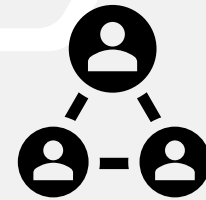


# WELCOME!

## While we are getting set up....

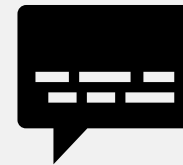
We would like to get to know our audience.



Please put your answer to the following questions in the chat.



Which organization are you affiliated with and  
what is your role?



# Health Equity and Cancer: The Impact of Data Collection and Distribution

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January 16, 2025

11 AM – 12 PM



NYSCC QUARTERLY  
MEETING SERIES



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# Housekeeping

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Please mute your line.

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If you have a question, please type it in the Chat Box.

---

Questions will be answered after the presentations.

---

This meeting is being recorded.

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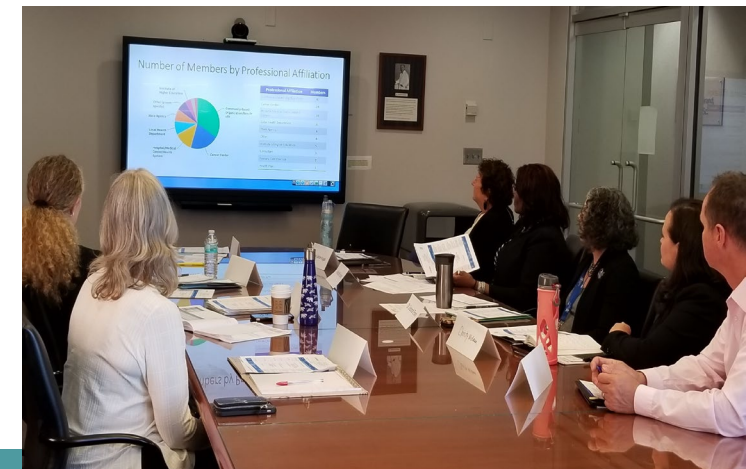
A link to the recording will be e-mailed to everyone who registered.

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# About Us

## *Working Together, Reducing Cancer, Saving Lives*

**We are New Yorkers from all walks of life who work together to reduce the burden of cancer.**





# Join Today!



➤ *Learn about state-wide cancer prevention efforts*

➤ *Find resources to promote and implement Cancer Plan priorities and measure progress*

➤ *Collaborate with other members to achieve Cancer Plan goals and objectives*

Join an Action Team to implement Cancer Plan priorities



Colorectal Cancer



HPV Coalition



Skin Cancer



Healthy Eating and Active Living (HEAL)



Environmental Carcinogens



Lung Cancer



Survivorship

# NYSCC Quarterly Meeting Series: Health Equity and Cancer



## *Upcoming Meetings*

- **Inequities in NYS Communities and Actions for Improvement**  
Tuesday, March 18<sup>th</sup>, 11:00 AM to 12:00 PM
- **Navigating the Complexities of the Cancer Care Continuum**  
Thursday, May 15<sup>th</sup>, 11:00 AM to 12:00 PM
- **Survivorship (Part 1)**  
Tuesday, September 16<sup>th</sup>, 11:00 AM to 12:00 PM

[Quarterly Member Meeting Series | New York State Cancer Consortium](#)



# Pre-Meeting Poll



# **Health Equity and Cancer:**

## *The Impact of Data Collection and Distribution*





# Session Objective:

- After participating in this session, attendees should be able to describe the impact of health equity and interpret the distribution of cancer-related data by examining the different factors involved in data collection.

# Meet Our Speakers





# Emily Payne, MSPH

## Comprehensive Cancer Control Evaluation Lead

NYS Department of Health, Bureau of Chronic Disease  
Evaluation & Research

---

An epidemiologist with over seven years experience helping state and local programs translate data to action with expertise in overdose, harm reduction, and chronic disease. Her work has been published in Centers for Disease Control and Prevention's Morbidity and Mortality Weekly Report, Journal of Public Health Management and Practice, Journal of Substance Use and Addiction Treatment, Harm Reduction Journal, and American Journal of Emergency Medicine.



# Tabassum Insaf

## Director of the Bureau of Cancer Epidemiology Scientific Director of the NYS Cancer Registry

NYS Department of Health, Bureau of Cancer  
Epidemiology

---

In this role she oversees cancer surveillance and extramural research along with directing the scientific operations of the NYS cancer registry. She is the principal investigator for New York for both the National Program of Cancer Registries and the National Cancer Institute's SEER program. Dr Insaf's research areas include environmental and chronic disease epidemiology, small area surveillance, longitudinal and multilevel methods, spatial epidemiology, and geographic information systems. Dr. Insaf holds a PhD in Epidemiology from the University at Albany and an MPH in Epidemiology from the University of Massachusetts, Amherst. She also has a medical degree (MBBS) from India and holds an academic appointment at the University at Albany School of Public Health.



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# **NYSCC Quarterly Member Meeting**

**January 16<sup>th</sup>, 2025 | Emily Payne, MSPH**



# DATA SOURCES AND USE



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# CONCEPTUAL FRAMEWORK

- Growing our collective knowledge and evidence to achieve goal of greater health equity and better outcomes in cancer prevention, detection, and care
  - Decrease risk factors
  - Screen people
  - Diagnose early
  - Treat effectively and equitably
  - Support survivors
- Connections between individual-level action and long-term outcomes
- Population data does not represent an individual person
- Data are not always be available- how do we use what we have?

# USE CASE: PLANNING FUNDING APPLICATION

- What counties have the highest incidence?
- What counties have the highest mortality?
- What counties have late-stage disease diagnosed?
- Where are screening rates the lowest?
- Where are the populations that experience disparities in outcomes?
- Where are those who are eligible?
  - Has geographic location impacted ability to reach those eligible?

**Note:** Example based on application for funding for the CDC National Breast and Cervical Early Detection Program which helps support the NYS Cancer Services Program. The CSP helps uninsured New Yorkers get breast cervical and colorectal screening and diagnostic services at no cost.

# DATA SOURCE TYPES

- Populations and demographics
- Population-based surveys
- Outcomes data

# POPULATIONS AND DEMOGRAPHICS

- Population characteristics: US Census
  - Demographics, including health insurance status, income, and location
- Social Vulnerability Index: American Community Survey



# POPULATION-BASED SURVEYS

- Population behaviors
  - BRFSS- Behavioral Risk Factor Surveillance System (Adults)
  - YRBS- Youth Risk Behavior Survey (High school youth)
  - Youth Tobacco Survey (Middle and high school youth)
- Population opinions: Chronic Disease Public Opinion Poll

# OUTCOMES DATA

- Population cancer outcomes: NYS Cancer Registry
- All-payer hospital data: Statewide Planning and Research Cooperative System- SPARCS
- Death data: Vital Statistics
- Health Insurance Payer Performance: eQARR
- Healthcare Infrastructure and Utilization: HRSA Health Center Program Uniform Data System (UDS)

# POPULATIONS AND DEMOGRAPHICS



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# US CENSUS AND AMERICAN COMMUNITY SURVEY

United States<sup>®</sup>  
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2020 Census Results

Verify a Survey

2030 Census

2026 Census Test

2022 Economic Census

International Database (IDB)

Emergency Management

Migration Drives Highest Population Growth in Decades

December 19, 2024

The U.S. population grew by nearly 1.0% between 2023 and 2024, according to the new Vintage 2024 population estimates released today by the U.S. Census Bureau.

Learn More



<https://data.census.gov/>



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Health

Hispanic Origin

Housing

Income and Poverty

International Trade

Migration/Geographic Mobility

Population

Population Estimates

Public Sector

Race

Redistricting

Research

Voting and Registration

Subtopics

Annual Capital Expenditures Survey (ACES)

The Annual Capital Expenditures Survey (ACES) provides estimates on business spending for new and used structures and equipment.

Disability

The Census Bureau collects data on disability primarily through the American Community Survey (ACS) and the Survey of Income and Program Participation (SIPP).

Enhancing Health Data (EHealth) Program

Research program that identifies existing gaps in federal statistics which can be filled by enhancing health records with unique Census Bureau data assets.

Fertility

Information about the fertility of American women both for the nation as a whole as well as for individual states and lower level geography.

