

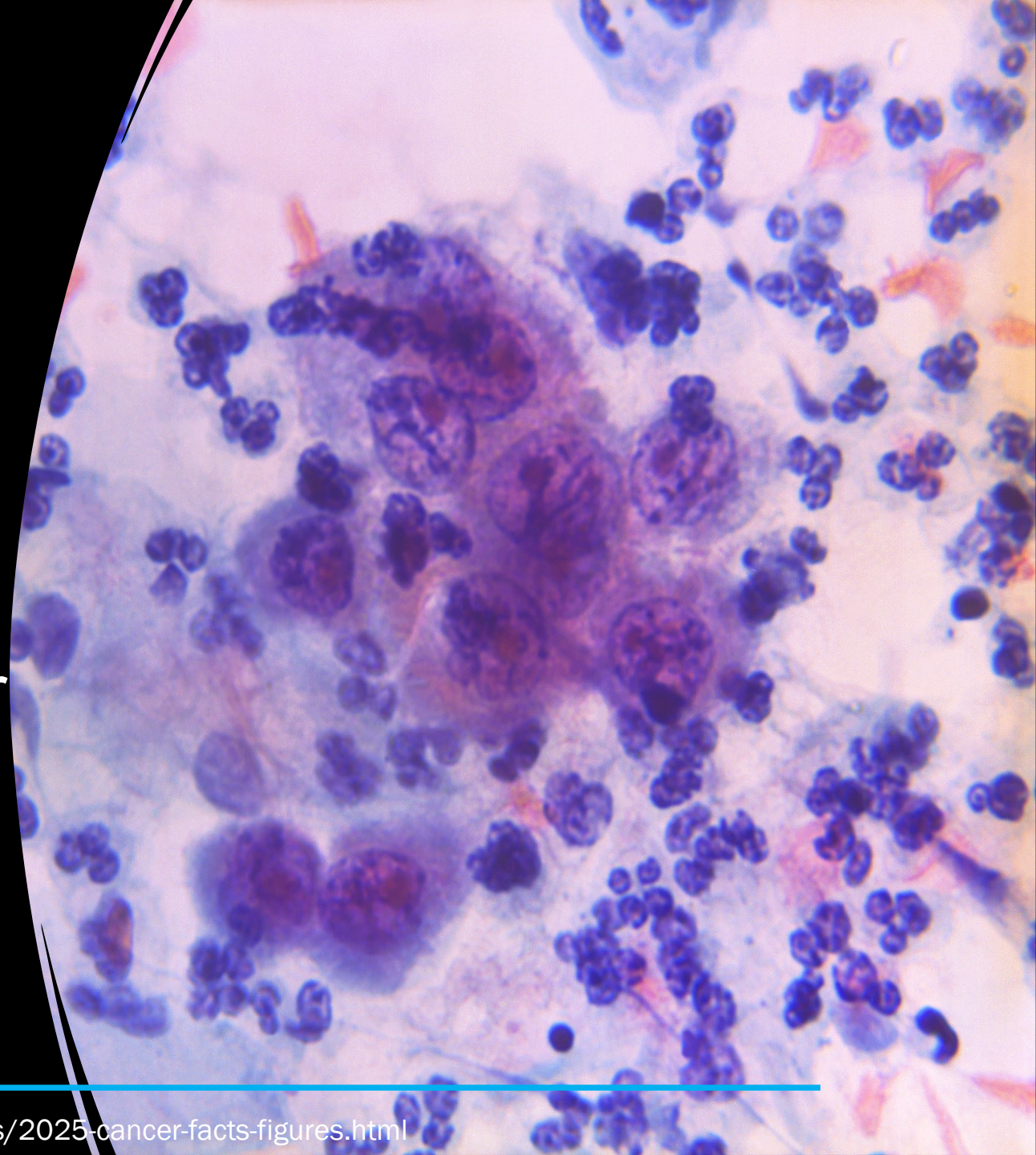
Why are state cancer registries critically important in the fight against cancer?

1. Registries tell you how important cancer is

1 in 3 Americans will get cancer

Every day, 5,600 Americans are newly diagnosed with cancer

Every minute, 1 American dies from cancer



2. Registries are a cornerstone of cancer research

PubMed research publications including “cancer registry/ registries”, “SEER”, or “cancer surveillance” → **42,756 research papers**

Even more studies & clinical guidelines cite cancer registry data, covering:

- Trends in incidence and mortality
- Cancer in children, adolescents, young adults
- Early onset cancer (<50)
- How to prevent cancer
- How best to screen for cancer
- What are the causes of cancer?
- Who is at greater risk of cancer?
- Investigating “cancer clusters”
- Is treatment effective?
- Is treatment cost effective?
- Developing new treatments
- Developing standard treatment guidelines
- How long do people live after diagnosis?
- Factors predicting good or bad outcomes
- Who is at risk of a second cancer?
- Whose family is at greater risk of cancer?

2. Registries are a cornerstone of cancer research

The most cited publications on aging & cancer are registry-based
(Top 10 from Web of Science through 2022)

Rank	Article title	Times cited	Published	Citations per year
1	Cancer statistics, 2010	39,141	2010	3262
2	Cancer statistics, 2014	20,730	2014	2591
3	Cancer statistics, 2016	16,789	2016	2798
4	Cancer statistics in China, 2015	12,298	2016	2050
5	Cancer statistics, 2008	9642	2008	689
6	Cancer statistics, 2009	9047	2009	696
7	Cancer statistics, 2018	6774	2018	1693
8	Cancer statistics, 2007	6614	2007	441
9	Effects of chemotherapy and hormonal therapy for early breast cancer on recurrence and 15-year survival: an overview of the randomized trials	5599	2005	329
10	Cancer statistics, 2020	5533	2020	2766.5

