# MAINE CANCER PLAN: INSIGHTS FROM COMMUNITY ENGAGEMENT

FINDINGS

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During the development of this report, ChatGPT 4.0 was employed to streamline the literature review and enhance efficiencies in the introductory section. The authors validated all references and excluded any potential plagiarism. The underlying ideas and content were developed by the authors themselves.

## Contents

**INTRODUCTION ..... 5**
Cancer in Maine ..... 6
Current Cancer Plan (2021 – 2025) ..... 6
Cancer Plan 2021 - 2030 ..... 7
**METHODOLOGY ..... 9**
Cancer Listening Sessions ..... 10
Triangulation ..... 11
**GOAL 1: PREVENTION ..... 12**
Perceptions of Cancer Prevention Strategies ..... 15
Factors Limiting Effectiveness of Strategies ..... 15
Challenges Across Priority Communities ..... 17
Black, Indigenous, and People of Color Communities ..... 17
LGBTQIA+ Communities ..... 17
Low Income Communities ..... 18
Rural Communities ..... 18
Recommendations for Improving Cancer Prevention Strategies ..... 19
**GOAL 2. SCREENING ..... 21**
Perceptions of Cancer Screening and Early Detection Strategies ..... 24
Factors Limiting Effectiveness of Screening and Early Detection Strategies ..... 24
Challenges Across Priority Communities ..... 25
Black, Indigenous, and People of Color Communities ..... 25
LGBTQIA+ Communities ..... 26
Low Income Communities ..... 26
Rural Communities ..... 27
Recommendations for Improving Cancer Screening and Early Detection Strategies ..... 28
**GOAL 3. TREATMENT ..... 29**
Perceptions of Cancer Treatment and Care Strategies ..... 32
Factors Limiting Effectiveness of Treatment and Care Strategies ..... 32
Challenges Across Priority Communities ..... 33
Black, Indigenous, People of Color Communities ..... 33
LGBTQIA+ Community ..... 34

Low Income Communities....34
Rural Communities....35
Recommendations for Improving Cancer Treatment and Care Strategies....35
**GOAL 4. SURVIVORSHIP....37**
Perceptions of Cancer Survivorship Strategies....40
Factors Limiting Effectiveness of Survivorship Strategies....40
Challenges Across Priority Communities....41
Black, Indigenous, and People of Color Communities....41
LGBTQIA+ Communities....41
Low Income Communities....42
Rural Communities....43
Recommendations for Improving Survivorship Strategies....43
**REFERENCES....45**

# INTRODUCTION

## Cancer in Maine

Cancer remains a significant public health concern in Maine, with the state consistently reporting higher cancer incidence rates compared to the national average. The overall cancer age-adjusted incidence rate for Maine is 483.2 per 100,000 compared with 439.1 for the U.S (Maine Cancer Registry, 2024). According to the US Centers for Disease Control and Prevention (CDC), Maine has elevated rates of certain cancers, including lung, colorectal, and breast cancers (National Cancer Institute, 2024). Maine's aging population, elevated smoking and obesity rates, and challenges in accessing preventive screenings and treatment, particularly in rural areas, contribute to these disparities (American Cancer Society, 2023). Furthermore, the rural geography of Maine exacerbates barriers to comprehensive cancer care and support, leading to heightened inequities among underserved populations. Understanding these trends is essential to inform the revision of Maine's cancer plan and target effective interventions.

## Current Cancer Plan (2021–2025)

The Maine Cancer Plan 2021-2025, developed by Maine's Statewide Cancer Coalition, serves as a comprehensive guide to reduce the cancer burden in Maine. The Plan recognizes cancer as the leading cause of death in Maine, contributing to 22% of deaths in 2018. It builds on two decades of cancer control progress while addressing persistent disparities in cancer incidence, mortality, and access to care across the state.

**Framework and Goals.** The plan includes the six primary goals addressing the entire cancer care continuum:

1. Prevention: Reducing cancer risks through evidence-based strategies targeting tobacco, obesity, alcohol, UV exposure, and environmental hazards like radon and arsenic.
2. Screening: Promoting early detection via increased adoption of evidence-based cancer screening.
3. Treatment: Enhancing access to timely, high-quality, evidence-based cancer treatments.
4. Survivorship: Improving quality of life for cancer survivors through support services.
5. Palliative Care: Expanding access to high-quality, comprehensive palliative care throughout treatment.
6. End-of-Life Care: Providing timely and high-quality end-of-life support for patients.

**Foundational Themes.** The Plan emphasizes five cross-cutting themes:

- Equity and Inclusion: Addressing inequities in health outcomes influenced by socioeconomic, geographic, and demographic factors.
- Shared Decision-Making: Empowering individuals in their healthcare decisions.
- Policy, Systems, and Environmental Change: Promoting large-scale changes to impact population health.
- Evidence-Based Approaches: Ensuring strategies are backed by scientific research.

- Measurement and Evaluation: Tracking progress with Specific, Measurable, Achievable, Realistic, and Timebound (SMART) objectives.

**Key Features.** The Plan invites collective action to improve cancer prevention, care, and survivorship across Maine, setting a path for equitable and sustainable improvements in cancer outcomes.

The Plan aligns with national guidelines from the CDC's Comprehensive Cancer Control Program and incorporates input from over 75 collaborators. It includes targeted strategies for reducing disparities among Maine's rural and underserved populations. SMART objectives are set for each goal, with a 10% improvement target over five years.

The Plan provides actionable guidance for a broad audience, including individuals, healthcare providers, policymakers, and community organizations. It serves as a roadmap for advocacy, local initiatives, and system-wide changes to improve cancer outcomes statewide.

Acknowledging the impact of COVID-19, the Plan incorporates adaptive measures to address delays in care and increased disparities caused by the pandemic. Continuous reporting and partner engagement ensure the plan remains relevant and impactful.

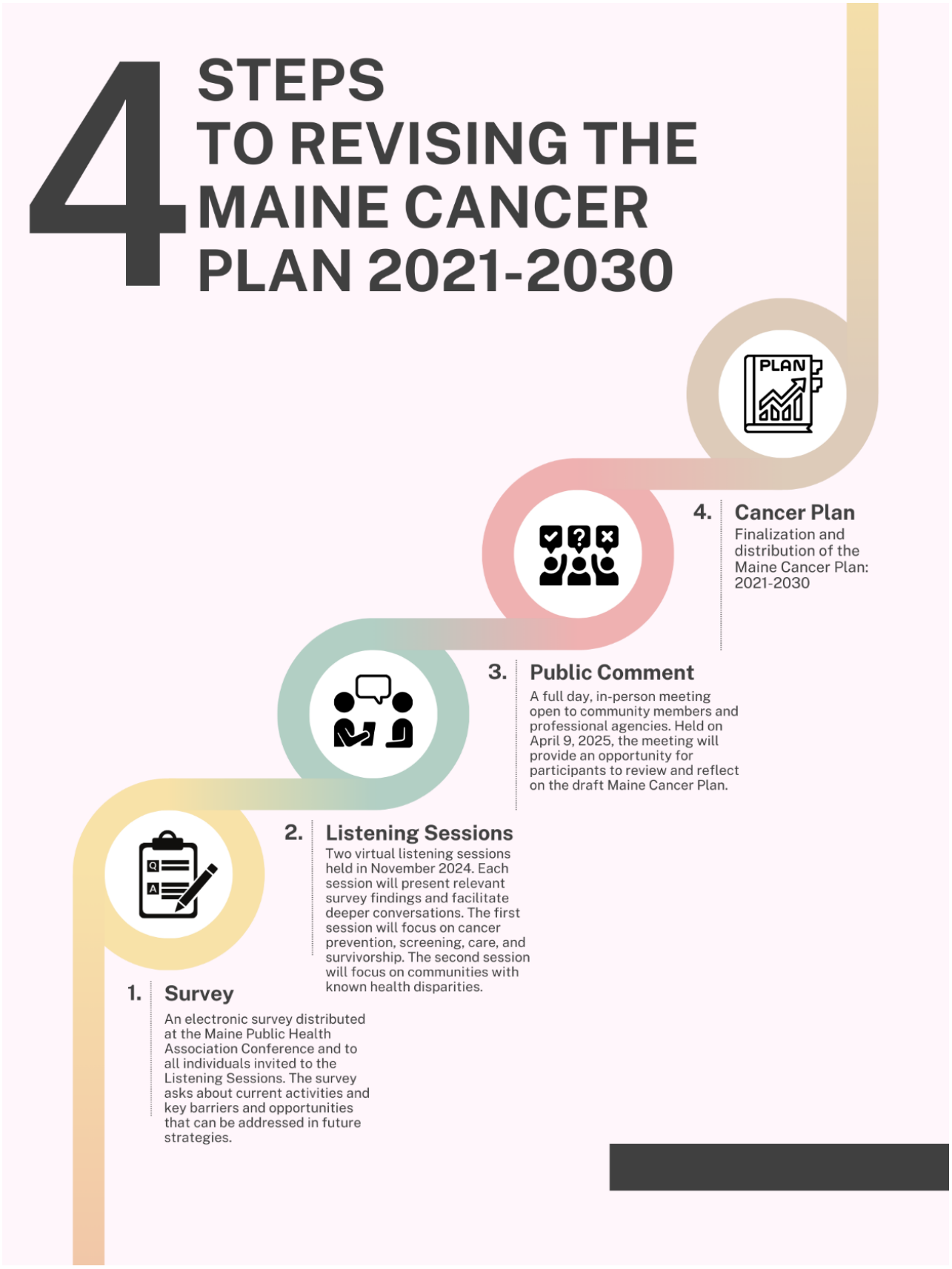
## Cancer Plan 2021-2030

**Maine State Cancer Coalition.** The US CDC funds the state Comprehensive Cancer Prevention and Control Program through a Cooperative Agreement to convene, maintain, provide staffing and support to a statewide cancer coalition. A core component of the Coalition is to develop and implement a state cancer plan which informs and is congruent with US CDC requirements as well as the Comprehensive Cancer Program's work plan. In 2024, the Maine Cancer Coalition convened a Maine Cancer Plan Committee to extend the current Plan to a ten-year plan (2020–2030). Community input and engagement in this process is crucial to ensure the Plan is comprehensive, inclusive, and tailored to meet community needs.

**Community engagement.** In collaboration with the Maine CDC Comprehensive Cancer Control Program (MCCCP) and the Maine Cancer Plan Committee, Partnerships For Health (PFH) implemented a formative evaluation to provide avenues for interested partners to contribute towards the expanded Plan.

**Approach.** The revision process for the Maine Cancer Plan (2020–2030) involves a four-step engagement strategy designed to gather diverse perspectives and ensure comprehensive input (see Figure 1). The process began with an electronic survey, distributed widely, including at the Maine Public Health Association Conference, to capture current activities, barriers, and opportunities for future strategies. This was followed by listening sessions, with two virtual events scheduled for November 2024. The first session addressed topics such as cancer prevention, screening, care, and survivorship, while the second focused on communities with known health disparities. Next, a public comment phase in April 2025 will invite community members and professionals to a full-day, in-person meeting to review and discuss the draft Plan. The final step is the finalization and distribution of the Maine Cancer Plan 2021–2030, informed by the insights gathered throughout these stages. This collaborative approach ensures the plan reflects the needs and priorities of Maine's diverse populations.

