

# Overview of the New Mexico Tumor Registry

Research University

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**HEALTH SCIENCES**  
NEW MEXICO TUMOR REGISTRY





Susan G. Komen  
Foundation

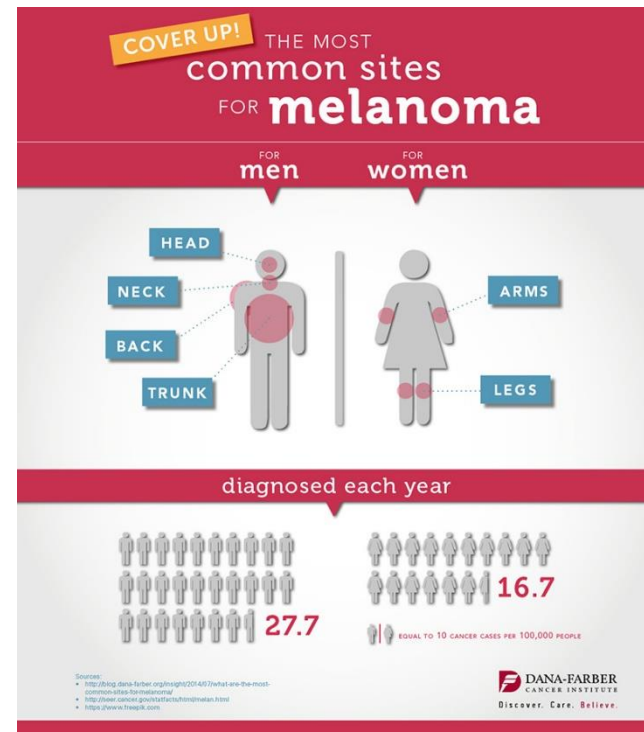
**1 in 8**

**WOMEN**

WILL BE DIAGNOSED WITH  
*Breast Cancer*  
IN THEIR LIFETIME



National Breast Cancer  
Foundation



The risk of  
**CANCER**



**EXAMPLES OF CANCER DISPARITIES**



**BREAST CANCER**

African American women are nearly twice as likely as white women to be diagnosed with triple-negative breast cancer and are much more likely than white women to die from breast cancer.



**KIDNEY CANCER**

The highest rates of kidney cancer cases and death in the United States occur among **American Indians/Alaska Natives**.



**LIVER CANCER**

Rates of liver cancer are higher among **American Indians/Alaska Natives and Asian and Pacific Islanders** than other racial/ethnic groups.



**PROSTATE CANCER**

African American men are more than twice as likely as white men to die from prostate cancer.



**CERVICAL CANCER**

Women in rural areas are twice as likely to die from cervical cancer as women in more urban areas.