3. We provide data for many important studies

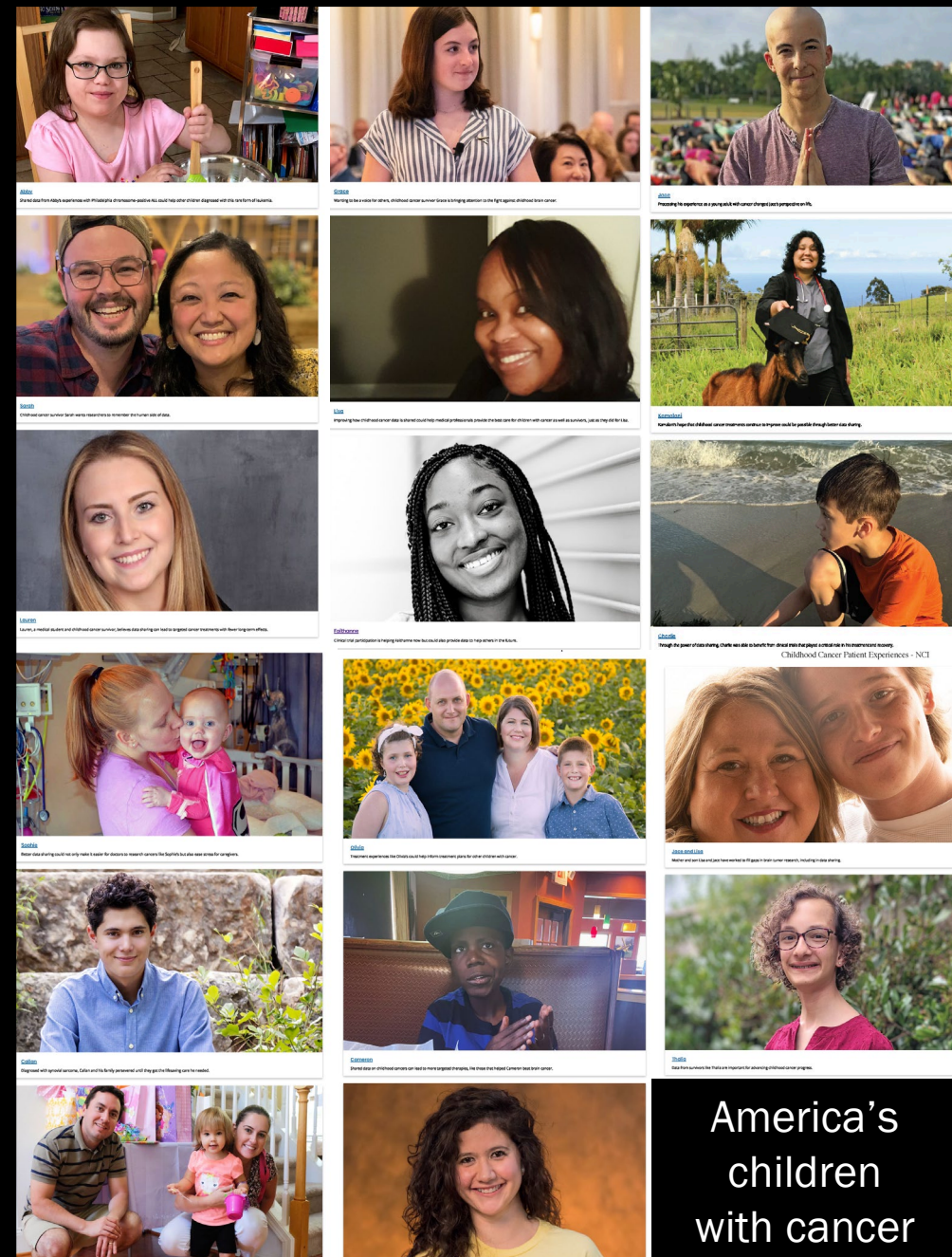
EXAMPLES

- Breast Cancer Surveillance Consortium
- California Teachers Study
- Cohort Study of Lead-Exposed Workers
- Colon Cancer Family Registry
- Cancer Prevention Study-3
- Childhood Cancer Survivor Study
- Iowa Women's Health Study
- National Childhood Data Initiative
- National Firefighter Registry for Cancer
- New England Bladder Cancer Study
- NIH-AARP Study
- Skin Cancer Prevention Study
- Southern Community Cohort Study
- Transplant Cancer Match Study
- U.S. Radiologic Technologist Study
- Women's Health Initiative

3. We provide data for many important studies

National Childhood Cancer Data Initiative

- Aims to pool data for every US child, adolescent & young adult with cancer, using cancer registry data to create the largest, strongest possible dataset for research
- This initiative needs data from every state. Funding for all state cancer registries is critical



America's
children
with cancer

4. We provide data for many important public health interventions

EXAMPLES

Breast & Cervical Cancer Early Detection Program

- Congressionally mandated CDC-funded screening for low-income women

Comprehensive Cancer Collaboration

- Cancer coalitions in all states to reduce the burden of cancer

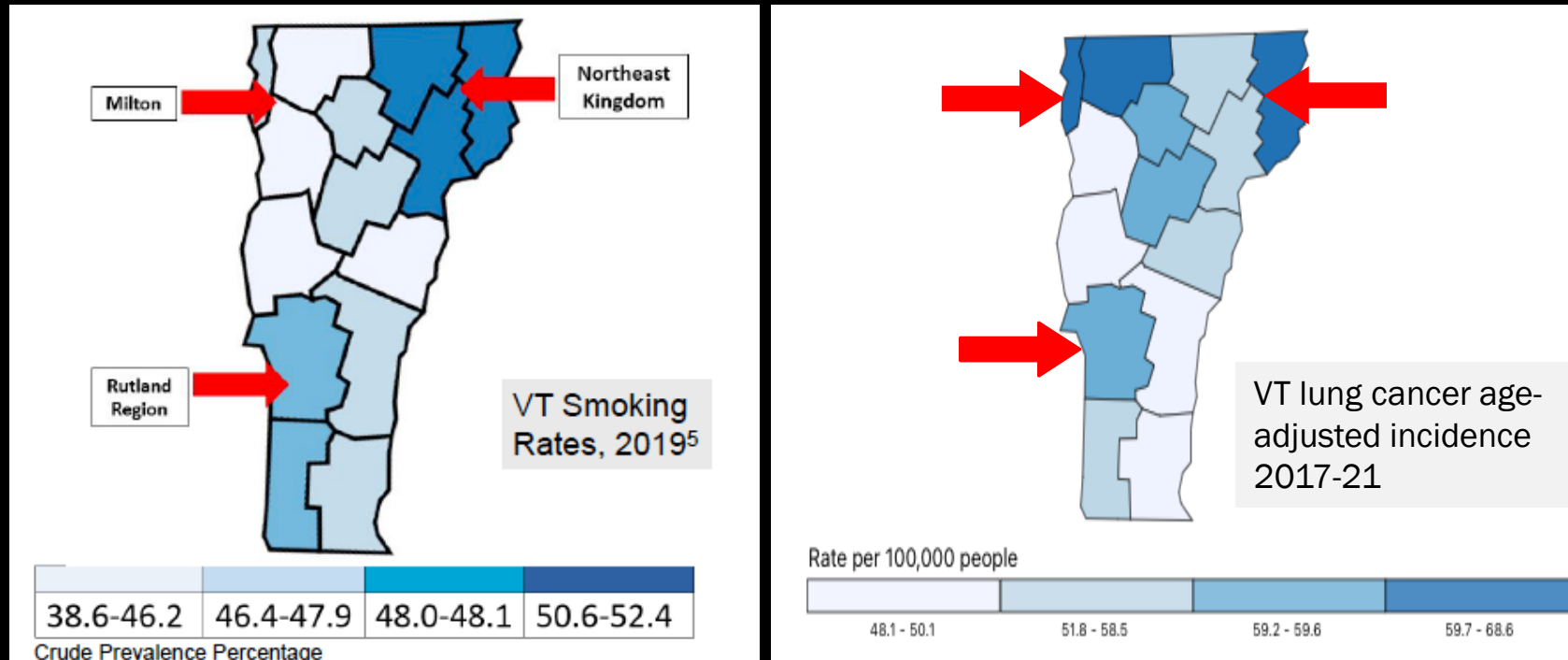
NCI Cancer Center Support Grants (P30)

