Utah Cancer Registry

Policies and Procedures: Disclosure of Registry Data

Table of Contents

	Page
1. Utah Cancer Registry Mission Statement	1
2. Background: Utah Cancer Registry Authorization and Guidance for Disclosing Cancer Case Information	2
3. Definitions	3
4. Disclosure of De-identified Cancer Case Information	5
4.1 Aggregate Cancer Case Data	5
4.1.1 Conditions on de-identified, aggregate data reports	5
4.1.2 Purpose of de-identified, aggregate data reports	5
4.1.3 Other sources of aggregate cancer data	6
4.2 De-identified Record-level Cancer Data	6
4.2.1 Challenges of de-identifying record-level cancer data	6
4.2.2 Sources of de-identified, record-level cancer data	7
4.3 Request and Review Process for Disclosure of De-identified Cancer Case Data	7
4.3.1 Initiating the request	7
4.3.2 Review process for requests for aggregate cancer data	7
4.3.3 Review process for requests for de-identified record-level cancer data	7
4.3.4 Requests for de-identified record-level cancer data linked to other data	8
5. Disclosure of Identifiable or Limited Cancer Case Information for Public Health	8
5.1 Utah Department of Health Programs	8
5.2 County, Regional, or Local Health Agencies in Utah	9
5.3 Federal Health Agencies	9
5.3.1 NCI SEER Program	9
5.3.2 CDC NPCR	9
5.4 National Cancer Surveillance Quality Improvement Projects	9
5.5 Central Cancer Registries in Other States	10
5.6 Request and Review Process for Disclosure of Identifiable or Limited Cancer Case Data to Public Health Users	10
5.7 Exclusions	11
6. Disclosure of Identifiable or Limited Cancer Case Information for Research	11
6.1 Research as Part of UCR's mission	11
6.2 Contacting Cancer Cases for Research Recruitment	12
6.2.1 Contact protocols	12
6.2.2 Confirming vital status before a contact attempt	12
6.2.3 Contacting next-of-kin or proxies	13
6.2.4 Rapid case ascertainment	13
6.2.5 Multiple studies contacting the same individual through UCR	13
6.2.6 Data on non-participants	14
6.3 Disclosing Identifiers Without Consent	14
6.4 Linkage of Other Identifiable Data to UCR Cases	14
6.5 Exclusions	15
6.6 Out-of-State Cancer Cases	15
6.7 Reporting Delay for Disclosure for Research	15
6.8 Disposition of Cancer Case Information	16
6.9 Publications	16

6.10 Request and review process for disclosure of identifiable or limited cancer data for research 16
6.10.1 Initiating the request and developing the protocol 16
6.10.2 The research protocol for review 17
6.10.3 RGE review 17
6.10.4 Investigator assurances and data use agreement 17
6.10.5 Documentation of review and approval 18
7. Disclosure of Identifiable or Limited Cancer Case Information to Research Resources 18
7.1 Utah Population Database 18
7.2 National Research Resources 19
7.3 Review Process for Disclosure of Limited or Identifiable Cancer Data to Research Resources 19
8. Disclosure of Identifiable or Limited Cancer Case Information to Others 19
8.1 Individuals 19
8.2 Department of Justice 20
8.3 Health Care Providers 20
8.4 Linkages for Surveillance 20
8.5 Data Management Contractors 21
8.6 Review Process for Disclosure of Identifiable or Limited Cancer Case Data to Others 21
9. References Cited 22

1. Utah Cancer Registry Mission Statement

The Utah Cancer Registry promotes public and population health in Utah by collecting and managing cancer incidence and mortality data for the state. The registry disseminates information to support cancer prevention and control, facilitates cancer research, and monitors cancer trends. We are committed to obtaining high quality data and to protecting the confidentiality of individuals.

2. Background: Utah Cancer Registry Authorization and Guidance for Disclosing Cancer Case Information

The Utah Cancer Registry (UCR) has functioned as a statewide, population-based cancer registry since 1966. Under Utah Administrative Code Rule R384-100, the Cancer Reporting Rule (1), the UCR has the responsibility of collecting and managing cancer incidence and mortality data for the state. The rule directs health care providers to report information for each cancer case diagnosed or treated in Utah to UCR. The purpose statement of the rule includes "Through the routine reporting of cancer cases, trends in cancer incidence and mortality can be monitored and prevention and control measures evaluated." Data collected by UCR under the rule are described as follows:

> R384-100-6. Case Report Contents.
> (1) The contents of the report for each reportable case shall include identifiable health data. This data may include: (a) facility and provider identifiers; (b) patient identifiers, demographics; (c) medical history and risk factors; (d) date and method of diagnosis; (e) primary site; (f) stage of disease; (g) tissue diagnosis; (h) laboratory data; (i) radiology data; (j) dates and methods of treatment; and (k) follow-up.

The Cancer Reporting Rule states that although cancer records are collected and managed by UCR, the Utah Department of Health and Human Services (UDHHS; formerly Utah Department of Health, UDOH) retains ownership of the records. The Cancer Reporting Rule cites authority from the Utah Health and Human Services Code, 26B-1-202, Department authority and duties, and 26B-7-227 Detection and Management of Chronic and Communicable Disease and Public Health Emergencies (2). The rule further states that reports under the rule are confidential under 26B-8-4 Health Statistics (2).

UCR is administered within University of Utah Health. A Memorandum of Agreement (MOA) between the University of Utah (UNIVERSITY) and UDHHS signed June 22, 2020 (3, 4) includes a section describing UCR's responsibility to protect confidential cancer information and circumstances in which the data can be disclosed. The MOA directs UCR to establish written policies and procedures regarding data disclosure, with oversight of the policies by the Utah Cancer Registry Advisory Committee (AC). These written policies must be approved in writing by UDHHS. This document, Utah Cancer Registry Policies and Procedures for Disclosure of Registry Data, herein also referred to as UCR Policies, presents those policies.

