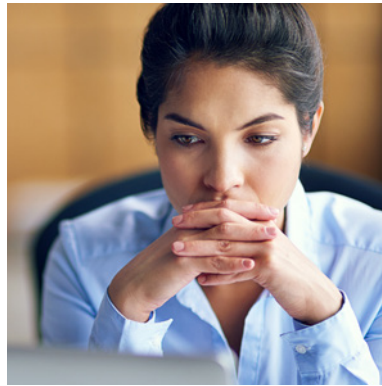




# 2022-2027 Illinois Comprehensive Cancer Control Plan



*The 2022-2027 Illinois Comprehensive Cancer Control Plan is dedicated to all Illinoisans whose lives have been affected by cancer.*



# Illinois Comprehensive Cancer Control Plan

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# Illinois Comprehensive Cancer Control Plan

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We are immensely grateful to Sarah Christian for her assistance with the development, coordination, and editing of the plan, as well as her oversight and leadership with the work groups and focus groups.

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# Illinois Comprehensive Cancer Control Plan

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# Illinois Comprehensive Cancer Control Plan

## GOALS AT A GLANCE

### PREVENTION

- Goal 1. Increase healthy living habits among youth and adults.
- Goal 2. Reduce exposure to environmental carcinogens.
- Goal 3. Prevent tobacco-related lung cancers among youth and adults.
- Goal 4. Prevent human papillomavirus (HPV)-related cancers.
- Goal 5. Promote awareness of hereditary cancers and use of genetic counseling.

### SCREENING AND EARLY DETECTION

- Goal 1. Increase cancer screening.
- Goal 2. Reduce late-stage cancer diagnosis.
- Goal 3. Reduce cancer mortality rates.

### DIAGNOSIS, TREATMENT, AND SURVIVORSHIP

- Goal 1. Promote awareness and access to navigation services, including financial navigation and care navigation to reduce disparities in cancer health outcomes.
- Goal 2. Increase diagnosis of high-risk patients with familial or genetic risk factors.
- Goal 3. Increase awareness of ongoing care coordination for monitoring, follow-up, and recurrence screening.
- Goal 4. Raise awareness of the need for increased quality of life for enhanced recovery and survivorship and available resources.
- Goal 5. Support the availability of telehealth and outreach programs.



# Illinois Comprehensive Cancer Control Plan

## EXECUTIVE SUMMARY

The Illinois Department of Public Health (IDPH) is pleased to share the 2022-2027 Illinois Comprehensive Cancer Control Plan (“plan”). The plan provides a roadmap to guide cancer prevention, screening, treatment, and survivorship activities throughout Illinois.

Cancer remains the second leading cause of death, after heart disease, in Illinois for 2019 for all ages.<sup>1</sup> For children through age of 17 and young adults ages 18 through 24 in 2019, cancer was the fourth leading cause of death. Cancer is the first leading cause of death in 2019 for adults aged 45 to 64 and 65 to 84.

Cancer affects all population groups, but some population groups are disproportionately affected due to social, environmental, and economic disadvantages. For all types of cancer in 2017, Black males were disproportionately affected more than other race/ethnicities of males.<sup>2</sup>

Illinois has made great strides in the fight against cancer, but Illinoisans must continue to work to reduce and to prevent cancers. We must work together to address the community members who have historically been marginalized, whether according to race, ethnicity, age, gender, sexual orientation, gender identity, disability, religion, or language, among others, and develop strategies and policies to address health disparities and/or health inequities with the end result of furthering health equity to reduce and to prevent cancer.

The 2022-2027 plan updates the information from the 2016-2021 plan in a reformatted layout, plus includes expanded sections. More emphasis has been placed on health equity and health disparities. We have placed an importance on including the voices and opinions of those for whom this document is created: the people of Illinois impacted by cancer, the caregivers and support persons, and the cancer survivors. Quotes from people impacted by cancer are interspersed throughout the document.

We encourage organizations, health systems, community groups, employers, and Illinoisans to review the plan and incorporate the plan’s goals, objectives, and strategies within their organizations or groups to help reduce cancer incidence in Illinois.

With your help, we will increase awareness of and access to cancer education, screening, treatment, and long-term survivorship care for all Illinoisans, regardless of geography, financial status, insurance coverage, or any other characteristic.

By working collaboratively, we will strengthen the fight against cancer, decrease death and suffering from cancer, and enrich the lives of the people of the state of Illinois.

For more information, contact the Illinois Department of Public Health Comprehensive Cancer Control Program at 217-782-3300 or [DPH.CompCancer@illinois.gov](mailto:DPH.CompCancer@illinois.gov).

---

<sup>1</sup> IDPH. (2019). Leading Causes of Death by Age Group, Illinois Residents, 2019. Retrieved from <https://dph.illinois.gov/content/dam/soi/en/web/idph/files/leading-causes-by-age-2019.pdf>

<sup>2</sup> CDC. (2017). United States Cancer Statistics: Data Visualizations. Retrieved from <https://gis.cdc.gov/Cancer/USCS/DataViz.html>



525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • [www.dph.illinois.gov](http://www.dph.illinois.gov)

My fellow Illinoisans:

I am pleased to support the 2022-2027 Illinois Comprehensive Cancer Control Plan. The Illinois Cancer Partnership coalition and the Illinois Department of Public Health Comprehensive Cancer Control Program collaborated to develop this plan to address the burden of cancer in Illinois.

Cancer is the second leading cause of death among Illinoisans and is a significant public health issue in Illinois. The *2022-2027 Illinois Comprehensive Cancer Control Plan* provides a framework to reduce the burden of cancer through action and collaboration by academic institutions, community-based organizations, health care providers, individuals, local health departments, nonprofit organizations, and policymakers.

The plan is updated and revised every five years to reflect where Illinois is regarding the goals, objectives, and strategies that were set to reduce the burden of cancer and improve the lives of Illinois residents with cancer. The plan addresses all stages along the cancer continuum from prevention to screening and early detection to diagnosis, treatment, and survivorship for pediatric, young adults, and adults. Each priority area addresses specific needs to reflect the plan's overarching goal to reduce the burden of cancer. A specific focus addresses health equity and health disparities, including strategies for community engagement, rural health, and lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities. This section highlights the voices of people in Illinois affected by cancer and how cancer treatment can be improved on the continuum of care.

On behalf of the Illinois Department of Public Health, I extend my appreciation for the time and contributions of all who assisted in the development of this plan. Together, we can reduce the burden of cancer and ensure a better quality of life for persons with cancer in Illinois.

Sincerely,

Ngozi O. Ezike, MD  
Director  
Illinois Department of Public Health

**PROTECTING HEALTH, IMPROVING LIVES**

*Nationally Accredited by PHAB*

# Illinois Comprehensive Cancer Control Plan

## INTRODUCTION

Cancer is a term used for diseases in which abnormal cells divide uncontrollably and invade other tissues and spread to other parts of the body through the blood and lymph systems. Cancer is not just one disease, but many diseases of which there are more than 100 types. The overarching goal is to reduce cancer incidence and mortality in Illinois by addressing all domains of the cancer continuum, from primary prevention to survivorship and to palliative care.

*Cancer affects everyone, but not everyone equally.*

Community Town Hall Participant

The plan provides a roadmap to guide cancer prevention work and control activities in Illinois through the implementation of high need, high feasibility, and evidence-based strategies. The plan is intended to mobilize stakeholders and partners through the following: policy, environmental, and system change; health equity advocacy; program development; clinical improvements; evaluation and surveillance enhancements; and other

cancer prevention and control efforts. Execution of the plan will require a collective effort by stakeholders and partners, including individuals, local health departments, health care systems, academic institutions, state departments and divisions, nonprofit organizations, and others. Stakeholders and partners are encouraged to incorporate these goals, objectives, and strategies within their strategic plans. Effective implementation of these ambitious, yet imperative goals will require an ongoing, coordinated, and collaborative effort.

This plan is based upon the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control's Cancer Plan Self-Assessment Tool. It includes the core components and a description of the process used to develop the plan; goals, objectives, and strategies; stakeholder involvement; disease burden data; cancer and health disparities; and evaluation.

## DEVELOPMENT OF THE PLAN

The plan was developed by the Illinois Cancer Partnership (ICP) and its 2022-2027 Comprehensive Cancer Control Plan work groups.

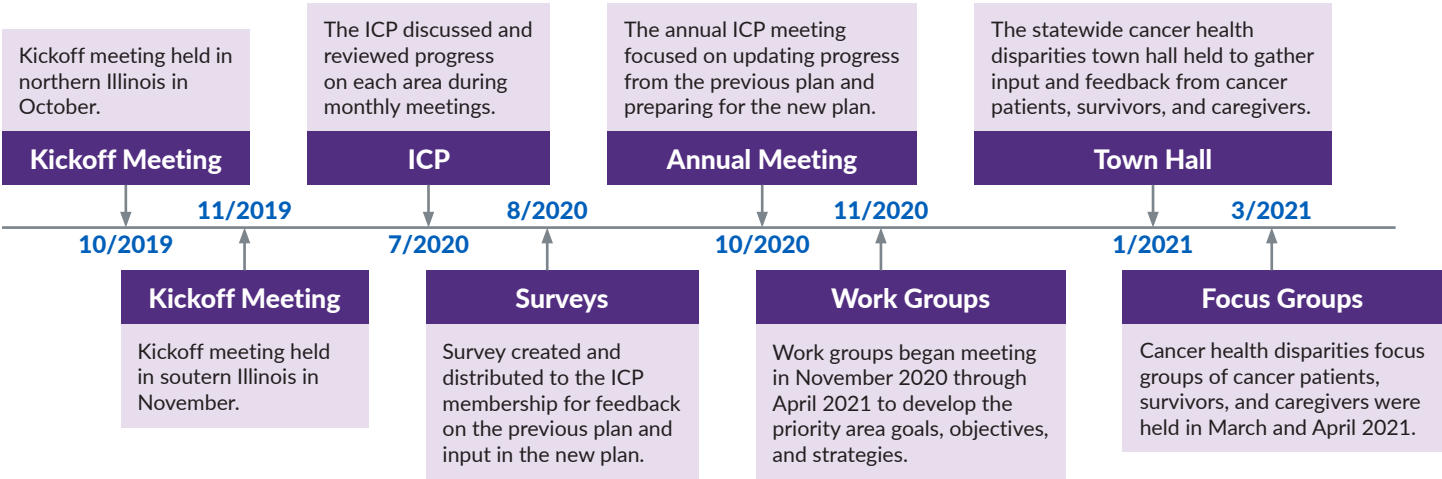
The ICP is a coalition of stakeholders across the state dedicated to reducing the incidence, morbidity and mortality of cancer and to enhance survivorship. The ICP vision is for all Illinoisans to be educated about cancer and its risks and prevention practices; have the opportunity for a lifestyle conducive to reducing cancer risks; have access to the highest form of cancer care, including early diagnosis and treatment; and benefit from well-planned policies and adequate resources.

The ICP purpose is to develop, to implement, and to evaluate a state Comprehensive Cancer Control Plan and collaboratively accomplish the goals set forth in the Comprehensive Cancer Control Plan to reduce the incidence and to monitor the planning process to ensure effective cancer prevention services are reaching populations most at risk. Figure 1 summarizes the timeline of the development.



# Illinois Comprehensive Cancer Control Plan

Figure 1. Cancer Plan Development Timeline



Two kickoff meetings for the 2022-2027 plan were held—one in northern Illinois (October 2019) and one in southern Illinois (November 2019). During these meetings, participants created the three overarching workgroups: 1) Prevention, 2) Screening and Early Detection, and 3) Diagnosis, Treatment, and Survivorship. The meeting participants developed a vision statement and set initial goals and objectives for each workgroup.

The ICP began discussing strategies during the monthly meetings in August 2020.

The Illinois Comprehensive Cancer Control Program (ICCCP) contracts with the University of Illinois College of Medicine at Rockford to provide evaluation of the ICCCP, including collecting, analyzing, compiling, and evaluating the progress toward objectives of the ICP and the work of the comprehensive cancer control program. In August 2020, the ICCCP collaborated with the University of Illinois College of Medicine at Rockford evaluation team to distribute a survey to Illinois cancer partners to capture feedback from the 2016-2021 plan and to collect considerations for the future plan.

Survey participants noted the following strengths of the 2016-2021 plan:

- Clear strategies, goals, and activities
- Comprehensive
- Focus on:
  - Early detection
  - Health equity
  - HPV (human papillomavirus)
  - Prevention
- Provides information and resources

# Illinois Comprehensive Cancer Control Plan

For the 2022-2027 plan, survey participants wanted the following included:

- Robust and clear strategies, goals, and activities
- More data
- Tobacco use in youth, such as vaping and e-cigarettes
- Radon
- Social determinants of health and health disparities
- Financial burden/toxicity
- Focus on rural areas
- Direction for plan implementation
- More information for cancer survivors

In October 2020, the ICCCP focused the ICP Annual Meeting on preparing to update the plan. Presentations included a community engagement plan, COVID-19 and cancer, health equity and cancer, HPV burden report, Illinois cancer data, introduction to the work groups, progress on the 2016-2021 goals and objectives, rural health disparities, and survey results.

The plan is based upon the priority areas of prevention; screening and early detection; and diagnosis, treatment, and survivorship. Health equity is embedded within each priority area.

In September 2020, sign up for work group members was opened to the ICP coalition, the ICP listserv, and other stakeholders. Work group members were able to indicate their preference of work groups: prevention; screening and early detection; and diagnosis, treatment, and survivorship.

In October 2020, work group members volunteered to lead the work groups, and a training was held on how to facilitate the work group meetings. Resources were distributed to work group leaders to assist in developing specific, measurable, attainable, realistic, and timely (SMART) objectives. Work sheets were provided to document goals, objectives, and strategies. The three work groups started meeting in November 2020 to create goals, objectives, and strategies in their respective priority areas. Work groups concluded by April 2021.

**GOALS** are overarching changes we want to see.

**OBJECTIVES** are the measurable accomplishments necessary to meet the goal.

**STRATEGIES** are specific actions that can be taken to achieve the objective.

- **Goals** are the overarching change we want to see in Illinois. The goal statement explains what the program wishes to accomplish. It sets the fundamental, long-range direction. Typically, goals are broad general statements.
- **Objectives** are the measurable accomplishments necessary to meet the goal. Objectives break the goal down into smaller parts that provide specific, measurable, attainable, realistic, and timely actions by which the goal can be accomplished.
- **Strategies** are specific actions that can be taken to help achieve the objective. Strategies are based on research and best practices when possible.

# Illinois Comprehensive Cancer Control Plan

In order to expand information on health equity, the ICCCP collaborated with the University of Illinois Cancer Center's Community Engagement and Health Equity (CEHE) office to implement a community engagement strategy to understand cancer disparities in Illinois and to obtain the feedback and input of the people who are directly impacted by cancer: patients, survivors, and caregivers. The purpose was to capture individual perspectives that could then be reflected in the plan.

In January 2021, CEHE held a statewide cancer town hall to hear from the community regarding how cancer impacts their life, strategies to improve cancer outcomes, and what can the state do to improve cancer disparities.

As a follow-up to the town hall, CEHE held eight focus groups, three general population focus groups, as well as focus groups specifically for rural residents, survivors, young survivors, caregivers, and Spanish speakers. The focus groups allowed a deeper dive into health equity and cancer disparities. This information is presented in the Health Disparities section of this plan.

Throughout the development of the plan, information was continuously discussed and reviewed with the ICP.

## USING THE PLAN

The plan is for Illinois' public health agencies, community organizations, health care systems, health insurers, educators, researchers, employers, and professional organizations.

Each objective in the plan includes a list of actionable strategies to incorporate and to tailor to fit individual and organizational goals and strategic initiatives. The plan should be used as a strategic guide for stakeholders throughout Illinois. The plan will help raise awareness and inform partners about efforts throughout the state.

Organizations are recommended to integrate new strategies with existing programs, such as chronic diseases, prevention, education, and service delivery.

When using the plan, consider the following:

- Review the goals to determine which fit within or may be added to your organization, agency, or group's mission or vision. Identify the objectives and strategies that may be incorporated within your structure.
- Set short-term and long-term objectives for annual goals, department goals, and individual goals and actions.
- Meet with partner organizations and agencies within your region to discuss how to collaboratively address and to implement goals, objectives, and strategies.
- Identify data that you currently collect or may need to be collecting to track progress towards the goals, objectives, and strategies.
- On a regular basis, review the data collected with your team. Identify any trends, strengths, or weaknesses to determine if adjustments are needed.

IDPH and the ICCCP will be responsible for providing technical assistance and educational opportunities. The ICCCP, ICP Executive Committee, and the ICP subcommittees (Prevention; Screening and Early Detection; and Diagnosis, Treatment, and Survivorship) will be responsible and involved in implementing the plan with training, technical assistance, and funding, when available, for grant-related activities.

A resource plan and budget will be developed and maintained as a separate document. The resource plan indicates what is needed to implement the plan, which includes a variety of current and potential funding sources.

## Illinois Comprehensive Cancer Control Plan

This plan shall be reviewed annually, and updates published as addendums to the plan.

For guidance in identifying evidence based interventions, consult The Community Guide at <https://www.thecommunityguide.org/> or the Centers for Disease Control and Prevention at <https://www.cdc.gov/cancer/ncccp/index.htm>.

**The contents of this plan are intended for strategic planning, informational, and educational purposes only and not for the purpose of rendering medical advice nor intended to substitute for professional medical advice, diagnosis, or treatment. Consult your physician or other qualified health care professional for medical advice or any questions regarding a medical condition.**



# Illinois Comprehensive Cancer Control Plan

## GOALS, OBJECTIVES, AND STRATEGIES

This section includes the goals, objectives, and strategies for each of the three priority areas: Prevention; Screening and Early Detection; and Diagnosis, Treatment, and Survivorship and health equity embedded into each area.

The goals reflect overarching changes we want to see in Illinois.

**The goals for each of the three priority areas – 1) Prevention; 2) Screening and Early Detection; and 3) Diagnosis, Treatment, and Survivorship – reflect changes that we want to see in Illinois.**

The objectives are measurable accomplishments necessary to meet the goal. The objectives were made to be specific, measurable, attainable, realistic, and timely (SMART) to facilitate the assessment of progress made towards meeting these objectives over the next five years (2022-2027). Data sources used for the objectives are listed in parentheses after each objective and are publicly available so anyone can track Illinois's progress towards meeting these objectives. This also ensures that these data sources will still be available in 2027.

The strategies are specific actions that can be taken to achieve the objectives. The strategies are divided into different topics/levels, including, policy, health systems, environmental changes, and health equity. Even though there are several strategies listed, it is not expected that all of these will be used or accomplished in the span of five years by any one person or organization. This section provides several examples of strategies in order to accomplish the objectives. Strategies can be incorporated into organizations' strategic plans or added to the organization, agency, or group's mission or vision.

The three work groups reviewed publicly available data to set baseline figures and targets. Data utilized included the Illinois State Cancer Registry, Healthy People 2020 and 2030, Illinois Behavioral Risk Factor Surveillance System (BRFSS), American Lung Association, Youth Risk Behavior Surveillance System (YRBSS), and TeenVaxView.

The Healthy People (HP) initiative is designed to guide national health promotion and disease prevention efforts to improve the health of the nation.<sup>3</sup> Released by the U.S. Department of Health and Human Services (HHS) every decade since 1980, HP identifies science-based objectives with targets to monitor progress and to motivate and to focus action. Every decade, the Healthy People initiative develops a new set of science-based, 10-year national objectives with the goal of improving the health of all Americans.

BRFSS is a state-based program that gathers information on risk factors among Illinois adults 18 years of age and older through monthly telephone surveys.<sup>4</sup> Established in 1984 as a collaboration between the U.S. Centers for Disease Control and Prevention (CDC) and state health departments, BRFSS has grown to be the primary source of information on behaviors and conditions related to the leading causes of death for adults in the general population. BRFSS collects data on different topics in certain years.

<sup>3</sup> U.S. Department of Health and Human Services. (n.d.). Healthy People 2030. Retrieved from [https://www.cdc.gov/hchs/healthy\\_people/index.htm](https://www.cdc.gov/hchs/healthy_people/index.htm).

<sup>4</sup> Illinois Behavioral Risk Factor Surveillance System. (2019). Retrieved from <http://www.idph.state.il.us/brfss/default.asp>.

# Illinois Comprehensive Cancer Control Plan

The Youth Risk Behavior Surveillance System (YRBSS) is a system of surveys. It includes a national school-based survey conducted by CDC and state, territorial, tribal, and local surveys conducted by state, territorial, and local education and health agencies and tribal governments. YRBSS monitors six categories of health-related behaviors that contribute to the leading causes of death and disability among youth and adults, including:

- Behaviors that contribute to unintentional injuries and violence.
- Sexual behaviors related to unintended pregnancy and sexually transmitted diseases, including HIV infection.
- Alcohol and other drug use.
- Tobacco use.
- Unhealthy dietary behaviors.
- Inadequate physical activities.

TeenVaxView provides immunization survey data collected by CDC. The CDC collects immunization data from local, state, and federal health departments through surveys and other data sources, such as immunization information systems to estimate vaccination coverage and to identify where additional efforts are needed to increase vaccination coverage.

Each work group evaluated the data described above to set the target. Targets were generally set for a 5% to 10% change over the five years. Where applicable, the HP2030 goal is listed as a reference.

## Additional Information Sources

- CDC State Tobacco Activities Tracking and Evaluation (STATE) System: <https://www.cdc.gov/statesystem/interactivemaps.html>
- CDC Tobacco Use Data Portal: <https://chronicdata.cdc.gov/browse?category=Tobacco+Use>
- United States Cancer Statistics: Data Visualizations: <https://gis.cdc.gov/Cancer/USCS/DataViz.html>
- National Institutes of Health National Cancer Institute: <https://statecancerprofiles.cancer.gov/>

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<sup>5</sup> Youth Risk Behavior Factor Surveillance System (2019). Retrieved from <https://www.cdc.gov/healthyyouth/data/yrbs/results.htm>.

<sup>6</sup> TeenVaxView. (2019). Retrieved from <https://www.cdc.gov/vaccines/imzmanagers/coverage/teenvaxview/data-reports/hpv/dashboard/2019.html>.

# Illinois Comprehensive Cancer Control Plan

## PREVENTION

Prevention is stopping cancer before it starts. This includes promoting healthy living habits amongst adults and youth to reduce the risk of cancer occurring from a poor diet, drinking alcohol, and inadequate physical activity.

Smoking tobacco and exposure to second-hand smoke and other carcinogens are known risk factors to cause lung cancer. By not initiating smoking, quitting smoking, and reducing one's exposure to second-hand smoke and other environmental carcinogens, individuals can reduce their risk for developing cancer.

One form of cancer prevention is receiving the HPV vaccine,<sup>7</sup> which is known to protect against HPV that causes HPV-associated cancers. This vaccine is recommended for adolescents at the age of 11 or 12 through the age of 26. The vaccine can be given starting at the age of 9.

Lastly, knowing one's family history and utilizing genetic counseling can inform an individual of their risk of cancer through their genetic makeup. Knowing this information can help individuals determine whether getting screened earlier and / or more often is recommended based on their level of risk.

*I feel like prevention is the greatest that we can do in trying to reduce the number of people that are affected with cancer or maybe I should say we can catch it early and offer those early treatments to prevent it from spreading.*

Black Non-Hispanic community member from southern Illinois, 40 years of age

### The prevention goals are:

- Goal 1. Increase healthy living habits among youth and adults.**
- Goal 2. Reduce exposure to environmental carcinogens.**
- Goal 3. Prevent tobacco-related lung cancers among youth and adults.**
- Goal 4. Prevent HPV-related cancers.**
- Goal 5. Promote awareness of hereditary cancers and use of genetic counseling.**

### Goal 1: Increase healthy living habits among youth and adults.

- **Objective 1:** Decrease the percentage of high school students who did not eat vegetables from 7.9% to 7.1% by 2027 (YRBSS 2019).
- **Objective 2:** Decrease the percentage of high school students who drank a sugar-sweetened soda one or more times per day from 13.7% to 12.3% by 2027 (YRBSS 2019).
- **Objective 3:** Decrease the percentage of high school students who are obese (a body mass index of 30 or greater) from 15.2% to 13.7% by 2027 (YRBSS 2019).
- **Objective 4:** Increase the percentage of adults who eat one vegetable per day from 76.6% to 84.3% by 2027 (BRFSS 2019).
- **Objective 5:** Decrease the percentage of adults who are overweight (a body mass index between BMI is 25.0 to less than 30) or obese from 65.7% to 59.1% by 2027 (BRFSS 2019).

**Healthy People 2030 Target: 36.0%**

<sup>7</sup> Centers for Disease Control and Prevention. (2020, March 17). Retrieved from <https://www.cdc.gov/vaccines/vpd/hpv/hcp/recommendations.html>.

# Illinois Comprehensive Cancer Control Plan

- **Objective 6:** Decrease the percentage of adults who binge drink alcohol from 19.9% to 17.9% by 2027 (BRFSS 2019). Binge drinking for men is having five or more drinks and women having four or more drinks on one occasion.  
*Healthy People 2030 Target: 25.4%*
- **Objective 7:** Increase the percentage of adults ages 18-64 with health insurance coverage from 84.4% to 92.8% by 2027 (BRFSS 2019).  
*Healthy People 2030 Target: 92.1%*
- **Objective 8:** Increase the percentage of adults who visited a doctor in the past year from 76.5% to 84.2% by 2027 (BRFSS 2019).

## STRATEGIES

### *Policy Strategies*

- Engage employers to adopt cancer control plans and to adopt health improvement policies.
- Integrate healthy living principles in programs and policymaking (e.g., Health in All Policies).

### *System Strategies*

- Partner with health and hospital systems to promote healthy food and beverage choices.
- Promote access to and consumption of healthy beverages.
- Promote SNAP-Education and similar nutrition education assets.
- Promote access to fresh fruits and vegetables at food pantries.
- Engage patient navigators or community health workers to provide education, referral, and follow-up for those at high risk for poor health outcomes.

### *Environmental Changes Strategies*

- Provide access to free, safe drinking water, and limit access to sugary drinks in schools, places of work, and health care settings.
- Promote physical fitness in workplaces and physical education in all tax-funded programs, such as schools and park districts.
- Health Equity Strategies
- Educate the public about how and where to access health insurance coverage if uninsured or underinsured.
- Provide health insurance outreach and support to assist individuals whose employers do not offer affordable coverage, who are self-employed, or who are unemployed.
- Deliver patient education materials that are culturally and linguistically tailored to specific patient populations (print and online).
- Utilize education-related recommendations from The Community Guide to promote health equity.



# Illinois Comprehensive Cancer Control Plan

## Goal 2: Reduce exposure to environmental carcinogens.

- **Objective 1:** Decrease the amount of particulate matter the general public is exposed to from 9.5 microns to 8.3 microns in micrograms per cubic meter by 2027 (<https://www.americashealthrankings.org/explore/annual/measure/air/state/IL>).
- **Objective 2:** Increase the number of Illinois schools tested for radon from 89 to 200 by 2027 (IEMA School testing program for radon with American Lung Association).
- **Objective 3:** Reduce the percentage of tested classrooms with a  $\geq 4.0$  pCi/L measurement for radon from 9.7% to 8.7% by 2027 (IEMA School Testing Program for radon with American Lung Association).
- **Objective 4:** Reduce the percentage of tested schools with one classroom with a  $\geq 4.0$  pCi/L measurement for radon from 65.6% to 59.0% by 2027 (IEMA School Testing Program for radon with American Lung Association).

## STRATEGIES

### Policy Strategies

- Advocate for enforcement of U.S. Environmental Protection Agency (EPA) rules to reduce air pollution and to address climate change to increase the use of renewable energy sources.
- Advocate for increasing new zero emission and low emission hybrid vehicles on the road.

### System Strategies

- Support state and local policies that protect lung health from the impacts of a changing climate, including mitigation efforts in support of carbon neutrality, adaptation, and promoting community health resilience, especially in communities most heavily impacted by air pollution and climate change health risks.
- Support state and local policies that expand energy efficiency and non-combustion clean electricity usage and production, including wind, solar, geothermal, and tidal.
- Support state and local actions that require or ensure rapid transition to zero emission transportation solutions, including public fleet purchases, transit and school buses, ride-hailing systems.
- Support state and local policies that reduce traffic pollution and vehicle miles traveled through policies that prioritize investments in active transportation, mass transit, and smart growth.
- Support continuing funding for clean air enforcement, monitoring, and cleanup programs, including pollution reduction incentive.
- Promote use of new ICD-10 codes to capture data on contact with and suspected exposure to arsenic, lead, and asbestos.
- Promote the School Radon Testing program established by the Illinois Emergency Management Agency (IEMA).
- Promote the use of radon resistant construction techniques.

*We live by a steel mill, and all the chemicals and everything that comes out of there – I'm sure that's not healthy for us.*

White, non-Hispanic cancer survivor from southern Illinois, 52 years of age

# Illinois Comprehensive Cancer Control Plan

## Environmental Changes Strategies

- Reduce exposure to natural and to artificial ultraviolet radiation.
- Increase community demand for radon testing.

## Health Equity Strategies

- Support state efforts to eliminate the root causes of environmental injustices contributing to the health inequities related to exposure to poor air quality that affect the well-being of communities of color and historically underrepresented populations.

## Goal 3: Prevent tobacco-related lung cancers among youth and adults.

- **Objective 1:** Decrease the percentage of high school students who currently smoke cigarettes or used electronic vapor products in the last 30 days from 20.9% to 18.8% by 2027 (YRBSS 2019).
- **Objective 2:** Decrease the percentage of high school students who currently use smokeless tobacco in the last 30 days from 4.1% to 3.7% by 2027 (YRBSS 2019).
- **Objective 3:** Decrease the percentage of adults who are current smokers from 14.5% to 13.1% by 2027 (BRFSS 2019).  
*Healthy People 2030 Target: 5.0%*
- **Objective 4:** Decrease the percentage of adults who currently use smokeless tobacco from 2.7% to 2.4% by 2027 (BRFSS 2019).
- **Objective 5:** Increase the number of adults using to the Illinois Tobacco Quitline from 2,202 callers to 2,459 callers for FY2022 and 5% annually thereafter (Illinois Tobacco Quitline FY 2020).



## STRATEGIES

### Policy Strategies

- Advocate for continued state funding for tobacco control programs, including prevention, education, and cessation and ensure that funding is spent according to CDC's Best Practices for Comprehensive Tobacco Control Programs.
- Advocate to ensure continued access to cessation services for all those who want to quit smoking, including comprehensive coverage for cessation services under Medicaid, and both public and private insurance with a focus on disparate groups.
- Advocate for laws directed at minors' purchase, possession, or use to restrict minor's access to tobacco products.

# Illinois Comprehensive Cancer Control Plan

## System Strategies

- Support prohibiting the sale of all flavored tobacco products (including menthol).
- Promote use of the Illinois Tobacco Quitline through multiple channels targeting smokers, their physicians, health educators, and public health departments.
- Promote tobacco history screening and pack-year assessments in primary care settings.
- Refer at-risk patients for a low dose computed tomography (LDCT).
- Social media campaign targeting smokers with messaging that lung cancer diagnosed in early stages is curable.
- Collaborate with partners to provide school-based tobacco prevention programs that have age-specific classroom curricula and implemented as special school programs, media literacy training, and peer education programs.

## Environmental Changes Strategies

- Support the Smoke-Free Illinois Act and local comprehensive smoke-free laws that cover all bars, restaurants, casinos/gaming establishments and workplaces; without loopholes. Expand to include e-cigarettes, outdoor spaces, and multi-unit housing.

## Health Equity Strategies

- Increase the availability of tobacco use cessation services for individuals affected by tobacco-related disparities.
- Reduce client out-of-pocket costs to increase tobacco use cessation.
- Media campaign series to increase tobacco use cessation.
- Deliver patient education materials that are culturally and linguistically tailored to specific patient populations (print and online).
- Utilize education-related recommendations from The Community Guide to promote health equity.

