

R384. Health, Disease Control and Prevention, Health Promotion.

R384-100. Cancer Reporting Rule.

R384-100-1. Purpose Statement.

- (1) The Cancer Reporting Rule is adopted under authority of sections 26-1-30 and 26-5-3.
- (2) Cancers constitute a leading cause of morbidity and mortality in Utah and, therefore, pose an important risk to public health. Through the routine reporting of cancer cases, trends in cancer incidence and mortality can be monitored and prevention and control measures evaluated.
- (3) Cancer records are managed for research and statistical purposes by the Utah Cancer Registry on behalf of the Utah Department of Health. This Cancer Reporting Rule is adopted to specify the reporting requirements for cases of cancer to the Registry. The Utah Department of Health retains ownership and all rights to the records.

R384-100-2. Definitions.

- (1) "Health care facility" means the same as defined in Utah Code Section 78B-3-403
- (2) "Health care provider" means the same as defined in Section 78B-3-403
- (3) "Hospital" means the same as defined in Section 78B-3-403
- (4) "Anatomic pathology services" means the same as defined in Section 58-1-501.5
- (5) "Clinical laboratory" or "laboratory" means the same as defined in Section 58-1-501.5
- (6) "Identifiable health data" means the same as defined in Section 26-3-1(3)
- (7) "Research and statistical purposes" means the same as defined in Section 26-3-1(6)
- (8) "Laboratory" is defined as any facility that receives, refers, or analyzes clinical specimens.
- (9) "Follow-up" is defined as information to determine the vital status and disease status of a patient with a prior reportable cancer diagnosis. This includes patient demographics, date of last contact with a reportable case, cancer recurrence status, date of death, and cause of death.
- (10) "Registry" means Utah Cancer Registry.
- (11) "Department" means Utah Department of Health

R384-100-3. Reportable Cases.

- (1) Each case of cancer or reportable benign tumor, defined as reportable under current guidelines of the U.S. National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) Program or the U.S. Centers for Disease Control and Prevention National Program of Cancer Registries (NPCR) and diagnosed or treated in Utah shall be reported to the Utah Cancer Registry.
- (2) The registry provides a current, detailed list of reportable diagnoses, including links to current national guidelines, available:
 - (a) on the Registry's website <https://uofuhealth.utah.edu/utah-cancer-registry/>;
 - (b) by contacting the registry by email at ucr.info@hsc.utah.edu; or
 - (c) by contacting the registry by telephone at 801-581-8407.

R384-100-4. Entities Required to Report Cases.

- (1) Each entity involved in the diagnosis, staging, or treatment of cancer and licensed by the state shall report or provide information related to a reportable case to the registry. These entities include:
 - (a) health care facilities;
 - (b) health care providers;
 - (c) hospitals; and
 - (d) anatomic pathology services or clinical laboratories.
- (2) When more than one entity is involved in the diagnosis, staging, or treatment of a reportable cancer case, each entity involved is responsible to report.

R384-100-5. Entities That May Report Cases.

- (1) Any entity operating outside Utah or not licensed by the state and providing screening, diagnosis, staging, treatment, or follow-up of cancer for Utah residents may report or provide information related to a reportable case to the registry. These entities include:
 - (a) health care facilities;
 - (b) health care providers;
 - (c) hospitals; and
 - (d) anatomic pathology services or clinical laboratories.
- (2) Any entity that is not a healthcare facility, health care provider, hospital, or laboratory but has information related to screening, diagnosis, staging, treatment, or follow-up for Utah residents may report or provide information related a reportable case. These entities may include:
 - (a) entities contracted by Utah health care facilities to perform data abstraction and reporting;
 - (b) health care claim processors or other organizations that aggregate health or demographic data;
 - (c) cancer registries in other states; and
 - (d) federal agencies authorized to share data for public health purposes.