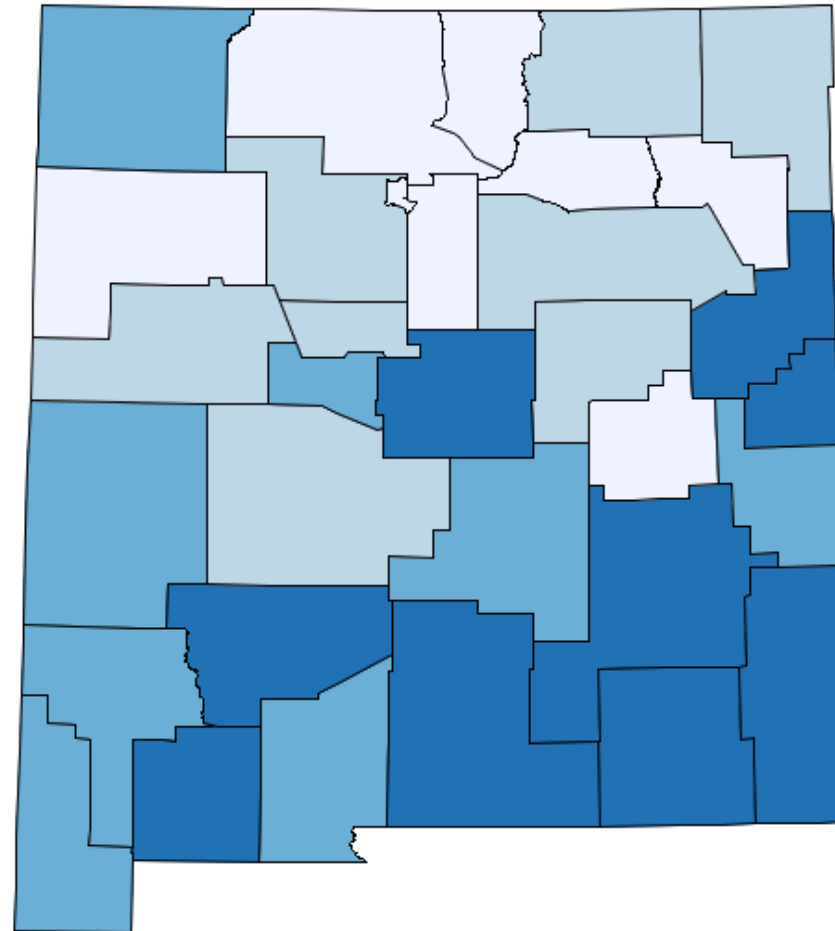


**MULTIPLE MYELOMA**

African Americans are twice as likely as whites to be diagnosed with and die from multiple myeloma.

