

Maine Transportation and Lodging Needs **Assessment** Report

Prepared for Maine's Impact Cancer Network and Maine Cancer Foundation

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MDR would like to thank Maine's Impact Cancer Network and Maine Cancer Foundation for the opportunity to work with them on this important project and the support and outreach to providers and patients during data collection.





EXECUTIVE SUMMARY

Project Background and Methodology

Maine's Impact Cancer Network's (MICN) Transportation Task Force and Maine Cancer Foundation (MCF) partnered with Market Decisions Research (MDR) to better understand the transportation and lodging needs of patients with cancer across Maine, particularly in the years following the COVID-19 pandemic. The goal was to identify current barriers, available resources, and opportunities to strengthen transportation and lodging systems that support patients in the future.

To achieve this, MDR conducted a mixed-methods study that incorporated multiple perspectives across Maine's cancer care system. The project included (1) a survey for transportation and lodging providers to assess service availability, barriers, and capacity; (2) in-depth interviews with clinical providers who coordinate access for cancer patients; (3) a survey for patients with cancer to capture lived experiences related to travel, lodging, and cost; and (4) a mapping and resource analysis to visualize the geographic distribution of cancer care and transportation services statewide.

Data collection combined online surveys and interviews, with outreach supported by MICN and MCF. Results were grouped together into a comprehensive needs assessment report.

Key Findings – Transportation and Lodging Provider Survey

Survey responses revealed a dedicated but overextended network of transportation and lodging providers across Maine. More than half of organizations (53%) offer both services, and nearly all rely on grant funding to sustain operations. However, 59% reported being unable to serve patients outside their designated service area, and over half experienced capacity limitations in the past year.

Volunteer and paid driver shortages was a major concern, with two in five providers citing lack of drivers or flight staff as an extreme barrier. Although many organizations have formed creative partnerships with Uber Health, hotels, and airlines, these options remained inconsistent or unavailable in rural areas. Providers emphasized that patient awareness is also a challenge - 63% said many patients are unaware of available lodging programs. Lodging partners often must limit eligibility to those traveling long distances or accompanied by caregivers. Despite these barriers, providers expressed deep commitment and resourcefulness in adapting to increasing patient needs.

Key Findings – Clinical Provider Interviews

Clinical providers consistently described transportation and lodging barriers as significant threats to patient treatment adherence. Many providers spent hours each week arranging rides, calling lodging programs, or rescheduling missed appointments. Unreliable transportation vendors, particularly in rural areas, were frequently cited as sources of patient distress and missed care. Providers also identified gaps in coordination between hospitals, transportation systems, and community partners. Despite improved communication since 2017, many noted that existing systems remain fragmented, forcing providers to rely on personal relationships and creative problem-solving. Providers



emphasized the need for more patient navigators and standardized processes to identify transportation and lodging needs early in the care journey. Many described a growing patient population with limited technology access, mobility challenges, and financial strain.

Key Findings – Patient Survey

Survey data from patients with lived experience highlighted the continuous and often overlapping challenges of transportation and lodging. Nearly two-thirds (63%) reported missing or rescheduling an appointment due to transportation issues, and 84% said the cost of transportation affected their ability to receive treatment. Most patients (90%) did not have a reliable transportation option, relying primarily on family or friends for rides.

Lodging barriers were also common. More than half (54%) typically stayed in hotels or motels during treatment, yet only 9% said they felt comfortable doing so. In contrast, 90% expressed comfort with hospitality houses, though only 36% had access to one. The majority (84%) had no backup plan if their primary lodging fell through, and 66% said lodging costs affected their ability to receive care. Many also noted discomfort discussing these needs with care teams even though many patients report having the conversations.

Key Findings – Mapping and Resource List

Mapping data highlighted the clustering of both chemotherapy and radiation treatment centers around the coastal, southern regions of the state. Access to radiation therapy was particularly limited, with only 9 facilities offering this care, compared to 15 in 2017. Only one radiation facility is located north of Bangor. Nearly half (7/16) of the counties only have one chemotherapy treatment facility each, while Washington County has none.

Several regional disparities emerged by county. About half (26/56) of the zip codes where residents would need to travel over 50 miles to reach radiation treatment and the majority (15/18) of the zip codes 50+ miles from chemotherapy were in Washington County. Aroostook county had the second largest number of zip codes over 50 miles from radiation therapy (9/56).

When considering both distance from treatment and population, there were areas distributed across the state with a high travel burden for radiation therapy. The highest travel burdens for chemotherapy were in the Central-Eastern to Northern regions of the state, across Aroostook, Hancock, Kennebec, Penobscot, and Washington counties.

Comparative Findings – Pre VS. Post Covid-19

Comparing the 2025 results with the previous 2017 Transportation Needs Assessment revealed how COVID-19 both intensified and reshaped barriers. In 2017, the primary challenge was fragmented coordination and limited transportation options. By 2025, those gaps have deepened amid staffing shortages, rising costs, and growing patient need. Providers now report higher demand with fewer volunteers and vehicles. The pandemic also disrupted the continuity of volunteer-based systems.



Patients' reliance on informal supports has increased, while their comfort and safety expectations have evolved. Providers have also had to adapt to incorporating virtual coordination, ride share partnerships, and grant-funded stopgaps. Despite these challenges, progress has been made. Awareness of transportation programs has increased, provider communication networks have strengthened, and innovative partnerships have developed.

Recommendations

Findings from this assessment point to the need for coordinated, patient-centered solutions that make transportation and lodging reliable, comfortable, and equitable for all Mainers receiving cancer care. Rebuilding and incentivizing the volunteer driver network remains essential, as many organizations continue to face shortages that limit capacity, particularly in rural regions. Expanding volunteer roles through a statewide "Travel Companion" program could also address patient needs beyond transportation, providing emotional support and mobility assistance. At the same time, many patients reported difficulty navigating online systems, highlighting the need for technology assistance and scheduling support to gain equitable access to modern transportation tools.

Improving communication is also critical. Many patients expressed discomfort or shame discussing access challenges with their care teams, suggesting the importance of helping patients feel ready to talk about these needs from the start. Clinical providers can be supported with empathetic communication tools, faster navigator introductions, and visible resources that normalize these conversations. On a systemic level, lodging should be elevated to the same priority as transportation. A "Lodging-as-Care" initiative could reframe lodging as an essential part of treatment continuity.

To address unpredictability in travel, MICN could pilot an "On-Call Transportation Backup Network" to cover last-minute ride cancellations or weather-related issues, while expanding mileage reimbursement options to support patients traveling beyond service boundaries and who are not comfortable driving with others. Additionally, improved data sharing and mapping tools would allow providers and patients to see real-time information about available resources, eligibility, and lodging proximity, making referrals faster and more efficient. Together, these strategies would help reduce travel strain, improve continuity of care, and bring essential services closer to home for rural Mainers.



Summary of Key Recommendations

Short-Term

- Rebuild and incentivize the volunteer driver network.
- Support technology assistance and scheduling help for patients.
- Help patients feel ready to discuss access needs from the start.
- Make lodging an equal priority with transportation in cancer access planning.
- Strengthen data sharing and mapping for real-time resource visibility.

Medium and Long-Term

- Build a statewide "Travel Companion" volunteer program.
- Establish an "On-Call Transportation Backup Network."
- Expand mileage reimbursement options.
- Utilize Community Health Outreach Workers (CHOWS) as local connectors.
- Invest in rural access hubs and community partnerships to close geographic gaps.



Methodology

Research Objectives and Background

The goal of this needs assessment was to support Maine's Impact Cancer Network's (MICN) Transportation Task Force and Maine Cancer Foundation (MCF) in understanding the current landscape of transportation and lodging resources available to patients with cancer across Maine. The study explored how access to these services has evolved since the COVID-19 pandemic and to identify barriers, gaps, and opportunities to improve service delivery and equity to patients.

The main study objectives were:

- Understand the availability and scope of cancer treatment and support services throughout the state of Maine.
- Assess the distances patients travel to receive treatment and the frequency of travel.
- Examine barriers and costs associated with transportation and lodging for patients with cancer.
- Identify eligibility requirements, and existing partnerships among service providers.
- Map gaps between available transportation and lodging services and patient need to inform future planning.

To meet these goals, MDR implemented a mixed-methods research design composed of four components:

- 1. **Survey of transportation and lodging providers** to capture service availability, eligibility requirements, and operational barriers.
- 2. **In-depth interviews with clinical providers** who assist patients with cancer with transportation and lodging needs.
- 3. **Survey of patients with cancer** to gather lived experiences with transportation and lodging during treatment.
- 4. **Provider mapping and a list of resources** to determine the distribution of providers and treatment centers statewide and estimate travel distances for patients in Maine.

Each component complemented the others, collectively providing a comprehensive understanding of access barriers, service gaps, and opportunities for improvement.

Sample

Each part of the project used targeted sampling strategies and community outreach to recruit the appropriate population:

- Transportation and Lodging Provider Survey: MDR and MICN developed a comprehensive list of transportation and lodging providers using existing partner networks and public databases. Snowball sampling was also used to identify additional relevant organizations.
- **Healthcare Provider Interviews:** Eligible participants included clinicians, oncology social workers, nurse navigators, and administrative staff involved in patient support and care



- coordination. Participants were recruited through MICN's statewide network and direct outreach to cancer treatment facilities.
- Cancer Patient Survey: MDR recruited respondents with help from MICN and MCF through outreach to cancer care organizations, support networks, and their partners across Maine. Participants were eligible if they had been diagnosed with cancer within the past five years and had received treatment within the state.

Surveys and Interview Guide

MDR developed two survey instruments and one qualitative interview guide in collaboration with MICN and MCF:

- Transportation and Lodging Provider Survey: Questions focused on service areas, eligibility criteria, operational capacity, funding sources, coordination with healthcare providers, and challenges in meeting patient demand.
- **Clinical Provider Interview Guide:** Interviews explored how transportation and lodging needs are identified and addressed, providers' experiences navigating service gaps, and perceived barriers and opportunities for current and future patients.
- Patient Survey: The survey captured demographics, distance traveled for treatment, transportation and lodging arrangements, costs, barriers, and comfort with available resources and technology.

Data Collection

Data collection occurred from May-August 2025. All surveys were distributed online. Surveys were programmed in Voxco, MDR's online data collection platform. Recruitment emails were sent to identify transportation and lodging provider contacts from sample lists provided by MCF and MICN. Reminder messages were distributed throughout the data collection period to encourage participation.

For the patient surveys, MCF and MICN sent out recruitment materials from MDR including flyers, project information, and the survey link to clinical providers and various cancer community groups. Each patient received a \$10 gift card to complete the survey.

Recruitment emails were also sent to the clinical provider sample lists with a booking link to schedule a virtual interview. In-depth interviews were conducted virtually over Microsoft Teams. Each interview lasted approximately 30–45 minutes, was recorded with permission, and transcribed, for qualitative thematic analysis.

In the end, there was a total of 17 lodging and transportation provider surveys, 5 interviews with clinical providers (with one interview being a group of two providers), and 115 patient surveys.

Mapping and Resource List

MDR developed a comprehensive list of oncology providers across Maine, using publicly available data. Using GIS mapping, MDR analyzed provider distribution and estimated the distances patients



travel for cancer treatment. This analysis helped identify geographic gaps in access to cancer care and transportation support.

MDR additionally calculated a travel burden score to estimate burden accounting for both population distribution and distance. This score is calculated by taking the number of reported cancer cases in a county and estimating the number of cases per zip code by share of county population. This number of cases was then multiplied by the estimated minimum distance patients would need to travel for treatment.

Data Analysis and Reporting

After data collection, MDR conducted a multi-step analysis process that included:

- Analyzing survey data to generate frequencies and cross-tabulations.
- Coding open-ended survey responses.
- After each interview, qualitative data was thematically analyzed to identify important themes and illustrative quotes.

Results were grouped together into a comprehensive needs assessment report, including:

- Key findings and supporting evidence from all survey and interview components.
- Analysis of service gaps and opportunities.
- Mapping visualizations of provider locations and travel distances.
- Differences between pre-Covid and post-Covid services (2017 vs 2025).
- Recommendations for improving equitable access to transportation and lodging for patients who have cancer in Maine.



Overview of Maine Cancer Data

Over the past 10 years, the overall cancer incidence rate in Maine has shown no significant change.¹ According to Maine Cancer Registry data on 2022 cases, both Maine cancer incidence and mortality rates are higher than national rates. The overall age-adjusted cancer incidence rate for Maine is 471.8 per 100,000, compared to 442.3 per 100,000 in the US.¹ The age-adjusted cancer mortality rate for Maine is 153.8 per 100,000, compared to 143.6 per 100,000 nationally.¹

NIH Cancer Institute and Maine Cancer Registry data also revealed differences in incidence rate by county. The 2017-2021 cancer incidence rates from the NIH showed that incidence rates in Washington, Piscataquis, Penobscot, and Hancock counties were significantly higher than the state overall (see Map 1).² Additionally, mortality rates were significantly higher than the state overall in Somerset and Washington counties.¹

- 1. 2025 Maine Cancer Snapshot, 2025. Maine Department of Health and Human Services, Maine Cancer Registry. August 2025.
- 2. State Cancer Profiles, 2025. NIH National Cancer Institute, *State Cancer Profiles Incidence Rates Table*. statecancerprofiles.cancer.gov. Accessed 2 Oct. 2025.



1. Many providers delivered both transportation and lodging services and patient needs keep rising.

Over half (53%) of respondents delivered both transportation and lodging, highlighting the need for a combination of services. At the same time, 53% reported being unable to serve eligible patients within the last year because of funding or capacity limits. This duality shows providers are committed but stretched thin.

• "We have been able to stay just ahead of the need, but it is growing."

2. Mobility and accessibility was prioritized among providers and services, but specialized needs remained challenging.

Most transportation providers accommodated walkers (92%) and wheelchairs (67%), and 85% always allowed a caregiver or companion. However, patients who required more hands-on support often faced barriers, since many policies limit what drivers can do for liability reasons.

3. Scheduling systems balanced flexibility and strain.

Transportation providers have made efforts to let patients set pickup times (69%) and accommodate urgent requests (46%). Still, about one-third required same-day or 48-hour advance requests, reflecting the pressure of balancing patient-centered flexibility with limited driver availability and complex appointment schedules.

4. Volunteer labor was vital but unreliable.

Transportation services frequently depended on volunteer drivers and flight staff (38%), making these services highly vulnerable to shortages. Recruitment challenges meant that even committed providers could not always meet growing demand.

5. Weather, staffing, and driver shortages were persistent barriers.

Two-in-five transportation providers said lack of drivers or flight staff was a moderate or severe barrier. Unpredictable Maine weather intensified these challenges, forcing providers to prioritize some patients over others.

6. The most common transportation assistance provided were rides to appointments, taxi vouchers, and gas cards

80% of providers covered rides to appointments for cancer patients. 40% said they provide gas cards and taxi or rideshare vouchers.



7. Lodging policies varied widely, unintentionally excluding some patients.

Nearly half (45%) of lodging providers required patients to live a certain distance from treatment to qualify for lodging, and over one-third (36%) required a caregiver to stay overnight. These policies, designed for fairness and safety, unintentionally excluded some patients without caregivers or those who live just inside or outside eligibility boundaries.

8. Financial challenges were universal, with most providers dependent on grants.

Nearly 9 in 10 providers (88%) relied on grant funding for their services, and 71% offered discounted options year-round. Providers consistently flagged funding as their biggest barrier, citing increasing patient needs and rising costs of transportation and lodging. This dependency made the entire system vulnerable to funding shifts.

9. New partnerships extended reach but highlighted rural inequities.

Providers worked with Uber Health, Lyft, airlines, bus lines, and hotels, often praising these partnerships. However, rural patients were less able to benefit, as rideshare services are unavailable outside urban centers. In these regions, providers fell back on gas cards or volunteers, leading to inequitable access across Maine.

• "We can only provide \$250 towards Ubers for each family per stay. That usually doesn't cover their entire treatment regimen."

10. Lodging providers believe the most common barrier for patients is the lack of awareness of services.

63% of lodging providers reported that lack of awareness of services among patients was either a moderate or extreme barrier. Second biggest barrier was the cost of lodging availability.

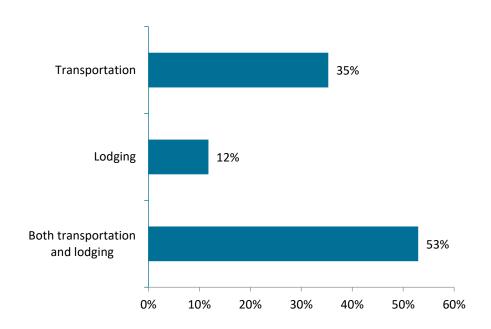
11. Since the COVID-19 pandemic, providers reported significant increases in requests and resources.

In one case there was more than 30% in a single year. Rising cancer incidence and lack of specialized in-state treatment options made patients travel greater distances and need more lodging.

"We have experienced a 30%+ increase in requests from cancer patients in Maine who need to seek specialized care and treatment that is not available to them within the state."



Q1: Which of the following services or support do you provide to cancer patients?



	Count	%
Transportation	6	35%
Lodging	2	12%
Both transportation and lodging	9	53%
Total	17	100%

Summary

Half of respondents (53%) report they provide both transportation and lodging services.



Q2: What is the name of your organization?

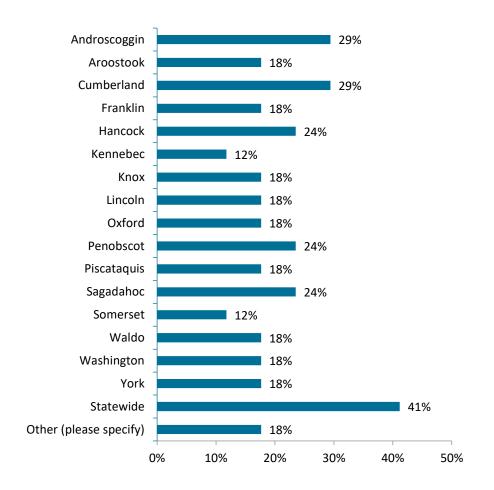
Comments
American Cancer Society
Angel Flight of New England
Beth C. Wright Cancer Resource Center
Clayton's House of the Dempsey Center
Dean Snell Cancer Foundation
Fisher House Boston
Friends in Action
HEADstrong Foundation, Nick's House Boston
ITNPortland
Joe Andruzzi Foundation
Northern Maine Medical Center
Penquis CAP, Inc.
SNELL Foundation
Snell Foundation
Waldo Community Action Partners
Western Maine Transportation Services
I prefer not to answer

Summary

17 organizations provided data on their services.



Q3: What is your service area?



	Count	%
Androscoggin	5	29%
Aroostook	3	18%
Cumberland	5	29%
Franklin	3	18%
Hancock	4	24%
Kennebec	2	12%
Knox	3	18%
Lincoln	3	18%
Oxford	3	18%
Penobscot	4	24%
Piscataquis	3	18%
Sagadahoc	4	24%
Somerset	2	12%
Waldo	3	18%

Summary

More than a third (41%) of respondents report their service area is statewide. Around a third (29%) report that their service area includes Androscoggin and Aroostook counties.



	Count	%
Washington	3	18%
York	3	18%
Statewide	7	41%
Other (please specify)	3	18%
Total	17	100%

Comments

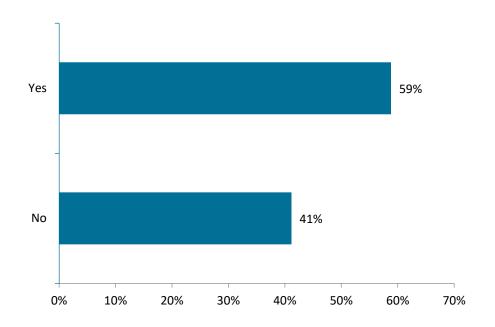
Brunswick and Harpswell

Statewide for lodging and the Counties check for Transportation at this time

We provide financial assistance to cancer patient being treated at New England Cancer Specialists in Topsham. Those patients come from multiple counties in Maine.



Q4: Can you transport patients outside of your service area? E.g. to a treatment center in Boston?



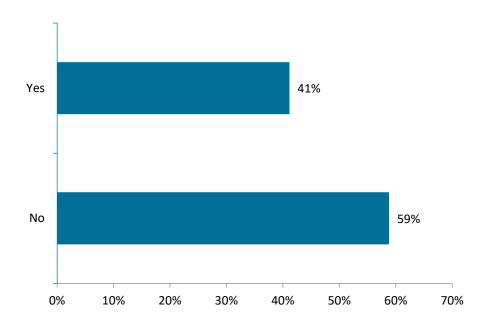
	Count	%
Yes	10	59%
No	7	41%
Total	17	100%

Summary

More than half (59%) of respondents provide transportation outside of their service area.



