

**PEDIATRIC ONCOLOGY GROUP OF ONTARIO (POGO)
 PROJECT-SPECIFIED PRIVACY IMPACT ASSESSMENT FORM
 (FOR ALL POGO PROJECTS – *must be accompanied by POGONIS Data Request Form*)**

| |
|-------------------------|
| A. PROJECT TITLE |
| |

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|-----------------------|
| B. THE PROJECT |
|-----------------------|

1) Full written proposal appended [] Y

2) Name the project participants/staff. Provide qualifications and contact details here **or** on attached sheet (**required**). At least one POGO scientist must be named for all projects as Investigator or Co-investigator.

| Role | Name | Phone | E-mail |
|---|------|-------|--------|
| Principal Investigator and Co-investigators | | | |
| Research Coordinator | | | |
| Programmer/ Biostatistician | | | |
| Admin Support | | | |

3) Please provide the affiliation of each person noted above who will have access to personal Health Information and the reason why it is necessary for this individual to have access.

| | |
|-------------------------|-------|
| Name: | _____ |
| Affiliation: | _____ |
| Reason for Access: | _____ |
| Related Qualifications: | _____ |
| | |
| Name: | _____ |
| Affiliation: | _____ |
| Reason for Access: | _____ |
| Related Qualifications: | _____ |
| | |

4) Is data to be linked with other datasets? _____ → [] **Y** [] **N**

5) If you answered yes to #4, please indicated why this research cannot reasonably be accomplished without a link to other information?

6) What types of data are being used (check all that apply)? Identify those which are being linked to administrative datasets.

| Type | To be linked |
|---|--------------------------|
| <input type="checkbox"/> other administrative | <input type="checkbox"/> |
| <input type="checkbox"/> survey | <input type="checkbox"/> |
| <input type="checkbox"/> registry | <input type="checkbox"/> |
| <input type="checkbox"/> primary clinical | <input type="checkbox"/> |
| <input type="checkbox"/> chart abstraction | <input type="checkbox"/> |
| <input type="checkbox"/> other (describe) | <input type="checkbox"/> |

7) What databases are you planning to use? (check all that apply)
 Indicate dates of data to be used. (Note: Year means year for which data is summarized. Fiscal year is defined as: 1 April 2001 – 31 March 2002 = fiscal 2001.)
 Other reference dates are the usual date of interest.

| Type | Reference | Date Range (fiscal year) |
|-------------------------------------|------------------------|--------------------------|
| Databases | | |
| <input type="checkbox"/> POGONIS | Registration | to |
| <input type="checkbox"/> HHR | Health Human Resources | to |
| <input type="checkbox"/> POFAP | Financial Assistance | to |
| <input type="checkbox"/> Interlink | Community Nursing | to |
| <input type="checkbox"/> CIHI-DAD | Discharge | to |
| <input type="checkbox"/> CIHI-SDS | Discharge | to |
| <input type="checkbox"/> CIHI-CACRS | Registration | to |
| <input type="checkbox"/> CIHI-OCCPS | Admit | to |
| <input type="checkbox"/> CIHI-NRS | Admit | to |
| <input type="checkbox"/> ODB | Service | to |
| <input type="checkbox"/> OHIP | Service | to |
| <input type="checkbox"/> OHCAS | Application | to |
| <input type="checkbox"/> OPWD | Year | to |
| <input type="checkbox"/> RCS-LTC | ? | to |
| <input type="checkbox"/> RPDB | N/A | N/A |

| Composite Databases (i.e., OHIP + CIHI + ODB) | | |
|--|----------|----|
| <input type="checkbox"/> ODD | Incident | to |
| <input type="checkbox"/> OMID | Admit | to |

| Restricted Databases | | |
|--|-------------------|----|
| <input type="checkbox"/> CCN (approval required) | Removal from list | to |
| <input type="checkbox"/> OCR (special agreement required)* | Diagnosis | to |
| <input type="checkbox"/> RCSN † | ? | to |

| Surveys | | |
|-------------------------------|---------------------------------|------|
| <input type="checkbox"/> OHS | <input type="checkbox"/> linked | Year |
| <input type="checkbox"/> NPHS | <input type="checkbox"/> linked | Year |
| <input type="checkbox"/> CCHS | <input type="checkbox"/> linked | Year |

| Other Databases | | |
|--|------|----|
| <input type="checkbox"/> ARIS | ? | to |
| <input type="checkbox"/> EFFECT | | to |
| <input type="checkbox"/> MIS | Year | to |
| <input type="checkbox"/> OTR | ? | to |
| <input type="checkbox"/> custom clinical dataset | | to |
| <input type="checkbox"/> others (please name) | | to |

***Note:** All studies planning use of OCR data must be logged and submitted to Cancer Care Ontario by Privacy Officer (contact for details). † Written application to the Stroke Network Publication Committee.

