



**AIRA**  
AMERICAN IMMUNIZATION  
REGISTRY ASSOCIATION

# INFORMATION REQUEST

Topic: Data Governance/Data Exchange

**Request Date:** December 15, 2021

**Information Requested:**

Given the broader immunization data needs experienced during the pandemic, an AIRA member has asked if IIS programs have examples of data governance/data usage policies they would be willing to share. Please respond to this email with any examples.

**Requesting Member:** AIRA

**Responding Member(s):** Ellen Amore (RI)

**Results:**

**RI:**

RHODE ISLAND DEPARTMENT OF HEALTH POLICY  
KIDSNET

CONFIDENTIALITY GUIDELINES FOR ACCESS TO RHODE ISLAND KIDSNET DATA

NOTICE: these guidelines, in whole or in part, are subject to revisions by the Rhode Island Department of Health (RIDOH) at any time without advanced notice provided to all interested parties and/or providers in the furtherance of protecting the confidentiality of the protected healthcare information contained in KIDSNET.

I. INTRODUCTION:

KIDSNET was established as a confidential, computerized child health information system to facilitate the collection and appropriate sharing of health data with healthcare providers, parents, maternal and child health programs, and other child service providers for the provision of timely and appropriate preventive health services and follow up. The information contained in KIDSNET is subject to the confidentiality and disclosure requirements of state and federal healthcare confidentiality laws. This policy is intended to delineate and ensure a firm level of confidentiality. Section II of this policy describes the USERS authorized to access KIDSNET data and provides an overview of the scope of



Rhode Island KIDSNET usage agreement policy. Information on the varying degrees of access to KIDSNET by different users is delineated in Section III of this policy.

## II. Access to KIDSNET and Agreements to Protect Confidentiality

Direct access to KIDSNET is permitted for the sole purpose of providing information and documentation needed for coordinating childhood preventive health care. Indirect access to data may also be granted for IRB approved research or public health surveillance or public health program evaluation on behalf of the RIDOH.

KIDSNET USERS are defined as anyone with authorized RIDOH approved access to KIDSNET. To participate and have direct access to KIDSNET data, the USER'S organization must sign a RIDOH KIDSNET USER agreement and individual USERS of that organization must each sign a confidentiality agreement stating they will maintain the confidentiality of the patient preventive healthcare information and will only use the information to provide patient care or to confirm that individual patient preventive healthcare requirements have been met or to coordinate follow-up care for those services. As described in detail below in Section III different USER types will have varying degrees of access to KIDSNET. Anyone wishing to use KIDSNET must be authorized and approved by RIDOH and register by signing the required user/usage and confidentiality agreements.

Access to KIDSNET and authorized USERS are **limited** to the following categories:

1. Healthcare providers (public or private) that treat children.
2. Managed care organizations and health insurers
3. Public or private Rhode Island schools
4. Licensed Rhode Island child-care facilities.
5. Rhode Island Department of Education and its contractors or community partners responsible for assuring preventive health care and associated follow-up
6. Rhode Island Department of Health and its contractors or community partners responsible for assuring preventive health care and associated follow-up, including but not limited to Home Visiting Agencies, WIC and Lead Centers
7. Rhode Island Department of Children, Youth and Families and its contractors responsible for assuring preventive health care and associated follow-up



8. Rhode Island Executive Office of Health and Human Services and its contractors responsible for assuring preventive health care and associated follow-up, including but not limited to Early Intervention and CEDARR Centers
9. Researchers affiliated with an academic institution performing IRB approved public health related research or performing program evaluation or surveillance on behalf of the RIDOH.

KIDSNET users are authorized by their affiliated organization. The organization assumes full responsibility and liability for the individual usage of KIDSNET, including any penalties associated with the improper usage of KIDSNET and/or data associated with KIDSNET.

Physicians practicing outside the state of Rhode Island but treating a child with information in KIDSNET may request information from KIDSNET for care coordination. KIDSNET will not contain restrictions for children with out of state addresses.

KIDSNET user agreements shall be re-authorized every three (3) years or sooner and an organization shall be recertified as a KIDSNET user organization. KIDSNET user agreements are re-verified through reestablishing and confirming that the organization continue to have staff with at least one of the above referenced categories of authorized USERS and/or is an authorized agent of one of the above referenced authorized USER categories. The organizational status of an individual authorized USER will be recertified through contact with the licensing agency or the parent organization (e.g. LEA office for a school). Under the KIDSNET user agreement, organizations are required to immediately terminate access to any user no longer meeting the criteria for access. It will be the responsibility of the USER organization to investigate and resolve the issues related an individual not being re authorized.