Disclosure of cancer registry data by UCR is thus primarily guided by the state through the Utah Cancer Reporting Rule, most recently updated August 2, 2021 (1), and the MOA between the University of Utah and the UDHHS, most recently updated in June 2020 (3, 4). Under the MOA, review and documentation by UDHHS of UCR data sharing is described as follows:

> *"*[UDHHS] *agrees to maintain a separate document entitled* [UDHHS] *Approved UCR Data Disclosures which will contain a list of use cases for disclosing cancer case information that have previously received* [UDHHS] *approval. This document may be updated by the CHDI Director with input from the* [UDHHS] *Chief Privacy Officer and* [UDHHS] *legal counsel as needed."*

The Approved UCR Data Disclosures document describes approved data sharing use cases including sharing from UCR to UDHHS programs, sharing from UDHHS to UCR, and sharing from UCR to others. Information in the Approved UCR Data Disclosure document includes, for

each approved data sharing use case, the data requestor category, the purpose of sharing, specific data to be shared, authority under Utah code, and UDHHS approval date. This document is updated or modified as needed. UCR or UDHHS may propose language be added describing a new use case of data sharing or may propose modification of language describing a previously approved use case. New data sharing use cases become active after review and approval by UDHHS.

UCR has a longstanding affiliation with and funding from the U.S. National Cancer Institute's Surveillance, Epidemiology and End Results (NCI SEER) program (Contract No. HHSN261201800016I), and therefore UCR Policies must be in keeping with that contract and with federal guidelines on data security and human subjects research referenced therein. Utah Cancer Registry participates in and is funded by the Center for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR) and is committed to protection of confidentiality and security of data under the standards of that program (5). Further, UCR's policies must comply with data security and confidentiality policies of the University of Utah (6). However, UCR data do not fall within the University of Utah's Covered Entity as defined for the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) and UCR data are not directly governed by HIPAA rules.

This UCR Policies document will be reviewed every five years, and updated as needed, as specified in the MOA.

Use of *italics* in these UCR Policies indicates wording drawn directly from the 2020 MOA (3, 4) between the University of Utah and UDOH, now UDHHS.

3. Definitions (in alphabetical order)

> *"**Advisory Committee Subcommittee**" means a subcommittee consisting of the UCR director, RGE director and* [UDHHS] *CHDI director or their designee.*
>
> *"**Cancer case information**" means any information obtained from* [UDHHS] *or collected pursuant to Cancer Reporting Rule R384-100.*
>
> "**CDC NPCR**" means Centers for Disease Control and Prevention, National Program of Cancer Registries.
>
> *"**CHDI**" means the Center for Health Data and Informatics within the* [UDHHS].
>
> *"**Data**" means information about individuals, whether identifiable, de-identified, or aggregate.*
>
> *"**Data Steward**" means a UDOH staff member or designee with the responsibility to safeguard, protect, and optimize the use of data disclosed by* [UDHHS].
>
> *"**De-identified data**" means data that conforms to the standard for de-identification established in the Privacy Rule (45 CFR § 164.514).*
>
> "**UDHHS**" means Utah Department of Health and Human Services, the name of the department that now has responsibility for disease surveillance in the state formerly

in the purview of Utah Department of Health (UDOH), and with ownership of UCR data formerly assigned to UDOH.

*"**Disclose**" or "**disclosure**" means access to, or the communication of, data to any individual or organization outside the* [UDHHS].

*"**Identifiable data**" or "**Identifiable health data**" means any item, collection, or grouping of data which makes the individual supplying it or described in the data identifiable. With regard to individuals, the term means any item, collection or grouping of data which contains the name of the individual or any identifying number, symbol, other identifying characteristics, or any unique grouping of data, which, when combined with other available data, makes the individual recognizable. With regard to organizations that have received an assurance of non-disclosure from the* [UDHHS]*, the term means any item, collection or grouping of data, which makes the organization as recognizable as if a name had been affixed. Identifiable data may also be referred to as 'restricted data' or 'limited data'.*

*"**Limited data**" means data that does not contain 16 of the 18 identifiers itemized by the Privacy Rule for creating de-identified data. (45 CFR § 164.514) Of the 18 identifiers, it may only contain: 1) dates such as admission, discharge, service, date of birth, date of death; 2) city, state, five digit or more ZIP Code; and 3) ages in years, months, or days or hours, and single category for those ages 89 and older. Limited data is considered to be identifiable data and subject to the same restrictions unless an exception is granted in writing.*

"**NCI SEER**" means National Cancer Institute Surveillance, Epidemiology, and End Results Program

"**Research and statistical purposes**" means the same as defined in Utah Health and Human Services Code 26B-8-401 (2).

*"**Restricted data**" means Identifiable data that contains one or more of the 16 identifiers (other than those allowed in limited data sets) itemized by the Privacy Rule for creating de-identified data. (45 CFR § 164.514). See definitions for 'identifiable data' and 'limited data' above.*

*"**UCR Advisory Committee (AC)**" means a group of representatives from community-based providers, health care facilities,* [UDHHS]*, and epidemiologists and biostatisticians who advise and establish policy on enhancing and using the cancer registry data for prevention and control of cancer and for research, collaborate with other cancer programs, develop and refine quality improvement initiatives, and establish and promote greater awareness and use of cancer registry data."*

*"**Utah Resource for Genetic and Epidemiologic Research (RGE)**" is a* [University of Utah] *data resource created by Executive Order of the Governor of the State of Utah (February 20, 1986) for the collection, storage, study, and dissemination of medical and related information to be used for the purpose of reducing morbidity and mortality or for the purpose of evaluating and improving the quality of hospital and medical care.*

4. Disclosure of De-identified Cancer Case Information

4.1 Aggregate Cancer Case Data

> *"UNIVERSITY may disclose de-identified* [UDHHS] *Data, such as frequencies, cross-tabulations, incidence rates, survival rates, and other summary statistical reports derived from identifiable* [UDHHS] *Data; provided, however, that such disclosure does not include sufficient information that would allow the requester to identify, by whatever means including linkage with other databases, the subject of the information. De-identified* [UDHHS] *Data that is disclosed must follow UDOH data suppression guidelines found on the Utah Department of Health Indicator Based Information System website."*

4.1.1 Conditions on de-identified, aggregate data reports

To assure that the de-identification conditions are met, UCR will remove any potentially identifiable information before disclosing aggregate data. Data that are disclosed must follow the UDHHS data suppression guidelines (7). This includes addressing potential identifiability due to small sample sizes by masking cell case counts fewer than 11 and/or by applying standards of suppression based on relative standard error. By definition, aggregate data for a geographic area that is smaller than a county or a UDHHS small health statistical area is not considered to be de-identified.

In order to adhere to the principle that the identity of the individual or organization that reported cancer case information not be disclosed, UCR generally will not disclose aggregate data of the number of cancer cases treated by specific providers, facilities, or health care systems. When UCR receives a request for a data summary specific to a facility or health care system, UCR will communicate with that institution's representative on UCR's Advisory Committee or with a hospital administrator at that institution. UCR may refer the requestor to the institution for the data or may compile the requested summary information and work with the institution to agree on a data release that is acceptable to the institution.

