

North American Association of Central Cancer Registries, Inc.

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Interstate Data Exchange Guidelines

August 2019



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Interstate Data Exchange Task Force

Susan Gershman, PhD, CTR (Chair)
Massachusetts Cancer Registry

Lori Havener, CTR
NAACCR

David Bang, PhD, MPH, CHES
CDC NPCR

Carrie Bateman, BS
Utah Cancer Registry

Linda Bloschies, CTR
Vermont Cancer Registry

Sally A. Bushhouse, PhD
Minnesota Cancer Surveillance System

Julia R. Espinoza, MS, RHIT, CTR
Wyoming Cancer Surveillance Program

Theresa M. Juster, MPH
New York State Cancer Registry

Richard Knowlton, MS
Massachusetts Cancer Registry

Keith Laubham, MS
Arizona Cancer Registry

SuAnn McFadden, CTR
Utah Cancer Registry

Bonnie Redeford, CTR
Illinois State Cancer Registry

Joseph Dean Rogers, MS
CDC NPCR

Martin A. Whiteside, DC, PhD, MSPH
Tennessee Cancer Registry

Melanie A. Williams, PhD
Texas Cancer Registry

Reda J. Wilson, MPH, CTR
CDC NPCR

Georgia Armenta Yee, BSW, CTR
Arizona Cancer Registry

CDC = Centers for Disease Control and Prevention
NAACCR = North American Association of Central Cancer Registries
NPCR = National Program of Cancer Registries

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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 Interstate Data Exchange Task Force of the North American Association of Central Cancer Registries, Inc. (NAACCR) adopted as its charge the development of operational interstate 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 and/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 Guidelines has been updated to address several interstate 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-State Data Exchange Agreement (ISDE) was developed and championed by Dr. Susan Gershman, Director of the Massachusetts Cancer Registry, and colleagues at the Massachusetts Department of Public Health. NAACCR promoted this opportunity and coordinated the ISDE with central registries in North America. An ongoing list of those participating in ISDE is hosted by NAACCR and can be found at www.naacr.org/national-interstate-data-exchange-agreement/. The standard language of the agreement provides mutual data privacy assurances and assurances that the receiving registry will use the data only as specified in the agreement. All of the standard-setting agencies support the use of the ISDE.

The ISDE 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 ISDE establishes a legal framework for the secure interstate exchange of data on individuals who receive a cancer diagnosis or treatment in a state other than their state of residence. Becoming a receiving state is not possible without becoming a sending state. All of the current ISDEs 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 ISDE 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. The minimum data items recommended for data exchange can be found in the Required Status Table of the [Data Standards and Data Dictionary, Volume II](#).

3 How to Exchange Data

3.1 Sign the Agreement

The ISDE Agreement was announced to the NAACCR community in the NAACCR Narrative Fall 2010. It was noted that the old data exchange agreements—

- Were outdated
- Were inconsistent
- Required separate review and approval
- Did not address current topics, such as Call for Data and linkages with National Death Index and Indian Health Service
- Did not include the sharing of information from records of out-of-state diagnoses with local and/or regional public health agencies, including NAACCR; Centers for Disease Control and Prevention (CDC)/ National Program of Cancer Registries (NPCR); and the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute.

For a copy of the agreement, download the [National Interstate Data Exchange Agreement](#) and follow the steps below:

1. The proper authority at the Central registry reviews the agreement and adds state-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 Interstate Data Exchange Agreements should be faxed to the NAACCR office at 217-698-0188 or sent to info@naaccr.org.
4. NAACCR updates the list on its website of states that have signed agreements, including any specific restrictions. A listserv announcement to the NAACCR community is released as soon as a new registry is added.
5. The registry contacts other participating states to determine the logistics of how data will be exchanged.

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

3.2 Identify States for Data Exchange

The contact information for each state's Registry Director and person responsible for electronic exchange is included on page 3 of each signed ISDE Agreement. Ideally, the person responsible for electronic exchange should be contacted by either telephone or email to initiate the ISDE process. If the person responsible for electronic exchange is no longer in that position, ask the Registry Director for the name of the person responsible for ISDE agreements. The initial conversation with the ISDE registry contact should include the following:

- A count of the state registry's records on patients from the other state, 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 minimum 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 ISDE 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. The additional conditions are available in the [National Interstate Data Exchange Agreement](#). Reviewing the conditions may help guide the decision on which states to exchange data.

3.2.1.1 Patient contact

Many states have special restrictions on whether the receiving registry can contact patients. Sending registries with this type of restriction must ensure that the ISDE Addendum contains the specific information on such restrictions. Any time that interstate data exchange data are used in research, receiving registries must review the restrictions and ensure that they are followed.

3.2.1.2 Provider contact

Some states 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 ISDE 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 or more frequently with bordering states. The standard-setting agencies may have specific data exchange requirements for the central cancer registries they support; those requirements supersede these recommendations.

3.4 Minimum Data Items

The proposed set of data items is a suggested list of the minimum data items to be included when they are available. It is possible that not all items will be available in the data being exchanged.

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. These fields include the patient identifiers (so that the receiving registry can confirm this is the only reporting source for the patient/cancer); the cancer diagnosis (primary site, laterality, histology, behavior, and date of diagnosis); race and ethnicity; gender; age at diagnosis; and the patient's address at diagnosis (so that sub-state regional rates also can be as complete as possible).

3.5 Minimum 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). The minimum set of edits, which relates to the minimum set of data items (see [Section 3.4](#)), should be applied to data exchange files before transmission (see the Edits Metafile: www.naacrr.org/standard-data-edits/). The intent of the ISDE edit sets is to ensure that valid codes are assigned to each data item, with very few interfield edits that check for consistency between fields. Blank fields are allowed for data items marked "Transmit if available." If the exchanging registries agree to include data items in addition to the minimum data items, the edit set should include edits that evaluate those data items. A minimum of 99 percent of exchanged records should pass the minimum edit set.

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 interstate data exchange, including file transfer protocol (FTP), secure Cloud storage, CD-ROM, paper abstracts or records, state-created web applications, and web applications provided by agencies, such as the National Interstate Data Exchange Application System (N-IDEAS) created by the CDC. Electronic data transfer with secure encryption is the preferred method.

3.6.1 N-IDEAS

The 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 the 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 3 months before submission deadlines for the reporting year of that record's diagnosis date.

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. 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 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 interstate 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 ISDE Records

Sending and receiving registries should discuss and establish an agreed-upon method to identify records received through the ISDE agreement and to identify the sending registry. Identifying ISDE records is important to ensure that the receiving registry complies with the appropriate ISDE agreement. Sending or receiving registries may consider identifying records transmitted and/or received through ISDE by flagging each record (e.g., electronically applying a flag to a state-specific field within the central registry database) or using an NAACCR data item, such as the Date Case Report Exported [2110] or Unusual Follow-Up Method [1850] (neither item is currently well defined for use by a central registry).

4 Issues

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. The registries also might consider whether exchange of pathology-only records might be appropriate.