



CANCER*care*®

# Patient Access & Engagement Report



2016

# Highlights Slides

## Table of Contents



Background and Objectives	3
Survey 1: Diagnosis	5
Survey 2: Treatment Planning	15
Survey 3: Communications	26
Survey 4: Finances and Insurance	39
Survey 5: Symptoms and Side effects	53
Survey 6: Survivorship	65

# Background and Objectives



Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by masters prepared oncology social workers and world-leading cancer experts.

The 2016 CancerCare Patient Access and Engagement Report is intended to visibly and effectively represent the voice of cancer patients, advocate for their access to the best and most advanced care, and define and promote patient engagement to enhance their quality of life and optimize their outcomes. Through fielding 6 surveys and collecting the responses of more than 3000 people who have been diagnosed with cancer, this report:

- Defines engagement specifically as it relates to cancer patients
- Identifies barriers to cancer patient engagement with care providers
- Characterizes the financial, emotional, social and quality of life costs of cancer to patients and families
- Recommends strategies and programs to promote cancer patient access and engagement

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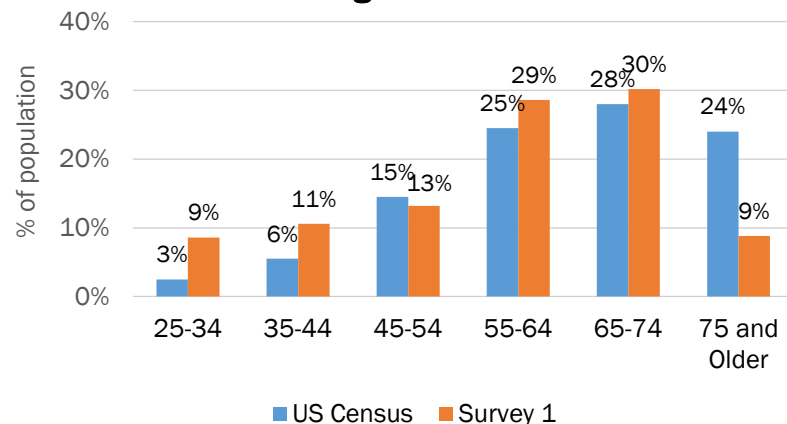
## Michael K. Wong, MD, PhD, FRCPC

Berle and Lucy Adams Chair in Cancer Research; Professor of  
Clinical Medicine; Section Chief, Solid Tumor USC Norris  
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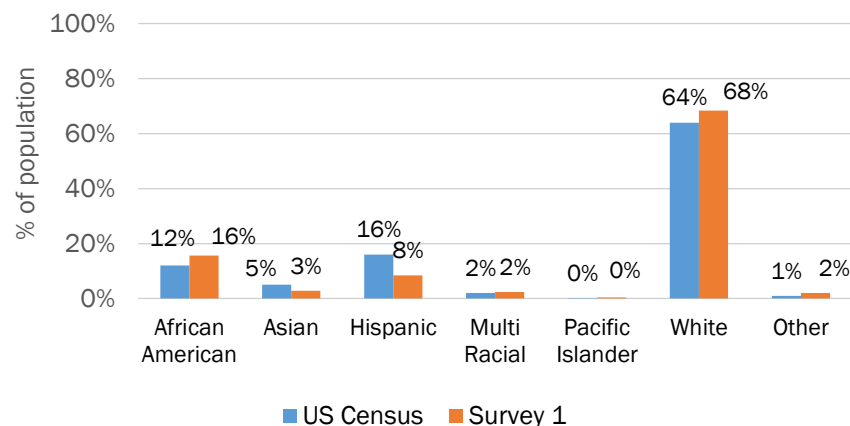
## Survey 1: Diagnosis

# Survey 1: Diagnosis

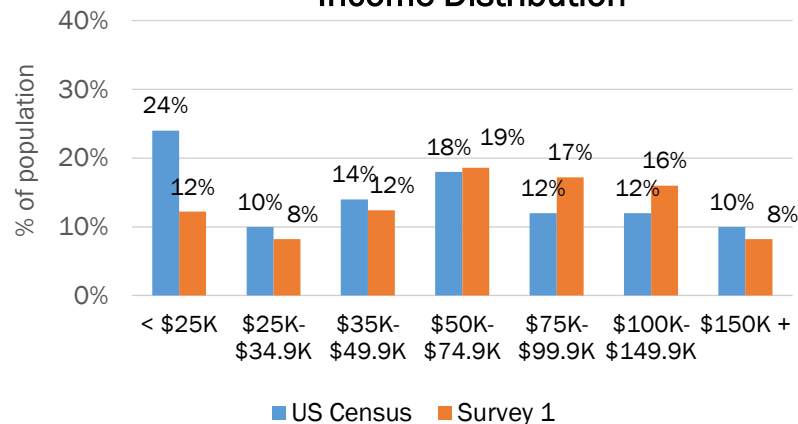
## Age Distribution



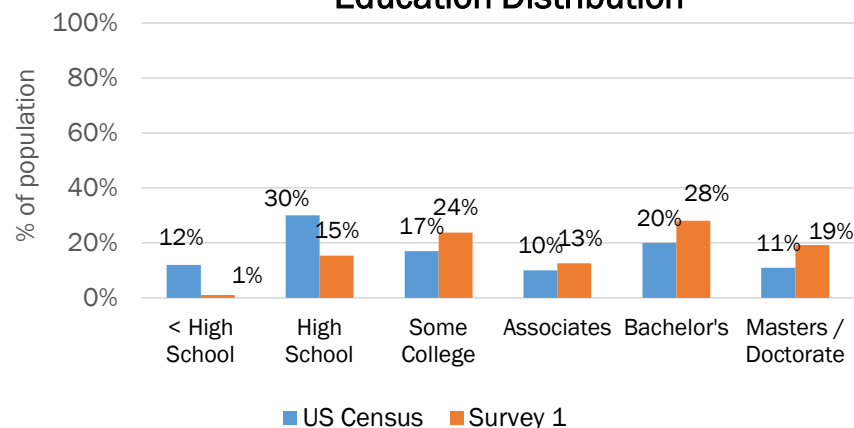
## Ethnic Distribution



## Income Distribution



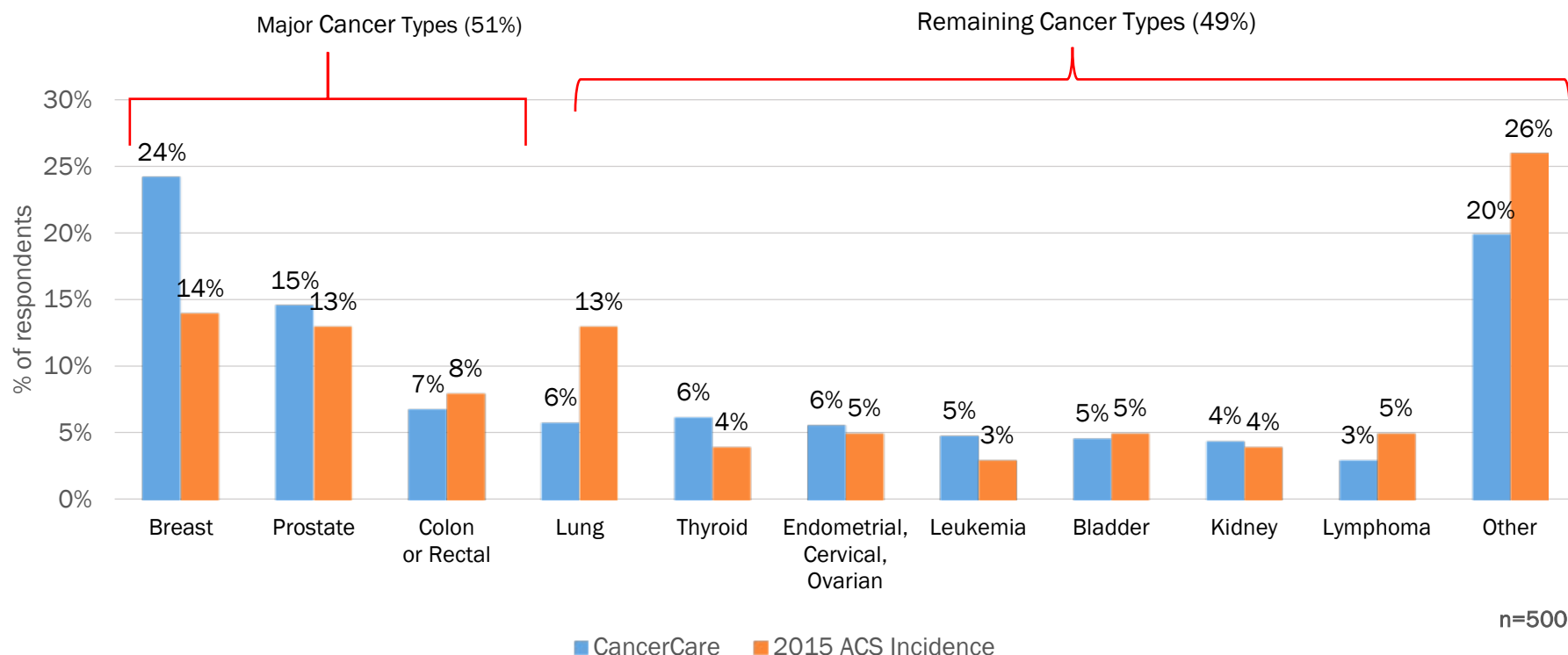
## Education Distribution



n=500

Respondents to this survey were diagnosed with a range of cancer types. By design, participants were selected to achieve a roughly 50/50 split between those presenting with one of the four most common cancer types (breast, prostate, colon or rectal, lung) and all others. Non-melanoma skin cancer was excluded from the sample.

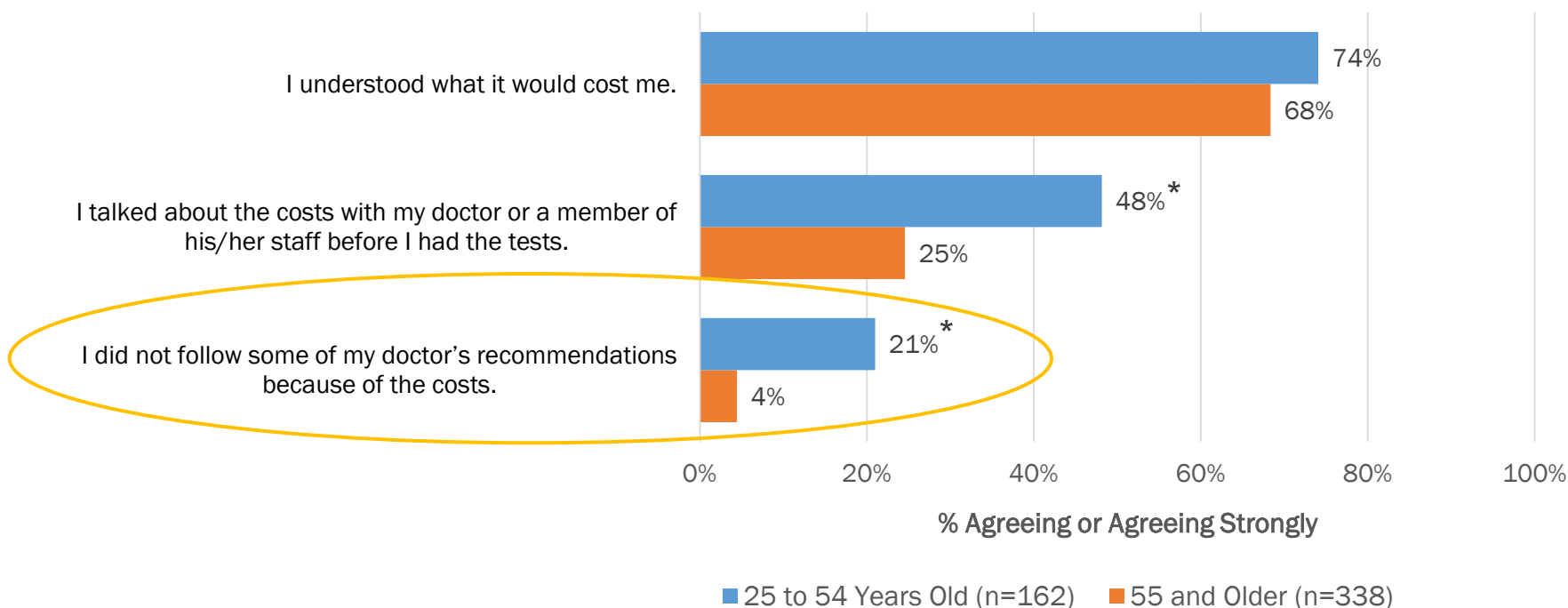
## Distribution of Respondents by Cancer Type – Survey 1



4. What type of cancer were you most recently diagnosed with?

Most patients understood the risks and purpose of diagnostic testing. Once cancer was suspected, most patients followed their doctors' recommendations for further testing. Nearly one-half of those aged 25 to 54 years discussed test costs with their doctor, as compared to 25% of older patients. More than one-fifth of the 25- to 54-year-old respondents did not follow some of their doctors' recommendations because of cost.

## Testing Costs



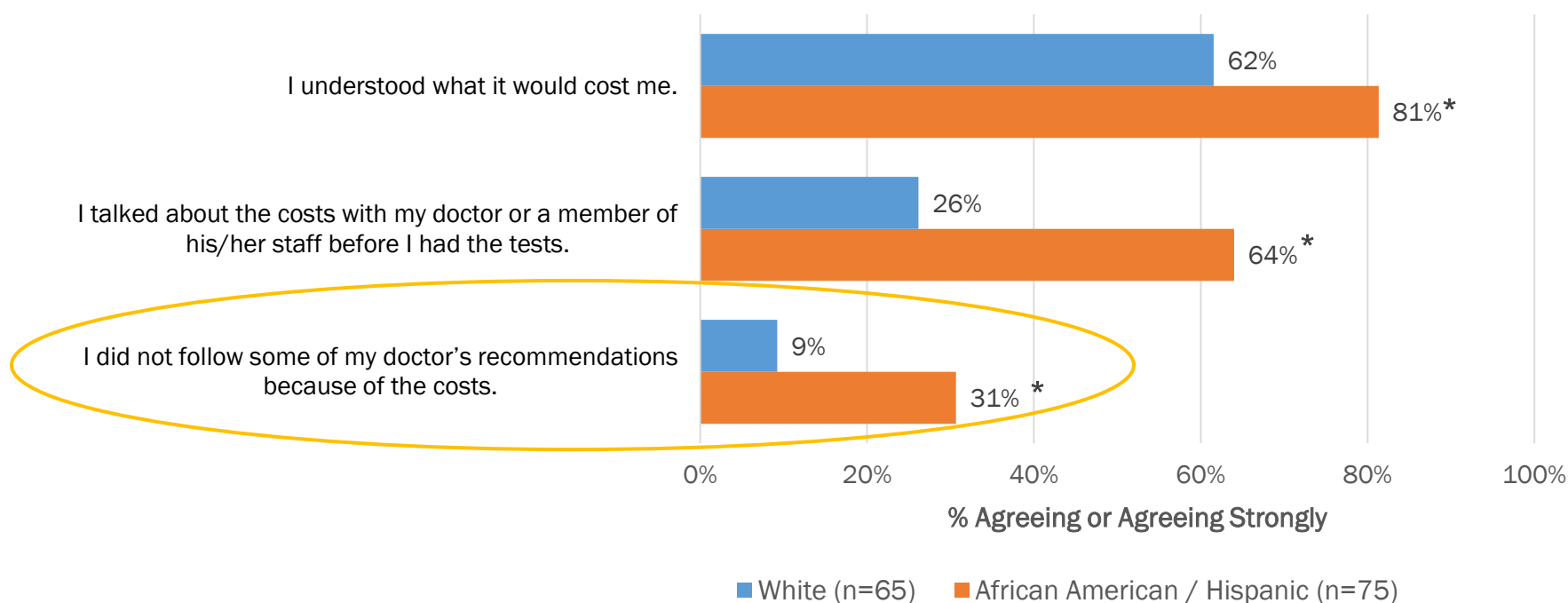
\*Indicates statistically greater at 90% confidence level

7. Thinking about all that occurred when you were getting tests to find out whether you had cancer, please indicate if you agree or disagree with EACH of the following statements.



African American/Hispanic patients aged 25 to 54 were significantly more aware of and concerned about costs of diagnostic tests than their white counterparts. Nearly one-third of African American/Hispanic patients did not follow some of their doctors' recommendations because of cost.

## Testing Costs - Ages 25 to 54



\*Indicates statistically greater at 90% confidence level

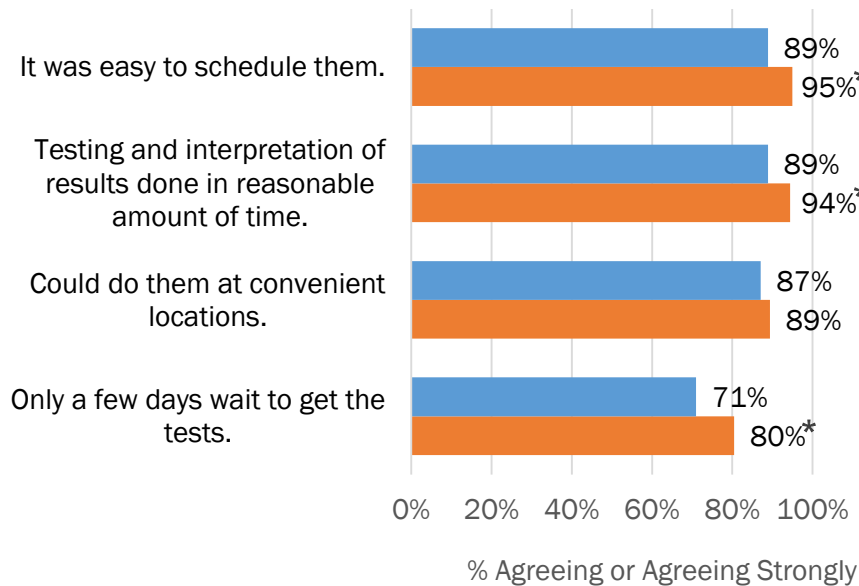
7. Thinking about all that occurred when you were getting tests to find out whether you had cancer, please indicate if you agree or disagree with EACH of the following statements.

Nearly all respondents said they had convenient and timely access to diagnostic testing and confidence in their diagnosing clinicians. Notwithstanding the high level of confidence they had in the medical professionals who diagnosed them, more than one-fourth of the 25- to 54-year-old respondents did not agree with and did not follow testing recommendations.



