



KIDSNET Data Sharing and Release

This document outlines the policies and procedures that KIDSNET will use when responding to requests for data and for data-related projects.

It is KIDSNET's policy to ensure that data are used to assess needs and support program management and evaluation, health policy, and surveillance activities. It is also KIDSNET's policy to ensure that the data collected and used are for appropriate purposes and that all individually identifiable data are kept confidential. Requests for KIDSNET data will be prioritized based on who is requesting the information, for what purpose, and the deadline.

1. **Aggregate *non-identifiable* data:**

- Non-identifiable information in aggregate format can be released to appropriate third parties. All data released will meet the RIDOH Small Numbers Policy to ensure that aggregate data are truly non-identifiable.
- The programs from which data are requested will be notified and program staff will have the opportunity to review the request and response prior to the data's release (unless it is data that has already been made publicly available).

2. **Aggregate or individually identifiable data for *research* purposes:**

- Requests for data to be used for research purposes must be submitted to and approved by the Rhode Island Department of Health's (RIDOH) Institutional Review Board according to its policies and procedures stated at: http://health.ri.gov/programs/detail.php?pgm_id=145

3. **Confidential or *personally identifiable* information:**

- Personally identifiable data from KIDSNET will be shared only if determined to be permissible according to state and federal confidentiality and program authorization laws according to the "Confidentiality Guidelines for Access to Rhode Island KIDSNET data". Blocked KIDSNET records will not be included. Once data are identified to be permissible, a data sharing agreement will be developed and signed by KIDSNET and the requesting data partner. The agreement will, at a minimum, outline the following information:
 - i. Purposes of the data sharing agreement
 - ii. What data will be shared
 - iii. How the data will be used (including any secondary release of information if proposed and allowed)
 - iv. Protections to ensure confidentiality and privacy of the information
 - v. What happens to the data once the analysis/project is completed
- The data sharing agreement can be modified as mutually agreed upon by both parties.
- Additional uses of data or new data elements to be shared will require a modification to the data sharing agreement.
- KIDSNET will develop and monitor any such agreements with input from any program manager whose data are involved in the agreement.

4. Special Conditions:

In addition to the above policies, KIDSNET has identified three categories of potential users and lists below any specific requirements related to sharing and releasing data to those entities.

A. Release to Data Partners:

- KIDSNET works in strong collaboration and partnership with organizations that assist in program evaluation needs assessment and data analysis activities. RIDOH may contract with these agencies to jointly carry out core public health functions (assessment, assurance, and policy development) in which there is mutual agreement. If such an agreement already exists, KIDSNET and others who are involved in the process will jointly determine the process of releasing data to such partners given the special conditions.

B. Release to Students:

- Every effort will be made to accommodate student projects, requests for internships, and public health experiences.
- Students working on a data project will need to conduct their work, supervised by a KIDSNET or other RIDOH staff member, as agreed. Depending on the project, this could include a program manager, KIDSNET appointed staff member, or the chief of Data and Evaluation. Ideally, all three of the above-mentioned staff would be aware of the project.
- Work-study students and student scholars (interns) will be acting as an agent of RIDOH for the program in which they work. In this capacity, they will be asked to sign a confidentiality statement and will be educated about state and federal confidentiality laws by their supervisor.
- Having signed the agreement and been trained (as stated above) the student will be allowed to collect, assess, and analyze individually identifiable information for their specific project or job-related duties. Blocked KIDSNET records will be excluded.
- Students whose project or work is considered “research” will need to go before RIDOH’s Institutional Review Board, as stated in section 2 above.
- Files containing data from KIDSNET will not be accessible or released for off-site access without special permission. Permission will only be granted if there are sufficient assurances that the data are properly protected. KIDSNET will grant permission.

C. Release to Others:

- KIDSNET will review all KIDSNET data requests and will consult with the respective program managers if data from other programs is requested.
- Based upon a review by KIDSNET and the program manager(s), as it applies, a determination will be made as to whether the release of the data is permissible according to state and federal confidentiality and program authorization laws. If it is determined that data can be shared, the requestor will be considered a data partner and all policies and procedures related to developing a data sharing agreement will be followed.

To request KIDSNET data, contact:

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