North American Association of Central Cancer Registries, Inc.

Inter-registry Data Exchange Guidelines

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NAACCR
North American Association of
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Acknowledgments

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1 Introduction

The primary purpose of any cancer registry is to collect complete, timely, and high-quality data that are available for use in cancer prevention, control, and research. The multiple aspects of data collection specific to the population-based cancer registry require staff to evaluate all operational and procedural activities. Staff also must identify those activities that have the greatest impact on timeliness, quality, and completeness of data collection.

Because data collection standards are so critical to high-quality data and because registry experience and staffing vary considerably, the Inter-registry Data Exchange Task Force of the North American Association of Central Cancer Registries, Inc. (NAACCR) adopted as its charge the development of operational inter-registry data exchange guidelines for population-based cancer registries.

A population-based cancer registry must include all cancers occurring in residents of its coverage area, regardless of where the patients received their cancer diagnosis or where they are being treated. Without data exchange, patients who are seeking diagnosis or treatment outside their residential state, province, or territory may not be counted in the population-based statistics, either within a more localized central registry or within a broader regional or national database.

The identification and sharing of information of residents whose cancer is diagnosed or treated outside a central registry's coverage area are essential for accurate and complete population-based reporting. Collection and exchange of these records between registries are possible because of the standardization of data elements and reporting formats provided by NAACCR. Incomplete case ascertainment in population-based cancer registries can have a significant negative effect on the accurate assessment of the cancer burden in a state, province, or territory. Accurate and complete data enable each registry to better assess cancer incidence among its populations.

This version of the Inter-registry Data Exchange Guidelines has been updated to address several inter-registry data exchange issues identified by the Task Force. These updates address: the identification of the states, provinces, and territories for exchange; the content and format of data exchange; the quality of exchanged data; the mode of exchange; and the timeline for data exchange. All of these topics are discussed in greater detail within this document.

2 Data Exchange Agreement

Because central cancer registries need to have data on their residents whose cancer is diagnosed or treated in another state, the National Inter-registry Data Exchange Agreement (IDE) (formerly National Inter-State Data Exchange Agreement (ISDE)) was developed and championed by Dr. Susan Gershman, who was the Director of the Massachusetts Cancer Registry at that time, with colleagues at the Massachusetts Department of Public Health. NAACCR promoted this opportunity and coordinated the IDE with central registries in North America. Central registries may have limitations with sharing their data outside their country and should review their policies prior to exchanging data.

An ongoing list of those registries participating in IDE can be found at www.naaccr.org/national-interstate-data-exchange-agreement/. The standard language of the agreement provides mutual data privacy assurances and ensures that the Receiving Registry will use the data only as specified in the agreement. All the standard-setting agencies support the use of the IDE.

The IDE is patterned after the National Association for Public Health Statistics and Information Systems Inter-Jurisdictional Exchange (IJE) agreement, which provides the legal framework for states to provide their nonresident vital records to the person's state of residence. Like the IJE, the IDE establishes a legal framework for the secure inter-registry exchange of data on individuals who receive a cancer diagnosis or treatment in a state other than their state of residence. Becoming a Receiving Registry is not possible without a Sending Registry. All the current IDEs together become one agreement under which each state (or "Trading Partner") may—through a mutual agreement with another Trading Partner—send its nonresident data to the other Trading Partner and receive data on its own residents from the other state. Each pair of Trading Partners must determine the details of their exchange, such as when and how the data transfers will take place and if record-level or consolidated records will be exchanged. The IDE specifies that the exchanged data should pass edit checks and contain records in the current NAACCR standard data exchange format, excluding information specifically exempt from release by the Sending Registry, in accordance with the restrictions in their Addendum.

3 How to Exchange Data

3.1 Sign the Agreement

The IDE Agreement of 2010 replaced individual agreements between registries, allowing for a standardized agreement that could be utilized by all registries. The agreement was again revised in 2021 and includes:

- Standard definitions of terms used in the agreement,
- That written permission is not required from the Sending Registry for the release of:
    - Identifiable information when the Receiving Registry has also received cancer information from an in-state reporting facility,
    - A limited data set to researchers conducting studies facilitated by the Virtual Pooled Registry Cancer Linkage System (VPR),
    - De-identified data.
- Linkages with the National Childhood Cancer Registry and NCI's Breast Cancer Surveillance Consortium as additional examples of supporting federally funded surveillance programs.

