



# Community Plan

## January 2018



To our fellow Mainers:

Maine's Impact Cancer Network members have spent the last two years getting to know each other, building relationships, and laying a foundation for engaging in the collaborative work required to reduce cancer in Maine. Our Leadership Roundtable listened to and learned from over 600 Mainers from across the state about their experiences with cancer. They told us how cancer affects them, the change they want to see in Maine, and how we can make those changes happen by working together.

It was through these conversations that we formed our common agenda, or shared vision, for reducing the impact of cancer in Maine. It builds upon the great work organizations across the state have been engaging in for decades, and it brings those organizations, and new colleagues, together to work collaboratively to improve our systems for addressing cancer in Maine.

Thank you for taking the time to read our community plan and to all of you who have helped us get to this point, and are currently partnering with us. We believe this plan will provide you with continued inspiration to join our movement. We cannot do this work alone, and we are counting on Mainers and Maine organizations to engage in this work with us. We want this to be your plan too. If you see an issue or opportunity we might have missed, reach out to us, and together we can create a place for you.

On behalf of Maine's Impact Cancer Network, thank you,

Jennifer Dumas  
Chair  
Maine's Impact Cancer Network

Gayle Brazeau  
Vice-Chair  
Maine's Impact Cancer Network



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## Executive Summary

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For over 40 years, Maine Cancer Foundation (MCF) has been working to reduce cancer incidence and mortality in Maine. MCF has been doing this work alongside individuals and organizations across Maine, who are also dedicated to alleviating cancer's burden and the various impacts it has on people and communities. Although strides have been made to reduce the impact of cancer in Maine, it remains the state's number one leading cause of death, with death rates higher than the national average. Despite all of our best efforts, cancer has continued to take a steady and devastating toll on our communities. To change this story, MCF realized that current strategies may need to evolve and become more innovative. In 2015, Maine Cancer Foundation began to explore the collective impact framework as a way to build relationships, strengthen collaborations, and create systems change in order to have the impact we all want – reducing cancer's impact on individuals and communities in Maine.

Maine's Impact Cancer Network (the Cancer Network) was the result of this exploration, and now represents a collaboration of people with lived experience with cancer, non-profits, businesses, and government who are working together toward a shared vision to change the landscape of cancer in Maine. Using the collective impact framework, which includes a common agenda, shared measurement system, mutually reinforcing activities, continuous communication, and backbone support, the Cancer Network hopes to change the story of cancer in Maine.

After gathering input from 670 people throughout Maine, the Cancer Network's Leadership Roundtable, a multi-sector group who guides the Cancer Network's strategic thinking and vision, with support from MCF staff, created a the common agenda to reduce cancer's impact and increase collaboration to create system change. This common agenda includes the key themes of healthcare system collaboration, access to transportation and care, education, advocacy, and survivorship. Maine Cancer Foundation is currently the backbone support for the Cancer Network, providing staff, resources, and funding, but intends to share the role to fully foster collaboration.

The Cancer Network will address the common agenda through the work of Task Forces. These multi-sectoral, collaborative, action-oriented groups base their work on the implementation ideas proposed by the 670 Mainers the Cancer Network consulted with via community conversations. The Task Forces currently include Transportation, Employer Strategies, Cancer Resources and Support Centers, Palliative Care, Rehabilitation and Survivorship, and Advocacy. Their work is evaluated by a Data Team, comprised of statisticians, researchers, and epidemiologists, who will track Maine's cancer incidence and mortality rates as well as the Network's influence. The Cancer Network places a focus on evaluation to help members learn from their work, assess, and re-focus as needed to ensure the work is always moving forward and representing the needs and wants of Mainers. This also creates an opportunity for new ideas to come to the table, and for new members to join in the work of the Network.

The Cancer Network wants its members and Mainers in general, to recognize the following community plan as their plan too. In order to make the impact we want on cancer in this state, we need to work better together. We need to create a community that fosters relationships, embraces trust, shares resources and best practices, and ultimately creates a change in our systems so no person, family, or community has to face cancer alone.



## Acknowledgements

Maine's Impact Cancer Network's community plan would not be possible without the support and participation of our friends, both new and old, colleagues, stakeholders, and partners. Thank you to the several hundred people across Maine who helped organize and participate in our community conversations. Your input, experiences, and expertise are the foundation for our shared vision to address cancer in Maine. Thank you to the individuals who volunteer their time on our Leadership Roundtable providing our strategic guidance – Gayle Brazeau, Peggy Belanger, John Cronan, Jennifer Dumas, Tara Hill, Eric Jarvi, Susan Maataoui, and Michael Reisman – and on our Data Team assisting in the identification of our shared measures – Tim Cowan, Ed Li, Zakia Nelson, Molly Schwenn, and Andrew Williams. We thank Paul Born, cofounder and co-CEO of the Tamarack Institute, who continues to work with us providing training and guidance on the collective impact framework. Thank you to the many members of the Cancer Network's Task Forces. Without you, we would not be able to engage in this great work, improving our collaboration and systems and reducing the impact of cancer for Mainers. Lastly, thank you to Maine Cancer Foundation who has committed fiscal sponsorship to provide backbone support. Heather Drake, MCF Program Manager, has been instrumental in launching the Network and forming important relationships, providing administrative support and leadership that has created essential momentum for our Network. Thank you also to MCF staff, Tara Hill, Aysha Sheikh, Katelyn Michaud, Kristen Smith, Kelly Martin, Ashley MacMillan, and Julia Bachelder who provide support day in and day out.



## Addressing Cancer in Maine: Using the Collective Impact Framework

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In 2015, Maine Cancer Foundation (MCF) began to explore ways to address the high rates of cancer in Maine in a more strategic and collaborative way. Given the gravity and complexity of cancer in Maine, MCF recognized that reducing the cancer burden could not be achieved if organizations continue to work in silos. Maine Cancer Foundation chose the collective impact framework as a way to bring people together from across the state to learn about their experiences with cancer and create action around what is working and identify the gaps that need to be filled. The collective impact framework emphasizes the need to connect people from four sectors: non-profit organizations, the business community, those with lived experience with cancer, and government. By connecting people and organizations, and hearing from those directly affected by cancer, the framework provides an opportunity for dialogue, relationship building, and ultimately a commitment to work together to create system-wide change. The collective impact framework has five conditions:

**Common Agenda**  
**Shared Measurement System**  
**Mutually Reinforcing Activities**  
**Continuous Communication**  
**Backbone Support**

- **Common Agenda**

The common agenda is defined as a shared understanding of the issue being addressed and an agreed upon approach to solving it. In order to form our common agenda, the Cancer Network heard from 670 people over the course of a year, with representation from the four sectors of non-profit organizations, the business community, those with lived experience with cancer, and government. Together we developed our shared understanding of cancer in Maine and identified the following key themes: healthcare system collaboration, access, education, advocacy, and survivorship. While the common agenda exists in its current state, it remains emergent, enabling it to be amended as necessary to reformulate goals and strategies and bring on new partners.

