Frequently Asked Questions

Research Data Requests at CCO

1. What is involved in a typical research data request?

A typical research data request takes several months to complete. Once the completed Application Package is submitted, a feasibility assessment is conducted to ensure CCO has the data being requested, and that we have the ability to complete the request. The Data Disclosure Team at CCO then works with the requestor to draft the Dataset Creation Plan and estimate the cost of the request. The request is reviewed by the Data Disclosure Working Group, which is comprised of research, privacy and data subject matter experts. The Working Group recommends the request for approval by the Data Disclosure Subcommittee. Once approved, the CCO analyst can begin the work, which may include creating a study cohort, extracting the data required, linking multiple datasets, and quality assurance steps. Some dialogue with the research team will be required. Upon completion of the data extraction and quality check, the data is disclosed in a secure manner.

2. Is REB approval required for all research requests?

Yes. At CCO, the disclosure of record-level data for the purposes of a research project requires the prior approval of a Research Ethics Board (REB). CCO requires that the approving REB comply with the requirements set out in Ontario's *Personal Health Information Protection Act (PHIPA)* and its Regulations. As part of the Research Data Request Intake Form, please provide a copy of the REB approval letter.

The ***Personal Health Information Protection Act, 2004*** is an Ontario law that governs the collection, use and disclosure of personal health information (PHI) within the health sector. The objective is to keep PHI confidential and secure, while allowing for the effective delivery of health care. Under this legislation, persons and organizations that provide health care are collectively known as "health information custodians."

3. At what point during my research project should I contact CCO with questions about my data request or the data request process?

We encourage you to contact the Data Disclosure Team as early in your research approval process as possible. By contacting the team early, you will get a better understanding of data availability and its limitations, expected request timelines, and estimated costs associated with your data request. Please note that despite this initial review by the Data Disclosure Team prior to grant and ethics approval, the Application Package will not be considered complete without all of the required documentation.

4. What is the Application Package deadline for submission?

Month (Year 2017)	Complete Application Package Submission Deadline
January	12/21/2016
February	1/18/2017
March	2/15/2017
April	3/22/2017
May	4/19/2017
June	5/24/2017
July	6/21/2017
August	7/19/2017
September	8/23/2017
October	9/20/2017
November	10/18/2017
December	11/22/2017

Please note, your application will not be reviewed at the next WG meeting if submitted after the deadline, if the package is incomplete, or if there are outstanding questions about any component of the Application Package.

A review by the Data Disclosure Working Group does not guarantee approval by the Data Disclosure Subcommittee.

5. Does cost recovery apply to all data requests?

Yes, an administrative fee, as well as an hourly analytical fee will be applied to all research data requests. The administrative fee accounts for the time and effort required for an initial feasibility assessment, completing the Dataset Creation Plan, as well as bringing research data requests before the Data Disclosure Subcommittee. The analytical fee accounts for all of the work of data analysts, which may include creating a cohort for the study, extracting the data required, linking multiple datasets, and quality assurance steps.

6. How do I estimate the cost of my data request for the purposes of a grant submission?

Where requested, the Data Disclosure Team will support researchers in their grant submission by providing a cost estimate of the data request in advance of submission of the Application Package. The accuracy of the estimate will depend on the level of detail the research team provides about the data they will be requesting. The estimate will be based on the complexity of the data request (e.g. size of the cohort, number of databases to be linked, number of data elements etc.). However, provision of a cost estimate does not guarantee approval by the Data Disclosure Subcommittee.

7. How long will it take to complete my request?

The length from intake to data disclosure will depend on several factors, including the completeness of Application Package and the complexity of the request. A fulfillment time estimate will be provided as part of the Dataset Creation Plan.

Requestors should plan for approximately 2 months from the submission of the Application Package to the approval of the request by the Data Disclosure Subcommittee. This length of time can be reduced if the Research Data Request Form is **as complete as possible**.

The complexity of your request is determined by the number of data sources required, the type of data required (some datasets are more complex than others), the size of your study cohort, whether the cohort is generated by the CCO analyst, as well as the type of quality assurance steps required.

For simple data requests, where the data is derived from a single dataset (e.g. the Ontario Cancer Registry only), the estimated fulfillment time is 60 business days from Data Disclosure Subcommittee approval. For a complex request (where data is derived from multiple data sources and a cohort is generated by the CCO analyst), a fulfillment time estimate will be provided as part of the Dataset Creation Plan.

8. What documents are required to complete the Research Request Intake Form?

In order to complete the Application Package, the following documents are required:

- Research protocol;
- Approval letter from a Research Ethics Board (REB). The REB must meet the requirements of s.44(2) of the Personal Health Information Protection Act, 2004 (PHIPA) and s.16 of Ontario Regulation 329/04 (see FAQ #2 for more information on PHIPA and REB);
- Copy of the REB application form, including relevant requests for amendments;
- Evidence of funding approval to cover costs associated with the data request;
- Name of the sponsoring organization and/or grant details; and,
- Components of the dataset creation plan (if applicable).