## Goal 4: Prevent HPV-Related Cancers.

- **Objective 1:** Increase the percentage of female adolescents ages 13-17 who have at least received one dose of the HPV vaccine from 72.1% to 79.3% by 2027 (TeenVaxView 2019).
- **Objective 2:** Increase the percentage of male adolescents ages 13-17 who have at least received one dose of the HPV vaccine from 71.3% to 78.4% by 2027 (TeenVaxView 2019).
- **Objective 3:** Increase the percentage of female adolescents ages 13-17 who are up to date on the HPV vaccine from 55.2% to 60.7% by 2027 (TeenVaxView 2019).  
**Healthy People 2030 Target: 80%**
- **Objective 4:** Increase the percentage of male adolescents ages 13-17 who are up to date on the HPV vaccine from 54.5% to 60% by 2027 (TeenVaxView 2019).  
**Healthy People 2030 Target: 80%**

# Illinois Comprehensive Cancer Control Plan

## STRATEGIES

### *Policy Strategies*

- Recommend all vaccinations are entered into the state immunization information system.
- Recommend state public health department reports HPV vaccination rates.

### *System Strategies*

- Recommend the HPV vaccine for children at age 9 when vaccination can be started.
- Recommend the HPV vaccine for children at ages 11 or 12 for routine vaccination.
- Recommend and support adolescents and young adults to receive the HPV vaccine through age 26.
- Support the Illinois' Strategic Action Plan to Eliminate Vaccine Preventable Cancers and recommended policy, systems, and practice changes.
- Disseminate promising practices to health and hospital systems, providers, parents, public health partners, et al.
- Explore health plan/payer partnerships to prioritize adolescent vaccination series.
- Develop and share social media content (stories and video) on positive patient experiences, provider practice improvement, and current research.
- Deploy co-branded public awareness messaging with prevention partners.
- Integrate education about early cancer prevention in school settings and curricula.
- Host public educational forums throughout the year.
- Expand partnership opportunities during annual events, such as Cervical Cancer Awareness Month (January), International HPV Awareness Day (March), Back-to-school vaccination (summer).
- Utilize National HPV Vaccination roundtable resources for clinicians, nurses and medical assistants, oral health care provider, support staff et al., including guidance for effective provider recommendation, patient reminder systems, provider reminder systems, provider assessment and feedback (e.g., scorecards), reduction of structural barriers, professional practice roundtables, and learning collaboratives.

### *Environmental Changes Strategies*

- Provide community-wide education.

### *Health Equity Strategies*

- Deliver patient education materials that are culturally and linguistically tailored to specific patient populations (print and online).
- Utilize education-related recommendations from The Community Guide to promote health equity.
- Collaborate with local partners to educate the community about HPV vaccination for cancer prevention.
- Collaborate with local health officials and community organizations to address challenges, such as transportation and health care costs to increase HPV vaccinations.

# Illinois Comprehensive Cancer Control Plan

## Goal 5: Promote awareness of hereditary cancers and use of genetic counseling.

- **Objective 1:** Promote two resources annually to patients on hereditary cancer risks and cancer genetic counseling services.
- **Objective 2:** Promote two resources annually to providers on hereditary cancer risks, such as breast, ovarian, and colorectal cancers.
- **Objective 3:** Increase the number of certified genetic counselors in Illinois by 10% from 77 to 85 by 2027 (<https://findageneticcounselor.nsgc.org/In-Person-FindaGC?reload=timezone>).

## STRATEGIES

### Policy Strategies

- Providers follow U.S. Preventive Service Task Force (USPSTF) recommendation for genetic counseling for potentially high-risk women and men.

### System Strategies

- Promote “Know Your Family’s Health History” available at <https://www.dph.illinois.gov/topics-services/life-stages-populations/genomics>.
- Expand efforts to collect cancer family histories, to conduct risk assessments, and to refer patients to genetic counseling services in primary care settings (FQHCs, local health departments, etc.).
- Expand community outreach efforts to increase public awareness of family history, hereditary cancers, and genetic counseling.
- Create or promote public awareness campaigns (such as governor’s proclamations, news releases, and social media dissemination of awareness days) (e.g., March 22 Lynch Syndrome Awareness Day, Thanksgiving National Family Health History Awareness Day, etc.).
- Educate providers to initiate dialogue around genetic counseling and testing.
- Promote the addition of accredited genetic counselor programs.

*I think my family initially was very quiet when talking about cancer... my mom was diagnosed with cancer and she had a really aggressive form of ovarian cancer that we started to open up and talk more about it and be more transparent with our health.*

White, non-Hispanic cancer caregiver from suburban Cook County, 27 years of age

### Environmental Changes Strategies

- Educate and increase awareness of genetic counseling and testing.

### Health Equity Strategies

- Develop and disseminate culturally and linguistically appropriate patient education materials (print and online).
- Encourage new cancer genetic services in underserved areas, such as satellite clinics, telemedicine, cancer genetic clinic partners with local public health departments, and/or primary care providers in rural areas.

*When I did my genetic testing and we did the whole history of the family, everyone’s like, “Oh, can I get a copy of that?” So, having your family history and medical history, I should say, was very helpful for me and to be able to give it to other family members as well just so they could know what the background is for medical. Because I have a lot of cousins and they’re like, “Wait, can I have that?” Because if we don’t talk about it, they don’t know about it.*

White, non-Hispanic cancer survivor from Cook County, 36 years of age

# Illinois Comprehensive Cancer Control Plan

## SCREENING AND EARLY DETECTION

Screening and early detection is screening for cancer in its earliest stage when treatment works best.

Screening tests are available for lung, colorectal, breast, prostate, and cervical cancer. Each cancer type has recommendations for when to start screening and the frequency. By screening for cancers that have a screening test, it can be caught in an earlier stage.

*I still actually have a tendency to not be very up on certain type of screenings, but I think that your family doctors definitely play a large role in enforcing it. And that's definitely how I ended up with catching my diagnosis.*

White, non-Hispanic cancer survivor and caregiver from central Illinois, 57 years of age

*Some people don't have access or are afraid, especially in the Black community and Brown communities. But if you have that option, get it done so the people around you can see that -hey, prevention is the best medicine. You don't have to be afraid.*

Black, non-Hispanic cancer survivor from Cook County, 57 years of age

By increasing cancer screenings for these cancer types based on current recommendations and identifying individuals who may be more at risk for some cancers can reduce a late-stage cancer diagnosis. This can help reduce the cancer mortality rate.

### The screening and early detection goals are:

- Goal 1. Increase cancer screening.**
- Goal 2. Reduce late-stage cancer diagnosis.**
- Goal 3. Reduce cancer mortality rates.**

### Goal 1: Increase cancer screening.

- **Objective 1:** Increase lung cancer screening among adults 50-80 years of age from 6.3% to 6.9% by 2027 (American Lung Association 2019).  
*Healthy People 2030 Target: 7.5%*
- **Objective 2:** Increase colorectal cancer screening among adults 45-75 years of age from 66.7% to 73.4% by 2027 (State Cancer Profiles 2018).  
*Healthy People 2030 Target: 74.4%*
- **Objective 3:** Increase breast cancer screening among females 40 years and older from 73.1% to 80.4% by 2027 (State Cancer Profiles 2018).  
*Healthy People 2030 Target: 77.1%*
- **Objective 4:** Increase prostate cancer screening among Hispanic males 50-69 years of age from 17.3% to 19.0% by 2027 (BRFSS 2018).
- **Objective 4.1:** Increase prostate cancer screening among Black Non-Hispanic males 50-69 years of age from 29.4% to 32.3% by 2027 (BRFSS 2018).

# Illinois Comprehensive Cancer Control Plan

- **Objective 5:** Increase cervical cancer screening among females 21-65 years of age from 69.1% to 76.0% by 2027 (State Cancer Profiles 2018).

*Healthy People 2030 Target: 84.3%*

## STRATEGIES

### *Policy Strategies*

- Work with partners, community organizations and businesses to implement policies to reduce client out-of-pocket costs and structural barriers to screening (e.g., mobile mammography vans, transportation, and child care).

### *System Strategies*

- Create a resource guide for uninsured and underinsured individuals to promote screening.
- Advocate to increase providers and community education of awareness on the up-to-date cancer screening guidelines.
- Promote the Illinois Breast and Cervical Cancer Program (IBCCP) to all eligible women.
- Utilize quality improvement strategies to analyze and to improve current screening policies and procedures.
- Utilize current USPSTF and other nationally recognized guidelines.
- Engage state and federal partners, such as Illinois Primary Health Care Association (IPHCA) and federally qualified health centers (FQHCs), to increase the use of proven colorectal colon cancer screening tests, specifically in clinical settings.
- Educate providers about the effectiveness of stool-based testing for those at average risk of developing colon cancer.
- Engage stakeholders in identifying gaps in lung cancer screening.
- Identify appropriate evidence-based interventions to increase availability and access to lung cancer screenings.
- Educate providers about how to recognize ovarian cancer signs and symptoms and how to diagnose the presence of ovarian cancer through blood, imaging, and tissue tests.
- Promote and encourage the participation in regional and statewide cancer coalitions.

### *Environmental Changes Strategies*

- Provide group education to increase community demand for cancer screening services.
- Provide one-on-one education to increase community demand for cancer screening services.
- The USPSTF recommends annual screening for lung cancer with low-dose computed tomography in adults aged 50-80 years who have a 20-pack-a-year smoking history and currently smoke or have quit within the past 15 years.

# Illinois Comprehensive Cancer Control Plan

## Health Equity Strategies

- Advocate for patient navigation to address social determinants of health and barriers to access to care (lack of transportation, cost, lack of insurance, etc.).
- Develop and disseminate materials for informing, raising awareness, and educating community members on cancer screening that are culturally appropriate and accessible for people of varying literacy levels.
- Advocate for targeted outreach and screening for minority high-risk populations, utilizing cancer incidence, mortality, and late-stage diagnosis data to prioritize high-risk communities and population.
- Raise awareness on racial and ethnic disparities for cancer screenings.
- Advocate for health care providers, community education, and awareness for:
  - Prostate cancer screening among minority population (Hispanic and Black males).
  - Breast cancer screening among minority population (Black females).
  - Colorectal cancer screening among minority population (Black adults).
  - Cervical cancer screening among minority population (Hispanic and Black females).
- Provide focused education to underrepresented populations through community partnerships.
- Provide focused ovarian cancer awareness and education to women in rural and medically underserved areas with health care professional shortages through community partnerships.

## Goal 2: Reduce late-stage cancer diagnosis.

- **Objective 1:** Reduce late-stage lung and bronchus cancer diagnosis from 45.4% to 40.9% among adults 50 years and older by 2027 (State Cancer Profiles 2013-2017).
- **Objective 2:** Reduce late-stage colorectal cancer diagnosis from 24.1% rate to 21.7% among all ages of adults by 2027 (State Cancer Profiles 2013-2017).
- **Objective 3:** Reduce late-stage breast cancer diagnosis from 45.6% to 41.0% among females of all ages by 2027 (State Cancer Profiles 2013-2017).
- **Objective 4:** Reduce late-stage prostate cancer diagnosis from 24.0% to 21.6% among males ages 50 years and older by 2027 (State Cancer Profiles 2013-2017).
- **Objective 5:** Reduce late-stage cervical cancer diagnosis from 3.8% to 3.4% among females 21-65 years of age by 2027 (State Cancer Profiles 2013-2017).

## STRATEGIES

### Policy Strategies

- Work with partners, community organizations, and businesses to implement policies to reduce client out-of-pocket costs and structural barriers to screening (e.g., mobile mammography vans, transportation, and child care).

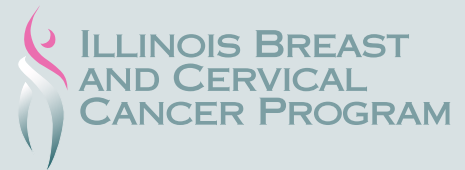
### System Strategies

- Create a resource guide for uninsured and underinsured individuals to promote screening.
- Promote genetic counseling, testing and establish a means of getting access to it.



# Illinois Comprehensive Cancer Control Plan

- Support and encourage the use of family history assessments and genetic testing for colorectal cancer (i.e., Lynch syndrome), breast cancer, and ovarian cancer.
- Advocate to increase providers and community education of awareness on up-to-date cancer screening guidelines.
- Promote IBCCP to all eligible women.
- Utilize Quality Improvement to analyze and to improve current screening policies and procedures.
- Advocate for health care providers and community education and awareness on late-stage cancer diagnoses, including breast, prostate, lung, colorectal, cervical, and ovarian cancers.
- Utilize current USPSTF and other nationally recognized guidelines.
- Engage state and federal partners, such as IPHCA and FQHCs, to increase the use of proven colorectal colon cancer screening tests, specifically in clinical settings.
- Educate providers about the effectiveness of stool-based testing for those at average risk of developing colon cancer.
- Identify appropriate evidence-based interventions to increase availability and access to lung cancer screenings.
- Educate providers about how to recognize ovarian cancer signs and symptoms and how to diagnose the presence of ovarian cancer through blood, imaging, and tissue tests.
- Promote and encourage the participation in regional and statewide cancer coalitions.



Call  
Illinois Women's Health-Line  
**888-522-1282**

**TTY 800-547-0466**  
(hearing impaired use only)

Visit  
[www.cancerscreening.illinois.gov](http://www.cancerscreening.illinois.gov)

## *Environmental Changes Strategies*

- Provide group education to increase community demand for cancer screening services.
- Provide one-on-one education to increase community demand for cancer screening services.

## *Health Equity Strategies*

- Advocate for patient navigation to address social determinants of health and barriers to access to care (lack of transportation, cost, lack of insurance, etc.).
- Advocate for targeted outreach and screening for minority high-risk populations by utilizing cancer incidence, mortality, and late-stage diagnosis data to prioritize high-risk communities and populations.
- Develop and disseminate materials for informing, raising awareness, and educating community members on cancer screening that are culturally appropriate and accessible for people of varying literacy levels.
- Raise awareness on racial and ethnic disparities for cancer screenings.
- Provide focused education to underrepresented populations through community partnerships.
- Provide focused ovarian cancer awareness and education to women in rural and medically underserved areas with health care professional shortages through community partnerships.

# Illinois Comprehensive Cancer Control Plan

## Goal 3: Reduce cancer mortality rates.

- **Objective 1:** Reduce the lung and bronchus cancer mortality rate from 41.1 to 38.5 among adults 50-80 years of age by 2027 (State Cancer Profiles 2014-2018).  
*Healthy People 2030 Target: 25.1 per 100,000*
- **Objective 2:** Reduce the colon and rectum cancer mortality rate from 14.7 to 13.7 among adults 50-75 years of age by 2027 (State Cancer Profiles 2014-2018).  
*Healthy People 2030 Target: 8.9 per 100,000*
- **Objective 3:** Reduce the breast cancer mortality rate from 21.0 to 20.1 among females 45 years and older by 2027 (State Cancer Profiles 2014-2018).  
*Healthy People 2030 Target: 15.3 per 100,000*
- **Objective 4:** Reduce the prostate cancer mortality rate from 20.0 to 19.0 among males 45 years and older by 2027 (State Cancer Profiles 2014-2018).  
*Healthy People 2030 Target: 16.9 per 100,000*
- **Objective 5:** Reduce the cervical cancer mortality rate from 2.3 to 2.2 among females 21-65 years of age by 2027 (State Cancer Profiles 2014-2018).

## STRATEGIES

### Policy Strategies

- Work with partners, community organizations, and businesses to implement policies to reduce client out-of-pocket costs and structural barriers to screening (e.g., mobile mammography vans, transportation, and child care).
- Raise awareness of the need to remove out-of-pocket costs patients may receive if polyps were removed during their screening colonoscopy for Illinois privately insured and Medicaid beneficiaries.
- Remove the loop-hole billing and out-of-pocket costs for colorectal cancer diagnostic testing.

### System Strategies

- Promote genetic counseling, testing, and establish a means of getting access to it.
- Support and encourage the use of family history assessments and genetic testing for colorectal cancer (i.e., Lynch syndrome), breast cancer, and ovarian cancer.
- Advocate to increase providers and community education of awareness on up-to-date cancer screening guidelines.
- Promote IBCCP to all eligible women.
- Utilize quality improvement strategies to analyze and to improve current screening policies and procedures.
- Utilize current USPSTF and other nationally recognized guidelines.
- Engage state and federal partners, such as IPHCA and FQHCs, to increase the use of proven colorectal colon cancer screening tests, specifically in clinical settings.

*I would say for me... the screening and all that, to tell you the truth, that focus didn't come so much from my family as from my health care providers. They're the ones who zoom in on me and say, "Get that mammogram," or "Hey, let's get that colonoscopy." That's where I got the messages, from my health care providers for the most part.*

White Hispanic/Latino cancer survivor from Cook County, 52 years of age

# Illinois Comprehensive Cancer Control Plan

- Educate providers about the effectiveness of stool-based testing for those at average risk of developing colon cancer.
- Engage stakeholders in identifying gaps in lung cancer screening.
- Identify and implement appropriate evidence-based interventions to increase availability and access to lung cancer screenings.
- Educate providers about how to recognize ovarian cancer signs and symptoms and how to diagnose the presence of ovarian cancer through blood, imaging, and tissue tests.

## Environmental Changes Strategies

- Provide group education to increase community demand for cancer screening services.
- Provide one-on-one education to increase community demand for cancer screening services.

## Health Equity Strategies

- Advocate for patient navigation to address social determinants of health and barriers to access to care (lack of transportation, cost, lack of insurance, etc.).
- Develop and disseminate culturally and health literacy sensitive materials for informing, raising awareness, and educating community members on cancer screening.
- Advocate for targeted outreach and screening for minority high-risk populations, utilizing cancer incidence, mortality, and late-stage diagnosis data to prioritize high-risk communities and populations.
- Raise awareness on racial and ethnic disparities for cancer screenings.
- Advocate for health care providers, community education, and awareness for:
  - Prostate cancer screening among minority population (Hispanic and Black males).
  - Breast cancer screening among minority population (Black females).
  - Colorectal cancer screening among minority population (Black adults).
  - Cervical cancer screening among minority population (Hispanic and Black females).
- Provide focused education to underrepresented populations through community partnerships.
- Utilize community partnerships to provide focused ovarian cancer awareness and education to women in rural and medically underserved areas with health care professional shortages.

*But what would've been great, and hospitals have this but ours doesn't – it would be to have a patient navigator. I had friends who did have patient navigators and it just blew my mind. I mean, they basically take care of all that stuff for you, answer your questions.*

White, non-Hispanic cancer survivor from Central Illinois, 66 years of age

# Illinois Comprehensive Cancer Control Plan

## DIAGNOSIS, TREATMENT, AND SURVIVORSHIP

Diagnosis, treatment, and survivorship includes providing support and services to cancer patients, survivors, and their caregivers to address social, emotional, and financial challenges they may face to increase quality of life.

Promoting awareness and access to different supports and services includes navigation, ongoing care coordination, genetic counseling, and telehealth or outreach programs.

Most measures in this priority area will be used based on the organization implementing the objective to reach the goal. Most objectives in this area do not have a data source due to the data on these objectives not being collected or not existing currently regarding cancer survivorship issues in Illinois.

*I just heard about a friend, "Don't say anything. He's got cancer, but he doesn't want to talk about it." I go like, "Why not?" Do you realize how much love you can get if you put it out there? Because people do care. They want to. That's it.*

White, non-Hispanic cancer survivor and caregiver from Cook County, 82 years of age

The diagnosis, treatment, and survivorship goals are:

- Goal 1. Promote awareness and access to navigation services, including financial navigation and care navigation, to reduce disparities in cancer health outcomes.**
- Goal 2. Increase diagnosis of high-risk patients with familial or genetic risk factors.**
- Goal 3. Increase awareness of ongoing care coordination for monitoring, follow-up, and recurrence screening.**
- Goal 4. Raise awareness of the need for increased quality of life for enhanced recovery and survivorship and available resources.**
- Goal 5. Support the availability of telehealth and outreach programs.**

**Goal 1: Promote awareness and access to navigation services, including financial navigation and care navigation, to reduce disparities in cancer health outcomes.**

- **Objective 1:** Promote four educational opportunities for patient navigators per year.  
*Measure: Distribution of patient navigator educational opportunities per year.*
- **Objective 2:** Develop a resource document of supportive services.  
*Measure: Completion and distribution of the resource document.*

## STRATEGIES

### Policy Strategies

- Educate decision-makers about economic and insurance barriers related to health care for cancer survivors.
- Educate policy- and decision-makers about the role and value of long-term follow-up care for cancer survivors.

# Illinois Comprehensive Cancer Control Plan

- Establish policies that create an environment conducive to program implementation and other cancer survivorship changes.
- Promote policy changes that support addressing cancer as a long-term, chronic disease.

## System Strategies

- Make intentional efforts/generate opportunities to build collaboration with and to leverage existing patient navigation platforms.
- Focus educational opportunities to increase navigation in communities that experience disparities in diagnosis, treatment, and cancer outcomes.
- Develop a catalogue of hospital-based and community-based cancer support resources for organizations that have limited navigation services on-site.
- Promote patient navigation and community health worker programs.
- Develop, test, maintain, and promote patient navigation or case management programs that facilitate optimum care.
- Develop, test, maintain, and promote patient navigation systems for people living with cancer.
- Increase community-clinical linkages to community support services.
- Set up programs to help individual cancer survivors (e.g., provide transportation to treatment, meals, respite care for caregivers, child care, etc.).
- Develop and disseminate public education programs that empower survivors to make informed decisions.
- Teach survivors how to access and evaluate available information.
- The Illinois Cancer Partnership (ICP) Survivorship Subcommittee will develop a roadmap for navigating through treatment and support services.

*I'd like to see increased access to quality care, because just having the care by itself without the quality doesn't provide a lot.*

Black, non-Hispanic cancer caregiver from central Illinois, 65 years of age

## Environmental Changes Strategies

- Develop and disseminate public education programs that empower survivors to make informed decisions.
- Implement evidence-based cancer plans that include all stages of cancer survivorship. See <https://cdc.gov/cancer/survivors/life-after-cancer/survivorship-care-plans.htm> for more information.

*My mother is a cancer survivor, and I'm actually in cancer research. And we have cancer in the family, and I just realized we don't talk about it.*

Black, non-Hispanic community member from Cook County, 37 years of age

## Health Equity Strategies

- Identify resources for cancer survivors in communities that experience disparities in diagnosis, treatment, and cancer outcomes.
- Provide cultural competency training for health care providers to promote health equity.
- Encourage culturally specific health care settings to promote health equity.
- Use linguistically and culturally appropriate health education materials to promote health equity.

# Illinois Comprehensive Cancer Control Plan

## Goal 2: Increase diagnosis of high-risk patients with familial or genetic risk factors.

- **Objective 1:** Improve awareness of guidelines for surveillance, diagnosis and appropriate treatment based on tumor characteristics (i.e., Lynch syndrome).

*Measure: Compare the percentage of Microsatellite Unstable (MSI-H) cancers reported to the National Cancer Data Base before and after providing resources.*

- **Objective 2:** Increase referrals to genetic testing.

*Measure: Survey genetic counselors about referral pattern before and after resources are provided.*

## STRATEGIES

### Policy Strategies

- Providers follow USPSTF recommendation to recommend genetic counseling for potentially high-risk people.

### System Strategies

- Provide resources about guidelines of cancer screening.
- Promote genetic testing referral resources for people diagnosed with cancer.
- Educate providers to engage in dialogue around genetic counseling and testing.
- Promote the addition of accredited genetic counselor programs.

### Environmental Changes Strategies

- Educate and promote awareness of genetic counseling and testing.

### Health Equity Strategies

- Develop and disseminate culturally and linguistically appropriate patient education materials (print and online).
- Encourage new cancer genetic services in underserved areas, such as satellite clinics, telemedicine, cancer genetic clinic partners with local public health departments and/or primary care providers in rural areas.

## Goal 3: Increase awareness of ongoing care coordination for monitoring, follow-up, and recurrence screening.

- **Objective 1:** Promote awareness among health care providers of guidelines for surveillance and follow-up.

*Measure: Promote guidelines to four organizations with health care providers per year.*

- **Objective 2:** Promote existing resources to share with associations to educate providers on the elements of navigation.

*Measure: Identify five associations each year to distribute materials to their constituency (25 total over five years).*

- **Objective 3:** Increase patient and provider awareness of survivorship care coordination and guidelines by directing patients and providers to survivorship resources (use QR code).

*Measure: Distribute materials to at least five patient advocacy organizations per year.*

*I think that it would be very helpful if all oncology offices had a direct link to a social worker or counseling department, let alone if there was just an area on the check-in desk where there was business cards for where to seek help.*

Black, non-Hispanic cancer caregiver from central Illinois, 65 years of age

# Illinois Comprehensive Cancer Control Plan

## STRATEGIES

### Policy Strategies

- Establish and/or disseminate guidelines that support quality and timely service provision to cancer survivors.
- Encourage integrated multidisciplinary teams of health care providers.
- Educate policy- and decision-makers about economic and insurance barriers related to health care for cancer survivors.
- Promote policy changes that support addressing cancer as a long-term, chronic disease.

### System Strategies

- Promote utilization of survivorship care programs.
- Promote awareness of the importance of advance care planning.
- Improve accessibility of advance care planning documents within and across health systems.
- Create health system strategies to routinely assess and to review advance care plans throughout the cancer experience, including diagnosis, treatment, survivorship, and end of life.
- Increase community-clinical linkages to community support services.
- Promote the benefits and use of survivorship care plans with cancer survivors and their caregivers.
- Promote systems change to integrate survivorship care plans into systems of care.
- Identify a list of organizations for materials to be used for distribution.
- Share resources with the Illinois Breast and Cervical Cancer Program (IBCCP), WiseWoman, and other state and local health programs for distribution within their programs.
- The ICP Survivorship Subcommittee will create and disseminate a survey to collect baseline data on what types of care coordination is currently provided.

### Environmental Changes Strategies

- Develop and disseminate public education programs that empower survivors to make informed decisions.
- Educate the public that some cancers are curable, some are a chronic disease, and that people can live with and do survive.

### Health Equity Strategies

- Provide cultural competency training for health care providers to promote health equity.
- Promote culturally specific health care settings to promote health equity.
- Use interpreter services or bilingual providers to promote health equity.
- Use linguistically and culturally appropriate health education materials to promote health equity.

*Location does impact survivorship. It impacts people going to the doctor. It impacts how people will make the decisions on what they're going to do to take care of themselves and their family because of lack of resources or resources that are there that they don't feel like they are deserving of or don't understand them.*

Black, non-Hispanic cancer survivor and caregiver from Cook County, 69 years of age

# Illinois Comprehensive Cancer Control Plan

**Goal 4: Raise awareness of the need for increased quality of life for enhanced recovery and survivorship and available resources.**

**Healthy People 2030 Objective – Increase quality of life for cancer survivors. Status: Research.**

- **Objective 1:** Decrease the percentage of days (8-30 days) where cancer patients' and survivors' mental health was not good from 9.7% to 8.7% by 2027 (BRFSS 2019).
- **Objective 2:** Decrease the percentage of days (8-30 days) cancer patients and survivors were kept from doing their usual activities due to their health from 15.4% to 13.9% by 2027 (BRFSS 2019).
- **Objective 3:** Decrease the percentage of cancer patients and survivors who are overweight or obese from 11.3% to 10.2% by 2027 (BRFSS 2019).
- **Objective 4:** Decrease the percentage of cancer patients and survivors who binge drink alcohol from 4.8% to 4.3% by 2027 (BRFSS 2019).
- **Objective 5:** Promote clinical trials to current cancer patients.  
*Measure: Promote clinical trials in two educational documents each year (newsletter, brochure, flyer, etc.).*
- **Objective 6:** Increase the number of Illinois providers certified in hospice and palliative medicine from 207 to 228 by 2027.<sup>8</sup>

## STRATEGIES

### Policy Strategies

- Promote the use of integrated multidisciplinary teams of health care providers.
- Promote policy changes that support addressing cancer as a long-term, chronic disease.

### System Strategies

- Provide education to cancer survivors and caregivers on the impact of continued tobacco use and refer to tobacco cessation resources to decrease reoccurrences and secondary cancers.
- Provide education to cancer survivors and caregivers on national nutrition and physical activity guidelines to decrease reoccurrences and secondary cancers.
- Promote disease self-management workshops or classes to cancer survivors and to caregivers.
- Partner with collaborating organizations to assess palliative care needs.
- Assess and enhance provision of palliative services to cancer survivors.
- Provide education to patients and to caregivers on comprehensive information regarding legal and ethical end-of-life care options, such as advance directives and living wills.
- Promote earlier hospice care transitions for qualifying cancer patients.
- Disseminate resources to educate providers on physical quality of life assessment and resources to address reduced quality of life.

*I was the primary caregiver for my mom when she was going through her treatment, and the office visits were just incredible. I mean, from the receptionist, the nurses, the doctors, everybody was just great.*

White, non-Hispanic cancer caregiver from suburban Cook, 27 years of age

<sup>8</sup> Healthgrades Operating Company. (2021). Retrieved from <https://www.healthgrades.com/specialty-directory>.



# Illinois Comprehensive Cancer Control Plan

- Promote the use of existing lifestyle change programs.
- Utilize community health workers (CHWs) or patient navigators to recommend patients and survivors to a lifestyle change program.
- Promote or provide educational resources on alcohol misuse to providers and to patients.
- Implement the utilization of established provider reminder systems that identify patients eligible for available clinical trials.
- Promote participation by diverse populations in clinical trials to help ensure research conducted is relevant and serves the needs of diverse communities.
- Discuss available clinical trials in multi-disciplinary tumor board meetings.
- Develop methods to encourage referral for appropriate clinical trials when not available in the local community/practice.
- Utilize the electronic medical record as a mechanism to increase enrollment in clinical trials.

## Environmental Changes Strategies

- Develop and disseminate public education programs that empower survivors to make informed decisions.
- Educate health care providers about cancer survivorship issues from diagnosis through long-term treatment effects and end-of-life care.
- Implement evidence-based cancer plans that include all stages of cancer survivorship.
- Provide information to cancer survivors, health care providers, and the public about cancer survivorship.

*At first, I was terrified... "Oh, I'm gonna be this guinea pig." But I've been on it. I decided to go with the clinical trial, and I am so happy I did because it's keeping me stable. And I'm lucky enough, I don't have side effects.*

White, non-Hispanic cancer survivor from suburban Cook, 60 years of age

## Health Equity Strategies

- Promote resources and webinars to educate providers on a trauma-informed, health equity approach to cancer survivorship.
- Promote access to quality treatment and to clinical trials.
- Ensure culturally specific health care settings to promote health equity.
- Use interpreter services or bilingual providers to promote health equity.
- Use linguistically and culturally appropriate health education materials to promote health equity.

## Goal 5: Support the availability of telehealth and outreach programs.

**Healthy People 2030 Objective: Increase the use of telehealth to improve access to health services. Status: Research.**

- Objective 1: Promote continued availability of telehealth for patients.  
*Measure: Further research needs to be done for data sources that collect this information in Illinois.*
- Objective 2: Promote educating patients on how to utilize telehealth platforms and other technology.  
*Measure: Availability of curriculum or training resources for clinic staff and CBOs to support patient use of telehealth platforms. Organizations assess the patient's ability to access internet from home.*

# Illinois Comprehensive Cancer Control Plan

## STRATEGIES

### Policy Strategies

- Promote policy changes that support addressing cancer as a long-term, chronic disease.

### System Strategies

- Utilize comprehensive telehealth interventions to help adults who have chronic diseases that are affected by dietary behaviors.
- Share best practices from patient telehealth experiences.
- Monitor changes in payor policies for telehealth.
- Utilize staff (office assistants or CHWs) to educate patients on how to use these platforms when checking in for an appointment.

### Environmental Changes Strategies

- Provide information to cancer survivors, health care providers, and the public about cancer survivorship and meeting their needs.

### Health Equity Strategies

- Ensure culturally specific health care settings to promote health equity.
- Use interpreter services or bilingual providers to promote health equity.
- Use linguistically and culturally appropriate health education materials to promote health equity.

*I'm a big fan of the tele-nurse because they're 24/7 and you can call them and get like almost instantaneous advice. And every time I would call, they would call the doctor and confirm it.*

White, non-Hispanic cancer survivor from suburban Cook, 60 years of age



# Illinois Comprehensive Cancer Control Plan

## CALL TO ACTION - WHAT YOU CAN DO

Whether you are a cancer patient, cancer survivor, caregiver of a cancer patient, community member, student, employer, health care professional, or policy maker, everyone can play a role in helping with the prevention, early detection, treatment, and survivorship of cancer in Illinois. Table 1 lists the action steps.

