DCCPS Research Resources

New Grantee Workshop Moderator: David Dean Jr.

> Richard Moser Laura Dwyer Margaret Mayer Janet de Moor Jennifer Croswell Kathy Cronin

> > October 31, 2023





Bringing Health Communication Data to Life

The Health Information National Trends Survey (HINTS)

Presentation at the New Grantee Workshop

Richard P. Moser, PhD Senior Methodologist, Health Information National Trends Survey **Behavioral Research Program** Training Director, DCCPS October 31, 2023

https://hints.cancer.gov/



NATIONAL CANCER INSTITUTE **Division of Cancer Control Population Sciences**

hints.cancer.gov

Cancer Communication: An Extraordinary Opportunity (2001 - 2003)

- A workshop on cancer risk communication, held in 1998, became the basis of a JNCI Monograph published in 1999 ("Cancer Risk Communication: What We Know and What We Need To Learn")
- Following this workshop and monograph, **cancer communication** was identified as an "Extraordinary Opportunity" in NCI's by-pass budget in 2001, 2002, and 2003. This led to the creation of the Health Communication and Informatics Research Branch, which remains the only health communication-focused branch at NIH



The Nation's Investment in Cancer Research

A Budget Proposal for Fiscal Year 2001



Cancer Research A Plan and Budget Proposal for Fiscal Year 2002



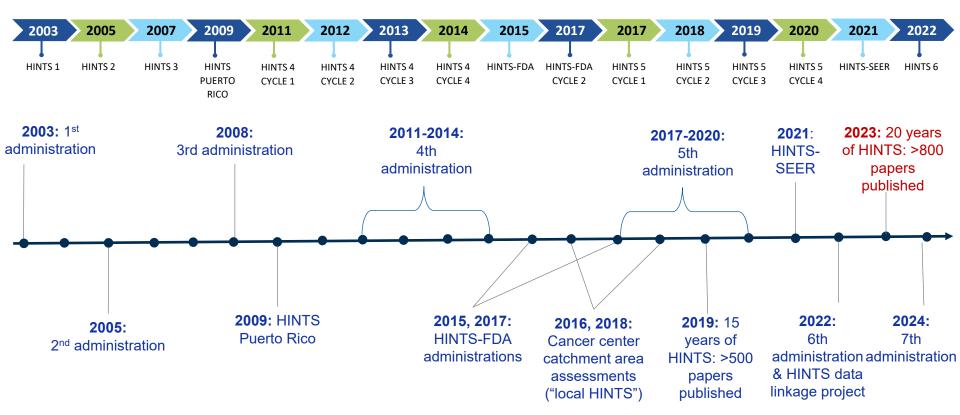
The Nation's Investment in Cancer Research A Plan and Budget Proposal for Fiscal Year 2003

"...there is a need for a public institution such as NCI to provide leadership in the cancer communications arena; the broad and reasoned perspective that NCI brings to patients and healthcare providers alike is essential to successfully implement communication strategies to reduce the cancer burden." (2001)

Timeline



HINTS: One of NCI's longest running surveys





Nationally Representative

- Cross-sectional; random, probability-based sample of US postal addresses
- US civilian, non-institutionalized adults (18+)

Core Communication Content

- Health information seeking
- Technology use (Internet, mobile apps, EHRs, PHRs)
- Trust in health information sources

Oversample of African Americans and Hispanics and (new from 2022 forward) rural Zip codes

- Patient-provider communication
- · Health-related knowledge, attitudes, behaviors

Data Collection

- Biennial from 2003 to 2009; Annual from 2011-2020
- Biennial from 2022 (HINTS 6) forward

- Mixed-mode (paper and web)
- Fielded 16 times since 2003, surveying more than 63,000 U.S. adults





Latest HINTS Data Resources

- HINTS Data Linkage Project (HDLP; 2020)*
- HINTS-SEER (2021)*
- HINTS 6 (2022)
 - * **Restricted use files—need to make request:** https://hints.cancer.gov/data/restricted-data.aspx











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Bringing Health Communication Data to Life

Thanks!

Richard (Rick) P. Moser moserr@mail.nih.gov



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Frank M. Perna, Ed.D., Ph.D. Program Director, Behavioral Research Program

Laura Dwyer, Ph.D.

