



Listening Report May 2017



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Executive Summary

At the 2016 Challenge Cancer Conference, Maine Cancer Foundation introduced the collective impact framework as a way to bring stakeholders throughout Maine together to address cancer through relationship building, collaboration, and systems improvement. The initiative, known as Maine's Impact Cancer Network (the Cancer Network), held its first community conversation at the 2016 Challenge Cancer Conference and began the process of building dialogue and relationships among stakeholders representing four sectors of Mainers: non-profit organizations, the business community, those with lived experience with cancer, and government. The conversation focused on three questions:

- What is happening in your life, organization, or community with regard to cancer?
- What is the change you would like to see in your life, organization, or community with regard to cancer?
- How can we work together to make these changes happen?

Over the course of a year, the Cancer Network held 19 community conversations and several one-on-one conversations, fielded a survey, and collaborated with two other organizations to share information from previous conversations. In total, 670 people representing the four sectors and a myriad of communities and organizations were engaged. The stories and information they shared ultimately informed the Cancer Network's common agenda to reduce the impact of cancer on individuals and communities in Maine through collaboration and systems improvement.

This report is an overview of what stakeholders across the state perceive is happening with cancer; what they would like to change with regard to cancer; and their ideas for how we can work together to make change. It highlights the key themes that were heard throughout the community conversations. These key themes create a foundation for a common agenda, which will be agreed upon by stakeholders in order for the Cancer Network to move toward reducing the burden of cancer in Maine.

Please join us as we confirm the common agenda with our communities, develop implementation strategies to move the work forward, and commit to putting these important actions in place to reduce the impact of cancer in Maine.



Purpose

In 2015, Maine Cancer Foundation (MCF) began to explore ways to strategically and collaboratively address the high rates of cancer in Maine. Maine's cancer rates are staggering. It is the leading cause of death in our state, with 3,200 people dying each year, and more than 8,300 Mainers receiving a cancer diagnosis each year.¹ Given the gravity and complexity of these statistics, MCF recognized that reducing the cancer burden could not be achieved if organizations continued 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. 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, it provides an opportunity for dialogue, relationship building, and ultimately a commitment to work together to create system-wide change.

Maine Cancer Foundation held its first community conversation and introduced the collective impact framework as part of their Challenge Cancer Conference in May 2016. The conversation emphasized dialogue and collaboration between the four sectors by bringing together MCF's Membership (a professional network for individuals working in oncology), as well as business leaders, government officials, and those who have experienced cancer in their lives. At the conference a multi-sector, statewide steering committee, called the Leadership Roundtable (LRT) was introduced to oversee the collective impact work. The result was buy-in and a commitment by those in attendance to continue with the collective impact framework as a way to address cancer in Maine. Following the Conference, MCF hired a Program Manager to oversee this process and the initiative was named Maine's Impact Cancer Network (the Cancer Network.)

Together, MCF staff and the LRT began to identify people and organizations to engage in community conversations across Maine. The subsequent conversations yielded qualitative data from both large and small group conversations, one-on-one interviews, and a survey. This report details who was engaged in the conversations and the key themes that emerged from the conversations. All of this information directly informed the creation of the Maine's Impact Cancer Network's common agenda to address cancer in Maine.

Who We Listened To

From the May 2016 conference through April 2017, Maine's Impact Cancer Network held 19 community conversations and conducted 92 one-on-one interviews, ultimately hearing from 670 Mainers.

In addition to leading its own conversations, the Cancer Network benefited from partnerships with organizations who had conducted their own conversations and circles as part of other listening initiatives and shared their qualitative data for use by the Cancer Network. These conversations and circles took place in 2015 and 2016. These partnerships resulted in the ability to collect information

¹ *Maine Cancer Surveillance Report 2014*. Augusta, ME: Maine Center for Disease Control and Prevention; 2014.



from 184 additional stakeholders. Combined, community conversations, one-on-one conversations, and survey distribution resulted in input from 670 people.

The Cancer Network sought to hear from individuals representing the four sectors: non-profit organizations, the business community, those with lived experience with cancer, and government. Although each sector was represented in the conversations, not all of the sectors were represented equally.

We heard from people representing:

- AccessHealth
- American Cancer Society
- Aroostook County Action Program
- Bath Iron Works
- Cancer Community Center
- Cancer Resource Center of Western Maine
- Cumberland District Public Health Council
- Dempsey Center
- Dempsey Center's Healing Tree Youth Group
- Healthy Androscoggin REACH Team
- Island Communities
- Knox County Residents
- Maine Breast Cancer Coalition
- Maine Cancer Foundation Board of Directors
- Maine Cancer Foundation Membership
- Maine Cancer Foundation Tri for a Cure 2016 Participants
- Maine Department of Health and Human Services
- Maine Health Equity Alliance
- Maine Legislature
- Maine Medical Center
- Maine Migrant Health Program
- Mid-Coast Parkview Hospital
- MSAD 75
- Passamaquoddy Tribe Members
- Queer Community Health Alliance
- Regional Medical Center at Lubec
- Sebasticook Valley Hospital Women's Group
- Stephen's Memorial Hospital
- Town of Scarborough Human Resources
- University of New England
- Washington County Cancer Survivor Conference attendees
- Washington County Wellness Network
- Youth Building Alternatives
- York Hospital

What We Asked

At each community conversation we asked three important questions:

1. What is happening in your life, organization, or community with regard to cancer?
2. What is the change you would like to see in your life, organization, or community with regard to cancer?
3. How can we work together to make these changes happen?

One-on-one conversations followed a similar framework, but were more fluid to allow for dialogue to happen naturally. The survey was derived from the three questions, but asked more in-depth questions with both closed and open ended responses.



Summary of Community Conversations

Below is a summary of what we heard from the conversations, organized by question.

What is Happening in Your Life, Organization, or Community with Regard to Cancer?

Community conversation participants spoke at length about what they have experienced and perceived with cancer in Maine.

Current Successes

Participants acknowledged while there is much work to be done to address cancer, there are also **many things going well**.