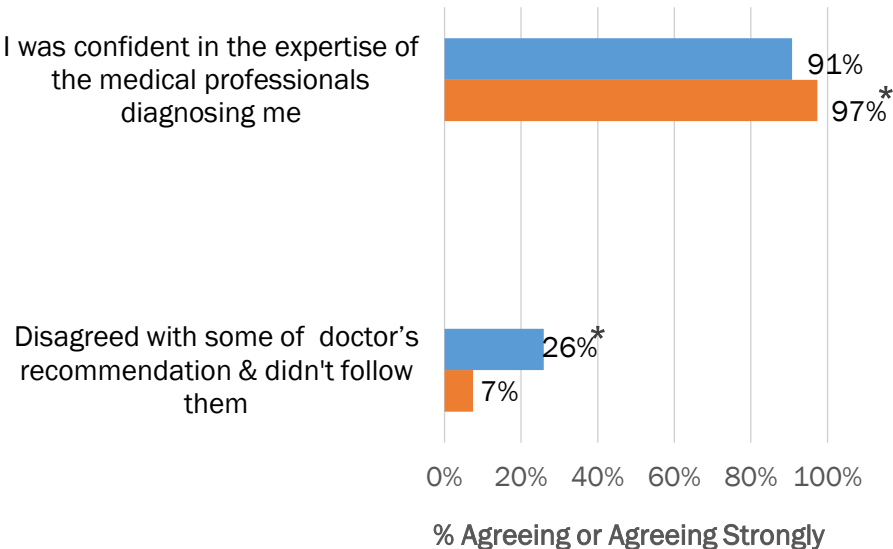
## Opinions About Testing

Convenience



■ 25 to 54 Year Olds (n=162) ■ 55 and Older (n=338)

Confidence in Medical Professional



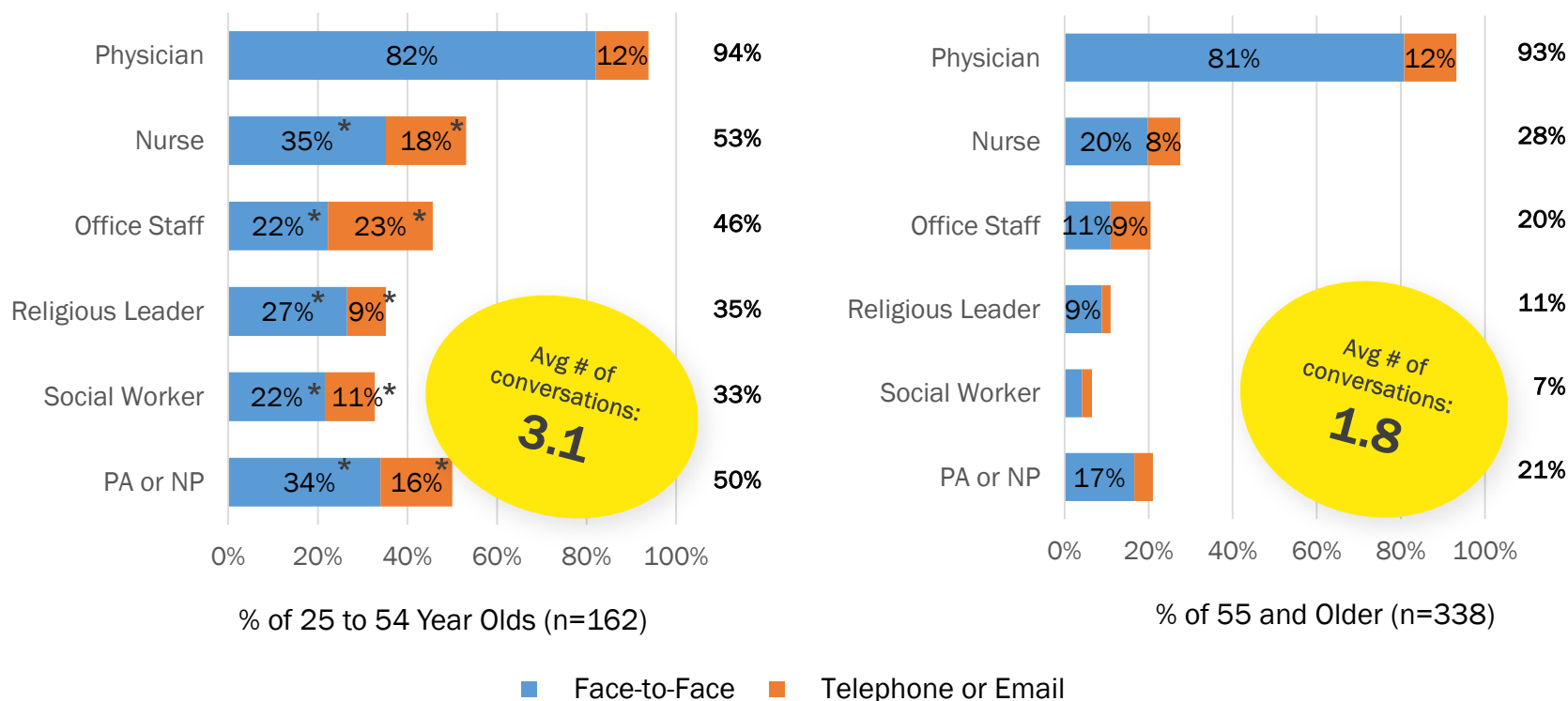
■ 25 to 54 Year Olds (n=162) ■ 55 and Older (n=338)

*\*Indicates statistically greater at 90% confidence level*

7. Thinking about all that occurred when you were getting tests to find out whether you had cancer, please indicate if you agree or disagree with EACH of the following statements.

Nearly all respondents had conversations with doctors after learning they had cancer. Respondents aged 25 to 54 years engaged in conversations with PAs, NPs, physician office staff, religious leaders, and social workers at a much higher rate than did patients 55 years and older.

## Conversations Patients Had Shortly After Cancer Diagnosis



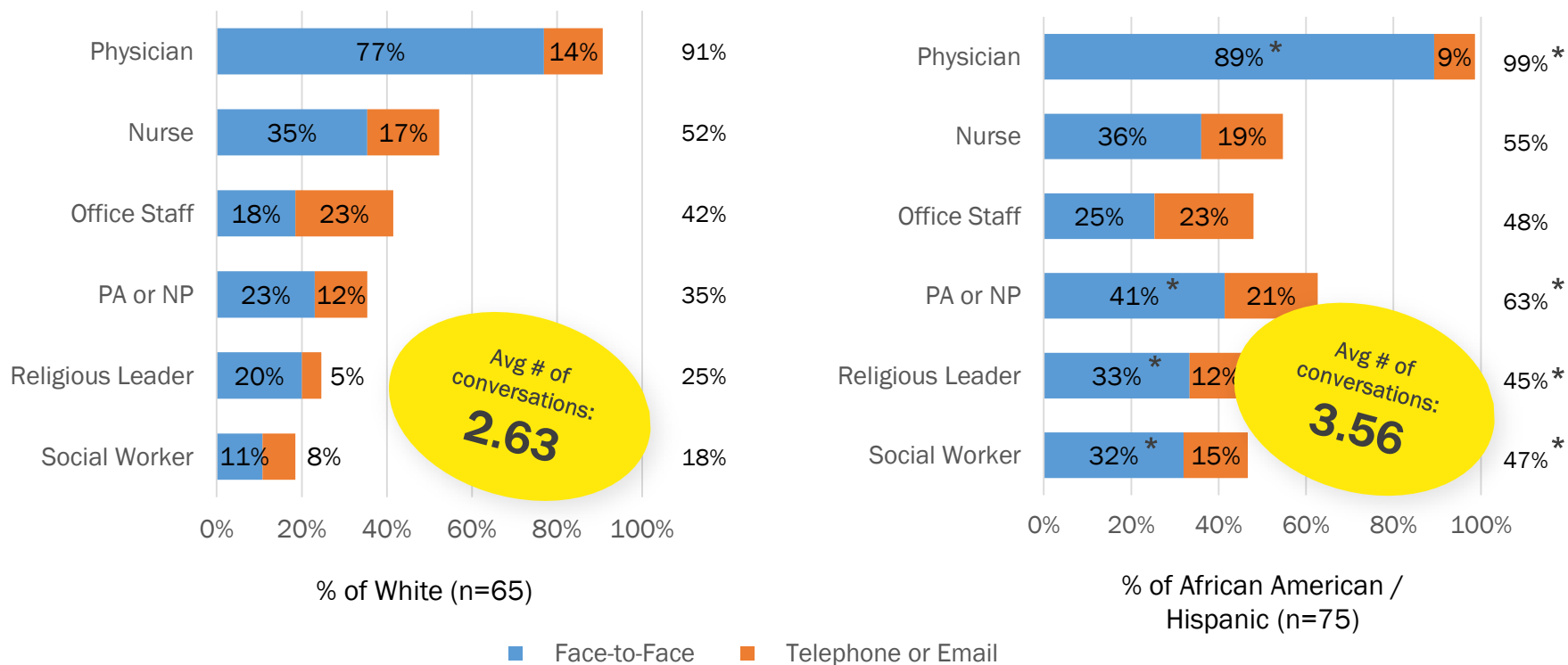
\*Indicates statistically greater at 90% confidence level

10. Please indicate if you had a face-to-face or a telephone conversation or an email exchange with any of the following within a few business days after you were first told you that you definitely had cancer

African American / Hispanic respondents aged 25 to 54 years engaged in more conversations following their diagnosis than did their white counterparts. They were significantly more likely to speak with PAs, NPs, social workers, and religious leaders than white patients in this age bracket.



## Conversations Patients Had Shortly After Cancer Diagnosis – 25 to 54 years old

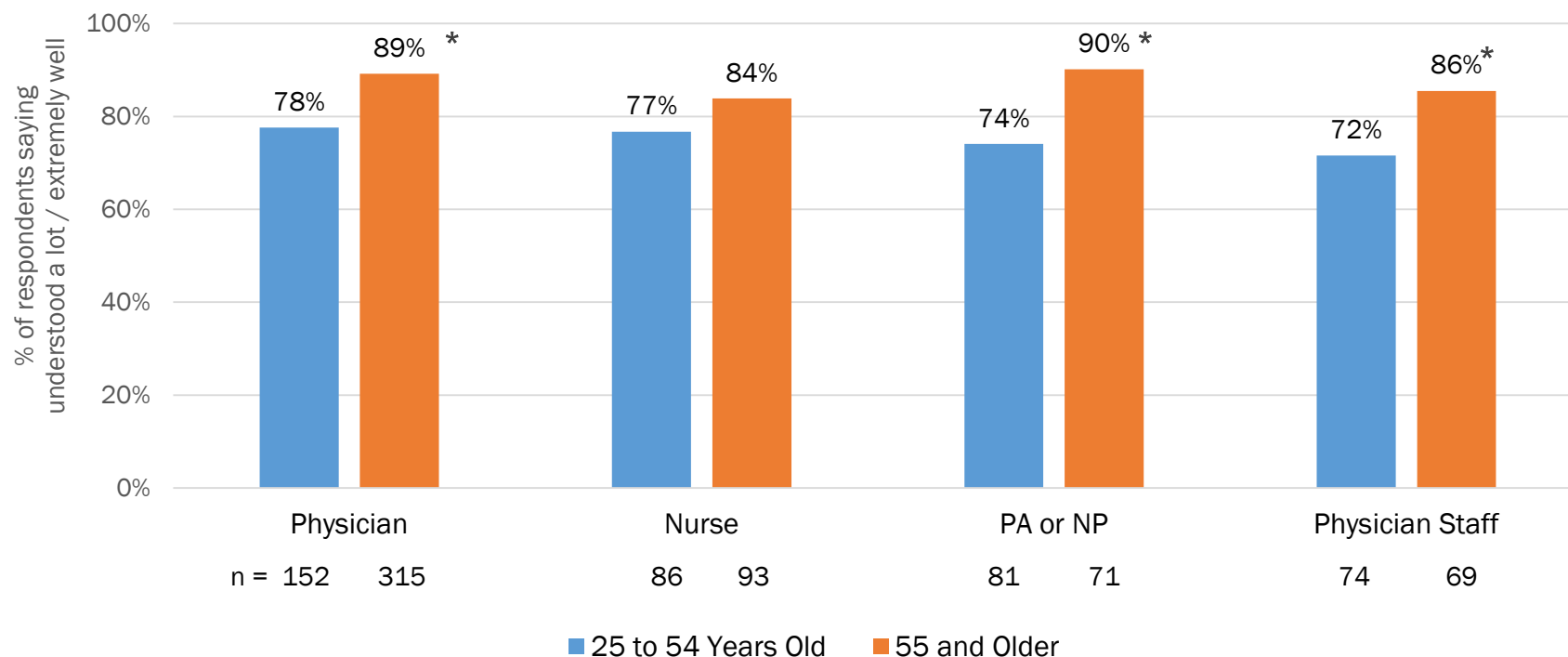


\*Indicates statistically greater at 90% confidence level

10. Please indicate if you had a face-to-face or a telephone conversation or an email exchange with any of the following within a few business days after you were first told you that you definitely had cancer

Most respondents reported understanding the conversations they had with clinicians regarding their diagnosis. Older respondents were significantly more likely to say they understood conversations “a lot” or “extremely well” than those respondents aged 25 to 54 years.

## Level of Understanding of Conversation



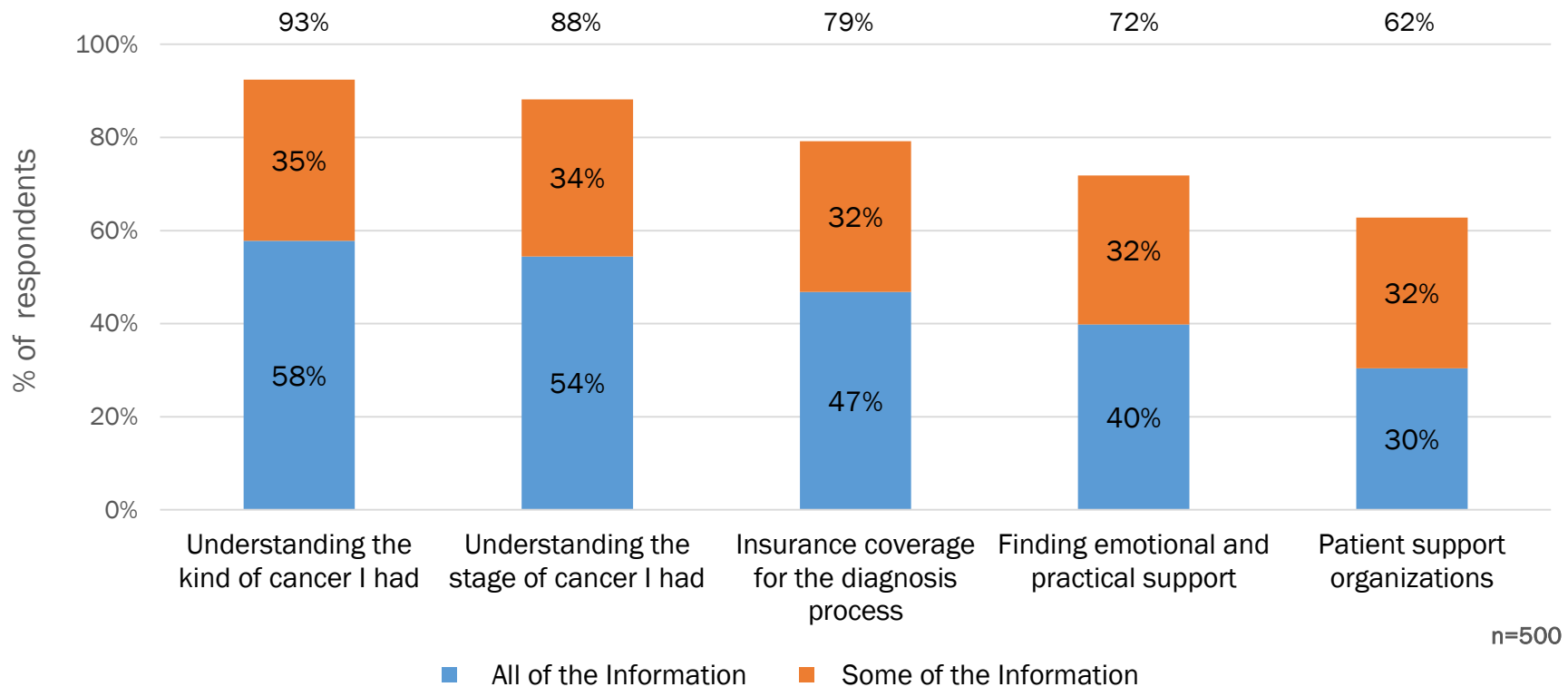
NOTE: 162 survey respondents were 25 to 54 Years Old and 338 survey respondents were 55 and Older; only those reporting a conversation with each care team member are included in table above

\*Indicates statistically greater at 90% confidence level

13. You indicated you had a conversation with (pipe in Q10 selections). How well did you understand that conversation?

Just over one-half of all survey respondents, regardless of ethnicity or other factors, claimed to have had all of the information they needed about their cancer when they were first diagnosed. Even fewer had sufficient information on insurance coverage for the diagnosis process, finding emotional and practical support, and patient support organizations.

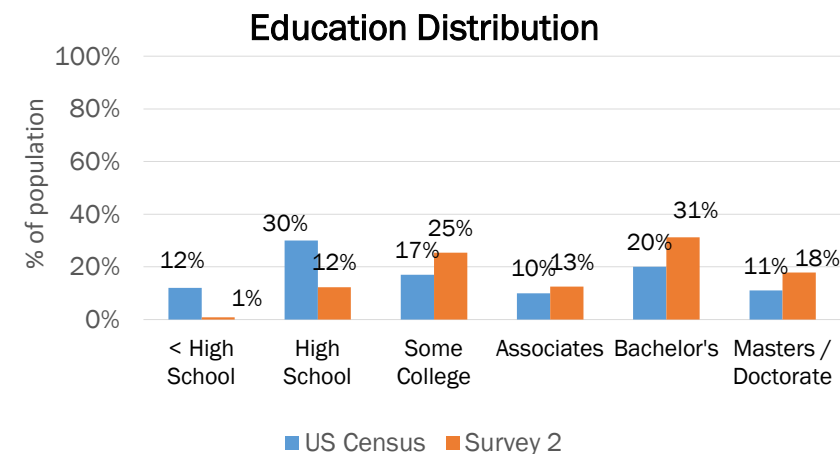
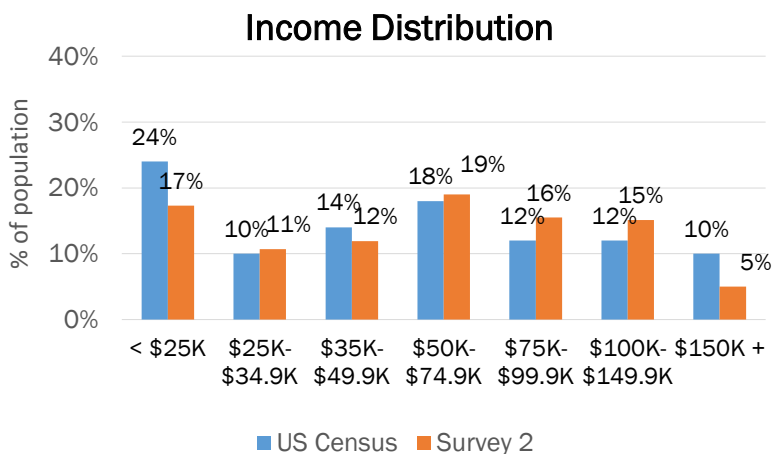
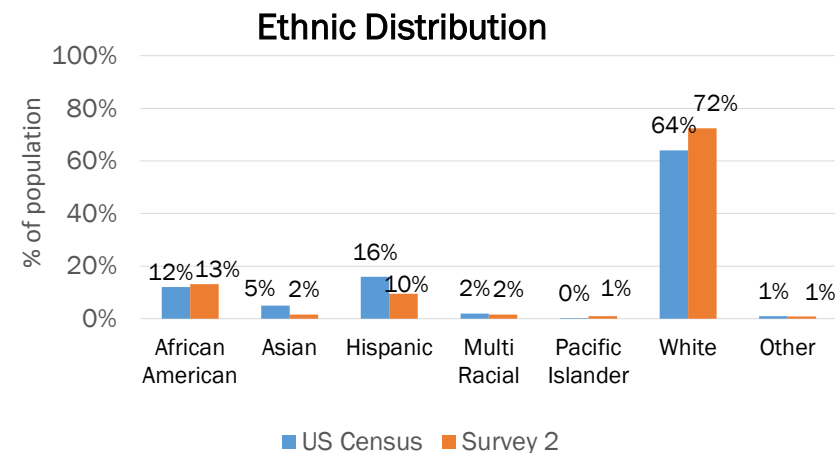
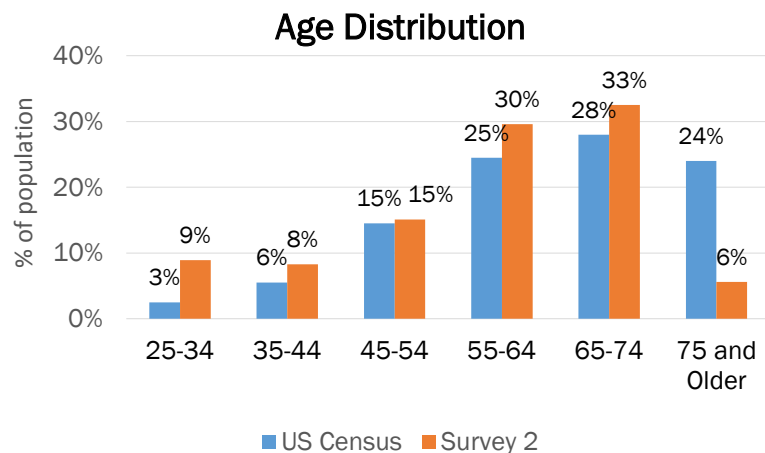
## % of Respondents Receiving All or Some of the Information They Needed



17. Please think back to when you first learned you definitely had cancer. How much of the information you needed on the following topics did you have?

