Cancer in Iowa: 99 Counties Project

Frequently Asked Questions

The **Cancer in Iowa: 99 Counties Project** aims to solve community-specific cancer issues in all 99 counties of Iowa. Questions included in this document have come directly from participants of the county presentation discussions. We will continue to update with additional questions and answers as the 99 Counties Project progresses.

The Iowa Cancer Registry (ICR) has been serving Iowa since 1973. As part of the National Cancer Institute's SEER Program, ICR tracks cancer rates, survival, and deaths among Iowans. ICR provides important data and resources to support cancer research, public health efforts, and education in Iowa.

Iowa Cancer Registry Website: www.iowacancerregistry.org

Cancer in Iowa: 99 Counties Project website: www.iowacancerregistry.org/99

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99 Counties Project

Question: Where can I find a copy of the county presentations and/or contact information?

Answer:

Slides from each county's presentations, as well as relevant resources and other information regarding the 99 Counties Project, will be posted on our website (www.iowacancerregistry.org/99) either the day of or 1-2 days following the presentation date. If you don't see the information you are looking for, please reach out to us at: icr-99countiesproject@uiowa.edu.

Question: When is the next 99 Counties Meeting?

Answer:

You can find a list of past meetings, upcoming meetings, and those yet to be scheduled on our website Cancer in Iowa: 99 Counties Project. When available, we will post meeting details and links to register for the events.

Slides from each county's presentations, as well as relevant resources and other information regarding the 99 Counties Project, will be posted either the day of, or 1-2 days following, the presentation date. If you don't see the information you are looking for, please reach out to us at: icr-99countiesproject@uiowa.edu.

Question: Do the statistics in the presentation include seasonal workers who may not be residents?

Answer:

Our statistics include every person who is a resident of Iowa at the time of their diagnosis. If a seasonal worker was not a resident of Iowa during the time periods used in the presentation, they would not be included in the data for this report and presentation.

Question: What is considered 'late stage' in the 99 Counties Project presentations?

Answer:

In the 99 Counties Project presentations, early stage is defined as those cancers diagnosed at the localized stage. Late stage is defined as those cancers that have spread beyond the original site of the cancer. This would include regional and distant. Learn more about cancer staging at https://www.cancer.org/cancer/diagnosis-staging/staging.html.

Question: Where do we get the data on behavioral risk factors?

Answer:

The data on behavioral risk factors used in this presentation comes from the Behavioral Risk Factor Surveillance System survey. This survey is the largest continuously conducted health survey system in the world and is administered by the Centers for Disease Control and Prevention (CDC).

Iowa Cancer Registry

Question: What is the role of the Iowa Cancer Registry?

Answer:

The Iowa Cancer Registry (ICR) is a population-based cancer registry, meaning it collects cancer data, which is a reportable disease, on all Iowa residents. The ICR has been a member of National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program since its inception in 1973. SEER provides national population-based statistics on the number of cancer cases and mortality rates. Along with the National Cancer Institute, ICR is funded by the University of Iowa and the State of Iowa.

Information we collect includes: new cancer cases, stage at diagnosis, treatment, survival, cancer deaths, and demographics (e.g., sex at birth, race/ethnicity, age at diagnosis, etc.).

Information we do not collect: environmental exposures, health behaviors (e.g., smoking, drinking, etc.), height and weight, and family history.

Question: I was diagnosed with cancer in another state, is my information still collected by the Iowa Cancer Registry?

Answer:

Collection of cancer data is based on where individuals lived when they were diagnosed. If you were a resident of Iowa but diagnosed at an out-of-state hospital or clinic, your information is still collected by the Iowa Cancer Registry through arrangements with surrounding States and other healthcare providers.

For individuals that attend a college or university, collection of cancer data is still based on where the individual lived (address of residence) at the time of diagnosis. So, if a student was diagnosed in Iowa, but the main address of residence was in another state, that student would not be included in Iowa cancer statistics. Their data would be transmitted to their state of residence's cancer registry.

Question: The most recent data presented is only from 2021. Is there a way to speed up data collection so we can have more timely information?

Answer:

While more timely information is something the SEER program is working on, cancer data collection still takes time. We collect over 200 variables on every person with cancer across the multitude of cancer types, and that data needs to be verified for quality. However, we are working with major health systems in Iowa to implement electronic pathology records, so every time they call something cancer, it sends us an electronic, automated message.

Question: If the Registry shows a cluster of cancer diagnosis, who do you notify and how is the public notified?

Answer:

If an elevated risk of cancer is found through a cancer cluster investigation, it will be reported to the State Medical Director at Iowa Department of Health and Human Services. They will then determine whether it will be directed to the CDC for further investigation.

