

TRAVEL ASSISTANCE SURVEY REPORT





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Executive Summary

Objective

Every year, 3.6 million Americans miss doctor appointments due to a lack of reliable transportation. (Community Transportation Association of America). There is a serious need for reliable transportation and a significant lack of options available to patients across the country. The Patient Access Network (PAN) Foundation distributed a transportation assistance survey in Fall 2019 to understand whether people with serious illnesses faced transportation barriers that impeded their ability to seek care from their physicians or pick up medications from their pharmacies.

At the time of survey distribution, PAN had been operating a transportation program, providing a grant to eligible participants to book up to 10 Lyft rides with a \$14 subsidy per ride. The program served 249 patients who enrolled in the program through PAN's call center.

The objective of this survey was two-fold.

- 1. To understand patient attitudes towards ride-sharing services and to ascertain what barriers patients felt existed that prevented them from accessing these services (e.g. cost, mobility).
- 2. To determine how PAN could enhance the program's capabilities to better serve its patients.

Findings

The survey data supported many of the findings and feedback received from patients enrolled in PAN's transportation assistance program. The findings confirmed that any future program must be expanded to serve a wider audience of patients and be more inclusive of patients' needs.

Providing transportation assistance will allow seniors to resolve several barriers to receiving care. There are a variety of transportation-related barriers that prevent seniors from seeing their physicians.

- Relying on others for transport (61 percent, n=2,326)
- Tardiness to appointments due to transportation problems (14 percent, n=528)
- Missing appointments due to transportation problems (18 percent, n=679)
- Transportation-related costs are too high (14 percent, n=530)

Seniors' accessibility issues limit the types of transportation available to get appropriate care. The issue of accessibility is both in patient mobility (e.g. ambulatory vs. wheelchair use), and geography (e.g. limited transportation resources are available in rural regions). Patients need a large range of options for transportation assistance to cover all their accessibility needs.

• Use a cane, crutches, a walker or a wheelchair to get around (43 percent, n=1,706)

The need for travel assistance to the doctor's office is greater than to the pharmacy.

- Picked up medications with a ride from family member or friend (51 percent, n=1,430)
- Travel to a pharmacy within five miles of their home (73 percent, n=2,055)
- Travel to a doctor's office within five miles of their home (23 percent, n=878)

The physician visits required travel to a greater distance, and are scheduled in advance. Pharmacy visits are not dictated by the pharmacist's schedule and do not require the patient to be present.



Scope

Purpose

By distributing this survey, PAN sought to understand patient concerns and how it could address gaps in the current landscape of transportation assistance. Some national organizations and hospitals do provide aid free of charge or at reduced rates to eligible patients, but this assistance often has nuanced, restrictive eligibility criteria, and few qualify for the programs. Many organizations limit support to long-distance travel, offering air transportation for those traveling to another state. Most charitable patient assistance foundations, PAN included, operate travel funds tied to specific disease states, however, many of these are tailored to rare diseases; patients with chronic diseases or cancer often do not have any resources available to them for travel assistance. This excludes the majority of people suffering from serious illnesses from finding resources.

Methodology

The survey included 31 multiple choice questions, some of which could be answered with multiple selections, and others which had open-text options to provide additional feedback. The questions were focused around four key themes to better structure survey findings and recommendations:

- 1. Patient demographics,
- 2. Experience and comfort level using rideshare services,
- 3. Experience and issues in getting to and from the doctor's office, and
- 4. Experience and issues in getting to and from the pharmacy.

See Appendix A for a copy of the survey.

Distribution

The survey was distributed by email to 19 national advocacy organizations across rare, cancer and chronic disease areas, who shared the survey over their social media channels and list servs. PAN also distributed the survey by email to its patients who were currently receiving co-pay assistance. In total, PAN received 4,640 responses. The target audience was the senior citizen community, and 72 percent (n=2,886) of responses received were from this group. This does not mean that other groups do not also require transportation assistance, but it should be noted that the survey does predominantly include the perspectives of seniors because this is the group that primarily benefits from PAN's assistance programs. All survey participants were diagnosed with a chronic, cancer or rare disease.



Findings and Recommendations

Limited access to transportation prevents seniors from getting the care they need.

To ensure maximum program utilization, it is important to understand physical limitations of the Medicare population to appropriately structure a transportation assistance program.