*When someone tells me they don't feel good or something, [I ask] "When's the last time you saw your doctor? Do you have a doctor? What can I do to help you?"*

Black, non-Hispanic cancer survivor and caregiver from Cook County, 67 years of age

**Table 1. Call to Action.**

INDIVIDUALS		
Prevention	Screening and Early Detection	Diagnosis, Treatment, and Survivorship
<ul style="list-style-type: none"> <li>Quit smoking or never start smoking.</li> <li>Avoid/reduce exposure to secondhand smoke.</li> <li>Maintain a healthy diet by eating the recommended amounts of fruits and vegetables.</li> <li>Exercise at least 30 minutes per day.</li> <li>Get vaccinated against vaccine-preventable cancers, such as human papillomavirus (HPV) and Hepatitis B.</li> <li>Reduce alcohol consumption.</li> <li>Test your home for radon and implement mitigation strategies, such as sealing cracks and other openings in the foundation and modifying house or room pressure and ventilation.</li> <li>Promote increasing air flow in your house by opening windows and using fans and vents to circulate air. Natural ventilation in any type of house is only a temporary strategy to reduce radon.</li> <li>Collect family health history and share with your provider.</li> <li>Reduce exposure to UV radiation and wear sunscreen.</li> </ul>	<ul style="list-style-type: none"> <li>Get your recommended cancer screenings regularly and on time based on age and sex (colorectal, lung, cervical, breast, and prostate cancers).</li> <li>Visit a dental office and have an oral exam.</li> <li>Update family history and share with your provider.</li> <li>Ask about genetic counseling services.</li> </ul>	<ul style="list-style-type: none"> <li>Support cancer survivors through the continuum of survivorship from diagnosis to remission.</li> <li>Get a copy of your cancer treatment plan and instructions on what to do after treatment.</li> <li>Ask your medical provider about services to help with symptoms from cancer or its treatment.</li> <li>Ask about support groups.</li> <li>Explore clinical trials.</li> <li>Complete an advance care plan.</li> <li>Volunteer to help those affected by cancer.</li> <li>Share your knowledge with others in your family.</li> </ul>

# Illinois Comprehensive Cancer Control Plan

## COMMUNITY ORGANIZATIONS

Prevention	Screening and Early Detection	Diagnosis, Treatment, and Survivorship
<ul style="list-style-type: none"> <li>• Provide areas for physical activity.</li> <li>• Encourage participation in wellness programs.</li> <li>• Implement smoke-free policies.</li> <li>• Provide healthy foods and drinks at events.</li> <li>• Provide information on ways to prevent cancers.</li> <li>• Provide at-home radon kits.</li> <li>• Assist community members with signing up for insurance.</li> <li>• Collaborate to address and to remove barriers to prevention.</li> <li>• Provide family health history tools.</li> <li>• Establish partnerships with local health care organizations to raise awareness and to educate community members.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide screening events.</li> <li>• Encourage individuals to receive their recommended screenings.</li> <li>• Collaborate to address and remove barriers to screening and early detection.</li> <li>• Establish partnerships with local health care organizations to raise awareness, educate, and increase access to screening and early detection services for community members.</li> <li>• Disseminate family health history and genetic counseling services information.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide or host cancer survivor groups.</li> <li>• Provide information for cancer patients and survivors.</li> <li>• Collaborate to address and to remove barriers to diagnosis, treatment, and survivorship.</li> <li>• Provide information about genetic services.</li> </ul>

## SCHOOLS

Prevention	Screening and Early Detection	Diagnosis, Treatment, and Survivorship
<ul style="list-style-type: none"> <li>• Implement healthy lunch programs.</li> <li>• Implement smoke-free policies.</li> <li>• Provide time for recess each school day.</li> <li>• Educate about healthy foods and physical activity.</li> <li>• Educate parents and students on the HPV vaccine.</li> <li>• Test buildings for radon.</li> <li>• Implement HPV vaccination campaign in conjunction with school nurses and other school health staff.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide education on the HPV vaccine and cervical cancer and oral cancer screenings.</li> <li>• Implement HPV vaccination campaign in conjunction with school nurses and other school health staff.</li> </ul>	<ul style="list-style-type: none"> <li>• Educate staff and personnel on cancer treatment and survivorship.</li> <li>• Provide counseling services for students and parents going through cancer treatment.</li> </ul>

# Illinois Comprehensive Cancer Control Plan

## EMPLOYERS

Prevention	Screening and Early Detection	Diagnosis, Treatment, and Survivorship
<ul style="list-style-type: none"> <li>• Offer employee insurance benefits for wellness programs.</li> <li>• Provide breaks to encourage health behaviors.</li> <li>• Provide education on cancer prevention.</li> <li>• Adopt smoke-free policies.</li> <li>• Increase awareness of importance of family history.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide benefit time for employees to get their recommended screenings.</li> <li>• Provide information on screening and early detection.</li> <li>• Establish an incentive program to encourage employees to get recommended screenings.</li> </ul>	<ul style="list-style-type: none"> <li>• Support cancer survivors to be able to continue being successful employees.</li> </ul>

## HEALTH CARE PROFESSIONALS

Prevention	Screening and Early Detection	Diagnosis, Treatment, and Survivorship
<ul style="list-style-type: none"> <li>• Educate patients on recommendations for healthy eating habits and physical activity.</li> <li>• Educate on the HPV vaccine.</li> <li>• Encourage patients who are smokers to quit smoking by recommending smoking cessation programs.</li> <li>• Educate on the risks of binge and chronic drinking.</li> <li>• Encourage sun safety behaviors.</li> <li>• Collect family health history annually and assess risks; refer to genetic counseling/ testing when appropriate.</li> <li>• Utilize community/patient navigators to conduct outreach to community members and stakeholders to educate and raise awareness of cancer prevention.</li> <li>• Demonstrate ongoing leadership commitment to inclusivity for lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients and families.</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage age-appropriate lung cancer screening for patients who are current or former smokers.</li> <li>• Recommend age- and sex-appropriate cancer screenings (colonoscopy, Pap test, mammogram, or PSA test).</li> <li>• Encourage patients to see a dentist and have an oral exam.</li> <li>• Collect and update family health history annually and assess risks; refer to genetic counseling/testing when appropriate.</li> <li>• Use electronic medical records and other reminder systems to keep individuals up to date on screenings and vaccinations.</li> <li>• Utilize community/patient navigators to conduct outreach to community members and to stakeholders to educate and to raise awareness of screening and early detection services.</li> <li>• Monitor organizational efforts to provide more culturally competent and patient- and family-centered care to LGBTQ patients, families, and communities.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide appropriate medical care for cancer patients and survivors.</li> <li>• Provide referrals to patient navigation services.</li> <li>• Encourage patients to participate in clinical trials.</li> <li>• Refer patients to tobacco cessation programs if they are current smokers.</li> <li>• Refer patients to lifestyle change programs.</li> <li>• Be able to refer patients to palliative and hospice care when needed.</li> <li>• Be able to refer patients to mental health services.</li> <li>• Refer patients for genetic counseling and testing as appropriate.</li> </ul>

# Illinois Comprehensive Cancer Control Plan

## HEALTH INSURERS AND POLICY MAKERS

Prevention	Screening and Early Detection	Diagnosis, Treatment, and Survivorship
<ul style="list-style-type: none"> <li>• Support the access and coverage of smoking cessation programs and nutrition programs.</li> <li>• Support the implementation of policies for healthier environments.</li> <li>• Support collection of family health history, risk assessment, and appropriate genetic counseling/testing services.</li> <li>• Include LGBTQ community members in policy planning steps.</li> </ul>	<ul style="list-style-type: none"> <li>• Promote the coverage and access of all recommended cancer screenings.</li> <li>• Ensure no cost sharing for recommended cancer screenings and immunizations.</li> <li>• Support coverage of genetic counseling/testing services.</li> <li>• Include LGBTQ community members in policy planning steps.</li> </ul>	<ul style="list-style-type: none"> <li>• Support legislation that funds cancer treatment, including palliative care.</li> <li>• Reduce out-of-pockets costs for participating in clinical trials.</li> <li>• Support coverage of genetic counseling and genomic testing.</li> </ul>



# Illinois Comprehensive Cancer Control Plan

## CANCER BURDEN IN ILLINOIS

The Illinois State Cancer Registry is the only population-based source for cancer incidence information in Illinois. Cancer cases are collected through mandated reporting by hospitals, ambulatory surgical treatment centers, non-hospital affiliated radiation therapy treatment centers, independent pathology labs, dermatologists, and through the voluntary exchange of cancer patient data with other (mostly nearby) states.

In this section, the burden of cancer upon Illinoisans is described with an overview of data covering state demographics, cancer incidence, and cancer mortality.

Six priority cancers have been identified based upon the opportunity for prevention and early detection:

- Female breast
- Cervical
- Colorectal
- Lung
- Prostate
- Skin

Each of the priority cancers have the following detailed information:

- General statistics
- Risk factors
- Prevention and early detection
- Additional information sources
- Data measures and targets
- Incidence and mortality by race and ethnicity
- Counties with the highest incidence

**INCIDENCE:** The number of new cases of a disease diagnosed in each year.

**MORTALITY:** The number of deaths of a disease each year.

In addition to the priority cancers, information is provided on the 13 cancer types that are most common for late-stage diagnosis:

- Bladder
- Brain
- Esophagus
- Kidney and renal pelvis
- Leukemia
- Liver
- Non-Hodgkin lymphoma
- Oral cavity and pharynx
- Ovarian
- Pancreas
- Stomach
- Thyroid
- Uterus

Information provided includes the following:

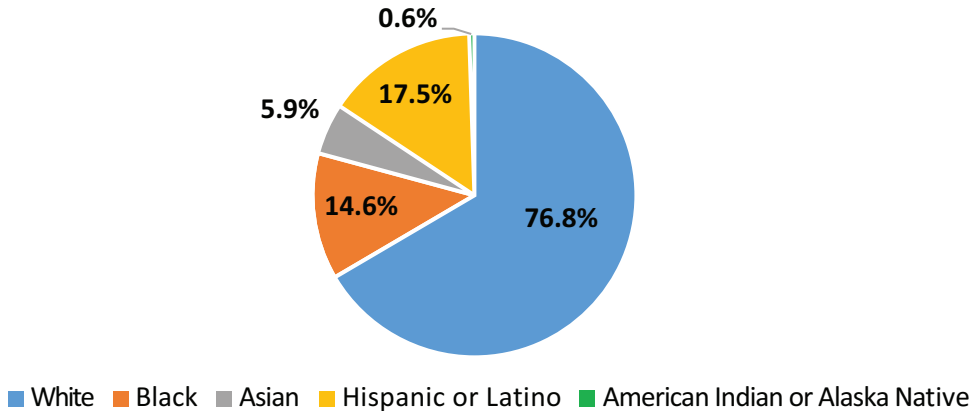
- Risk factors
- Incidence rate by cancer and for late-stage diagnosis
- Mortality rate

# Illinois Comprehensive Cancer Control Plan

## DEMOGRAPHICS

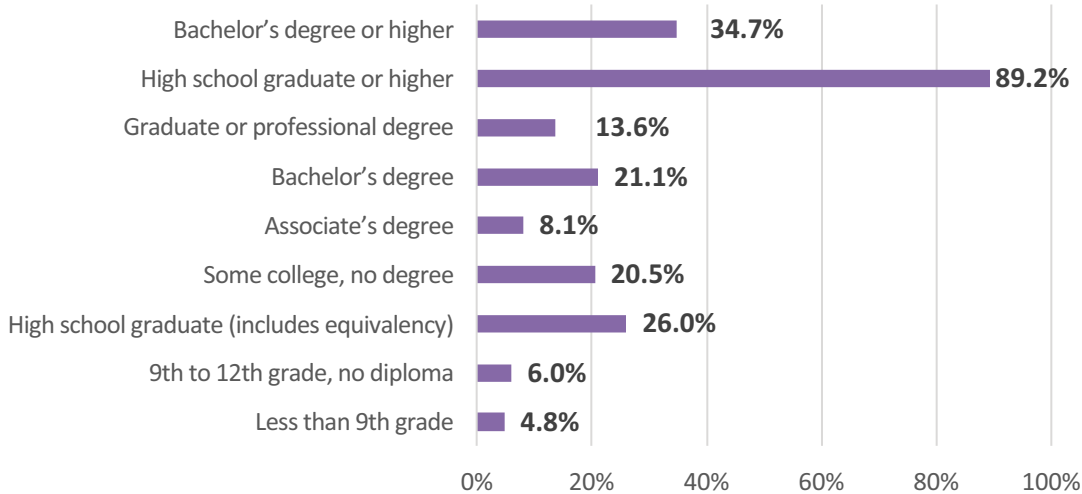
According to U.S. census data, the population estimate for the state of Illinois in 2019 was 12,671,821. Figure 2 demonstrates the Illinois population by race: 76.8% White, 14.6% Black, 5.9% Asian, 17.5% Hispanic or Latino, and 0.6% American Indian and Alaska Native.<sup>9</sup> Hispanics may be of any race.

Figure 2. Illinois Population Estimate, by Race and Ethnicity (2019 U.S. Census).



According to U.S. census data, from 2015-2019, 89.2% of Illinois residents 25 years of age or older and had graduated from high school. Figure 3 shows the percentage of the population by educational attainment.<sup>10</sup>

Figure 3. Educational Attainment in Illinois: Persons 25 Years and Older (2015-2019 U.S. Census).



<sup>9</sup> U.S. Census Bureau. (2019). QuickFacts; Illinois. Retrieved from <https://www.census.gov/quickfacts/fact/table/IL/PST045221>.

<sup>10</sup> U.S. Census Bureau. (2019). American Community Survey: Data Profiles. Retrieved from <https://www.census.gov/acs/www/data/data-tables-and-tools/data-profiles/>.



# Illinois Comprehensive Cancer Control Plan

According to the U.S. census data in 2019, 22.6% of the Illinois population is under 18 years of age and 77.4% is 18 years of age or older, as shown in figure 4.10

Figure 4. Illinois Population Estimate Under and Over 18 Years (2019 U.S. Census).

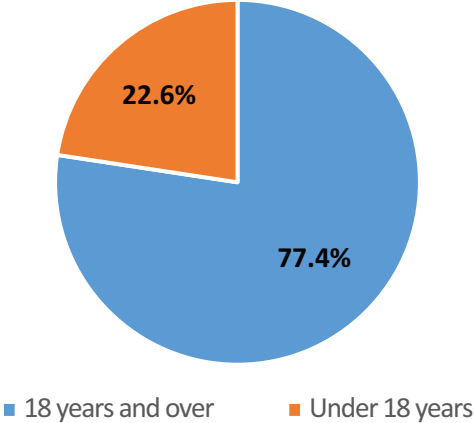
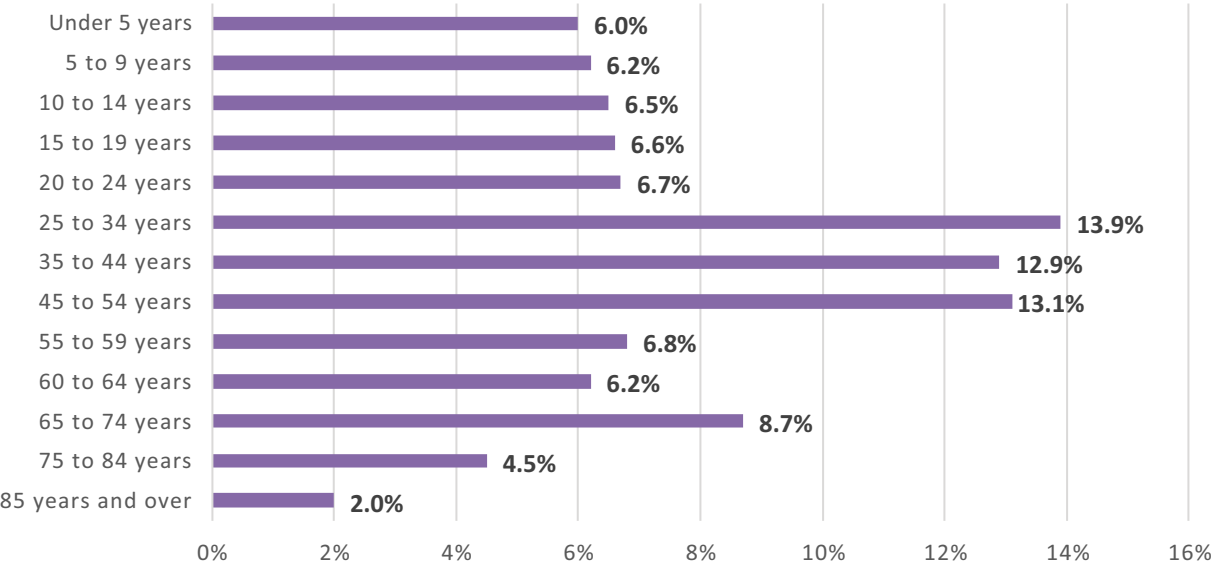


Figure 5 shows the distribution of Illinois residents by age in 2019.<sup>10</sup>

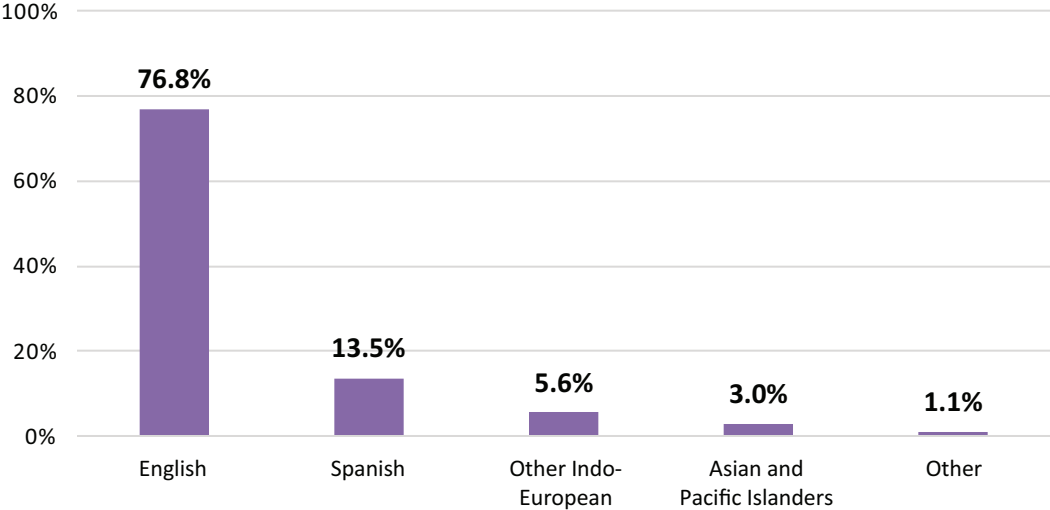
Figure 5. Illinois Population Estimate, by Age Group (2019 U.S. Census).



# Illinois Comprehensive Cancer Control Plan

In 2019, 76.8% of Illinois residents reported English as the language spoken at home. Other languages spoken at home include 13.5% Spanish, 5.6% other Indo-European, 3% Asian and Pacific Islanders, and 1.1% other languages.<sup>10</sup> See figure 6.

Figure 6. Illinois Population Estimates, by Languages Spoken at Home (2015-2019 U.S. Census).

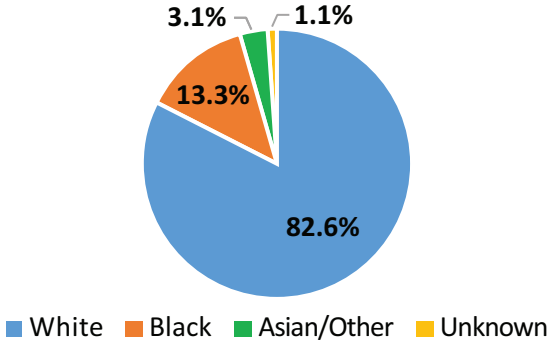


# Illinois Comprehensive Cancer Control Plan

## CANCER INCIDENCE

A total of 1,891,426 cases of invasive cancer among Illinois residents were reported to the Illinois State Cancer Registry (ISCR) from 1986 through 2017, including 69,222 new cases reported in 2017.<sup>11</sup> The overall race distribution for cases in 2017, as shown in figure 7, was 82.6% White, 13.3% Black, 3.1% Asian/other races, and 1.1% unknown race. All of the following data came from the ISCR.

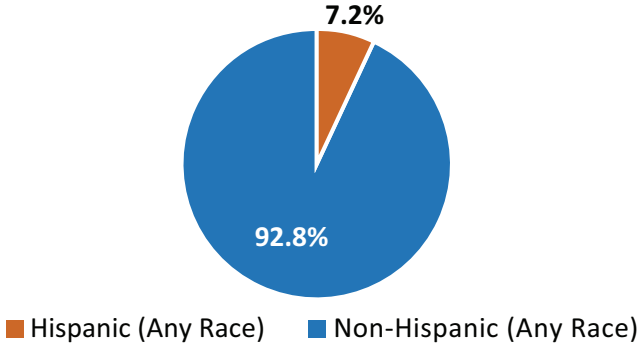
Figure 7. Cancer Incidence among Illinois Residents by Race (1986-2017 ISCR).



For the ethnicity/race categories, a total of 1,712,498 cases of invasive cancer among Illinois residents were reported to ISCR from 1990 through 2017. Figure 8 shows the ethnicity/race distribution for cases diagnosed in 2017 of 7.2% Hispanics (any race) and 92.8% non-Hispanics (any race); among non-Hispanic cases, non-Hispanic Whites accounted for 81.5% and non-Hispanic Blacks 14.2%.

In 2017, Black males continued to have the highest overall age-adjusted invasive cancer incidence rates of all major race/gender groups, as shown in figure 9. In general, males and females of Asian/other races in Illinois had substantially lower cancer incidence rates than the White or Black populations.

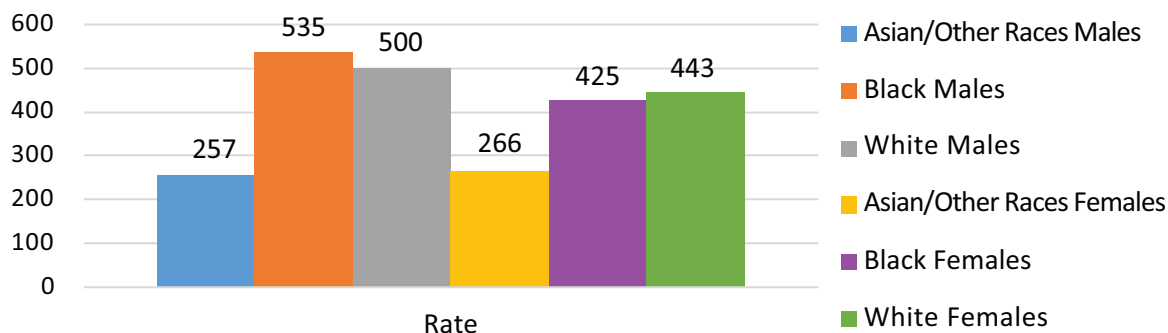
Figure 8. Cancer Incidence by Ethnicity (1990-2017 ISCR).



<sup>11</sup> Garner K, Shen T. Illinois State Cancer Incidence Review and Update, 1986-2017. Epidemiologic Report Series 20:06. Springfield, Ill.: Illinois Department of Public Health, April 2020.

# Illinois Comprehensive Cancer Control Plan

Figure 9. Overall Age-Adjusted Cancer Incidence per 100,000 Population (2017 ISCR).



Breast cancer was the most commonly diagnosed cancer among females in Illinois, accounting for 29.8% of 34,687 invasive cancer diagnoses in females during 2017.<sup>11</sup> The predominance of breast cancer among females persists for all major race and ethnicity groups.

The incidence of female breast cancer diagnosed in the in-situ stage increased steadily for every race and ethnicity group in the period of 1986-1999 with an annual percent increase of 8.2 but slowed after 1999. The annual percent change between 1999 and 2012 was an increase of 1.7 for all races.

Between 2012 and 2017, the annual percent change in breast cancer diagnoses in the in-situ stage decreased by 1.9% annually in the overall Illinois population. The trend suggests that screening mammography usage and the earlier detection of breast cancer among Illinois women overall has plateaued.

For Illinois males, prostate cancer was the most frequently diagnosed invasive cancer, accounting for 24.1% of 34,535 new cancer diagnoses in men during 2017. Black males had the highest prostate cancer incidence rates among all race groups, approximately 67.7% higher than those observed for White males and over three and a half times those observed for males of Asian/other races in 2017.

The incidence of male prostate cancer had an 18.7% annual increase between 1989 and 1992. The rate then dropped slightly before plateauing between 1995 and 2008. From 2008 to 2013 the annual percent change for prostate cancer incidence indicated a 9.2% decrease on average. After 2013 the trend again flattened out through 2017. The same trend was seen across 1986-2017 in both White and Black men.

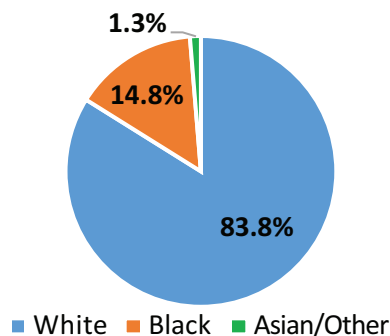
A total of 18,342 new cases of cancer were diagnosed during 1986-2017 among Illinois children aged 0 to 19 years. The three most common diagnostic sites for childhood cancer in Illinois were, in descending order, leukemia, central nervous system, and lymphoma.

# Illinois Comprehensive Cancer Control Plan

## CANCER MORTALITY

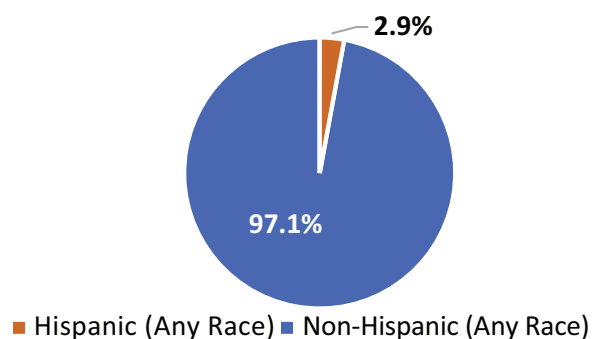
According to the ISCR, from 1986 through 2017, 780,990 Illinois residents died from cancer.<sup>12</sup> Figure 10 demonstrates the race distribution for these deaths as 83.8% among the White population, 14.8% in the Black population, and the remainder among the Asian/other race population group (1.3%).

Figure 10. Cancer Mortality by Race (1986-2017 ISCR).



From 1990 through 2017, 687,359 Illinois residents died from cancer, as shown in figure 11. The distribution for these deaths was 2.9% Hispanic (any race) and 97.1% non-Hispanics (any race). Among non-Hispanic deaths, 83.2% were non-Hispanic Whites and 15.4% non-Hispanic Blacks.

Figure 11. Cancer Mortality by Ethnicity (1990-2017 ISCR).

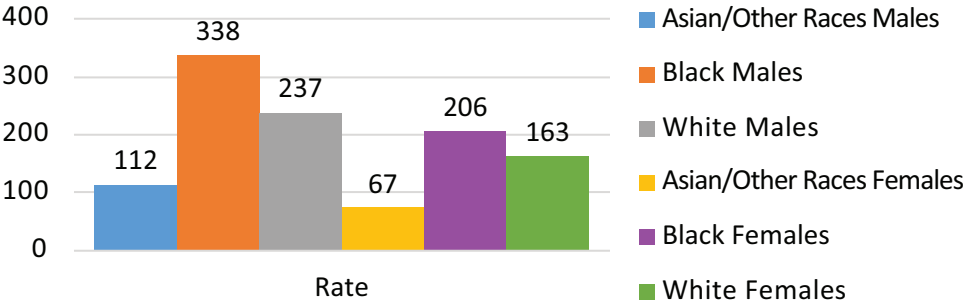


Black males had the highest overall age-adjusted mortality rates from cancer from 1986 through 2017, about 42% higher than the rate for White males and three times the rate for males identified as Asian or other races (Figure 12). Similarly, Illinois' cancer mortality rates for Black females exceeded those for White females by about 27% and were over two and a half times those observed among females identified as Asian or other races in Illinois. Non-Hispanic males and females (any race) had mortality rates that were almost twice that of their Hispanic (any race) counterparts.

<sup>12</sup> Garner K., Shen T. Illinois Cancer Mortality Review and Update, 1986-2017. Epidemiologic Report Series 20:07. Springfield, Ill.: Illinois Department of Public Health, April 2020.

# Illinois Comprehensive Cancer Control Plan

Figure 12. Overall Age-Adjusted Cancer Mortality per 100,000 Population (1986-2017 ISCR).



Based on age-adjusted cancer mortality rates, covering 1986-2017, lung cancer remains the leading cause of death from cancer for both Illinois males and females, followed by prostate cancer for males, and breast cancer for females. The third leading cause of cancer death is from colorectal cancer for both males and females.

From 1986 through 2017, among males of all races, over one-third of all cancer deaths were from cancer of the lung and bronchus (30.8%), 10.6% were from prostate cancer, and 10.4% were from cancer of the colon and rectum. These three cancers accounted for more than half of all cancer deaths (51.8%).

From 1986 through 2017, 23.3% of all cancer deaths among females of all races were due to cancer of the lung and bronchus, 16.3% were due to cancer of the breast, and 11.0% were due to cancer of the colon and rectum. These three cancers made up 50.6% of all cancer deaths in females.



# Illinois Comprehensive Cancer Control Plan

## PRIORITY CANCERS

### FEMALE BREAST CANCER

#### General Statistics

- **Leading cause of death**<sup>13</sup>
  - In Illinois, breast cancer is the most common cancer in women and the second leading cause of cancer death in women.
  - In Illinois, breast cancer incidence rates are highest in Black and White women and lowest in Hispanic women, and mortality rates are highest in Black women and lowest in Hispanic and Asian or Pacific Islander women.
- **New diagnoses (Incidence)**<sup>14</sup>
  - In the United States, the incidence of breast cancer has increased from 124.8 per 100,000 in 2008 to 125.1 per 100,000 in 2017.
  - In Illinois, the incidence of breast cancer has increased from 127.1 per 100,000 in 2008 to 132.0 per 100,000 in 2017.
  - In 2017, there were a total of 250,520 new breast cancer cases in the United States and a total of 10,332 new breast cancer cases in Illinois.
- **Deaths (Mortality)**<sup>15</sup>
  - In the United States, mortality of breast cancer has decreased from 22.6 per 100,000 in 2008 to 19.9 per 100,000 in 2017.
  - In Illinois, mortality from breast cancer has decreased from 23.8 per 100,000 in 2008 to 20.4 per 100,000 in 2017.
  - In 2017, there were a total of 42,000 deaths from breast cancer in the United States and a total of 1,708 deaths from breast cancer in Illinois.



#### Risk Factors<sup>16</sup>

- The primary risk factors for breast cancer include being a woman and older age. Women at higher risk for breast cancer include those with a family history of breast cancer or those with inherited changes (mutations) in their BRCA1 or BRCA2 genes. Other risk factors include:
  - Starting period before age 12.
  - Starting menopause after age 55.
  - Having dense breasts.
  - Having already had breast cancer or certain breast conditions such as atypical hyperplasia or lobular carcinoma in situ (LCIS).
  - Having a family history of ovarian cancer.
  - Having received radiation treatments to the chest before age 30.
  - Pregnant women who took the drug diethylstilbestrol (DES) between 1940 and 1971, or women whose mothers took DES while pregnant with them.
  - Not physically active and being overweight or obese.

## Illinois Comprehensive Cancer Control Plan

- Taking hormone therapy medications that include estrogen and progesterone for more than five years during menopause.
- Taking certain birth control pills.
- Giving birth to first child after age 30 or having never been pregnant.
- Drinking alcohol.

### Prevention and Early Detection<sup>16</sup>

- Screening for breast cancer is recommended for women ages 40 to 74 years.
  - Two screening tests are available:
    - A mammogram is an X-ray of the breast.
    - A breast MRI (magnetic resonance imaging) uses magnets and radio waves to take pictures of the breast; it is used along with mammograms to screen women at high risk.
  - Other exams include:
    - A clinical breast exam is when a doctor uses their hand to feel for lumps or changes.
    - A breast self-exam to become familiar with how your breasts look and feel; if there are any new changes or unusual signs, speak with a health care provider.
- Risk reduction methods for women at high risk of breast cancer include:
  - Preventive medications (chemoprevention)
  - Preventive surgery to remove healthy breasts
- Lifestyle factors that can lower a person's risk for breast cancer include:
  - Maintaining a healthy weight and diet.
  - Getting regular exercise.
  - Not drinking alcohol or limiting the number of drinks consumed.
  - Breastfeeding, if possible.
  - Having a discussion with a physician about the benefits and risks of taking hormone replacement therapy or birth control pills.



