

Utah Environmental Public Health Tracking Program

Third Party Application for Access to Secure IBIS-PH for Public Health Professionals

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Utah Environmental Public Health Tracking Program
Third Party Application for Access to Utah’s Secure Indicator-Based Information System for Public
Health (IBIS-PH) for Research Projects

Table of Contents

I. Overview of the Utah Tracking Network	
A. Background	3
B. Definition of Third Party User	3
C. Description of the Utah Tracking Program	3
D. Organization of the Utah Tracking Program	4
E. Data Structure in the Utah Tracking Network Data Warehouse	5
F. Standards-based Data Security	6
II. Application for Access to Secure IBIS-PH: Research Projects	
A. The Application Structure	8
B. Application Review Procedures	9
III. Monitoring Data Access and Use	
A. General	10
B. The SRB	10
C. Periodic Status Reports	10
D. Public Presentation Approval	11
IV. Third Party Consent Policies	11
V. Accessing Secure Data	13
Appendix 1. Instructions for Obtaining Secure IBIS-PH Access: Public Health Professionals	14
Appendix 2. Secure IBIS-PH Access Request: Public Health Professionals	16
Appendix 3. Secure IBIS-PH Access Agreement Form: Public Health Professionals	20

I. Overview of the Utah Tracking Network

A. Background. In 2002, Congress provided the Centers for Disease Control and Prevention (CDC) funding to begin developing a National Environmental Public Health Tracking Network (National Tracking Network) and to develop environmental health capacity within state and local health departments. With CDC funding, the Environmental Epidemiology Program (EEP) within the Utah Department of Health (UDOH) implemented a statewide Utah Environmental Public Health Tracking Network (Utah Tracking Network). The Utah Environmental Public Health Tracking Program (Utah Tracking Program) participates with the National Tracking Network.

B. Definition of Third Party Users

1. The data contained within the Utah Tracking Network is provided by data owners. The data owners, having authority and stewardship over their agency's data, are first-party users of their agency's data. The Utah Tracking Program serve as custodians of the data and are second-party users for activities involved in preparing data for the Utah Tracking Network. A third-party user is any person or agency who accesses Utah Tracking Network data that they do not own through Utah's Secure Indicator Based Information System for Public Health (Secure IBIS-PH) or in any other way for the purpose of conducting public health investigations or research (This includes the Utah Tracking Program and any data sharing partners accessing other agencies' data.). Secure IBIS-PH (further described below) contains data that are not made available to the public because they are aggregated at a fine enough granularity to require additional protections. Public data are made available to the public through IBIS-PH and do not require the protections instituted through these policies and procedures.
2. Public health professionals are defined as any third-party users who need to access the data in Secure IBIS-PH for a part of their work for the UDOH, Utah local health districts, or other state or local agencies whose duties involve human health. This definition includes public health employees at all levels, including directors and other officials. These same individuals, however, fall under the definition for "researchers" when they are involved in research papers and other activities not directly related to routine surveillance and other job-related duties. In these activities, these individuals must follow the guidelines outlined in the *Third Party Application for Access to Secure IBIS-PH for Research Projects*.

C. Description of the Utah Tracking Program

The Utah Tracking Program consists of four major components:

1. **Data Warehouse:** A data warehouse of relevant public health outcome, biomonitoring, population, environmental monitoring, environmental hazards, and geographic data. Initially, the Utah Tracking Network started with limited data around specific data topics. Prioritization for implementing additional data content is conducted in concert with CDC. The Utah Tracking Network data warehouse content continues to grow as funding and resources are made available.
2. **Data Sharing:** Data sharing refers to methods to transmit data between the data warehouse, data owners, the National Tracking Network infrastructure, and data

users. Different methods are used depending on the role of the connecting entity. Where possible, the Utah Tracking Program takes advantage of other UDOH data transaction capabilities. For example, the public can access indicator data derived from data contained in the data warehouse through IBIS-PH (<http://ibis.health.utah.gov>). Bulk transactions of data to the National Tracking Network occur through the Utah Department of Environmental Quality's National Environmental Information Exchange Node (NEIEN). For researchers and public health professionals who receive Utah Tracking Program Scientific Review Board (SRB) approval, data at finer granularity is made available through a Secure IBIS-PH data query module.

