee Activities

### Membership and Meetings

The DSC was joined by newly appointed Public Members Jessy Dame and Susanna Gurr. Sabrina Luke (College of Nurses and Midwives Member) and Shirley Wong (Ministry of Health Member) were reappointed during 2023. Please see Appendix A for further details.

The DSC met 11 times in 2023, primarily through teleconference. An extended in-person meeting was held in May for focused policy discussions.

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<sup>1</sup> [https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/08038\\_01#section16](https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/08038_01#section16)

## Data Access Requests

The DSC adjudicates requests to use data contained in PharmaNet and/or a health information bank for research purposes. These requests may be brought forward via Ministry of Health programs, the Canadian Institute for Health Information (CIHI)<sup>2</sup> or the Data Innovation Program (DIP).<sup>3</sup>

When DSC approves a data access request, a research agreement is prepared. Research agreements are signed by the Principal Applicant, their Institution, and the Ministry of Health (represented by the Chief Data Steward).

Both new data access requests and amendments to existing research agreements are approved by the DSC.

### Counts

#### *New Data Access Requests*

The DSC received 29 requests for new projects in 2023.

- Comparatively, there were 34 requests for new projects in 2022. The average number of new requests received from 2016 to 2022 was 28.
- Of the 29 new requests received in 2023, 14 were adjudicated within 2023, 1 was withdrawn and addressed as an organizational request and 14 were carried forward to 2024.

The DSC adjudicated 30 requests for new projects in 2023.

- Comparatively, 24 requests were adjudicated in 2022. The average number of requests adjudicated from 2016 to 2022 was 24.
- Of the 30 new requests adjudicated in 2023, 1 was received by DSC in 2021<sup>4</sup>, 16 received in 2022 and the remainder received in 2023.
- No CIHI requests were adjudicated in 2023.
- 1 DIP request was adjudicated in 2023.

For historical data, please see Appendix B.

#### *Amendments*

In addition to receiving and adjudicating new data access requests, the DSC also received and adjudicated requests for nested Student DAR amendments, extension amendments and other primarily data-related amendments.

	Received in 2023 (count)	Adjudicated in 2023 (count)
<b>Student DAR amendment</b>	17	10
<b>Extension request</b>	13	12
<b>Data related &amp; other</b>	24	17

<sup>2</sup> 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.

<sup>3</sup> PharmaNet data can be requested for research purposes through 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.

<sup>4</sup> The request submitted in 2021 was submitted incomplete and spent over 14 months awaiting revisions.

## Timelines

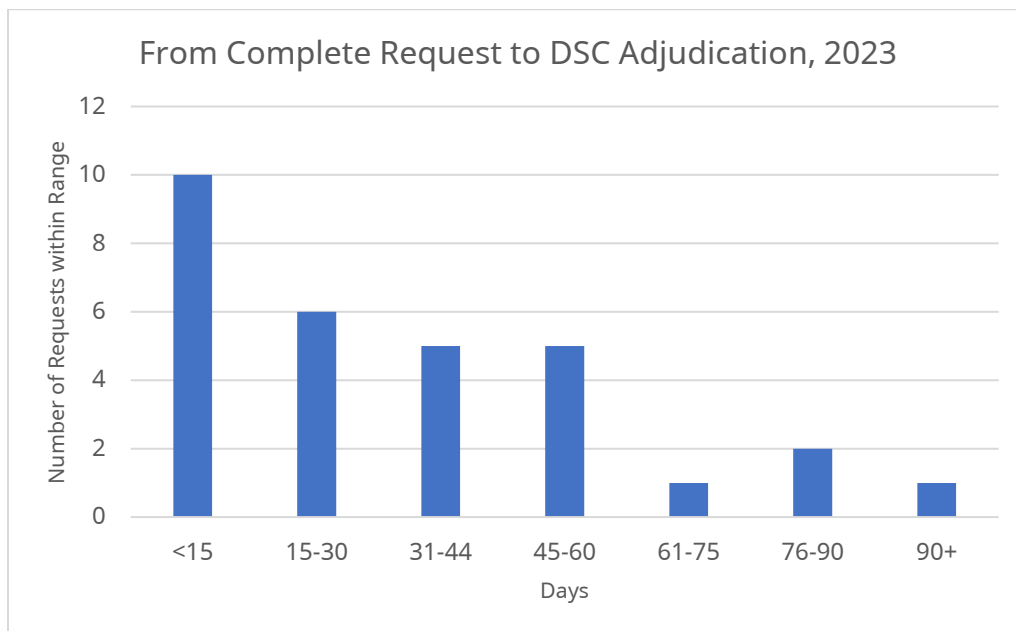
There are several steps in the data access request process. Both application completion and data provisioning may add significantly to the total wait time experienced by the researcher.