- 57 NCI-designated Comprehensive Cancer Centers, whose work includes outreach to reduce cancer burden in catchment areas

World Trade Center Health Program

- Covers health care for 137,000 responders and survivors

4. We provide data for many important public health interventions



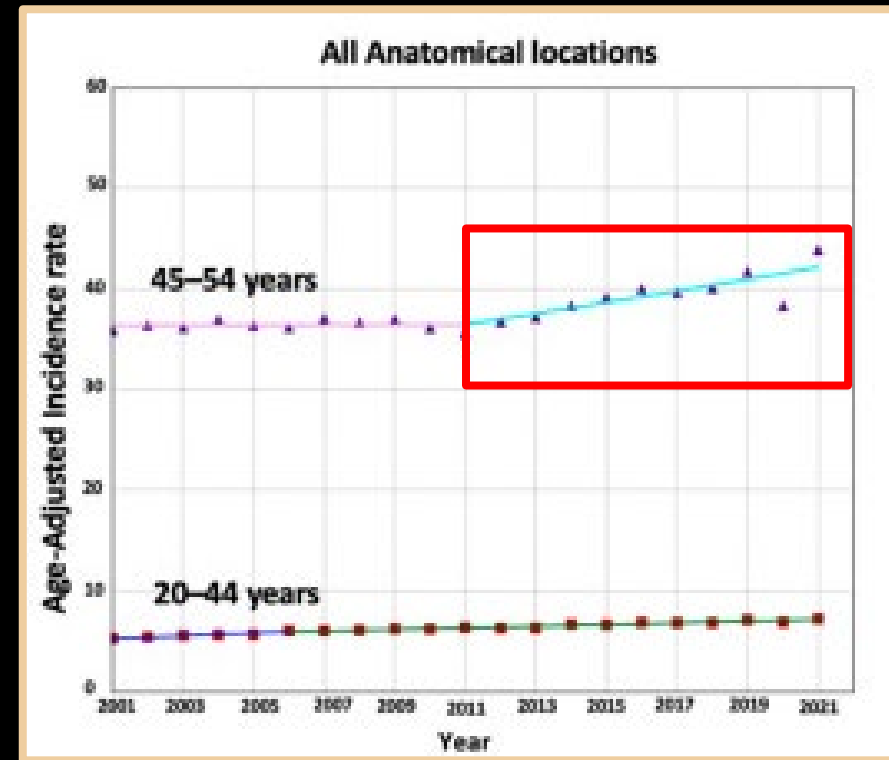
Lung cancer screening interventions in Vermont targeted resources to areas of greatest need, based on smoking prevalence & lung cancer incidence

5. We identify concerning trends over time

Early-onset colorectal cancer is increasing:

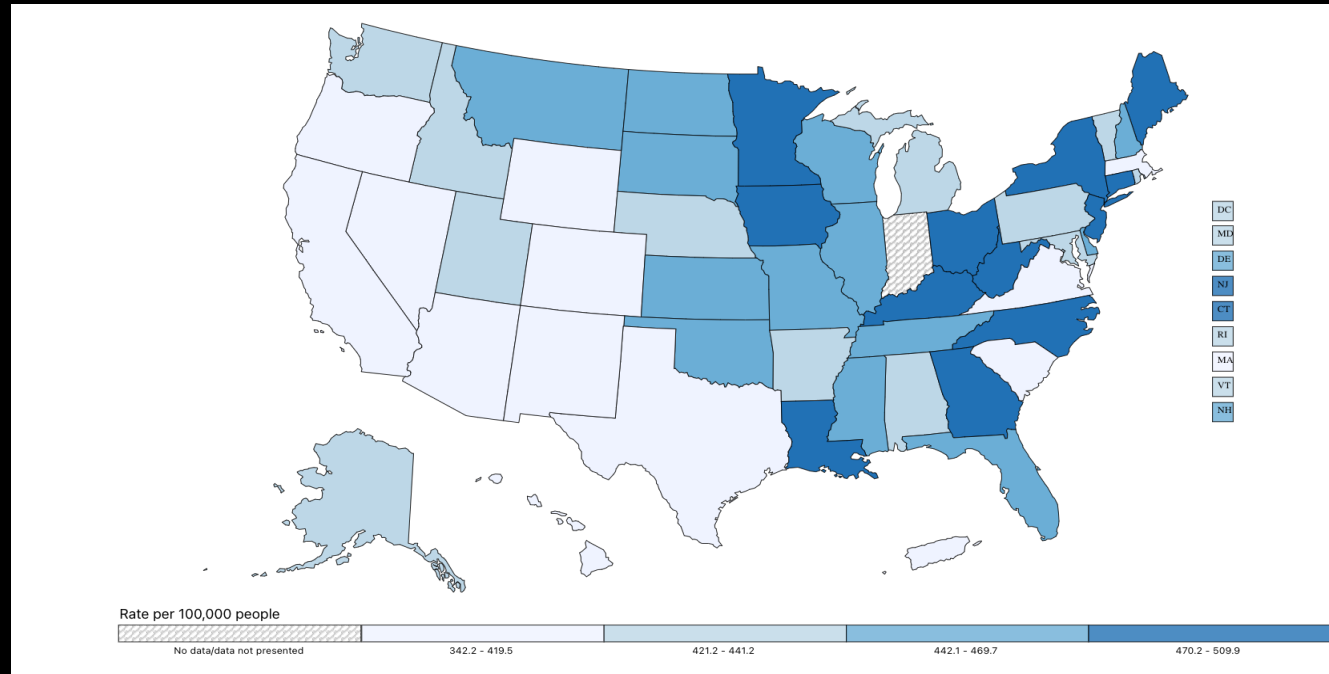
- in ages 45-54 by 0.7% per year
- in ages 20-44 by 1.5% per year

