

# CANCER REGISTRY DATA ACCESS



## CANCER REGISTRY LEGISLATIVE INTENT

“This cancer registry should provide a central data bank of accurate, precise, and current information which medical authorities state will assist in the research for the prevention, cure, and control of cancer. The information contained in the cancer registry may be used as a source of data for scientific and medical research.” (81-642)

## LB 1172 (VON GILLERN)

Requires the Department of Health and Human Services to reply to data requests in eight weeks.

Legislation addressing the timeline of data requests was not necessary until now because data requests used to be approved in a timely fashion.

There are researchers at universities being denied access and told they do not meet the qualifications to be an approved researcher.

## THE PROBLEM

The purpose of the cancer registry is to decrease cancer and cancer related deaths. Without registries, our actions to fight cancer are guess work.

Researchers request access to data to see cancer trends, discover causes of cancer, and to monitor the effectiveness of cancer prevention strategies and treatments.

Cancer researchers in Nebraska are struggling to get data requests approved by the state in a timely fashion, and in some cases, requests are pending for over a year. Sometimes the request are denied on the grounds that the requester has not met the qualifications to be an “approved researcher” despite having valid credentials.

Delays in data approval hinder advancements in cancer research and prevent researchers from applying for valuable grants from the National Institutes of Health (NIH). NIH grants are the backbone of research funding.

Without access to data, our researchers have to use data from other states and can’t make proven advancements in Nebraska cancer prevention. We also risk losing top cancer researchers to states where they can access data and do their lifesaving work.

## PROCESS FOR DATA REQUEST

81-666. “The department may approve an individual or entity to be an approved researcher upon application and proof satisfactory to the department that the applicant is a qualified researcher, that the data will be used for bona fide scientific or medical research for prevention, cure, or control of certain diseases or injuries, and that the applicant will maintain the confidentiality and security of data obtained.”

The application shall include the qualifications of the applicant, purpose and summary of the research project, the location of the research project, the identify of the research funder, the specific data requested, a description of how confidentiality will be maintained, justification for contact with patients if applicable, and other information as determined necessary by the department.

Nebraska statutes and DHHS regulations do not detail a process for approval of the data requests or who determines approval. Some state, like Louisiana, detail the process of approval in their statues. and formalize a registry review committee that makes determinations on approval or denial. (1)

## TYPES OF DATA REQUESTS

- Aggregate - Statistical data that does not include patient-identifying information
- Individualized - Patient-identifying or case-specific, de-identified data. This information allows researchers to dig deeper into causes and outcomes.

## DATA COLLECTED IS CONFIDENTIAL

Aggregate data is kept entirely confidential.

For individualized data requests, researchers cannot contact a patient or patient’s family unless the registry first gets permission from the patient or patient’s family.



## ADDITIONAL INFORMATION

In 2023, the Nebraska cancer registry lost its Gold status with the organization monitoring the quality of cancer registries. (2)

DHHS is required by statue to produce a cancer registry report every year. The 2023 report used 2019 data, while other states like South Dakota, are already producing 2021 data. (3)

Other public health data is also difficult to obtain. This data access issue goes beyond the cancer registry.

### Sources

(1) Louisiana Cancer Registry Statute [https://sph.lsuhs.edu/wp-content/uploads/2018/11/LTR\\_law\\_all\\_pages.pdf](https://sph.lsuhs.edu/wp-content/uploads/2018/11/LTR_law_all_pages.pdf)

(2)North American Assoc. of Central Registries <https://www.naaccr.org/certified-registries/#CertificationHistory>

(3)South Dakota Cancer Registry Report-, May 2023 <https://www.getscreenedsd.org/media/2021%20Preliminary%20Report.pdf>

Nebraska Cancer Registry Statues 81-642-81-650 and 81-663-81-675