Scientific Program Manager, Cape Fox Facilities Services / Behavioral Research Program



Learn about CLASS at class.cancer.gov

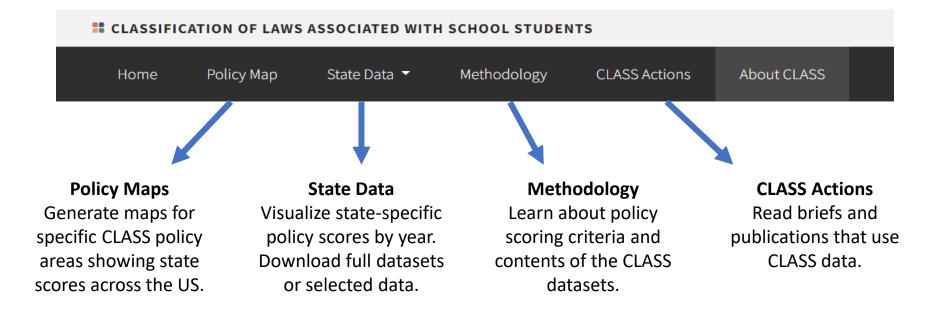
The Classification of Laws Associated with School Students (CLASS) is a scoring system that monitors, classifies, and evaluates school policies that have been codified into law across the United States:

- Physical education
- Nutrition
- Vaccination
- Sun safety

CLASS codes **state laws** as they compare to national standards and recommendations. Data are currently available for 2003-2021.

CLASS scores for state laws are available at elementary, middle, and high school levels and as a summary score.

CLASS Resources



Visualization Tools

Maps are available for all policy areas. Examples:

Physical Education

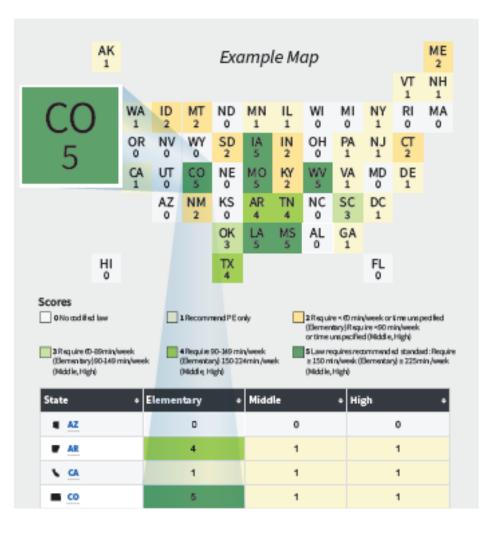
- Recess time
- PE class standards
- Adapted PE

Nutrition

- Competitive foods
- School meal environment
- Classroom parties and events

Other Policies

- Sun safety
- School vaccinations
- Coordinated school health

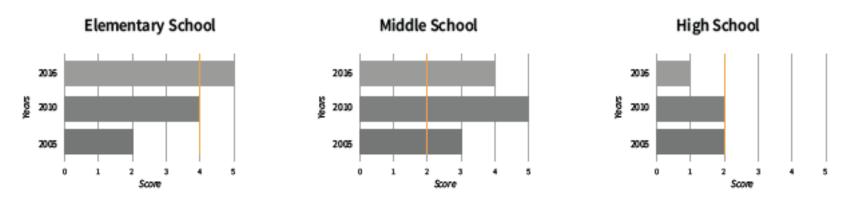


State Profiles Tool

The profiles tool allows users to create state-specific reports by year, with each report containing charts for all policy areas in PE and nutrition. Each chart indicates state scores across each grade level for a specific policy area and compares scores to the national median. Data can be printed, downloaded, or used for presentations.

Example State Charts

Grey bars show a selected state's policy score by school type. Yellow lines represent the national median* for that particular policy area.



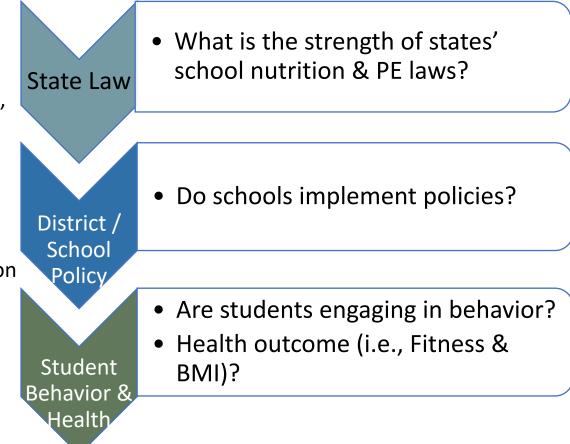
*Half the states receive a score above the median and the other half receive a score below the median.

