



Patient Level Data Access Requests

Cancer in Young People in Canada/ Cancer Chez les Jeunes au Canada program (CYP-C /CCJC)

The Cancer in Young People in Canada/ Cancer Chez les Jeunes au Canada program (CYP-C /CCJC) is a collaborative effort between the Public Health Agency of Canada (PHAC) and the C¹⁷ Council.

1. Research proposal (attach additional pages as necessary for each section):

a) Project title

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b) Name, address and affiliation of Principal Investigator and co-investigators

Name		Access to patient level data? Y	N
Role	Principal Investigator		
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
Role	Co-Investigator		
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
Role			
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			



- c) Name, address and affiliation of other individuals (ex. Research co-ordinator, statistician, admin support) who will have access to the data.

Name		Access to patient level data? Y	N
Role			
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
Role			
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
Role			
Address			
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Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
Role			
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			

c) Name, address and affiliation of other individuals (ex. Research co-ordinator, statistician, admin support) who will have access to the data. [continued]

Name		Access to patient level data? Y	N
Role			
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
Role			
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
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Affiliation			
Reason for Access			
Related Qualifications			
Name		Access to patient level data? Y	N
Role			
Address			
Phone			
Email			
Affiliation			
Reason for Access			
Related Qualifications			



d) Background

e) Objectives and rationale



f) References (optional)

-) Planned method(s)/proposed analysis including all sub-group analyses planned. *If post-hoc sub-group analysis is planned, the CYP-C Data Access, Use and Publications Committee must be notified in writing prior to conducting the analysis.

Those using the data will not attempt to link or allow others to link the data with individually identified records in another database without approval from the Data Access, Use and Publications Committee. See section 5.

) Publication/Knowledge Translation plan

) Time schedule for the proposal including anticipated date of completion:

- Anticipated start-up date (dd/mm/yy): _____
- Anticipated time to completion (months): _____
- Anticipated time data will be retained in identifiable form and the reason:

Describe retention and disposal policies to be applied to this project:

- Document shredding Y
- Destruction of electronic media (magnetic and optic disks, cartridges, CDs) Y
- Anticipated dataset destruction date (dd/mm/yy): _____

2. Funding and ethics approval

- a) Is funding available to conduct the proposed work? **Y**
- b) If yes, indicate the funding source for the proposed work

- c) Has Research Ethics Board approval already been obtained? **Y**
If yes, attach submitted proposal and approval letter

3. The CYP-C Data Access, Use and Publications Committee will adjudicate applications based upon the following considerations:

- a) Duplication with previously approved proposal.
- b) Project feasibility and availability of requested data elements.
- c) Scientific validity.
- d) Importance/relevance to childhood cancer.
- e) Timeline for completion and publication.
- f) Investigative teams with representation from at least 2 provinces will be encouraged when the national data set is being used. The purpose of this request is to foster collaboration across sites.

4. Prior to release of Data, researchers must ensure:

- a) Approval by the CYP-C Data Access, Use and Publications Committee.
- b) Data Security and Privacy
 - Submission of a signed Data Confidentiality and Publication Agreement to CYP-C Data Access, Use and Publications Committee by all project staff. [] **Y**
 - Methods of protection must include:
 - physical measures such as locked filing cabinets and locked access to offices; [] **Y**
 - organizational measures such as security clearances and limiting access on a “need to know” basis; [] **Y**
 - electronic copies of the information must be stored in a computer that is not connected to the Internet unless it is appropriately safeguarded (i.e., firewalls, up-to-date anti-virus software, etc); [] **Y**
 - access to the records are protected by passwords specific to those records (secured independently from the password required to access the computer); [] **Y**
 - data will not be transmitted by email or carried on a mobile device such as a USB key unless encrypted. [] **Y**
 - Data will not be published or presented in which an individual is identifiable. In addition to small cell sizes, information on any single individual will not be published. [] **Y**
- c) Data on Ontario-only cohorts may not be presented as those requests must be submitted directly to the Pediatric Oncology Group of Ontario
- d) A copy of institutional REB approval and application must be received by Data Access, Use and Publication Committee.

5. Linkage with other Datasets (if applicable - attach additional pages as necessary for each section)

a) Indicate why this research can not reasonably be accomplished without a link to other information:

b) Indicate the dataset to be linked to and describe its purpose:

c) Indicate the CYP-C data elements to be linked and the linkage process: