

**ACCESS TO AND USE OF POGONIS DATA**  
**Last modified: September 24, 2009**

**Guidelines**

There have been an increasing number of requests for the use of POGO Networked Information System (POGONIS) data. These requests have been made primarily by partner hospitals and researchers.

Hospitals and researchers typically request data/data sets/analyses to either initially determine the appropriateness/feasibility of a research question and/or to answer specific research study questions within a defined protocol. It is, therefore, imperative that guidelines are set out to address this increasing number of requests for data, while ensuring the confidentiality of personal health information.

Requests for POGONIS data can be either for anonymized aggregate data or for research proposals requiring access to individual level data.

Anonymized data requests are addressed via the POGO Database Administrator as outlined below.

Data requests for research proposals require strict adherence to POGO's privacy and security policies. Therefore, the process below must be followed carefully.

**Process for Anonymized Data for Aggregate Information**

- a) The requestor completes the POGO Data Request Form, which clearly identifies the purpose of the data requested.
- b) The POGO Database Administrator/Privacy Officer processes the data request following approval.
- c) Once completed, the POGO Database Administrator/Privacy Officer provides the list of required data to the requestor.
- d) Each requestor agrees in writing to acknowledge the use of POGONIS data in all publications.

## **Process for Research Proposals Requesting Individual Record-Level Data**

- a) The requestor must complete a Project Specific Privacy Impact Assessment (PIA), which includes detailed information regarding 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. REB approval and consent form (if necessary) should be attached.
- b) The POGO Data Administrator, in consultation with the POGO Medical Director and the Senior Associate Research and Planning, reviews the Project Specific Privacy Impact Assessment.
- c) The PIA and full written proposal are forwarded to the POGO Research Unit Steering Committee for review and approval with the understanding that REB approval must be secured prior to data being released.
- d) If approved, the researcher is notified of the decision and that REB approval must be secured and notification forwarded to the POGO Database Administrator.
- e) The requestor must enter into a Non-Disclosure/Confidentiality Agreement and a Researcher Agreement that stipulates their requirements regarding the use, retention, safeguarding and disclosure of personal health information.
- f) Once REB is obtained, the POGO Database Administrator will conduct the analysis and release the data.
- g) The POGO Database Administrator advises each researcher that a Data Compliance Audit Form must be completed yearly.
- h) Each researcher agrees in writing to acknowledge the use of POGONIS data in all publications.