

2018 Member Survey

Report of Findings

September 4, 2018

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Introduction

For this research, a total of 979 online surveys were completed among kidney disease patients.



Study Purpose

- The information from this survey will help drive advocacy efforts. It will allow Dialysis Patient Citizens to better understand patient challenges to better serve and offer solutions.
- Similar studies were conducted from 2012-2016.
 - Some comparisons are made, where applicable.



Data Collection

- To accomplish objectives, DPC emailed their database to invite participation in an online survey.
- This research includes 979 survey completes.
 - The only requirement for participation in the survey is that they have Chronic Kidney Disease.
- Survey completion began on July 27, 2018 and continued through August 14, 2018.



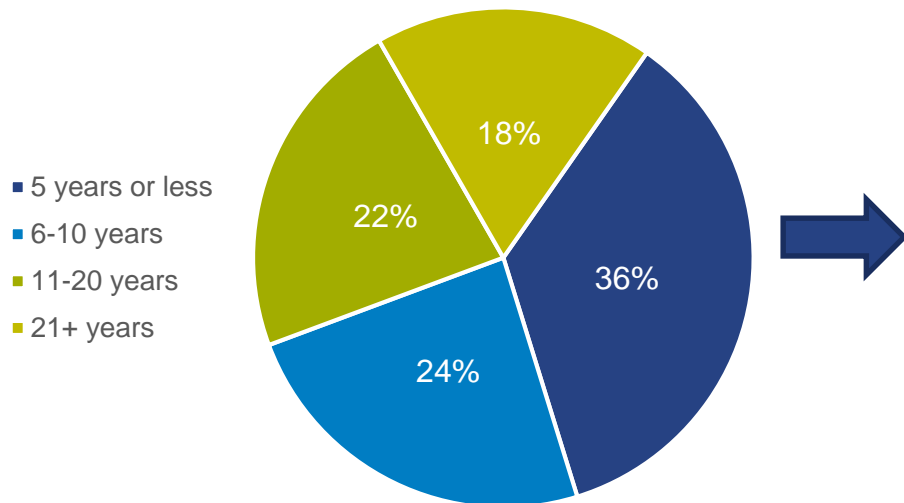
Margin of error (95% confidence level) for the total respondents (n=979) is +/- 3.1%

Treatment

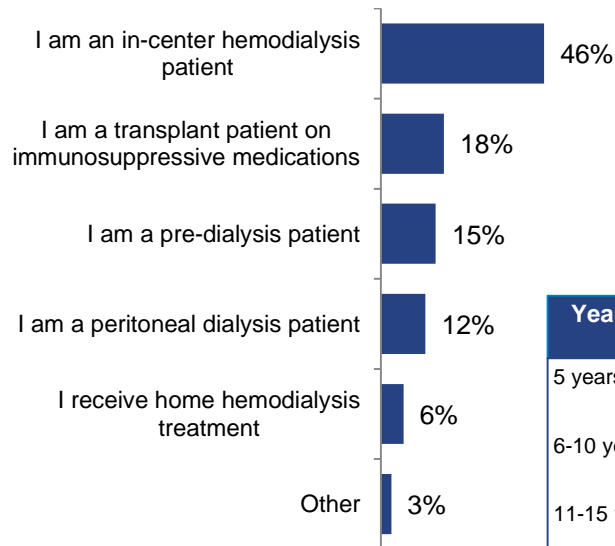
Diagnosis & Treatment

In-center hemodialysis is the most common treatment type among individuals with CKD.

First Diagnosis



Type of Treatment



Years on Dialysis (n=657)	
5 years or less:	71%
6-10 years:	19%
11-15 years:	5%
16+ years:	5%
Mean 5.1	

Base: All Respondents (n=979)

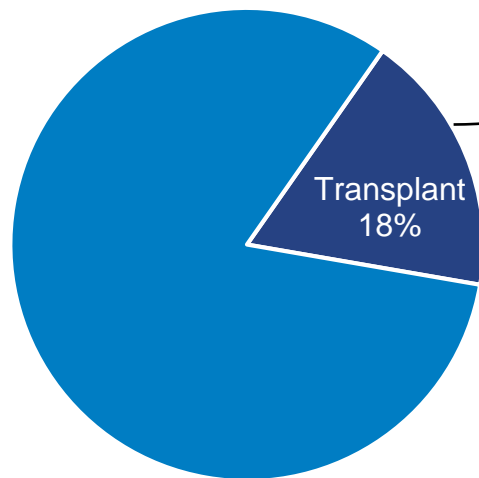
Q2alt. How many years has it been since you were first diagnosed with kidney disease?

Q3. What treatment do you receive for your chronic kidney disease (CKD)? Select one.

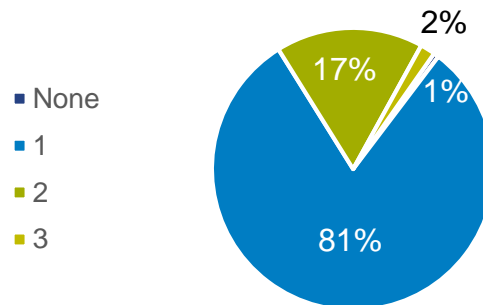
Q4a. How many years have you been on dialysis?

Transplant Patients

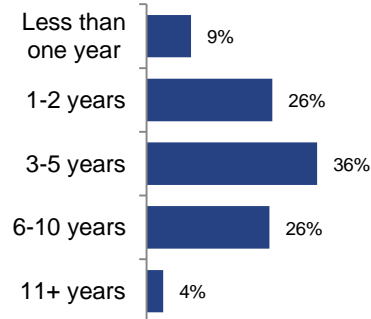
Nearly 1 in 5 dialysis patients have had a kidney transplant with most spending 3-5 years on dialysis before receiving their transplant.



of Transplants (n=172)



Time Spent on Dialysis Prior to Transplant (n=172)



Avg. = 4.2 years

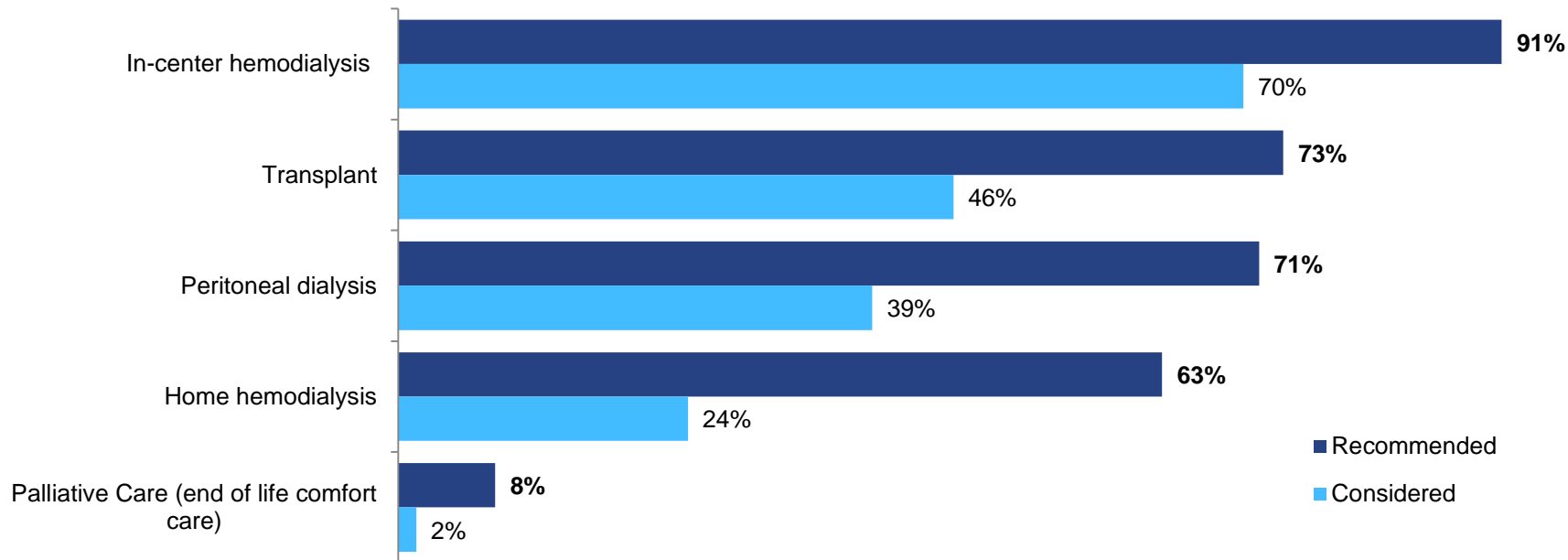
Base: Patients with Kidney Transplants (n=172)

Q4b. How many kidney transplants have you had?

Q4c. How many years were you on dialysis prior to your transplant?

Treatment Options: *Recommended vs. Considered*

The 3 most recommended treatment options are in-center hemodialysis, transplants, and peritoneal dialysis. Home dialysis continues to have the largest gap between recommended and considered.



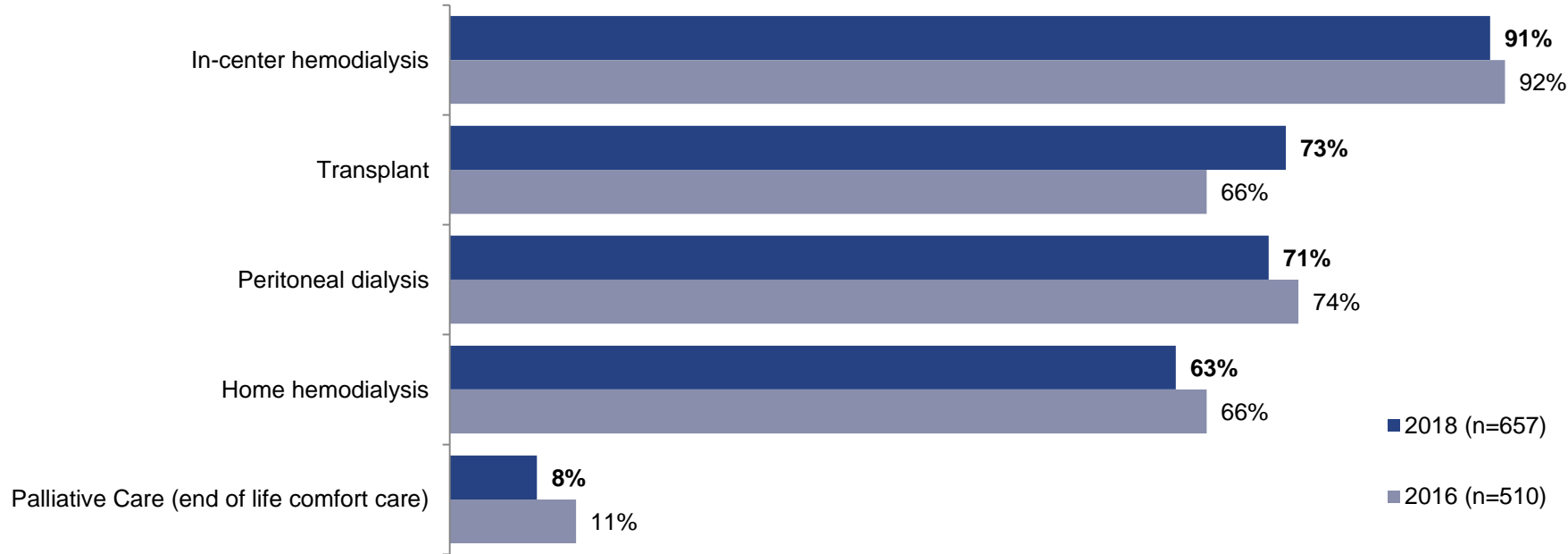
Base: Current Dialysis Patients (n=657)

Q5. What treatment options were you informed of by your healthcare team? Please select all that apply.