There are various physical and financial limitations that have been barriers to transportation to the doctor's office. In the past year:

- 61 percent of respondents (n=2,330) have had trouble getting to their doctor's offices.
- 18 percent of respondents (n=679) have missed a doctor's appointment because of transportation problems.
- 21 percent of respondents (n=792) reported that physical disabilities, vision problems or mobility limitations prevented them from seeing their doctors. Having physical disabilities places additional restrictions on what travel resources are available to patients and considerations for appointments and transportation that able-bodied patients do not need to worry about.
- 14 percent of respondents (n=530) reported that the cost of gasoline, public transportation, or other transportation-related costs prevented them from seeing their doctors.
- 26 percent of respondents (n=996) have delayed scheduling a doctor's appointment in the past year, because transportation is too much trouble

Many patients are mobile, yet still rely on others for travel assistance to the doctor's office. Most respondents (86 percent, n=3,380) are ambulatory or use a cane, crutches or a walker and therefore it is not surprising that 56 percent of respondents (n=2,131) stated they drove themselves to their doctor appointments in the past year.

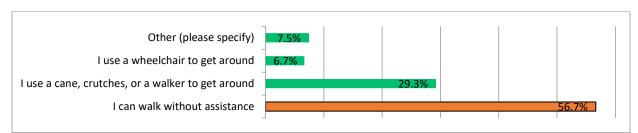


Figure 1. Q8: Which statement best describes how mobile you are?

It is surprising that 61 percent of respondents (n= 2,326) relied on family members, friends or caregivers for assistance, showing that there is a need to provide patients with independence and ability to be more mobile. A doctor's visit is something that needs to be planned; relying on another person's schedule and availability is challenging and could impede the patient from receiving timely treatment.



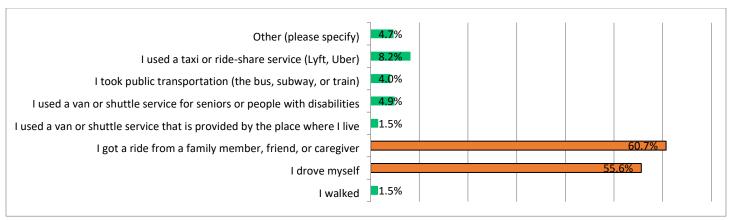


Figure 2. Q9: In the past year, how did you get to your doctor's appointments? Select all answers that apply to you.

Most seniors have limited experience with ride-sharing apps.

The survey data shows that 24 percent of respondents (n=963) have used ride-sharing services in the past. The lack of utilization can speak to a variety of factors, explored in more detail in Figure 3. 64 percent of respondents (n=1,910) stated they simply never needed to use this service in the past.

The "Other" category provided further clarification (13.5 percent of responses, n=402). These respondents wrote in their concerns and expressed that they had an excessive distance to travel, and noted a caregiver was currently available to provide transport.

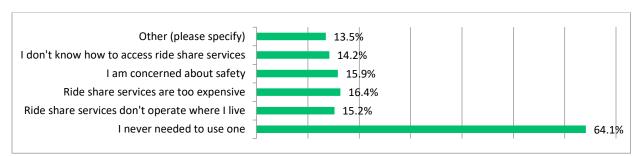


Figure 3. Q5: Why haven't you used a ride sharing service before? Select all answers that apply to you.

To create an inclusive program which will support the greatest number of patients, it is necessary to include multiple transportation options for patients to access. Ride-sharing services have revolutionized the way people access their healthcare, but they do have limitations: limited geographic reach, cost, safety and vehicle accessibility.



Despite living far from the doctor's office, patients do not want to pay out-of-pocket for transport. Although patients recognize they need financial assistance to travel to their doctors, 47 percent (n=633) of respondents stated that the most they are willing to pay for a one-way ride was \$5 or less. However, 52 percent (n=1,972) of respondents also stated that their doctor's office is more than 10 miles away.



Figure 5. Q7: What is the most you would be willing to pay for a one-way ride to your doctor?

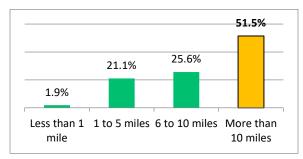


Figure 4. Q11: How far is your doctor's office from your home?

If these respondents were to utilize a ride-sharing service for their trip, they would pay much more than \$5 for transportation, yet are still reluctant to take advantage of this service because of their unfamiliarity with ride-sharing services or unwillingness to pay out-of-pocket for a different service. These patients are more likely to turn to their family and caregivers for assistance instead. In these situations, they risk missing appointments, scheduling appointments at their convenience, and may increase reliance on others.

