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# Maine Cancer Foundation Transportation Needs Assessment Summary Report

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## Summary of Key Recommendations

The key recommendations of the Maine Cancer Foundation Transportation Needs Assessment are:

1. Increase capacity and access to regional and community transportation providers
2. Increase the capacity and number of informal volunteer and community-based transportation networks
3. Improve and expand public transportation options and funding
4. Partner with hospitals to provide transportation to their cancer patients
5. Advocacy for transportation funding
6. Education, outreach and navigation to inform patients about transportation options and remove barriers
7. Pilot and test innovative solutions to transportation issues
8. Expand access to oncology providers and facilities in rural areas (particularly Washington County and Southern Aroostook County)
9. Create a statewide transportation group to continue this work

The full executive summary, providing the background and rationale for the project, methodology and key findings is presented below.

## Background

Access to transportation is an important social determinant of health. It is a critical factor in determining the health and wellbeing of individuals. It is also a significant barrier for many in Maine, leading to preventable disparities in health status and disease outcomes. Maine is one of the most rural states in the U.S. and lacks the public transportation infrastructure of larger, more urban states.

Cancer patients are particularly vulnerable to a lack of transportation for several reasons. Patients receiving treatment require a high level of care with many doctor's visits. The cost of transportation as well as childcare/elder care, with consequent lost wages, can quickly become a financial burden. Many cancer patients are unable to drive themselves due to their illness and either have to pay for transportation services or rely heavily on family and friends to drive them to appointments.

Previous research has shown that a lack of transportation is associated with less healthcare utilization, less routine medical care and missed medical appointments, particularly for those from lower economic backgrounds.<sup>1</sup> Healthcare related travel difficulties have been associated with lower income levels, being female, living alone, and having less education.<sup>2</sup> For cancer patients, a lack of transportation has been shown to impact the likelihood that cancer patients receive first line chemotherapy<sup>3</sup> and travel distance has been shown to affect the types of treatment that cancer patients choose to receive.<sup>4</sup>

The Maine Cancer Foundation recognizes the importance of transportation for cancer patients and is working to improve access to care by providing grant funding to transportation agencies serving cancer patients in need. Starting in 2016, the Maine Cancer Foundation conducted community conversations with non-profits, businesses, those with lived experience with cancer and government. Transportation issues were a major theme in these discussions, prompting the need for a more in-depth look at the topic.

In 2017, the Foundation contracted with Market Decisions Research (MDR) to conduct a comprehensive statewide transportation needs assessment. This assessment will help the Maine Cancer Foundation better understand the need for transportation service grant funding around the state, improve current operations, and help develop new opportunities for grant-making in regions most in need of additional services.

### Assessment Goals

This assessment examines the need and opportunities for transportation services support for cancer patients in Maine. Specifically, the goals are to:

- Examine the availability and scope of cancer treatment services by location
- Understand distances that cancer patients travel to receive treatment in different regions of the state

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<sup>1</sup> Syed, S. T., Gerber, B. S., & Sharp, L. K. (2013). Traveling towards disease: transportation barriers to health care access. *Journal Of Community Health*, 38(5), 976-993

<sup>2</sup> Branch, L. G., & Nemeth, K. T. (1985). When elders fail to visit physicians. *Medical Care*, 23(11), 1265-1275.

<sup>3</sup> Salloum, R. G., Smith, T. J., Jensen, G. A., & Lafata, J. E. (2012). Factors associated with adherence to chemotherapy guidelines in patients with non-small cell lung cancer. *Lung Cancer*. 75(2), 255-260.

<sup>4</sup> Terry Meden; Celeste St. John-Larkin; Deborah Hermes; et al. (2002). Relationship Between Travel Distance and Utilization of Breast Cancer Treatment in Rural Northern Michigan. *JAMA*. 2002;287(1):111

- Know more about the barriers and costs associated with transportation in the state
- Compare cancer incidence and mortality and availability of cancer services by county
- Analyze the gaps that exist in transportation services versus need in Maine and develop a plan to address highest need areas

## Methodology

This comprehensive transportation needs assessment combined data from multiple sources, including inpatient and outpatient hospital encounters, the Maine Cancer Registry, licensed provider lists and a survey of transportation service providers. This approach allowed transportation issues to be examined from multiple levels, including access to care (where are providers and facilities located?), the availability of transportation services (what services are currently available to patients?) and the travel patterns of patients (where patients are going to receive care?). A summary of the research questions and data sources is provided in the table below.

Areas of Focus	Primary Questions	Data Sources
<b>Access to care</b>	Where are cancer care providers located in the state? What types of care do they provide? What is the availability of providers for patients?	Licensed provider lists / Hospital information
<b>Availability of transportation services</b>	What transportation options are available for each county and region? What are the restrictions of these options in terms of cost or eligibility? Where do gaps exist in availability of service compared to need?	Survey of transportation providers
<b>Cancer burden by geography</b>	What is the cancer incidence and mortality rates by county? What are the groups that are disproportionately impacted by cancer?	Maine Cancer Registry / NPCR-CSS Maine Behavioral Risk Factor Surveillance System
<b>Patient travel experience and burden</b>	Where are patients going to receive services? What is the distance they traveled? How does travel differ by patient demographics and type of treatment received?	Maine hospital encounter data

## Survey of transportation providers

To collect information about the services currently available, a survey was conducted with organizations that provide transportation services to cancer patients in Maine. The goal of this survey was to gather more information about the transportation services available to patients across the state, and help to understand more about the gaps and barriers that exist in availability of services.

The survey instrument was developed collaboratively by MDR and the Maine Cancer Foundation and included 14 questions about these organizations' operations and the services they offer to cancer patients. A full list of organizations included in the sample can be found in Appendix B.

A total of 22 surveys were completed with transportation agencies and organizations (5 were Maine Cancer Foundation grantees and 17 were non-grantees). Every county in the state was represented by at least two organizations that provided services to the county. The grantee surveys were conducted via email as a part of a grant renewal process with the Foundation. Non-grantees were surveyed by phone by MDR in May 2017. The response rate for the survey was 71%, meaning we spoke to nearly three-quarters of the organizations included in our sample list.

## Geographic Analysis

To better understand access to oncology care and where patients travel to receive cancer treatment in the state, MDR conducted a geographic analysis that examined:

- The location of facilities providing oncology treatment and types of treatment provided
- The distances patients travel to receive care and travel patterns around the state
- The burden of travel by key geographic and demographic factors

This was accomplished by first creating a database of facilities providing oncology treatment. This information was compiled by MDR and included the address of the facility, the types of treatment offered, the number of part-time and full-time oncologists, and other information about the scope of services provided.

To examine the travel patterns of cancer patients, the 2015 Maine outpatient and inpatient Hospital Encounter dataset was obtained from the Maine Health Data Organization. Cancer related diagnoses were flagged in the datasets using ICD-9 and ICD-10 codes (ICD-9: 140–239, V58, ICD-10: C00–D48, Z51). A comprehensive list of classifications used to define cancer diagnoses is provided in Appendix A.

Out-of-state patients who received care in Maine were removed from the dataset as were cases missing zip codes or with incomplete zip codes. Note that Maine cancer patients who received care at an out-of-state hospital are not included in the Maine hospital encounter datasets; as a result, travel by Maine patients to hospitals outside the state is not captured in this analysis. The final datasets used in analysis included all cancer diagnoses encounters from Maine residents at in-state hospitals and clinics.

The final number of cancer-related encounters in the datasets included:

- Outpatient: n = 263,020
- Inpatient: n = 10,645

MDR used the Google Maps' Application Program Interface (API) to calculate distances between the zip code of patient and the address of the facility where they received care. Geographic Information System

(GIS) software was used to map oncology facility locations and travel distances. MDR also analyzed travel patterns by county and municipality for several types of cancer treatment, diagnoses and other factors.

## **Limitations**

The biggest limitation of this needs assessment and analysis is that it includes only Maine-based providers. Travel to hospitals outside the state is a significant factor for many cancer patients, but the scope of the assessment and the available data is limited to Maine. Maine Cancer Foundation has conducted qualitative research previously that included information about out-of-state travel needs, but it does remain an area that requires more research. A possible next research step would be to conduct a more comprehensive review of out-of-state travel needs.

Another limitation is that the currently available data are often a few years old. At the time of the assessment, the most recently available hospital encounter dataset included 2015 data. Information about cancer incidence is even older. However, this is offset somewhat by the primary data collection efforts to collect information from transportation providers, which was conducted in 2017. Also, information on the available oncology facilities and providers was compiled in 2017.