Q6. Of the dialysis options that you were informed of, which did you seriously consider? Please select all that apply.

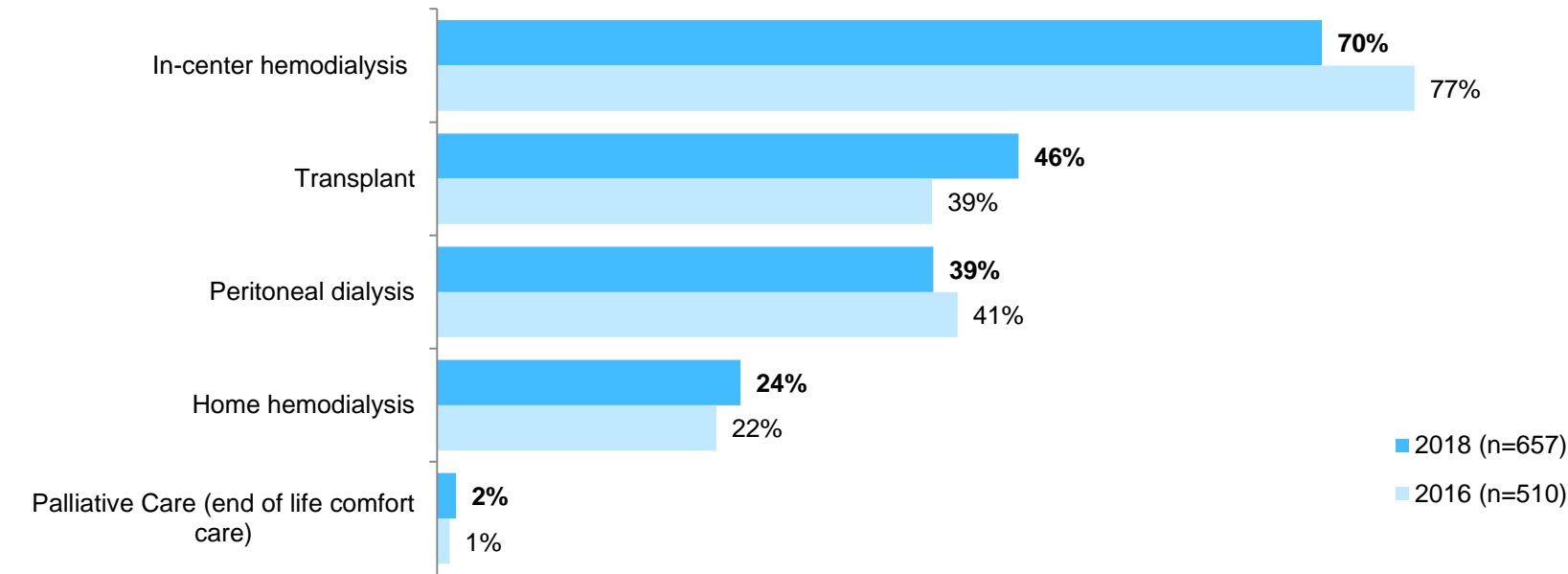
Treatment Options Recommended: 2018 vs. 2016

Dialysis patients are slightly better informed in 2018 about transplants than they were in 2016.



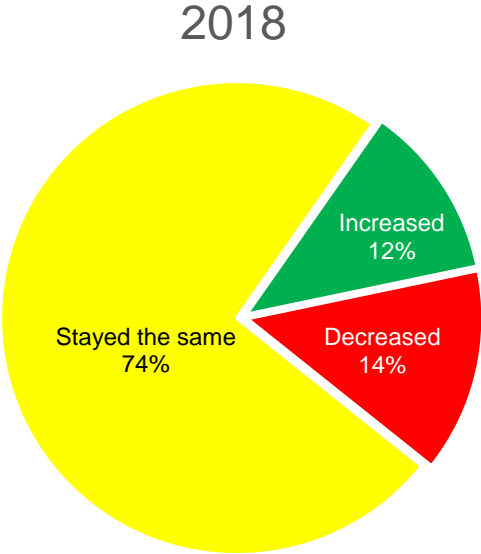
Treatment Options Considered: 2018 vs. 2016

In-center hemodialysis remains the most considered treatment option in 2018.



Time Spent with Health Care Providers: *Changes Within the Past Year*

3 of 4 patients claim that their time spent with nurse, technicians, etc. has remained the same over the past year.

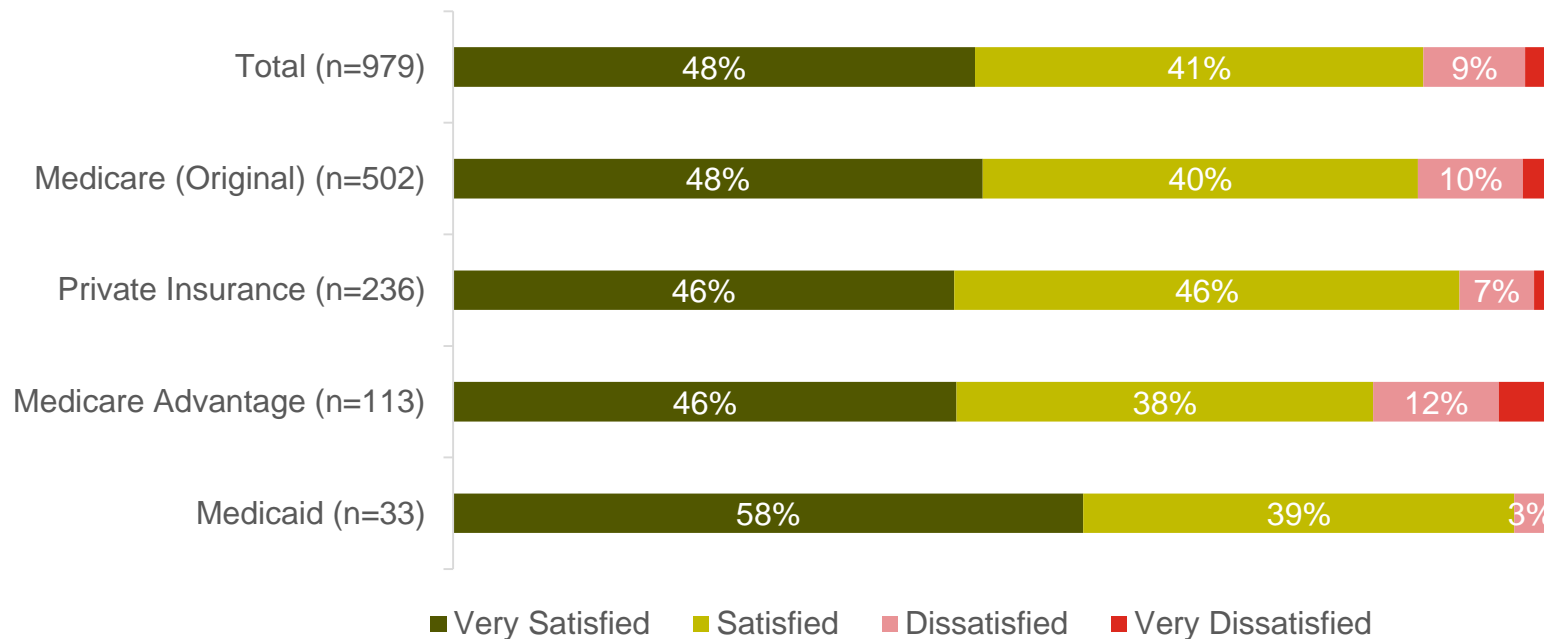


Base: Current Dialysis Patients (n=657)
Q15. In the past year, has time spent with health care providers (nurses, technicians) in your primary dialysis center...?

Satisfaction:

Satisfaction With Doctor's Concern for Overall Health

In general, most people feel satisfied with their doctor's concern for their overall health.



Base: All Respondents (n=979)

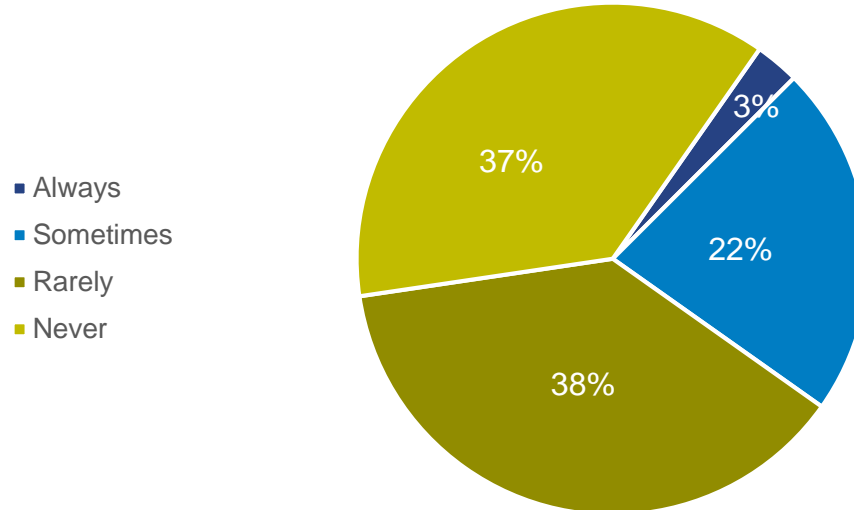
Q17. How satisfied have you been with the concern of doctors for your overall health rather than just for an isolated symptom or disease?

Problems Getting Access to Care:

Obtaining Medication

One-quarter of survey respondents indicated that they always or sometimes have issues getting access to the necessary medications.

Frequency of issues with getting access to medication



Base: All Respondents (n=979)

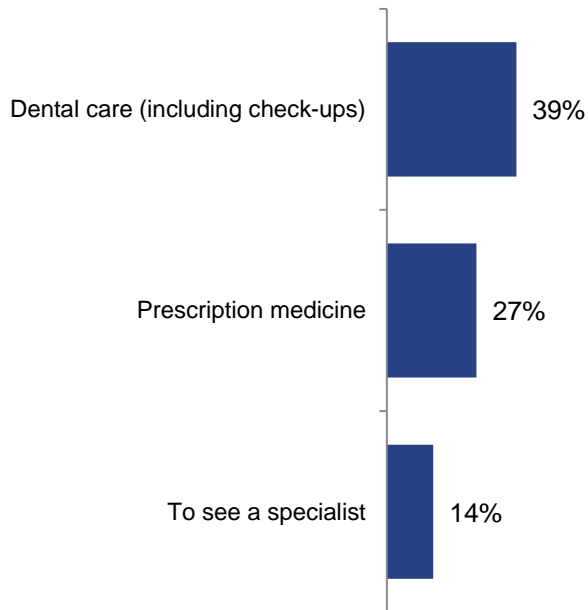
Q18. How often do you have problems getting access to necessary medications? Select one.

Problems Getting Access to Care:

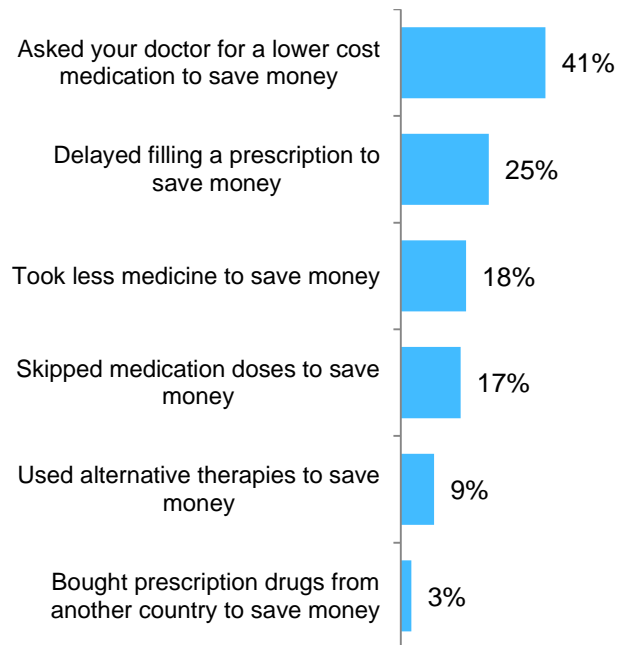
Affordability

Nearly 2 in 5 people stated that they could not afford dental care within the past year. In addition, an almost identical amount of people had also asked their doctor for lower cost medication in order to save money.