In several areas across the State, participants highlighted that they are **part of caring, supportive communities**. Participants also discussed **access to cancer screening programs**, many of which are free, including the Maine Breast and Cervical Health Program. In the Mid-Coast area there are several free skin screening clinics and churches share information and host screenings. Mid-Coast Hospital also offers some screenings on the weekends. The Healthy Community Coalition of Greater Franklin County promotes screenings and prevention, tobacco cessation, and collaborates with non-traditional partners like food pantries and Meals on Wheels.

Participants spoke of **transportation assistance programs** available through the Kennebec Valley Community Action Agency, Neighbors Driving Neighbors in Western Kennebec, and American Cancer Society's Road to Recovery statewide program. In St. George, rides are coordinated through the Neighbor to Neighbor Ride Assistance Program.

Community conversation participants highlighted the **benefits of support groups** and being able to gain access to resources through local organizations. In Norway, there is the new Cancer Resource Center of Western Maine, which offers nutrition and wellness programs, while Stephen's Memorial Hospital has a new infusion room and the ability to offer local care to its community members.

Several regions also highlighted their **connection to cancer community and resource centers**, such as Beth C. Wright, the Cancer Community Center, the Dempsey Center, and the Cancer Care Center at PenBay Medical Center.

Barriers, Challenges, and Gaps

The community conversations also highlighted the **barriers, challenges, and gaps** with regard to cancer in Maine. While some topics were particular to a certain region or population, such as the lack of an oncologist in Washington County; the quality of care at clinics serving Maine tribal communities; or the lack of culturally competent providers for New Mainers and the LGBTQ+ community, other topics are ubiquitous across the State.

A **lack of access to transportation** was highlighted in nearly every community conversation, facing not only those in rural areas, but those in suburban and urban areas as well. Transportation issues ranged from having to travel long distances to access care, to traveling during the winter, to a lack of coordination between transportation services (i.e. a patient can take an angel flight – free



transportation for those in need of life-saving medical care – to Portland, but will not have transportation when they land), to a lack of affordable housing options at the site of care when overnight stays are needed.

Communities who have access to patient navigators or community health workers see them as a major asset in helping coordinate and navigate screenings, treatment, and care; however, a **lack of navigators and CHWs** is seen as a barrier to those accessing the health system. Patient navigators in Maine help guide patients through the care system and community health workers are members of their communities who act as a bridge between providers and patients and advocate for needs. Without help coordinating care, patients often feel left on their own and several participants noted that without someone to help with coordination, they would not have been able to navigate the system themselves or receive high quality care.

Similar to navigating within health systems, another common theme was a **lack of collaboration between health systems, public health practitioners, and providers**. Several conversation participants voiced concern about recent changes in Maine's public health funding, vacancies within Maine's Center for Disease Control, lack of MaineCare expansion, and concern over potential discontinuation of the Affordable Care Act.

Participants also discussed **inconsistencies with their providers** and high rates of turnover, along with difficulties in obtaining referrals and long wait times for appointments. Along with a lack of access to providers, participants talked about the **lack of palliative care throughout a diagnosis**, which focused on improving the quality of life for a patient with serious illness, and a **lack of holistic or alternative health options**, due to either a lack of offerings or reluctance of a provider to suggest them.

Participants also spoke about patients receiving a cancer diagnosis, with many being **late stage, a rare diagnosis, or occurring in younger patients**. They voiced confusion about **the difficulty in understanding cancer prevention and screening guidelines**, because of the rate at which guidelines change and how they sometimes vary between health systems.

There were also reports of **mixed messaging in prevention efforts**, especially in school systems that may promote the youth obesity prevention program Let's Go!, but also celebrate with less healthy food options. Included in school discussions were the **lack of staff to dedicate to prevention education** and a **lack of public health funding for youth prevention and health promotion programs**.

Another overarching topic was the **inability to pay for care and a lack of financial resources**. This came across in terms of a lack of health insurance coverage; disconnects between preventative screening and diagnostic care costs; a lack of drug price controls and access to drug assistance programs; and a lack of financial navigators.

What is the Change You Would Like to See?

Participants were able to identify **several changes they would like to see** with regard to cancer in Maine, with many repeated themes throughout various regions. Overall, Mainers would like to see more access to transportation, including **connectivity between travel modes, ride-sharing opportunities, and regional transportation centers**. In line with transportation, Mainers would like to see more



opportunities for local care, including **mobile health clinics, telemedicine, and screenings offered in non-health settings**, such as Churches or health fairs.

Participants discussed an overall need for **more education about cancer** for individuals of all ages. They would like to see schools focus on **social and emotional learning and youth empowerment**, with prevention education beginning in earlier grades and more supports for youth, such as opportunities to become involved in extracurricular activities or having a caring adult in their life. Additionally, participants stressed the importance of **educating providers on how to listen and have compassion**. There is also a desire to see **more inter-professional education**, with all health care disciplines working together, beginning in their post-secondary schooling. Education should also come in the form of **messaging that is targeted to specific groups**, such as outdoor laborers, new Mainers, and the LGBTQ+ community, and **follow the principles of health literacy**, which enables people to obtain, communicate, process, and understand health information, including data. Participants would also like to see **more education on environmental exposures and risk factors**.

Increased collaboration and information sharing between health systems and with cancer resource centers is a change strongly expressed by participants. There is overall agreement **health systems need to put patients first**, at the center of care and not their profit margin. Participants would also like **more care coordinators and advocates for patients**, including an increased use of the community health worker model. They would also like more information on and access to **clinical trials**.

Participants stressed they don't always know what resources and supports exist or where to find them and would like to see an **inventory of resources** that is up to date and easily accessible and **workgroups** to share information and best practices. They would also like **supports for caregivers, mental health counseling**, and **palliative care** throughout a diagnosis. Additional supports also need to be put in place for children with cancer and children affected by cancer.

Lastly, participants would like to see more **access to health insurance, expansion of MaineCare**, and opportunities for financial support and cost transparency. They would like **funding for prevention, treatment, and research**.

How Can We Work Together to Make These Changes Happen?

Throughout the conversations, the number one way participants said **we can make change happen** is by **collaborating and working together**.

Specifically, participants believe we should have more **multi-disciplinary teams** and invite top-level management, alternative practitioners, resource providers, and non-traditional partners to the discussion on cancer prevention and treatment. This could lead to providers having more awareness of and willingness to **promote local resources and financial supports**. Participants want to see more **inclusion of people with lived experience** in the cancer dialogue. They believe change can happen by continuing the conversation through **community forums and workgroups focused on cancer**. They also believe it's important to **bring resources to where people naturally congregate**, such as work places like farms, fisheries, or businesses; churches; and community centers. Participants believe change can happen with **expansion of the health care workforce** in Maine.