Health Care and Social Assistance

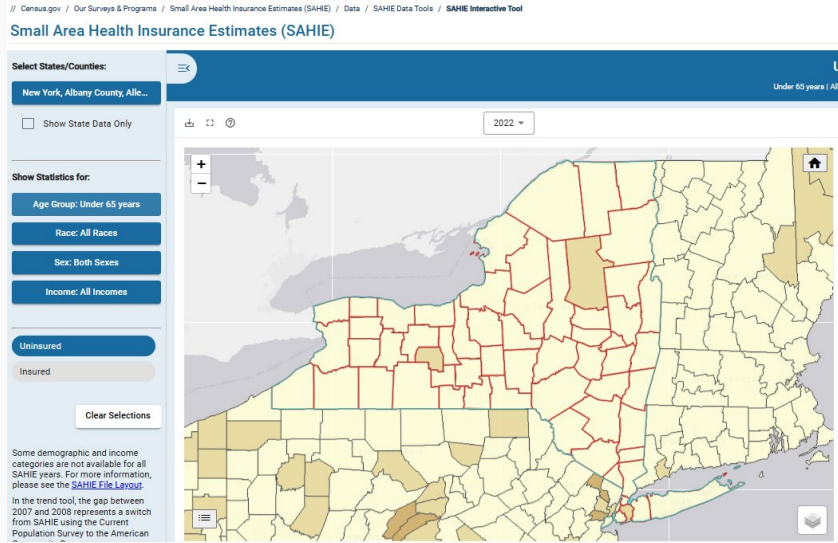
Collected data on health care industries using three surveys: the Economic Census, the Annual & Quarterly Services, and the County Business Patterns.

Health Insurance

The Bureau collects health insurance data using three national surveys: CPS ASEC, ACS, and SIPP.

Small Area Health Insurance Estimates (SAHIE)

The Small Area Health Insurance Estimates (SAHIE) program produces single-year estimates of health insurance coverage for every county in the U.S.



# RURALITY DATA

Based on decennial **Census** and **American Community Survey**.

## NO STANDARD DEFINITION...

Common **classification systems** include:

- Census Bureau's urban-rural codes
- Office of Management and Budget (OMBs) Urban Influence Codes (**UICs**)
- Rural-Urban Continuum Codes (**RUCCs**)
- Rural Urban Commuting Area (**RUCAs**)

Counties, zip-codes, census tracts can be categorized based on factors influencing agency work:

- Population density
- Size of region
- Proximity to metro or micropolitan area

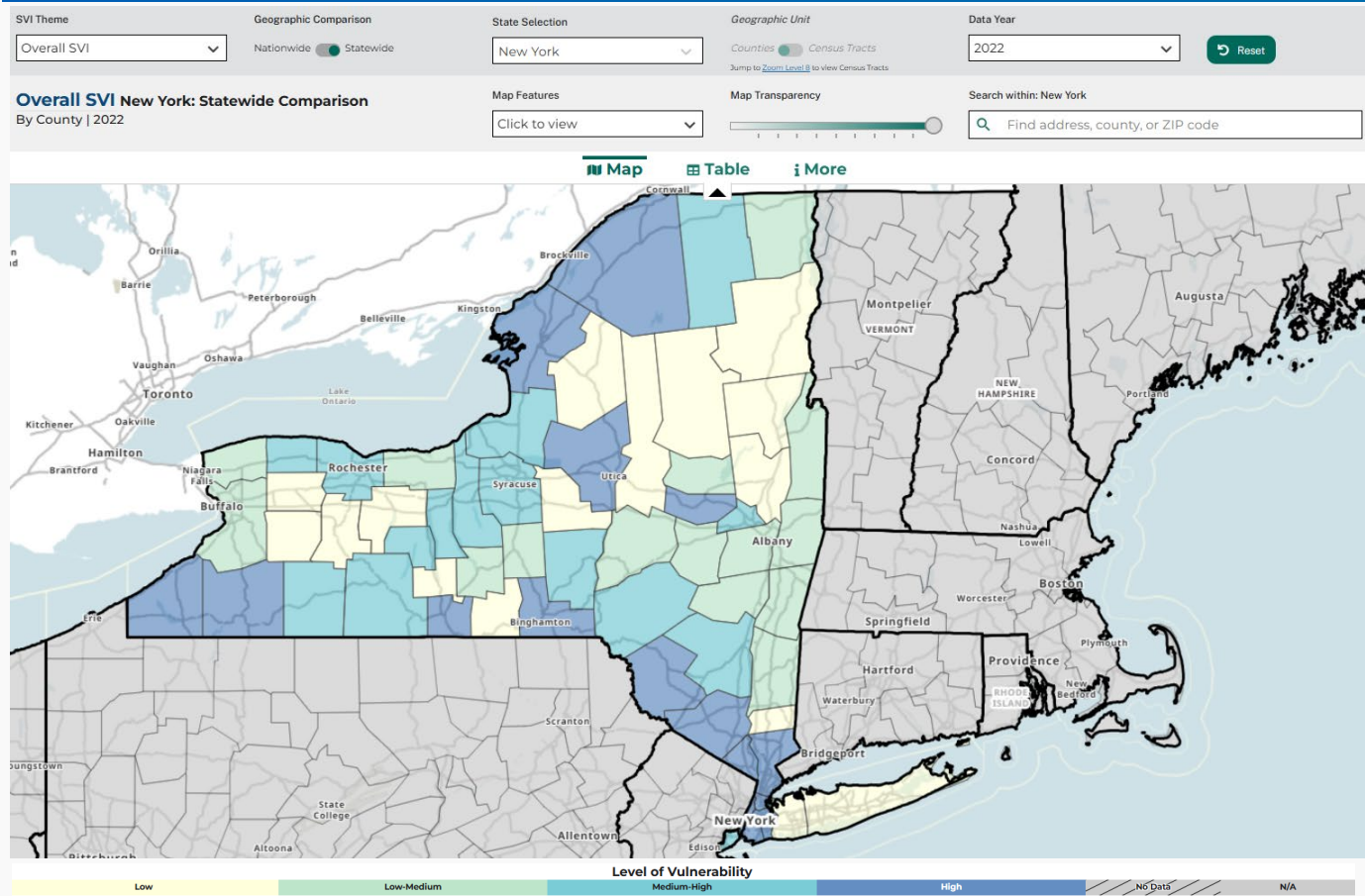
**HRSA (Health Resources & Service Administration)** combines info from USDA and OMB to define rural at census tract level.





# SOCIAL VULNERABILITY

## ATSDR Agency for Toxic Substances and Disease Registry



American Community Survey (ACS), 2018-2022 (5-year) data for the following estimates:

Overall Vulnerability	Socioeconomic Status	Below 150% Poverty Unemployed Housing Cost Burden No High School Diploma No Health Insurance
	Household Characteristics	Aged 65 & Older Aged 17 & Younger Civilian with a Disability Single-Parent Households English Language Proficiency
	Racial & Ethnic Minority Status	Hispanic or Latino (of any race) Black or African American, Not Hispanic or Latino Asian, Not Hispanic or Latino American Indian or Alaska Native, Not Hispanic or Latino Native Hawaiian or Pacific Islander, Not Hispanic or Latino Two or More Races, Not Hispanic or Latino Other Races, Not Hispanic or Latino
	Housing Type & Transportation	Multi-Unit Structures Mobile Homes Crowding No Vehicle Group Quarters



<https://www.atsdr.cdc.gov/place-health/php/svi/svi-interactive-map.html>

# POPULATION-BASED SURVEYS



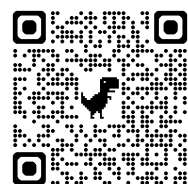
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# BEHAVIORS



## Behavioral Risk Factor Surveillance System

CDC



[https://www.cdc.gov/brfss/data\\_tools.htm](https://www.cdc.gov/brfss/data_tools.htm)

### Prevalence Data & Data Analysis Tools

[Print](#)



Find city and county data collected through the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) project, the Web Enabled Analysis Tool (WEAT), interactive maps, and other resources provided through BRFSS.

### Prevalence and Trends Data


Using the Prevalence and Trends Data Tools, users may produce charts for individual states or the nation by health topic. Users may select specific years or request multiple year data. The Prevalence and Trend Data Tools will produce line graphs for multiple years and bar charts for single years for each selected indicator.

Search State or National Level Data on Cancer Screenings and Risk Factors

NYSDOH



[https://health.data.ny.gov/Health/Behavioral-Risk-Factor-Surveillance-System-BRFSS-H/jsy7-eb4n/about\\_data](https://health.data.ny.gov/Health/Behavioral-Risk-Factor-Surveillance-System-BRFSS-H/jsy7-eb4n/about_data)



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Behavioral Risk Factor Surveillance System (BRFSS) Health Indicators by County and Region

Expanded year surveys allow for county level estimates of many variables



Department of Health

# NYS BRFSS BRIEFS AND REPORTS

## BRFSS

Annual BRFSS Datasets and Metadata

County Level Data (Expanded BRFSS)

Health Care Coverage by Demographic Group

BRFSS Summary Reports

Information for Action Reports

Health Data New York

CDC BRFSS Website



<https://www.health.ny.gov/statistics/brfss/>

## Summary Report



The Behavioral Risk Factor Surveillance System (BRFSS) is an annual telephone survey of adults developed by the Centers for Disease Control and Prevention conducted in all 50 States, the District of Columbia, and several US Territories. The New York BRFSS is administered by the New York State (NYS) Department of Health (DOH) to provide statewide and regional information on behaviors, risk factors, and use of preventive health services related to the leading causes of chronic and infectious diseases, disability, injury, and death.

