

# Frequently Asked Questions

*To help the public understand what a cancer registry does, the Arkansas Central Cancer Registry (ACCR) has gathered and provided answers to Frequently Asked Questions (FAQs). Additionally, we have provided topics and resources for Oncology Data Specialists as well as cancer data sources for cancer supporters.*

## About the Arkansas Central Cancer Registry

### What is cancer?

Cancer is a disease that is caused by many reasons. These reasons can include your genes (DNA), and your environment (home, school, work, alcohol, or smoking).

Cancer happens when cells split apart without control and spread into close parts of your body like your organs (stomach, breast, prostate) and tissues (blood, bone, muscle).

### What does the Arkansas Central Cancer Registry do?

The Arkansas Central Cancer Registry collects and stores information from new cancer cases. The cancer case information comes from clinics and hospitals who diagnose (find) and/or treat cancer patients in Arkansas.

### Where is the Arkansas cancer registry located?

The Arkansas Central Cancer Registry is located within the Arkansas Department of Health in Little Rock, AR.

### Why is cancer data collected?

Arkansas law requires the Arkansas Central Cancer Registry to collect cancer data (information) to help keep a close eye on the disease.

### What is cancer data used for?

Cancer data helps health providers (doctors, physicians) and researchers learn more about cancer in an area, what can cause cancer, what the best treatment is for patients, and helps find more ways to prevent (avoid) cancer.

### What kind of cancer data is collected?

Arkansas Central Cancer Registry collects five types of information, at a minimum:

1. Information about the **patient**: This includes their name, age, race, ethnicity, and sex.
2. Information about the **cancer**: This includes the type of cell and the organ or tissue where cancer was found.
3. Information about **how serious the cancer is**: This includes how far the cancer spreads.
4. Information on the **treatment for the cancer**: This includes what action the healthcare provider will take to treat the cancer, such as medicines, surgery, or therapy.

5. Information on **patient outcomes** (result): This includes if the patient is still living, is deceased, and how long a person with cancer has lived.

### **Who helps report cancer data to the Arkansas Central Cancer Registry?**

An Oncology Data Specialist (ODS) collects and edits cancer data to ensure the information is correct, complete, and up-to-date data on cancer cases.

Once the cancer data is correct with the right codes, it is sent to the Arkansas Central Cancer Registry.

### **What is an Oncology Data Specialist (ODS)?**

An ODS, formerly known as a Certified Tumor Registrar (CTR), is a person trained in medical coding with knowledge of the human body. An ODS knows what codes to use for cancer cases. They are the backbone of any cancer registry for correct and up to date cancer systems.

For more information on a career as an ODS, please visit the [National Cancer Registrars Association](#) page.

### **Can I report my own cancer case?**

No, the registry does not accept self-reports of cancer from the public. The Arkansas Central Cancer Registry only collects reportable cancers from professionals such as clinics, hospitals, pathology labs, and other required cancer reporters.

### **Can I get information regarding cancer of a loved one?**

No, the registry does not provide protected health information (PHI) to the public, including information requests from cancer patients. Please contact your health care provider for medical records.

### **How do I report that people are getting cancer in my area?**

If you are concerned (worried) about multiple people being diagnosed with cancer in your area, please email [ADH.ACCR@Arkansas.Gov](mailto:ADH.ACCR@Arkansas.Gov).

One of our staff members will reach out for an interview to collect more information about the area of concern and the cases.

The Arkansas Department of Health has a process for investigating (looking into) suspected cancer clusters (large number of cases in an area). To know more about the investigation process, please read the ADH [‘Guidelines for Investigating Clusters of Chronic Diseases’](#).

### **Where can I find the “Your Cancer Resource Guide” booklet?**

“Your Cancer Resource Guide” is offered through the Arkansas BreastCare Program. An electronic version is available on the Arkansas BreastCare Program’s website which you may access by clicking [here](#). Individuals, facilities, and organizations can also contact 1-833-693-2942 to request printed guides.

## For Oncology Data Specialists (ODS) and Vendors

### Does Arkansas offer continuing education or informational trainings?

The Arkansas Central Cancer Registry offers training through a web-based education portal called FLccSC (pronounced flossy). FLccSC stands for Fundamental Learning Collaborative for the Cancer Surveillance Community. It assists new and seasoned ODS', as well as students, data reporters, physician office staff, and registry staff.

To register for FLccSC, please visit the [Arkansas FLccSC portal](#) page.

### Which cancer diagnoses do I send and what are ACCR's required data items?

ACCR publishes its casefinding and data items lists on its utility page. For case reporting resources, please visit the [ACCR Utilities page](#).

### What are the current standards and guidelines for submitting cancer data?

You can find standards and guidelines for submitting cancer data on the [ACCR Utilities page](#).