3. Analytic Tools: The Tracking Program also provides a number of tools for researchers and public health professionals to manipulate, analyze, and model the data. The Utah Tracking Program works within the National Tracking Network framework to prioritize, acquire, and develop tools for the Utah Tracking Network. Additional tools are added as they become available.
4. Staff: The Utah Tracking Program consists of a small staff with experience and expertise in environmental epidemiology, toxicology, geographic information systems, analytical methodology, health education, and data management.

D. Organization of the Utah Tracking Program

1. The National Tracking Program (<http://www.cdc.gov/ephtracking/> for more information) works with the funded state and local health agencies, collaborating federal agencies (e.g., the Environmental Protection Agency), and collaborating public health organizations (e.g., the Association of State and Territorial Health Officials) through a series of work groups, semi-annual conferences, and progress reporting. There are three work groups with participation from all of the collaborating or funded partners: the Program, Marketing and Outreach (PMO) workgroup; the Standards and Network Development (SND) workgroup; and the Content Workgroup (CWG). Within the workgroups, teams are organized to research specific topics and present recommendations to the National Tracking Network forum.
2. The Utah Tracking Program is composed of staff within the EEP. Staff include research scientists, health educators, and information technologists. The Utah Tracking Program is responsible for participating within the National Tracking Network, implementing and maintaining the Utah Tracking Network, recruiting and working with data sharing partners, and providing support to IBIS-PH users. The Utah Tracking Program serves as the custodian for the data maintained in the data warehouse.
3. The Utah Tracking Program recruits and collaborates with other agencies in Utah who collect and register data of interest to the network as data sharing partners. Based on a data sharing agreement between the Utah Tracking Program and the data owner, the data owner provides data to the Utah Tracking Network on a cyclic basis. The Utah Tracking Program provides services to the data and then aggregates the data for incorporation into the data warehouse. Data services include standardization to national data standards, geocoding and georeferencing,

some statistical summarization, and connecting with corresponding aggregated data within the warehouse. Some of the initial data sharing partners include the Utah Cancer Registry, the UDOH Office of Vital Records and Statistics, the UDOH Office of Health Care Statistics, the UDOH Blood Lead Registry, and the UDEQ. Data sharing partners maintain their responsibilities and rights as owners of the data maintained in the Utah Tracking Network data warehouse. Those responsibilities and rights extend to the source, derived, aggregated, and summarized data.

4. The Utah Tracking Program is governed by an executive committee composed of department and division level administrators from the UDOH, UDEQ, and the Utah Department of Technology Services. The role of the executive committee is to ensure that the Utah Tracking Network meets the state architectural, data quality, and system security standards. The executive committee also guarantees executive support for the project.
5. Use of data within the Utah Tracking Network is regulated by the SRB. The SRB includes a representative from each of the data owners with decision making authority. The SRB reviews and approves data suppression rules and Secure IBIS-PH access requests in order to ensure that data use and security standards are met. The SRB acts as an advisory body to the Utah Tracking Program and is the forum to resolve disputes over Utah Tracking Network data operations. The SRB, working within the Tracking Network Advisory Committee (TNAC), also assists the Utah Tracking Program in long-term planning issues and policy development.
6. The TNAC consists of technical experts in environmental epidemiology and information technology recruited from data owners, data users, and other collaborating partners. The TNAC is a technical forum to assist the Utah Tracking Program in identifying and resolving implementation challenges.

E. Data Structure in the Utah Tracking Network Data Warehouse

1. **Source Data:** Data sharing partners provide source data to the Utah Tracking Program as described in the data sharing agreement between the data owners and the Utah Tracking Program. The data sharing agreement outlines the roles and responsibilities of the data owner as the steward for their data and the Utah Tracking Program, as the custodian, acting for the data owner, to service and protect the data. Source data are not available through Secure IBIS-PH.
2. **Derived Data:** The Utah Tracking Program derives additional data from the source data through standardization and data services. Examples of derived data are assignment of standardized diagnostic groupings, assignment of standardized demographic information, linkage to census or other population-based data, and geocoding and georeferencing the data. The Utah Tracking Program may also compute measures of quality for the data. These data may contain identifying information carried over from the source data. Unless otherwise specified by the data owner, derived data may be acquired through Secure IBIS-PH with specific approval from the data owner. The data owner may require the identifying data

to be removed or masked when released to third-party researchers or public health professionals.