If you are concerned about a specific cancer cluster in your community, please email us at ICR-CancerConcerns@uiowa.edu. If possible, the Registry will conduct an analysis comparing the expected number of cancers in the area to what has been observed. A written report of the results will be sent to you and a meeting to discuss the results will be offered.

Environmental Concerns

Question: Does the Registry collect information on environmental factors. If not, why?

Answer:

The Iowa Cancer Registry, as well as all other population-based cancer registries, does not collect environmental factors or exposure information. The Registry is funded in part by the National Cancer Institute. We have the public health authority from the state of Iowa to collect data on cancer, and we are only funded to collect those variables on cancer. The Iowa Cancer Registry only collects data found within a person's medical records.

However, the Iowa Cancer Registry participates in the Agricultural Health Study. In this large prospective cohort study, 89,000 pesticide applicators and their spouses from Iowa and North Carolina have participated. The goal of this study is to learn about how agriculture, lifestyle and genetic factors affect the health of farming populations.

Question: It seems obvious, living in a farming state, that there is a relationship between agricultural products (e.g. pesticides, herbicides, etc.). I am concerned about these environmental exposures in my community. Is it possible for researchers to include agricultural products and other environmental exposures in their research?

Answer:

Many Iowans understandably have questions about the potential links between environmental exposures and cancer. This is an important area of continued research, and Iowans are right to ask questions and want to take precautions. The Iowa Cancer Registry does not collect any data on environmental risk factors, but we do share our data with researchers to support studies of environmental risk factors and cancer. Below are some resources you can explore if you are concerned about cancer and environmental exposures in your community.

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The Center for Health Effects of Environmental Contamination (CHEEC) at the University of Iowa is a multidisciplinary environmental health research center comprised of faculty and researchers located in the University of Iowa Colleges of Public Health, Engineering, and Liberal Arts and Sciences, and State Hygienic Laboratory. CHEEC supports and conducts research to identify, measure and study adverse health outcomes related to exposure to environmental toxins. CHEEC is involved in a variety of epidemiologic studies of rural and urban populations in Iowa, mainly focused on drinking water contaminants and health effects.

Anyone concerned with arsenic exposure (or other ground contamination) or on a private well is encouraged to get their water tested. The Private Well Grant Program, offers reimbursement for water tests of private well water, well closure of abandoned wells, and well reconstruction or repair.

The Environmental Health Sciences Research Center has prepared a series of fact sheets in response to concerns from the community members about the connection between contaminants in our environment and health outcomes such as cancer and other diseases. These fact sheets can be downloaded at: https://ehsrc.public-health.uiowa.edu/communityengagement/resources-information/

Question: How do we get researchers to come to our community and test wells and/or houses for environmental exposures?

Answer:

The Center for Health Effects of Environmental Contamination (CHEEC) at the University of Iowa is a multidisciplinary environmental health research center comprised of faculty and researchers located in the University of Iowa Colleges of Public Health, Engineering, and Liberal Arts and Sciences, and State Hygienic Laboratory. CHEEC supports and conducts research to identify, measure and study adverse health outcomes related to exposure to environmental toxins. CHEEC is involved in a variety of epidemiologic studies of rural and urban populations in Iowa, mainly focused on drinking water contaminants and health effects.

You can connect with your county's environmental health specialist.

If you are interested in having more testing done in your community it is also important to let your local and state representatives know. The more awareness we can bring regarding your community's cancer concerns may open doors to more connections, resources, and funding opportunities.

Question: What is being done to look at PFAS (i.e., forever chemicals)?

Answer:

There are proposals to get PFAS regulated in the municipal water supply. As part of the CHEEC program, when they are testing in small towns, for example private wells, they will also look for traces of PFAS. In general, more testing and data collection is needed to have a better understanding.

Question: Are there concerns about the town water?

Answer:

If you are on the municipal water supply, there are federal regulations that establish acceptable levels of arsenic or nitrates, etc. Currently there are proposals to get PFAS regulated in the municipal water supply.

Question: What is Radon?

Answer:

Radon is an invisible, tasteless, odorless, radioactive gas. It is naturally produced by radium and uranium in the soil, left by glaciers moving through Iowa millions of years ago. This gas can become harmful when it becomes trapped and concentrated in the air. For example, it can leak into a basement through a crack in the foundation or space around a pipe. Iowa has very high rates of elevated indoor radon levels.

Radon is the second leading cause of lung cancer, and the leading cause of lung cancer among nonsmokers.

Radon can be tested for using at home radon test kits. Elevated radon levels can be treated by installing mitigation systems and can be expensive. Learn more about Radon testing and mitigation at Iowa Health & Human Services: hhs.iowa.gov/radiological-health/radon and Iowa Cancer Consortium canceriowa.org/radon/

Question: Radon testing and mitigation can be expensive. What can be done at the community level to make this more accessible and/or affordable?