Q5: Can you serve patients who live outside your service area?



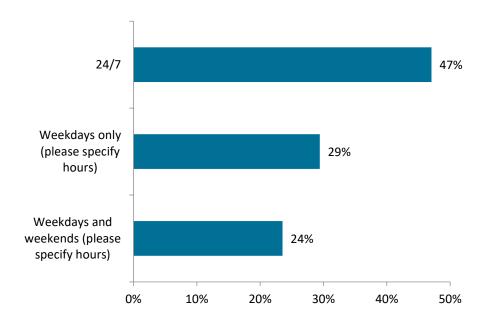
	Count	%
Yes	7	41%
No	10	59%
Total	17	100%

Summary

More than half (59%) cannot serve patients who live outside of their service area.



Q6: What are your hours of operation?



	Count	%
24/7	8	47%
Weekdays only (please specify hours)	5	29%
Weekdays and weekends (please specify hours)	4	24%
Total	17	100%

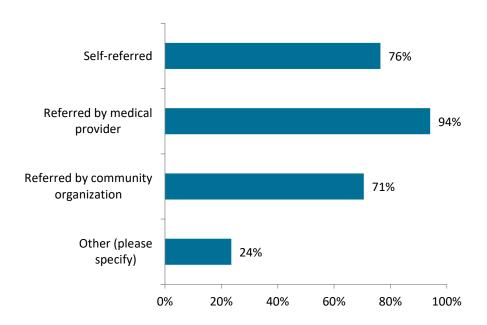
Comments
7:00 AM - 5:00 PM
7am-7pm
As resources are available.
M-F 8-5 Sat 9-1 at certain locations
M-F 8am- 5pm
Patients can stay with us Monday -Thursday nights. Our office hours are Monday - Friday 8:30 am to 4:30 pm
Transportation from 7am until 5 pm (Monday-Friday) Lodging solutions available weekday and weekends
Typically 7:00 a.m. to 6:00 p.m.
We do not have a physical office. We deliver assistance to the NECS office in Topsham.

Summary

Nearly half of providers (47%) report they are available 24/7.



Q7: Please describe how patients are connected/referred to your organization.



	Count	%
Self-referred	13	76%
Referred by medical provider	16	94%
Referred by community organization	12	71%
Other (please specify)	4	24%
Total	17	100%

Comments
Outreach and social media
Patient Advocates
Patient Advocates at NECS look for patients who are struggling and help them connect with us.
Patients can learn about DSCF through multiple channels. They are directly referred to us through the Financial Advocate at NECS who

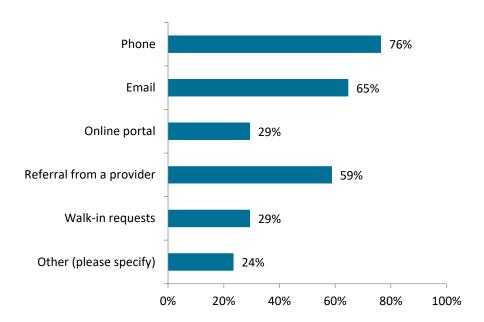
provides us with a list of patients and their specific needs.

Summary

The majority (94%) of respondents report that patients are referred to them through medical providers. Three-quarters (76%) said that patients can self-refer.



Q8: How can patients contact you to apply for services? Please select all that apply.



	Count	%
Phone	13	76%
Email	11	65%
Online portal	5	29%
Referral from a provider	10	59%
Walk-in requests	5	29%
Other (please specify)	4	24%
Total	17	100%

Comments
Must call us as a NEW Patient but after that they can request rides using
Mobile APP or still call us
Online Application
Patient Advocates
Patients contact the NECS Financial Advocate who sends their individual needs to us. All contact is confidential.

Summary

Three-quarters (76%) of respondents report that patients can contact them via phone to apply for services. Two-thirds (65%) report that patients can reach out through email.



Q9: What information do patients need to provide when applying for services?

Comments

Contact info (name, address, phone, email if they have it). Rides or Lodging can only be requested if patient is needing this service/s for a cancer treatment related appointment/s, treatment center name and address, patients' mobility status. We will ask for dates/times of needed service

Contact information so we can perform an intake

Explain Need.

For transportation services patients need to provide their name and address, as well as the address of where they are going. They need to be in active cancer treatment confirmed by an oncology social worker.

Location of treatment being received, date, time of appointment

Medical Diagnosis and copies of receipts

Name, address, phone number, social security number, mobility issues, MaineCare number, DOB,

Name, Birth date, Disability if any,

Name, DOB, Address, Diagnosis, Oncologist they are being treated by, approximate length of treatment/stay, their caregiver's information, ss# for background checks, any other pertinent info

Nature of need, amount needed, household resources, patient status

Personal demographics, MaineCare status, income (for use of other resources if needed, but not required for Maine Cancer Foundation use)), address, phone number.

Proof of military service, proof of medical care (contact with medical team or hospital provided schedule of care)

The Financial Advocate qualifies each patient before sending them on to us.

They complete an application form with demographic and service needs info

We conduct a patient intake that includes all of their pertinent information (name, address, DOB, phone, doctor, medical condition, etc.) along with their required dates of travel for medical appointments. We do require that patients are able to get in and out of general aviation aircraft given we are not an air ambulance.

We have a number of questions we ask during initial intake, too many to list here, then time/location questions for rides.

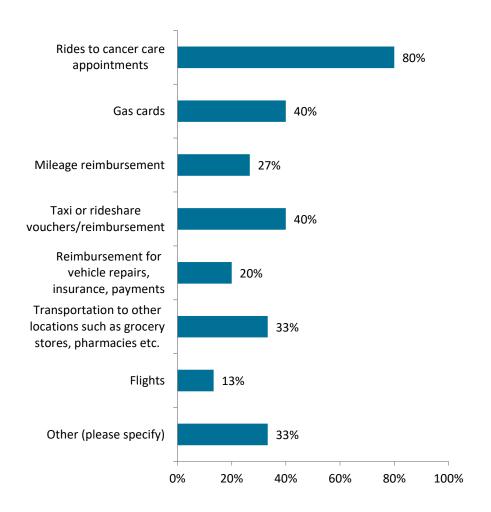
We need a referral from a medical provider stating that they are or will be receiving cancer treatment. They also have to be traveling at least 30 miles one way to access treatment so we will need their home address

Summary

According to respondents, patients commonly need to provide their basic contact information, cancer diagnoses, information about any disabilities or mobility issues that may impact their transportation needs, and dates and times of needed rides.



Q10: What type of transportation assistance do you provide for cancer patients? (Please select all that apply)



	Count	%
Rides to cancer care appointments	12	80%
Gas cards	6	40%
Mileage reimbursement	4	27%
Taxi or rideshare vouchers/reimbursement	6	40%
Reimbursement for vehicle repairs, insurance, payments	3	20%
Transportation to other locations such as grocery stores, pharmacies etc.	5	33%
Flights	2	13%
Other (please specify)	5	33%
Total	15	100%

Summary

Four-in-five respondents (80%) said they provide rides to appointments for cancer patients. Two-in-five respondents (40%) each report that they provide gas cards and taxi or rideshare vouchers.



Comments

Any destination that is related to cancer care.

Any other household bills like utilities, mortgage, etc... Nothing other than gas or food cards goes directly to patients. We don't do reimbursement.

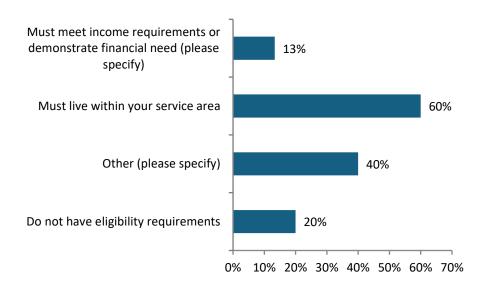
Bus, Ubers/Lyfts, Train

Lodging reimbursement

We pay for vehicle repairs, insurance, car payments, and registration. DSCF makes a direct payment to the company providing the services. Often patients do not have the funds to pay for the service and then get reimbursed.



Q11: Do you have eligibility requirements to receive transportation services? (Please select all that apply)



	Count	%
Must meet income requirements or demonstrate financial need (please specify)	2	13%
Must live within your service area	9	60%
Other (please specify)	6	40%
Do not have eligibility requirements	3	20%
Total	15	100%

Comments
active treatment
Although income is not an eligibility requirement for MCF use,
Must be independently ambulatory or bring a caregiver to supply assistance
must be over 55 or over 18 with a disability, or over 18 and undergoing cancer treatment regardless
The patient must be in active treatment at NECS is Topsham.
The patient must be qualified by the Financial Advocate.
There is not technically an income requirement, however those of lower income may be prioritized.
We don't ask our patients about their income or require them to

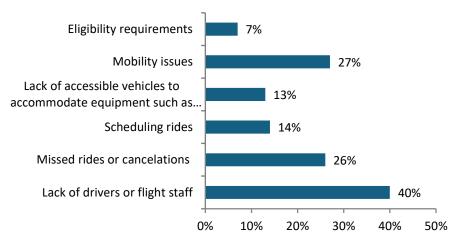
demonstrate a financial need. Our understanding is that they are facing a medical emergency journey and need AFNE's assistance to get to the medical care they need.

Summary

Nearly two-thirds (60%) of respondents report that patients must live within their service area to qualify for transportation services.



Q12: How much of a barrier are the following for patients using your transportation services?



^{*}Chart depicts the percentage responding moderate or extreme barrier.

	Not a barrier	Somewhat of a barrier	Moderate Barrier	Extreme Barrier	Not sure
Eligibility requirements	80%	13%	-	-	7%
Mobility issues	40%	33%	7%	-	20%
Lack of accessible vehicles to accommodate equipment such as wheelchairs	53%	7%	27%	-	13%
Scheduling rides	67%	20%	13%	-	-
Missed rides or cancelations	60%	13%	7%	7%	13%
Lack of drivers or flight staff	20%	47%	13%	13%	7%
Lack of awareness of services	7%	47%	33%	7%	7%

Summary

Two-in-five respondents (40%) report that a lack of drivers or flight staff is a moderate or extreme barrier to patients using transportation services.



Q13: What other common barriers do patients experience when using your transportation services?

Comments

Confusion associated with Alzheimer's or dementia

I haven't experienced many barriers thus far, we use the UBER health program so it's quite simple. It comes through as a text message, they don't need to download or use the app. It's been great

Lyft is not available in the rural areas of Maine

Mostly our inability to provide rides outside of our service area, the need to wait for pick-up following treatments, and the preference or need for one-on-one transportation which we can't provide.

None. We strive to make access to transportation services simple and easy.

Not knowing what is offered

not sure

Patients find their own transportation, we provide mileage reimbursement

Patients who are in need of having an escort go with them, but they don't have anyone to go.

unsure

We do require patients and companions to have a back up plan given the weather can hinder a flight and we know that for many patients it has taken months to schedule their appointments with specialists. Many also lack the funding for food when attending medical appointments/treatment. We provide them with financial support so they can eat and be comfortable.

We don't have a lot of barriers for service, but can't accommodate those who can not self-transfer from a wheelchair.

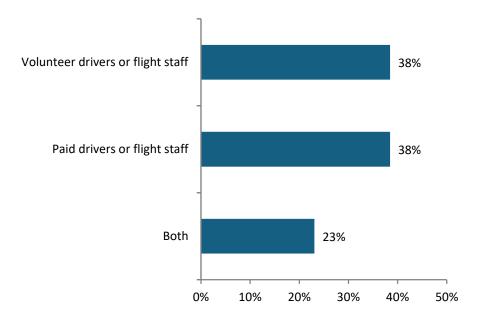
We have a "two-day notice" policy for scheduling rides. This can sometimes present a barrier if oncology schedules are not submitted or called in on time.

Summary

Respondents reported a variety of barriers patients experience when using their transportation services, including challenges due to other conditions like Alzheimer's or mobility issues, need for patients to find their own transportation to receive reimbursement, or unpredictable weather.



Q14: What type of drivers or flight staff do you have?



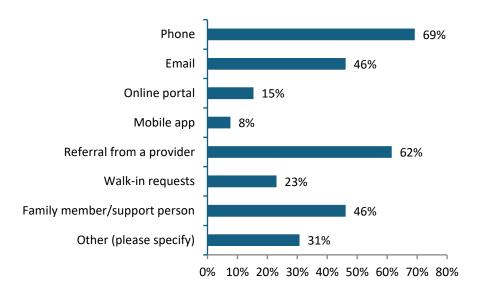
	Count	%
Volunteer drivers or flight staff	5	38%
Paid drivers or flight staff	5	38%
Both	3	23%
Total	13	100%

Summary

More than a third (38%) of respondents reported that transportation was provided by volunteer drivers and flight staff, while another 38% reported that services were provided by volunteers.



Q15: How can patients contact you to schedule a ride? Please select all that apply.



	Count	%
Phone	9	69%
Email	6	46%
Online portal	2	15%
Mobile app	1	8%
Referral from a provider	8	62%
Walk-in requests	3	23%
Family member/support person	6	46%
Other (please specify)	4	31%
Total	13	100%

Comments

Contact Patient Advocates

Often times we work directly with social and case workers who understand our process and get arrange the free air and ground transportation quickly and efficiently. For many of our patients, they have never left their geographic area let along flown so arranging our services could be challenging but our mission/flight coordinators are compassionate and work with each patient as if they were their own family member.

Patient Advocates make request and setup scheduled rides

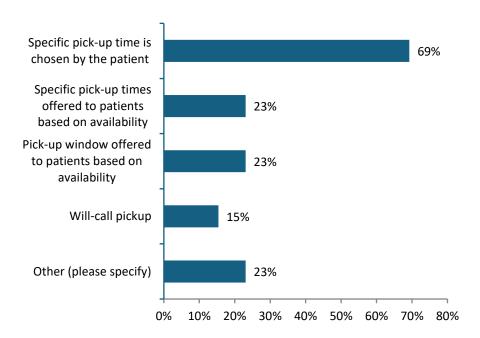
This service is just for guests CURRENTLY staying at Nick's House- so they often just let me know throughout the day

Summary

More than a third (69%) of respondents who provide transportation services say that patients can contact them by phone to schedule a ride.



Q16: When scheduling a ride, how is the pick-up time determined? (Please select all that apply)



	Count	%
Specific pick-up time is chosen by the patient	9	69%
Specific pick-up times offered to patients based on availability	3	23%
Pick-up window offered to patients based on availability	3	23%
Will-call pickup	2	15%
Other (please specify)	3	23%
Total	13	100%

Comments

Our ride "ticketing" system automatically calculates a pickup window based on the appointment time.

Pick up time to get to the patient to the appointment from Clayton's House is determined by the patient's appointment time. Pick up time from appointment back to Clayton's House is based on the anticipated end time of the patient's appointment and the availability of the driver to pick up.

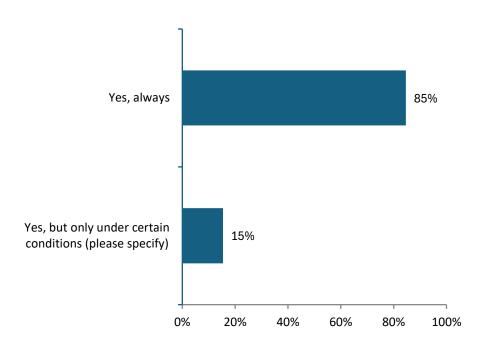
We follow the policy and procedures of the agencies we work with

Summary

More than a third (69%) of respondents who provide transportation services said that pick-up times are determined by the patient.



Q17: Do you allow patients to bring a caregiver/companion when receiving transportation services?



	Count	%
Yes, always	11	85%
Yes, but only under certain conditions (please specify)	2	15%
Total	13	100%

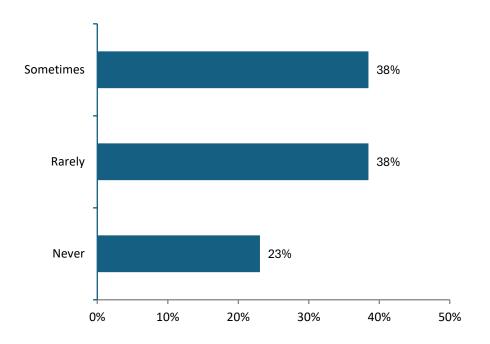
Comments
Some of the agencies have restrictions
The need for an escort must be stated at time of ride request.

Summary

The majority (85%) of respondents report that patients are always allowed to bring a caregiver or companion.



Q18: Are rides shared with other patients?



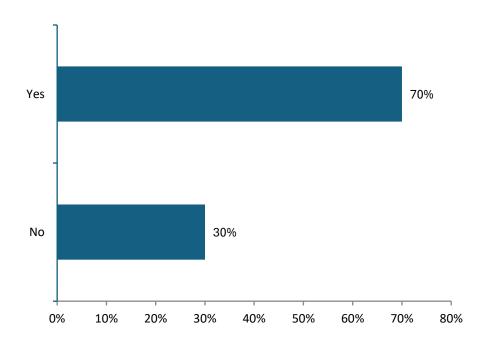
	Count	%
Sometimes	5	38%
Rarely	5	38%
Never	3	23%
Total	13	100%

Summary

More than a third (38%) of respondents report that rides are sometimes shared with other patients, while another 38% report that they are rarely shared.



Q19: If a patient is immunocompromised, can special accommodations be made?



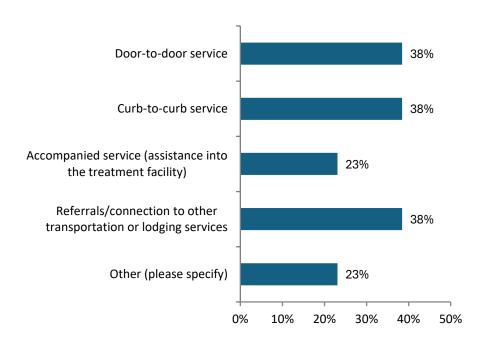
	Count	%
Yes	7	70%
No	3	30%
Total	10	100%

Summary

More than two-thirds (70%) of respondents report that special accommodations can be made for immunocompromised patients.



Q20: What types of transportation assistance do you provide? (Please select all that apply)



	Count	%
Door-to-door service	5	38%
Curb-to-curb service	5	38%
Accompanied service (assistance into the treatment facility)	3	23%
Referrals/connection to other transportation or lodging services	5	38%
Other (please specify)	3	23%
Total	13	100%

Comments

All of our transportation is either ride share or gas voucher.

We will schedule tickets on bus and train when required. Our earth angels/ ground crew volunteers are amazing and support patients by ensuring they safely and conveniently get to where they need to be.

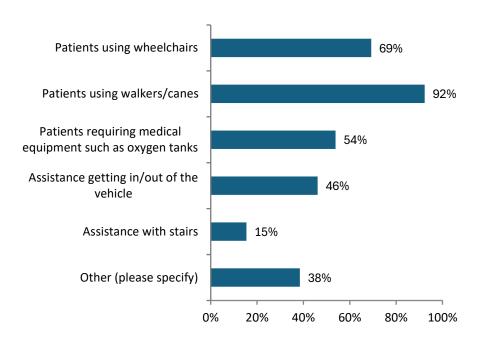
We work directly with transportation agencies and advocate on behalf of patients needs. So all the above

Summary

More than a third (38%) report that they provide door-to-door transportation assistance, while 38% provide curb-to-curb service.



Q21: What mobility needs can you accommodate? (Please select all that apply)



	Count	%
Patients using wheelchairs	9	69%
Patients using walkers/canes	12	92%
Patients requiring medical equipment such as oxygen tanks	7	54%
Assistance getting in/out of the vehicle	6	46%
Assistance with stairs	2	15%
Other (please specify)	5	38%
Total	13	100%

Comments

All of our rides are facilitated through Uber Health

Patients must be able to transfer in and out of the care by themselves or with assistance of caregiver that accompanies them, wheelchair can be transported but driver not allowed to handle, must be patients' caregiver lifting chair in and out of car.

Unsure about most of these.

Summary

Nearly all (92%) of respondents report that their organizations can accommodate patients using walkers or canes. More than two-thirds report that they can accommodate patients using wheelchairs.