3. **Aggregated or Summarized Data:** The Utah Tracking Program further aggregates or summarizes the data using SRB approved schema and computes additional summary statistics for the data. The aggregated or summarized data are de-identified. These are the data that are generally available through IBIS-PH. Aggregated or summarized data usually include the following elements:
 - a. Area location unit
 - b. Time location unit
 - c. Demographic unit (for health outcome or biomonitoring data)
 - d. Analyte identity (for environmental monitoring data)
 - e. Diagnostic unit (for health outcome or biomonitoring data)
 - f. Measure unit (for environmental monitoring data)
 - g. Case count (for health outcome or biomonitoring data)
 - h. Concentration (for environmental monitoring data)

Other data that may be included with the aggregated or summarized data include:

 - i. Standardized population count
 - j. Census-based socio-economic indicators
 - k. Rate statistics (incidence/prevalence, 95% confidence)
 - l. Summary statistics (count, range, standard deviation)
 - m. Geographic assignment success score
4. **Connecting Corresponding Data:** The Utah Tracking Program connects data from different sources by geographic location unit (i.e., 2000 census block group) and time unit (i.e. year). Individuals with records in two or more health outcome registries will NOT be linked without specific SRB approval.

F. Standards-based Data Security

1. State confidentiality and protected public health information definitions and security requirements for data collected and maintained by the UDOH, including all subordinate agencies and activities, are promulgated in the Utah Health Code (Title 26) and UDOH rules.
2. The following laws specifically apply to the protection of confidential health data:
 - a. 26-3-7: Disclosure of health data – limitations.
<http://www.le.utah.gov/UtahCode/getCodeSection?code=26-3-7>
 - b. 26-3-10: Department measures to protect security of health data.
<http://www.le.utah.gov/UtahCode/getCodeSection?code=26-3-10>
 - c. As per 26-23-6, any entity that violates any provisions of these laws is guilty of a class B misdemeanor for the first violation, and for any subsequent similar violation within two years, is guilty of a class A misdemeanor. This entity may be assessed a penalty not to exceed \$10,000 per violation.
<http://www.le.utah.gov/UtahCode/getCodeSection?code=26-23-6>
3. The following rules apply to the protection of confidential health data under specific circumstances:

- a. R380-25: Submission of data through an electronic data exchange.
<http://www.rules.utah.gov/publicat/code/r380/r380-025.htm>
 - b. R380-250: HIPAA privacy rule implementation.
<http://www.rules.utah.gov/publicat/code/r380/r380-250.htm>
 - c. As per FR Doc 06-1376 (except as provided in subsection (b)), any person who violates a provision of HIPAA shall be assessed a penalty of not more than \$100 for each violation, except that the total for all violations of an identical requirement or prohibition during a calendar year may not exceed \$25,000.
<http://www.hhs.gov/ocr/privacy/hipaa/administrative/enforcementrule/enforcementfinalrule.html>
4. In addition, rules allowing the collection of data by UDOH programs and agencies and UDEQ programs and agencies have additional data security provisions that apply to data contained within the Utah Tracking Network.
 5. National standards for public health data security are implemented by the Public Health Information Network (PHIN; see <http://www.cdc.gov/phिन/> for more information). The PHIN is CDC's forum for public health information system standards. The physical and programmatic architecture of the Utah Tracking Network complies with PHIN standards.
 6. The Utah Tracking Program receives data that contain identifiable and confidential or protected information from some data owners. This information is used by the Utah Tracking Program to assist in the services (particularly geocoding and georeferencing) provided to the data. Typically health outcome or biomonitoring data are aggregated by the Utah Tracking Program in terms of demographics (age/sex groupings), location (area-based scales such as county, zip code, or census areas), time (year or multi-year periods), and diagnostic groups. The Utah Tracking Program works with the SRB to determine appropriate aggregation schema for health data. All information that may increase the risk of identifying persons or patients is stripped from the data before implementation. Aggregated case counts not meeting a standard minimum (typically 5 or more) by the SRB for that data set are masked. The Utah Tracking Program will not connect case information from one data sharing partner to case information from another data sharing partner without review and approval from the SRB. This will ensure that the connection does not result in disclosure of confidential information. The Utah Tracking Program may connect population based (i.e., population counts, area socio-economic status indicators, etc.), exposure based (i.e., proximity indicators), or summary based (i.e., rates, counts, etc.) data to aggregated health outcome tables.
 7. The Utah Tracking Network shares architectural resources with the Utah National Electronic Disease Surveillance System (NEDSS) and has adopted NEDSS standards and policies for
 - a. Acceptable use
 - b. Data disaster and recovery
 - c. Data encryption