All authorized USERS registered to use KIDSNET agree to comply with the user agreement developed for access by their respective user role. At a minimum they agree to the following:

1. USERS will handle all information and documents obtained through KIDSNET in a confidential manner in accordance with state and Federal confidentiality laws.
2. USERS will restrict their use of KIDSNET to accessing information and generating documentation only as necessary to properly conduct the administration of their duties as they relate to preventive care coordination and treatment of their patients/clients/students/participants.



3. USERS understand that all KIDSNET transactions are logged and are subject to audit for overall usage and access.
4. USERS will not utilize information of documentation obtained through KIDSNET for personal use or to any individual not directly involved with conducting the duties of the authorized USER as they relate to the administration, recording and reviewing of preventive healthcare records in KIDSNET.
5. USERS will not attempt to copy all or any part of the KIDSNET database for any unapproved purpose.
6. USERS will carefully and deliberately safeguard their access privileges and password for KIDSNET and will not permit the use of such access privileges by any other person, unless expressly authorized by RIDOH.
7. USERS agree to report any threat to or violation of the confidentiality of KIDSNET to RIDOH.
8. USERS will agree to fully comply with all State and Federal confidentiality laws.

Any improper and/or unauthorized use of KIDSNET will result in the revocation of the USERS access privileges and may result in further penalties under State and Federal Law.

### III. ACCESS TO AND DISCLOSURE OF KIDSNET INFORMATION

Access to KIDSNET is restricted to the authorized USERS listed in II who:

1. have a specific existing responsibility to enter and/or access children's preventive healthcare records in KIDSNET,
2. have signed the required user, data sharing and/or confidentiality agreements and are otherwise compliant with the terms and conditions of accessing KIDSNET.

USERS are classified and provided a discrete level of access based upon the information they need to carry out existing specific functions, duties and statutory requirements. Access is granted by RIDOH to USERS only on a need to know basis. Specifically, USERS are only granted access to the KIDSNET preventive healthcare records of the children for whom the USER is providing services/treatment and/or supports.

The following are permitted purposes for access to identified KIDSNET data:



1. Coordination of care for public health services. Access will only be permitted to information related to care that the user coordinates. Use is limited to patients or clients served by the requesting entity.
2. IRB approved research.
3. Population-based surveillance of childhood public health services or outcomes. Data analysis to inform local, state or national public health policy.
4. Evaluation of a public health related program.

In addition, requests for access to identified KIDSNET data must meet all of the following criteria:

1. Requests must be made by an endorsed USER with responsibilities for care coordination of public health services, public health surveillance, or public policy.
2. There must be a clear description of how the requested data elements will contribute to the proposed care coordination, research, surveillance, public policy, or evaluation.
3. Requested data must fall under approved informed consent and “opt out” policies of KIDSNET and programs that contribute data to KIDSNET.
4. The originating data source must approve the request.
5. Legal authority to release the data must be present.
6. Re-release of identifiable data is not permitted.
7. Transfer and storage of data must be secure.
8. A data sharing agreement, user agreement, contract, or memorandum of understanding describing the purpose and terms of the data access is in place.

As such authorized USERS that are:

1. Providers are granted full access to KIDSNET preventive healthcare information and may add new children to the data base, add immunization records and view other



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preventive healthcare status and encounters, to ensure that the child is up to date with preventive healthcare. This is limited only to children for whom the Providers provide health care services and treatment.

2. Managed Care Organizations can only view the specific preventive healthcare history and health care status of a particular child to coordinate care and verify health care history.
3. School/day care /camps can only view lead screening, developmental screening and immunization history and health care status of an enrolled identified student to verify screening status, immunization and/or health care history of that child.

All requests for public health research use of KIDSNET data should be directed to the RIDOH IRB. The request will be approved, refused or returned for additional information.

Any breach or violation of this policy and the User/Usage Agreement or confidentiality agreement signed by the authorized USER will result in the immediate revocation of the USER's access privileges and may result in further penalties and sanctions as provided for in various state and federal statutes and regulations.