

# Arizona Cancer Registry information

## 1. What is the Arizona Cancer Registry?

The Arizona Cancer Registry (ACR) is a population-based system that collects, manages and analyzes information on the incidence, survival and mortality of people diagnosed with cancer in Arizona.

# 2. How is my information given to the registry? Does the state need my consent to put my information in the registry?<sup>i</sup>

Your doctor and hospital are required by state and/or federal regulations to report information about your cancer, treatment, and limited background information (like your age and race) to the cancer registry. The state does not require your consent for this process because cancer is legally defined as a "reportable" condition, which means that collecting this information serves a significant and useful purpose for patients, the community, and overall public health.

### 3. What kind of information do the registries collect? "

Specific information that is collected varies across states, but most of the information is related to your cancer diagnosis and treatment, as well as some background information. Basic examples include:

- Cancer type and stage.
- Treatments (such as what type of surgery, chemotherapy, and radiation you had, if any).
- Age, race, and sex.
- The address where you live at the time of your diagnosis, patient address history is not collected or kept by the ACR.

#### 4. What is the purpose of cancer registries? "

Cancer registries are used to collect and analyze data on cancers in the region or state. State and health care professionals look for patterns and trends that address questions such as:

- Are more people getting cancer than in the past?
- Are certain locations having more or less cases of cancer?
- Do certain cancers occur more in one group of people than others?
- Are cancer treatments improving?
- Are certain treatments not working?

The results are used to help improve the health of the community and patients overall.

#### 5. How does the Arizona Department of Health Services (ADHS) track cancer cases?

The ACR is the designated program under the Arizona Department of Health Services that is tasked with collecting information on cancer cases across the state of Arizona.

Cancer cases are reported to the registry by providers (aka doctors), hospitals, pathology laboratories, and clinics.

## **General information on cancer**

#### 6. What is cancer?

Cancer is a term used for diseases in which abnormal cells divide without control and can invade other tissues. There are more than 100 kinds of cancer.<sup>iv</sup>

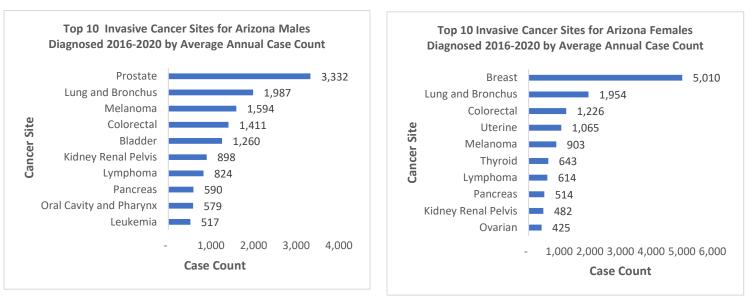
#### 7. How common is cancer?

Cancer is the second leading cause of death and one out of every five deaths in the United States is due to cancer.<sup>v</sup> In the United States, the American Cancer Society estimates that 40 out of 100 men and 39 out of 100 women will be diagnosed with cancer during their lifetime.<sup>vi</sup> Between 2016-2020, the United States experienced approximately 8.5 million new cases of cancer.<sup>vii</sup>

#### 8. What are the most common types of cancer?

Skin cancer is the most common cancer in the United States.<sup>viii</sup> Melanoma is reportable in Arizona; however, basal and squamous skin cancer types are not reportable cancers.

In Arizona, the most common type of cancer for males is prostate cancer and the most common type for females is breast cancer, as shown in the figures below.



#### Leading cancer sites by gender from 2016-2020

#### 9. What causes cancer?

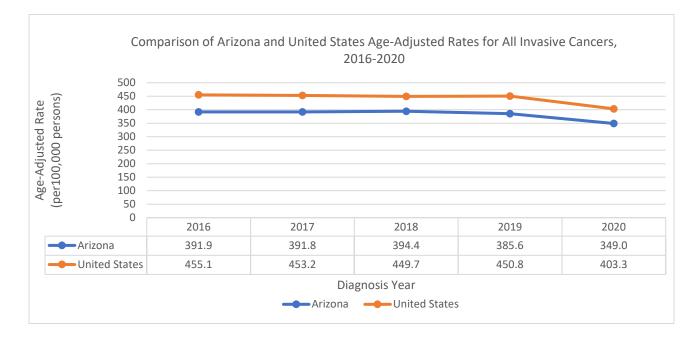
It is not known what causes most cancers. An individual's risk for developing cancer can be elevated by prolonged exposure or participation in known risk factors associated with cancer.