*Figure 1. Revision to the Maine Cancer Plan Process*

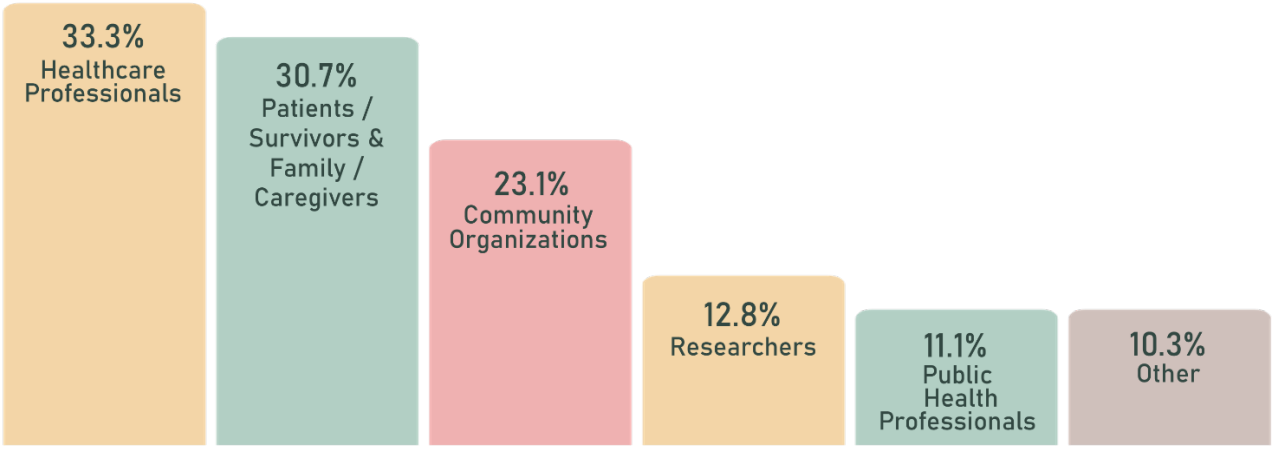


# METHODOLOGY

An electronic survey was developed to assess the effectiveness of current cancer-related strategies, identify barriers to success, and gather suggestions for alternate approaches. The survey was distributed at the Maine Public Health Association Conference in October 2024 and was included in electronic invitations to the two Cancer Listening Sessions. Participants in the Listening Sessions were also encouraged to complete the survey at the end of each session.

A total of 117 individuals completed the survey. Respondents represented an equitable distribution of roles, including healthcare professionals (33.3%), community organizations and public health professionals (34.2%), and individuals with lived experience (30.7%) (see Figure 2 for details). Survey results were analyzed using descriptive statistics and are reported under the relevant topic areas in this report.

*Figure 2. Survey Respondents (n=117)*




## Cancer Listening Sessions

Two virtual Listening Sessions were conducted via Zoom in November 2024. The first session focused on general cancer topics such as prevention, screening/detection, treatment/care, and survivorship while the second centered on communities experiencing cancer-related disparities, such as LGBTQIA+ individuals, Black, Indigenous, and People of Color (BIPOC), low-income and rural populations. Participants had the option to register for one or both sessions.

**Attendance.** Twenty-three people attended the general session and 19 people attended the disparities session. There were seven people who attended both sessions.

**General Listening Session.** The general session began with an overview of the session's purpose, a brief description of the current cancer plan, and a summary of survey findings. Participants engaged in small group discussions covering prevention, screening and early detection, treatment and care, and survivorship. Each breakout group discussion started with a summary of survey findings relevant to the topic, followed by a dialogue on barriers and potential solutions. Participants shared ideas either verbally or through an anonymous digital whiteboard platform, IdeaBoardz.

Each participant was able to attend discussions on three of the four topics. Following the breakout room discussions, facilitators summarized the challenges and solutions identified, and participants were invited to add additional thoughts to the IdeaBoardz for the topic they did not

attend. The palliative care and end-of-life care discussion was held in a large group format, following a similar structure.

**Disparities Listening Session.** The disparities-focused session began with an explanation of the session's purpose and an overview of the current cancer plan. Participants joined one of four breakout groups, each focused on a specific community: LGBTQIA+, rural, low-income, or BIPOC.

In the small groups, facilitators guided discussions on the unique barriers faced by the specific communities and explored potential solutions across cancer prevention, screening and early detection, treatment and care, and survivorship. Participants shared their thoughts verbally or via the anonymous IdeaBoardz platform. After the breakout discussions, facilitators presented a summary of challenges and solutions for each community. A final large group discussion explored the intersectionality of identity and disparities, encouraging participants to reflect on shared and unique challenges.

## Triangulation

All small group discussions were recorded, and emerging themes were summarized alongside contributions from IdeaBoardz. These insights were triangulated with survey findings and synthesized into the relevant topic areas reported in this document.

PREVENTION

## SUMMARY

**Perceptions of Cancer Prevention Strategies**

Survey results reveal that while 65.8% of respondents viewed efforts as effective, significant disparities emerged across different groups. Public health professionals showed the highest confidence, with 92.3% rating efforts as effective. In contrast, only 37.7% of patients, survivors, caregivers, or family members rated efforts as effective, with an equal percentage expressing uncertainty. Community organization representatives and healthcare professionals reported moderate confidence (64.7% and 66.7% effective, respectively). Researchers showed the least confidence, with only 33.3% considering efforts effective and 50.0% uncertain.

**Factors Limiting Effectiveness of Strategies**

- **Cultural barriers.** Cultural differences, cited by 52.6% of respondents, pose significant challenges to the success of cancer prevention programs. Strategies that fail to respect diverse norms and practices may alienate communities, reducing engagement. Fear and stigma, particularly prevalent in immigrant and refugee populations, discourage open discussions about health and prevent individuals from seeking preventive measures like screenings or adopting healthier lifestyles.
- **Awareness and misunderstanding.** Gaps in awareness about healthy behaviors, screenings, and cancer risks are significant obstacles to prevention. Many individuals lack sufficient knowledge about the impact of tobacco and alcohol use or the importance of regular screenings. Misunderstandings about cancer risks, influenced by cultural differences, further complicated efforts, as the concept of "risks" may not resonate universally or may be interpreted differently.
- **Funding and resource limitations.** Funding constraints, noted by 44.7% of respondents, limit the scope and sustainability of cancer prevention programs. A lack of access to resources that support healthy lifestyles, such as affordable nutritious food and safe physical activity spaces (42.1%), further exacerbates disparities. These limitations often leave underserved communities without the tools needed to adopt and maintain preventive behaviors.
- **Public outreach and campaigns.** Inadequate community outreach (40.4%) and insufficient public awareness campaigns (36.0%) hinder the effectiveness of prevention programs. Without targeted and accessible communication strategies, many individuals remain unaware of available services or the importance of preventive measures, resulting in missed opportunities to engage vulnerable populations.
- **Public health system collaboration.** Limited collaboration within the public health system, highlighted by 35.1% of respondents, leads to fragmented and siloed efforts. This lack of coordination reduces the overall impact of cancer prevention initiatives, making it harder to address systemic issues comprehensively.
- **Environmental testing and remediation.** Cumbersome processes for environmental testing and remediation hinder prevention efforts and make it difficult for individuals and communities to access timely and effective interventions, reducing the overall accessibility and impact of these critical activities.

**Challenges Across Priority Communities**

- **BIPOC communities** face cultural and generational communication gaps, resource shortages, and trust issues with healthcare providers. Prevention programs often lack cultural relevance, and acculturation gaps between youth and parents hinder collective engagement in prevention efforts. Resource gaps, such as limited transportation and food access, further exacerbate disparities.
- **LGBTQIA+ communities** face systemic data collection gaps, particularly regarding sexual orientation and gender identity in EHRs, which prevent tailored interventions. Higher rates of cancer risk factors, such as tobacco and alcohol use, along with stigma and healthcare access barriers, limit preventive efforts.
- **Low-income communities** experience stigma from healthcare providers, inadequate access to preventive education, and limited vaccination availability. Outreach efforts are often inconsistent, and materials are not always cognitively or linguistically accessible, leaving these populations underinformed about cancer risks and prevention strategies.
- **Rural communities** encounter significant transportation challenges, including unreliable medical transportation and mobility issues. Awareness gaps persist, as generational differences complicate messaging, and behavioral misconceptions about cancer risks limit engagement in prevention activities.

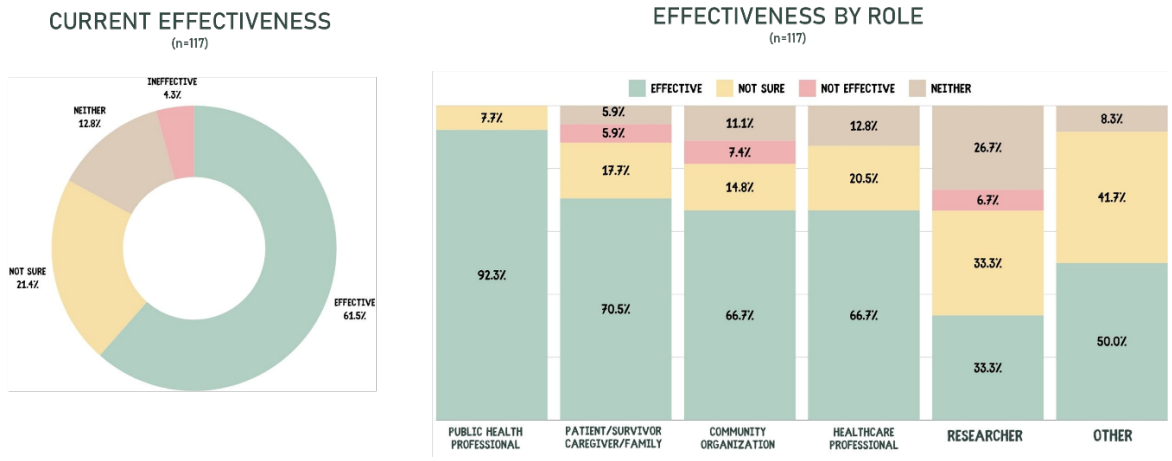
**Recommendations for Improving Cancer Prevention Strategies**

- **Increase education and awareness.** Expanding education about cancer prevention through trusted Community Health Workers (CHWs), patient navigators, and providers who are culturally competent can help dispel fears and reduce stigma. Consistent and clear messaging about risks, screenings, and healthy behaviors across public health systems is critical.
- **Strengthen collaboration and partnerships.** Increasing collaboration by establishing partnerships across programs and divisions can minimize siloed efforts and foster coordinated approaches to cancer prevention. Collaborative funding opportunities could further support these initiatives.
- **Enhance community outreach.** Leveraging traditional and digital media to cater to generational preferences, along with community-based outreach programs, can broaden the reach of prevention messaging. Schools and after-school programs are valuable venues for engaging youth and promoting healthy behaviors.
- **Provide support for environmental testing.** Simplifying processes for testing homes and water for contaminants and increasing support for families through community messengers and financial assistance, can enhance prevention efforts.
- **Implement culturally relevant strategies for priority communities.** Tailored initiatives, such as youth-led programs for BIPOC communities, improved SOGI data collection for LGBTQIA+ populations, and mobile health clinics for low-income and rural residents, can help address unique barriers and reduce cancer disparities across Maine.

