National Cancer Database

* Access approval process
  + Must be from a CoC accredited program
    - Data use agreement, terms
    - Letter of support from CoC accredited program
    - Application
  + When ACDB was established any hospital could voluntarily report data to the NCDB.
  + In 1996, all CoC-approved hospitals were required to report cancer cases to the NCDB, and in 2001, participation and the associated advantages of reporting to the NCDB were limited to hospitals who had earned CoC approval.
* Need for specialized software
  + Data exists in PUFs (Participant User Files)
    - HIPPA compliant data file
  + Statistical analysis software
    - SAS, SPSS,Strata,SPLUS,Other
* Granularity of publicly accessible data
  + Walled Data
    - Full dataset contains data on 21 million cancer patients diagnosed between 1985 and 2005
    - Data from 1,430 hospitals
  + Publicly accessible data includes benchmark reports
    - 14 most commonly diagnosed solid tumors in United States
    - Users are provided access to data from ten diagnosis years (2008-2017)
    - Slightly more than 11 million cases
* Institutional goals & governing bodies (How does this impact the availability of the data?)
  + CoC oversees ACDB and is a multidisciplinary consortium of professional organizations that strive to improve cancer care through setting standards, prevention, research, education, and the monitoring of comprehensive cancer care. The CoC also accredits hospitals as cancer centers based on their ability to provide a broad range of cancer-related services and specialists.
  + NCDB was started in 1989 by American College of Surgeons and the commission on cancer.
  + Goal of striving to improve cancer care through setting standards, prevention, research, education, and the monitoring of comprehensive cancer care
  + NCDB is housed at ACoS headquarters.
* Data analysis of selected cancers or cancer variables
  + Mostly descriptive data, raw form
  + Quality-of-care reports
  + Users of the data have:
    - Examined surgical and adjuvant therapy treatment trends
    - Studies of rare cancers (i.e., pancreatic neuroendocrine tumors)
    - Subset analyses (i.e., stage I pancreatic cancer patients undergoing resection)
  + Studies using NCDB data have addressed important clinical questions in areas where clinical trials may be challenging.

Surveillance, Epidemiology, and End Results

* Access approval process
  + Institutional users can access after completing the following steps:
    - Complete registration form with initial required agreements
    - Provide signing official
    - Acquire SEER\*Stat username
* Need for specialized software
  + SEER\*Stat statistical software
* Granularity of publicly accessible data
  + SEER cancer incidence and survival data originate from population-based cancer registries covering approximately 34.6% of the population in the United States.
  + SEER\*Explorer application provides interface between user and data
    - This is accomplished with SEER\*Explorer application
    - Application is web based and operates in browser and connected to SEER database.
  + Data is updated annually and available as a public service in print and electronic formats.
* Institutional goals & governing bodies (How does this impact the availability of the data?)
  + SEER is an authoritative source for cancer statistics in the United States
  + Provides information on cancer statistics in an effort to reduce the cancer burden among the U.S population.
  + SEER is supported by the Surveillance Research Program in NCI’s Division of Cancer Control and Population Sciences (DCCPS).
  + Data is freely accessible via a web browser.
* Data analysis of selected cancers or cancer variables
  + SEER program registries routinely collect data on patient demographics, primary tumor site, tumor morphology and stage at diagnosis, first course of treatment, and follow-up for vital status.
  + The population data used in calculating cancer rates is obtained periodically from the Census Bureau.
  + Quality control has been an integral part of SEER since its inception. Every year, studies are conducted in SEER areas to evaluate the quality and completeness of the data being reported.