- d. HIPAA security implementation
 - e. Information sensitivity
 - f. Intrusion response
 - g. Password
 - h. Perimeter security
 - i. Physical security
 - j. Security compliance
 - k. User authentication and administration
8. The Utah Tracking Network supports several levels of access. The least restrictive levels of access provide data aggregated at higher levels of granularity. More restrictive levels provide access to data at finer granularity. The levels of access are
- a. Public (through IBIS-PH)
 - b. Public Health (through Secure IBIS-PH)
 - c. Researcher (through Secure IBIS-PH)
 - d. National (through the National Tracking Network)

Generally, publicly available data are aggregated to the county level for broad diagnostic groupings. Publicly accessible data may or may not provide age/sex stratification depending on the level of security required by the data owner. Public health professionals and researchers may apply for Secure IBIS-PH access to query data. Source data may not be accessed through Secure IBIS-PH. Secure IBIS-PH data are aggregated to support analysis at a finer resolution than the data available through IBIS-PH. The system will present only the analytical results (generally standardized rates or rate ratios). The Utah Tracking Program will exchange data with the National Tracking Network in bulk through the NEIEN node. Those data may be used for regional and national environmental health studies. The aggregation schema for those data will be developed through collaboration with the CWG and implemented after review and approval by the SRB. SRB approved researchers and public health professionals can access and retrieve subsets of data aggregated at finer resolution than provided through the National Tracking Network or IBIS-PH. Since those data are considered potentially identifying by the SRB, the public health professionals and researchers who access secure data through Secure IBIS-PH or in any other way must meet requirements set by the SRB.

II. Application for Access to Secure IBIS-PH: Research Projects

- A. The Application Structure** for public health professionals to access Utah Tracking Network data through Secure IBIS-PH or in any other way consists of the components that follow. All individuals who need to directly log into the Secure IBIS-PH or otherwise directly handle secure data must complete a separate application. This application must be submitted both electronically (PDF) and on paper (with signatures).
- 1. Instructions for Obtaining Secure IBIS-PH Access: Public Health Professionals (Appendix 1).
 - 2. Secure IBIS-PH Access Request: Public Health Professionals (Appendix 2). Public health professionals may request access to specific query modules (for

specific geographic regions and data topics) that are directly related to their public health program activities.

- a. *Use of Secure IBIS-PH data for surveillance and other routine public health activities requires submission of a separate application and research proposal for review and approval by the SRB. That Application can be found in the document Third Party Application to Secure IBIS-PH for Public Health Professionals.*
 - b. 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>) Research that will involve human subjects must receive IRB approval before commencing research. IRB approval must be obtained from all institutions participating in the 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. *The SRB does not serve as an IRB. Applications requiring an IRB must apply for IRB approval separately.*
3. Secure IBIS-PH Access Agreement Form: Public Health Professionals (Appendix 3). This is essentially the binding contract between the public health professionals and the data owner(s) to comply with SRB data protection and security protocol and other requirements. There may be program personnel (who do not need to directly access or handle Utah Tracking Network data) with whom public health professionals need to discuss the data or who may perform an administrative function. Although these program members are not required to submit a Secure IBIS-PH Access Request, they must complete and submit a separate signed Secure IBIS-PH Access Agreement Form (Appendix 3).

B. Application Review Procedures

1. Public health professionals requesting access to Secure IBIS-PH query modules should submit a completed application to the Utah Tracking Program manager. The Utah Tracking Program will forward copies of the application to the SRB for review. The SRB may approve or deny access, may determine additional conditions for access, and/or may meet to discuss the application before approving access. In all matters, the data owner(s) of the Secure IBIS-PH query module(s) in question will have the final say in approving or denying access.
 - a. The Utah Tracking Program, on behalf of the SRB, will keep a written record of the standards developed by the SRB to grant or deny data access. Additionally, the Utah Tracking Program will keep written minutes of all meetings and discussions regarding the application.
 - b. The Utah Tracking Program anticipates that the criteria for approving or denying data access will develop as a living document as the SRB gains experience with processing data applications.
2. Whatever the decision, the public health professional will be contacted within two weeks of submitting an application.