Participants believe we can also make change happen by **supporting employers**, specifically small businesses who may feel a larger impact from a cancer diagnoses. Employers can work with their insurance brokers to offer **incentives to employees who engage in healthy behaviors**, bring opportunities like **lunch and learns** into the office place, and offer **time off** to receive screenings. Workplaces could also be an opportunity to promote Let's Go programming and cooking classes.

Youth who are affected by a cancer diagnosis in their family would like organizations to give **scholarships** so they have an opportunity to enjoy their childhood. They also believe they can be better served with more information about and access to **guardian ad litem**s or court appointed individuals who represent the best interests of a child.

Several participants wanted greater awareness of the resources available to them. Suggestions to make this happen include **asset mapping of resources** in Maine and advertising in local **newsletters and newspapers**, as well as using social media. Another way to get information out is to have local **ambassadors or liaisons** between the health community and community members.

Themes: What We Heard

Although Maine is a diverse state with varying assets, challenges, and barriers, similar themes developed throughout the listening process. Five key themes emerged:

- **Health Care System Collaboration** – There is an overall desire to see health systems in Maine better collaborate with each other, including increasing collaboration between 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 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 number of people who are employed in the health care workforce as a whole.
- **Education on 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, providers, the K-12 education system, and the business community. There is also a need to educate people on the current resources available both locally and regionally.
- **Advocacy** – The cancer issues affecting Mainers need to be made aware of to Maine legislators and government departments. This in turn, should lead to changes in policy to support cancer prevention, detection, and treatment.
- **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.



Appendix

Washington County Wellness Network Community Circles, Fall 2014 – Spring 2015, 69 participants

Participants report patients often have to travel long distances for even simple procedures; Down East Community Hospital doesn't offer chemotherapy; there is a lack of communication between cancer care and primary care providers and there needs to be more coordination; providers don't always interact well with patients or seem to care; screenings aren't happening early enough resulting in delayed diagnosis; and there is no oncologist in Washington County. Participants also reported on the difficulties navigating the system, including a lack of patient advocates and communication about services available and a lack of patient advocates who address financial issues. Participants report there is a lack of education about treatment side effects; young cancer patients aren't taken seriously; patients need more ways to connect with the community; and patients need more support groups and ways to resolve grief, anger, and frustrations through holistic care.

Knox County Community Health Needs Assessment, January – April 2016

Knox County, January 2016, 35 participants

Participants report that it is important to get the word out, but there is a lot of information and changes in screening guidelines. There is a need to raise awareness and educate more people, specifically with regard to the working waterfront and melanoma and diet/nutrition and its impact on prevention/treatment of cancer. Underserved populations don't have access to transportation. The Healthy Maine Partnerships don't provide funding for cancer screening and education and there will be changes to tobacco funding in the future. Participants would like to see more education at schools, child care centers, YMCAs, churches, and employers and an inventory of what healthcare resources exist and where the gaps are. Participants would also like to see health fairs offer screenings, specifically skin screenings and increases in access through transportation and insurance. They would like to have a community health navigator, or other professional who could serve as a liaison between the medical community and the public, particularly around issues such as health literacy, feeling comfortable receiving information, and ways to find funding. Finally, they would like to utilize other events like health fairs, the lobster festival, and community events to share information and educate the public.

St. George, January 2016, 12 participants

Participants note the positive resources available including: the Cancer Care Center at PenBay Medical Center, skin assessment at the Fisherman's Forum, Maine Cancer Foundation, free skin clinics at PenBay Medical Center, the Maine Breast and Cervical Health Program, and the Neighbor to Neighbor program in St. George. Participants would like to see screenings paired with other educational events; more attention on health literacy; programming and screening more accessible through mobile health clinics; more education on melanoma; education targeted to lobstermen; free sunscreen access; and information on melanoma prevention in vacation rental packets. Participants would like to see more information on what resources are available; more informational packets from Maine CDC; more prevention in schools; and more information for the woodlot and fishing community on sun exposure.

PenBay Medical Center Nursing Leadership, January 2016, 20 participants

Participants would like to see more access to primary care services and screening, along with more visible information on disease prevention and health promotion. They would also like to see meaningful collaboration with integrative medicine providers. Participants think it is important to include alternative



practitioners, such as acupuncture, hypnotherapy, and massage therapy, and occupational health nurses.

Union, February 2016, 8 participants

Participants report positive resources available include: the Livestrong Program, local groups who help coordinate ride services (ex: Rockland Bereavement Group), Gagnon Fund offsetting costs with gas cards, U-Rock Hutchinson Center, and churches sharing information and hosting screenings. Participants would like to see more sharing of information, more free skin screenings offered outside of the hospital, more education for local students about skin cancer, and more education for farmers and outdoor workers about sunscreen.

PenBay Medical Center Department Heads, March 2016, 20 participants

Participants report physicians and population health colleagues are working together to fill the gaps for patients that have not been screened at the appropriate time. While it is still hard to reach people for colorectal screenings, there have been increases in numbers when providers have held open houses. Participants believe there needs to be more messaging around the importance and ease of colorectal cancer screening and that it's important for primary care providers to give patients more encouragement to seek colonoscopies and for providers to not accept "no" as an answer from their patients. Participants also believe there needs to be more support around healthy eating, including cooking classes and Let's Go for adults, along with an increase in knowledge about Waldo CAP's transportation resources, which provide rides to appointments for MaineCare patients. Participants see possible partnerships with churches as sites for providing screenings, YMCAs to target active older adults, and Rotary clubs.

PenBay Medical Center Leadership Team, April 2016, 20 participants

Participants report they have current partnerships with a cancer care committee, physician practices, urology, radiology, oncology, psych support, and schools. They report non-insured patients have to pay for screenings and that many mammograms are self-referred because patients lack a primary care physician. They also report that at wellness visits data is being collected by using a checklist of barriers to care that will allow appropriate resources to be developed by physicians. Participants also believe there needs to be more prevention education, screenings, clinics for melanoma, knowledge of family history of cancer, and financial and transportation support. They suggest that town newsletters could provide educational information with a number to call that focuses on one health topic each month.

