



**AIRA**  
AMERICAN IMMUNIZATION  
REGISTRY ASSOCIATION

# INFORMATION REQUEST

Topic: Handling IIS Opt-Outs

**Request Date:** July 8, 2021

**Information Requested:**

An AIRA member has questions about how IIS are handling data when an individual opts out of IIS participation. Please briefly describe:

- Your process for allowing individuals to opt-out of your system.
- Your process for handling an individual's demographic and immunization data once they communicate they would like to opt out.

**Requesting Member:** AIRA

**Responding Member(s):** Kim Gulliver (CO), Sydney Kuramoto (MN), Amanda White (MS), Mary Woinarowicz (ND), Kathryn Cruz (NM), David Baron (TN),

**Results:**

**CO**

Colorado is an opt-out state. We require any entity that submits data to us (manually or electronically reported) to put notification and opt-out processes in place. They do not need to talk with each patient but have to put Notification in place in some way so that patients can make an informed decision. Here's more information on the [CIIS Notification options](#) they have. A clinic is responsible for ensuring the patient can get our Opt-Out form, but then the patient is responsible for filling it out and sending it into CIIS. Here is more information on the [Opt-Out process](#) and recommendations for clinics.

When a patient sends the Opt-Out form to CIIS we will process it in our IIS. When we do this process, all vaccine information is purged from the system and we do not have a way to get this information back. In addition, we remove most identifying information, but we do keep first name, last name, DOB, Gender, City, County and Zip Code for matching purposes. If data comes in electronically and matches to this record, it will not be loaded. In addition, user in CIIS will see an icon identifying the patient as an opt-out and they cannot access the record.



Patients do have the option to rescind their Opt-Out. That form is included on the Opt-Out page linked above. When they rescind their opt-out, we'll make their profile active again, but a provider would be responsible for updating the demographics and adding the vaccine history back in.

## **MN**

Here is MN response to the Opt-out request.

- Your process for allowing individuals to opt-out of your system.
  - Individuals can submit an online MIIC Privacy Setting Change Request form and then health department staff process the request and update the individual's IIS record.
- Your process for handling an individual's demographic and immunization data once they communicate they would like to opt out.
  - Depending on the opt-out option they choose we do the following:
    - Opt-out Seal: The record is locked to an organization that only state health department staff can access in the event that they would like opt back into MIIC or request a copy of their record themselves.
    - Opt-out Purge: The record is locked to an organization that only state health department can access in the even that they would like to opt back into MIIC. It is also purged of all information except for minimal demographic information (name and birthdate) to ensure that users do not create a new record for the client. A nightly script is set-up to ensure any information that may have been added to the record (via data exchange) during the day is deleted.

## **MS:**

Mississippi does not allow individuals to opt out of MIIX.

## **ND:**

Handling IIS Opt-Outs in North Dakota

- North Dakota only allows adults 19 and older to opt out of the NDIIS. We have a mandatory reporting requirement for kids 18 and younger so we do not allow anyone in that age group to opt out. Adults wanting to opt out of the NDIIS must submit our online opt out form. The online form sends an email to our shared IIS email inbox and a member of the IIS team updates the record in the NDIIS. We previously allowed our provider to mark an IIS record as opted out but found that



they were using the field inappropriately. Now only immunization program staff are able to mark a record as opted out.

- Once a record has been marked as opted out in the NDIIS, only immunization program staff can see or access the record. We keep the record in the system in case the individual chooses to opt back in sometime in the future. Then none of their previous information is lost and we aren't creating a new record. No changes can be made to the client record while in an opt out status and no new immunizations can be added to the record by any user.
  - No other IIS UI users are able to see the record of someone who has opted out unless they attempt to create a new record for that same person. If a user is in the UI and attempts to create a new record that matches (based on first name, last name and birthdate exact match), they get a warning that says they are attempting to add a new record for a client that already exists and has opted out of the NDIIS. They need to contact the immunization program if the person opted back in and needs to be reset to active.
  - If an interoperable EHR attempts to query a record marked as opted out, we return an RSP with no patient history or forecast. If an EHR sends a VXU message for an opted out record, we send a ACK with error back and no information is added to the patient's record.

## **NM:**

NM is an opt out state and there are two options:

1. They can choose not to participate in NMSIIS (our IIS), in which they'd need to complete the attached Decline to Participate form, and then we mark their profile in NMSIIS as one to not add any immunizations to
2. They can also choose to remove any potential existing record in NMSIIS, our IIS. They would have to complete the attached Decision to Remove Record form and then we would add a note to their existing record and delete their patient record in the IIS. (Even when records are deleted in the IIS, they come up when an admin user searches for them but show as deleted and have the notes indicating their decision to opt out.)

## **TN**

An individual or the parent or legal guardian of a child may request that immunization information not be recorded in the Tennessee Immunization Information System (TennIIS). Individuals may opt to resume recording immunization information in TennIIS at any time.



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When opting out, an individual's basic identifying information such as name and date of birth remains in TennIIS and the record is flagged as being "opted-out." If any healthcare provider or electronic medical record system attempts to submit vaccine records for that individual, the vaccine data will be unable to update immunization information on that record.

To begin a TennIIS opt-out request, patients/parents/guardians can contact the TN Department of Health Central Office or the TennIIS Help Desk by phone or email. Once the request has been received, TennIIS staff will email, fax, or mail an Immunization Registry Change of Status request form that must be completed and signed, and then faxed, emailed, or mailed back to TDH before an opt-out request can be authorized. When the completed form is received, TennIIS staff print a copy of the immunization record from TennIIS and mail it to the patient/parent/guardian along with a confirmation letter for their records. TennIIS staff then delete all immunization information from the patient record, leaving only the demographic information in TennIIS. If the patient is not already in TennIIS, a letter is sent to the patient/parent/guardian informing them that we are not able to prevent immunization records from being entered in TennIIS without basic demographic information that can be flagged as opted-out.

For questions about Tennessee's opt-out process, please contact David Baron at [David.Baron@tn.gov](mailto:David.Baron@tn.gov).