

# **Cancer Data Registry of Idaho Data Release Policy**

**March 2018**

## **Purpose of Policy**

The Cancer Data Registry of Idaho (CDRI) analyzes and disseminates cancer incidence and mortality data to assist with health care assessment, evaluation, and planning; identifying populations at increased risk of cancer; facilitating research related to cancer etiology, prevention, and control; monitoring trends in cancer incidence and cancer mortality for appropriate and timely interventions; and investigating public cancer concerns.

## **CDRI Data Release Goals**

- Maximize Idaho cancer incidence and cancer mortality data availability and use
- Release meaningful and epidemiologically sound cancer incidence and cancer mortality data, while still maintaining the privacy of individuals and small populations
- Provide data at a level sufficient to answer the question, while still protecting the confidentiality of the cancer patient and/or cancer reporting entity
- Comply with all federal and state laws, rules, and Idaho Department of Health and Welfare (IDHW) policies

## **Confidentiality**

Protecting patient confidentiality and other protected health information (PHI) is paramount to the Cancer Data Registry of Idaho and required by state law (Idaho Code §57-1706). Subsequently, the following procedures have been developed for releasing individual record level cancer incidence data and aggregate statistics.

Please note when reading these data release procedures, that “may be released” is permissive and should not be interpreted to mean “is required to be released.” If at any time upon review of a data request there is concern regarding the protection of patient confidentiality or other restricted health information, the CDRI has the discretion to request prior review and approval by the IDHW Cancer Analysis Work Group (CAWG), IDHW Division of Public Health Institutional Review Board (DPH-IRB) and/or the Office of the Attorney General for the state of Idaho before releasing any data.

## **Standard Methods Used by the CDRI for Minimizing Risk of Patient or Reporting Entity Disclosure**

- Release aggregate rather than individual record level de-identified data
- Release de-identified rather than identified individual record level data
- Apply numerator/denominator rules for data aggregation/cell suppression
- Employ complementary data suppression

- Reduce geographic specificity
- Aggregate years of data
- Remove extremely rare events (e.g., transsexual cancers, prostate cancer in a male less than 20 years old)
- Provide only those variables necessary to answer the question
- Categorize and recode variables to aggregate data values (e.g., provide age groups rather than individual age, provide an age rather than date of birth and actual date of diagnosis, provide only diagnosis year rather than actual date of diagnosis)

### **Acknowledgment of CDRI Incidence Data and CDC Support**

CDRI requests that any person or organization reporting results or analyses using CDRI incidence data include the following statement of acknowledgement in the analysis, presentation, report, or publication:

“Cancer incidence data have been provided by the Cancer Data Registry of Idaho, <date>.”

We acknowledge the National Program of Cancer Registries (NPCR), Centers for Disease Control and Prevention, for its support of CDRI under cooperative agreement #NU58DP006270.

### **Data Charges**

The CDRI reserves the right to charge for data requests at any time. The CDRI will notify the requester in advance of fulfilling the request if charges will be assessed. In general, there will be no charge for data requests for cancer incidence or cancer mortality information that can be completed in less than two hours. Detailed requests will most likely result in a charge for CDRI services.

### **Release of Idaho Cancer Incidence Data**

1. No person will attempt to use these data to learn the identity of any person or cancer reporting entity without prior CAWG and IRB approval.
2. If the identity of any person or cancer reporting entity should be discovered inadvertently:
  - No use will be made of this knowledge
  - The CDRI Epidemiologist, Chris Johnson, MPH, will be advised immediately of the incident by calling (208) 489-1380
  - The information that would identify an individual or cancer reporting entity will be safeguarded or destroyed, as requested by CDRI
  - No one else will be informed of the discovery
3. Data requests will be completed using the most current and complete Idaho resident cancer incidence data available. Statewide data will be at least 90% complete before being used to fulfill data requests, in accordance with national cancer surveillance standards.