### Breast Cancer Screening New York State Adult Females, 2022

**Introduction**  
Breast cancer is the most diagnosed cancer after skin cancer and the second leading cause of cancer death among women in New York State (NYS). Over 2,500 deaths each year are attributed to breast cancer. Early detection through screening can significantly reduce the risk of death. The United States Preventive Services Task Force (USPSTF) recommends that all women aged 50 to 74 years undergo biennial mammography. In New York State, the Department of Health encourages all cisgender women who can benefit from early detection to get screened.

**Health Equity**  
Non-Hispanic Black women have the highest breast cancer mortality rates in New York State. These disparities are largely due to differences in access to and utilization of breast cancer screening services. Addressing these disparities requires targeted efforts to increase screening rates among underserved populations.



### Key Findings

- An estimated 79.4% of females 50-74 years



**Table 1. History of mammogram (ever, within past year, within past 2 years) as reported by New York State females\* 50 to 74 years of age, by selected characteristics, Behavioral Risk Factor Surveillance System, 2022.**

	Ever Had Mammogram		Mammogram Within past year		Mammogram Within past 2 years	
	%	95% CI	%	95% CI	%	95% CI
NYS Statewide	96.0	94.9-97.1	62.2	59.8-64.6	79.4	77.3-81.5
Age						
50-64	95.6	94.1-97.1	63.0	59.9-66.1	79.2	76.4-81.9
65-74	96.7	95.3-98.1	60.8	57.0-64.7	79.8	76.4-83.2
Race/Ethnicity						
Asian, non-Hispanic	92.3	85.8-98.8	54.8	39.2-70.4	66.9	51.4-82.3
Black, non-Hispanic	95.9	92.7-99.2	64.9	58.0-71.7	84.7	79.7-89.7
Hispanic	95.4	91.4-99.3	62.1	55.2-69.1	81.7	75.5-87.8
White, non-Hispanic	96.8	95.8-97.7	63.7	61.2-66.2	79.6	77.5-81.7
All other race groups combined <sup>b</sup>	98.2	94.8-100.0	46.6	28.9-64.3	74.3	58.9-89.7
Annual Household Income						
Less than \$25,000	95.2	92.7-97.6	54.6	47.6-61.5	74.9	69.3-80.5
\$25,000 - \$49,999	95.5	93.3-97.7	56.2	50.2-62.3	73.6	67.9-79.3
\$50,000 and greater	97.6	96.0-99.2	66.9	62.0-71.8	81.3	76.8-85.9
Missing <sup>c</sup>	95.6	93.5-97.8	64.2	59.4-69.0	83.4	79.6-87.1
Educational Attainment						
Less than high school	94.6	90.8-98.4	55.5	46.1-64.9	77.5	69.6-85.5
High school or GED	95.0	92.7-97.3	59.2	54.1-64.3	76.4	72.1-80.8
Some post-high school	95.6	93.1-98.1	61.7	56.9-66.4	78.6	74.2-82.9
College graduate	97.4	96.4-98.4	66.7	63.4-69.9	82.3	79.5-85.2
Healthcare Coverage						
Private	97.0	95.5-98.4	65.1	61.8-68.5	82.0	79.3-84.8
Medicare	97.2	96.0-98.5	60.8	56.3-65.3	79.3	75.3-83.3
Medicaid	94.5	91.5-97.4	59.4	50.9-68.0	75.5	67.2-83.7
Other insurance	90.3	83.6-97.1	61.0	52.7-69.4	76.1	68.5-83.7
No insurance	93.0	85.4-100.0	31.3	18.1-44.5	51.1	35.5-66.7
Regular Health Care Provider						
Yes	96.3	95.2-97.4	63.7	61.3-66.2	81.0	78.9-83.2
No	90.4	83.8-97.1	36.1	25.9-46.2	53.2	42.3-64.1
Disability <sup>d</sup>						
Yes	96.1	94.5-97.6	56.5	52.2-60.8	75.8	72.2-79.5
No	95.9	94.5-97.3	64.9	62.0-67.8	81.0	78.4-83.6
Residence						
New York City (NYC)	96.2	94.8-97.7	59.5	55.2-63.9	79.9	76.1-83.8
NYS excluding NYC	95.8	94.4-97.3	63.9	61.0-66.7	79.1	76.6-81.6
Sexual Orientation and Gender Identity <sup>e</sup>						
Lesbian, gay, bisexual, transgender, queer/questioning, and/or intersex	94.0	88.0-100.0	53.8	42.6-65.0	66.1	54.8-77.3
Heterosexual/straight cisgender	96.4	95.2-97.5	62.6	59.9-65.2	79.9	77.6-82.2

## IFA: Information for Action

### Healthy Behaviors among New York State Cancer Survivors

Information for Action #2024-22 | Release Date: September 2024



A cancer survivor is a person who has cancer or who has had it in the past.<sup>1</sup> Over 1.1 million cancer survivors live in New York State.<sup>2</sup> Cancer survivors are at a greater risk of developing the same cancer or a new, unrelated cancer than people who have never had cancer. This may be due to treatment effects, genetics, or health behaviors like smoking, exercise, diet, and alcohol use that contributed to the first cancer. These challenges, physical, psychosocial, and underscore the importance of survivor wellness.<sup>3</sup>

The National Comprehensive Cancer Network (NCCN) and the American Cancer Society (ACS) recommend healthy behaviors that reduce the risk of cancer recurrence and death among survivors. These behaviors include: not smoking, limiting alcohol consumption, maintaining a healthy weight, and engaging in physical activity. Unfortunately, disparities in these behaviors persist, highlighting the need to address the conditions in which we live and work. By improving the social determinants of health, all survivors can be empowered to make choices that improve their health and thrive beyond their diagnosis.

### Public Health Opportunity

To support cancer survivors and all New Yorkers, **health care providers** can:

- Educate cancer survivors on healthy behaviors like quitting smoking, a balanced diet, exercise, and limiting alcohol while being mindful of the socioeconomic and cultural factors that may impact a cancer survivor's health.



[https://www.health.ny.gov/statistics/prevention/injury\\_prevention/information\\_for\\_action/](https://www.health.ny.gov/statistics/prevention/injury_prevention/information_for_action/)

### BETWEEN 2018-2021, AMONG NEW YORK STATE CANCER SURVIVORS

90.3% report not drinking excessively.

88.8% report not currently smoking.

74.1% report eating fruits or vegetables daily.

67.7% report engaging in physical activity.

50.2% report not currently drinking.

34.5% report maintaining a healthy weight.

For more information, please send an Action report, visit the [NYS BRFSS](https://www.health.ny.gov/statistics/brfss/) page.  
1. New York State Department of Health, [cancer/survivorship/index.htm](https://www.health.ny.gov/statistics/brfss/).  
2. New York State Cancer Registry, [from https://www.health.ny.gov/statistics/brfss/](https://www.health.ny.gov/statistics/brfss/).  
3. Centers for Disease Control and Prevention. Retrieve from <https://www.cdc.gov/cancer/>.  
4. Hannah Arem, Scherezade K. M. among Cancer Survivors in the U.S.



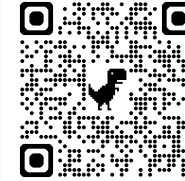
Department of Health



# YOUTH BEHAVIORS



## Youth Risk Behavior Surveillance System (YRBSS)



<https://www.cdc.gov/yrbs/index.html>

### YRBS Explorer

This tool provides visualization of YRBSS data and allows public site users to view data.



### Data and Documentation

2023 National and Combined datasets now available in Access and ASCII.



### 2023 Youth Risk Behavior Survey Results

Read top highlights from the 2023 YRBS results.