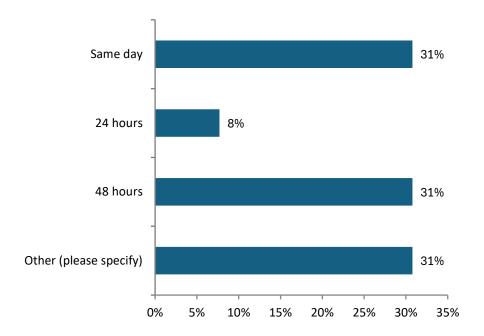
Comments

We are not an air ambulance, so we do require patients to be able to access general aviation aircraft which can be challenging at times. Our volunteer pilots assist patients and companions entering and accessing the aircraft. And when we use commercial aviation, our partners assist the patients throughout their journey.

We work directly with transportation agencies and advocate on behalf of patients needs. So all the above



Q22: How far in advance must a patient request transportation?



	Count	%
Same day	4	31%
24 hours	1	8%
48 hours	4	31%
Other (please specify)	4	31%
Total	13	100%

Comments

At least one full business day in advance. More notice is helpful

They usually require a 48 notification. We work directly with transportation agencies and advocate on behalf of patients needs. So all the above

We try to accommodate all requests. We have had patients call the day before and we have been able to accommodate them. For the safety of our patients as well as our volunteers, we do try to ask that they give us at least 48 to 72 hours notice.

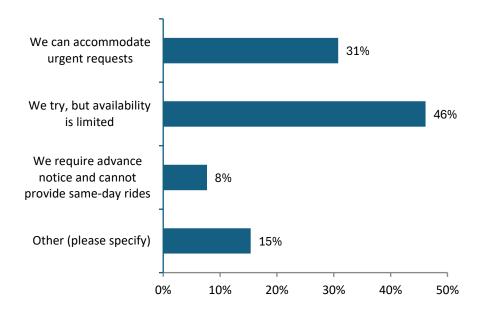
we urge 5 days but accept a request subject to driver availability the same day.

Summary

Neary a third (31%) of respondents report that patients must request transportation same day, while an additional 31% report that patients must make a request 48 hours in advance.



Q23: How do you handle last-minute transportation requests?



	Count	%
We can accommodate urgent requests	4	31%
We try, but availability is limited	6	46%
We require advance notice and cannot provide same-day rides	1	8%
Other (please specify)	2	15%
Total	13	100%

Comments

We do have a few volunteer drivers and we use staff when we are unable to make accommodations with agencies or volunteers. We work directly with transportation agencies and advocate on behalf of patients needs. So all the above

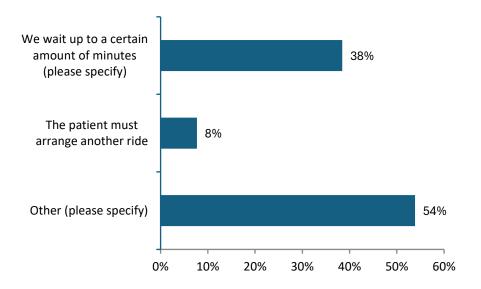
We will do our best to accommodate same day requests, but often lack capacity. We are rarely able to serve last-minute requests, unless a prearranged call-for-pickup is scheduled.

Summary

Nearly half (46%) of respondents report that they try to accommodate last minute requests for transportation, but availability is limited.



Q24: If a patient is running late, what is your policy?



	Count	%
We wait up to a certain amount of minutes (please specify)	5	38%
The patient must arrange another ride	1	8%
Other (please specify)	7	54%
Total	13	100%

Comments

10

Driver will wait for as long as they are able and many can accommodate appointment that goes later than expected, but some may have to leave if wait is longer than 1 hour.

Drivers will wait 10 minutes, or longer if schedule allows. If driver has to leave, that driver or another will come back to ensure the patient isn't left without a ride.

For ground transportation, when utilizing our volunteer ground crew members, we have more flexibility but if using a car service such as Uber/Lyft, we try to reschedule as much as possible. When traveling via our general aviation volunteer pilots, they have some flexibility but also have a certain window that they must adhere to for their flight plan. And for commercial aviation, if the patient is late, then they may miss their flight - this is beyond our control.

I may have chosen an option that was incorrect. All of our transportation is ride-share.

Summary

More than half (54%) of respondents report that they have other policies for when a patient is running late. Many specified upon follow-up that they will wait as long as possible without missing another ride and that they will help arrange another ride if it's not possible to wait any longer.



Comments

Rides are scheduled via Lyft so the driver may not be able to wait if the patient does not communicate with them

This is situation-specific, but we will go out of our way not to strand a rider.

This is up to the Uber driver. We have often had to reschedule when a ride is missed.

We give a 1/2 hour window for the initial pickup and will wait 10 minutes after that window. For the return, we wait as long as we can, but if the driver has to leave for another transport, we will send another driver as soon as we can. It may be a while, depending on resources, but we don't strand a patient at their facility.

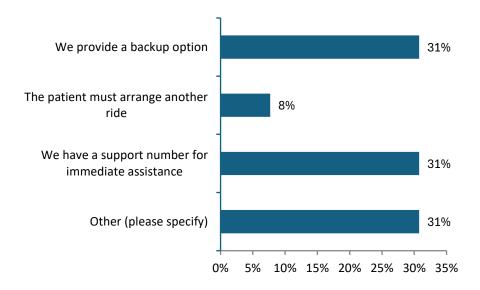
We wait 10 minutes, but we try calling the patient before we leave. If the patient is able to let us know they will be late, we will reschedule the ride for when they are ready.

we wait until it is not possible to get to the appointment on time,

We work directly with transportation agencies and advocate on behalf of patients needs. So all the above



Q25: What is the process if a patient's scheduled ride does not show up?



	Count	%
We provide a backup option	4	31%
The patient must arrange another ride	1	8%
We have a support number for immediate assistance	4	31%
Other (please specify)	4	31%
Total	13	100%

Comments

depending upon the circumstances, paid staff will step in

Patient can call and let us know, we will call driver to see if they have been delayed.

The rider can call our passenger relations team to ask. Usually this is due to a bus being delayed by traffic.

We do have a few volunteer drivers and we use staff when we are unable to make accommodations with agencies or volunteers. We work directly with transportation agencies and advocate on behalf of patients needs. So all the above

Summary

A third (31%) of respondents provide a backup option if a patient's ride doesn't show, and 31% have a support number for immediate assistance.



Q26: How do you handle and communicate extreme weather conditions?

Comments

Does not apply as we do not provide rides. We supply patients with gas cards to get to treatments and appointments.

If a ride has been scheduled, we typically call riders directly if a service is being delayed or shut down by weather. If a ride is on a commuter route or fixed-route service, we alert riders on our Facebook page. Again, we do our best not to strand riders.

If transportation is cancelled it is on our website, social media accounts, local TV stations. Even if transportation is cancelled, we try to do all of the cancer treatment and dialysis rides.

N/A

Patient and drivers will be notified if program is suspended due to weather conditions. This rarely happens.

Speak directly to the patient

This scenario has not occurred yet

TV announcement

We do not offer emergency services so cannot offer backup plans due to weather conditions

We monitor the weather consistently given aviation is determined on weather conditions. If we believe that patients flight may be canceled, we provide them with options to either fly a day earlier or see if they can reschedule their appointment. We also require patients to have a back up plan for travel.

We rely on our clinical partners to navigate scheduling and communication which is done by website, social media, text, and calls.

We will assess road conditions, and cancel rides as needed to keep riders and drivers safe. We have drivers that are comfortable driving in adverse weather with 4 wheel drive who are willing to help riders keep essential appointments like cancer care or dialysis.

We work closely with all transportation agencies and follow up with our patients

Web, Phone

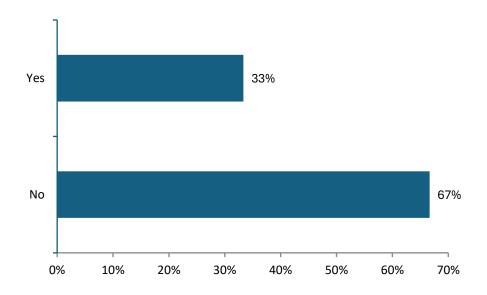
When we close due to weather, all passengers are called. We try to provide cancer care and dialysis transportation with extreme caution.

Summary

Respondents reported various ways of notifying adverse weather, including advertising cancellations on social media or TV broadcast, or calling patients directly. Multiple respondents mentioned prioritizing patients receiving cancer care or dialysis even if they must suspend broader services.



Q27: Do you require the patient to confirm a ride before it's sent out to get them? For example, through a text or phone call?



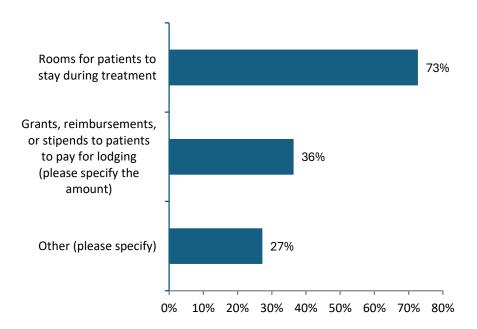
	Count	%
Yes	5	33%
No	10	67%
Total	15	100%

Summary

Two-thirds (67%) of respondents do not require patients to confirm rides before they are sent out to get them.



Q28: Which of the following lodging services do you provide?



	Count	%
Rooms for patients to stay during treatment	8	73%
Grants, reimbursements, or stipends to patients to pay for lodging (please specify the amount)	4	36%
Other (please specify)	3	27%
Total	11	100%

Comments

Daily rate for lodging per night

Extended Stay America partnership that offers free and deeply discounted nights and our Hope Lodge (HL) sites around the country that offer free lodging. Closest HL's to Maine are located in Boston, VT and NY.

We have agreement with hotels and have a discount. We usually make the reservation and pay for the hotel

We pay hotels / lodging directly. We approve up to \$1000 per request. We have negotiated rates to make sure we are stretching every dollar.

We pay the lodging provider directly.

We provide a Visa gift card to patients to pay for their hotel stay. We also provide funds to assist with meals.

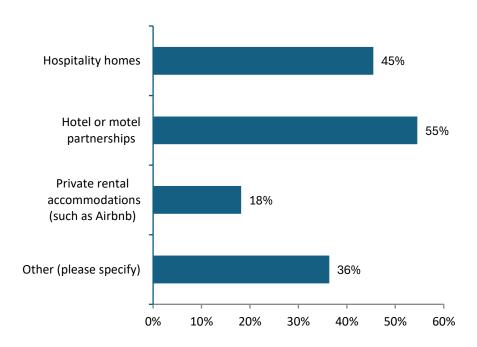
We work closely with hospitality homes as well as hotels who provide us discounts.

Summary

Nearly two-thirds (73%) of lodging provider respondents provide rooms for patients to stay during treatment.



Q29: What types of lodging do you provide or coordinate? (Please select all that apply)



	Count	%
Hospitality homes	5	45%
Hotel or motel partnerships	6	55%
Private rental accommodations (such as Airbnb)	2	18%
Other (please specify)	4	36%
Total	11	100%

Comments

Are Hope Lodges are facilities specifically designed to accommodate cancer patients and their caregivers. They provide private rooms and communal spaces for dining and entertainment.

N/A Patients find own accommodations and we provide reimbursement at a set daily rate.

We have a large house with 6 bedrooms, each family has one bedroom. We provide all other amenities such as laundry, parking, cleaning etc..

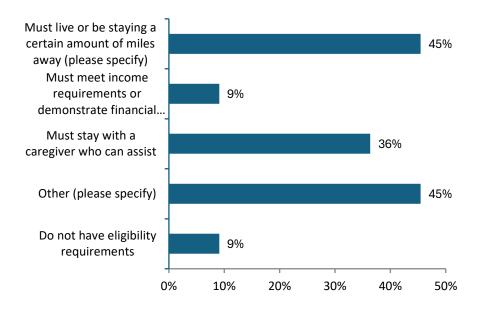
We work with all the above

Summary

More than half (55%) of respondents report that they coordinate hotel or motel partnerships.



Q30: Do you have patient requirements for lodging eligibility? (Please select all that apply)



	Count	%
Must live or be staying a certain amount of miles away from the medical facility or treatment center (please specify)	5	45%
Must meet income requirements or demonstrate financial need (please specify)	1	9%
Must stay with a caregiver who can assist	4	36%
Other (please specify)	5	45%
Do not have eligibility requirements	1	9%
Total	11	100%

Comments
25 miles from Boston
30+ miles
Eligibility requirements based of town of residing in.
Live more than 40 miles from treatment center
Must be traveling 30 or more miles one way to reach the treatment center
Patient advocates weigh each situation. Some patients are required to stay within a certain geographic area close to our campus and Mercy in order to take part in certain clinical trials or treatment types. That becomes costly for patients.
patient/family must live more than 40 miles from the medical facility

some scenarios do not require a care partner to stay

Summary

Nearly half (45%) of respondents report that patients must live a certain distance from their treatment facility to be eligible for lodging services. Additionally, 36% reported that patients must stay with a caregiver who can assist them.



Comments

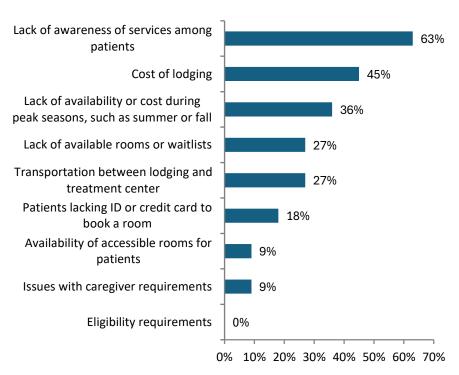
The patient has to be qualified by the Financial Advocate at NECS in Topham.

We work with all the above

When a patient is unable to travel to and from an appointment, on the same day, we assist them to arrange overnight accommodations.



Q31: How much of a barrier are the following for patients using your lodging services?



^{*}Chart depicts the percentage responding moderate or extreme barrier.

	Not a barrier	Somewhat of a barrier	Moderate barrier	Extreme barrier	Not Sure
Lack of awareness of services among patients		36%	45%	18%	
Cost of lodging	45%	9%	27%	18%	
Lack of availability or cost during peak seasons, such as summer or fall	36%	18%	18%	18%	9%
Lack of available rooms or waitlists	45%	27%	9%	18%	
Transportation between lodging and treatment center	27%	45%	27%		

Summary

Nearly two-thirds (63%) of respondents reported that lack of awareness of services among patients was either a moderate or extreme barrier.



	Not a barrier	Somewhat of a barrier	Moderate barrier	Extreme barrier	Not Sure
Patients lacking ID or credit card to book a room	55%	18%	9%	9%	9%
Availability of accessible rooms for patients	36%	45%		9%	9%
Issues with caregiver requirements	27%	55%	9%		9%
Eligibility requirements	55%	36%			9%



Q32: What other common barriers do patients experience when using your lodging services?

Comments

cost of meals/food is somewhat of a barrier for families coming to Boston for medical care

food resources

Many patients have never traveled before and look to us to walk them thru the process.

None that I'm aware of

not sure

Occasionally, a patient waits until the last minute to request assistance.

They have problems getting their patient advocates to send their referral to us in a timely manner which sometimes causes us to not have a room for them by the time we get the referral because we are already booked by that point.

This survey is well done and covers most [barriers] and issues

Summary

Two respondents reported that the cost of food while travelling was an additional barrier faced by patients using lodging services.



Q33: How far in advance must a patient request lodging?

Comments

A week or 2 weeks ideally but we do have amazing relationships with hospitality homes and other venues that assist us.

As soon as possible, lodging requests are granted based on availability, start date and date of request

Depends on the flow of things. We always tell patients to call us as soon as they know. We only have 9 room currently and they fill up fast. For instance, right now it is August 6th and we are booked solid with waiting lists until the last week in September.

no limit, can be same day if necessary

returning guests can call 24 hours in advance, new guests require 3-5 days due to processing time of the referral.

There isn't a set requirement of advanced notice- it all depends on the schedule

We don't have requirements but waiting certainly impacts availability and possibly price.

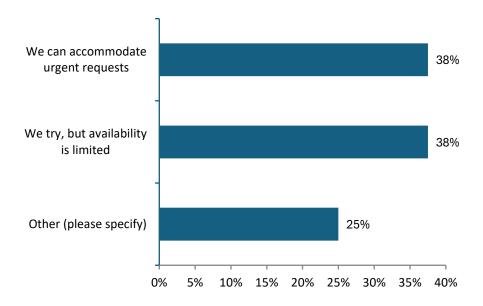
We work with all agencies and follow their policies and procedures

Summary

Many respondents don't have a set of defined policies, but encourage that patients request services as soon as possible, as requests are granted by availability. Other respondents report specific policies, including 1-2 weeks in advance or 24 hours.



Q34: How do you handle last-minute lodging requests?



	Count	%
We can accommodate urgent requests	3	38%
We try, but availability is limited	3	38%
Other (please specify)	2	25%
Total	8	100%

Comments

Some Hope Lodges have a little more flexibility due to availability, some have a very long wait list. Our hotel partnership may be able to handle last minute requests

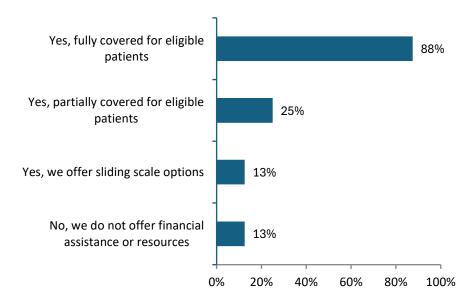
We try to process the request as quickly as possible however, staffing may be an issue and may not be possible to accommodate the request in the needed time fram.

Summary

More than a third (38%) of respondents report that they can accommodate urgent lodging requests, while another 38% report that they try but availability is limited.



Q35: Do you offer financial assistance for lodging? (Please select all that apply)



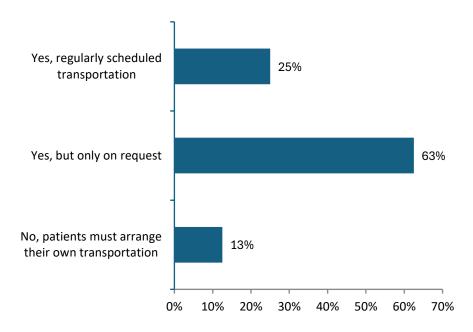
	Count	%
Yes, fully covered for eligible patients	7	88%
Yes, partially covered for eligible patients	2	25%
Yes, we offer sliding scale options	1	13%
No, we do not offer financial assistance or resources	1	13%
Total	8	100%

Summary

The majority (88%) of respondents report that lodging is fully covered for eligible patients.



Q36: Do you provide transportation between lodging and treatment facilities such as shuttles or reimbursement for taxis or rideshares?



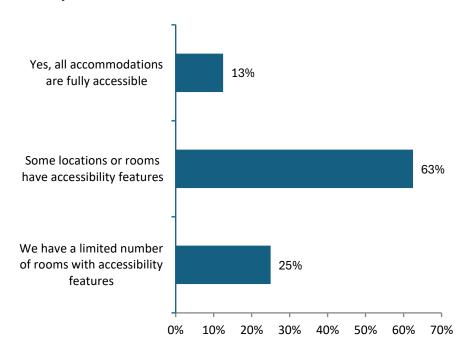
	Count	%
Yes, regularly scheduled transportation	2	25%
Yes, but only on request	5	63%
No, patients must arrange their own transportation	1	13%
Total	8	100%

Summary

Nearly two thirds (63%) of respondents report that they provide transportation between lodging and treatment facilities upon request.



Q37: Do you offer lodging with accessibility features for patients with mobility issues?



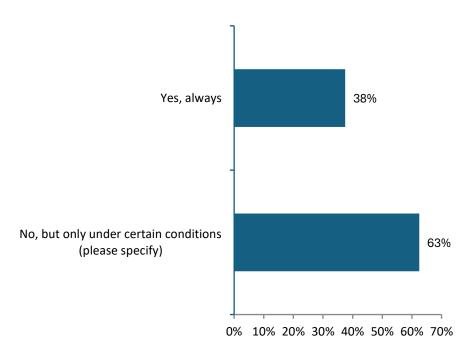
	Count	%
Yes, all accommodations are fully accessible	1	13%
Some locations or rooms have accessibility features	5	63%
We have a limited number of rooms with accessibility features	2	25%
Total	8	100%

Summary

Nearly two-thirds (63%) of respondents report that some rooms or locations within the lodging they provide have accessibility features.



Q38: Do you require patients to bring a caregiver/companion with them?



	Count	%
Yes, always	3	38%
No, but only under certain conditions (please specify)	5	63%
Total	8	100%

Comments

A care partner is required for those receiving chemotherapy and immunotherapy during their stay.