And the Colon Cancer Family Registry, using cancer registry data has taught us a lot about inherited cancer syndromes & early-onset cancer (>700 published research papers)



6. We identify concerning patterns

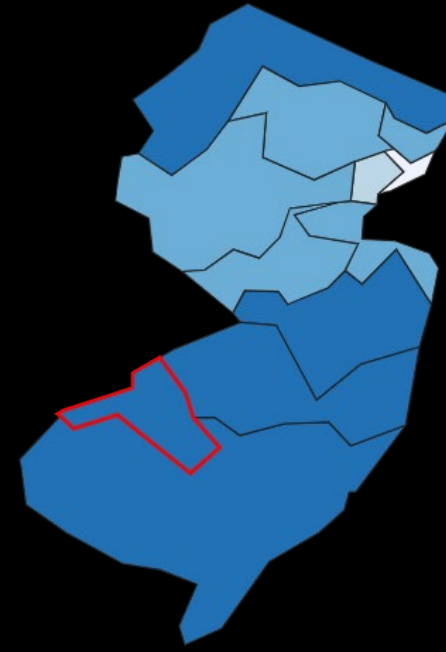
Kentucky's cancer rate is 39% higher than New Mexico's



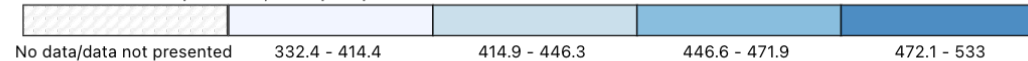
7. We inform legislators about cancer in their districts

California Congressional District 24 has the highest rate of cancer in CA - 22% higher than District 28

New Jersey Congressional District 1 has the highest rate of cancer in NJ - 14% higher than District 12



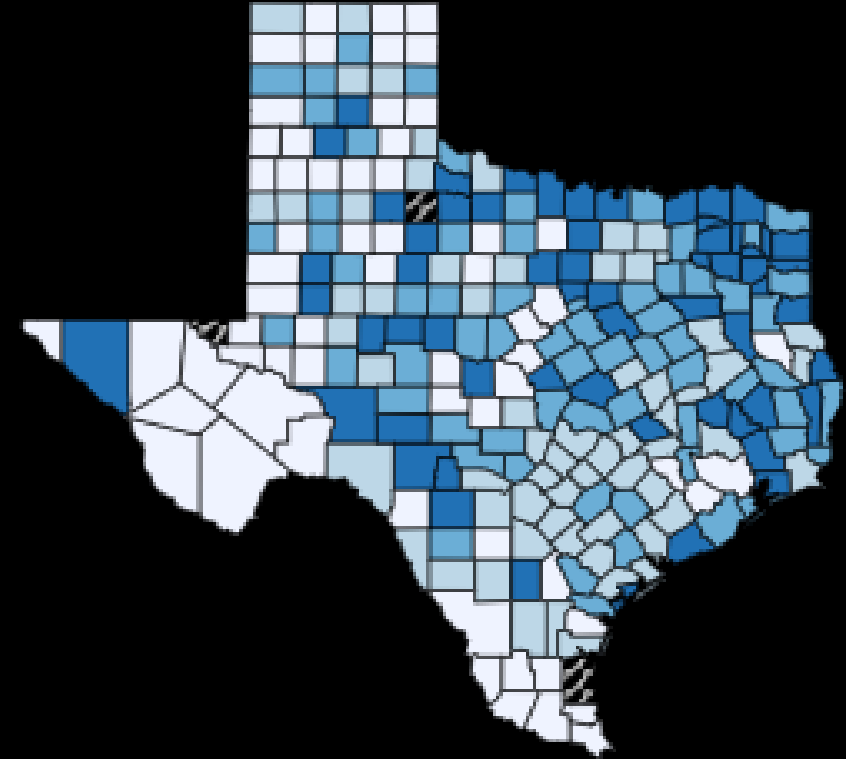
Estimated rate per 100,000 people



8. We inform legislators about concerning trends

Texas Cancer Registry reported to legislators on cancers before age 50, with increases in:

- Early-onset uterine cancer (APC 3.5%)
- Early-onset colorectal cancer (APC 2.3%)
- Early-onset kidney cancer, breast cancer



APC = Annual Percent Change

<https://narrative.naaccr.org/tcr-investigates-early-onset-cancer-trends/> <https://gis.cdc.gov/cancer/USCS/#/StateCountyTerritory/>

9. We inform public policy



President Trump cited cancer statistics in Feb 2025 Executive Order:

“Across 204 countries and territories, the United States had the highest age-standardized incidence rate of cancer in 2021, nearly double the next-highest rate. Further, from 1990-2021, the United States experienced an 88 percent increase in cancer, the largest percentage increase of any country evaluated.”

10. We provide data to investigate community cancer concerns

EG Camp LeJeune Study, North Carolina

1953-85 - US Marine Corps Base Camp Lejeune's drinking water highly contaminated eg TCE, benzene, vinyl chloride

54 US Cancer Registries identified cancers for the study

↑ hematological cancers, lymphoma, & cancers of esophagus, larynx, thyroid, lung

~ 1 million people exposed over 32 years

Disability & healthcare benefits provided to Veterans & families

10. We provide data to investigate community cancer concerns

EG Merrimack, NH Kidney Cancer Study

- PFAS manufactured in Merrimack Town, NH, entered public drinking water via air from the factory
- 2023 Merrimack Town kidney cancer SIR 1.42 (95% CI 1.10-1.81)
- Led to State funding of pilot study to investigate it and the factory is being demolished

State Rep Wendy Thomas has dealt with “cancer that she attributes to 12 PFAS chemicals detected in her blood above the toxic limit for humans”



Article by Mara Hoplamazian, <https://www.nhpr.org/nh-news/2024-12-13/saint-gobain-is-demolishing-its-facility-in-merrimack-but-what-will-happen-to-lingering-contamination>
<https://www.dhhs.nh.gov/sites/g/files/ehbemt476/files/inline-documents/sonh/cancer-incident-report-merrimack-nh-january2023.pdf>
<https://newhampshirebulletin.com/2025/01/30/those-harmed-by-forever-chemicals-have-six-years-to-sue-in-nh-lawmakers-want-more-time/>