## Overview of Maine Cancer Data

From 2009-2013, Maine had an average of 8,222 new cancer cases diagnosed each year. Cancer is the leading cause of death in the state, accounting for 3,227 deaths in 2013. According to the Maine Cancer Registry, in 2013 Maine's age-adjusted cancer incidence rate was 463.8 per 100,000 population and its cancer mortality rate was 174.8 per 100,000 population. Both are significantly higher than the U.S. average.<sup>5</sup>

Cancer incidence rates are higher among older adults and those with lower income and education levels. Within Maine, cancer rates differ significantly by county. Downeast Maine and York County had the highest overall age-adjusted cancer rates in the state from 2009-2013, while Franklin county had the lowest age-adjusted rate (See Figure 5).

Disparities in social determinants of health and health behaviors between the counties may be the root cause of some of the differences in cancer rates. For example, Washington County has one of the highest age-adjusted cancer incidence rates in the state. It also has one of the highest adult smoking rates (24.3%), and tobacco use has been shown to be one of the leading causes of cancer. Adults living in Downeast and Northern Maine also tend to be older and have lower education and household income levels compared to other parts of the state. These are other factors generally associated with higher cancer incidence.

More information about cancer incidence and mortality in Maine can be found in the Maine Annual Cancer Reports, from the Maine CDC Cancer Registry.

Using data from the Behavioral Risk Factor Surveillance System (BRFSS), Maine has better breast and colorectal cancer screening rates than the U.S. average. Four in five (81%) women aged 50+ have had a mammogram within the past two years, compared to only 76% percent of women in the U.S. Three-quarters (75%) of Maine adults aged 50-75 have fully met the U.S. Preventive Services Task Force recommendations for colorectal cancer screening, compared to 66.6% for the U.S. average.<sup>6</sup>

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<sup>5</sup> The Maine 2016 Annual Report on Cancer, Maine CDC Cancer Registry. Accessed from: [http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/reports/documents/Maine-2016-Annual-Report-of-Cancer\\_06292017.pdf](http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/reports/documents/Maine-2016-Annual-Report-of-Cancer_06292017.pdf)

<sup>6</sup> Behavioral Risk Factor Surveillance System, National Center for Chronic Disease Prevention and Health Promotion. Division of Population Health. Accessed from: <https://www.cdc.gov/brfss/brfssprevalence/index.html>



## Survey of Transportation Providers

MDR conducted a survey of 22 organizations providing transportation services to cancer patients around Maine. These organizations ranged from small, community transportation networks to national transportation providers with services around the county.

Not surprisingly, most of the organizations providing transportation services in the state are small and regionally or community focused. This reflects the community-based approach that is often used to address public health issues in Maine. The majority of these transportation providers are made up of less than 25 volunteer or paid drivers. Most serve less than 50 patients per year, and only one in five serve more than 75 patients. The majority of providers offer free transportation to qualified individuals through MaineCare or to those living in the community in the case of volunteer organizations. Others offer discounted or low cost fares, while a few are paid services.

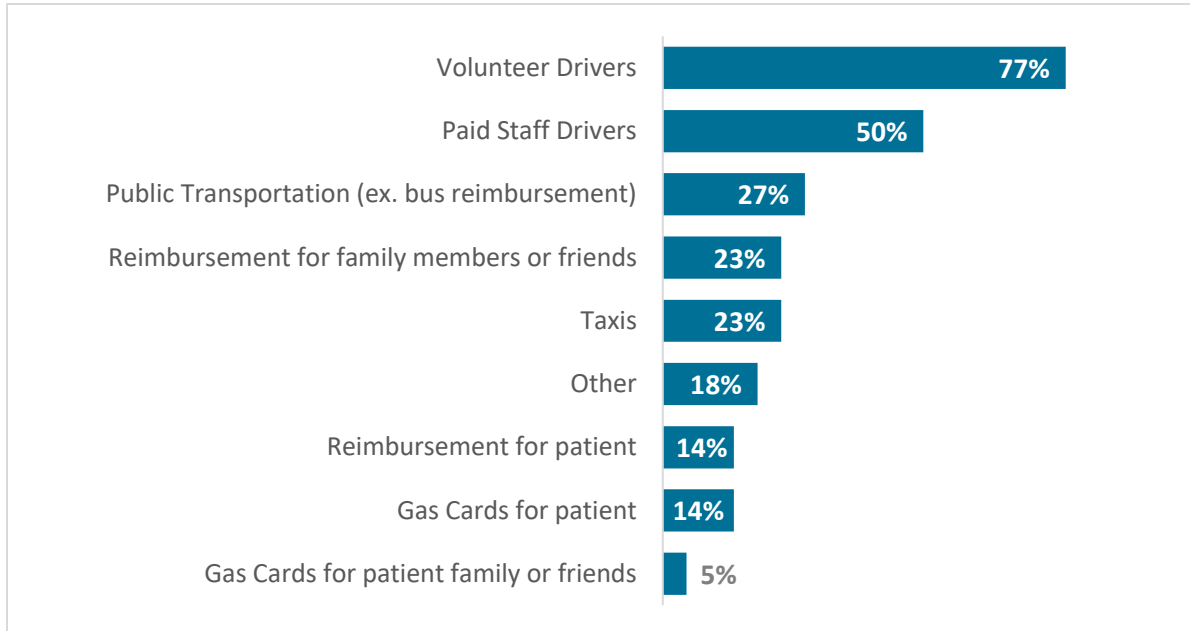
For a list of the organizations included in the sample, please see Appendix B.

The key findings from the survey included:

### **Transportation organizations provide many types of services to cancer patients, but volunteer drivers make up the core of many programs.**

- Three-quarters of organizations use volunteer drivers to provide rides, while half use paid drivers.

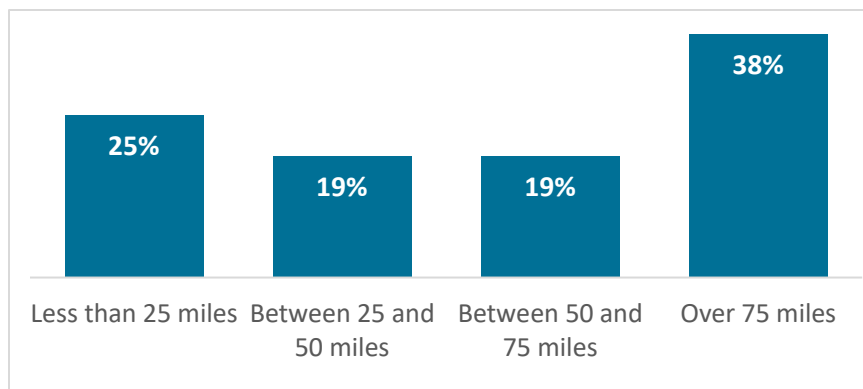
**Figure 1. Types of Services Provided to Patients**



Maine is a large and rural state, and many cancer patients rely on these programs to travel very long distances for many trips. Without the support they provide, many would not have the resources to travel to get needed care.

- Cancer patients who receive transportation services travel an average of **70 miles per trip**
- Many patients require multiple trips over large distances in the state to receive services. On average, 4 in 5 patients require more than one trip and the median number of trips required was 10

Figure 2. Average Round Trip Distance for Cancer Patients Receiving Services

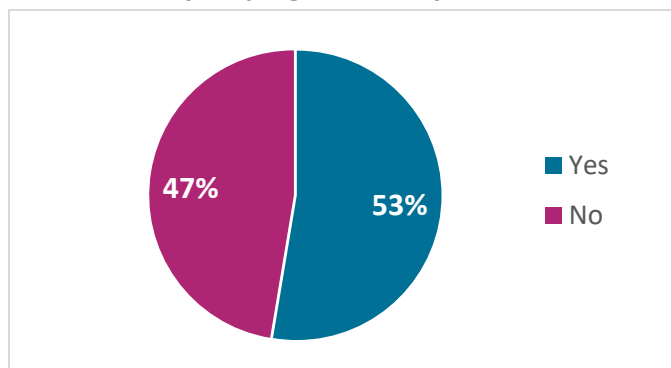


Cancer patients in Maine face significant transportation barriers that impact their ability to receive care.

- Patients have to travel very long distances to receive services
- A lack of public transportation in the state leaves many patients without an inexpensive method of travel
- Some patients lack family and friends available to help drive them to appointments
- The cost of owning a vehicle or hiring taxis can be prohibitive
- The inability to drive due to illness is significant issue for cancer patients

Nearly half of transportation providers reported having to turn away patients over the past year because they lacked the resources to meet demand. This means it is likely some patients are not getting needed care because they lack transportation.

Figure 3. Could you help every cancer patient who contacted your program in the past 12 months?





## Geographic Analysis of Cancer Treatment Availability and Distance

The geographic analysis of cancer care transportation examined travel from two perspectives: Access to care (where oncology providers and facilities are located?) and patient experience (where patients are traveling to receive care?). This provides a full picture of transportation around the state and allows for a greater understanding of whether gaps are due to a lack of providers in the area, or because patients are not able to access the care available for other reasons. For this project MDR created a database of all oncology facilities in the state, with information about the location, types of treatment provided, and number of part and full-time providers at the site.