For many of our patients, they are facing a very uncertain healthcare journey so we do allow them to bring a caregiver/companion with them. In the instance of a child, both parents can accompany the patient if requested.

If the patient has extreme needs or is a fall risk.

If the patient is staying in the lodging we provide they must either be safe to care for themselves or have a caregiver. For example, patients coming for the 3 day Deep Brain Stimulation are not allowed to be alone per the medical team so they are required to have a caregiver.

We follow agencies policies and procedures

Summary

Nearly two-thirds (63%) of respondents report that they only require patients to bring a caregiver or companion with them under certain circumstances.



Q39: What is your cancellation policy for lodging?

Comments

24 hours

48 hour notification is requested

Hope Lodge-We ask patients to cancel as soon as they know they will not be staying with us so we can schedule another patient for lodging. With our Hotel Program, patients schedule their own lodging dates/needs and would need to follow hotel policies

I just ask that the patients and families let me know as soon as anything changes. No penalties, just courtesy

We ask them to let us know as soon as they can. We know some if it is out of their control because of their medical conditions.

We do not have one.

We follow agencies policies and procedures

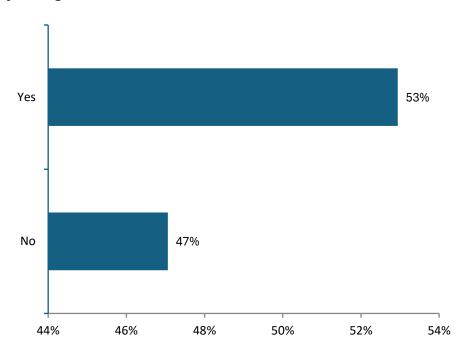
we prefer 24 hours notice, but families being served can cancel at any time with our team directly

Summary

Many respondents reported that they request patients let them know of any cancellations as soon as they can.



Q40: Within the past 12 months, have you been unable to provide services to an eligible patient due to capacity issues or a lack of funding?



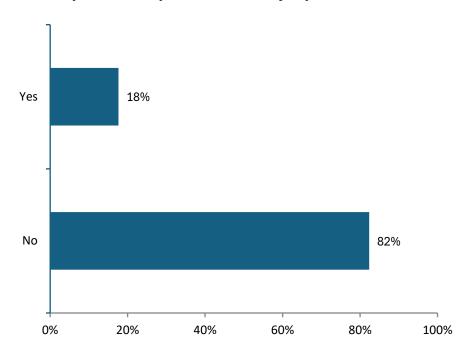
	Count	%
Yes	9	53%
No	8	47%
Total	17	100%

Summary

More than half (53%) of respondents report that they were unable to provide services to an eligible patient due to lack of capacity or funding within the past 12 months.



Q41: Do you currently have a waitlist for your services?



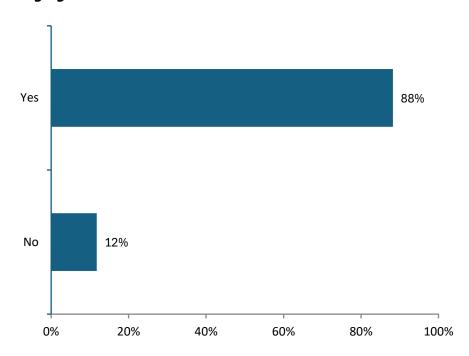
	Count	%
Yes	3	18%
No	14	82%
Total	17	100%

Summary

The majority (82%) of respondents report that they do not currently have a waitlist for services.



Q42: Do you receive grant funding to support transportation or lodging?



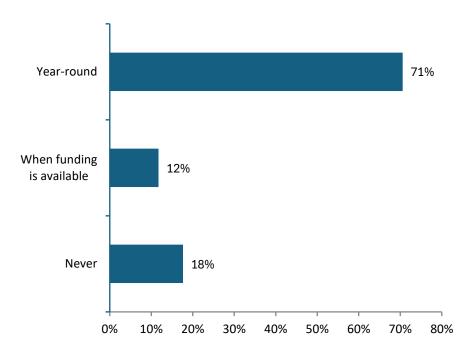
	Count	%
Yes	15	88%
No	2	12%
Total	17	100%

Summary

The majority (88%) of respondents report that they receive grant funding to support their lodging and transportation services.



Q43: When do you offer discounted transportation or lodging for medical stays?



	Count	%
Year-round	12	71%
When funding is available	2	12%
Never	3	18%
Total	17	100%

Summary

More than two thirds (71%) of respondents report that they offer discounted transportation or lodging services year-round.



Q44: How do you collaborate with other transportation or lodging services?

Comments

Beth Wright Center is a resource center so we work directly with all partners and we also partner with others when needed

For over 29 years, Angel Flight NE has been coordinating flights for patients to access specialized medical care and treatment. More than 40% of our patients are from Maine and 80% of them are facing rare and ultra-rare forms of cancer. We work closely with partners from ground transportation to commercial aviation partners such as JetBlue and Cape Air. We also have relationships with hospitality homes, hotels/motels and other means of lodging. Ensuring that a patient's healthcare journey is covered and they need to only focus on getting well is our goal.

For transportation, we utilize UBER health platform, I am in communication with all the other lodging facilities in Boston- I do my best to help an applicant explore all options to make sure we are the right fit. If we don't have availability for their treatment dates, I send along their info, or put them in touch directly with another resource that may have something available. I also have a list of subsidized hotels/motels.

make and receive referrals

No

no

The Financial Advocate wok with this.

This is not a part of our process.

We are in touch with similar nonprofits but do not formally collaborate We call and setup special pricing for patients.

We collaborate with other cancer support centers throughout the state.

We have purchased bus passes through Concord Coach Lines and Greyhound. If the trip is covered by MaineCare and PA has been approved for out-of-state transportation, we pay for the hotel.

We only provide lodging so we are frequently sharing information about transportation organizations with our families

We pay a local transportation service to provide our transportation requests to and from oncology appointments and/or the Dempsey Center and Clayton's House.

We refer to other transportation and lodging services when we are unable to help

We use uber health for ride sharing and Irving for gas cards.

Summary

Respondents utilize a variety of partnerships to provide services, including third party ride providers such as Uber Health, commercial airlines, or bus lines. Others report coordinating with other hospitality homes or hotels.



Q45: What transportation or lodging resources are working well?

Comments

All of them.

Funding from Maine Cancer Foundation, MDOT, and MaineCare.

General Aviation, Commercial Aviation, Ubers/Lyfts, Hospitality Homes and Various Motels/Hotels in Hub Cities.

Lyft where it is available. Gas gift cards for the more rural areas in Maine are very helpful for patients but we are limited in funding in offering these programs

Our cancer hospitality house works well. Especially since we are free with no restrictions. As far as transportation services, as an observer of my guests who rely on transportation services, I that there are some major issues there. They are quite often forgotten, not picked up, or picked up but not on time. Sometimes there is an issue because we are not a Medicare/Mainecare reimbursable facility so they just flat out refuse to transport them to or from our facility.

Our Hope Lodges work well it is just a capacity issue. Our transportation program is still slowly growing from temporary shut-down due to pandemic.

PALS, Angel Flight East

RTP

The grants from Maine Cancer Foundation.

The greatest issues are around individuals who need or want one-on-one volunteer rides, or rides being needed at our peak hours.

The program is going well, and we have been happy to provide free rides for cancer care and screening in our area.

The Uber Health has been great- very easy to schedule/setup and very simple for patients

Uber Health has been helpful in organizing transportation. Our hotel partners have been great.

Volunteer drivers in their own vehicle and gas

We provide transportation services with both agency vehicles/drivers and volunteers. Both are working well.

Summary

Many respondents said that Uber Health and Lyft are working well for them, while one respondent noted that its less available in rural areas, leading them to rely more on gas cards.



Q46: What would improve your ability to provide transportation or lodging services to cancer patients in Maine?

Comments

coordination of appointment times with care provider

Cross board collaborations

Dedicated vehicles might, but Uber has been great so far.

Everyone could always benefit from additional funding.

Funding for the transportation expense that we pay for. We do not charge guests to use transportation services we arrange for them via RTP.

It wouldn't be through Western Maine Transportation Services, but more volunteer drivers are needed. Although it's also nothing we can affect, treatments being offered closer to patients' hometowns would remove many transportation issues.

More drivers

More funding

More funding and more awareness of the service we offer.

More funding to help people who transport themselves so they can receive mileage reimbursement. We do not have enough funding to allow for reimbursement for more than two trips a week.

More volunteer and paid drivers.

More volunteer drivers.

Raising awareness and funding - at this time we cannot provide lodging for doctors visits alone due to high usage, we hope to have the funding in the future to include lodging for appointments considering many patients still must travel to Boston for them.

The clear answer is additional funding. We have experienced a 30%+ increase in requests from cancer patients in Maine who need to seek specialized care and treatment that is not available to them within the state of Maine. The four most common newly diagnosed cancers in Maine patients are rare forms of lung and bronchus, female breast, prostate, and colon / rectum cancers. With many counties being unserved for specialized care and treatment, patients must travel longer distances for treatment of these forms of cancer. Each flight costs us between \$300 to \$500 to coordinate let alone the rising costs of commercial aviation which has increased 40%. Securing additional funding is becoming more challenging with many other nonprofits who leveraged government grants not receiving this type of funding. AFNE's vital free air transportation is breaking down the barriers of distance and healthcare for better outcomes.

We can only provide \$250 towards Ubers for each family per stay. That usually doesn't cover their entire treatment regimen, if we awarded more financial help we could potentially provide more per family. Easing that heavy burden a little more.

We have been able to stay just ahead of the need but it is growing.

Summary

Many respondents mentioned they could expand their capacity with more funding and more volunteers.



KEY FINDINGS – Clinical Provider Interviews

1. Transportation barriers went beyond distance and cost. Reliability and trust were just as important for patients.

Clinical providers shared how frequently their patients report missed pickups, rigid schedules, or canceled rides, leading many to mistrust available options. This has sometimes caused patients to decline services entirely, even when they qualify.

- "I have a lot of patients that could use things like Midcoast Connector or Modivcare, but have had bad experiences because of missed visits, late visits, or canceled pickups. So, they start mistrusting it and don't want to use it anymore, and then we're in a pickle because that's really the only option.
- "I have one patient...he has daily radiation. We're three weeks in, and he's had four days where he hasn't been picked up."

2. Hidden logistical challenges created additional transportation stress and missed care for patients.

Providers said their patients struggled with inconsistent or confusing expectations for arrival, wait, and departure times. This has complicated scheduling transportation overall.

- "It's complicated to know what your pickup and drop-off times are. For certain scans, they
 want you there two hours early...but that's not clear in your instructions. Patients have no way
 of knowing what time they're going to need to be picked up or dropped off."
- "Pharmacy didn't have the meds ready...patient had a reaction, and now it's an extra hour and the ride I scheduled is gone."
- "There's a 45-minute window before their pickup, so they have to be ready and waiting, which is exhausting for patients."

3. Providers identified that grant funding was the backbone of both transportation and lodging assistance - but this reliance made services fragile.

Providers repeatedly stressed that nearly all assistance programs are grant-funded, leaving patients vulnerable when funding lapses or shifts.

- "We're very lucky to have grant funding, but if we lose grant funding, then we're back to square one of having to piece things together for patients."
- "All of these agencies across the state are grant funded for our cancer patients. We are so reliant upon grant funding again."



4. Providers repeatedly acted as "travel and lodging agents," highlighting the lack of dedicated infrastructure for patient navigation.

Many staff described spending large portions of their time arranging rides or lodging, detracting from their clinical role.

- "It's me, and lately it's felt like a lot, honestly. I just feel like a travel agent some days."
- "I will organize some patients' rides because they don't feel comfortable calling Modivcare."
- "We would love to have a nurse navigator here. There's just such a huge need."

5. Mobility and accessibility issues created more unique barriers that were rarely addressed by existing services.

Patients with wheelchairs, walkers, or declining mobility frequently could not use mainstream transportation programs, even if they technically qualified.

- "If the patient can't put the walker in the vehicle themselves, the driver's not going to do that. So, I have to look at other alternatives."
- "A lot of patients aren't really safe to travel alone. They need an escort, and often they don't have anyone."
- "None of these programs are willing to take patients if they've had any kind of anesthesia even if it's been hours later."

6. Lodging options were limited by accessibility, privacy, and patient preferences.

Providers explained that hospital-affiliated housing often had stairs, shared bathrooms, or required long lead times, making them impractical for many patients. Patients frequently preferred familiar hotel environments, even if less affordable.

- "They like the idea of a hotel room that feels familiar rather than a shared common space of a house that they're not familiar with."
- "Clayton's House needs a lot of lead time, and I usually don't have that."
- "Gary's House, Brackett House...all have stairs and shared bathrooms, which is a barrier."

7. Non-medical factors like caregiver availability, credit cards, and food access determined whether lodging is usable.

Even when lodging was secured, patients were sometimes unable to check in without a credit card, or struggled with meals if they lacked transportation while staying near treatment centers.



- "Sometimes it's having a credit card or a valid license to do a check-in at a hotel...that's been a huge barrier."
- "If they're transportation dependent and staying somewhere, sometimes it's even access to food."
- "Lodging programs often require a caregiver to stay overnight, which many patients don't have."

8. Local partnerships and resource creativity were essential but inconsistent across regions.

Some providers have built strong relationships with regional transportation services or foundations, while others rely on ad hoc solutions. This inconsistency means patient experience depends heavily on where they live and who their provider is.

- "Working together, we were able to obtain a grant through their support...so additional funding for this shutdown time."
- Midcoast Connector has been amazing I can call and get a real person instead of fighting with a phone tree."
- "Some areas have strong local foundations; others, we're piecing it together week by week."

9. Technology and digital literacy are emerging but were simultaneously critical barriers for patients.

Programs that required online requests or app-based scheduling (e.g., Uber links, ACS Road to Recovery) often excluded elderly, rural. or less tech-savvy patients.

- "They had been sent a link to request their ride through Uber, and they're not very tech savvy, so they don't know how to navigate through that."
- "Most of my patients don't use an app or don't know how to access it to see who's picking them up."
- "ACS Road to Recovery requires an app, so I can't recommend it to patients who don't use smartphones."

10. Transportation and lodging challenges directly impacted treatment adherence and mental health.

Providers reported patients canceling appointments or experiencing significant anxiety over travel and lodging logistics, highlighting the connection between access barriers and health outcomes.



- "There are patients that are canceling appointments because they're having anxiety about how they're gonna get there and where they're gonna stay once they get there."
- "It's not just the distance it's the stress of the unknown, not knowing if your ride will show up."
- "We sometimes have to delay treatment just because transportation failed that day."

"We have patients that truly have no one. They're estranged from family, don't have a friendly neighbor, and then to say they can't get a port placed to start chemo or can't have surgery because they don't have a human escort — it's just wild."

"I know the rules better than most of the staff there, and I have to push them to get things done. With cancer patients, we don't have the luxury of letting things slide."

"A lot of programs are strictly drivers. They don't touch patients for liability reasons, which I completely get - but then what about the 80-year-old who can't get her walker in and out of the car? That means she can't use the program at all."

"In Northern Maine, patients are already traveling hours for care. When the radiation center shuts down, they'll be driving 150 miles one way. In the middle of winter, that's just not realistic for an elderly patient."



KEY FINDINGS – Patient Survey

1. Transportation was the greatest barrier for patients to access cancer treatment.

Almost all patients reported lacking reliable transportation. Nearly two-thirds had missed or rescheduled appointments because of transportation challenges, demonstrating a direct impact on care.

- 90% of patients did not have reliable transportation to appointments.
- 84% said transportation costs affected their ability to receive treatment.
- 63% had missed or rescheduled care due to transportation barriers.

2. Patients relied heavily on informal networks for transportation services.

Family and friends provided most of the transportation support for patients, highlighting the absence of dependable and formal systems. This reliance created vulnerability if those transportation supports were unavailable.

• 67% relied primarily on family or friends for transportation to appointments.

3. Long-distance travel for cancer care was common and burdensome.

Many patients traveled far from home for treatment - increasing costs, stress, and the need for lodging.

- 33% traveled 50–99 miles, and 31% traveled 100 miles or more.
- 41% reported always staying overnight near their treatment center.

4. Lodging was not only a major cost barrier for patients, but options did not always align with patient preferences.

Patients overwhelmingly preferred hospitality houses, but most ended up in hotels or motels due to availability. Comfort and cost were also key issues.

- **54%** stayed in hotels/motels
- 90% said they would be comfortable staying in a hospitality house, yet only 36% had done so.
- **66%** said lodging costs affected their ability to receive treatment.



5. Few patients had backup plans for transportation and lodging, increasing risk of missed care.

When transportation or lodging plans fell through, most patients had no alternatives, leaving them with canceled or delayed treatment.

- **61%** lacked a backup transportation option.
- 84% lacked a backup lodging plan.

6. Volunteer driver services were a trusted but underused solution.

Patients expressed strong comfort with volunteer-based services, suggesting a major opportunity for expansion.

• 91% said they would feel comfortable using a volunteer driver program.

7. The hidden costs of care extend far beyond treatment itself.

Patients emphasized that the financial burden of transportation and lodging wasn't just about large expenses like hotels or long drives, it's the accumulation of smaller, ongoing costs (gas, meals while traveling, overnight stays) that wear down their ability to maintain consistent treatment.

- 84% reported transportation costs affected treatment.
- 66% said lodging costs affected treatment.

8. Conversations with healthcare teams were inconsistent and sometimes uncomfortable.

While many patients said they discussed transportation and lodging with providers, nearly half did not feel comfortable doing so - indicating a need for more proactive and sensitive communication from care teams.

- **86%** said they discussed these topics with their healthcare team.
- 51% did not feel comfortable in those conversations.



9. Technology was a barrier for many patients, limiting access to services.

While some felt comfortable with technology, many needed help scheduling rides or navigating digital systems. This highlighted a gap for patients who weren't tech-savvy but are expected to arrange their own services online.

- 40% felt only "somewhat comfortable" using technology for arranging services.
- 62% needed assistance scheduling rides or using technology if not relying on family/friends.

10. Missed appointments are far more likely due to transportation than lodging.

While 63% reported missing or rescheduling due to transportation issues, only 16% reported doing so because of lodging – highlighting that transportation was the more urgent barrier to address.

84% had not missed or rescheduled appointments due to lodging.

11. Initial connections to care were quick, but ongoing barriers continued.

Half of patients were connected with a treatment facility within a month of diagnosis, suggesting timely entry into the system. Yet transportation and lodging obstacles threaten continuity and completion of care.

• 51% connected with a treatment facility within one month of diagnosis.

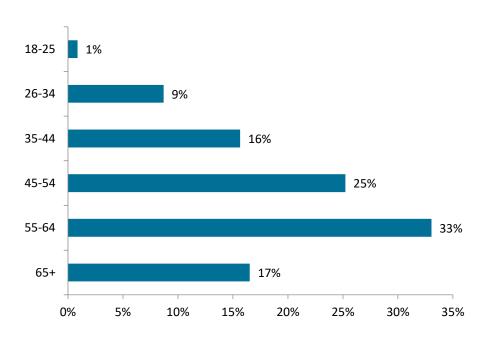
12. Living in rural areas magnified both distance and dependence.

Most patient respondents were from rural counties, which meant longer travel distances, limited public transit, and fewer nearby lodging options. Rural patients were particularly vulnerable to missed appointments, higher costs, and reliance on informal networks to reach care.

- 33% traveled 50–99 miles for treatment, and 31% traveled 100 miles or more.
- Patients in rural areas reported that they depend heavily on family or friends for both transportation and housing during treatment.



Q1: What is your age?



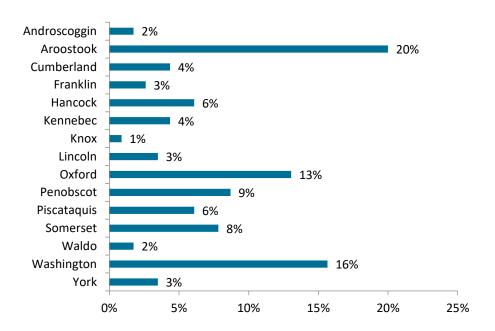
	Count	%
18-25	1	1%
26-34	10	9%
35-44	18	16%
45-54	29	25%
55-64	38	33%
65+	19	17%
Total	115	100%

Summary

A third (33%) of patient respondents reported they were between 55-64 years of age, while a quarter (25%) reported they were between 45-54.



Q3: Which county do you currently live in?