Data & Methodology

Download full datasets (SPSS, Excel, Stata) or selected data to analyze school laws related to nutrition, physical activity, and health.

For example:

- <u>Link the data</u> with other surveillance, health, and education data sets
- Track changes in laws over time
- Evaluate factors associated with implementation of laws



Don't Miss CLASS!

CLASS.CANCER.GOV

For general CLASS inquiries and PErelated funding inquiries, contact:



Frank M. Perna, Ed.D., Ph.D. Program Director and Health Psychologist Health Behaviors Research Branch Behavioral Research Program pernafm@mail.nih.gov

For nutrition-related funding inquiries, contact:



Tanya Agurs-Collins, Ph.D., R.D. Program Director and Nutritionist Health Behaviors Research Branch Behavioral Research Program collinsta@mail.nih.gov

All About TUS-CPS

Margaret Mayer, PhD, MPH NCI, DCCPS, Tobacco Control Research Branch

October 31, 2023





TUS-CPS At-a-Glance

TUS-CPS is the largest nationally representative survey of tobacco use among US adults. It is available in two forms:

| | Single Survey Waves | Harmonized Dataset |
|-------------------|--|--|
| Content | Collects extensive data on tobacco use, including information on current use, history of use, flavors, cessation, prices, policies, and attitudes | TUS-CPS variables consistent across two or more survey waves |
| Size | Approx. 150,000 self-respondents per wave (on average); 210,000 with proxy responses | 1,730,884 self-respondents |
| Timing | Every 3-4 years; 1992-1993, 1995-1996, 1998- 1999, 2000, 2001-2002, 2003, 2006-2007, 2010-2011, 2014-2015, 2018-19, <i>2022-23</i> (coming soon!) | Includes all waves (1992-2019) |
| Data Available in | SAS (Stata and R materials for 2018-19 to be available by the end of 2023) | SAS (Stata and R materials to be available in early 2024) |

Features

- All data includes detailed demographic and employment information (via CPS)
- Individual survey waves:
 - Support national, state, and some sub-state analyses
 - Can be linked with other supplements of the Current Population Survey, including the Annual Social and Economic Supplement (detailed sociodemographic data), the Food Security Supplement, the American Time Use Supplement, and more
 - Full 2022-23 survey wave will be released in spring 2024 (September 2022 to be released this winter)
- Harmonized Dataset:
 - Easily compare estimates over time with harmonized variables
 - Pool survey waves to increase sample size

Using TUS-CPS

- Visit our website (<u>cancercontrol.cancer.gov/tus-cps</u>) to find:
 - Database of publications using TUS-CPS
 - Datasets and questionnaires September 2022 data coming soon!
 - User guides
 - Webinars
- Questions?
 - <u>ncidccpsbrpadvances@mail.nih.gov</u>
 - <u>margaret.mayer@nih.gov</u>



www.cancer.gov/espanol

www.cancer.gov



NATIONAL CANCER INSTITUTE Division of Cancer Control & Population Sciences

Medical Expenditure Panel Survey (MEPS): Experiences with Cancer Survivorship Supplement



Medical Expenditure Panel Survey (MEPS)

- Nationally representative panel survey fielded by the Agency for Healthcare Research and Quality (AHRQ).
- Captures comprehensive data on healthcare utilization and expenditures.
- Sample includes ~13K families and ~27K individuals.
- Publicly available from <u>https://meps.ahrq.gov/mepsweb/</u>

MEPS Experiences with Cancer Survivorship Supplement

- Collaboration among NCI, American Cancer Society, Centers for Disease Control and Prevention, NIH Office of Behavioral and Social Sciences Research, LIVESTRONG and AHRQ.
- Fielded in 2011, 2016 and 2017.
- Captures information about financial hardship, work disruption, healthcare utilization, and other related topics from cancer survivors participating in the MEPS.
- Sample includes 1,419 (2011), 1,236 (2016), 718 (2017) cancer survivors.



The MEPS Experiences with Cancer Survivorship Supplement is a valuable resource to study the burden of cancer and its treatment.