11. We identify people at greater risk from cancer

- Firefighters are at greater risk of cancers
 - Pleura (60% higher risk), testis (34%), thyroid (22%), melanoma (21%), prostate (15%), colon (14%), bladder (12%), rectum (9%)
- Firefighter Cancer Registry Act of 2018
 - Began the National Firefighter Registry for Cancer, run by NIOSH
- This initiative needs data from every state.
Funding for all state cancer registries is critical



11. We identify people at greater risk from cancer

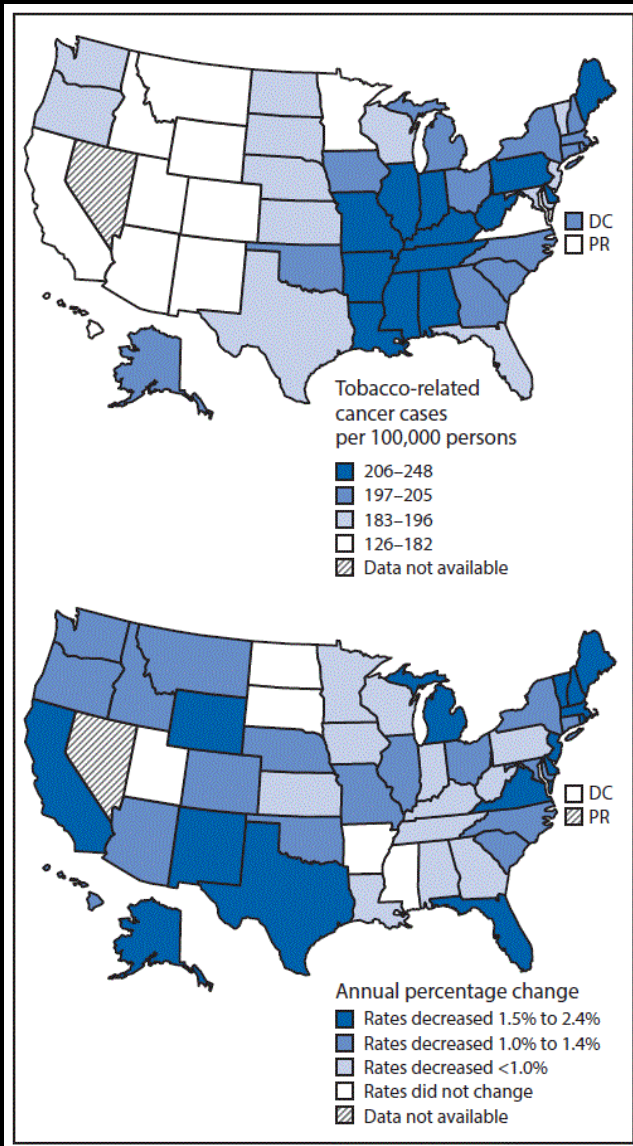
FANS Study (PI Scarlett Gomez)



Investigates the unexpectedly high rates of lung cancer in
Female Aasian Never Smokers

- Usually, 15% of people diagnosed with lung cancer are 'never smokers'
- But 57% of Asian American women diagnosed with lung cancer have never smoked

12. We show if investments in public health are working



Tobacco causes at least 12 types of cancer

These cancer rates are very different on the east and west sides of the country

Tobacco-related cancer incidence has decreased significantly in 44 states

Age-adjusted rate of tobacco-related cancers (2009–2013) and trends in rates (2004–2013), by state — NPCR and SEER, United States

13. Registries help identify causes of cancer

Our understanding of cancer risk due to ionizing radiation was based on cancer registries in Hiroshima and Nagasaki, Japan



13. Registries help identify causes of cancer

... 80 years on, minimizing radiation exposure from CT scans is being prioritized.

~ 4870 cancers may result from the 4 million CT scans done every year on US children.

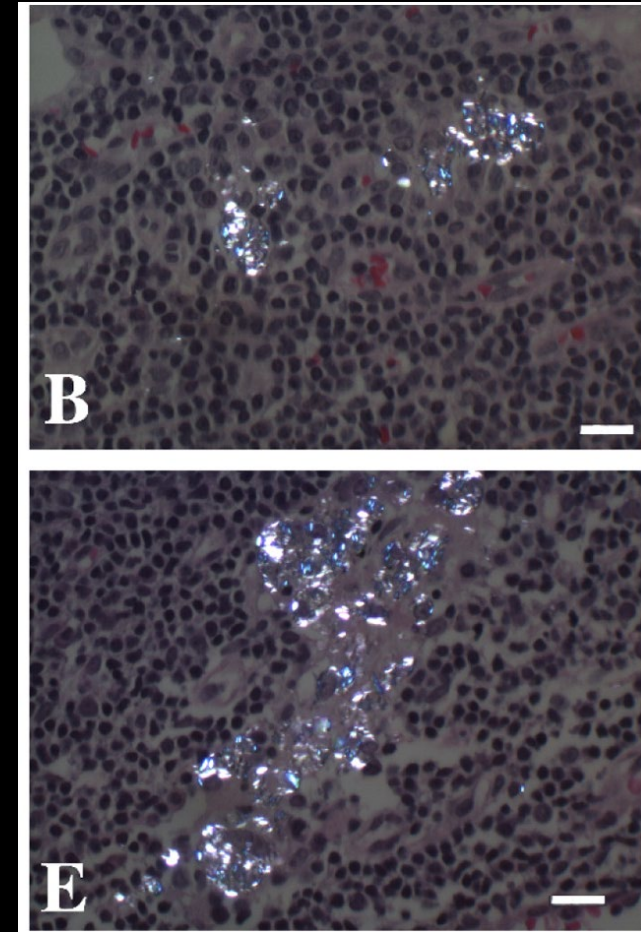


13. Registries help identify causes of cancer

Ovarian cancer studies -

- 1992 - talcum powder linked to ovarian cancer
- Talc contaminated with asbestos is classified as a carcinogen (IARC Group 1)
- Talc alone is classified as a probable carcinogen (IARC Group 2A)