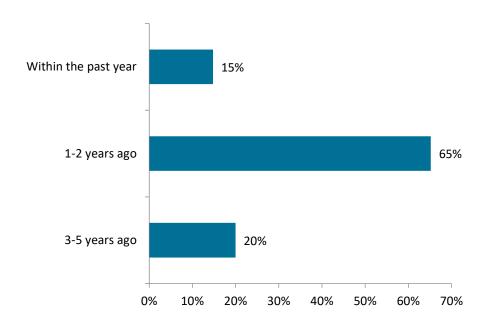
	Count	%
Androscoggin	2	2%
Aroostook	23	20%
Cumberland	5	4%
Franklin	3	3%
Hancock	7	6%
Kennebec	5	4%
Knox	1	1%
Lincoln	4	3%
Oxford	15	13%
Penobscot	10	9%
Piscataquis	7	6%
Somerset	9	8%
Waldo	2	2%
Washington	18	16%
York	4	3%
Total	115	100%

Summary

One-in-five (20%) respondents reported that they lived in Aroostook County.



Q5: Approximately how long ago were you diagnosed with cancer? If you have received more than one diagnosis, please answer about the most current one.



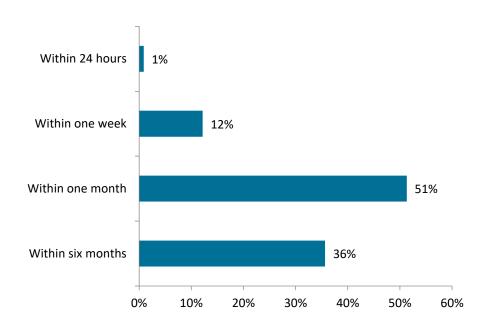
	Count	%
Within the past year	17	15%
1-2 years ago	75	65%
3-5 years ago	23	20%
Total	115	100%

Summary

Nearly two-thirds (65%) of respondents reported that they been diagnosed with cancer 1-2 years ago.



Q6: How long after receiving your diagnosis before you were connected with a treatment facility?



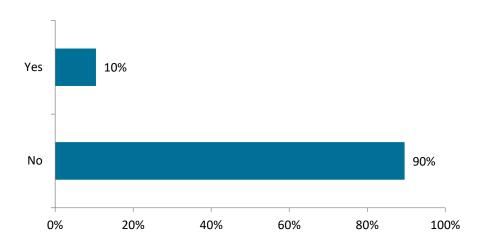
	Count	%
Within 24 hours	1	1%
Within one week	14	12%
Within one month	59	51%
Within six months	41	36%
Total	115	100%

Summary

Half (51%) of respondents reported they were connected with a treatment facility within one month of receiving their cancer diagnosis.



Q7: Did you have a reliable mode of transportation to travel to cancer treatment appointments?



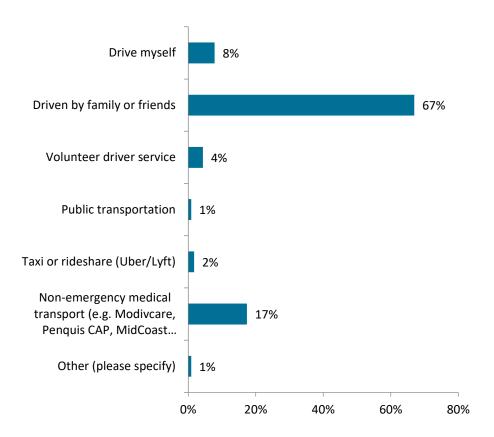
	Count	%
Yes	12	10%
No	103	90%
Total	115	100%

Summary

The majority (90%) of respondents reported they did not have a reliable mode of transportation to travel to cancer treatment appointments.



Q8: What was your primary mode of transportation to your cancer treatment?



	Count	%
Drive myself	9	8%
Driven by family or friends	77	67%
Volunteer driver service	5	4%
Public transportation	1	1%
Taxi or rideshare (Uber/Lyft)	2	2%
Non-emergency medical transport (e.g. Modivcare, Penquis CAP, MidCoast Connector, Down East Community Partners, Kennebec	20	17%
Other (please specify)	1	1%
Total	115	100%

Comment

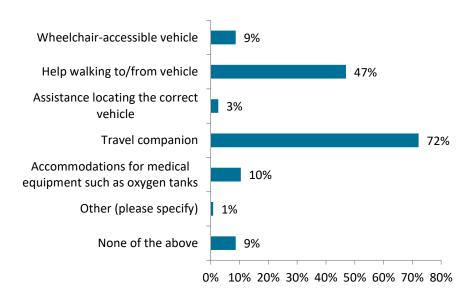
Family for locate. Bus to Boston to get to Dana Farber Cancer Center

Summary

Two-thirds (67%) of respondents reported that they were primarily driven to cancer treatment by family and friends.



Q9: Did you require assistance when traveling to treatment? (Please select all that apply)



	Count	%
Wheelchair-accessible vehicle	10	9%
Help walking to/from vehicle	54	47%
Assistance locating the correct vehicle	3	3%
Travel companion	83	72%
Accommodations for medical equipment such as oxygen tanks	12	10%
Other (please specify)	1	1%
None of the above	10	9%
Total	115	100%

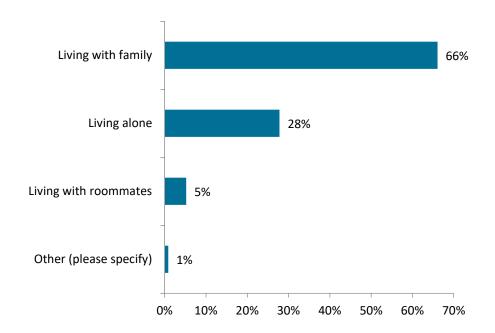
Comment
Cane currently and my wife assist me when possible

Summary

Nearly three-quarters (72%) of respondents reported that they required assistance from a travel companion.



Q10: What was your living arrangement when you were receiving cancer treatment?



	Count	%
Living with family	76	66%
Living alone	32	28%
Living with roommates	6	5%
Other (please specify)	1	1%
Total	115	100%

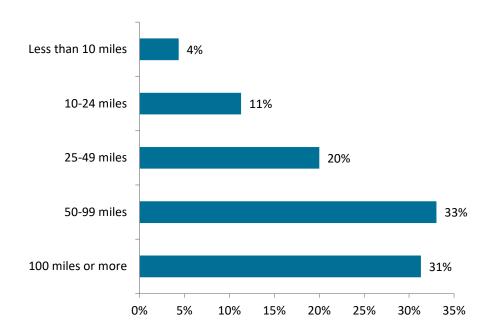
Comment
I stayed in a hotel in the city I travelled to.

Summary

Two-thirds (66%) of respondents reported that they were living with family while receiving cancer treatment.



Q12: How far did you typically travel (one way) for treatment?



	Count	%
Less than 10 miles	5	4%
10-24 miles	13	11%
25-49 miles	23	20%
50-99 miles	38	33%
100 miles or more	36	31%
Total	115	100%

Summary

A third (33%) of respondents reported that they typically travelled 50-99 miles for cancer treatment, while slightly fewer (31%) reported that they travelled 100 miles or more.

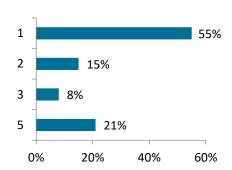


Q13: How often did you travel for treatment?

	Count	%
Enter number of times per week	84	73%
Enter number of times per month	24	21%
Other (please specify)	7	6%
Total	115	100%

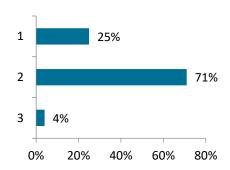
Please enter number of times per week

	Count	%
1	46	55
2	13	15
3	7	8
5	18	21
Total	84	100



Please enter number of times per month

	Count	%
1	6	25
2	17	71
3	1	4
Total	24	100



Comment

My treatment was in cycles, so I'd have to go down for a few days in a row every three weeks.

I had a bilateral mastectomy and reconstruction. Then I had some complications.

Currently medical appointments x 3 or more monthly

Initially 1x month then every 6 months.

I went for surgery, then check ups every six months.

every 90 days

Once every three weeks

Summary

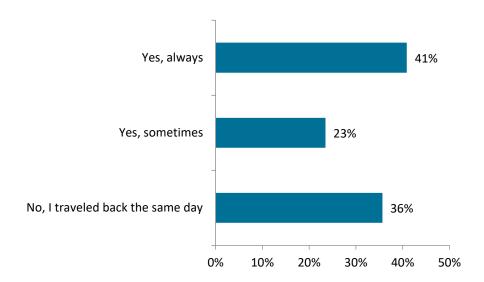
Nearly three-quarters (73%) of respondents reported that they travelled for treatment on a weekly basis.

Of those who travelled weekly, more than half (55%) reported that they travelled once per week.

Of those who travelled monthly, nearly three-quarters (71%) reported that they travelled twice a month.



Q14: Did you ever stay overnight near your treatment center?



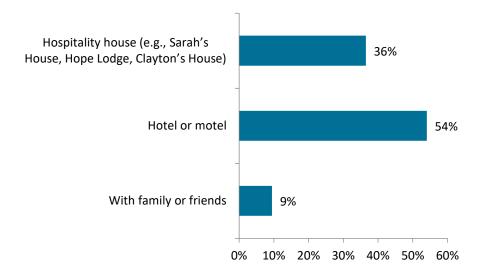
	Count	%
Yes, always	47	41%
Yes, sometimes	27	23%
No, I traveled back the same day	41	36%
Total	115	100%

Summary

Two-in-five (41%) of respondents reported that they always stayed overnight near their treatment center.



Q15: If you stayed overnight, where did you typically stay?



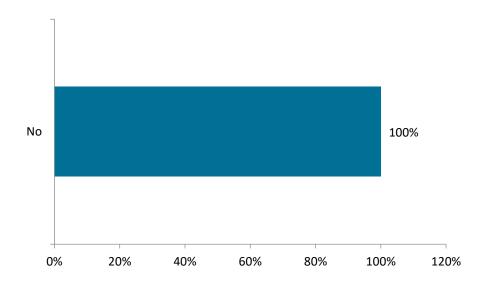
	Count	%
Hospitality house (e.g., Sarah's House, Hope Lodge, Clayton's House)	27	36%
Hotel or motel	40	54%
With family or friends	7	9%
Total	74	100%

Summary

More than half (54%) reported that they typically stayed at a hotel or motel.



Q16: Did you have to fly to receive cancer treatment?



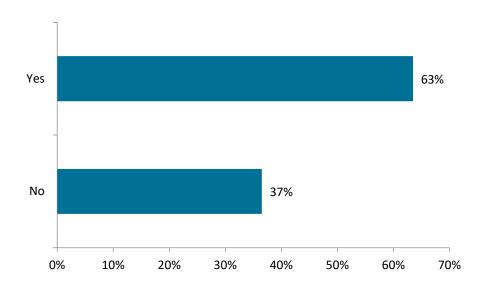
	Count	%
No	115	100%
Total	115	100%

Summary

All respondents (100%) reported that they did not have to fly to receive cancer treatment.



Q18: Have you ever missed or had to reschedule a cancer care appointment due to a lack of transportation?



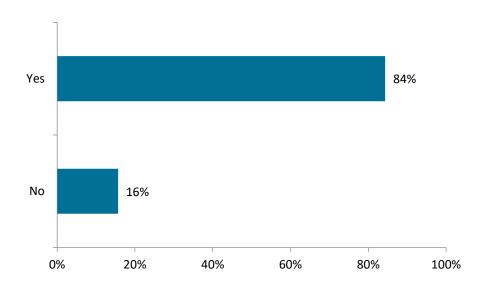
	Count	%
Yes	73	63%
No	42	37%
Total	115	100%

Summary

Nearly two-thirds (63%) of respondents reported that they had missed or rescheduled a cancer care appointment due to lack of transportation.



Q19: Did the cost of transportation affect your ability to receive treatment?



	Count	%
Yes	97	84%
No	18	16%
Total	115	100%

Summary

The majority (84%) of respondents reported that the cost of transportation affected their ability to receive treatment.



Q20: How did the cost of transportation affect your ability to receive your cancer treatment?

	Count	%
Financial Strain from Gas Costs	77	79%
Impact on Family and Friends	28	29%
Reliance on Social Workers for Financial Assistance	22	23%
Wear and Tear on Vehicles	20	21%
Unreliable Transportation Services	9	9%
Childcare Challenges	2	2%
Other	4	4%
I Prefer Not to Answer	3	3%
Total	97	100%

"We had to cut back on other essentials some weeks just to afford the gas. We seriously considered skipping a couple of treatments near the end because of the cost, but we managed to scrape by."

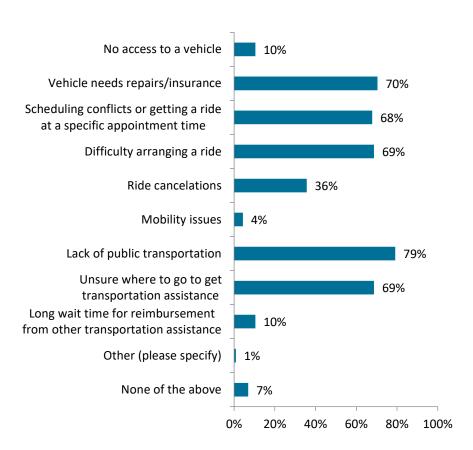
"A social worker eventually helped me get some gas cards which was a huge relief but for the first few months it was a real struggle."

Summary

Of those who reported that the cost of transportation affected their ability to receive services, more than three-quarters (79%) cited the financial strain due to gas costs.



Q21: What other specific transportation challenges did you experience? (Please select all that apply)



	Count	%
No access to a vehicle	12	10%
Vehicle needs repairs/insurance	81	70%
Scheduling conflicts or getting a ride at a specific appointment time	78	68%
Difficulty arranging a ride	79	69%
Ride cancelations	41	36%
Mobility issues	5	4%
Lack of public transportation	91	79%
Unsure where to go to get transportation assistance	79	69%
Long wait time for reimbursement from other transportation assistance	12	10%
Other (please specify)	1	1%
None of the above	8	7%
Total	115	100%

Summary

When asked what transportation challenges they experienced, respondents most commonly cited a lack of public transportation (79%), followed by the need for vehicle repairs and insurance (70%), and difficulty arranging a ride (69%).

"Bus can cancel service ride times.
Has resulted in sudden overnight need to find lodging in Boston or Portland when I could not get back to Bangor or 3 different occasions."



Q22: Please describe what specific types of mobility issues you experienced related to transportation.

Comment

I needed someone to help me get in and out of the car when I felt weak after chemotherapy.

I needed a wheelchair-accessible vehicle and help getting in and out of the vehicle.

After my chemo sessions, I was often very weak and tired, so I definitely needed help walking to and from the vehicle.

I needed oxygen tank accommodations in vehicles and help climbing into high trucks after chemo.

I needed help walking to/from the vehicle and carrying my portable oxygen tank.

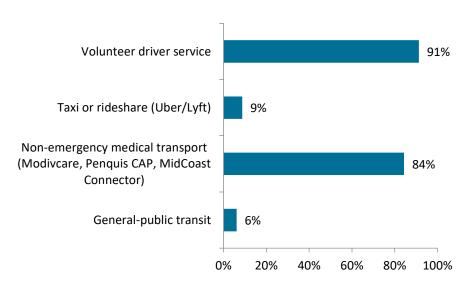
Summary

Out of the 4% of respondents who reported that their mobility issues created transportation challenges, 5 provided comments with additional detail.

Respondents universally mentioned that they needed help getting to and from or in and out of the car. Several respondents also mentioned the need to transport additional health equipment like wheelchairs or oxygen tanks.



Q23: How comfortable would you be using the following transportation options to travel for treatment?



^{*}Chart depicts the percentage responding very comfortable or somewhat comfortable.

	Very comfortable	Somewhat comfortable	Somewhat un- comfortable	Very un- comfortable	Not applicable	Not sure
Volunteer driver service	45%	46%	2%	2%	3%	2%
Taxi or rideshare (Uber/Lyft)	1%	8%	23%	67%	2%	-
Non- emergency medical transport*	19%	65%	7%	3%	3%	3%
General- public transit	1%	5%	73%	16%	4%	1%

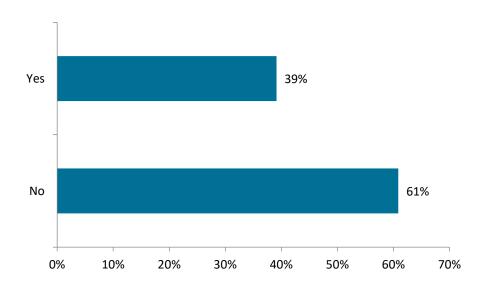
^{*} Including Modivcare, Penquis CAP, MidCoast Connector, etc.

Summary

Nearly all (91%) of respondents reported they would be very comfortable or somewhat comfortable using a volunteer driver service to travel for treatment.



Q24: If your primary transportation plan failed, did you have a backup option?



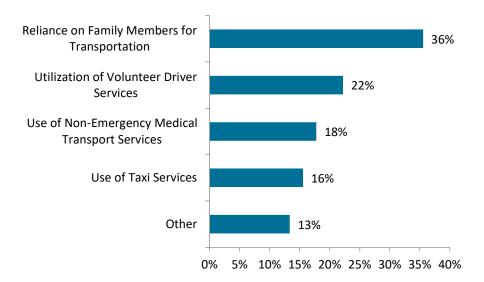
	Count	%
Yes	45	39%
No	70	61%
Total	115	100%

Summary

Three-in-five (61%) respondents reported that they did not have a backup option if their primary transportation plan failed.



Q25: What was your backup transportation option?



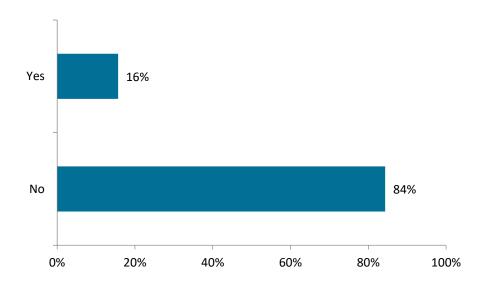
	Count	%
Reliance on Family Members for Transportation	16	36%
Utilization of Volunteer Driver Services	10	22%
Use of Non-Emergency Medical Transport Services	8	18%
Use of Taxi Services	7	16%
Other	6	13%
Total	45	100%

Summary

Among the respondents who reported that they had a backup transportation option (39%), more than a third (36%) reported that they relied on family members for transportation.



Q26: Have you ever missed or had to reschedule a cancer care appointment due to issues with lodging? (being able to stay close to your treatment location)?



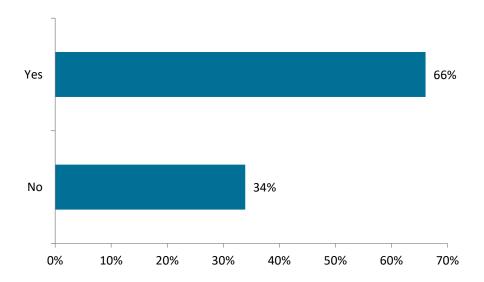
	Count	%
Yes	18	16%
No	97	84%
Total	115	100%

Summary

The majority (84%) of respondents reported they had not missed or rescheduled a cancer care appointment due to issues with lodging.



Q27: Did the cost of lodging affect your ability to receive treatment?



	Count	%
Yes	76	66%
No	39	34%
Total	115	100%

Summary

Two-thirds (66%) of respondents reported the cost of lodging affected their ability to receive treatment.



Q28: How did the cost of lodging affect your ability to receive your cancer treatment?

	Count	%
High Financial Burden of Lodging Costs	66	88%
Impact on Treatment Adherence	30	40%
Dependence on Lodging Assistance Programs	24	32%
Physical and Emotional Toll of Commuting	22	29%
Inadequate Availability of Lodging Assistance	15	20%
Lack of Awareness of Lodging Assistance Options	7	9%
I Prefer Not to Answer	3	4%
Total	75	100%

"Expensive hotel stays in Boston."

"Staying in a hotel near the hospital was expensive, I had to cut down other expenses."

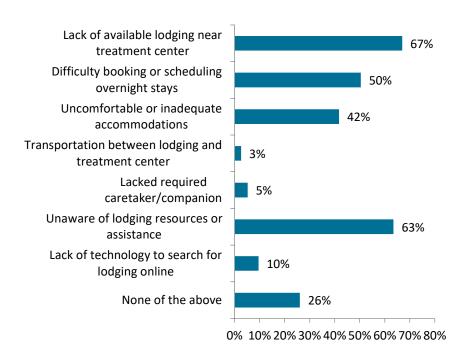
"The financial worry was so immense it made it hard to even focus on the treatment itself."