Search Questions

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Unintentional Injuries and Violence

Tobacco Use

Alcohol and Other Drug Use

Sexual Behaviors

Dietary Behaviors

Physical Activity

Obesity, Overweight and Weight Control

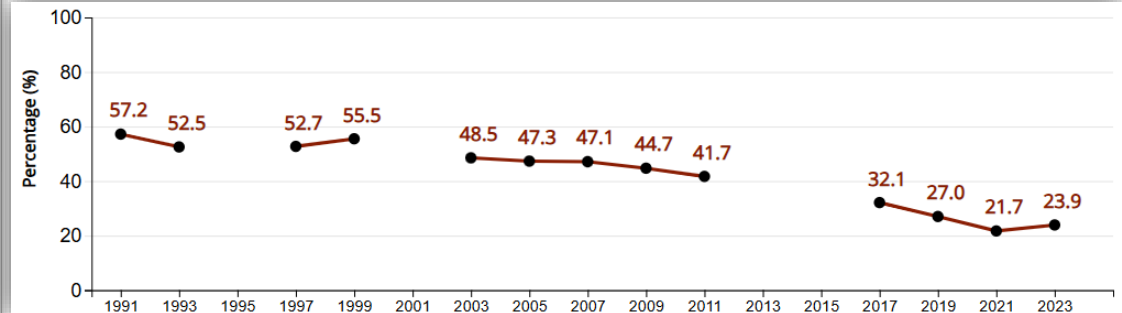
Other Health Topics

[See All Topics](#)

Alcohol And Other Drug Use

### High School Students Who Currently Drank Alcohol\*

Location New York (Excluding New York City) ▼



ALSO available from CDC...  
National Youth Tobacco Survey (YTS) Datasets



<https://www.cdc.gov/tobacco/about-data/surveys/national-youth-tobacco-survey.html>



Department of Health



# NYS PUBLIC OPINION POLLS

Department of Health

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Health Facilities

Health Data

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You are Here: [Home Page](#) > [Statistics & Data](#) > Division of Chronic Disease Prevention: Information for Action (IFA) Reports

## Division of Chronic Disease Prevention: Information for Action (IFA) Reports

The Information for Action (IFA) is a brief communication that provides relevant data to mobilize public health action. Each IFA includes a take home message, quick facts containing relevant data to support the take home message, language describing a public health opportunity and contact information for obtaining more information. Data used in an IFA typically come from data systems designed to capture information about New York residents, but occasionally include data from national data systems. IFAs are available under the following categories:

Information for Action

County-level Information for Action

Chronic Disease Public Opinion Poll

### Chronic Disease Public Opinion Poll

The New York State Department of Health conducts an annual survey of adult residents of New York State to understand the public's beliefs about public health issues and to assess support for public health policies to address chronic disease and promote health. Available reports provide relevant data to mobilize public health action.

INFORMATION FOR ACTION # 2023-01  
RELEASE DATE: 2/22/2023



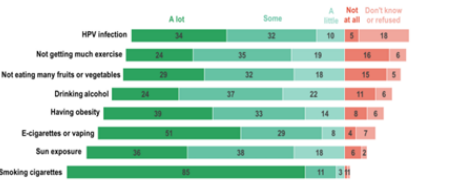
### Addressing Gaps in New Yorkers' Cancer Prevention Knowledge



Each year, over 118,000 New Yorkers learn they have cancer.<sup>1</sup> Nearly half of all cancer cases could be prevented, with smoking, excess body weight, and drinking alcohol being the leading causes of cancer.<sup>2</sup> A recent survey found that some adult New Yorkers do not know certain lifestyle factors increase their risk of getting cancer. For example, about 1 in 4 New Yorkers (23%) are unaware human papillomavirus (HPV) infection increases a person's risk and 1 in 6 New Yorkers (17%) are unaware drinking alcohol increases a person's risk.

New Yorkers need to know they can lower their risk of getting cancer by making choices like avoiding tobacco, protecting their skin, limiting the amount of alcohol they drink, keeping a healthy weight, exercising, and getting the HPV vaccine.<sup>3</sup> But knowing how to lower cancer risk is not enough. Policy, systems, and environmental (PSE) strategies are critical to changing laws, rules, and environments that support healthy choices and healthy communities.<sup>4</sup> PSE strategies also play an important role in advancing health equity. Systemic racism influences the environments in which people live, work, and play, and those environments affect the lifestyle choices people have. Black New Yorkers have a greater risk of developing and dying from many cancers than New Yorkers who are not Black, including colorectal, cervical, and prostate cancers.<sup>5</sup> Communicating with the public about cancer prevention and promoting PSE strategies to community and government leaders are critical steps towards reducing the burden of cancer for all New Yorkers.

Figure 1. Percentage of Adults Who Think the Following Things May Affect a Person's Chances of Getting Cancer



Data Source: NYS Division of Chronic Disease Prevention Chronic Disease Public Opinion Poll 2022

#### Public Health Opportunity

- A coordinated approach, including strategies outlined in the [NYS Comprehensive Cancer Control Plan](#), includes:
- Ensure that people are provided with the information and support they need to adopt healthy lifestyles.
  - Invest in and educate about prevention-based programs that promote PSE strategies aimed at reducing exposure to cancer risk factors for all New Yorkers.
  - Increase the availability of proven strategies to reduce the number of preventable cancers such as taxing cigarettes to reduce smoking and increasing vaccination rates to protect against cancer-causing HPV infections.
  - Collaborate with partners outside of the health sector to address the root causes of health inequities, like structural racism, to promote equity in health outcomes like cancer.

For more information, please send an e-mail to [BCD@health.ny.gov](mailto:BCD@health.ny.gov) with IFA #2023-01 in the subject line. To access other information for Action reports, visit the [NYS DOH public website](#): [http://www.health.ny.gov/statistics/prevention/injury\\_prevention/information\\_for\\_action/index.htm](http://www.health.ny.gov/statistics/prevention/injury_prevention/information_for_action/index.htm)

1. American Association for Cancer Research (2022). [AACR Cancer Disparities Progress Report 2022](#). Retrieved December 6, 2022 from <https://www.aacr.org/cancer-disparities-progress-report-2022>

2. American Association for Cancer Research (2022). [AACR Cancer Disparities Progress Report 2022](#). Retrieved December 6, 2022 from <https://www.aacr.org/cancer-disparities-progress-report-2022>

3. Centers for Disease Control and Prevention (2022). [Healthy Chosen to Lower your Cancer Risk](#). Centers for Disease Control and Prevention. Retrieved December 6, 2022 from [https://www.cdc.gov/cancer/prevention/healthy\\_chosen\\_to\\_lower\\_your\\_cancer\\_risk.htm](https://www.cdc.gov/cancer/prevention/healthy_chosen_to_lower_your_cancer_risk.htm)

4. University of Illinois Chicago. [Policy, Systems, and Environmental Change](#). Retrieved December 6, 2022 from <https://uic.edu/health-equity/policy-systems-and-environmental-change>



Department of Health

## And Risk Factors

INFORMATION FOR ACTION # 2024-02  
RELEASE DATE: 3/26/2024



### Understanding New Yorkers' Opinions on Policies to Reduce Excessive Alcohol Use

Excessive alcohol use is an important public health issue in New York with 1 in 5 New Yorkers reporting excessive alcohol use in the form of either binge or heavy drinking.<sup>1</sup> Excessive alcohol use can cause injuries, violence, and chronic diseases.<sup>2</sup> More than 8,050 New Yorkers die each year due to excessive alcohol use.<sup>3</sup> Moreover, the economic impact is staggering, costing the state's economy an estimated \$16.3 billion in 2010.<sup>4</sup> The harmful effects of alcohol are disproportionately felt in low income communities and communities of color.<sup>5</sup> The health, safety, and socioeconomic harms attributable to alcohol can be effectively reduced through evidence-based policies and prevention programs. A January 2023 survey of adult residents of New York found that support for alcohol-related policies varies.

- Three-quarters (75%) of New York adults support requiring additional health warnings on alcohol containers and 56% support banning outdoor advertising of alcohol.
- Nearly half of New York adults support increasing the sales tax on alcohol products and just under half (47%) support limiting the days or hours that alcohol is sold.
- Forty-one percent support decreasing the number of stores that sell alcohol products.

Figure 1: Support for Policies to Reduce Excessive Alcohol Use Among NYS Adults



Data Source: State College Research Institute/New York State Department of Health, January 2023

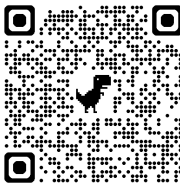
#### Public Health Opportunity

Policies that reduce the availability and affordability of alcohol can reduce excessive drinking and promote safer and healthier communities. An understanding of public sentiment towards alcohol-related policies is important for educational efforts that aim to raise awareness of and build support for policies. Increasing awareness among New Yorkers of the harms associated with excessive alcohol use and that there are well-researched, effective policies that can reduce these harms can foster implementation of these effective policies.

For more information about this report or other alcohol-related data and resources in New York State, visit the Department of Health's [Alcohol Surveillance and Epidemiology Program's website](#) or contact [AlcoholData@health.ny.gov](mailto:AlcoholData@health.ny.gov).

#### References:

1. New York State Department of Health. [Binge and Heavy Drinking](#). New York State Behavioral Risk Factor Surveillance System Brief, No. 2024-08.
  2. Centers for Disease Control and Prevention. [Alcohol and Public Health](#). Retrieved June 5, 2023. <https://www.cdc.gov/alcohol/public-health/index.htm>
  3. Centers for Disease Control and Prevention. [Alcohol-Related Disease Impact \(ARDI\) Application](#). 2024. Available at <https://www.cdc.gov/ncj110101/ARDI/default.htm>
  4. Galletly J, Galletly KB, Brachery ES, Tondel LE, Beaver RD. 2010 National and state costs of excessive alcohol consumption.
  5. [Issue Brief: Excessive Alcohol Use](#). National Association of Chronic Disease Directors. July 2020. Accessed August 2, 2023.
  6. Centers for Disease Control and Prevention. [Preventing Excessive Alcohol Use](#). <https://www.cdc.gov/alcohol/preventing-excessive-alcohol-use/index.htm>
- Disclaimer: This report is partially supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services as part of a financial assistance award totaling \$100,000. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by Centers for Disease Control and Prevention, the U.S. Department of Health and Human Services, or the U.S. Government.