## Survey 2: Treatment Planning

# Survey 2: Treatment Planning

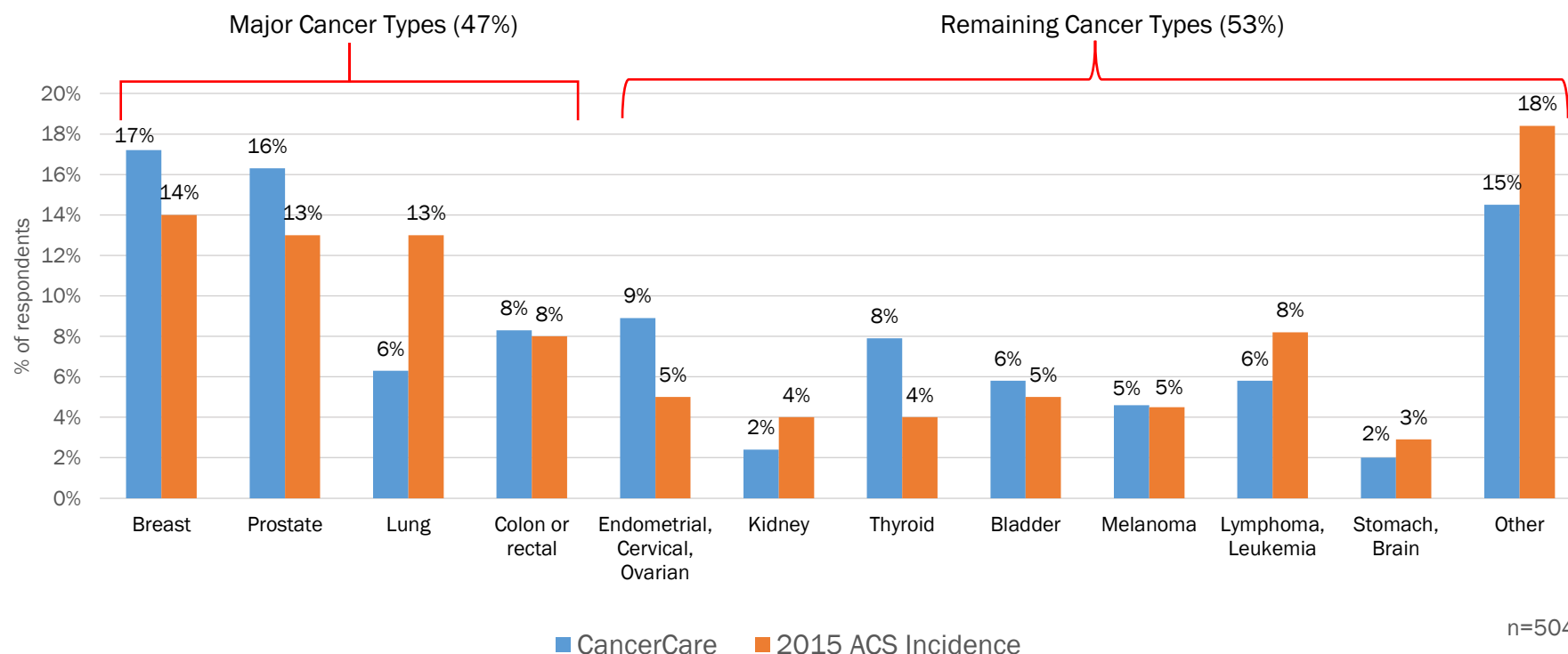


n=504



Respondents to this survey were diagnosed with a range of cancer types. By design, participants were selected to achieve a roughly 50/50 split between those presenting with one of the four most common cancer types (breast, prostate, lung, and colorectal) vs all others. Non-melanoma skin cancer was excluded from the sample.

## Distribution of Respondents by Cancer Type – Survey 2



6. What type of cancer were you most recently diagnosed with?

Respondents reported not having enough information on many aspects of their treatment. Only two-thirds said they had enough information on the “benefits of the treatment plan.” Notably, anywhere from 28% to 72% of respondents said they did not have enough information on the other 14 topics tested. Fewer than half felt adequately informed on whether or not they would be able to work, costs of treatment, and clinical trial opportunities. Those treated in academic centers were more likely to report having enough information than those treated elsewhere.



### % of Patients With Enough Information About Aspects of Cancer Treatment

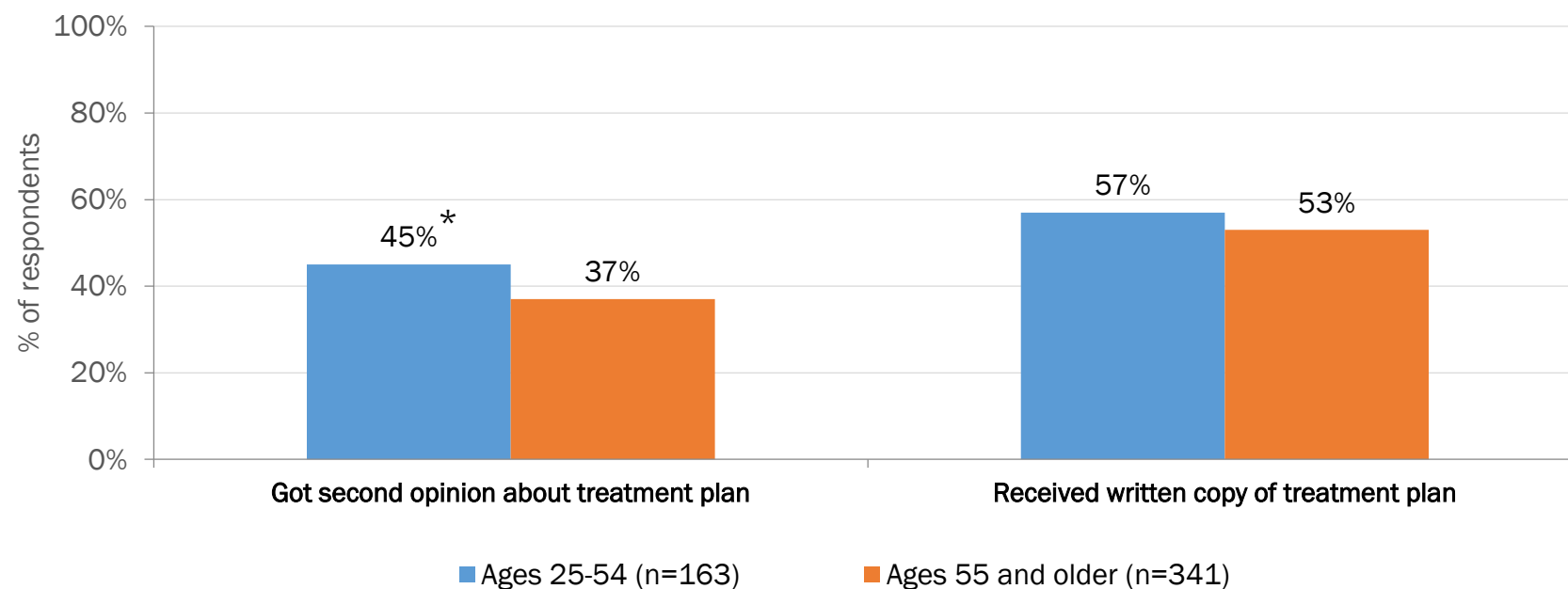
	Treatment Facility	
	Academic Medical Center	Community Hospital/Cancer Center/MD
Number of Respondents	148	325
The benefits of the treatment plan	72%	66%
The possible side effects of the treatments	69%	63%
The goals of the plan (cure, control, keeping you comfortable)	71%	60%
The symptoms you may experience	66%	60%
The reasons your team recommended this treatment plan	67%	60%
The impact on your activities of daily living	70%	52%
The risks of the treatment plan	64%	54%
The medicines you need to take	62%	55%
Whether or not you'll be able to work	45%	43%
The care you will need at home	45%	42%
The emotional impact of cancer and its treatment	53%	38%
The cost to you of the treatment plan	37%	36%
Other treatment options your care team considered	36%	30%
The responsibilities of your caregiver(s)	20%	16%
Clinical trial opportunities	18%	12%

Indicates significantly greater at 90% Confidence Level

14. From the list below, please select the aspects of your cancer treatment where you feel you have enough information?

Fewer than one-half of respondents got a second opinion about their treatment plan; those aged 25 to 54 were more likely to do so than those 55 and older. Just over one-half of respondents, regardless of age, were given a copy of their treatment plan. Of those in active treatment when they responded to this survey, 66% were given a written or online copy of this plan.

## Finalizing the Treatment Plan



\* Indicates directionally greater at 90% confidence level

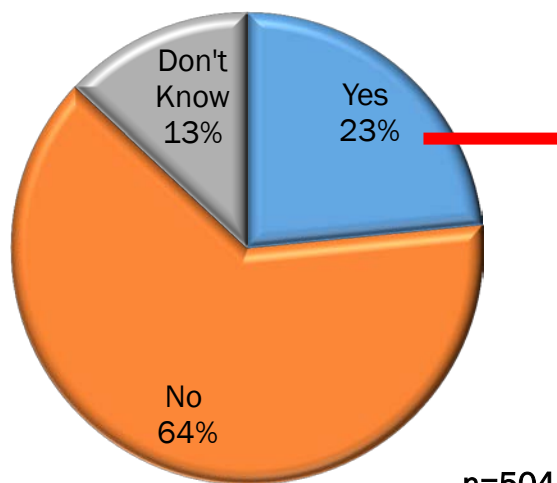
20. Did you get a second opinion from another doctor about your cancer treatment plan?

21. Has your care team given you a written (paper or online) copy of your cancer treatment plan?

Only one-quarter of respondents reported having access to a Patient or Nurse Navigator. Of those however, the vast majority said the navigator was helpful. Among patients with the four most common cancers, 29% were provided with a navigator, compared with 18% of those with less common cancers.

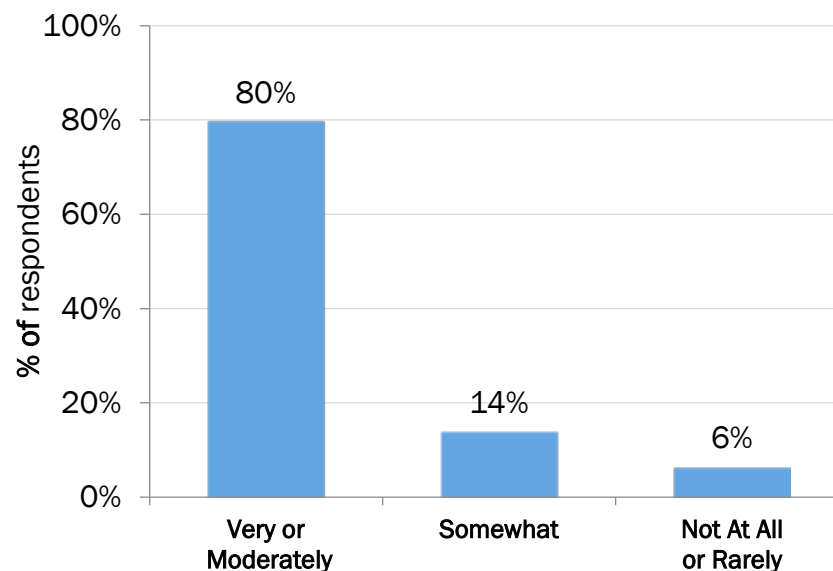
### Patient Navigator Provided

(% of respondents)



n=504

### Helpfulness of Patient Navigator

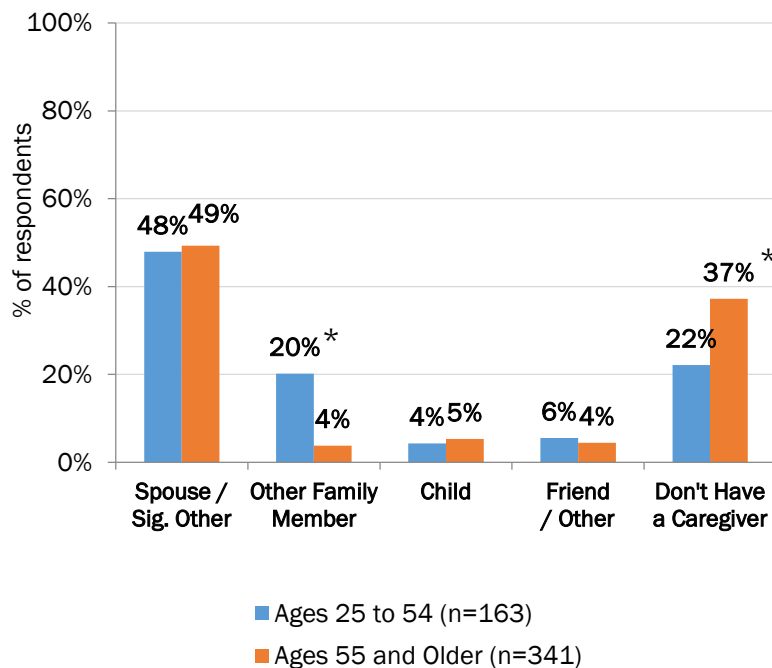


n=118

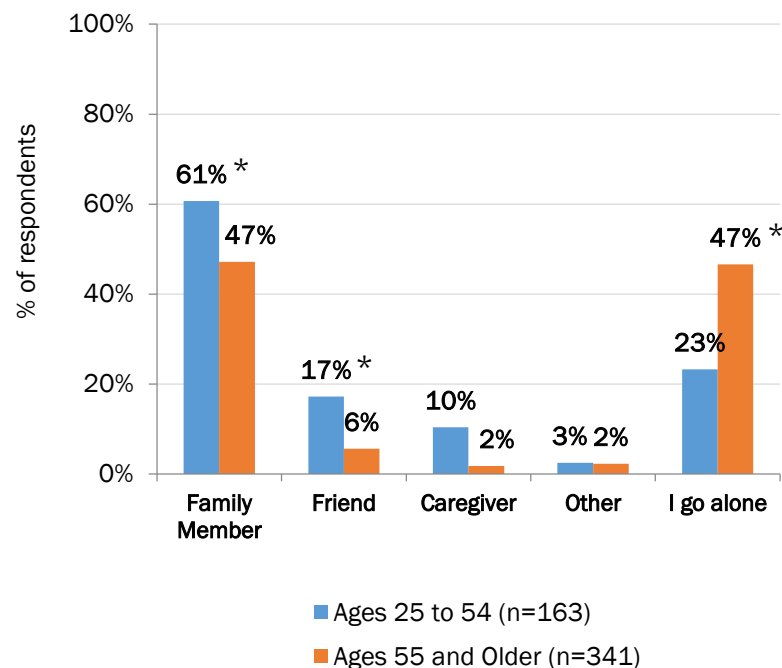
33. Has your doctor/treatment center provided you with a "Patient Navigator" or "Nurse Navigator" to help you through your treatment?
34. How helpful has the "Patient Navigator" or "Nurse Navigator" been to you?

Most respondents indicated their spouses were their primary caregivers and that family members accompanied them to doctor visits. One-quarter to one-third of respondents reported not having a caregiver. Those 55 and older were more likely to not have a caregiver and to visit the doctor alone.

Patients' Primary Caregiver



Who Accompanies Patient to Doctor Visits

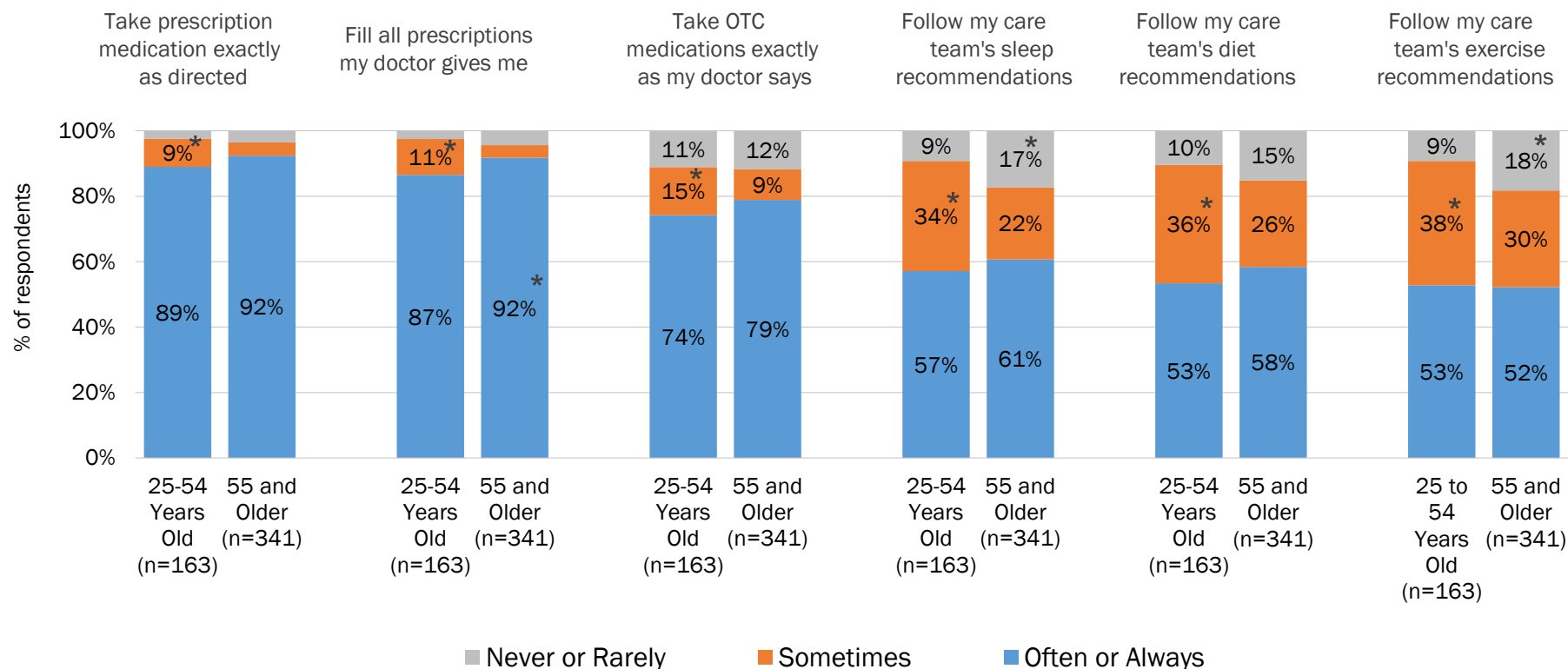


\* Indicates statistically greater at 90% confidence level

12. Who usually accompanies / accompanied you to a treatment session or visit with your doctor?  
35. Who is your main caregiver?

