



# KIDSNET

## DATA SHARING AND RELEASE POLICY

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

It is the policy of KIDSNET to ensure that data and information are used to assess needs, support program management and evaluation, health policy, and surveillance activities. It is also KIDSNET's policy to ensure that the program data collected and used is for appropriate purposes and that all individually identified data be kept confidential.

### 1. Aggregate non-identifiable data:

- Non-identifiable information in aggregate format can be released to appropriate third parties. Requests for KIDSNET data will be prioritized based on who is requesting the information, for what purpose, and deadline. Cell size will be also considered in assuring that aggregate data is truly non-identifiable
- If the data requested from KIDSNET involves data from more than one program, the programs for which data are requested will be notified and the program staff will have the opportunity to review the data request and the data response prior to the release (unless it is data that already has 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 HEALTH's Institutional Review Board according to its policies and procedures stated in [www.health.ri.gov/topics/irb.php](http://www.health.ri.gov/topics/irb.php).

### 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. Once 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 following information:
  1. Purposes of the data sharing agreement
  2. What data will be shared
  3. How the data will be used (including any secondary release of information if proposed and allowed)
  4. Protections to assure confidentiality and privacy of the information
  5. 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
- The KIDSNET operations manager will develop and monitor any such agreements with the input from any program manager whose data is involved in the agreement.
- Data sharing agreements must be reviewed and signed at least annually or as mutually agreed upon.



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#### 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. HEALTH may contract with these agencies to jointly carryout core public health functions (assessment, assurance, and policy development) in which there is mutual agreement. If such an agreement already exists, the KIDSNET operations manager 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 in the Department of Health's building, supervised by a KIDSNET or Family Health Staff member, as agreed. This could include a program manager, the KIDSNET operations manager or the chief of Data and Evaluation (depending on the project). Ideally, all three of the above-mentioned staff would be aware of the project.
- Work-study students and student interns will be acting as an agent of the Department of Health 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.
- Students whose project or work is considered "research" will need to go before the Department's Institutional Review Board, as stated in section 2 above.
- Data 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 is properly protected. The KIDSNET operations manager will grant permission.

##### C. Release to Others

- The KIDSNET operations manager will review all requests for KIDSNET data and will consult with the respective program managers if data from other programs is requested. The KIDSNET operations manager will also inform the chief of the Data and Evaluation Unit of any requests received.
- Based upon a review by KIDSNET operations manager, chief of Data and Evaluation, the program manager and/or any combination of the above, 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, then the requestor will be considered a data partner and all policies and procedures related to developing a data sharing agreement will be followed.

**Contact to request data from KIDSNET:**  
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