Maine Cancer Foundation Annual 2016 Conference, May 2016, 95 participants

Participants report shifting statewide priorities, a weak and threatened public health infrastructure, and competition and a lack of collaboration among health systems. There is also a lack of health insurance and confusing and changing guidelines for cancer prevention and screening. Participants would like to see increased data collection and quality measures for cancer in Maine; patient centered care; inclusion of Mainers with lived experience in cancer planning; secure health insurance for all Mainers; increased funding for prevention; screening, treatment, and research; and addressing the fear around cancer and building trust with providers. They would like to see the state work together in order to reduce the redundancy of cancer services by organizations, improving patient navigation, increasing evidence-based prevention and screening, and providing events to bring the cancer community together.

Maine Cancer Foundation Tri for a Cure Participants, July 2016, one-on-one interviews, 81 participants



Participants report wanting better genetics screening; increased awareness of all types of cancer; increased self-care; increased focus on physical activity and better nutrition; increased use of sunscreen; an easier way for people in remote areas to access treatment such as mobile health clinics; funding for a regional transportation center; more support for families and caregivers; an increased focus on prevention and treatment for men; more healthcare available on weekends; sensitivity training for health care providers; and to address the disconnect between screening and prevention guidelines and practice through primary care providers.

Washington County Cancer Survivors Conference, October 2016, 40 participants

Participants report medical bankruptcy issues, especially for young adults, and a lack of funding sources for the uninsured, which may lead to avoiding screenings. There is frequent turnover with primary care providers and no oncology providers in Washington County. Because there are no oncologists, participants report long drives to the Lafayette Center (2.5-3 hours each way); no recognition by providers and staff of the time and effort patients put in to access care, sometimes requiring daily trips; a lack of places to stay near care sites; difficulty traveling in winter, leading to delays and disruptions in care; and no cohesive travel services. Participants also note there is a challenge with "rural attitudes" of not needing care; stereotyping of being from Down East; and increased risk factors due to the types of jobs available in Washington County. Participants would like to see mental health counseling for both adults and youth affected by cancer; business support and other mechanisms to advertise resources; patient driven care; mobile health clinics and use of non-health settings for screenings; access to ride sharing and sharing of patient information to organize rides; virtual work groups and telemedicine; better sharing of medical history between health systems/providers; more medical schools and professionals working to cultivate medical students who will remain in the community; and education on how to get screened, environmental and social risk factors for cancer, and financial resources and navigation.

Maine Cancer Foundation Board of Directors, October 2016, 25 participants

Participants would like to see an end to generational poverty; increased access to healthcare and transportation; an increase in patient navigators; Medicaid expansion; an increased tobacco tax; partnerships with businesses and employers; increases in screenings; mobile health clinics; an increase in genetic screening; and a focus on behavioral change. Participants would like to see the state work together by forming and increasing partnerships with organizations providing cancer prevention and care; working with top level health systems management; working with media outlets on prevention messaging; focusing on policy changes; including people with lived experience; conducting an asset map of state resources and services; and strategically examining what is changeable.

Dempsey Center Youth Group, November 2016, 7 participants

Before the youth participants had experiences with cancer, few of them paid attention to it or knew what the impacts of a cancer diagnosis could mean. Participants would like to see more people receiving help with financial problems and medical debt; universal health care; help for youth who are orphaned due to cancer; compassion around the reality of cancer; education for peers to help with understanding how tough cancer is; and help explaining their own feelings to their peers. Participants would like to see the state-sponsored scholarships for youth affected by cancer so they can do fun things; resources for guardianship issues and guardian ad litem; and more social workers working with schools if students/classmates are experiencing cancer and need assistance.



Maine Migrant Health Program, December 2016, one-on-one interview

The interviewee described how migrant health workers have difficulties accessing care because they are transient and often don't have access to transportation. Delays in getting preventative screenings and delays between a positive screen and treatment, as well as a lack of access to clinical trials is common. English is a second language for a majority of the migrant worker population, literacy levels are low, and they often don't come from a culture of disease prevention. Lastly, it was reported that Community Health Workers don't always have the necessary education with regard to cancer treatment. The interviewee would like to see increased access to clinical trials; increasing navigation capacity within Maine's community health worker workforce; and more bi-directional sharing from the patient and community perspective. The state can work together to build relationships and bridges across systems and create connections between hospital systems and cancer resource centers to deliver care and resources that the Maine Migrant Health Program cannot provide.

LGBTQ+ Lived Experience, December 2016, one-on-one interview

The interviewee described his experience as a member of the LGBTQ+ community and providing cancer resources to the community, relaying personally that primary care providers seem to be well versed in cancer screening guidelines and that there isn't a lack of services for LGBTQ+ individuals, but few have taken advantage of tobacco cessation programs. He reported that reaching the LGBTQ+ population is hard without specific media and programming targeting LGBTQ+ Mainers. The interviewee would like to see more specific messaging and media targeting the LGBTQ+ population and smoking cessation programs offered in places that are accepting and affirming.

Caregivers Lived Experience/Passamaquoddy Tribe, January 2017, 4 participants

Participants report the lack of access to cancer treatment in Washington County, resulting in 8-hour round trips to and from Portland for care. They said there is a lack of places to stay in Portland, but that some hotels do offer discounts if you know to ask for them. Participants described positive experiences in Boston, that they would want in Portland, such as Hospitality Home which provides resource lists and personalized care check-ins for caregivers. Participants described how health systems may use different medicines/equipment, which makes it hard to receive the same care at home if local providers are not credentialed in certain procedures or do not use the same protocol. Participants noted positive experiences due to relatives working within the MaineHealth system who help them navigate care and insurance issues and support received from Beth C. Wright Cancer Center. Participants note dissatisfaction with the care they received at the tribal health clinic, correlating it in part to high turnover among providers and a lack of consistent oversight from management. They would like to see more education for providers and more education for youth and families on prevention, particularly through media and commercials/advertisements. They would also like to see more traveling nurses, more patient champions and advocates, more financial counseling, and swifter referrals for insurance so care isn't delayed.