In Past 12 months, % couldn't afford...



In Past 12 months, % that...



Base: All Respondents (n=979)

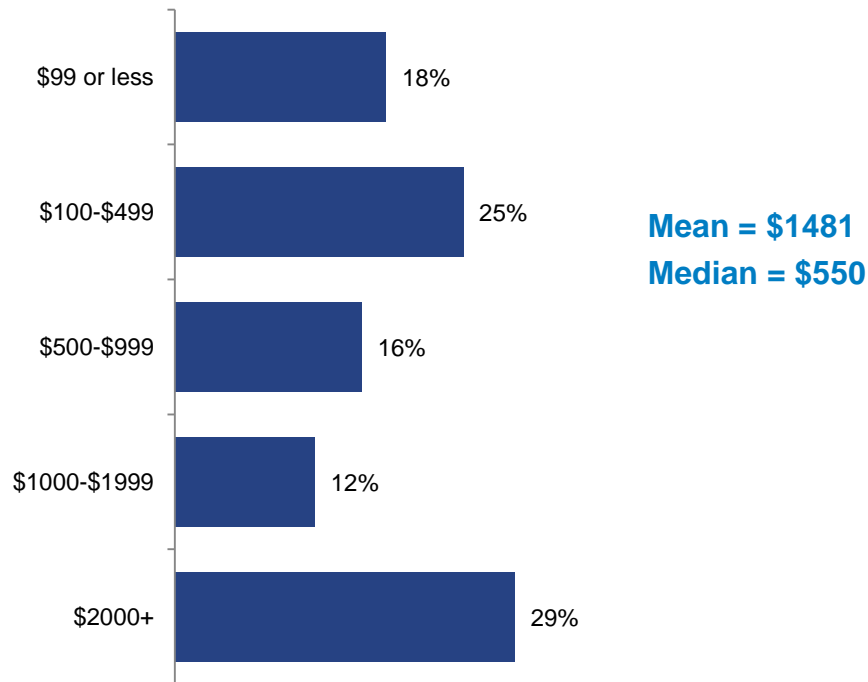
Q19. DURING THE PAST 12 MONTHS, was there any time when you needed any of the following, but didn't get it because you couldn't afford it?

Q20. DURING THE PAST 12 MONTHS, were any of the following true for you?...

Health Care Expenditures:

Out-of-Pocket Payments

The majority of patients spent \$2000+ out-of-pocket for health care in 2018.



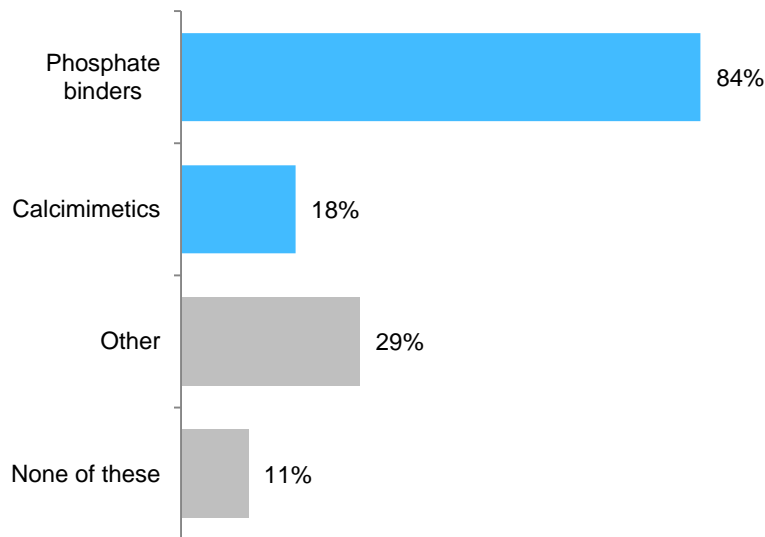
Base: All Respondents (n=979)

Q24. Thinking of the current calendar year of 2018 (January through today), about how much did you pay out-of-pocket for all your health care you received, meaning payments you made from your own funds, not payments made on your behalf by insurers or others? Please make your best estimate.

Oral Medications: Being Used by Patient & Monthly Expenditures

Phosphate binders is by far the most common type of oral medication being used among dialysis patients. Typical expenditures vary dramatically among patients.

Current Dialysis Patients Use...



**Those Who Use Phosphate Binders /
Calcimimetics (n=560)**

Monthly expenditures		Beginning of the year (January)	Most recent purchase
Phosphate Binders	Mean	\$124.95	\$74.05
	Median	\$15.00	\$10.00
Calcimimetics	Mean	\$101.28	\$97.52
	Median	\$1.10	\$0.50

Base: Current Dialysis Patients (n=657)

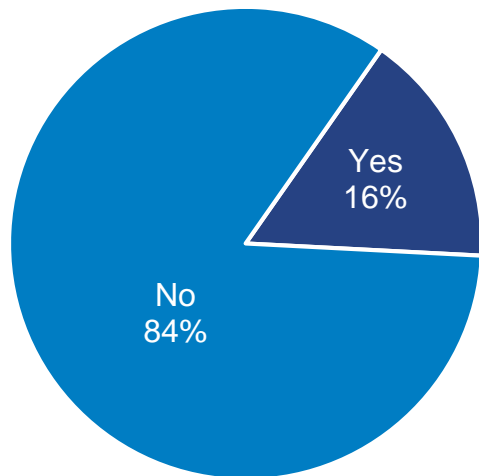
Q21. Which of the following oral medications are you currently using? Please select all that apply

Q22. [SKIP IF Q21=4] On average, how much do you spend monthly after insurance? Please answer separately for beginning of the year vs. currently.

Emergency Dialysis: *Hospitalization & Transition Back to Dialysis Center*

Less than 1 in 5 patients have been admitted into a hospital for emergency dialysis within the last 12 months. Over half of these patients believed that they had a smooth transition from hospital back to their dialysis center.

Hospitalized because of emergency dialysis in the past year

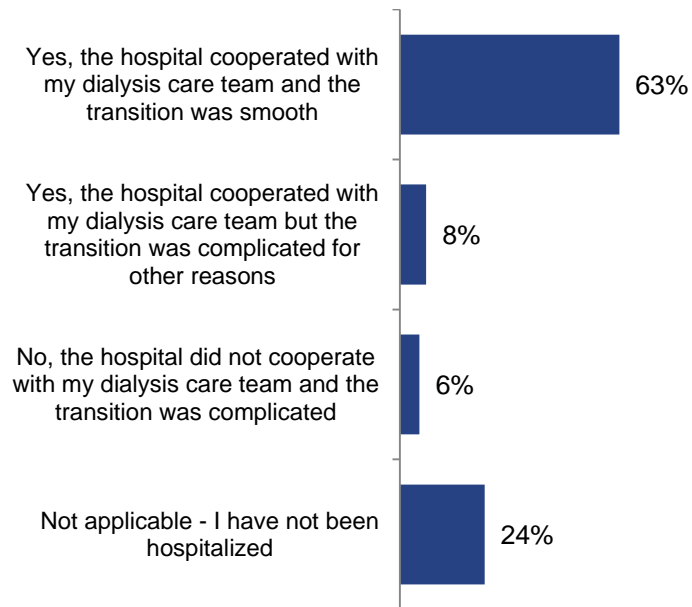


Base: Current Dialysis Patients (n=657)

Q8. Within the last year, have you had to be admitted to the hospital for emergency dialysis?

Q9. Thinking back to the last time you were hospitalized, did the hospital do everything it could to ensure a safe and proper transition of your care back to your dialysis facility and nephrologist, such as giving you clear written discharge instructions and sending your charts to the dialysis clinic?

Smoothness of transition



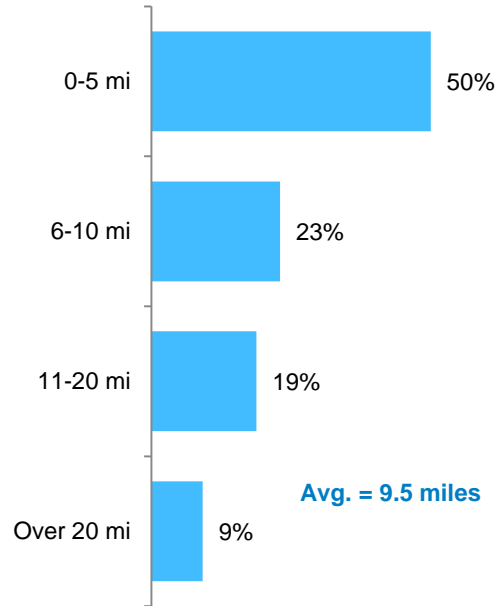
Dialysis Facility

Location of Dialysis Facility

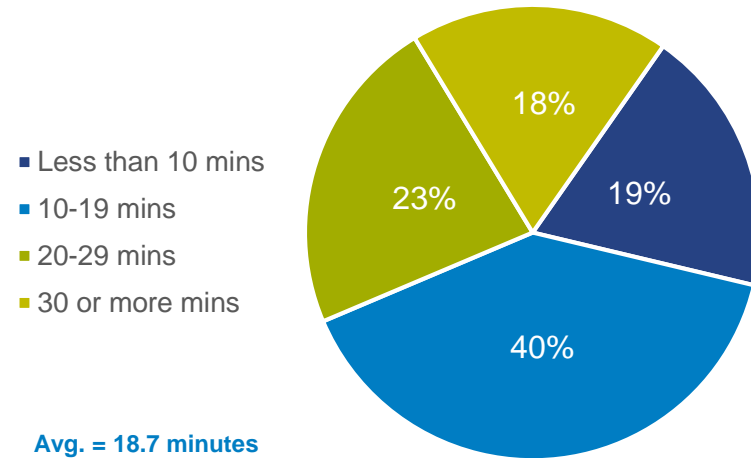
Time / Distance Spent Getting to Facility

The average dialysis patient spends 18.7 minutes (or travels 9.5 miles) in order to get to their dialysis facility.

of miles to get to dialysis facility



of minutes to get to dialysis facility



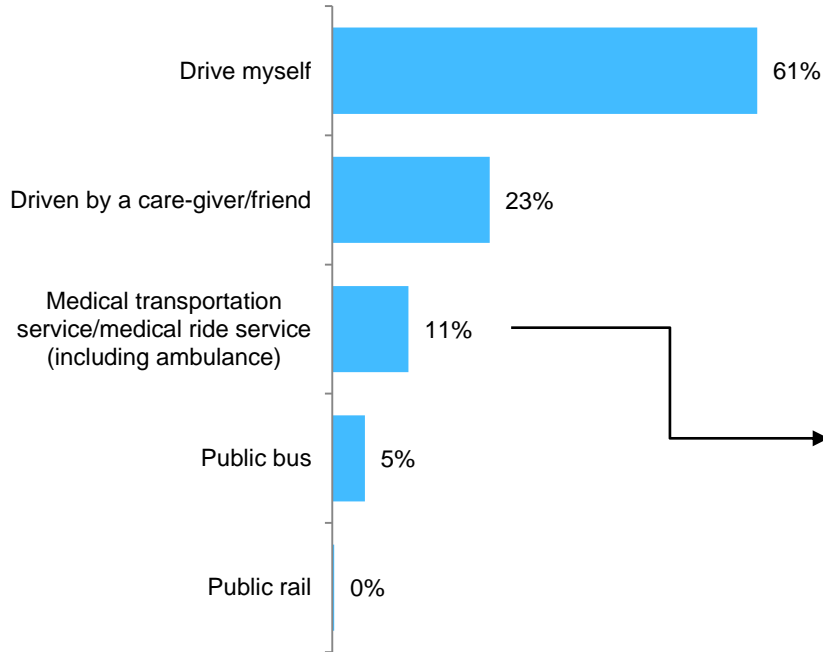
Base: Current Dialysis Patients (n=657)

Q12. How far away is your primary or current dialysis facility in miles?