- **Shared Measurement System**

In order to ensure Maine's Impact Cancer Network and its members are staying accountable to the common agenda, while also learning from our work, it is imperative to have a shared measurement system. A shared measurement system provides a set of agreed upon metrics and indicators that serve as check points to determine if the Cancer Network's initiatives are meeting their goals or whether they need to be reevaluated or redefined. Shared measurement systems encourage local organizations to align their efforts on shared outcomes, enable them to collectively track and evaluate their progress and offer organizations opportunities to benchmark their results against – and learn from – their peers.<sup>i</sup>



- **Mutually Reinforcing Activities**

Mutually reinforcing activities are programs and activities that organizations are already conducting, but in this case they are coordinated to create greater influence in addressing cancer. Maine's Impact Cancer Network acknowledges there are numerous organizations acting across the State on cancer-related activities, working on everything from reducing cancer rates, to increasing prevention, to improving outcomes for patients. Yet, it also acknowledges the need to bring these organizations together so the activities and outcomes mutually reinforce each other and reduce the impact of cancer.

- **Continuous Communication**

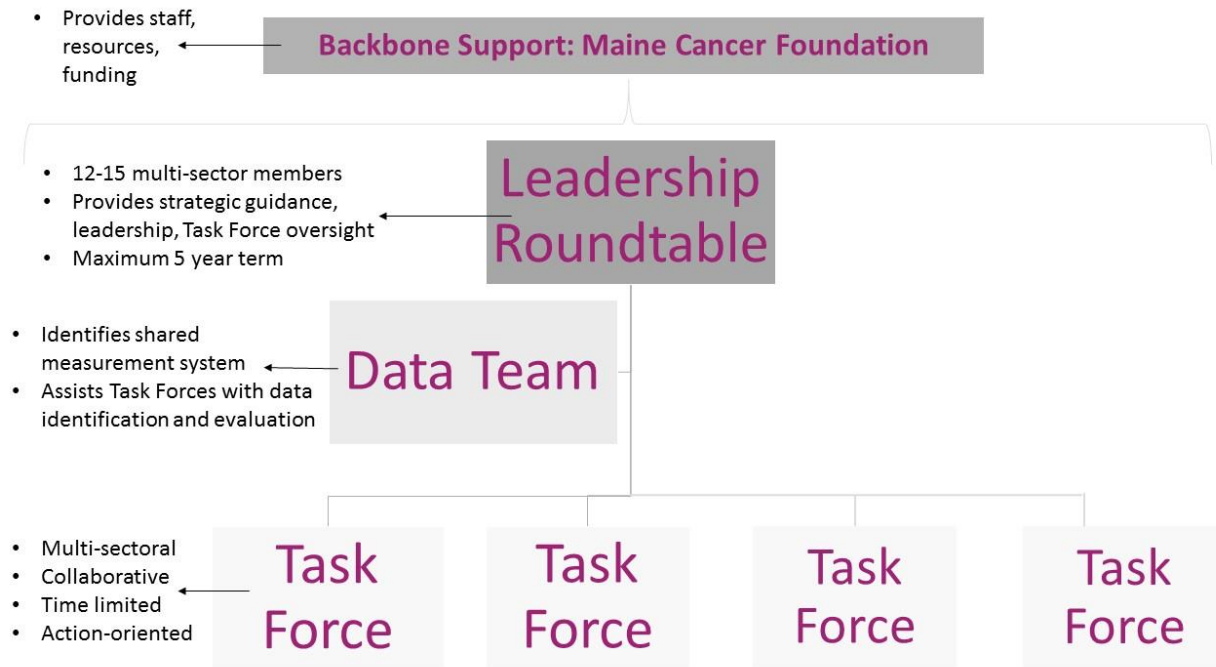
One of the reasons the collective impact framework is successful, is because it stresses the importance of building relationships, trust, and respect between stakeholders. In order to do this, the Cancer Network's stakeholders need to be in communication with each other to stay informed, exchange ideas, and discuss what is and is not working. Since its outset, the Cancer Network is keeping members informed through articles in the Maine Cancer Monthly newsletter, MCF's general newsletter, and MCF's website. Over time, the Cancer Network will develop its own form of regular communication and will strive to create a virtual platform that fosters an exchange of ideas, best practices, and collaboration. Maine Cancer Foundation will continue to support an annual cancer conference to bring both its Membership and the Cancer Network's members together for networking and learning and to host learning opportunities throughout the year.

- **Backbone Support**

The role of a backbone organization in collective impact is to provide support and coordination. The collective impact model places emphasis on identifying an organization or preferably a group of organizations, who are willing and able to dedicate required resources. Maine Cancer Foundation is well suited to play the role of the backbone organization given its presence as a statewide organization, with resources dedicated solely to impacting cancer in Maine; its unbiased and unaffiliated nature; and nimble structure, with support and guidance from its Board of Directors. As the backbone organization and fiscal sponsor, MCF has committed funding, staff, and resources to coordinate and organize Maine's Impact Cancer Network. MCF has made it a point to set the Maine's Impact Cancer Network outside of its own goals and objectives, ensuring the Cancer Network is representative of Mainers and their self-identified goals. MCF is committed to seeing Maine's Impact Cancer Network through to achieving its goals and addressing cancer in the State. However, MCF also values the support of other organizations and funders and welcomes them to the table to share the backbone support role. Ultimately, MCF hopes to share or pass on the role of the backbone organization and not be the sole driver of the Cancer Network. Please see Figure 1 for the Cancer Network's governance structure.