2023 - Johnson & Johnson discontinued talc-based baby powder

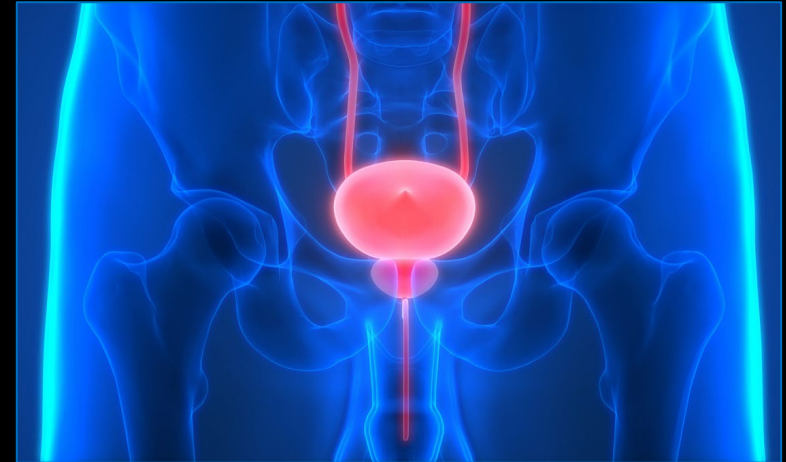


Talc in ovarian cancer lymph nodes

13. Registries help identify causes of cancer

Bladder cancer studies -

- Exposure to arsenic in drinking water is linked to bladder cancer
 - **even at low concentrations**
- 2021 NH law reduced arsenic MCL in drinking water from 10 to 5 ppb....
- ... and led to a large birth cohort study of early life exposures to arsenic & other environmental health risk factors

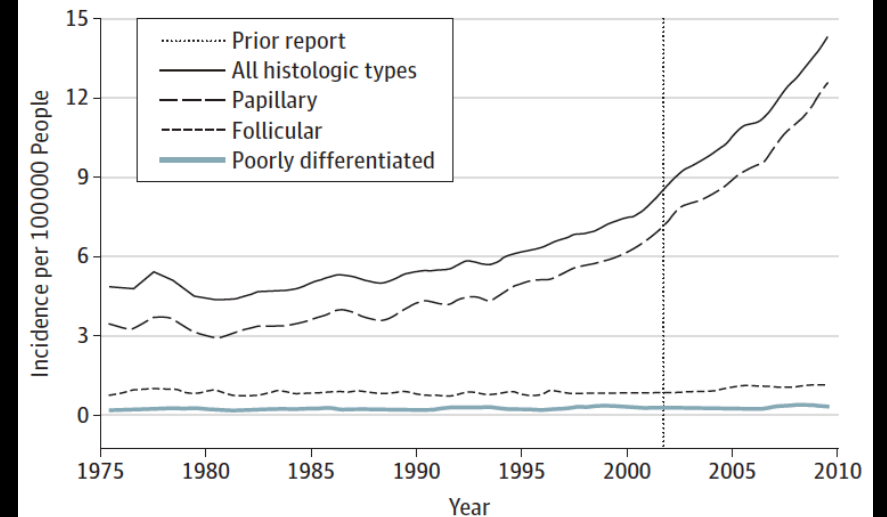


13. Registries help identify causes of cancer

Thyroid cancer studies -

- Increasing thyroid cancer in US first reported through Connecticut Cancer Registry after Chernobyl disaster,¹ driven by small papillary thyroid cancer²
- Mortality is stable
- Radiologic imaging is playing a role in diagnosis or causality³

Figure 2. Thyroid Cancer Incidence by Histologic Type, 1975 to 2009



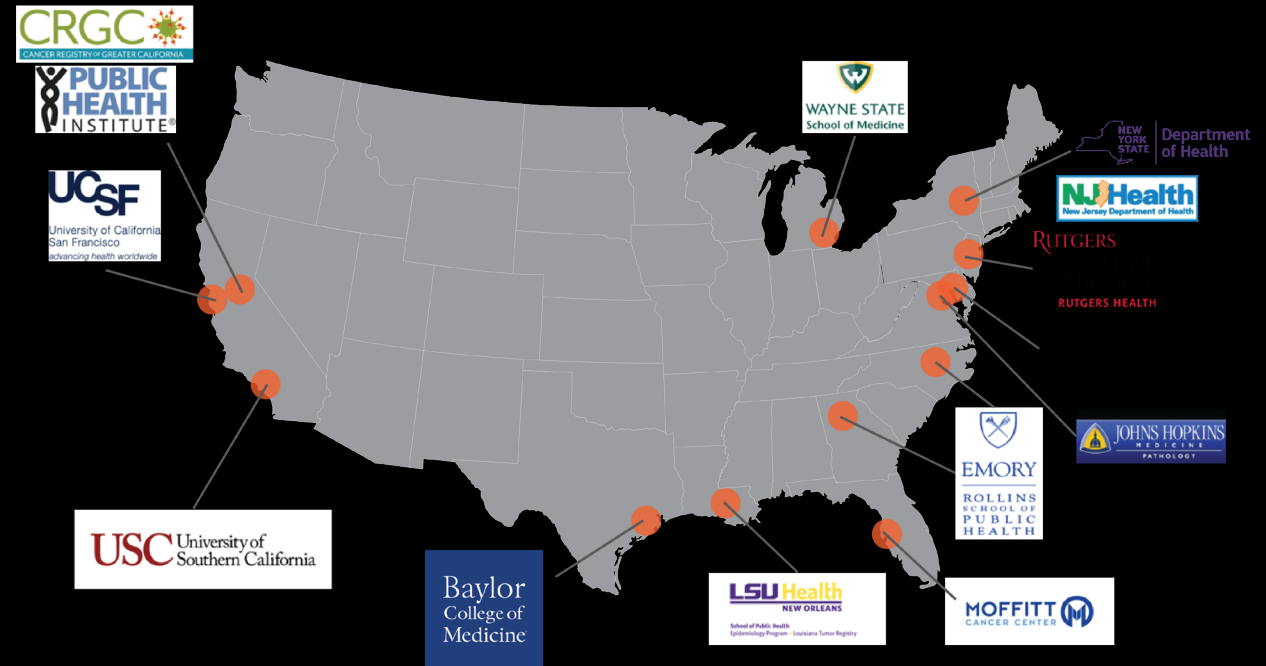
Trends are shown for thyroid cancer of all histologic types and for the 3 major histologic groups: papillary, follicular, and poorly differentiated cancers (anaplastic and medullary). Data are from Surveillance, Epidemiology, and End Results (SEER) 9, 1975 to 2009, maintained by the National Cancer Institute, National Institutes of Health, released April 2012, based on the November 2011 submission.

