



I-CARE Registry Security and Confidentiality Policy

The Immunization Data Registry Act [410 ILCS 527] authorizes the Illinois Department of Public Health (IDPH) to develop and maintain an immunization data registry to collect, store, analyze, release and report immunization data. Accordingly, IDPH has established the Illinois Comprehensive Automated Immunization Registry Exchange (I-CARE Registry). Protecting the privacy of clients and the security of the data contained in the I-CARE Registry is a high priority for IDPH. This security and confidentiality policy defines provisions under which the I-CARE Registry operates.

Access to the Registry is limited to users that have enrolled in the Registry with IDPH. Patient specific information is available only to authorized users. The privacy of participants and the confidentiality of information contained in the Registry shall be protected at all times by all authorized users.

I. Provider Site Agreement

The Provider Site Agreement must be signed by the site manager or designee, who assumes responsibility for the proper use and protection of registry data at their site. Each site must designate authorized users, who will be issued user names and passwords. Each individual user must also sign the Individual User Agreement and Confidentiality Statement (User Agreement), stating that s/he has read the IDPH Security and Confidentiality Policy and agrees to abide by its provisions. The User Agreement must be kept with the employee personnel file as documentation.

The Site Manager shall notify the IDPH when accounts need to be deleted or created due to changes in personnel.

Users who willfully misuse information contained in the registry will have their access immediately restricted by IDPH. An incident report will be filed and following investigation, appropriate action taken, which may include civil fines and penalties.

II. Client Participation

Immunization data may be reported to the Registry without the specific written authorization of a client.

The client or the client's parent, guardian or legal custodian may have the client's record excluded from the Registry by completing Illinois' Immunization Registry Opt-Out Registry Form (Op-Out Form) and submitting the complete form to the provider. The complete Opt-Out

form shall be maintained at the provider’s office in the client’s file. If a client opts out of the Registry, the Registry will lock the record so that it is not retrievable by anyone other than the provider site that marked the record protected. If any provider subsequently tries to add the same client to the Registry, the provider will be warned that the client has been excluded from the Registry, and the provider will be unable to save the record. Only IDPH has the ability to view or unlock a locked record.

III. Access to and Disclosure of Registry Information

The information contained in the I-CARE Registry shall be used only for the following purposes:

1. To provide immunization services to the client, including reminder/recall notices.
2. To permit schools to determine the individual immunization status of their students.
3. To eliminate the administration of duplicate immunizations.
4. To provide or facilitate third party payments for immunizations, e.g., medical assistance.
5. To assess immunization coverage rates.
6. To accomplish other public health purposes as determined by IDPH.

Any non-health use of I-CARE Registry data is prohibited and no user shall attempt to copy the database or software used to access the Registry without written consent from IDPH.

Users, defined as anyone with access to the I-CARE Registry, must register and sign an I-CARE User Agreement. Users are categorized into one of the following user types:

- 1) Health Care provider
- 2) Local Health Department
- 3) Elementary or secondary schools
- 4) Licensed child care center
- 5) Licensed child-placing agency
- 6) College or University
- 7) Illinois Department of Public Health employees and their authorized agents (e.g., I-CARE staff)

The following table outlines the different types of I-CARE access allowed for each user group type.

User Type	View Immunizations	View Demographics	Add/Edit Information
Health Care Providers	•	•	•
Local Health Department	•	•	•
Schools/Colleges/University	♦♦	♦♦	
Child Care Centers	♦♦	♦♦	
Child-placing Agency	♦♦	♦♦	
IDPH/Agents	•	•	•

- Has authorization to access all information
- Has authorization to access a subset of information, with contact information removed

View Immunizations means that the user has permission to view the entire immunization history and status (i.e., whether or not the client is up to date with recommended immunizations)

View Demographics means that the user can view information about the client, including the client's name, date of birth, mother's maiden name, address and telephone number.

Add/Edit Information means that the user can add new immunizations to a client's record and edit immunizations already previously recorded in a client's record. If an immunization was recorded as new, meaning that it was drawn from a provider's inventory, no other provider may edit the immunization. Providers may edit historical immunizations not marked as given by an agency. Users may add a new client record into the I-CARE Registry or alter the details on a client already contained in the I-CARE Registry.

IV. User Participation

Every individual who wishes to participate as a user of the I-CARE Registry must sign and comply with the I-CARE Registry Security and Confidentiality Policy. Any use of the I-CARE Registry that violates the Agreement and Policy will subject the user to revocation of the user's access privileges and may result in penalties for improper disclosure of health information.

The User Agreement must be signed by a representative of the participating entity, prior to any training on use of the I-CARE Registry and gaining access to the Registry data. Users will be assigned defined roles: Key Master, Add/Edit/Delete, Add/Edit/, Reports Only, View Only and Offline/Historical.

- Key Master – Can create employees, new clinics, and all the above
- Add/Edit/Delete – Can add, edit and delete information in I-CARE
- Add/Edit – Can only add and edit, but not delete information in I-CARE
- Reports Only – Can only run reports in I-CARE
- View Only – Can only view information in I-CARE
- Offline/Historical – not an user of I-CARE

Site administrators may enroll users who have been trained in the use of the I-CARE Registry at the appropriate access level and have signed the User Agreement. The Site Administrator will maintain a file of signed User Agreements and will require new agreements to be signed by users every two years. The participating entity or school assumes responsibility for the individual's usage of the I-CARE Registry. Providing access to outside organizations is strictly forbidden, (example, health departments providing access to a school).

Only personnel whose assigned duties include functions associated with the immunization of clients can be given access to Registry information. All personnel, including permanent and temporary employees, volunteers, contractors, and consultants, are required to sign a User Agreement before gaining access to the Registry. Whenever a user terminates the employment

or other status, that person's I-CARE Registry user account must be removed immediately. A user taking an extended leave of absence must have the account status set to Inactive. Users who fail to access the I-CARE Registry for more than 60 consecutive days will have their accounts inactivated by IDPH.

Access to the Web Site will be allowed only through registry approved access procedures. Each person granted access to the I-CARE Registry must have a unique login ID and password. Shared login IDs and passwords will not be permitted. Users are prohibited from disclosing registry access codes or protocol to unauthorized persons. Site administrators will ensure that users have been adequately trained to use the registry and are not given any higher level of access than that necessary to perform their assigned duties.

Identifying information contained in the I-CARE Registry will only be accessible to IDPH personnel, their authorized agents and authorized users. Requests for data for research purposes that go beyond the scope of the individual provider's patients or the local health department area of jurisdiction must be forwarded to the IDPH Immunization Program.

I-CARE Registry data identifying clients will not be disclosed to unauthorized individuals, including law enforcement, without the approval of the IDPH Director. All subpoenas, court orders, and other legal demands for I-CARE Registry data received by any authorized user of the I-CARE Registry must be brought to the attention of the IDPH staff, who will consult IDPH legal counsel.

V. Security Procedures

All enrolled sites shall maintain reasonable and appropriate administrative, technical and physical safeguards to ensure the integrity and confidentiality of the Registry information. IDPH Registry staff may conduct periodic assessments on privacy and security policies.