Financial hardship among cancer survivors



Use of prescription drugs by cancer survivors

Psychosocial

outcomes





Patient and provider communication



Cancer care utilization and expenditures among

Work disruption

and employment

changes due to

cancer



Analyses comparing cancer survivors to those without a history of cancer

A MEPS Experience with Cancer Survivorship **Supplement Working Group** is open to researchers working with these data. Contact Michael Halpern michael.halpern@nih.gov

or Sharon McCarthy sharon.mccarthy@nih.gov



The National Health Interview Survey Cancer Control Supplement

Jennifer Croswell, MD, MPH





- The oldest ongoing national health survey in the U.S.
- Conducted by the National Center for Health Statistics (NCHS, part of CDC)
- Administered by the Census Bureau
- Cross-sectional, population-based, good generalizability
- Majority in-person
- >30,000 interviews per year
- Questionnaires, documentation, and datasets all publicly available for research use

NHIS Cancer Control Supplement

- Started in 1987
- Collaborative sponsorship by NCI and CDC
- Pre-2019 (overall NHIS redesign), 20-minute module every 5 years
- Post-2019, yearly 5-minute module of rotating content

| | | 2019 | 2020 | 2021 | 2022 | 2023 | 2024 | 2025 | 2026 |
|-----------------------|----------------|-----------------------------------|-------------------------------|-----------------------------------|--------------------|-----------------------------------|-------------------------------|-----------------------------------|--------------------|
| Rotating NHI Core | S | Preventive services | Health behavior | Preventive services | Health behavior | Preventive services | Health behavior | Preventive services | Health behavior |
| | | | | Rotating conditions | Care utilization | | Rotating conditions | Care utilization | |
| | | Mental health | Employme | ent | Mental health | Employme | nt | Mental health | Employme |
| control supplement | 00:30 00:30 | Colorectal cancer screening | Skin cancer | Colorectal cancer screening | Diet and nutrition | Colorectal cancer screening | Skin cancer | Colorectal cancer screening | Diet and nutrition |
| | 00:30 00:30 | | | | | Screening | | bereening | |
| | 00:30 00:30 | Breast cancer screening | Lung cancer screening | Breast cancer screening | | Breast cancer screening | Lung cancer screening | Breast cancer screening | |
| | 00:30 | /Prostate | Physical | /Prostate | Tobacco | /Prostate Risk | Physical | /Prostate | Tobacco |
| | 00:30 | Cervical cancer screening | activity: environ- ment | Cervical cancer screening | | | activity: environ- ment | Cervical cancer screening | |
| | 00:30 | /Prostate | Emerging | /Prostate Emerging | Emerging | Emerging | Emerging | /Prostate Emerging | Emerging |
| | | | topics | topics | topics | topics | topics | topics | topics |

Cancer Control Module Rotating Content



Goal: Aligning rotating content on the cancer control module with content on the core and rotating core of the NHIS

Timeline for content usually requires development of module 1.5 to 2 years before administration

Utility of NHIS Data

National **Estimates**



Cancer Screening Test Receipt — United States, 2018

INSIDE

36 CDC's Emergency Manage Worldwide, 2013–2018

January 15, 2021

measures. NHIS-imputed income files were used. NHIS data

from 2005, 2008, 2010, 2013, 2015, and 2018 were used to

examine differences across years in percentages of persons who were up to date with screening, according to USPSTF recom-mendations in effect for each year. For 2018, "up-to-date"

status was defined as receipt of the following: mammography within 2 years among women aged 50-74 years for breast

within 2 years among women aged 30–74 years for breast cancer screening; Pap test within 3 years for women aged 21–65 years or Pap test plus human papillomavirus (HPV) test (co-testing) within 5 years for women aged 30–65 years for cer-vical cancer screening (among women without hysterectomy);

Worldwide, 2013–2018 Of Assessment of Neonatal Abstinence Syndrome Surveillance — Pennsylvania, 2019 64. Allergic Reactions including Anaphylaxis After Receipt of the First Dose of Pfizze-BioNTech COVID-19 Vaccine — United States, December 14–23, 2020

Bates of COVID-19 Among Residents and Staff Members in Nursing Homes — United States, May 25-November 22, 2020

Candida auris Outbreak in a COVID-19 Specialty Can Unit — Florida, July-August 2020

Mitigation Policies and COVID-19–Associated Mortality — 37 European Countries, January 23 June 30, 2020

s and COVID-19-Associated

Susan A. Sabatino, MD¹; Tiever D. Thompson¹; Mary C. White, ScD¹; Jean A. Shapiro, PhD¹; Janet de Moor, PhD²; V. Paul Doria-Rose, DVM, PhD²; Tainya Clarke, PhD³; Lisa C. Richardson, MD¹