## For Researchers/Principal Investigators Requesting Data (Case Level Data)

### How do I request cancer case level data for a research study or grant?

If you are interested in requesting cancer data from the Arkansas Central Cancer Registry, please follow the steps below:

#### I: Before Submitting your Data Request

1. Prepare a clean, finalized study protocol to upload as part of the data request, and
2. Obtain IRB approval or waiver letter to upload as part of the data request, and
3. Review the data items available for request\*

\*Not all variables are available to request. To view them, please visit the document titled ACCR Data Items Available for Request via REDCAP.



ACCR Data Items  
Available for Request

**Please carefully select the variables of interest that align with your protocol study.** If there is a variable for which we are unsure aligns with your study based on the protocol, we will ask about it prior to approving.

#### II: Submit the Data Request

All requests go through the ['ADH Data Request Form'](#) link.

Complete all required fields in the form. *Please have your clean, finalized protocol study and IRB letter ready to upload.*

**NOTE:** To select the Arkansas Central Cancer Registry data items, under '**Dataset name**' select '**Arkansas Cancer Registry**'. The variables will auto-populate to check the data items that you are requesting for your study.

### III: After Submitting your Data Request

Our Science Advisory Committee, Chief Science Officer, and Arkansas Central Cancer Registry cancer surveillance manager will review your request and uploaded documents.

If we should have any questions or require clarification, the cancer surveillance manager will reach out to the provided contact information.

For additional information on the data request process, please visit the [Arkansas Department of Health's Office of the Chief Science Officer](#) webpage.

### Can ACCR data be used for another research project (secondary data sharing)?

NCI designated researchers with approved ADH Science Advisory Committee data requests may participate in secondary data sharing as specified in their grant and protocol. ACCR data may not be shared to a third party past the secondary sharing of data. Non-NCI designated researchers must include secondary data sharing in their protocol and present their request to the Science Advisory Committee.

### What is the small number standard for population data?

ACCR suppresses all non-zero counts which are less than ten for reports to be released to the public, unless they meet exceptions specified by ACCR. This does not apply to approved research data requests in which the researcher agrees to ACCR's small number standard. For questions related to small number standards, please contact [ADH.ACCR@arkansas.gov](mailto:ADH.ACCR@arkansas.gov).

## For Cancer Advocates/Partners for Publicly Available Cancer Data

### Where can I readily view cancer data?

To help make our data available for quick and free use, the Arkansas Central Cancer Registry works with partners and reporting agencies to provide free public access to our data. Below are the types of data sources that you can use to view Arkansas and/or national cancer data:

#### **Incidence Data (New Cancer Cases) including Arkansas:**

1. Cancer-Rates.info Data Visualization (hosted by Kentucky Cancer Registry): <https://cancer-rates.info/ar/>
2. CDC WONDER (Incidence via Data Request Form): <https://wonder.cdc.gov/cancer-v2022.html>

#### **Mortality Data (Cancer Deaths) including Arkansas:**

1. CDC WONDER (Mortality via Data Request Form): <https://wonder.cdc.gov/cancermort-v2021.html>
2. Geospatial Atlas for Cancer Mortality: <https://gis.cancer.gov/canceratlas/>
3. Catchment Areas of NCI-Designated Cancer Centers: <https://gis.cancer.gov/ncicatchment/>

#### **Comprehensive Cancer Data (Incidence, Mortality, Prevalence, Survival, Screenings, Risk Factors, Geographic, etc.):\***

1. United States Cancer Statistics, Data Visualizations Tool: <https://gis.cdc.gov/Cancer/USCS/>
2. State Cancer Profiles: <https://statecancerprofiles.cancer.gov/data-topics/incidence.html>

3. CDC WONDER Statistics Overview: <https://wonder.cdc.gov/Tobacco>
4. Policy: <https://gis.cancer.gov/tobaccopolicy/viewer/>
5. Cancer Map Stories: <https://gis.cancer.gov/mapstory/>
6. Geospatial Tools (*General Overview*: <https://gis.cancer.gov/>):
  - a. Geographic Cancer Atlas: <https://gis.cancer.gov/canceratlas/>
7. NIH NCI SEER Interactive Tools List (*General Overview*: <https://seer.cancer.gov/statistics/interactive.html>):
  - a. CI\*Rank (Ranked Incidence and Mortality Rates by State, County, and Special Region): <https://surveillance.cancer.gov/cirank/query/>
  - b. SEER\*Explorer and NCCR\*Explorer: <https://seer.cancer.gov/statistics-network/>
  - c. Cancer Query Systems: <https://seer.cancer.gov/canques/>
  - d. Cancer Stat Facts: <https://seer.cancer.gov/statfacts/>

***\*Not all data sources will include Arkansas data and figures***

## Can't find what you are looking for?

If you have any questions or need clarification not answered in this FAQ, please email: [ADH.ACCR@Arkansas.Gov](mailto:ADH.ACCR@Arkansas.Gov) and one of our staff members will follow up with your inquiry.