

# UTAH CANCER REGISTRY

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To: Royale Anne Hinds

Of: NAACCR

Fax: 217-698-0188

From: Antoinette Stroup

Message: Inter-Registry Resident Data Exchange

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**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 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. 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. 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. 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.
5. 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. 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. All information provided to the 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. The 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 in the Addendum. For the purpose of this Agreement, identifiable information shall be defined as in the HIPAA Privacy Rule (45 CFR 164.514).
8. The cancer incidence data provided under this Agreement may be used for the following purposes and as specified by the Sending Registry for:
- Aggregated statistical tabulations and analyses;
  - 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;
  - Research conducted or approved by the Receiving Registry unless otherwise specified in the Addendum;
  - 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;
  - 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;
  - Sharing records with State Health Departments for surveillance or community health assessment activities; and
  - Sharing of case data with other central registry entities in the Receiving Registry's state.
9. 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. 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.
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 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.
12. 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.
13. 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.
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.

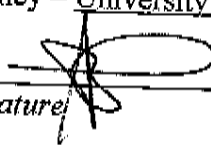
15. All notices required or desired to be made to this Agreement by any Trading Partner shall be sent to NAACCR as well as to any Receiving Registry of the Trading Partner.

Trading Partner:

Central Cancer Registry – Utah Cancer Registry

Agency – University of Utah

Signature



Director, UCR  
Title

11/21/2011  
Date

**CONTACT PERSON:**

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## Addendum to Trading Partner Agreement of Utah Cancer Registry

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

Pursuant to the Memorandum of Agreement between the University of Utah and the Utah Department of Health (UDOH), effective as of November 1, 2006, as amended:

1. All cancer case information collected by the Utah Cancer Registry (UCR) (including cancer case information collected under previous agreements and arrangements) is the property of the Utah Department of Health (UDOH).
2. The UCR may only disclose identifiable cancer case information to a bona fide cancer registry that has entered into a signed agreement with UCR to exchange identifiable cancer case information regarding:
  - a. Individuals who are residents of the collaborating registry's area of coverage and may have been diagnosed or treated for cancer in Utah; or
  - b. Individuals who are residents of Utah and may have diagnosed or treated for cancer in the collaborating registry's area of coverage.
3. The UCR is prohibited from disclosing identifiable cancer case information if:
  - a. The sole source of such information for a cancer case registered in UCR was a cancer registry in another state; and,
  - b. The UCR is bound by an agreement with that cancer registry to not release identifiable cancer case information for such cases.
4. Notwithstanding any language in the Agreement to the contrary, the UCR may disclose identifiable cancer case information to the University of Utah Resource for Genetic and Epidemiologic Research (RGE) in accordance with the UCR's Policies and Procedures for Research Use of Utah Cancer Registry Data: Exchange of Data between Research Resources (<http://ucr.utah.edu/pdf/PandPRequestRegistryDataComplete.pdf>).
5. Recipients of identifiable cancer case information shall protect such information in accordance with the provisions of Title 26, Chapter 3 of the Utah Code and any applicable rules promulgated by the Utah Department of Health.
6. UCR is a governmental entity under the Governmental Immunity Act of Utah, Utah Code §§ 63G-7-101 to -904, as amended (the "Act"). Nothing in the Agreement shall be construed as a waiver by UCR of any protections, rights, or defenses applicable to UCR under the Act, including without limitation, the provisions of section 63G-7-604 regarding limitation of judgments. It is not the intent of UCR to incur by contract any liability for the operations, acts, or omissions of any third party and nothing in the Agreement shall be so interpreted or construed. Without limiting the generality of the foregoing, and notwithstanding any provisions to the contrary in the Agreement, any indemnity obligations of UCR contained in the Agreement are subject to the Act, are limited to the amounts established in section 63G-7-604 of the Act, and are further limited only to claims that arise from the negligent acts or omissions of UCR.

7. Notwithstanding anything to the contrary in the Agreement, UCR shall comply with applicable law when making decisions about use and re-release of information exchanged pursuant to this Agreement.
8. Notwithstanding anything to the contrary in the Agreement, UCR shall provide any necessary notification contemplated by sections 10, 11, and/or 13 of the Agreement as soon as reasonably practicable after gaining knowledge of circumstances giving rise to a duty to notify.
9. For the purposes of this Addendum "Identifiable cancer case information" means any cancer case information that, either from the data disclosed or in combination with other data, identifies the subject of the cancer case information or identifies the individual or organization who reported the cancer case information