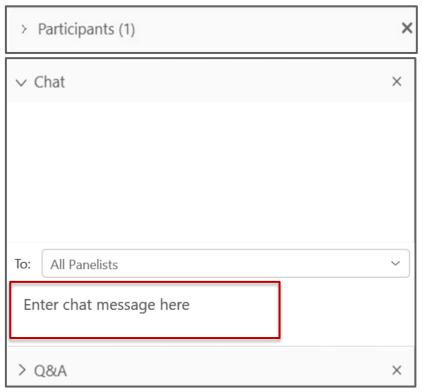
Introduction to Publicly Available Resources for Cancer Prevention and Control Research

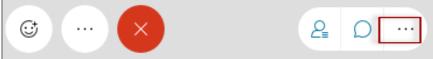
Presentation for T-32 Fellows
Richard P. Moser, PhD
Karen Emmons, PhD



Using WebEx and Webinar Logistics



- All lines will be in listen-only mode
- Submit comments at any time using the
 Q&A feature and select All Panelists
- You may need to activate the appropriate panel using the menu option found at the bottom of your screen



This webinar is being recorded

Webinar Series Organizers



Richard P. Moser, Ph.D.

Training Director and Research Methods Coordinator NCI Division of Cancer Control and Population Sciences



Karen Emmons, Ph.D.

Professor Social and Behavioral Sciences Harvard T.H. Chan School of Public Health

Welcome!

Purpose:

- To introduce publicly available data resources that are relevant to cancer prevention and control
- To help fellows consider use of these resources to answer new and innovative questions that fall within NCI priorities



Tools for Cancer Research

- Expand skills
- Enhance career opportunities
- Caveats
 - Not meant to be comprehensive
- Interactive: your input needed



"Give me six hours to chop down a tree and I will spend the first four sharpening the axe."

Abraham Lincoln

Agenda

Note: We'll stop after each section for Q & A and input from attendees

- 1. Using Secondary Health Data
- 2. Broad, Population-Level Data
- 3. Youth-Focused Data
- 4. Cancer-Focused Data
- 5. Data Collection Tools
- Research Methods/Data analysis Tools
- 7. Data Visualization Tools
- 8. Other Resources

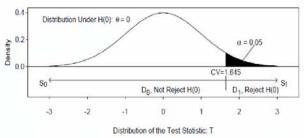


Using Secondary Health Data

- Hypothesis generation/testing
- Publications
 - Check on websites/Pubmed for current publications
- Strengths:
 - Large samples
 - Many different constructs
 - Population estimates (national, census regions; possibly state/county/census tract)
 - Testing trends over time (where possible)
 - Used for data linkages

- Limitations:
 - Non-experimental
 - Constructs measured by fewer items
 - May require special statistical software/methods/permission
 - Sensitive information
 - Geocodes
 - Accounting for complex samples







Broad, Population-Level Data

National Health Interview Survey

https://www.cdc.gov/nchs/nhis/index.htm

Population

Households, families, adults and children

Method

Face to face interview

Content

Health conditions and behaviors, access to and use of health services

Physical activity, smoking, alcohol use

Cancer supplements

-Screening in 2021, 2023...

-Physical activity environment in 2020, 2024...

CAM

Immunization/vaccination usage

Tobacco and E-cig Use

Food Security

Data

n~40,000 households (~87,000 individuals)

Initiated in 1957

Note

To see list of core/rotating/supplements: https://healthcaredelivery.cancer.gov/nhis/

New: Interactive data query system



National Health and Nutrition Examination Survey (NHANES)

Population

Children and Adults

Method

Face to face interview

Physical exams

Content

Chronic and Infectious Disease Prevalence

Mental health and cognitive functioning

Energy Balance

Respiratory disease

Anthropometry

Biospecimens (DNA, serum, plasma, urine)