## Perceptions of Cancer Prevention Strategies

Figure 3 illustrates perceptions of the current effectiveness of cancer prevention efforts among survey respondents (n=117) and how these perceptions vary by role. Overall, 65.8% of respondents rated current cancer prevention efforts as effective, while 12.8% found them ineffective, and 21.4% were unsure. When broken down by role, public health professionals overwhelmingly viewed prevention efforts as effective (92.3%). In contrast, only 37.7% of patients, survivors, caregivers, or family members found efforts effective, with a noteworthy portion (37.7%) expressing uncertainty. Respondents from community organizations and healthcare professionals were more balanced, with 64.7% and 66.7% respectively rating efforts as effective. Researchers showed lower confidence, with only 33.3% considering efforts effective, and 50.0% responding as unsure.

*Figure 3. Respondents Perceptions of the Effectiveness of Current Cancer Prevention Strategies*




## Factors Limiting Effectiveness of Strategies

**Fear and stigma, compounded by cultural barriers, limit engagement in cancer prevention efforts.** Fear was frequently identified as a significant barrier to prioritizing cancer prevention, particularly within immigrant and refugee communities. Many individuals avoid discussing potential health issues, including cancer, due to cultural taboos or a reluctance to "invent problems." This avoidance often delays preventive actions, leaving communities vulnerable. Cultural barriers, reported by 52.6% of survey respondents, further exacerbate these challenges, as diverse norms and practices influence how communities perceive and engage with prevention initiatives. These factors underscore the importance of culturally tailored approaches to reduce stigma and encourage open conversations about cancer prevention.

> "We need to talk openly about why Maine's cancer rates are so high, and we need good/better research in the State to identify root causes and go after those. If we can get to prevention and awareness raising in schools and communities, when people are young, we may start to see rates go down."
> - survey respondent

**Lack of awareness and understanding of cancer risks hinders prevention efforts.** Both survey data and listening sessions revealed that many Maine residents lack sufficient knowledge about healthy lifestyles, cancer risks, and preventive measures. A lack of public awareness campaigns, noted by 36.0% of survey respondents, highlights the need for stronger educational initiatives. Additionally, many residents struggle to understand the concept of "cancer risks," particularly when messaging focuses on behaviors such as tobacco or alcohol use without addressing cultural nuances or providing relatable contexts. This disconnect limits the effectiveness of outreach programs, as prevention strategies may not resonate with their intended audiences. Participants also identified limited access to healthy lifestyle resources, such as nutritious food, safe spaces for physical activity, and smoking cessation tools, as a barrier for 42.1% of respondents, further complicating prevention efforts.

> "Do people really understand what risk means in regard to health and wellness? Most outreach is about risks but may not be understood." - IdeaBoardz

**Funding constraints and inadequate collaboration weaken the public health response.** A lack of funding, reported by 44.7% of respondents, remains a critical limitation for sustaining and expanding cancer prevention programs. This financial challenge is mirrored in the siloed structure of public health systems, where limited collaboration between programs reduces opportunities for integrated approaches to prevention. With 35.1% of respondents citing insufficient coordination among organizations, the need for stronger partnerships and shared strategies is evident. Federal funding mechanisms, often focused on single diseases, further perpetuate these silos, making it difficult to address overlapping risk factors and health outcomes effectively.

> "Prevention, promotion of whole foods, plant-based diets, avoidance of all alcohol (pull the pink ribbons off alcohol bottles - replace with black box warning for cancer), and promotion of healthy lifestyles (exercise, stress reduction, etc.) for more to prevent cancer than screenings, screenings are for detection, not prevention." - survey respondent

**Inadequate community outreach and environmental challenges further limit effectiveness.** Inadequate outreach efforts, mentioned by 40.4% of respondents, leave gaps in engaging and educating Maine's communities about cancer prevention strategies. Participants noted that healthcare providers often lack the time to discuss healthy lifestyles with patients, while outreach materials fail to address cultural and linguistic diversity. Environmental risk factors, such as radon and arsenic exposure, pose additional challenges. The processes for testing homes, water, and environments in Maine were described as cumbersome, deterring families from conducting tests. Even when contaminants are identified, the application process for remediation funding can be overly complex, limiting access to necessary support. These systemic barriers highlight the need for simplified procedures and community-based support to improve environmental health and cancer prevention outcomes.

> "Cultural barriers – among immigrants and New Mainers. If they can't see or feel any health issue, they don't want to discuss it or worry about it or take any preventive actions." - IdeaBoardz

## Challenges Across Priority Communities

### Black, Indigenous, and People of Color Communities

**Challenges.** BIPOC communities face several unique challenges in cancer prevention efforts. The acculturation gap, particularly between youth and parents, creates generational divides that complicate communication about health issues, making it harder to address prevention collectively. Many prevention programs lack cultural relevance, which diminishes their effectiveness in engaging these communities. Resource gaps also present significant barriers, as practical needs such as transportation, food, and financial support for BIPOC families remain unaddressed. Furthermore, building trust within BIPOC communities is a challenge for clinical teams, particularly when providers are not familiar or trusted members of the community, further limiting access to preventive care.

**Solutions.** To overcome these challenges, culturally relevant and community-driven initiatives are essential. Youth-led programs, such as culturally appropriate food initiatives, can play a pivotal role in raising awareness and fostering engagement in prevention efforts. Leveraging local community assets, such as immigrant children's prevention navigators, can help bridge gaps in access to health services. Clinical teams must prioritize building visible and meaningful connections within the community to foster trust and make healthcare interactions more approachable. Adopting holistic prevention strategies that address interconnected issues like tobacco use, nutrition, and transportation can provide a comprehensive framework for improving cancer prevention in BIPOC communities.

> "Have people with lived experience and shared identity on the clinical care teams." - IdeaBoardz

### LGBTQIA+ Communities

**Challenges.** The LGBTQIA+ community faces unique challenges in cancer prevention due to systemic data gaps and heightened exposure to certain risk factors. One significant challenge is the lack of comprehensive data collection on sexual orientation and gender identity (SOGI), particularly within electronic health records (EHRs). Without systematic SOGI data, health systems are often ill-equipped to identify and support LGBTQIA+ individuals in their cancer prevention efforts. This gap exacerbates inequities, as prevention programs and resources may fail to address the specific needs of this population. Furthermore, members of the LGBTQIA+ community often experience higher rates of cancer due to risk factors such as tobacco and alcohol use, as well as increased likelihood of substance use. These risks are compounded by barriers to healthcare access, stigma, and discrimination, which can deter individuals from seeking preventive care or engaging in risk-reduction behaviors.

**Solutions.** Addressing these challenges requires targeted and systemic solutions. Health systems should prioritize optimizing EHRs to incorporate robust SOGI data collection, enabling better identification of LGBTQIA+ individuals who could benefit from preventive services. Alongside this, public health efforts should focus on implementing tailored risk-reduction programs, such as tobacco cessation initiatives designed specifically for the LGBTQIA+ community. Expanding data collection and evaluation efforts around cancer prevention for this population is also critical; understanding specific cancer risks and disparities in Maine's LGBTQIA+

> "Improve general LGBTQIA+ data collection and information about the population to inform targeted interventions." - IdeaBoardz

community will allow health systems and public health agencies to design more effective interventions. Finally, further research into HPV vaccination rates among older LGBTQIA+ adults is needed, as lower uptake in these groups may represent an opportunity to mitigate cancer risks associated with HPV.

## Low Income Communities

**Challenges.** Low-income communities in Maine face significant challenges in accessing cancer prevention resources, as identified during the cancer listening session. Stigma from healthcare providers, particularly toward individuals with disabilities, can lead to reluctance to conduct screenings or provide appropriate care, further marginalizing these populations. Additionally, access to preventive education throughout the lifespan is limited, with many materials not being cognitively or linguistically accessible to all individuals. This lack of tailored education leaves gaps in awareness about cancer risks and prevention strategies. Compounding these issues, the availability of vaccinations is often inadequate, and outreach efforts are inconsistent, leaving many low-income individuals without the resources or information needed to engage in cancer prevention effectively. These barriers collectively contribute to disparities in cancer outcomes for low-income communities.

**Recommendations.** To overcome these challenges, a multi-faceted approach is essential. Expanding community and interdisciplinary partnerships can strengthen local cancer prevention efforts by pooling resources and expertise. Policy interventions targeting environmental carcinogen exposure, such as reducing air pollution and hazardous chemicals in low-income areas, are critical to mitigating preventable cancer risks. Mobile health clinics and rural outreach programs can play a pivotal role in increasing access to education and preventive services, while ensuring that educational materials are available in multiple languages and accessible formats will broaden their impact. Smoking cessation programs specifically tailored to low-income populations, along with efforts to improve provider capabilities and reduce waiting times for screenings and care, can further support these communities. Increasing health literacy across all stages of cancer prevention, from awareness to treatment, is a fundamental strategy to reduce cancer disparities and improve outcomes for low-income individuals in Maine.

> "Utilize outreach programs (e.g., mobile health clinics, rural outreach) to educate about cancer prevention." - IdeaBoardz

## Rural Communities

**Challenges.** Rural communities encounter significant challenges in cancer prevention due to barriers such as transportation, limited awareness, behavioral misconceptions, and generational divides. Transportation difficulties are a recurring issue, with rural patients often facing challenges in accessing medical appointments for preventive care or education. Medical transportation services, such as Motivecare, may be unreliable and require advanced scheduling, making them less accessible for those with urgent needs. Mobility limitations, particularly among elderly residents, further exacerbate these issues, as many lack adequate support to navigate vehicles or medical facilities. Awareness challenges are also prevalent, as effective messaging needs to address generational preferences: older residents tend to respond better to traditional media like print or mail, while younger individuals are often more engaged through social media or school-

based initiatives. Additionally, behavioral misconceptions, such as misinformation about cancer risk factors like sun exposure, diet, and exercise, create obstacles to prevention. Topics such as HPV vaccination may also be hindered by stigma and misunderstandings, further complicating prevention efforts.

**Solutions.** To address these challenges, various approaches could be considered. Expanding reliable and accessible transportation options, including same-day services or mobility assistance, may help rural residents access preventive care more easily. Increasing awareness might involve leveraging both traditional and digital media to cater to different generational needs. Schools and after-school programs could serve as key platforms for delivering education on cancer prevention and fostering healthier behaviors. For youth, restorative approaches that provide resources for tobacco cessation instead of punitive measures could address issues like vaping and smoking more effectively. Elderly residents might benefit from education on self-advocacy and assistance with health system technologies, potentially through the support of CHWs or similar roles. Efforts to combat misinformation and reduce stigma, particularly around topics like HPV vaccination, may also support more informed decision-making and encourage a prevention-focused culture in rural areas.