# Illinois Comprehensive Cancer Control Plan

## Additional Information Sources

- American Cancer Society (ACS): <https://www.cancer.org/cancer/breast-cancer.html>
- American Society of Clinical Oncology (ASCO): <https://www.cancer.net/cancer-types/breast-cancer>
- Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/cancer/breast/>
- Illinois State Cancer Registry (ISCR): <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>
- National Cancer Institute (NCI): <https://www.cancer.gov/types/breast>
- State Cancer Profiles (NIH/NCI/CDC): <https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=illinois>
- U.S. Preventive Service Task Force: (USPSTF): <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/breast-cancer-screening>



<sup>13</sup> Garner K, Shen T. Illinois State Cancer Incidence Review and Update, 1986-2017. Epidemiologic Report Series 20:06. Springfield, Ill.: Illinois Department of Public Health, April 2020.

<sup>14</sup> U.S. Cancer Statistics Working Group. (2020). U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. [www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz).

<sup>15</sup> Garner K, Shen T. Illinois State Cancer Mortality Review and Update, 1986-2017. Epidemiologic Report Series 20:07. Springfield, Ill.: Illinois Department of Public Health, April 2020.

<sup>16</sup> Centers for Disease Control and Prevention. (2020). Breast Cancer. <https://www.cdc.gov/cancer/breast>.

# Illinois Comprehensive Cancer Control Plan

**Table 2. Female Breast Cancer Measures for Illinois.<sup>17</sup>**

Cancer Measure	Baseline (per 100,000) (2017)	Target (per 100,000) (2025) †
Incidence rate	132.0	127.8
Mortality rate	20.4	17.8

2017 data is from the Illinois Department of Public Health. (2019). Illinois state cancer registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

† The target rate was determined by calculating the annual average percent change from 2008 to 2017, the latest available incidence data and mortality data. The targets were set for 2025 based on the projected rates from 2018 through 2025.

**Table 3. Female Breast Cancer Incidence and Mortality by Race and Ethnicity in Illinois (2017).**

Race/Ethnicity	Incidence (per 100,000)	Mortality (per 100,000)
All Races (includes Hispanic)*	132.0	20.4
White (includes Hispanic)*	132.8	19.6
Black (includes Hispanic)*	133.9	29.0
Hispanic (any race)*	96.3	9.5
Race/Ethnicity	Incidence (per 100,000)	Mortality (per 100,000)
Non-Hispanic White*	137.0	20.5
Non-Hispanic Black*	135.9	29.6
Asian/Other Races*	105.4	Data not available
Other Races*	Data not available	9.2
Hispanic‡	98.0	9.5
Asian/Pacific Islander‡	111.6	10.0
American Indian/Alaskan Native‡	Data not available	Data not available

\* Data is most recent 2017 data from the Illinois Department of Public Health. (2019). Illinois state cancer registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

‡ Data is most recent 2017 data from the U.S. Cancer Statistics Working Group. (2020). U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. [www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz)

<sup>17</sup> Calculations for all target rates:

- 1) The percent change was calculated from year to year from 2008 to 2017, the latest available data. E.g. (current year's rate - previous year's rate) / previous year's rate \* 100 = Individual years percent change
- 2) All the individual years percent change were added, and an annual average percent change was calculated.
- 3) Projected rates were calculated as: (1 - annual average percent change) \* previous year's rate, for each year up to 2025.

E.g. Projected incidence rate for 2018 = (1 - annual average percent change) \* 201

# Illinois Comprehensive Cancer Control Plan

Table 4. Female Breast Cancer – 20 Counties with Highest Incidence in Illinois (2013-2017).

Overall State Incidence	133.1
County	Incidence (per 100,000)
Warren	173.1
Scott	169.5
Ford	167.6
Greene	167.0
Mercer	162.3
Grundy	158.3
White	153.6
Shelby	152.1
Tazewell	151.7
Union	151.5
Carroll	149.7
Morgan	149.2
Sangamon	148.9
Livingston	148.7
Bond	148.0
Henderson	144.5
Marion	144.4
McLean	144.2
Perry	143.4
Lake	142.8

Data is most recent data from 2013-2017 (5-year average) for all races from the National Cancer Institute. (2021). State cancer profiles: Incidence rates table. <https://statecancerprofiles.cancer.gov/incidencrates/index.php>

# Illinois Comprehensive Cancer Control Plan

## CERVICAL CANCER

### General Statistics

- **Leading cause of death**<sup>18</sup>
  - In Illinois, among the leading causes of cancer deaths in women, cervical cancer is number 14 out of 18.
  - In Illinois, cervical cancer incidence and mortality rates are highest in Black and Hispanic women and lowest in White women.
- **New diagnoses (Incidence)**<sup>19</sup>
  - In the United States, the incidence of cervical cancer has decreased from 8.0 per 100,000 in 2008 to 7.5 per 100,000 in 2017.
  - In Illinois, the incidence of cervical cancer has decreased from 9.7 per 100,000 in 2008 to 7.3 per 100,000 in 2017.
  - In 2017, there were a total of 12,831 new cervical cancer cases in the United States and a total of 514 new cervical cancer cases in Illinois.
- **Deaths (Mortality)**<sup>20</sup>
  - In the United States, mortality from cervical cancer has decreased from 2.4 per 100,000 in 2008 to 2.2 per 100,000 in 2017.
  - In Illinois, mortality from cervical cancer has decreased from 2.8 per 100,000 in 2008 to 2.1 per 100,000 in 2017.
  - In 2017, there were a total of 4,207 deaths from cervical cancer in the United States and a total of 157 deaths from cervical cancer in Illinois.



### Risk Factors

- The primary risk factor for cervical cancer is having an HPV infection. HPV is a common virus that can be passed from one person to another during sex. Many strains of HPV exist, and most strains are not associated with cervical cancer. Other factors that increase risk of cervical cancer include:
  - Having other sexually transmitted infections such as HIV, chlamydia, gonorrhea, syphilis.
  - Having a weakened immune system.
  - Tobacco smoking.
  - Using birth control pills for five or more years.
  - Having given birth to three or more children.
  - Having many sexual partners.
  - Women whose mothers took the drug diethylstilbestrol (DES) while pregnant with them in the 1950s.

# Illinois Comprehensive Cancer Control Plan

## Prevention and Early Detection<sup>21</sup>

- Screening for cervical cancer is recommended for women ages 21 to 65 years. Two screening tests are available:
  - The Pap test or Pap smear looks for precancers, which are cell changes on the cervix that might become cervical cancer if they are not treated.
  - The HPV test looks for HPV that can cause cell changes, and it can be used alone or at the same time as the Pap test.
- The HPV vaccine protects against HPV and may reduce the risk of HPV-related cancers, including cervical cancer. The CDC recommends HPV vaccination for children at age 11 or 12, but it can be started at age 9. It is also recommended for everyone through age 26, if not previously vaccinated.
- Lifestyle factors that can lower a person's risk for cervical cancer include:
  - Using condoms during sex
  - Limiting the number of sexual partners
  - Not smoking



<sup>18</sup> Garner K, Shen T. Illinois State Cancer Incidence Review and Update, 1986-2017. Epidemiologic Report Series 20:06. Springfield, Ill.: Illinois Department of Public Health, April 2020.

<sup>19</sup> U.S. Cancer Statistics Working Group. (2020). U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. [www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz).

<sup>20</sup> Garner K, Shen T. Illinois State Cancer Mortality Review and Update, 1986-2017. Epidemiologic Report Series 20:07. Springfield, Ill.: Illinois Department of Public Health, April 2020.

<sup>21</sup> Centers for Disease Control and Prevention. (2021). Cervical Cancer. <https://www.cdc.gov/cancer/cervical>.

# Illinois Comprehensive Cancer Control Plan

## Additional Information Sources

- American Cancer Society (ACS): <https://www.cancer.org/cancer/cervical-cancer.html>
- American Society of Clinical Oncology (ASCO): <https://www.cancer.net/cancer-types/cervical-cancer>
- Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/cancer/cervical/index.htm>
- Illinois State Cancer Registry (ISCR): <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>
- National Cancer Institute (NCI): <https://www.cancer.gov/types/cervical>
- State Cancer Profiles (NIH/NCI/CDC): <https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=illinois>
- U.S. Preventive Service Task Force (USPSTF): <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/cervical-cancer-screening>

**Table 5. Cervical Cancer Measures for Illinois.**

Cancer Measure	Baseline (per 100,000) (2017)	Target (per 100,000) (2025) †
Incidence rate	7.3	6.0
Mortality rate	2.1	1.7

2017 data is from the Illinois Department of Public Health. (2019). Illinois State Cancer Registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

† The target rate was determined by calculating the annual average percent change from 2008 to 2017, the latest available incidence data and mortality data. The targets were set for 2025 based on the projected rates from 2018 through 2025.

**Table 6. Cervical Cancer Incidence and Mortality by Race and Ethnicity in Illinois (2017).**

Race/Ethnicity	Incidence (per 100,000)	Mortality (per 100,000)
All Races (includes Hispanic)*	7.3	2.1
White (includes Hispanic)*	7.2	1.9
Black (includes Hispanic)*	9.7	3.7
Hispanic (any race)*	8.6	2.4
Non-Hispanic White*	7.0	1.9
Non-Hispanic Black*	9.8	3.8
Asian/Other Races*	3.8	Data not available
Other Races*	Data not available	Data not available
Hispanic‡	8.7	2.4
Asian/Pacific Islander‡	4.1	Data not available
American Indian/Alaskan Native‡	Data not available	Data not available

\* Data is most recent 2017 data from the Illinois Department of Public Health. (2019). Illinois State Cancer Registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

‡ Data is most recent 2017 data from the U.S. Cancer Statistics Working Group. (2020). U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. [www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz)

# Illinois Comprehensive Cancer Control Plan

Table 7. Cervical Cancer – 20 Counties with Highest Incidence in Illinois (2013-2017).

Overall State Incidence	7.7
County	Incidence (per 100,000)
Henry	14.5
Macoupin	12.4
Vermilion	12.1
Rock Island	11.1
Tazewell	10.3
Peoria	9.8
Macon	9.7
St. Clair	9.7
Winnebago	8.5
Cook	8.3
Kankakee	7.8
La Salle	7.6
Sangamon	7.3
Madison	7.1
DeKalb	6.6
Will	6.4
Kane	6.2
McLean	6.0
Lake	5.9
Champaign	5.4

Data is most recent data from 2013-2017 (5-year average) for all races from the National Cancer Institute. (2021). State cancer profiles: Incidence rates table. <https://statecancerprofiles.cancer.gov/incidencerates/index.php>

# Illinois Comprehensive Cancer Control Plan

## COLORECTAL CANCER

### General Statistics

- **Leading cause of death**<sup>22</sup>
  - Colorectal cancer is the fourth leading cause of cancer deaths in Illinois.
  - In Illinois, colorectal cancer incidence and mortality rates are higher in males than in females.
  - In Illinois, colorectal cancer incidence and mortality rates are highest in Black populations and lowest in Asian/Pacific Islander and Hispanic populations.
- **New diagnoses (Incidence)**<sup>23</sup>
  - In the United States, the incidence of colorectal cancer has decreased from 45.9 per 100,000 in 2008 to 36.8 per 100,000 in 2017.
  - In Illinois, the incidence of colorectal cancer has decreased from 50.9 per 100,000 in 2008 to 40.4 per 100,000 in 2017.
  - In 2017, there were a total of 141,425 new colorectal cancer cases in the United States and a total of 6,073 new colorectal cancer cases in Illinois.
  - Between 2013 and 2017, colorectal cancer was the third most commonly diagnosed cancer in males and in females in Illinois.
- **Deaths (Mortality)**<sup>24</sup>
  - In the United States, mortality from colorectal cancer has decreased from 16.5 per 100,000 in 2008 to 13.5 per 100,000 in 2017.
  - In Illinois, mortality from colorectal cancer has decreased from 18.2 per 100,000 in 2008 to 14.6 per 100,000 in 2017.
  - In 2017, there were a total of 52,547 deaths from colorectal cancer in the United States and a total of 2,223 deaths from colorectal cancer in Illinois.
  - Between 2013 and 2017, colorectal cancer was the third leading cause of cancer death in males and in females in Illinois.



<sup>22</sup> Garner K, Shen T. Illinois State Cancer Incidence Review and Update, 1986-2017. Epidemiologic Report Series 20:06. Springfield, Ill.: Illinois Department of Public Health, April 2020.

<sup>23</sup> U.S. Cancer Statistics Working Group. (2020). U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. [www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz).

<sup>24</sup> Garner K, Shen T. Illinois State Cancer Mortality Review and Update, 1986-2017. Epidemiologic Report Series 20:07. Springfield, Ill.: Illinois Department of Public Health, April 2020.



# Illinois Comprehensive Cancer Control Plan

## Risk Factors<sup>25</sup>

Modifiable risk factors for colorectal cancer include:

- Overweight or obesity
- Lack of physical activity
- Poor diet
- Smoking tobacco
- Alcohol use

Non-modifiable risk factors for colorectal cancer include:

- Age
- Personal history of colorectal cancer, polyps, or bowel disease
- Family history of colorectal cancer
- Inherited syndromes

## Prevention and Early Detection<sup>25</sup>

Lifestyle factors that can lower a person's risk for colorectal cancer include:

- Maintaining a healthy weight
- Engaging in regular physical activity
- Following a healthy diet
- Not smoking cigarettes
- Limiting alcohol intake

Engaging in regular colorectal cancer screening can identify and remove precancerous polyps, which can reduce the risk for colorectal cancer. Screening can also detect colorectal cancer at an earlier stage when treatment may be easier, and survival may be improved. The USPSTF announced in May 2021 the recommendation for colorectal screening to start at age 45 years and continue until age 75 years. Illinois currently has 803,237 residents' ages 45-49, which will add to the 50-75 years of age Illinois residents that are also recommended for colorectal cancer screening.



<sup>25</sup> American Cancer Society. (2021). Colorectal Cancer. <https://www.cancer.org/cancer/colon-rectal-cancer.html>.

# Illinois Comprehensive Cancer Control Plan

The American Cancer Society recommends that people at average risk of colorectal cancer begin regular screening at age 45. The age to begin screening, the type of test used, and the frequency of screening is based on individual and familial factors and prior screening results. The following are the different tests used to screen for colorectal cancer:

- Stool-based tests that check the stool for blood or altered DNA.
  - Highly sensitive fecal immunochemical test (FIT) every year.
  - Highly sensitive guaiac-based fecal occult blood test (gFOBT) every year.
  - Multi-targeted stool DNA test (mt-sDNA) every three years.
- Direct visualization tests which look inside the colon for abnormalities.
  - Colonoscopy every 10 years. Colonoscopy has a distinct advantage over other screening methods. Precancerous polyps can be removed during the procedure.
  - CT colonography (virtual colonoscopy) every five years.
  - Flexible sigmoidoscopy (FSIG) every five years.

## Additional Information Sources

- American Cancer Society (ACS): <https://www.cancer.org/cancer/colon-rectal-cancer.html>
- American Society of Clinical Oncology (ASCO): <https://www.cancer.net/cancer-types/colorectal-cancer>
- Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/cancer/colorectal/>
- Illinois State Cancer Registry (ISCR): <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>
- National Cancer Institute (NCI): <https://www.cancer.gov/types/colorectal>
- State Cancer Profiles (NIH/NCI/CDC): <https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statername=illinois>
- U.S. Preventive Services Task Force (USPSTF): <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/colorectal-cancer-screening#fullrecommendationstart>

**Table 8. Colorectal Cancer Measures for Illinois.**

Cancer Measure	Baseline (per 100,000) (2017)	Target (per 100,000) † (2025)
Incidence rate	40.4	33.0
Mortality rate	14.6	12.1

2017 data is from the Centers for Disease Control and Prevention. (2020). United States Cancer Statistics: Data Visualizations. <https://gis.cdc.gov/Cancer/USCS/DataViz.html>

† The target rate was determined by calculating the annual average percent change from 2008 to 2017, the latest available incidence data and mortality data. The targets were set for 2025 based on the projected rates from 2018 through 2025.

# Illinois Comprehensive Cancer Control Plan

**Table 9. Colorectal Cancer Incidence and Mortality by Race and Ethnicity in Illinois (2017).**

Race/Ethnicity	Incidence (per 100,000)		Mortality (per 100,000)	
	Male and Female		Male and Female	
All Races (includes Hispanic)*	40.4		14.6	
White (includes Hispanic)*	39.9		13.8	
Black (includes Hispanic)*	46.3		22.9	
Hispanic (any race)*	33.1		8.8	
Asian/Pacific Islander*	28.2		8.0	
American Indian/Alaska Native*	Data not available		Data not available	
	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>
All Races <sup>‡</sup>	47.0	35.0	17.4	12.5
White Non-Hispanic <sup>‡</sup>	47.2	35.2	16.8	12.3
Black Non-Hispanic <sup>‡</sup>	56.2	41.3	27.9	20.3
Hispanic (any race) <sup>‡</sup>	40.2	26.3	12.7	5.6
Asian/Other Races <sup>‡</sup>	34.5	21.8	Data not available	
Other Races <sup>‡</sup>	Data not available		10.6	4.7

\*Data for both sexes is most recent 2017 data from Centers for Disease Control and Prevention. (2020). United States Cancer Statistics: Data Visualizations. <https://gis.cdc.gov/Cancer/USCS/DataViz.html>

<sup>‡</sup>Data for males and females is most recent 2017 data from Illinois Department of Public Health. (2019). Illinois State Cancer Registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

# Illinois Comprehensive Cancer Control Plan

Table 10. Colorectal Cancer - 20 Counties with Highest Incidence in Illinois (2013-2017).

Overall State Incidence	42.5
County	Incidence (per 100,000)
Stark	67.8
Edwards	67.2
Richland	65.1
McDonough	60.1
Montgomery	59.8
Shelby	59.3
Logan	58.8
Calhoun	58.0
Warren	57.1
Effingham	57.1
Cass	56.0
Williamson	56.0
Menard	55.7
De Witt	55.7
Marion	55.7
Hamilton	55.6
Cumberland	55.6
Scott	55.6
Christian	55.0
Wabash	54.7

Data is most recent data from 2013-2017 (5-year average) for all races from the National Cancer Institute. (n.d.). State Cancer Profiles.  
<https://statecancerprofiles.cancer.gov/index.html>

# Illinois Comprehensive Cancer Control Plan

## LUNG CANCER

### General Statistics

- **Leading cause of death**<sup>26</sup>
  - In Illinois, lung cancer is the leading cause of cancer death and is the third most common cancer.
  - In Illinois, lung cancer incidence and mortality rates are higher in males than females.
  - In Illinois, lung cancer incidence and mortality rates are highest in Black individuals.
- **New diagnoses (Incidence)**<sup>27</sup>
  - In the United States, the incidence of lung cancer has decreased from 67.4 per 100,000 in 2008 to 55.2 per 100,000 in 2017.
  - In Illinois, the incidence of lung cancer has decreased from 72.1 per 100,000 in 2008 to 61.2 per 100,000 in 2017.
  - In 2017, there were a total of 221,121 new lung cancer cases in the United States and a total of 9,429 new lung cancer cases in Illinois.
- **Deaths (Mortality)**<sup>28</sup>
  - In the United States, mortality of lung cancer has decreased from 49.6 per 100,000 in 2008 to 36.7 per 100,000 in 2017.
  - In Illinois, mortality from lung cancer has decreased from 52.2 per 100,000 in 2008 to 39.1 per 100,000 in 2017.
  - In 2017, there were a total of 145,849 deaths from lung cancer in the United States and a total of 6,009 deaths from lung cancer in Illinois.



### Risk Factors<sup>29</sup>

- The primary risk factor for lung cancer is cigarette smoking. Other tobacco products, including cigars or pipes, also increase the risk for lung cancer. Other risk factors include:
  - Breathing in secondhand smoke from another person's cigarette, pipe, or cigar.
  - Exposure to radon (a naturally occurring gas from rocks and dirt that can get trapped in houses and buildings).
  - Workplace exposure to other substances, such as asbestos, arsenic, diesel exhaust, and some forms of silica and chromium.
  - A personal or family history of lung cancer.
  - Previous radiation therapy to the chest.

<sup>26</sup> Garner K, Shen T. Illinois State Cancer Incidence Review and Update, 1986-2017. Epidemiologic Report Series 20:06. Springfield, Ill.: Illinois Department of Public Health, April 2020.

<sup>27</sup> U.S. Cancer Statistics Working Group. (2020). *U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017)*: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. [www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz).

<sup>28</sup> Garner K, Shen T. Illinois State Cancer Mortality Review and Update, 1986-2017. Epidemiologic Report Series 20:07. Springfield, Ill.: Illinois Department of Public Health, April 2020.

<sup>29</sup> Centers for Disease Control and Prevention. (2020). Lung Cancer. <https://www.cdc.gov/cancer/lung>.

# Illinois Comprehensive Cancer Control Plan

## Prevention and Early Detection<sup>29</sup>

- Screening for lung cancer is recommended for adults 50 to 80 years of age who have a 20 pack-a-year smoking history and currently smoke or have quit within the past 15 years.
  - Only one recommended screening test is available:
    - A low dose computed tomography (LDCT) scan involves an X-ray machine that uses a low dose of radiation to make images of the lungs.
- Lifestyle factors that can lower a person’s risk for lung cancer include:
  - Not smoking
  - Avoiding secondhand smoke
  - Testing your home for radon
  - Protecting yourself from carcinogens at work
  - Choosing a healthy diet
  - Getting regular exercise

## Additional Information Sources

- American Cancer Society (ACS): <https://www.cancer.org/cancer/lung-cancer.html>
- American Society of Clinical Oncology (ASCO):  
<https://www.cancer.net/cancer-types/lung-cancer-non-small-cell>  
<https://www.cancer.net/cancer-types/lung-cancer-small-cell>
- Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/cancer/lung/>
- Illinois State Cancer Registry (ISCR):  
<https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>
- National Cancer Institute (NCI): <https://www.cancer.gov/types/lung>
- State Cancer Profiles (NIH/NCI/CDC):  
<https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=illinois>
- U.S. Preventive Service Task Force: (USPSTF):  
<https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/lung-cancer-screening>

**Table 11. Lung Cancer Measures for Illinois.**

Cancer Measure	Baseline (per 100,000) (2017)	Target (per 100,000) (2025) †
Incidence rate	61.2	52.9
Mortality rate	39.1	30.4

2017 data is from U.S. Cancer Statistics Working Group. (2020). U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute.  
[www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz)

† The target rate was determined by calculating the annual average percent change from 2008 to 2017, the latest available incidence data and mortality data. The targets were set for 2025 based on the projected rates from 2018 through 2025.

# Illinois Comprehensive Cancer Control Plan

Table 12. Lung Cancer Incidence and Mortality by Race and Ethnicity in Illinois (2017).

Race/Ethnicity	Incidence (per 100,000)		Mortality (per 100,000)	
	Male and Female		Male and Female	
All Races/Ethnicities*	61.2		39.1	
White*	61.8		39.3	
Black*	69.9		47.8	
Hispanic*	31.1		14.5	
Asian/Pacific Islander*	26.6		13.8	
American Indian/Alaskan Native*	Data not available		Data not available	
Race/Ethnicity	Incidence (per 100,000)		Mortality (per 100,000)	
	Male	Female	Male	Female
All Races†	70.6	54.3	46.9	33.2
White†	69.7	56.0	46.5	33.9
Black†	90.2	56.9	62.1	38.3
White Non-Hispanic†	73.3	58.9	49.0	36.1
Black Non-Hispanic†	91.3	57.7	63.2	39.0
Hispanic (any race)†	35.4	26.1	21.6	9.1
Asian/Other Races†	37.3	16.6	Data not available	
Other Races†	Data not available		20.7	7.7
<p>* Data is most recent 2017 data from the U.S. Cancer Statistics Working Group. (2020). U.S. Cancer Statistics Data Visualizations Tool, based on 2019 submission data (1999-2017): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. <a href="http://www.cdc.gov/cancer/dataviz">www.cdc.gov/cancer/dataviz</a></p> <p>† Data is most recent 2017 data from the Illinois Department of Public Health. (2019). Illinois state cancer registry. <a href="https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry">https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry</a></p>				

# Illinois Comprehensive Cancer Control Plan

Table 13. Lung Cancer – 20 Counties with Highest Incidence in Illinois (2013-2017).

Overall State Incidence	63.7
County	Incidence (per 100,000)
Hardin	133.6
Pulaski	112.1
Brown	108.9
Franklin	108.3
Logan	106.7
Christian	99.4
Gallatin	97.8
Mason	97.2
De Witt	95.8
Macoupin	94.9
Macon	94.5
Johnson	94.5
Massac	93.9
Richland	93.7
Alexander	92.1
Putnam	91.7
Schuyler	90.6
Cass	90.2
Montgomery	89.5
Williamson	89.5

Data is most recent data from 2013-2017 (5-year average) for all races and both sexes from the National Cancer Institute. (2021). State cancer profiles: Incidence rates table. <https://statecancerprofiles.cancer.gov/incidencerates/index.php>



# Illinois Comprehensive Cancer Control Plan

## PROSTATE CANCER

### General Statistics

- **Leading cause of death**<sup>30</sup>
  - Prostate cancer is the second leading cause of cancer deaths in males in Illinois.
  - In Illinois, incidence and mortality rates of prostate cancer are highest in Black populations and lowest in Asian/Pacific Islander populations.
- **New diagnoses (Incidence)**<sup>31</sup>
  - In the United States, the incidence of prostate cancer has decreased from 152.7 per 100,000 in 2008 to 106.5 per 100,000 in 2017.
  - In Illinois, the incidence of prostate cancer has decreased from 165.4 per 100,000 in 2008 to 111.2 per 100,000 in 2017.
  - In 2017, there were a total of 207,430 new prostate cancer cases in the United States and a total of 8,313 new prostate cancer cases in Illinois.
  - Between 2013 and 2017, prostate cancer was the most commonly diagnosed cancer in males in Illinois.
- **Deaths (Mortality)**<sup>32</sup>
  - In the United States, mortality from prostate cancer has decreased from 23.0 per 100,000 in 2008 to 18.9 per 100,000 in 2017.
  - In Illinois, mortality from prostate cancer has decreased from 23.7 per 100,000 in 2008 to 20.6 per 100,000 in 2017.
  - In 2017, there were a total of 30,486 deaths from prostate cancer in the United States and a total of 1,273 deaths from prostate cancer in Illinois.



### Risk Factors<sup>33</sup>

Risk factors for prostate cancer include:

- Age
- Race/ethnicity
- Family history
- Inherited genetic syndromes

### Prevention and Early Detection<sup>33</sup>

It may not be possible to prevent prostate cancer since known risk factors are non-modifiable. Research is being done to examine possible modifiable factors that can lower the risk. These lifestyle factors include:

- Maintaining a healthy weight
- Engaging in regular physical activity
- Following a healthy diet

For males between the ages of 55 and 69 years, the decision to undergo prostate cancer screening with periodic prostate specific antigen (PSA)-based testing should be an informed one after discussing the potential benefits and risks with a health care provider.

# Illinois Comprehensive Cancer Control Plan

## Additional Information Sources

- American Cancer Society (ACS): <https://www.cancer.org/cancer/prostate-cancer.html>
- American Society of Clinical Oncology (ASCO): <https://www.cancer.net/cancer-types/prostate-cancer>
- Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/cancer/prostate/index.htm>
- Illinois State Cancer Registry (ISCR): <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>
- National Cancer Institute (NCI) : <https://www.cancer.gov/types/prostate>
- State Cancer Profiles (NIH/NCI/CDC): <https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=illinois>
- U.S. Preventive Services Task Force (USPSTF): <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/prostate-cancer-screening>

**Table 14. Prostate Cancer Measures for Illinois.**

Cancer Measure	Baseline (per 100,000) (2017)	Target (per 100,000) † (2025)
Incidence rate	111.2	79.3
Mortality rate	20.6	18.3

Data is most recent data from 2017 data from Illinois Department of Public Health. (2019). Illinois State Cancer Registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

† The target rate was determined by calculating the annual average percent change from 2008 to 2017, the latest available incidence data and mortality data. The targets were set for 2025 based on the projected rates from 2018 through 2025.

**Table 15. Prostate Cancer Incidence and Mortality by Race and Ethnicity in Illinois (2017).**

Race/Ethnicity	Incidence (per 100,000)	Mortality (per 100,000)
All Races (includes Hispanic)*	111.2	20.6
White (includes Hispanic)*	103.2	18.5
Black (includes Hispanic)*	173.1	43.5
Hispanic (any race)*	80.6	16.1
Non-Hispanic White*	105.8	18.6
Non-Hispanic Black*	176.1	44.4
Asian/Other Races*	47.2	Data not available
Other Races*	Data not available	7.9
Hispanic‡	81.5	16.1
Asian/Pacific Islander‡	48.5	8.3
American Indian/Alaskan Native‡	Data not available	Data not available

\*Data is most recent 2017 data from Illinois Department of Public Health. (2019). Illinois State Cancer Registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

‡Data is most recent 2017 data from Centers for Disease Control and Prevention. (2020). United States Cancer Statistics: Data Visualizations. <https://gis.cdc.gov/Cancer/USCS/DataViz.html>

# Illinois Comprehensive Cancer Control Plan

Table 16. Prostate Cancer - 20 Counties with Highest Incidence in Illinois (2013-2017).

Overall State Incidence	109.1
County	Incidence (per 100,000)
Washington	159.1
Grundy	149.5
Marion	139.7
Jefferson	137.9
Scott	137.9
Effingham	137.5
Morgan	136.5
Schuyler	134.3
Kendall	129.3
DeKalb	125.2
Will	125.2
Alexander	124.1
Sangamon	123.5
Clay	123.1
Wayne	121.8
Douglas	121.7
White	121.2
La Salle	121.1
Woodford	120.7
Macon	120.0

Data is most recent data from 2013-2017 (5-year average) for all races from the National Cancer Institute. (n.d.). State Cancer Profiles.  
<https://statecancerprofiles.cancer.gov/index.html>

## SKIN CANCER

Skin cancer is the most common form of cancer in the United States. Skin cancers are divided into two groups: nonmelanoma and melanomas of the skin. Nonmelanoma skin cancer includes basal cell and squamous cell carcinoma, the most common forms of skin cancer. Both are considered highly treatable. Melanomas of the skin are less common but more likely to spread to other parts of the body if left untreated, making them more serious forms of skin cancer.

### General Statistics

- **Leading cause of death**<sup>34</sup>
  - Melanomas of the skin are the 19th leading cause of cancer deaths in Illinois.
  - In Illinois, melanomas of the skin incidence and mortality rates are higher in males than females.
  - In Illinois, melanomas of the skin incidence and mortality rates are highest in White populations.
- **New diagnoses (Incidence)**<sup>35</sup>
  - In the United States, the incidence of melanomas of the skin has increased from 20.0 per 100,000 in 2008 to 22.7 per 100,000 in 2017.
  - In Illinois, the incidence of melanomas of the skin has increased from 17.9 per 100,000 in 2008 to 22.7 per 100,000 in 2017.
  - In 2017, there were a total of 85,686 new cases of melanomas of the skin in the United States and a total of 3,288 new cases of melanomas of the skin cases Illinois.
  - Between 2013 and 2017, melanomas of the skin were the seventh most commonly diagnosed cancer in Illinois.
- **Deaths (Mortality)**<sup>36</sup>
  - In the United States, mortality from melanomas of the skin has decreased from 2.7 per 100,000 in 2008 to 2.1 per 100,000 in 2017.
  - In Illinois, mortality from melanomas of the skin has decreased from 2.3 per 100,000 in 2008 to 2.0 per 100,000 in 2017.
  - In 2017, there were a total of 8,056 deaths from melanoma in the United States and a total of 300 deaths from melanoma in Illinois.