UNE School of Social Work, January 2017, one-on-one interview

The interviewee focused on the need to think about illness as a combination of environmental risk factors and the choices we make as individuals, with the number of environmental risk factors typically



associated with socioeconomic status. The discussion stressed the need to incorporate more prevention education into training for health care professionals and to incorporate social workers into prevention, treatment, palliative care, and hospice. However, the current challenge is that there are not jobs for social workers in prevention. The interviewee pointed to the opportunity to combine inter-professional education and healthcare practice focused across the health professions with a link to health policy.

Maine State Legislator, January 2017, one-on-one interview

The interviewee discussed the need to think creatively when talking about public health issues, specifically cancer and links to the environment. Most legislators are aware that issues exist, but if they are not presented as something “new” or are confounded with other issues, they can often get lost. The discussion focused on the connection between environmental contaminants such as mining near water sources and dioxin and other pollutants in the water. The interviewee also stressed the need to describe issues in terms of the impact on disease and safety and convey messages using specific metrics and measurements.

UNE School of Social Work, January 2017, one-on-one interview

The interviewee focused on the need for early screening and diagnosis as well as screening across the lifespan, with an emphasis on more supports for children with cancer, such as palliative care and integration of social work. The interviewee also stressed the positive aspects of cancer care, particularly in breast cancer and leukemia, with increasing survival rates and the support social workers are able to offer, when utilized by families making hard decisions. However, healthcare providers need to give patients more time at appointments and not dismiss what patients tell them. The interviewee suggests training healthcare professionals earlier with a focus on listening and inviting patients to help inform the development of healthcare curriculums. The interviewee suggests educating everyone on these issues, from providers, to legislators, to voters and focusing on collaboration throughout the processes.

UNE Human Resources Department, January 2017, one-on-one interview

The interviewee gave an overview of UNE's benefit package which includes an employee assistance program including seminars on cancer and caregiving; individualized care to help employees get back to work; and an online tool that provides monetary incentives for employees to receive cancer screenings and other healthcare. Barriers to receiving preventative healthcare include long waits for doctor appointments; changing prevention and screening guidelines; employees inundated with information; not knowing all of the health insurance benefits they receive; and a lack of knowledge of family history. Human resources departments can create better relationships with their insurance brokers and providers to make sure all benefits are taken advantage of and by prioritizing wellness within their departments, which comes with a need to know about cost savings. Other possible solutions can be setting up mobile health clinics, similar to bringing in flu shot providers, providing more incentives when employees engage in healthy behaviors, and collaboration between providers' offices and larger organizations in the form of lunch and learns and helping with coordination of care.

Mid-Coast Public Health District, January 2017, 10 participants

Participants described what is currently happening in the mid-coast area with prevention education in schools through Let's Go and MSAD 75 health education curriculums including tobacco education, sun cancer prevention, and sexual health. Participants report some pediatric healthcare providers use the Let's Go messaging, but there are inconsistencies between providers, with some not discussing



prevention at all with youth. There is also mixed messaging about prevention in schools, for example, schools may use Let's Go, but then teachers within the same school still use sugary foods as a reward or take away recess as a punishment. There is a lack of school staff to dedicate time to prevention. Mid-Coast Hospital does provide free FIT testing to underserved populations and free screening on the weekends and American Cancer Society is providing FIT testing to the homeless population. Participants discussed the unraveling of Maine's public health system; public health positions that are being left unfilled within the Maine CDC; risks that federal funding for cancer prevention won't be accepted; a lack of knowledge of public health prevention within the CDC and Maine Administration; and a lack of State messaging and marketing on cancer prevention, specifically tobacco. Participants would like to see well supported care, specifically palliative care at all stages of a cancer diagnosis and more care coordinators and advocacy for patients. They believe there should be more outreach to rural areas; more education for youth on tobacco prevention; more education for youth on empowerment; more school-based health centers and health coordinators; and a tobacco tax increase. Participants would like to see the State work together in a similar way as Maine's response to the opioid epidemic – more policy that starts at the State and moves down to towns and more task forces to move the work forward, including funding for the work. In this regard, they would like to see more collaboration within public health and alignment with social determinants of health. There needs to be creative thinking in terms of prevention messaging and to address health outcomes and coordinate all the health plans that exist. Lastly, participants would like to see better provider/patient relationships, more alternative medicine, and working with those in higher positions, such as Superintendents, to better understand the competing priorities they face and how we can work together to address them.

Town of Scarborough HR Department, January 2017, 2 participants

The interviewees gave an overview of the Town of Scarborough's benefits package including an employee assistance program, short and long term disability, generous time off and generous health benefits. They described a work culture that promotes employees taking time off to receive the preventative screenings, including the ability to use flex and comp time. Their health insurance broker promotes cancer screenings at certain times during the year and most buildings have designated smoking areas, though there isn't control for employees who work in the field and there seems to be a large population who use chew tobacco. The police and fire departments take advantage of Aflak benefits, which include incentives to receive screenings. Smaller businesses are more impacted by employees taking time off or who have to manage a chronic disease, so the interviewees would like to see a temporary worker pool. They also need more information about the return on investment for promoting health prevention.

Sebasticook Valley Healthy Women's Health Group, February 2017, 10 participants

Participants report experiencing different cancers, which come with varying diagnoses and needs. Patients, including both those who are self-pay and those with insurance, have financial needs related to their cancer diagnosis. There is a lack of transportation, with patients needing to travel to Bangor for some care. Participants report a lack of holistic care options, with providers sometimes unwilling to offer it; a lack of palliative care; a lack of hospice; a disconnect when trying to communicate with families; confusion around health insurance for both providers and patients; and high drug costs, increasing the burden for hospitals who pick up costs when patients can't pay. There is also a push for evidence-based programs from grantors, but applicants don't always know what evidence-base programs are, making it more difficult to receive funding. Lastly, participants enjoy being a part of EMHS, because it enables



better coordination of care and benefits from the partnership between EMHS and Dana-Farber. Participants would like to have a better way to pay for diagnostic care and to communicate to patients why and when care will move to a deductible. They would like more drug price controls and drug assistance programs, along with more prevention education and education about the link to cancer with the environment, radon, and obesity and more programming in schools, which was cut with the loss of public health funding. Participants would like a way to share resources and best practices among patient navigators and providers; more networks for patients; more forums for collaboration; engagement of Health InfoNet; better collaboration between cancer centers; and more funding.