### Access to Care

**Access to cancer care in Maine is heavily concentrated in Southern Maine, specifically in the region along the coast between Scarborough and Brunswick.**

- Of the approximately 200 oncologists in the state, nearly half are located in Cumberland County.
- Of the 48 facilities with an oncologist on staff, 11 are in Cumberland County and 7 are in York County. Maine has a small number of facilities that provide radiation treatment (15), and seven of those sites are in Cumberland County. (See figure 8).

**Most of the state lives within 35 miles of a cancer care facility, but these facilities can't always provide the types of services needed by patients.**

- Most of Northern, Western and Downeast Maine lives 50+ miles from the nearest radiation treatment facility, and some communities are 100+ miles away. (See figure 9).

**Cumberland, Kennebec and Penobscot Counties serve as primary destinations for cancer patients in Maine.**

- This is not a surprise given the large, regional hospitals in these areas, but it is important to ensure that patients even in rural areas have access to reliable transportation to these core regions.

### Patient Experience

**Transportation is an issue that impacts cancer patients in all parts of the state, but the needs and barriers of each community differs based on circumstances.**

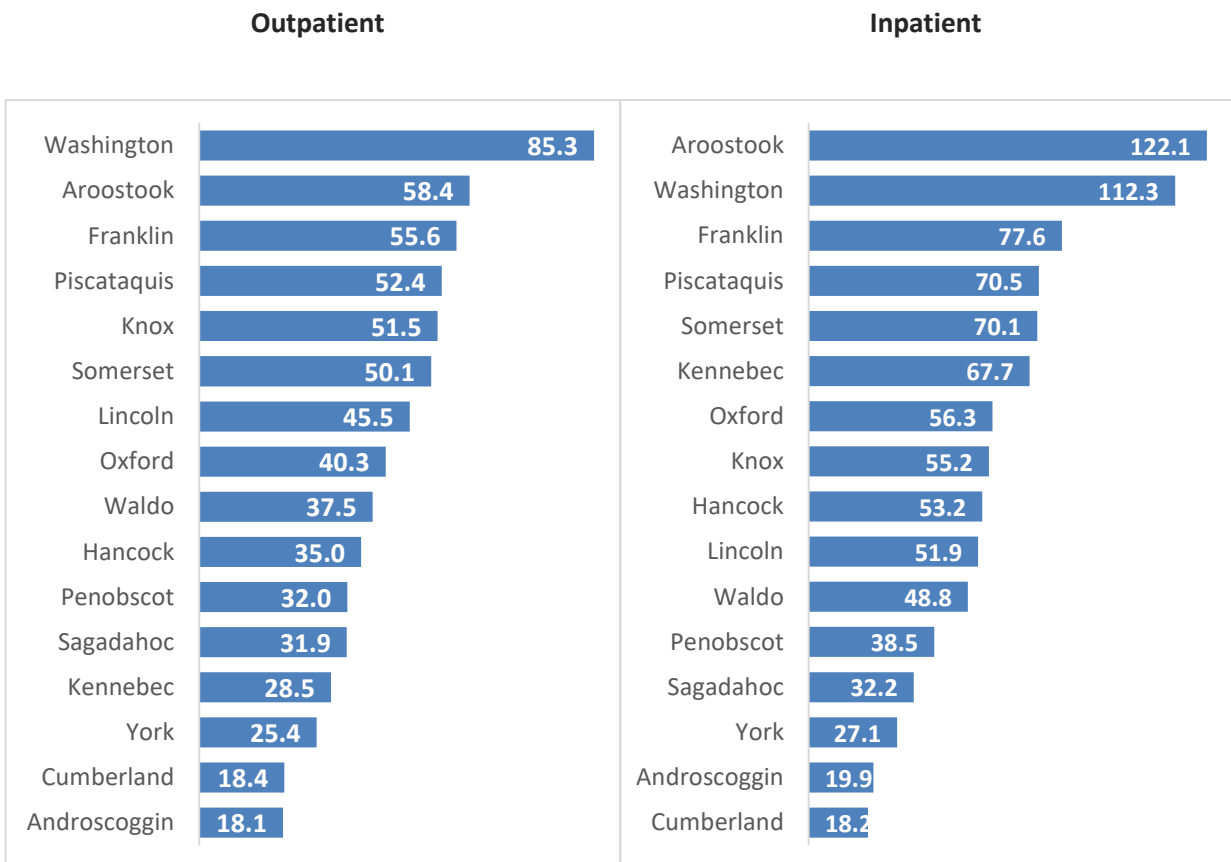
- Cancer patients in Maine traveled an average of 34.8 miles to receive outpatient care and 46.4 miles to receive inpatient care.
- Those living in rural areas do experience much longer travel distances, but the populations in these areas are lower.
- Patients living in Southern and Central Maine have facilities closer to home, but these areas have much larger populations.

- There are large differences in travel burden for inpatient care by cancer site (e.g., breast, lung) although the total number of visits for inpatient care is relatively low compared to outpatient care.

**Patients living in the most rural areas of the state travel 4-6 times further to receive cancer treatment than those living in urban areas.**

- Travel distances of 100+ miles for cancer treatment are not uncommon in rural parts of Maine.
- Patients living in Washington County are subjected to the longest travel times in the state for cancer care. They travel an estimated 85 miles for all types outpatient cancer care, 126 miles to receive chemotherapy treatment and 144 miles for radiation treatment. Those in Aroostook, Franklin, Piscataquis and Somerset also deal with very long travel distances.
- Patients in Aroostook and Washington Counties travel 100+ miles on average for inpatient cancer care.
- Rural areas also generally have higher rates of cancer incidence.
- However, despite much longer travel distances, the average number of visits made by patients does not differ greatly by geography (Urban areas: 2.6 visits per patient; Isolated rural areas: 2.8 visits).

**Figure 4. Average Round-Trip Travel Distance by County, 2015**



**Lower socio-economic status is associated with higher levels of cancer incidence and longer travel distances. This results in higher need and more transportation barriers for this group.**

- Medicaid beneficiaries travel further than others to receive cancer care. This may be because a higher percentage live in rural areas, such as Aroostook County (where 28% of cancer visits were paid by Medicaid) and Washington County (28%), compared to Kennebec (11%), York (14%) and Cumberland (15%).
- Since they have to travel further and have higher cancer incidence rates, it is critically important that low-income patients in rural areas have access to low or no-cost transportation

**Patients receiving chemotherapy or radiation treatment have an average of 7-8 treatment visits.**

- Many long trips for appointments can create a large burden and cost to patients, family, friends, caregivers and others who assist with providing rides.
- Those receiving radiation treatment travel further (47.2 miles per trip) and make more visits (7.9 on average) than patients receiving Chemotherapy (37.4 miles) or Immunotherapy (28.6 miles)

**Number of Patients and Visits by Type of Treatment, 2015**

	Miles (Round-Trip)	Cases	Patients	Visits per Patient
Chemotherapy	37.4	23,583	3,536	6.7
Radiation	47.2	16,823	2,142	7.9
Immunotherapy	28.6	1,272	331	3.8

**A lack of oncologists in rural parts of the state, particularly in Washington County and Southern Aroostook County, results in excessive travel distances. These areas would benefit the most from access to nearby oncologists.**

- Lincoln, Sagadahoc and Washington Counties lack any oncology providers.
- Patients in Washington County drive an estimated 126 miles to receive chemotherapy treatment. Piscataquis, Franklin and Aroostook also travel large distances for chemotherapy.
- Patients in Aroostook and Washington Counties travel nearly 150 miles on average to receive radiation treatment.
- Excessive travel impacts the motivation and ability of patients in rural areas to get needed care.
- This points not just to an issue of transportation, but of access to providers, and the need for oncology providers in the region.

**Maine cancer patients travel over 1.7 million miles per year to receive treatment and 9.6 million miles for all types of hospital-based cancer care.**

- Note that these estimates likely understate the total travel distance since they do not consider out-of-state travel. They also don't consider other costs such as loss of wages for those assisting with transportation or lodging expenses.

## Maine Cancer Transportation Summit

On June 12, 2017, Maine Cancer Foundation hosted the Maine Cancer Transportation Summit at Maple Hill Farm & Conference Center in Hallowell. The Summit brought together regional and community transportation providers from inside and outside the state, Mainers affected by cancer and other individuals and organizations interested in improving cancer patients' access to care.

Maine Cancer Foundation and Market Decisions Research presented the results of the transportation needs assessment at the summit and discussed with attendees the potential solutions for improving transportation options for cancer patients in Maine. The summit provided the Foundation with an opportunity to learn more about what is happening with cancer-related transportation in Maine: what resources currently exist? What costs are associated with transportation? Is there system-level change that can happen to eliminate this barrier for cancer patients?

Discussion groups were held during the second half of the summit and focused on four questions related to transportation resources, needs and barriers in the state. The results of these discussion groups are summarized below.

### **1. What does your organization do well regarding transportation and lodging services for Maine cancer patients? Could other groups replicate your work?**

- Discussion group participants noted that regional and community transportation providers in Maine have years of experience providing services, understand the specific needs of their communities and patients. Potential solutions to transportation barriers should utilize their experience as a resource.
- Transportation providers, patient navigators and others always try to find a way to meet the needs of their communities and turn away very few patients as a result. Many will track when and why a person can't be helped, which can be used when requesting additional funding in the future.
- Cost and a lack of resources are certainly a barrier, and restrictions or issues that occur are often related to funding.
- There are no-cost options available to cancer patients across the state. ACS Road to Recovery Network is a resource that generally works well in all but the most rural parts of the state.
- Providers have been incorporating more technology to assist with scheduling and coordination of transportation, such as mobile apps used by drivers and call center software to log call history and improve scheduling.
- Many organizations go beyond simply providing a ride and help patients physically, emotionally and with other unmet needs.
- These organizations also have the ability to provide community education and prevention on transportation issues. They help educate community health workers and other healthcare providers on the available transportation resources in the area.
- In addition to transportation, many help connect patients with available transportation resources (e.g. the MaineHealth resource line) or provide other services to help and refer patients to make sure all their needs are met.

## **2. Are there unique challenges of serving cancer patients in your community that have not been mentioned today?**

- There is considerable time and effort required to train drivers and volunteers. It requires recruitment, background checks, and multiple training sessions (including training on privacy laws and behavior, safety and security, among others).
- It also can be difficult to find volunteer drivers to participate in programs.
- There is a lot of risk associated with transportation, including accidents and other security issues.
- It can be difficult for drivers to coordinate and manage schedules. They may not be able to accommodate last-minute changes in a patient's schedule or appointments that run long.
- Transportation can be an issue for patients requiring non-ambulatory care or those with mobility issues. Volunteers don't always have handicap accessible vehicles or may not be physically able to assist someone with a physical disability. This may require an ambulance ride, which can be time consuming and expensive.
- The need for more funding is always an issue, especially when resources are declining (such as the loss of the Susan G Komen breast cancer research foundation affiliate in Maine).
- It can be difficult for organizations to get the word out about their services, especially when they don't have the resources to market their services.
- Some types of assistance, such as travel reimbursements or gas cards, don't address everyone's needs or the fact that some patients don't have the ability to drive.
- A lack of treatment services in parts of the state make accessing care difficult. For example, Maine Medical Center has the only gynecological cancer practice in the state
- It can be a challenge to manage urgent versus non-emergency transportation; and hard to determine who needs the most help when resources are limited.
- It is important to remember the human aspect to transportation and why this is important. Cancer patients should have opportunities made available so they don't need to beg for help.

## **3. In addition to recommendations presented today, do you have other ideas or suggestions?**

Those participating in the discussion group had many specific ideas on how to improve access to cancer care and transportation in Maine. They are grouped into general categories below.

### Funding

- Funding sources can be restrictive and time consuming to manage. More general funding and funding made available for promotion/marketing of resources.
- Partnerships with healthcare organizations and local corporations for fundraising and grants
- There is a need to think of creative ways to generate funding for these services, such as a vanity license plate.
- A universal system of financial/transportation applications



## Training

- Training programs that can be shared by transportation providers
- Additional training for healthcare providers on what resources are available

## Programs/technological solutions

- RideHealth is a HIPAA-compliant platform that enables healthcare providers to schedule, request and pay for rides on behalf of patients
- Aunt Bertha is a crowdsourcing platform that connects people to services in their area
- GoMaine, the statewide commuter services program sponsored by Maine DOT and the Maine Turnpike Authority, could be a resource for community-oriented transportation and ride sharing.
- CarShare, used in Boston, is a mobile application allowing an individual to share their car
- Community Concepts has a grant to work with hospitals to figure out how to better schedule patients, which helps with ride coordination and decreases no show rates for the hospitals. For example, all patients from Lewiston are scheduled on Mondays and Tuesdays.

## Meeting all the needs of patients

- Cancer patients have varying needs and need help from different resources.
- It can be important to reach out to patients with a phone call and discuss their specific situation.
- It is important to provide ride services for prevention in addition to treatment.
- Find ways to bring screening services to patients in the communities where they live. Telemedicine/videoconferencing for multiple programs may be an option to increase access to care.
- Airbnb is creating a program called OpenHomes for refugees but it will also be open for patients
- Look into having a transportation coordinator in each area and a database for everyone, not just cancer patients

## **4. How can we stay connected? Are you already involved in transportation related groups? Are there organizations you would like to collaborate with?**

There are a number of existing groups in the state and nationally with an interest in expanding access to transportation. Some of those brought by in the discussion groups include:

- Maine Transit Association - Maine's regional transportation providers, regional planning agencies, city bus operators, and commuter bus and carpool services are all members of this organization.
- National Rural Transit Assistance Program
- Maine Primary Care Association and Federally Qualified Health Centers have started "Not Just a Ride" and bringing together transportation and healthcare providers to work on solutions.
- Community Transportation Association of America
- Community Health/Action Organizations
  - Maine Health Access Foundation

- Kennebec Valley Community Action Program
- Other community organizations like Lions Club and Chambers who are engaged in communities
- Regional Planning Commissions/Municipal organizations
  - PACTS (Portland Area Comprehensive Transportation System)
  - KACTS (Kittery Area Comprehensive Transportation System)
  - Greater Portland Council of Governments
  - Southern Maine Planning and Development Commission
- Senior organizations
  - Agency on Aging
  - Senior Transportation Group
  - AARP

## Solutions to Transportation Issues in Maine

The recommendations provided below are based on overall findings and results found in this needs assessment and in the literature. While Maine is a large and rural state made up of many small communities, it is important to remember that the challenges faced by each community are unique. The recommendations provided below are not a one size fits all approach. Instead, the solutions required for a community must meet the specific needs and circumstances of the area.

The solutions to approaching transportation needs in the state are complex, but include the following:

### **1. Increase capacity and access to regional and community transportation providers**

Community and regional transportation providers play a key role in Maine's transportation network and are a key player in reducing transportation barriers. Many patients lack the ability to pay for their own transportation, and would not be able to travel to get care without the support and services they receive from transportation providers.

However, many transportation providers in the state are at capacity and need additional funding to expand services, especially in rural areas and in communities with high levels of need. In addition, there is always a need for additional low or no-cost transportation services for patients who cannot afford to travel otherwise. Many cancer patients, especially those who are elderly, either can't afford, or don't have the ability to drive to appointments. Maine also lacks an adequate public transportation infrastructure, so the state's transportation providers must fill the gap of providing low or no cost services to the many patients who don't have any other transportation options.

Many of the organizations in the state survive on public funds, grants and donations. Cuts to funding (particularly MaineCare) would have a devastating impact on Maine's transportation network and put the ability of cancer patients to travel to appointments at risk. This highlights the importance of advocacy related to transportation funding. It is critical to demonstrate the importance of sustaining and improving transportation services to leaders at the local, state and federal level. For cancer patients, this funding could be the difference between life and death.

### **2. Increase the capacity and number of informal volunteer and community-based transportation networks**

Given Maine's rural and often isolated geography, some communities have come together to create volunteer networks to assist elderly, sick and other adults with transportation needs. These groups include Neighbors Driving Neighbors, South Berwick Volunteer Network, as well as others. This approach builds on the strong ties of Maine communities using a neighbor helping neighbor approach to transportation.

The informal nature of these groups is both a strength and a weakness, but it is often the only viable option when funding is limited or not available. To assist with the establishment and growth of community groups, organizations like Maine Cancer Foundation and other agencies could provide training, resources, help recruiting volunteer drivers, access to technology and/or other support. Maine already has established groups that can share their experience and serve as models for volunteer transportation networks in other communities. Developing a how-to guide on establishing volunteer community transportation networks could prove useful for other communities looking to establish their own volunteer network.

### **3. Improve and expand public transportation options and funding**

Maine has one of the lowest per capita expenditures on public transportation in the country. Traditional forms of public transportation can play a key role in transportation for patients in the state's urban areas. However, most communities in the state have little to no access to public transportation options. In more rural areas, it is important to explore other forms of publicly-funded transportation that fit the varying needs of Maine's diverse communities. This can include:

- More public-funding for regional and community-based transportation services
- Expansion of urban public transportation into surrounding suburban areas (such as the Husky Line, Metro BREEZ bus or Downeaster expansion)
- Partnerships with ride-sharing services or transportation providers such as Uber and Lyft to provide subsidized rides
- Additional funding for travel reimbursements
- Implementation of technology to support ride-sharing and other driver networks
- Air travel for those needing care outside of the state
- Other services related to travel, such as lodging

Transportation service providers also noted the need for assistance in procuring additional funding, such as connecting with partners for fundraising, and more flexibility in the funding they do receive, such as using it for marketing of services, to make them more responsive to the needs of the communities they serve.

### **4. Partner with hospitals to provide transportation to their cancer patients**

Hospitals can implement programs to better connect their cancer patients with transportation services and coordinate travel. Hospitals have a financial incentive in preventing patients from missing appointments. It can be a win-win situation: the patient receives help with transportation to get the treatment they need and the hospital avoids the loss of revenue associated with missed appointments.

This approach is being implemented by a growing number of hospitals around the country and involves the hospital partnering with an existing transportation provider or service to provide more coordinated appointments and transportation. A platform like RideHealth, which enables healthcare providers to schedule, request and pay for rides on behalf of patients, could be used to facilitate this type of approach.

### **5. Advocacy for transportation funding**

A lack of resources and the need for additional public funding for transportation was an issue identified in both our survey and the transportation summit discussion groups. Many service providers have difficulty procuring funding, while at the same time resources are being cut within the state. This highlights the importance of advocacy on this issue. It is important that the costs and burden of travel for cancer patients who are sick and often can't afford transportation be made clear to leaders at the state and federal levels. This is especially true for the poorest and most vulnerable populations, who often live in the most rural areas of the state.

A recent example is the Act To Improve Public Transportation in Maine, a bill that proposed additional funding to support and expand local volunteer driver networks, to create a pilot purchase of service program, and for regional transportation providers throughout the state to expand their services.

## **6. Education, outreach and navigation to inform patients about transportation options and remove barriers**

Cancer patients may not always be aware of the options available to them or may feel they can't ask for help. In addition, lower socio-economic status is associated with higher levels of cancer incidence and longer travel distances. The result is higher need and more barriers to travel for those less likely to understand their options and with less ability to afford services. This is a critical group for outreach, education and navigation assistance.

The American Cancer Society Road To Recovery and Maine's regional and community transportation providers often play a critical role in education and outreach by connecting with patients to identify their specific needs and service requirements. However, it is important that patients are referred to these services and that follow-up occurs so that patients aren't left without help. Organizations like the Maine Cancer Foundation can help provide much needed outreach and education, especially to vulnerable populations. Hospitals and other community health organizations can also be a resource to educate patients on all of their options.

## **7. Pilot and test innovative solutions to transportation issues**

Traditional transportation services can be expensive to implement, especially in rural areas with dispersed populations. This is an opportunity to pilot innovative or technological-based approaches that may provide a solution to the logistical and operational issues that exist when providing transportation services. For example, online platforms like Veyo and Trip2 already allow patients to access non-emergency medical transportation using technology-driven solutions and real-time analytics to improve patient experience. A platform like RideHealth can help healthcare providers assist their patients with getting transportation, improving care coordination and reducing missed appointments.

While technology alone is not a solution, pilot programs that combine the potential of technology with established driver networks or regional transportation providers may lead to a greater ability to provide low-cost transportation services, meet patient needs, and sustain services over the long-term.

## **8. Expand access to oncology providers and facilities in rural areas (particularly Washington County and Southern Aroostook County)**

Expanding access to oncologists in rural areas of the state reduces the need for regular, long trips for treatment that put unneeded stress on cancer patients and their families. Those living in rural areas with the longest travel distances tend to be older and have lower household incomes. These are groups most likely to lack the ability to drive or afford the cost of transportation. Rural areas in Maine tend to also have higher cancer incidence rates.

The results of the needs assessment clearly show that Washington County and Southern Aroostook County are areas most in need of oncologists, as many patients in these areas drive over 100 miles

to receive cancer care. While these areas may not be able to support a full-time provider, they would greatly benefit from (at a minimum) a visiting or part-time oncologist who could provide some relief from the huge travel distances patients in these areas are forced to drive.

Despite the significant challenges of implementation and sustainability, telemedicine is a long-term solution for bringing providers into rural areas. There are still legal and policy issues that need to be resolved before telemedicine can reach its potential. However, Maine's hospitals should take the initiative on telemedicine services with the goal of better serving individuals in all parts of the state, including the most rural areas. It is also important that broadband access be made available to residents in rural areas to ensure that patients can access telemedicine services once they are available.

## **9. Create a statewide transportation group to continue this work**

Maine Cancer Foundation's Transportation Summit brought together a group of stakeholders committed to improving access to transportation for cancer patients. The group shared their experiences providing services, talked about issues and discussed potential solutions. There is an opportunity to continue a group like this to provide strategic and coordinated guidance and advocacy for transportation issues on a statewide level. This group could continue to address the many needs and barriers identified in this assessment, including issues related to funding, training, coordination, advocacy, education and outreach.

## Appendix A: ICD-9 and ICD-10 Classification Codes

Cancer-related diagnoses were defined using ICD-9 and 10 codes. In the fourth quarter of 2015, hospitals began reporting ICD-10 codes to MHDO. As a result, ICD-9 codes were used to define cases in Q1-Q3, while ICD-10 codes were used to define cases in Q4 2015.

### Definitions used for needs assessment

#### All cancer sites (primary diagnosis):

ICD-9: 140-239

ICD-10: C00-C96, D00-D49

#### Chemotherapy (primary or secondary diagnosis)

ICD-9: V58.11

ICD-10: Z51.11

#### Radiation (primary or secondary diagnosis)

ICD-9: V58.0

ICD-10: Z51.0

#### Immunotherapy (primary or secondary diagnosis)

ICD-9: V58.12

ICD-10: Z51.12

#### Breast Neoplasm (primary or secondary diagnosis)

ICD-9: 174

ICD-10: C50

#### Lung Neoplasm (primary or secondary diagnosis)

ICD-9: 162

ICD-10: C34

#### Colon Neoplasm (primary or secondary diagnosis)

ICD-9: 153, 159.0

ICD-10: C18, C20.9, C26.0

#### Prostate Neoplasm (primary or secondary diagnosis)

ICD-9: 185

ICD-10: C61

#### Urinary Neoplasm (primary or secondary diagnosis)

ICD-9: 188

ICD-10: C67

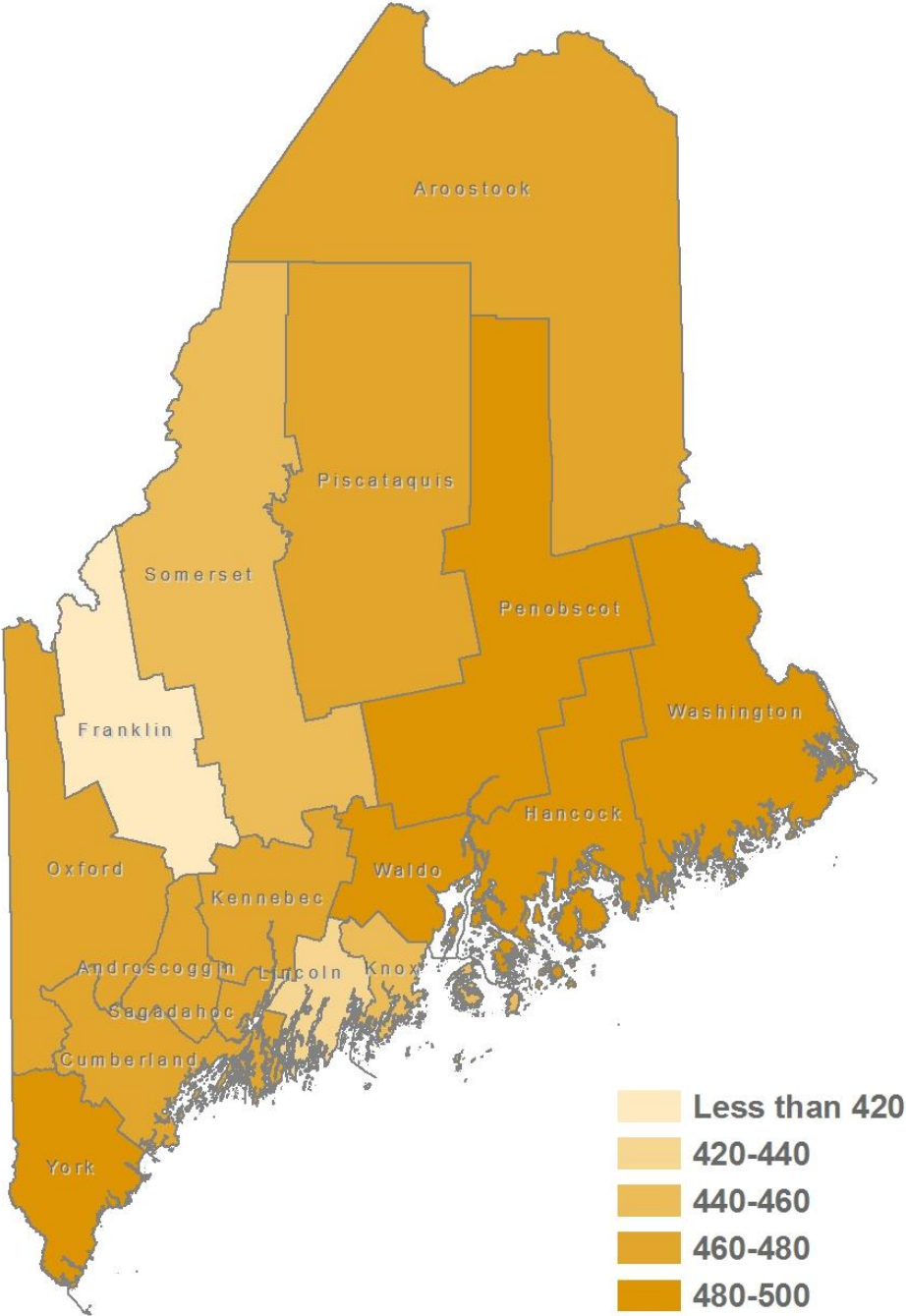
## Appendix B: Transportation Providers in Survey