# Illinois Comprehensive Cancer Control Plan

## Risk Factors

Risk factors for skin cancer include:

- Exposure to ultraviolet (UV) radiation from natural or artificial sunlight
- Fair complexion
  - Light-colored skin
  - Freckling
  - Blue or green eyes
  - Blond or red hair
- Moles
- Personal history of skin cancer
- Family history of skin cancer
- Older age
- Exposure to arsenic
- Radiation treatment
- Weakened immune system

## Prevention and Early Detection<sup>37</sup>

Skin cancer is not preventable, but certain factors can lower your risk:

- Limit exposure to UV radiation.
  - Avoid being in the sun for long periods of time.
  - Avoid being in the sun in the middle of the day when UV radiation is most intense.
  - Wear sun-protective clothing, hats, and sunglasses.
  - Use sunscreen:
    - Use a broad-spectrum sunscreen with sun protection factor (SPF) of 15 or higher.
    - Put on all exposed skin 30 minutes before going out.
    - Reapply every two hours or after swimming, sweating, and toweling off.
  - Avoid artificial sunlight such as sun lamps, tanning beds, or tanning salons.
- Examine skin regularly.
- Teach children to protect themselves from the sun.

Currently, there is insufficient evidence to determine the balance of benefits and harms of visual examination by a health care provider to screen for skin cancer in adults.

# Illinois Comprehensive Cancer Control Plan

## Additional Information Sources

- American Cancer Society (ACS): <https://www.cancer.org/cancer/skin-cancer.html>
- American Society of Clinical Oncology (ASCO): <https://www.cancer.net/cancer-types/melanoma>
- Centers for Disease Control and Prevention (CDC): <https://www.cdc.gov/cancer/skin/index.htm#>
- Illinois State Cancer Registry (ISCR): <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>
- National Cancer Institute (NCI): <https://www.cancer.gov/types/skin>
- State Cancer Profiles (NIH/NCI/CDC): <https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=illinois>
- U.S. Preventive Services Task Force (USPSTF): <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/skin-cancer-screening>

Table 17. Melanomas of the Skin Measures for Illinois.

Cancer Measure	Baseline (per 100,000) (2017)	Target <sup>†</sup> (per 100,000) (2025)
Incidence rate	22.7	28.2
Mortality rate	2.0	1.8

2017 data is from the Centers for Disease Control and Prevention. (2020). United States Cancer Statistics: Data Visualizations. <https://gis.cdc.gov/Cancer/USCS/DataViz.html>

<sup>†</sup>The target rate was determined by calculating the annual average percent change from 2008 to 2017, the latest available incidence data and mortality data. The targets were set for 2025 based on the projected rates from 2018 through 2025.



# Illinois Comprehensive Cancer Control Plan

**Table 18. Melanomas of the Skin Incidence and Mortality by Race and Ethnicity in Illinois (2017).**

Race/Ethnicity	Incidence (per 100,000)		Mortality (per 100,000)	
	Male and Female		Male and Female	
All Races (includes Hispanic)*	22.7		2.0	
White (includes Hispanic)*	27.0		2.4	
Black (Includes Hispanic)*	Data not available		Data not available	
Hispanic*	5.5		Data not available	
Asian/Pacific Islander*	Data not available		Data not available	
American Indian/Alaska Native*	Data not available		Data not available	
	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>
All Races‡	28.2	18.7	2.9	1.4
White‡	32.9	22.7	3.4	1.7
Black‡	0.8	0.7	Data not available	Data not available
White Non-Hispanic‡	Data not available	Data not available	3.7	1.8
Hispanic (any race) ‡	Data not available	Data not available	Data not available	Data not available
Asian/Other Races‡	2.1	1.3	Data not available	Data not available
Other Races‡	Data not available	Data not available	Data not available	Data not available

\*Data for both sexes is most recent 2017 data from Centers for Disease Control and Prevention. (2020). United States Cancer Statistics: Data Visualizations. <https://gis.cdc.gov/Cancer/USCS/DataViz.html>

‡Data for males and females is most recent 2017 data from Illinois Department of Public Health. (2019). Illinois State Cancer Registry. <https://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>

# Illinois Comprehensive Cancer Control Plan

Table 19. Melanomas of the Skin - 20 Counties with Highest Incidence in Illinois (2013-2017).

Overall State Incidence	20.4
County	Incidence (per 100,000)
Piatt	51.4
Ford	45.4
De Witt	43.3
Woodford	36.8
McLean	35.0
Hamilton	35.0
Mercer	35.0
Douglas	34.4
Pike	33.2
Marion	31.9
Adams	31.6
Bureau	31.5
Lee	31.4
Williamson	30.7
Ogle	30.4
Coles	29.7
Iroquois	29.7
Livingston	29.7
Champaign	29.6
Franklin	29.3
Hancock	29.3

Data is most recent data from 2013-2017 (5-year average) for all races from the National Cancer Institute. (n.d.). State Cancer Profiles.  
<https://statecancerprofiles.cancer.gov/index.html>



# Illinois Comprehensive Cancer Control Plan

## ALL OTHER CANCERS – LATE-STAGE DIAGNOSIS

Late-stage diagnosis is a term used to describe cancer that is far along in its growth and has spread to the lymph nodes or other places in the body. In table 20, the risk factors are described for other cancer types, outside of the priority cancers previously described, that are most common for late-stage diagnosis.

**Table 20. Late-Stage Cancer Types Risk Factors.**

Cancer Type	Risk Factors
Bladder <sup>38</sup>	<ul style="list-style-type: none"> <li>• Family history of bladder cancer</li> <li>• Gene mutations</li> <li>• Smoking</li> <li>• Exposure to chemicals, such as processing paint, dye, metal, and petroleum products</li> <li>• Drinking well water contaminated with arsenic</li> <li>• Chronic urinary tract infections</li> </ul>
Brain <sup>39</sup>	<ul style="list-style-type: none"> <li>• No one known cause</li> <li>• Some brain cancers can be linked to family history, radiation exposure and a weakened immune system</li> <li>• Genetic disorders</li> </ul>
Esophagus <sup>40</sup>	<ul style="list-style-type: none"> <li>• Smoking</li> <li>• Drinking alcohol</li> <li>• Gastroesophageal reflux disease (GERD)</li> <li>• HPV</li> </ul>
Kidney and Renal Pelvis <sup>41</sup>	<ul style="list-style-type: none"> <li>• Smoking</li> <li>• High blood pressure</li> <li>• Taking certain pain medicine for a long period of time</li> <li>• Having hepatitis C</li> <li>• Having kidney stones</li> <li>• Having the sickle cell trait</li> <li>• Being exposed to trichloroethylene</li> </ul>
Leukemia <sup>42</sup>	<ul style="list-style-type: none"> <li>• No one known cause</li> <li>• Smoking</li> <li>• Family history of leukemia</li> <li>• Previous cancer treatment</li> <li>• Exposure to certain chemicals</li> <li>• Genetic disorders</li> </ul>

<sup>38</sup> Centers for Disease Control and Prevention. (2020, October 7). *Bladder Cancer*. Retrieved from <https://www.cdc.gov/cancer/bladder/index.htm>.

<sup>39</sup> American Cancer Society. (2021). *Brain and Spinal Cord Tumors in Adults*. Retrieved from <https://www.cancer.org/cancer/brain-spinal-cord-tumors-adults>.

<sup>40</sup> American Cancer Society. (2021). *Esophagus Cancer*. Retrieved from <https://www.cancer.org/cancer/esophagus-cancer>.

<sup>41</sup> Centers for Disease Control and Prevention. (2020, October 7). *Kidney Cancer*. Retrieved from <https://www.cdc.gov/cancer/kidney/index.htm>.

<sup>42</sup> Mayo Clinic. (2021). *Leukemia*. Retrieved from <https://www.mayoclinic.org/diseases-conditions/leukemia/symptoms-causes/syc-20374373>.

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Cancer Type	Risk Factors
Liver <sup>43</sup>	<ul style="list-style-type: none"> <li>• Hepatitis B or C</li> <li>• Smoking</li> <li>• Drinking alcohol</li> <li>• Having cirrhosis</li> <li>• Having nonalcoholic fatty liver disease</li> <li>• Diabetes</li> </ul>
Non-Hodgkin Lymphoma <sup>44</sup>	<ul style="list-style-type: none"> <li>• Family history</li> <li>• Radiation exposure</li> <li>• Having a weakened immune system</li> <li>• Autoimmune disease</li> <li>• Certain infections</li> </ul>
Oral Cavity and Pharynx <sup>45</sup>	<ul style="list-style-type: none"> <li>• Tobacco use</li> <li>• Drinking alcohol</li> <li>• HPV</li> <li>• Ultraviolet (UV) light</li> <li>• Weakened immune system</li> </ul>
Ovarian <sup>46</sup>	<ul style="list-style-type: none"> <li>• Middle-aged or older</li> <li>• Family history or gene mutations</li> <li>• Have had breast, uterine, or colorectal cancer</li> <li>• Have a genetic mutation of BRCA1 or BRCA2 or one associated with Lynch syndrome</li> <li>• Have endometriosis</li> <li>• Have an Eastern European or Ashkenazi Jewish background</li> <li>• Never have given birth</li> </ul>
Pancreas <sup>47</sup>	<ul style="list-style-type: none"> <li>• Smoking</li> <li>• Obesity</li> <li>• Diabetes</li> <li>• Chronic pancreatitis</li> <li>• Exposure to certain chemicals</li> </ul>
Stomach <sup>48</sup>	<ul style="list-style-type: none"> <li>• H. pylori infection</li> <li>• Smoking</li> <li>• Drinking alcohol</li> <li>• Previous stomach surgery</li> <li>• Being overweight or obese</li> <li>• Genetic disorders</li> </ul>

<sup>43</sup> Centers for Disease Control and Prevention. (2021, January 19). *Liver Cancer*. Retrieved from <https://www.cdc.gov/cancer/liver/index.htm>.

<sup>44</sup> American Cancer Society. (2021). *Non-Hodgkin Lymphoma*. Retrieved from <https://www.cancer.org/cancer/non-hodgkin-lymphoma.html>.

<sup>45</sup> American Cancer Society. (2021). *Oral Cavity and Oropharyngeal Cancer*. Retrieved from <https://www.cancer.org/cancer/oral-cavity-and-oropharyngeal-cancer>.

<sup>46</sup> Centers for Disease Control and Prevention. (2021, March 8). *Ovarian Cancer*. Retrieved from <https://www.cdc.gov/cancer/ovarian/index.htm>.

<sup>47</sup> American Cancer Society. (2021). *Pancreatic Cancer*. Retrieved from <https://www.cancer.org/cancer/pancreatic-cancer>.

<sup>48</sup> American Cancer Society. (2021). *Stomach Cancer*. Retrieved from <https://www.cancer.org/cancer/stomach-cancer>.

# Illinois Comprehensive Cancer Control Plan

Cancer Type	Risk Factors
Thyroid <sup>49</sup>	<ul style="list-style-type: none"> <li>• Family history</li> <li>• Radiation exposure</li> <li>• Iodine in your diet</li> <li>• Inherited genetic conditions</li> </ul>
Uterus <sup>50</sup>	<ul style="list-style-type: none"> <li>• Older than 50 years of age</li> <li>• Taken estrogen by itself (without progesterone)</li> <li>• Had trouble getting pregnant</li> <li>• Had fewer than five periods in a year before starting menopause</li> <li>• Taken tamoxifen</li> <li>• Family history of uterine, colon, or ovarian cancer</li> </ul>

Table 21 highlights the incidence rate, mortality rate, and incidence rate for late-stage diagnoses per 100,000 population for the 13 cancer types known for late-stage diagnosis.<sup>51</sup>

**Table 21. Late-Stage Cancer Diagnosis Incidence and Mortality.**

Cancer Type	Incidence Rate per 100,000 (Illinois) 2013-2017	Mortality Rate per 100,000 (Illinois) 2014-2018	Incidence Rate – Late Stage per 100,000 (Illinois) 2013-2017
Bladder	21.1	4.4	2.7
Brain	6.3	4.2	0.9
Esophagus	4.8	4.1	3.5
Kidney and Renal Pelvis	18.0	3.8	5.4
Leukemia	13.4	6.3	13.1
Liver	7.7	6.4	3.4
Non-Hodgkin Lymphoma	19.5	5.4	13.1
Oral Cavity and Pharynx	12.2	2.7	7.8
Ovarian	11.0	6.8	8.2
Pancreas	13.5	11.3	10.7
Stomach	7.2	3.2	4.3
Thyroid	15.1	0.5	5.0
Uterus	30.0	5.6	8.6

<sup>49</sup> American Cancer Society. (2021). *Thyroid Cancer*. Retrieved from <https://www.cancer.org/cancer/thyroid-cancer>.

<sup>50</sup> Centers for Disease Control and Prevention. (2019, August 19). Retrieved from <https://www.cdc.gov/cancer/uterine/index.htm>.

<sup>51</sup> NCI. (n.d.). *State Cancer Profiles*. Retrieved from <https://statecancerprofiles.cancer.gov/quick-profiles/index.php?statename=illinois>

## CANCER IN CHILDREN, ADOLESCENTS, AND YOUNG ADULTS

Cancer in children is rare when compared to cancer occurring in adults. About 15,000 children younger than 20 are diagnosed with cancer each year in the United States.<sup>52,53</sup> Pediatric cancer death rates have dropped by nearly 70% over the past 40 years. Cancer is still the leading cause of death from disease among children from birth to age 14.

No exact definition exists to differentiate childhood cancers from adolescent and young adult cancers. Cancers in young adults are those that start between the ages of 20 to 39 years of age.<sup>54</sup> Eighty thousand young adults ages 20 – 39 are diagnosed with cancer each year.

The most common types of cancer in children aged 0 to 14 years are:<sup>52</sup>

- Bone
- Brain and spinal cord tumors
- Leukemia
- Lymphoma (Hodgkin and non-Hodgkin)
- Neuroblastoma
- Retinoblastoma
- Rhabdomyosarcoma
- Wilms tumor

The most common types of cancer in adolescents aged 15 to 19 years are:<sup>53</sup>

- Brain and spinal cord tumors
- Leukemia
- Lymphoma
- Melanoma
- Ovarian
- Sarcoma
- Testicular
- Thyroid

The most common types of cancer in young adults aged 20 to 39 are:<sup>54</sup>

- Breast
- Brain and spinal cord tumors
- Colorectal
- Gynecological
- Lymphoma
- Melanoma
- Sarcoma
- Testicular
- Thyroid

<sup>52</sup> American Cancer Society. (2021). Cancer in Children. Retrieved from <https://www.cancer.org/cancer/cancer-in-children.html>

<sup>53</sup> American Cancer Society. (2021). Cancer in Adolescents. Retrieved from <https://www.cancer.org/cancer/cancer-in-adolescents.html>

<sup>54</sup> American Cancer Society. (2021). Cancer in Young Adults. Retrieved from <https://www.cancer.org/cancer/cancer-in-young-adults.html>

# Illinois Comprehensive Cancer Control Plan

## Risk Factors

Risk factors influence a person's chance of getting cancer, but this occurs over a longer duration of time.<sup>53</sup> Risk factors are not thought to increase children's, adolescents, or young adults risk for cancer as in older adults with lifestyle behaviors, such as smoking, alcohol use, etc.

- Other risk factors that could be associated with cancer in children are radiation exposure or other environmental exposures and acquired or inherited gene mutations.
- Other risk factors that could increase the chance of an adolescent or young adult getting cancer are environmental exposures, acquired or inherited gene mutations, ultraviolet (UV) radiation from tanning beds, and treatment from a childhood cancer, HPV infection, and human immunodeficiency virus (HIV) infection.

## Prevention and Early Detection

Lifestyle risk factors, such as smoking, being overweight, not exercising, and eating unhealthy foods, play a role in many types of adult cancers. However, most lifestyle risk factors do not play a role in childhood cancers. Since cancer in children is rare, it is hard to detect if no symptoms are present.

Some children inherit DNA changes (mutations) from a parent that increase their risk of certain types of cancer. These changes are present in every cell of the child's body, and they can often be tested for in the DNA of blood cells or other body cells. Some of these DNA changes are linked only with an increased risk of cancer, while others can cause syndromes that also include other health or developmental problems.

However, most childhood cancers are not caused by inherited DNA changes. They are the result of DNA changes that happen early in the child's life, sometimes even before birth. Every time a cell divides into two new cells, it must copy its DNA. This process isn't perfect, and errors sometimes occur, especially when the cells are growing quickly. This kind of gene mutation can happen at any time in life and is called an acquired mutation.

Some risk factors that can be reduced in adolescents are limiting exposure to environmental risk factors, such as radiation exposure and UV radiation, and receiving the HPV vaccine. No cancer screening tests for children and adolescents are recommended, as cancer is not common for this age group. Cancer is not usually screened for if there are no signs or symptoms.

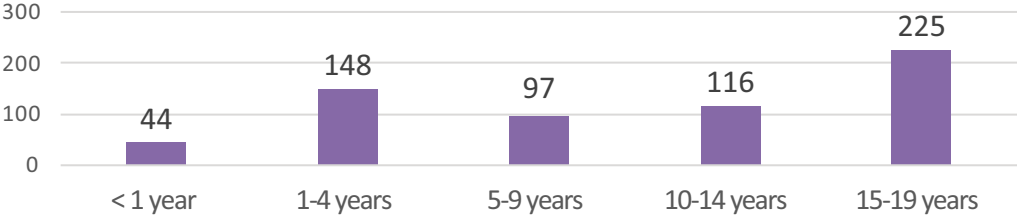
For young adults, reasons why cancer may not be detected early on include infrequent visits to the doctor or not having a primary care doctor. Financial issues and insurance coverage may impact whether or not a person goes to the doctor. Cancers are not common between ages 20 and 39. Many screening tests to look for cancer in people in this age group are not recommended unless they have an increased risk.

# Illinois Comprehensive Cancer Control Plan

## Incidence: Cancer in Children, Adolescents, and Young Adults

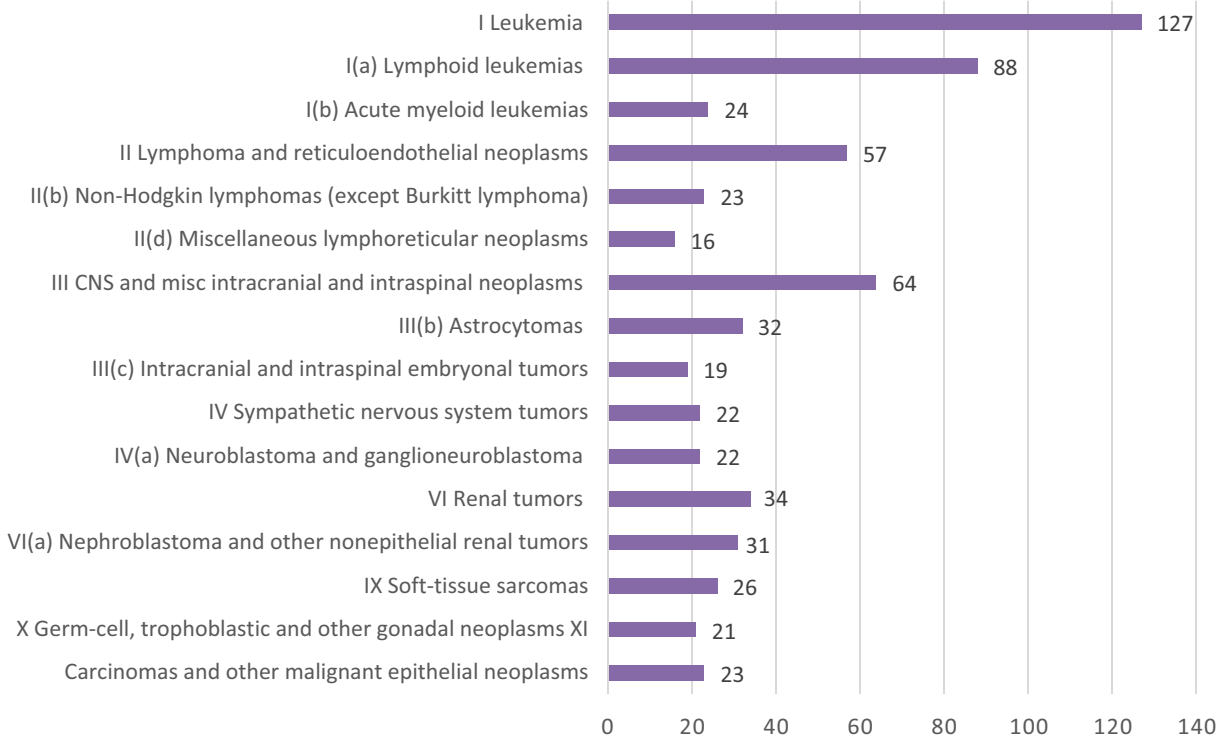
Figure 13 below summarizes the incidence rate for all childhood invasive cancers combined for 2017 in Illinois.<sup>55</sup>

**Figure 13. All Childhood Invasive Cancers Combined by Age Group per 1,000,000 for 2017 in Illinois.**



Figures 14-16 shows the incidence by cancer types for childhood, adolescent, and young adults for 2017 in Illinois.<sup>55</sup>

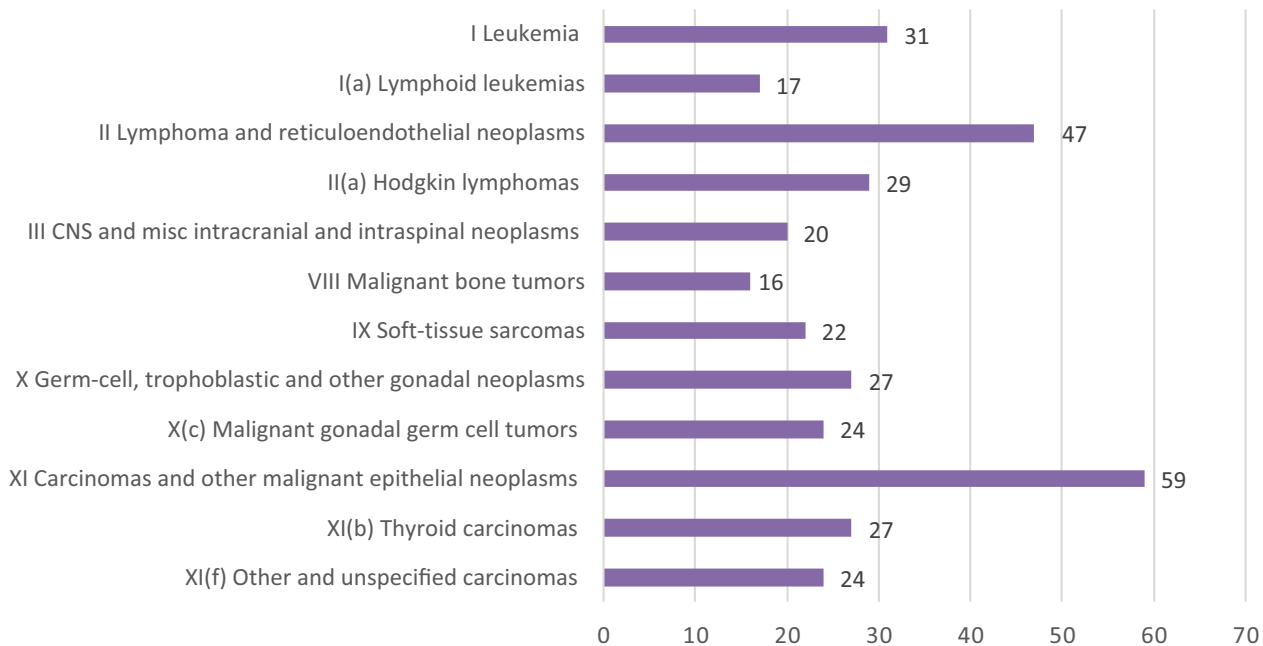
**Figure 14. 2017 Incidence for Ages 0-14 per 1,000,000 Population in Illinois.**



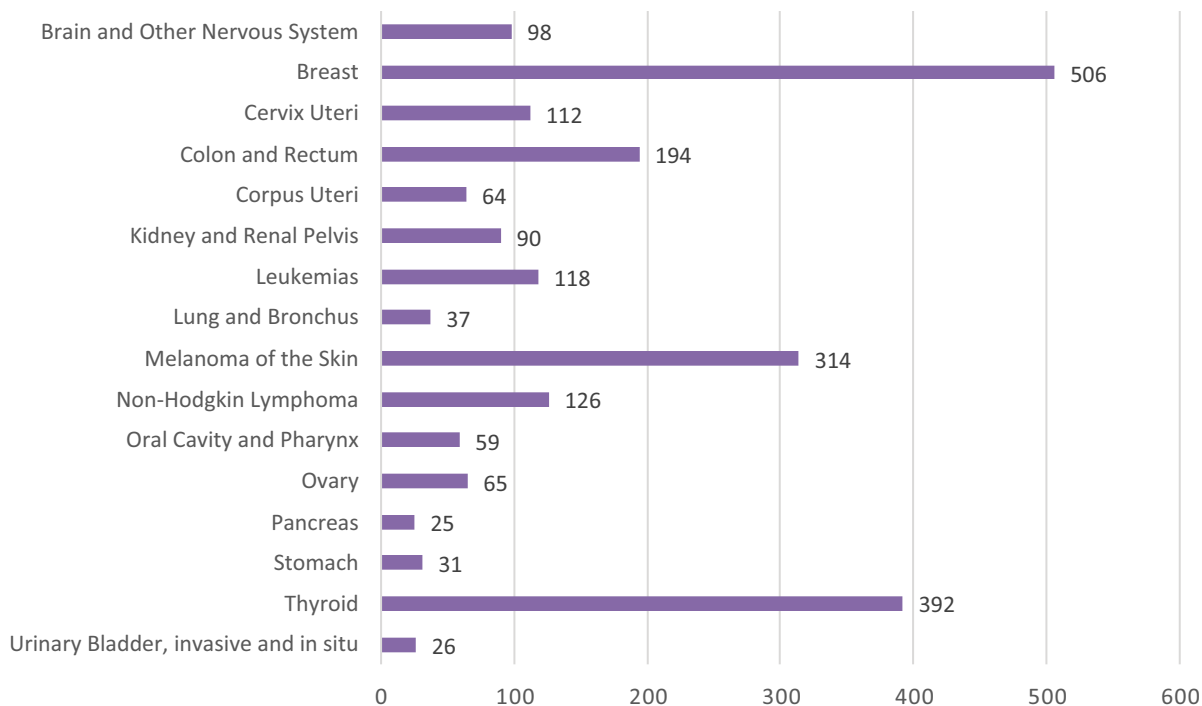
<sup>55</sup> United States Cancer Statistics - Incidence: 1999 - 2017, WONDER Online Database. United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2020. Retrieved from <http://wonder.cdc.gov/cancer-v2017.html>.

# Illinois Comprehensive Cancer Control Plan

**Figure 15. 2017 Incidence for Ages 15-19 per 1,000,000 Population in Illinois.**



**Figure 16. 2017 Incidence for Ages 20-39 per 100,000 Population in Illinois.**

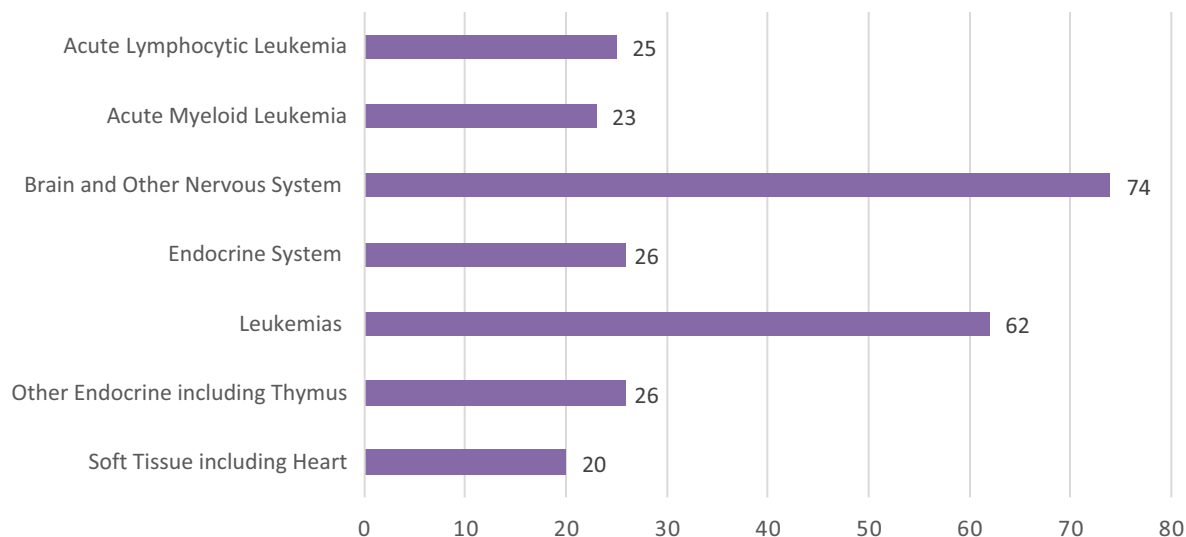


# Illinois Comprehensive Cancer Control Plan

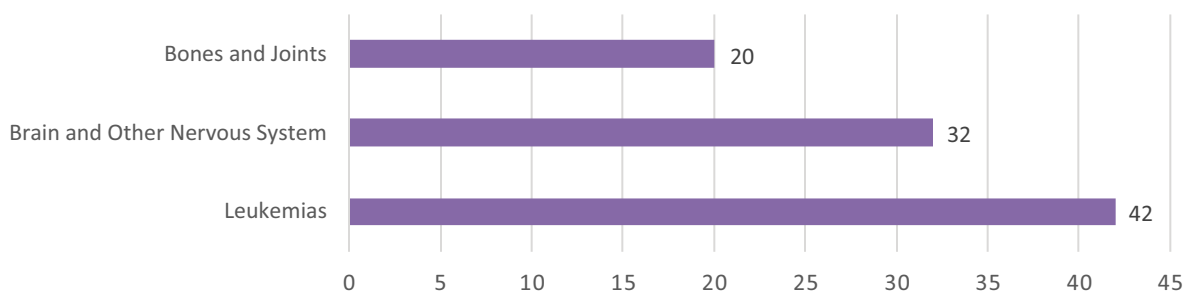
## Mortality: Cancer in Children, Adolescents, and Young Adults

Figures 17-19 shows the mortality rate for childhood, adolescent, and young adults for 2013-2017 in Illinois.<sup>56</sup>

**Figure 17. 2013-2017 Mortality for Ages 0-14 per 100,000 Population in Illinois.**



**Figure 18. 2013-2017 Mortality for Ages 15-19 per 100,000 Population in Illinois.**

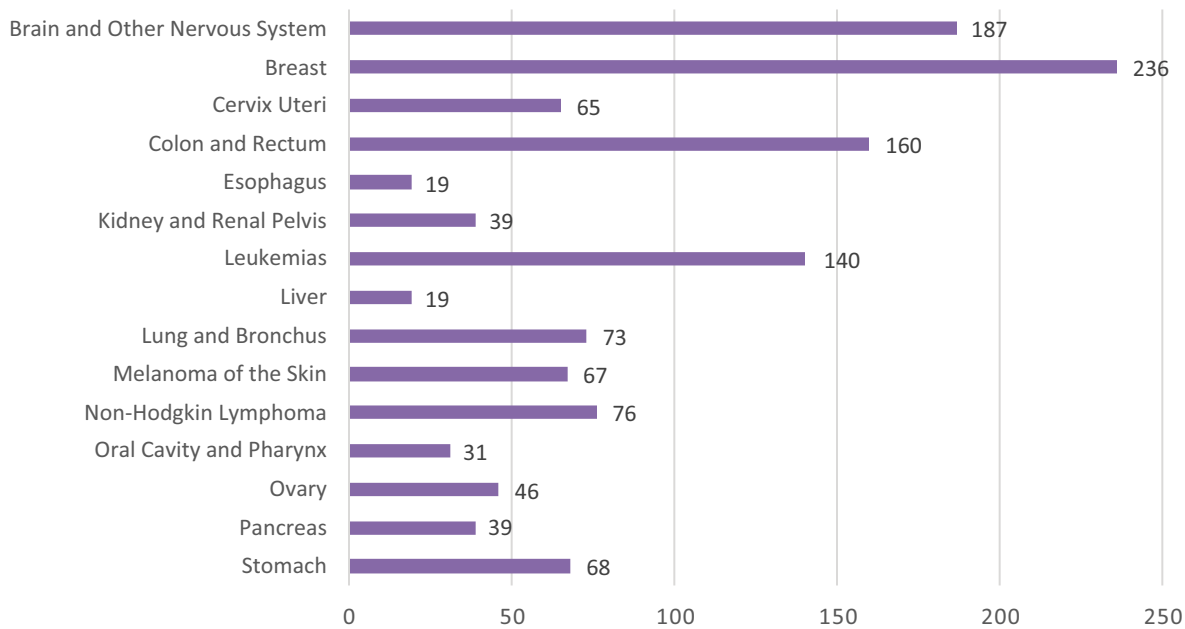


<sup>56</sup> United States Cancer Statistics - Mortality: 1999 - 2017, WONDER Online Database. United States Department of Health and Human Services, Centers for Disease Control and Prevention; 2020. Retrieved from <http://wonder.cdc.gov/CancerMort-v2017.html>.