Unless specified by the Sending Registry, Receiving Registries utilizing the 2010 versus the 2021 version are required to obtain written permission from the Sending Registry for research, including the re-release of records, not approved by the Receiving Registry's Institutional Review Board. This would include limited data sets facilitated by the VPR.

For a copy of the agreement, download the National Inter-registry Data Exchange Agreement and follow the steps below:

1. The proper authority at the Central Registry reviews the agreement and adds registry-specific restrictions if needed.
2. The appropriate registry representative signs the agreement.
3. The agreement is sent to NAACCR; the Central Registry retains a copy of the agreement. All signed National Inter-registry Data Exchange Agreements should be emailed to the NAACCR contact listed on the Inter-Registry Data Exchange Agreement web page.

4. NAACCR updates the IDE website list of registries that have signed agreements, including any specific restrictions. A listserv announcement to the NAACCR community is released when a new registry is added.
5. The registry contacts other participating registries to determine the logistics of how data will be exchanged.

NAACCR maintains an updated map on its website: www.naaccr.org/national-interstate-data-exchange-agreement/.

3.2 Identify Registries for Data Exchange

The contact information for each registry's authorized representative and person responsible for electronic exchange is included on page 3 of each signed IDE Agreement. Registry contact information is also available on the NAACCR Inter-Registry Data Exchange page (https://www.naaccr.org/national-interstate-data-exchange-agreement/). It may be helpful for registries to include more than one contact person or a general contact on the NAACCR webpage in case of staff turnover.

Ideally, the person responsible for electronic exchange should be contacted by either telephone or email to initiate the IDE process. If the person responsible for the electronic exchange is no longer in that position, ask the Registry Director for the name of the person responsible for IDE agreements. Email questions2us@naaccr.org for the Registry Director contact information. Registries should begin by contacting their bordering states and territories. The initial conversation with the IDE registry contact should include the following:

- A count of the registry's records on patients from the other registry, by diagnosis year
- Data transfer mechanisms—details on how the Receiving Registry can obtain data and information on the Sending Registry's preferred methods
- Data content - details on what type of records the Sending Registry will deliver (source-level or consolidated)
- Data to be provided in addition to the critical data items, including nonstandard data items per standard-setting agencies' specifications
- Discussion of each registry's restrictions on data exchange and use

This initial transfer of records often will include records for diagnosis years, starting with the registry's reference year up to the current date. Thereafter, future file exchanges should follow the guidance outlined in Section 3.3, Timeline. Central registries also should identify the manner in which the transfer of records will occur; see Section 3.7, Identification and Tracking.

3.2.1 Restrictions

Sending Registries may add additional permissions or restrictions on the data to be provided to Receiving Registries by completing the IDE agreement Addendum. It is essential that the Receiving Registries familiarize themselves with, and take action to ensure compliance with, the additional permissions and restrictions specified in each Addendum. See Section 3.7.1 for suggestions on how to manage restrictions on data exchanged through IDE. The additional conditions are available in the National Inter-registry Data Exchange Agreement. Reviewing the conditions may help guide the decision on which registries to exchange data.

3.2.1.1 Patient contact

Many registries have special restrictions on whether the Receiving Registry can contact patients. Sending Registries with this type of restriction must ensure that the IDE Addendum contains specific information on such restrictions. Any time that inter-registry data exchange data are used in research, Receiving Registries must review the restrictions and ensure that they are followed. See Section 3.7.1 for more information.

3.2.1.2 Provider contact

Some registries also have restrictions on if, when, and how providers named in the received records can be contacted. Sending Registries with this type of restriction must ensure that the IDE Addendum contains specific information on such restrictions. Receiving Registries must review the restrictions and ensure that they are followed.

3.3 Timeline

At a minimum, data exchange must be completed annually. Registries may choose to exchange more frequently with bordering states or territories. The standard-setting agencies may have specific data exchange requirements for the central cancer registries they support. It is recommended to follow the requirements of your standard setters when determining how often to exchange with other registries.

