



# Nevada Central Cancer Registry

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# What is a Cancer Registry?

- “State-based cancer registries are data systems that collect, manage, and analyze data about cancer cases and cancer deaths. In each state, medical facilities (including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories) report these data to a central cancer registry.”
  - <http://www.cdc.gov/cancer/npcr/about.htm>
- Population Based, Retrospective Data Collection
  - Allows for capturing diagnosis, as well as initial treatment information
- National requirements for reporting
  - Within 24 months from year of diagnosis
- Registries do not track incidence as diagnoses occur
  - Cannot be used to identify cancer clusters
  - Not real-time data




# Nevada Central Cancer Registry (NCCR)

- Established and governed by NRS and NAC 457
- Primary purpose
  - Collect, register, and maintain a record of reportable cases of cancer occurring in the state
- Uses of the data
  - Evaluate the appropriateness of measures for the prevention and control of cancer
  - To conduct comprehensive epidemiological surveys of cancer and cancer related deaths
- De-identified data reported to Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) and North American Association of Central Cancer Registries (NAACCR)
  - Reporting began in 1995
- NCCR Website
  - [http://www.health.nv.gov/VS\\_NVCancerRegistry.htm](http://www.health.nv.gov/VS_NVCancerRegistry.htm)




# How Data Is Collected

- Abstracting
  - State
    - NCCR Cancer Registrars visit facilities and abstract cases
  - Hospitals and Other Facilities
    - Facility Cancer Registrars abstract cases and submit information to the NCCR
  - Pathology Labs
    - Pathology reports sent to NCCR for case finding and supporting information
  - Information from all sources is consolidated
    - Final comprehensive case is reported to NPCR and NAACCR
- Data sharing with other states
  - Reports received from other state registries of diagnosis and treatment information for Nevada Residents
  - Reports sent to other state registries for their residents who are diagnosed or treated in Nevada
  - Formal written agreements with 11 states, including all surrounding states
    - NPCR Data Exchange Requirements
      - Written agreements
      - Confidentiality
      - Data transmitted securely



# National Standards for Data Quality and Completeness

- NAACCR
  - **Gold Standard Certification for 7 of Past 8 Years!**
  - Gold Standard Requirements
    - Percent completeness of case ascertainment: At least 95%
    - Percent missing/unknown race: Less than 3%
    - Percent missing/unknown sex, age and county: Less than 2%
    - Percent of cases death certificate only: Less than 3%
    - Duplicate cases: Less than 1 per 1,000
    - Percent passing quality control edits: 100%
- CDC NPCR
  - In compliance with grant reporting requirements
  - Goals
    - 24 month completeness: 95%
    - 12 month completeness: 90%
    - Percent passing quality control edits: 100%



# Linkages With Other Programs

- State Office of Vital Records
  - Case finding
    - Death Certificate Only Cases
  - Survival Information
  - Demographic information updates
  - Grant requirement
- Hospital Discharge Data
  - Case finding
  - Supporting Information
- Women's Health Connection (WHC) – Breast and Cervical Cancer Early Detection Program
  - Benefits both programs
    - Case finding for NCCR
    - Treatment information for WHC
    - Grant requirement
- Indian Health Services – US Department of Health and Human Services
  - Improve estimates of cancer incidence among American Indian / Alaska Natives (AI/ANs)
  - Improve the quality of cancer surveillance data for AI/ANs in NPCR registries
  - Supports CDC goal to eliminate racial and ethnic health disparities
  - Cancer incidence data for AI/ANs included in *United States Cancer Statistics* (USCS) annually
  - Grant requirement



# Value of the Data

- Identify areas where Nevada differs from the rest of the country
  - Identify burden of disease and disparities
    - Allows prevention programs to target interventions
  - Information for policy development
  - Evaluation of program outcomes
- Due to consistent high quality of Nevada data, information is included in nationally published statistics
- Research