These risk factors are those that can be modified (tobacco use and maintaining a healthy weight) and others that cannot be modified (inherited genetic mutations and family history). <sup>ix</sup>

Scientists continue to study cancer causes. For example, there have been many studies that have allowed scientists to conclude smoking causes lung cancer. In the United States, cigarette smoking is linked to about nine out of 10 lung cancer cases.  $\times$ 

## 10. How does Arizona incidence compare to the United States?

Arizona incidence rates are lower than the national U.S rate.



#### 11. What is an age-adjusted rate?

An age-adjusted rate is a statistical measure that allows groups of people to be compared in a way that the age distribution differences between the groups in a study do not affect what is being measured.<sup>xi</sup>

#### 12. What is a risk factor?

A risk factor is something that can increase an individual's susceptibility to developing disease. The American Cancer Society estimated that over 40% of all cancers in the general population can be attributed to potentially modifiable risk factors.<sup>xii</sup>

Common modifiable risk factors for cancer are tobacco use, excess body weight, excess alcohol consumption, and infectious agents.<sup>xiii</sup>

Non-modifiable risk factors include inherited genetic mutations, gender, race, and advancing age.

A person's environment that they live in can also impact cancer risk if exposed, over a period of time, to environmental health hazards.<sup>xiv</sup>

#### 13. What can you do personally to prevent cancer?

A substantial proportion of cancers could be prevented.<sup>xv</sup> Opportunities exist to reduce cancer risk and prevent some cancers.

Cancer risk can be reduced by avoiding tobacco, limiting alcohol use, limiting exposure to ultraviolet rays from the sun and tanning beds, eating a diet rich in fruits and vegetables, maintaining a healthy weight, being physically active, and seeking regular medical care.<sup>xvi</sup>

Screening can help find cervical, colorectal and breast cancers at an early, treatable stage.

Vaccines also can reduce cancer risk. The human papillomavirus (HPV) vaccine helps prevent most cervical, vaginal, vulvar, penile, anal, and oral cancers.<sup>xvii</sup> The hepatitis B vaccine can reduce liver cancer risk.<sup>xviii</sup>

## **Cancer concern analysis**

#### 14. What is a cancer concern analysis?

A cancer concern analysis is conducted when a member of the public reports to ACR that they are concerned about an unusual number of cancer cases being diagnosed in their community.

These concerns are typically a response to a suspected environmental exposure that is perceived to be causing people to be diagnosed with cancer.

When a cancer concern is reported, the ACR follows a protocol based on Centers for Disease Control and Prevention (CDC) guidelines using cancer registry data to determine whether or not there is an excessive amount of cancer cases being diagnosed in a defined geographic area (County and Primary Care Areas).

Standardized incidence ratios (SIRs) and 95% confidence intervals are calculated to determine if there are more cancer cases in a certain area then we would expect to see and if that difference is statistically significant.

#### 15. How does the ACR define a cancer cluster?

The ACR cancer concern protocol aligns with the Centers for Disease Control and Prevention (CDC) 2022 Guidelines for Examining Unusual Patterns of Cancer and Environmental Concerns which defines a cancer cluster as "a greater than expected number of the same or etiologically related cancer cases that occurs within a group of people in a geographic area over a defined period of time."

For further information on the cancer cluster definition please visit the CDC 2022 Guidelines, here.

#### 16. What does the ACR do to address cancer concerns?

The registry follows a protocol for inquiries from the public, health professionals, or others concerned about cancer. The protocol includes collecting initial information, providing education,

and assessment of current data. ADHS programs meet on a quarterly basis to discuss cancer concerns and health assessments in the community.

#### 17. What are common challenges and limitations to cancer concern analysis?<sup>xix</sup>

- 1. Mathematical limitations- small number of individual cases in the area of concern.
- 2. Defining a cancer case.
- 3. Determining the time period when the unusual pattern started.
- 4. Defining the geographic area of focus.
- 5. Lack of data on cancer latency periods.
- 6. Lack of sufficient data to assess the relationship between cancer and environmental factors.

Cancer registry data has limitations in a cancer concern analysis. Cancer registries do not collect information on patient address history, occupational exposures, environmental exposures, or all lifestyle factors that can be related to cancer risk (diet, tobacco use, exercise, alcohol consumption, etc.).

#### 18. What is a latency period?

A latency period is the time frame from when an individual is exposed to something that can cause disease to when that individual experiences symptoms or is diagnosed.<sup>xx</sup> The ACR does not collect data that can determine latency period.

#### 19. What is a Primary Care Area (PCA)?

PCAs are geographic regions designated to represent Arizona communities while maintaining sufficient population numbers for statistical analysis.

These regions are defined by existing political and community boundaries, demographics and common utilization of primary care services.

PCAs were created using population data from the 2010 census. Due to this, our statistical analysis using PCA populations is limited to cancer cases diagnosed 2010 or later. The ACR assigns the PCA by geocoding the address at diagnosis of each reported case.