Data

N~5,000/Year

Initiated in 1960's; Annual since 1999

2017-2020 latest available data

On-line tutorial

Note

Supplemental food survey available: What We Eat in America



Centers for Disease Control and Prevention National Center for Health Statistics







Population

Adults (18+)

Method

Random Digit Dial telephone survey State Administration

Content

Behaviors associated with chronic diseases, injuries, and infectious diseases

Sexual behavior

Smoking

Cancer screening

Diet and exercise

Data

>400,000 subjects/year

Core questions asked of everyone and state-specific modules

Data can be combined across states to get national estimates

Includes D.C., Puerto Rico, U.S. Virgin Islands, Guam

2019 are latest available data; maps also available

Notes

SMART BRFSS—city-level and surrounding counties estimates

American Time Use Survey



Population

Adolescents/adults 15 and older

Method

Self report telephone interview using 24 hour recall

Content

Estimates of activities people do (work, childcare, socializing, exercising, eating, educational, sports and religious activities), whom they were with, and the time spent doing them by sex, age, educational attainment, labor force status, and other characteristics, as well as by weekday and weekend day.

Eating and health module.

Data

n ~ 13,000 per year

Data currently available: 2003-2019

Note

Data files can be linked to Current Population Survey (CPS)





The Tobacco Use Supplement to the Current Population Survey

Population - Adolescents/adults 15+ 1992-06; 18+ 2007-

Method – National HH address-based frame, 8 panels

Conducted every 3-4 years by Census for NCI

64% telephone (allows cell phone if preferred); 36% in-home

Translated into Spanish and 4 Asian languages

Content: Monitor, evaluate and conduct research on Cigarette & other tobacco product usage patterns;

Cessation- attempts, intentions, & treatment

Policy- work, home, "real" price, attitudes & clinician advice

Data: ~240,000 U.S. respondents per cycle; 2018-2019 are latest data;

Notes:

National, state, sub-state estimates;

Health disparities (e.g. race/ethnicity; low SES, rural)

Economic aspects with CPS detailed occupational, & health disability data

Panel design links to other CPS data (e.g., ASEC, ATUS, Food Security, Internet Use)

Panel design allows for adding prospective Follow-Up (2002-03, 2010-2011)

Linkage to outcome data (mortality and SEER data) through NLMS



Population

Non-Institutionalized US Adults (18+)

Method

2003, 2005: Random digit dial (RDD)

2008: Dual frame/dual mode

HINTS 4-5: Self-administered mail survey

HINTS 5 Cycle 3: Mixed mode

Data

14 Iterations (2003-2020)

HINTS 5 Cycle 4 data released Jan 2021

HINTS FDA 1 & 2

NIH NATIONAL CANCER INSTITUTE

https://hints.cancer.gov/

Content

Health communications trends and practices

Cancer information access and usage

Cancer risk perception

Mental models of cancer

Health behaviors

Caregiving

Note

Web pilot study done with HINTS 5 Cycle 3 (2019)

Tutorial on website

Medical Expenditure Panel Survey



Population

Nationally representative household survey, with additional follow-up of their medical providers (doctors, hospitals, etc.), and separate survey of employers across the United States about health insurance

Household Survey Method

Five in-person interviews

Content

Demographics, health status

Employment, insurance coverage and access to care

Health care utilization and expenditures

Data

Subset of NHIS with N= ~40,000/survey

New cohort initiated annually

Note

Has overlapping panel component

Latest data from 2019; ongoing data release schedule (see website for schedule)





AllofUs Research Hub

Population

Goal of a cohort of 1 million (50% from ethnic/racial minority groups)

Method

From electronic health records (EHRs), biospecimens, surveys, and other measures

Content

Environment: drug exposure; medical utilization

Lifestyle: tobacco, alcohol, drugs

Biology: sodium, glucose, medical history

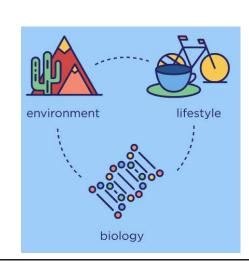
Genomic sequence data

Data

Includes physical measures; biological samples; wearables data

Note





https://www.researchallofus.org/

California Health Interview Survey

Population

Adult, adolescent and child questionnaires Very diverse racial/ethnic population





Method

Telephone survey (landline/cell phone) of all California counties; moving to mixed mode (web and telephone) for 2019

Content

Health behaviors (Diet/drug use/sexual/sun safety)

Health status

Health conditions (asthma, diabetes etc.)