Q13. How many minutes, on average, does it take you to get to your dialysis facility?

Primary Mode of Transportation to Dialysis Facility

Only 1 in 10 patients state that they use medical ride services to get to their dialysis center.



MOST FREQUENTLY USED MEDICAL RIDE SERVICE

Van or sedan (not taxi)		39%
Wheelchair-accessible vehicle		25%
Stretcher-accessible vehicle		4%
Lyft or Uber		4%

Base: Current Dialysis Patients (n=657)

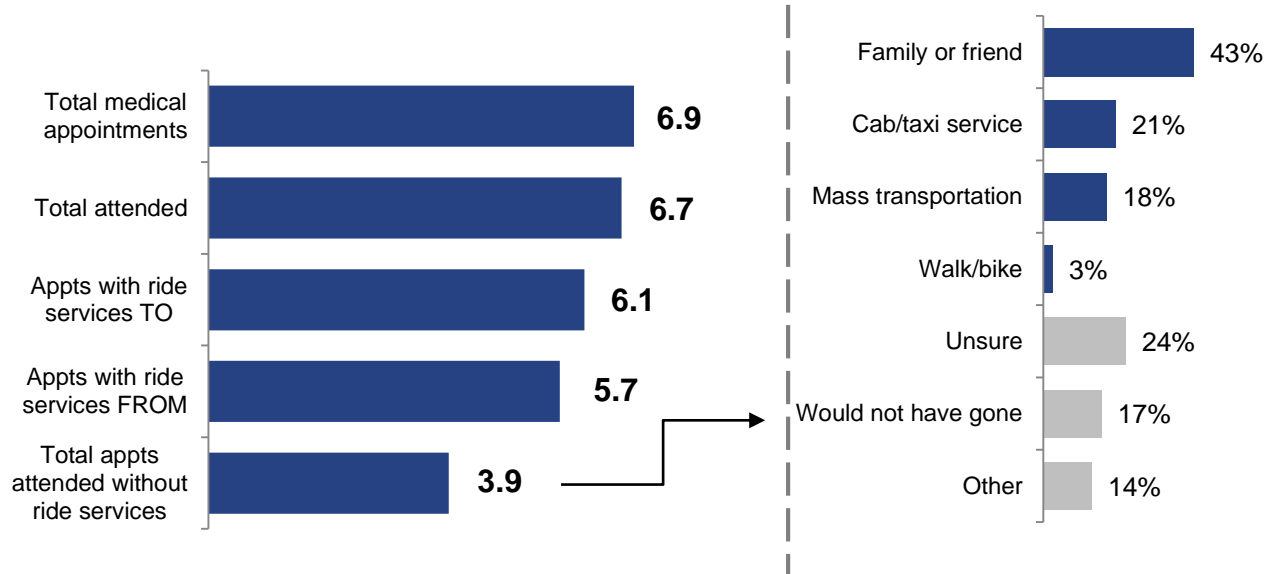
Q10. What is your primary mode of travel to your current dialysis facility? Select one.

Q10a. What type of medical ride service do you use most frequently? Select one.

Patients Using Medical Transportation Services

of Appointments (Scheduled vs. Attended)

The vast majority of those currently using medical transportation attend most of their appointments. If they did not have access to rides, the number of attended appointments would decline dramatically.



Base: Patients Who Use Medical Transportation Services/ Medical Ride Services (n=72) [Q10=3]

Q10b. How many medical appointments, per month, do you typically have scheduled to treat your condition?

Q10c. How many of those medical appointments, per month, would you say that you go to?

Q10d. Of the [ANSWERQ10c] medical appointments you go to per month... How many of them do you use ride services for the trip to the appointment?

Q10e. Of the [ANSWERQ10c] medical appointments you go to per month... How many of them do you use ride services for the trip home from the appointment?

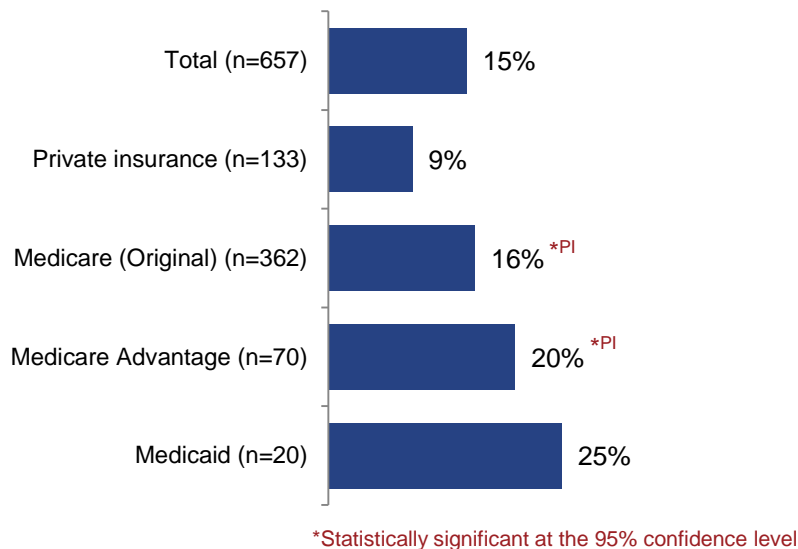
Q10f. If you did not have access to medical rides, how many of your [ANSWERQ10b] monthly appointments do you believe you would attend?

Q10g. If you did not have access to medical rides, how would you get to and from your medical appointments?

Difficulty Attending Medical Appointments

By Primary Health Plan

1 out of 7 dialysis patients say they have difficulty attending their appointments. Those with Medicare or Medicare Advantage are more likely than private insurance patients to indicate this.



Base: Dialysis Patients (n=657)

Q11. Do you have difficulty attending all of your medical appointments?

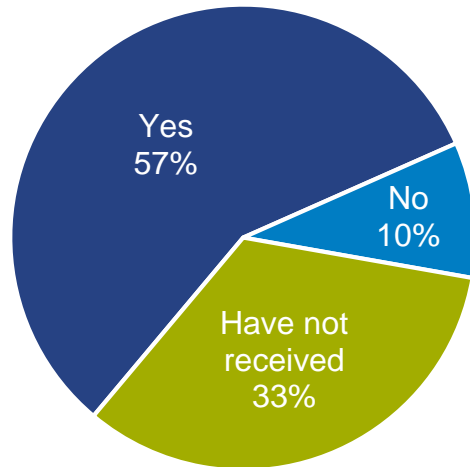
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Medicare In-Center Hemodialysis Survey:

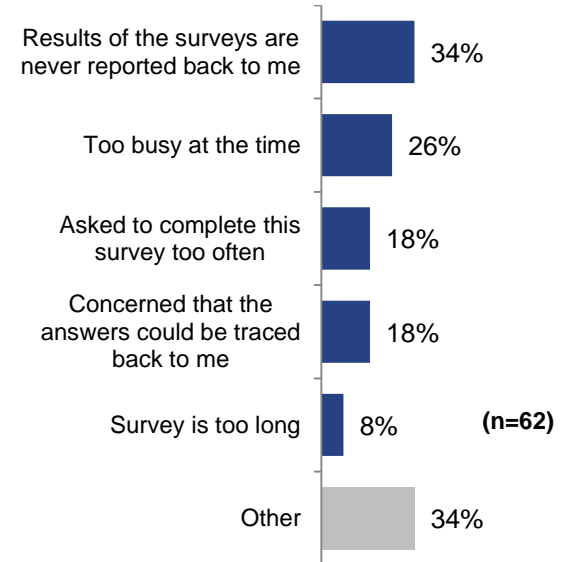
Survey Completion

About 3 in 5 patients completed the In-Center Hemodialysis Survey. Those that did not complete the survey cited that the main reason they did not was because the survey results were never reported back to them.

Survey Completion



Reasons not to...



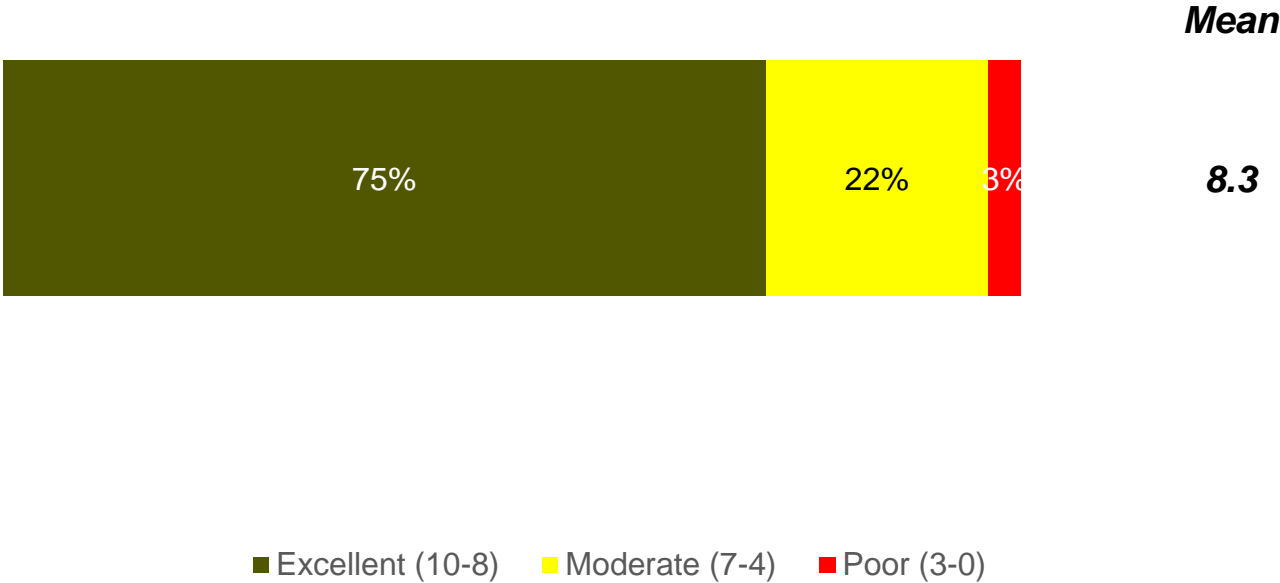
Base: Current Dialysis Patients (n=657)

Q23. Most dialysis patients are asked to complete the "Medicare In-Center Hemodialysis Survey." This is the survey mailed twice each year asking about your experiences with the dialysis center and clinicians. Thinking back to the last time you received the survey, did you complete it and mail it back?

Q23a. [ASK IF Q23=2] Why did you not complete the "Medicare In-Center Hemodialysis Survey" the last time you received it? Select all that apply.

Quality Care Rating

Three-quarters of dialysis patients believe they are receiving excellent quality care from their facility.