## Recommendations for Improving Cancer Prevention Strategies

**Education around cancer and cancer prevention.** Participants noted the importance of continued education around cancer and cancer prevention, particularly from patient navigators, CHWs, and other health professionals who are trusted resources within the community. Part of this education should be focused on reframing the conversation around cancer; that cancer is not necessarily a death sentence and there are ways people can prevent it. Promotion of cancer prevention education by CHWs and other community-based support people helps to ensure culturally and linguistically appropriate access to information. In addition, health care providers could benefit from cultural competency/humility training to better support their ability to provide cancer prevention education and support to all Maine residents.

**Consistent cancer prevention messaging.** Within public health and Maine's health care system, providers and professionals should be sharing the same message(s) around cancer prevention with patients and communities. This would include promoting screenings, promoting healthy lifestyles, and connecting people to similar resources and information to support them. Some specific messaging noted by participants included education about the links between cancer and alcohol/tobacco/and drug use, as well as the promotion of treatment for alcohol and tobacco use. This would ensure Maine residents are getting clear and actionable information to support them in preventing cancer, regardless of the source or avenue of the information.

> "Education around cancer prevention – try to reframe the cancer conversation; consider cultural aspects – explain what cancer is and the importance of prevention. Education that cancer is not necessarily a death sentence. Help people understand the options around cancer." - IdeaBoardz

**Increase collaboration within public health system.** To minimize the work within the public health sector that happens within silos, participants suggested establishing more partnership groups and collaboration around prevention, particularly between different programs and divisions within the Maine CDC. This would allow partners to (1) understand what each other is doing around the risk and preventive factors associated with cancer prevention and (2) identify areas for potential collaboration and support. In addition, participants shared that there may also be opportunities for programs to work together to seek funding opportunities that promote this collaboration further.

**Increase support for environmental testing.** Participants suggested a number of ways to increase support for Maine families in testing their homes and water for potential environmental contaminants that are linked to cancer. First, using trusted community messengers (e.g., CHWs, public health nurses, communication organizations, etc.) to support families in accessing free test kits from Maine CDC, completing the testing process, and understanding the next steps. Second, participants recommended that the process for families to apply for funding assistance to address cancer-related environmental issues be simplified to increase access to cost-effective remediation activities.

> "Connect people to arsenic/radon test kits from Maine CDC through trusted messengers (CHWs, clinical staff)."
> - IdeaBoardz

SCREENING

## SUMMARY

**Perceptions of Cancer Screening and Early Detection Strategies**

Among respondents (n=117), 64.7% rated current cancer screening efforts as effective, while 5.5% found them ineffective, and 31.1% were unsure. Public health professionals expressed the highest confidence, with 94.6% rating efforts as effective, followed by patients, survivors, caregivers, and family members (75.5%), and community organizations (74.5%). Healthcare professionals were slightly less confident, with 71.7% rating current efforts as effective and 15.7% unsure. While the majority of respondents found efforts effective, uncertainty across all groups highlights room for improvement in communication and outreach.

**Factors Limiting Effectiveness of Strategies**

- **Financial, logistical, and systemic barriers restrict access to cancer screenings.** Lack of health insurance coverage (59.8%) and transportation challenges, especially in rural areas (35.0%), were major obstacles. Long wait times for appointments (39.3%) and limited healthcare system capacity further delayed diagnosis and treatment. Mobility challenges and insufficient accommodations compounded disparities, particularly for individuals with disabilities.
- **Educational and cultural barriers reduce screening participation.** Limited awareness about the importance of screenings (47.0%), coupled with fear, stigma (35.0%), and language or cultural barriers, hindered participation. Gender-specific and inconsistent messaging about screening recommendations further confused patients, undermining efforts to promote screenings.

**Challenges Across Priority Communities**

- **BIPOC Communities.** Mistrust, systemic inequities, and cultural barriers hinder screening uptake. Historical and ongoing mistrust in healthcare systems, fear of procedures, and cultural differences in decision-making prevent BIPOC individuals from seeking cancer screenings. Structural barriers, such as language difficulties and lack of community-centered resources, exacerbate these challenges.
- **LGBTQIA+ Communities.** Confusion around guidelines and mistrust limit care. Conflicting screening guidelines and a lack of knowledge among providers and patients create significant gaps, especially for anal cancer screenings. Mistrust of healthcare systems and limited affirming care further discourage screenings.
- **Low-Income Communities.** Practical and financial barriers discourage participation. Many low-income individuals lack paid time off to attend screenings and face significant transportation challenges. Limited provider awareness of their unique needs and fragmented referral systems contribute to poor outcomes.
- **Rural Communities.** Geographic and systemic barriers restrict access. Transportation difficulties, a lack of specialists, and low awareness about screening opportunities hinder early detection. Stigma around procedures and vaccine reluctance further prevent individuals from seeking care.

**Recommendations for Improving Cancer Screening and Early Detection Strategies**

- **Increase accessibility through mobile and community-based services.** Mobile screening vans and free or reduced-cost screenings in underserved areas can address transportation and financial barriers for rural and low-income populations. Hosting screenings at trusted community locations such as schools, faith-based organizations, and food pantries can further improve access and engagement. Providing home test kits and offering insurance-covered ride-share services can benefit individuals with mobility challenges, limited transportation options, or healthcare hesitations.
- **Foster inclusivity with tailored communication and culturally competent care.** Developing culturally and linguistically appropriate materials can improve health literacy and encourage participation among BIPOC, LGBTQIA+, and immigrant populations. Gender-affirming practices, such as the use of inclusive language and acknowledgment of diverse healthcare needs, can make screenings more welcoming and accessible. CHWs are vital in bridging gaps, offering guidance, simplifying medical information, and fostering trust within communities.
- **Enhance education and awareness for patients and providers.** Public education campaigns targeting stigma reduction—especially for procedures like HPV vaccination—can normalize preventive care across all priority communities. Increased provider training on screening guidelines and the unique needs of underserved populations, including LGBTQIA+ and rural residents, is critical to improving care coordination. Promoting organ-based screening practices for LGBTQIA+ individuals can ensure more precise and inclusive recommendations.
- **Strengthen healthcare systems and workforce capacity.** Expanding the availability of screening specialists, such as dermatologists and technicians, particularly in rural areas, can reduce delays in care. Workforce development initiatives should emphasize the recruitment and training of providers to meet the needs of underserved populations. Improving referral systems with streamlined, closed-loop care models can prevent patients from falling through the cracks.
- **Support screenings through workplace policies and targeted health initiatives.** Employers should be encouraged to provide paid time off for employees to attend screenings, reducing practical barriers for low-income workers. Men's health initiatives should focus on normalizing annual check-ups and screenings from an early age, addressing gender-specific gaps in participation.
- **Engage trusted community spaces to build trust and promote participation.** Leveraging trusted spaces such as churches, local organizations, and community centers can provide a sense of safety and accessibility for BIPOC and immigrant populations. Technology, such as mobile health apps or patient portals, can improve access when coupled with CHW assistance to help patients navigate these tools effectively.

## Perceptions of Cancer Screening and Early Detection Strategies

Figure 4 provides insights into the perceived effectiveness of cancer prevention efforts among respondents (n=117) overall and across different roles. Overall, 64.7% of respondents rated current efforts as effective, while 5.5% found them ineffective, and 31.1% were unsure. Breaking this down by role, public health professionals demonstrated the highest confidence, with 94.6% rating efforts as effective. Among patients, survivors, caregivers, or family members, 75.5% found efforts effective, but 11.7% were unsure, and 5.6% deemed them ineffective. Similarly, community organizations reported 74.5% effectiveness, though 11.8% were unsure, and 5.9% found efforts ineffective. Healthcare professionals showed slightly less certainty, with 71.7% rating efforts as effective, while 15.7% were unsure.

*Figure 4. Respondents Perceptions of the Effectiveness of Current Cancer Screening Strategies*

## Factors Limiting Effectiveness of Screening and Early Detection Strategies

**Financial barriers are a primary obstacle to accessing cancer screening services.** Among survey respondents (n=117), the most commonly reported challenge was a lack of health insurance coverage (59.8%), which restricts affordability and access to screening services. Similarly, insufficient insurance coverage was cited as a barrier for individuals whose plans do not cover specific screenings. Transportation difficulties, particularly in rural areas, further compound access challenges, with 35.0% of respondents highlighting this obstacle. For individuals without reliable vehicles, accessing distant or limited screening facilities can be nearly impossible.

**Logistical barriers delay timely diagnosis and treatment.** Long wait times for appointments, noted by 39.3% of respondents, delay diagnoses and reduce opportunities for early intervention and effective treatment. Furthermore, healthcare system limitations—such as insufficient screening facilities in underserved areas and time constraints faced by providers—exacerbate disparities in access. Mobility limitations and the lack of accommodations at screening locations pose additional hurdles, particularly for individuals with physical disabilities.

> "Individuals with different mobility requirements not being able to get certain screenings." - IdeaBoardz

**Educational and cultural gaps hinder participation in cancer screening programs.** Nearly half (47.0%) of respondents identified a lack of awareness about the importance of screening, underscoring the need for enhanced public education efforts. Fear and stigma surrounding cancer screenings—reported by 35.0%—discourage individuals from seeking care, particularly among Maine's immigrant and refugee populations, where cultural and language differences often lead to misunderstandings about the importance of early detection. Gender-specific and inconsistent messaging further undermines participation, as men may feel excluded from programs often framed around women's health, and unclear guidance on screening schedules and family risk history creates confusion.

> "Men's health is not as heavily focused on screening as women's health – regarding messaging." - IdeaBoardz

**Psychological and systemic obstacles amplify disparities in cancer screening access.** The fear of cancer diagnosis, compounded by concerns about procedural risks and financial burdens, deters individuals from pursuing care. Structural barriers, such as language and cultural differences (cited by 35.90% of respondents), create additional challenges. Logistical and financial obstacles—such as the lack of accessible facilities, transportation difficulties, and insurance-related barriers—underscore the need for targeted strategies to address these gaps.

## Challenges Across Priority Communities

### Black, Indigenous, and People of Color Communities

**Challenges.** Screening among BIPOC communities face numerous barriers that hinder participation and access. Complex decision-making in clinical settings, often shaped by hierarchical structures, can lead to confusion or frustration for patients, making shared decision-making challenging. Historical and ongoing mistrust in healthcare systems, coupled with trauma from past experiences, frequently prevents individuals from seeking essential screenings like Pap smears or colonoscopies. Additionally, fear and anxiety surrounding medical procedures—such as the discomfort of invasive screenings or fear of needles—act as deterrents. Cultural beliefs, language barriers, and a legacy of systemic inequities further compound these issues, making it difficult for BIPOC populations to fully engage with screening programs.