UCR will follow best practices for documentation and quality assurance of aggregate data. Aggregate data summaries disclosed by UCR will include documentation of methods and source data for the summary. When one UCR staff member generates an aggregate data report or summary, a second staff member will assure quality by reviewing the query and/or by performing independent coding of the same query. The second staff member will also review the report format and labeling to assure complete and correct documentation.

4.1.2 Purpose of de-identified, aggregate data reports

UCR may report aggregate, de-identified cancer case information on its own initiative to carry out its mission to monitor trends and disseminate data. This will be done routinely in the biennial report, "Cancer in Utah." Other reports may be produced between editions of "Cancer in Utah." UCR will collaborate with UDHHS cancer programs and with the Utah Cancer Action Network to report aggregate cancer data reports addressing the goals and needs of those programs.

UCR will produce and disclose de-identified aggregate cancer case information in response to requests from individuals or organizations outside UCR. Providing data for research and public health purposes is emphasized in UCR's mandate and mission. UCR's contract with the NCI SEER program and its role at the University of Utah both emphasize facilitating cancer research. Accordingly, requests from researchers for summary data such as case counts or incidence rates for the purpose of planning future research will be treated as high priority and will be responded to as quickly as possible. In keeping with UCR's public health surveillance mission and its cooperative agreement with the CDC NPCR program, requests from UDHHS or other public health agencies within the state for aggregate cancer data for public health and cancer control purposes are also a high priority for UCR.

UCR can also respond to requests for aggregate cancer information from others if the purpose of the request is consistent with cancer control, public health, and/or dissemination of data to the public. Examples may include requests from health care organizations or from other organizations with missions addressing public health and/or cancer control. Requests for cancer information from news media received by UCR will be communicated to the UDHHS public relations office. UCR will work with UDHHS to determine the most appropriate response to these requests.

UCR staff can perform queries and produce aggregate data reports in response to requests from outside organizations as described above. However, staff time that is available to devote to these activities is limited. UCR reserves the right to refer a requestor to a publicly available source of aggregate cancer information.

4.1.3 Other sources of aggregate cancer data

Utah cancer case data are disclosed by UCR to UDHHS for its Public Health Indicator-Based Information System for Public Health Data (IBIS) (8). IBIS provides public health indicator reports as well as offers users the ability to produce custom data summaries.

Aggregate summaries of UCR data may also be queried through national cancer data resources, including the NCI SEER Research Data (SEER*Stat) (9), CDC's United States Cancer Statistics (10), and the North American Association of Central Cancer Registries (NAACCR) Cancer in North America Public-use (CiNA) data set (11). Disclosure of data from UCR to each of these resources is reviewed and approved by UDHHS as described in section 5 below.

4.2 De-identified Record-Level Cancer Data

> *"UNIVERSITY may disclose record-level de-identified* [UDHHS] *Data as approved in writing by* [UDHHS] *and as provided in this Agreement and related subagreements."*

4.2.1 Challenges of de-identifying record-level cancer data

Even when personal identifiers such as name and date of birth are not included in a record-level cancer case data set, the potential for re-identification of individuals may be present through

combinations of variables, for example if an individual is diagnosed with a rare cancer type and is a member of a racial group that is represented by few Utahns. Therefore, the MOA requires that disclosure of record-level data is treated differently than disclosure of de-identified aggregate data.

4.2.2 Sources of de-identified, record-level cancer data

Among the national cancer data resources mentioned above (section 4.1.3), some allow for users to obtain record-level de-identified data. The NCI SEER Research Plus database (9) and the NAACCR CiNA research databases (11) are sources for record-level cancer incidence data from Utah and other state registries. UCR may provide a de-identified record-level data set following review and approval.

4.3 Request and Review Process for Disclosure of De-identified Cancer Case Data

4.3.1 Initiating the request

Requests to obtain de-identified cancer case data from UCR should be initiated by an email to ucr.info@hsc.utah.edu. The requestor should describe the data requested and should clearly state the purpose for the requested data such as research, pre-research planning, or public health. In addition, requests can be submitted through a UCR research pre-application form available from our website, https://uofuhealth.utah.edu/utah-cancer-registry/research.

4.3.2 Review process for requests for aggregate cancer data

If the request is for aggregate cancer information that is to say summaries such as frequencies, cross-tabulations, incidence rates, etc. as described in section 4.1 above, the email request or web form described in 4.3.1 is usually the only documentation required. Each request for aggregate cancer information will be reviewed by the UCR research manager and/or the UCR biostatistician to assure that the purpose of the request is in keeping with UCR purposes of data disclosure as described in section 4.1.2 above. If so, the request can be approved.

The UCR research manager and/or the UCR biostatistician will consider the priority to place on a request according to UCR priorities also described in section 4.1.2. A UCR staff member will usually be assigned to perform data queries and analyses to respond to the request. However, UCR staff resources are limited and there may be times when, depending on UCR priorities, UCR will recommend that a data requestor obtain data through one of the online data resources described in 4.1.3 rather than directly from UCR. For each of these online data resources, users will be required to agree to privacy and confidentiality conditions. The University of Utah IRB has determined that use of SEER Research data by University of Utah investigators does not require IRB review (12).

4.3.3 Review process for requests for de-identified, record-level cancer data

UCR will usually recommend that researchers interested in obtaining record-level cancer case information access the data through the SEER (9) or CiNA (11) databases, including agreeing to the privacy and confidentiality conditions of each source.

If a research requestor requires record-level data with variables that are not included in the data available through one of the online resources, for example variables representing tumor characteristics and treatment information, a request may be made for data disclosure directly from UCR. The request should be initiated by filling out a UCR research pre-application, available from the UCR website https://uofuhealth.utah.edu/utah-cancer-registry/research/. The research application and review process will follow the process for requests for identifiable data, described in section 6.10 below. As part of the review and approval process for a research request for record-level UCR data, the investigator will be asked to sign a Data Security Assurances agreement and all individuals who will access the study data must sign a confidentiality assurance and provide documentation of human subjects research training. Copies of these agreements can be found at https://rge.utah.edu/forms.php.