American Cancer Society - Road to Recovery program	Mermaid Transportation
Aroostook Regional Transportation System	MidCoast Connector
Beth C. Wright Cancer Resource Center	Neighbors Driving Neighbors
Boston Shuttle - VA Maine Healthcare System	Penquis/Lynx Mobility Services
Catholic Charities Maine	People Plus - Volunteer Transportation Network
Community Concepts Transportation	Provide A Ride
ConnectShuttle	Rangeley Region Health Appointment Transportation
Corporate Angel Network	Regional Transportation Program (RTP)
Dean Snell Cancer Foundation	Rural Community Action Ministry
Dempsey Center	South Berwick Volunteer Network
Freeport Community Services	The Center
Independent Transportation Network	Waldo County Community Partners
Island Connections	Washington-Hancock Community Agency
Kennebec Valley Community Action Program (KVCAP)	Western Maine Transportation Services
Lake Region Senior Service, Inc.	York County Community Action Program
LogistiCare	

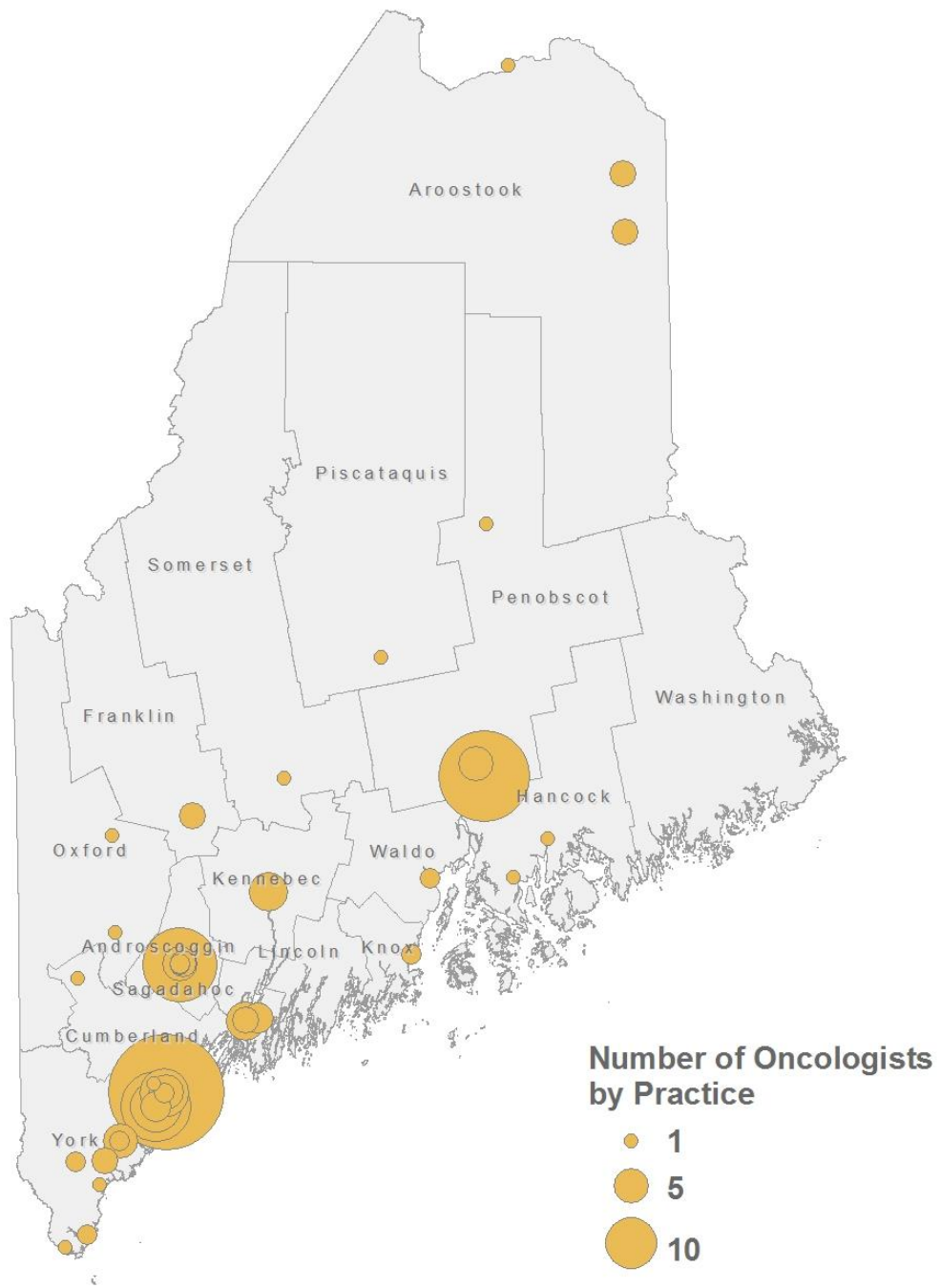


# Appendix C: Additional Maps and Figures

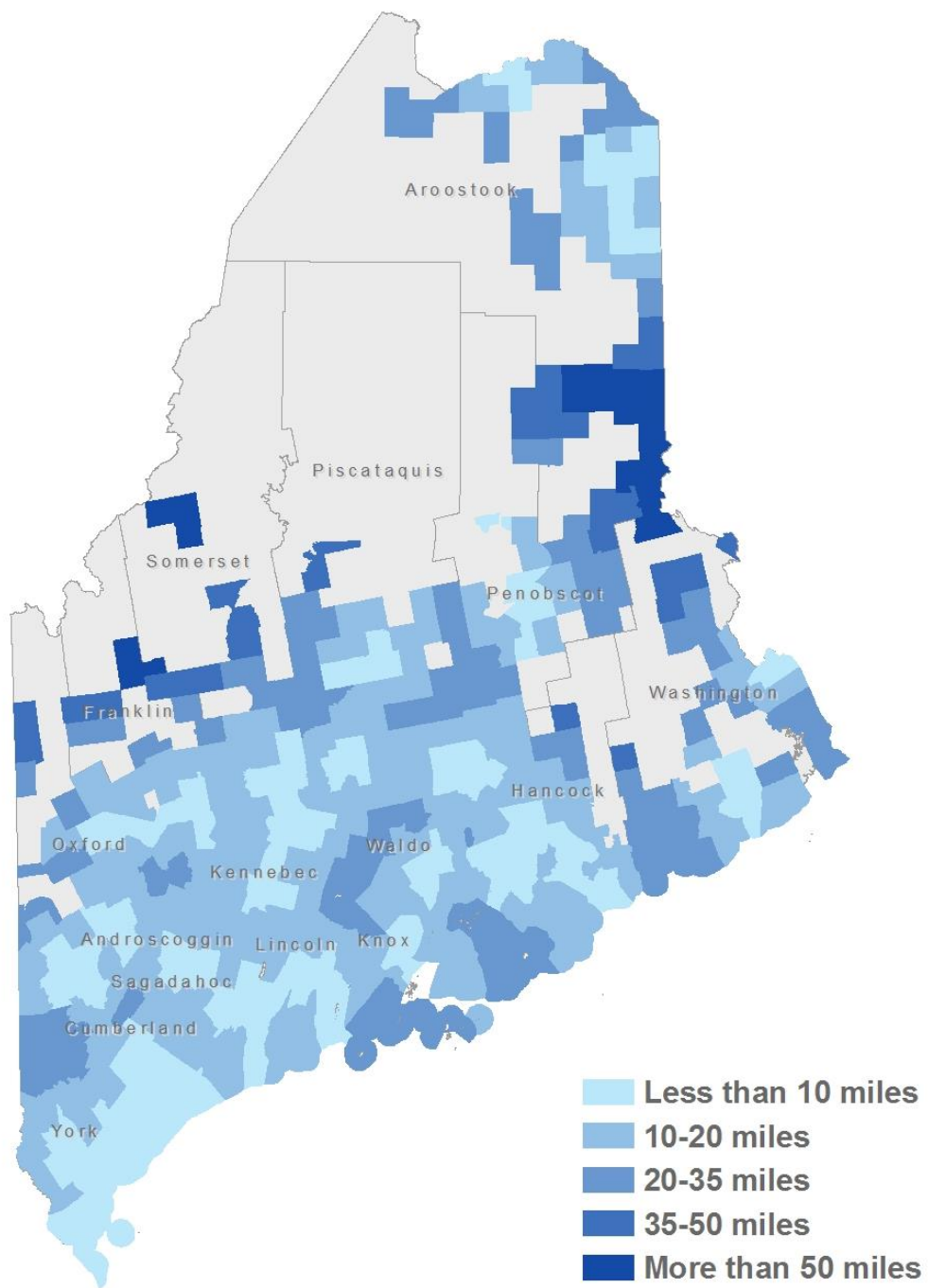
Figure 5. Age-Adjusted Incidence Rates Maine by County, All Cancer Sites, 2009-2013. Source: Maine CDC Cancer Registry



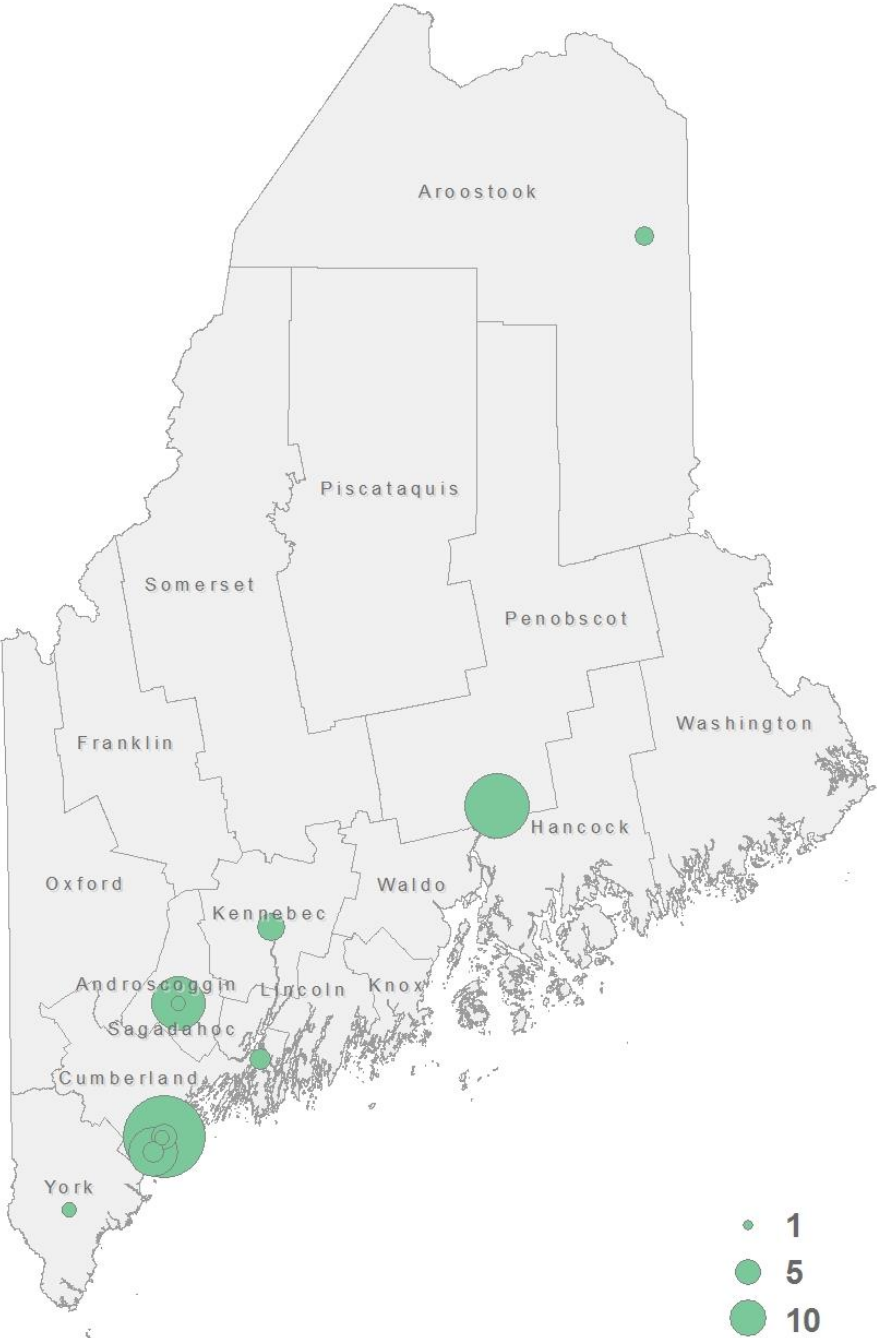
**Figure 6. Cancer Treatment Sites in Maine by Size and County Source: 2017 MDR Hospital Oncology Dataset**