[https://www.health.ny.gov/statistics/prevention/injury\\_prevention/information\\_for\\_action/](https://www.health.ny.gov/statistics/prevention/injury_prevention/information_for_action/)


# OUTCOMES DATA



Department  
of Health

# CANCER REGISTRY DATA

(Tabassum to cover/demo)



An official website of New York State. [Here's how you know.](#) ▾

[Department of Health](#)[Individuals/Families](#)[Providers/Professionals](#)[Health Facilities](#)[Health Data](#)[About Us](#)[Search](#)

You are Here: [Home Page](#) > [Statistics & Data](#) > New York State Cancer Registry and Cancer Statistics

## New York State Cancer Registry and Cancer Statistics

Cancer is one of the most common chronic diseases in New York State, and is second only to heart disease as the leading cause of death. Each year, over 116,000 New Yorkers are diagnosed with cancer. The New York State Cancer Registry is pleased to provide cancer statistics through this Web page. Contact the Cancer Registry at [nyscr@health.ny.gov](mailto:nyscr@health.ny.gov) for questions or comments.

The most recent year for which data on new cases and cancer deaths are available is 2021.

### Information about the New York State Cancer Registry

- [About the New York State Cancer Registry](#)
- [About Age-Adjusted Rates and 95% Confidence Intervals](#)
- [Considerations When Comparing Cancer Statistics Over Time](#)
- [About Mortality Data](#)
- [About New York City Neighborhoods Data](#)

### Cancer Statistics In New York State

#### Cancer Statistics Dashboards



<https://www.health.ny.gov/statistics/cancer/registry/>



Department  
of Health

Includes **Dashboards, Data Files,** and  
details on **Methodology** for looking at  
**incidence** and **mortality** data

# SPARCS AND VITAL STATISTICS DATA

## Statewide Planning and Research Cooperative System (SPARCS)

- All payer reporting system
- Patient level detail on characteristics, services, diagnoses, treatments, and charges for inpatient and outpatient (ambulatory surgery and emergency services)
- Public use files through [Health Data NY](#)

## Vital Statistics

- Live births, Fetal Deaths, Mortality
- Two-year data lag for releases
- Many reports available:



### Vital Statistics Data Utilized by the New York State Department of Health

Data Usage	Website
New York State County/ZIP Code Perinatal Data Profile	<a href="https://www.health.ny.gov/statistics/chac/perinatal/">https://www.health.ny.gov/statistics/chac/perinatal/</a>
New York State Prevention Agenda Dashboard	<a href="https://apps.health.ny.gov/public/tabvis/PHIG_Public/pa/">https://apps.health.ny.gov/public/tabvis/PHIG_Public/pa/</a>
New York State Community Health Indicator Reports	<a href="https://apps.health.ny.gov/public/tabvis/PHIG_Public/chirs/">https://apps.health.ny.gov/public/tabvis/PHIG_Public/chirs/</a>
New York State County Health Indicators by Race/Ethnicity	<a href="https://www.health.ny.gov/statistics/community/minority/county/">https://www.health.ny.gov/statistics/community/minority/county/</a>
New York State Leading Causes of Death	<a href="https://apps.health.ny.gov/public/tabvis/PHIG_Public/lcd/">https://apps.health.ny.gov/public/tabvis/PHIG_Public/lcd/</a>
New York State Maternal and Child Health Dashboard	<a href="https://apps.health.ny.gov/public/tabvis/PHIG_Public/mch/">https://apps.health.ny.gov/public/tabvis/PHIG_Public/mch/</a>
Opioid-related Data in New York State	<a href="https://www.health.ny.gov/statistics/opioid/">https://www.health.ny.gov/statistics/opioid/</a>
New York State Cancer Registry	<a href="https://www.health.ny.gov/statistics/cancer/registry/">https://www.health.ny.gov/statistics/cancer/registry/</a>
New York State Health Connector Suicide Dashboard	<a href="https://nyshc.health.ny.gov/web/nyapd/suicides-in-new-york">https://nyshc.health.ny.gov/web/nyapd/suicides-in-new-york</a>
New York State Hospital Profiles – Maternity Information	<a href="https://profiles.health.ny.gov/hospital/">https://profiles.health.ny.gov/hospital/</a>
New York State Environmental Public Health Tracking	<a href="https://www.health.ny.gov/environmental/public_health_tracking/">https://www.health.ny.gov/environmental/public_health_tracking/</a>
New York State Birth Defects Registry	<a href="https://www.health.ny.gov/diseases/birth_defects/#data">https://www.health.ny.gov/diseases/birth_defects/#data</a>

[https://www.health.ny.gov/statistics/vital\\_statistics/vs\\_reports\\_tables.htm](https://www.health.ny.gov/statistics/vital_statistics/vs_reports_tables.htm)

# HEALTHCARE PAYER PERFORMANCE

Department of Health

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You are Here: [Home Page](#) > [Managed Care Reports](#) > eQARR - An Online Report on Quality Performance Results for Health Plans in New York State

eQARR - An Online Report on Quality Performance Results for Health Plans in New York State

Show Instructions

Year: 2023 ▼Payer: Commercial HMO ▼Domain: Adult Health ▼Sub Domain: Managing Acute Illness for Adults ▼

Produce Visualization

Table

Bar Chart

Scatter Plot

Managing Acute Illness for Adults - Statewide - Commercial HMO

Plan Names ↕	Advising Smokers to Quit <sup>1</sup>	Discussing Smoking Cessation Medications <sup>1</sup>	Discussing Smoking Cessation Strategies <sup>1</sup>	Appropriate Testing for Pharyngitis (Ages 18-64) <sup>1</sup>
Anthem BlueCross and BlueShield	--	--	--	58▼
CDPHP	--	--	--	78
Excelsus BlueCross BlueShield	82	64	52	78▲
Highmark Western and Northeastern New York, Inc.	--	--	--	79▲
HIP (EmblemHealth)	--	--	--	53▼
Independent Health	81	68	67	75
MVP Health Care	97▲	71	56	75
Univera Healthcare	82	64	52	78▲
Statewide Average	84	68	57	77
National Average	NA	NA	NA	70

Key

▲ Significantly better than the regional average for measures in the Perinatal Health subdomain or significantly better than the state average for all other measures

▼ Significantly worse than the regional average for measures in the Perinatal Health subdomain or significantly worse than the state average for all other measures

-- Sample size too small to report.

\* A lower rate is desirable. For more information about the risk-adjustment methodologies, see the [Technical Notes](#) section.

Includes  
cancer  
screening  
and other  
chronic  
disease  
indicators

[https://www.health.ny.gov/health\\_care/managed\\_care/reports/eqarr/](https://www.health.ny.gov/health_care/managed_care/reports/eqarr/)

Compare Commercial, Essential, Medicaid Managed Care, HARP, and HIV-SNP

NEW YORK STATE  
Department of Health

1/17/2025 | 33

# HRSA UDS DATA

data.HRSA.gov

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Maps

Tools

Topics

Help



<https://data.hrsa.gov/tools/data-reporting/program-data>

Home > Tools > Health Center Program UDS Data > Data Overview



## Health Center Program Uniform Data System (UDS) Data Overview

Each calendar year, HRSA Health Center Program awardees and look-alikes are a core set of information, including data on patient characteristics, services processes and health outcomes, patients' use of services, staffing, costs, and re-standardized reporting system known as the UDS. View the [most recent national data](#) and [national program look-alike data](#).



## Data Downloads

### Area Health Resources Files ⓘ

Note:

- The 2022-2023 AHRF contains a number of changes (e.g., new variable names, subset files in CSV format). Please review "What's New" in the AHRF technical documentation for more information.
- Please contact [NCHWAInquiries@hrsa.gov](mailto:NCHWAInquiries@hrsa.gov) for technical questions about the Area Health Resources Files (AHRF) data. Historical data are available for some variables in the AHRF county level data file. Please review the AHRF Technical Documentation (excel) for a list of variables and years included in the published data file.

#### 2022-2023 County Level Data

Technical documentation	(Approx. 1.9 MB)	ZIP
CSV	(Approx 23.6 MB)	CSV
ASCII format	(Approx 17.6 MB)	ASCII
SAS format	(Approx 17.6 MB)	SAS

#### 2022-2023 State and National Level Data

Technical documentation	(Approx. 1.05 MB)	ZIP
CSV	(Approx 507 KB)	CSV
ASCII format	(Approx 550 KB)	ASCII
SAS format	(Approx 222 KB)	SAS

Information on health facilities, health professions, measures of resource scarcity, health status, economic activity, health training programs, and socioeconomic and environmental characteristics.