PAN does not want to deter patients from using a program benefit due to cost. PAN also does not want to cause undue concern by having patients contribute additional personal funds to complete a trip to their doctors. For these reasons, it is important to consider a full reimbursement program rather than providing a partial reimbursement for travel.



The need for travel assistance is greater to the doctor's office instead of the pharmacy.

To ensure a focused assistance program, it is necessary to identify the types of services that patients most need to access. Arranging transportation to doctor's visits was a greater need for patients.

Almost all patients will see their doctors at least once in a six-month period.

The survey data demonstrates that an expanded program length will capture almost every respondent's appointments in at least a six-month period. 98.9 percent of respondents (n=3,788) visited a doctor at least once every six months. To ensure success and maximum benefit utilization, it will be important to plan a program that lasts at least this duration of time.

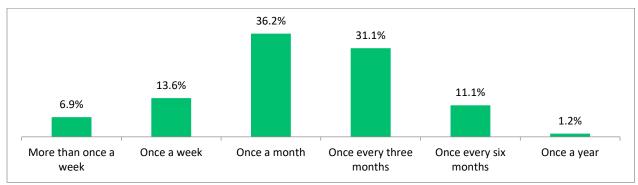


Figure 6. Q18: Thinking about all the doctors who managed your care over the past year, which of the selections below best describes how often you have a doctor's appointment?

Pharmacies are much closer and easier for patients to access than doctor offices.

Pharmacy visits were not as difficult for patients to arrange; 73 percent of respondents (n=2,055) reported the local pharmacy was less than one mile to five miles away from their homes. As previously noted in this report, over half of respondents said their doctor's office was more than 10 miles away.

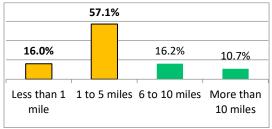


Figure 7. Figure 8. Q25: How far is your local pharmacy from your home?

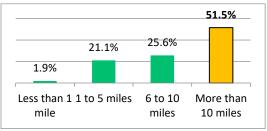


Figure 8. Q11: How far is your doctor's office from your home?

Travel to doctor appointments as previously noted, has been difficult. Many of these rides are being completed by other means—a ride from a caregiver, ridesharing, taxi, specialty vans, etc. Rides to pharmacies are not as significant an issue due to close proximity.

A majority of respondents sought treatment for chronic diseases other than cancer.

While disease distribution was spread across cancer, chronic disease and rare disease, 57 percent of respondents (n=2,272) reported suffering from chronic disease and 28 percent (n=1,122) suffer from cancer. This number is likely higher, due to the free-text nature of the "Other" category which included 736 free-text responses, many of which fall under the "Chronic Disease" category. These



include COPD, MS, Parkinson's, diabetes, heart disease, asthma. Patients falling under the Chronic Disease category require continuous treatment and multiple visits to doctors to maintain their care. A transportation assistance program should be designed with this frequency of visits in mind. It is also important to consider that these types of visits are more likely to be taken at a physician's office instead of requiring visits to the pharmacy.

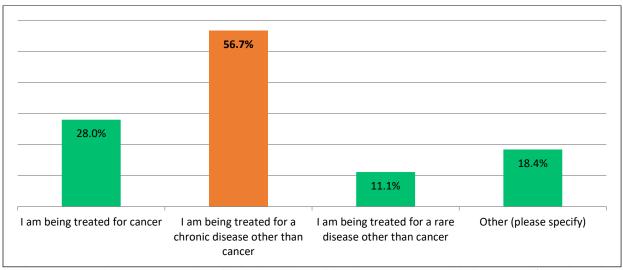


Figure 9. Q3: Which statements describe the health condition(s) you are currently being treated for? Select all answers that apply to you.



Next Steps

A New Transportation Assistance Program

PAN recognizes that patients' financial obstacles go beyond co-pay assistance. The pilot program and survey findings concluded that PAN can increase its impact and effectiveness by being more inclusive of patient needs. In 2020, PAN will implement a new transportation assistance program for Medicare beneficiaries, open to all disease states covered by PAN. Eligible patients will receive a prepaid card with the flexibility to choose any form of transportation that meets their needs, for use to and from their physician's appointments.

PAN can develop an inclusive program with broader eligibility requirements and fewer restrictions on use.