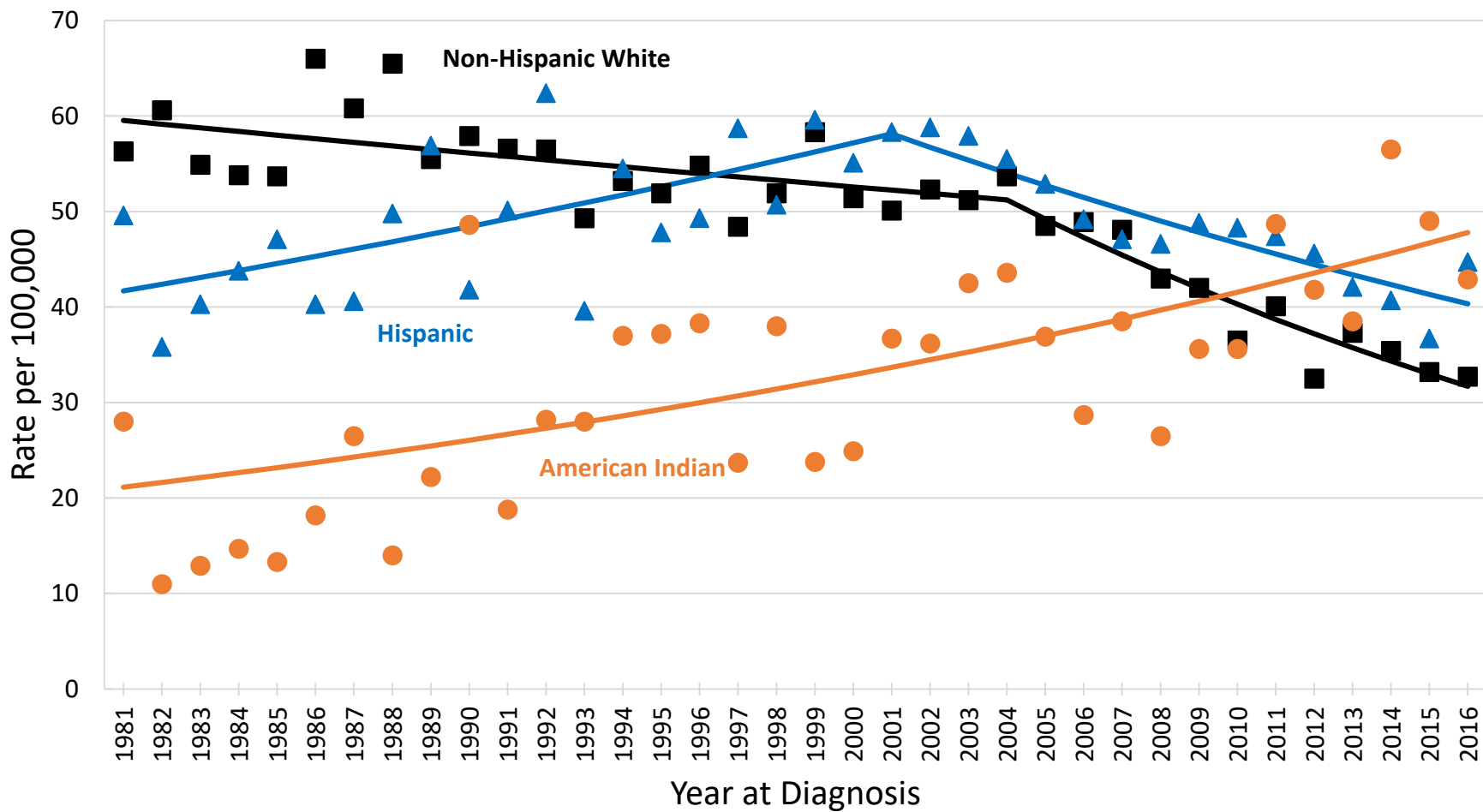
National Cancer Institute

**Cancers of the Lung and Bronchus**  
Average Annual Age-Adjusted Incidence Rate per 100,000 (US 2000 Standard)  
New Mexico Residents, 2012-2016



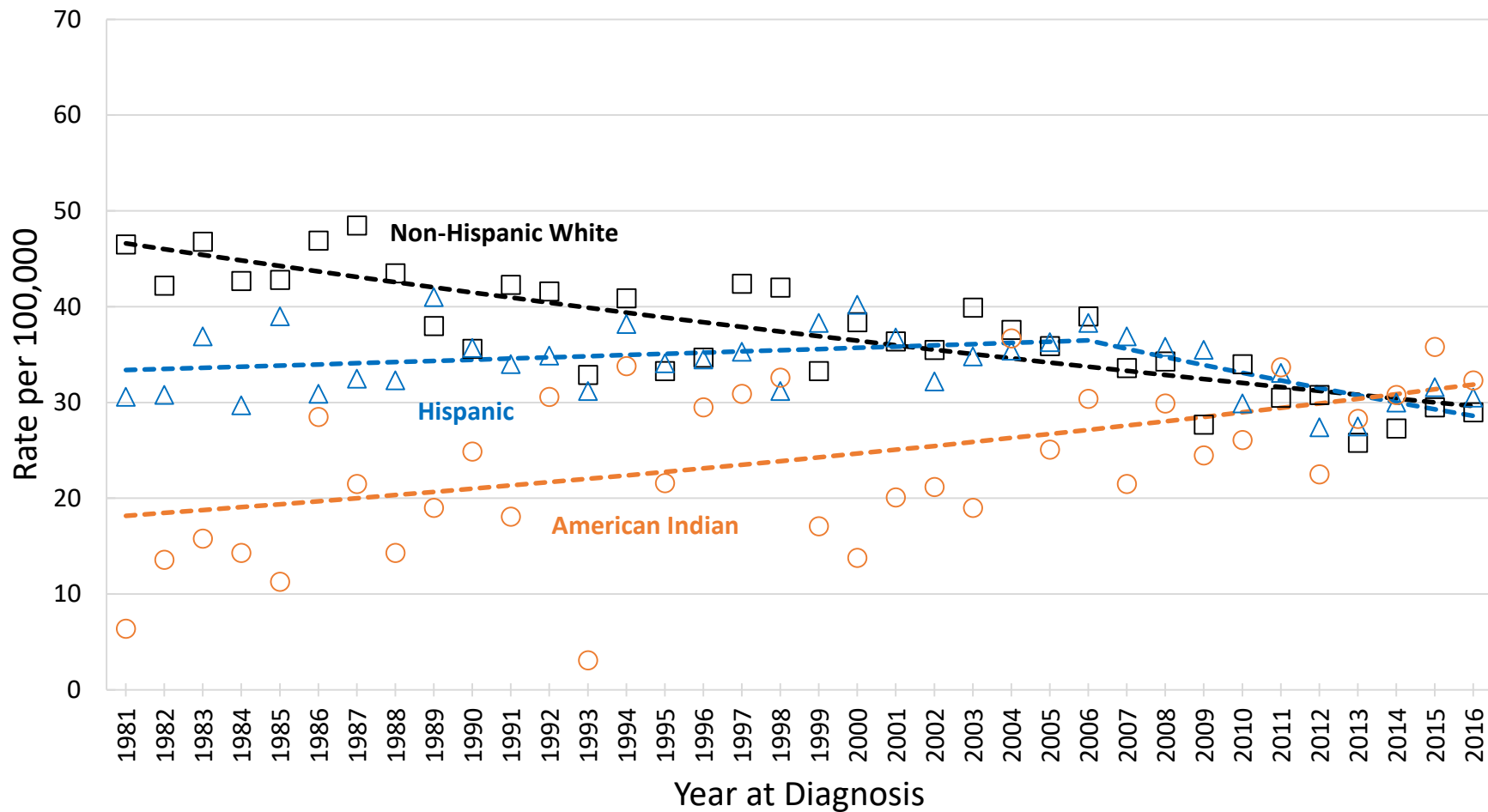
Incidence Rate (Quartiles)    12.7-35.2    35.3-40.5    40.6-50.8    50.9-63.5