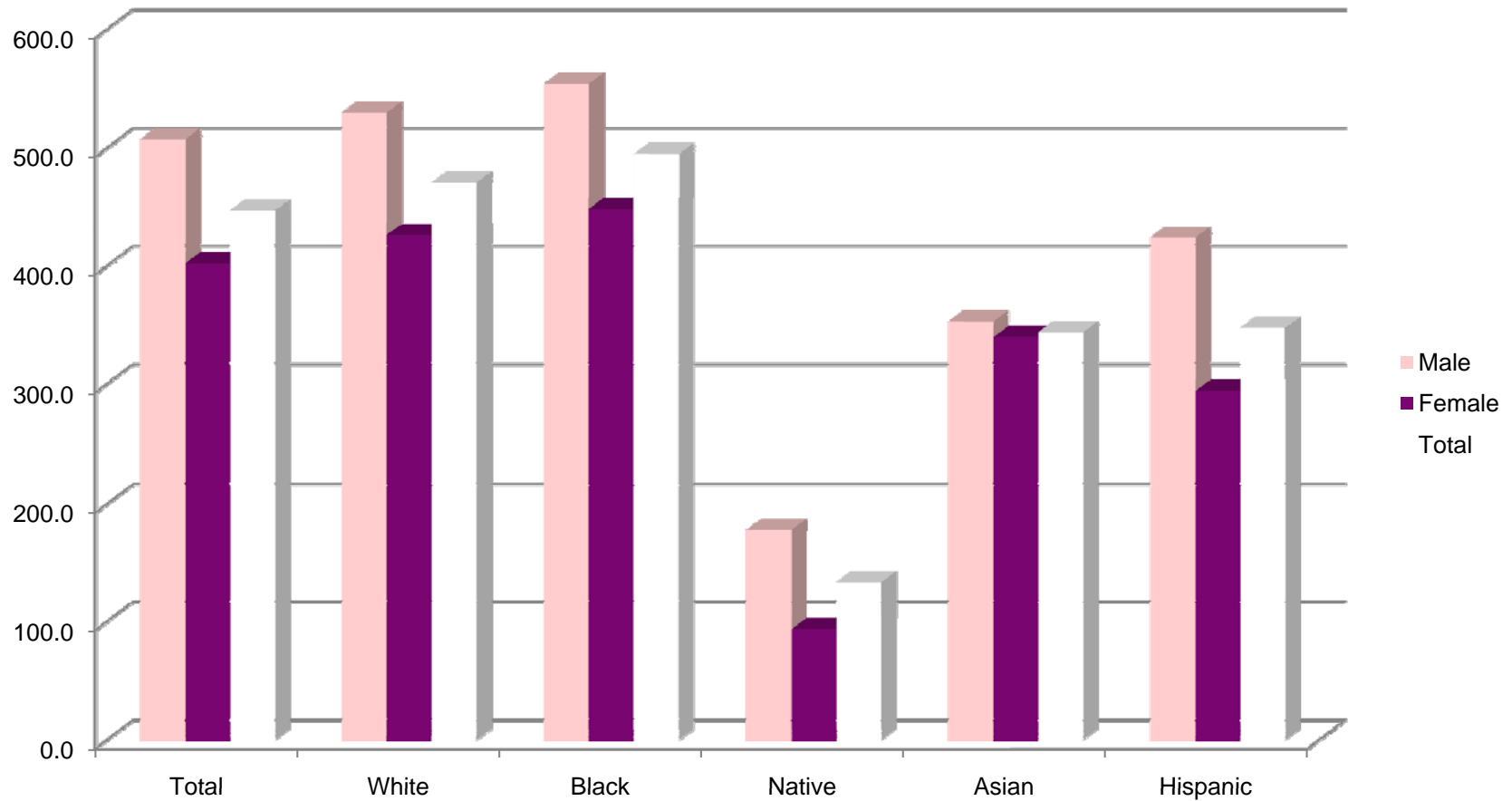
# Case Data –2008

- Just completed Annual Call for Data!
- Total 2008 Cases Reported to NPCR and NAACCR