The vast majority of patients said they filled and took prescription medication as prescribed, though 8% to 14% reported they complied never, rarely, or sometimes. Compliance with taking OTC medications was lower, as was adherence to recommendations regarding diet, sleep, and exercise, which ranged from 55% to 60%, with 9% to 18% never or rarely complying. (Note: see survey 4, where respondents reported lower levels of compliance regarding prescription medications.)

## Treatment Adherence

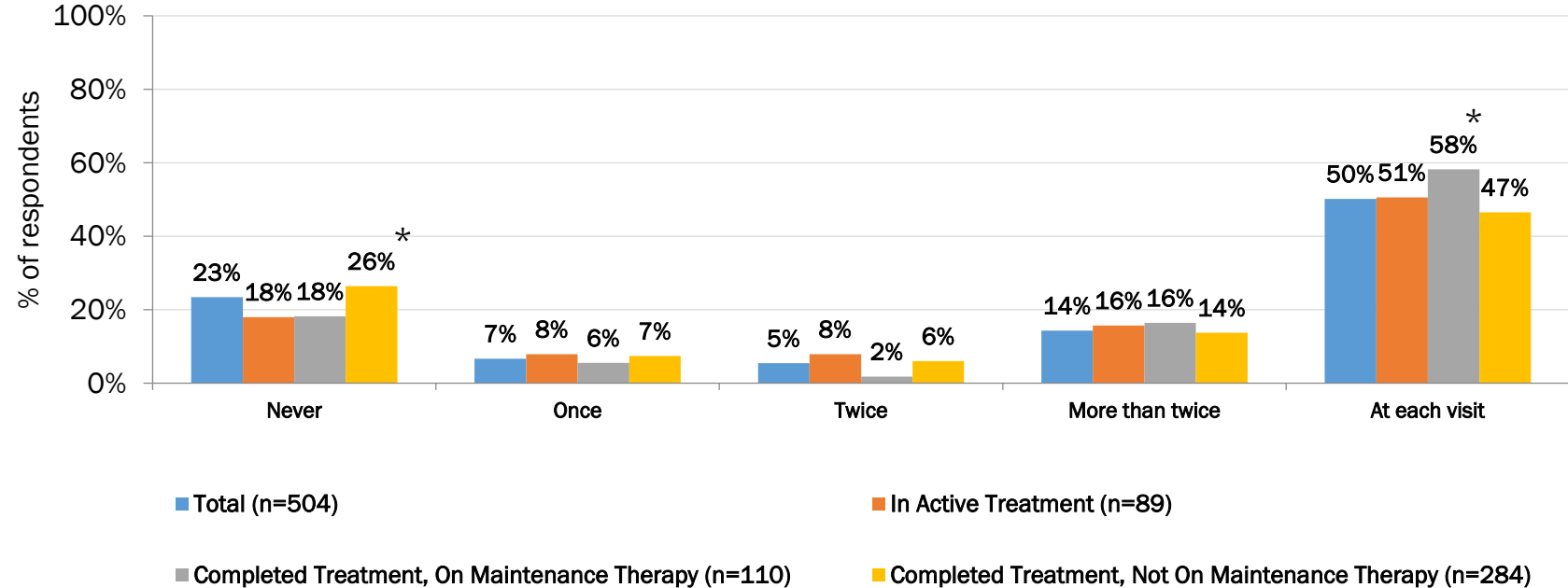


\*Indicates statistically greater at 90% confidence level

32. How often do you do each of the following?

Physician inquiries about distress did not differ by a patient’s treatment status. Roughly 70% to 75% of respondents reported their care team asked about their level of distress. If asked, most patients said the inquiry was repeated each time they visited the physician. (Note that in survey 3, fewer than one-half of patients reported being asked by their care team if they were distressed specifically regarding certain key issues.)

Frequency Care Team Asks About Level of Distress

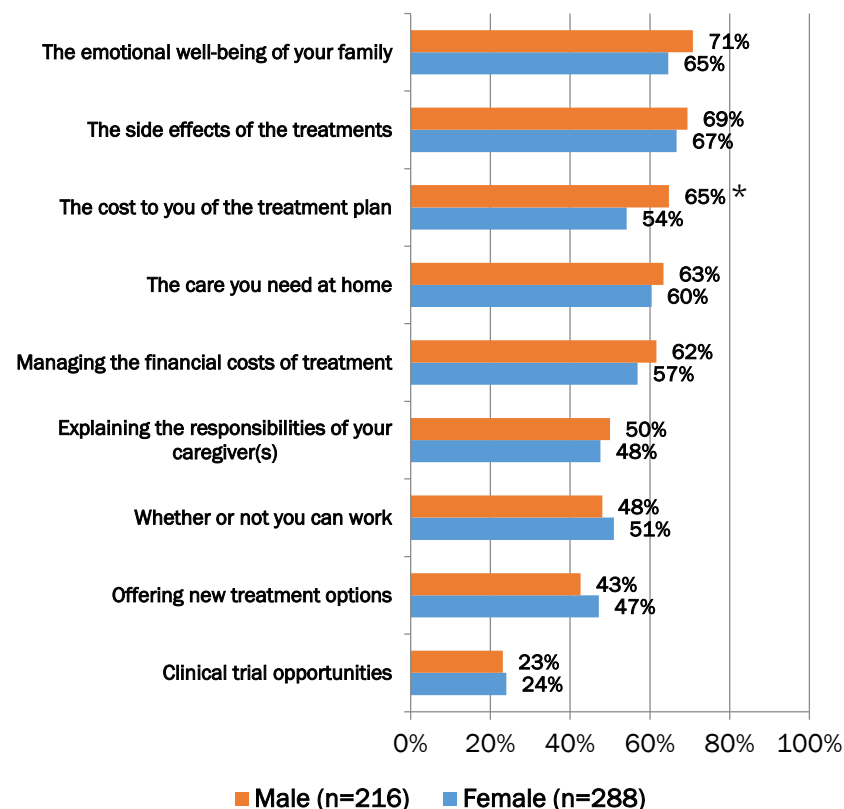
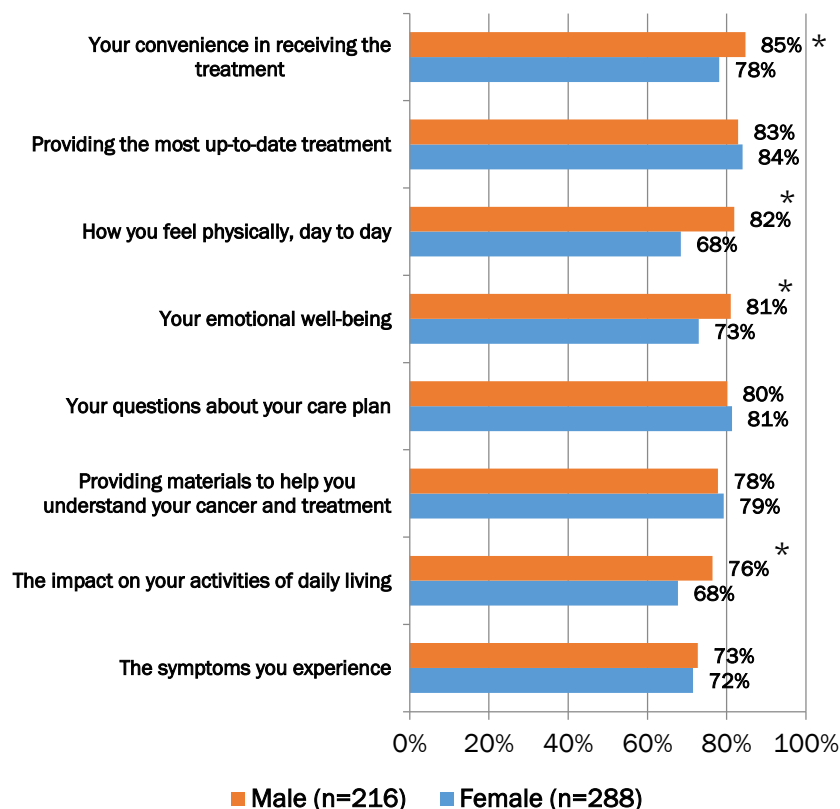


\* indicates directionally greater at 90% confidence level

31. How frequently has your care team asked you about your level of distress (e.g, anxiety, extreme upset, or emotional pain)?

For most aspects of care, 60% to 80% of respondents reported being very or somewhat satisfied with the amount of attention paid by their care team. Overall, men were more satisfied than women. Patient satisfaction levels were quite low regarding team attention to clinical trial opportunities and to a lesser extent offering new treatment options.

## Very or Somewhat Satisfied with Attention Care Team Pays to Aspects of Care



\*Indicates statistically greater at 90% confidence level; ^ indicates directionally greater.

Q. 30 Please rate how satisfied you are with the attention your team pays to the following aspects of your cancer care.



Overall, most respondents said they trusted their doctors, knew the medications they took, and believed they were getting the best possible care. Among those treated in the community, 30% did not agree they were getting the most advanced cancer care available, compared to only 14% of those treated in academic centers. Fewer than one-half said their care team knew their end-of-life wishes. Younger respondents were significantly more likely than those 55 and older to have suggested new treatment options, considered alternative treatments, switched providers, and taken medicines they did not disclose to their care team.

## Opinions about Their Cancer Treatment

	Overall % Agreeing	Age		Treatment Facility	
		25 - 54 Years Old (n=163)	55 and Older (n=341)	Academic Medical Center (n=148)	Community Cancer Center/Hospital/ MD (n=325)
I trust my doctor's decisions/advice regarding treatment of my cancer.	90%	89%	90%	93%	89%
I know what each of my medications is for.	84%	83%	84%	89% *	81%
I am getting the best cancer care for me.	83%	81%	84%	94% *	80%
I am getting the most advanced cancer care available.	74%	76%	73%	86% *	70%
I always take my cancer medications on schedule.	59%	69% *	54%	57%	58%
My care team knows my end-of-life wishes.	44%	42%	45%	46%	44%
I am considering or have considered alternative treatments for my cancer.	21%	37% *	14%	24%	20%
I suggest new treatment options or ways to treat my cancer to my doctor.	23%	33% *	18%	23%	22%
I switched to a new doctor or treatment center.	16%	25% *	11%	18%	15%
I take medicines that I don't tell my care team about.	9%	17% *	5%	9%	10%

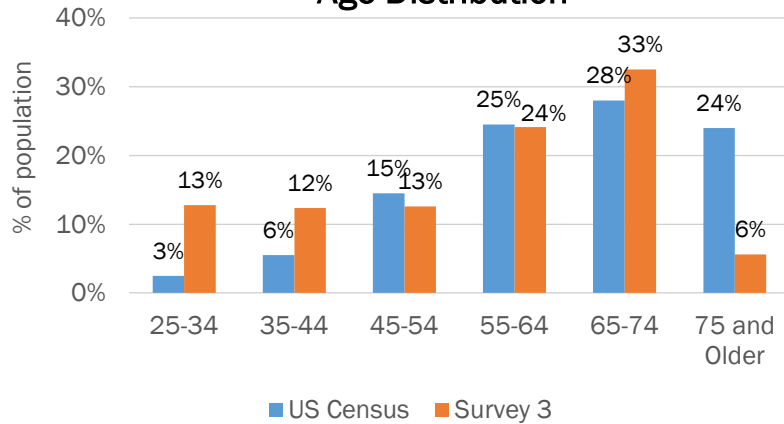
\*Indicates statistically greater at 90% confidence level

37. Thinking about all that has happened since you began treatment for your cancer, please indicate if you agree or disagree with EACH of the following statements:

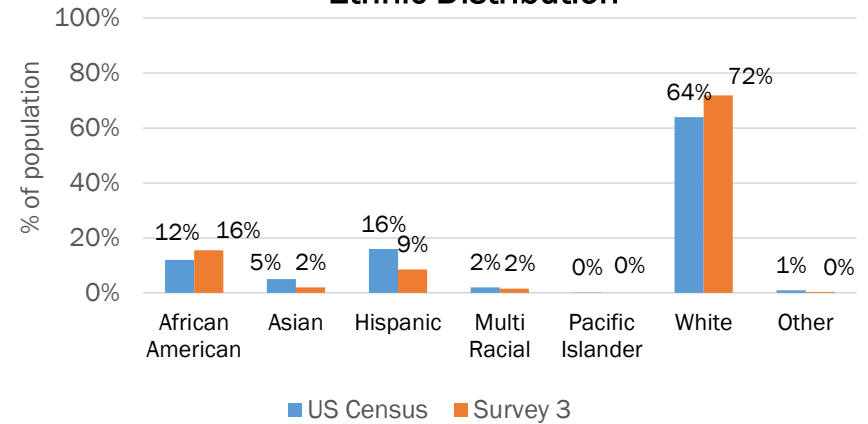
## Survey 3: Communication

# Survey 3: Communication

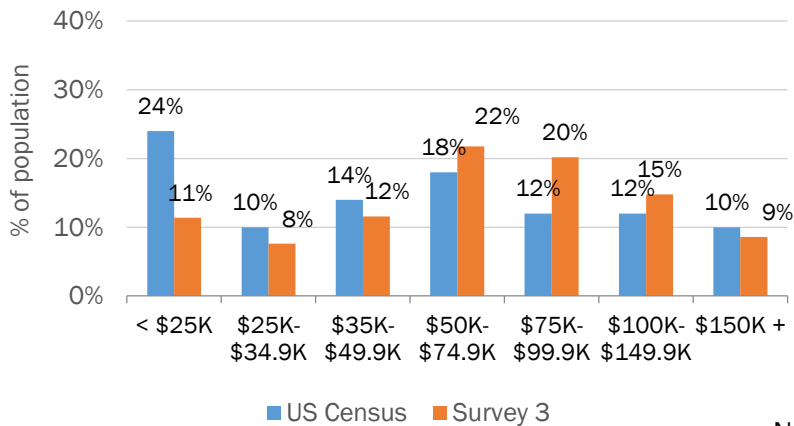
## Age Distribution



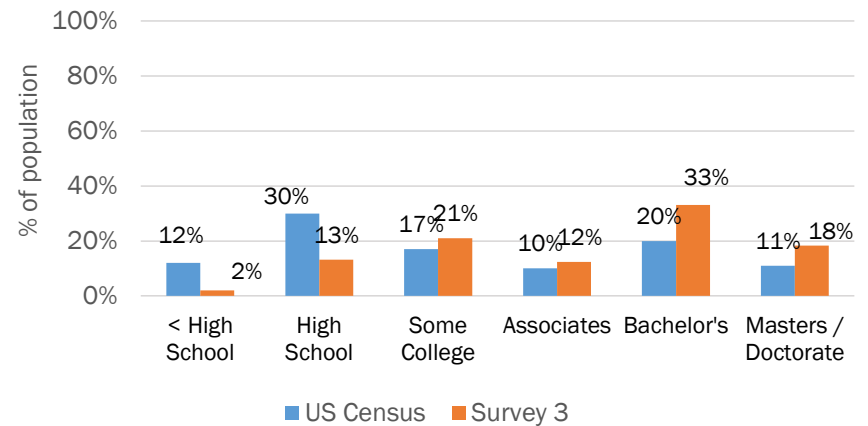
## Ethnic Distribution



## Income Distribution



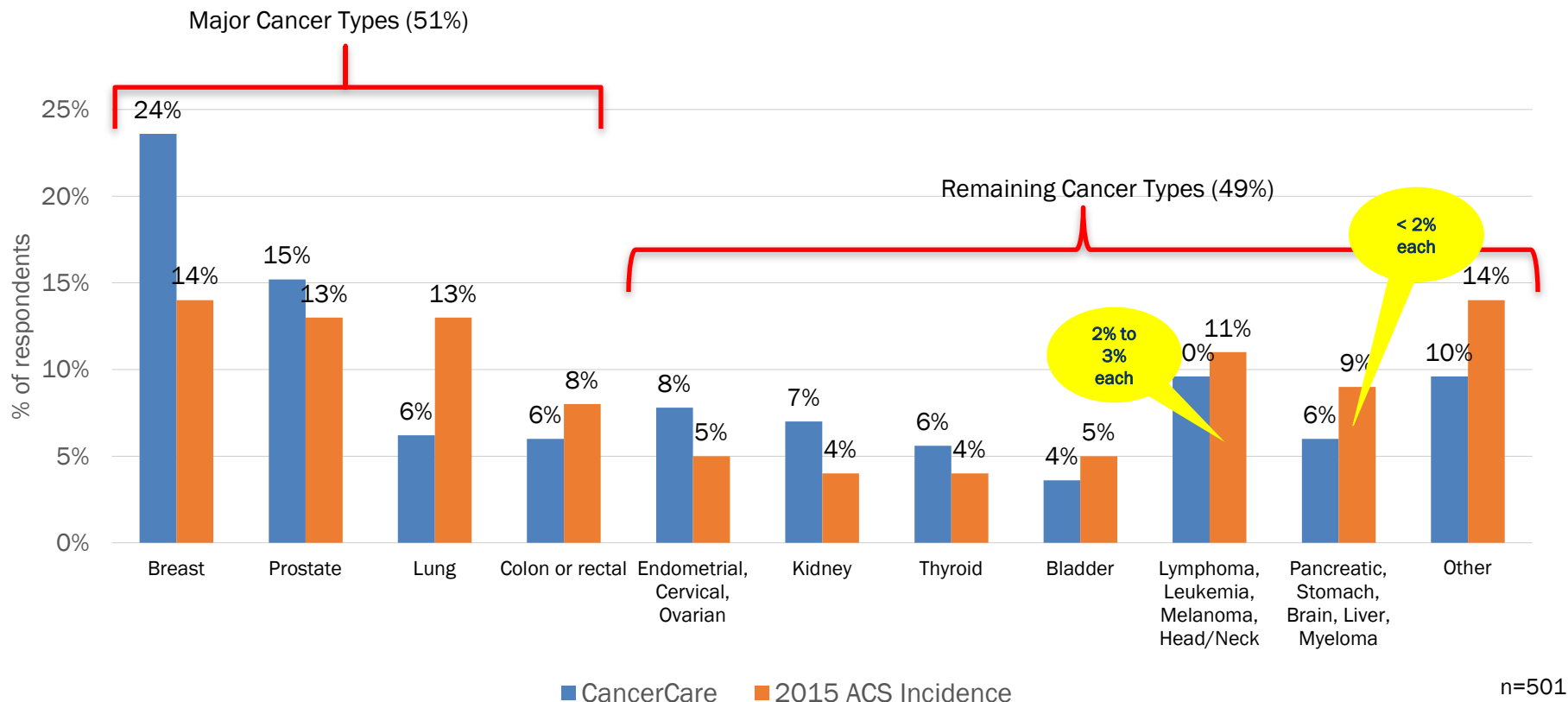
## Education Distribution



N=501

Respondents to this survey were diagnosed with a range of cancer types. By design, participants were selected to achieve a roughly 50/50 split between those presenting with one of the four most common cancer types (breast, prostate, lung, and colorectal) and all others. Non-melanoma skin cancer was excluded from the sample.

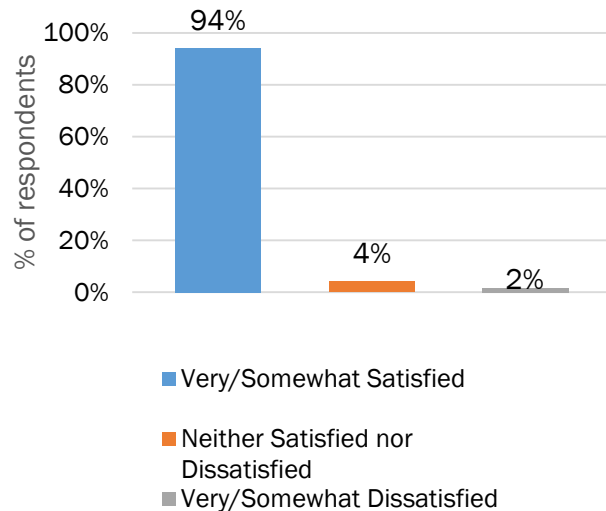
## Distribution of Respondents by Cancer Type – Survey 3



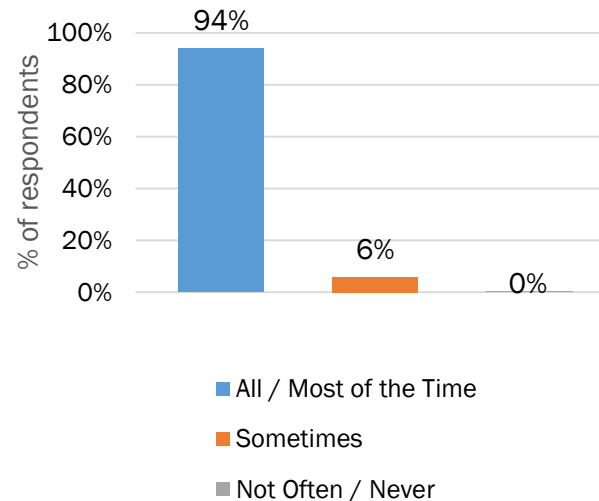
5. What type of cancer were you most recently diagnosed with?

Regardless of sex, ethnicity or where they were treated, respondents indicated they were satisfied with their care coordination, understood what their health-care providers were discussing with them most or all of the time, and were able to connect with their health-care team in a reasonable amount of time.

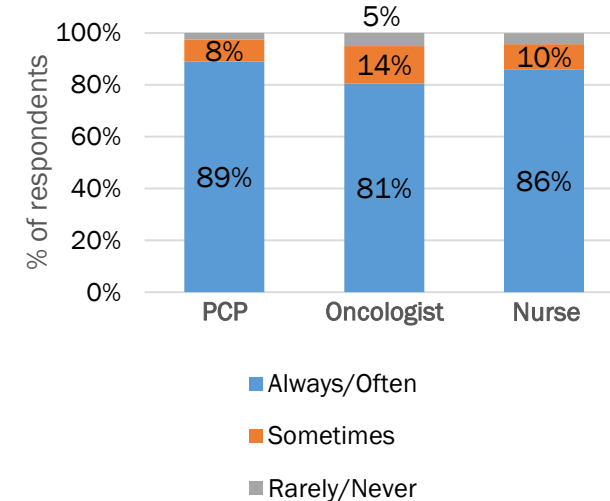
**Satisfaction with Coordination  
by Care Team**



**Understand What Health-Care  
Providers are Discussing**



**Able to Connect with Care Team  
in Reasonable Time**



N=501

13. Overall, how satisfied are you with how well your care is coordinated by the members of your clinical care team

15. Overall, how often do you feel you understand what your healthcare providers are discussing with you?

20. When you contact the members of your cancer care team, how often are you able to connect with them in a reasonable amount of time?

Overall, respondents voiced relatively positive opinions of the conversations and relationships they had with their doctors. Those 55 years and older were significantly more positive than 25 to 54 year old patients. However, 57% of the younger group found their doctors were open to suggestions regarding alternative or complementary therapies, compared to 48% of those 55 years and older.

## Patients' Perceptions of their Doctors

	Often or Always Agree		Never or Rarely Agree	
	25-54 Years Old (n=189)	55 and Older (n=312)	25-54 Years Old (n=189)	55 and Older (n=312)
My doctor listens to my concerns.	84%	92%	4%	2%
My doctor speaks to me using language I can understand.	82%	94%	8%	2%
I am confident that I can tell my doctor my concerns even when he or she does not ask.	82%	92%	8%	3%
My doctor is easy to talk to.	80%	91%	5%	3%
My doctor is kind and compassionate.	77%	90%	6%	2%
My doctor shares with me (or provides me access to) the information in my medical records.	77%	80%	9%	8%
My doctor asks for my input and opinion.	70%	71%	8%	10%
My doctor is open to suggestions about alternative or complementary therapies.	57%	48%	13%	9%

  Indicates statistically greater at 90% confidence level

31. Please indicate how often you believe the following statements to be true?

Among respondents aged 25 to 54 years, whites were significantly more likely than African Americans / Hispanics to report that their doctors spoke in understandable language and that they had confidence in being able to tell their doctor their concerns. On the other hand, African American / Hispanic respondents were significantly more likely to report that their doctors listened to their concerns and asked for their input and opinions.

## Patients' Perceptions of their Doctors – Ages 25 to 54

	Often or Always Agree		Never or Rarely Agree	
	White (n=82)	African American / Hispanic (n=96)	White (n=82)	African American/ Hispanic (n=96)
My doctor speaks to me using language I can understand.	87%	76%	2%	13%
I am confident that I can tell my doctor my concerns even when he or she does not ask.	87%	74%	2%	14%
My doctor is easy to talk to.	82%	77%	4%	5%
My doctor is kind and compassionate.	82%	72%	4%	8%
My doctor shares with me (or provides me access to) the information in my medical records.	80%	72%	6%	12%
My doctor listens to my concerns.	57%	82%	13%	4%
My doctor is open to suggestions about alternative or complementary therapies.	52%	60%	9%	17%
My doctor asks for my input and opinion.	37%	73%	30%	9%

  Indicates statistically greater at 90% confidence level

31. Please indicate how often you believe the following statements to be true?

African American / Hispanic respondents were more likely than whites to have complaints about communications with their care teams. Roughly 20% of African Americans / Hispanics had a complaint regarding a lack of cultural competence or respect, compared to less than 10% of whites.

## Patient Complaints About Medical Care

		Often or Always Agree			Never or Rarely Agree	
		White (n=360)	African American /Hispanic (n=121)		White (n=360)	African American /Hispanic (n=121)
I am uncomfortable talking with my care team about how my cultural, religious, and personal values affect my treatment		7%	20%		58%	64%
I can't speak with my care team members in my preferred language		6%	17%		51%	60%
My doctor shows a lack of respect for my cultural, religious, and personal values		5%	17%		72%	65%
I feel that 'I'm not being heard'		4%	16%		84%	69%
It's hard to understand what the doctor is saying about my treatment		4%	19%		82%	66%
The services to translate communication into my preferred language aren't good		3%	22%		39%	49%

Indicates statistically greater at 90% confidence level

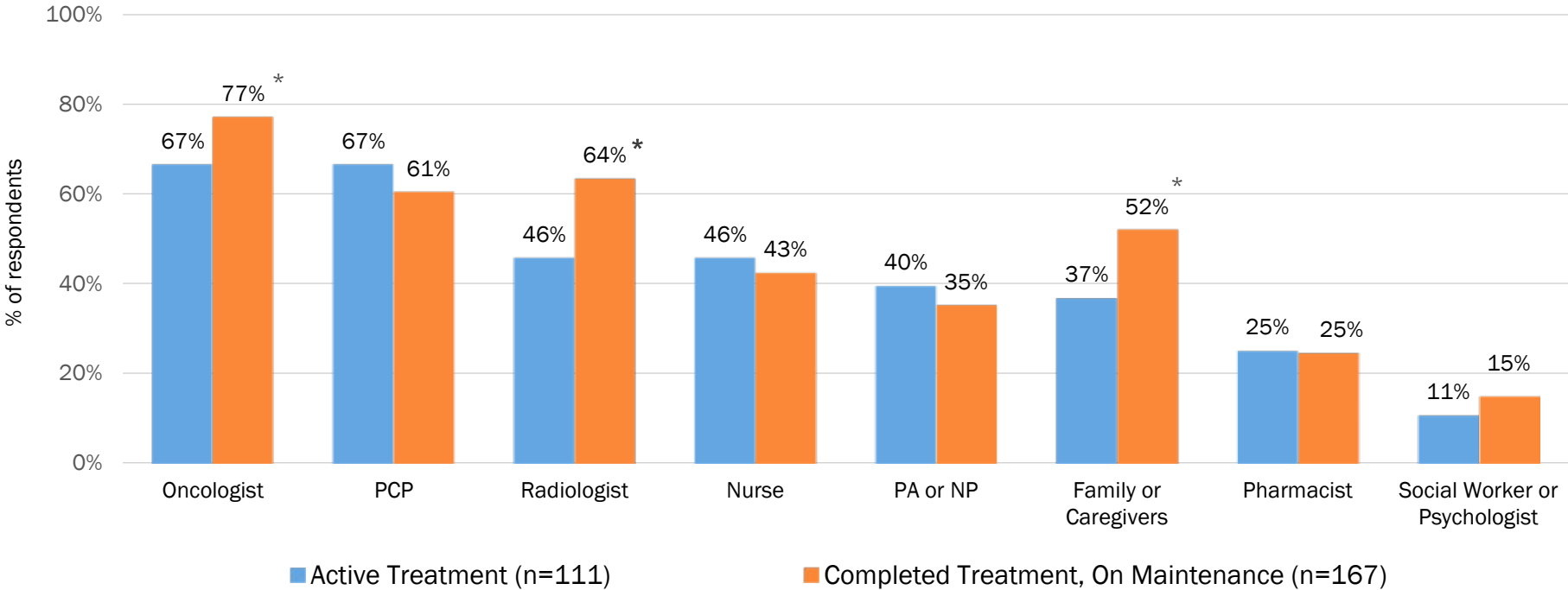
32. The following are complaints that some patients have about medical care. Please indicate how often you have or had these complaints during your cancer treatment.



A majority of respondents considered oncologists, primary care physicians, radiologists, and family or caregivers to be on their cancer care teams. Nurses were considered team members by nearly one-half of respondents. Oncologists, radiologists, and family or caregivers were more likely to part of the team after active treatment ended.



### Care Team Members



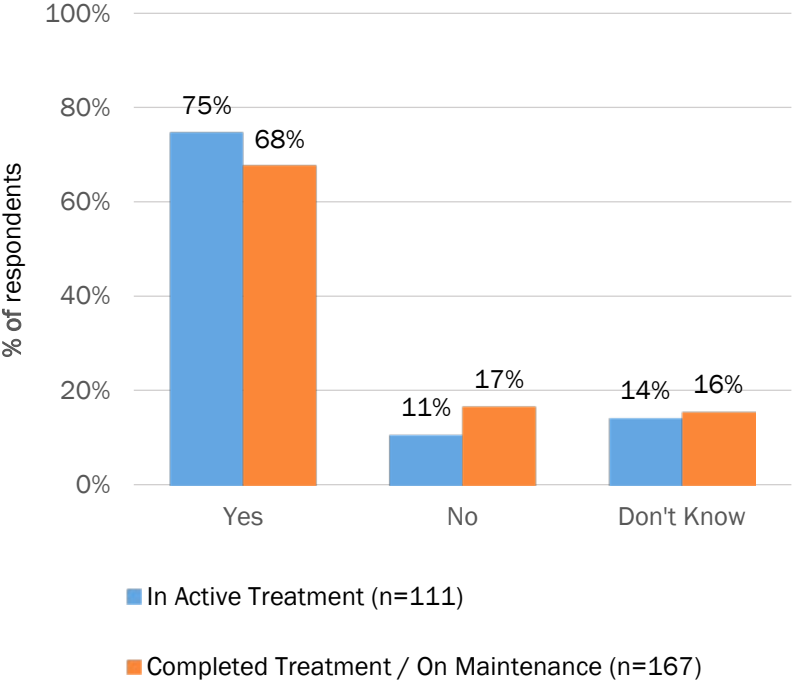
\* Indicates statistically greater at 90% confidence level

9. Which of the following do you consider to be members of your cancer care team?
11. You indicated that a family member or caregiver is a member of your cancer care team. Is he or she authorized to communicate with the clinical care team on your behalf?

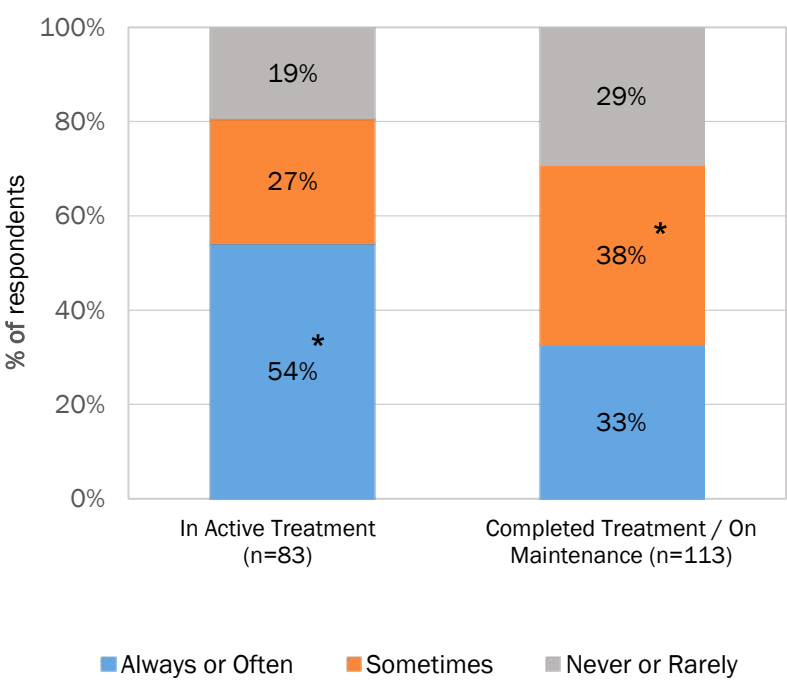
The majority of respondents in active treatment or on maintenance therapy reported having access to and using patient portals. More than one-half of those in active treatment reported they often or always used it and only one-fifth reported rarely or never using it. 40% of those aged 25 to 54 years used the portal “always or often” compared to 28% of those 55 years and older.



Patient Portal Provided by Physician



Use of Patient Portal

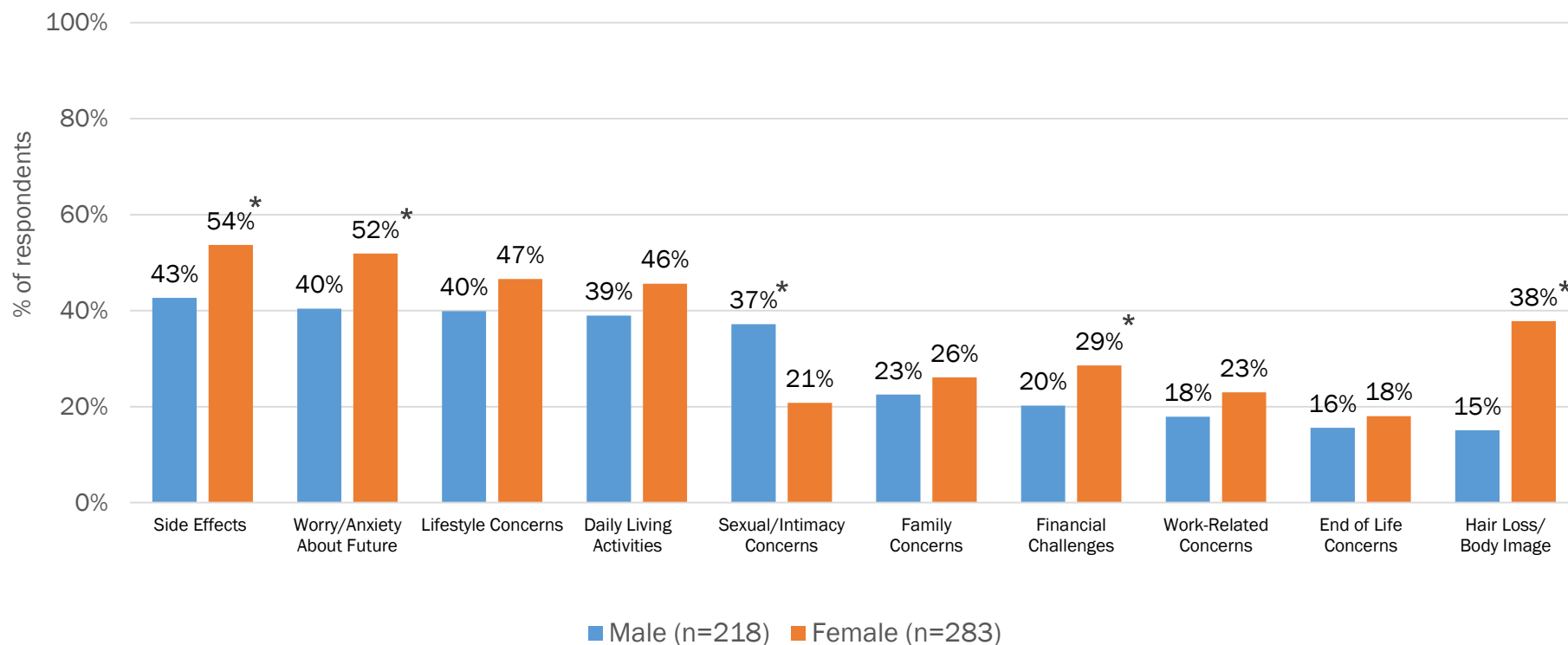


\* Indicates statistically greater at 90% confidence level

21. Does the physician treating you for cancer offer a patient portal (a secure online website that provides 24-hour access to personal health information)?
22. How often do you use it?

Fewer than half of patients who responded to the survey were asked by their care team if they felt distressed regarding various important aspects of their lives. Women more often mentioned being asked about side effects, worry about the future, financial concerns, and hair loss/body image, while men were more often asked about sexual and intimacy concerns.

