

Appendix 1: Instructions for Obtaining Secure IBIS-PH Access: Research Projects

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The Utah Environmental Public Health Tracking Program (Utah Tracking Program) is an activity within the Utah Department of Health that makes data available from health outcome registries, biomonitoring registries, environmental monitoring information systems, and environmental hazards databases in a data warehouse. The Utah Tracking Program serves as a custodian of the data which is owned by several agencies and programs. The data owners retain the role of data owners/stewards for data stored within the Utah Environmental Public Health Tracking Network (Utah Tracking Network) data warehouse.

Research projects using data in Utah's Secure Indicator Based Information System for Public Health (Secure IBIS-PH) require the approval of a research proposal from the data owner(s) through the Utah Tracking Program's Scientific Review Board (SRB). The instructions below pertain to specific research projects. (Please see separate instructions contained in the *Third Party Application for Access to Secure IBIS-PH for Public Health Professionals* for more information about obtaining surveillance and work-related access to Secure IBIS-PH.)

All research that will involve human subjects requires review by an Institutional Review Board (IRB), as per Title 45 Code of Federal Regulations Part 46 (<http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm#46.101>). If your research will involve human subjects, you must receive IRB approval before commencing research. IRB approval must be obtained from all institutions participating in your research in any way. The participatory functions of institutions may include sponsoring, collaborating, playing an advisory role, providing data and other resources, or any other involvement not listed here.

Applications for research projects that require an IRB must submit for IRB approval separately. The applications may be submitted concurrently, but data will not be released until proof of IRB approval has been received. The SRB does not substitute for an IRB.

To apply for SRB approval to access and use Utah Tracking Network data, through Secure IBIS-PH or any other means, please complete the items that follow. While each researcher involved in the project must submit a Data-use Agreement Form, only one complete application is required per research project.

- 1. Research Proposal Cover Sheet.** Attach a cover sheet that provides the title of your project, the organization sponsoring the research project, and the primary contact information for your project.
- 2. Secure IBIS-PH Access Request.** Completely fill out the Secure IBIS-PH Access Request, including which data query modules or datasets you need to access. Provide the specific details (data topic, geographic area, time period, etc.) you will need to study.
- 3. Data-use Agreement Form.** Review the Secure IBIS-PH Access Agreement form and submit signed and dated copies for all research project personnel as Attachment A to the Research Proposal Cover Sheet. All research project personnel (whether they need to directly log into Secure IBIS-PH, otherwise directly handle secure data, or they will perform an administrative function or be involved in discussions related to the data) must complete and submit a separate signed Data-use Agreement Form.

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4. **Research Proposal.** Use the Research Proposal Guidelines to create a Research Proposal. The Research Proposal should be submitted as Attachment B to the Research Proposal Cover Sheet. If the proposed study requires IRB approval, the documentation submitted to the IRB must be submitted with the Research Proposal. The documentation submitted to the IRB may be used in place of or in conjunction with the research proposal, so long as all the points in the Research Proposal Guidelines are addressed.
5. **IRB Approval.** If the research proposal requires IRB approval, a copy of the approval letter should be attached as Attachment C to the Research Proposal Cover Sheet. If the IRB has not yet approved the proposal, the approval letter should be submitted to the Utah Tracking Program once it is received. Data will not be released until IRB approval has been received.
6. **Letters of Support.** Letters of support, particularly from research collaborators, can strengthen the proposal. Letters of support are optional. If provided, Letters of Support should be attached as Attachment D to the Research Proposal Cover Sheet.

Completed applications with all of the above items attached should be submitted to the Environmental Epidemiology Program at the Utah Department of Health in BOTH of the following formats:

- one original, signed, paper copy.
- one electronic copy as a PDF.

Completed applications should be submitted to:

Environmental Epidemiology Program
ATTN: Utah Tracking Program Scientific Review Board
Utah Department of Health
P.O. Box 142104
Salt Lake City, Utah 84114-2104
Fax: (801) 538-6564

AND

EEP@utah.gov

The Environmental Epidemiology Program will coordinate the SRB review process. The SRB will review complete applications and approve and/or provide feedback on the application within two weeks of submission. After the SRB has approved your request, the Utah Tracking Program will provide specific instructions on accessing the data you requested.