**12,321 cases**

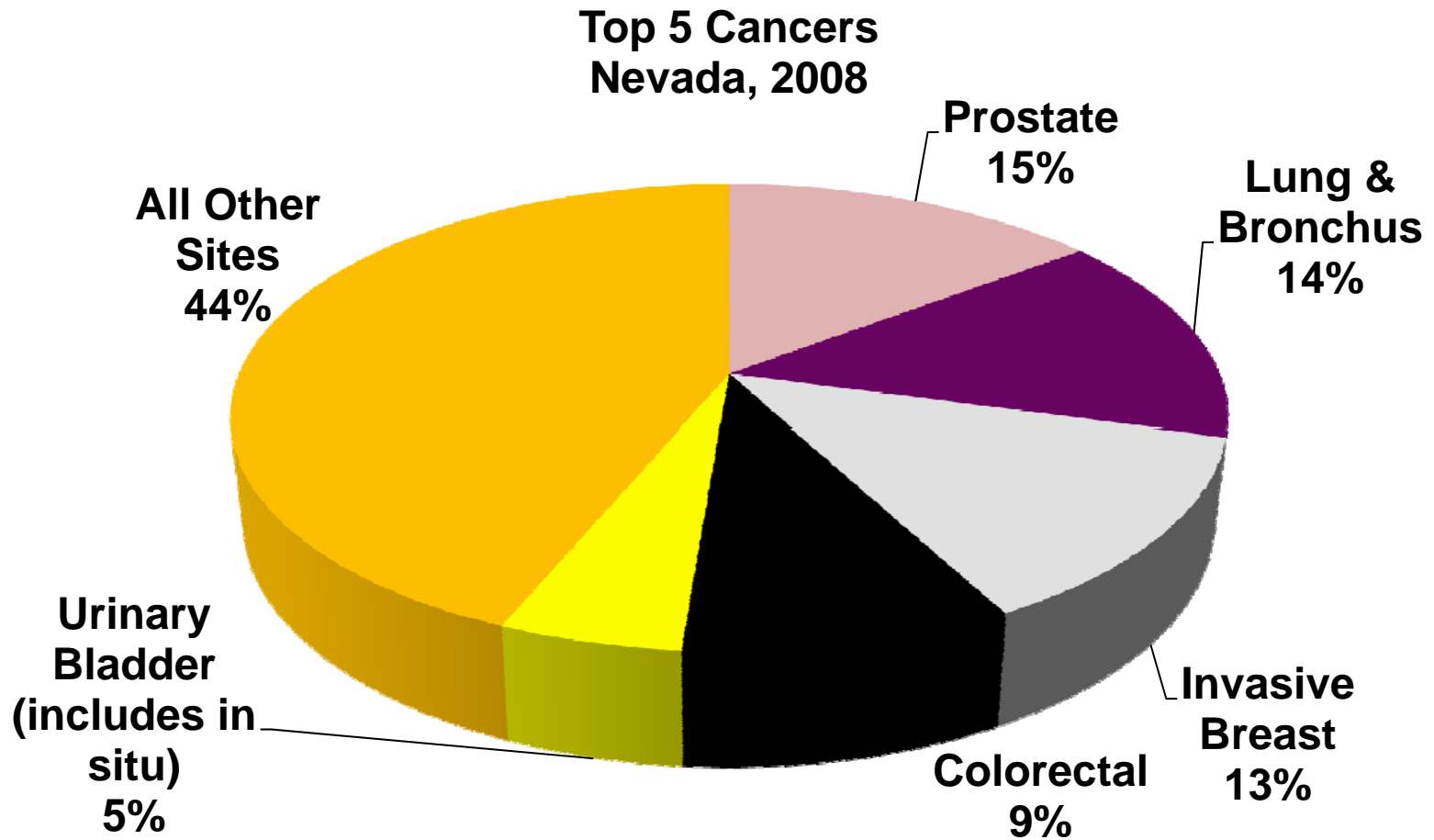
- Highest number of cases ever reported
  - Males – 6,415 cases
  - Females – 5,900 cases

# Age-Adjusted Cancer Incidence Rates by Gender and Race/Ethnicity – Nevada, Preliminary 2008



Note: Excludes in situ cases, except urinary bladder.  
Data are not final and are subject to change.