# Illinois Comprehensive Cancer Control Plan

Figure 19. 2013-2017 Mortality for Ages 20-39 per 100,000 Population in Illinois.



## Strategies

The American Childhood Cancer Organization has identified action items specifically for childhood cancers.<sup>57</sup>

- Research new, less toxic therapies for treating childhood cancer.
- Ensure children diagnosed with cancer (and their families) have equitable access to quality health care and psychosocial programs.
- Ensure equitable access to educational opportunities for children with cancer.
- Ensure children (and their families) have knowledge of the long-term effects of childhood cancer treatment and have equitable access to high quality follow-up care.
- Increase awareness of childhood cancer among families, health care professionals, schools, and society as a whole.

In addition to the strategies listed elsewhere in this plan, the following lists strategies by topic area.

## Research

- Work with state and national partners to support funding for pediatric cancer research.
- Support research leading to new therapies targeted specifically for children with cancer that are effective and less toxic.
- Promote basic/molecular research leading to an improved understanding of the causes of childhood cancers.

<sup>57</sup> American Childhood Cancer Organization. (2021). State. Retrieved from <https://www.acco.org/state/>.

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## Equitable Access to Quality Health Care and Psychosocial Programs

- Work with childhood cancer advocacy organizations to support efforts aimed at improving pediatric cancer patients' quality of life from diagnosis onward.
- Identify and address family medical education needs (diagnosis, treatment, late-effects, support programs, sibling support, and respite care).
- Educate human resource professionals as to the full extent of resources available to pediatric cancer caregivers through the Family Medical Leave Act.
- Provide strong recommendation for parents and caregivers to receive early and ongoing assessment of their mental health needs.
- Provide bereavement follow-up for parents/caretakers.

## Health Care Providers/Insurers

- Expand workforce training in pediatric palliative care.
- Increase awareness of clinical trial in the pediatric/adolescent population.

## Equitable Access to Education

- Educate patients, parents, and educators on academic challenges faced by childhood cancer patients.
- Work with school intervention specialists to raise awareness among patients, families, educators, and administrators of the support that should be available through the school system.

## Long-term Effects

- Increase education about long-term consequences of cancer treatment for pediatric, adolescent, and young adult patients.
- Educate families about the need for long-term follow-up care to monitor the late effects of childhood cancer treatment and to promote healthy survivorship.
- Promote utilization of recommendations/standards for follow-up care (COG Passport for Care, Psychosocial Standards of Care Project for Childhood Cancer).

## Awareness

- Increase general awareness of the incidence and impact of pediatric cancer on children in Illinois.
- Increase awareness of the need for novel pediatric cancer therapies.
- Increase awareness of the impact of pediatric cancer on survivors and their families.

## Additional Information Sources

- American Childhood Cancer Organization: <https://www.acco.org/we-can-help/>
- Childhood Cancer STAR Project: <https://www.cdc.gov/cancer/npcr/pediatric-young-adult-cancer.htm>

# Illinois Comprehensive Cancer Control Plan

## HEALTH EQUITY AND HEALTH DISPARITIES

In the previous section, the populations at highest risk for cancer or cancer mortality were reviewed, as well as the highest risk groups for priority cancers. In this section, health equity and how health disparities impact cancer screening, early detection, and treatment are discussed.

All Illinoisans deserve to live long, healthy lives, free of modifiable differences in health status and outcomes.

Health inequities affect everyone. Disparities in health status exist between many population groups, with the greatest disparities found between people of different racial or ethnic groups, and between people of different socioeconomic statuses. Significant racial/ethnic and income disparities are observed when examining the rates of illnesses and conditions, such as diabetes, heart disease, depression, lung and breast cancer, and infant mortality. Interventions to reduce health inequities can improve the health of all communities. Health inequities exist for the lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities.

*There's been a lot of discussion about health care disparities, and I just called it ZIP code health care when I've given talks about it. Your zip code determines your access as well as the type of environment that you are living that injures your health.*

Black, non-Hispanic cancer survivor from Cook County, 60 years of age

*I'm connected with the LGBTQ community, and just finding an open and affirming provider that's not going to have bias about your sexual orientation is like a whole extra step and can be complicated for people to overcome and make sure that they feel safe with a doctor.*

White, non-Hispanic cancer caregiver from Williamson County, 39 years of age

Health disparities are a particular type of health differences closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identify; geographical location; or other characteristics historically linked to discrimination or to exclusion.

## COMMUNITY ENGAGEMENT STRATEGY TO UNDERSTAND CANCER DISPARITIES IN ILLINOIS

“Cancer affects everyone but not everyone equally” and this extends to communities in Illinois. The Illinois Comprehensive Cancer Control Program (ICCCP), in collaboration with the University of Illinois Cancer Center’s Community Engagement and Health Equity (CEHE) office, implemented a community engagement strategy for the 2022-2027 Illinois Comprehensive Cancer Control Plan. The overall goals of the collaboration were 1) to develop a plan to engage diverse stakeholders in the development process of the plan, and 2) to receive community feedback on cancer disparities and needs in Illinois. Enlisting the participation of stakeholders from the community ensures that the 2022-2027 plan reflects the expertise, voices, and priorities of Illinoisans who are directly impacted by cancer, including cancer patients, survivors, and caregivers. The community engagement strategy included a statewide town hall, as well as eight focus groups. Throughout the development of the plan, information from the community engagement efforts was continuously discussed and reviewed with the ICP and the Prevention; Screening and Early Detection; and Diagnosis, Treatment, and Survivorship work groups.

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## METHODS

On January 26, 2021, CEHE hosted a statewide town hall followed by eight focus groups in March and April 2021. The objectives of the town hall and focus groups were to: 1) identify cancer-related problems, barriers, and gaps that Illinoisans experience; 2) identify solutions, facilitating factors, and strengths to address the problems; and 3) propose recommendations based on findings. The approach, development, and analysis of the town hall and the focus groups were guided by the Model for Analysis of Population Health and Health Disparities, the Centers for Disease Control and Prevention's Community Health Assessment and Group Evaluation (CHANGE) Action Guide, and the Community Tool Box.<sup>58</sup> The town hall facilitator guide and the semi-structured focus group guide included questions about biologic responses and pathways (genetic factors), individual demographics and risk factors (socioeconomic status and health behaviors), the social and physical context (environment, social relations, social norms, and beliefs), and fundamental causes (policy, health care system, and discrimination). This project (Protocol #2020-1552) received a formal Determination of Quality Improvement status according to University of Illinois at Chicago institutional research policy.

### Town Hall

The virtual town hall was open to all interested individuals. A registration link was sent out via IDPH's, the ICP's, and CEHE's partner and stakeholder networks. During the 90-minute virtual town hall and in breakout rooms, participants discussed how cancer impacts their life, strategies to improve cancer outcomes in Illinois, and what the state can do to improve cancer disparities. The town hall and its breakout rooms were hosted by a facilitator and a note taker. Immediately following the town hall, notes were composed to align with the facilitator guide. The notes were reviewed and then organized by the topic areas in which they were discussed with attendees.



<sup>58</sup> Warnecke RB, Oh A, Breen N, Gehlert S, Paskett E, Tucker KL, Lurie N, Rebbeck T, Goodwin J, Flack J, Srinivasan S, Kerner J, Heurtin-Roberts S, Abeles R, Tyson, FL, Patmios G, Hiatt RA. (2008). Approaching health disparities from a population perspective: the National Institutes of Health Centers for Population Health and Health Disparities. *American Journal of Public Health*, 98(9), 1608–1615; Centers for Disease Control and Prevention. (2019). CDC Community Health Assessment and Group Evaluation (CHANGE) Action Guide. Retrieved December 10, 2020, from <https://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/tools/change/downloads.htm>; Center for Community Health and Development. (n.d.). Community Tool Box. Retrieved December 10, 2020, from <https://ctb.ku.edu>.

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## Focus Groups

As a follow-up to the town hall, CEHE hosted eight focus groups to delve deeper into themes about health equity and cancer disparities. Interested individuals were asked to complete a basic demographic form that included questions about geographic residence in Illinois, whether they were a cancer survivor and/or caregiver, insurance status, and race and ethnicity. Participants were selected using purposive sampling methods to maximize group heterogeneity and to ensure a broad group of individuals were represented in the focus groups. Three general population focus groups were held, as well as focus groups specifically for rural residents, survivors, young survivors, caregivers, and Spanish speakers. The focus groups, held both during the week and on weekends, were audio-recorded and ranged between 75-98 minutes (M= 83 minutes) and had on average seven participants (range of 5 to 10 participants). Participants received a \$40 gift card to thank them for their time. The focus groups were transcribed professionally, checked for accuracy, and de-identified prior to analysis. The analytic team used content analysis procedures and developed a codebook to facilitate the identification of themes and subthemes. The final codebook consisted of 58 codes. Finally, the town hall notes and focus group findings were synthesized and are presented together below.

## RESULTS

The major themes from the town hall and focus groups are presented to first describe the factors that contribute to cancer disparities among Illinoisans, aligning with the Model for Analysis of Population Health and Health Disparities framework (fundamental causes, the physical and social context, and individual demographic and risk factors), followed by proposed solutions, recommendations, and priorities across the cancer continuum. Finally, a brief section on the impact of COVID-19 on cancer is presented. Exemplary quotes are included in the results text and supplemental tables will present additional sample quotes.

## Participants

The town hall had a total of 62 participants (Table 22). Town hall participants were asked to report their affiliations and could select as many categories as they felt were applicable. About a third (36%) of participants reported being an academic affiliate, 16% reported they were from a community-based organization, and 13% were from a hospital or clinical setting. About 13% reported being a cancer survivor and 10% reported they were a current or past caregiver of a cancer patient.



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Table 22. Characteristics of Town Hall Participants. (n=62)

Characteristic	Number	%
Hispanic, Spanish, or Latino origin	11	18
Race		
Asian	6	10
Black or African American	15	24
White	38	61
Race not reported	3	5
Affiliation <sup>1</sup>		
Cancer survivors	8	13
Caregiver for a cancer patient (current or past)	6	10
Community member	5	8
Academic affiliate	22	36
Community-based organization	10	16
Hospital/Clinical setting	8	13
Government agency/Health department	5	8

<sup>1</sup> Town hall participants asked to select all that applied.

The eight focus groups had 53 participants from Illinois (Table 23). About 62% reported being a cancer survivor and 47% were a current or past caregiver of a cancer patient. Most (94%) participants were female, and on average 52 years of age. About 15% reported their ethnicity as Hispanic, Spanish, or Latino origin, and nearly a quarter (25%) reported their race as Black or African American. Regarding current health insurance coverage, about a quarter (27%) were covered by Medicare, Medicaid, or through the Affordable Care Act (ACA) marketplace, and 6% were uninsured. Finally, regarding geographic representation, about 26% of participants were rural residents, and 16 of Illinois's 102 counties were represented in at least one of the focus groups (Figure 20).



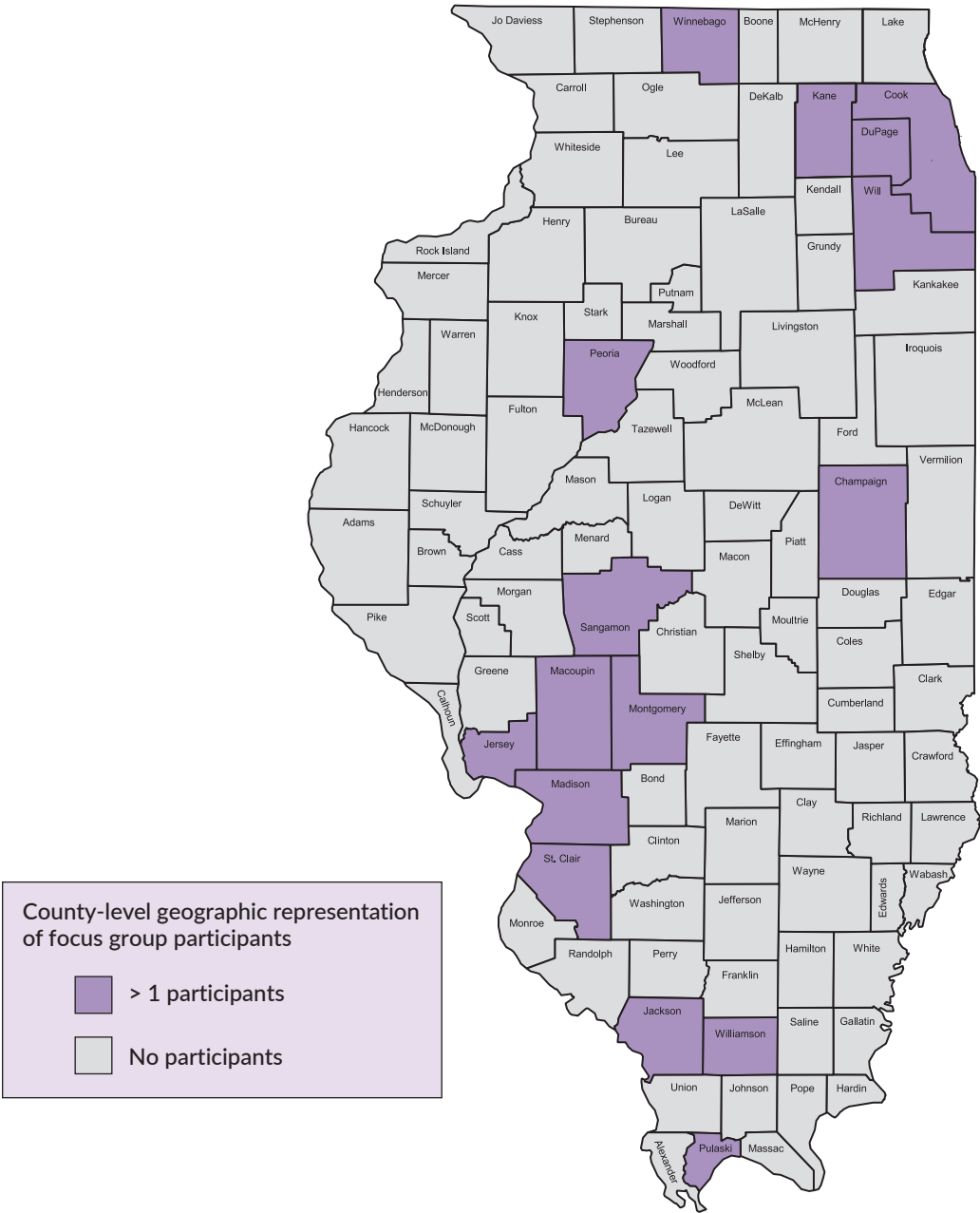
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**Table 23. Characteristics of Focus Group Participants. (n=53)**

Characteristic	Number	%
Ever diagnosed with cancer	33	62
Age at cancer diagnosis (n=33)		
< 40 years of age	8	24
40-59 years of age	18	55
> 60 years of age	7	21
Current or past caregiver for a cancer patient	25	47
Gender		
Female	50	94
Male	3	6
Age (M = 52 years, Range = 25-88 years)		
< 40 years of age	12	23
40-59 years of age	25	47
> 60 years of age	16	30
Hispanic, Spanish, or Latino origin	8	15
Race		
Black or African American	12	23
American Indian/Alaska Native	1	2
Asian	1	2
White	39	73
Current health insurance coverage		
Private	33	61
Medicare	9	17
Medicaid	2	4
Coverage through the ACA	3	6
Other source of coverage	3	6
Uninsured, no coverage	3	6
Preferred language for focus group		
English	48	91
Spanish	5	9
Current rural residence	14	26
Abbreviation: ACA = Affordable Care Act		

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Figure 20. Geographic representation of focus group participants for the 2022-2027 Illinois Comprehensive Cancer Control Plan community engagement strategy.



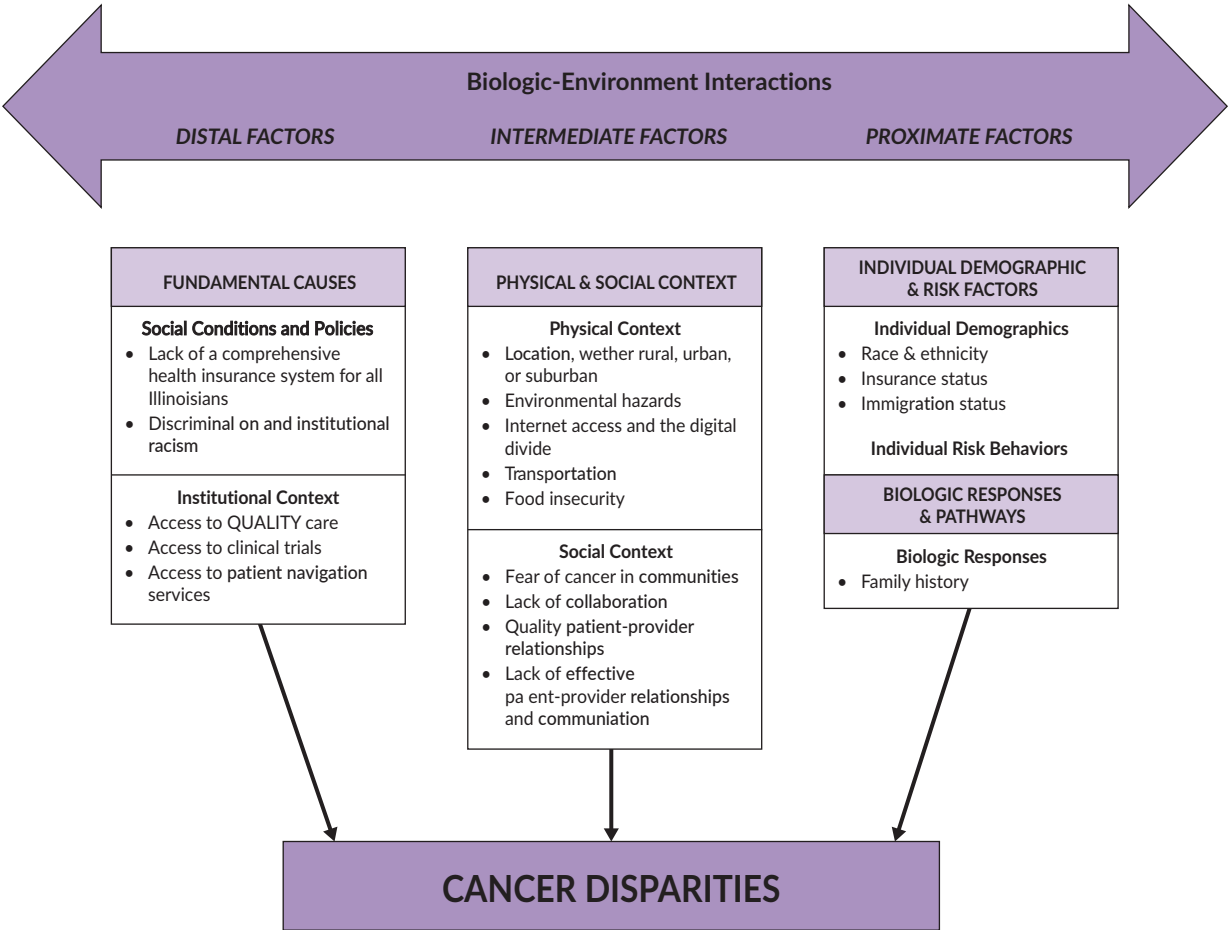
## Factors that Contribute to Cancer Disparities among Illinoisans

Town hall and focus group participants described how fundamental causes, the physical and social context, individual demographic and risk factors, and biologic responses and pathways contributed to disparities across the cancer continuum for Illinoisans, depicted in Figure 21, and in line with the Model for Analysis of Population Health and Health Disparities framework. The sections below describe each of the factors in greater depth.



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Figure 21. Factors that Contribute to Cancer Disparities among Illinoisans.



*Fundamental Causes*

Participants described several fundamental causes, those distal determinants of health that include population social conditions, policies that affect social conditions, and the policymaking bodies that influence or determine them that contribute to disparate health.

**Social conditions and policies.** Overall, the lack of a comprehensive health insurance system for all and discrimination were identified as being the primary social conditions and policies that contributed to cancer disparities across the cancer continuum.

**Lack of comprehensive health insurance system for all Illinoisans.** Although Illinois was a Medicaid expansion state through the Patient Protection and ACA, a significant segment of the population remains uninsured or underinsured (unaffordable out-of-pocket costs and deductibles). The costs of cancer screenings and preventative care were often too expensive for these individuals, and thus were at times avoided. One cancer survivor noted the unaffordability of their ACA plan.

*And even though the term is Affordable Care Act, the insurance, if you're paying it on your own – which I am right now – is not very affordable. (African American cancer survivor from Cook County, 60 years of age)*

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*It's been said we don't have a health care system; we have a sick care system. And that's because people don't, and they're not encouraged, to seek out health care. They're encouraged to get better if they're sick. And only if they can afford it. (Non-Hispanic White cancer survivor from central Illinois, 57 years of age)*

Further, it was noted that Medicaid managed care organizations (MCOs) are not comprehensive in terms of geographic coverage for all communities. So, some communities struggle to access cancer care, even when insured. One cancer survivor discussed having clinical options because of their insurance.

*My insurance is through the Affordable Care Act. When Illinois extended Medicaid to cover low-income individuals, I qualified. And I find having that as my insurance affects who I can see... I feel that the quality of health care I'm getting... because of my insurance is less. It isn't as good. (Non-Hispanic White cancer survivor from central Illinois, 57 years of age)*

**Discrimination.** Discrimination, both within the historical context as well as within the medical system, was discussed as a major contributor to cancer disparities. Specially, a lack of trust between patients and providers was perceived to be a significant issue that impacted engagement with the health system.

*Some people don't have access or are afraid, especially in the Black community and Brown communities. (African American male cancer survivor from Cook County, 57 years of age)*

*And I've heard from friends – in particular, friends who are not White, who do not feel like doctors trust or actually listen to them and validate what they're experiencing. (Non-Hispanic White cancer survivor from Cook County, 34 years of age)*

Relatedly, there were conversations about how people of color and undocumented populations specifically may not engage with the health system due to internalized stigma. One person described how people in their community avoid safety net screening programs.

*We also want people to understand that the financial help that they give us, from the state, in the hospitals and clinics is because it's a part of what we also pay in taxes as immigrants. Don't feel like they're giving you something for free or are doing you a favor. (Latina community member Cook County, 48 years of age)*

**Institutional context.** A lack of access to health systems, services, and quality care were described as major drivers of cancer disparities in Illinois. Participants expressed the belief that not all health systems provide equivalent standards of care and groups with lower socioeconomic status may be receiving worse care.

**Access to quality care.** Access to care, although important, is not sufficient to address health disparities if the care is not of high quality. Specially, it was noted that access to cancer centers and research institutions was important.

*[Access to a research institution] is literally a lifeline. You have access to clinical trials... and the response time is phenomenal if you're in a location that has that kind of infrastructure. But most... in this country do not live near a major research hospital. And I do not expect that we can be successful at treating cancer early, or even getting people treatment that they need, without the access. Access is everything. (African American cancer survivor from Cook County, 60 years of age)*

**Access to clinical trials.** Clinical trial research leads to exciting and important discoveries for addressing cancer, especially around screening and treatments, yet not everyone is able to access them. One cancer survivor talked about how they felt their survival was a result of previous clinical trials.

*I feel strongly that I am going to live and survive cancer because of 20 years of clinical trials that women were willing to endure. And I feel like I stand on the shoulders of a lot of women who did the clinical trials for... all the*

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*drugs that I'm now taking that are saving my life. So, I pray for those people every day and I pray for their families and the survivors of those women. When I was diagnosed, I volunteered to join a clinical trial.... As someone in cancer treatment, if we can contribute to the science of treatment, we can and we should. (Non-Hispanic White cancer survivor from rural, central Illinois, 55 years of age)*

However, even for those with access to clinical trials, the decision to participate was not always an easy one to make. People discussed weighing the potential risks and benefits of participating, as well as potential burdens, like travel and time, involved with being part of a clinical trial. For some, participating in a clinical trial was seen as a last-ditch effort to address their cancer.

*At first, I was terrified... "Oh. I'm gonna be this guinea pig." But I've been on it. I decided to go with the clinical trial, and I am so happy I did because it's keeping me stable. And I'm lucky enough, I don't have side effects. (White cancer survivor from suburban Cook County, 60 years of age)*

*I think [my participation in a clinical trial] would just depend upon the situation, what my health situation is, and what the details of the trial are, I would be willing to participate depending upon those things. But then again, I might not be willing to participate depending upon those things. (Non-Hispanic White cancer survivor from rural, southern Illinois, 48 years of age)*

African American cancer patients, who have traditionally been excluded from clinical trials research, may also be hesitant to participate in clinical trials research, in part due to historical medical mistreatment.

*It was a big issue as far as who was coming to them and asking [to participate in a clinical trial]... I mean, especially like individuals from African American communities. Who is asking me to be a participant? Because I don't necessarily trust everybody out here. (African American community member from Cook County, 37 years of age)*

**Access to patient navigation services.** Another important access issue, especially for those undergoing diagnostic and treatment procedures, is related to patient navigation services. Patient navigators were viewed as an essential member of the patient care team and can improve and enhance patients' experiences throughout the cancer continuum by coordinating care, offering support and education, and identifying resources, yet they are not available universally or equitably.

*But what would've been great, and hospitals have this but ours doesn't – it would be to have a patient navigator. I had friends who did have patient navigators and it just blew my mind. I mean, they basically take care of all that stuff for you, answer your questions. (Non-Hispanic White cancer survivor from central Illinois, 66 years of age)*

*And so, there are insurance companies that do have patient navigators... And there are hospitals that have patient navigators... But they're so few and far between. (African American cancer survivor from Cook County, 60 years of age)*

### *Physical and Social Context*

The physical and social contexts are intermediate factors through which the distal effects of fundamental factors are experienced and impact cancer disparities. Participants described how their community's physical and social contexts were important determinants of health and contributors to health disparities.

**Physical context.** Abundant discussions were held on the importance of place and where one lives and how this determines health. Specifically, environmental hazards, internet access and the digital divide, transportation, and food insecurity were discussed.

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**Location, location, location.** Where a person lives impacts their access to facilities and to resources, to quality of care, and their ability to support their overall health and cancer-care needs. One person talked about the importance of place in determining health.

*There's been a lot of discussion about health care disparities, and I just called it ZIP code health care... Your ZIP code determines your access as well as the type of environment that you are living that injures your health. (African American cancer survivor from Cook County, 60 years of age)*

Discussions were held specifically related to the challenges faced by rural communities in Illinois, and the fact that they included many aging individuals as well as those of lower socioeconomic status. Some felt that rural populations were more likely to receive substandard care.

*So, if you're in a hard-to-reach region, why should you get third tier treatment? It's an unequal distribution of medical care in the state and it has been for a very, very long time. (Non-Hispanic White cancer survivor from rural, central Illinois, 55 years of age)*

Living in an urban area, on the other hand, was sometimes described as a barrier, but at other times as an asset to addressing cancer disparities. For example, some urban areas are medically underserved, including communities on the South Side of Chicago. During the town hall, people discussed the closure of a Chicago hospital, which provided cancer treatment to a high-risk population. As a result, patients are having to travel far outside their neighborhood for treatment which may be difficult depending on resources they have available. Conversely, people discussed how the advantages of living in an urban area. In some urban areas, there is easy access to resources, like patient/nurse navigators, community and support services, and community health centers.

**Environmental hazards.** Both rural and urban communities discussed their risk of exposure to carcinogens that affect the air, food, or water sources. The suspected sources of the environmental hazards differed between rural and urban populations, wherein farms and coal mines were identified by rural residents and factories and other waste-producing companies were identified by urban residents.

*I live in a very rural part. There are farms, coal mines. And in my small community, I mean, there aren't a lot of people, but I don't know of anyone who has not had cancer in their family. It seems like almost every day it's like someone said, "Oh, did you know so-and-so down the road has cancer? This person has cancer." (Non-Hispanic White caregiver from rural, southern Illinois, 48 years of age)*

*I think if one lives in an urban area, your air quality probably isn't very good. So, that probably has a lot to do with cancer diagnoses. (Non-Hispanic White cancer survivor from Cook County, 58 years of age)*

**The digital divide and telehealth.** Participants made a recognition that the digital divide is a contributor to cancer disparities. Although telehealth has opened the door of opportunity and is allowing patients a way to connect with their health care provider virtually, many communities still do not have internet service nor know how to use technology. Further, this limits opportunities to engage with online education and resources. Cost was noted as a major barrier, specifically for rural residents. The digital divide has perhaps widened during the COVID-19 pandemic, when people have had to rely on telehealth for their care. Because many people are no longer physically attending appointments, they have not been able to be screened or receive treatment. This barrier is especially impactful in the older population, where many of the elderly do not know how to operate technological devices or connect virtually with providers.

*I will say, for my mother-in-law who's 73, during COVID..., and because of technology – she wasn't technology savvy – she was discouraged and didn't do it. So, she went through a lot of pain as a result of that was the only thing that they offered her. So, I just imagine that community who may not be comfortable with technology and having to do that would struggle. (African American cancer survivor and caregiver from central Illinois, 49 years of age)*

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While telehealth does not offer the same experiences or clinical services as in-person visits, some welcomed its availability. Telehealth eliminated travel times and costs, allowed for more patient-provider interaction.

*I'm going to share someone else's story... She has a mental health issue and was constantly, again because of transportation, was a no show or would arrive at her appointments late and then couldn't be seen. And she loves telehealth because she doesn't have to rely on anyone else... She hopes that they always keep that because it's so successful for her. (African American cancer caregiver from rural, central Illinois, 65 years of age)*

**Transportation.** Some people have cars and get around easily, some use public transportation, and some bike or walk for care, while others rely on family and friends. Rural, suburban, and urban communities experience transportation barriers, which makes it difficult to navigate appointments, attend support groups, buy healthy food, and go to health facilities for exercise. One person described their frustration in that this was a barrier that was not discussed enough with health care providers.

*I mean, not everyone has access to a vehicle... Quite often, the medical profession doesn't consider that... And in a way, it's like blaming the victim because I don't have access to what I need to get there... Access for me is difficult. And somehow, they never seem to ask those questions. You know, what can we do to help you get here? Do you need a ride? Something like that. None of that becomes a conversation. (African American cancer survivor and caregiver from central Illinois, 49 years of age)*

In rural and suburban areas, public and private transportation and ride share options are limited. Contrarily, urban areas generally have greater walkability, access to public transportation, ride sharing options, and resources. However, within cities, there are barriers to public transportation in high crime areas. Public transportation can also be challenging to neighborhoods in urban areas that have limited and changing bus routes based on time or other outside factors.

**Food insecurity.** In high need communities, food deserts, and/or food swamps have a negative impact on one's overall health. Food deserts greatly impact cancer rate, treatment, and survival. In these neighborhoods there is a lack of affordable, healthy foods, and a surplus of processed, unhealthy, fast food. Food pantries are a viable option to address this barrier, but pantries come with a certain stigma that can sometimes deter patients who could benefit from using them.

**Social context.** The social context includes community and neighborhood demographic characteristics, such as community poverty, education, and income levels, residential segregation, as well as social networks and norms. Participants discussed a sense that community organizations are struggling to reach out and connect with other organizations and community members to address health equity and create awareness of existing resources. One person described the availability of funds and programs for cancer screening in their community, but that corresponding outreach need to accompany programs for it to reach those who need it most.