Cramer. Surgery 2010. 148(6): 147-1153

14. We help understand how complex cancer is

The RESPOND cohort

- The largest study ever of prostate cancer health in 12,500 African American men
- Participants identified through cancer registries



15. Our data is cited in key clinical guidelines

- Breast cancer screening 2024
 - All women screen every other year from 40 (vs. start between 40-50)
- Colorectal cancer screening 2021
 - Start to screen from 45 (lowered from 50)
- Lung cancer screening 2021
 - Annual low-dose CT in adults 50-80y with a 20 pack-year smoking history and currently smoke or have quit within past 15 years.



15. Our data is cited in key clinical guidelines

Skin cancer: screening	2023
Breast Cancer: Medication Use to Reduce Risk	2019
BRCA-Related Cancer: Risk assessment, genetic counselling & testing	2019
Pancreatic Cancer: Screening	2019
Cervical Cancer: Screening	2018
Prostate Cancer: Screening	2018
Skin Cancer Prevention: Behavioral Counseling	2018
Ovarian Cancer: Screening	2018
Thyroid Cancer: Screening	2017
Oral Cancer: Screening	2013



Trends in five-year relative survival (%), US, 1975-2020

Site	1975-77	1995-97	2014-2020
All sites	49	63	69
Breast (female)	75	87	91
Colon & rectum	50	61	64
Leukemia	34	48	67
Liver & intrahepatic bile duct	3	7	22
Lung & bronchus	12	15	27
Melanoma of the skin	82	91	94
Non-Hodgkin lymphoma	47	56	74
Ovary	36	43	51
Pancreas	3	4	13
Prostate	68	97	97
Uterine cervix	69	73	67
Uterine corpus	87	84	81

Survival is age adjusted for normal life expectancy and are based on cases diagnosed in the Surveillance, Epidemiology, and End Results (SEER) 9 areas for 1975-1977 and 1995-1997 and in the SEER 22 areas for 2014-2020; cases followed through 2021.
Data source: Surveillance, Epidemiology, and End Results program. National Cancer Institute, 2025.
©2025, American Cancer Society, Inc., Surveillance and H





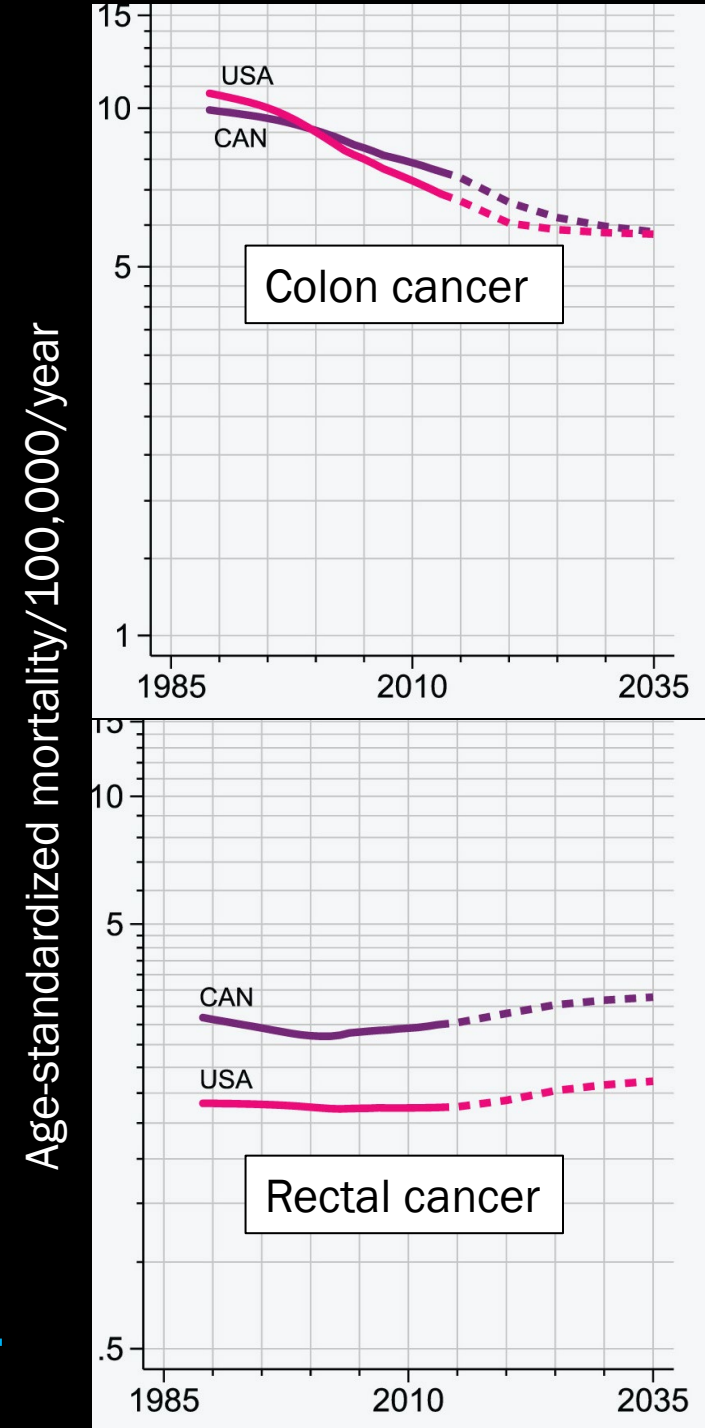
16. We show you if cancer treatments are working

EXAMPLE

Compared to the 1970's, twice as many patients (67% v 34%) now live more than 5 years after leukemia diagnosis

17. We help plan for the future

- Despite decline in overall colorectal cancer mortality rate (2013-2035), there are opposite trends for colon  and rectal cancer 
- The number of rectal cancer deaths will double by 2035 in the U.S.