Please note, the information across all documents must be consistent.

9. Who oversees CCO's data disclosure process?

The Data Disclosure Working Group and the Data Disclosure Subcommittee (DDSC) form the governance structure within CCO that reviews and approves all research data disclosures. Prior to obtaining request approval by the DDSC, all research data requests undergo an extensive review by the Data Disclosure Working Group. The Working Group is comprised of CCO research, privacy and data subject matter experts. The DDSC also oversees the policies and procedures associated with data disclosure at CCO.

10. How are data classified at CCO (i.e. aggregate vs. record-level)?

CCO data is classified according to the following schema:

a) Identifiable Record-Level Data: Data that includes elements that directly identify an individual. By definition, identifiable record-level data contains PHI.

b) De-identified Record-Level Data**:** Data that includes elements that may constitute identifying information because there may be reasonably foreseeable circumstances in which the data could be utilized, alone or with other information, to identify an individual (e.g. if linked with publicly available data). Thus, de-identified record-level data may contain PHI.

c) Aggregate Data**:** Summed and/or categorized data that is analyzed and placed in a format that precludes further analysis (for example, in tables or graphs) to prevent the chance of revealing an individual's identity (individual records cannot be reconstructed). Aggregate data does not include PHI.

d) Published Data**:** Data that is made available to the public. Published data does not include PHI.

11. How do I know what datasets and data elements are available at CCO?

CCO's DataBook summarizes the data elements available in commonly-requested datasets, including: ALR, WTIS, NDFP, ePath, CIRT, ORRS and DAP-EPS: https://www.cancercare.on.ca/ext/databook/db1516/).

For a summary of data elements for OCR, OHIP eClaims, CIHI DAD or CIHI NACRS, please email datarequest@cancercare.on.ca.

12. How do I get access to CCO data for a new individual on my study team?

The Research Data Disclosure Agreement (RDDA) is used to add new individuals requiring access to CCO data. The following steps outline the process:

a. New individual fills out schedule B of the RDDA and signs Schedule A of the RDDA
b. The Principal Investigator signs pages 6 and 11 of the RDDA
c. Primary Contact sends a copy of the signed agreement to datareqeust@cancercare.on.ca
d. Appropriate CCO representatives sign the RDDA
e. The Data Disclosure Team sends a copy of the fully executed agreement to the Primary Contact and Principal Investigator
f. New individual can access CCO data

13. What is the preferred method of data transfer for CCO?

For the purposes of data disclosures, CCO's method of choice is Managed File Transfer (MFT). MFT is used to provide secure external data transfers through a network. Users can send or receive files using a client application or via a web interface. During the intake phase of your data request, the Data Disclosure Team will provide you with a form to set up an MFT account. Once the MFT account is set up, you will be provided with further instructions on how to access the data files.

14. What are the Information & Privacy Commissioner (IPC) Fact Sheets and how do I access them?

CCO uses the IPC to guide the security and protection of CCO's identifiable record level data. The following are the relevant Fact Sheets for research data disclosure in Ontario:

- Fact Sheet #16: Health-Care Requirement for Strong Encryption, July 2010
- Fact Sheet #12: Encrypting Personal Health Information on Mobile Devices, May 2007
- Fact Sheet #14: Wireless Communication Technologies: Safeguarding Privacy & Security
- Fact Sheet #10: Secure Destruction of Personal Information, December 2005
- Best Practices for the Secure Destruction of Personal Health Information, October 2009

All Fact Sheets can be found at: https://www.ipc.on.ca/english/phipa/PHIPA-Fact-Sheets/

15. How long can I retain CCO data?

Data disclosed by CCO for research purposes must not be retained for a period longer than the time set out in the approved research protocol. Researchers must return or destroy all data provided by CCO within 60 days of the date indicated on the Research Data Request Form.

16. What should I do with CCO data once it is no longer needed?

CCO data must be returned to CCO or destroyed within 60 days of the date indicated on the Research Data Request Form. The researcher should supply CCO with a Certificate of Destruction setting out the date, time and location of the secure destruction, the method of secure destruction employed, as well as details of the items destroyed. The Certificate of Destruction will bear the signature of the persons who securely destroyed the information. A Certificate of Destruction from a third party service provider will be acceptable if it contains all of this information required. A copy of a Certificate of Data Destruction can be obtained by contacting datarequest@cancercare.on.ca.

Should you want to return data to CCO, please contact the Data Disclosure Team in advance in order to confirm the appropriate transfer method. Question 13 lists some of the acceptable methods of data transfer.

17. Where should I send my questions about the data request process?

Contact the Data Disclosure Team using Datarequest@cancercare.on.ca.