4.3.4 Requests for de-identified record-level cancer data linked to other data

UCR data are linked to other UDHHS data, to health care system data, and to Utah genealogies through the Utah Population Database (UPDB), a research resource housed at the Huntsman Cancer Institute at the University of Utah. The linkage, and disclosure of the linked data, are governed by the MOA between the University and UDHHS (3). Requests for record-level linked data, even if the data to be received by the researcher will be de-identified, are subject to review by the University of Utah IRB and by the RGE review committee in accordance with MOA requirements (13) and RGE policy, and as described in section 6.10.

Requests to link UCR cancer case information to research cohorts are subject to the review process for requests for identifiable information; see sections 6.4 and 6.10.

5. Disclosure of Identifiable or Limited Cancer Case Information for Public Health

> *"UNIVERSITY may disclose identifiable* [UDHHS] *Data to persons with written approval of UDOH, as specified in this Agreement, or as specified in a separate data sharing agreement that incorporates all terms of this Agreement through the UNIVERSITY data resources identified in Subagreements."*
>
> *"The* [University of Utah] *shall develop and implement written policies and procedures detailing…approval procedures for... public health projects."*
>
> *"UDOH agrees to maintain a separate document entitled* [UDHHS] *Approved UCR Data Disclosures which will contain a list of use cases for disclosing cancer case information that have previously received* [UDHHS] *approval. This document may be updated by the CHDI Director with input from the UDOH Chief Privacy Officer and UDOH legal counsel as needed."*

5.1 Utah Department of Health and Human Services Programs

Under Utah law, UDHHS is the owner of UCR data, and UCR data are used by several UDHHS programs. UCR annually provides complete incident cancer case data with geographic information to the UDHHS Environmental Public Health Tracking Program. The data are made

available on the UDHHS Public Health Indicator Based Information System (IBIS) (8), allowing users to query and view aggregated, de-identified data online. UCR conducts a biennial linkage of cancer data with individuals served by the UDHHS Utah Cancer Control Program's Breast and Cervical Cancer Screening Program activities. Limited or identifiable UCR cancer case data are also disclosed to other UDHHS programs as approved by through the process described in section 5.6.

5.2 County, Regional, or Local Health Agencies in Utah

A county or regional health department or health district within the state of Utah may request non-public UCR data or to link identifiable UCR data to other data for a public health purpose. The request is subject to review and approval as described in in section 5.6.

5.3 Federal Health Agencies

5.3.1 NCI SEER Program

To meet contractual obligations for UCR's participation in the NCI SEER Program, UCR will disclose limited, record-level cancer case surveillance data files to NCI SEER. Surveillance data are released to NCI under the Federal Public Health Act and are protected according to NCI governing laws. NCI SEER uses the surveillance data to report on national cancer trends (14). NCI SEER also makes these cancer case data available to public health and research users through the SEER Research and Research Plus databases (9). NCI SEER requires a process for access to the data, including a data use agreement and user authentication. The data that UCR submit to NCI SEER are also shared with NAACCR, which compiles cancer registry data from registries across the US and Canada in CiNA (11), and with the International Agency for Research on Cancer, which compiles international cancer surveillance data.

5.3.2 CDC NPCR

In fulfillment of its cooperative agreement with the CDC to participate in NPCR, UCR submits limited record-level cancer surveillance data to CDC. CDC is authorized to collect cancer surveillance data under the Federal Cancer Registries Amendment Act (Public Law 102-515) and commits to data confidentiality protections as documented by CDC (5). CDC NPCR uses the surveillance data to report on national cancer trends (15). CDC NPCR also makes these cancer surveillance data available to public health and research users through US Cancer Statistics (10).

5.4 National Cancer Surveillance Quality Improvement Projects

UCR actively participates in data collection for projects intended to provide insight on the current quality of cancer registry data and to develop new or improved data sources and methods for cancer surveillance. These projects are in almost all cases sponsored by the NCI SEER program or the CDC NPCR. UCR's role in these projects may include collecting data items that are not currently specified as required reportable data items. UCR remains within its scope as defined in the Cancer Reporting Rule (1) when collecting non-reportable data items related to cancer diagnosis or treatment for surveillance quality improvement projects. For these national surveillance quality improvement projects, UCR will report the special non-reportable data items, along with de-identified cancer case information in the form of conventional cancer case

data items, to the national organization for evaluation of data pooled across multiple registries and for data dissemination.

5.5 Central Cancer Registries in Other States

Under the Cancer Reporting Rule (1), health care providers in Utah report cancer cases who are diagnosed or treated in the state to UCR. These reports include patients who are residents of other states but are diagnosed or treated in Utah. For each state to have complete cancer surveillance data for its residents, cancer case information reported to UCR will need to be disclosed to the state of residence. The reverse is also true - reports of cancer diagnosis or treatment of Utah residents in other states will need to be disclosed to UCR. The North American Association of Central Cancer Registries (NAACCR) has developed a National Interstate Data Exchange Agreement (16) under which participating central registries exchange data for cancer cases reported to a registry in one state but determined to reside in another state. Each state signing the agreement commits to data protection and confidentiality for exchanged data.
The NAACCR Interstate Data Exchange Agreement states that records received through data exchange shall not be re-released for research.

5.6 Request and Review Process for Disclosure of Identifiable or Limited Cancer Case Data to Public Health Users

Under the MOA signed in June 2020 (4), each instance of disclosure of UCR data for public health purposes is subject to UDHHS approval. UCR may disclose identifiable cancer case information to entities recorded in the document entitled Approved UCR Data Disclosures, maintained by UDHHS. This list may be updated, if necessary, after review and approval by the UDHHS Center for Health Data and Informatics Director with input from the UDHHS Chief Privacy Officer and UDHHS legal counsel as needed.

Documentation of requests for additions to the “Approved UCR Data Disclosures” document will be maintained in UCR’s shared drive in a dedicated folder. Documentation will include supporting information, such as the purpose for the data disclosure, to whom the data will be disclosed, key communications about the data disclosure request, the specific data items requested, and the date and outcome of UDHHS review.

Each public health data disclosure described under 5.1 through 5.5 above, including disclosure to UDHHS programs, federal health agencies, and cancer registries in other states, has been reviewed and approved by the UDHHS Center for Health Data and Informatics Director as described in the MOA. Each approved data disclosure for public health is documented in the Approved UCR Data Disclosures document.