# Incidence of Cancers of the Colon and Rectum Male New Mexico Residents, 1981-2016



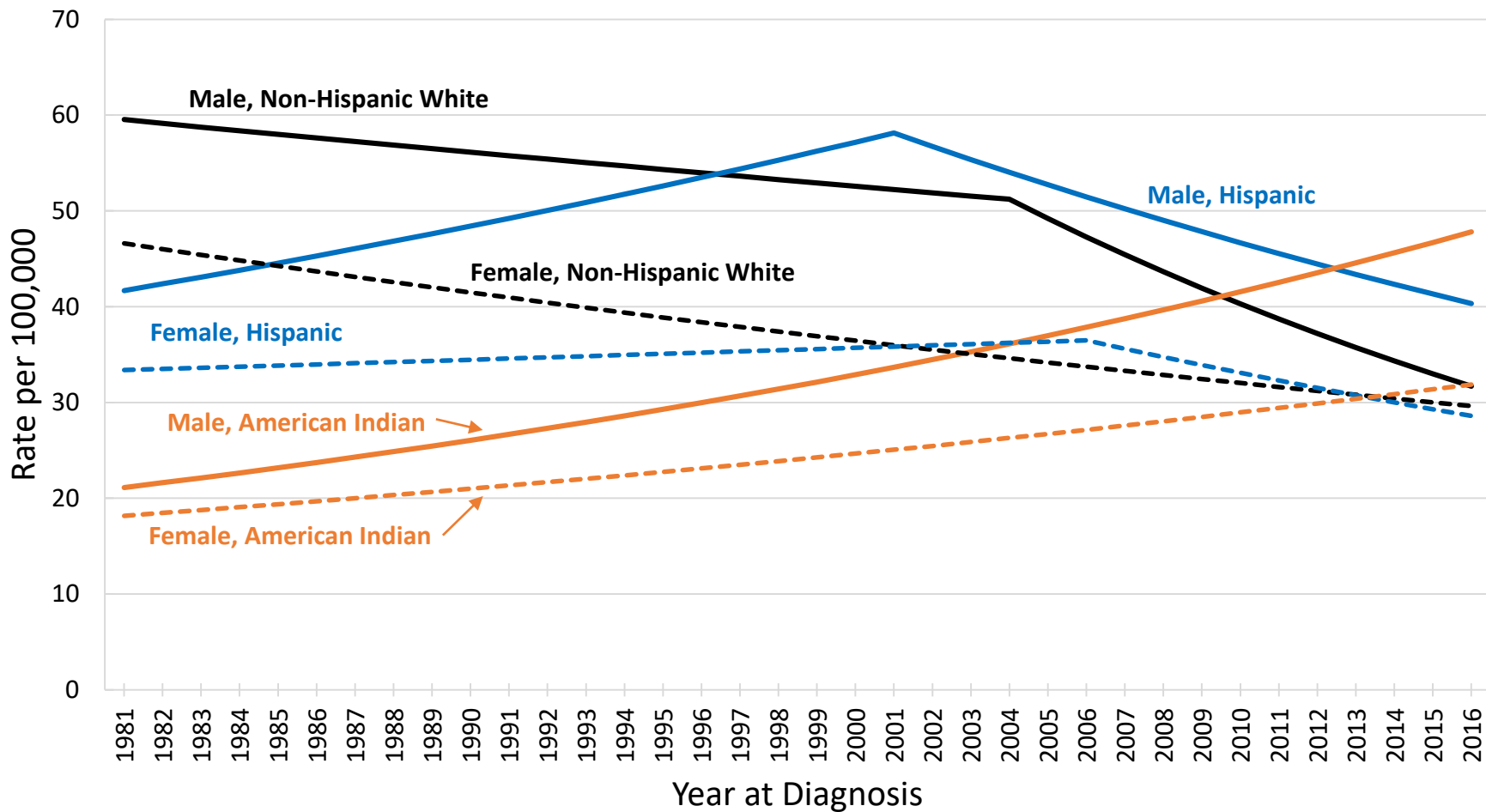
Average Annual Age-Adjusted Incidence Rate (US 2000 Standard)  
Source: New Mexico Tumor Registry