Department of Health

# USE CASE: PLANNING FUNDING APPLICATION

- What counties have the highest incidence? **REGISTRY**
- What counties have the highest mortality? **REGISTRY**
- What counties have late-stage disease diagnosed? **REGISTRY**
- Where are screening rates the lowest? **BRFSS**
- Where are the populations that experience disparities in outcomes? **CENSUS**
- Where are those who are eligible and hardest to reach?
  - Historical reach **CENSUS SMALL AREA HEALTH INSURANCE ESTIMATES** and **CANCER SERVICES PROGRAM HISTORICAL DATA**
  - Rurality **CENSUS**



# COMPOSITE ANALYSIS OF NEED

Mortality	Incidence	Regional Distant Stage Incidence	Population Screening (BRFSS)	Disparities	Reach of CSP <sup>1</sup>	Rurality
<b>BREAST</b>				Counties with Largest % of Uninsured Black Population*	Underperforming	At least 70% of Populaion is Rural
Significantly above Statewide Average (SWA)			Significantly below SWA	Albany County	Bronx County	Allegany
Orange	Wyoming	Wyoming	Sullivan	Bronx County	Erie County	Chenango
Erie	Warren	Kings (Brooklyn)	Rockland	Erie County	Monroe County	Columbia
Bronx	Albany		Mid-Hudson Region	Greene County	Nassau County	Delaware
Kings (Brooklyn)	Putnam			Kings County	New York County	Essex
NYC	Ontario			Monroe County	Niagara County	Greene
	Schenectady			Nassau County	Oneida County	Hamilton
	Erie			New York County	Onondaga County	Lewis
	Nassau			Schoharie County	Queens County	Otsego
	Monroe			Westchester County	Ulster County	Schoharie
	Broome					Schuyler
	Westchester					Sullivan
	New York (Manhattan)					Yates
	NYS Excl NYC					

\*Highlighted because of disparities in mortality and incidence  
<sup>1</sup> Based on 2019 SAHIE and 2019 CSP Screenings

The above summary was used in the NYSDOH's latest application for funding through the  
**National Breast and Cervical Cancer Early Detection Program**

# THANK YOU!



Department  
of Health

**Emily Payne**  
Epidemiologist &  
Comprehensive Cancer  
Control Program Evaluator  
[Emily.Payne@health.ny.gov](mailto:Emily.Payne@health.ny.gov)



# How do we Utilize data in NYS

Tabassum Insaf, PhD, MPH, MBBS

Director, Bureau of Cancer Epidemiology

Scientific Director, New York State Cancer Registry

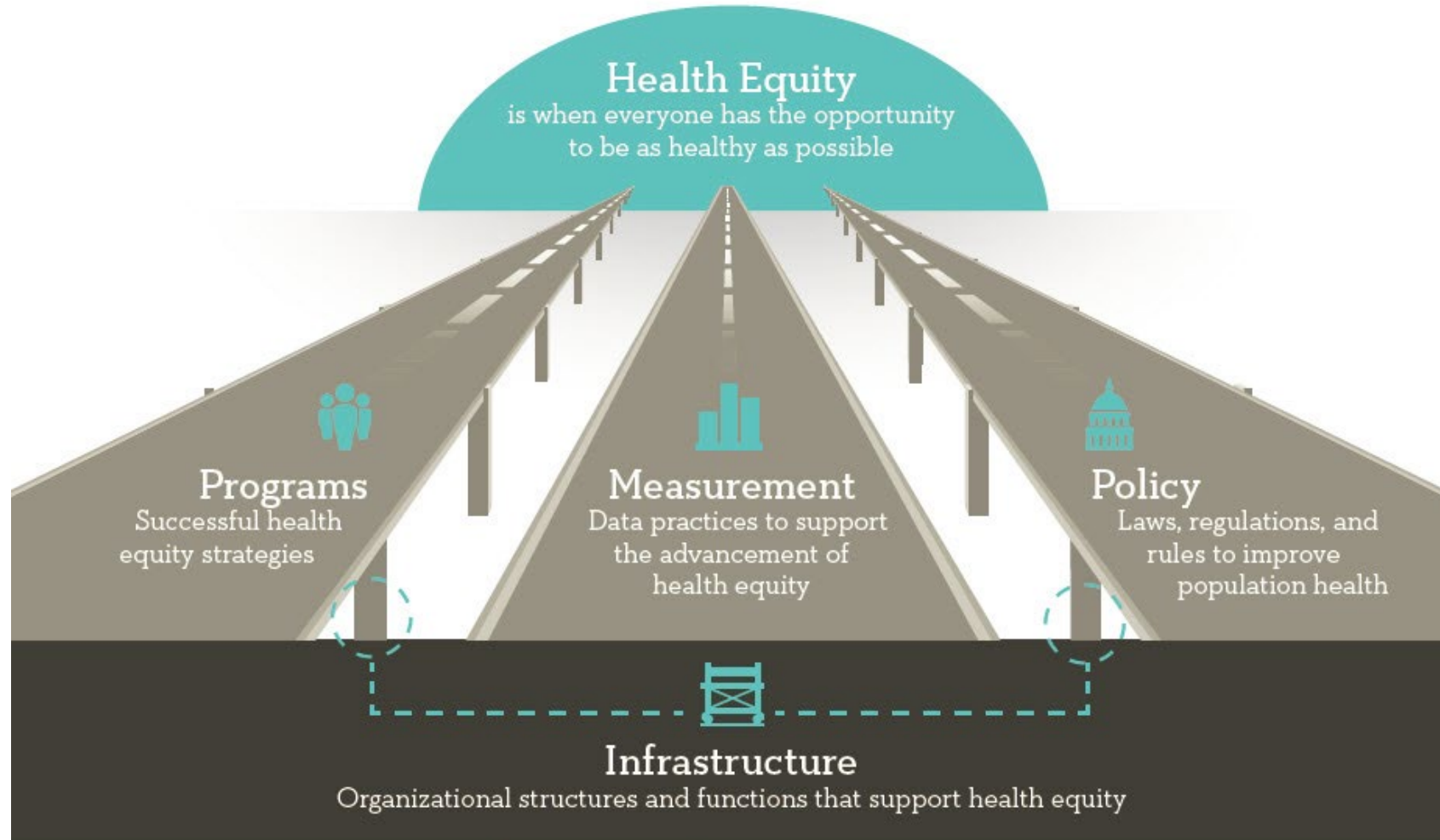
[Tabassum.Insaf@health.ny.gov](mailto:Tabassum.Insaf@health.ny.gov)

# Health Equity and Cancer

Registry data with focus on race/ethnicity data

Current Research projects

# PAVING THE ROAD TO HEALTH EQUITY



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



# Why Do U.S. Cancer Health Disparities Exist?

Complex and interrelated factors contribute to cancer health disparities in the United States. **The factors include, but are not limited to, differences or inequalities in:**

## ENVIRONMENTAL FACTORS

- Air and water quality
- Transportation
- Housing
- Community safety
- Access to healthy food sources and spaces for physical activity



## SOCIAL FACTORS

- Education
- Income
- Employment
- Health literacy



## CULTURAL FACTORS

- Cultural beliefs
- Cultural health beliefs



## BEHAVIORAL FACTORS

- Tobacco use
- Diet
- Excess body weight
- Physical inactivity
- Adherence to cancer screening and vaccination recommendations



## CLINICAL FACTORS

- Access to health care
- Quality of health care



## PSYCHOLOGICAL FACTORS

- Stress
- Mental health



## BIOLOGICAL AND GENETIC FACTORS



# U.S. Cancer Health Disparities

Adverse differences in numerous measures of cancer burden exist among certain U.S. population groups. Examples of disparities in cancer incidence and death rates include:

**MORE THAN  
TWICE**

African American men have a prostate cancer **death rate that is more than twice** that for white men.

**20%  
MORE LIKELY**

Hispanic children are **20 percent more likely to develop leukemia** than non-Hispanic white children.

**TWICE  
AS LIKELY**

Asian/Pacific Islander adults are **twice as likely to die from stomach cancer** as white adults.

**TWICE  
AS LIKELY**

American Indian/Alaskan Native adults are **twice as likely to develop liver and bile duct cancer** as white adults.

**51%  
MORE LIKELY**

Adolescents and young adults (ages 15 to 39) with head and neck cancer who have no insurance are **51 percent more likely to die from their disease** than those who have private insurance.

**35%  
HIGHER**

Men living in the poorest U.S. counties have a **colorectal cancer death rate that is 35 percent higher** than that for men living in the most affluent U.S. counties.

**70%  
MORE LIKELY**

Bisexual women are **70 percent more likely to be diagnosed with cancer** than heterosexual women.