**Figure 1: Maine's Impact Cancer Network's Governance Structure**



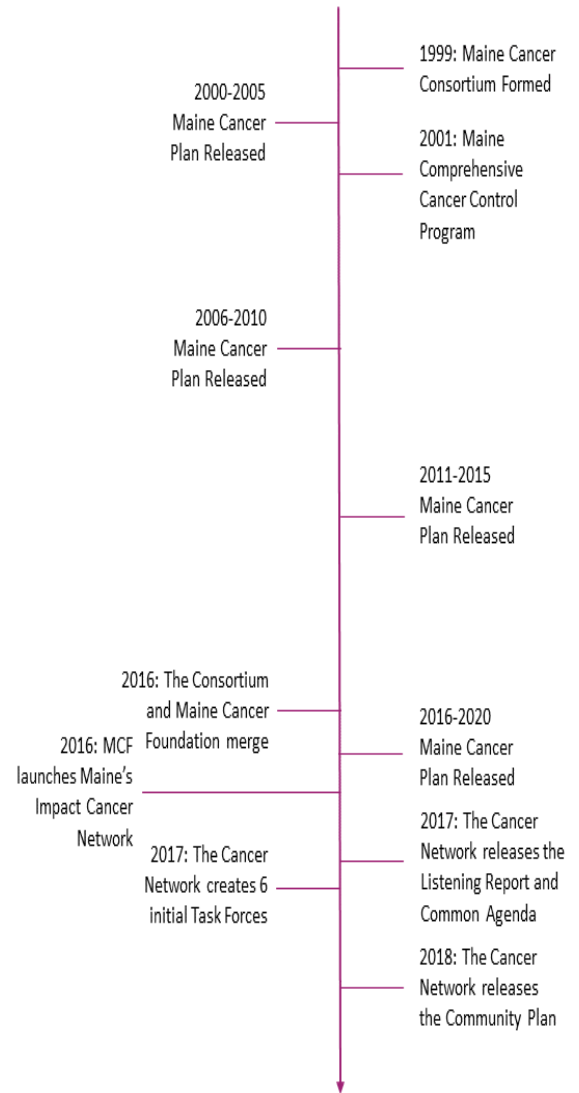




## The Landscape of Cancer in Maine: Collaborative History

Organizations and individuals throughout Maine have been working tirelessly to reduce the rate of cancer and its impact on Mainers. To help channel these efforts in the late 1990s, the US Centers for Disease Control provided support and funding to create cancer consortiums in every state. The Maine Cancer Consortium (the Consortium) formed in 1999 to develop and implement a comprehensive cancer control plan. Comprised of individuals and organizations committed to reducing the burden of cancer in Maine, it was coordinated on a statewide level and was in place through 2015. During the Consortium's tenure, the Maine Center for Disease Control and Prevention created the Maine Comprehensive Cancer Control Program, with funding from the U.S. Centers for Disease Control and Prevention, and every five years has created a comprehensive cancer control plan for Maine, with implementation of the plan carried out by the Consortium members and statewide partners. The Maine Comprehensive Cancer Control Program released its most recent report in February 2017, which covers 2016-2020.

In 2015, the Maine Centers for Disease Control and Prevention redirected funding to other priorities, and the Consortium was unable to continue its work in its current form. Given the complementary nature of their missions and resources, the Consortium and Maine Cancer Foundation voted to merge to form a single, joint organization, retaining the name Maine Cancer Foundation. The goal of the merger was to combine expertise and capacity in order to foster sustainability and action, thus having a greater impact on reducing the burden of cancer in Maine. For the first two years, MCF maintained the Consortium's structure of workgroups comprised of oncology professionals, and promoted the inclusion of those with lived experience with cancer on the workgroups as well. With the launch of the Maine's Impact Cancer Network Task Forces, the workgroups have shifted their focus to shared learning and networking primarily amongst oncology and public health professionals. The Cancer Network's Task Forces are now focused on carrying out time limited, action oriented tasks with participation of the four sectors.



## The Landscape of Cancer in Maine: Cancer Rates

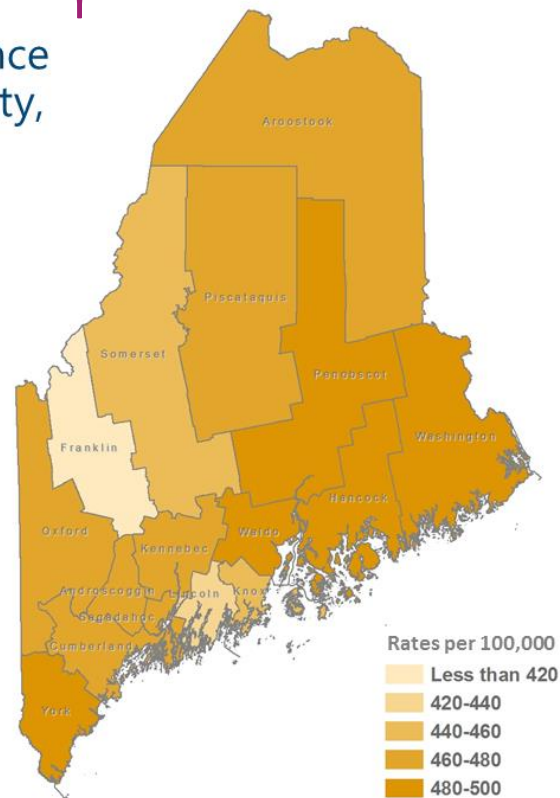
**Cancer is  
Maine's  
leading cause  
of death.**

Historically, Maine has had significantly higher rates of cancer than the United States (470 versus 443 per 100,000 people respectively.) In 2014, the most recent year for which we have Maine cancer data available, there were 8,309 new cancer cases in Maine and 3,222 cancer deaths.<sup>ii</sup> Recent trends show the incidence rate of cancer in Maine remaining stable while death rates are falling. However, even with falling mortality rates, cancer continues to be the leading cause of death in Maine, contributing to 35% of deaths and is the leading cause of potential life lost before the age of 75.<sup>iii</sup> For Mainers, the leading causes of cancer are lung, non-lung tobacco related, colorectal, and prostate among men and breast among women, with the remainder caused by all other cancers.<sup>iv</sup>

Cancer rates vary depending on where you live in Maine. From 2010-2014, Penobscot, Washington, and York Counties experienced the highest age-adjusted cancer incidence rates in the state. Franklin County has the lowest age-adjusted incidence rates, but the most recent trends in Franklin County show new cancer cases rising.<sup>v</sup>