When a UDHHS program or a county or regional health department or health district has a public health purpose for a new or modified request for limited, record-level, or identifiable UCR data, UCR will meet with a representative of the program to discuss the process (e.g., identifiers from UDHHS sent to UCR for linkage, or the reverse), eligibility criteria for cases, and data elements requested. The two programs will then jointly write the data disclosure request

language. The proposed language will be sent to UDHHS for review for Approved UCR Data Disclosures.

Quality improvement projects will require documentation similar to a research project, including a project protocol and information on data storage and disposition. The UDHHS Center for Health Data and Informatics Director will review the project. If the project includes release of identifiable or limited data, all individuals who will access the data will be required to sign a confidentiality and data use agreement.

5.7. Exclusions

For disclosures of data used for public health purposes, UCR will exclude reports on cancer cases who are residents of another state. In contrast to disclosures for research purposes (see Section 6.5), disclosures for public health do not exclude data for cancer cases for whom the sole source of information was a Veterans Health Administration facility, individuals who have requested their information be removed from the registry, and/or individuals that have requested that their information be withheld.

6. Disclosure of Identifiable or Limited Cancer Case Information for Research

> *"UNIVERSITY may disclose identifiable* [UDHHS] *data to persons with written approval of* [UDHHS]*, as specified in this Agreement, or as specified in a separate data sharing agreement that incorporates all terms of this Agreement through the UNIVERSITY data resources identified in subagreements..."*
>
> *"*[University of Utah] *may disclose record-level cancer case information for bona fide research or public health purposes provided that the request is for minimum necessary data"...*
>
> *"Requests for cancer case information for research must have IRB approval..."*

6.1 Research as Part of UCR's Mission

Research facilitation is a key part of UCR's mission. Stakeholders at the University of Utah's Huntsman Cancer Institute and at NCI SEER particularly emphasize the importance of UCR data in cancer research. Uses of the surveillance data for research are recognized under the Cancer Reporting Rule (1) purpose statement ("Cancer records are managed for research and statistical purposes by the Utah Cancer Registry") and under the MOA as quoted above. UCR Policies have been developed to support this part of our mission, and at the same time to protect privacy and confidentiality consistent with state laws and regulations for surveillance data.

One of the following conditions must be met in order for identifiable data to be disclosed: the subject of the cancer case information has provided consent to release their information to the researcher; or, the researcher requests minimum necessary identifying variables to achieve study aims, the research could not otherwise be accomplished, and the approving IRB has authorized a waiver of informed consent.

6.2 Contacting Cancer Cases for Research Recruitment

> *"No contact of any individual identified by* [UDHHS] *Data may be made either by* [University of Utah] *or recipients of* [UDHHS] *Data without prior written consent of UDHHS and pursuant to any provisions in subagreements for specific UDHHS Data".*

Researchers may work with UCR for research recruitment of cancer cases. UCR may disclose contact information of individuals identified by UCR data for research purposes only if the individual has given their permission (Utah Code 26B-8-406). To meet this requirement, UCR will attempt to contact the individual using information available in our records. Contact will follow an established protocol (see section 6.2.1 below), and all contact attempts will be documented in a tracking database. If we reach an individual and they give permission to release their contact information, UCR staff will document this in the tracking database prior to releasing their information. If an individual refuses to have their information released, this will be documented in the tracking database and their information will not be released. If UCR staff are unable to reach the individual, we will document the contact attempts and their contact information will not be released.

6.2.1 Contact protocols

UCR staff will contact research participants using evidence-based strategies to achieve good response proportions. Contact protocols will include multiple contacts and usually will include multiple modes, beginning with a postal letter. UCR staff will work with researchers to tailor study-specific contact protocols, which may include collection of consent forms and/or questionnaires.

For all reportable cancers, UCR obtains data for address at diagnosis as part of its surveillance efforts. If UCR research staff are unable to reach the case at the address in cancer registry records, or if several years have passed since the address information was received, UCR research staff will make reasonable attempts to obtain new contact information. This may include using forwarding address information provided by the U.S. Postal Service or by an individual responding to the study contact attempt who is not the intended recipient. UCR staff may search secure online proprietary databases for new contact information.

6.2.2 Confirming vital status before a contact attempt

As part of our best practices, UCR research staff will make reasonable efforts to discover whether a cancer case may have died before attempting to contact the person as a potential research participant. This is particularly important if the case is elderly and/or if the case was diagnosed with a type or stage of cancer that indicates poor prognosis. The purpose of these efforts is to avoid causing distress to other household members by sending mail addressed to a person who is deceased. UCR staff will primarily use death information obtained from the UDHHS and may also contact the hospital registry that reported the case for new follow-up information, or may conduct online searches of newspaper obituaries.

6.2.3 Contacting next-of-kin or proxies

For a study protocol that includes UCR contacting cancer cases, UCR will determine in advance how study staff should proceed if it is determined that the cancer case eligible to be contacted for the study is deceased. For some protocols it may be appropriate for UCR staff to contact a family member or other proxy. UCR may contact a proxy if the purpose is to obtain information about the case from the proxy, and if the information from the proxy is important to the research question. If it is determined that the case is deceased before any attempt to contact that case is initiated, UCR staff will wait until three months after the date of death of the cancer case to attempt to contact a proxy. If a UCR staff member learns that the case is deceased only when contacting a household by telephone, the staff member will use their judgment to decide whether to initiate a conversation about proxy participation. If the researcher wishes to contact family members of a deceased cancer case for the purpose of recruiting the family members into a study because UPDB data indicates that those family members are part of a high-risk cancer family, the initial contact with the family will be made through RGE.

6.2.4 Rapid case ascertainment

For research requests to contact cancer patients, it is often desirable to contact a case soon after diagnosis rather than wait until the cancer case record is considered final for cancer registry reporting purposes. There are several reasons for contacting cases closer to the time of diagnosis: individuals with certain cancers may have short survival; the case may relocate and the contact information that UCR has becomes out of date; individuals may be more motivated to participate in research closer to their diagnosis date; or the research may involve collecting information that can better be obtained closer to the time of diagnosis.

For approved studies, UCR will conduct rapid case ascertainment of potentially eligible cases. UCR staff will review potentially eligible cases close to the time that an initial report is received by the registry. If the case is confirmed by a certified tumor registrar to be a likely eligible case, UCR research staff will proceed to contact the case for the study. UCR typically avoids contacting individuals within six weeks after cancer diagnosis, a time when cancer patients and their families are likely to be experiencing unusual stress, unless contact closer to diagnosis has been reviewed and approved by UDHHS and the RGE committee.