Cancer history and prevention

Health insurance

Data

Latest data available is for 2018 ~20,000 respondents/survey

http://healthpolicy.ucla.edu/chis/Pages/default.aspx

Note

Many Latino and Asian groups represented; oversamples of Koreans and Vietnamese Fielded in five languages: English, Spanish, Chinese, Vietnamese, and Korean Restricted geo-coded data available



Canadian Community Health Survey (CCHS)



Population

Children (12+) to adults

Coverage: 98% in the provinces; in Territories: 92% in the Yukon, 96% in the

Northwest Territories and 92% in Nunavut

Method

50% in-person; 50% telephone interviews

Content

Disability, Diseases and health conditions

Factors influencing health; Injuries

Health services performance and utilization

Mental health and well-being

Prevention and detection of disease

Data

n= ~120,000; 2001, 2003, and 2005 collected biennially 2007 onward collected annually; sampling frame changed in 2015

Note

2019 latest data available

https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3226



Canadian Health Measures Survey (CHMS)



Population

Ages 6-79

Covers ~ 97% of Canadians

Method

In-person interviews and physical exams

Content

Nutrition, smoking habits, alcohol use, medical history, current health status, sexual behavior, lifestyle and physical activity, the environment and housing characteristics, socioeconomic variables

Blood measures; urine measures, accelerometry, nutrition;

Obesity, hypertension, cardiovascular disease;

Data

n= ~5,000; launched in 2007; biennial

Note

Latest data from 2019



Youth-Focused Data

Youth Risk Behavior Surveillance System (YRBSS)

Population

9th-12th grade students

Method

National, state, tribal, special populations Biennial, school-based and local surveys

Content

Behaviors that contribute to unintentional injuries and violence

Sexual behaviors; STDs, HIV

Alcohol and other drug use

Tobacco use

Dietary behaviors

Physical activity



https://www.cdc.gov/healthyyouth/data/yrbs/index.htm

Data

~12,000-16,000 respondents per survey

Note

Data collected since 1991

Most recent data from 2019 (released August, 2020)

National Survey on Drug Use and Health



Population

12 and older

Method

In-person interview



Use of tobacco products, alcohol, illicit drugs by friends and self; treatment for substance abuse and mental health disorders; perceived risk of drug use; health care access and coverage

Data

N= ~70,000/year Conducted annually

Note

National and state-level data

Began in 1971; 2019 most recent data

Data available through ICPSR



Monitoring the Future

Population

8th, 10th and 12th grade students

Method

Multi-stage area probability sample;

On-site questionnaires completed at school; follow-up with subset of subjects

Content

Drug (prescription, illicit, OTC), tobacco, alcohol, steroid use, vaping; alcohol availability; risk perceptions of drug use; HIV/AIDS

Data

N= ~50,000/year from public and private schools

Note

Data available through ICPSR

Core and topical questions

Started in 1975; 2019 most recent data



a continuing study of American youth



Population

Adolescents (grades 7 thru 12) from 80 High Schools and 52 Middle Schools; started in 1994-95, follow-up in 2008 (ages: 24-32) and 2016-2018;

Method

In-school questionnaire and in-person interview

Content

Health conditions and behaviors; access to and use of health services; social, psychological and physical well-being; risk behaviors; biospecimen collection

Data

 $N = \sim 6.504$

Note

Follow-up data available in waves; most recent from 2016-2018 Data now managed by ICPSR





Classification of Laws Associated with School Students

RESEARCHERS go to CLASS to:

Download data to analyze school dietand physical activity-related laws.