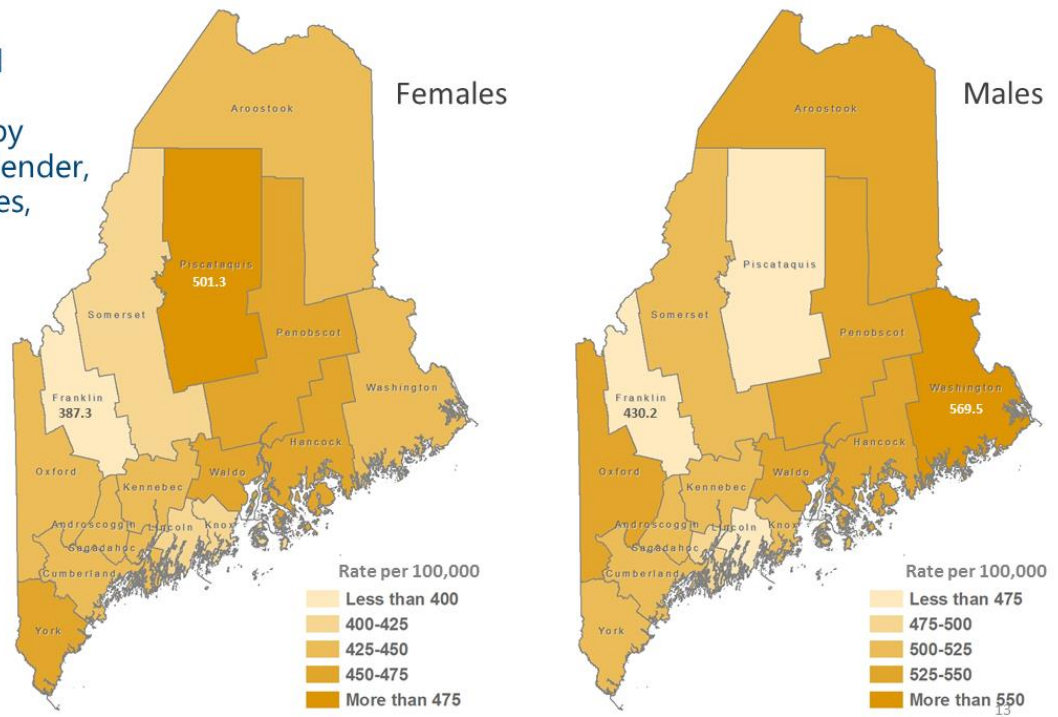
### Age-Adjusted Incidence Rates Maine by County, All Cancer Sites, 2009-2013

	Age-Adjusted Rate
Franklin County (lowest)	405.6
US (SEER+NPCR)	448.4
Maine	473.9
Washington County (highest)	499.5



Overall, new cases of cancer are statistically significantly higher among men in most counties.<sup>vi</sup> Looking at both geographic and gender differences, men have the highest incidence rates of cancer in Washington County, while women have the highest incidence rates in Piscataquis County and both genders have the lowest incidence rates in Franklin County, with men also having low incidence rates in Piscataquis County.<sup>vii</sup>

### Age-Adjusted Incidence Rates Maine by County and Gender, All Cancer Sites, 2009-2013



Source: Maine Cancer Registry and the CDC's National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) November 2015 data submission.



## The Landscape of Cancer in Maine: Prevention

Almost ½ of cancer deaths can be prevented.

Almost half of cancer deaths can be prevented by early detection and improvements in personal health<sup>viii</sup>. Depending on the type of cancer, early detection can lead to the removal of abnormal cells or tumors, or it can prevent the onset of disease and death. The two leading risk factors of preventable cancer incidence and mortality are tobacco use and obesity.

### Lifestyle Risk Factors

- Tobacco

Lung cancer is the leading cause of cancer-related deaths in Maine, with a majority (80% to 90% in the U.S.) of those cases attributed to tobacco use. Quitting smoking can help prevent lung cancer, with risk of developing lung cancer dropping by half, ten years after a person quits smoking.<sup>ix</sup> Despite being a recipient of tobacco settlement funding, and a prior national exemplar of tobacco prevention best practices, tobacco use rates among Maine adults exceed those at the national level, with almost 20% of Mainers ages 18 and older identifying as current smokers (U.S. rate: 16.7%). Fifty percent of adult Mainers identify as having been a smoker at one point in their lives (U.S. rate: 41%).<sup>x</sup> According to the 2017 Maine Integrated Youth Health Survey (MIYHS,) 14% of high school aged youth report having smoked cigarettes or cigars, or used chewing tobacco, snuff, dip or dissolvable tobacco products at least once in the past 30 days, with those rates highest in Piscataquis (23%), Oxford (19%), and Franklin Counties (18%).<sup>xi</sup> Public health advocates have been determinedly working to change the statistics and most recently were awarded a win, when Maine became the fourth state to increase the legal smoking age to 21.

**20% of adult Mainers are current smokers.**

**31% of adult Mainers are considered obese.**

**Smoking and obesity are both risk factors for cancer.**

- Obesity

Research is increasingly proving the risk that being overweight or obese plays in the incidence of several types of cancer. Fat, especially fat located at the waist, is active in producing growth stimulants and increasing cell division. People with excess fat may have cells that are dividing more rapidly, thus increasing their risk of cancer.<sup>xii</sup> As of 2015, 31% of Mainers were considered obese based on body mass index, while a similar 31% of adult Mainers were considered to be at a healthy weight; 13% of high school students were considered obese.<sup>xiii</sup> Nutrition and physical activity can play a role in preventing excess body weight, and subsequent increased risk of cancer. Certain antioxidants may decrease cancer risk and some foods, such as processed meats, are known carcinogens; however, there is no conclusive evidence eating fruits and vegetables reduces the risk of cancer development. Eating fruits and vegetables does contribute to a healthy weight and weekly moderate physical activity has been shown to decrease the risk of certain cancers.<sup>xiv</sup>



## The Landscape of Cancer in Maine: Cancer Incidence

Lung  
Colorectal  
Breast  
Prostate

Maine's Impact Cancer Network's common agenda addresses all types of cancer as one disease. However, four specific cancers occur more often in the Maine population than others.<sup>xv</sup> Below is a brief description of rates, risk factors, and early detection for lung, colorectal, breast, and prostate cancer.

### Lung

- Rates and Risk Factors
  - Maine's lung cancer rates are 30% higher than the national average, with Maine men having higher rates than Maine women. Cigarette smoking, radon gas and secondhand smoke can all contribute to lung cancer. Radon gas is the second leading cause of lung cancer in Maine, and while radon can be detected in a person's home, mitigation can be expensive and financial resources are not always available. For every 2 out of 5 adults who dies from lung cancer, but are not smokers themselves, secondhand smoke is a contributing factor.<sup>xvi</sup>
- Detection and Screening
  - Seventy-five percent of the time, lung cancer cases are detected late, prohibiting the ability for adequate treatment,<sup>xvii</sup> and often meaning the cancer has spread to other parts of the body. Currently, there is only one type of screening available for lung cancer – low-dose computed tomography (low-dose CT.)

