ACCESS TO AND USE OF POGO DATA

Guidelines

Hospital partners, knowledge users and/or researchers regularly request data, datasets, and/or analyses to:

- determine a population to be reported on
- assess the appropriateness or feasibility of a research question
- answer specific research study questions within a defined protocol

It is therefore imperative that guidelines are set out to ensure the confidentiality of this personal health information.

Requests for POGO data are either for anonymized aggregate data or for research proposals/projects requiring access to individual-level data. All requests are evaluated by POGO's Senior Database Administrator & Privacy Officer, following the processes outlined below.

Process for Aggregate Information

a) The requestor completes the POGO Data Request Form, which clearly identifies the purpose of the data requested.

b) The Senior Database Administrator & Privacy Officer processes the data request following approval.

c) Once completed, the Senior Database Administrator & Privacy Officer provides the list of required data to the requestor.

d) Each requestor agrees in writing to acknowledge the use of POGO data in all presentations and publications.

Process for Research Proposals Requesting Individual Record-Level Data

a) The requestor must complete a POGO Data Request Form as well as a Project-Specific Privacy Impact Assessment (PIA) which includes detailed information such as the purpose for obtaining the requested data, the required data elements, identification of personal health information that could potentially be associated with increased risk to privacy and the mitigating actions to ensure privacy is maintained, etc. A full project proposal, REB approval, and consent form (if necessary) must be attached.

b) The Senior Database Administrator & Privacy Officer, in consultation with the Medical Director and Senior Scientist, review the Project-Specific PIA.

c) The project team members must enter into a Confidentiality and Non-Disclosure Agreement and a Researcher Agreement that stipulates their requirements regarding the use, retention, safeguarding, and disclosure of personal health information.

d) Once all privacy-related documentation is complete, and the research team has completed privacy training with the POGO Privacy Officer, the Senior Database

Administrator & Privacy Officer will instruct the data team to process the requested data.

e) The Senior Database Administrator & Privacy Officer advises each researcher that an audit may be conducted at any point during the project's implementation.

f) The POGO Research Unit Steering Committee is notified of the project at regular committee meetings.

g) As per the Researcher Agreement, each researcher agrees in writing to acknowledge the use of POGO data in all presentations and publications.