3. The SRB will direct any questions, concerns, or requests for clarification about the application to the Utah Tracking Program manager who will then provide those comments to the public health professional. The public health professional can respond by modifying and resubmitting the application or by submitting a memorandum of response for consideration by the SRB.
4. Approval must be obtained from each data owner whose query module(s) will be accessed.
5. Upon SRB approval, the Utah Tracking Program will register an account for the public health professional to access Secure IBIS-PH. The Utah Tracking Program will provide the public health professional a memorandum of instruction which may include details about accessing appropriate query modules in Secure IBIS-PH, data security requirements, and the process the SRB will use to monitor Secure IBIS-PH access and data use.
6. The Utah Tracking Program will be available by phone and email during regular business hours to assist the public health professional with problems accessing Secure IBIS-PH.
7. The UDOH and associated programs, including the Utah Tracking Program and the SRB, do not guarantee the accuracy of the data they provide through Secure IBIS-PH or in any other way.
8. The UDOH and associated programs, including the Utah Tracking Program and the SRB, do not guarantee that Secure IBIS-PH and other forms of data access will be functional. The Utah Tracking Program, the SRB, and the UDOH members are not liable for problems accessing or processing data or failures by public health professionals to meet deadlines because of problems with data or access.
9. The Utah Tracking Program tracks and logs Secure IBIS-PH access and activity. The SRB can review those logs.
10. The public health professional's Secure IBIS-PH access will be renewed annually upon verification that work responsibilities continue to warrant access.

III. Monitoring Data Access and Use

- A. General.** All public health professionals must agree to SRB review of their access and interpretation of Secure IBIS-PH data. The Utah Tracking Program will give approved public health professionals a memorandum of instruction that details the review process.
- B. The SRB** will review the public health professional's access to and use of Secure IBIS-PH data to ensure:
 1. Maintenance of data security and protection of confidential information.
 2. Appropriate acknowledgement of the data owner agency.
 3. Status of findings that relate to or impact the data owners' public health objectives.
- C. Periodic Status Reports.** At the request of the data owner(s) and/or SRB, the Utah Tracking Program will coordinate with the public health professional to review their Secure IBIS-PH access and use. Reviews may include information about new public health staff members, changes in staff members' responsibilities and need to access the data, and updates about surveillance findings. The Utah Tracking Program will report their findings to the SRB. The public health professional should respond and provide requested information to the Utah Tracking Program manager within 10 days.

D. Public Presentations. The public health professional will provide copies of all intended public presentations or publications that incorporate any form of Utah Tracking Network data for SRB review and approval. This requirement ensures both the synchronization of data owner agency objectives with findings that use their data, as well as the appropriate acknowledgement of the data owner and the Utah Tracking Network. The public health professional will submit those documents to the Utah Tracking Program manager at least 30 days before the anticipated public release. Public release includes submission for publication (even though the actual publication may not result immediately after submission). The public health professional agrees to satisfy any SRB concerns regarding intended public presentation of findings before the presentation can occur. The Utah Tracking Program will provide the public health professional a memorandum of approval for public presentation after the SRB has approved the presentation.

IV. Third Party Consent Policies

- A.** This section addresses the responsibilities of public health professionals regarding data obtained from Secure IBIS-PH or otherwise obtained from the Utah Tracking Network. The public health professional agrees to comply with these policies through the Secure IBIS-PH Data Access Agreement Form: Public Health Professionals (Appendix 3).
- B.** Data is defined to include the original tabulated data obtained from Secure IBIS-PH, as well as all manipulations, tabulations, aggregations, and summarizations that the public health professional generates and that are derived from Utah Tracking Network data obtained through Secure IBIS-PH or in any other way.
- C.** Public presentations are defined as any published paper, abstract, brief, report, letter, poster, speech, article, or other presentation that discloses data, information about the data, information about the data owner, or information about the Utah Tracking Network that is made available to the public (including organizational peers) through peer-reviewed or un-reviewed journals, magazines, newsletters, professional or public conferences, public or organizational meetings, or other forums or events to which persons not associated with the public health professionals (i.e., any individual who has not submitted a Secure IBIS-PH Access Agreement Form and received SRB approval) could be in attendance or have access.
- D.** The public health professional will provide the SRB with draft and final copies of public presentation materials for approval at least 30 days before the public presentation or submission for publication (even if submission will not immediately result in publication).
- E.** The public health professional agrees to comply with applicable federal, state, department and program statutes, rules, policies, use restrictions, and requirements regarding security, management, use, and disclosure of data obtained from Secure IBIS-PH.
- F.** Data obtained from the Utah Tracking Network, through Secure IBIS-PH or in any other way, will only be used for work-related activities as outlined in the Secure IBIS-PH Access Request (Appendix 2). The data will not be used for research or work-related objectives not disclosed to and approved by the SRB. The public health professional will disclose all intended data uses to the SRB through the initial Secure IBIS-PH Access Request or by written amendments.
 - 1. All use of Secure IBIS-PH data for research objectives requires submission of the application contained in the document *Third Party Application for Access to Secure IBIS-PH for Research Projects*. This application includes a research proposal that must that must be reviewed by the SRB. (Please contact the Utah