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.
- (2) The reportable data for each case shall include information as specified by the registry, according to the type of entity reporting.
 - (a) Each Utah hospital shall report:
 - i. each data item identified as reportable by SEER and NPCR;
 - ii. text documentation to support reportable data items, as described in guidance from national organizations that set standards for cancer registries; and
 - iii. any additional data items identified as reportable in Utah by the department and the registry.
 - (b) Each Utah health care provider and non-hospital health care facility shall report:
 - i. facility, provider, and patient identifiers;
 - ii. diagnosis;
 - iii. dates, methods, and results of cancer-directed screening and diagnostic procedures provided under their care;
 - iv. dates and methods of treatment provided under their care; and
 - v. follow-up.
 - (c) Each Utah laboratory shall report:
 - i. facility, provider and patient identifiers;
 - ii. diagnosis; and
 - iii. results of cancer-directed laboratory examinations, assays, and tests performed or reported by that laboratory.
 - (d) Any laboratory outside Utah may report:
 - i. facility, provider, and patient identifiers;
 - ii. diagnosis; and
 - iii. results of cancer-directed laboratory examinations, assays, and tests performed or reported by that laboratory.
 - (e) Any cancer registry program in another U.S. state and territory may disclose cancer case report information for Utah residents that have been reported to another state, if both programs are party to a data exchange agreement.
 - (f) Any federal agency authorized to provide data for public health purposes may disclose demographics, follow-up, or other information relevant to reportable cases who are Utah residents.
- (3) The registry provides current, detailed lists of reportable data items and data specifications, which can be obtained:
 - (a) from the registry's website <https://uofuhealth.utah.edu/utah-cancer-registry/>;
 - (b) by contacting the registry by email at ucr.info@hsc.utah.edu; or
 - (c) by contacting the registry by telephone at 801-581-8407.

R384-100-7. Format of Case Reports and Procedures for Reporting.

- (1) Each reporting entity shall submit data in an electronic format acceptable to the registry. Information on the acceptable data formats can be obtained:
 - (a) from the registry's website <https://uofuhealth.utah.edu/utah-cancer-registry/>;
 - (b) by contacting the registry by email at ucr.info@hsc.utah.edu; or
 - (c) by contacting the registry by telephone at 801-581-8407.
- (2) The format for the data will depend on the type of entity reporting.
 - (a) Each hospital shall submit an abstract for each reportable case. The abstract shall be structured and coded according to standards agreed upon by national organizations and promulgated by the North American Association of Central Cancer Registries (NAACCR). Each abstract shall pass quality checks, referred to as edits, specified by the registry. A metafile describing standards for the abstract contents and specifications of edits will be updated at least annually and can be obtained from the registry website or by contacting the registry.
 - (b) Each health care provider and non-hospital health care facility shall submit:
 - i. a NAACCR-format abstract;
 - ii. an electronic file generated by an electronic health record (EHR) using Health Level 7 (HL7) or other electronic format;
 - iii. health care claims in the currently approved electronic format; or
 - iv. another electronic format specified by or agreed upon with the registry.

(c) Each laboratory shall report data electronically, using Health Level 7 (HL7) or other electronic format agreed upon with the registry.

(d) Any other entity shall submit data in an electronic format agreed upon with the registry.

(3) Each reporting entity shall submit case reports directly to the registry unless the entity has existing mechanisms of reporting to the department. In the latter case, the reporting entity may submit case report data to the department to be forwarded to the registry.

R384-100-8. Time Requirements.

(1) Each hospital shall submit case reports to the registry within six months of the date of diagnosis or date first seen for the reportable condition.

(a) Initial hospital case reports submitted within six months should include, at a minimum, patient identifiers, and diagnosis.

(b) Each hospital shall submit complete case reports no later than one year after the end of the year of diagnosis.

(c) Each hospital shall submit annual follow-up to the registry within 13 months of the date the patient was last contacted by facility personnel.

(2) Each health care provider and non-hospital health care facility shall report encounters for screening, diagnosis, treatment, or follow-up of a reportable case within six months of the encounter.

(3) Each laboratory shall submit case reports no less frequently than once every six months.

R384-100-9. Data Quality Assurance.

(1) Records maintained by each entity required to report are subject to review by registry personnel acting on behalf of the department to assure the completeness and accuracy of reported data.

(2) Electronic case reports submitted by reporting entities are subject to review by registry personnel for data quality including meeting data quality standards established by national cancer registry organizations. Each entity required to report is responsible to revise electronic report documents to correct deficiencies identified by registry review or as needed to meet standards.

R382-100-10. Confidentiality of Case Reports.

All case reports required by this rule are confidential under the provisions of Title 26, Chapter 3, Health Statistics and are not open to inspection except as allowed by Title 26, Chapter 3, Health Statistics. The registry shall maintain each report according to the provisions of Title 26, Chapter 3, Health Statistics.

R384-100-11. Non-compliance with Reporting Regulations.

Enforcement provisions and penalties for the violation or for the enforcement of public health rules, including this Cancer Reporting Rule, are prescribed under Section 26-23-6.

KEY: cancer, reporting requirements and procedures

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Authorizing, and Implemented or Interpreted Law: 26-1-30; 26-5-3