4. For research projects with CAWG and IRB approval, files containing individual cancer records with personal identifiers will not contain cancer records reported to CDRI solely by other state registries, the Mountain Home Air Force Base (MHAFB), the Veterans Health Administration (VHA), or solely via death certificate (DCO) due to confidentiality requirements from these sources. De-identified files and aggregate statistical analyses will contain these records. Idaho resident cases reported solely by out of state, MHAFB, VHA, and DCO account for approximately 10% percent of the total cancer incidence data.
5. Rates will not be suppressed for statistical stability reasons if confidence intervals and/or standard errors for the rates are provided to allow evaluation of rate statistical stability. Generally, an incidence or mortality rate with fewer than 16–20 cases or deaths will result in a standard error of the rate that is at least 25% as large as the rate itself. Equivalently, a 95% confidence interval around the rate at least as large as the rate itself is also generally considered unstable.
6. *All personal identifiers* (name, date of birth, social security number, date of death, address (excluding county), census tract, block, latitude/longitude, reporting health care facility, pathology laboratory, or health care practitioner) must be removed from data before release, unless prior approval is obtained from CAWG.
7. *Statewide, public health district, and county level total counts* by cancer primary site may be released for single years without concern for the numbers of cases/small cell size.
8. Rates and counts will be suppressed for individual years and geographic levels below county in order to protect confidentiality when there are fewer than six cases of the cancer primary site of interest.
9. *For less than three years combined sub-county level data*, prior CAWG approval must be obtained before release.
10. *ZIP Code level counts* may only be released without prior CAWG approval for:
  - a. A minimum of three years combined data and grouped by no more than two additional variables (i.e., sex and cancer site, cancer site and race/ethnicity)
  - b. If age is requested, only ten year or greater age groups will be used
11. *Rates at the ZIP Code level* will not be provided by CDRI, due to the lack of zip code level population data for all data years and the small numbers of cases.
12. *Geocodes* for Idaho census tract and census block group are maintained by CDRI. Neither geocodes at the census tract or census block group level, nor address data, will be released without CAWG and IRB approval.

13. *Aggregate or individual record-level data containing no other personal identifiers other than the name(s) of a specific health care facility, clinical laboratory, or health care practitioner* may only be released if:
  - a. The data release is to the health care facility, clinical laboratory, or health care practitioner that originally reported the data, or
  - b. Prior written authorization is obtained from the health care facility, clinical laboratory, or health care practitioner that reported the data; and CAWG approval is obtained.
14. CDRI may provide *patient-specific information* back to the reporting entity that supplied the specific data (health care facility, clinical laboratory, and/or health care practitioner) without CAWG approval.
15. *Patient-specific information* may be shared with another state central cancer registry by CDRI after receiving a written request and confirming there is a current out-of-state data exchange agreement between the requesting state registry and CDRI.
16. *An individual's cancer record* or information contained on that cancer record may only be released to the individual if they submit a notarized PATIENT'S RECORD REQUEST FORM (available at [idcancer.org](http://idcancer.org)). For deceased patients, immediate family members may request the cancer record by submitting a notarized RELATIVE RECORD REQUEST FORM FOR DECEASED PATIENTS. CDRI also has a mechanism to release information about a patient to a parent or legal guardian of the patient if the patient is a minor, legal guardian if the patient is incapacitated, or an attorney ad litem for the patient. These requests require submission of a notarized CDRI RECORD REQUEST FORM FOR PATIENTS WHO ARE ALIVE and proof of relation and/or acknowledgement of legal representation. Cancer Data Registry of Idaho data are not considered an "Open Record."

### **Release of Idaho Cancer Mortality Data**

1. Under agreement with the IDHW DPH Bureau of Vital Records and Health Statistics (BVRHS), CDRI may provide aggregate cancer mortality statistics for Idaho resident deaths occurring from 1970 to the most recently available mortality year. CDRI refers all other requests for mortality data to BVRHS.
2. CDRI utilizes the same data release procedures for releasing statistical data for both cancer incidence and cancer mortality data.
3. CDRI populates database records for deceased cases with the patient's state, date, and underlying cause of death and death certificate number via annual linkages with Idaho mortality data provided by BVRHS and the National Center for Health Statistics National Death Index (NCHS-NDI).

4. For CAWG-approved studies involving CDRI cancer cases, fact and date of death may be provided by CDRI without BVRHS approval. Additional approval must be secured from BVRHS in order for CDRI to supply cause of death information.
5. Data with personal identifiers and information provided by the NCHS–NDI may be released if approved by CAWG. A list of these studies and approvals is provided to the NDI on an annual basis.

### **Acknowledgment of Mortality Data Provided by the CDRI**

The CDRI requests that any person or organization reporting results or analyses using mortality data *provided by CDRI* include the following statement of acknowledgement in the analysis, presentation, report, or publication:

“Data source: Bureau of Vital Records and Health Statistics, Division of Public Health, Idaho Department of Health and Welfare, <date>.”

### **Questions or Additional Information**

For any questions or additional information regarding CDRI data release policies, please contact Chris Johnson, CDRI Epidemiologist, at (208) 489-1380 or [cjohnson@teamiha.org](mailto:cjohnson@teamiha.org).