Tracking Program for an application form or if you are not sure whether your use of Secure IBIS-PH data constitutes “research.”)

- G.** The public health professional will not provide, distribute, disclose, or otherwise share Utah Tracking Network data, obtained from Secure IBIS-PH or in any other way, to or with other persons or public health professionals unless approved by the SRB.
- H.** Computer systems to which the data is loaded for use and storage will be maintained in a secure environment with controlled access. The computer system will use, as a minimum, a password access protocol. Computer systems will not be removed from the secure controlled environment while containing stores of the data (i.e., computer systems will not be taken home, etc.).
- I.** Electronic (i.e., flash drives, portable hard drives, CD-ROMs), paper (i.e., print-outs), or other forms of the data not stored on a computer system storage device (i.e., a hard drive), will be stored in a locked storage container (i.e., a locked filing cabinet or drawer).
- J.** The public health professional agrees to restrict access to public health professionals who have submitted a complete application to the SRB and whose access to the query modules on Secure IBIS-PH or to otherwise handle secure data has been approved by the SRB. Public health professionals must individually receive approval from the data owner(s) before being given access to Utah Tracking Network data through Secure IBIS-PH or in any other way.
- K.** The public health professional agrees to comply with additional restrictions, requirements, and stipulations described by the SRB.
- L.** The public health professional agrees to be monitored by the SRB through the Utah Tracking Program, to provide progress and status reports as requested, and to meet other review process requirements as requested by the SRB.
- M.** The public health professional will acknowledge the Utah Tracking Network and the data owner(s) in all public presentations of Utah Tracking Network data and the findings derived from the data.
- N.** The public health professional has an affirmative obligation to notify the Utah Tracking Program within 24 hours of any change in employment, personnel or of associated public health professionals (specifically, as listed in the form Secure IBIS-PH Access Request: Public Health Professionals [Appendix 2]). Upon notification, the Utah Tracking Program will terminate all data rights for those individuals no longer involved in the tasks for which data access was granted.
 - 1. The Utah Tracking Program will terminate Secure IBIS-PH access for all public health professional whose responsibilities no longer warrant data access. Under the supervision of the Utah Tracking Program, that public health professional whose access is terminated agrees to erase or return all forms of data and data storage. Approval of any impending publications or presentations will be at the discretion of the SRB.
- O.** At the discretion of the SRB, the Utah Tracking Program has the right to terminate the public health professional’s access to Utah Tracking Network data, through Secure IBIS-PH or in any other way, with or without cause. Any breach by the public health professional, or any associated individuals or organization, warrants termination of access.
 - 1. Upon access termination, the Utah Tracking Program will oversee the erasure of all documents, databases, and all other electronic storage units containing any form of Utah Tracking Network data. Any other data or storage devices will be returned by the Utah Tracking Program. Approval of any impending publications or presentations will be at the discretion of the SRB.

V. Accessing Secure Data

Upon approval of the application, data will be made available in one of the following ways:

- A.** The Utah Tracking Program will create an account for the researcher on Secure IBIS-PH and will notify the researcher of the account. Separate instructions on how to navigate through Secure IBIS-PH will be provided in a memorandum of instruction.
- B.** Access to data query modules will generally be through Secure IBIS-PH. All decisions on permitting other means to access data (CD, DVD, secure FTP account, etc.) will be at the discretion of the data owner(s). The data owner(s) may also impose additional restrictions to access certain data (e.g., allowing review of data only under direct supervision of the data owner(s)).

**Instructions for Obtaining Secure IBIS-PH Access:
Research Projects**

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.

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

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. If the research requires an IRB approval, that approval will have to be obtained separately from the SRB approval. The SRB does not substitute for an IRB.