**Maine Spotlight:** The Maine Lung Cancer Coalition is promoting the use of low-dose CT scans. They are specifically targeting those in rural, underserved.

### Colorectal

- Rates and Risk Factors
  - Colorectal cancer is the third most commonly diagnosed cancer in Maine, and is the third leading cause of cancer deaths in Maine. There are several risk factors for colorectal cancer including age, using tobacco, being overweight or obese, heavy drinking, low physical activity level, family history, and diseases of the gastrointestinal tract.<sup>xviii</sup>
- Detection and Screening
  - Screening is the only way to detect colorectal cancer, a disease with few, if any, symptoms, making it important to engage in recommended screenings. Colorectal cancer screening rates vary across Maine, with the highest screening rates in Kennebec County (79.2% screened) and the lowest rates in Washington County (65.4% screened) as indicated by the 2012-2014 data.<sup>xix</sup> From 2009 to 2014, Maine was a recipient of the U.S. Department of Health and Human Services' Colorectal Cancer Control Program, which provided free colorectal screening to uninsured and underinsured eligible Mainers. Despite the

**Maine Spotlight:** Maine health care providers are actively promoting the use of an at home colorectal cancer screening test – the fecal immunochemical test (FIT test).



availability of continued funding for the ME CRC Screening program, Maine opted to discontinue the program in 2014.

## Breast

- Rates and Risk Factors
  - The age-adjusted incidence rates for Maine females from 2008 to 2010 was 125 per 100,000 people, a significant decrease from 2000-2002. Maine breast cancer death rates have slightly decreased, with rates remaining relatively stable since 2004.<sup>xx</sup> Several preventable and non-preventable risk factors exist for breast cancer. These are, respectively, age, early menstrual period, late onset of menopause, dense breasts, personal history, lack of physical activity, being overweight or obese, and taking oral contraceptives.<sup>xxi</sup>
- Detection and Screening
  - Maine has been funded since 1994 through the U.S. Department of Health and Human

**Maine Spotlight: The Maine Breast Cancer Coalition supports Mainers through advocacy, financial assistance, and education.**

Services to administer the Maine CDC Breast and Cervical Health Program (MBCHP.) The MBCHP provides free breast and cervical cancer screening and diagnostic services to underserved women, along with education and support to community partnerships.<sup>xxii</sup> Almost 80% of Maine women ages 40 and older have had a mammogram in the past two years.<sup>xxiii</sup> Breast cancer screening rates from 2012-2014 were highest in York County (82.6%) and lowest in Waldo County (68.6%).<sup>xxiv</sup>

## Prostate

- Rates
  - Prostate cancer is the most common occurring cancer among Maine men, but has been declining over recent years. Most recent data show 80 percent of prostate cancers in Maine are diagnosed at an early stage, yet this number is still below that of the US rate. While research has yet to show whether prostate cancer can be prevented, age, family history, and race are seen as risk factors.<sup>xxv</sup>
- Detection and Screening
  - The U.S. Preventative Services Task Force recently changed its prostate cancer screening recommendations from a D, meaning the benefits of screening do not outweigh the harms, to a C rating, recommending men have a discussion with their providers about screening. Changes in the recommendation will not be reflected in available data, but those data do show, that even with a D rating, about half of Maine men 50 years and older, report having a prostate cancer screening in 2012.<sup>xxvi</sup>

**Maine Spotlight: The Maine Coalition to Fight Prostate Cancer works to raise awareness of prostate cancer and the importance of early detection.**



## Maine's Impact Cancer Network's Common Agenda

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The common agenda maps Maine's Impact Cancer Network's course for addressing cancer in Maine. The Cancer Network's Leadership Roundtable, along with Maine Cancer Foundation, developed the common agenda key themes through a three-step process. The first step involved listening to Mainers, followed by a narrowing of their concerns and desires into an initial set of themes, objectives and implementation ideas; and finally further refinement based on a scoring rubric (See Appendix D) and willingness to engage around those topics. The Cancer Network's work is carried out by Task Forces each with their own focus that contributes to the broader common agenda. At any point, Cancer Network members may elect to work on an implementation idea presented, or propose a new idea, as part of the collective impact initiative.

### Common Agenda: Key Themes

- **Healthcare System Collaboration** – There is an overall desire to see health systems in Maine better collaborate with each other, including increasing collaboration between health care providers, sharing medical records, and working better with outside organizations. Non-profit organizations, resource centers, and public health organizations and coalitions need to increase collaboration with each other as well.
- **Access** – There is a need for increased access to transportation services, ride sharing capabilities, and free or reduced cost housing options near cancer care centers. At the same time, there is a call for more local care, patient navigators and community health workers, and an increase in the healthcare workforce to provide that care.
- **Education about Cancer Prevention, Detection, and Treatment** – An increase in education related to cancer prevention, detection, and treatment needs to happen throughout the state. This increase in education must reach community members, patients, medical providers, the K-12 education system, and the business community. There is also a need to educate people about the current resources available both locally and regionally.
- **Advocacy** – The cancer issues affecting Mainers need to be communicated to and advocated for with Maine legislators and government departments. Community members want to know what is happening with their government and how they can also engage. Local officials, too, need to be engaged so cancer policies are introduced and enacted at all levels.
- **Survivorship** – Both youth and adult survivors need increased access to services, including palliative care throughout a diagnosis, support groups, guardianship supports, and assistance from employers when returning to work.

#### Common Agenda:

- Healthcare System Collaboration
- Access
- Education
- Advocacy
- Survivorship





## Maine's Impact Cancer Network's Work Plan

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The Cancer Network's work plan is grounded in the common agenda key themes with current work topic areas chosen based on enthusiasm and energy to accomplish shared goals. The work plan is achieved through the formation of multiple, inter-disciplinary Task Forces, collaboration with organizations and stakeholders in the Cancer Network, and recruitment of those who may contribute to the common agenda, but are not yet involved.