Use the data to:Examine laws within and across grade levels.

- •Link the data with other surveillance, health, and education data sets.
- •Track changes in laws over time.
- •Evaluate factors associated with implementation of laws.

POLICYMAKERS go to CLASS to:

•Monitor how state PE and nutrition policies compare to other states using the map and state report functions.

Use the data

to:Examine whether states are meeting the most current standards and recommendations for PE and nutrition.

•Evaluate how state laws compare to other states.

SCHOOL BOARDS, TEACHERS, AND THE PUBLIC go to CLASS to:

•Examine how local policies compare to state laws.

Use the data to: Examine laws within and across grade levels.

https://class.cancer.gov/

Policy Areas Covered In CLASS Include:

Physical Education (11 across grade levels)

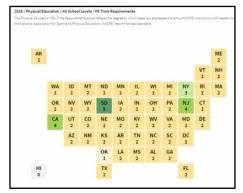
- PE class time and curriculum standards
- · PE teacher and staffing requirements
- Proficiency requirements
- Physical activity time requirements
- · Moderate-to-vigorous activity in PE
- Assessment of health-related fitness
- · Recess time
- Joint-use agreement provisions

Nutrition (19 across grade levels)

- Competitive food and beverage standards
- School meal environment and reimbursable meals
- · Potable water and nutrition education requirements
- Food service director qualifications
- · Coordinating or advisory council requirements
- · Farm-to-School provisions and marketing restrictions
- Body mass index screening
- Provisions around parties, events, and fundraisers

Data and maps

 Latest data from 2019







Population

Dyads of caregivers and their adolescent children (12-17) between Apr-Oct 2014

Method

Surveys; subset wore accelerometer and completed activity log

Content

Diet-related and Physical Activity related behaviors

Behavioral Correlates (sun-safety, tobacco, sleep)

Community/neighborhood/home environment

Data

N=1,479 dyads

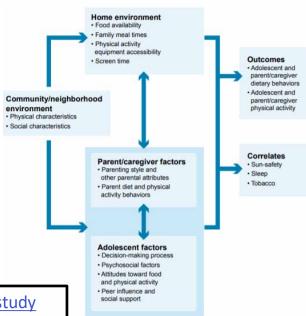
Note

Geodata available with neighborhood characteristics;

restricted access

NATIONAL CANCER INSTITUTE

https://cancercontrol.cancer.gov/brp/hbrb/flashe-study



Cancer-Focused Data



NATIONAL CANCER INSTITUTE

Surveillance, Epidemiology, and End Results Program

Population

Children to adults

Method

Data collected from cancer registries that cover ~50% of the US population; follow-up with individual cases until death



Content

Cancer incidence, prevalence, and survival data; cancer site, stage, morphology, treatment; limited demographics (age, race/ethnicity, marital status, region)

Data

100% of cancer cases in registries (16); Six million cases with 550,000 added each year; 1973 to 2018;

Note

Need specialized software to analyze (SEER*Stat or SEER*Prep) downloaded from website;

Must sign user agreement to obtain; limited to research purposes

SEER linked to Medicare, Medicare Health Outcomes, CAHPS





PATH: Population Assessment of Tobacco and Health



Population

Household-based, nationally representative, longitudinal cohort study of adults and youth

Method

In-person interview with additional study activities

Content

Self-report

Biomarker data files

Biospecimens (urine, serum, plasma, genomic DNA)

Data

n~46,000 in wave 1; up to wave 4 of data collection (n=52,731) biomarker data not available for all

Note

Started in 2013

Must request access to data and outline proposed project



Interactive Diet and Activity Tracking in AARP (IDATA)

Population

Adults aged 50-74

Method

Survey and biomarkers Self-report and wearables



Content

Physical activity self-report, physical activity objective monitors, diet, participant characteristics, biomarkers