To apply for approval to access and use Utah Tracking Network data on Secure IBIS-PH or in any other way, please complete the steps that follow. All individuals who need to directly log into the Secure IBIS-PH or otherwise directly handle secure data must complete a separate application.

1. 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 (specifying the geographic region), reasons why accessing this information is related to your work, and time frame (up to one year, with annual renewals upon verification that your public health responsibilities continue to warrant access to the data).

2. Secure IBIS-PH Access Agreement Form. Review the Secure IBIS-PH Access Agreement Form, and attach a signed and dated copy to the Secure IBIS-PH Access Request. All program personnel with whom public health professionals need to discuss the data or who may perform an administrative function must complete and submit a separate signed Secure IBIS-PH Access Agreement Form, even if they do not need to directly access or handle Utah Tracking Network data.

Appendix 1: Instructions for Obtaining Secure IBIS-PH Access: Public Health Professionals 15

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.

Secure IBIS-PH Access Request: Public Health Professionals

Name: _____ Position Title: _____

Organization: _____ Department: _____

Date Access is Needed: _____ Duration Access is Needed: _____

Phone Number: (____) _____ Fax Number: (____) _____

E-Mail Address: _____ Employee I.D. Number: _____

Mailing Address (work): Street _____

City _____ State _____ Zip Code _____

Please indicate which **data topic(s)**, within your scope of work, you will need to access on the secure portal. **If you need to access data topics at different geographic areas (e.g., if your work-related activities required you to access mortality data at a state level, but to access birth defect data only for certain local health districts), please attach a detailed explanation of the specific geographic areas needed for each data topic requested.**

- | | | | |
|------------------------|--------------------------|--------------------------------------|--------------------------|
| Cancer Registry | <input type="checkbox"/> | Blood Lead Levels | <input type="checkbox"/> |
| Mortality | <input type="checkbox"/> | Inpatient Hospital Discharges | <input type="checkbox"/> |
| Births | <input type="checkbox"/> | Emergency Department Visits | <input type="checkbox"/> |
| Birth Defects | <input type="checkbox"/> | Air Monitoring Data | <input type="checkbox"/> |
| Poison Control | <input type="checkbox"/> | Drinking Water Sample Data | <input type="checkbox"/> |

Please indicate which **geographic area(s)**, within your scope of work, that you will need to access on the secure portal:

State of Utah (all Local Health Districts)

Specific Local Health District(s):

- | | | | |
|--------------------------|--------------------------|-----------------------|--------------------------|
| Bear River | <input type="checkbox"/> | Summit County | <input type="checkbox"/> |
| Central Utah | <input type="checkbox"/> | Tooele County | <input type="checkbox"/> |
| Davis County | <input type="checkbox"/> | TriCounty | <input type="checkbox"/> |
| Salt Lake County | <input type="checkbox"/> | Utah County | <input type="checkbox"/> |
| Southeastern Utah | <input type="checkbox"/> | Wasatch County | <input type="checkbox"/> |
| Southwestern Utah | <input type="checkbox"/> | Weber County | <input type="checkbox"/> |

(This section to be completed by the Data Owner(s) and Utah Tracking Program)

Data Owner Signature and Comments		
<hr/>		
Query Module		Signature
Access Approved <input type="checkbox"/>	Access Denied <input type="checkbox"/>	Need Additional Information <input type="checkbox"/>
Comments:		

(Each data owner will be provided a separate copy to sign and provide comments.)

Data Owner Signature and Comments		
<hr/>		
Query Module		Signature
Access Approved <input type="checkbox"/>	Access Denied <input type="checkbox"/>	Need Additional Information <input type="checkbox"/>
Comments:		

Data Owner Signature and Comments		
<hr/>		
Query Module	Signature	
Access Approved <input type="checkbox"/>	Access Denied <input type="checkbox"/>	Need Additional Information <input type="checkbox"/>
Comments:		

Your application has been reviewed and approved.	
<hr/>	
Utah Tracking Program Manager	Date approved

**Secure IBIS-PH Access Agreement Form:
Public Health Professionals**

This agreement must be completed by all research personnel will have access to Utah Tracking Network data in any form and in any phase of the project.

Name: _____ Position Title: _____

By initialing the following boxes and signing this agreement form, you (the public health professional named above) agree to comply with the following agreements and assurances supporting application for access to Utah Tracking Network data through Secure IBIS-PH or in any other form (to include all manipulations, tabulations, aggregations, summarizations, and verbal communication generated from the data).