Additional best practices:

- Work closely with the Receiving Registry on a timeline to allow the Receiving Registry sufficient time to process the data prior to the annual data submission deadline.
- Notify the Receiving Registry when there are no cases to transmit for a particular exchange timeframe.

The table below provides an example schedule for when to send exchange data.

Data Exchange Frequency	Months to Send Data to Participating Registries
Two times per year	January, July
Four times per year	January, March, June, August

3.4 Critical Data Items

The most critical data items for data exchange are those needed to generate an incident record, so that the rates published by a registry are as complete as possible.

The table below provides a list of data items that are necessary for central registries to perform adequate processing of a cancer incidence case. Most central registries will transmit more complete data than those listed below; the intent of this list is to demonstrate a minimum standard that should be taken into consideration by a central registry when creating out-going Inter-registry Exchange files for other central registries.

Inter-registry Data Exchange Critical Data Items			
NAACCR Item #	**NAACCR Item Name**	**NAACCR Item #**	**NAACCR Item Name**
70	Addr at DX--City	500	Type of Reporting Source
80	Addr at DX--State	522	Histologic Type ICD-O-3
90	County at DX Reported	523	Behavior Code ICD-O-3
100	Addr at DX--Postal Code	764	Summary Stage 2018
160	Race 1	1760	Vital Status
190	Spanish/Hispanic Origin	1791	Follow-up Source Central
220	Sex	2230	Name--Last
240	Date of Birth	2232	Name--Birth Surname
390	Date of Diagnosis	2240	Name--First
400	Primary Site	2250	Name--Middle
410	Laterality	2320	Social Security Number
490	Diagnostic Confirmation	2330	Addr at DX--No & Street

3.5 Edits

It is well recognized that standardized data edit checks are an important component of ensuring data quality and reliability. These standardized edits are grouped into various edit sets to meet the intended purpose (e.g., hospital, pathology laboratory, or physician reporting).

Exchanging registries should perform the latest NAACCR CiNA edits.

The Receiving Registry should process the records according to its data processing system, keeping in mind that the exchange record may not include all specific state/provincial data items and may not pass state/provincial edits.

3.6 Data Transfer Mechanisms

Multiple data transfer mechanisms are available for inter-registry data exchange, including secure file transfer protocol (SFTP), secure Cloud storage, state-created web applications (e.g., state-specific Web Plus sites), and web applications provided by agencies, such as the National Interstate Data Exchange Application System (N-IDEAS). Electronic data transfer using N-IDEAS with secure encryption is the preferred method.

Sending Registries should use a standard filename convention that identifies the direction and date of transfer e.g., NY2VTDDMMYYYY. This naming convention makes it clear for both the Sending and Receiving Registries.

3.6.1 N-IDEAS

CDC's N-IDEAS is a secure data transfer mechanism with data editing, encryption, and file notification capabilities. Both the Sending and Receiving Registries receive automatic email notifications at each transfer point for process tracking—file upload, file download, and reminder of pending file expiration date. The files are uploaded to a secure location on the CDC's National Program of Cancer Registries

(NPCR) Cancer Surveillance System server and remain encrypted throughout the transaction, providing security protection so that only authorized personnel at the Receiving Registry have access to the data file. This access does not extend to CDC or its contractor. Once the Sending Registry uploads a file, it no longer has access to that file except to delete it. Sending Registries may set an expiration date for uploaded files so that the files are deleted if not downloaded by that date. All files are deleted from the server once downloaded to prevent them from remaining on the system indefinitely.

The system was developed using an n-tier solution with .Net technologies and XML web services following National Institute of Standards and Technology (NIST) standards for security and advanced encryption standards to encrypt data. Encrypted data are sent over an HTTPS (hypertext transfer protocol secure) protocol, providing additional security. N-IDEAS includes the following components:

- Client Application—performs optional edits, parses a single file of nonresident records into multiple files for transmission to the appropriate state, and provides a history of data exchanges. This component is a desktop application on the registry user's computer.
- Reporting Website—allows the CDC/NPCR to track data exchange activities using this system.
- XML Web Services—used to transfer data files over a secure HTTPS network and provide email notification services to inform users of available exchange options.
- Windows Services—provide automatic deletion of expired files from the server.