*For the ladies that cannot afford to get their mammograms, the [name of county health department] [has] grants. Once they get their hands on that money, then it's our job to go out there and share it in those populations, then say, "Hey, what you need to do is you need to contact A, B, and C, and there's money to cover your mammogram costs and any other type of your regular annual checkups that you have..." It's gonna be up to people like us that... approach our legislatures because that's where the money is...and how important it is that they provide these grants and these resources for these communities. We can't have our communities dying for lack of knowledge. (African American caregiver from central Illinois, 72 years of age)*

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**Fear of cancer in communities.** Many communities fear the word “cancer” and noted it invokes negative emotions and feelings of “death, fear, stress, and the unknown.” The “unknown” that participants talk about is not limited to the person diagnosed with cancer’s state of health, but other factors: how to navigate insurance, what to expect in treatment, the future, finances, family, etc. This anxiety of the unknown is further amplified in undocumented communities because of lack of resources available.

*I think part of it is the fear of the expense of medical care, not understanding it –having insurance or not, understanding insurance, and that financial fear. (Asian cancer survivor and caregiver from Cook County, 63 years of age)*

Despite this fear, participants also discussed how cancer can also be associated with opportunities, especially related to improving treatments and continued learning.

**Patient-provider relationship.** The impact of patient-providers relationships across the cancer continuum were discussed extensively. First, participants identified essential elements of patient-provider relationships - humane and compassionate care, trust, and communication – and a need to establish a medical home.

*For me it's a partnership, and if you're going to judge or not be able to listen and communicate and acknowledge that I have value in my own health care, then it's not a relationship that's going to work for me. (Non-Hispanic White caregiver from southern Illinois, 39 years of age)*

*You... need to establish a relationship with a primary care doc, because they're gonna be your advocate and your referral system and with everything. So, I'm very blessed that I had a great family doc that I've been able to lean on. (Non-Hispanic White cancer survivor from northern Illinois, 44 years of age)*

*My doctors lead the way in [influencing my decisions to get screened for different cancers]... But I really trust my – god, I'm gonna get emotional. I trust my doctors so much.... They've done so much for me, and I think that the trusting relationship we've had has been the key. So, I pay attention to my body... I'm blessed with really good doctors, and they lead the way, and I let them. (Non-Hispanic White cancer survivor from central Illinois, 57 years of age)*

Participants discussed a lack of effective communication between patients and health care providers as a major barrier to achieving quality relationships. They attributed this to a multitude of factors, including providers’ implicit biases and lack of cultural cognizance, patient literacy levels, and communication skills. People felt that some providers make assumptions based on the culture, appearance, or financial status of the patient. Communication skills are essential for both patients and providers, so that patients can better advocate for themselves and their loved ones, and so providers can deliver messages in appropriate, understandable fashion. Table 24 includes supplemental quotes about patient-provider relationships and communication.

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**Table 24. Supplemental patient-provider relationship and communication quotes.**

Quote	Participant description
<i>It's all about finding – I'm connected with the LGBTQ community, and just finding an open and affirming provider that's not going to have bias about your sexual orientation is like a whole extra step and can be complicated for people to overcome and make sure that they feel safe with a doctor.</i>	Non-Hispanic White caregiver from southern Illinois, 39 years of age
<i>I also feel like there is also that demeanor especially for people of color – sorry to bring up race issues – but I feel like there is a demeanor that doctors have, especially towards people of color like, “You don’t know any better.” Like, they don’t want to listen to you. It’s like, “Man, are you really a doctor? Why are you treating me like I’m trash?”...Talk to me because I’m a human being. Not a second-class human being but a human being just like you.” So, unfortunately, if you are Black, that’s something that you have to live with. You have to educate yourself like [name of other focus group participant] said, before you go in, know your talking points. Stick to your talking points.</i>	African American community member from rural southern Illinois, 40 years of age
<i>Having a conversation with the doctor may not be as understandable, and people don’t know how to continue to say, “I don’t understand” or “tell me in a different way.” So, it’s also a point of literacy and understanding. So, the doctor went to medical school and he or she is an expert. But if they can’t deliver that message and that information in a way that’s understandable, then they haven’t done a good job. And so, I may sit in the office, I may get lots of information which is good pertinent information. But if I don’t understand it, I don’t have anything.</i>	African American cancer survivor and caregiver from central Illinois, 49 years of age
<i>I'm not usually worried about a doctor believing me or following up on if I say something and they're like, "No, we think you're fine." I feel very comfortable pressing and being like, "Well, nope. I disagree." And I'm still reluctant sometimes to go to the doctor, but once I'm there I feel comfortable advocating. And I also feel like my doctors listen to me.</i>	Non-Hispanic White cancer survivor from Cook County, 34 years of age
<i>I was sent to a neurosurgeon... And they started talking around me. I'm sitting there and these two doctors are talking like I'm not in the room. And they said, "We think she should do this," and I'm thinking, "I'm here. Somebody wanna say something to me? I could answer a question." And so, my response to that was to tell my doctor that I wasn't going to do it. And I canceled all future appointments. And I put a note in the file. "When you have somebody in the room with you, you don't talk over them. I'm not a simpleton. But more importantly, I'm a patient."</i>	African American cancer survivor from Cook County, 60 years of age
<i>I went to a doctor to talk about some issues... and she didn't wanna listen to me... She told me that she knew what was wrong with me, she didn't have to listen to me. And I asked her, "How did you know?" And she said, "Because I've been to school for five years." And I'm like, "I've been in my body for 40 years. So, how can you know me better than me?"</i>	African American caregiver from rural southern Illinois, 40 years of age

## Individual Demographics, Risk Factors, and Biologic Responses and Pathways

Demographics, risk factors, and biological responses and pathways are proximal, individual-level determinants of health. Overall, town hall and focus group attendees had minimal discussion of individual-level risk factors and health behaviors. When they were mentioned, it was typically in relation to the different social and physical community contexts that shape behavior, such as access to resources and safety and engagement in physical activity. While individual demographics and risk factors, especially insurance status and immigration status, were described as contributing to cancer disparities across the continuum among Illinoisans, they were not perceived to be the primary drivers of the disparities. Concerning biologic responses and pathways, attendees had conversations about knowing one’s family health and cancer history.

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**Insurance status.** Overall, participants noted concerns that being uninsured or underinsured means neglecting your health simply because care is unaffordable otherwise. For example, people discussed the inability to get screened for cancer without insurance, hesitation to engage with screening in the event because if cancer is detected, the care will be unaffordable, and the exorbitant cost of treatment.

*Health insurance plays such a huge role in cancer screening... When you end up losing your insurance, you have no other choice but to then start neglected your health... My oncologist appointments are only covered because I'm under a cancer study and they're helping me with those, and I can only go to the annual ones. I can't go if I have a complaint or anything. I can't go in... The low income, we are definitely, sadly affected by the fact that we have to neglect our health (Non-Hispanic White cancer survivor and caregiver from Central Illinois, 57 years of age).*

*A lot of people I know of lower income, of no health care or can't afford it, are afraid if they go get screened, they're gonna be in debt because of the bills that are gonna be coming their way. (African American male cancer survivor from Cook County, 57 years of age)*

*You know, I'm blessed to have a husband, and I've told him many times that were it not for our insurance coverage, I don't know where I'd be. Ovarian cancer is a very expensive treatment. CT scans are \$12,000 sometimes. I just don't know how people could do it if they were not covered. I really don't. (Latina cancer survivor and caregiver from Cook County, 48 years of age)*

**Immigration status.** In conversations concerning those in undocumented communities, participants noted the perception that they are less likely to utilize resources or seek medical care. For some, this may be due to fear of engaging with a health system, a lack of knowledge about where to receive care, or having to deal with long wait times for appointments.

*There's a lot of people who have the thought that... [name of public hospital] isn't good because that's where all of the immigrants go, but... people who don't have resources to go to another hospital go there, and that's why they take a long time. Personally, I can say that years ago it was like that... They gave me an ultrasound [appointment] in six months. When I got to six months, I didn't have the pain anymore. (Latina community member from Cook County, 48 years of age)*

**Biologic Responses and Pathways.** Participants discussed the importance of knowing their family history to assess their person cancer risk. Once cancer was diagnosed in a family, this opened up conversation opportunities. This also prompted other family members to engage in genetic testing.

*When I did my genetic testing and we did the whole history of the family, everyone's like, "Oh, can I get a copy of that?" So, having your family history and medical history, I should say, was very helpful for me and to be able to give it to other family members as well just so they could know what the background is for medical. Because I have a lot of cousins and they're like, "Wait, can I have that?" Because if we don't talk about it, they don't know about it. (Non-Hispanic White cancer survivor from Cook County, 36 years of age)*

*Once we found out there was a genetic mutation in the family - so now, one of my cousins who's younger than me, she actually got screened for it and so she's talking to a specialist to see what her options are so that she has more of a choice with it. (Non-Hispanic White cancer survivor from rural southern Illinois, 36 years of age)*

## *Proposed Recommendations and Funding Priorities to Improve the Health of Illinoisans across the Cancer Continuum*

During the town hall and focus groups, participants were asked to recommend and prioritize strategies and funding to address cancer disparities in Illinois. These strategies were organized and presented by policy and systems, clinical, community, and individual-level recommendations. These recommendations span the entire cancer care continuum, from with prevention and continuing through survivorship.



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**Policy and systems level recommendations.** Overall, there was a strong sense that there should be continued advocacy, from policy makers, health care systems, providers, patients, and community members to ensure that all those who need health care receive it, irrespective of cost. One person described the ease of getting a COVID-19 vaccine at no cost and wondered why the receipt of cancer treatment was not free.

*I just think about being able to go into a clinic and get a COVID vaccine for free. Why is it...? Why aren't more treatments available like that, regardless of what your income level is and what your financial situation is? I just think that the health care system in this country has a lot to be desired. (Non-Hispanic White cancer survivor and caregiver from suburban Cook County, 60 years of age)*

Relatedly, the need for more affordable cancer screening for early detection and genetic counseling as prevention measures to improving health disparities was discussed often. One person stated:

*Why can't we just make these services affordable to everybody? If they can't afford them, let's find a way of paying for those services so that we can, in the long run, save more lives. (African American community member from rural southern Illinois, 40 years of age).*

At the health systems level, participants recommended a need for building trust and ensuring quality, standardized care for all. Health care organizations can enhance diversity among providers and recruit oncologists of color that mirror the communities they serve. This is especially important as there have been tremendous shifts in the health care landscape in terms of health care system closures, consolidations, and mergers. It is essential to set the same standard of care for all hospitals/cancer centers to ensure that all patients receive the same care no matter where they go for screening or where they receive treatment.

*I think when it comes to the institutions... there's probably a handful [of well-known health care institutions] ... and it could be that those systems have figured it out... but why can't everybody else figure it out? Why is a really big teaching hospital... not doing what [name of hospital] doing?... Why can't all of these institutions offer the same?... Everyone at McDonald's knows how to flip a hamburger the same way. Why can't everyone who does intake at a hospital, or a nurse navigator have the same kinda playbook of how to treat somebody? (Non-Hispanic White cancer survivor from central Illinois, 49 years of age)*

**Clinical level.** Several recommendations were suggested to address clinical-level factors that contribute to health disparities. These included access to patient navigation, improved patient provider communication, and provider trainings.

**Patient navigation.** It was clear that those who had access to patient navigation resources fared better in traversing treatment and survivorship. People discussed how important it was for everyone to have access to this clinical resource, and the importance of including information about counseling/emotional support and financial resources. Patient navigators can help to navigate the health care system and multilingual navigators are especially important. Also, navigation should include a billing advocate or interpreter that helps patients understand their coverage. One person compared their experience of not have a patient navigator to those of their friends, who did have access.

*But what would've been great, and hospitals have this but ours doesn't –it would be to have a patient navigator. I had friends who did have patient navigators and it just blew my mind. I mean, they basically take care of all that stuff for you, answer your questions. And pretty much on our own to figure things out, I had to have homecare. And the poor social worker, she's just one person. So, she ended up getting us a list of possibilities. We called them all – my family – and just nothing clicked. And then, we finally hooked up with a company, business, that could do it for me. And I don't know what I would've done without it because my family couldn't do that. So, I really wish there were more patient navigators. (Non-Hispanic White cancer survivor from central Illinois, 66 years of age).*

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**Communication.** When patients and providers communicate effectively, patients' fears and uncertainties are addressed by care teams and providers can start to build trust in marginalized communities they serve. Participants talked about the need for communication to be bi-directional, respectful, and empathetic, and the importance of treating all patients equally, regardless of race, immigration status, sexual orientation, and/or socioeconomic status. One person described the need for provider education concerning communication.

*...we need to do a better job at teaching... doctors [that] are in med school... how to communicate effectively...and empathetically because some of these doctors – bam bam bam – I'm out of here. It's like, "I cannot be bothered with questions. You have any questions, talk to my nurse. They'll let me know what you need." There is that attitude like, "I'm up here and you are down here, and I will just look on top of your head and just walk by you." So, I feel like the doctors need to get to your level, eye on eye, talk to you as an individual, especially and adult individual, where you are both respecting one another but still creating that space of respect... Doctors need to learn how to communicate effectively with their patients. (African American community member from rural southern Illinois, 40 years of age)*

In addition to the recommendation for effective communication between patients and providers, there is a need for primary care providers, specialists, and care teams to communicate better.

*If you have cancer... sometimes [the specialists] ... don't relay the information to the primary care physician or they don't have the kind of communication that needs to occur... I think that then affects the care because the specialist may tell me something, and if it's documented when I go to my primary care, then I can have the conversation with him or her, and that can provide a different lens from which to view. And that doesn't happen even with the electronic record. (African American cancer survivor and caregiver from central Illinois, 49 years of age).*

**Provider training.** Health care professionals should undergo additional training to address cultural competency. Participants recommended that these trainings should raise awareness among providers about the need to be understanding of their patients' preferences, even if they differ from their own. For example, in some cultures, women prefer female only providers, or make health decisions based on family input. If providers are better equipped to serve patients of diverse backgrounds, they can provide culturally appropriate resources, services for undocumented individuals, and more evidence-based interventions. Providers should understand communities they serve and its culture around cancer.

**Community level.** Community organizations, members, and health care providers can come together to address cancer disparity issues in Illinois. Specific recommendations included increased access to community navigators, ensuring that transportation needs are met for both rural and urban communities, and addressing food insecurity by establishing food depositories throughout the state.

**Community navigators.** It was recommended that cancer patients and survivors, as well as those engaging in cancer screenings, have access to community navigators. Because navigators are embedded in their communities, they are aware of the cancer-related resources and services. They can also help health care professionals understand the community's needs and help to create linkages to community resources. A variety of different disciplines can provide navigation services, including community health workers and health promoters.

*I think part of it is, too – with our minority communities, is that it's almost as if we have to plant patient navigators in the community – or the churches or community groups – who speak the language. Not saying – the language as far as community, and nuance, and beliefs, and understand the community to help them trust the medical system. (Asian cancer survivor and caregiver from Cook County, 63 years of age).*

**Individual level.** At the individual-level, the need to increase awareness and education opportunities about cancer among communities was a top recommendation among town hall and focus group participants. Specific topics of education included prevention/risk reduction, programs and resources available within a community,

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the existence of disparities and their impact, navigating the health care system, treatment options, including getting a second opinion, what to expect during treatment, and participation in clinical trials. Additionally, patients should be given information, so they are better equipped to ask questions and advocate for themselves. One cancer survivor talked specifically about the need for more individuals to be aware of screening guidelines.

*I think there's a lack of knowledge about when to get screened... I was surprised that, as a cancer survivor, how little I knew about other cancers. I was just floored... if I don't know about other cancers and screening timing, how is the general population going to know?.... There's gotta be a way to present it to different communities and different age groups where it's not as scary. (Asian cancer survivor and caregiver from Cook County, 63 years of age)*

**Funding priorities.** Participants shared their thoughts and ideas on how funds should be prioritized to address cancer in Illinois. First, it was noted that community organizations doing collaborative work should be prioritized if addressing cancer disparities, especially around screening, should be prioritized for funding. People also stated that cancer prevention should be kept in mind as the ultimate goal for funding priorities. There was a concern that COVID-19 was diverting available dollars and resources that had previously been allocated for cancer. Table 25 presents additional information about specific activities that were discussed and recommended for funding.

**Table 25. Funding Priorities to Address Cancer Disparities in Illinois.**

Funding priority	Quote	Participant description
Social/emotional/ educational support and patient navigation.	<i>...at the main clinics and hospitals and midsize areas, it's hit or miss whether an oncologist and their nurses are familiar with social/emotional support. And I think if there was more established connection and funding for that social work/ counseling side, to refer patients to that, if they wanted, would be great.</i>	Non-Hispanic White male cancer survivors from central Illinois, 35 years of age
	<i>There are hospitals that have patient navigators... but they're so few and far between... That's the biggest problem... there was some discussion in the creation of the Affordable Care Act about creating a community health plan that could fund that. And, of course, it never got to fruition because they continued to eat away at it. But a lot of people recognized that it's not just the cancer but it's across the board. And the question is, who funds the patient navigators.</i>	African American cancer survivor from Cook County, 60 years of age
Cancer prevention efforts and research.	<i>There's a lot of emphasis on screening and catching it [cancer] early, which is obviously good, but... there needs to be a lot more emphasis on prevention and what actually causes cancer.</i>	Non-Hispanic White cancer survivor from northern Illinois, 55 years of age
Distribution of funds to different types of cancers.	<i>When men start getting ovarian cancer, that's when the research money will come up. That's what happened with breast cancer... Another interesting thing... how money is spent on different types of cancers.</i>	Non-Hispanic White cancer survivor from Cook County, 81 years of age

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## Cancer in the Era of COVID-19

Given the timing of the community engagement efforts, it is not surprising that the topic of COVID-19 was discussed repeatedly, and not only in relation to the cancer continuum. These conversations included discussions of health equity, as well as the fear and uncertainty surrounding COVID-19 as it overtook the U.S. health system. These conversations included discussions of health equity. Supplemental quotes about COVID-19 are included in Table 26 at the end of this section.

### *COVID-19 has unveiled long-standing health inequalities*

On one hand, the global pandemic exacerbated health inequities and disparities, especially among racial and ethnic minority groups, rural residents, and people in lower socioeconomic standing. But on the other hand, as COVID-19 unveiled these long-standing health inequalities, it presented an opportunity for people to have conversations about that may not have occurred otherwise.

*There's been... groups in the history of the United States that have been specifically mistreated or failed by the medical system... We're seeing that right now even with certain people groups not feeling safe to go get COVID testing or treatment or vaccines because of the history of how they've been treated. (Non-Hispanic White cancer survivor from central Illinois, 29 years of age)*

*One of the few good things about the COVID discussion is that health equity issues are finally coming into discussion by a broader audience. I think a lot of people weren't even aware that living in a rural community could impact the quality of your life, the quality of your health, the length of your life. And I think that's one of the few blessings... So, as terrible as COVID has been, I'm grateful that this is the discussion that's starting to occur. (Asian cancer survivor and caregiver from Cook County, 63 years of age)*

### *Hesitation and fear to engage with health systems*

Most certainly, COVID-19 affected engagement in cancer screenings. For some, the fear of contracting COVID-19 outweighed the benefits of engaging in non-cancer screenings. Additionally, the shifting public health guidance was confusing for some. One person stated:

*I think for people who don't already have a diagnosis, there might have been some pause on [engaging in screenings], "Should I go out, should I not? Is this really something to be concerned about? Is it not something to be concerned about? Should I wait it out? Should I not?" So, I think there was a lot in the very beginning, a lot of confusion on what you can and cannot do. (Non-Hispanic White caregiver from suburban Cook County, 27 years of age)*

Others that did contract COVID-19 delayed their engagement in cancer screenings. One person spoke of their experiences and their preferences to wait until they were vaccinated against COVID-19 to return to a clinical setting for a mammogram.

*I was supposed to get a mammogram...but unfortunately, I got sick with COVID-19, and I had a hard time with it. I had a very hard time. And, I was supposed to have the appointment at the beginning of - at the end of 2020... So, honestly, I canceled it because I didn't feel safe... Fortunately, I got the second vaccine, so I feel safer to be able to go to a clinic and do my checkup. So, I preferred to just not go and hold off here and just ask God that when I go to get the tests, everything will come out okay. (Latina community member from Cook County, 48 years of age)*

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## Medical prioritization of COVID-19 efforts

In addition to individuals' hesitations to engage with screenings, many health systems paused their screening appointments to prioritize their COVID-19 response efforts. People spoke of cancelled and backlog appointments for screenings and how this may translate into missed diagnoses. During the rural focus group, a participant described a huge decrease in screenings.

*I think they estimate that there's been a decrease in screening by up to 90% in some areas, like, take a mammogram or prostate cancer. I don't know if that's right or not.... So, I think COVID's had a huge impact and I think oncologists are expecting a huge spike in the number of cases because we will have had so many undetected cases. It'll be a pity. (Non-Hispanic White cancer survivor from rural central Illinois, 55 years of age)*

In addition to a pauses, delays, and cancellations of appointments for screen-able cancers, those individuals undergoing diagnostic and treatment procedures also experienced service interruptions. One person described challenges that recently diagnosed breast cancer patients experienced.

*I spoke to two people who recently were diagnosed with breast cancer, and I think the most they've gotten is one appointment... Because of COVID, more than anything, there are backups on the appointments. (Latina community member from Cook County, 48 years of age)*

**Table 26. Supplemental Focus Group Quotes about COVID-19.**

Summary	Quote	Participant description
Impact of COVID-19 on cancer screenings.	<i>I think...when the pandemic began, exactly a year ago, a lot of appointments were canceled. Even appointments that were for cancer exams... They weren't allowing people into the hospitals unless it was an emergency. The hospitals started getting filled with people for COVID-19, so they gave priority to the pandemic.</i>	Latina community member Cook County, 48 years of age
	<i>In the communities that I work in with health advocacy, it's... valid [excuses for not engaging in cancer screening] such as, "I no longer have insurance. Because of COVID, I got laid off," or "Now, my anxiety –or I'm suffering from mental health, and a screening is not priority right now," or... "I just forgot because so many other things are going on in the world." It's not just, "I was busy at work and forgot to get my screening," or "it's a myth, that I don't believe screenings work." COVID has made so many other reasons for people to not get screened.</i>	African American cancer survivor and caregiver from central Illinois, 49 years of age
Impact of COVID-19 on late-stage diagnoses.	<i>I don't know that there's going to be a way to quantify it, but I'm terrified of the number of cancer cases that are caught in later stages as a result of not going in during COVID.</i>	Non-Hispanic White cancer survivor from Cook County, 34 years of age
African Americans had disproportionately higher COVID-19 mortality rates.	<i>I live in a very, very, very Black town, very Black part of Chicago... We had among the highest COVID incidence and cases... [and] mortality. And I think that the myriad of systematic influences that allow that, also are the same persistent for cancer.</i>	African American community member from Cook County, 37 years of age

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Summary	Quote	Participant description
Telehealth is here to stay.	<i>When we are over COVID and... back to somewhat semblance of normalcy, I think telehealth is here to stay... It does provide, particularly those people out in the boondocks, or those who don't have... transportation - it does give you an access to health care... I don't particularly like it. I prefer face-to-face, but that's just me.</i>	Non-Hispanic White cancer survivor, central Illinois, 88 years of age

## CONCLUSION

The results of the community engagement strategy for the 2022-2027 Illinois Comprehensive Cancer Control Plan indicate that Illinoisans experience disparities across the cancer continuum. These disparities are a result of multilevel determinants of health, and include fundamental factors, like policies and social conditions; intermediate factors, including physical and social contexts; and proximate factors, such as individual demographics and risk factors. Participants from the town hall and focus groups proposed a number of policies, clinical, community, and individual-level recommendations to address the disparities. These recommendations should be considered by stakeholders, including community organizations, providers and oncologists, policy makers, and researchers, who are concerned with eliminating cancer disparities in Illinois. Undoubtedly, eliminating cancer disparities in Illinois will be a challenge, especially considering the COVID-19 pandemic. However, Illinois has an abundance of resources and assets to address this challenge, as well as a dedicated group of stakeholders who continue to work and advocate for the health of all Illinoisans.

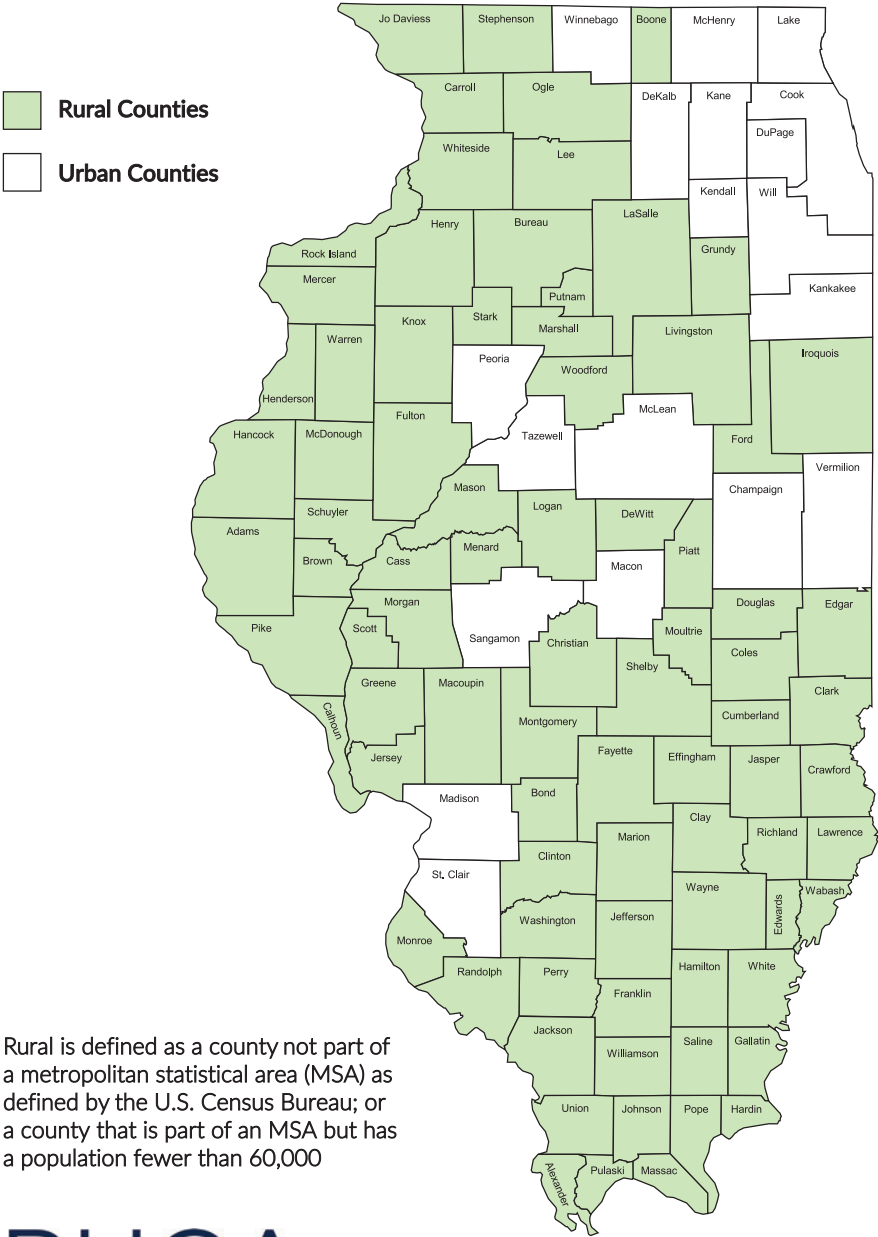


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## RURAL HEALTH

Illinois residents living in rural areas face unique challenges and health disparities that impact cancer prevention, screening and early detection, and diagnosis, treatment, and survivorship. Figure 22 shows Illinois counties by either rural or urban classification.<sup>59</sup>

Figure 22. Illinois Counties by Rural or Urban Classification.



Rural is defined as a county not part of a metropolitan statistical area (MSA) as defined by the U.S. Census Bureau; or a county that is part of an MSA but has a population fewer than 60,000



Prepared by the Illinois Primary Health Care Association December 2020

<sup>59</sup> Illinois Department of Public Health. (2020, December). Illinois Counties by Rural/Urban Classification. Retrieved from [http://www.idph.state.il.us/RuralHealth/Rur\\_Urb\\_2021.pdf](http://www.idph.state.il.us/RuralHealth/Rur_Urb_2021.pdf).

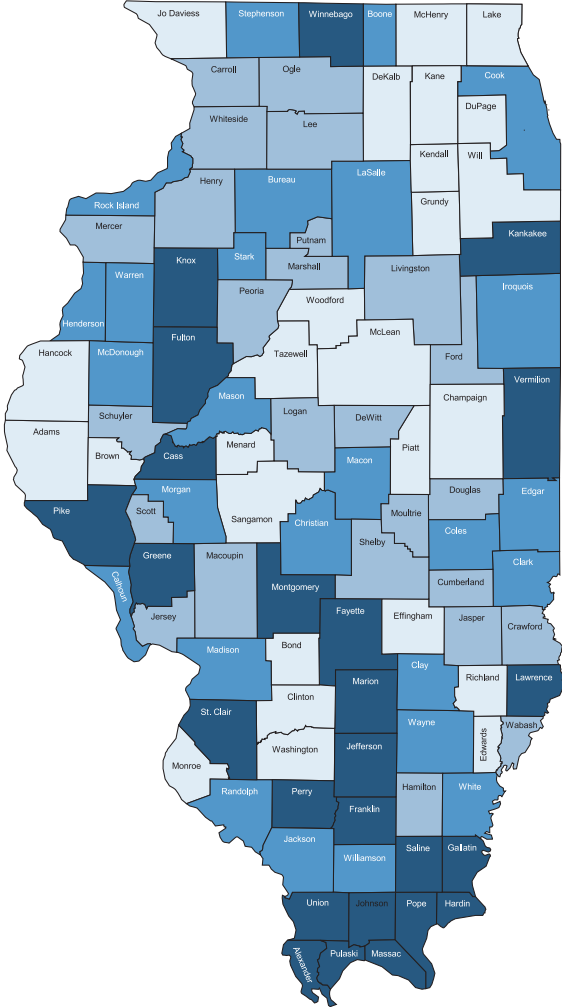
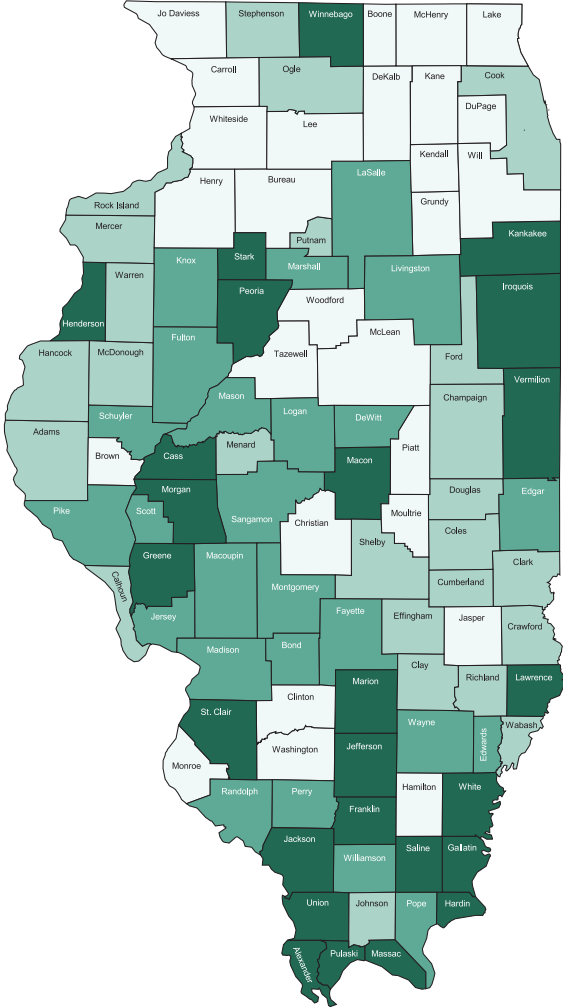
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## GEOGRAPHIC DISPARITIES

Figure 23 shows the overall ranking by health outcomes by county.<sup>60</sup> Overall health outcomes are based upon how long people live and how healthy people feel while alive. The healthiest county is ranked number one. Counties with the best overall rankings are in the lightest shade and counties with the lowest overall rankings are in the darkest shade. Figure 24 shows the overall ranking by health factors by county.<sup>61</sup> Health factors are based upon health behaviors, clinical care, socioeconomic, and physical environment factors. Health factors are an estimate of the future health of counties as compared to other counties within a state.