Summary

Of the respondents who reported that the cost of lodging affected their ability to receive services (66%), the majority (88%) mentioned that the cost created a high financial burden.



Q29: What other lodging challenges have you experienced? (Please select all that apply)



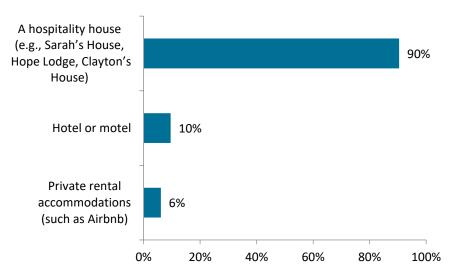
	Count	%
Lack of available lodging near treatment center	77	67%
Difficulty booking or scheduling overnight stays	58	50%
Uncomfortable or inadequate accommodations	48	42%
Transportation between lodging and treatment center	3	3%
Lacked required caretaker/companion	6	5%
Unaware of lodging resources or assistance	73	63%
Lack of technology to search for lodging online	11	10%
None of the above	30	26%
Total	115	100%

Summary

Two-thirds (63%) of respondents reported that they experienced challenges due to a lack of available lodging near their treatment center. Respondents also commonly cited that they were unaware of lodging resources or assistance (63%) and had difficulty booking or scheduling overnight stays (50%).



Q31: How comfortable would you be staying overnight at the following while receiving treatment?



^{*}Chart depicts the percentage responding very comfortable or somewhat comfortable.

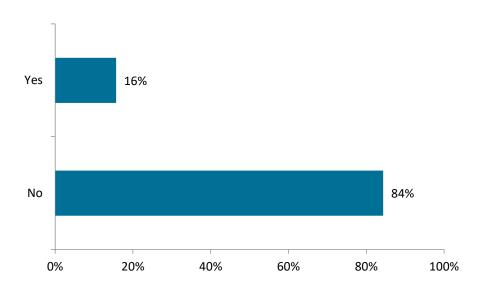
	Very comfortable	Somewhat comfortable	Somewhat un- comfortable	Very un- comfortable	Not applicable	Not sure
A hospitality house (e.g., Sarah's House, Hope Lodge, Clayton's House)	73%	17%	4%	•	3%	2%
Hotel or motel	4%	5%	38%	49%	3%	1%
Private rental accommodations (such as Airbnb)	3%	3%	26%	60%	5%	3%

Summary

The majority (90%) of respondents reported they would be very comfortable or somewhat comfortable staying at a hospitality house while receiving treatment.



Q32: If your primary lodging plan failed, did you have a backup option?



	Count	%
Yes	18	16%
No	97	84%
Total	115	100%

Summary

The majority (84%) of respondents reported they did not have a backup plan if their primary lodging plan failed.



Q33: What was your backup lodging option?

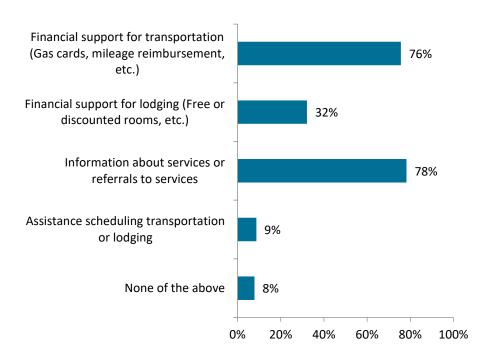
Comment
Family's home
Family
Friends.
Staying with friends who lived nearby
Sarah's House
Hope Lodge
Motel
The cheap motel.
Motel
nearby relative
cheap motels like the Augusta Inn
Motel
Hotel
Motel
Sometimes I was able to stay with relatives in the Portland area, but
I didn't want to burden them too often.
a private rental (an Airbnb)

Summary

Of the respondents who reported that they had a backup lodging option if needed (16%), many stated that they would stay in hotels or motels. Several also mentioned staying with family or friends.



Q34: Have you received any of the following support for transportation or lodging? Please select all that apply.



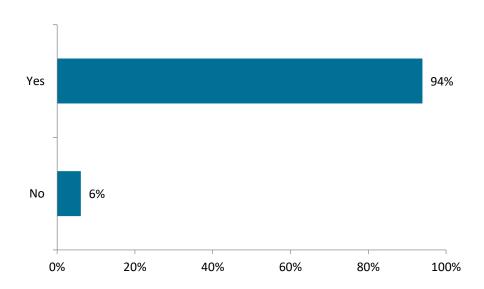
	Count	%
Financial support for transportation (Gas cards, mileage reimbursement, etc.)	87	76%
Financial support for lodging (Free or discounted rooms, etc.)	37	32%
Information about services or referrals to services	90	78%
Assistance scheduling transportation or lodging	10	9%
None of the above	9	8%
Total	115	100%

Summary

More than three-quarters (78%) of respondents stated that they have received information about services or referrals to services.



Q35: Was there any support that you needed but did not receive?



	Count	%
Yes	108	94%
No	7	6%
Total	115	100%

Summary

Nearly all (94%) respondents reported that they needed additional support they did not receive.



Q36: What support did you need but were not able to get?

	Count	%
Financial Support for Lodging Costs	50	47%
Need for Reliable and Flexible Transportation Services	38	36%
Financial Assistance for Transportation Costs	30	28%
Help Navigating Assistance Programs	13	12%
Childcare Support During Treatment	7	7%
Support with Food Costs During Treatment	7	7%
Other	5	5%
Total	106	100%

"I wish there had been more consistent assistance scheduling rides, especially on short notice when I was feeling very ill."

> "I really, really needed some kind of financial support for lodging. Even just for one night a week."

Summary

Nearly half (47%) of respondents reported that they needed but were not able to get help with lodging costs, while 36% mentioned reliable, flexible transportation services, and 28% mentioned help with transportation costs.



Q37: What are the reasons you were not able to get the support you needed?

	Count	%
Long Waiting Lists and Limited Availability	47	44%
Eligibility and Income Restrictions	29	27%
Lack of Awareness About Available Support Services	27	25%
Geographical and Logistical Barriers	21	19%
Insufficient Scope of Support Services	21	19%
Complex and Overwhelming Application Processes	12	11%
Other	3	3%
Not Sure	1	1%
I Prefer Not to Answer	3	3%
Total	108	100%

"Volunteer shortages in rural areas. Some programs had waitlists longer than my treatment timeline. Felt "too rich" for aid but too poor for real comfort."

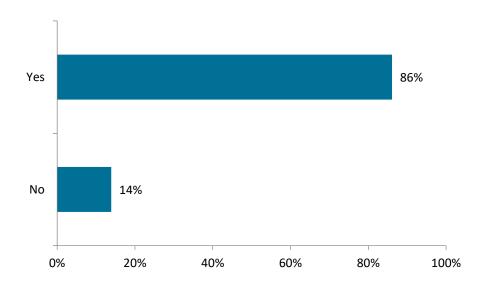
"I think it was just a matter of high demand and not enough available volunteer drivers to cover everyone in the rural parts of the state."

Summary

Nearly half (44%) of respondents who mentioned that they were not able to get all of the support they needed reported that this was due to long waiting list and limited availability.



Q38: Did you discuss transportation and lodging options with your healthcare team?



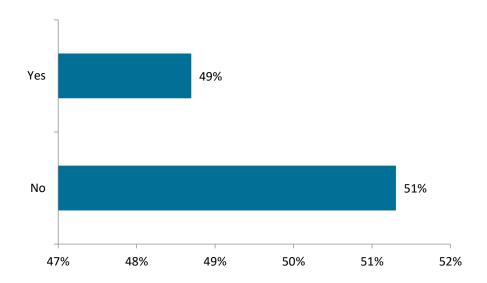
	Count	%
Yes	99	86%
No	16	14%
Total	115	100%

Summary

The majority (86%) of respondents reported that they discussed transportation and lodging with their healthcare team.



Q39: Did you feel comfortable talking to your healthcare team about your transportation and lodging during your cancer treatment?



	Count	%
Yes	56	49%
No	59	51%
Total	115	100%

Summary

Half (51%) of respondents reported they did not feel comfortable discussing transportation and lodging with their healthcare team.



Q40: Why did you feel uncomfortable talking about transportation and lodging with your healthcare team?

	Count	%
Embarrassment and Shame in Admitting Financial Struggles	30	55%
Cultural and Personal Pride in Self-Reliance	25	45%
Fear of Being a Burden	24	44%
Guilt and Vulnerability	23	42%
Perception of Medical Staff's Role	16	29%
Assumption of Personal Responsibility	13	24%
Other	2	4%
I Prefer Not to Answer	1	2%
Total	55	100%

"Maine men fix their own problems. Felt shame needing charity at 68."

"At first I felt ashamed, like I was failing my family by not being able to afford the costs of my own care."

Summary

Out of those who felt uncomfortable talking about transportation and lodging with their healthcare team, more than half (55%), mentioned embarrassment and shame in admitting financial struggles.



Q41: What would make you feel more comfortable using transportation and lodging services?

	Count	%
Proactive Introduction of Services	58	59%
Normalization and Non-Judgmental Approach	51	52%
Clear and Accessible Information	24	24%
Specific Needs and Barriers	22	22%
Dedicated Support Staff	16	16%
Reliability and Accountability of Services	11	11%
Other	1	1%
Not Sure	2	2%
I Prefer Not to Answer	10	10%
Total	99	100%

"It would be helpful if information about these services was given to every single patient right at the start, as a standard part of the treatment package."

"If the doctor or nurse brought it up first and said "Many of our patients struggle with this, here's how we can help," it would feel less like asking for a handout."

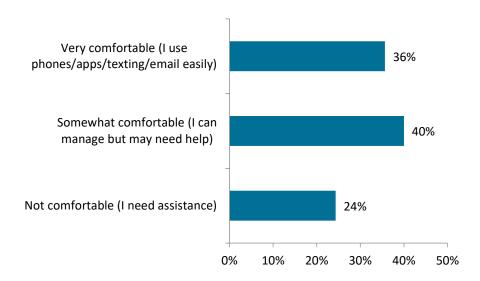
"It would be so much easier if the intake process included questions about your family life. Not just "do you have a ride treatment?"

Summary

Three-in-five (59%) respondents mentioned that proactive introduction of services would make them feel more comfortable using them.



Q42: What level of comfort do you have with technology for arranging transportation and lodging?



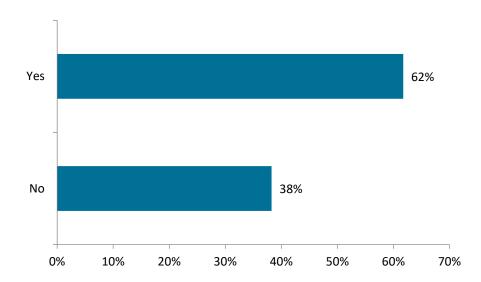
	Count	%
Very comfortable (I use	41	36%
phones/apps/texting/email easily)	41	30%
Somewhat comfortable (I can manage but may	46	40%
need help)	40	40%
Not comfortable (I need assistance)	28	24%
Total	115	100%

Summary

Two-in-five (40%) respondents reported that they felt somewhat comfortable with technology for arranging transportation and lodging.



Q43: If you used transportation other than family or friends, did you need assistance with scheduling or using technology to arrange rides?



	Count	%
Yes	71	62%
No	44	38%
Total	115	100%

Summary

Nearly two-thirds (62%) of respondents reported that they needed assistance scheduling rides or using technology if they used transportation other than family and friends.



Q44: Do you have any additional thoughts on how transportation and lodging support for cancer patients can be improved in Maine?

	Count	%
Financial Support for Transportation and Lodging	33	34%
Need for More Lodging Options in Rural Areas	28	29%
Improved Information and Awareness	24	25%
Increased Volunteer Driver Programs	18	19%
Enhanced Coordination and Oversight of Transportation Services	17	18%
Support for Caregivers and Families	15	16%
Other	8	8%
Total	96	100%

"Focus on the rural areas like ours! Better coverage for volunteer drivers or subsidized rides for long distances."

"We desperately need more lodging capacity like expanding places like Sarah's House."

"More recognition of the "hidden" costs would be great. It's not just about gas money. For families, it's about lost wages for the caregiver who has to drive, the cost of childcare for other kids, and the extra cost of buying prepared food because you're too sick or busy to cook."

Summary

A third (34%) of respondents reported that they believe more financial support for transportation and lodging could improve these programs. Respondents also mentioned a need for more support in rural areas (29%), and for increased information and awareness (25%).



D1: What type of cancer are you currently receiving (or have received) treatment for?

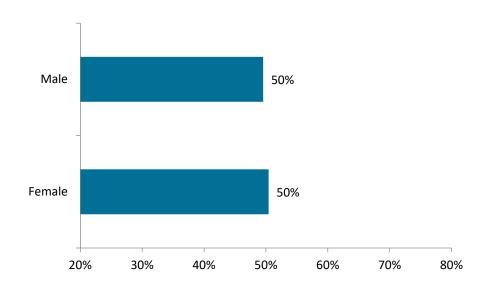
	Count	%
Breast Cancer Diagnosis	28	24%
Colorectal Cancer Diagnosis	17	15%
Prostate Cancer Diagnosis	17	15%
Lung Cancer Diagnosis	12	10%
Ovarian Cancer Diagnosis	7	6%
Other	32	28%
I Prefer Not to Answer	2	2%
Total	115	100%

Summary

Respondents most commonly reported that they had received treatment for a breast cancer diagnosis (24%), followed by colorectal cancer (15%), and prostate cancer (15%).



D2: What is your gender?



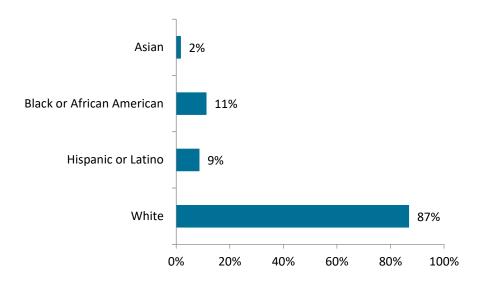
	Count	%
Male	57	50%
Female	58	50%
Total	115	100%

Summary

Half (50%) of the survey respondents reported they were male, while half (50%) reported they were female.



D3: What is your race and/or ethnicity? Please select all that apply.



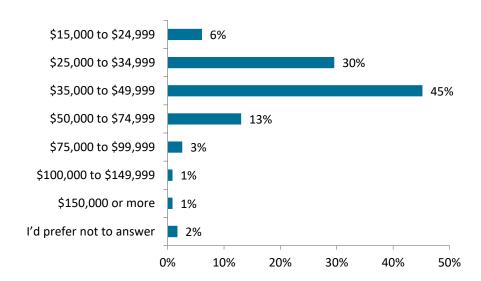
	Count	%
Asian	2	2%
Black or African American	13	11%
Hispanic or Latino	10	9%
White	100	87%
Total	115	100%

Summary

The majority (87%) of respondents identified themselves as white.



D4: Into which of the following income categories includes your annual household income before taxes?



	Count	%
\$15,000 to \$24,999	7	6%
\$25,000 to \$34,999	34	30%
\$35,000 to \$49,999	52	45%
\$50,000 to \$74,999	15	13%
\$75,000 to \$99,999	3	3%
\$100,000 to \$149,999	1	1%
\$150,000 or more	1	1%
I'd prefer not to answer	2	2%
Total	115	100%

Summary

Nearly half (45%) of respondents reported their annual household income fell into the range between \$35,000 to \$49,999.



KEY FINDINGS – Mapping and Resource List

1. Patients across the state experience uneven access to cancer care.

Access to cancer treatment in Maine is unevenly distributed, with regional gaps in both chemotherapy and radiation therapy availability. Radiation therapy treatment centers are particularly scarce, clustering around the coastal and the southern regions of the state (see Map #2 below).

- **34** treatment centers across the state offer chemotherapy treatment.
- 9 locations across the state currently offer radiation therapy, only one of which is north of Bangor. These centers are located across 6 counties in Maine out of 16 total- Androscoggin, Aroostook, Cumberland, Kennebec, Penobscot, and York counties.
- There are no treatment facilities located in Washington County, while 7 other counties only have one treatment facility each.

2. Residents of several rural counties must travel long distances for care, particularly for radiation therapy.

Access to cancer treatment in Maine has become increasingly limited, particularly in rural counties. These regions either lack comprehensive oncology services, have no treatment centers at all, or have few treatment centers for large areas, leaving residents with few local options for care.

- Out of the **56** zip codes where patients have to travel over 50 miles to reach the nearest radiation treatment center, **26** are in Washington County, and **9** are in Aroostook County.
- Multiple radiation treatment centers have closed or consolidated since 2017, when previous findings showed **15** radiation treatment centers across the state.
- Out of the **18** zip codes where patients have to travel over 50 miles to reach the nearest chemotherapy treatment center, **15** are in Washington County, **2** are in Aroostook, and **1** is in Somerset.

3. Residents face high radiation travel burden across the state and face high chemotherapy travel burden in multiple locations.

The travel burden faced by patients, a metric that accounts for distance from treatment, cancer prevalence, and population, is high for radiation treatment in areas across the state. Residents face the highest chemotherapy travel burden scores in the Central-Eastern to Northern regions of Maine (see Map #5 and #6).

• **55** zip codes have a radiation travel burden score of 800+. These zip codes are distributed across every county except for Androscoggin. **9** are located in Washington county.



• 13 zip codes have a chemotherapy travel burden score over 800. They are in the Central-Eastern to Northern areas of the state, located in Aroostook, Hancock, Kennebec, Penobscot, and Washington counties.

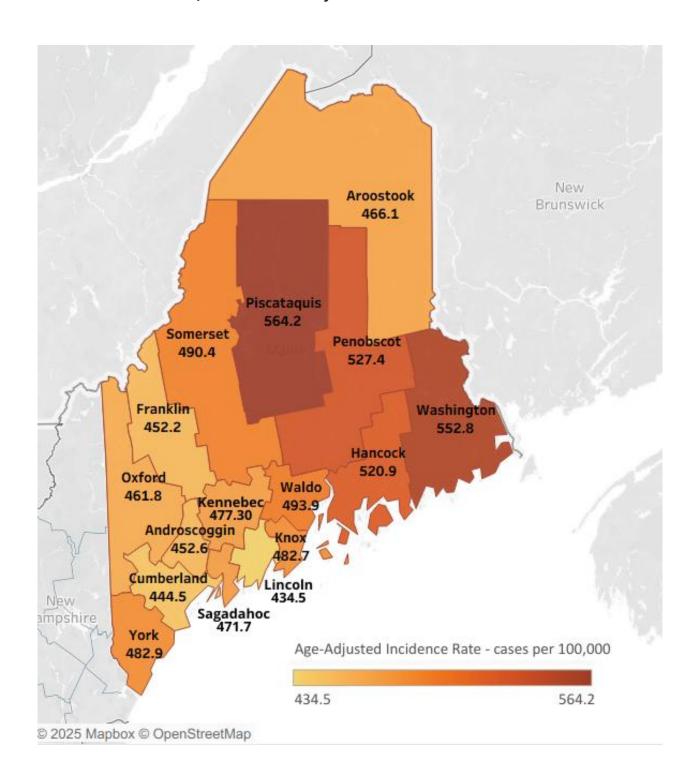
KEY FINDINGS – Resource List

Practice/Service Organization	County	City
MaineHealth Franklin Hospital- Franklin Health Center	Franklin	Farmington
MaineHealth Stephens Hospital	Oxford	Norway
St. Joseph Healthcare	Penobscot	Bangor
Topsham Care Center	Sagadahoc	Topsham
MaineHealth Waldo Hospital	Waldo	Belfast
MaineHealth Mid Coast Hospital	Cumberland	Brunswick
MaineHealth Lincoln Hospital- Miles Campus	Lincoln	Damariscotta
MaineHealth Pen Bay Hospital	Knox	Rockport
MaineHealth Maine Medical Center - Biddeford Campus	York	Biddeford
MaineHealth Mid Coast Hospital - Parkview Campus	Cumberland	Brunswick
New England Cancer Specialists - Kennebunk	York	Kennebunk
MaineHealth Maine Medical Center - Cancer Care Blood Disorders and IV Therapy - South Portland	Cumberland	South Portland
New England Cancer Specialists - Topsham	Sagadahoc	Topsham
Northern Light Mercy Cancer Care	Cumberland	Portland
Northern Light Mayo Hospital	Piscataquis	Dover- Foxcroft
Northern Light Maine Coast Hospital - Ellsworth	Hancock	Ellsworth
Bridgton Hospital Specialty Clinics	Cumberland	Bridgton
Rumford Hospital Specialty Clinics	Oxford	Rumford
Cary Medical Center	Aroostook	Caribou
Millinocket Regional Hospital	Piscataquis	Millinocket
Mount Desert Island Hospital	Hancock	Bar Harbor
Redington-Fairview General Hospital	Somerset	Skowhegan
York Hospital- York	York	York
York Hospital- Wells	York	Wells
York Hospital- Kittery	York	Kittery
MaineGeneral's Harold Alfond Center for Cancer Care in Augusta*	Kennebec	Augusta
MaineHealth Maine Medical Center - Portland Campus*	Cumberland	Portland
MaineHealth Maine Medical Center - Sanford Campus*	York	Sanford
MaineHealth Maine Medical Center - Scarborough Campus*	Cumberland	Scarborough
New England Cancer Specialists - Rock Row*	Cumberland	Westbrook
MaineHealth Barbara Bush Children's Hospital*	Cumberland	Portland
Northern Light AR Gould Hospital*	Aroostook	Presque Isle
Northern Light Eastern Maine Medical Center - Brewer*	Penobscot	Brewer
Central Maine Medical Center *	Androscoggin	Lewiston

^{*} Locations with radiation therapy available

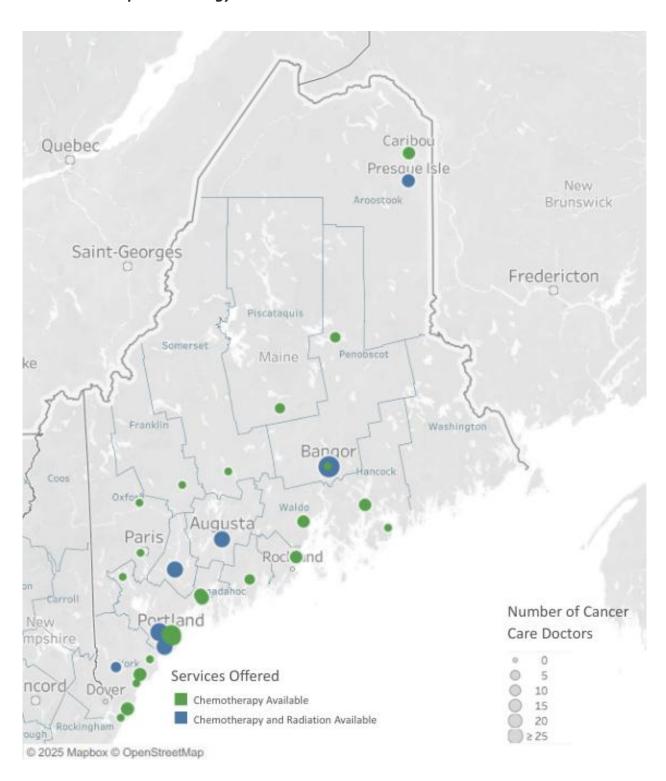


Map 1. Age-Adjusted Cancer Incidence Rates by County – cases per 100,000. Source: NIH National Cancer Institute, State Cancer Profiles - Incidence Rates Table.