**Solutions.** Addressing these challenges requires tailored, community-centered approaches. CHWs play a vital role in bridging gaps by mediating conversations, simplifying complex medical information, and ensuring follow-up for screening appointments. Utilizing trusted community spaces, such as churches or local organizations, can foster a sense of safety and accessibility, reducing reliance on clinical settings alone. Integrating technology, like mobile health apps or patient portals, can enhance access, but their effectiveness increases when CHWs help patients navigate these tools and understand their benefits. These strategies collectively address systemic barriers and build trust to promote screening uptake in BIPOC communities.

> "Even if patient can understand [the] English language, the provider still needs a CHW to understand the patient's context, hesitance, confusion." - IdeaBoardz

## LGBTQIA+ Communities

**Challenges.** Confusion around cancer screening guidelines creates significant barriers to care. Multiple national and specialty organizations provide guidelines, but these often conflict or fail to address the nuanced needs of individuals based on gender identity and sexual orientation. Limited knowledge among providers and patients about appropriate screenings, particularly for LGBTQIA+ individuals, exacerbates the issue, leaving gaps in awareness about necessary procedures, such as anal cancer screenings. Additionally, mistrust of clinical providers and health systems further discourages individuals within the LGBTQIA+ community from seeking care, stemming from a lack of affirming care and lived experience. Finally, a shortage of screening specialists in niche areas, like anal cancer, leads to delays in services and results, compounding access challenges.

> "... multiple and varied guidelines around appropriate screenings/cadence of screenings based on gender identify and sexual orientation." - IdeaBoardz

**Solutions.** Enhancing education and workforce development is critical to addressing these barriers. Targeted education campaigns for both providers and patients can bridge gaps in awareness, particularly within the LGBTQIA+ community. Collaboration with community partners and health navigators can further promote screening awareness and connect individuals to preventive services. Providers should adopt organ-based screening practices to ensure standardized recommendations that align with the unique needs of LGBTQIA+ individuals. Additionally, workforce development initiatives, such as training providers and technicians on updated screening guidelines and the specific needs of LGBTQIA+ individuals, can improve access and reduce delays in care.

## Low Income Communities

**Challenges.** Low-income individuals in Maine face several significant barriers to accessing cancer screening and early detection services, contributing to poorer outcomes. A primary issue is the lack of paid time off, which forces many to choose between earning income and attending potentially life-saving screenings. Reliable transportation is another persistent challenge, particularly for those in rural or isolated areas with limited access to healthcare facilities. Additionally, some healthcare providers lack the necessary training and awareness to address the specific needs of low-income or rural patients, leading to suboptimal referral practices and fragmented care. These obstacles collectively create systemic inequities, leaving many individuals unable to access or prioritize cancer screenings.

**Solutions.** Addressing these challenges requires a multifaceted approach to improve accessibility, affordability, and coordination of cancer screening services. Partnerships with local healthcare providers in underserved areas and mobile health units can bring essential screenings, such as mammograms, colonoscopies, and Pap smears, directly to remote communities. Expanding free or low-cost screening programs, through sliding scale fees or state-funded initiatives, can alleviate financial burdens, while hosting community-based events at schools, faith-based organizations, and food pantries can

> "... address financial barriers, such as copays and lack of insurance, by providing sliding scale fees or state-funded programs." - IdeaBoardz

make screenings more accessible. Increasing reimbursement for screening procedures can incentivize healthcare providers to serve low-income and rural populations. Clear communication tailored to individuals facing language, cognitive, or hearing barriers is essential to ensure understanding and compliance with care. Additionally, improving referral systems by adopting closed-loop care models can help prevent patients from falling through the cracks. By implementing these solutions, Maine can take significant steps toward equitable cancer prevention and early detection for low-income individuals.

## Rural Communities

**Challenges.** Several challenges hinder effective cancer screening and detection in rural and underserved areas. Transportation remains a significant barrier, especially for rural patients who struggle to access screenings or other cancer-related appointments. This challenge is compounded for elderly individuals who often require additional support to attend appointments. Stigma around cancer screenings and the HPV vaccine was also frequently mentioned, reflecting a need for broader societal efforts to normalize these preventive measures. Access to screenings is another issue, as many rural patients are unaware of where to go for screenings, such as during primary care visits. A shortage of specialists, such as dermatologists in rural areas, further limits opportunities for early detection. Additionally, cultural differences in shared decision-making processes can complicate discussions about cancer prevention and screening. Vaccine reluctance, particularly regarding the HPV vaccine, emerged as a specific example of broader hesitancy that delays or prevents preventive care. Finally, a lack of awareness and health literacy—among both patients and providers—about what cancers can be screened for, when screenings are appropriate, and how to access these services contributes to missed opportunities for early detection.

**Solutions.** To address these challenges, respondents highlighted several strategies to improve cancer screening and detection. Expanding mobile health services and offering screenings closer to home can mitigate transportation barriers, particularly for rural and elderly patients. Efforts to reduce stigma, especially around the HPV vaccine, through public education and provider engagement are critical to improving uptake. Strengthening the role of primary care providers in care coordination can help patients better access screenings and understand their importance. Workforce development, such as increasing the number of dermatologists in rural areas and raising awareness among healthcare providers, can ensure patients receive timely and appropriate screenings. Encouraging shared decision-making practices that respect cultural differences can also improve patient engagement and acceptance of preventive care. Finally, comprehensive public health campaigns and provider training can enhance awareness about screening guidelines and the availability of services, empowering both patients and providers to prioritize early detection.

> "... communicating and health promotion targeted for rural communities."
> - IdeaBoardz

## Recommendations for Improving Cancer Screening and Early Detection Strategies

**Mobile screening services and free screenings can overcome key barriers to access.** Introducing mobile screening vans to underserved or rural areas would remove transportation barriers and make services more accessible. Additionally, providing no-fee screenings would eliminate financial obstacles, ensuring cost is not a deterrent. Extended screening hours would accommodate individuals with busy schedules, offering flexibility for those unable to attend during traditional office hours.

> "Mobile units that can provide access to all types of screenings." - survey respondent

**Home-based and transportation solutions can increase participation.** Providing free home test kits would enable individuals to conduct initial screenings in the privacy of their homes, benefiting those with transportation challenges or healthcare hesitations. Utilizing ride-share services such as Uber, Lyft, or taxis, potentially covered by insurance, could further alleviate transportation issues for individuals without reliable vehicles.

**Culturally and linguistically tailored communication fosters inclusivity.** Materials provided in multiple languages would help non-English-speaking individuals understand the importance of screenings, while gender-affirming practices, including the use of gender-neutral language and correct pronouns, would make screenings inclusive and respectful of all identities.

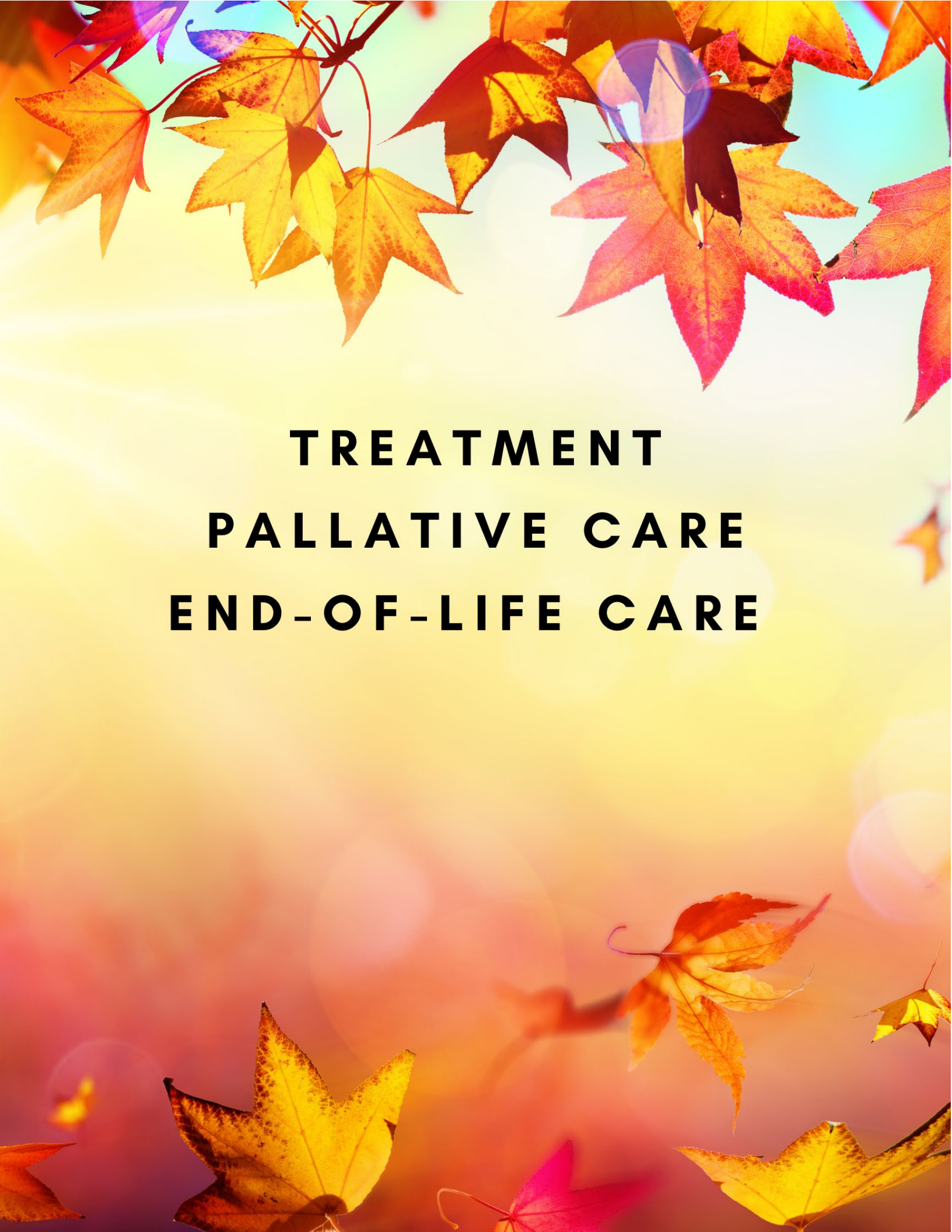
> "Utilize Ride Shares/Uber/Lyft/Taxis – and make this coverable by insurance." - IdeaBoardz

**Community engagement and provider advocacy are essential for improving screening rates.** Employing CHWs to guide individuals through the screening process and provide education would leverage local relationships to build trust. Additionally, healthcare providers need to proactively promote screenings, addressing patient concerns and emphasizing their importance during visits.

**Men's health initiatives and healthcare system improvements can normalize and prioritize screenings.** A targeted men's health initiative focusing on the importance of annual physicals and screenings from an early age would normalize regular check-ups. A systems approach, emphasizing education for healthcare providers about the critical role of cancer screening, would help prioritize screenings within patient care.

