



Brian Sandoval
Governor



Richard Whitley
Director

State of Nevada
Department of Health and Human Services

Reporting Cancer in Nevada
Division of Public and Behavioral Health
Nevada Central Cancer Registry
September 2018






What is the Nevada Central Cancer Registry (NCCR)?

The NCCR is a **population-based registry** that maintains data on newly diagnosed cancer patients within the state of Nevada to calculate cancer incidence and mortality rates.

The NCCR began collecting cancer incidence data in 1989. In 1995, the NCCR began receiving funding from the National Program of Cancer Registries (NPCR) through the Centers for Disease Control and Prevention (CDC).



Regulations


The NCCR is governed by **Nevada Revised Statutes (NRS) 457** and **Administrative Codes (NAC) 457** with the primary purpose of collecting comprehensive, timely, and accurate data on incidences of cancer among Nevada residents. State regulation made cancer a reportable disease in Nevada effective 1983.



Who Reports Information to the Registry?

Traditional cancer data collection has been primarily from hospitals. As medical advances have occurred, diagnosis and treatment of certain cancers has moved from the acute care setting to being fully cared for within a physician/medical office and therefore **never received and counted** by the registry.

Examples: melanoma of the skin; prostate cancer; and many hematopoietic malignances.



What Cancers are Reportable?

All malignant cancers, except basal cell and squamous cell of skin of non-mucoepidermoid sites.

All in situ cancer, except carcinoma in situ of the cervix uteri, cervical intraepithelial neoplasia, grade III (CIN III), and prostatic intraepithelial neoplasia, grade III (PIN III).

All primary tumors of the following sites:

- brain
- meninges
- spinal cord, cranial nerves and other parts of the central nervous system
- pituitary gland, craniopharyngeal duct and pineal glands

Borderline papillary or serous ovarian tumors




Casefinding

Casefinding is a systematic method of locating all potentially eligible cases to be reported to the NCCR

The best method(s) of casefinding will vary depending the following:

- Practice specialty
- Patient caseload
- Availability of reports/logs
 - Disease index of ICD-10-CM codes
 - Billing reports (procedures and treatments)
 - Appointment logs
 - Laboratory/pathology reports

It is recommended that the physician office use a system to track casefinding, determination of reportability and case submission.



What cancer information is reported to the registry?

The NCCR operates under the Standards set by the National Program of Cancer Registries (NPCR) and the North American Association of Central Cancer Registries (NAACCR).

Information collected includes:


Patient information (e.g. age, gender, race, social address at diagnosis, place of birth, marital status, occupation and industry)

Anatomic site of the primary tumor

Histology (cell type) of the cancer

Stage of disease at diagnosis

First course of treatment



What about privacy and HIPAA?

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule **allows “covered entities” (health care providers) to disclose protected health information to public health authorities when required by federal, tribal, state, or local laws** [45 CFR 164.512(a)(1)].

Central cancer registries are considered public health authorities because state laws mandate their duties.

Written authorization from the individual before reporting protected health information to the state cancer registry is not required under HIPAA. The provision of the Privacy Rule authorizing disclosure of protected health information as required by law is an exception to the requirement for written authorization.




What about privacy and HIPAA?

All cancer data is kept strictly confidential under all Protected Health Information (PHI) and Health Insurance Portability and Accountability Act (HIPAA) laws and guidelines.

NRS 457.060-457.130 also provides guidance on protecting confidential Registry data.

De-identified data is sent to federal agencies to use for national statistics, for research and analysis.




How is cancer information reported to the registry?

Option 1: Secure file upload in text, excel, HL7 or NAACCR format through a secure on-line application.

Option 2: Online abstracting by a certified tumor registrar (CTR) to the NCCR. Web Plus is a web-based application that collects cancer data securely over the public Internet.

Option 3: Paper Reporting: Hard copy submission via mail, fax, or file upload of the NCCR cancer incidence reporting form. Specific reporting forms are available for specialty groups.

The NCCR has various tools to assist in identification of cases, and determining which cases to report.




How does a physician's office start reporting?

Contact the Nevada Central Registry 775-684-5968.

Complete a demographic form to obtain office, contact, and reporting option information.


Based on your reporting option staff will provide various tools to assist in cancer case reporting.



What does the cancer registry do with the cancer information?

All cancer information is maintained in a database. The NCCR supplements hospital data with reports from facilities and providers who diagnose and/or treat cases that are not seen in a hospital. In addition, death certificates and pathology laboratory reports are used to help identify cases that are missed in this routine reporting by hospitals, health care facilities and providers of health care offices.

One patient can have several records in the database if seen at more than one facility. All of this information is consolidated into one comprehensive record for each patient.



What does the cancer registry do with the cancer information?

Every November, the NCCR submits data for a specific diagnosis year to the CDC-NPCR and NAACCR for data evaluation and certification. If the data reaches certain standards, Nevada's data is included in national data reports such as the United States Cancer Statistics (USCS) and other analytic data sets.

NPCR Program Standards

National Data Quality Standard – 24 month

- 95% Complete
- 3% or Less Death Certificate Only Cases
- 1 per 1,000 or fewer unresolved duplicate rate
- Maximum percent missing for critical fields
 - 2% Age, Sex, County at Diagnosis
 - 3% Race
- 99% Pass CDC Edits



What does Cancer Registry data tell us?

Who is getting cancer (for instance, by race, age, or sex)?

What types of cancer are increasing or decreasing?

Where will prevention efforts have the biggest impact?

When are screening or prevention strategies working?

How far has the cancer spread, and are we catching cancer early?



What is Cancer Data used for?

With cancer registry data, lawmakers can see if certain policies have had an impact, such as:

Improving access to diagnose and treat cancer earlier, when it's more cost **effective and costs less.**

Encouraging healthy behaviors (like vaccinations, exercising, or quitting smoking) that lead to **fewer people getting cancer.**

Doctors can tell cancer patients how long people with a certain type of cancer tend to live after diagnosis and if they qualify for clinical trials.

Patients can obtain an abstract of their cancer case(s).

Researchers can **find risk factors and places where more cancers happen or determine what treatments work best.**

For additional information on cancer statistics and databases available to researchers, please visit the CDC website below.

[Cancer Data and Statistics Tools](#)

If you have a specific data request, please e-mail the Office of Analytics at data@dhhs.nv.gov and an analyst will contact you.



Thank You

Christine Pool

cpool@health.nv.gov

775-684-3221



To start reporting, please contact me or call 775-684-5968 or visit our web-site at:

[http://dpbh.nv.gov/Programs/NCCR/Nevada_Central_Cancer_Registry_\(NCCR\)_-Home/](http://dpbh.nv.gov/Programs/NCCR/Nevada_Central_Cancer_Registry_(NCCR)_-Home/)

This presentation was supported by the Grant or Cooperative Agreement Number, **NU58DP006306**, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.