Data

n=1082; participants assigned to 1 group (of 4) and followed a specified 12 month assessment protocol (2012-2013)

Note

All participants wore accelerometers

Must request access to data and outline proposed project through Cancer Data

Access System (CDAS)

https://cdas.cancer.gov/idata/

NIH-AARP Diet and Health Study



Population

50-71 adult members of AARP 1995-1996; 2004

Method

Mailed questionnaires; follow-up occurred in 2004

Content

Dietary behaviors

Lifestyle Questions

Risk Factors

Cancer and health status

Data

n~566,000 for baseline questionnaire; n~327,000 for risk factor questionnaire

Note

Must propose potential project





https://dietandhealth.cancer.gov/

Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial

Population

Adults aged 55-74

Method

Population-based randomized trial design

Content

Determine effects of screening on cancer-related mortality and secondary endpoints in men and women

Biologic materials

Risk factor information

Data

n=78,234 women n=76,704 men

Note

Initial data collected in 2006; additional data collected through 2015

Must request access to data and outline proposed project through Cancer Data

Access System (CDAS)



https://cdas.cancer.gov/plco/

CANCER SCREENING TRIAL

National Lung Screening Trial

Population

Adults aged 55-74; current or former heavy smokers

Method

Screening trial

Compared two types of detection: 1) CT; 2) X-ray;

Content

Mortality

Risk

Smoking status and behaviors

Data

n=53,454

August 2002 to April 2004

Note

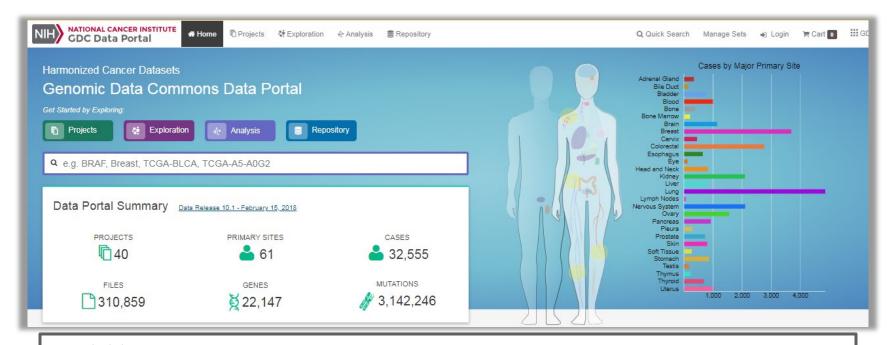
Must request access to data and outline proposed project

https://cdas.cancer.gov/nlst/



Data Search/Repositories

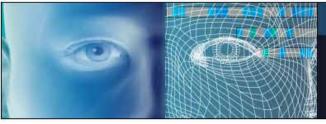
Genomic Data Commons



Available:

The Cancer Genome Atlas (TCGA)

Therapeutically Applicable Research to Generate Effective Treatments (TARGET)



dbGaP

The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the data and results from studies that have investigated the interaction of genotype and phenotype in Humans.

Purpose

For accessing individual-level phenotype, exposure, genotype, and sequence data, and the associations between them. dbGaP assigns stable, unique identifiers to studies and subsets of information from those studies, including documents, individual phenotypic variables, tables of trait data, sets of genotype data, computed phenotype-genotype associations and groups of study subjects who have given similar consents for use of their data.

Collections

Individual level genomic data

Autism-omics studies

Open translational science in Schizophrenia (OPTICS)

Note

Data access request necessary Includes data browser



HealthData.gov



Purpose

Makes high value health data more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all

Data Sources

CMS, CDC, FDA, NIH (4,523 datasets)

Dataset Types

Health, State, National, Medicare, Hospital, Quality, Community, Inpatient

Note

Feedback webpage has answers to common questions Includes blog posts

https://www.healthdata.gov/

National Collaborative on Childhood Obesity Research

- Catalogue of Surveillance Systems
 - 100 public data sets
 - Related to childhood obesity research
- Health behaviors, outcomes, and determinants
- Policies and environmental factors
- Measure registry



CEDCD Cancer Epidemiology Descriptive Cohort Database

- CEDCD gives info about cohort studies that follow groups of persons over time for cancer incidence, mortality, and other health outcomes
- Searchable database with general study info
- No individual level data; cohort data only
- Can search for enrollment counts, cancer counts, and biospecimen counts
- 46 cohorts representing over 6.5 million people







Purpose

An international consortium of more than 750 academic institutions and research organizations, Inter-university Consortium for Political and Social Research (ICPSR) provides leadership and training in data access, curation, and methods of analysis for the social science research community

Data Sources

Data archive of more than 250,000 files of research in the social and behavioral sciences. It hosts 21 specialized collections of data in education, aging, criminal justice, substance abuse, terrorism, and other fields

Access

https://www.icpsr.umich.edu/icpsrweb/

Note

Can see collection of articles, books, reports, and other materials that have used ICPSR data

https://www.icpsr.umich.edu/web/pages/

Purpose

Provides maps, data, reports and dashboard to the public. The data integrates with external sources, such as the U.S. Census Bureau, providing information about HRSA's grants, loan and scholarship programs, health centers and other public health programs and services

Data Sources

The HDW manages data from more than 30 HRSA and other federal government

sources

Content

Health centers
Health workforce
Healthcare systems
Rural health



Note

National/State/County-level data Area Health Resource files, latest data 2020

https://data.hrsa.gov/

NIH Data Sharing Repositories

Open Domain-Specific Data Sharing Repositories:

https://www.nlm.nih.gov/NIHbmic/domain specific repositories.html

Including:

- Genomic data commons
- Proteomic data commons

Other NIH Data Resources:

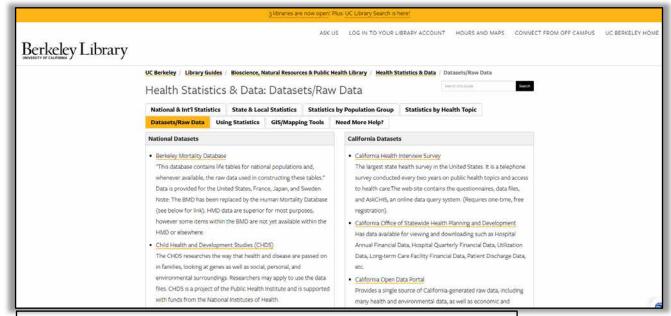
https://www.nlm.nih.gov/NIHbmic/other data resources.html

Including:

- Science of Behavior Change (SOBC) repository
- The Cancer Target Discovery and Development (CTD2) Network Data Portal

UC Berkeley Library





Links to datasets:

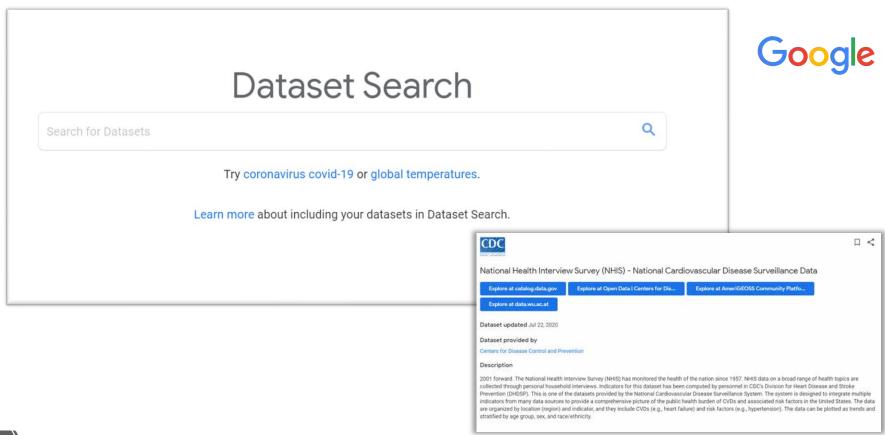
- National
- California-based
- International