6.2.5 Multiple studies contacting the same individual through UCR

Situations arise in which a group of cancer cases has been contacted by UCR for participation in a research study, and then a second researcher wishes to contact cancer cases with overlapping eligibility criteria. In this case, UCR will contact both researchers to make them aware of this overlap. The researchers will be encouraged to arrive at a plan, for example time delay between contact for the two different studies, to support good recruitment rates and thus the research integrity of both studies.

UCR, when contacting an individual for a second study, will acknowledge this in the wording of the cover letter, for example "We know that you were recently contacted regarding a research study. We are now contacting you regarding a different study for which you may be eligible."

6.2.6 Data on non-participants

For research protocols in which UCR contacts potential participants, UCR will provide information to the researcher on eligible individuals whom UCR was unable to contact or who declined to have contact information released to the researchers. This will be in the form of de-identified record-level information on case characteristics such as year of diagnosis, age, sex, and stage. This data is for the purposes of complete study reporting and the need to describe non-participating eligible cases when describing study results.

UCR will ask that researchers return to UCR or destroy identifying data for cancer cases who were contacted by UCR and agreed to have identifiers released to the researcher but who did not ultimately consent to the study protocol. This will typically be within six months of the researcher receiving the identifiable cancer case information. Further, UCR will request that the researcher report to UCR the reason for each case's non-participation, e.g. declined to participate, unable to locate, or not eligible. This information is for UCR's purposes of understanding factors related to study participation and ongoing quality improvement of recruitment processes.

6.3 Disclosing Identifiers Without Consent

Language in the MOA, as quoted above, describes circumstances in which UCR may disclose identifiers in research data sets without consent of the individuals. In keeping with the spirit of disclosing the minimum necessary information to perform research, for projects that will not obtain consent from participants, UCR will propose alternatives to the release of identifying data. Examples of alternatives to releasing identifying data:

- For research projects requesting exact dates such as date of birth, date of cancer diagnosis, and date of death, UCR will propose to: a) calculate the number of days between two events of interest and release number of days as a variable; or b) perturb dates. In the case of perturbed dates, the amount of perturbation will not be revealed to the investigator but may be as little as two days. UCR's preference will be to release the data items representing days between events or perturbed dates but not exact dates.
- For research projects requesting provider identifiers, UCR will work with the researcher to identify the characteristic of the provider that is of interest, e.g. specialty or distance between patient address and provider office, and will propose to link provider identifiers to the data items representing the characteristic. UCR's preference will be to release the data items representing provider characteristics but not provider identifiers.
- For research projects requesting geographic areas such as zip code or census tract, UCR will work with the researcher to identify the characteristics of the geographic unit that are of interest, e.g. socioeconomic variables or distance between patient address and facility, and will propose to link case identifiers to the data items representing characteristics. UCR's preference will be to release the data items representing characteristics of the geographic unit but not zip code or census tract.

6.4 Linkage of Other Identifiable Data to UCR Cases

For a research project that requests UCR identifiers for the purpose of linking to a research data set or list of consented participants, UCR's preference will be that UCR or UPDB staff perform the linkage. Researchers may securely transmit identified data to the registry, and UCR will

return information on records that were found to link. Researchers transmitting data to UCR for linkage should be aware that UCR is outside the University of Utah's Covered Entity and that therefore informed consent or an IRB waiver of informed consent must be obtained for this disclosure of data to UCR.

For a research project requesting that UCR disclose identifiable data to an Honest Broker or Trusted Third Party for data linkage, UCR will request documentation of the Third Party's procedures to protect data confidentiality and its legal obligation (e.g. contract with a federal agency) to do so. Such a request will be evaluated in the RGE review process on a case-by-case basis.

6.5 Exclusions

For disclosure of identifiable data UCR will exclude the following cases:

- Cases for whom the sole source of information was a cancer registry in another state, due to restrictions in the Interstate Data Exchange agreement among state cancer registries.
- Cases for whom the sole source of information was a Veterans Health Administration facility. This exclusion is in accordance with the terms of UCR's agreement with the Veterans Health Administration.
- Individuals who have requested that their information be removed from the registry and/or that their information be withheld will not be included in *any* research dataset.

Individuals who have contacted UCR and requested that they not be contacted for research will be excluded from projects involving *contact* with cancer cases but will be included in all other research data sets.

6.6 Out-of-State Cancer Cases

Under state rule, UCR receives reports of cancer cases diagnosed or treated in Utah regardless of the state of residence of the case. UCR data are complete only for Utah residents. Residents of other states are likely to have received diagnostic procedures and/or care outside of Utah which would not be reported to UCR. Data for non-Utah-resident cases reported to UCR have not been subject to UCR's coding and editing procedures. Because the data for out-of-state cases are incomplete, UCR recommends that researchers limit UCR data requests to cases who are Utah residents. Including residents of other states who received treatment in Utah in a research data set would create a non-population-based and non-representative sample. However, if an investigator describes a research question for which cancer case data from non-Utah residents would still be relevant, after taking into account these limitations, the AC or RGE committee will consider the request.

6.7 Reporting Delay for Disclosure for Research

Cancer case reports are often received by UCR six months after diagnosis, and sometimes reports are further delayed. UCR's processes of consolidating, editing, and quality assurance for cancer cases require additional time to complete. UCR observes SEER program deadlines for compiling complete cancer case report data for each calendar year. Data verified by UCR as meeting our completeness and quality standards are submitted to SEER for a November deadline

23 months after the end of the diagnosis year. Therefore, the highest quality data for research requests for record-level cancer data and/or data linkage are available after this submission deadline. UCR submits a more limited data set including cancer case diagnosis date, site, and histology to SEER in February, 13 months after the end of the diagnosis year. These 13-month data may be made available to researchers if justified by research need and if the data quality issues will not compromise the research.

6.8 Disposition of Cancer Case Information

All record-level cancer case information disclosed by UCR must be destroyed or returned to UCR at the end of the research project, upon request of UCR, or upon termination of the agreement between the researcher and UCR. The standard period for approval of a research project using identifiable or record-level non-public UCR data is five years. Near the end of that period, UCR will contact the investigator to determine whether the investigator will request to renew the project. If the project is not renewed, UCR will request that the investigator confirm that the data have been destroyed.

A protocol that includes re-sharing of Utah Cancer Registry reportable, coded data items may be approved if: a) the re-sharing is included in the investigator's approved NIH Data Sharing Plan; and b) the Data Sharing Plan is reasonably sufficient to prevent re-identification of individuals.

