

**North American Association of Central Cancer Registries
Agreement for Administering the Central Cancer Registry
Inter-registry Resident Data Exchange**

This Agreement establishes the terms and conditions for the exchange of resident cancer case information between participating member registries of the North American Association of Central Cancer Registries (NAACCR) (hereafter referred to as “Trading Partners”). This Agreement will be executed in counterparts representing each participating NAACCR member registry, with each such signed agreement deemed to be an original, and all such counterparts together shall constitute one and the same instrument. This Agreement is administered by NAACCR, which is not a party to the Agreement. Each Trading Partner may rescind or modify its participation in this Agreement by notifying NAACCR of the details of the rescission or change.

Each Trading Partner agrees to specify in detail any additional permissions and/or restrictions affecting the use, release and re-release of its information by another Trading Partner. These specifications will be included in the Addendum, hereby incorporated into this Agreement, and will be posted on the NAACCR website. Each Trading Partner agrees to update and keep current all information in the Addendum by informing NAACCR of any changes to statute, regulation, or policy that impact this Agreement.

By signing this Agreement, the central cancer registry listed below agrees to become a Trading Partner in the exchange of cancer incidence data, acting as a Sending Registry and/or a Receiving Registry with regard to resident cancer data for all participating member registries and hereby agrees:

1. That the Sending Registry will provide all cancer registry records and information concerning cases of cancer 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 release by the Sending Registry in accordance with the restrictions in the Addendum.
2. That the information exchanged under this Agreement is governed by the state laws, regulations and/or policies of the Sending Registry relating to cancer patient data use, release and re-release.
3. That information will be provided electronically, whenever practical. The latest data core edits will be run on the data by the Sending Registry, and the data shall be formatted to follow the most current NAACCR data exchange record layout, shall contain sufficient information to be used for statistical and administrative purposes, and shall be transmitted through a mutually agreed-upon secure method that ensures against inappropriate access to the information.
4. That all transmittals of cancer registry records 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 forward all cancer case reports within 18 months of the end of the diagnosis year.
5. That any and all data that may lead to the identification of any patient is strictly privileged and confidential, and the receiving registries agree to keep all such data strictly confidential.
6. That a Receiving Registry shall maintain the confidentiality of the exchanged patient identifying data and has legal protections in place under state and/or federal law to be able to

protect the data from release in any manner contrary to the terms of this Agreement. Such confidentiality shall be maintained notwithstanding termination of this Agreement.

7. That all information provided to a Receiving Registry remains the property of the Sending Registry where the information originated and the confidentiality laws of the Sending Registry apply to any request for release of identifiable information. By signing this Agreement, a Receiving Registry agrees to use or re-release records containing identifiable information exchanged under this Agreement in full compliance with the terms and conditions of this Agreement and as specified by the Sending Registry within the Addendum. For the purpose of this agreement identifiable information shall be defined as in the HIPAA Privacy Rule (45 CFR 164.514).

8. That the cancer incidence data provided under this Agreement may be used for the following purposes and as specified by the Sending Registry for:

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 or approved by the Receiving Registry unless specified in the addendum.

d. Sharing of partially de-identified information with local and/or national public health agencies, including NAACCR and the CDC/NPCR Coordinated Call for Data, and the National Cancer Institute's Surveillance, Epidemiology, End Results (NCI/SEER) Call for Data, and for the support of public health programs, with an agreement that provides appropriate restrictions on the use and release of the shared information.

e. Conducting linkages with and providing case information to the Breast and Cervical Cancer Control Program and Colorectal Cancer Control Program under the terms of a written Memorandum of Understanding or other means that provides for the appropriate restrictions on the use and release of the shared information.

f. The receiving registry may share records with State Health Departments for surveillance or community health assessment activities.

g. Sharing of case data with other central registry entities in the Receiving Registry's state.

9. That the Receiving Registry will restrict access to cancer incidence data or identifiable information on a cancer patient 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. That all officers, agents, and employees shall keep all such data strictly confidential; and that the Receiving Registry shall communicate the requirements of this Agreement to all officers, agents, and employees, shall discipline all persons who may violate the requirements of this Agreement, and shall notify the Sending Registry in writing within 2 working days (48 hours) of any violation of this Agreement, including full details of the violation and corrective actions to be taken.

11. That the Receiving Registry will notify the Sending Registry if, in the conduct of approved research or other activities, 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 2 working days (48 hours) of the release of the data.

12. That any other use or release of information from records provided to a Receiving Registry that is not authorized by the terms of this Agreement requires the written permission of the Sending Registry.

13. That in the event that the Receiving Registry receives a subpoena or other compulsory legal process compelling disclosure of confidential data, the Receiving Registry agrees to notify the Sending Registry within 2 working days (48 hours) of receipt of the subpoena or other compulsory legal process. Additionally, should the Receiving Registry receive such a subpoena or other compulsory legal process, it shall take all legal steps reasonably necessary to oppose the subpoena or other compulsory legal process.

14. That the Receiving Registry shall bear liability for loss, expense, attorneys' fees or claims, for injury or damages arising out of acts or omissions in the performance of this agreement related to data provided by the Sending Registry.

15. That this Agreement shall remain in effect from the date of execution unless notified of a change by the appropriate official.

16. That all notices required or desired to be made to this Agreement shall be sent to NAACCR for notification to all parties.

Addendum

Additional permissions and restrictions on the use of cancer information from this Sending Registry.