## Distress Concerns Raised by Care Team Members

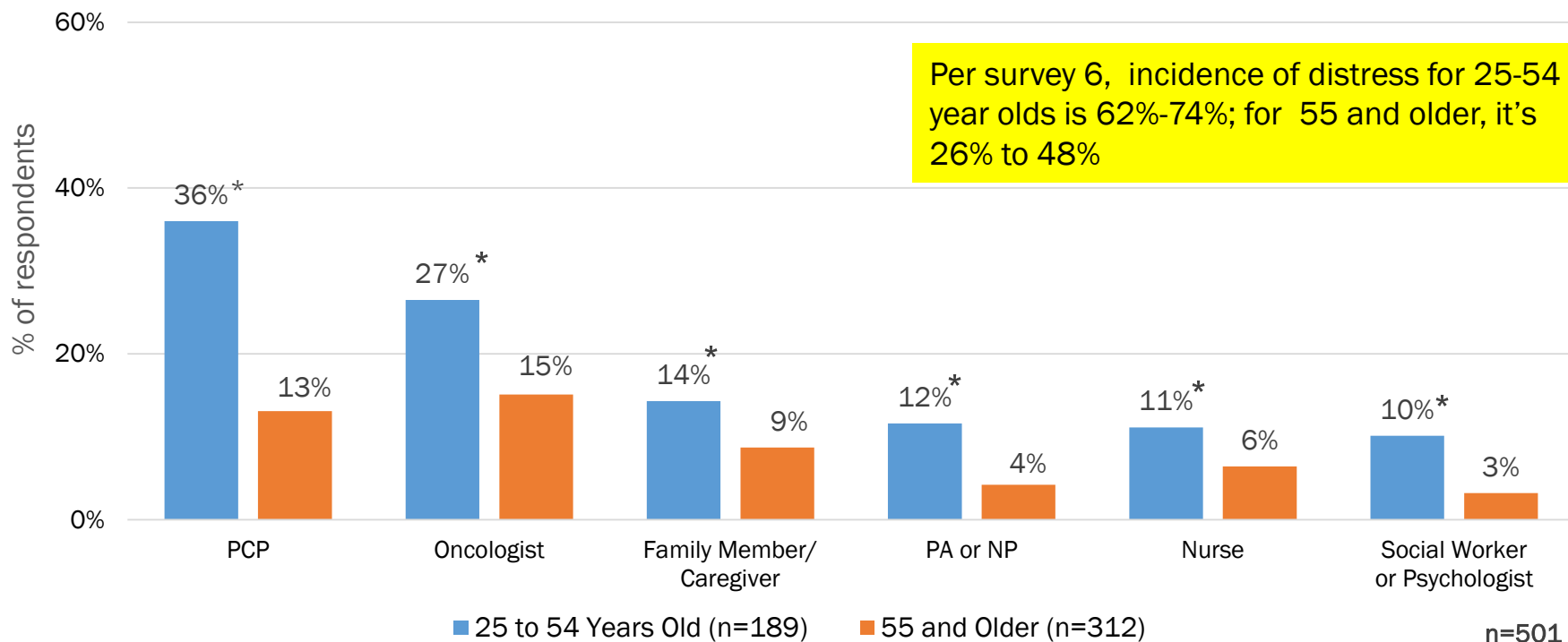


\*Indicates statistically greater at 90% confidence level

26. Has a member of your cancer care team ever asked if you were feeling distressed (e.g. anxious, extremely upset, or in emotional pain) related to any of the following issues? Please select all the issues about which you have been asked.

Despite the prevalence of emotional and financial distress among people with cancer, respondents to the survey indicated that care team members did not often refer them to services or professionals for support. Among those aged 25 to 54 years, 36% said they received a referral for emotional distress from their primary care physician and 27% from their oncologist. Respondents aged 55 years and older were rarely referred.

## Care Team Members Making Support Referrals - Emotional

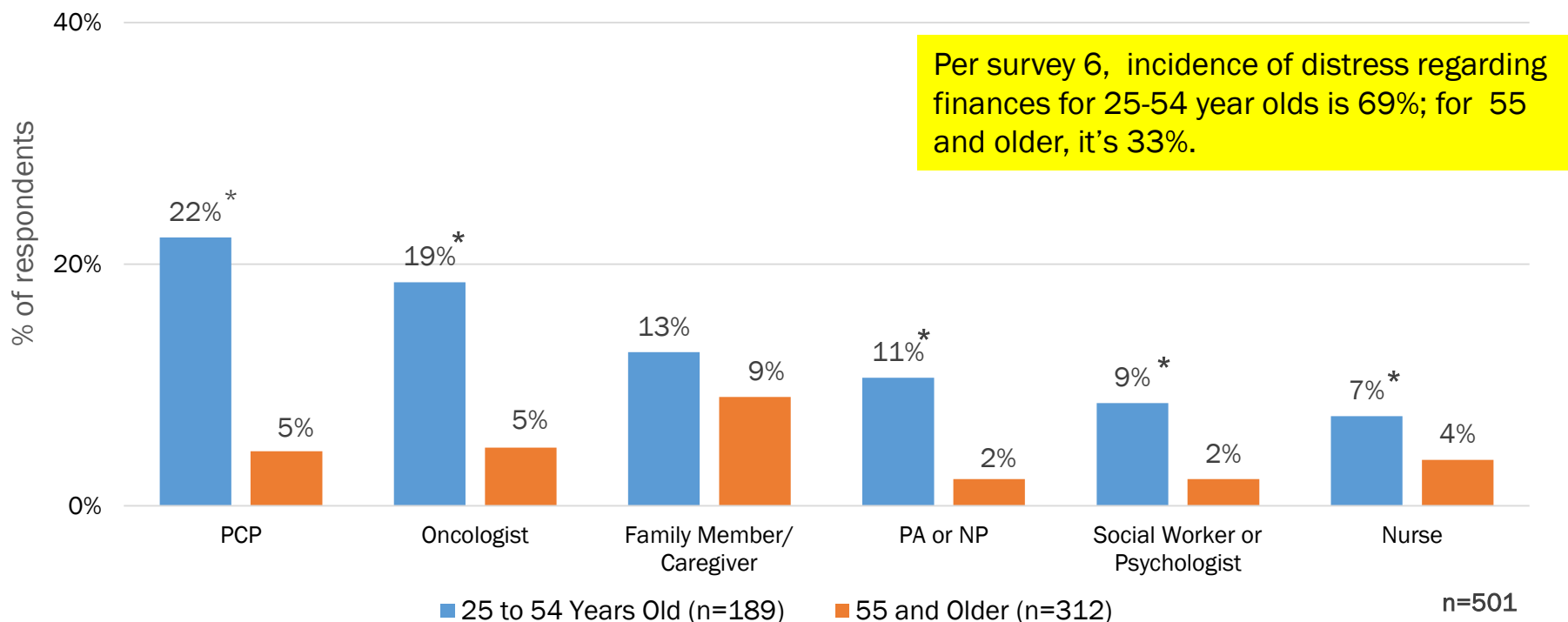


\*Indicates statistically greater at 90% confidence level

27. Which of the following members of your cancer care team have referred you to a patient support service or professional to help you cope with emotional distress?

Referrals for financial support were even lower than those for emotional support. Similarly, however, primary care physicians were more likely to refer than other care team members, and referrals were rarely made for respondents 55 years and older.

## Care Team Members Making Support Referrals - Financial

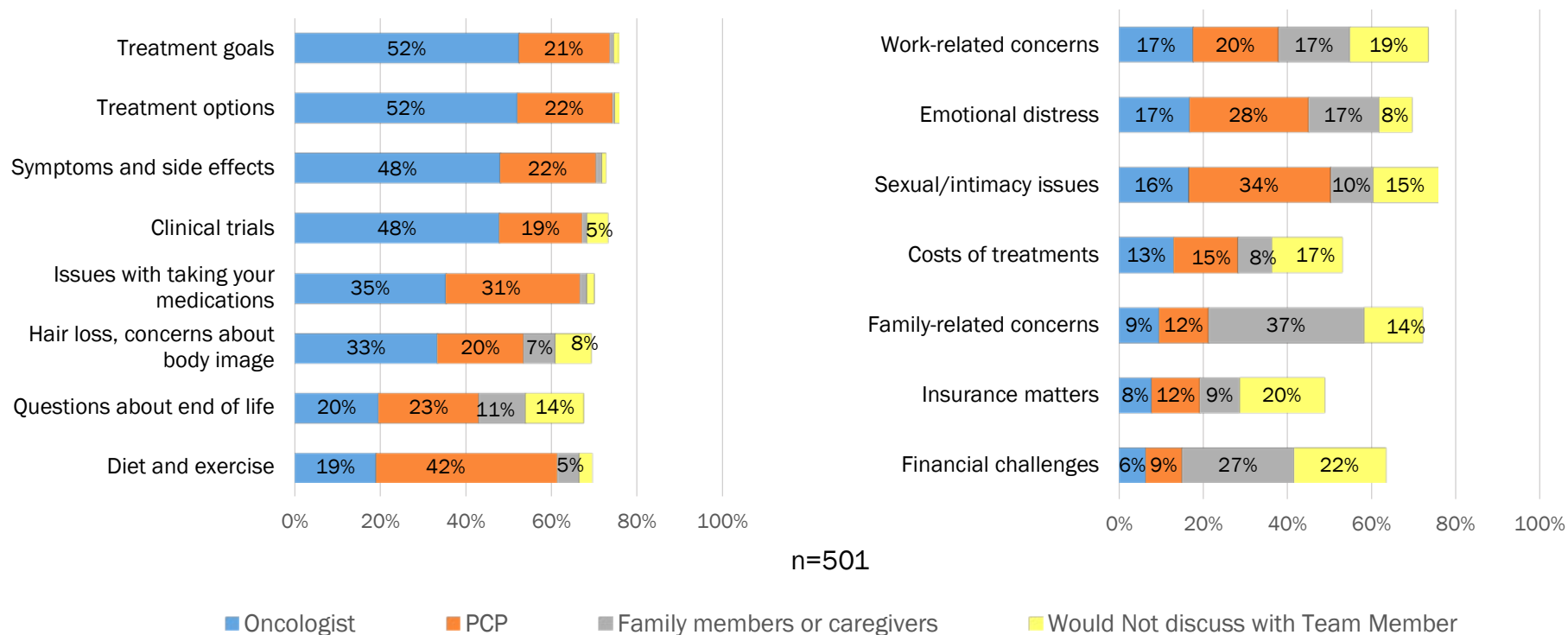


\*Indicates statistically greater at 90% confidence level

28. Which of the following members of your cancer care team have referred you to a patient support service or professional to help you cope with financial distress?

The patients surveyed generally chose to discuss treatment-related issues with their oncologists. There were some issues, however, that they preferred to discuss with their primary care physicians, including diet and exercise, sexual/intimacy and work concerns, emotional distress, and end of life. Family members or caregivers were preferred by some for discussions regarding their families, financial challenges, work-related concerns, and emotional distress. Nurses/PAs/NPs were mentioned by fewer than 10% of respondents as the first choice for discussing any of the topics listed.

## Preferred Care Team Member For Discussions

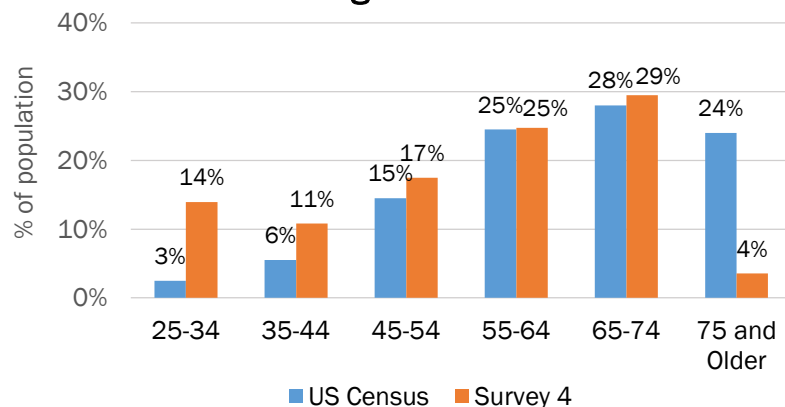


19. Please indicate the member of your cancer care treatment team who would be your first choice for discussing each of the following topics.

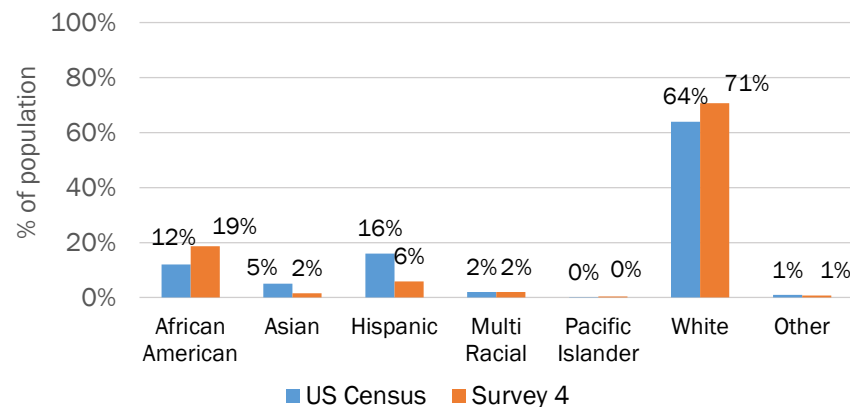
## Survey 4: Finances and Insurance

# Survey 4: Financial & Insurance

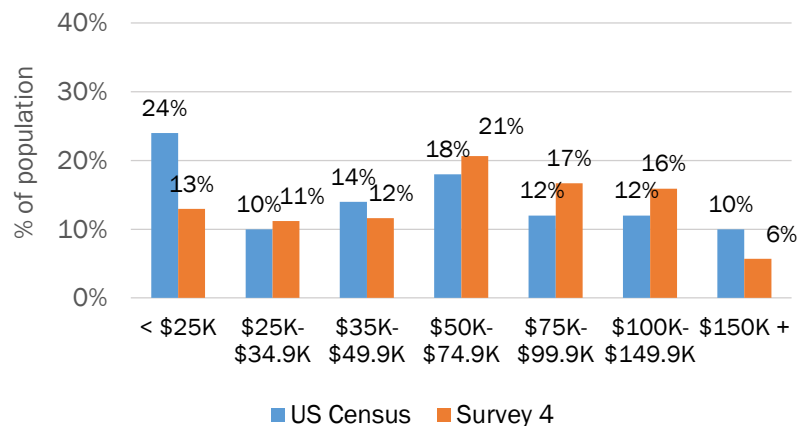
## Age Distribution



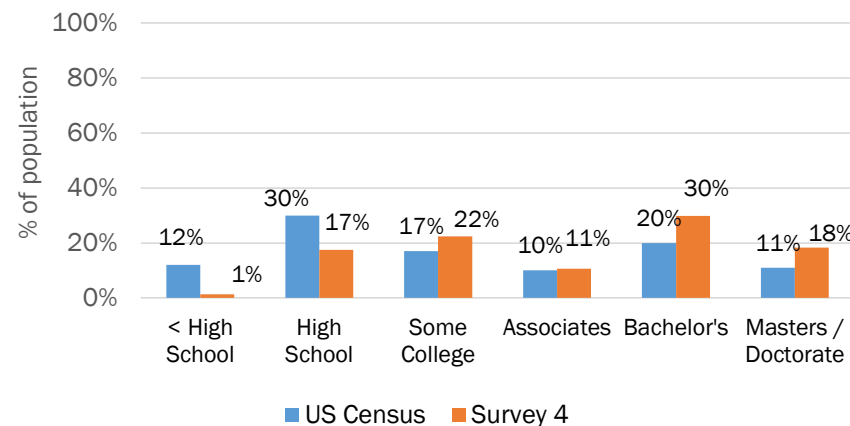
## Ethnic Distribution



## Income Distribution



## Education Distribution



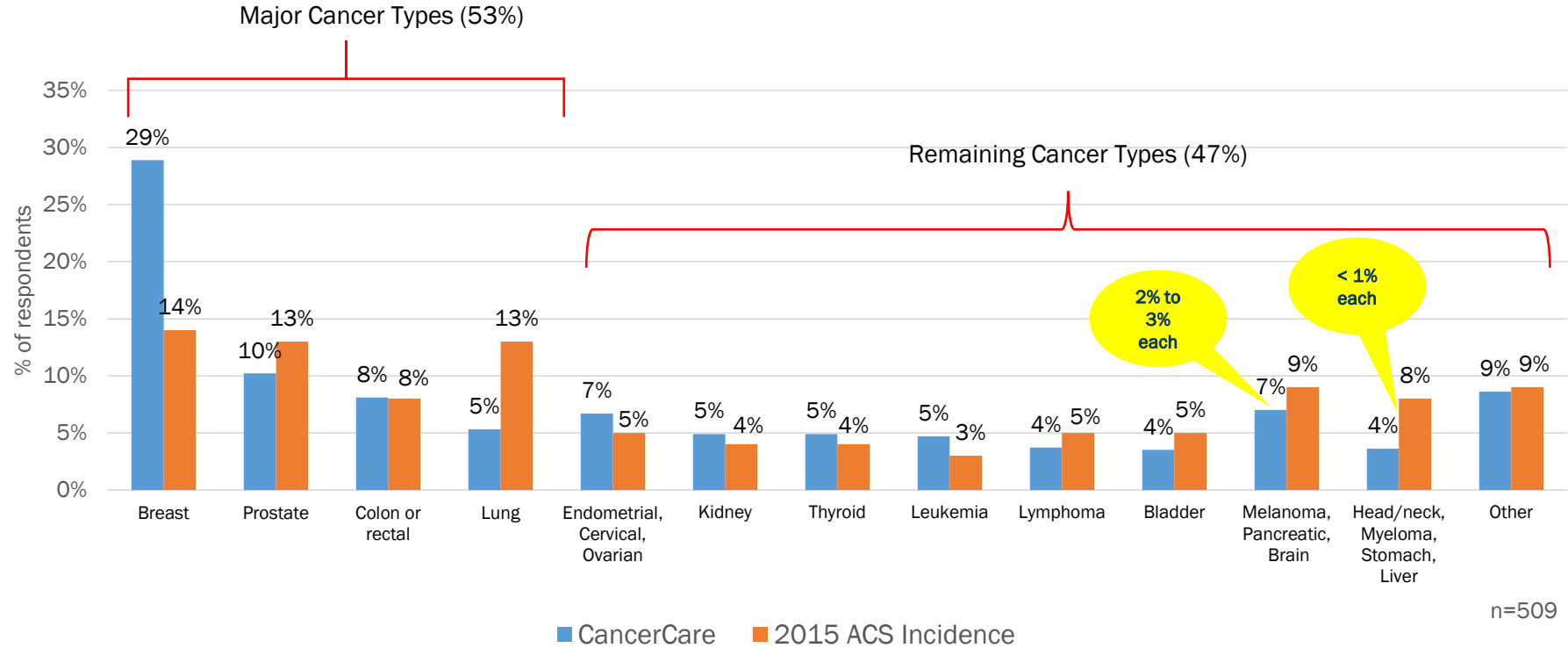
n=509



Respondents to this survey were diagnosed with a range of cancer types. By design, participants were selected to achieve a roughly 50/50 split between those presenting with one of the four most common cancer types (breast, prostate, colorectal, and lung) and all others. Non-melanoma skin cancer was excluded from the sample.