17. We help plan for the future

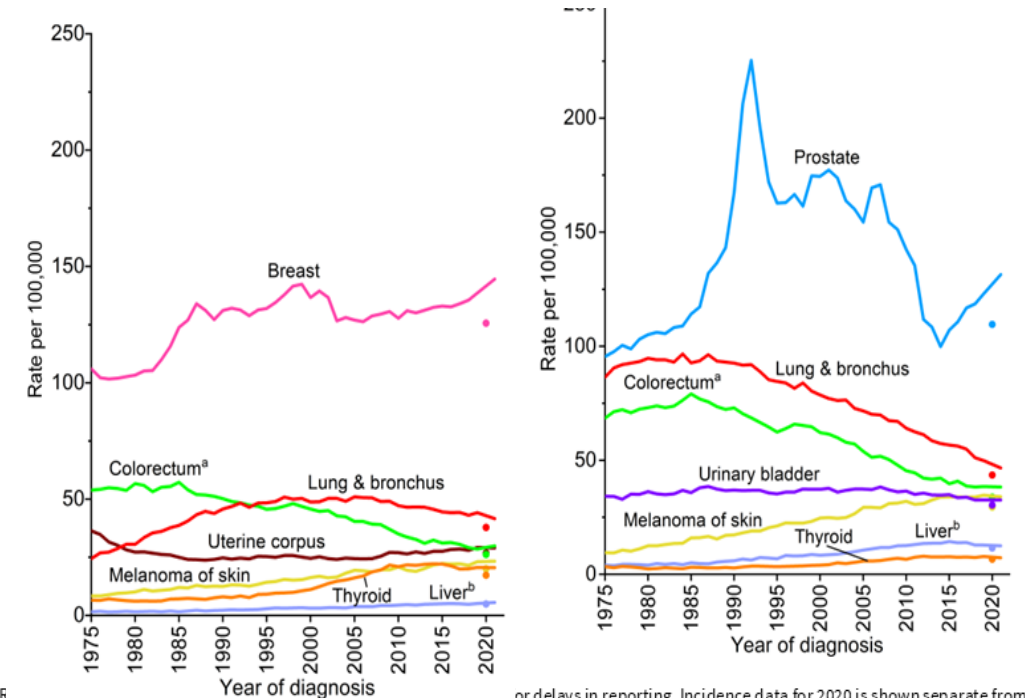
Cancer surveillance helps plan for the future but national and state cancer patterns are not necessarily the same

EXAMPLE

- US liver cancer is decreasing by 1.2% each year
- But in Maine, it's increasing by 2.7%

Every state must have a cancer registry

US trends in cancer incidence, Females and males, 1975-2021



R

^aExcludes appendix

^bIncludes intrahepatic bile duct.

Data source: Surveillance, Epidemiology, and End Results program, National Cancer Institute, 2024.

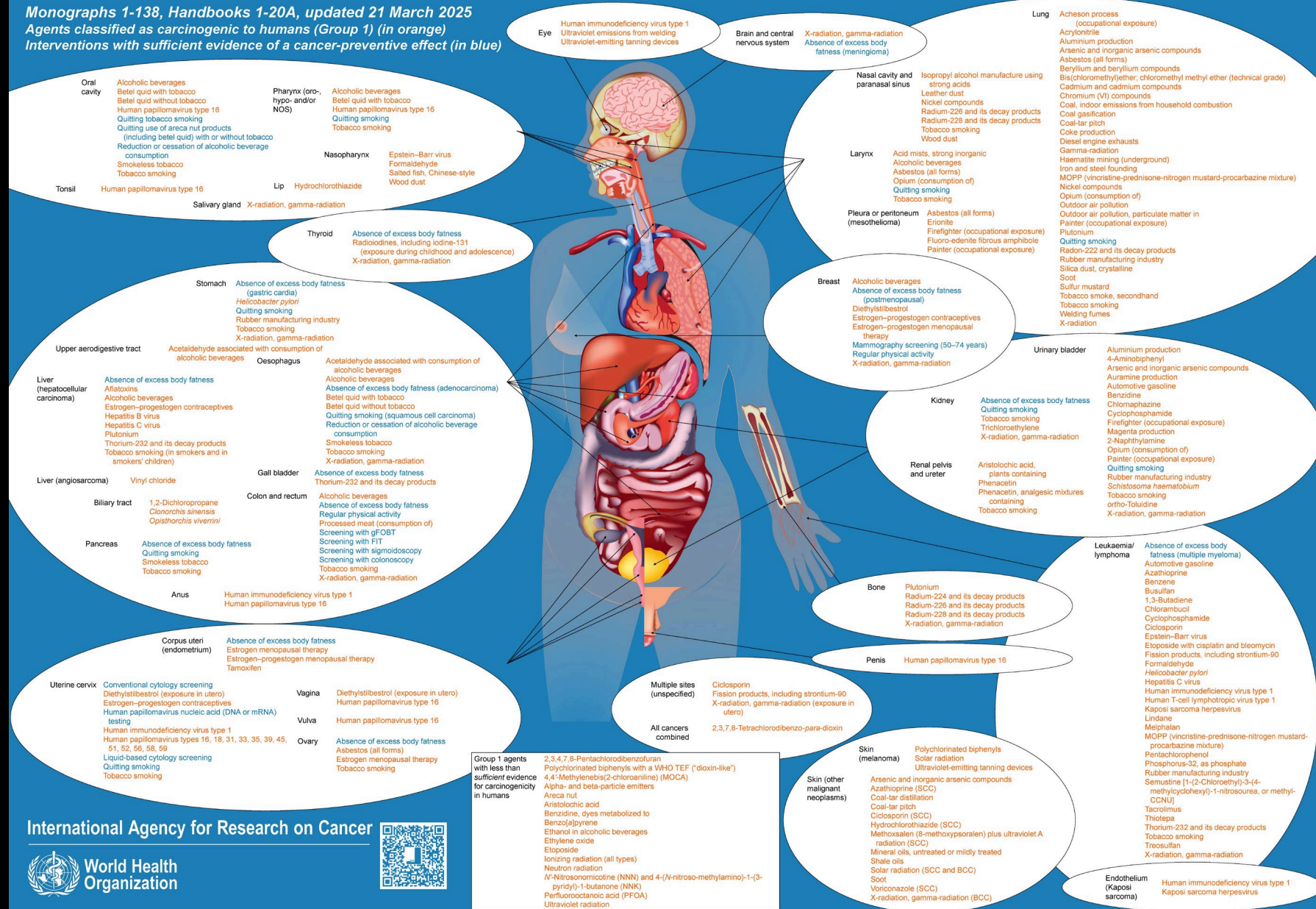
©2025, American Cancer Society, Inc., Surveillance and Health Equity Science

or delays in reporting. Incidence data for 2020 is shown separate from trend line.

Human Cancer: Known Causes and Prevention by Organ Site

IARC Monographs on the Identification of Carcinogenic Hazards to Humans and Handbooks of Cancer Prevention

Monographs 1-138, Handbooks 1-20A, updated 21 March 2025
Agents classified as carcinogenic to humans (Group 1) (in orange)
Interventions with sufficient evidence of a cancer-preventive effect (in blue)



International Agency for Research on Cancer



Our data are the basis for much of what we know about cancer and how to fight it.

Without cancer registration in every state to tell us what's going on, we are blindfolded in this fight.