Screening for breast cancer, cervical cancer, and colorectal cancer (CRC) reduces mortality from these cancers * However. carreering test receipt has been below national targets with dis-parities observed in certain populations (1,2). National Health Interview Survey (NHIS) data from 2018 were analyzed to estimate percentages of adults up to date with U.S. Preventive Services Task Force (USPSTF) screening recommendations. Services Task Force (USFSTE) screening recommendations. Screening reservery remained below material Healthy Polo-2020 (HP2202) targets, although CRC test receipt mered the target. Disputises were vision, with transitiandly hor test many structures of care. Continued monitoring helps assess progress toward targets and could inform efforts to promose screening and reduce burriers for nuderscreed populations. Data from the 2018 NHLS, an annual array of a national progressmittee sample of the civilian, noninstitutional del US, and coloread care screening test review to HSPT IF constrained and coloread care screening test review to HSPT IF constrained to the screening test provides of the civilian nd colorectal cancer screening test receipt per USPSTF recommendations. Information about tests was collected from one mendations. Information about rests was collected from one randomly selected adult per family (final sample adult response rate was 53.1%) (3). Respondents were asked whether they had ever received each test and when they received their most recent test. Respondents with a personal history of the cancer in question were excluded from analysis for that cancer type. in question were excluded from analysis for that cancer type. Percentages with Kom-Graubard confidence intervals (4) are presented overall and by sociodemographic and health care access factors. Percentages of respondents who were up to date with screening were also age-standardized to the 2000 U.S. standard population, consistent with HP2020 cancer screening



U.S. Department of Health and Human Services Centers for Disease Control and Prevention

QuickStats

Goal Setting and Trends

HEALTHY PEOPLE 2030



Assessing disparities and informing interventions





www.cancer.gov/espanol

www.cancer.gov

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

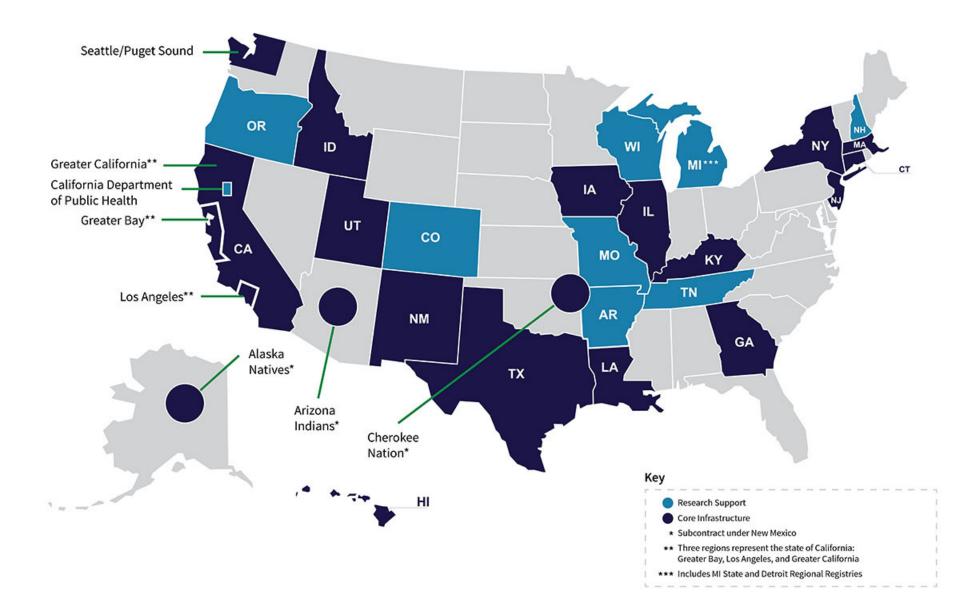


DCCPS New Grantee Workshop

October 30-31, 2023

Kathy Cronin, PhD Surveillance Research Program Division of Cancer Control and Population Sciences National Cancer Institute

SEER Registries



Background For SEER

SEER Data

- Diagnosis, treatment, and outcomes of cancer since 1973
- Provide data on U.S. cancer incidence, survival and prevalence
- Population-based registries representing almost 50% of the U.S. population
- Over 700,000 incident cases reported annually

