**Research Data Request Form**

When to use this form

This form is used to request data from CCO to support a research study. Requests for data for non-research purposes should be made using one of the appropriate forms located on the CCO website: <https://www.ccohealth.ca/en/request-data-for-research>. Requests for cost estimates should be directed to: Datarequest@cancercare.on.ca.

Sections of this form to be completed:

## [CONTACT INFORMATION](#_CONTACT_INFORMATION)

## [PROJECT DESCRIPTION](#_PROJECT_DESCRIPTION)

## [RESEARCH APPROVALS](#_RESEARCH_APPROVALS)

## [DATASET CREATION PLAN](#_DATASET_CREATION_PLAN)

## [DATA LINKAGES, DATA FLOW AND FUTURE DATA REQUESTS](#_DATA_LINKAGES,_DATA)

## [PHIPA REB PLAN COMPLIANCE CHECKLIST](#_F._PHIPA_REB)

## TIMELINE FOR DATA RETENTION, AND DESTRUCTION

## [CO-INVESTIGATOR(S) AND PERSONS WHO MAY HAVE ACCESS TO REQUESTED DATA](#_H.CO-INVESTIGATOR(S)_AND_PERSONS)

Please ensure the appropriate signature is provided in section G.

Append the following documents to complete your Application Package:

1. Research plan
2. 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 the FAQs for more information on PHIPA);
3. Copy of the REB application form, including relevant requests for amendments;
4. Evidence of funding approval to cover costs associated with the data request;
5. Components of the dataset creation plan (if applicable).

## Submit your completed form to Datarequest@cancercare.on.ca. Please ensure information provided is consistent across all documentation.

Research Data Request Process

CCO’s research data request process is broken up into 5 key steps:

* **Intake** – The intake phase begins with the submission of a complete data request Application Package to datarequest@cancercare.on.ca . During this phase, the Data Disclosure team will review your Application Package for completeness and will provide you with a request number assigned to your project.
* **Review** – The review phase involves a detailed review of your Application Package by CCO to determine data availability, limitations and request feasibility. It is during this phase that the Data Disclosure Working Group (DDWG), comprised of CCO subject matter experts reviews your Application Package and makes a recommendation for approval. Your team may be contacted during the review to clarify any questions and to instruct your team about any application changes. You will also be provided with a cost estimate.
* **Approval** – With approval from the DDWG, and once all outstanding items have been addressed, the Data Disclosure Subcommittee (DDSC is the governing body at CCO that oversees data disclosure) reviews the updated Application Package and approves the request. Following approval, the Research Data Disclosure Agreement (RDDA) is executed, and the administrative fee invoice is issued.
* **Fulfilment** – Fulfillment begins after the RDDA is fully executed. An analyst assigned to your project and work with the research team to finalize the Dataset Creation Plan and begin data extraction. Depending on the complexity of your request, more than one analyst from more than one team within CCO might be working on the data extraction and quality check of data.
* **Disclosure** - Once the data request is completed, and the administrative invoice payment has been received, data is disclosed using the appropriate method. The final invoice for analytical hours is issued to the PI.

Cost Recovery

A cost estimate for your request will be provided in advance of fulfilment. The PI will be asked to return a signed copy of the cost estimate to CCO. An administrative fee and an hourly analytical fee will be applied to all requests as follows:

* The administrative fee ($2100) accounts for the time and effort required for an initial feasibility assessment, completing the dataset creation plan, and bringing research data requests before the Data Disclosure Subcommittee.
* The analytical fee ($75/hr) accounts for 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.
* Pathology report fee ($37.50/hr) accounts for the work required to extract reports from CCO’s pathology databases.

Request Timeline

The length of the intake, review and approval for each data request varies based on the complexity of the data request and completeness of the Application Package. Requestors should plan for approximately 2 months from the submission of the completed Application Package to the approval of the request by the Data Disclosure Subcommittee (DDSC). Please note, the Data Disclosure Working Group will not review the request until the Application Package is complete, including REB approval.

