

# Maine Cancer Foundation Cancer Transportation Needs Assessment

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#### **Presentation Outline**

- Background and need for assessment
- Cancer transportation needs assessment goals
- Assessment process and data sources
- Maine cancer incidence and screening rates
- Survey of transportation providers
- Geographic analysis of treatment availability and distance
- Transportation Summit overview
- Conclusions and recommendations



### Background and Need for Assessment

Transportation is a significant barrier in a rural state like Maine.

- Cost of transportation
- Lost wages
- Access to care
- Impacts vulnerable populations

#### Purpose of assessment

- Understand need for transportation and gaps
- Improve grant funding
- Develop new opportunities in regions most in need of additional services

The Maine Cancer
Foundation recognizes
this important issue and
works to improve access
to care by providing
grant funding to
transportation agencies
serving cancer patients
in need.



#### Maine Cancer Foundation Community Conversations

- Starting in 2016, Maine Cancer Foundation conducted community conversations with non-profits, businesses, government and those with lived experience with cancer.
  - Transportation issues were a major theme in these discussions
- This work examines access to care and transportation as well as the travel burden of cancer patients around the state.
  - Comprehensive analysis that combines data from multiple sources
  - Leverage knowledge of experts to discuss solutions



#### Research on Healthcare and Transportation

- A lack of transportation was associated with less health care utilization, less routine medical care and missed medical appointments. [1]
- Cancer patients less likely to own a vehicle were significantly less likely to receive first line chemotherapy. [2]
- Adults with a personal driver's license, family or friends who could provide transportation, or access to public transportation had twice as many chronic care visits than those who did not. [3]
- In Massachusetts, healthcare related travel difficulties were associated with lower income levels, being female, living alone, and having less education. [4]
- Breast cancer patients living farther away from a radiation oncology facility were significantly more likely to undergo a mastectomy rather than be treated with radiation therapy. [5]

<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> 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>[3]</sup> Guidry J.J., Aday L.A., Zhang D., Winn R.J. (1997). Transportation as a barrier to cancer treatment. Cancer Practice [01 Nov 1997, 5(6):361-366]

<sup>[4]</sup> Branch, L. G., & Nemeth, K. T. (1985). When elders fail to visit physicians. Medical Care, 23(11), 1265–1275.

<sup>[5]</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

#### Cancer Transportation Needs Assessment Goals

This assessment examines the need and opportunities for transportation services support for cancer patients in Maine.

- Availability and scope of cancer treatment services by location
- Distances patients travel to receive treatment around the state
- Barriers and costs associated with transportation
- Cancer incidence and mortality compared to availability of cancer services
- Gaps in transportation services versus need
- Develop a plan to address highest need areas



### Aligns with the Maine Cancer Plan, 2016-2020

Maine Cancer Plan Vision: To reduce the burden of cancer in Maine through coordinated efforts addressing the greatest cancer-related needs

...by promoting healthy behaviors, improving access to preventive and therapeutic cancer care, reducing cancer disparities and fostering statewide partnerships that enable a synergistic approach to reducing the physical, emotional and economic impact of cancer in Maine.



## Assessment process and data sources

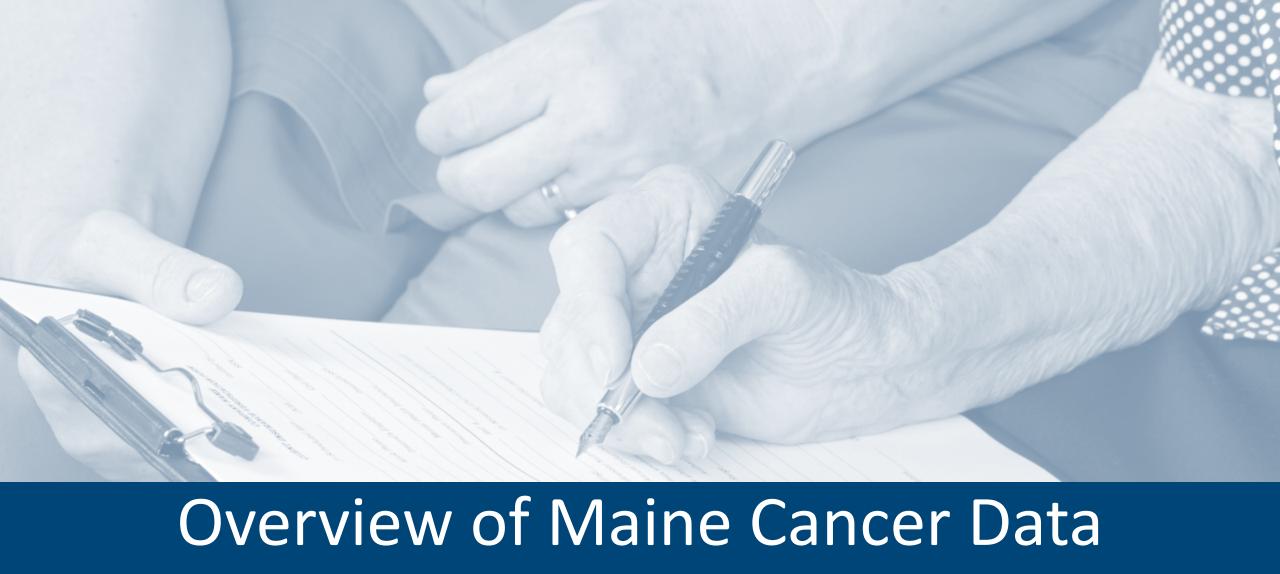
Areas of Focus	Primary Questions	Data Sources
Availability of treatment	Where are cancer care providers located in the state? What types of care do they provide? How many days are providers available for patients?	Licensed provider lists
Availability of transportation services	What transportation options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



#### Limitations

- Analysis primarily looks at Maine-based providers.
  - Travel outside the state for care is a significant factor for many
  - Community conversations and transportation survey touch on out-of-state travel issues
  - Available data and scope of the assessment is limited for now
  - Next step would be to conduct more comprehensive review of out-of-state travel needs
- Most currently available data are often a few years old.
- Primarily a quantitative analysis





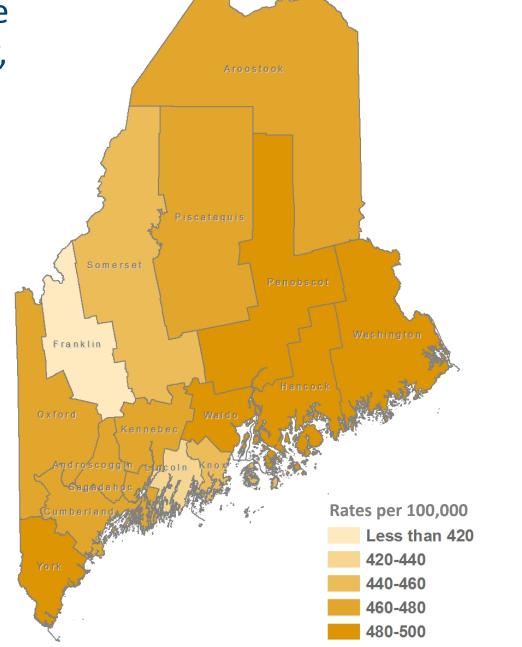
#### The Overall Burden of Cancer in Maine

- An average of 8,222 new cancer cases are diagnosed per year.
  - Cancer is the leading cause of death in the state, accounting for 3,227 deaths in 2013
- Maine's age-adjusted cancer incidence and mortality rates are significantly higher than the U.S.
- Cancer rates are higher among older adults, males, and those with lower income and education levels.
- Data from CDC's National Program of Cancer Registries Cancer Surveillance System.