Aroostook County, February 2017, 26 participants

Participants report having to travel to care with the only pediatric site in Brewer; the financial impact on care; out migration of the younger population which leaves people without a caregiver network; a longer survival rate putting more stress on caregivers; the financial impact of care and the perception insurance companies dictate what is covered; a lack of collaboration and knowledge of what other organizations are doing; the high smoking rates and acceptance of smoking, along with a fear of marijuana's impact on lung cancer rates; and a lack of knowledge of the resources available in Aroostook County, with a perception you have to travel South. Participants would like to see more collaboration; more preventative care and early detection; an increase in the awareness of available services; a local pediatric facility; more education on exposures and causes; education and incentives for healthy lifestyles; more support for small businesses; more transportation options; better case management and care coordination; consistency in providers; and more funding for cancer navigators. Participants would like health care providers and navigators to collaborate; more cancer workgroups; an increase in multidisciplinary teamwork; more holistic care; and increases in funding.

Maine Medical Center Patient Navigator and Social Work Teams, February 2017, 8 participants

Participants cite transportation as a barrier for both rural and non-rural patients and financial issues for both those with and without health insurance. With health insurance comes more people seeking care, putting pressures on the health system, and a lack of quality, consistent providers, enough providers, and those who accept new patients and patients with MaineCare. Participants mention the loss of wages and employee benefits for people who are diagnosed with cancer and work in small business. Late entry to care, specifically for older men, is also a problem. There is a lack of knowledge of prevention; older adults lack supports; there is lack of home care; a lack of trust from the community; and issues associated with survivorship like sex, mental health, and back to work issues that aren't always addressed. Lastly, they say there is competition between health care and a lack of collaboration. Participants would like to see more prevention education for providers and community members, potentially through PSAs, electronic highway signs, and social media. They say there is a lack of government focus on prevention, which calls for more advocacy work and also a lack of consistent guidelines within health care. There needs to be more attention focused on HPV as it relates to head and neck cancers; more transportation options; more local care; shorter wait times for care; an increased focus on expanding the healthcare workforce, including public health nurses; and increasing use of telemedicine.

Healthy Androscoggin REACH Partnership, February 2017, 3 participants

Participants discussed how New Mainers, specifically Africans, do not have an awareness of or culture of prevention because it isn't a primary focus of the health system in Africa. They also report there is a lack of access to providers in Maine, especially those who are culturally competent, and support for New



Mainers in the health system. There also exists confusion around the health insurance system and what is and is not billed for. The Community Health Workers educate New Mainers on the importance of mammography and go as a group to get screened and are currently working to develop relationships with male populations to engage in similar initiatives. Participants say there need to be more culturally competent providers, with the push coming from the top of health systems, as opposed to piece meal throughout. They would like to see more training about cancer and other social issues that impact health care (heating, housing, food, etc.) and reimbursement for culturally competent Community Health Workers. Participants suggest using already established community meeting spaces as forums for educating people about prevention and culturally competent medical offices can begin with materials featuring people of different races and ethnicities and welcoming office signs.

Maine's Impact Cancer Network Survey, February 2017, 30 respondents

Survey respondents predominately represented people who are or have been a caregiver of someone with cancer; someone they know has been affected by cancer; and/or they work at a non-profit directly or indirectly involved with cancer. Respondents primarily work in Washington County, Cumberland County, and Hancock County. Eighty-three percent of respondents say cancer very much affects their community. Over half of respondents say financial issues as they relate to cancer are a big problem in their community. In thinking about access, 61% of respondents say access to transportation is a big problem in their community, followed by access to screenings (46%) and access to treatment (43%.) When asked about patient supports, respondents say there needs to be more mental health counseling (57%,) more financial education (50%,) more patient centered care (46%,) and more patient navigators (46%.) Forty-five percent of respondents say there needs to be more education for outdoor laborers about cancer screening and prevention. Fifty-five percent of respondents report that collaboration between hospital systems is an important issue that requires attention. Seventy-nine percent and 69% of respondents say there needs to be an increase in health insurance coverage and an increase in the tobacco tax respectively.

Healthy Community Coalition of Greater Franklin County, March 2017, 22 participants

Participants describe things that are going well with cancer prevention and care in Franklin County including: screenings and prevention promotion through the Healthy Community Coalition, tobacco prevention and cessation, and collaborating with food pantries and Meals on Wheels. There are also in-services focused on palliative care for clinical staff. Participants say they do have an oncology practice in Franklin County, but there are no radiation services and the system's only oncologist is there just a few days a week. Some patients have to travel to Augusta every day for treatment. There is no public transportation option and only one taxi, making travel a barrier. Costs of medications are also too high and Prescription Assistance Programs aren't available for everyone. Participants would like to see a ride sharing program; more transportation services; more comfortable transportation; better roads; more education for youth and adults on prevention; more tobacco prevention funding; more education about healthy eating and exercise; and more education for the transgender community about hormone therapy and regular check-ups.

Maine Lung Cancer Coalition Communications Advisory Group, March 2017, 9 participants

Participants highlighted the lack of transportation, especially for non-MaineCare recipients and the elderly who are above the MaineCare threshold. Participants did note Kennebec Valley Community Action Program provides transportation, American Cancer Society has a Road to Recovery program, and



Western Kennebec has a Neighbors Driving Neighbors volunteer program.

Participants say people lack knowledge of what services are available to them, they lack insurance and access to care. MaineGeneral does have Community Health Workers (CHWs) but they are grant funded. They also promote CarePartners, but not many people know about it. Participants would like to see more education about the return of investment of prevention and that cancer isn't a death sentence but needs to be caught early. They would also like to see tobacco de-stigmatized and education that tobacco use is an addiction that needs treatment. Participants would like to see a pro-active, coordinated public health system and medical professionals and public health professionals working together to demonstrate the data, savings, and personal stories associated with the importance of prevention. Participants would like more cost transparency and empathy training for providers. They would also like to see an increased use of the CHW model and inclusion of more people with lived experience. They would also like messaging that is both global and specific to the population being targeted, with messaging from peers and multiple outlets. Lastly they would like to see all chemicals included in cancer prevention messaging and partnerships with unusual allies.