**Workplace policies and consistent messaging can remove practical and informational barriers.** Encouraging employers to allow employees to attend screenings without using paid time off (PTO) would reduce financial and logistical barriers for workers. Consistent, clear messaging about cancer screening recommendations and timing would ensure people know what screenings they need and when. Additionally, ensuring providers are aware of and can accommodate patients' mobility needs would help make screenings accessible for everyone, regardless of physical limitations.

> "CHWs working with individuals to get them to screenings with their built relationships with community members." - IdeaBoardz


TREATMENT
PALLATIVE CARE
END-OF-LIFE CARE

## SUMMARY

**Perceptions of Cancer Treatment and Care Strategies**

Approximately half of respondents (49.1%) rated cancer treatment and care efforts as excellent, while others described them as fair (23.7%), poor (7.0%), or were unsure (20.2%). Public health professionals, individuals with lived experience, and community organizations reported similar ratings, with about half considering efforts excellent. Healthcare professionals were the most polarized group, with 70.3% rating efforts as excellent but 21.6% describing them as poor. Researchers and other respondents expressed mixed opinions, with higher levels of uncertainty and less favorable evaluations.

**Factors Limiting Effectiveness of Cancer Treatment and Care Strategies**

- **Geographic and accessibility barriers limit care for rural and marginalized groups.** Long distances to treatment centers, particularly in rural counties, create significant obstacles, with 62.6% of respondents identifying this as a major challenge. Marginalized groups, including incarcerated individuals and those with disabilities, face additional barriers to accessing tailored, quality care.
- **Financial and insurance limitations create significant hardships.** High treatment costs and inadequate insurance coverage, lead to financial strain for patients and their families. A lack of coverage for integrative therapies exacerbates disparities in access to holistic care.
- **Resource shortages strain workforce capacity and care delivery.** Workforce shortages, including a lack of specialists and palliative care resources, lead to delays and unmet patient needs. Long wait times for treatment and insufficient support resources further impede timely and effective care.
- **Awareness and education gaps hinder informed decision-making.** Limited understanding of palliative care, its distinction from hospice care, and a lack of knowledge about clinical trials restrict patient options and empowerment.
- **Cultural and emotional challenges reduce access to compassionate care.** Language and cultural barriers may prevent effective care delivery for diverse populations. Fear, anxiety, and a lack of psychological support further hinder patient well-being and engagement.

**Challenges Across Priority Communities**

- **BIPOC communities.** Transportation difficulties, financial strain, and limited access to culturally competent care contribute to disparities in treatment outcomes. Historical mistrust and a lack of inclusive healthcare environments further exacerbate these challenges.
- **LGBTQIA+ communities.** Negative healthcare experiences and concerns about medication interactions, particularly for transgender individuals, create distrust and complicate cancer care.
- **Low-income communities.** Many lack reliable means to travel to treatment centers or adequate healthcare coverage, compounding their difficulties in accessing care. Language and cultural barriers also pose significant obstacles.

- **Rural communities.** Long distances, limited availability of specialists, and cultural barriers prevent equitable access to care for rural residents. Clinical trial access remains a particular challenge for older adults in these areas.

**Recommendations for Improving Cancer Treatment and Care Strategies**

- **Increase education and awareness to empower patients and caregivers.** Educating patients and caregivers about palliative care and its distinction from hospice care can improve understanding and decision-making. Expanding access to information about clinical trials and their potential benefits may empower individuals to explore advanced treatment options and innovative research.
- **Expand community and peer support networks to enhance well-being.** Peer mentorship programs, such as pairing patients with survivors of similar cultural backgrounds or diagnoses, can offer invaluable emotional and practical support. Caregiver support programs that provide training, counseling, and respite care can reduce burnout and help caregivers better manage their responsibilities. Partnering with community-based organizations trusted by BIPOC and LGBTQIA+ individuals can further bridge gaps in care and foster trust.
- **Broaden access through telehealth and coordinated care efforts.** Expanding telehealth services can address geographic barriers and improve access to treatment and care for rural communities. Collaboration among local hospitals, cancer centers, and community organizations can enhance care coordination, ensuring smoother transitions between treatment stages and better outcomes for patients. Establishing patient navigator programs to guide individuals through the complexities of treatment can help low-income and marginalized individuals access the care and support they need.
- **Promote holistic support to improve patient outcomes.** Group cooking classes and education on "food as medicine" can encourage better nutrition and foster social connection. Expanding insurance coverage to include complementary care modalities can address physical, emotional, and social needs during treatment. Subsidized transportation options and community volunteer driver programs can help low-income patients overcome logistical barriers to accessing care.
- **Ensure culturally competent care to reduce disparities.** Training providers in cultural competency can foster stronger relationships with patients, enhancing trust and adherence to treatment plans. Employing interpreters and using inclusive language and gender-affirming practices can help reduce barriers for non-English speakers and LGBTQIA+ individuals. Community-based strategies, such as holding events at trusted spaces like churches and cultural centers, can improve access for BIPOC and immigrant populations.
- **Prioritize equity and inclusion in care strategies.** Addressing systemic barriers faced by marginalized populations, such as incarcerated individuals, those with disabilities, and LGBTQIA+ communities, is critical to ensuring equitable access to high-quality treatment and care. Supporting hospitals in their efforts to achieve Commission on Cancer accreditation. This recognition would potentially enable more clinical trial opportunities in underserved areas. These efforts must be guided by a commitment to creating an inclusive healthcare system that meets the diverse needs of all patients.

## Perceptions of Cancer Treatment and Care Strategies

Figure 5 presents perceptions of the current effectiveness of cancer treatment and care in Maine (n=114), both overall and by role. Overall, half of respondents (49.1%) rated cancer treatment and care efforts as excellent, while the other half considered them fair (23.7%), poor (7.0%), or unsure (20.2%). When analyzed by role, approximately half of public health professionals (46.2%), people with lived experience (49.5%) and community organizations (51.5%) viewed treatment and care as excellent. Healthcare professionals had the most polarized views, with 70.3% rating treatment and care as excellent and 21.6% considering it poor. Researchers and respondents categorized as "other" displayed mixed opinions, with 53.3% and 41.7%, respectively, rating efforts as excellent, while higher proportions expressed uncertainty or less favorable evaluations.

*Figure 5. Respondents Perceptions of the Effectiveness of Current Cancer Treatment Care Strategies*

## Factors Limiting Effectiveness of Treatment and Care Strategies

**Geographic and accessibility barriers.** The rural geography of Maine poses significant challenges, with 62.6% of survey respondents citing the distance to treatment centers as a major obstacle. Long travel distances, particularly in rural counties like Hancock and Washington, make accessing specialized cancer care and palliative services difficult. Additionally, marginalized groups, such as incarcerated individuals and those with physical or verbal disabilities, face systemic barriers that limit access to tailored, quality care.

**Financial and insurance limitations.** High treatment costs, reported by 54.8% of respondents, place a substantial financial burden on patients and their families, often leading to financial distress. Insurance limitations, cited by 52.2%, further exacerbate these challenges, leaving many patients underinsured or facing significant out-of-pocket expenses. A lack of coverage for complementary therapies and integrative care highlights systemic gaps in providing holistic and supportive care options.

> "Have more locations that are staffed with trained people so that provide statewide cancer treatments are available specifically for women's needs. I had to drive my 91-year-old mother-in-law 3 hours one way to Southern Maine for the only specialist for surgery and treatment. The long rides were more difficult for her than the surgery and treatment." - survey respondent

**Resource shortages and workforce capacity.** A shortage of specialists, reported by 28.7% of respondents, and long wait times for treatment

(30.4%) highlight critical workforce capacity issues in oncology and related fields. These delays in accessing care negatively affect patient outcomes. Additionally, there is insufficient availability of coordinated palliative care services and comprehensive support resources, leaving patients and families without the guidance needed to navigate complex treatment and end-of-life care processes.

**Awareness and education gaps.** A lack of understanding about palliative care and its distinction from hospice care limits patients' ability to make informed decisions. Limited awareness of available clinical trials and their potential benefits further restricts access to advanced treatment options. These gaps in awareness and education underscore the need for targeted efforts to improve health literacy and patient empowerment.

**Cultural and emotional challenges.** Cultural and linguistic differences, noted by 24.4% of respondents, create barriers to effective communication and care delivery. Patients from diverse backgrounds often face reduced access to culturally sensitive care, leading to misunderstandings and gaps in treatment. Emotional challenges, such as fear, anxiety, and a lack of psychological support, are frequently overlooked, leaving patients without critical resources to cope with the stress of cancer treatment and end-of-life care. Addressing these barriers through culturally competent care and emotional support is essential for improving patient outcomes and overall well-being.

> "Considering equity – access to quality care for incarcerated patients. … Considerations around disabilities in cancer treatment, palliative care, and hospice care – making care most accessible for people with verbal and physical disabilities." - IdeaBoardz

## Challenges Across Priority Communities

### Black, Indigenous, People of Color Communities

**Challenges.** Accessing cancer treatment presents significant barriers for BIPOC communities, influenced by systemic and social factors. Limited transportation, financial strain, and a shortage of specialists in underserved areas make accessing timely and effective care difficult. Fear and mistrust of the healthcare system further complicate treatment engagement, as historical and ongoing inequities create skepticism about the quality and intentions of care. Additionally, a lack of cultural competency among healthcare providers can make patients feel misunderstood or uncomfortable, leading to lower adherence to treatment plans and decreased trust in recommendations. These challenges collectively contribute to disparities in cancer treatment outcomes for BIPOC individuals.

**Solutions.** Implementing culturally competent care is essential to improving treatment experiences and outcomes for BIPOC communities. Training healthcare providers to understand and respect cultural differences can foster stronger relationships with patients, enhancing trust and adherence to treatment plans. Peer support programs that pair patients with survivors from similar cultural backgrounds can offer encouragement and shared understanding, helping patients navigate their treatment journey. Partnering with trusted community organizations can further bridge gaps in care by providing guidance and support to patients throughout the treatment process, ensuring they feel supported and connected to reliable resources.

## LGBTQIA+ Community

**Challenges.** LGBTQIA+ individuals often face unique barriers in accessing cancer care due to systemic and individual-level challenges. Previous negative experiences in healthcare, such as a lack of affirming or inclusive care, contribute to distrust in the healthcare system and reluctance to seek treatment. For transgender individuals, potential interactions between hormone therapies and cancer treatments add complexity to their care, requiring careful management and individualized attention. These challenges underscore the need for more inclusive, knowledgeable, and patient-centered approaches in cancer care for LGBTQIA+ individuals.

**Solutions.** Promoting open communication and affirming care is essential to building trust and improving outcomes for LGBTQIA+ individuals. Clinical providers can foster an inclusive care environment by offering affirming services, addressing patients' unique needs, and creating safe spaces for open dialogue about treatment plans, including medication interactions and hormone regimen. Supporting and strengthening community-based organizations that provide vital resources and advocacy for LGBTQIA+ individuals is another key solution. These organizations can play a critical role in bridging gaps in care and offering emotional and logistical support throughout cancer treatment and beyond.