# Presentation Outline

Health Equity and Cancer

**Registry data with focus on race/ethnicity data**

Current Research projects

# Changes in NYSCR Reporting Requirements

NEW YORK STATE DEPARTMENT OF HEALTH  
Bureau Of Cancer Epidemiology

**Malignant Neoplasm--Confidential Case Report**

1. SOUND EX	2. LAST NAME	3. FIRST NAME	4. M.I.	5. MAIDEN NAME	6. DISTRICT NO.	7. YEAR
8. 9. USUAL RESIDENCE--Street Number and Name		10. CITY, TOWN OR VILLAGE		11. STATE	12. ZIP CODE	13. COUNTY
14. AGE	15. DATE OF BIRTH M M D D Y Y Y Y	16. STATE OR COUNTRY OF BIRTH	17. DATE OF DISCHARGE M M Y Y	18. DATE OF DEATH M M D D Y Y	19. CPT RACT	
20. SEX 21. <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 9	22. MARITAL STATUS Never Married <input type="checkbox"/> 1 Married <input type="checkbox"/> 2 Widowed <input type="checkbox"/> 3 Divorced <input type="checkbox"/> 4 Separated <input type="checkbox"/> 5 Unknown <input type="checkbox"/> 9		23. SOCIAL SECURITY NO. - -		24. FULL NAME OF PATIENT'S PHYSICIAN	
25. RACE White <input type="checkbox"/> 1 Black <input type="checkbox"/> 2 American Indian <input type="checkbox"/> 3 Chinese <input type="checkbox"/> 4 Japanese <input type="checkbox"/> 5 Hawaiian <input type="checkbox"/> 6 Other Specify _____						
27. OF SPANISH ORIGIN?? No <input type="checkbox"/> 0 Mexican <input type="checkbox"/> 1 Puerto Rican <input type="checkbox"/> 2 Cuban <input type="checkbox"/> 3 Central or So. American <input type="checkbox"/> 4 Other Spanish Origin <input type="checkbox"/> 5 Specify _____						
28. IS THIS THE FIRST REPORTABLE? Yes <input type="checkbox"/> No <input type="checkbox"/> Unk <input type="checkbox"/> IF NO, GIVE PREVIOUS SITE & DATE OF DIAGNOSIS M M Y Y						
29. WAS THIS CANCER DIAGNOSED AT ANOTHER HOSPITAL? Yes <input type="checkbox"/> No <input type="checkbox"/> IF YES, GIVE HOSPITAL NAME AND CITY						
30. DATE OF ORIGINAL DIAGNOSIS? M M Y Y		31. PRIMARY SITE (INCL. LATERALITY FOR PAIRED ORGANS)		32. SITE	33. LAT	
34. HISTOLOGIC TYPE						
35.						
36. METHOD OF DIAGNOSTIC CONFIRMATION Histology <input type="checkbox"/> 1 Micro Test <input type="checkbox"/> 2 Cytology/Confirm <input type="checkbox"/> 3 Lab Test <input type="checkbox"/> 4 Direct Visual <input type="checkbox"/> 5 X-Ray <input type="checkbox"/> 6 Clinical <input type="checkbox"/> 7 Unknown <input type="checkbox"/> 8 OF DISEASE WHEN FIRST DIAGNOSED						
37. SUMMARY STAGE In Situ <input type="checkbox"/> 0 Localized <input type="checkbox"/> 1 Regional Spread <input type="checkbox"/> 2 Distant <input type="checkbox"/> 3 Not Applicable <input type="checkbox"/> 5 Unknown <input type="checkbox"/> 9						
38. HOSPITAL, TUMOR REGISTRY OR PHYSICIAN REPORTING Name: Address:		39. USUAL OCCUPATION		40.	41. KIND OF BUSINESS OR INDUSTRY	
42.		43. NAME AND LOCALITY OF FIRM OR COMPANY		44. DATE ABSTRACTED M M Y Y		
45. SOURCE		46. HOSPITAL	47. CIGARETTE SMOKER? Present <input type="checkbox"/> 1 Former <input type="checkbox"/> 2 Never <input type="checkbox"/> 3 Unknown <input type="checkbox"/> 9		48. ABSTRACTOR'S INITIALS	
49.						

DOH 1553 (5/89) p. 1 of 2

Collect over 500 data items electronically as Xml files

- Personal identifiers
- Demographic variables
- Tumor Characteristics
- Prognostic indicators
- Treatment information
- Reporting facility information
- Some book-keeping items (i.e., coding version)
- Supporting text (i.e., documentation to validate codes)
- Patient follow up information

Until 1995

2024

Electronic Clinical  
Laboratory Reporting  
System

- Pathology Reporting

Statewide Planning and  
Research Cooperative  
System

- Data linkage studies
- Address, SSN and other  
information

Vital Records (Including  
NYC vital records)

- Mortality status
- Childhood cancers-  
specific studies

National Death Index

Medicaid

- Linkage and collaborative  
research

Other DOH programs

- Congenital malformations  
registry
- Newborn blood spots
- AIDS institute
- Cancer Services Program

Social Security  
Administration

Lexis Nexis

# Data Linkages



# Availability of NYSCR Data

- New interactive and user friendly data dashboard provides age-adjusted incidence and mortality rates for 23 cancer sites, stratified by sex, race, ethnicity and geographic region (<https://www.health.ny.gov/statistics/cancer/registry/>)
- [Special Reports](#) (e.g., Snapshot of Cancer in NYS, tobacco and alcohol related cancers)
- Cancer mapping application
- [Community Health Indicators Reports](#)

Departmental  
web site

## [NYS Cancer Data](#)

- Data by county (years 1995-2021)
- Data by NYC neighborhood (years 2001-2021)

Public access  
data sets

- [CDC Wonder](#)
- [U.S. Cancer Statistics Data Visualizations Tool](#)
- [NCI SEER Cancer Fast Stats](#)
- [SEER\\*Explorer](#)
- [CDC's Environmental Public Health Tracking Network](#)
- [Annual Report to the Nation on the Status of Cancer](#)
- [Cancer in Five Continents](#)
- [GLOBOCAN database](#)

Data submissions to  
standard setters

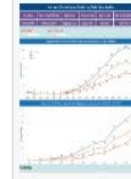
- New York State/Region Cancer Statistics Dashboards



[Overview of Cancer Statistics in New York State](#)



[Cancer Incidence and Mortality Rates by Year](#)



[Cancer Incidence and Mortality Rates by Age](#)



[Cancer Incidence and Mortality Rates by Expanded List of Cancer Sites](#)



[Childhood Cancer Incidence Rates in New York State](#)



[Distribution of Stage at Cancer Diagnosis by Race/Ethnicity and Year](#)

- New York County/NYC Neighborhood Cancer Statistics Dashboards



[Cancer Incidence and Mortality Rates by County](#)



[Cancer Incidence and Mortality Rates by Race and Ethnicity](#)



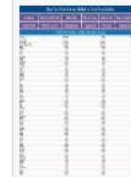
[Cancer Incidence Rates by New York City Neighborhood \(PUMA\)](#)



[Distribution of Stage at Cancer Diagnosis by County](#)

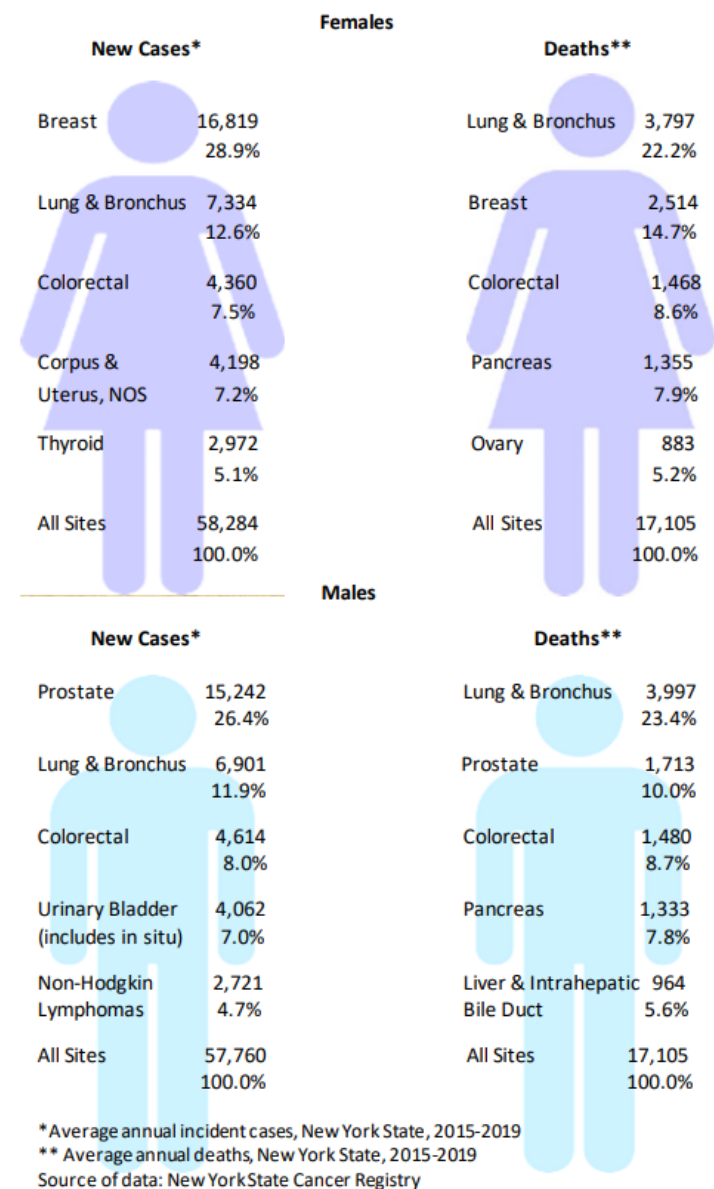


[Estimates of Cancer Survivors by County](#)