# 20. What is statistical significance? How is it determined? How can a standardized incidence ratio (SIR) be elevated but not significant?

For the purpose of cancer concern analysis, statistical significance is a term used to indicate if the difference between the observed and expected cases in the SIR is large enough that it is unlikely due to random chance. <sup>xxi</sup>

The 95% confidence interval is the range of values that contains the true SIR. A 95% confidence interval is used to determine statistical significance, stability and the precision of the SIR.

When we refer to 95% confidence intervals, we can say we are 95% confident that the true SIR is within this range of values.

To determine statistical significance from the confidence interval, we determine if the null value (SIR=1.0) lies within the 95% confidence interval values. The null value (SIR=1.0) represents no

difference between the observed and expected cases. If the confidence interval contains the null value, we cannot rule out the possibility that the true SIR=1.0 and there is no difference between observed and expected cases. For stability and precision, if the SIR is unstable, the confidence interval will be wide with room for variability. If the SIR is stable, the confidence interval will be narrow with less room for variability. Sample size is a large factor in the stability of the SIR, small case counts lead to more imprecise calculations and wider confidence intervals.

If the standardized incidence ratio is elevated (greater than 1.0) but is not statistically significant, that means we cannot conclude that the difference in cases is not due to chance. We cannot draw conclusions about cancer in a population based on unreliable or unstable measures.

### 21. What do I do if I have a concern for cancer in my community?

If you have a concern for cancer in your community, please contact the ACR at <u>azcancerregistry@azdhs.gov</u>.

Please email the ACR with details regarding the cancer cases you are noticing such as:

- Number of cases.
- Cancer types.
- Ages at diagnosis.
- Address or city at time of diagnosis.
- Any environmental exposure concerns.
- The best way to contact you.

## **Environmental health**

**22.** How do you determine which contaminants in the environment have the greatest risk?<sup>xxii</sup> Risk is a measure of the chance that a person will be harmed. It is determined by the "hazard" (i.e. anything that can cause harm such as asbestos, arsenic, or radon) and the "exposure".

Exposure is coming into contact with a substance by swallowing, breathing, or touching the skin or eyes.<sup>xxiii</sup> Risk can be reduced by reducing exposure.

# 23. Where can I find information on the current health assessments involving cancer and environmental risk factors done by the Arizona Department of Health Services (ADHS)?

- a. How can a concerned citizen learn of the results of the current health assessments done by ADHS?
  - i. The ACR collects, manages and analyzes cancer cases in Arizona. Cancer reports can be accessed on the <u>ACR webpage</u>.
  - ii. The ADHS Environmental Toxicology Program conducts public health assessments and health consultations using available data to find out if people are being exposed to hazardous substances. If so, the Program determines whether that exposure is harmful and should be stopped or reduced. Published reports can be accessed on the Office of Environmental Health webpage.

#### b. How does the ADHS do health consultations which involve environmental hazards?

- i. The ADHS Environmental Toxicology Program follows a three-step process for health consultations:
  - 1. Reviews information received such as environmental data, and community inputs.
  - 2. Evaluate the information to determine exposure levels in the affected community.
  - 3. Determines if the exposure is a problem and provides recommendations.

## Additional resources:

- 1. ACR Data Dashboard
- 2. ACR Annual Report and Infographics
- 3. ADHS Data Request Webpage (includes list of publicly available data assets)
- 4. ADHS Well Woman HealthCheck Program
- 5. ADHS SunWise
- 6. ADHS Tobacco Education and Prevention
- 7. Arizona Cancer Coalition & Arizona Comprehensive Cancer Control Plan
- 8. <u>American Cancer Society</u>
- 9. CDC How Cancer Registries Work
- 10. CDC 2022 Guidelines for Examining Unusual Patterns of Cancer and Environmental Cancers
- 11. <u>CDC Standardized incidence Ratios (SIR): A Match-based Approach to Evaluating Unusual</u> <u>Patterns of Cancer</u>
- 12. CDC Investigating Cancer Clusters and Unusual Patterns of Cancer: Challenges and Limitations
- **13.** <u>CDC United States Cancer Statistics (USCS) Data Visualizations Tool</u>
- 14. CDC Environmental Public Health Tracking Network

<sup>&</sup>lt;sup>i</sup> Centers for Disease Control and Prevention. (n.d.). What You Need to Know About Cancer Registries: Frequently Asked Questions for Patients and Their Families. CDC. Retrieved November 27, 2023, from

https://www.cdc.gov/genomics/implementation/toolkit/file/what\_is\_a\_cancer\_reg.docx

<sup>&</sup>lt;sup>ii</sup> Centers for Disease Control and Prevention. (n.d.). What You Need to Know About Cancer Registries: Frequently Asked Questions for Patients and Their Families. CDC. Retrieved November 27, 2023, from

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https://www.cdc.gov/genomics/implementation/toolkit/file/what\_is\_a\_cancer\_reg.docx

<sup>&</sup>lt;sup>iv</sup> Centers for Disease Control and Prevention. (2014, August 13). *Cancer*. CDC. Retrieved September 13, 2023, from https://www.cdc.gov/tobacco/basic\_information/health\_effects/cancer/index.htm

<sup>&</sup>lt;sup>v</sup> U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999-2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <u>https://www.cdc.gov/cancer/dataviz</u>, released in June 2023.