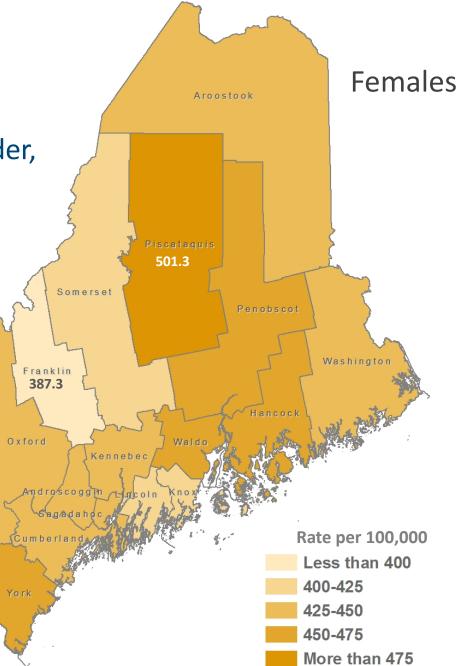
Age-Adjusted Incidence Rates Maine by County, All Cancer Sites, 2009-2013

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

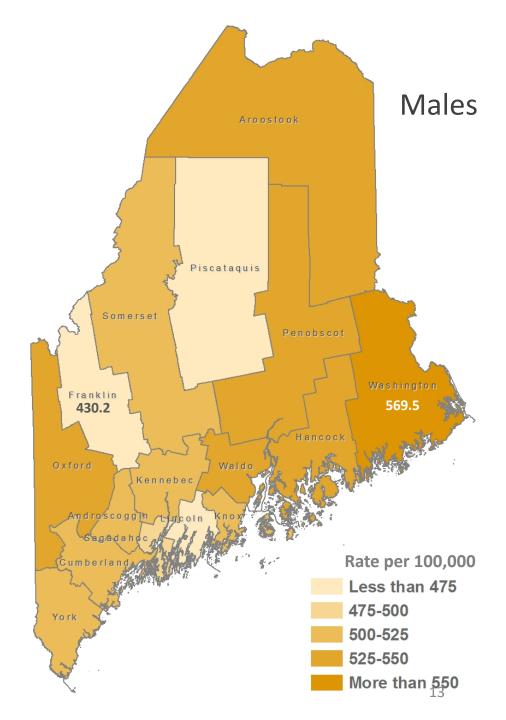


Source: Maine Cancer Registry and the CDC's National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) November 2015 data submission.

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



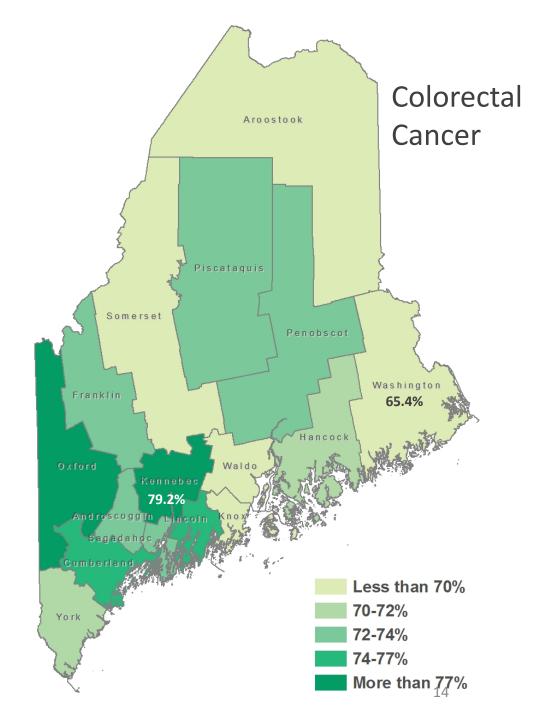
Source: Maine Cancer Registry and the CDC's National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) November 2015 data submission.



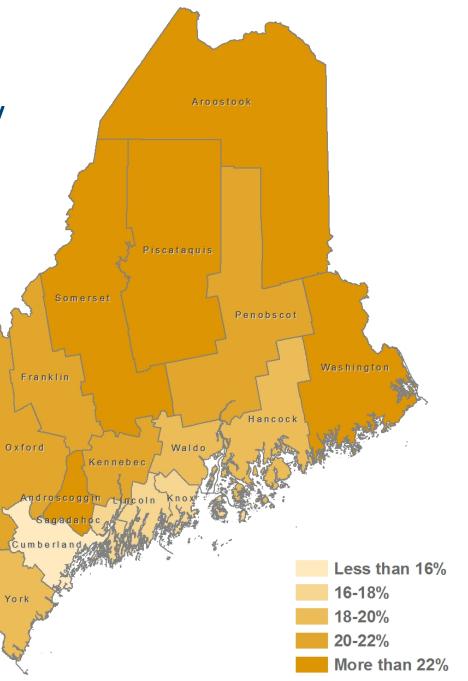
Cancer screening rates by county 2012-2014

**Breast** Aroostook Cancer Piscataquis Somerset Penobscot Franklin 68.6% Kennebec scoggin Lincoln Less than 70% 70-74% 82.6% 74-76% 76-80% 80% or More

Source: Maine Behavioral Risk Factor Surveillance System (BRFSS), Maine Center for Disease Control



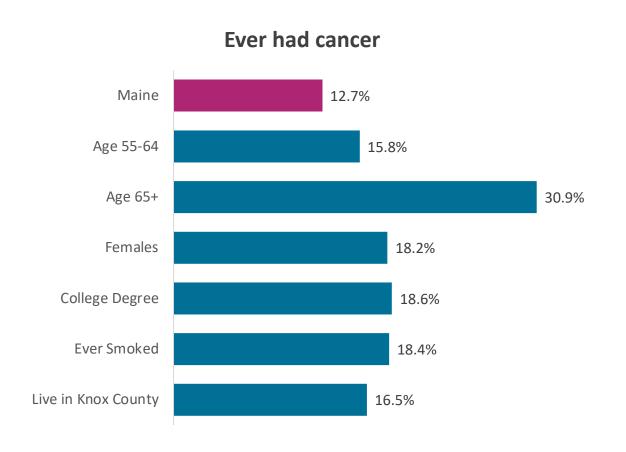
Current Adult Cigarette Smoking Rates Maine by County 2012-2014



Source: Maine Behavioral Risk Factor Surveillance System (BRFSS), Maine Center for Disease Control

#### Percentage of Maine adults who have had cancer

Maine BRFSS, 2012-2014



All factors in this table are statistically significant in regression model at p < .001

Older adults, females, those with a college degree, former and current smokers, and those who live in Knox County are more likely to have had cancer than other groups.

Differences in cancer rates and survivorship around the state may be due, in part, to the underlying demographic and socio-economic differences within the counties





#### Transportation Service Provider Survey

SUMMARY OF SURVEY METHODS

- Survey was conducted with organizations that provide transportation services to cancer patients in Maine.
  - Collect information about the transportation services available to patients across the state
  - Gaps and barriers that exist in availability of services
- Surveys were conducted via phone and email in spring of 2017.
  - Small sample sizes, grantee and non-grantee results have not been broken out
- A total of 22 surveys completed (5 MCF grantees and 17 non-grantees) out of 31 organizations
- Survey response rate of 71%



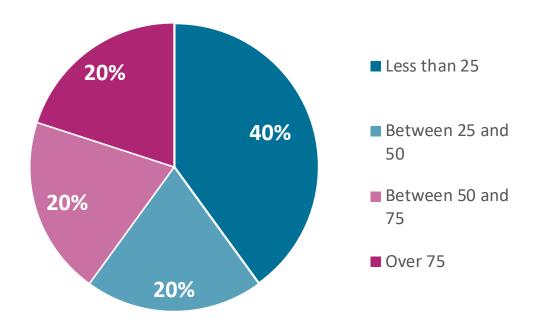
## Organizations included in the sample

Mermaid Transportation	
MidCoast Connector	
Neighbors Driving Neighbors	
Penquis/Lynx Mobility Services	
People Plus - Volunteer Transportation Network	
Provide A Ride	
Rangeley Region Health Appointment Transportation	
Regional Transportation Program (RTP)	
Rural Community Action Ministry	
South Berwick Volunteer Network	
The Center	
Waldo County Community Partners	
Washington-Hancock Community Agency	
Western Maine Transportation Services	
York County Community Action Program	



# Two in five organizations served less than 25 cancer patients in the past 12 months

## Number of cancer patients served by program in the past 12 months

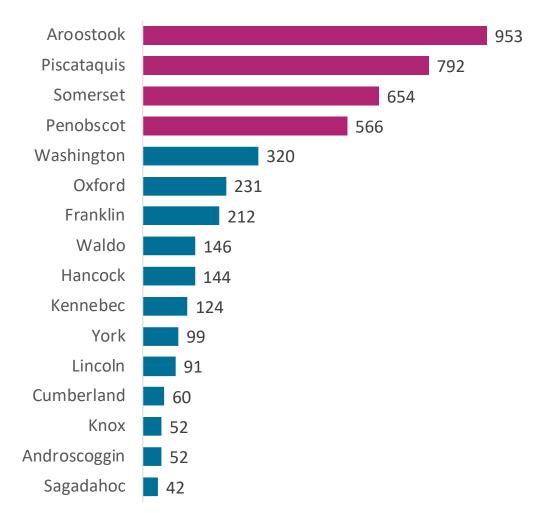


Maine is a state of small communities and that is reflected in the size and scope of these organizations. Many serve a small number of patients in a neighbor helping neighbor type of approach.



#### Average square miles covered by transportation providers

#### **Square Miles per Transportation Organization in each County**



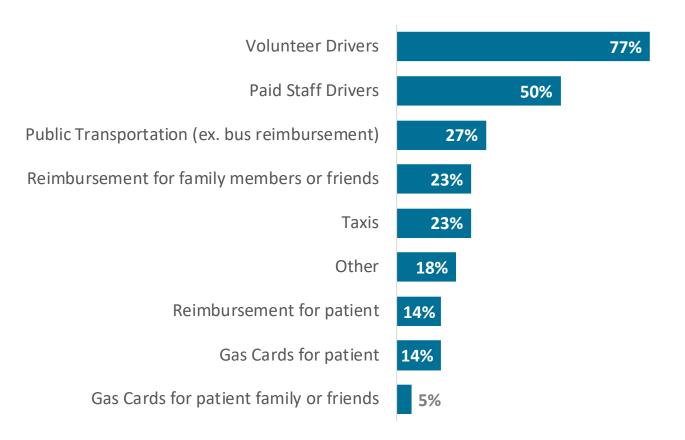
While each county has access to several transportation organizations, those operating in the northern part of the state have huge potential distances to cover compared to the geographically smaller counties in the south.

This great distance impacts viability of potential solutions in some parts of the state.



# Three-quarters of organizations use volunteer drivers to provide rides

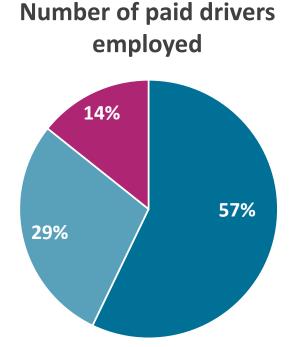
#### Services provided to cancer patients

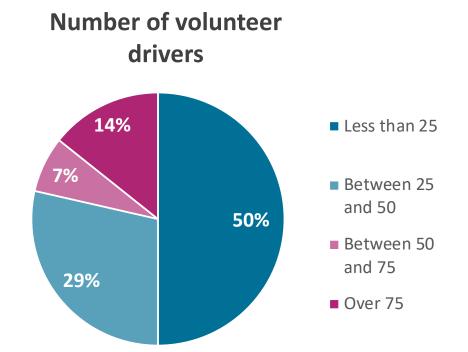


While organizations provide many different types of services to patients, volunteer drivers make up the backbone of many transportation service providers in the state



## The majority of organizations are made up of less than 25 drivers



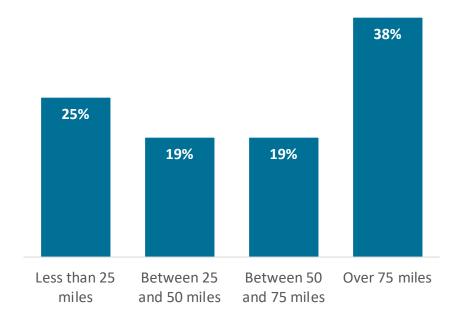


Many organizations in the state are made up of a small network of drivers, which again reflects the small-community approach often used to address public health issues in Maine.



### Many patients require multiple trips over large distances in the state to receive services

## Average round trip distance in miles for cancer patients



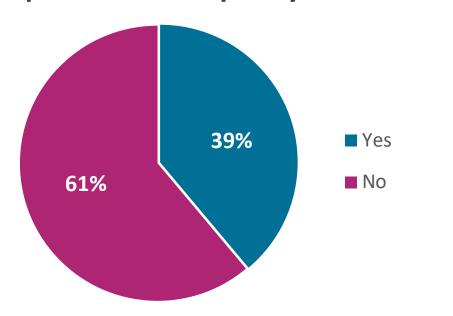
Cancer patients
receiving
transportation
services traveled an
average of 70 miles
per trip

On average, 4 in 5 cancer patients required more than one trip



# Nearly two-thirds of organizations provide transportation services regardless of finances

## Does organization require patients to meet financial requirements to qualify for services



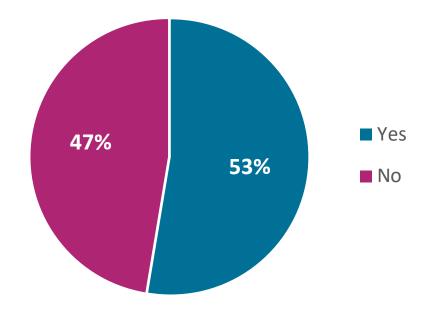
Among those who require patients to complete a financial screening or meet certain financial requirements to qualify for services, MaineCare eligibility is the most common criteria.

Some services are only available for specific populations (disabled, veterans)



# Nearly half of the organizations surveyed could not meet the need in their area during the past year

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



#### How are services advertised to patients

Given the high need for transportation, some organizations do not need to advertise their services and find that word of mouth is sufficient.

- Provider offices and hospitals
- Community outreach and education
- Referrals
- Local advertising



#### Cancer patients face a number of transportation barriers

## Distance travel treatment themselves patients transportation drive due car help drivers public like having insurance family funding repairs vehicle area impairment friend lack medical Inability

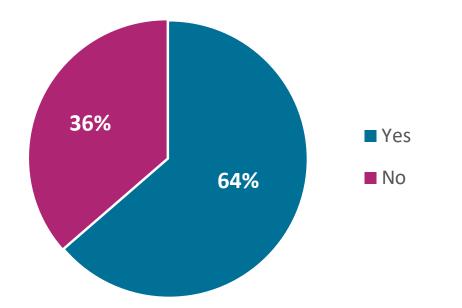
"Geography. Sometimes the area where they are doesn't allow for them to participate in programs and they can't pay for taxis."

"Reliable transportation that allows a patient get treatment in a reasonable time frame."



# Impact of potential policy changes and events on ability to provide services

Are there events/policy changes that will impact your services and/or patients' access to transportation in the region?



Organizations are funded through public funding, grants and donations, so any change in even one component of that flow can severely impact their ability to provide services.

In particular, changes or cuts to MaineCare would have a huge negative impact to transportation services in the state.



#### **Transportation Survey Summary**

- Many organizations are small and community-driven.
- Volunteer drivers make up the core of these organizations.
- Patients rely on these services to travel very long distances for many trips. Otherwise, many lack the resources to travel.
- Half reported not being able to meet demand.
- A lack of public transportation in the state leaves patients without an affordable way of getting to care. Taxis are not public transportation.
- Disruptions in funding, such as a cut to MaineCare, could have a catastrophic impact.





## Geographic Analysis

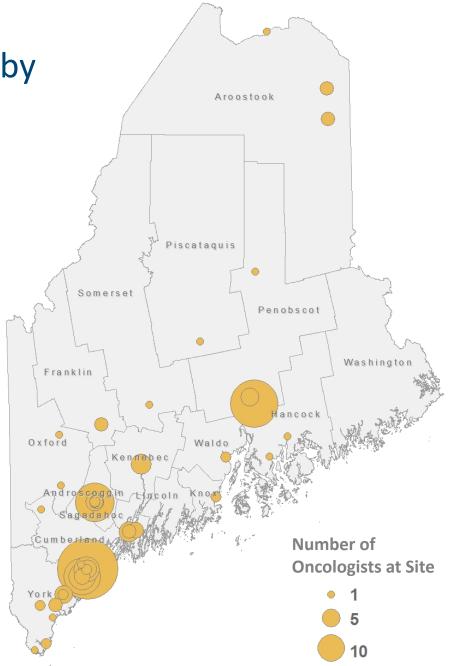
### Methodology of Geographic Analysis

- Created database of facilities providing oncology treatment.
- Used Google Maps Application Program Interface (API) to calculate distance between all Maine zip codes and nearest oncology treatment facilities.
- Mapped provider addresses and distance information using Geographic Information System (GIS) software.



Cancer Treatment Sites by

Size and County

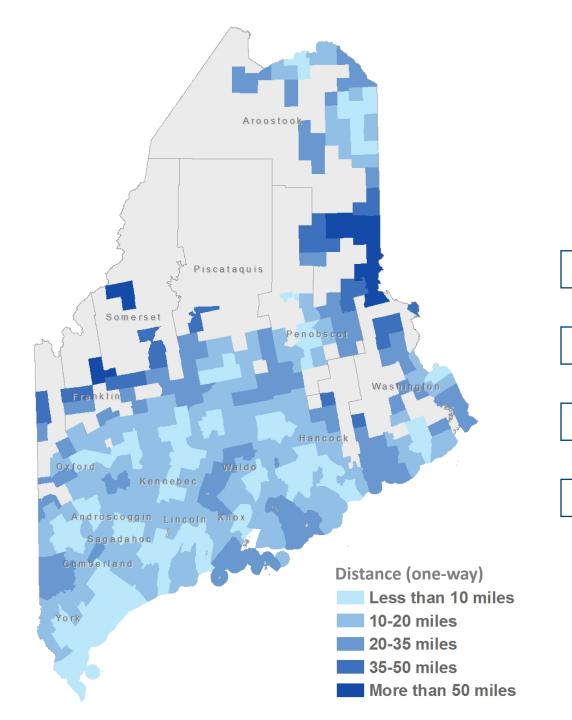


Approximately half of the state's oncologists are located in Cumberland County.

Lincoln, Sagadahoc and Washington Counties do not have any oncology providers

Data Source: Maine Licensed Provider List Area Health Resources File, National Center for Health Workforce Analysis

# Minimum travel distance to receive chemotherapy treatment



## Minimum Travel Distances (one-way)

Dennistown (90 miles)

Jackman (81 miles)

Hodgdon (60 miles)

Houlton (54 miles)

Greenville (35 miles)

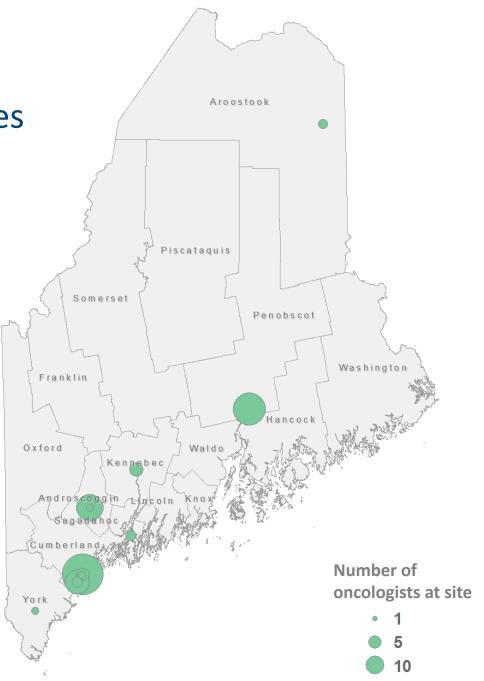
Limerick (28 miles)

Orono (11 miles)

Portland (1.6 miles)

Radiation Treatment Sites

by Size and Location

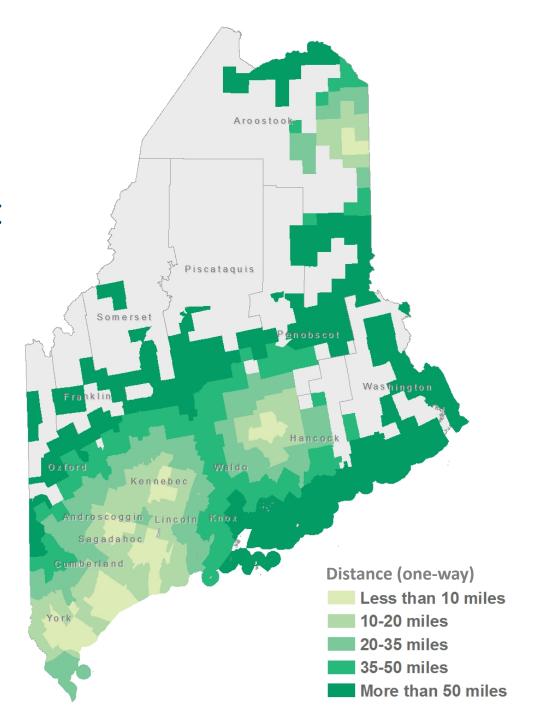


Maine has a limited number of facilities that provide radiation treatment.

Half of those sites are located in Cumberland County.

Source: MDR review and data collection Area Health Resources File, National Center for Health Workforce Analysis

# Minimum travel distance to receive radiation treatment



## Minimum Travel Distances (one-way)

Dennistown (133 miles)

Jackman (126 miles)

Eastport (120 miles)

Lubec (112 miles)

Calais (109 miles)

Machias (87 miles)

Millinocket (85 miles)

Portland (1.6 miles)

#### Analysis of Maine Hospital Encounter Data

#### METHODOLOGY

- This analysis examined the distances cancer patients travel to receive care, travel patterns around the state, and travel burden by key factors.
- 2015 Maine outpatient and inpatient Hospital Encounter dataset obtained from the Maine Health Data Organization.
- Identified cancer related diagnoses using ICD-9 and ICD-10 codes (ICD-9: 140–239, V58, ICD-10: C00–D48, Z51). See comprehensive list of classifications provided in appendix.
- Using Google Maps API, calculated distances between zip code of patient and the address of the facility where they received care.
- Analyzed travel patterns overall and by county and municipality for different types of cancer treatment, diagnoses and other factors.



### Analysis of Maine Hospital Encounter Data

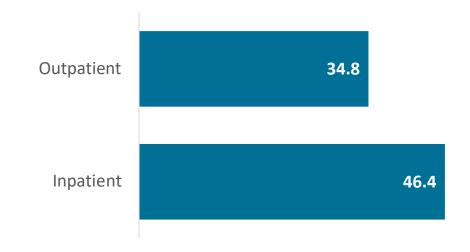
#### METHODOLOGY

- Final datasets used in analysis included all cancer diagnoses encounters at instate hospitals and clinics
  - Note that out-of-state travel is not captured in this analysis
- Cases removed from the final dataset included:
  - Out-of-state patients who received care in Maine
  - Cases missing zip codes or incomplete zip codes
- Final number of cancer-related encounters in final dataset:
  - Outpatient: n = 263,020
  - Inpatient: n = 10,645
- Travel distances calculated in miles



### Average Distance Traveled by Cancer Patients in Maine

#### **Average Round-Trip Distance (in Miles) by Setting, 2015\***



	Miles (Round- Trip)	Cases	Patients	Visits per Patient
Outpatient	34.8	263,020	92,070	2.9
Inpatient	46.4	10,645	8,488	1.3

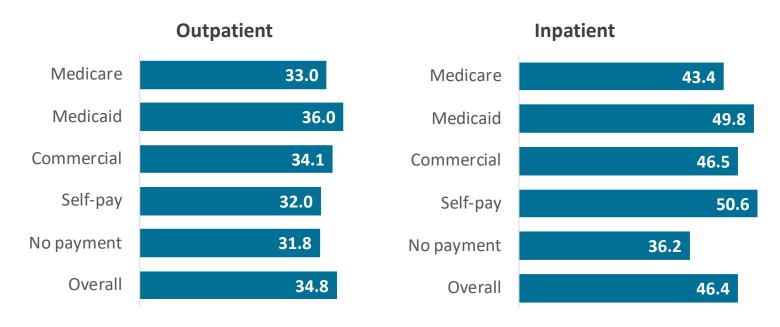
Cancer patients in Maine traveled an average of 34.8 miles to receive outpatient care and 46.4 miles to receive inpatient care.

<sup>\*</sup> includes all cancer diagnoses (ICD-9: 140–239, ICD-10: C00–D48), not only treatment.



### Average Distance Traveled by Payor Type

#### Average Round-Trip Distance (in Miles) by Payor Type, 2015\*



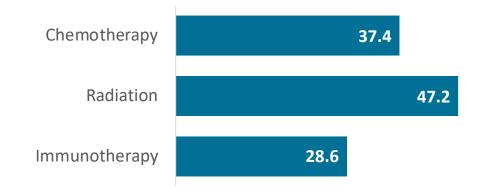
Medicaid beneficiaries travel further than others to receive cancer care. This may be due to the fact that a higher percentage live in rural areas, such as **Aroostook County (where** 28% of cancer visits were paid by Medicaid) and Washington County (28%), compared to Kennebec (11%), York (14%) and Cumberland (15%).

<sup>\*</sup> Encounters may have more than one type of payor.



### Average Distance Traveled by Type of Treatment

#### Average Round-Trip Distance (in Miles) by Type of Treatment, 2015



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

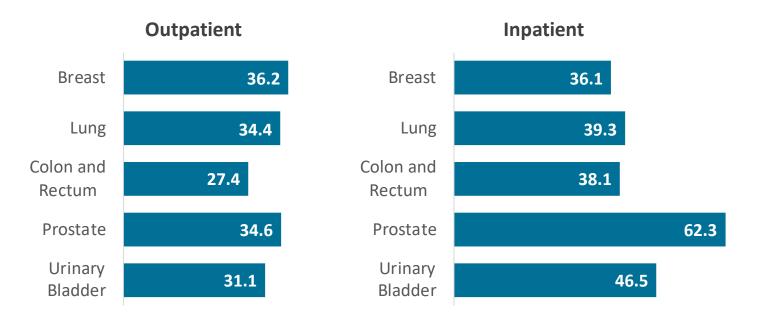
	Miles (Round- Trip)	Cases	Patients	Visits per Patient
Chemotherapy	37.4	23,583	3,536	6.7
Radiation	47.2	16,823	2,142	7.9
Immunotherapy	28.6	1,272	331	3.8

Those receiving radiation treatment travel further and make more visits than patients receiving other types of treatment.



## Average Distance Traveled by Cancer Site

#### Average Round-Trip Distance (in Miles) by Type of Cancer Site, 2015\*



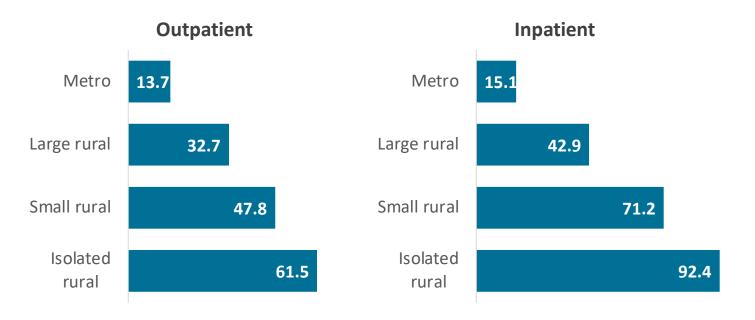
There are large differences in travel burden for inpatient care by cancer site, although the number of visits is relatively low compared to outpatient care.

<sup>\*</sup> Leading cancer sites in Maine, Maine Annual Cancer Report 2016



### Average Distance Traveled by Rurality

#### Average Round-Trip Distance (in Miles) by Rurality, 2015



Rural-Urban Commuting Areas were created by the Federal Office of Rural Health Policy and the Economic Research Service and combine population statistics with information about communizing patterns to identify how rural a community is. Examples include:

Metro: Portland, Bangor Small rural: Wells, Houlton, Millinocket, Belfast

Large rural: Augusta, Gorham, Waterville Isolated rural: Madawaska, Bethel, Southwest Harbor, St. George

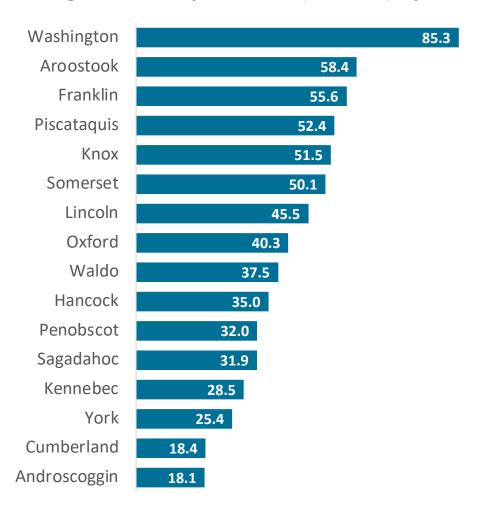
Those living in the most rural areas of the state travel 4-6 times further to receive cancer treatment than those living in metro areas.

However, the average number of visits made by patients does not differ greatly by geography (Metro 2.6 visits, Isolated rural 2.8 visits).



## Average Distance Traveled by County

#### Average Round-Trip Distance (in Miles) by County (Outpatient), 2015

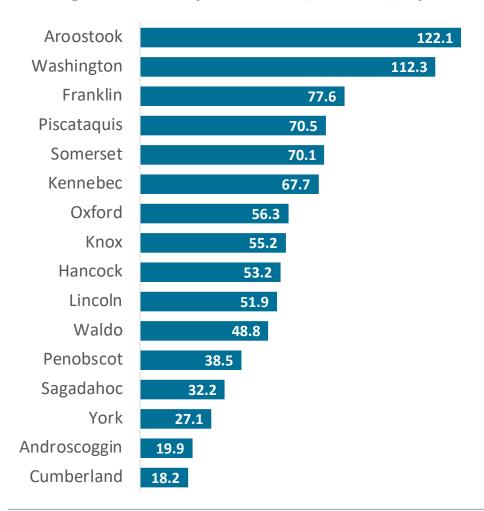


Patients living in Washington County are subjected to the longest travel times in the state for outpatient cancer services. They travel nearly 30 miles further per trip than those in Aroostook County.



### Average Distance Traveled by County

#### Average Round-Trip Distance (in Miles) by County (Inpatient), 2015



Patients in Aroostook and
Washington Counties travel 100+
miles on average for inpatient
cancer care. While Washington
County lacks both outpatient and
inpatient cancer services,
Aroostook County primarily lacks
services for inpatient care.



## Average Number of Trips Taken per County by Patients

#### Average Number of Visits by County (Outpatient), 2015

	Miles (Round- Trip)	Cases	Patients	Visits per Patient
Androscoggin	18.1	20,544	6,546	3.1
Aroostook	58.4	21,293	6,435	3.3
Cumberland	18.4	43,754	16,009	2.7
Franklin	55.6	5,946	2,722	2.2
Hancock	35.0	12,769	5,149	2.5
Kennebec	28.5	33,996	8,683	3.9
Knox	51.5	8,669	2,987	2.9
Lincoln	45.5	6,744	2,439	2.8
Oxford	40.3	13,475	4,507	3.0
Penobscot	32.0	26,051	8,692	3.0
Piscataquis	52.4	4,031	1,266	3.2
Sagadahoc	31.9	4,744	2,069	2.3
Somerset	50.1	14,972	4,160	3.6
Waldo	37.5	10,199	3,062	3.3
Washington	85.3	7,367	3,008	2.4
York	25.4	28,303	14,252	2.0
Total		263,020	92,070	2.9

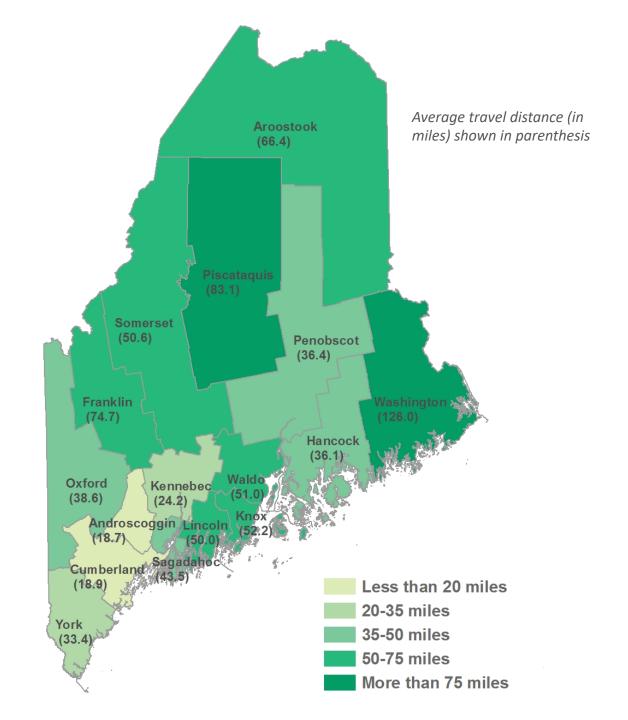
The average number of trips taken by patients varies by county, but counties with longer travel distances, on average, don't necessarily take fewer trips.



# Average Round-Trip Distance by County (Chemotherapy Treatment)

Patients in Washington County drive an average of 126 miles to receive chemotherapy treatment. This points not just to an issue of transportation, but of access to providers, and the need for oncology providers in the region.

Piscataquis, Franklin and Aroostook also have large travel times for chemotherapy treatment.





## Where Patients Go for Chemotherapy Treatment

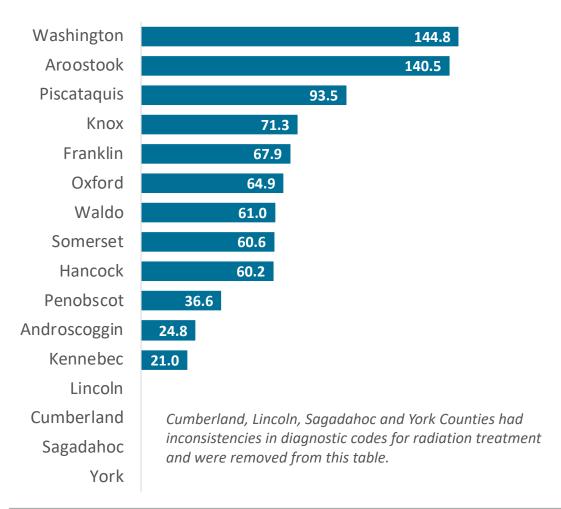
Datients who live to	Are most likely to receive chemotherapy
Patients who live in	treatment in:
Androscoggin	Androscoggin (82%)
Aroostook	Aroostook (86%)
Cumberland	Cumberland (91%)
Franklin	Kennebec (69%)
Hancock	Penobscot (55%)
Kennebec	Kennebec (94%)
Knox	Kennebec (53%)
Lincoln	Kennebec (68%)
Oxford	Cumberland (33%)
Penobscot	Penobscot (97%)
Piscataquis	Penobscot (92%)
Sagadahoc	Cumberland (47%), Kennebec (44%)
Somerset	Kennebec (67%)
Waldo	Kennebec (61%)
Washington	Penobscot (90%)
York	Cumberland (58%)

Cumberland, Kennebec and Penobscot Counties serve as primary destinations for many receiving chemotherapy treatment in the state.



#### Average Round-Trip Distance by County (Radiation Treatment)

#### Average Round-Trip Distance by County (Radiation treatment), 2015



Patients in Aroostook and Washington Counties travel nearly 150 miles on average to receive radiation treatment.



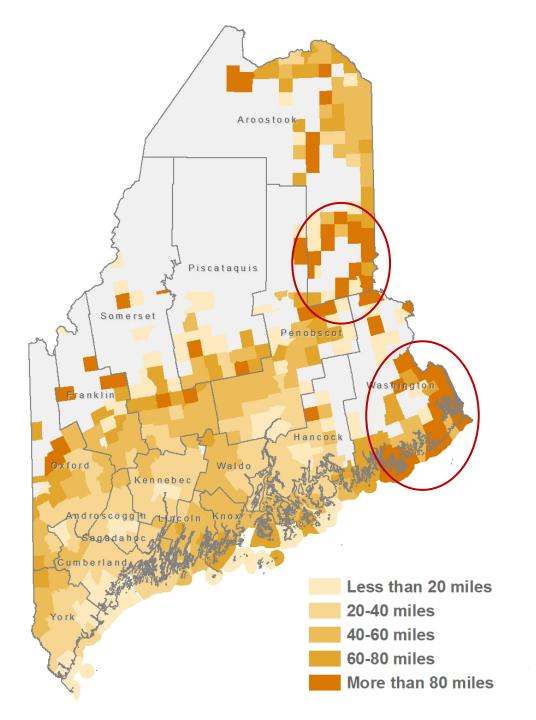
# Average Round-Trip Distance (In Miles) for All Cancer Related Care by Municipality

Patients in Washington County and southern Aroostook County travel the furthest, on average, in the state to receive cancer care (more than 80 miles per trip).

These areas would benefit the most from more access to nearby oncology providers.

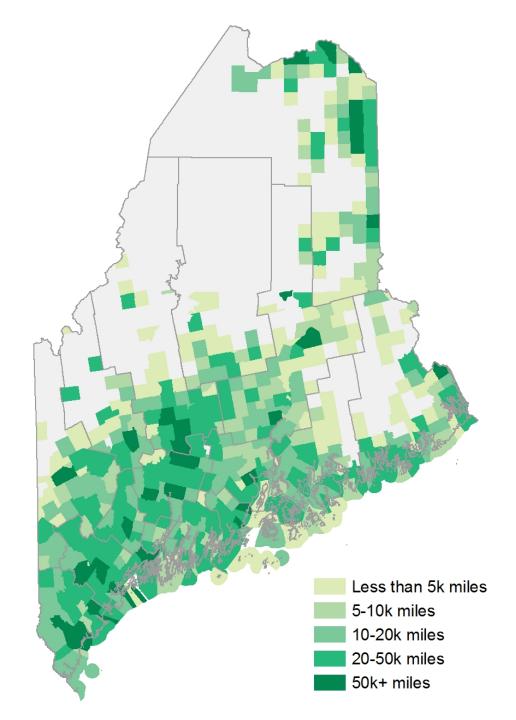
Municipalities with less than 50 cases have been removed from the results.





## Total Number of Miles Driven by Municipality, All Cancer Patients

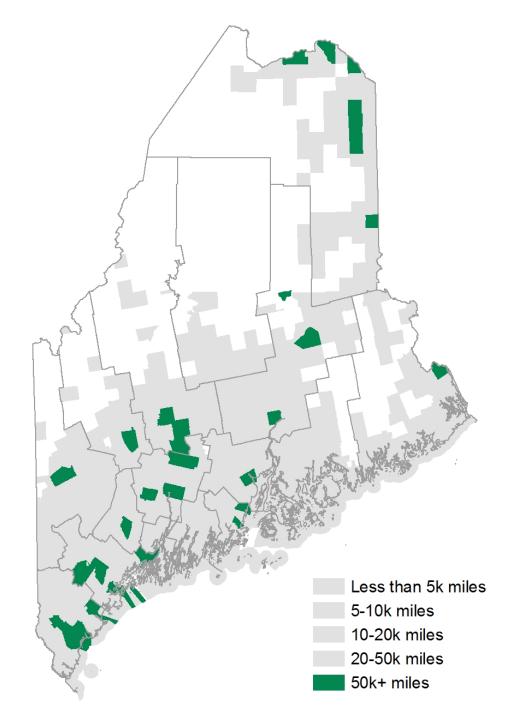
This map is an estimate of the total number of miles traveled by municipality for all cancer patients receiving in-state care. The darkest green areas represent areas where patients travel more than 50,000 miles annually.





## Total Number of Miles Driven by Municipality, All Cancer Patients

High burden travel areas exist all around the state. Northern and Downeast Maine have smaller populations, but much longer travel distances, while Southern and Central Maine have facilities closer to home, but have a greater number of cancer patients.





### Average miles driven and cost

	Estimated Miles Traveled		sportation Cost*
All Cancer Diagnoses	9,637,857	\$	1,638,436
Treatment Specific (Chemotherapy,		<b>خ</b>	201.074
Treatment Specific (Chemotherapy, Radiation, Immunotherapy)	1,712,199	\$	291,0

Maine cancer patients travel over 1.7 million miles per year to receive treatment.

Note that these numbers understate total travel cost since they do not consider out of state travel, or other costs such as loss of wages for those assisting with transportation or lodging expenses.

<sup>\*</sup> Calculated using the Standard Mile Rates from the IRS of .17 cents per mile for medical travel



### Summary of Geographic Analysis

- Transportation is an issue that impacts cancer patients in all parts of the state.
  - Rural areas have less population, but longer travel distances, while Southern and Central Maine have facilities closer to home, but larger populations and more cancer patients.
- Those 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 are not uncommon in rural parts of Maine.
  - Rural areas also generally have higher rates of cancer incidence.
- Lower socio-economic status is associated with higher levels of cancer incidence and longer travel distances. Results in higher need, more barriers to travel among this critical group.



### Summary of Geographic Analysis (continued)

- Those receiving chemotherapy or radiation treatment require an average of 7-8 visits.
  - This can create a large burden and cost to patients, family, friends, caregivers and others who assist with providing rides.
- A lack of oncologists in rural parts of the state, particularly in Washington County and Southern Aroostook County, result in excessive travel distances.
  - Impacts the motivation and ability of patients in rural areas to get needed care.
  - More than a transportation issue, these areas need greater access to nearby oncologists.





## Transportation Summit Overview

- Maine Cancer Foundation hosted the summit at Maple Hill Farm & Conference Center in Hallowell on June 12, 2017
- Attended by regional and community transportation providers,
   Mainers affected by cancer and other stakeholders interested in improving cancer patients' access to care.
- Provided the Foundation with an opportunity to learn more about what is happening with cancer-related transportation in Maine.
- Discussion groups held during the second half of the summit and focused on questions related to transportation resources, needs and barriers in the state.



SUMMARY OF DISCUSSION GROUP CONVERSATION

## What does your organization do well regarding transportation and lodging services for Maine cancer patients?

- Transportation providers have years of experience and understand the specific needs of their communities and patients.
- Always try to find a way to meet the needs of their communities and turn away very few patients.
- There are no-cost options available across the state. ACS Road to Recovery Network works well in all but the most rural parts of the state.
- Incorporating more technology to assist with scheduling and coordination of transportation.
- Go beyond simply providing a ride and help patients physically, emotionally and with other unmet needs.
- Provide community education on transportation issues and resources.



SUMMARY OF DISCUSSION GROUP CONVERSATION

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

- Time and effort required to recruit, background check and train drivers and volunteers. Also difficult to find volunteer drivers to participate in programs.
- Coordinating and managing schedules. Drivers cannot always accommodate last-minute schedule changes.
- Patients requiring non-ambulatory care or those with mobility issues. Volunteers don't always have handicap
  accessible vehicles or are physically able to assist.
- The need for more funding is always an issue, especially when resources are declining.
- Getting the word out about services, or lack resources to market services.
- Travel reimbursements/gas cards don't address everyone's needs.
- A lack of treatment services in parts of the state.
- Managing urgent versus non-emergency transportation when resources are limited.
- Important to remember human aspect to transportation. Cancer patients should have opportunities made available so they don't need to beg for help.



SUMMARY OF DISCUSSION GROUP CONVERSATION

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

- <u>Funding</u>: Funding can be restrictive, need more general funding, assistance/partnerships for fundraising and grants.
- <u>Training</u>: Shared training programs for transportation providers, additional training for healthcare providers on available transportation resources.
- Programs/technological solutions:
  - GoMaine: Statewide commuter services program
  - RideHealth: Enables healthcare providers to schedule, request and pay for rides on behalf of patients.
  - Aunt Bertha: Connects people to services in their area
  - CarShare: Mobile application allowing an individual to share their car.
  - Community Concepts working with hospitals to figure out how to better schedule patients, which helps with ride coordination and decreases no show rates for the hospitals.
- <u>Meeting all the needs of patients</u>: Cancer patients have varying needs and require help from different resources. A personal touch (phone call) is often required to discuss specific situation and needs.



SUMMARY OF DISCUSSION GROUP CONVERSATION

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

- 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
- Regional planning commissions
- Municipal organizations
- Senior organizations





## Conclusions and Recommendations

### Solutions to Transportation Issues in Maine

It is important to remember that each community is unique and requires solutions that meet the specific needs and circumstances of patients in the area.



Increase access to transportation services



Education and outreach to inform patients about transportation options and remove barriers



Increase the number and capacity of informal volunteer and community-based transportation



Pilot and test innovative solutions to transportation issues



Improve and expand public transportation options and funding



Expand access to oncology providers and facilities in rural areas



Partner with hospitals to provide transportation to their cancer patients



Create a statewide transportation group to continue this work



Advocacy for transportation funding



#### Increase Capacity and Access to Transportation Providers and Services

- Community and regional transportation providers play a major role in Maine's transportation network and are a key player in reducing transportation barriers.
- Many are at capacity, and need additional funding to expand services, especially in rural areas and in communities with high transportation needs.
- There is always the need for more low or no-cost transportation services.
  - Many patients lack the ability to pay for transportation, and would not be able to travel without free or discounted transportation options.
- Many of these organizations survive on public funds, grants and donations. Cuts to funding (particularly Medicaid) would have a devastating impact to Maine's transportation network and put the ability of cancer patients to travel to appointments at risk.
- Advocacy for transportation funding is important to sustaining and improving services.



## Increase the Capacity and Ability of Informal Volunteer and Community-Based Transportation

- Maine already has established groups that can serve as models for volunteer transportation networks in other communities (Neighbors Driving Neighbors, South Berwick Volunteer Network, as well as others).
- Builds on the strong ties of Maine communities using a neighbor helping neighbor approach.
- Option when funding is limited or non-existent.
- However, assistance is needed to help build and maintain these groups and provide training, support and funding.
  - Organizations need support and guidance with training, recruiting volunteer drivers, coordination and scheduling, access to technology and other resources and support.
  - A how-to guide to establishing volunteer community transportation networks.



#### Improve and Expand Public Transportation Options and Funding

- Maine has one of the lowest per capita expenditures on public transportation in the country.
- Most communities in the state have little to no access to public transportation.
- Traditional forms of public transportation play a key role in the infrastructure of the state's urban areas. 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.
  - Community-based publicly-funded transportation
  - Expansion of urban public transportation into surrounding suburban areas
  - Travel reimbursements
  - Partnerships with ride-sharing services or transportation providers
  - Air travel needs and options
  - Other services related to travel, such as lodging



## 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.
- A win-win situation: patient receives help with transportation and hospital avoids the loss of revenue associated with missed appointments.
- This approach is being implemented by a growing number of hospitals around the country.
- Involves the hospital partnering with an existing transportation provider or service to provide more coordinated appointments and transportation.
- A platform like RideHealth, enabling healthcare providers to schedule, request and pay for rides on behalf of patients, could be used to facilitate this approach.



#### Advocacy for Transportation Funding

- Lack of resources and the need for additional public funding for transportation was identified in the survey and transportation summit discussion groups.
- Many service providers have difficultly procuring funding, while at the same time resources are being cut within the state.
- It is important that the costs and burden of travel for cancer patients 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.
- Act To Improve Public Transportation in Maine, 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.



## Education, Outreach and Navigation to Inform Patients about Transportation Options and Remove Barriers

- Patients are not always aware of the options available or may assume they can't ask for help.
- Lower socio-economic status is associated with higher levels of cancer incidence and longer travel distances.
  - Results in higher need and more barriers to travel for those with the least ability to afford it.
  - Critical group for outreach, education and navigation assistance.
- Important to make it as easy as possible for patients to connect with services.
- American Cancer Society Road To Recovery
- Additional supports and assistance may be needed in conjunction with transportation
  - Lodging
  - Assistance with appointments and scheduling
  - Grocery shopping and other day-to-day needs



#### Pilot and Test Innovative Solutions to Transportation Issues

- Traditional transportation services can be expensive to implement, especially in rural areas with dispersed populations.
- Opportunity to pilot innovative or technological-based approaches to solve logistical and operational issues.
  - RideHealth is an online platform to help healthcare providers assist their patients with getting transportation, improving care coordination and reducing missed appointments.
  - Veyo and Trip2 allow patients to access non-emergency medical transportation using technology-driven solutions and real-time analytics to improve patient experience.
- 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.



#### Expand Access to Oncology Providers and Facilities in Rural Areas

- Expanding access to oncologists in rural areas reduces the need for regular, long trips for treatment that put stress on cancer patients and their families.
  - Those living in rural areas tend to be older, have lower household incomes, and have higher cancer incidence rates. These are groups who are most vulnerable to a lack of transportation.
- Washington County and Southern Aroostook County are areas most need of providers.
- Explore options for a visiting or part-time oncologist in rural areas that may not support a full-time provider.
- Despite significant challenges of implementation and sustainability, telemedicine is a long-term solution for bringing providers into rural areas.
  - Maine's hospitals should take initiative on telemedicine services with the goal of better serving individuals in all parts of the state, including the most rural areas.
  - Issues of broadband access in rural areas.



#### Statewide Transportation Group to Continue this Work

- Maine Cancer Transportation Summit brought together a group of stakeholders committed to improving access to transportation for cancer patients.
- Opportunity for a group to continue to provide strategic and coordinated guidance and advocacy for cancer related transportation issues on a statewide level.
- Can work to address many needs and barriers identified in this assessment, including issues related to access, funding, training, coordination, advocacy, education and outreach.





## Appendix



## Appendix: 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):	Immunotherapy (primary or secondary diagnosis)	Colon Neoplasm (primary or secondary diagnosis)
ICD-9: 140-239	ICD-9: V58.12	ICD-9: 153, 159.0
ICD-10: C00-C96, D00-D49	ICD-10: Z51.12	ICD-10: C18, C20.9, C26.0
Chemotherapy (primary or secondary diagnosis)	Breast Neoplasm (primary or secondary diagnosis)	Prostate Neoplasm (primary or secondary diagnosis)
ICD-9: V58.11	ICD-9: 174	ICD-9: 185
ICD-10: Z51.11	ICD-10: C50	ICD-10: C61
Radiation (primary or secondary diagnosis)	Lung Neoplasm (primary or secondary diagnosis)	<b>Urinary Neoplasm (primary or secondary diagnosis)</b>
ICD-9: V58.0	ICD-9: 162	ICD-9: 188
ICD-10: Z51.0	ICD-10: C34	ICD-10: C67