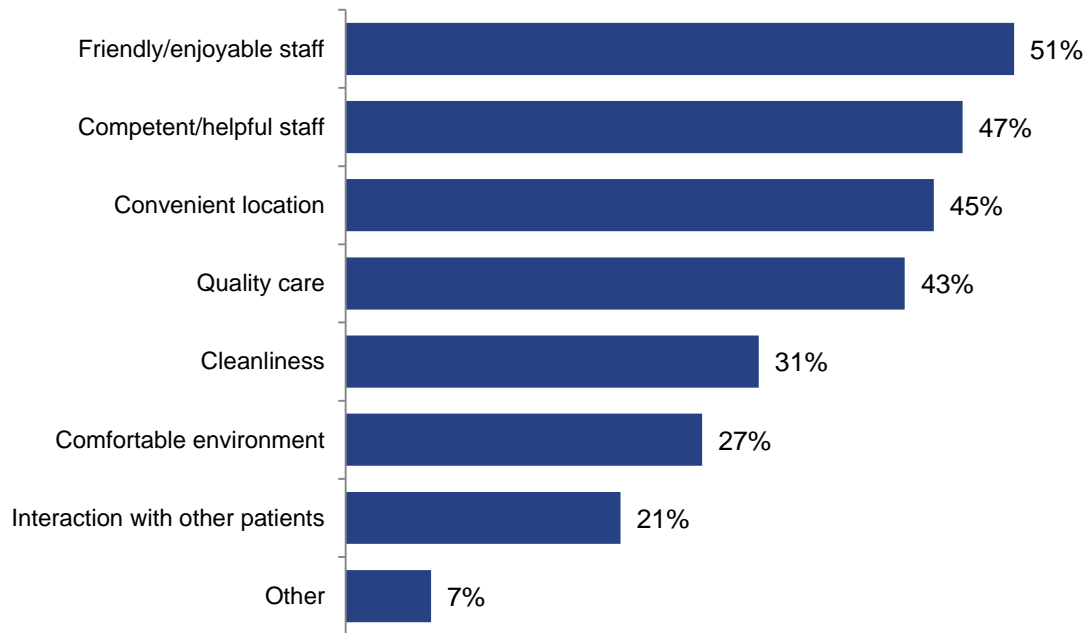


Base: Current Dialysis Patients (n=657)
Q33. How would you rate the quality care you currently receive at your dialysis facility? Please use 1-10 point scale where 1=Poor and 10=Excellent quality of care.

Positives Regarding Dialysis Facility

What Patients Like Most Is...

The two main positives behind what patients like in their dialysis facility is that the staff is friendly/enjoyable and competent/helpful.

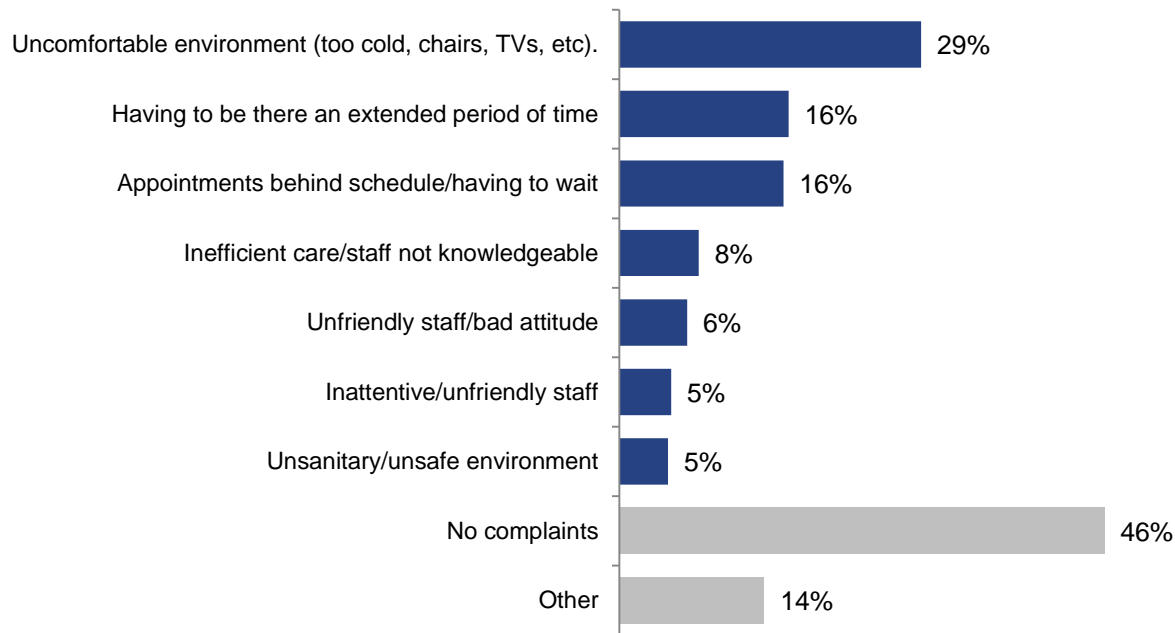


Base: Current Dialysis Patients (n=657)

Q34. What do you like best about your dialysis facility? Select all that apply.

Negatives Regarding Dialysis Facility: *What Patients Dislike Most is...*

A little over half of dialysis patients have concerns with their dialysis facility. The top complaints about dialysis centers are uncomfortable environment, long visits, and extended wait times.



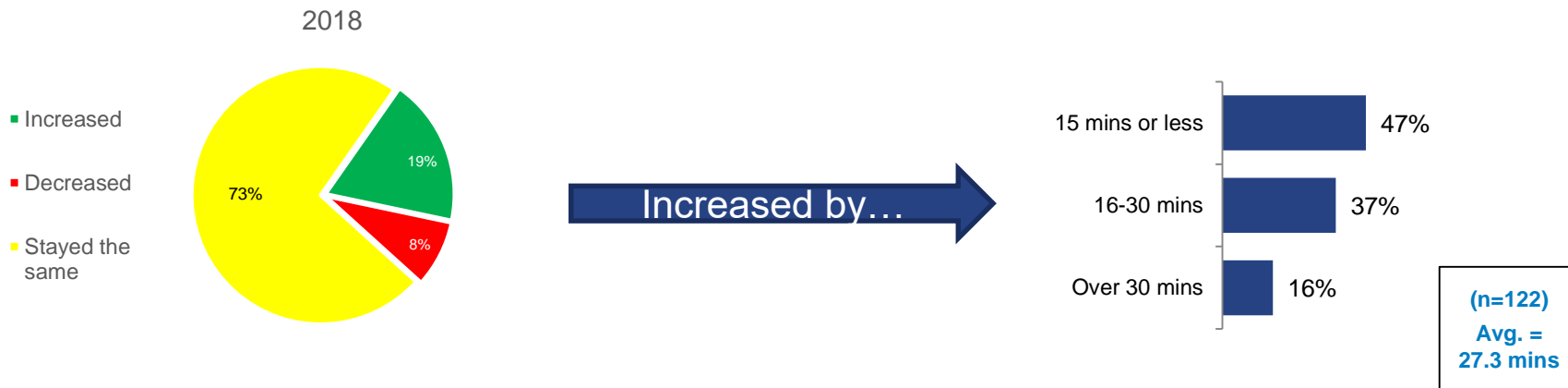
Base: Current Dialysis Patients (n=657)

Q35. What concerns or complaints do you have about your dialysis facility?

Wait Times for In-Center Dialysis Facility: *Changes Within the Past Year*

About 1 in 5 patients believe that wait times have increased over the past year, however, half of these patients state that the wait time has only increased by 15 minutes or less.

Wait Times



Base: Current Dialysis Patients (n=657)

Q14. In the past year, have wait times for your in-center dialysis facility...?

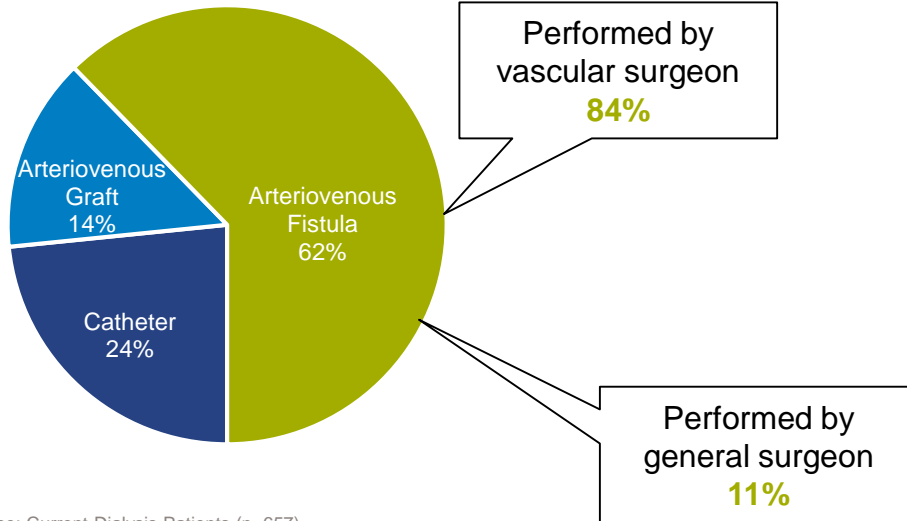
Q14a. How long, on average, have wait times for your in-center dialysis facility increased?

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Fistula Patients:

Type of Access, Surgeon, and Fistula Problems

Type of Access



Base: Current Dialysis Patients (n=657)

Q36. What type of access do you currently have? Select one.

Q36a. Was your fistula surgery performed by a general surgeon or a vascular surgeon?

Q37. Have you had any problems with your fistula?

Q38. How long did it take to get the problem fixed?

(n=409)

- **43%** of patients indicated that they have had issues with their fistula now or in the past.

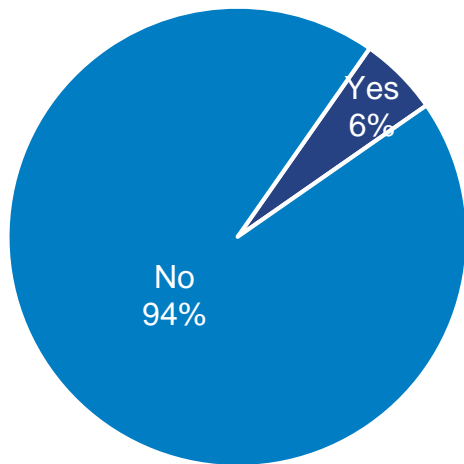
(n=174)

- On average, the fistula problem took **almost 4 days** to be resolved

Dialysis Vascular Access Center Closures

A small amount of fistula patients have had vascular access centers close on them during the past couple years. The good news is that most of these patients only need to travel 5 miles or 15 minutes to get to another facility to receive treatment.

Vascular Access Centers that have closed



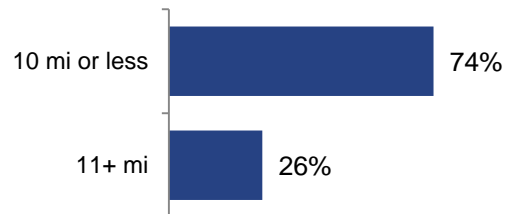
Base: Fistula Patients (n=409)

Q39. In the past few years, have any dialysis vascular access centers closed where you used to receive care?

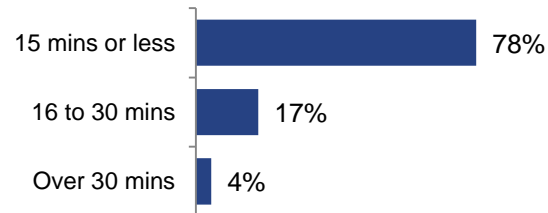
Q39a. How much farther do you have to travel now to receive care for your access? You can answer with number of miles or number of minutes more that you have to travel.