### Distribution of Respondents by Cancer Type – Survey 4

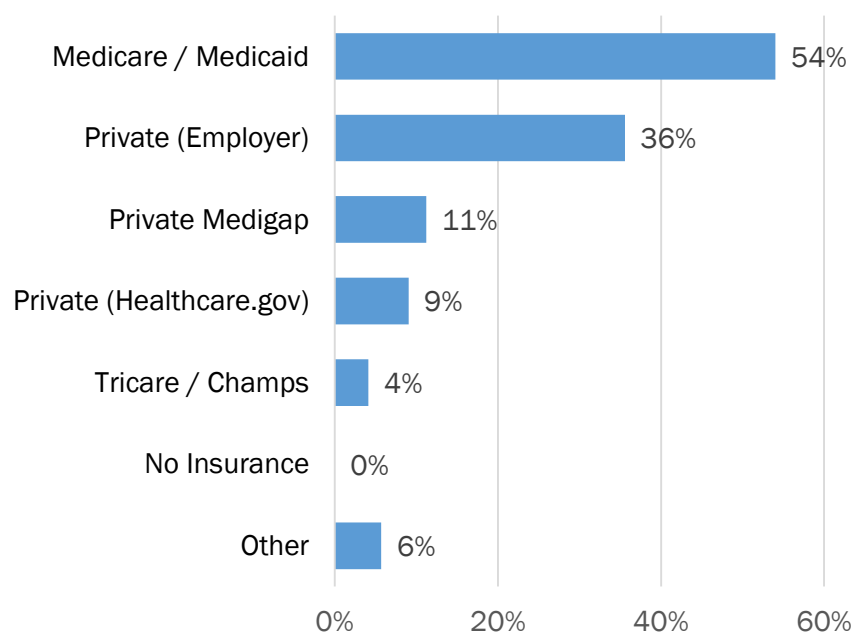


6. What type of cancer were you most recently diagnosed with?

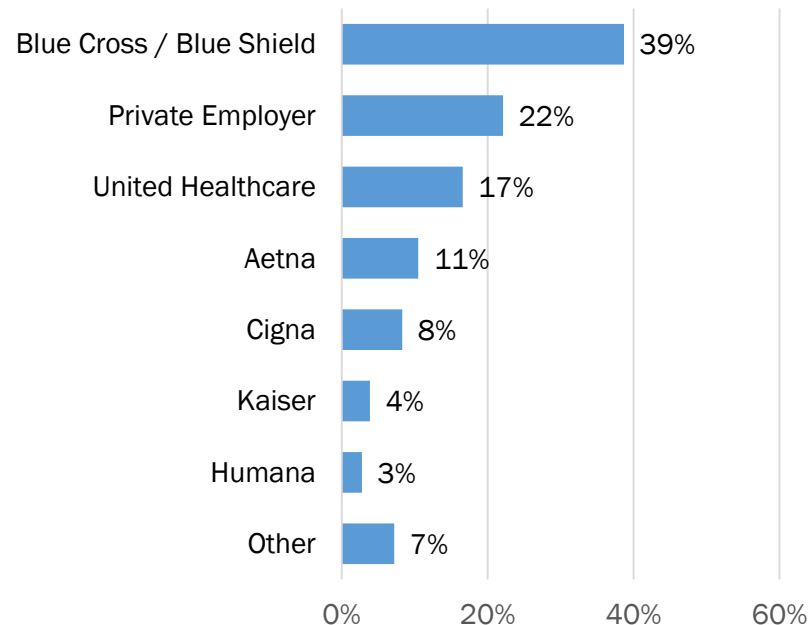
Just over one-half of survey respondents were covered by Medicare or Medicaid. Blue Cross/Blue Shield was the leading private insurer.

## Type of Insurance and Provider

Type of Healthcare Insurance  
(n=509)

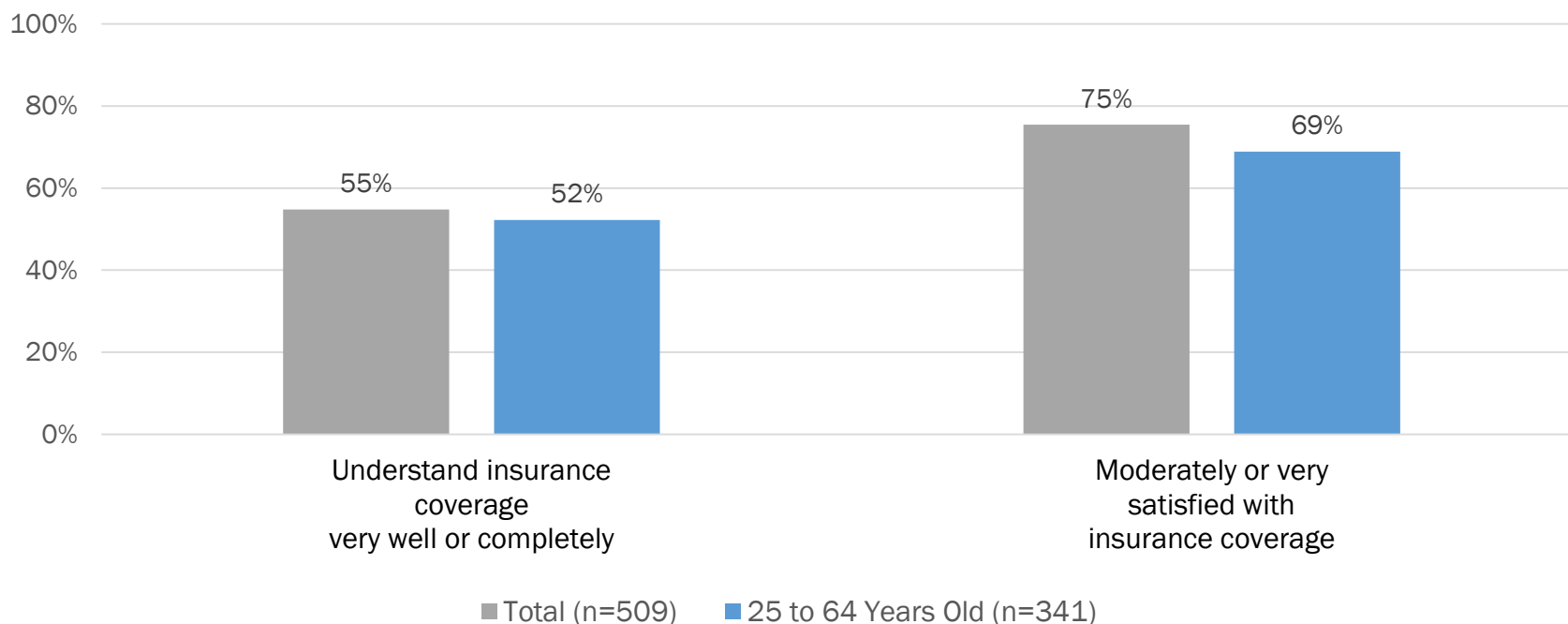


Insurance Provider  
(n=181)



About one-half of total respondents reported understanding their insurance coverage for cancer “completely” or “very well.” Nearly 70% of the 25- to 64-year-old respondents reported being moderately or very satisfied with their insurance coverage.

## Perceptions of Insurance Coverage

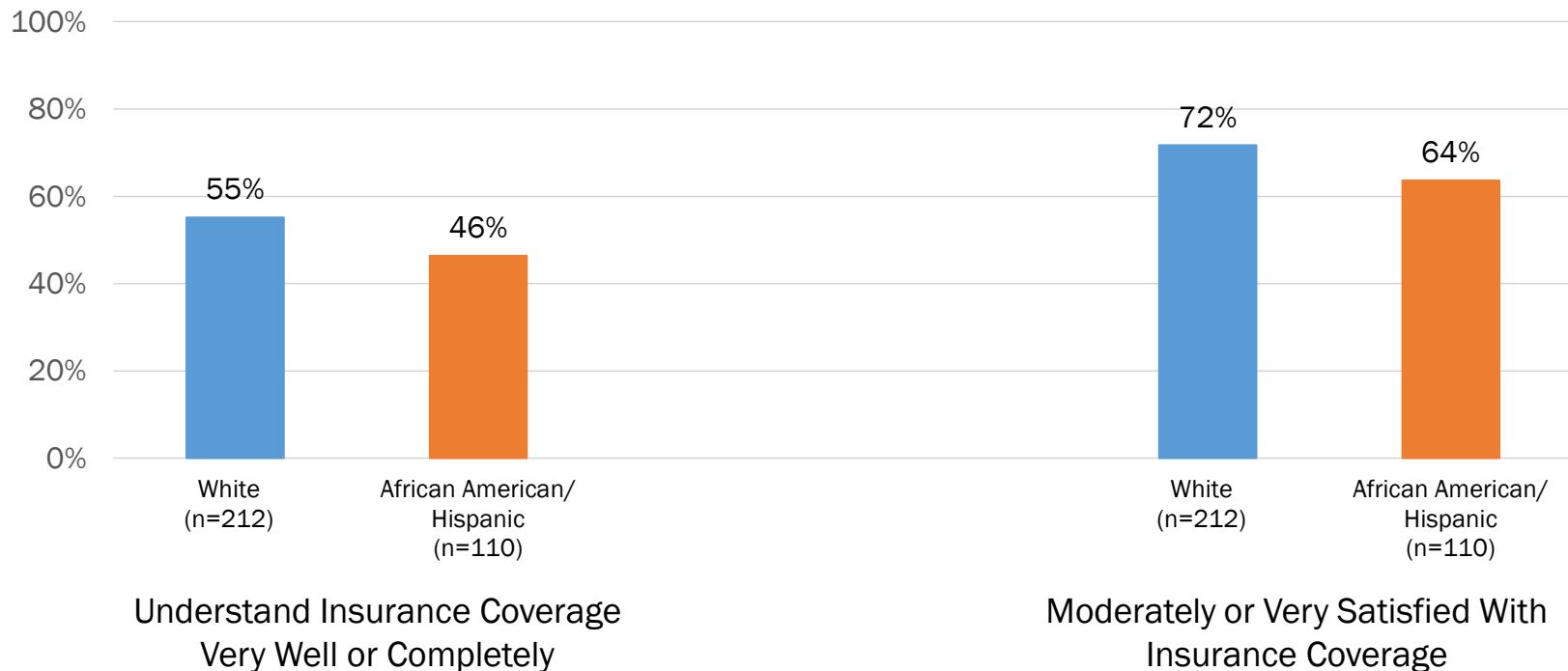


11. Overall, how well do you think you understand what your insurance covers for your cancer care?

13. Overall, how satisfied are you with your insurance coverage for your cancer treatment?

Among respondents ages 25 to 64 years, on average 52% reported understanding their insurance coverage very well or completely and 69% said they were moderately or very satisfied with their insurance coverage. African American / Hispanic respondents' answers were directionally lower than their white counterparts.

## Perceptions of Insurance Coverage – 25 to 64 Years Old



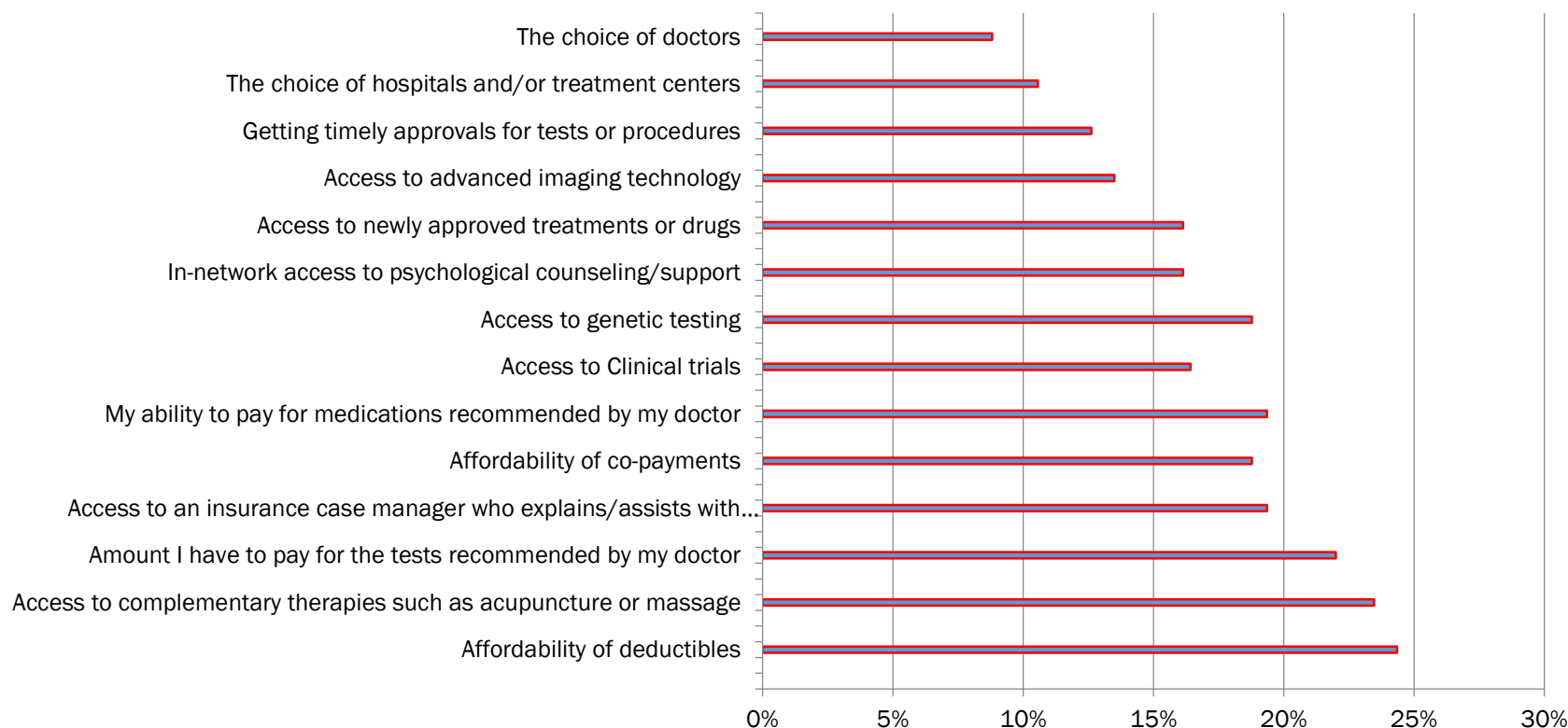
11. Overall, how well do you think you understand what your insurance covers for your cancer care?

13. Overall, how satisfied are you with your insurance coverage for your cancer treatment?

Among respondents 25 to 64 years old, approximately 10% - 25% reported being very or somewhat dissatisfied with certain aspects of their insurance coverage. Those areas that garnered the most dissatisfaction were access to new treatments or genetic testing, ability to pay for medications, affordability of co-payments and deductibles, co-pays for tests, access to complementary therapies, and access to an insurance case manager.

## Dissatisfaction With Aspects of Insurance Coverage for Cancer

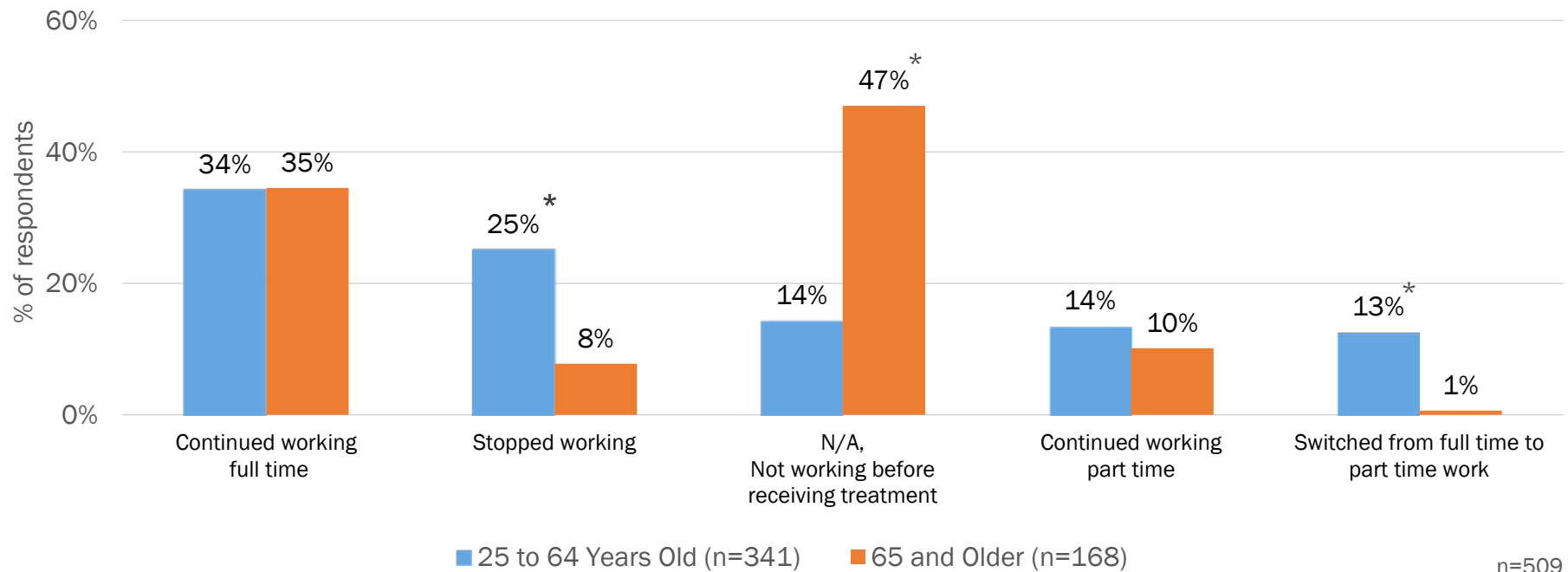
25 to 64 Years Old (n=341)



Q. 14: How satisfied are you with the following aspects of your insurance coverage for your cancer treatment?

Of those respondents 25 to 64 years old, 25% stopped working during treatment and 13% switched from full-time to part-time employment. One-third of all respondents continued to work full-time.