Figure 23. Overall health rankings.

Figure 24. Overall rankings in health factors.



RANK 1 - 26 27 - 51 52 - 77 78 - 102 NOT RANKED (NR)

RANK 1 - 26 27 - 51 52 - 77 78 - 102 NOT RANKED (NR)

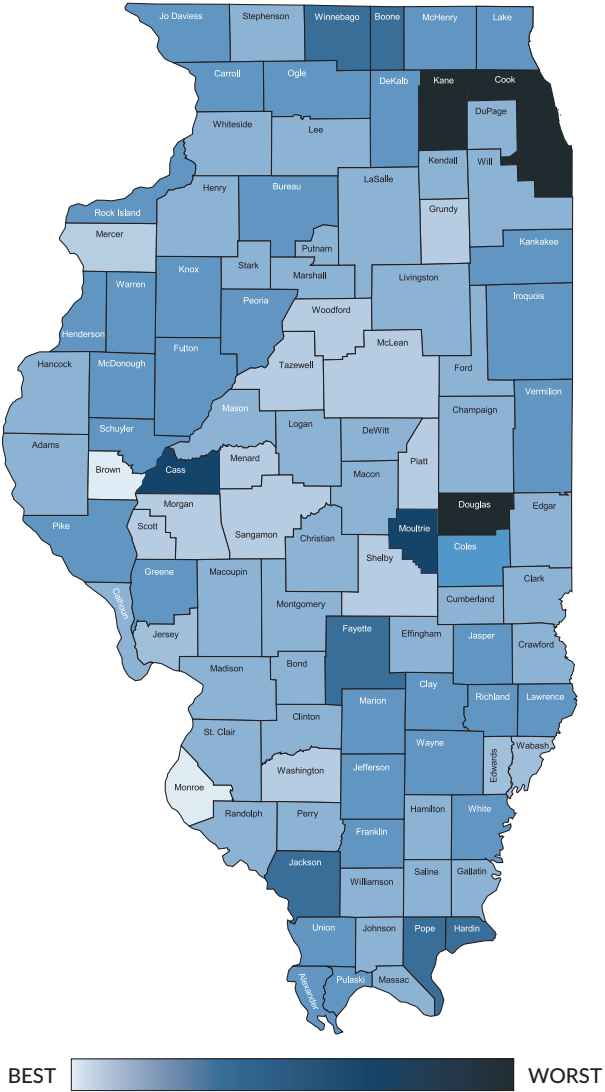
Lack of health insurance coverage is a significant barrier to accessing needed health care and to maintaining financial security.<sup>61</sup> Individuals without insurance coverage may have serious health consequences as individuals may seek less preventative care and delay care. Uninsured individuals may be unable to pay medical bills, resulting in financial consequences and medical debt. Figure 25 shows the percentage of the population under 65 years of age without health insurance coverage.

<sup>60</sup> County Health Rankings. (2021). Illinois. Retrieved from <https://www.countyhealthrankings.org/app/illinois/2021/overview>.

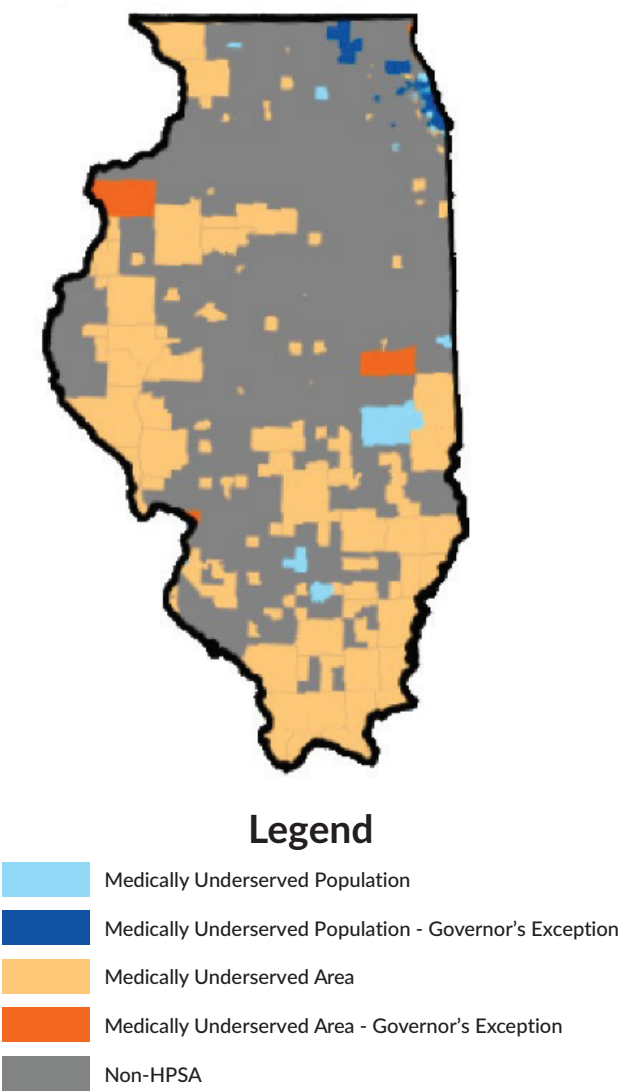


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**Figure 25. Percentage of population under age 65 without health insurance.**



**Figure 26. Medically underserved areas and populations.**



The Health Resources Services Administration (HRSA) has defined Health Professional Shortage Areas (HPSAs), which are geographic areas, population groups, or health care facilities designated by HRSA as having a shortage of health professionals (figure 26 above).<sup>61</sup> Medically Underserved Areas (MUAs) and Medically Underserved Populations (MUPs), identify geographic areas and populations with a lack of access to primary care services.

The Southern Illinois University School of Medicine Department of Population Science and Policy published a report, *Building a Healthier Rural Illinois*, describing the most pressing issues facing rural Illinois.<sup>62</sup>

<sup>61</sup> Department of Health and Human Services Health Resources Services Administration. (2021). Shortage Areas. Retrieved from <https://data.hrsa.gov/topics/health-workforce/shortage-areas>.

<sup>62</sup> Southern Illinois University School of Medicine Department of Population Science and Policy. (2021, March). *Building a Healthier Rural Illinois*. Retrieved from [https://www.siumed.edu/sites/default/files/u8191/buildingahealthierruralillinois\\_understandingandaddressingthechallengesofcovid-19\\_final.pdf](https://www.siumed.edu/sites/default/files/u8191/buildingahealthierruralillinois_understandingandaddressingthechallengesofcovid-19_final.pdf).

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- Rural counties have higher rates of smoking, obesity, child poverty, and teen pregnancies compared to urban counties. The result is Illinois residents living in rural areas are more likely to die from the five leading causes of death (heart disease, cancer, unintentional injuries, chronic lower respiratory disease, and stroke).
- Rural hospitals also provide fewer mental health services. Mental health providers are often in shortest supply.
- Rural communities are at a disadvantage because of food, health care, social service, and internet data deserts. Many rural communities have insufficient access to essential services, such as grocery stores, health care providers, public transportation, and educational institutions, as compared to urban communities.
- Rural areas also experience organizational and technological disconnections. Large areas across Illinois cannot access broadband or internet with speeds of at least 25 Mbps. In addition to having limited or no quality high speed internet access, many rural residents do not have the hardware or skills needed to take advantage of high-speed internet. A lack of access to technology prevents rural residents from accessing work and learn at home opportunities, applying for jobs or schools online, and maximizing opportunities to receive care via telehealth. Many rural residents, especially older individuals, may either distrust technology or lack the know-how to access services that were pushed online like virtual physician visits.
- Rural residents also suffer from disconnected social service sectors. The lack of collaboration between health care systems, schools, and public health departments may result in duplication of services. Increased collaboration between these entities could reduce silos and duplication of services.

*I live in a very rural part...and in my small community, I mean, there aren't a lot of people, but I don't know of anyone who has not had cancer in their family. It seems like almost every day it's like someone said, "Oh, did you know so-and-so down the road has cancer? This person has cancer. That person."*

White non-Hispanic cancer caregiver from Williamson County, 48 years of age

*I think one of the few good things about the COVID discussion is that health equity issues are finally coming into discussion by a broader audience. I think a lot of people weren't even aware that living in a rural community could impact the quality of your life, the quality of your health, the length of your life. And I think that's one of the few blessings, is that we are now starting to talk about issues like health equity, and patient navigators, and living in rural communities, and how that impacts the quality of your life. So, as terrible as COVID has been, I'm grateful that this is the discussion that's starting to occur.*

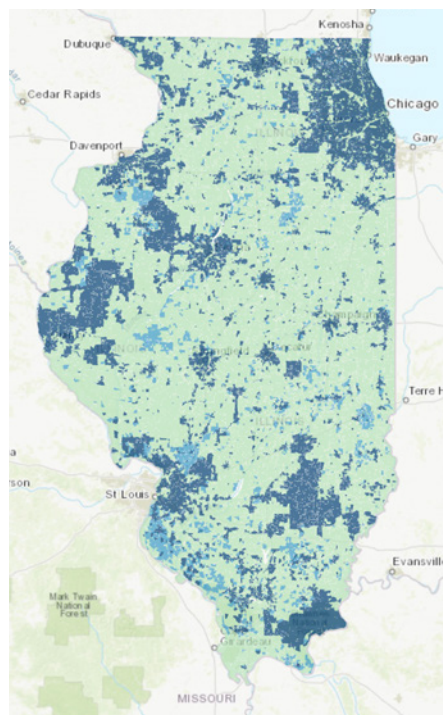
Asian Hispanic/Latino cancer survivor and caregiver from Cook County, 63 years of age

The Federal Communications Commission reports on internet service providers reporting broadband service.<sup>63</sup> The FCC currently defines a “broadband” internet connection as one that provides at least 25 Mbps for download speed and 3 Mbps for upload. Figure 27 shows large parts of Illinois with internet speeds of less than 25 Mbps download and 3 Mbps upload. The reports warns that data coverage may be overestimated as providers report broadband deployment data at the census block level and not every home may have service within the census block.




<sup>63</sup> Illinois Broadband. (2020). Retrieved from <https://illinois.maps.arcgis.com/apps/webappviewer/index.html?id=f9101de0f4564384836f4905bd0b3e2e>.

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Figure 27. Illinois broadband coverage.



Three Fixed Wireline (e.g. DSL, cable) speed tiers have been calculated:

-  Underserved (Less than 25 Mbps downstream or 3 Mbps upstream or no service available)
-  Minimum 25 Mbps downstream or 3 Mbps upstream and less than 100 Mbps downstream and 20 Mbps upstream
-  Minimum 100 Mbps downstream and 20 Mbps upstream

Census block data was obtained from US 2010 Census Data <https://www.fcc.gov/reports-research/data/staff-block-estimates> and <https://www.census.gov/cgi-bin/geo/shapefiles/>

## RURAL HEALTH STRATEGIES

For some types of cancer, patients living in rural areas may be more likely to be diagnosed with cancer at a more advanced and less treatable stage.<sup>64</sup> Strategies to enhance access include reducing travel distance to access health care by offering mobile screening/treatment and telemedicine. Mobile cancer screening and treatment may connect rural communities with health care services. Services provided by mobile units include various cancer screenings, prevention education, early detection, and health counseling.

The following strategies will help to build healthy rural communities, improve health, and reduce cancer disparities.<sup>65</sup> More information on these strategies is available at <https://www.countyhealthrankings.org/take-action-to-improve-health/what-works-for-health>.

- **Chronic disease self-management (CDSM) programs:** Provide educational and behavioral interventions that support patients' ability to actively manage their condition(s) in everyday life.
- **Clinic-based interventions for human papillomavirus (HPV) vaccination:** Combine information about HPV and the benefits of vaccination with efforts to support vaccine series completion (e.g., patient and parent education or reminders, physician education, etc.).
- **Community health workers:** Engage professional or lay health workers to provide education, referral and follow-up, case management, home visiting, etc. for those at high risk for poor health outcomes; also called promotores de salud.

<sup>64</sup> Geographic Health Equity Alliance. (n.d.). Addressing Rural Cancer Health Disparities. Retrieved from [https://www.cadca.org/sites/default/files/CADCA\\_Rural%20Cancer%20Publication.pdf](https://www.cadca.org/sites/default/files/CADCA_Rural%20Cancer%20Publication.pdf).

<sup>65</sup> County Health Rankings and Roadmap. (2021). What Works for Health. Retrieved from <https://www.countyhealthrankings.org/take-action-to-improve-health/what-works-for-health>.

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- **Culturally adapted health care:** Tailor health care to patients' norms, beliefs, and values, as well as their language and literacy skills.
- **Faith community nursing:** Position registered nurses within a parish or similar faith community, or in a health care system to serve as a liaison to congregations; also called parish nursing or congregational nursing.
- **Health insurance enrollment outreach and support:** Provide health insurance outreach and support to assist individuals whose employers do not offer affordable coverage, who are self-employed, or who are unemployed.
- **Health literacy interventions:** Increase patients' health-related knowledge via efforts to simplify health education materials, improve patient-provider communication, and increase overall literacy.
- **Higher education financial incentives for health professionals serving underserved areas:** Expand incentives such as scholarships and loans with service requirements and loan repayment or forgiveness programs for health care providers who practice in rural or other underserved areas.
- **Human papillomavirus (HPV) vaccine education:** Inform adolescents, young adults, and parents about HPV and its consequences, as well as the benefits of vaccination, via videos, printed materials, online content, or in-person efforts.
- **Medical homes:** Provide continuous, comprehensive, whole person primary care that uses a coordinated team of medical providers across the health care system.
- **Patient financial incentives for preventive care:** Use payments, vouchers, and other incentives to encourage patients to undergo preventive care, such as screenings, vaccinations, etc.
- **Patient navigators:** Provide culturally sensitive assistance and care coordination, and guide patients through available medical, insurance, and social support; also called systems navigators.
- **Patient shared decision making:** Support joint decision making between health care practitioners and patients through shared decision making (SDM); part of patient-centered care.
- **Rural training in medical education:** Expand medical school training and learning experiences focused on the skills necessary to practice successfully in rural areas.
- **Rural transportation services:** Establish transportation services for areas with low population densities using publicly funded buses and vans on a set schedule, dial-a-ride transit, volunteer ridesharing, etc.
- **Telemedicine:** Deliver consultative, diagnostic, and treatment services remotely for patients who live in areas with limited access to care or would benefit from frequent monitoring; also called telehealth.
- **Telemental health services:** Provide mental health care services (e.g., psychotherapy or counseling) via telephone or videoconference.
- **Text message-based health interventions:** Provide reminders, education, or self-management assistance for health conditions, especially chronic diseases, via text message.

## LESBIAN, GAY, BISEXUAL, TRANSGENDER, AND QUEER (LGBTQ) COMMUNITIES

The American Society of Clinical Oncology (ASCO) states LGBTQ communities are disproportionately affected by seven types of cancer: anal, breast, cervical, colorectal, lung, prostate, and uterine.<sup>66</sup> LGBTQ communities are at risk of poor access to cancer prevention, screening, care, cancer survivorship, quality of life, and cancer outcomes. Due to stigma and stress, LGBTQ people may be more hesitant to disclose their sexual orientation and gender identity to their health care providers, which may decrease their cancer survivorship outcome. The National LGBT Cancer Network provide the following strategies.<sup>67</sup>

### LGBTQ Patient-Centered Outcome Recommendations.

1. Stigma
  - a. Providers and health care management should become educated about the stigma-related stress many LGBTQ people carry into the health care setting.
    - Provide cultural competency training for all staff.
    - Include LGBTQ leaders on community advisory bodies.
2. Health care environment
  - a. Health care institutions and offices should actively convey that LGBTQ-welcoming behavior is a core expectation of all staff.
    - Include mandatory staff training.
    - Reinforce such welcome through the actions of management and public relations staff. For example, an article could be written on LGBTQ diversity for an employee newsletter.
    - Develop an LGBTQ study group.
  - b. Health care institutions and offices should convey a zero-tolerance environment for any discriminatory behavior on the part of staff.
    - Include scenarios and possible responses in annual staff trainings
  - c. Health care institutions and offices need to broadcast their LGBTQ-welcoming policies and training to potential and current patients
    - Include LGBTQ measures and nondiscrimination protections on intake forms.
    - Prominently display LGBTQ protections/welcome on website and in waiting rooms.
    - Partner with local LGBTQ community-based organizations for public events, in public materials.
    - Tailor ads to LGBTQ media outlets.
    - Participate in and display the results from the Human Rights Campaign Healthcare Equality Index report card.
  - d. LGBTQ-welcoming policies and training should be broadcasted to the public in situations where there's greater historic stigma, such as in religious institutions, or regions with no LGBTQ civil rights protections.

<sup>66</sup> American Society of Clinical Oncology. (2021, January 21). The Barriers to Care Faced by LGBTQ People With Cancer: An Expert Perspective. Retrieved from <https://www.cancer.net/blog/2021-01/barriers-care-faced-lgbtq-people-with-cancer-expert-perspective>.

<sup>67</sup> National LGBT Cancer Network. (2021). LGBT Patient-Centered Outcomes. Retrieved from <https://cancer-network.org/resources/lgbt-patient-centered-outcomes/>.

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- e. Ensure LGBTQ employees can safely be out at the workplace.
  - Sponsor an LGBTQ employee group.
  - Include LGBTQ status on employee satisfaction surveys and ask about safety and being out at work.
3. Disclosure and safety
  - a. Collect evidence to see if LGBTQ patients feel safe coming out at your institution and use evidence to increase safety.
    - Ask about LGBTQ status on patient satisfaction surveys.
    - Ask about LGBTQ status on employee surveys and their relative safety.
    - Convene LGBTQ employees as an advisory body, to suggest steps to increase patient safety.
    - Include LGBTQ leaders on community advisory bodies to provide a constant source of feedback.
    - Conduct an environmental scan of the facility to check how and when safety is conveyed to LGBTQ patients.
4. Respect LGBTQ-patient support teams
  - a. Conduct a scan to see how the office/institution conveys welcome for alternative support teams. Use findings to augment the message to staff and patients alike.
    - Prominently display policies ensuring alternative families are respected during care.
    - Train staff in the steps to comply with the early designation of health care proxy.
    - Include designation of health care proxy materials in routine intake forms.
    - Allow patient to designate important support team members as well as health care proxy on forms and/or patient records.
5. Expectations of gender conformity
  - a. Conduct a scan to see when the office/institution presumes gender conformance in care. Use findings to build welcome for all gender nonconforming patients Due to the high chance of poor care, get input on the treatment of transgender patients and make changes to augment their welcome.
    - Review educational materials for gender presumptions.
    - Offer LGBTQ-specific educational materials that avoid gender conformity expectations.
    - Include training on gender assumptions in mandatory cultural competency care.
    - Convene focus group of former transgender patients to get input on satisfaction and enhancements.
6. Culturally appropriate support and information
  - a. Collect referral lists for LGBTQ-welcoming providers, including local mental health providers.
    - Call referral sources in advance to ask if they are LGBTQ welcoming and follow up with the patient to ensure they were welcomed.
    - Offer referrals to LGBTQ support groups or develop one if none exists.
  - b. Review all educational materials to remove heterosexist language choices (e.g., “husband” “married,” etc.)
  - c. Ensure providers are educated in how to speak about sex and sexuality to LGBTQ patients.

## GENERAL STRATEGIES

The following are strategies from the National Stakeholder Strategy for Achieving Health Equity.<sup>68</sup>

1. Increase awareness about health disparities
  - Blog or tweet about health disparities in your community or share information via Facebook.
  - Contact the media with stories about health disparities in your community.
  - Write a letter to the editor or an opinion-article for your local newspaper.
  - Speak at health fairs, PTA and school board meetings, civic meetings, faith-based events, and other community gatherings.
2. Become a leader for addressing health disparities
  - Educate others about disparities and share stories about model programs with local organizations or community leaders, and the National Partnership for Action (NPA).
  - Start a petition to get local citizens to support policy recommendations and submit the petition to the appropriate elected officials.
  - Organize a meeting of local organizations representing diverse sectors and work together to ensure health disparities is on the local and state health agenda.
  - Form coalitions with local organizations representing diverse sectors and leaders from different racial, ethnic, and other groups affected by health disparities to address common barriers and to join the NPA.
  - Serve as a mentor to a young person in your family, neighborhood, or community. Educate him/her on the issues, encourage him/her to make healthy lifestyle choices, and guide him/ her to resources.
3. Support healthy and safe behaviors in your community
  - Be a role model and serve nutritious foods at work or social functions.
  - Involve your employees in a group physical activity or challenge. Participate in National Health Observances – such as AIDS Awareness Days – by sponsoring local health events or encouraging loved ones and colleagues to take action to address their health.
  - Host seminars in your local library, school, workplace, or other venue to discuss health disparities in your community. Topics could include reducing asthma triggers in the home, managing obesity and chronic illnesses, or how to enroll in public health insurance programs.
4. Improve access to health care
  - Partner with a local health care provider or employer to offer free health screenings in your workplace or place of worship.
  - Ask local health care providers to translate health and health care information or connect them to an individual or organization who can provide translation services.
  - Establish a Community Health Worker or Promotoras de Salud program in your community.

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<sup>68</sup> U.S. Department of Health and Human Services Office of Minority Health. (2021). National Partnership to End Health Disparities Toolkit for Community Action Toolkit (2021). Retrieved from [https://minorityhealth.hhs.gov/npa/files/Plans/Toolkit/NPA\\_Toolkit.pdf](https://minorityhealth.hhs.gov/npa/files/Plans/Toolkit/NPA_Toolkit.pdf)

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### 5. Create healthy neighborhoods

- Advocate for more sidewalks, bike lanes, and recreation facilities in your neighborhood.
- Encourage local schools, workplaces, and assisted living facilities to provide healthier lunch and snack options.
- Ask your neighborhood supermarket to provide fresh fruit and vegetables to the local foodbank, ask local restaurants to provide healthy menu options, or organize a farmers' market that accepts food stamps.
- Work with your local government and organizations in your community to collect and to track data about health disparities and monitor changes over time.

### Additional Information Sources

- American Cancer Society (ACS): [Advancing Health Equity – Addressing Cancer Disparities](#)
- CDC National Comprehensive Cancer Control Program: [Cross-Cutting Priorities | CDC](#)
- CDC Office of Minority Health & Health Equity (OMHHE): [Health Disparities and Strategies Reports - Minority Health - CDC](#)
- Intercultural Cancer Council: <http://www.interculturalcancerCouncil.org/iccs-library/>
- National Cancer Institute: <https://www.cancer.gov/about-nci/organization/crhd/about-health-disparities/resources>





## APPENDICES

### ACRONYMS

ACS	American Cancer Society
BRFSS	Behavioral Risk Factors Surveillance System
CDC	Center for Disease Control and Prevention
CEHE	Community Engagement Health Equity Office
EPA	Environmental Protection Agency
FQHC	Federally Qualified Health Center
HPV	Human Papillomavirus
IBCCP	Illinois Breast and Cervical Program
ICP	Illinois Cancer Partnership
ICCCP	Illinois Comprehensive Cancer Control Program
IDPH	Illinois Department of Public Health
IEMA	Illinois Emergency Management Agency
IPHCA	Illinois Primary Health Care Association
ISCR	Illinois Cancer Registry
LDCT	Low Dose Computed Tomography
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer
NCCCP	National Comprehensive Cancer Control Program
NCI	National Cancer Institute
NPA	National Partnership for Action
SES	Socioeconomic Status
USPSTF	United States Preventive Services Task Force
UV	Ultraviolet
YRBFSS	Youth Risk Behavior Factor Surveillance System

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## GLOSSARY

**BRCA1 and BRCA2:** The genes most commonly affected in hereditary breast and ovarian cancer are the breast cancer 1 (BRCA1) and breast cancer 2 (BRCA2) genes. Some mutations in the BRCA1 and BRCA2 genes prevent them from working properly.

**Burden:** The impact of an illness or disease on one's health and daily life.

**Cancer:** Diseases in which abnormal cells divide without control and can invade nearby tissues.

**Comprehensive Cancer Control:** An approach that brings together key partners and organizations to develop a plan to reduce the number of community members who get or die from cancer.

**Disparity:** Differences in cancer measures, such as incidence due to race/ethnicity, gender, geography, income, or other characteristics.

**Early detection:** Methods used to identify cancer before it has spread to other parts of the body.

**Health disparities:** A particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage.

**Health equity:** The attainment of the highest level of health for all people.

**Healthy People 2030:** National objectives to improve health of Americans over the next decade.

**Incidence:** The number of new cases of a disease diagnosed in each year.

**Invasive:** Cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues.

**Lynch syndrome:** Also known as hereditary non-polyposis colorectal cancer (HNPCC), is the most common cause of hereditary colorectal (colon) cancer.

**Mortality:** The number of deaths of a disease each year.

**Prevention:** Interventions or actions that aim to prevent disease before it occurs.

**Prevalence:** The proportion of the population with a disease.

**Social determinants of health:** Conditions in environments in which people live, work, and play.

**Surveillance:** Continuous collection of health data for planning, implementation, and evaluation.

**Survivorship:** From the time someone is diagnosed with cancer and throughout their lifespan.

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## 2019 NOVEL CORONAVIRUS DISEASE (COVID-19)

In December 2019, a new coronavirus was first identified in Wuhan, China. On January 21, 2020, the first case of the 2019 novel coronavirus was confirmed in a Washington state resident who returned from Wuhan, China, on January 15, 2020<sup>69</sup>. On January 24, 2020, a woman in Chicago who returned from Wuhan, China, became the second case of COVID-19 identified in the United States. By mid-March 2020, the number of known cases increased into the double digits and the president released a national disaster proclamation and Gov. JB Pritzker issued a stay-at-home executive order.<sup>70</sup> Virtually all gatherings of people were restricted, significantly impacting day-to-day life for individuals in Illinois, the U.S., and worldwide. More information regarding the history and timeline of COVID-19 is available at <https://www.ajmc.com/view/a-timeline-of-covid19-developments-in-2020>.

At the beginning of the COVID-19 pandemic, cancer screenings and elective procedures were halted to prioritize needs due to the pandemic and to reduce the spread of COVID-19.<sup>71</sup> The American Cancer Society published a report, available at <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/special-section-covid19-and-cancer-2021.pdf>, stating that one electronic medical record company estimated an 80% to 90% decline in screening for breast, cervical, and colorectal cancers during March and April 2020 as compared to the same period in 2019. Nationally, cancer screenings had increased slightly by June 2020, but were still down 29% to 36% as compared to pre-pandemic screenings. HPV vaccinations decreased 73% from February and April 2020. Other effects from the COVID-19 pandemic included people already in active treatment for cancer. This affected 79% of respondents who experienced delays in receiving care.

*In the communities that I work in with health advocacy, it's given more excuses, and I mean valid ones such as, "I no longer have insurance. Because of COVID, I got laid off," or, "Now, my anxiety or I'm suffering from mental health, and a screening is not priority right now," or ... "I just forgot because so many other things are going on in the world." So, it's not just, "I was busy at work and forgot to get my screening, or it's a myth, that I don't believe screenings work." COVID has made so many other reasons for people to not get screened.*

Black, non-Hispanic cancer survivor and caregiver from central Illinois, 49 years of age

*I don't know that there's going to be a way to quantify it, but [I'm] terrified of the number of cancer cases that are caught in later stages as a result of not going in during COVID.*

White, non-Hispanic cancer survivor from Cook County, 34 years of age

Due to delayed or missed screenings, it is likely there has been a decrease in cancer diagnoses and an increase of cancer diagnoses in more advanced stages as a result. It is also predicted to be an increase in cancer mortality due to delayed screenings and diagnoses of cancer in a more advanced stage.<sup>70</sup> The National Cancer Institute predicts a 1% increase in deaths from breast and colorectal cancer over the next 10 years; however, this could be an underestimate. The following image is adapted from the American Cancer Society's Cancer Facts and Figures 2021. Figure 28 shows the potential impact of the COVID-19 pandemic on future cancer outcomes.

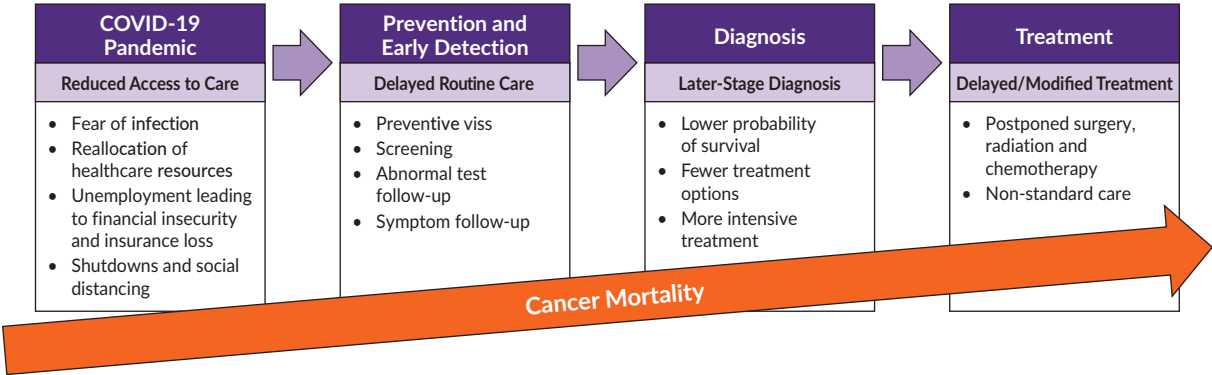
<sup>69</sup> AJMC. (2021). A Timeline of COVID-19 Developments in 2020. Retrieved from <https://www.ajmc.com/view/a-timeline-of-covid19-developments-in-2020>.

<sup>70</sup> State of Illinois. (2021). Executive and Administrative Orders. Retrieved from <https://www2.illinois.gov/government/executive-orders>.

<sup>71</sup> American Cancer Society. (2021). Cancer Facts and Figures 2021. Retrieved from <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/special-section-covid19-and-cancer-2021.pdf>

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Figure 28. Potential Impact of COVID-19 Pandemic on Future Cancer Outcomes



## EVALUATION

One of the goals of the ICCCP is to engage with stakeholders to develop the 2022-2027 Illinois Comprehensive Cancer Control Plan. The plan is meant to guide stakeholders statewide in their actions related to cancer prevention and management. Evaluation activities related to the 2022-2027 Illinois Comprehensive Cancer Control Plan will assess the quality of the plan and the efforts made to disseminate the plan to stakeholders. The ICCCP has contracted with the University of Illinois College of Medicine Rockford to provide evaluation activities for the program. Specifically, the evaluation process will review the progress made with the goals and SMART objectives that are measurable in the short, intermediate, and long terms. The dissemination plan and the various dissemination related materials will also be reviewed to assess their effectiveness and reach. Data will be obtained and documented on an ongoing basis by the evaluation team throughout the FY2022 year of the ICCCP.

Table 28 shows the evaluation design and methods for the 2022-2027 Illinois Comprehensive Cancer Plan.

Table 28. Evaluation design.

Evaluation Questions	Indicators	Data Collection Sources	Data Collection Methods	Data Collection Timing	Data Analysis
(1) To what extent has the ICP executed the development of the plan? (2) To what extent do the priority area work groups develop SMART goals and objectives? (3) To what extent does the plan identify measurable short-term, intermediate, and long-term indicators? (4) To what extent is the plan disseminated to stakeholders?	(1) Priority area work groups execution of deliverables and timelines (2) Stakeholder engagement (3) Goals and objectives that are specific, measurable, attainable, results-oriented, and time-phased (4) Development of a dissemination plan (5) Reach of the plan	(1) Meeting minutes (2) Notes from evaluation team observation of priority area work group meetings (3) Priority area work group plan documents (4) Data collection sources identified in the plan for each indicator (5) Dissemination plan documents and materials (handouts, infographics, PPT templates, etc.)	(1) Abstract from meeting minutes (2) Evaluation team observation (3) Abstract from plan documents (4) Abstract from data collection sources identified in the plan for each indicator (5) Abstract from dissemination materials	Ongoing	Document review of meeting minutes Document review of evaluation team notes Document review of priority area work group materials Annual review of progress towards short-term, intermediate, and long-term indicators Document review of dissemination plan and associated documents