# Incidence of Cancers of the Colon and Rectum Female New Mexico Residents, 1981-2016



Average Annual Age-Adjusted Incidence Rate (US 2000 Standard)  
Source: New Mexico Tumor Registry

# Incidence of Cancers of the Colon and Rectum New Mexico Residents, 1981-2016



Average Annual Age-Adjusted Incidence Rate (US 2000 Standard)  
Source: New Mexico Tumor Registry

# What is a Cancer Registry?

- A database of information on cancer diagnosis, characteristics, treatment, and outcomes
- An information system designed for the collection, storage, and management of data on persons with cancer

# What is a Population-Based Cancer Registry?

- Collect data on new cancer cases in a defined population
- Emphasis on epidemiology and public health
  - Cancer patterns
  - Temporal trends
  - Cancer control and prevention
  - Guide resource allocation and health policy
  - Research



# What is Public Health Surveillance of Cancer?

The systematic collection  
of information on cancer

*- and -*

Timely and effective use of such information  
for the purposes of cancer prevention and control

# **NMTR Mission Statement**

Provide timely, high quality data to support public health surveillance, scientific research, patient care, public health practice and public policy to diminish the burden of cancer

# What is the NMTR?



- Population-based, central cancer registry
- Conduct public health surveillance for cancer

# What is the NMTR?



- Data is collected on incident cancer cases who reside in the coverage area at time of diagnosis
- Area of coverage New Mexico Statewide and Native Americans in Arizona in collaboration with the Arizona Cancer Registry



# Our History

- 1966: Established
- 1969: Statewide coverage
- 1973: Founding member of the SEER Program
- Ongoing:
  - Data from the NMTR has contributed to our understanding of the burden of cancer
  - Use of the data assists with the development of cancer prevention and control efforts
  - NMTR-affiliated faculty and staff are involved in cancer surveillance efforts nationally and internationally

# Components that make Cancer Surveillance in New Mexico Possible

- Data Collection
- Research and Data Use
- Information Technology
- Business Administration

Dr. Chuck Wiggins – Director – oversees all operations of the New Mexico Tumor Registry

# Data Collection

Data are collected from a variety of sources including medical records, pathology reports, death certificates, and more.

- Patient Characteristics  
Ex., name, sex, date of birth, race/ethnicity
- Tumor Characteristics  
Ex., histology, behavior, grade, primary site, stage of disease at diagnosis, date of diagnosis, place of residence (at diagnosis and current)
- Treatment Summary (First Course of Cancer-Directed Therapy)  
Ex., treatment modality, date treatment initiated, facility, physician
- Outcome  
Ex., vital status, date of last information, cause of death for deceased individuals

# Research and Data Use

- Analyzes the data and generates reports
- Collaborates with researchers at UNM, as well as with regional, national and international researchers
- Cancer control and prevention efforts with the New Mexico Department of Health and patient advocacy groups
- Provides educational opportunities for UNM students, faculty, and others