Note: Also contains links to statistical and GIS-related resources

https://guides.lib.berkeley.edu/publichealth/healthstatistics/rawdata

Google Dataset Search

https://datasetsearch.research.google.com/



re3data.org: Registry of Repositories



 Can search by keyword or browse repositories by subject, content type, or country



Data Collection Tools

Crowd-Sourced Research Participants

- Online labor market
- Primary data collection
- Fast and relatively cheap
- Large samples
- Can randomize respondents
- Longitudinal designs
- Representativeness may be concern
- Examples:
 - Mechanical Turk (Mturk)





https://www.mturk.com/



https://www.prolific.co/

- Multiple uses:
- Image processing
- Data verification/clean-up
- Surveys....

On-line Panels/Survey Tools

- Oftentimes used for marketing
- Dedicated, paid users
- Primary data collection
 - Provides sample and/or
 - Data collection tool
- Survey work
 - Probability and non-probability based
- Representativeness may be concern
- Comparison studies done















Research Methods/Data Analysis Tools

Example Statistical Trainings





Free e-learning to get you started

- · Free how-to SAS tutorials
- SAS Programming 1
- · Statistics 1
- · SAS Programming for R Users
- · SAS Platform Administration: Getting Started
- SAS Viya Enablement

Start Now

Start Now

Start Now

Start Now

Start Now

https://www.sas.com/en_us/learn/academic-programs/resources/free-sas-e-learning.html



https://statisticalhorizons.com/

Machine Learning

Remote Seminar Kevin Grimm, Instructor August 11-14

Sold Out

Structural Equation Modeling:

Part I

Remote Seminar
Paul Allison, Instructor
August 11-14

Sold Out

Mediation, Moderation, and Conditional Process Analysis: A Second Course On Demand

Andrew Hayes, Instructor August 24-September 21

Propensity Score Analysis

Remote Seminar Shenyang Guo, Instructor September 10-12

Multilevel and Mixed Models Using Stata

Remote Seminar Stephen Vaisey, Instructor September 24-26

Latent Growth Curve Modeling

Remote Seminar

Gregory Hancock, Instructor

October 1-3

Introduction to Python for Data Analysis*

Remote Seminar

Jason Anastasopoulos, Instructor October 1-3

Analysis of Complex Survey Data

Remote Seminar
Ann O'Connell, Instructor
October 8-10

Meta-Analysis

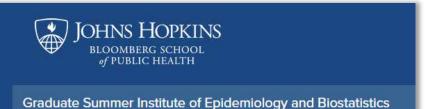
Note: Fee based

Stats/Research Methods Trainings



Center for Research Methods & Data Analysis CRMDA

http://crmdaclone.drupal.ku.edu/



https://www.jhsph.edu/departments/epidemiology/continuing-education/graduate-summer-instituteof-epidemiology-and-biostatistics/index.html



The Methodology Center

advancing methods, improving health

https://methodology.psu.edu/





https://www.khanacademy.org/



https://datic.uconn.edu/



Analytic Support



Institute for Digital Research & Education Statistical Consulting

https://stats.idre.ucla.edu/

- Statistical software:
 - Syntax
 - Output
- Choosing the correct statistical test
- Trainings



DATA ANALYSIS EXAMPLES					
	Stata	SAS	SPSS	Mplus	R
Regression Models					
Robust Regression	<u>Stata</u>	SAS			<u>R</u>
Models for Binary and Categorical Outcomes					
Logistic Regression	Stata	SAS	<u>SPSS</u>	Mplus	<u>R</u>

Data Visualization Tools

The State Cancer Profiles Website



- A collaborative effort between NCI and CDC
- Part of Cancer Control P.L.A.N.E.T.
- Cancer-related incidence, prevalence and mortality
- Risk behaviors
- County and/or state-level

