

**North American Association of Central Cancer Registries
National Interstate Data Exchange Agreement
(Updated 7/23/2021)**

Defined Terms for the purpose of this Agreement:

- “Cancer Information” shall mean all information regarding a patient with a reportable cancer, including identifiers, demographics, provider and facility information, and diagnosis and treatment information.
- “Central Cancer Registry” means a population-based information system designed for the collection, management, and analysis of all cancer patient data within a specific geographical area.
- “De-Identified Information” shall mean health information that does not identify an individual and for which there is no reasonable basis to believe that the information can be used to identify an individual. Health information is considered de-identified (1) if stripped of all of the 18 direct identifiers defined under the HIPAA Privacy Rule (45 CFR 164.514), or (2) if an expert in statistical and scientific method determines that there is a very small risk that the information could be used alone or in combination with other information to identify an individual.
- “Identifiable Information” shall have substantially the same meaning as the term is used in the HIPAA Privacy Rule (45 CFR 164.514). It includes information concerning an individual that because of name, identifying number, mark or description, in combination with other available information, can be associated with a particular individual. The 18 HIPAA identifiers include name, address (geographic subdivisions smaller than state), all elements (except years) of dates and exact age if over 89, telephone number, fax number, email address, Social Security Number, medical record number, health plan beneficiary number, account number, certificate or license number, vehicle identifiers and serial numbers, device identifiers and serial numbers, web URL, Internet Protocol Address, finger or voice print, photographic image, and any other characteristic that could uniquely identify the individual.
- “Interstate-exchange-only cases” shall mean a case in the Receiving Registry where the only information on the cancer was received through interstate exchange from the Sending Registry. There is no other report of the case submitted by any other institution.
- “Limited Data Set” shall have substantially the same meaning as the term is used in the HIPAA Privacy Rule (45 CFR 164.514). A Limited Data Set may not include information about a patient that allows direct identification (e.g. Name, address, SSN, etc.), but may include indirect identifiers (e.g. dates of birth, dates of service, age in years, etc.).
- “Patient” shall mean a person who is currently receiving, is registered to receive, or in the past has received diagnosis or medical treatment for cancer or another condition reportable to Central Cancer Registries.
- “Receiving Registry” shall mean the Central Cancer Registry that receives resident cancer information from the Central Cancer Registry where the cancer or non-malignant brain tumor was diagnosed or treated.
- “Sending Registry” shall mean the Central Cancer Registry that shares resident cancer information with the Central Cancer Registry where the patient resides.

This Agreement establishes the terms and conditions for the exchange of cancer information between participating member registries (“Trading Partners,” collectively) of the North American Association of Central Cancer Registries (“NAACCR”). This Agreement will be executed in counterparts by each Trading Partner, with each such signed Agreement deemed to be an original, and all such counterparts together shall constitute one and the same instrument. The executed counterparts of the Agreement shall be maintained by NAACCR, but NAACCR is not a party to the Agreement.

Each Trading Partner agrees to specify in detail any additional permissions and/or restrictions affecting the use and release of its cancer information by other Trading Partners. These specifications will be included in the Addendum, hereby incorporated into this Agreement. Each Trading Partner agrees to update and keep current all information in the Addendum by informing NAACCR in writing of any changes to law, regulation or policy that impact the Agreement or Addendum, and expressly authorizes NAACCR to provide a copy of the Trading Partner’s executed counterpart (and any Addendum thereto), as may be revised or modified, to any other Trading Partner at any time.

Each Trading Partner may rescind or modify its participation in this Agreement by sending a written notice of rescission or a copy of revisions to NAACCR. Each Trading Partner acknowledges that it is its responsibility to provide written notification to NAACCR of any rescission or modification of its participation in this Agreement, including any revision of the Trading Partner’s Addendum or this Agreement.

By signing this Agreement, the authorized signatory for the Central Cancer Registry agrees that:

1. It is a Trading Partner in the exchange of cancer information with all other Trading Partners, acting as the Sending Registry and/or the Receiving Registry with regard to cancer information.
2. The Sending Registry will provide all cancer information occurring in non-residents and contained in the Sending Registry to the Receiving Registry where the reported cancer cases reside, except information specifically exempt from transmission by the Sending Registry in accordance with the restrictions in the Addendum.
3. Cancer information will be provided electronically, whenever practical, at the discretion of the Sending Registry. Prior to exchange, the latest data core edits will be run on the data and resolved by the Sending Registry, and the data will be formatted to follow the most current NAACCR XML standard guidelines (available on naaccr.org). The cancer information shall be transmitted through a mutually agreed-upon secure method that minimizes, to the greatest extent feasible, the risk of any unauthorized access to the information.
4. All transmittals of cancer information are to be made following a timetable mutually agreed upon by Trading Partners. To ensure optimum utilization of the records, Trading Partners shall make every reasonable effort to transmit all cancer information within eighteen (18) months of the end of the diagnosis year.
5. The cancer information exchanged under this Agreement may only be used by the Receiving Registry for purposes authorized in Paragraph 8 of this Agreement or any other purposes authorized in writing by the Sending Registry. The Receiving Registry agrees to use records containing identifiable information exchanged under this Agreement in full compliance with the terms and conditions of this Agreement and any specific conditions required by the Sending Registry in the Addendum.
6. Any and all cancer information that could be used to identify any patient is strictly privileged and confidential, and the Receiving Registry agrees to keep all such data strictly confidential.
7. A Receiving Registry must have in place and utilize legal protections under state and/or federal law to protect a Sending Registry's identifiable cancer information from use or release in any manner contrary to the terms of this Agreement. A Receiving Registry agrees to maintain the confidentiality of all exchanged identifiable cancer information from unauthorized use or release. Such confidentiality shall be maintained notwithstanding termination of this Agreement.
8. Except as otherwise specified in the Addendum, the cancer information provided under this Agreement may be used by the Receiving Registry for the following purposes:
 - a. Aggregated statistical tabulations and analyses;
 - b. Linking with appropriate databases {e.g., *death certificates, hospital discharge databases, Indian Health Service, National Death Index*} as necessary for cancer registry activities intended to acquire or enhance cancer case information;
 - c. Research conducted by the Receiving Registry or external researchers that has been approved by the Receiving Registry's Institutional Review Board, or other reviewing body, and/or any external researcher's Institutional Review Board. Sending Registry's written permission for Receiving Registry release of data is only required when release includes identifiable information on interstate-exchange-only cases. Written permission from the Sending Registry is not required for the following:
 - i. Release of identifiable information where the Receiving Registry has also received cancer information from an in-state reporting facility.
 - ii. Release of a limited data set to researchers conducting studies facilitated by the Virtual Pooled Registry Cancer Linkage System.
 - iii. Release of de-identified data.
 - d. Sharing of a limited data set with local and/or national public health agencies, including NAACCR, CDC/NPCR, and the NCI/SEER Calls for Data, for the support of public health programs, with an agreement that provides appropriate restrictions on the use and release of the shared information;
 - e. Using cancer information to perform linkages in support of federally funded surveillance programs (e.g. Breast and Cervical Cancer Control Program, Colorectal Cancer Control Program, NCI's Breast Cancer

Surveillance Consortium, and the National Childhood Cancer Registry, etc.) under the terms of a written agreement or other means that provides for the appropriate restrictions on the use and release of the shared information;

f. Sharing cancer information with, or within, State Health Departments for surveillance or community health assessment activities; and

g. Sharing of cancer information with other cancer registry entities in the Receiving Registry's state.

9. The Receiving Registry will restrict access to identifiable cancer information that was supplied by a Sending Registry under the terms of this Agreement from being released to anyone not employed in the direct operation of the Receiving Registry, except as specifically authorized within the terms of this Agreement. Employees may include those involved in the processing, administration, quality control review, and statistical surveillance of cancer incidence data.

10. All officers, agents and employees of a Receiving Registry shall keep all cancer information strictly confidential. The Receiving Registry shall communicate the requirements of this Agreement to all officers, agents, and employees, shall discipline or take other appropriate action against all persons who may violate the requirements of this Agreement, and shall notify the Sending Registry in writing within two working days (48 hours) of discovery of any violation of this Agreement, including full details of the violation and corrective actions to be taken.

11. The Receiving Registry will notify the Sending Registry if, in the conduct of approved research or other activities involving the Sending Registry's data, there is a breach or misuse of a cancer patient's identifying information or potentially identifying information. Should a breach or misuse take place, the Receiving Registry must notify the Sending Registry in writing within forty-eight (48) hours of discovery of the release of the data, and shall take all feasible measures to mitigate loss or damages related to such breach or misuse, including, but not limited to, bearing sole responsibility for reasonable costs, including attorneys' fees, related to mitigating the breach or misuse (to the extent authorized by state law).

12. Any other use or release of cancer information provided to the Receiving Registry that is not authorized by the terms of this Agreement requires the written permission of the Sending Registry.

13. In the event that the Receiving Registry receives a subpoena or other compulsory legal process compelling disclosure of identifiable cancer information, the Receiving Registry agrees to notify the Sending Registry within forty-eight (48) hours of receipt of the subpoena or other compulsory legal process and to take all legal steps reasonably necessary to oppose the subpoena or other compulsory legal process.

14. This Agreement shall remain in effect as to any Trading Partner from the date of its execution until a duly authorized representative of that Trading Partner notifies the other Trading Partners of a change or termination of this Agreement through written notification to NAACCR or until superseded by a revised National Interstate Data Exchange Agreement.

15. All notices required or desired to be made to this Agreement by any Trading Partner shall be sent to NAACCR as well as to any Receiving Registry of the Trading Partner.

Trading Partner:

Central Cancer Registry New York State Cancer Registry

Agency New York State Department of Health

Maria J. Kobayashi Director, Bureau of Cancer Epidemiology 8/18/2021
Signature Title Date

CONTACT PERSON:

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Addendum to Trading Partner Agreement of New York State Cancer Registry

Additional permissions and restrictions on the use of cancer registry information from this Trading Partner.

None