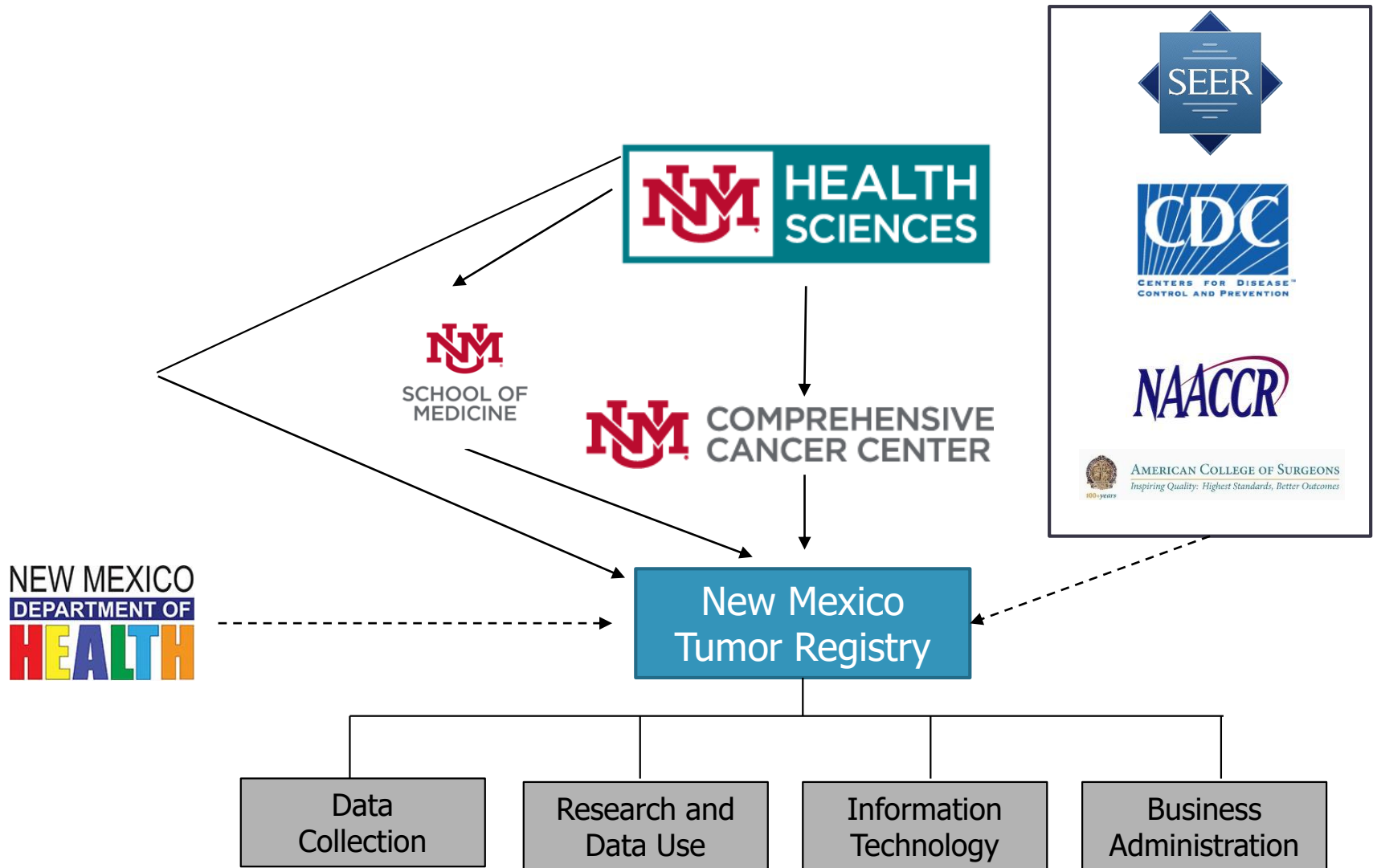
# Information Technology

- Provides technical assistance and support
- Manages and exchanges electronic data
- Creates and maintains databases
- Ensures data/network security and safety

# Business Administration

- Manages the daily financial activities
- Prepares and monitors the budget
- Administers human resources activities
- Develops and implements business policies and procedures

# A Very Basic Organizational Chart





# UNM Health Sciences Center

- Our host institution
- Comprehensive Cancer Center
- School of Medicine, Department of Internal Medicine, Division of Epidemiology, Biostatistics, and Preventive Medicine
- Human Research Review Committees/Human Research Protections Office
- Research collaborations
- Mentorship