This system is available, at no cost, to all NAACCR registries. Contact the CDC NPCR, support@npcrcss.org, for more information or to request access.

3.7 Identification and Tracking

Exchanged records should be selected by Addr at DX State [80], where the state is not the Sending Registry's state, and the other state is a participant in the data exchange.

Records should have a minimum diagnosis year of the registry's reference year and a maximum diagnosis date of the current date. Identified records should be sent at least annually (see Timeline 3.3).

The Sending Registry should determine an appropriate method to identify all records created or loaded since the last exchange with the other state.

- If the Sending Registry sends individual abstracts, some options are to compare the date of the previous exchange with such fields as Date Case Report Exported [2110], Date Case Report Received [2111], or Date Case Report Loaded [2112].
- If the registry sends consolidated records, multiple approaches can be taken, depending on the registry's data management system:
  - Use the same variable options as the individual abstracts.
  - Use system dates that identify when the record first appeared in the system.
  - Create a tracking system to maintain a list of records that are already sent to the state and to track acknowledgement from the Receiving Registry that they have successfully received the data. Such a list could include the Patient ID Number [20], Tumor Record Number [60], date sent, or Addr at DX State [80].

- The registry should send initial records as type A, using the methods described above. Although not all registries utilize the type M record, it is recommended that updated records be sent as type M.
    - Updated records can be identified using the field Date Case Last Changed [2100].

The best practice for inter-registry data exchange is that registries maintain a record-tracking system and provide acknowledgment of receipt of data. This tracking method could be a simple checklist, an Excel file, or a tracking system built into the registry software. The items to consider tracking may include the name of the exchanging registry, contact information, a count of records included in the file, a date-stamp for when the file was sent or received, the range of records (e.g., diagnosis date, date first seen, date case created), the method of exchange, and a comment field.

Acknowledgment could be an email reply, completion of a form, or a more integrated approach in which the computer receiving the data transmits a receipt to the sending computer.

3.7.1 Flagging IDE Records

Sending and Receiving Registries should discuss and establish an agreed-upon method to identify records received through the IDE agreement and to identify the Sending Registry.

Registries must have a way to identify records transmitted and received through the IDE agreements. Transmitted IDE records can be identified by electronically applying a flag to a state-specific field within the central registry database or using a NAACCR data item, such as the Date Case Report Exported [2110]. For records received through IDE, the Receiving Registry must have a way to identify the Sending Registry to ensure that any handling of the exchanged record complies with the associated IDE agreement. Central registry software systems should have the ability to flag, identify, and report on the central registry associated with the incoming source records (e.g. records received from Florida, Massachusetts, etc.) or that contribute to the consolidated record. The Reporting Facility Restriction Flag [1856] is recommended to identify records affiliated with IDE that potentially should not be released based on agreements with the underlying reporting facilities/sources. The Reporting Facility Restriction Flag was implemented in 2023 and replaces the use of Unusual Follow Up Method [1850] or the State Requestor field, which was retired in v22.

4 Registry Specific Considerations

4.1 Source versus Consolidated Records

Sending and Receiving Registries will need to negotiate whether the records exchanged will contain source or consolidated information. Whereas source records contain information about the providers, consolidated information may not. Consolidation of records can cause delays in transmission, depending on the Sending Registry's resources.

4.2 Other Considerations

- Sending Registries should check outgoing records to confirm the validity of all necessary date data items. For instance, the date of diagnosis is required and should not be left blank.
- Sending Registries should remove voided or deleted abstracts from the outgoing file. Registries uncertain about whether their databases export deleted abstracts should review the extract specifications or consult with their vendor.

- Registry-specific data items should not be included in files shared with other registries.
- Registries should notify states when no data have been identified to be shared with their registry.
- Sharing duplicate records continues to be an issue. Some software extract based on Date Case Last Changed [2100], which is a field that is updated during normal quality assurance processes.
- Registries should negotiate whether they will send/receive other record types (e.g. pathology, physician records, etc.).