

**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 (“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, release and re-release of its 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 statute, regulation or policy that impact this Agreement 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 central cancer registry listed below agrees to become a Trading Partner in the exchange of cancer incidence data, acting as the Sending Registry and/or the Receiving Registry with regard to resident cancer data for all other Trading Partners and hereby agrees that:

1. The Sending Registry will provide all cancer registry records and information concerning diagnosis and treatment 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. 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.
3. 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 eighteen (18) months of the end of the diagnosis year.
4. The information exchanged under this Agreement may only be used by the Receiving Registry for purposes authorized in Paragraph 7 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. Identifiable information exchanged under this Agreement may not be re-released by the Receiving Registry without written permission of the Sending Registry.

For the purpose of this Agreement, identifiable information shall be defined as in the HIPAA Privacy Rule (45 CFR 164.514).

5. Any and all data that may lead to the identification of any patient is strictly privileged and confidential, and the Receiving Registry agrees to keep all such data strictly confidential.
6. 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. 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 by the Receiving Registry that has been approved by the Receiving Registry's Institutional Review Board, unless otherwise specified in the Addendum; All other research, including re-release of records, requires written permission of the Sending Registry;
- 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. Sharing records with State Health Departments for surveillance or community health assessment activities; and
- g. Sharing of case data with other central registry entities in the Receiving Registry's state.

8. 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.

9. 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 two working days (48 hours) of any violation of this Agreement, including full details of the violation and corrective actions to be taken.

10. 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 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.

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

12. 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 forty-eight (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.

13. 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.

14. 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: California Cancer Registry
Agency: California Department of Public Health

Kurt P Snipes Director, CCR 1/29/16
Signature Title Date

CONTACT PERSON FOR ELECTRONIC EXCHANGE:

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Addendum to Trading Partner Agreement of California Cancer Registry

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

1. Cancer case information supplied by the California Cancer Registry (CCR) can be used for any registry-related purpose as outlined above, but release of identifiable or potentially re-identifiable CCR data is not permitted without the prior written approval of the CCR. This includes release for research as listed in item 7c of the Standard Agreement. Researchers seeking data with identifiers must submit their request to the California Protection for Human Subjects (CPHS) Institutional Review Board (IRB) through CalPROTECTS or other mechanism available at the time of submission and approved by the CPHS IRB. Secondly, the Receiving Registry will notify CPHS if, in the conduct of approved research or other activities involving the CCR'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 CCR according to item 10.

2. Pursuant of the California Health and Safety Code section 103885, the receiving state shall not grant access to, disclose, admit, produce or otherwise make available any part of the CCR data in any civil, criminal, administrative, or other tribunal or court proceeding, whether voluntarily or under compulsion. The receiving state shall immediately notify the CCR Data Custodian and the Chief, Chronic Disease Surveillance and Research Branch, California Department of Public Health by telephone and fax of the receipt of any subpoena, discovery request, court order, search warrant or other form of compulsory legal process or threat of compulsory legal process in which CCR data and/or documents, data files or other materials containing CCR data are sought to be produced or examined. The receiving state shall immediately take all necessary legal action to oppose and resist any such compulsory legal process, e.g. file a motion to quash or written objections to a subpoena, or file written objections to a discovery request and opposition to a motion to compel.