<sup>&</sup>lt;sup>vi</sup> American Cancer Society. (2022, October 2). *Cancer Facts & Figures 2022*. Retrieved September 13, 2023, from https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2022/2022-cancer-facts-and-figures.pdf

<sup>vii</sup> U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999-2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <u>https://www.cdc.gov/cancer/dataviz</u>, released in June 2023.

viii Centers for Disease Control and Prevention. (n.d.). *Basic Information About Skin Cancer*. CDC. Retrieved October 4, 2023, from https://www.cdc.gov/cancer/skin/basic\_info/index.htm

<sup>ix</sup> Centers for Disease Control and Prevention. (n.d.). *Risk Factors and Cancer | CDC*. Centers for Disease Control and Prevention. Retrieved January 29, 2024, from https://www.cdc.gov/cancer/risk\_factors.htm

<sup>×</sup> Centers for Disease Control and Prevention. (2014, August 13). *Cancer*. CDC. Retrieved September 13, 2023, from https://www.cdc.gov/tobacco/basic\_information/health\_effects/cancer/index.htm

<sup>xi</sup> National Cancer Institute. (n.d.). *Glossary of Statistical Terms*. SEER Cancer. Retrieved January 29, 2024, from https://seer.cancer.gov/cgi-bin/glossary/glossary.pl

<sup>xii</sup> American Cancer Society. (2022, October 2). *Cancer Facts & Figures 2022*. Retrieved September 13, 2023, from https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2022/2022-cancer-facts-and-figures.pdf

xiii Centers for Disease Control and Prevention. (n.d.). *Risk Factors and Cancer | CDC*. Centers for Disease Control and Prevention. Retrieved January 30, 2024, from https://www.cdc.gov/cancer/risk\_factors.htm

x<sup>iv</sup> Centers for Disease Control and Prevention. (n.d.). *Introduction to Environmental Public Health Tracking*. CDC. Retrieved September 13, 2023, from https://www.cdc.gov/nceh/tracking/tracking-intro.html

<sup>xv</sup> Mendes, E. (2017, November 21). *More than 4 in 10 Cancers and Cancer Deaths Linked to Modifiable Risk Factors*. American Cancer Society. Retrieved January 30, 2024, from https://www.cancer.org/research/acs-research-news/more-than-4-in-10-cancers-and-cancer-deaths-linked-to-modifiable-risk-factors.html

<sup>xvi</sup> Mendes, E. (2017, November 21). *More than 4 in 10 Cancers and Cancer Deaths Linked to Modifiable Risk Factors*. American Cancer Society. Retrieved January 30, 2024, from https://www.cancer.org/research/acs-

research-news/more-than-4-in-10-cancers-and-cancer-deaths-linked-to-modifiable-risk-factors.html <sup>xvii</sup> Centers for Disease Control and Prevention. (n.d.). *HPV Cancers are Preventable | CDC*. Centers for Disease

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https://www.cdc.gov/cancer/dcpc/prevention/vaccination.htm

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https://www.cdc.gov/nceh/cancer-environment/pdfs/challenges-and-limitations-508.pdf

<sup>xx</sup> National Cancer Institute. (2022, October 2). *NCI Dictionary of Cancer Terms*. National Cancer Institute. Retrieved September 13, 2023, from https://www.cancer.gov/publications/dictionaries/cancer-terms/expand/L

<sup>xxi</sup> National Library of Medicine. (n.d.). *Finding and Using Health Statistics*. National Library of Medicine. Retrieved November 20, 2023, from https://www.nlm.nih.gov/oet/ed/stats/02-930.html

<sup>xxii</sup> Arizona Department of Health Services. (n.d.). *ADHS - Environmental Toxicology - Home*. Arizona Department of Health Services. Retrieved October 11, 2023, from https://www.azdhs.gov/preparedness/epidemiology-disease-control/environmental-toxicology/index.php#additional-resources

<sup>xxiii</sup> Agency for Toxic Substances and Disease Registry. (n.d.). *Glossary of Terms | ATSDR*. Agency for Toxic Substances and Disease Registry. Retrieved January 2, 2024, from https://www.atsdr.cdc.gov/glossary.html