### New Data Access Requests

In 2023, the average duration from request ready, i.e., complete & unambiguous, to DSC adjudication was 33 days.

53% of new data requests were adjudicated within 30 days of being ready. 87% within 60 days.



For historical data, please see Appendix B.

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

The DSC and the OIPC meet annually to discuss issues of mutual interest. The 2023 joint meeting was held on November 20<sup>th</sup>.

The “Request to Contact” process framework was established through collaboration across the DSC, the Ministry of Health, 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 DSC and the Information and Privacy Commissioner must approve all

such requests in advance. No new Requests to Contact were received or approved in 2023. One existing research project that included a previous Request to Contact was amended.

## Data Stewardship Committee Policies and Procedures

To ensure the required reporting between the provincial and federal governments could be completed, the DSC considered and passed a motion recommending disclosure directives not be made in relation to the Medical Assistance in Dying Oversight Repository health information bank.

Additionally, the DSC discussed policy including:

- Declarations of Research Independence
- Maximum DAR Data Retention/Extension Policy
- DSC Member Conflict of Interest Policy
- Indirect for-profit funding via non-profit societies that receive for-profit donations
- Aligning with CABRO guidance for Level 2 Boards and best practices for equity and retention by providing per-meeting remuneration for DSC Members not supported by a salary or stipend
- Linkages with data fields from datasets other than the First Nations Client File (FNCF) related to Indigeneity

The Data Stewardship Committee is committed to supporting ongoing improvements to health data access for research in the public interest while safeguarding privacy. Strategies to improve the timeliness of different steps in the data access request process continue to be explored.

Sincerely,



Colin Dormuth

Chair of the Data Stewardship Committee

## Appendix A: DSC Membership 2023

<b>Name:</b>	<b>Location:</b>	<b>Position:</b>	<b>By order:</b>	<b>Expiry:</b>
<b>Coss, Michael</b>	Vancouver	Health Authority Rep.	MO 484 December 31, 2021 MO 396 December 31, 2022	December 31, 2024
<b>Dame, Jessy</b>	Surrey	Public Member	MO 83 March 27, 2023	March 31, 2025
<b>Dormuth, Colin</b>	Victoria	Chair	MO 449, December 31, 2017 MO 363, December 31, 2019 MO 391 December 31, 2022	December 31, 2024
<b>Elderfield, Andrew</b>	Victoria	Chief Data Steward	MO 525, December 22, 2016	At Pleasure
<b>Gurr, Susanna</b>	Burnaby	Public Member	MO 84 March 27, 2023	March 31, 2025
<b>Keirstead, Graeme</b>	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
<b>Luke, Sabrina</b>	Vancouver	BC College of Nurses and Midwives Member	MO 397 December 29, 2022 MO 415 December 10, 2023	December 31, 2026
<b>Malfair, Suzanne</b>	Vancouver	College of Pharmacists Rep.	MO 482 December 31, 2021 MO 395 December 31, 2022	December 31, 2024
<b>Moraes, Karen</b>	Surrey	Pharmaceutical Research Rep.	MO 206, May 13, 2021 MO 393 December 31, 2022	December 31, 2023
<b>Nguyen, Julie</b>	Burnaby	Public Member	MO 398 December 29, 2022	December 31, 2023
<b>Puyat, Joseph</b>	Vancouver	Health Research Rep.	MO 483 December 31, 2021 MO 394 December 31, 2022	December 31, 2024
<b>Wong, Shirley Mei-Ling</b>	Victoria	Ministry Rep.	MO 122, April 1, 2019 MO 111, March 31, 2021 MO 85 March 27, 2023	March 31, 2025

## Appendix B: New Data Access Requests Adjudicated by the DSC, 2010 to 2023

<b>Year</b>	<b>Received (count)</b>	<b>Adjudicated (count)</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
<b>2022</b>	34	24	5	61
<b>2023</b>	29	30	1	153

### Notes:

- Metrics are from Population Data BC Quarterly Reports and the Ministry of Health.
- Approval times from years before 2020 are based on the date the request was initially received to when the request was adjudicated by DSC. For 2020 to present, approval times are based on the date by which the request was ready, i.e., complete & unambiguous, to DSC adjudication.
- Depending on application date, review/response time, and DSC meeting dates, a request may not be adjudicated in the same year it is received.