The Cancer Network is approaching our shared work in the following three ways:

- **Task Force Activities:** Collaborative projects that are time limited and directly contribute to the common agenda. They have leaders and are supported by MCF staff and the LRT. Projects have the potential for shared learning and to be implemented statewide
- **Quick Wins:** Short-term activities that can be taken on by a single organization or a collaboration that contribute to the mission of Maine's Impact Cancer Network and/or the common agenda and have the potential for shared learning or bringing to scale. They may or may not be completed by a Task Force.
  - Example: Town and Country Federal Credit Union updated their employee policy to enable any qualifying employee to take two days to prepare for and have a colorectal screening. These days off are in addition to any other form of paid time off.
  - Example: University of New England students have reinvigorated their Oncology Club in an effort to learn from and collaborate with those working in the oncology field and to give back to their community.
- **Mutually Reinforcing Activities:** Activities organizations are already doing well that contribute to the mission of Maine's Impact Cancer Network and/or the common agenda, or may be modified to contribute to it.
  - Example: The Maine Lung Cancer Coalition is leading an effort to develop the infrastructure and inter-institutional collaboration needed to expand access to evidence-based lung cancer prevention and screening services, and to facilitate earlier and more effective treatment of lung cancer patients across Maine.

### Task Forces:

- Transportation
- Employer Strategies
- Cancer Resources and Support Centers
- Palliative Care
- Rehabilitation and Survivorship
- Advocacy





## Common Agenda: Task Force Activities

To date, Task Forces have been created to address the topic areas listed below. At any point new Task Forces may be created, or original ones may dissolve as the work evolves and is accomplished.

- **Transportation**

Maine is one of the most rural states in the nation, with the most citizens living in rural areas. Transportation and its relationship to access to care are a significant barrier to health care for Mainers, specifically for those with a cancer diagnosis. Without local access to cancer detection and treatment services, Mainers are faced with the need to travel to receive their screenings and, if diagnosed with cancer, treatment. **In almost every community conversation transportation was raised as a major barrier to receiving necessary care.**

Market Decisions Research recently conducted a transportation assessment to better understand Mainers access to transportation as it relates to cancer treatment. They found those living in the most rural areas of the state travel 4-6 times further to receive treatment than

Cancer survivors in Washington County travel **126 miles** roundtrip for each chemotherapy appointment and **145 miles** roundtrip for each radiation treatment.

those living in metro areas, with the average number of visits made not differing greatly by geography. Cancer survivors in Washington County drive an average of 126 miles roundtrip for chemotherapy treatment, which may largely stem from the lack of oncology providers in the area. Washington County survivors also travel the most miles to receive radiation treatment (144.8 miles,) with those in Aroostook County a close second (140.5 miles.) While cancer survivors who live in rural areas have long distances to travel, transportation is also problematic for

urban areas, given the larger population that needs to travel and that 4 out of 5 providers say they are at capacity. This calls for a variety of approaches, including expanding access to care in rural areas and expanding regional transportation in urban areas.<sup>xxvii</sup> The goal of the Transportation Task Force is to bring together both those providing transportation services and users of the systems to find ways to work together to promote awareness of services and bridge gaps.

- **Employer Strategies**

**Employers play a unique role in cancer prevention and with cancer survivors.** In terms of prevention, employers are able to promote the health of their employees to foster a more productive workforce. Eighty-four percent of employers who support preventative care say their employees are healthy and 59% say they have increased productivity.<sup>xxviii</sup> For employers who offer employer-based health insurance, they may be more likely to promote insurance as a benefit and encourage their employees to take advantage of it. As is the current case, these employer-based plans include access to cancer prevention services for those of qualifying age. Given that 12% of Maine adults have at one point received a cancer diagnosis, with almost half



of those falling within a working age (18 to 64 years old)<sup>xxix</sup>, it is likely an employer, especially a large employer, will have an employee who is a cancer survivor or a caregiver. Employers are then in a position to support those employees while they work during treatment or upon a return to work after treatment. The aim of the Employer Strategies Task Force is to work with employers and their human resources departments to promote cancer prevention and transitions to work after a cancer diagnosis. The Task Force may also investigate possibilities to work with cancer survivors to enable them to be self-advocates upon a return to work.

**12% of Maine adults have had any cancer, and almost 50% of those fall into a working age.**

- **Cancer Resources and Support Centers**

In Maine, there are currently four organizations serving primarily as cancer resource or support centers. These are the Cancer Community Center in South Portland, The Dempsey Center in Lewiston, the Cancer Resource Center of Western Maine in Norway, and the Beth C. Wright Cancer Resource Center in Ellsworth. **While some areas of the state have access to cancer resource or support centers, others do not; of note are Central and Northern Maine.**

In addition to specialized cancer resource and support centers, several other resources for cancer survivors and caregivers exist throughout the state. The problem, as identified by community conversation participants, **is there is a lack of knowledge about which resources exist, where they are, and how to access them.**

The Cancer Resources and Support Centers Task Force intends to gain a better understanding of the cancer resources available in Maine and how to best get that information to communities. A longer term project may be to determine the feasibility of creating more support centers throughout Maine.

- **Palliative Care**

Palliative care focuses on improving the quality of life for patients with a chronic illness and their families. Palliative care providers provide relief from the symptoms and stress of chronic illness by addressing physical, mental, emotional, social and spiritual needs. Most often palliative care is initiated at the outset of a diagnosis and throughout care in conjunction with traditional treatments. In 2015, the Maine Legislature passed a bill to create the Palliative Care and Quality of Life Advisory Council, with the goal of identifying information on palliative care in Maine and create a workplan including policy recommendations. The Council's baseline findings from 2016 found that 10 of the 34 hospitals interviewed have palliative care programs, while 7 of the 26 hospice programs offer palliative care. **Hospitals offering palliative care programs are located primarily in Southern Maine, with one location in Aroostook County and few, if any, in Western, Central, and Downeast Maine.** The status of hospice providers of palliative care is similar; however, there are no providers in Aroostook County.<sup>xxx</sup>

The community conversations in Maine opened up a discussion about the use of palliative care in Maine, and the misperception that palliative care is only used when treatment is no longer working or at the end of life. Those who are more aware of the concept of palliative care would



like to see palliative care emphasized and introduced earlier in the continuum of care, and for more education on the benefits of receiving palliative care. The aim of the Palliative Care Task Force is to take on these requests.

- **Rehabilitation and Survivorship**

People with a cancer diagnosis are living longer due to improvements in early detection and in cancer treatment. **It is estimated 67% of people diagnosed with cancer will live at least five years after diagnosis.**<sup>xxxix</sup> With these advances comes the need to ensure cancer survivors have the necessary health and well-being supports throughout their life, including psychological, social, spiritual, and financial to ensure they are living fully and to stave off susceptibility to secondary disease. While the definition of survivorship may vary among individuals, in this regard cancer survivorship begins on the first day of a diagnosis and extends throughout a person's lifetime whether they are actively undergoing treatment or in complete remission.