OF THOSE WHO SAID YES TO Q39
(n=23)

Additional MILES traveled

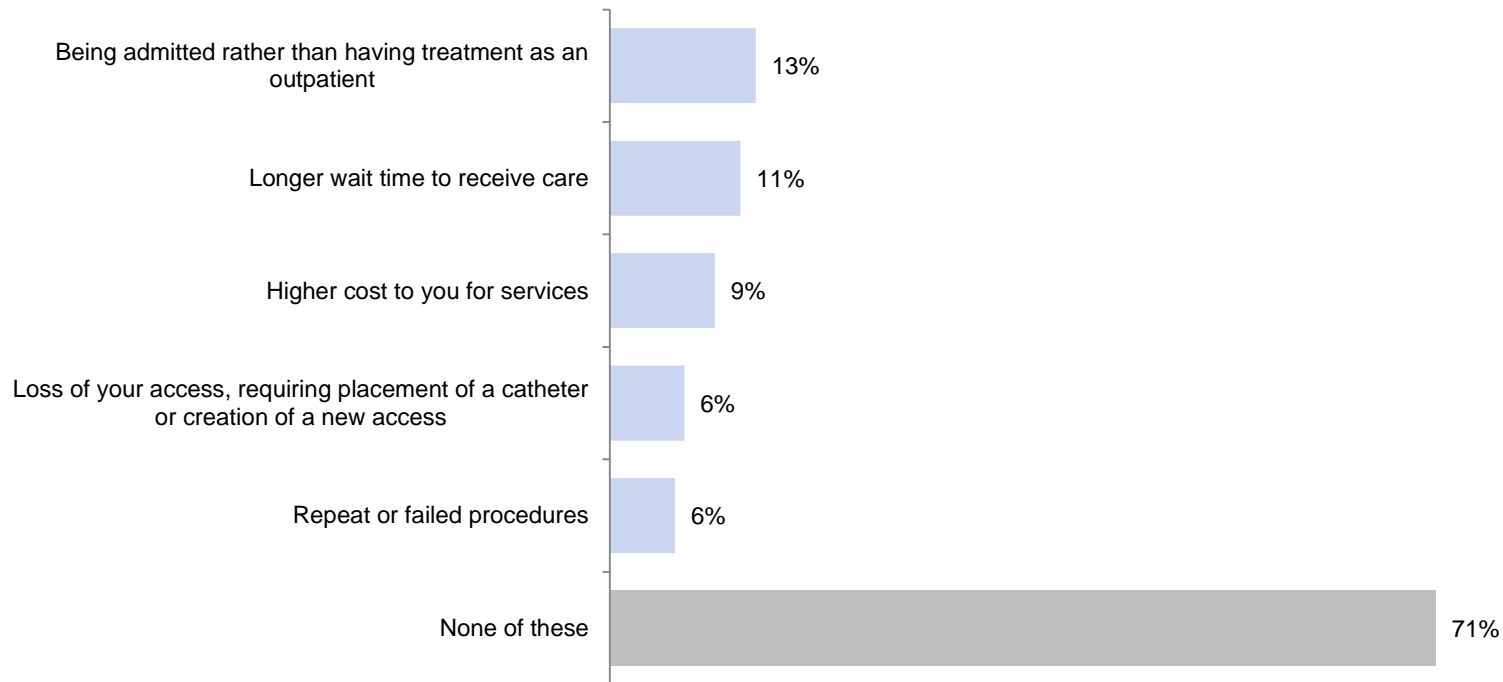


Additional MINUTES traveled



Hospital-Related Dialysis Issues & Concerns

Most fistula patients do not have any hospital-related issues, however, a few do cite being admitted into the hospital rather than having treatment as an outpatient.



Base: Fistula Patients (n=409)

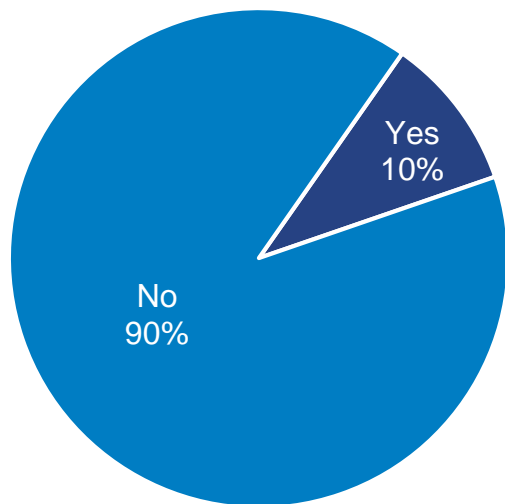
Q40. If you go to the hospital to receive care for your dialysis access, please indicate if you have experienced any of the following? Select all that apply.

Violence at Dialysis Centers:

Witnessing, Sources, and Confidence in Staff to Handle Situations

1 in 10 patients say that they have witnessed violence at their dialysis center with the primary source coming from another patient. Overall, most patients are unsure if their dialysis center is well equipped or prepared to deal with violent situations.

Witnessing Violence at Dialysis Center



Base: Current Dialysis Patients (n=657)

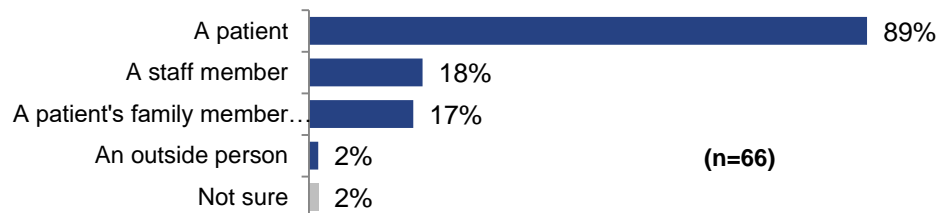
Q41. Have you ever witnessed violence at your dialysis center? (Hitting, kicking, threatening, or any other behavior that you thought was violent.)

Q42. Identify the source or sources of the violence (check all that apply)

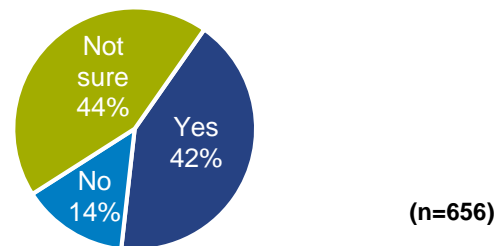
Q43. Are you confident that the staff at your dialysis center is adequately trained to deal with threats of violence or actual violent situations?

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Sources of violence



Confidence in staff to handle violent situations



Quality Metrics for Dialysis Facilities / Healthcare Bodies

Overall Quality of Dialysis Center:

Important Measures Facility Should be Accountable For

Caring, respectful staff and communication are the most important measures of a quality dialysis center for patients. Hospitalization or vascular access rates are relatively low.



Base: All Respondents (n=979)

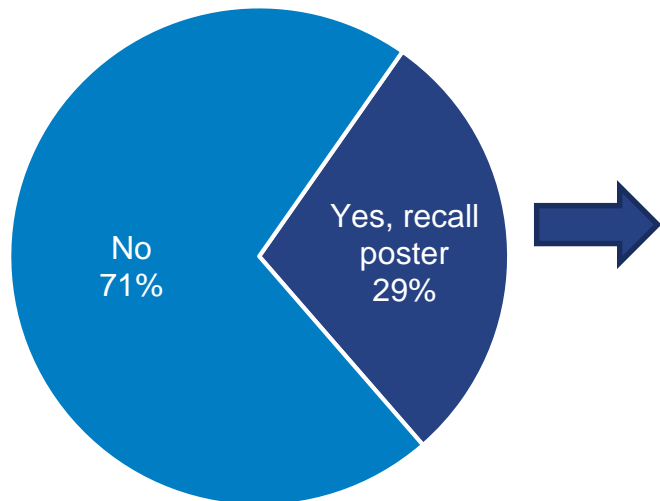
Q32. We would like you to select the most important measures when evaluating the overall quality of the [dialysis] facility. These should be measures that are important to you and measures you think a facility should be held accountable for. **Please select no more than 5 measures.**

Quality Incentive Program:

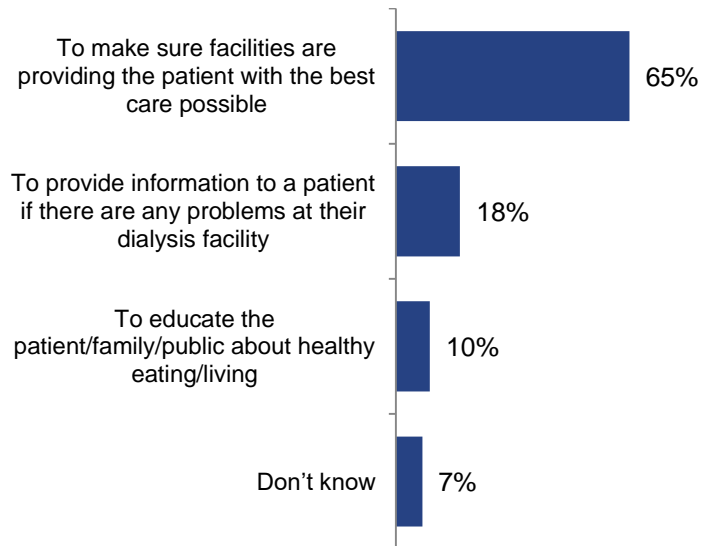
Awareness of Poster & Understanding of Program

Less than one-third of current dialysis patients recall seeing a Quality Incentive Program poster at their primary dialysis facility. The majority of those seeing the poster believe the program is to make sure the facility is providing patients with the best care possible.

Quality Incentive Program Poster Recall
(n=657)



Understanding of Program (n=190)



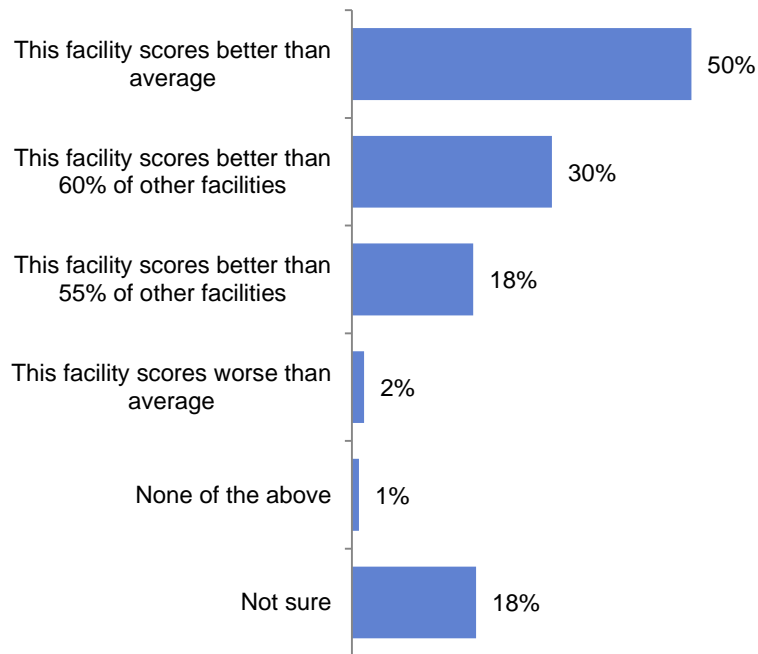
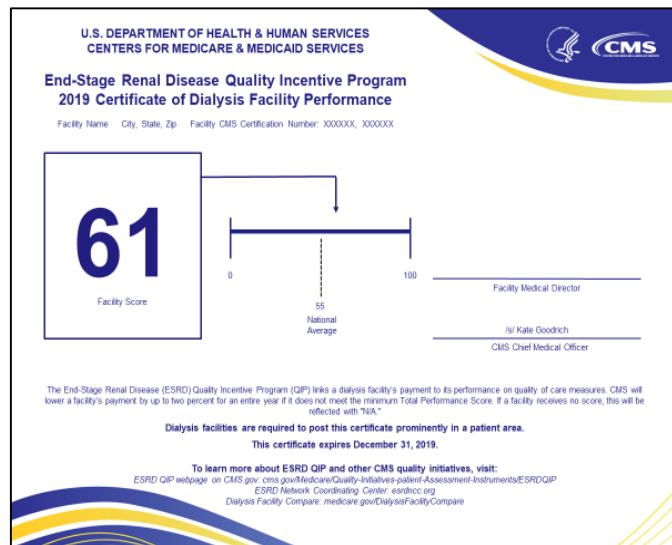
Base: Current Dialysis Patients (n=657)

Q16. Do you recall seeing a poster in your primary dialysis facility regarding the Quality Incentive Program?