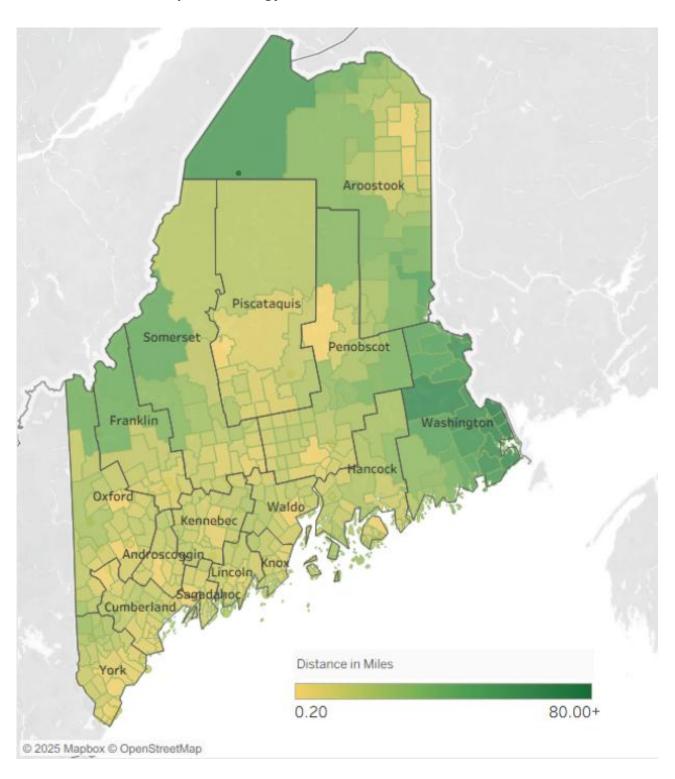


Map 2. Cancer care locations by services offered and number of cancer care doctors. Source: 2025 MDR Hospital Oncology Dataset



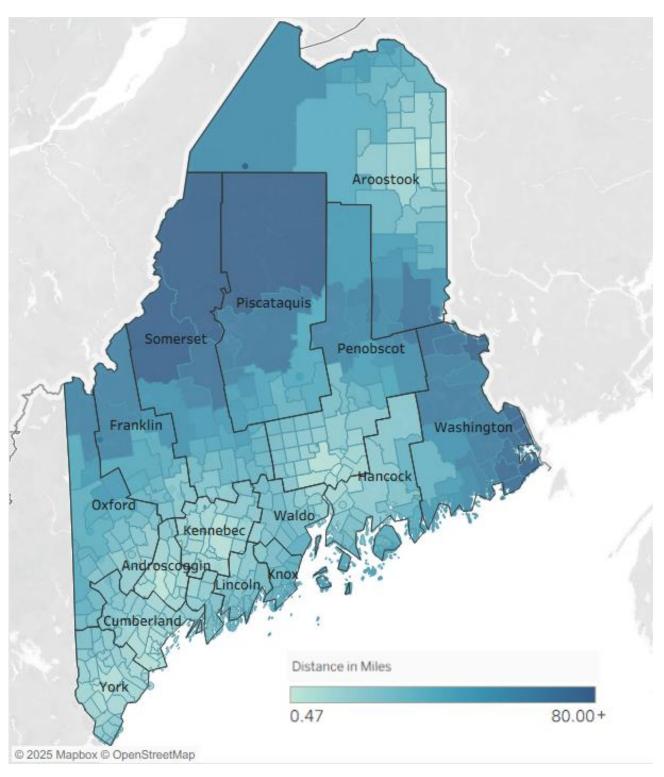


Map 3. Minimum one-way travel distance to receive chemotherapy treatment by zip code. Source: 2025 MDR Hospital Oncology Dataset



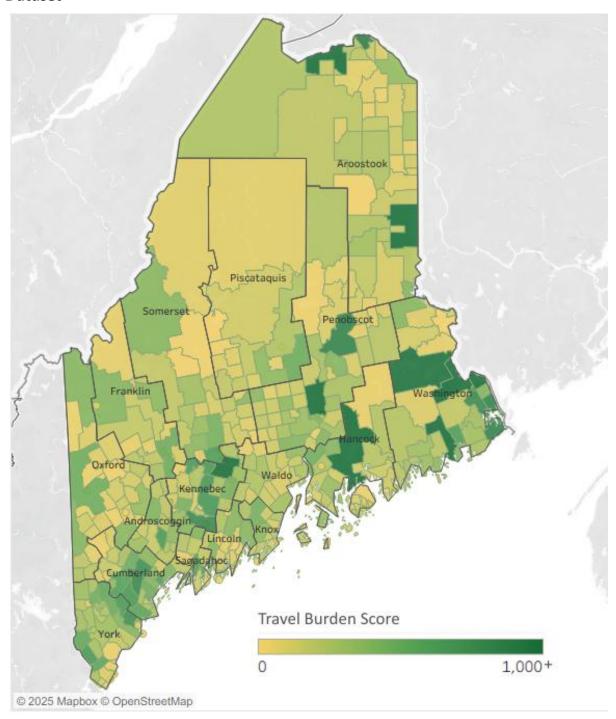


Map 4. Minimum one-way travel distance to receive radiation treatment by zip code. Source: 2025 MDR Hospital Oncology Dataset





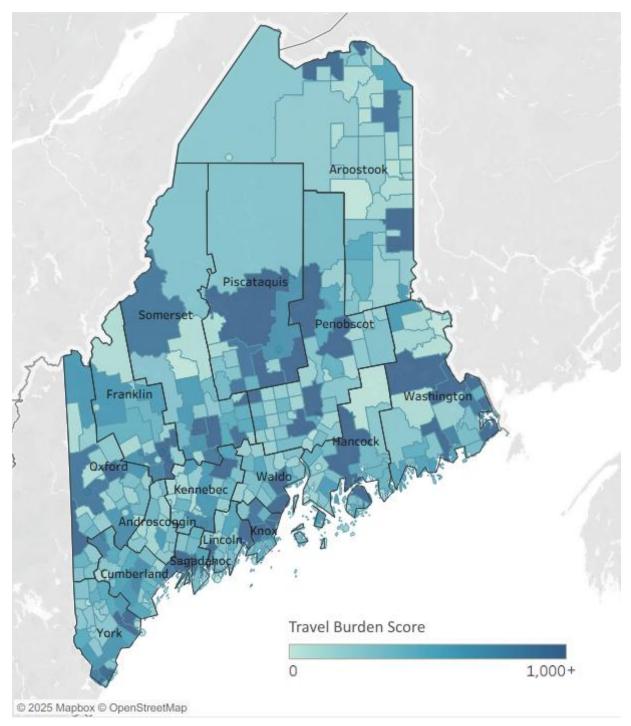
Map 5. Chemotherapy travel burden score by zip code. Source: 2025 MDR Hospital Oncology Dataset



- 1. View interactive map <u>here</u>.
- Travel burden score is calculated by taking the average number of reported cancer cases in a year per county and estimating the number of cases per zip code by share of county population. This number of cases was then multiplied by the estimated minimum distance patients would need to travel for treatment.



Map 6. Radiation travel burden score by zip code. Source: 2025 MDR Hospital Oncology Dataset



- 1. View interactive map here.
- Travel burden score is calculated by taking the average number of reported cancer cases in a year per county and estimating the number of cases per zip code by share of county population. This number of cases was then multiplied by the estimated minimum distance patients would need to travel for treatment.



COMPARATIVE FINDINGS – Pre Vs. Post Covid-19

Theme	Summary of Change (2017 → 2025)
1. Persistent Rural Barriers Intensified by Workforce Strain	The 2017 assessment found that rural Mainers (especially in Aroostook, Washington, Franklin, and Piscataquis counties) faced the longest travel distances for cancer care. These rural patterns remained nearly identical in 2025. But post-COVID workforce shortages, fewer volunteers, and clinic consolidations have exacerbated the issue. Patients continue to travel 50–100+ miles for treatment with limited local options.
2. Volunteer Driver Networks Shrinking and Overburdened	Volunteer drivers were once the "backbone" of Maine's cancer transportation system. By 2025, 38% of providers still relied on them, but recruitment and retention have declined. Safety concerns, rising fuel costs, and overall pandemic changes have reduced ride availability, particularly in rural regions.
3. Funding Instability and Capacity Limits	Chronic funding challenges identified in 2017 have grown. Nearly nine in ten providers (88%) rely on grants, and over half (53%) were unable to serve all eligible patients in the past year due to limited funds or capacity. Post-pandemic costs have risen sharply, further straining resources.
4. Uneven Technology Access Despite Rapid Adoption	In 2017, technology played a minimal role in coordination. By 2025, rideshare and online scheduling are common in southern and central Maine, but rural access remains inconsistent. Many patients needed help using digital systems. 62% said they need assistance with ride scheduling or apps.
5. Awareness of Services Remains a Major Barrier	Despite increased service availability, patients still struggled to find and access resources. Nearly two-thirds (63%) of providers rated patient awareness as a moderate or extreme barrier. Some patients only learned about programs during treatment crises.
6. Lodging Emerging as a Critical and Unmet Need	Lodging was secondary in 2017 but is now a central concern. Over half (54%) of patients stayed in hotels or motels. 90% would prefer hospitality homes, but only 36% have access to one. Shared lodging capacity remained limited as well.
7. Hidden Costs Continue to Undermine Treatment Continuity	In 2025, nearly all patients said transportation (84%) and lodging (66%) costs affected their ability to receive treatment. And that "hidden" costs like contributed to missed appointments and financial stress.
8. Improved Coordination Between	Providers are more engaged in connecting patients to transportation and lodging resources than in 2017. Nearly all (94%) transportation



Theme	Summary of Change (2017 → 2025)
Providers and Transportation Systems	organizations now receive referrals directly from medical providers. However, over half of patients (51%) still report feeling ashamed or uncomfortable discussing access challenges with their care team at first.
9. Increased Reliance on Informal and Community-Based Supports	Family and friends remained the primary mode of transport for two- thirds (67%) of patients. As formal systems struggled under demand, this leaves gaps for patients without strong social networks.
10. A More Holistic System Overall	The overall system is broader and more coordinated than in 2017, integrating financial, social, and health dimensions of access. Yet it remains fragile largely by underfunded community partners, volunteer networks, and short-term grants.



RECOMMENDATIONS

1. Rebuild and incentivize the volunteer driver network.

Volunteer shortages were one of the most reported transportation barriers from both providers and patients. Recruitment campaigns, reimbursement stipends, and flexible scheduling could help rebuild this workforce. Partnering with non-profits, community brokers, Community Health Outreach Workers (CHOWS), and veteran organizations may further expand reach, especially in rural counties.

2. Build a statewide "Travel Companion" volunteer program.

Beyond drivers, many patients struggled with travel anxiety, medical equipment, isolation, or mobility issues. MICN could expand volunteer roles beyond transportation to include companions who help patients navigate check-ins, carry bags, or provide emotional support.

3. Support technology assistance and scheduling help for patients.

Nearly two-thirds of patient respondents said they need help scheduling rides or using ride apps and overall technology. Incorporating more tech support for patients would improve equitable access to online systems.

4. Help patients feel ready to discuss access needs from the start.

Nearly half of patients said they felt ashamed or uncomfortable talking about transportation or lodging concerns with their care teams at first. Sharing this point more out in the open and spreading more awareness to clinical providers and integrating empathetic scripts, faster patient navigator introductions, and more visible signage about support options may help reduce stigma.

5. Make lodging an equal priority with transportation in cancer access planning.

Patients reported that affordable lodging was as critical as transportation needs for maintaining treatment continuity. MICN could create a "Lodging-as-Care" initiative, reframing lodging as an essential component of cancer care along with transportation.

6. Establish an "On-Call Transportation Backup Network."

Many patients did not have backup options when rides fell through due to weather, scheduling, or driver cancellations. MICN could pilot a standby driver hotline or network.

7. Strengthen data sharing and mapping for real-time resource visibility.

Providers still reported confusion about which programs serve which regions. Developing a live, interactive resource dashboard that maps service areas, eligibility, and lodging options may streamline referrals and help patients and providers plan more effectively for lodging.



8. Expand mileage reimbursement options.

More than half of provider organizations cannot serve patients outside their defined regions. More options for mileage reimbursement programs could help patients be reimbursed for self-driven trips to distant treatment centers. Some patients also preferred driving alone due to their own circumstances, mileage reimbursement would be a better option for these patients compared to ride shares, taxis, or volunteer drivers.

9. Utilize Community Health Outreach Workers (CHOWS) as local connectors.

To address the rural inequities, MICN could partner with more Community Health Outreach Workers (CHOWs) focused specifically on transportation and lodging access. These trained outreach workers could identify patients in need earlier, assist with ride scheduling and reimbursement paperwork, and connect families to nearby lodging or financial support. By operating at the community level, CHOWs could reach patients who may not engage directly with cancer centers or who feel uncomfortable disclosing financial or transportation struggles. This model would extend the reach of clinical care teams, strengthen trust in rural communities, and create a sustainable link between medical providers, local transportation networks, and social support systems.

10. Invest in rural access hubs and community partnerships to close geographic gaps.

Rural patients (especially in Downeast, Northern and Western Maine) continued to face the longest travel distances, limited lodging options, and inconsistent transportation coverage. MICN could collaborate more with local hospitals, public transit, and community centers to establish "Rural Access Hubs" that coordinate regional volunteer drivers, telehealth-supported pretreatment visits, and nearby temporary lodging. These hubs could serve as micro-networks that bring services closer to where patients live, helping to reduce travel strain and missed appointments.



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APPENDIX A: Transportation and Lodging Provider Survey

Survey Introduction

INTRO

Thank you for participating in this survey! Maine's Impact Cancer Network (MICN) is gathering information to understand the transportation and lodging needs of cancer patients in Maine. Your responses will help improve services and support for individuals receiving cancer care. Your participation in this survey is voluntary. The answers you give will be kept private and confidential. Your name will never be connected to your responses.

Your responses to the questions in this survey will help MDR, an independent research firm based out of Portland, Maine and hired by MICN to analyze the findings of the survey. The survey should take less than 10 minutes to complete. Please be honest with your answers. You do not have to answer any question you do not feel comfortable with.

If you have questions or need help accessing the survey you can contact the Project Manager, Allison Tippery at atippery@marketdecisions.com or by phone at (207) 767-6440 ext. 1116

By clicking "I agree" below you agree that you have read this form and agree to participate in this survey. You may print a copy of this page for your records.

- 1, I agree to participate in the survey
- 2, I do NOT agree to participate in the survey



Survey Questions

Screener Questions and Demographics

Q1. Which of the following services or support do you provide to cancer patients?

- 1, Transportation
- 2, Lodging
- 3, Both transportation and lodging
- 4, I only provide a list of transportation and/or lodging resources available in a patient's treatment location [SCREEN OUT]
- 99, I do not provide transportation or lodging services to cancer patients [SCREEN OUT]

Q2. What is the name of your organization?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q3. What is your service area?

LIST OF MAINE COUNTIES
INCLUDE STATEWIDE COVERAGE OPTION
95, Other (please specify) [OPEN END]

Q4. Can you transport patients outside of your service area? E.g. to a treatment center in Boston?

- 1, Yes
- 2, No

Q5. Can you serve patients who live outside your service area?

- 1, Yes
- 2, No

Q6. What are your hours of operation?

- 1, 24/7
- 2, Weekdays only (please specify hours) [OPEN END]
- 3, Weekdays and weekends (please specify hours) [OPEN END]

Q7. Please describe how patients are connected/referred to your organization.

- 1, Self-referred
- 2, Referred by medical provider
- 3, Referred by community organization
- 95, Other (please specify) [OPEN END]

Q8. How can patients contact you to apply for services? Please select all that apply.

- 1, Phone
- 2, Email
- 3, Online portal
- 4, Mobile app



- 5, Referral from a provider
- 6, Walk-in requests
- 95, Other (please specify) [OPEN END]

Q9. What information do patients need to provide when applying for services?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Transportation

[SHOW BLOCK IF Q1=1/3]

Q10. What type of transportation assistance do you provide for cancer patients? (*Please select all that apply*)

- 1, Rides to cancer care appointments
- 2, Gas cards
- 3, Mileage reimbursement
- 4, Taxi or rideshare vouchers/reimbursement
- 5, Reimbursement for vehicle repairs, insurance, payments
- 6, Transportation to other locations such as grocery stores, pharmacies etc.
- 7, Flights
- 95, Other (please specify) [OPEN END]

Q11. Do you have eligibility requirements to receive transportation services? (Please select all that apply)

- 1, Must meet income requirements or demonstrate financial need (please specify)[OPEN END]
- 2, Must live within your service area
- 3, Must live a certain distance from a medical facility or treatment center
- 4, Covered by MaineCare
- 95, Other (please specify) [OPEN END]
- 99, Do not have eligibility requirements

Q12. How much of a barrier are the following for patients using your transportation services?

- a, Eligibility requirements
- b, Mobility issues
- c, Lack of accessible vehicles to accommodate equipment such as wheelchairs
- d, Scheduling rides
- e, Missed rides or cancelations
- f, Lack of drivers or flight staff
- h, Lack of awareness of services
- 1, Not a barrier
- 2, Somewhat of a barrier
- 3, Moderate barrier
- 4, Extreme barrier



99, Not sure

Q13. What other common barriers do patients experience when using your transportation services?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

[ASK Q14 - Q25 IF Q10 = 1, 6, or 7 = RIDES OR FLIGHTS TO CANCER CARE APPOINTMENTS, OR RIDE TO OTHER LOCATIONS]

Q14. What type of drivers or flight staff do you have?

- 1, Volunteer drivers or flight staff
- 2, Paid drivers or flight staff
- 3, Both

Q15. How can patients contact you to schedule a ride? Please select all that apply.