The most recent Adult Cancer Survivors in Maine report was released by the Maine Center for Disease Control and Prevention in 2015, using data covering 2011 to 2012. This data shows

**1 in 10 Maine adults are cancer survivors.**

more than 1 in 10 Maine adults are cancer survivors, with higher rates of female survivors than men. Looking at cancer follow-up care, about 40% of Maine cancer survivors receive a written summary of all cancer treatments and 60% receive written instructions for routine cancer check-ups after completing their treatment. Maine cancer survivors with private health insurance are more likely to report receiving follow-up care than those with Medicare.<sup>xxxix</sup> Given these statistics and the outcomes of the

community conversations, the Rehabilitation and Survivorship Task Force will focus on working with both providers and survivors to make sure proper pathways are undertaken and necessary options made available to assist survivors with their health and social needs throughout life.

- **Advocacy**

For the past several years, Maine's public health infrastructure has been regarded as weak relative to other states. Unlike most states, local health departments do not exist by county or regionally, with only two public health departments, one in Portland and the other in Bangor, outside of the state's Department of Health and Human Services. This, coupled with an **ever-decreasing state public health budget, has limited the ability of local organizations to engage in prevention.** This is relevant to cancer because of the role public health initiatives typically play in reducing tobacco use and decreasing obesity. In November 2017, a referendum was passed to expand Medicaid, reversing an original decision to not accept federal funds to do so. Once enacted, this will enable more Mainers access to health care and cancer prevention services.

The community conversation participants often spoke of the **need for more public health and medical care funding**, as well as a litany of legislative initiatives they would like taken up by Maine government. There was also concern by both those who work within health systems and health care consumers regarding the future of the Affordable Care Act and its coverage of pre-existing conditions and prevention services.



Several individual organizations, such as ACS-CAN, Maine Public Health Association, American Heart Association, and American Lung Association, along with the collective efforts of the MPHA Tobacco Coalition and the Maine Lung Cancer Coalition are working on state and federal level policy and advocacy. The Advocacy Task Force will support these initiatives and work at the local policy level when appropriate. The Task Force may also lead efforts to create a unified message for Maine's health system and help Mainers learn how to advocate for themselves.



## Shared Measurement System

The Cancer Network's shared measurement system was developed by the Cancer Network's Data Team. It is the Cancer Network's indicator for whether we are achieving a reduction in the impact of cancer on Maine individuals and communities and to what extent collaboration and systems improvement have been realized. The Cancer Network's Data Team is a group of individuals with expertise in oncology, epidemiology, statistics, and evaluation.

In our work, there will be a focus on using data that makes sense and best reflects strategy and operations.<sup>xxxiii</sup> However, activities and projects may happen quickly, requiring nimbleness to identify projects and process measures. As with the common agenda, the shared measurements system is an evolving process. Adding to the complexity, is the nature of a shared measurement system, requiring multiple organizations and stakeholders to contribute to the evaluation of the Task Force initiatives and the Cancer Network's mission overall.

### Measures and Data Limitations

The Data Team has identified cancer incidence and cancer mortality as two measures for evaluating the Cancer Network's goal to reduce the impact of cancer on individuals and communities in Maine. Incidence and mortality will be monitored based on changes over time, as opposed to setting targets given the limitations of seeing significant decreases in the near future. The limitations are due to the nature of the issue, which incorporates biology, behavior change, and changing technology and screening and treatment recommendations, along with an inability to get timely data. From time to time, the Data Team may highlight changes in incidence and mortality of specific cancer when those data are available and show exceptional progress or lagging.

Evaluation of improvements in collaboration and systems, both aims of the Cancer Network, are more nuanced than incidence and mortality, but will be measured through interviews, surveys, and reporting. The Data Team will look at how Cancer Network members are working together, how engaged they are in the Cancer Network, and if they are changing their own day to day to work based on their involvement with the Network.

Lastly, each project of the Task Forces will have its own evaluation plan. Emphasis will be on the impact of the projects and their contribution to the common agenda, along with how well the Task Force works together in accomplishing their goals.



## Working Better, Together

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Maine is a state known for its kindness, generosity, and sense of community, all qualities for bringing people together at the same table. Knowing cancer cannot be tackled if our stakeholders, thought leaders, policy makers, and cancer survivors work in isolation or within their own networks, MCF took a bold step and spearheaded Maine's Impact Cancer Network. Along with reducing the impact of cancer in Maine, at the heart of the Cancer Network's mission is collaboration and systems improvement. The Cancer Network, with MCF's backing and support, is calling on every person impacted by cancer, every non-profit organization, every business, and our government officials to become involved in this effort – our common agenda.

This community plan is not intended to sit on a shelf, nor is it only an overview of what is happening with cancer in Maine. It is a call to action to work with your neighbors, pool your collective knowledge, and share resources to make a concerted effort to reduce the impact of cancer in Maine.

We call this a “community” plan, not just because it is for Mainers or Maine communities. We call it a “community” plan because the word community is based in the concept of “joint ownership.”<sup>xxxiv</sup> This is your plan too. We ask you to take ownership of the plan with us, our Leadership Roundtable, our Data Team, our community conversation participants, Task Force leaders and participants, and all those who are contributing in their own ways. We call on you to choose where you most belong; where you can gain the most fulfillment; and ultimately where you can help make an impact on reducing cancer in Maine and changing the way we work together.

To get involved, or for more information, contact Heather Drake, Program Manager, Maine Cancer Foundation at 207-773-2533 or [heather@mainecancer.org](mailto:heather@mainecancer.org)



## Appendices

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### Appendix A: Leadership Roundtable and Data Team Members

#### Leadership Roundtable

**Marguerite Belanger**

Oncology Nurse/Patient Navigator

**Gayle Brazeau, Vice-Chair**

Professor, College of Pharmacy  
University of New England

**John Cronan**

Associate, Litigation and Workers' Compensation  
Preti Flaherty

**Jennifer Dumas, Chair**

Senior Executive Pharmaceutical Sales Specialist  
AstraZeneca

**Tara Hill**

Executive Director  
Maine Cancer Foundation

**Eric Jarvi**

Treasurer  
Maine Pharmacy Association

**Susan Maataoui**

Psychologist  
Maine Veterans Healthcare System

**Michael Reisman**

Executive Director  
Beth C. Wright Cancer Resource Center

#### Data Team

**Tim Cowan**

Director, Center for Health Improvement  
MaineHealth

**Edward Li**

Associate Professor, College of Pharmacy  
University of New England

**Zakia Nelson**

Epidemiologist  
Independent Consultant

**Molly Schwenn**

Director, Maine Cancer Registry  
Maine Center for Disease Control

**Andrew Williams**

Health Services Researcher,  
Center for Research and Evaluation  
Maine Medical Center



## Appendix B: Maine's Impact Cancer Network Mission and Guiding Principles

**Mission:** To reduce the impact of cancer on individuals and communities in Maine through collaboration and systems improvement.