Community Health Worker, Maine Migrant Health Program, March 2017, one-on-one interview

The interviewee described his work with the Latin American farm worker population, typically seeing approximately 50 patients, with those numbers increasing during farming seasons. The population with which he works does not have a culture of prevention, so even those with health insurance may not seek care until it is too late. Patients have a difficult time navigating the system, in part because English is either not spoken or is a second language. The Community Health Workers (CHWs) are able to help translate, schedule appointments, and provide navigation assistance. The CHWs often have to provide transportation because patients don't have their own cars and if they aren't on MaineCare, can't access low cost or free transportation options. The interviewee described good working relationships with medical practices, but that they often lack educational materials in Spanish or if they are in Spanish, they are not in lay terms and practices lack interpreters. He also noted how patients don't know what chemicals they are working with and do not wear personal protective equipment. The interviewee said it is hard for farm workers to get time off and they are often hesitant to ask for it so CHWs try to help schedule appointments outside of work, but working hours are often long and can be 7 days a week. The interviewee says there is a need to hire more CHWs and interpreters in the health system; provide easy to understand medical information in Spanish; increase public transportation options; and for social workers or medical practices to go to farms to provide education on prevention and cancer with a CHW who can provide translation services.

Maine Legislators, March 2017, 3 participants

Participants discussed family and personal experiences with cancer and the difficulty in not wanting cancer to define their lives, but the prominent role it plays. There is a need to de-stigmatize cancer and provide more opportunities for screening. Participants discussed how federal dollars are not being used for cancer prevention in Maine. They highlighted the positive role the Cancer Community Center plays for constituents, the progress made in breast cancer treatment, and the efforts their towns are putting forward for more active living and healthy school lunches. Participants believe doctors should be more compassionate, listen to patients, and provide them with more time. In terms of policy in Maine, the opioid crisis has been taking a forefront ahead of other issues, but also presents problems for terminally ill patients who need prescription pain medications.



Cumberland District Public Health Council, March 2017, 24 participants

Participants discussed what is happening with cancer including hearing about more cases of cancer in young people and that cancer is everywhere; the effects of environment and diet as risk factors for cancer; that there are confusing screening guidelines; the impact on the work force; and more HPV vaccinations are occurring, but there is mixed information about it. They also discussed a lack of addressing cancer in any of the District Public Health Improvement Plans, but the Statewide Coordinating Council did add it to their list of priorities. They also discussed duplicated data gathering processes, with no real action to correct the problem after the discussion. The participants have concerns about the long term impacts of cancer which vary with age and diagnosis. Positive aspects discussed include more culturally competent care and outreach to vulnerable populations; sun safety grants; fundraising; and cancer awareness through national health days. In terms of change, participants would like more education about cancer rates and why Maine's rates are so high; prevention education for vulnerable populations; more support for survivors; more funding; access to prevention resources where people can easily obtain them; universal health care; more collaboration between providers; health promotion for overall wellness; tobacco prevention; inclusion of non-traditional partners; shared decision making; earlier introduction of palliative care; resources in multiple languages and use of cultural brokers; information on insurance as it pertains to prevention versus diagnostic charges; and closing the loop on data gathering. Participants think there should be multi-disciplinary collaboration; the use of innovative strategies, perhaps with technology; a prioritized list of specific and comprehensive goals; coordination of next steps; advocating for more funding; aligned efforts with unified talking points; that cancer screening should be brought to communities; education for caregivers; education for policy makers; de-stigmatization; and a changing conversation around food to contradict mainstream messaging.

Queer Community Health Alliance, March 2017, 9 participants

Participants spoke about having a queer community and a cancer community that don't overlap. There are diverse experiences depending on the social circles you are in, but there is universal substance use and large numbers of smokers. Participants say healthcare providers have a hard time asking about sexual orientation and gender identity and there needs to be more cultural awareness and competency. Participants say there is focus on STDs and hepatitis C, but rarely talk about cancer risk and prevention. There is a conservatism in the tribal communities which often prevents dialogue about sexual orientation, but this is changing. Participants also note agencies who serve the LGBTQ+ community and healthcare providers are working together and that providers are often well-intentioned, but not well-informed on how to work with the LGBTQ+ community. Participants would like to see a narrative about cancer in the LGBTQ+ community, more health education specific to the population, and more open dialogue between providers and people living with cancer. Participants would like to have more patient navigators and advocates who are either trained in cultural competency or identify as LGBTQ+. There needs to be more cultural competency training specifically with oncologists and trainings with healthcare providers should also include the front desk staff. Participants would like to see more work with nurses, as they are seen as more likely to have experience working with patients who have had traumatic experiences. Participants recommend taking cultural competency trainings focused on the LGBTQ+ community to areas that need them, such as the tribal population and to bring cultural competency trainings to conferences, like the nurses' conference. Participants also suggest working with



Maine Quality Counts on trainings for specific populations and coordinating a campaign with providers during Pride month to highlight cancer prevention and treatment. Lastly, participants would like to see more support for caregivers.

Youth Building Alternatives, March 2017, 18 participants

Participants report there is a lot of money required when you have a cancer diagnosis and that treatment isn't always covered, which means people may have to go without care. They have some skepticism of the government and industry related to trying to make money off of people who are sick and would like to see more information and access to clinical trials. A participant noted the federal government is proposing cuts to NIH and there are opportunities to write to legislators, but other participants were wary their voices would not be heard. Participants say there is mixed messaging around tobacco and hearing "don't smoke" isn't helpful messaging. To them illegal drugs are the number one threat, followed by alcohol, and cancer is not on their radar. The participants would like to see wealthier, influential people donate more to research and more research on food products and the link to cancer. They would like more education on cancer risk factors and environmental risk factors. They believe tobacco prevention should start in earlier grade levels, perhaps 5th grade and that young people need positive supports in their life to keep them away from higher risk habits. The participants are most likely to get their information through Google, Instagram, Snapchat, and Twitter.