Once a research request is approved by the DDSC and the Research Data Disclosure Agreement (RDDA) has been signed a data analyst is assigned to the work. For simple data requests, where the data is derived from a single dataset, the estimated fulfillment time is 60 business days from signature of the RDDA and payment of the administrative fee. For a complex request, where the data is derived from multiple data sources, a fulfillment time estimate will be provided and agreed upon with the research team (usually 60 business days or more). Please note, no data will be disclosed without a signed RDDA and payment of the administrative fee.

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| RESEARCH DATA REQUEST INFORMATION |
| CONTACT INFORMATION |
| Name of Principle Investigator | Click here to enter text. |
| Role/Title | Click here to enter text. |
| Name of Organization  | Click here to enter text. |
| Address  | Click here to enter text. |
| Phone  | Click here to enter text. |
| Email | Click here to enter text. |
|  |
| Name of Primary Contact  | Click here to enter text. |
| Role/Title |  Click here to enter text. |
| Name of Organization  | Click here to enter text. |
| Address  | Click here to enter text. |
| Phone  | Click here to enter text. |
| Email | Click here to enter text. |
| Please complete the Additional Research Team Members section at the end of this form with additional names of all Co-Investigator(s) and person(s) who will have access to requested data. |
| PROJECT DESCRIPTION |
| 1. Project Title | Click here to enter text. |
| Research Purposeand Clinical Relevance  | **Briefly describe the purpose of the research project, stating the research question or hypothesis to be examined and the clinical relevance of research findings.**Click here to enter text. |
| 2. Research Plan Append a full REB-approved research plan describing the research project. The research plan should include the objectives, methodology, and the anticipated public and/or scientific benefit. |
| 3. Analytical PlanDescribe the proposed analysis using CCO data.Click here to enter text. |
| RESEARCH APPROVALS |
| 1. Funding and Granting InformationDoes this research study have approved funding?[ ]  Yes [ ]  NoFunding Organization: Click here to enter text.Period of Grant: [ ]  N/AFrom: Click here to enter a date. To: Click here to enter a date.Amount of Grant: Click here to enter text. [ ]  N/A Amount available for data request: Click here to enter text. |
| 2. Ethics Approval Status Identify all Research Ethics Boards (REBs) who reviewed the research proposal, the status of the application(s), and any decision from each.  |
| REB | **Current Status** |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| NOTE: The REB(s) providing approval must demonstrate compliance with PHIPA under O.Regs 329/04 s.15 |
| DATASET CREATION PLAN |
| 1. Access to Existing DataDoes some or all of this request include access to an existing data set for a new research purpose?  [ ]  Yes [ ]  NoIf yes, please complete the table below |
| CCO Data Disclosure Request # | **PI Name** | **Study Title** | **Current Data Custodian**  |
| Click here to enter text. | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. | Click here to enter text. |  |
| 2. Data RequiredList all requested datasets and data elements in the table below. Where required, reference the Frequently Asked Questions for details about available data elements.*Note: The information listed in the table below (including the exact list of data elements, data sources, years and purpose of use) should also appear in the REB approved plan.*  |
| Dataset | **Variable(s)****List all required variables in a single cell** | **Year(s)** | **Rationale or Purpose of Use** |
| Choose an item. | Click here to enter text. | Click here to enter text. | Click here to enter text. |
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| 3. Inclusion CriteriaSpecify all inclusion criteria for data extraction. If subjects need to be identified by CCO, outline how they should be identified (e.g. index event [specific cancer, disease or procedure codes, timeframe for entering study, age restrictions, geographical location etc.). [ ]  Not ApplicableClick here to enter text. 4. Exclusion CriteriaSpecify all exclusion criteria for data extract.[ ]  Not ApplicableClick here to enter text.5. Cohort DetailComplete this section if the cohort will be provided to CCO.[ ]  Not ApplicableWhat variables will be provided to CCO to perform the linkage?Click here to enter text.6. Study DesignPlease specify the study design for this request (e.g., cohort study, case-control, data-cut). Click here to enter text.7. Study SizeOutline all groups involved in study (e.g. exposed, unexposed, cases, controls). If the number of study cases differs from the number of cases in the cohort applicable to this data request, please indicate. [ ]  Not ApplicableClick here to enter text.8. Preferred Format and Output VariablesSpecify the preferred format of the completed data (e.g., SAS file, Excel). Where possible, attach a template. If output should be formatted in a particular way, define how this should be done (e.g. age groups: 21-30, 31-40, 41-50, 51-54, 54+). Click here to enter text.9. Other ConsiderationsIf there are other important considerations that need to be captured, indicate them here.Click here to enter text. |
| DATA LINKAGES, DATA FLOW AND FUTURE DATA REQUESTS |
| 1. Data LinkagesComplete table below if the research involves linking CCO data to other datasets. Add rows to the table as required.  |
| Planned data linkages(list the databases that will be linked to CCO data) | **What variables will be used for the linkage?** |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
| Click here to enter text. | Click here to enter text. |
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| If CCO data is to be linked to other data include an explanation of why such linkage is necessary: Click here to enter text. 2. Data FlowBriefly describe how data, including CCO data, will be collected, linked, used, disclosed and retained for the purposes of this research study. (e.g. what data will come from where, where will the data go next, how will the data be transferred, how it will be used etc.)Click here to enter text.*NOTE:* * *Records of personal health information disclosed by CCO for research purposes must not be retained for a period longer than set out in the approved research plan. Researchers must destroy all data provided by CCO within 60 days of the date listed above.*
* *Assertions of the destruction of information will require that researchers supply CCO with a Certificate of Destruction setting out the date, time and location of the secure destruction and 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.*