### Guiding Principles

The Cancer Network will:

1. Include any person or organization whose work supports the mission of the Cancer Network and who agrees to work collaboratively. Collaboration includes: working synergistically; contributing to the Cancer Network's mission; sharing lessons learned; and thinking beyond program strategy to systems strategy.
2. Employ and optimize a systems approaches, but respect the goals of individual organizations.
3. Ensure the goals and objectives reflect those engaged in Maine's Impact Cancer Network.
4. Represent and incorporate the four sectors: lived experience, business, non-profit, and government.
5. Be a learning, flexible, and dynamic network, acknowledging this is an evolving process and we are open to change.
6. Support on-going learning and respectful communication.
7. Strive to base our work in evidence and data.
8. Include the five conditions of collective impact in its work: common agenda, shared measurement system, continuous communication, mutually reinforcing activities, and a backbone structure.





### Appendix C: Common Agenda Selection Criteria

1. Objectives and strategies will be based on information from community conversations, lessons learned, data, and research.
2. Objectives and strategies must have a defined time for completion.
3. Objectives and strategies may address specific geographic areas or specific populations even if they do not relate to the entire State or Cancer Network.
4. Objectives and strategies will strive to be measurable using qualitative and/or quantitative data, but the Cancer Network will keep in mind not everything has a baseline and will have the flexibility to address issues that are of interest to the Cancer Network.
5. Objectives and strategies can be visionary, as long as progress is being made toward the objective or strategy.
6. Objectives and strategies will strive to be grounded in evidence; this includes evidence-based, evidence-informed, and practice-based.
7. Objectives and strategies may replicate part of the 2016-2020 Maine Cancer Plan.
8. Priority will be given to objectives and strategies that have champions and resources to implement them. However, if there are no champions or resources, these objectives and strategies will be written as long-term goals.
9. The Cancer Network will address broad policy change.
10. The Cancer Network may address controversial topics, but will do so in a way that aims to bring together stakeholders for respectful dialogue on the topic and will not let controversial topics get in the way of getting other work done.



## Appendix D: Common Agenda Scoring Rubric

The Leadership Roundtable used the following six factors and definitions to guide their scoring of the common agenda implementation ideas:

- **Feasibility:** All necessary resources are currently available or are easy to obtain and there are organizations able and willing to engage in the work.
- **Measurability:** Data currently exist to track the progress of the implementation idea or are easy to identify and obtain.
- **Energizing:** The implementation idea is new, exciting, and/or has the potential to garner broad support.
- **Members Can Join Equally:** The implementation idea is not limited to one sector or person or organization.
- **Greatest Outcome:** The implementation idea has the potential for lasting impact on people or organizations throughout Maine or to be replicated for lasting impact in multiple geographic areas of the State.
- **Collaborative:** The implementation idea has the potential to involve more than one organization and at least two of the four sectors.

The final scores were then deliberated, and further refined based on their ability to produce big change (long-term, more than 1 year;) quick wins (short term, 1 month to 1 year goals;) and effect policy.



## Appendix E: Collective Impact Dictionary

**Backbone Organization:** An organization or group of organizations in collective impact that provide support, coordination and any necessary resources to support the initiative. Currently Maine Cancer Foundation, provides the funding, staff, and resources to convene and coordinate the Cancer Network.

**Common Agenda:** A shared understanding of the problem and a vision for changing it, highlight themes from community conversations and organized by goals, objectives, and strategies. This will evolve as needed to ensure needs are met and progress is being made toward the Cancer Network's mission.

**Community Conversation:** A forum to ask: What is happening? What is the change we would like to see? How can we work together to make this change happen? Community conversations can happen with diverse groups of stakeholders, groups of specific stakeholders, one-on-one interviews, or through surveying. These are the basis for the common agenda.

**Community Plan:** Encompasses the common agenda, shared measurement system, mutually reinforcing activities, and governance structure. This will be a living document in order to make sure needs are met, stakeholders are engaged, and progress is being made toward the Cancer Network's mission.

**Data Team:** Individuals with expertise in cancer data and evaluation across Maine. This group will be responsible for identifying data currently available and data needed to track and evaluate the collective impact work, both on the macro level and Task Force level.

**Engagement Strategy:** Overall strategy for engaging community members. It includes the strategy for the Listening Team and community conversations as well as how to keep Cancer Network members up-to-date and engaged in the work. It will include a method for news/education/resource delivery and an online platform for collaboration. The strategy encompasses continuous communication, which is a method for building trust and relationships.

**Governance Structure:** Developed by the LRT and MCF staff, it identifies the flow of leadership and communication.

**Leadership Roundtable:** Individuals representing lived experience with cancer, business, government, and non-profit organizations who will engage in the sense-making of the community conversations, Task Forces, and Data Team to help create a common agenda and guide the community planning process with MCF staff. The LRT is also tasked with identifying additional funding sources for the Cancer Network.

**Listening Team:** Individuals across Maine who can recruit conversation participants, convene conversations, and/or facilitate conversations. This is a fluid team that does not need to meet, but will be expected to provide MCF staff with an overview of how they conducted their conversation, the conversation participants, and notes from the conversation. The Listening Team's work is part of the engagement strategy.



**Mutually Reinforcing Activities:** Activities organizations are already doing and doing well that contribute to the mission of Maine's Impact Cancer Network and/or the common agenda, or may be modified to contribute to it.

**Quick Wins:** Short-term activities that can be taken on by a single organization or a collaboration that contribute to the mission of Maine's Impact Cancer Network and/or the common agenda and have the potential for shared learning or expansion. They may or may not be completed by a Task Force.

**Shared Measurement System:** Developed by the Data Team and MCF staff, this is a system available for members involved in collective impact that will collect data and measure results allowing for on-going assessment and evaluation of the common agenda and mutually reinforcing activities and shared accountability.

**Task Forces:** Stakeholders (individuals and organizations) who can engage collaboratively in activities, that contribute directly to the common agenda. Activities are time limited, based in evidence, and measurable. Task Forces help facilitate the "practice" of working together to create change. They have leaders and are supported by MCF staff and the Leadership Roundtable.



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