Q16a. What is your understanding of this program?

Quality Incentive Program: Poster Interpretation

Most patients believe that the number “61” on the poster represents that the following facility scores above average compared to other facilities.

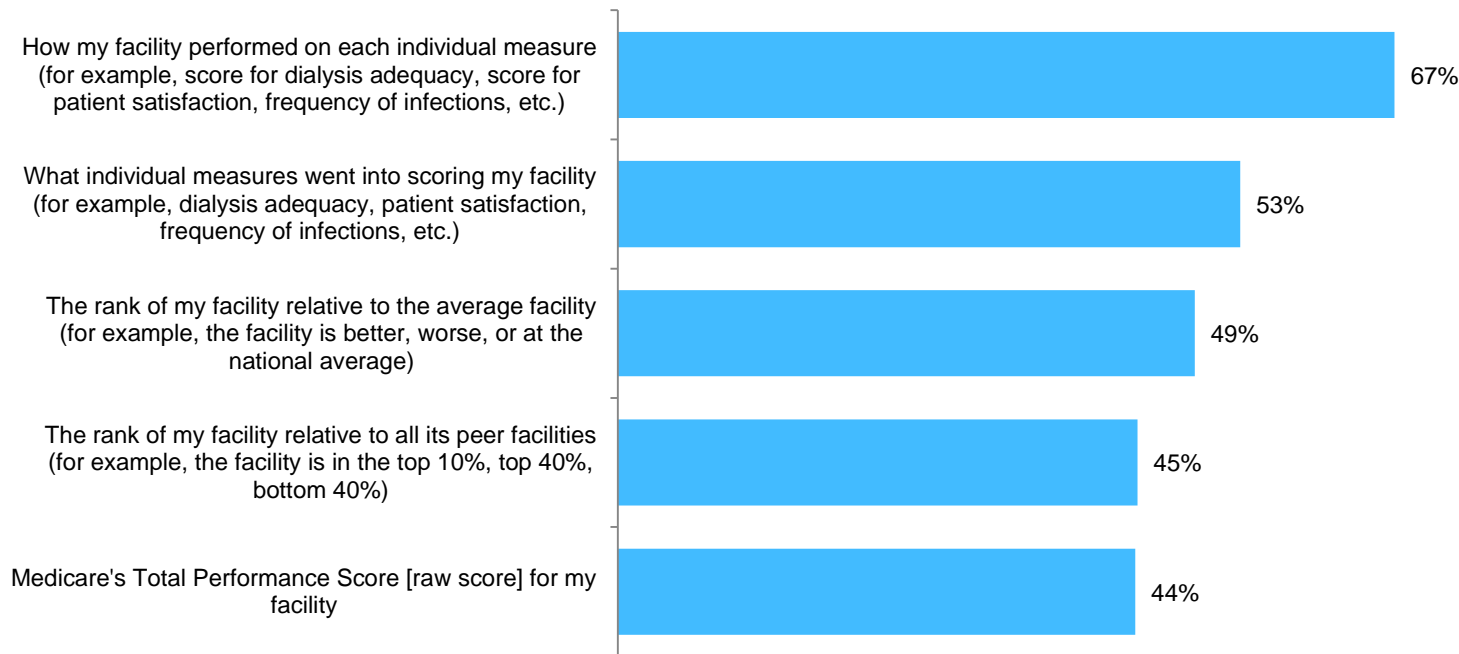


Base: All Respondents (n=979)

Q16d. Shown below is Medicare's new Quality Improvement Program poster that will be displayed in dialysis facilities beginning next year... To the best of your understanding, what does the number 61 on the poster mean? Select all that apply.

Quality Incentive Program: *Information Would Most Like to See Addressed on Poster*

Several patients stated that they would like to see how their facility performed on individual measures on the new Quality Incentive Program posters.



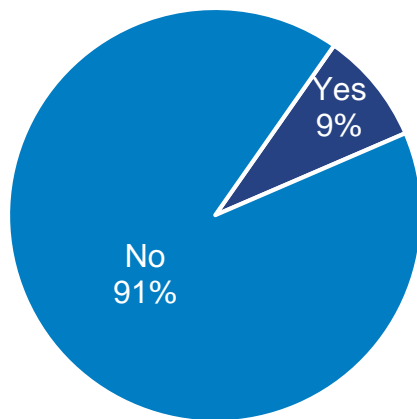
Base: All Respondents (n=979)

Q16e. In your own opinion, what information would you like to see on the Quality reporting poster in your facility. Select all that apply.

“Dialysis Facility Compare” / Opinions on Quality Care

Only 1 in 10 people have used the “Dialysis Facility Compare” feature on the Medicare website. Survey respondents also believe that the best way to ensure high-quality care is to have educated and activated caregivers who speak up for themselves.

Visited the Medicare website to use “Dialysis Facility Compare”



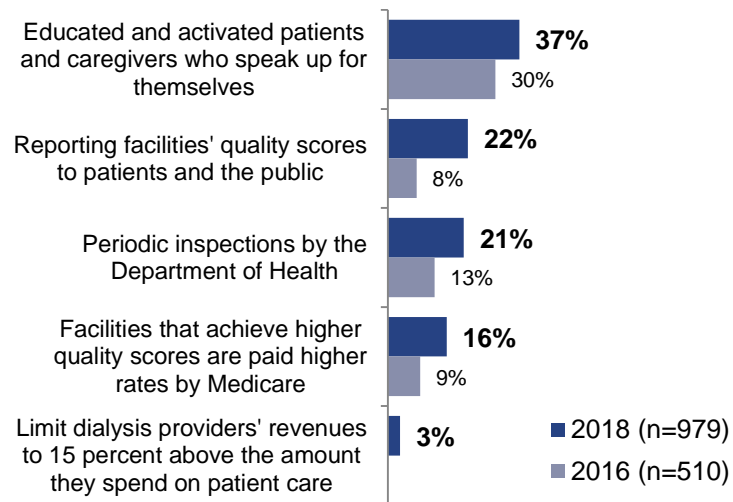
Base: All Respondents (n=979)

Q30. “Dialysis Facility Compare” is a tool on the Medicare website that helps beneficiaries compare the quality of care and patient experience at dialysis facilities in their area. In the past year, have you visited the Medicare website to use “Dialysis Facility Compare”?

Q31. In your opinion, which of the following is the best way to ensure high-quality care for dialysis patients? Select one.

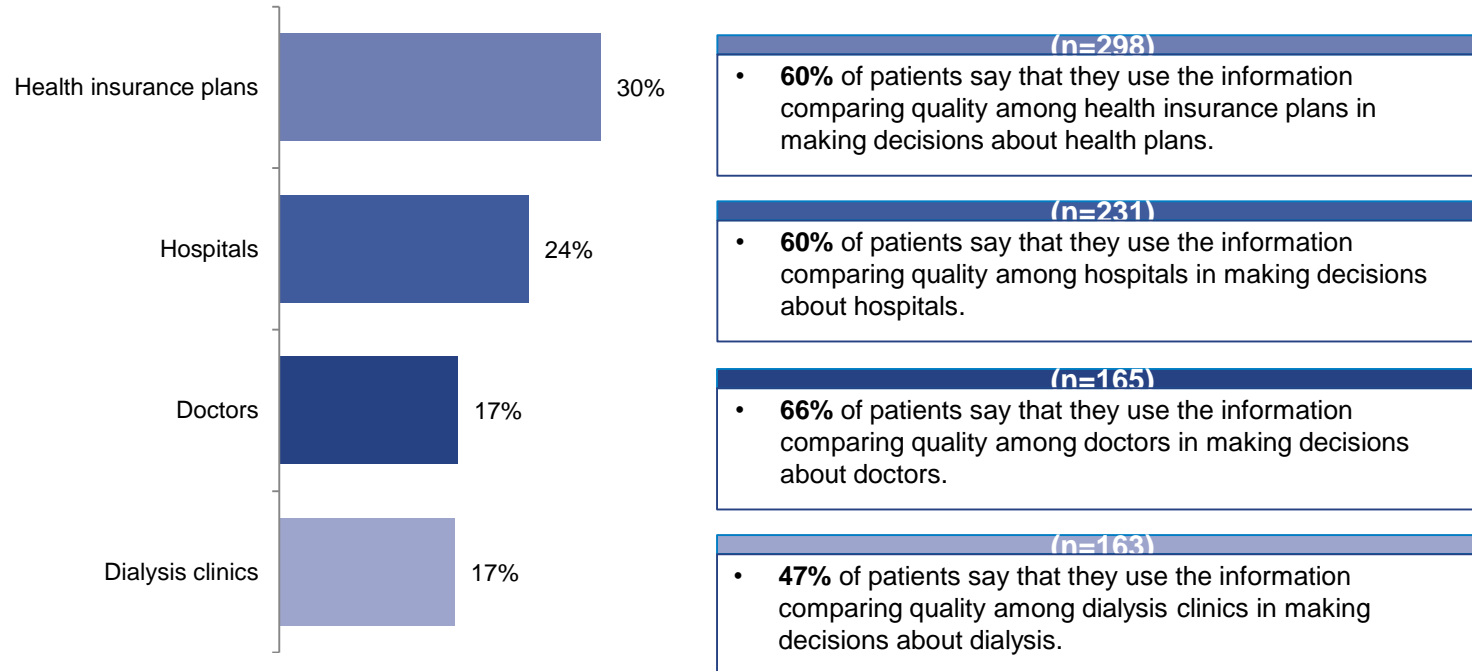
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Best way to ensure high-quality care for dialysis patients



Information Sources for Quality: *Use of Information*

Respondents are most likely to have received comparison information about health insurance plans. Nearly 1 in 5 respondents say that they have seen information comparing the quality between doctors. Of these individuals, two-thirds of them indicated that they use the information that they see or hear in making decisions about which doctor to choose.



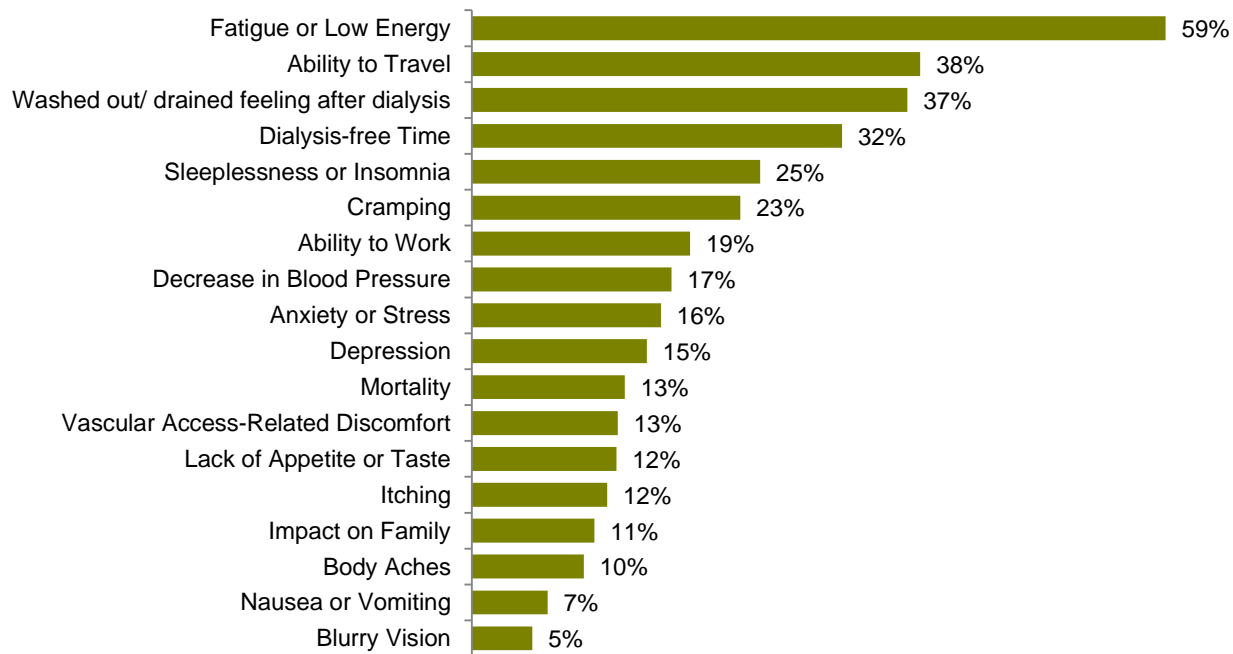
Base: All Respondents (n=979)

Q25. In the past 12 months, have you seen any information comparing quality of the following healthcare bodies?... Q26-Q29. Did you personally USE the information you saw comparing quality among...