Please contact Datarequest@cancercare.on.ca for a certificate of data destruction if required.3. Permanent Linkages Will CCO data will be permanently linked for your research project? (e.g. Does the research plan include data being kept indefinitely?)Yes [ ]  No [ ]  Click here to enter text.4. Future data requestsAre you planning to obtain additional CCO data for the purposes of this study in the future?Yes [ ]  No [ ]  If yes, please include any relevant information about future data requests in the table below (e.g. include what data elements will be requested, the data sources, years and request timelines). With this information, CCO *may* be able to expedite the review and approval process.  |
| Dataset | **Variable(s)** | **Year(s)** | **Expected future request date** |
| Choose an item. | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Choose an item. | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| Choose an item. | Click here to enter text. | Click here to enter text. | Click here to enter text. |
| G. TIMELINE FOR DATA RETENTION AND DESTRUCTION Date when access to PHI level data provided by CCO will no longer be required (I.e., when do you plan to destroy identified CCO data): Click here to enter a date. Date when access to de-identified CCO data will no longer be required (I.e., when do you plan to destroy all data):Click here to enter a date. |

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| Research Privacy RequirementsF. PHIPA REB PLAN COMPLIANCE CHECKLISTIn order to disclose data for research purposes, CCO must meet all of the requirements of the *Personal Health Information Protection Privacy Act, 2004* (PHIPA). The table below helps CCO understand how the research project meets each privacy requirement and where it is reflected in the REB application(s). \*Please DO NOT add text to this table – only note the document and page numbers. |
|  | **Requirement** | **Reference documents (e.g. REB Plan etc.)** | **Relevant section and page(s) where addressed** |
| 1. | REB approved Research Plan which includes: 1. The affiliation of each person involved in the research
2. The nature and the objectives of the research
3. The anticipated public or scientific benefit of the research.
 |  |  |
| 2. | Description of the research proposed to be conducted  |  |  |
| 3.  | Duration of the research  |  |  |
| 4. | Description of CCO data required and the sources (Note: please include a list of data elements and the source database(s) in the research plan) |  |  |
| 5. | Description of how PHI (including CCO’s data) will be used in the research study, including **linkages** to other data (description and/or source) as well as **how** the linkage(s) will be conducted. Please provide a detailed data flow as part of this requirement. |  |  |
| 6. | Explanation as to why the research:1. Cannot reasonably be accomplished without PHI (including CCO’s data)
2. Requires linkages outlined
 |  |  |
| 7. | Explanation as to why consent to the disclosure of PHI is not being sought from the individuals to whom the information relates, if applicable (e.g. if it is impossible or impracticable to address the research question if the prior consent of individuals is required)[[1]](#footnote-1) |  |  |
| 8. | Description of the reasonably foreseeable harms and benefits that may arise from the use of PHI (including CCO’s data) and how the researchers intend to address those harms. |  |  |
| 9.  | Description of:1. all persons who will have access to the information and
2. why access is necessary
3. Their roles in relation to the research and their related qualifications
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| 10. | Safeguards that the researcher will impose to protect the confidentiality and security of CCO data, **including** an estimate of how long information will be retained in an identifiable form and why. |  |  |
| 11.  | Information as to how and when the researcher will dispose of CCO data (please provide information for all copies including de-identified data if applicable) |  |  |
| 12.  | Funding source of the research |  |  |
| 13.  | Whether the researcher's interest in the disclosure of PHI or the performance of the research would likely result in an actual or perceived conflict of interest with other duties of the researcher |  |  |