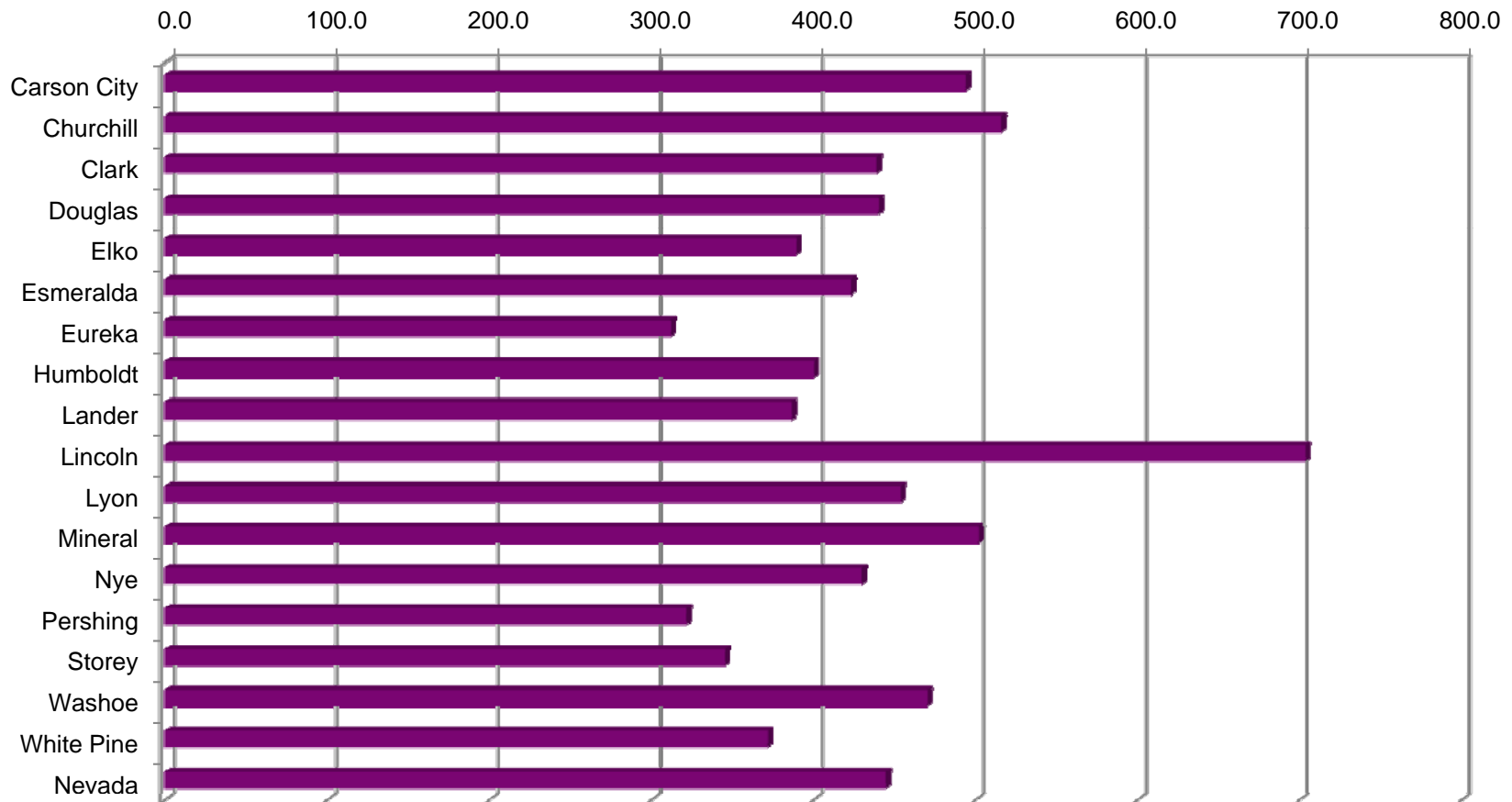
# Top 5 Cancers by Percentage of Incidence – Nevada, Preliminary 2008



Note: Excludes in situ cases, except urinary bladder.  
Data are not final and are subject to change.



# Age-Adjusted Cancer Incidence Rates by County of Residence – Nevada, Preliminary 2004-2008



Note: Excludes in situ cases, except urinary bladder.  
Data are not final and are subject to change.



# Uses of Incidence Data

- Program Planning and Evaluation
  - State Cancer Plan, NV Cancer Coalition
- Grant Requests
- Presentations
- Reports
- Research
- Hospital Planning and Treatment Evaluation
- Media
- Others...



# Uses of Incidence Data cont.

- Cancer Clusters

- Incidence data not useful for identifying clusters due to time lag required in data collection to acquire treatment data

- CDC Environmental Hazards and Health Effects – Cancer Clusters

- <http://www.cdc.gov/nceh/clusters/>



# Accessing Cancer Data

- Report on Cancer in Nevada: 2001-2005
  - [http://www.health.nv.gov/Cancer/NevadaCancerReport\\_2001-2005\\_FINAL\\_09132010.pdf](http://www.health.nv.gov/Cancer/NevadaCancerReport_2001-2005_FINAL_09132010.pdf)
  - CDC NPCR
    - <http://www.cdc.gov/cancer/npcr/>
  - United States Cancer Statistics (USCS)
    - <http://apps.nccd.cdc.gov/uscs/>
- NAACCR
  - <http://www.naacr.org/>
  - Cancer in North America
    - CINA+ Online
      - <http://www.cancer-rates.info/naacr/>
    - CINA Publications
      - [http://www.naacr.org/index.asp?Col\\_SectionKey=11&Col\\_ContentID=50](http://www.naacr.org/index.asp?Col_SectionKey=11&Col_ContentID=50)
- National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) Program
  - <http://www.seer.cancer.gov/>



# Future Plans

- Future Linkages
  - National Death Index
  - Social Security Death Index
- Web enabled reporting for facilities
- Geocoding of data
- Build infrastructure
  - Information technology
  - Data analysis
  - Data quality control



# Future Opportunities

- Further focused data analysis
- Integrate cancer data with other health related data in a Data Warehouse
  - Allow additional queries revealing where public health efforts should be focused
  - Existing programs can utilize information to target interventions
  - Improve outcomes for Nevadans
- Many possibilities for what can be done with the data