Answer:

Several counties and cities have financial assistance programs for radon mitigation.

In addition, communities can apply to receive grants to help with the cost of radon kits and radon mitigation. You can contact the Iowa Cancer Consortium to learn more: staff@canceriowa.org and canceriowa.org/radon/

Policy & Taking Action

Question: Is there any evidence to show that money and effort spent on planning and prevention of cancer are proven valuable? What policy changes can be done to make a difference?

Answer:

Yes, there are many studies that show prevention strategies are effective and key to preventing cancer, including, but not limited to, smoking cessation[1], sun protection measures[2], the HPV vaccine[3-5], as well as maintaining a healthy weight and staying physically active[6]. In fact, some of the most effective advances we've made against cancer have been through smoking prevention and cessation[1]. While a lot of money is spent on prevention, it is not nearly as much money as is spent on cancer treatment.

It's possible to find examples of cancer control policies that local governments and communities can implement to help reduce the burden of cancer. But it is important to note that every community is different in its infrastructure, resources, interests, and needs. Your expertise as community members and leaders and local policy makers is *key* to answering the question of what to do next. You know best what your community needs and what will work.

Some examples include, but are not limited to:

- Tobacco- and nicotine-free policies, reducing out-of-pocket costs for cessation treatments, and mass communications can help reduce lung cancer.
- Providing sunscreen and UV-safety education in outdoor occupational, recreation/tourism, and childcare settings can help prevent skin cancer.
- Engaging community health workers, developing clinic-specific interventions, and supporting care navigation are effective in addressing breast cancer.
- And educating about the link between tobacco, alcohol, and obesity and prostate cancer; and about the link between chemical exposures and prostate cancer; as well as promoting shared decision-making between individuals and providers helps reduce the burden of prostate cancer.

Cancer control partners like the Iowa Cancer Registry, the Iowa Cancer Consortium, Iowa HHS, and your local public health department can provide ideas, advise, and help find data, evidence, and other resources, but ultimately you are the experts.

A good place to start is by taking stock of the information presented and where the opportunities for change might be within your county, town, or organization. Use the Iowa Cancer Plan for inspiration and reach out to the Iowa Cancer Consortium for partnership in moving forward.

Additional resources:

- https://thecommunityguide.org/topics/cancer.html
- https://ebccp.cancercontrol.cancer.gov
- https://cancercontroltap.org/resources
- https://www.ruralhealthinfo.org/econtool
- https://triagecancer.org/state-laws

Question: How do folks begin to talk with legislators about their concerns, and how do they get involved in the legislative process?

Answer:

The Iowa Cancer Consortium (ICC) is a great place to start. While the ICC does not lobby for legislation, many of their partners do. The ICC has a policy work group, which convenes people who are active in policy, and are also advocates themselves, and interested in becoming active at the state and federal level. This would be a great opportunity to listen and hear what different groups are working on and which group you might want to connect with.

To join the policy work group and/or receive information you can become a member of the Iowa Cancer Consortium. To learn more go to: canceriowa.org/membership/

The American Cancer Society Cancer Action Network is another cancer advocacy organization, and you can sign up for action alerts: www.fightcancer.org/

Write to your state senators and representatives and let them know your concerns about your community.

Question: What can counties do for an implementation plan?

Answer:

The Iowa Cancer Plan is a good place to start. Cancer is a broad and complex disease and there are lots of different steps that individuals and counties and other entities can take to start working on prevention. It may also depend on what the community's area of interest is. Some examples could include tobacco use prevention, supporting radon testing and mitigation, and making communities more walkable and bikeable to name a few.

References

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2. US Department of Health and Human Services. Reports of the Surgeon General, in The Surgeon General's Call to Action to Prevent Skin Cancer. 2014, Office of the Surgeon General (US): Washington (DC).

3. Falcaro, M., et al., The effects of the national HPV vaccination programme in England, UK, on cervical cancer and grade 3 cervical intraepithelial neoplasia incidence: a register-based observational study. *Lancet*, 2021. 398(10316): p. 2084-2092.

4. Rosenblum, H.G., et al., Declines in Prevalence of Human Papillomavirus Vaccine-Type Infection Among Females after Introduction of Vaccine - United States, 2003-2018. MMWR Morbidity Mortality Weekly Report, 2021. 70(12): p. 415-420.

5. Rosenblum, H.G., et al., Human Papillomavirus Vaccine Impact and Effectiveness Through 12 Years After Vaccine Introduction in the United States, 2003 to 2018. *Annals of Internal Medicine*, 2022. 175(7): p. 918-926.

6. Rock, C.L., et al., American Cancer Society guideline for diet and physical activity for cancer prevention. *CA: A Cancer Journal for Clinicians*, 2020. 70(4): p. 245-271.