

NEBRASKA

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DEPT. OF HEALTH AND HUMAN SERVICES



Jim Pillen, Governor

December 31, 2024

The Honorable Ben Hansen
Members of the Health and Human Services Committee
Nebraska Legislature
P.O. Box 94604
Lincoln, NE 68509

Subject: Operational and Performance of Cancer Registry Program

Dear Chairman Hansen:

In accordance with Neb. Rev. Stat. § 81-650, please find attached a copy of the 2024 Annual Cancer Registry Program Operations Report. This report describes the operations and performance of the Nebraska Cancer Registry including facilities reporting, facility compliance, and research requests by the Nebraska Cancer Registry Program from July 2023 through June 2024.

Sincerely,

A handwritten signature in blue ink that reads "Charity Menefee".

Charity Menefee
Director, Division of Public Health

Attachment

Division of Public Health

Operational and Performance of Cancer Registry Program

December 2024

Neb. Rev. Stat. § 81-650

Nebraska Cancer Registry Program

Background

The Nebraska Cancer Registry (NCR) was founded in 1986, when the Nebraska Unicameral authorized funding for a state cancer registry using a portion of funds generated by the state's cigarette tax. The establishment of the registry successfully combined the efforts of many Nebraska physicians, legislators, concerned citizens, and the Nebraska Medical Foundation, all of whom had worked for years toward this goal. The Nebraska Medical Foundation also helped establish the registry with financial assistance. Since 1994, the NCR has received additional funding from the Centers for Disease Control and Prevention (CDC).

The NCR is managed by the Nebraska Department of Health and Human Services (DHHS). However, registry data is collected and edited by NCR staff under contract to Westat. Analysis of registry data and preparation of the annual statistical report are the responsibilities of DHHS.

The purpose of the registry is to gather data describing how many Nebraska residents are diagnosed with cancer, what types of cancer they have, how far the disease has advanced at the time of diagnosis, what types of treatment they receive, and how long they survive after diagnosis. These data are put to a variety of uses both inside and outside of DHHS. Within DHHS, they are used to identify high-risk populations and long-term disease trends, to compare Nebraska's cancer experience with the rest of the nation, to investigate reports of cancer clusters, and to help plan and evaluate cancer control programs. Outside of DHHS, the registry provides data upon request for research studies and public information and has provided data to the North American Association of Central Cancer Registries (NAACCR), the National Cancer Institute (NCI), the American Cancer Society (ACS), CDC, the University of Nebraska Medical Center, and Creighton University, among others. The NCR also contributes its data to several national cancer incidence databases. In recognition of the accuracy and completeness of the data collected, NAACCR has awarded the NCR its gold standard certificate of data quality for 25 consecutive years except for 2023 the registry received a silver standard. However, the registry was able to reobtain its gold standard certificate in 2024.

All individual records in the cancer registry are kept in strict confidence as prescribed by both state and federal law. The NCR follows all the privacy safeguards in the Health Insurance Portability and Accountability Act (HIPAA), although some procedural requirements do not apply to the registry.

DHHS welcomes inquiries about cancer from the public for aggregate statistics or general information from the registry. To obtain cancer data or information about the registry not included in this report, please refer to the Cancer Registry's website at <https://dhhs.ne.gov/Pages/Cancer-Registry.aspx>.

Reporting Facilities

To gather the necessary diagnosis, treatment, and other registry information, NCR works with 142 facilities.

- 19 Registry Hospitals (Hospitals with 50 or more cancer diagnoses annually)
- 68 Non-Registry Hospitals (Hospitals with less than 50 cancer diagnoses annually)
- 18 Other Hospitals

- 27 Physician and Surgery Centers
- 10 Laboratories

Ninety-seven (97) facilities comply with reporting; non-compliant facilities are primarily non-registry hospitals that do not regularly have cancer diagnoses and are small facilities or physicians' offices that may have difficulties with staffing or navigating technology or software. To improve compliance, additional training is provided as well as a free web application that is accessible online that does not require special hardware. Sixty (60) facilities, among all types of facilities, participate in electronic reporting via Web Plus, which results in improved timeliness and accuracy. Electronic reporting is primarily used by larger facilities with additional staffing and technological resources; however, the free web application provided to facilities, Web Plus, is increasing accessibility for smaller facilities to report without the additional burdens. Additionally, NCR staff offers faxing, email, and mail submissions to reduce the technological burdensome facilities may encounter.

Research Requests

In 2023, NCR received a total of eight research requests and was able to fill six of the eight. The two not able to be filled were due to conflicts with the statutory release of information or missing key documentation. In 2024, a total of six research requests have been received, with two approved and four in the review process at the time of this report.

Throughout 2024, the NCR team and Nebraska DHHS leadership have worked collaboratively with the University of Nebraska Medical Center and Creighton University to improve the research request process. The focus areas of this collaboration have been to improve the timeliness of data released to researchers, reduce the administrative burden for researchers, and improve access to data for researchers. This collaboration has resulted in the development of an agreement with each of the respective universities, expected to be fully executed by December 31, 2024. Progress and improvements in the research request process will be provided in future submissions of this report.