Little Cranberry Island Resident, March 2017, one-on-one interview

The interviewee described the process of accessing health care from an island. There is no care on the island, but there is an opportunity for telemedicine. However, some doctors and patients are reluctant to participate in telemedicine, as they would rather give and get care in person. With telemedicine, you can't always see your own doctor, as the technology is housed at Southwest Harbor Clinic. Most people will go to Mount Desert Island for care, but still need to find a ride to get there. There is a volunteer driver program. The ferry runs infrequently, so Isleford residents may end up off island all day in order to go to a single appointment. There are water taxi services, but they are not available year round. Two people have left the island in order to be closer to care, which takes a toll on an already small (65 people) community. The challenge of cancer diagnoses are further compounded by living on an island.

Long Island Resident, March 2017, one-on-one interview

The interviewee is a survivor and was a caregiver. She has had excellent health care coverage through Medicare and doesn't have to worry about most expenses. However, a friend was recently diagnosed and is worried about keeping her home and paying for care. Right now there is no telemedicine or medical care, with the exception of EMTs and the rescue boat on Long Island. They are trying to get a nurse to come out twice a week and the Aging in Place Committee, through the Island Institute, is writing a grant for an on-island clinic space, which will include a telehealth center and handicap accessible bathing facility. People can have access to a visiting nurse if their doctor prescribes it. The interviewee would like to see more people aware of the appeals process with insurance and that if a medicine isn't covered, but is deemed medically necessary by a provider, it will be covered. There should also be more awareness of financial navigators and the importance of island residents taking ownership of their own care. For example, if you know you're susceptible to infections, you can ask a provider to keep an antibiotic on hand. The Aging in Place Committee is also working with Casco Bay Lines to get a comfort room at the Portland ferry terminal and will help with rides once people are off island. Living on an island means there is a lot of additional planning necessary to access care.



Stephen's Memorial Hospital, March 2017, 10 participants

Participants discussed several positives happening in their community including: a caring community; the Cancer Resource Center, offering nutrition classes, beginning a wellness program, and increasing visibility; a new infusion room at Stephen's Memorial Hospital (SMH); increasing staff numbers at SMH; a MedAccess Fund to help patients with financial needs; Reiki; a patient navigator; and local care that can serve the community. Participants cited challenges in their community including: cancer rates; there are increasing numbers of uninsured patients; isolation; lack of transportation; lack of local specialty services; there are no radiation services; people are being diagnosed with cancer in late stages; there is no evaluation of the root cause of cancer; and people seem resistant to accepting free/reduced cost care. Participants would like to see a financial navigator; more complementary therapies and holistic care; more support from doctors to recommend patients see the navigators and go to the resource center; a community center for young people to go to and to access programming; more education about prevention (Healthy Oxford Hills does do some of this;); increased communication; identify why people aren't attending programming currently available; more people seeking routine health care; more male involvement; more information on environmental risk factors; more access to insurance and financial resources (SMH doesn't participate in CarePartners;); an Executive Director at the Resource Center; and health care institutions (CMMC, MaineHealth, etc.) working together and putting patients first. Participants suggest working together by accessing the room at the new Deering Memorial Community Center for programming; having SMH be more open to outside resources like the Resource Center and allowing outside groups to advertise their programming; networking with Maine Machine and New Balance to take services/resources to people; collaboration with churches, home care agencies, and Feel Good Food; more PSAs and education through local access television; ambassadors/liasons for communities; grant capacity for support services outside of medical offerings; and working with realtors to relay information on radon detection and mitigation.

Cancer Community Center, March 2017, 16 participants

Participants discussed the perception of an increasing prevalence of cancer occurring in clusters and that people are being diagnosed at a younger age and in later stages of cancer, along with diagnoses of rare cancers. They discussed several areas that are lacking, including: specialists, clinical trials, education for providers and the public, health insurance coverage, financial navigation, and opportunities to talk about cancer. Participants report difficulty coordinating care, not having one resource for patients to go to, and feeling like they have to be their own advocate and care coordinator. They also said caregivers don't have the support they need, and while some centers offer support groups for them, they aren't always offered at convenient times. Participants would like to see better access to transportation; better and more education for young people; champions in the government sector; more nurse navigators; and better communication. They would also like to see reliable, up-to-date information that is consistent in format and from doctor to doctor. Participants would like more specific cancer topics within support groups, more on-line support forums; access to free therapy; and more social workers. They would also like doctors who have knowledge about local resources and who will share those resources with patients. They would like to see what cancer organizations exist in Maine and what each one does. They also believe everyone should have their own advocate; the importance of hope was stressed; and help accepting the "new normal" associated with a cancer diagnosis. Participants would like to see more



collaboration within the health care system; more forums with diverse stakeholders and opportunities to share stories in multiple formats. Participants would like to see more welcoming and inviting health care systems. Lastly, participants would like better access to care and services; a reduction in the perception you have to go South for good care; and that where you live shouldn't dictate the care you receive.

University of New England Students and Faculty, April 2017, 24 participants

Participants discussed that most everyone in the room has had some experience with cancer in their personal lives and addressed the lack of resources and supports for families and caregivers. They discussed at length their desire as clinicians (physical therapy, occupational therapy, and pharmacy students) to be well-rounded, but currently don't have the skills to handle clinical experiences with cancer patients nor know how to monitor a patient's treatment and after care. Their current lack of skills leads some to avoid addressing cancer with patients because they don't have the confidence to do so yet. Participants also talked about the advancements with chemotherapy and its impacts on people, and how cancer doesn't discriminate among Mainers. Participants would like to see more education, perhaps in the form of informational packets, for patients and families. They would like to have more of a role in treatment and aftercare because physical therapy doesn't currently integrate into cancer care. They would like to have more crossover between professions and have a better understanding of their role in caring for their patients who have cancer. They would like to build connections with cancer centers for more experience, through things like shadowing and field work, in order to open the dialogue with other clinicians. They would like to see de-stigmatization of cancer and education through social media. Participants would like more collaboration with the health systems and between residents, which could be initiated by preceptors. They would like a formal site agreement between UNE and New England Cancer Specialists for a larger faculty presence there. Participants would like to continue to find ways to be at the table, including supporting the work of larger organizations; bridging with UNE's medical school; hosting and attending more inter-professional events and projects on cancer; observing the oncology floor; and continuing to build relationships and have cross-discipline dialogue. Participants would like to change the conversation around cancer care in that it is not something only oncologists can address, but that all health care providers should have the minimum capacities necessary to work with cancer patients. Lastly participants believe clinicians and providers need to engage in self-care, but also work with patients and families to better understand their needs.