[Population Counts by County/PUMA](#)

Figure 1. Most frequently diagnosed cancer types and causes of cancer death in males and females, New York State, 2015-2019



## Cancer Burden Reports

### General

- [Snapshot of Cancer in NYS](#) (PDF)

### Alcohol

- [Alcohol-Related Cancers in New York State, 2016-2020](#) (PDF)

### Cancer Screening

- [Screening-Detectable Cancers 2015-2019](#) (PDF)
- [Screening-Detectable Cancers 2013-2017](#) (PDF)
- [Screening Amenable Cancers in New York State, 2011-2015](#) (PDF)

### Environmental Health

- [Environmental Facilities and Cancer Mapping](#)

### Human Papillomavirus

- [HPV-Related Cancer Incidence and HPV Vaccination Rates in New York State, 2015-2019](#) (PDF)
- [HPV-Related Cancer Incidence and HPV Vaccination Rates in New York State, 2013-2017](#) (PDF)
- [HPV-Related Cancers and HPV Vaccination Rates in New York State, 2011-2015](#) (PDF)

### Obesity

- [Obesity-Related Cancers in New York State, 2004-2018](#) (PDF)

### Skin Cancer

- [Skin Cancer in New York State 2020 Report](#) (PDF)
- [Skin Cancer in New York State 2017 Report](#) (PDF)

### Tobacco

- [Tobacco-related Cancers in New York State, 2016-2020](#) (PDF)
- [Tobacco-related Cancers in New York State, 2014-2018](#) (PDF)

## + Information for Action Reports

## + Behavioral Risk Factor Briefs

## + New York State Cancer Programs Reports

# Race and Ethnicity Coding

## SEER Manual Background Information

- The SEER manual states that race and ethnicity are defined by specific physical, hereditary and cultural traditions or origins, not necessarily by birthplace, place of residence, or citizenship.
- All resources in the facility, including the medical record, face sheet, physician and nursing notes, photographs, and any other sources, must be used to determine race.



Data Item Name	Description	Coding	Notes
<b>Race 1 - Race 5 [#160-164]</b>	There are five race data items making it possible to code multiple races for one person.	Directly coded by facility CTR and consolidated at the central registry	<u>Sources in Priority Order:</u> a. The patient's self-declared identification b. Documentation in the medical record c. Death certificate
<b>Spanish/Hispanic Origin [#190]</b>	Used to identify patients with Spanish/Hispanic surname or of Spanish origin.	Directly coded by facility CTR and consolidated at the central registry	Coding Spanish Surname or Origin is not dependent on race. A person of Spanish descent may be White, Black, or any other race."

Data Item Name	Description	Coding	Notes
<b>NAPIIA [#193]</b>	NAACCR Asian/Pacific Islander Identification Algorithm	Derived by the NYS Central Registry	uses an algorithm to recode unknown/NOS values using birthplace and name.
<b>NHIA [#191]</b>	NAACCR Hispanic Identification Algorithm	Derived by the NYS Central Registry	The algorithm uses the following standard variables: Spanish/Hispanic Origin [190]; Name--Last [2230]; Name--Maiden [2390]; Birthplace [250]; Race 1 [160]; IHS Link [192]; Sex [220]
<b>IHS Link [#192]</b>	Indian Health Service Link- This variable captures the results of the linkage of the central registry database with the Indian Health Service patient registration database.	Coding is done by NYS Central Registry analytic staff, using the results of the linkage with IHS.	identifies American Indians who were misclassified as non-Indian in the registry

# Changes to come?

- With the 2020 census, improvements were made in coding and collection of race/ethnicity data
- enabled a more thorough and accurate depiction of how people self-identify, yielding a more accurate portrait of how people report their Hispanic origin and race within the context of a two-question format.
- reveal that the U.S. population is much more multiracial and more diverse than what was measured in the past.
- With the 2030 census, race and ethnicity data collection may change significantly
- Proposals for
  - Combining Race and Ethnicity into one variable  
[Census Ready to Study Combining Race, Ethnicity Questions \(usnews.com\)](https://www.usnews.com/story/health/census-ready-to-study-combining-race-ethnicity-questions)
  - adding a Middle Eastern and North Africa category.
- This likely means the way the cancer registry collects these data will change
- Denominator data used to calculate rates may change.

# Presentation Outline

Health Equity and Cancer

Registry data with focus on race/ethnicity data

**Current Research projects**

# Current Studies with a Racial Justice Focus



The North-South Breast Cancer Study

Diagnosis Experience Survey



Racial Disparity in Diagnostic Evaluation of Uterine Cancer

ORCHiD (Ovarian Cancer Epidemiology, Healthcare Access and Disparities)



RESPOND (Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers and Social Stress)



African American Cancer Epidemiology Study (AACES)



Reducing Disparities in the Adverse Impact of Cancer in Young Adult Latino Men



Effects of Respiratory Muscle Training on Dyspnea and Immunosuppression in Black and White Lung Cancer Survivors

# The North-South Breast Cancer Study

- Seeks to examine factors that contribute to differences in breast cancer aggressiveness and outcomes in women who are non-Hispanic Black (NHB) and non-Hispanic White (NHW)
  - Includes factors related to stress, discrimination, and perceived neighborhood characteristics
- Collaboration with Roswell Park Cancer Institute and Louisiana Tumor Registry
- Registry staff will contact up to 5,000 breast cancer patients per year (and their managing physician)



Diagnosis Experience Survey

## Racial Disparity in Diagnostic Evaluation of Uterine Cancer

- Seeks to reduce racial disparity in early diagnosis of uterine cancer by examining diagnostic pathways and identifying barriers to early diagnosis in women who are Black
- Registry staff contacted approximately 600 potentially eligible patients (and their managing physician) matched on race and diagnosis date
- Collaboration with Yale University and Georgia Cancer Registry



# ORCHiD (Ovarian Cancer Epidemiology, Healthcare Access and Disparities)



- Seeks to characterize healthcare access among Black, Hispanic, and White patients with ovarian cancer, and the impact of access on quality of treatment, supportive care, and survival
- Collaboration with Duke University- multistate study

# RESPOND (Research on Prostate Cancer in Men of African Ancestry)



- Seeks to identify why men of African Ancestry have higher risk of prostate cancer and more aggressive forms of the disease
  - Focuses on a wide range of potential factors, including genetic, lifestyle, social, and medical care-related factors
- Collaboration with University of Southern California; multistate study

# African American Cancer Epidemiology Study (AACES)



- Seeks to better understand the causes and survival of ovarian cancer and related cancers in African American women
  - Will examine multiple factors including social and built environment, patient characteristics, and tumor immune microenvironment
- Collaboration with Emory University and multiple other sites throughout the U.S.

## Reducing Disparities in the Adverse Impact of Cancer in Young Adult Latino Men

- Seeks to evaluate the efficacy of goal-focused emotion-regulation therapy (GET) as a novel behavioral intervention to enhance self-regulation through improved goal navigation skills, improved sense of purpose, and better ability to regulate emotional responses in Latino young adult men with a recent cancer diagnosis
- Collaboration with University of California, Irvine

# Effects of Respiratory Muscle Training on Dyspnea and Immunosuppression in Black and White Lung Cancer Survivors

- Seeks to enroll lung cancer survivors into a home-based respiratory muscle training program, to examine the impact on dyspnea, quality of life, and immune markers associated with improved prognosis
- Collaboration with Roswell Park- expected to begin in 2025

## Additional studies-

### Historic Red lining Study

- Collaboration with University at Buffalo- looking at effect of historic redlining on breast cancer incidence and outcomes.

### ENCLAVE project

- Multisite study with Greater Bay of California Cancer Registry- Study of cancer outcomes in ethnic enclaves (community neighborhoods)

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# Thank You !!

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