Evolution of SEER Over Time

SEER 9 covering years 1975+

- San Francisco-Oakland, Connecticut, Detroit, Hawaii, Iowa, New Mexico, Seattle, Utah, Atlanta
- Covers 9.4% of the US population

SEER 13 covering years 1992+

- SEER 9 plus San Jose-Monterey, Los Angeles, Rural Georgia, Alaska Natives
- Covers 13.4% of the US population
- SEER 18 covering years 2000+
 - SEER 13 plus California (excluding SF/SJM/LA), Kentucky, Louisiana, New Jersey, Georgia (excluding Atlanta and Rural Georgia)
 - Covers 27.8% of the US population

Evolution of SEER Over Time

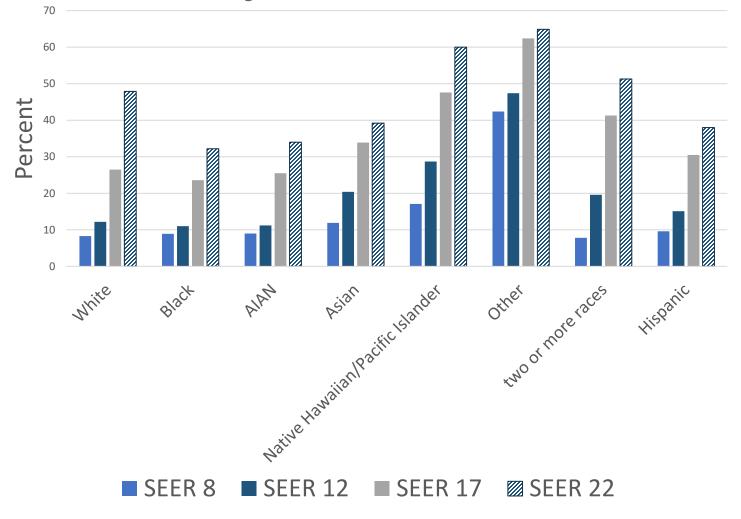
SEER 21 covering years 2000+

- SEER 18 plus Idaho, New York, and Massachusetts
- Covers about 35% of US population

SEER 22 covering years 2000+

- SEER 21 plus Illinois and Texas, minus Detroit
- Covers about 48% of US population

Population Coverage by Race/Ethnicity



Data in SEER Registries



- Demographic: age, gender, area of residence, race and ethnicity, insurance status, marital status.
- Tumor (cancer): primary cancer site, histology, morphology, stage, lab values and tumor markers
- Treatment: first course of treatment chemotherapy, surgery, radiation
- Outcome (follow-up for vital status): living or deceased, month and year of death and cause of death
- SEER data is linked at the county and census tract level with Census data and provide socio-economic variables based on residency
- Data is consolidated and available for analyses

Standard Statistics Reported Using SEER Data

- Incidence: Age-adjusted rate per 100,000
- Trends in incidence, annual percent change in rates, or average annual percent change over a specified time frame
- Prevalence of people alive with a previous diagnosis of cancer
- Cancer Survival Statistics (Relative or Cause Specific Survival)
- Probability of developing or dying of cancer over a lifetime

Where Are SEER Statistics Reported? <u>https://seer.cancer.gov/</u>

- SEER*Explorer
 <u>https://seer.cancer.gov/explorer/</u>
- Did You Know Videos highlight key topics and trends in cancer statistics

https://seer.cancer.gov/statistics/videos/

Fact Sheets – Plain language summaries of key statistics by cancer site

http://seer.cancer.gov/statfacts/

- State Cancer Profiles (County level information and Interactive Maps)
 http://statecancerprofiles.cancer.gov/
- Annual Report to the Nation provides an annual update of cancer incidence, mortality, and trends in the United States.

SEER*STAT Software

- https://seer.cancer.gov/seerstat/
- Software provides access to SEER database, US mortality files, and population data from the Census
- 16,060 SEER*STAT downloads last year
- Analyses can run from simple to complex
- SEER*Stat Tools Webinars https://seer.cancer.gov/news/seerstat-webinars.html

Statistical Software & Tools

https://surveillance.cancer.gov/tools/

Tools that use SEER*STAT output

- Joinpoint Trend Analysis
- Devcan Risk of Diagnosis and Death
- HD*Calc Health Disparities Calculator
- CanSurv Survival Models including Cure Models
- ComPrev and ProjPrev Complete and Projected Prevalence

Software available for download

Thank you!

Kathy Cronin cronink@mail.nih.gov