6.9 Publications

Researchers who obtain UCR data from UCR or from UPDB are asked to submit abstracts and manuscripts resulting from the research project for review by UCR or RGE prior to their submission for publication or presentation. UCR or RGE will review the abstract/manuscript to assure that UCR has been appropriately acknowledged and that no cancer case information is reported in a manner that is potentially identifiable. Potential identifiability due to small sample sizes should be addressed as described above (section 4.1.1), by masking cell case counts fewer than 11 and/or by applying standards of suppression based on relative standard error as defined by the UDHHS Report of Guidelines for Data Result Suppression (6). UCR will also compile bibliographies of published work resulting from UCR data disclosed by UCR or through UPDB for reporting to its funding and oversight organizations.

6.10 Request and Review Process for Disclosure of Identifiable or Limited Cancer Data for Research

6.10.1 Initiating the request and developing the protocol

Research requests for identifiable or limited UCR data can be initiated by providing investigator contact information and basic project information using the UCR Research Pre-Application available on our website (https://uofuhealth.utah.edu/utah-cancer-registry/research/). Researchers may contact the UCR research manager at ucr.info@hsc.utah.edu. UCR recommends one or more meetings with the UCR research manager to discuss the protocol, timeline, and budget for research activities to be performed by UCR before progressing to the next step which will be submitting a full research protocol for review by the RGE committee. The proposed research must receive human subjects research ethics review and approval by an

Institutional Review Board (IRB). If a research project proposing to use UCR data is submitted by an investigator outside the University of Utah, and if there is no University of Utah investigator engaged in the research, the protocol must be approved by the investigator's home IRB and does not require review by the University of Utah IRB. A university faculty researcher, or an individual of equivalent status as a researcher in another organization, must take responsibility for the research and data confidentiality.

6.10.2 The research protocol for review

The protocol must provide complete information about research goals, methods, analysis plan, sample size requirements, and data protection measures. The protocol must specify the cancer information requested, describe how the identifiable cancer information will be used, justify why this is the minimum necessary to accomplish the research objective, and specify the period of time in which the data will be utilized. The protocol should be entered into the University of Utah IRB Electronic Research Integrity and Compliance (ERICA) system.

6.10.3 RGE review

> *"Review of requests for disclosure of cancer case information by UNIVERSITY will be reviewed by UCR AC, RGE, or AC subcommittee in accordance with UCR POLICY."*

The RGE committee includes representatives from UDHHS and UCR and has the authority to review and approve UCR disclosure of data for research. The RGE application form and review process is integrated within University of Utah ERICA electronic IRB application and review system. Review by RGE for disclosure of UCR data and review by the IRB are separate but sequential steps. If no University of Utah researcher is engaged in the research, the online ERICA system is still used, but the protocol will be reviewed by RGE only.

Although the preferred pathway for review of research requests for UCR data is through the RGE committee, there may be a need to send a research data request for review by the AC. In order to assure timely review of these applications, a subcommittee of a minimum of three AC members, consisting of the UCR director, Resource for Genetic and Epidemiologic Research (RGE) director and UDHHS Center for Health Data and Informatics (CHDI) director or their designee, may provide review and approval on behalf of the AC. Approval requires a majority of favorable votes from the members of this subcommittee.

6.10.4 Investigator assurances and data use agreement

Following review and approval of a research request for UCR data, the investigator will be asked to sign two documents: Responsible/Principal Investigator Statement of Assurances; and Data Security Assurances. By signing these documents, the investigator agrees to protect data confidentiality and to limit use of the data to the approved project. All individuals who will access the study data must sign a confidentiality and data use agreement and provide documentation of human subjects research training.

6.10.5 Documentation of review and approval

Documentation of requests for review by RGE or AC and the date of their approval will be logged in UCR's research administrative database, along with other project-specific information, such as the requestor's name and other project personnel, key communications, the file path on UCR's servers for locating the project protocol, date and institution issuing IRB approval, and the specific data items requested. Documentation of RGE review, including UDHHS approval (17), will also be maintained in the University of Utah IRB's ERICA system.

7 Disclosure of Identifiable or Limited Cancer Data to Research Resources

UCR will share identifiable or limited data with research resources for the purpose of linking or aggregating UCR cancer case information with other data to increase the research value of the cancer data. This data sharing is subject to UDHHS approval.

7.1 Utah Population Database

> *UCR may release cancer case information to the University of Utah Resource for Genetic and Epidemiologic Research (RGE), the oversight body of the Utah Population Database, in accordance with RGE's Memorandum of Agreement with* [UDHHS] *and in accordance with UCR POLICY. UCR may provide annual updates of selected cancer case information to RGE at an agreed upon schedule and as mutually agreed upon by the UCR and RGE, and approved by* [UDHHS].
>
> *RGE shall make UCR data available to qualified and approved research projects in accordance with the RGE Policies and Procedures and UCR POLICY.* [UDHHS]*, through its appointed agent, will sit on the RGE Review Committee. Identifiable cancer case information provided by UCR to RGE will only be made available through RGE for projects approved by that* [UDHHS] *representative."*

UCR will at least annually release to UPDB an updated data set of final edited cancer case information. UCR data released to UPDB will include identifiers such as name and birth date for the purposes of linkage. Data that will become available for research use include variables comparable to what is available through SEER Research data. The same exclusions to the release of cancer case information that apply to researchers, described above in Section 6.5, apply to the data shared with UPDB. Transmission of identifiable data between UCR and UPDB shall be conducted via Secure File Transfer Protocol (SFTP).

Researchers wishing to use UCR data available through UPDB are encouraged to meet with the UCR research manager in advance of submitting a protocol for review. Requests for UCR data linked to other data by UPDB should be in the form of a protocol submitted through ERICA, and will be reviewed by RGE as described in section 6.

UPDB may perform linkages between UCR data held by UPDB and identifiable data provided by researchers after appropriate IRB and RGE review and approval. If UCR data items not normally disclosed to UPDB are requested to be provided in a linked UPDB data set, those data

items will be disclosed to UPDB for linkage with a record number used by UCR and UPDB. UPDB will not use the non-public data items or release them to other investigators.

The RGE Committee shall have voting UCR and UDHHS representatives. UDHHS or UCR, as the data steward, may veto proposals and publications involving UCR data as described in the RGE Policies and Procedures (17). The RGE shall not release any identifiable cancer case information obtained from UCR to the public, any governmental agency, any private organization, or any person, without the prior consent of UDHHS and UCR, as described in the RGE Policies and Procedures and these policies.