- 1, Phone
- 2, Email
- 3, Online portal
- 4, Mobile app
- 5, Referral from a provider
- 6, Walk-in requests
- 7, Family member/support person
- 95, Other (please specify) [OPEN END]

Q16. When scheduling a ride, how is the pick-up time determined? (Please select all that apply)

- 1, Specific pick-up time is chosen by the patient
- 2, Specific pick-up times offered to patients based on availability
- 3, Pick-up window offered to patients based on availability
- 4, Will-call pickup
- 95, Other (please specify) [OPEN END]

Q17. Do you allow patients to bring a caregiver/companion when receiving transportation services?

- 1, Yes, always
- 2, Yes, but only under certain conditions (please specify) [OPEN END]
- 3, No, we only transport patients

Q18. Are rides shared with other patients?

- 1, Always
- 2, Sometimes
- 3, Rarely
- 4, Never [SKIP TO Q20]

Q19. If a patient is immunocompromised, can special accommodations be made?

- 1, Yes
- 2, No



Q20. What types of transportation assistance do you provide? (Please select all that apply)

- 1, Door-to-door service
- 2, Curb-to-curb service
- 3, Accompanied service (assistance into the treatment facility)
- 4, Referrals/connection to other transportation or lodging services
- 95, Other (please specify) [OPEN END]

Q21. What mobility needs can you accommodate? (Please select all that apply)

- 1, Patients using wheelchairs
- 2, Patients using walkers/canes
- 3, Patients requiring medical equipment such as oxygen tanks
- 4, None of the above
- 5, Assistance getting in/out of the vehicle
- 6. Assistance with stairs
- 95, Other (please specify) [OPEN END]

Q22. How far in advance must a patient request transportation?

- 1, Same day
- 2, 24 hours
- 3, 48 hours
- 4, One week
- 95, Other (please specify) [OPEN END]

Q23. How do you handle last-minute transportation requests?

- 1, We can accommodate urgent requests
- 2, We try, but availability is limited
- 3, We require advance notice and cannot provide same-day rides
- 95, Other (please specify) [OPEN END]

Q24. If a patient is running late, what is your policy?

- 1, We wait up to a certain amount of minutes (please specify) [OPEN END]
- 2, We reschedule the ride for a later time
- 3, The patient must arrange another ride
- 95, Other (please specify) [OPEN END]

Q25. What is the process if a patient's scheduled ride does not show up?

- 1, We provide a backup option
- 2, The patient must arrange another ride
- 3, We have a support number for immediate assistance
- 95, Other (please specify) [OPEN END]

Q26. How do you handle and communicate extreme weather conditions?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer



Q27. Do you require the patient to confirm a ride before it's sent out to get them? For example, through a text or phone call?

- 1, Yes
- 2, No

Lodging

[SHOW BLOCK IF Q3=2/3]

Q28. Which of the following lodging services do you provide?

- 1, Rooms for patients to stay during treatment
- 2, Grants, reimbursements, or stipends to patients to pay for lodging (please specify the amount] [OPEN END]
- 95, Other (please specify) [OPEN END]

Q29. What types of lodging do you provide or coordinate? (Please select all that apply)

- 1, Hospitality homes
- 2, Hotel or motel partnerships
- 3, Private rental accommodations (such as Airbnb)
- 95, Other (please specify) [OPEN END]

Q30. Do you have patient requirements for lodging eligibility? (Please select all that apply)

- 1, Must live or be staying a certain amount of miles away from the medical facility or treatment center (please specify) [OPEN END]
- 2, Must meet income requirements or demonstrate financial need [OPEN END]
- 3, Must stay with a caregiver who can assist
- 95, Other (please specify) [OPEN END]
- 99, Do not have eligibility requirements

Q31. How much of a barrier are the following for patients using your lodging services?

- a, Lack of available rooms or waitlists
- b, Cost of lodging
- c, Transportation between lodging and treatment center
- d, Eligibility requirements
- e, Availability of accessible rooms for patients
- f, Issues with caregiver requirements
- f, Patients lacking ID or credit card to book a room
- g, Lack of availability or cost during peak seasons, such as summer or fall
- h, Lack of awareness of services among patients
- 1, Not a barrier
- 2, Somewhat of a barrier
- 3, Moderate barrier
- 4, Extreme barrier
- 99, Not sure



Q32. What other common barriers do patients experience when using your lodging services?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

[ASK Q33 - Q39 IF Q26 = 1 = Rooms for patients to stay during treatment]

Q33. How far in advance must a patient request lodging?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q34. How do you handle last-minute lodging requests?

- 1, We can accommodate urgent requests
- 2, We try, but availability is limited
- 3, We require advance notice and cannot accommodate last-minute requests

95, Other (please specify) [OPEN END]

Q35. Do you offer financial assistance for lodging? (Please select all that apply)

- 1, Yes, fully covered for eligible patients
- 2, Yes, partially covered for eligible patients
- 3, Yes, we offer sliding scale options
- 4, No, offer list of resources of lodging options
- 5, No, we do not offer financial assistance or resources

Q36. Do you provide transportation between lodging and treatment facilities such as shuttles or reimbursement for taxis or rideshares?

- 1, Yes, regularly scheduled transportation
- 2, Yes, but only on request
- 3, No, patients must arrange their own transportation

Q37. Do you offer lodging with accessibility features for patients with mobility issues?

- 1, Yes, all accommodations are fully accessible
- 2, Some locations or rooms have accessibility features
- 3, We have a limited number of rooms with accessibility features
- 4, No, we do not provide accessible lodging

Q38. Do you require patients to bring a caregiver/companion with them?

- 1, Yes, always
- 2, No, but only under certain conditions (please specify) [OPEN END]
- 3, No, we only house patients

Q39. What is your cancellation policy for lodging?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Policies & Funding



Q40. Within the past 12 months, have you been unable to provide services to an eligible patient due to capacity issues or a lack of funding?

1, Yes

2, No

Q41. Do you currently have a waitlist for your services?

1, Yes

2, No

Q42. Do you receive grant funding to support transportation or lodging?

1, Yes

2, No

98, Unsure

Q43. When do you offer discounted transportation or lodging for medical stays?

- 1, Year-round
- 2, Only during off-peak seasons
- 3, When funding is available
- 4, Never

Q44. How do you collaborate with other transportation or lodging services?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q45. What transportation or lodging resources are working well?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q46. What would improve your ability to provide transportation or lodging services to cancer patients in Maine?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

END Thank you very much for your feedback. Your time and opinions are appreciated!



APPENDIX B: Clinical Provider Interview Guide

Introduction:

Hello, my name is (introduce self). Thank you for your time and interest in this interview. I work for Market Decisions Research, an independent research firm in Maine, and I've been trained to lead this interview. We are working with Maine's Impact Cancer Network (MICN) on a research project. They are gathering information to understand the transportation and lodging needs of cancer patients in Maine. This is where you come in! Your responses will help improve services and support for individuals receiving cancer care.

The interview is voluntary. Any information you provide will be confidential and the data will be shared in summary form only. You may also skip any question you do not want to answer. The interview should take no longer than 45 minutes to complete.

If it is ok with you, this interview will be recorded and transcribed so you can have my full attention without too much notetaking. Nothing you say will be tied back to you and none of your comments will be used to identify you. Do you have any questions before we begin? I will start recording now.

IF ONLINE AND CAMERA OFF: If you happen to have a web camera, it would be great to have it on. Body language and facial expressions are important as they help us to better understand what a participant is saying or trying to say. If you are unable to do this, I understand.



TOPIC 1: Introduction

- Q1. Can you tell me about your role and the work you do with cancer patients?
- Q2. In which county or counties do you primarily practice?
- Q3. Does your facility have dedicated staff to assist patients with transportation or lodging needs? If so, how are they involved?

PROBE: Does your practice currently accept new patients?

TOPIC 2: Identifying Transportation Needs

Q4. How do you typically identify when a patient has a transportation barrier?

PROBE: Are there specific screening tools or conversations that help determine this? If so, please tell me more about them.

PROBE: Do patients self-report, or does staff observation play a role? What does this look like?

Q5. What are the most common transportation barriers your cancer patients face?

PROBE: Eligibility requirements, mobility issues, lack of available services in the region, etc.

TOPIC 3: Addressing Transportation Barriers

Q6. When a patient experiences transportation difficulties, what steps does your organization take to assist them?

PROBE: Walk me through the steps.

PROBE: Do you provide resource lists, referrals, direct assistance etc.?

Q7. Does your facility have a readily available transportation resource guide for patients? If so, how is it used?

PROBE: How could this resource be better?

- **Q8.** How do you approach mobility concerns for patients who require transportation assistance?
- O9. Do you assess whether a patient could receive treatment closer to home? If so, how?
- Q10. What strategies do you use to handle last-minute transportation issues, such as ride cancellations or no-shows?



PROBE: Does your facility charge no-show fees for missed appointments? Why or why not?

Q11. What are some ways you ensure patients arrive on time for treatment, considering transportation logistics?

Q12. Can you describe your facility's communication policy with transportation systems to coordinate timely arrivals and departures?

TOPIC 4: Lodging Support

We are doing great on time! The next topic I would like to hear about is lodging support.

Q13. What lodging resources are available to your cancer patients?

PROBE: Hospitality homes, hotel partnerships, financial assistance, etc.

PROBE: Do you or your practice assist patients in finding lodging options when treatment requires overnight stays?

Q14. What are the most significant barriers your patients face when seeking lodging assistance?

PROBE: Limited availability, cost, mobility concerns, transportation from lodging to treatment, etc.

Q15. How do you match lodging needs to patient requirements (e.g., accessibility, distance, support services)?

PROBE: Do you use screening tools, coordinate with facilities, or involve social workers/navigators?

TOPIC 5: Gaps, Resources, & Improvements

We are doing great on time! The final topic I would like to hear about is about gaps and improvements.

Q16. From your perspective, what are the biggest challenges in transportation and lodging for cancer patients in Maine?

Q17. Are there specific geographic areas where these challenges are particularly severe?

PROBE: Why are these areas more severe than others?

Q18. Do you have access to or provide financial support options such as grants, gas cards, or vouchers to assist patients? If so, what are the eligibility requirements for patients to access these resources?

Q19. Are there any existing transportation or lodging resources that are working particularly well?



PROBE: What makes them successful?

CLOSE

Q20. Do you have any additional thoughts on how transportation and lodging support for cancer patients can be improved in Maine?

Thank you for your time. This was a wonderful interview!



APPENDIX C: Patient Survey

Survey Introduction

INTRO

Thank you for participating in this survey! Maine's Impact Cancer Network (MICN) is gathering information to understand the transportation and lodging needs of cancer patients in Maine. Your responses will help improve services and support for individuals receiving cancer care across the state. Your participation in this survey is voluntary. The answers you give will be kept private and confidential. Your name will never be connected to your responses.

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By clicking "I agree" below you agree that you have read this form and agree to participate in this survey. You may print a copy of this page for your records.

- 1, I agree to participate in the survey
- 2, I do NOT agree to participate in the survey



Survey Questions

Screener Questions and Demographics

Q1. What is your age?

- 1, Less than 18 [SCREEN OUT]
- 2, 18-25
- 3. 26-34
- 4, 35-44
- 5, 45-54
- 6, 55-64
- 7,65+

Q2. Which state do you currently live in?

DROPDOWN OF STATES

IF NOT MAINE [SCREEN OUT]

Q3. Which county do you currently live in?

DROPDOWN OF MAINE COUNTIES

Q4. Have you ever been diagnosed with cancer?

- 1, Yes
- 2, No [SCREEN OUT]

Q5. Approximately how long ago were you diagnosed with cancer? If you have received more than one diagnosis, please answer about the most current one.

- 1, Within the past year
- 2, 1-2 years ago
- 3, 3-5 years ago
- 4, More than 5 years ago [SCREEN OUT]

Q6: How long after receiving your diagnosis before you were connected with a treatment facility?

- 1, Within 24 hours
- 2, Within one week
- 3, Within one month
- 4, Within six months
- 95, Other (please specify) [OPEN END]

The following questions ask about transportation and lodging during your cancer treatment. If you are currently still receiving treatment, please answer about your experiences to date.

Q7. Did you have a reliable mode of transportation to travel to cancer treatment appointments?

- 1, Yes
- 2, No

Q8. What was your primary mode of transportation to your cancer treatment?

1, Drive myself



- 2, Driven by family or friends
- 3, Volunteer driver service
- 4, Public transportation
- 5, Taxi or rideshare (Uber/Lyft)
- 6, Non-emergency medical transport (e.g. Modivcare, Penquis CAP, MidCoast Connector, Down East Community Partners, Kennebec Valley Community Action, ARTS)
- 7, Walking or Hitch hiking
- 95, Other (please specify) [OPEN END]
- 99, I do not have a primary mode of transportation

Q9. Did you require assistance when traveling to treatment? (Please select all that apply)

- 1, Wheelchair-accessible vehicle
- 2, Help walking to/from vehicle
- 3, Assistance locating the correct vehicle
- 4, Travel companion
- 5, Accommodations for medical equipment such as oxygen tanks
- 95, Other (please specify) [OPEN END]
- 99, None of the above

Q10. What was your living arrangement when you were receiving cancer treatment?

- 1, Living with family
- 2, Living alone
- 3, Living with roommates
- 4, No home/unhoused
- 5, Shelter
- 95, Other (please specify) [OPEN END]
- 99, I'd prefer not to answer

Q11. What town do/did you live in while receiving cancer treatment?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer



Travel Distance & Lodging

Q12. How far did you typically travel (one way) for treatment?

- 1, Less than 10 miles
- 2, 10-24 miles
- 3, 25-49 miles
- 4, 50-99 miles
- 5, 100 miles or more

Q13. How often did you travel for treatment?

- 1, Enter number of times per week: [OPEN END]
- 2, Enter number of times per month: [OPEN END]
- 95, Other (please specify) [OPEN END]

Q14. Did you ever stay overnight near your treatment center?

- 1, Yes, always
- 2, Yes, sometimes
- 3, No, I traveled back the same day [SKIP TO Q16]
- 4, Wanted to stay but unable to do so due to financial reasons

Q15. If you stayed overnight, where did you typically stay?

- 1, Hospitality house (e.g., Sarah's House, Hope Lodge, Clayton's House)
- 2. Hotel or motel
- 3, With family or friends
- 4, Private rental (such as Airbnb)
- 95, Other (please specify) [OPEN END]

Q16. Did you have to fly to receive cancer treatment?

- 1, Yes
- 2, No [SKIP TO Q18]

Q17. How did you fly to your cancer treatment?

- 1, Commercial flight
- 2, Medical flight (such as Angel Flight or Patient Airlift Services-PALS)
- 98, I'm not sure



Barriers & Challenges – Transportation

Q18. Have you ever missed or had to reschedule a cancer care appointment due to a lack of transportation?

- 1, Yes
- 2, No

Q19. Did the cost of transportation affect your ability to receive treatment?

- 1, Yes
- 2, No [SKIP TO Q21]

Q20. How did the cost of transportation affect your ability to receive your cancer treatment? [OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q21. What other specific transportation challenges did you experience? (Please select all that apply)

- 1, No access to a vehicle
- 2, Vehicle needs repairs/insurance
- 3, Scheduling conflicts or getting a ride at a specific appointment time
- 4, Difficulty arranging a ride
- 5, Ride cancelations
- 6, Mobility issues
- 7, Lack of public transportation
- 8, Unsure where to go to get transportation assistance
- 9, Language barrier
- 10, Long wait time for reimbursement from other transportation assistance
- 95, Other (please specify) [OPEN END]
- 99, None of the above

[ASK IF Q21 = 6 for Mobility issues]

Q22. Please describe what specific types of mobility issues you experienced related to transportation.

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q23. How comfortable would you be using the following transportation options to travel for treatment?

- a. Volunteer driver service
- b. Taxi or rideshare (Uber/Lyft)
- c. Non-emergency medical transport (Modivcare, Penquis CAP, MidCoast Connector)
- d. General-public transit
- 1, Very comfortable
- 2, Somewhat comfortable
- 3, Somewhat uncomfortable



4, Very uncomfortable

97, Not applicable

98, Not sure

Q24. If your primary transportation plan failed, did you have a backup option?

1, Yes

2, No [SKIP TO Q26]

Q25. What was your backup transportation option?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Barriers & Challenges – Lodging

Q26. Have you ever missed or had to reschedule a cancer care appointment due to issues with lodging? (being able to stay close to your treatment location)?

1, Yes

2, No

Q27. Did the cost of lodging affect your ability to receive treatment?

1, Yes

2, No [SKIP TO Q29]

Q28. How did the cost of lodging affect your ability to receive your cancer treatment?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q29. What other lodging challenges have you experienced? (Please select all that apply)

- 1, Lack of available lodging near treatment center
- 2, Difficulty booking or scheduling overnight stays
- 3, Uncomfortable or inadequate accommodations
- 4, Transportation between lodging and treatment center
- 5, Mobility issues
- 6, Lacked required caretaker/companion
- 7, Unaware of lodging resources or assistance
- 8, Lack of technology to search for lodging online
- 9, No credit card/debit card to reserve a room
- 95, Other (please specify) [OPEN END]
- 99, None of the above

[ASK IF Q29 = 5 for Mobility issues]

Q30. Please describe what specific types of mobility issues you experienced related to lodging.

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer



Q31. How comfortable would you be staying overnight at the following while receiving treatment?

- a. A hospitality house (e.g., Sarah's House, Hope Lodge, Clayton's House)
- b. Hotel or motel
- c. Private rental accommodations (such as Airbnb)
- 1, Very comfortable
- 2, Somewhat comfortable
- 3, Somewhat uncomfortable
- 4, Very uncomfortable
- 97, Not applicable
- 99, Not sure

Q32. If your primary lodging plan failed, did you have a backup option?

- 1, Yes
- 2, No [SKIP TO Q34]

Q33. What was your backup lodging option?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer



Information & Support

Q34. Have you received any of the following support for transportation or lodging? Please select all that apply.

- 1, Financial support for transportation (Gas cards, mileage reimbursement, etc.)
- 2, Financial support for lodging (Free or discounted rooms, etc.)
- 3, Information about services or referrals to services
- 4, Assistance scheduling transportation or lodging
- 95, Other (please specify) [OPEN END]
- 99, None of the above

Q35. Was there any support that you needed but did not receive?

1, Yes

2, No [SKIP TO Q38]

Q36. What support did you need but were not able to get?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q37. What are the reasons you were not able to get the support you needed?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q38. Did you discuss transportation and lodging options with your healthcare team?

1, Yes

2, No

Q39. Did you feel comfortable talking to your healthcare team about your transportation and lodging during your cancer treatment?

1, Yes [SKIP TO Q41]

2, No

Q40. Why did you feel uncomfortable talking about transportation and lodging with your healthcare team?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q41. What would make you feel more comfortable using transportation and lodging services?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Q42. What level of comfort do you have with technology for arranging transportation and lodging?

- 1, Very comfortable (I use phones/apps/texting/email easily)
- 2, Somewhat comfortable (I can manage but may need help)
- 3, Not comfortable (I need assistance)



Q43. If you used transportation other than family or friends, did you need assistance with scheduling or using technology to arrange rides?

1, Yes

2, No

Q44. Do you have any additional thoughts on how transportation and lodging support for cancer patients can be improved in Maine?

[OPEN END] (character limit = 1,000)

99, I'd prefer not to answer

Final Demographics

These final questions are for statistical purposes only.

D1. What type of cancer are you currently receiving (or have received) treatment for? [OPEN END]

(character limit = 1,000)

99, I'd prefer not to answer

D2. What is your gender?

- 1, Male
- 2, Female
- 3, Transgender or non-binary
- 95, Something else (please specify) [OPEN END]
- 99, I prefer not to answer

D3. What is your race and/or ethnicity? Please select all that apply.

- 1, American Indian/Alaska Native
- 2, Asian
- 3, Black or African American
- 4, Hispanic or Latino
- 5, Middle Eastern/North African
- 6, Native Hawaiian or other Pacific Islander
- 7, White
- 99, I'd prefer not to answer

D4. Into which of the following income categories includes your annual household income before taxes?

- 1, Under \$15,000
- 2, \$15,000 to \$24,999
- 2, \$25,000 to \$34,999
- 2, \$35,000 to \$49,999
- 3, \$50,000 to \$74,999
- 4, \$75,000 to \$99,999
- 5, \$100,000 to \$149,999



6, \$150,000 or more 98, I don't know 99, I'd prefer not to answer

END Thank you very much for your feedback. Your time and opinions are appreciated!