Currently, no charitable patient assistance foundation offers a non-disease-specific travel assistance program. This limits travel assistance to select patient groups and many patients do not have an opportunity to receive assistance. PAN will be the first charitable patient assistance foundation to fill this gap and serve more patients in need of assistance.

Existing transportation assistance programs are often tailored to rare diseases; patients with chronic diseases or cancer often don't have any resources available to them and do not have a source of funding on which they can rely. Additionally, eligibility requirements are often very restrictive. Because most programs are restricted in the types of benefits they provide (e.g. they might only provide flights, or ride-sharing services), this further impedes the patient's ability to use this kind of transportation assistance. In structuring a more flexible program which allows a wider scope of covered transportation services, PAN can truly provide patients with a broad range of illnesses access to the assistance they need to receive treatment.

Engagement with Advocacy Partners and Healthcare Providers

To continue enhancing and improving the travel program, it is important for PAN to rely on its network of advocacy partners and the audiences they serve. Advocacy groups have keen insight into the needs of their patients and can share this feedback with PAN directly; this will help shape the program. Advocacy groups can also share information on PAN's travel programs with targeted audiences across the country.

PAN should also engage the healthcare providers with whom it currently has strong relationships. Healthcare providers can identify patients who often reschedule or miss their health appointments due to transportation challenges and refer them to this service.

Future Updates

Sign up here to stay up to date on PAN's travel programs.



Appendix A: Survey Questions

- 1. Are you currently being treated for cancer, a chronic illness, or a rare disease?
 - Yes
 - No
 - I don't know

If respondent answers "No" or "I don't know" thank and end survey here.

- 2. What is your age?
 - Less than 18 years old
 - 19 34 years old
 - 35 64 years old
 - 65 years or older
- 3. Which statements describe the health condition(s) you are currently being treated for? **Select all answers that apply to you**.
 - I am being treated for cancer
 - I am being treated for a chronic disease other than cancer
 - I am being treated for a rare disease other than cancer
 - Other _____ [text field here if this is selected]
- 4. Have you ever used a ride sharing service like Uber or Lyft before?
 - Yes
 - No
 - I don't know

If "No" answer questions 5 and 6. If "I don't know" or "Yes" skip to question 8.

- 5. Why haven't you used a ride sharing service before? **Select all answers that apply to you.**
 - I never needed to use one
 - Ride share services don't operate where I live
 - Ride share services are too expensive
 - I am concerned about safety
 - I don't know how to access ride share services
 - Other _____ [text field here if this is selected]
- 6. Would you consider using a ride share service to get to your doctor's appointments if the service was affordable and available in your area?
 - Yes
 - No
 - I don't know

If "Yes," answer question 7. Otherwise skip to question 8



- 7. What is the most you would be willing to pay for a one-way ride to your doctor?
 - \$5 or less
 - \$6 to \$10
 - \$11 to \$20
 - More than \$20
- 8. Which statement best describes how mobile you are?
 - I can walk without assistance
 - I use a cane, crutches, or a walker to get around
 - I use a wheelchair to get around
 - Other _____[text field here if this is selected]

The next few questions ask about how you usually get to and from your doctor's appointments. If you see more than one doctor, please respond for the doctor who manages the main health condition you are currently being treated for.

- 9. <u>In the past year</u>, how did you get to your doctor's appointments? **Select all answers that apply to you**.
 - I walked
 - I drove myself
 - I got a ride from a family member, friend, or caregiver
 - I used a van or shuttle service that is provided by the place where I live
 - I used a van or shuttle service for seniors or people with disabilities
 - I took public transportation (the bus, subway, or train)
 - I used a taxi or ride-share service (Lyft, Uber)
 - Other: _____[text field here if this is selected]
- 10. <u>In the past year</u>, how did you get home from your doctor's appointments? **Select all answers** that apply to you.
 - I walked
 - I drove myself
 - I got a ride from a family member, friend, or caregiver
 - I used a van or shuttle service that is provided by the place where I live
 - I used a van or shuttle service for seniors or people with disabilities
 - I took public transportation (the bus, subway, train, or tram)
 - I used a taxi or ride-share service (Lyft, Uber)
 - Other: _____[text field here if this is selected]
- 11. How far is your doctor's office from your home?
 - Less than 1 mile
 - 1 to 5 miles
 - 6 to 10 miles
 - More than 10 miles
- 12. How much trouble is it for you to get to your doctor's office?
 - No trouble
 - A little trouble
 - Some trouble
 - A lot of trouble