8) Please list the personal health information/data that will be collected and/or used in this study which potentially, alone or in combination, could be associated with increased risk to privacy (identification of the individual).

birthdate postal code other (list below)

9) Is this a trainee/student/fellow project → **Y** **N**

C. DATA SECURITY/PRIVACY IMPACT

Internal Projects: → **N/A**

1) Complied with all POGO policies/procedures.
 Describe perceived need for modification: **Y**

External Projects (chart abstraction, primary data collection) —→ [] N/A

Does this project have special data concerns? What security measures are IN PLACE to prevent unauthorized access to, disclosure and/or loss of data? (Check all that apply).

- 1) Complied with all POGO policies/procedures in place —————→ [] **Y**
 Describe perceived need for modification:

- 2) Patient and POGO identifiers are sent to hospitals in password-protected Excel files (see Researcher/Abstractor’s Handbook)

- 3) Are laptops being used for abstraction? [] **Y** [] **N**
- Password-protected files and encryption software in place []
 - Laptop passwords can be changed regularly for protection of the data []
 - Policy in place for keeping disks, hardware, abstraction lists separated []
 - Anonymization at collection point: collected under unique study number []

- 4) Photocopying of charts/reports/test results to be done? [] **Y** [] **N**
 If Yes, plan to strip identifiers by:
- Black-out []
 - Photocopying with identifiers covered []

- 5) Do you plan to transmit data back to POGO? If so, append methods describing encryption methods and protections. [] **Y**

D. PUBLIC BENEFIT

- 1) Public benefit other than those in POGO mission statement (to provide a voice for children’s cancer control and treatment, and to plan for provincial needs and coordination) that are expected/anticipated from the project? Identify any potential impact (e.g. report cards).

E. ESTIMATION OF HARM

Note: Cell sizes less than or equal to 5 cannot be reported without prior written approval from the President/Executive Director/Medical Director of POGO and consent from patient/guardian or substitute decision maker.

- 1) Please describe the level at which the results will be reported (e.g. level of individuals, institution or region – smallest units).

2) Describe any way/s this study might identify, stigmatize, or otherwise harm patients, practitioners or institution(s).

a) If you identified potential harms above in (2), please detail the processes and procedures the researchers will implement to mitigate each of the potential harms.

F. ALTERNATIVES
(Legislation requires completion of this section)

1) Is it possible to do this research without using personal health information? **N**

2) Were any alternative methods considered/rejected as less privacy-invasive for achieving the desired objectives? If so, please describe briefly (this provides a means of assessing any real/potential privacy-adverse impact which may be challenged by external sources).

G. TIMEFRAME, DATA RETENTION/DESTRUCTION AND SPONSOR

1) Describe the proposed timeframe of the project:

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

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

- Stipulate retention period: hold until (dd/mm/yy): _____
- Document shredding **Y**
- Destruction of electronic media (magnetic and optic disks, cartridges, CDs) **Y**

- Dataset destruction date (dd/mm/yy): _____
- Dataset destruction time _____
- Dataset destruction location _____

3) What is the funding source for this study?

POGO Funded

- Investigator Initiated [] Y
- Core Funding (MOH) []

Externally Funded

- MOH Special Projects []
- Grants (Source) []
- Contract []

H. ETHICS APPROVAL STATUS

- Ethics approval sought by ED/Privacy Officer (anonymized data studies with Administrative data). [] Y
- Clinical study – ethics approval obtained (append copies of REB approval and patient consent form). []
- Clinical study *with linkage* to administrative data – ethics approval obtained (append copies of REB approval and consent form. []
Note: patients’ consent to link must be included)
- Chart abstraction study – ethics approval obtained (append copies of REB approval). []

I. COMPLIANCE WITH PRIVACY RULES FOR ALL STAFF

- Confidentiality agreements have been signed by ALL project staff. [] Y
- Staff have been familiarized with ALL POGO privacy and confidentiality policies and procedures. []
- Where data is being brought into POGO, formal research agreements *have been signed* (contact: Senior Associate Research and Planning). []
- Copies of proposal, ethics approval and privacy impact assessment have been filed with Privacy Officer. []
- Cell sizes less than or equal to 5 cannot be reported (any exceptions must be approved in writing by the President/ED/MD). []
- Your interest in the disclosure of the data for your research purpose will not result in actual/perceived or potential conflict of interest with your other duties as researcher. []

 Signature of Investigator/Scientist

 Date (dd/mm/yy)

 Medical Director

 Date (dd/mm/yy)

 Privacy Officer Approval

 Date (dd/mm/yy)