> "Promote culture of positive treatment and cancer care to break down potential distrust among LGBTQIA+ community members."
> - IdeaBoardz

## Low Income Communities

**Challenges.** Low-income individuals with cancer in Maine face significant barriers that hinder access to quality treatment and care. Reliable transportation is a primary challenge, as many patients lack the means to travel to treatment centers, particularly in rural areas. This issue is compounded for those who need someone to accompany them for support, as the absence of transportation options or assistance can make attending appointments nearly impossible. Language barriers and cultural differences further complicate care, particularly for non-English speakers, who may struggle to communicate their needs or understand treatment plans. Financial challenges also play a critical role, as many low-income patients lack sufficient healthcare coverage, leaving them vulnerable to the high costs of cancer care. Additionally, the lack of resources to maintain proper nutrition during treatment and limited support for caregivers exacerbate the difficulties faced by these communities.

**Solutions.** Addressing these challenges requires a multi-faceted approach focused on improving access, support, and equity in cancer care. Expanding transportation options, such as subsidized rides and community volunteer driver programs, can help patients reach treatment centers more reliably. Language support services and the hiring of culturally competent staff can bridge communication gaps and ensure that care is tailored to diverse needs. Financial assistance programs, developed in partnership with local hospitals and cancer centers, and expanded Medicaid options can reduce the economic burden on low-income patients. Patient navigator programs can guide individuals through the complexities of the healthcare

> "... patient navigator programs to assist low-income individuals in managing appointments, understanding treatment options, and accessing support."
> - IdeaBoardz

system, helping them manage appointments, understand treatment options, and access emotional and logistical support. Additionally, initiatives to provide nutritional assistance and resources for caregivers can address critical non-medical needs, ensuring that patients and their support systems are better equipped to manage the challenges of cancer treatment.

### Rural Communities

**Challenges.** Cancer treatment and care in Maine face numerous challenges that hinder access and quality of care. Workforce shortages were identified as the most pressing issue, with a critical need for more providers and specialists, including geriatric and pediatric care professionals, particularly in rural areas with aging populations. Cultural and language barriers also pose significant obstacles, as patients from diverse backgrounds may struggle to communicate their needs or navigate the healthcare system without adequate interpretation services. Financial burdens, including out-of-pocket expenses and insufficient insurance coverage, further exacerbate disparities, leaving many patients unable to afford necessary treatments. Additionally, while caregivers play a vital role in supporting patients, they often lack the resources and support needed to manage their responsibilities effectively, which can lead to burnout. Access to clinical trials, which could provide advanced treatment options, remains limited, particularly for older adults, due to a lack of accredited hospitals in the state.

**Solutions.** Addressing these challenges requires a comprehensive approach to improving workforce capacity, accessibility, and support systems. Expanding the healthcare workforce, including recruiting and retaining specialists in geriatric and pediatric oncology, is essential for addressing provider shortages in underserved areas. Increasing the availability of interpreters and culturally competent care can help reduce language and cultural barriers, ensuring more equitable treatment. Financial assistance programs and insurance reforms are necessary to alleviate the economic strain on patients and their families. Supporting caregivers through dedicated resources, such as counseling, respite care, and training, can enhance their ability to provide effective care while preventing burnout. Finally, encouraging hospitals to achieve Commission on Cancer accreditation (through the American College of Surgeons) would potentially enable more clinical trials opportunities in underserved areas, particularly for older adults.

> "... recruit and retain workforce - providers, nurses, specialists etc." - IdeaBoardz

## Recommendations for Improving Cancer Treatment and Care Strategies

**Improved education and awareness are essential to empower patients and caregivers.** Providing targeted education on palliative care, with a clear distinction from hospice care, can enhance understanding and decision-making for patients and caregivers. Accessible information about clinical trials and their potential benefits should also be made widely available, empowering individuals to explore advanced treatment options and participate in innovative research.

**Building community and peer support networks strengthens emotional well-being.** Initiatives like "Breast Buddies," which pair patients with survivors of similar age and diagnosis, provide invaluable guidance and emotional support through shared experiences. Similarly, connecting potential hospice participants with families who have experienced hospice care offers reassurance and practical insights, helping to alleviate fears and foster confidence in care decisions.

> "Peer support programs such as 'breast buddies' where patients in treatment are paired with a survivor with a similar stage and age at diagnosis." - IdeaBoardz

**Expanding access to care ensures more equitable healthcare delivery.** Telehealth options should be expanded to bridge geographical gaps and improve access to cancer treatment and palliative care services, particularly for individuals in isolated areas. Encouraging collaboration among local and regional stakeholders can also enhance care coordination, ensuring more seamless transitions between treatment stages and better outcomes for patients.

**Holistic support promotes overall well-being and fosters connection.** Implementing group cooking classes and educational sessions on "food as medicine" can encourage healthier habits and create opportunities for social interaction. Advocating for insurance coverage of complementary care modalities, such as integrative therapies, further supports patients' holistic well-being by addressing physical, emotional, and social needs.

**Equity and inclusion must be prioritized to address systemic barriers.** Developing inclusive strategies to support marginalized populations, including individuals with disabilities and those who are incarcerated, is essential for ensuring equitable access to high-quality cancer treatment and palliative care. By removing systemic barriers and tailoring care to diverse needs, healthcare systems can reduce disparities and better serve all patients.

> "Educate about palliative care and the difference between palliative care in and outside of hospice." - IdeaBoardz

SURVIVORSHIP

## SUMMARY

**Perceptions of Cancer Survivorship Strategies**

Almost half of respondents (40.3%) rated survivorship strategies in Maine as effective, while 42.1% were unsure, highlighting gaps in communication and engagement regarding available services. Public health professionals expressed the highest confidence, with 53.9% of respondents rating strategies as effective, while uncertainty was notably higher among patients, survivors, caregivers, and community organization members. Healthcare professionals and researchers offered mixed perspectives, reflecting varying degrees of confidence in the effectiveness of current strategies.

**Factors Limiting Effectiveness of Cancer Survivorship Strategies:**

- **A lack of awareness and fragmented care coordination limit access to survivorship services.** The most frequently reported barrier (59.1%) was a lack of awareness about available survivorship resources, leaving many survivors and caregivers unaware of essential services. Fragmented coordination among healthcare providers, cited by 44.8%, further complicates access and leads to unmet needs, particularly for rural patients facing transportation challenges.
- **Psychological and emotional support for survivors is inadequate.** Survivors frequently experience untreated emotional burdens such as anxiety, depression, and isolation, compounded by a lack of specialized mental health professionals.
- **Nutrition and health concerns are overlooked.** Limited access to nutritional counseling and poor-quality food options negatively impact survivors' long-term health, particularly for those in rural areas or facing financial constraints.
- **Resource and workforce shortages hinder survivorship care.** A shortage of survivorship specialists, hospice aides, and tailored programs restrict survivors' access to essential services, particularly in rural areas.

**Challenges Across Priority Communities**

- **BIPOC Communities:** Survivors face challenges accessing culturally sensitive emotional and psychological support. Disparities in follow-up care and rehabilitation services exacerbate health inequities, particularly in underserved areas.
- **LGBTQIA+ Communities:** LGBTQIA+ survivors face heightened risks of recurrence or new cancers and a lack of tailored support services. Isolation and limited access to community-specific resources further compound these challenges.
- **Low-Income Communities:** Financial and logistical barriers prevent access to rehabilitation, mental health services, and nutritional support. Survivorship care often lacks flexibility, leaving low-income survivors without access to long-term resources.
- **Rural Communities:** Survivors in rural areas face transportation challenges, food deserts, and limited access to hospice, palliative care, and peer support networks, resulting in isolation and diminished quality of life.

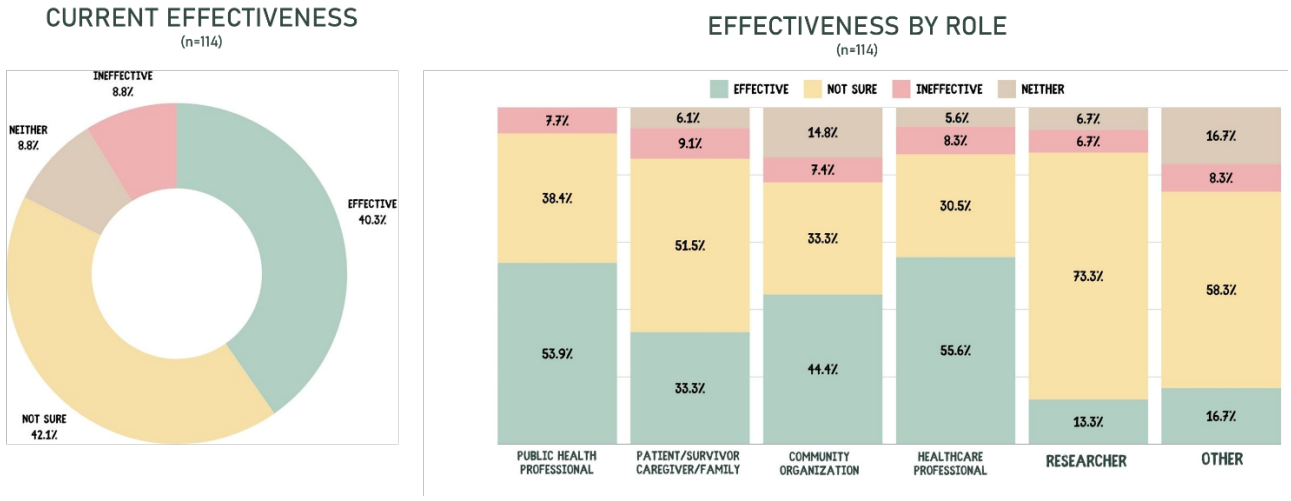
**Recommendations for Improving Survivorship Strategies**

- **Increase awareness and empower self-advocacy.** Educational campaigns promoting survivorship services and positive quality-of-life framing can help survivors better understand and access resources. Coaching programs can teach survivors to advocate for their needs and take control of their care.
- **Expand community and peer support networks.** Partner with local organizations to create accessible survivorship programs and peer support groups that foster connection and reduce isolation. These efforts should include culturally tailored programs for BIPOC and LGBTQIA+ communities.
- **Enhance provider training and care coordination.** Toolkits for providers can improve communication about survivorship care and ensure smooth care transitions. Designated EMR pathways and improved case management services can help survivors navigate available resources effectively.
- **Leverage technological solutions to address access barriers.** Telehealth services and mobile care options can support survivors in rural areas, addressing transportation and geographic challenges while connecting them to comprehensive care.
- **Promote nutrition and fitness programs.** Free evidence-based nutrition classes and survivor-led fitness initiatives can improve survivors' physical and mental health, while addressing social isolation. Local gyms and community centers should host these programs for accessibility.
- **Address workforce and resource gaps to strengthen survivorship care.** Scholarships for training programs, such as "Exercise is Medicine," can grow the survivorship-focused workforce. Expanding Maine's oncology provider capacity and insurance-supported cancer navigators can ensure all survivors have access to knowledgeable advocates and critical services.