7.2 National Research Resources

Research resources administered by the SEER program, i.e. SEER-Medicare and SEER-Medicaid, have an established data request process including a research application, documentation of IRB approval at the researcher's institution, and a data use agreement. The data released by SEER-Medicare to researchers does not contain identifiers from UCR data. With special request and justification, investigators may receive one or more of the following potentially identifying variables from the Medicare data: patient zip code, patient census tract, hospital zip code, hospital census tract, and provider identifier number. Protocols that request these potential identifiers are reviewed by the UCR director or their designee. UCR disclosure of identifiable data for the purpose of linkage to create research resources not under the University of Utah's authority is subject to review and approval by the UDHHS IRB.

NAACCR's Cancer in North America (CiNA) research database also has an established data request process including a research application and data confidentiality agreement. Requests are reviewed by the NAACCR Research Application Review Workgroup and representatives of registries of the states whose data are included in the research request. Active consent by UCR is required for any projects requesting state-specific data, area identifiers (e.g., county codes or census tract-derived area attributes), linked variables, or single year of age.

7.3 Review Process for Disclosure of Limited or Identifiable Cancer Data to Research Resources

Disclosure of data to research resources is subject to approval by UDHHS through review by and documentation in the Approved UCR Disclosures document. Research resources may receive identifiable cancer case information provided the resource has policies for disclosure of data to researchers that are acceptable to the UDHHS.

8. Disclosure of Identifiable or Limited Cancer Data to Others

8.1 Individuals

The subject of the cancer case information documented by UCR, or the subject's legal guardian if a guardian has been appointed, or the next of kin if the subject is deceased, may request an identifiable copy of their UCR record.

UCR will ask that the requestor complete a request form available on the UCR website and either: a) bring the form in person to the UCR office and present state-issued identification; or b) mail or email the form to UCR with a photocopy or image of state-issued identification. The request from the subject, guardian, or next of kin will be reviewed by the UCR Operations Manager to assure that documentation needed by UCR has been provided and to confirm that the identity of the cancer case described on the request form is a correct match to a cancer case in UCR records. UCR will retain the request form and a photocopy of the state-issued identification. UCR will print out the requested information and send it by U.S. mail or hold for pick up by the requestor.

8.2 Department of Justice

UCR data may be released to the Department of Justice upon receipt of a request signed by the subject of the cancer case information, the subject's legal guardian if a guardian has been appointed, or the next of kin if the subject is deceased, for purposes specified under 42 U.S.C. 2210 (2012) Radiation Exposure Compensation Act.

These requests will be reviewed by the UCR Operations Supervisor to assure that the documentation needed by UCR has been provided and to confirm that the identity of the cancer case described on the request form is a correct match to a cancer case in UCR records. UCR will complete a form with the requested information and send it by U.S. mail to the Department of Justice.

8.3 Health Care Providers

For a provider who has reported a cancer case to UCR, UCR may disclose additional information about the case obtained from other sources. This information may include diagnostic, treatment, and follow-up variables. In practice, UCR will most often disclose these data to hospital tumor registries that report cases to UCR on behalf of the providers at their institutions. With the approval of a hospital or other health care institution, UCR may disclose cancer case data for cases reported by the institution to an organization contracted by the facility to manage cancer data. UCR often receives treatment information six months after the diagnosis of the case, and sometimes reports are further delayed. Therefore providers and tumor registrars should not rely on UCR as a primary or real-time source of treatment information. For case follow-up data, UCR will provide vital status and date of last follow-up obtained from a variety of sources including UDHHS vital records. UCR will observe restrictions from the data source, such as UDHHS or National Death Index, on release of vital status, date of death, and cause of death.

8.4 Linkages for Surveillance

UCR may share data with organizations that assist UCR with linkage of identifiable cancer case information to other information for UCR's surveillance purposes. These include:

- Linkage with Social Security Administration to obtain vital status,
- Linkage with CDC National Death Index to obtain vital status,
- Linkage with Center for Medicare and Medicaid Services to obtain vital status, and
- Linkage with Indian Health Service to obtain enrollment status, used to designate individuals as being of American Indian race.

UCR releases cancer case identifiers to these organizations for the purpose of linkage, and information about linked records is returned to UCR. Each organization enters into a written agreement satisfactory to UDHHS agreeing to protect such data in accordance with UDHHS requirements and not permit further disclosure. The organizations delete identifiable UCR cancer case information following completion of the linkage. Each of these linkages has been approved by UDHHS as documented in the Approved UCR Disclosures document.

UCR observes restrictions on re-releasing data based on agreements with these organizations.

8.5 Data Management Contractors

> *Organizations providing data management services to UCR. These organizations must enter into a signed agreement with UCR subject to approval by* [UDHHS]. *These organizations must provide assurance that University of Utah and* [UDHHS] *data privacy and security requirements are met and that identifiable UCR cancer case information is not further disclosed by such organizations.*

UCR receives cancer case reports in electronic format and then performs a series of processes that result in its final quality-assured cancer registry data set. These processes include linking records representing the same case, consolidating, coding, editing, and quality assurance. Cancer registry data management software greatly facilitates these processes. UCR uses the SEER Data Management Software (SEER*DMS) product from Information Management Services (IMS) Inc., Rockville, MD to facilitate UCR's work with the data. UCR data are hosted within IMS Inc.'s secure server environment. UCR has a data security and hosting agreement with IMS Inc.

IMS employees who have signed a non-disclosure agreement may access UCR data to support UCR, including the following:

- Investigate technical support issues submitted by registry staff,
- Test algorithms developed by IMS staff for the benefit of the registry,
- Test algorithms developed by external organizations for the benefit of the registry, and
- On the Registry's behalf and after notifying the Registry, create summary reports and statistics containing non-identifiable aggregate cancer case information, such as frequencies and cross tabulations, and disclose such reports to NCI SEER staff. This would apply if the purpose of the request for aggregate data is consistent with cancer control, public health, or cancer registry process evaluation or improvement. The aggregate information must be de-identified as described in section 4.1 above.

8.6 Review Process for Disclosure of Identifiable or Limited Cancer Case Data to Others

Disclosure of UCR data to each recipient described above in Section 8 has been reviewed and approved by UDHHS and is documented in the Approved UCR Disclosures document.

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