New Product Development

New Product Development: *Conditions Would Most Like to See Addressed*

3 out of 5 patients would like to see fatigue/low energy addressed via new product development.

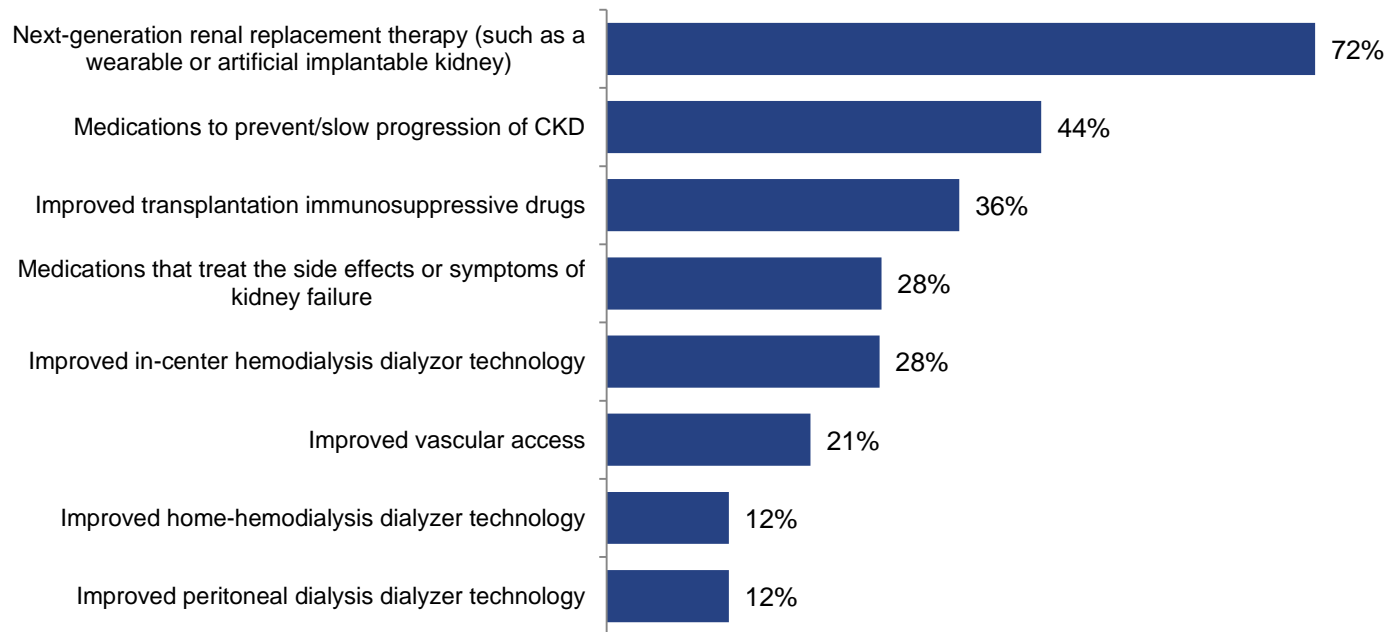


Base: All Respondents (n=979)

Q47. Which conditions below would you most like to see be addressed through new product development (drugs, devices, biologics, or otherwise)? Select up to 4 responses.

New Product Development: *Products Would Most Like to See Developed*

The most interest is in a next-generation renal replacement therapy.

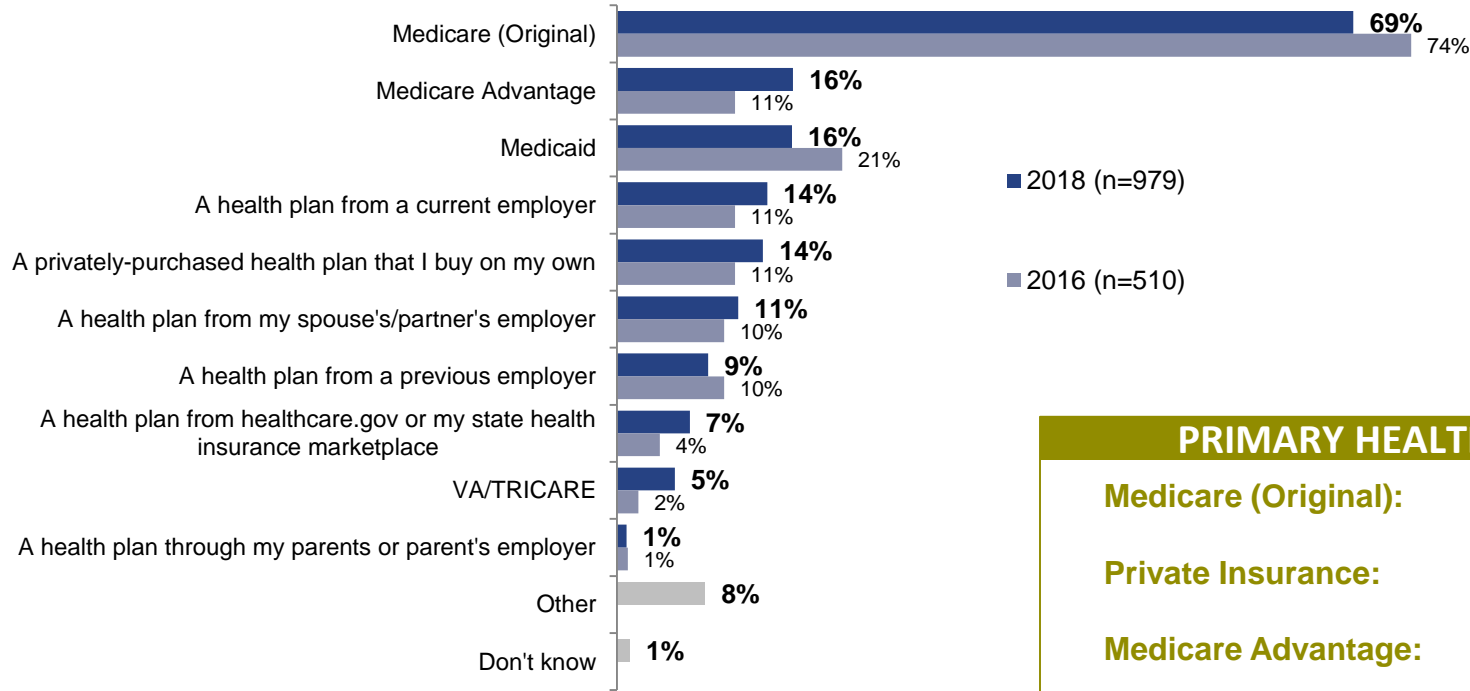


Base: All Respondents (n=979)

Q46. Which new products would you most like to see be developed and become available to you or to other kidney patients? Select up to 3 responses.

Appendix

Health Insurance Plans



PRIMARY HEALTH PLAN	
Medicare (Original):	51%
Private Insurance:	24%
Medicare Advantage:	12%
Medicaid:	3%

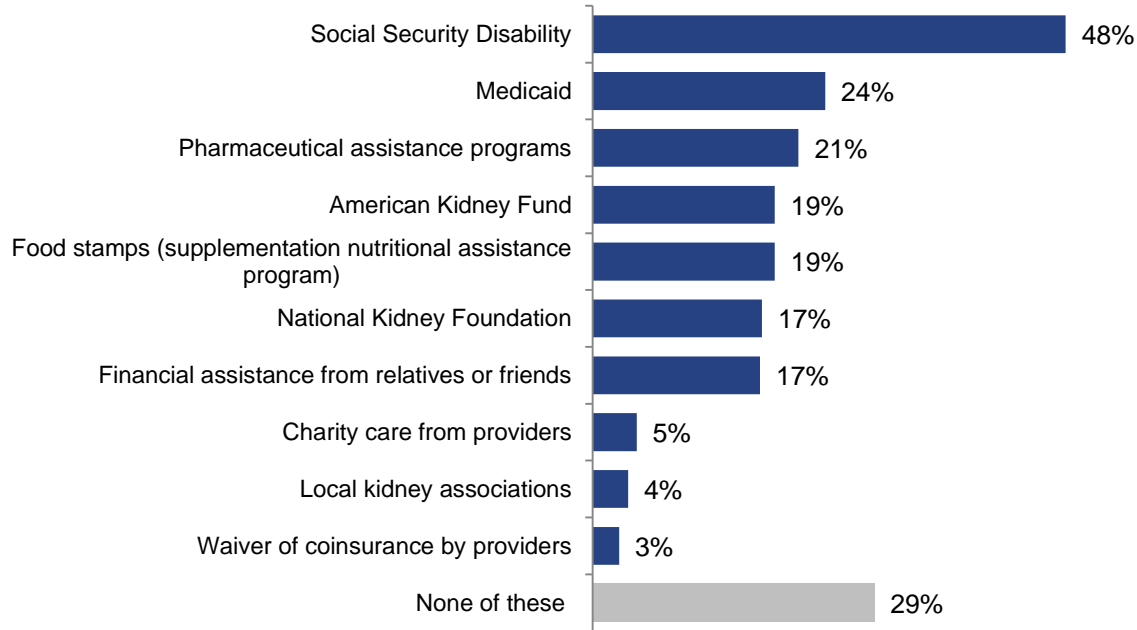


Base: All Respondents

Q44. Please select the type of health plan that insured you in 2018. Please select all that apply.

Q44a. Which one plan did you rely on MOST? Select one.

Financial / Assistance Programs Relied On

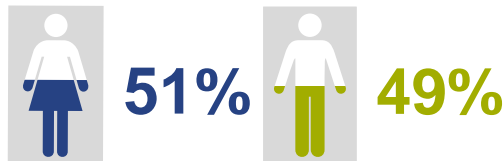


Base: All Respondents (n=979)

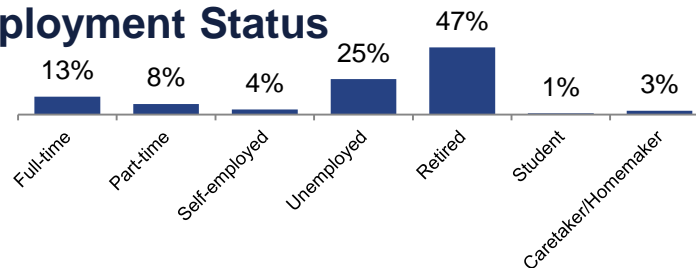
Q45. Which, if any, of the following financial or medical assistance programs have you ever relied on? Please select all that apply.

Demographics

Gender



Employment Status



Age

18-25	26-34	35-44	45-54	55-64	65-74	75+
1%	2%	9%	20%	31%	25%	12%

Average:
60.2 years

Base: All Respondents (n=979)

ETHNICITY

Caucasian (62%)
African American (22%)
Hispanic or Latino (6%)
Asian (2%)
American Indian or Alaskan Native (1%)
Native Hawaiian or Pacific Islander (1%)



Thank you!

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clearer vision  smarter decision