- 13. <u>In the past year</u>, have you delayed scheduling a doctor's appointment because transportation is too much trouble?
 - Yes
 - No
 - I don't know
- 14. <u>In the past year</u>, have you been more than 20 minutes late for a doctor's appointment because of transportation problems?
 - Yes
 - No
 - I don't know
- 15. In the past year, have you missed a doctor's appointment because of transportation problems?
 - Yes
 - No
 - I don't know
- 16. <u>In the past year</u>, has the cost of gasoline, public transportation, or other transportation-related costs prevented you from seeing your doctor?
 - Yes
 - No
 - I don't know
- 17. <u>In the past year</u>, have any physical disabilities, vision problems, or mobility limitations ever prevented you from seeing your doctor?
 - Yes
 - No
 - I don't know
- 18. Thinking about <u>all the doctors</u> who managed your care <u>over the past year</u>, which of the selections below best describes how often you have a doctor's appointment?
 - More than once a week
 - Once a week
 - Once a month
 - Once every three months
 - Once every six months
 - Once a year
- 19. How often do you go to a hospital, physician's office, or other medical facility for an outpatient treatment like an infusion, chemotherapy, or dialysis?
 - More than once a week
 - Once a week
 - Once a month
 - Once every three months
 - Once every six months
 - Once a year
 - Never-I do not receive any in-office treatments [if "Never" is selected, go to question 21]



- 20. How much trouble is it for you to get transportation to these outpatient treatments?
 - No trouble
 - A little trouble
 - Some trouble
 - A lot of trouble

The next few questions ask about the prescription medications you have taken <u>over the past year</u>. If you take more than one medication, answer the questions as they relate to <u>most</u> of the medications you have taken on a regular basis over the past year.

- 21. In the past year, how often did you refill your prescription medications?
 - Every 30 days
 - Every 60 days
 - Every 90 days
 - Other _____[text field here if this is selected]
- 22. In the past year, where did you fill your prescriptions? Select all answers that apply to you.
 - At my local pharmacy
 - At my doctor's office
 - Through a mail order or specialty pharmacy
 - Other _____[text field here if this is selected]

[If "local pharmacy" is NOT selected, survey ends here]

- 23. <u>In the past year</u>, how did you get to your local pharmacy to fill your prescriptions? **Select all answers that apply to you**.
 - I walked
 - I drove myself
 - I got a ride from a family member, friend, or caregiver
 - I used a van or shuttle service that is provided by the place where I live
 - I used a van or shuttle service for seniors or people with disabilities
 - I took public transportation (the bus, subway, train, or tram)
 - I took a taxi or ride-share service (Lyft, Uber)
 - Other: [text field here if this is selected]
- 24. In the past year, how did you get home from your local pharmacy? Select all answers that apply to you.
 - I walked
 - I drove myself
 - I got a ride from a family member, friend, or caregiver
 - I used a van or shuttle service that is provided by the place where I live
 - I used a van or shuttle service for seniors or people with disabilities
 - I took public transportation (the bus, subway, train, or tram)
 - I took a taxi or ride-share service (Lyft, Uber)
 - Other: _____[text field here if this is selected]



- 25. How far is your local pharmacy from your home?
 - Less than 1 mile
 - 1 to 5 miles
 - 6 to 10 miles
 - More than 10 miles
- 26. How much trouble is it for you to get transportation to your local pharmacy?
 - No trouble
 - A little trouble
 - Some trouble
 - A lot of trouble
- 27. <u>In the past year</u>, have you delayed filling a prescription because transportation to your local pharmacy was too much trouble?
 - Yes
 - No
 - I don't know
- 28. <u>In the past year</u>, have you decided not to fill a prescription because of problems with transportation to your local pharmacy?
 - Yes
 - No
 - I don't know
- 29. <u>In the past year</u>, has the cost of gasoline, public transportation, or other transportation-related costs prevented you from getting to your local pharmacy to fill your prescriptions?
 - Yes
 - No
 - I don't know
- 30. <u>In the past year</u>, have any physical disabilities, vision problems, or mobility limitations prevented you from getting to your local pharmacy to fill your prescriptions?
 - Yes
 - No
 - I don't know
- 31. <u>In the past year</u>, about how often did you go to your local pharmacy to drop off or pick up a prescription?
 - More than once a week
 - Once a week
 - Once a month
 - Once every three months
 - Once every six months
 - Once a year