Slides provided by Zaria Tatalovich

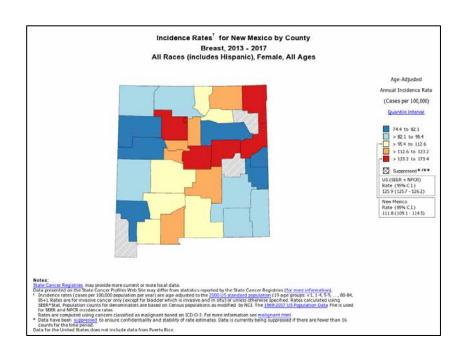
https://StateCancerProfiles.cancer.gov/

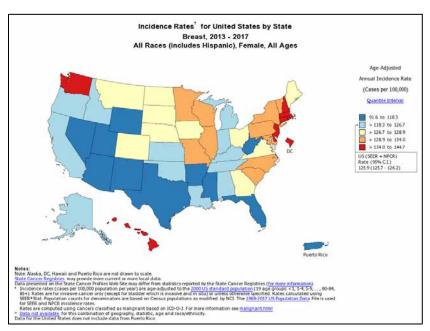


Available Presentation Types by Data Topic

	Demographics	Screening and Risk Factors	Cancer Knowledge	Incidence	Prevalence	Mortality
Interactive maps	₩(•	-	-		•
Tables						
Historical trends				**		**
5-year rate changes				72		7.
Rate-trend comparison by cancer						14
Rate-trend comparison by area						1

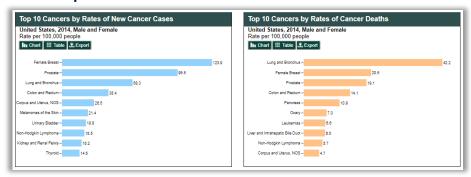
Breast Cancer Incidence in New Mexico and US by State





CDC: U.S. Cancer Statistics: Data and Data Visualizations

- Uses SEER and CDC cancer registry data that covers 100% of population
- 31 million cases (2001-2018)
- Can download data
- State/county statistics
- Incidence/prevalence/mortality
- Explore trends



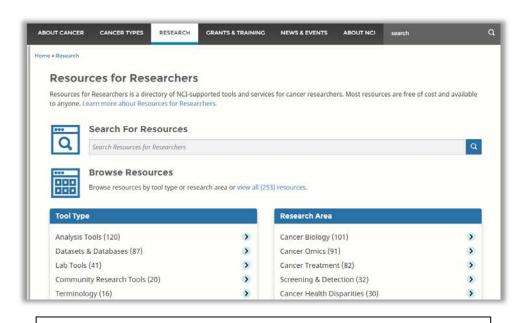
https://www.cdc.gov/cancer/uscs/index.htm



Other Resources

NCI Resources for Researchers

- Directory of NCI-supported tools and services for cancer researchers.
- Data, terminologies, analysis tools, including:
 - Genomic data commons
 - HINTS
 - NCI Meta-thesaurus
- Most are free



https://www.cancer.gov/research/resources

Bibliographies for Selected Datasets

- NHIS
 - https://www.cdc.gov/nchs/nhis/nhis_bibliography.htm
- NHANES
 - https://www.cdc.gov/nchs/products/databriefs.htm?program=nhanes
- TUS-CPS
 - https://cancercontrol.cancer.gov/brp/tcrb/tus-cps/publications-database
- SEER
 - https://seer.cancer.gov/publications/

Upcoming Webinars

 Deep Dive into Available Data Resources for Specific Cancer Prevention and Control Topics – Part 1

```
December 9, 2021
1:00 – 3:00 p.m. ET
```

 Deep Dive into Available Data Resources for Specific Cancer Prevention and Control Topics – Part 2

```
January 12, 2022
3:00 – 5:00 p.m. ET
```

Webinar recordings will be available 3-4 weeks after the event:



www.cancer.gov/espanol