Please initial each box.

I have read and shall comply with the Utah Tracking Program’s consent policies. (Refer to the *Third Party Application for Access to IBIS-PH for Public Health Professionals* <http://health.utah.gov/enviroepi/activities/EPHTP/NewEPHT/securedata.html>).

I will comply with all data use stipulations provided in writing by the data owner(s) as part of the approval of this application for access to data.

I will provide the SRB with draft and final copies of public presentations (defined as any published paper, abstract, brief, report, letter, poster, speech, article, or other presentation that discloses data or information about the data, the data owner, or the Utah Tracking Network that is made available to the public (including organizational peers) through peer-reviewed or un-reviewed journals, magazines, newsletters, professional or public conferences, public or organizational meetings, or other forums or events to which persons not associated with the public health professionals (i.e., any individual who has not submitted a Secure IBIS-PH Access Agreement Form and received SRB approval) could be in attendance or have access) as described with the SRB authorization to access the data. The data owner(s) will have opportunity to comment on or approve those reports prior to any publications or presentations.

I will provide the SRB with copies of public presentation materials for approval 30 days before the publication or submission for publication (even if submission will not immediately result in publication).

I will comply with all state and federal laws, as well as department and program statutes, rules, policies, use restrictions, and requirements regarding security, management, use, and disclosure, particularly those that protect the privacy of individuals and research subjects. I understand that violation of any local, state, or federal laws may subject me to criminal or civil prosecution or other penalties.

Appendix 3: Secure IBIS-PH Access Agreement Form: Public Health Professionals 21

- I will use Secure IBIS-PH, and any other form of Utah Tracking Network data, only for the work-related activities outlined in the Secure IBIS-PH Access Request and approved by the SRB.
- I will make no use of the data for research or work-related objectives, analyses, or other uses not described in the approved Secure IBIS-PH Access Request without prior written authorization from the data owner(s). Use of the data for specific research projects requires the submission of a separate application and research proposal to be reviewed and approved by the SRB. I will not conduct specific research projects, particularly any projects that require IRB approval, without written approval and authorization from the SRB.
- I will not provide, distribute, disclose, or otherwise share Utah Tracking Network data, obtained from Secure IBIS-PH data obtained from Secure IBIS-PH or in any other way, to or with other persons, researchers, or research projects unless approved by the SRB.
- I will follow the procedures and methods described in the Secure IBIS-PH Access Request and in any modifications made by the SRB.
- I will assure the integrity, confidentiality and the security of all Utah Tracking Network data in all forms. (See the online Policies and Procedure Manual for standards of data protection.)
- I will comply with any and all restrictions, requirements, and stipulations described by the SRB
- I agree to be monitored by the SRB through the Utah Tracking Program, to provide progress and status reports as requested, and to meet other review process requirements as requested by the SRB.
- I will acknowledge the data owner(s) and the Utah Tracking Network in all public presentations (defined above) of Utah Tracking Network data and the findings derived from the data.
- I understand that I have an affirmative obligation to notify the Utah Tracking Program within 24 hours of any change in employment for either myself or any associated public health professional so that data rights may be adjusted accordingly.
- I understand that the Utah Tracking Program, the SRB, and the Utah Department of Health (UDOH) do not guarantee the accuracy of the data they provide through Secure IBIS-PH or in any other way.
- I understand that the Utah Tracking Program, the SRB, and the UDOH do not guarantee that Secure IBIS-PH and other forms of data access will be functional. The Utah Tracking Program, the SRB, and the UDOH members are not liable for problems accessing or processing data or for failures by public health professionals to meet deadlines because of problems with data or access.
- I understand that the failure to abide by any of these agreements, by myself or any associated individuals or organizations, will result in an immediate termination of data access, as well as a

Appendix 3: Secure IBIS-PH Access Agreement Form: Public Health Professionals 22

denial of rights to data publication or presentation. Upon termination of access, I agree to erase all documents, databases, and all other electronic storage units containing any form of the data. I will return any other data or storage devices to the Utah Tracking Program. I understand that the SRB will have the discretion to approve or deny any impending publications or presentations involving Utah Tracking Network data.

Signature of Public Health Professional

Date: _____

Staff Member's Supervisor (PLEASE PRINT)

Signature of Staff Member's Supervisor

Date: _____