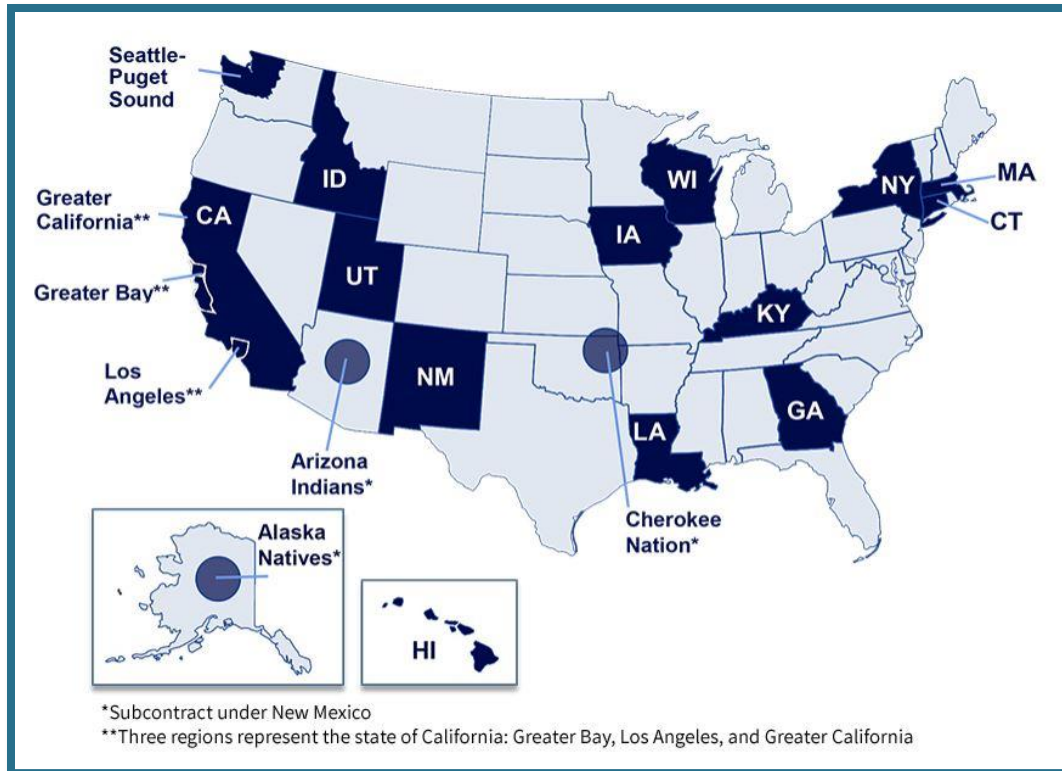
# UNM HSC is HIPAA Hybrid Covered Entity

- *"A covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law."*
- Health Insurance Portability and Accountability Act of 1996  
*Privacy and security provisions for safeguarding medical information*
- Public Health Surveillance is allowed under HIPAA  
*§ 164.512 Uses and disclosures for which consent, an authorization or opportunity to agree or object is not required*
- **NMTR is excluded from the UNM-HSC HIPAA Hybrid Covered Entity... except when we use the data for research purposes**

# New Mexico Department of Health



- NMTR is the NMDOH's designee for conducting public health surveillance of cancer
- Cancer is a reportable disease in New Mexico. A reportable disease must be:
  - Considered a risk to the public health
  - Monitored to assist in prevention and control
  - Designated and enforced by state government
  - Funded and administered by local, state, and federal agencies
- Collection of cancer data is mandated under state law (New Mexico Administrative Code: Title 7; Chapter 4; Part 3)
- Work together for cancer prevention and control efforts



- Provides information on cancer statistics in an effort to reduce the cancer burden among the U.S. population
- Funding agency of the NMTR

# Important Things to Remember

- Our work is conducted in accordance with prevailing legal and ethical standards
- Everything we do is governed by well-established policies and procedures
- Any uses of our data must outweigh risks
- We **must** protect:
  - Individuals
  - Institutions, e.g., Health Care Providers
  - Sovereign Tribal Governments

“Purification through use.”  
– Dr. Charlie Key



**Questions?**



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NEW MEXICO TUMOR REGISTRY

# Thank You!

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