## Perceptions of Cancer Survivorship Strategies

Figure 6 illustrates perceptions of the current effectiveness of survivorship strategies in Maine (n=114), both overall and by role. Overall, almost half of respondents (40.3%) rated survivorship strategies as effective, while 42.1% were unsure. This high level of uncertainty highlights significant gaps in awareness or communication regarding existing survivorship initiatives. When broken down by role, public health professionals expressed the highest confidence, with 53.9% rating strategies as effective, while 38.4% were unsure, and 7.7% found them ineffective. Among patients, survivors, caregivers, or family members, only 33.3% rated strategies as effective, with a substantial 51.5% reporting uncertainty, reflecting a need for better engagement and clarity about available survivorship resources. Community organization members showed similar trends, with 44.4% rating strategies as effective and 30.3% unsure. Healthcare professionals were more critical, with 55.6% finding strategies effective but 30.5% unsure and 5.6% rating them as ineffective. Researchers had mixed opinions, with 13.3% rating strategies as effective, yet 73.3% were unsure, and 6.7% rated them ineffective. Respondents in the "other" category were less positive, with 16.7% rating strategies as effective and 58.3% finding them ineffective.

*Figure 6. Respondents Perceptions of the Effectiveness of Current Cancer Survivorship Strategies*




## Factors Limiting Effectiveness of Survivorship Strategies

**Lack of awareness and fragmented care coordination hinder access to survivorship services.** The most frequently reported barrier, cited by 59.1% of respondents (n=105), is a lack of awareness about available survivorship services. This critical gap in communication leaves many individuals unaware of essential resources. Additionally, fragmented coordination among healthcare and support providers, identified by 44.8% of respondents, reflects systemic inefficiencies that result in confusion, duplicated efforts, and unmet needs for survivors navigating post-treatment care. Survivors in rural areas face additional challenges, as transportation difficulties and a lack of cohesive care systems create significant obstacles to accessing support services.

**Psychological and emotional support for survivors is insufficient.** Emotional challenges such as anxiety, depression, and feelings of isolation are common among survivors, yet 32.4% of respondents noted inadequate psychological and social support as a major barrier. Survivors often

struggle to find therapists who understand their unique needs, and this scarcity of specialized support leaves many dealing with untreated emotional burdens. Social isolation further compounds these challenges, diminishing survivors' quality of life and underscoring the need for targeted interventions.

**Nutrition and health concerns are inadequately addressed.** Access to evidence-based nutritional counseling is limited, and poor-quality food options provided by some healthcare facilities can negatively impact survivors' health. Financial constraints and the lack of virtual or free counseling options exacerbate barriers to maintaining a healthy lifestyle. For survivors in rural areas, these challenges are further amplified by limited access to local nutrition resources.

**Resource and workforce shortages limit comprehensive survivorship care.** A shortage of survivorship specialists, highlighted by 19.1% of respondents, reduces access to professionals equipped to address the unique challenges faced by cancer survivors. The limited availability of survivorship programs, such as tailored fitness initiatives or local support groups, further restricts access to essential services, especially in rural areas. Resource deserts, transportation challenges, and the absence of localized care exacerbate these issues, leaving many survivors without the support needed to promote long-term health and well-being.

## Challenges Across Priority Communities

### Black, Indigenous, and People of Color Communities

**Challenges.** BIPOC cancer survivors face unique challenges in accessing the support and care they need for successful survivorship. Emotional and psychological support services often lack cultural sensitivity, making it difficult for survivors to find resources that resonate with their lived experiences and identities. Additionally, disparities in health equity are evident, as survivors in rural or underserved areas frequently encounter barriers to follow-up care and rehabilitation services. These inequities leave many survivors without access to essential resources that promote long-term recovery and well-being, compounding the difficulties they face after treatment.

**Solutions.** Building community-based support programs can provide culturally relevant networks of care for BIPOC survivors. Peer groups and survivorship programs tailored to the unique needs of these communities can foster connection and understanding, creating safe spaces for survivors to share experiences and access guidance. Holistic survivor care should emphasize resources that address not only physical health but also mental, emotional, and social well-being. Incorporating culturally sensitive practices into these services ensures that survivors feel seen, understood, and supported, ultimately enhancing their quality of life and long-term outcomes.

### LGBTQIA+ Communities

**Challenges.** Cancer survivors, particularly LGBTQIA+ individuals, face increased risks of recurrence or new cancers, underscoring the critical need for ongoing prevention and screening efforts. Higher associated risk factors within the LGBTQIA+ community make this population especially vulnerable, yet tailored survivorship care addressing these risks remains limited. Additionally, many survivors experience a lack of support services and increased isolation. For LGBTQIA+ survivors, the scarcity of community-specific support groups or services further compounds feelings of disconnection and unmet emotional needs, leaving a significant gap in survivorship care.

**Solutions.** An integrated approach to survivorship care can help mitigate these challenges by fostering collaboration between cancer prevention, screening, and support services. Promoting these efforts among survivors can reduce silos and enhance access to resources that address both ongoing risks and overall well-being. Expanding peer support opportunities, such as establishing LGBTQIA+-specific recovery specialists and support groups, can provide survivors with emotional and practical guidance in a safe and affirming environment. Community-based organizations can play a pivotal role in these efforts, offering culturally competent support programs that empower survivors to manage ongoing risks while fostering a sense of belonging and connection.

> "... peer recovery specialists and/or support groups to promote survivorship support among LGBTQIA+ community members; having peer-to-peer support is proven to be effective." - IdeaBoardz

## Low Income Communities

**Challenges.** Low-income cancer survivors in Maine face significant barriers that impact their long-term well-being and access to necessary services. Ensuring continued access to screenings, rehabilitation, and mental health services is a key challenge, as financial and logistical barriers often prevent individuals from adhering to their survivorship care plans. Many survivors lack the resources to access physical therapy, counseling, or nutritional support, which are vital for managing long-term health. Additionally, the absence of survivorship groups tailored to low-income populations leaves survivors and their families without the emotional and social support they need. Survivorship care often comes with timeline limitations, making it difficult for individuals to access services years after treatment ends. These gaps create challenges in addressing both the physical and emotional aspects of survivorship, particularly for those navigating systemic inequities.

**Solutions.** To address these challenges, participants proposed implementing free or low-cost rehabilitation programs, including physical therapy, counseling, and nutritional guidance, to make survivorship care accessible for low-income individuals. Establishing survivorship groups that include families and support systems, and hosting them outside clinical settings at flexible times, can provide much-needed emotional and social support. Removing timeline limitations for survivorship services ensures that survivors can access care whenever needed, even years after treatment ends. Survivor networks can help individuals navigate social services and address psychological needs, while survivor advocacy programs can empower individuals to give back as ambassadors for cancer screening and survivorship care. Policy efforts, such as advocating for employment protections, paid sick leave, and disability benefits, are essential to supporting survivors' financial and professional stability. Additionally, continuing education about appropriate cancer screenings for survivors can promote long-term health, ensuring they remain proactive about their care as they age.

> "Ensure low-income survivors have access to ongoing screenings, rehabilitation, and mental health services as part of their survivorship care plan." - IdeaBoardz

### Rural Communities

**Challenges.** Cancer survivors face a variety of challenges that impact their long-term well-being, with a lack of awareness about survivorship services emerging as a major issue. Many survivors and caregivers remain unaware of available resources, including lifestyle and nutritional guidance, which are critical for maintaining health post-treatment. Access to services also poses significant barriers, particularly for rural patients who face transportation challenges in reaching survivorship care. Survivors and caregivers in rural areas may also contend with food deserts, limiting their ability to maintain healthy diets. A shortage of hospice, palliative care, and in-home health aides exacerbates these challenges, leaving many without essential support during their recovery. Additionally, survivors and caregivers often experience isolation due to insufficient access to peer or community-based support groups, further impacting their emotional and social well-being.

> "... trying to maintain a healthy lifestyle/diet when they may reside in food desert area with limited options." - IdeaBoardz

**Solutions.** To address these challenges, increasing awareness about survivorship services and resources is essential. Educational campaigns promoting the availability of services and emphasizing the importance of lifestyle and nutritional information can empower survivors to make informed decisions about their health. Expanding access to care through telemedicine and providing paid time off for survivors to access services can help reduce logistical barriers. Enhancing support systems, such as creating peer support networks and survivors and caregiver support groups, can alleviate feelings of isolation and foster community connections. Workforce improvements, including increasing the availability of hospice, palliative care, and in-home health aides, are critical for providing comprehensive survivorship care. Addressing transportation barriers through subsidized transportation programs and improving access to healthy food options in rural areas can further support the recovery and long-term health of survivors and their caregivers.

## Recommendations for Improving Survivorship Strategies

**Promoting survivorship awareness and self-advocacy empowers survivors to take control of their care.** Framing survivorship with a positive focus on quality of life can help survivors view their journey more constructively and reduce emotional barriers. Teaching self-advocacy through individualized coaching or training programs equips survivors with the skills and confidence to actively participate in decisions about their care and advocate for their needs.

**Community and peer support networks can alleviate isolation and foster connections.** Building community networks for survivors creates opportunities for mutual support and reduces social isolation. Partnering with local organizations, such as YMCAs, to develop survivorship programs provides accessible rehabilitation and support, helping survivors reconnect with their communities and enhance their well-being.

**Enhancing provider training and care coordination ensures better survivorship outcomes.** Training toolkits for healthcare providers can improve communication with patients about survivorship care and next

> "Cancer care navigators to provide patient advocacy covered by insurance and an option for those without insurance to receive the same." - IdeaBoardz

steps, ensuring a smoother transition from treatment to survivorship. Designated EMR pathways can prevent patients from being overlooked during care transitions, while improved case management services can guide survivors to the resources and support they need.

**Technological and mobile solutions can bridge accessibility gaps for survivors.** Mobile care and screening options, coupled with telehealth services, offer critical support for survivors in rural areas, addressing geographic barriers. Mobile care can also act as a link to additional services, ensuring survivors receive comprehensive care even in underserved regions.

**Expanding nutrition and fitness programs support survivors' long-term health.** Offering free, evidence-based nutrition classes and coaching empowers survivors to maintain healthy lifestyles and make informed dietary choices. Survivorship programs at local gyms, led by trained professionals, provide opportunities for survivors to rebuild physical strength, improve mental health, and combat social isolation.

> "More local gyms that have survivorship programs. Trained trainers to help build strength. It would also help with rehab and social isolation." - IdeaBoardz

**Addressing resource gaps and equity is essential to strengthening the survivorship workforce.** Scholarships for training programs supporting initiatives, such as "Exercise is Medicine," can increase the number of survivorship-focused professionals and enhance the quality of care available. Expanding Maine's oncology provider workforce and increasing support for cancer care navigators covered by insurance ensures survivors have access to knowledgeable advocates and resources, regardless of their insurance status.

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