**Figure 7. Minimum travel distance to receive chemotherapy treatment. Source: 2017 MDR Hospital Oncology Dataset**



**Figure 8. Radiation Treatment Sites in Maine by Size and Location. Source: 2017 MDR Hospital Oncology Dataset**



**Figure 9. Minimum travel distance to receive radiation treatment. Source: 2017 MDR Hospital Oncology Dataset**

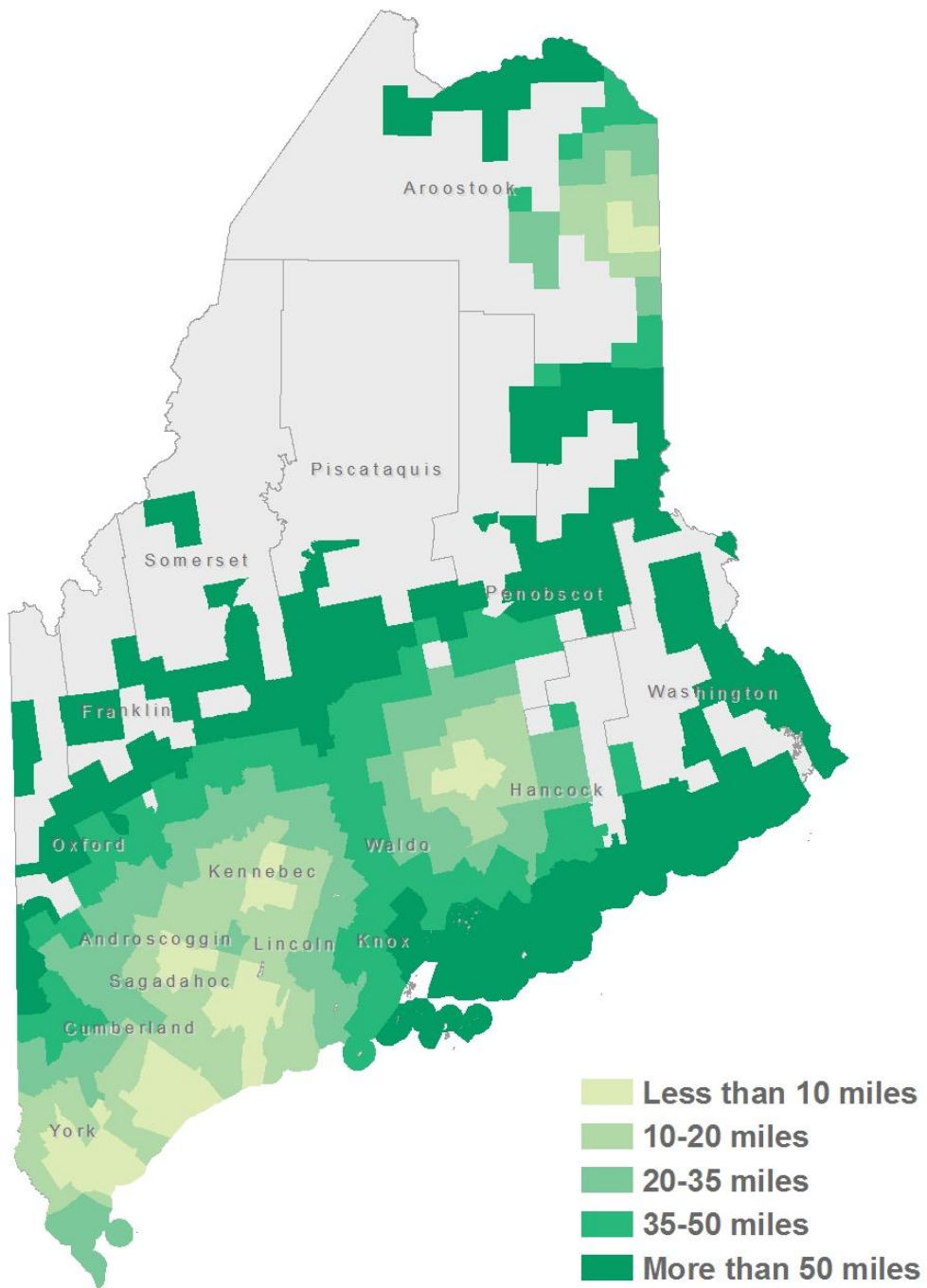
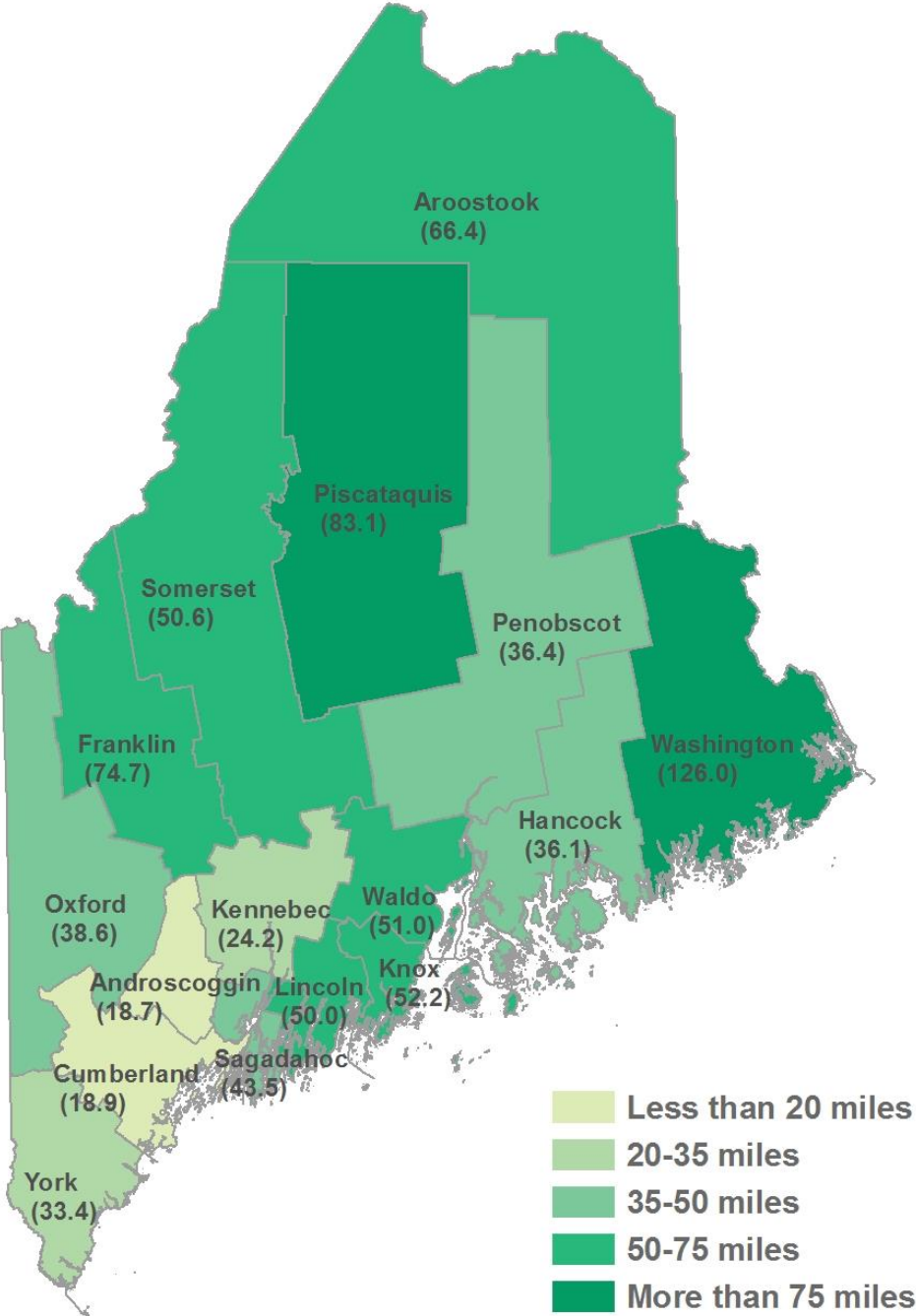
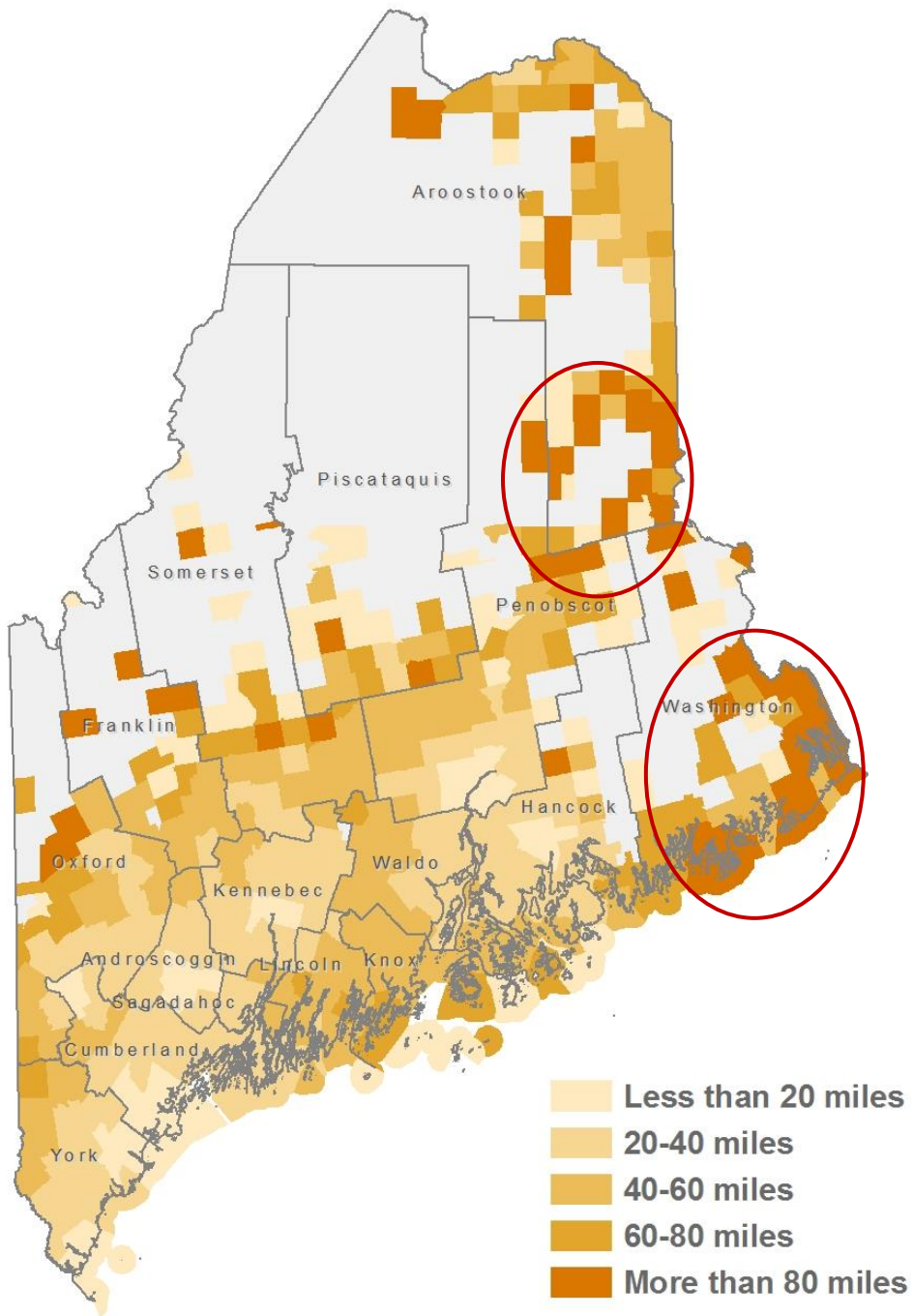


Figure 10. Average Round-Trip Distance by County (Chemotherapy Treatment). Source: 2015 MHDO Hospital Encounter Datasets





**Figure 11. Average Round-Trip Distance (In Miles) for All Cancer Related Care by Municipality**  
Source: 2015 MHDO Hospital Encounter Datasets



**Figure 12. Estimated Total Number of Miles Driven by Municipality, All Cancer Patients**  
Source: 2015 MHDO Hospital Encounter Datasets