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| 5. Acknowledgements by Principal Investigator The Researcher is requesting record level data from CCO. The Researcher understands and acknowledges that records requested may contain confidential personal health information (PHI) about individuals, including potentially identifiable information such as diagnoses dates, and names of physicians or hospitals, or may otherwise be in a form where individuals may be identifiable. If access to these records is approved, the Researcher must abide by the provisions of CCO’s Research Data Disclosure Agreement (RDDA).The Principal Investigator (PI) acknowledges and understands that the records requested may contain identifiable, record-level personal health information (PHI). If this information is released to the PI, the PI must abide by the provisions of CCO’s Research Data Disclosure Agreement (RDDA). If and when this request is approved by CCO, the PI and all those who will have access to the data will sign the required Non-disclosure/Confidentiality Agreement for Researchers before the data is provided by CCO. The PI will also provide a purchase order for the amount to be specified by CCO and pay the invoice promptly. In situations where the PI or others who will have access to data are students, the students’ academic supervisor or advisor is also required to sign the Non-disclosure/Confidentiality Agreement.1. The PI agrees to ensure that cell sizes less than or equal to 5 will not be reported without prior written approval from CCO.
2. The PI agrees to only conduct data linkages in accordance with the approved Research Proposal.
3. The PI agrees that the retention period for data received from CCO indicated in section F is consistent with the retention period set out in the approved Research Proposal.
4. The PI agrees to ensure security and protection of identifiable record level data in accordance with best practices, including the Information & Privacy Commissioner, Ontario *Fact Sheet # 16: Health-Care Requirement for Strong Encryption, Fact Sheet # 12: Encrypting Personal Health Information on Mobile Devices* and *Fact Sheet #14: Wireless Communication Technologies: Safeguarding Privacy & Security* (see FAQs for more information on IPC Fact Sheets).
5. The PI agrees to ensure that data returned or destroyed be done in a secure manner in accordance with the Information & Privacy Commissioner, Ontario *Fact Sheet # 10: Secure Destruction of Personal Information* and *Best Practices for the Secure Destruction of Personal Health Information.*
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| The Principal Investigator certifies that the information reported in this form and the appended Research Project Proposal, REB application and any other relevant supporting documents are accurate and agrees to comply with the terms and conditions contained in this form. |
| Name of Principal Investigator | Click here to enter text. |
| Title | Click here to enter text. |
| Signature |  |
| Date | Click here to enter a date. |

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| Additional Research Team Members |
| H.CO-INVESTIGATOR(S) AND PERSONS WHO MAY HAVE ACCESS TO REQUESTED DATA |

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| List all Co-Investigator(s) (CO-I) and other persons who may have access to the data. Please print additional copies of this page as required.  |
| Name | Click here to enter text. |
| Role/Title | Click here to enter text.**Co-I** [ ]  |
| Name of Organization  | Click here to enter text. |
| Email | Click here to enter text. |
| Why is access required for this person? | **If access to CCO data is not required, enter N/A**Click here to enter text. |
|  |
| Name | Click here to enter text. |
| Role/Title | Click here to enter text.**Co-I** [ ]  |
| Name of Organization  | Click here to enter text. |
| Email | Click here to enter text. |
| Why is access required for this person? | **If access to CCO data is not required, enter N/A**Click here to enter text. |
|  |  |
| Name | Click here to enter text. |
| Role/Title | Click here to enter text.**Co-I** [ ]  |
| Name of Organization | Click here to enter text. |
| Email | Click here to enter text. |
| Why is access required for this person? | **If access to CCO data is not required, enter N/A**Click here to enter text. |

1. Article 3.7- http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter3-chapitre3/#ch3\_en\_a3.7a [↑](#footnote-ref-1)