## Employment Status During Treatment

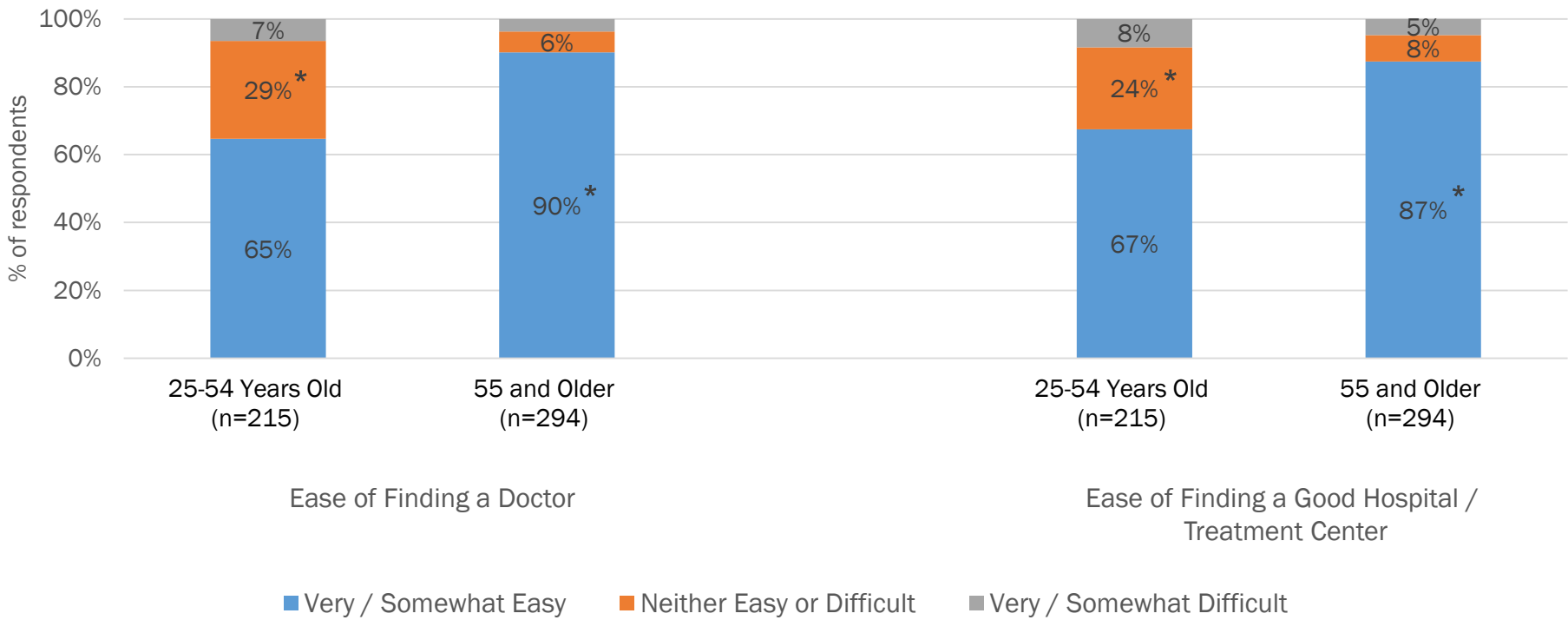


10. What was your employment status while you were being treated for cancer?

Respondents aged 55 years and older had a significantly easier time finding a doctor and/or hospital in their insurance plan than those younger than 55 years. About one-third of younger patients reported it was not easy.



### Ease of Finding Doctor or Treatment Center Taking Your Insurance

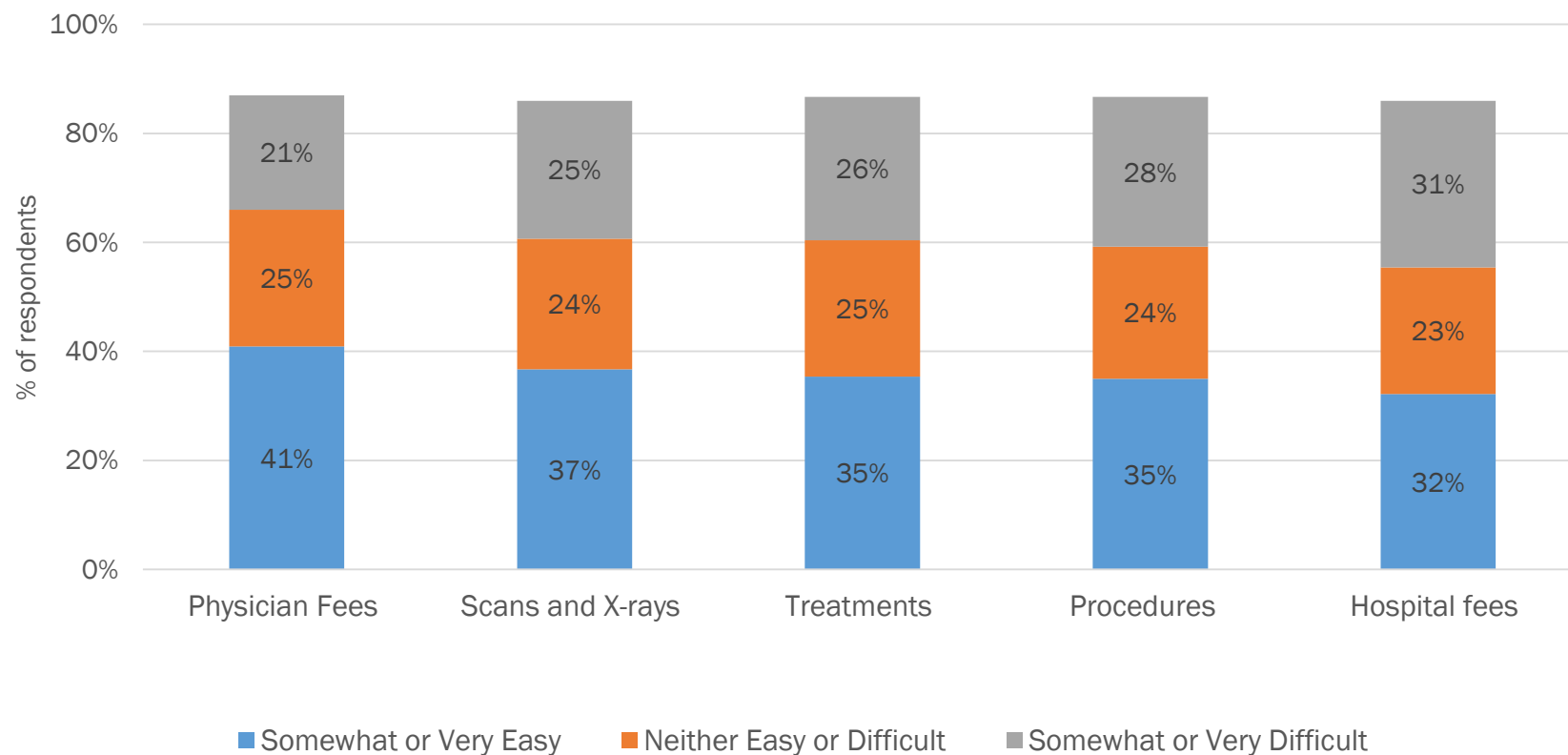


\* Indicates statistically greater at 90% confidence level

- 17. Overall, how difficult or easy was it to find a doctor to treat you for cancer who takes your insurance?
- 19. Overall, how difficult or easy was it to find a really good hospital or cancer treatment center that takes your insurance?

Roughly one-fifth to one-third of patients reported it was difficult to determine out-of-pocket costs before incurring the expense. This finding did not vary based on patients' demographics or the length of time since diagnosis. Out-of-pocket hospital fees were considered the most difficult to determine.

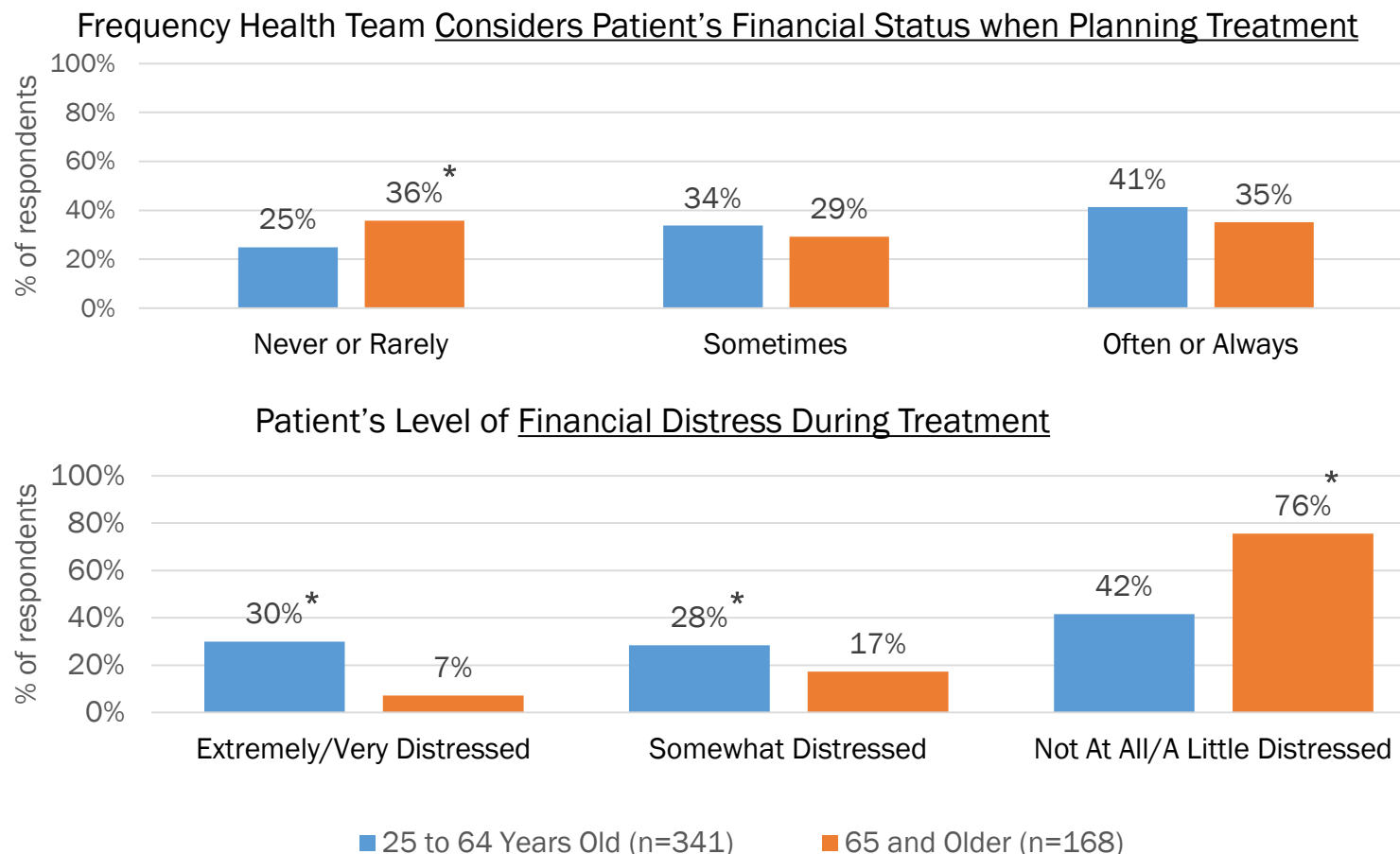
## Ease of Determining Out-of-Pocket Costs



44. How difficult or easy was it for you to determine the out-of-pocket cost of each of the following BEFORE you incurred the expense?



Among respondents under Medicare age, 25% reported that their financial situation was never or rarely considered by their care team in treatment planning and 34% said it was sometimes considered. Yet, 58% reported being distressed about their finances while in treatment.

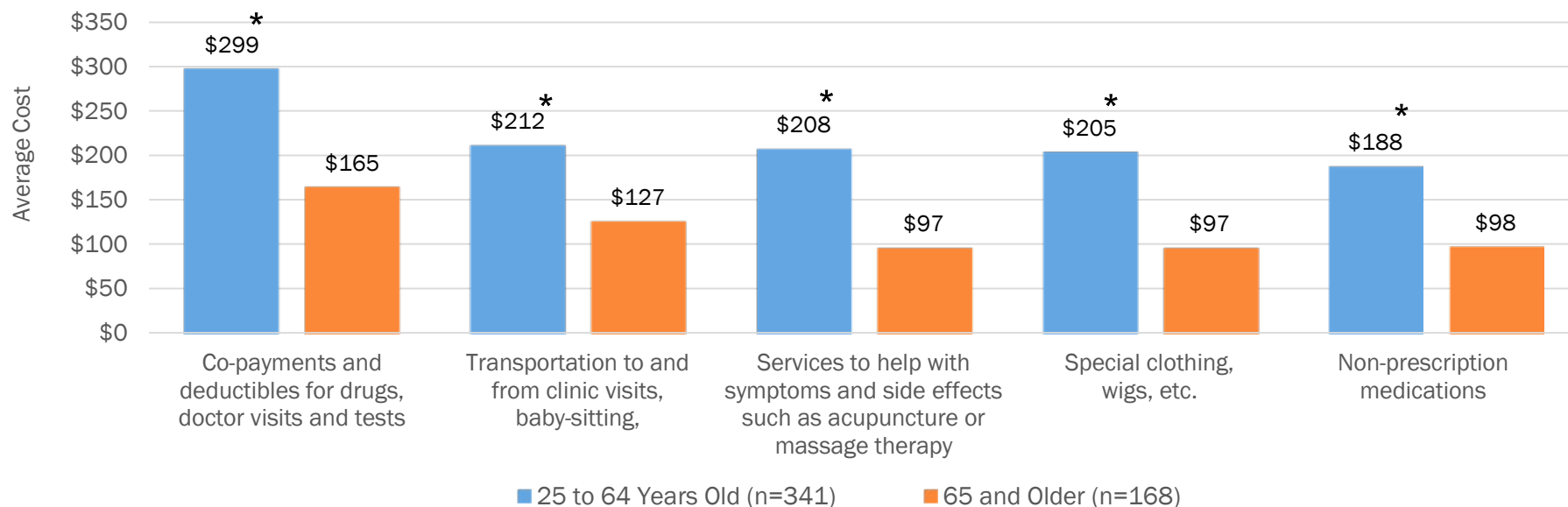


\*Indicates statistically greater at 90% confidence level

31. How often do you feel your healthcare team takes your financial situation into consideration when recommending treatment options?  
23. Thinking about the time when you were getting cancer treatment, how distressed (e.g. anxious, extremely upset, or in emotional pain) were you from thinking about your finances?

Average monthly out-of-pocket costs for patients in treatment, aged 25 to 64, were \$1,112 compared to \$584 for those 65 or older. About a quarter of the monthly expense was for co-pays and deductibles for drugs, doctor visits, and tests. Another third reflected spending on services and non-prescription medicines to help with symptoms and side effects.

## Average Monthly Out-of-Pocket Costs



\* Indicates statistically greater at 90% confidence level

45. Thinking about the time you were getting cancer treatment, on average, how much did you spend out of pocket each month on the following?

Many respondents, especially those aged 25 to 54 years, took steps to reduce the costs of treatment, some of which may have compromised their cancer treatment: 39% skipped doctors' appointments; 38% postponed or did not fill prescriptions; 34% skipped doses of prescribed drugs; 30% ordered medication from non-US sources; and 31% cut pills in half.

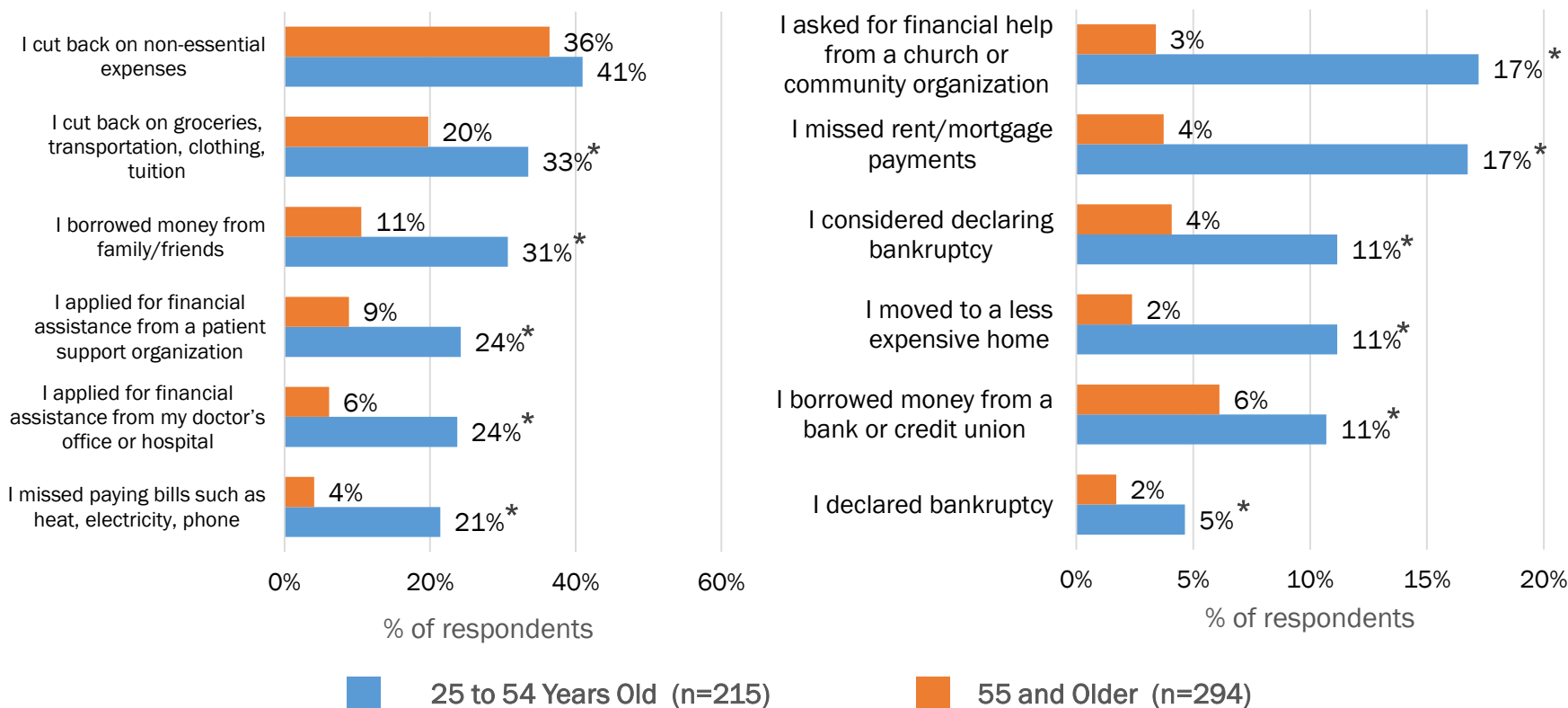
Steps Taken to Reduce Treatment Expenses	Done Often or Always		Done Sometimes	
	25 to 54 Years Old (n=215)	55 and Older (n=294)	25 to 54 Years Old (n=215)	55 and Older (n=294)
Apply for co-pay assistance to cover medication costs	27%	10%	17%	4%
Choose to use a lower cost medication than what the doctor recommended	27%	7%	16%	8%
Delay or skip complementary treatment	27%	7%	16%	5%
Apply for financial assistance for non-medical expenses such as transportation	25%	6%	18%	5%
Postpone or skip psychological counseling or support	24%	6%	16%	4%
Apply for financial assistance from my doctor/hospital	24%	4%	21%	7%
Discuss changing my treatment to one that costs less	24%	3%	19%	10%
Postpone or skip follow-up testing	23%	4%	16%	5%
Postpone or not fill prescriptions	21%	2%	17%	6%
Postpone or skip doctor's appointments	20%	2%	19%	7%
Skip dosages of prescribed drugs	20%	2%	14%	5%
Postpone or skip blood work	17%	2%	18%	3%
Order medications on-line from non-US sources	16%	3%	14%	2%
Cut pills in half	14%	4%	17%	4%

Indicates statistically different at 90% confidence level

25. How often do you do each of the following in order to REDUCE your expenses related to your cancer treatment?

Expenses related to a cancer diagnosis had an impact on numerous aspects of patients' finances. One-third of respondents aged 25 to 54 years cut back on essentials such as groceries and transportation and/or borrowed from family/friends; one-quarter applied for assistance from patient organizations or providers; 21% missed utility bills; and 17% missed rent/mortgage payments.

## Experiences Due to Treatment Bills



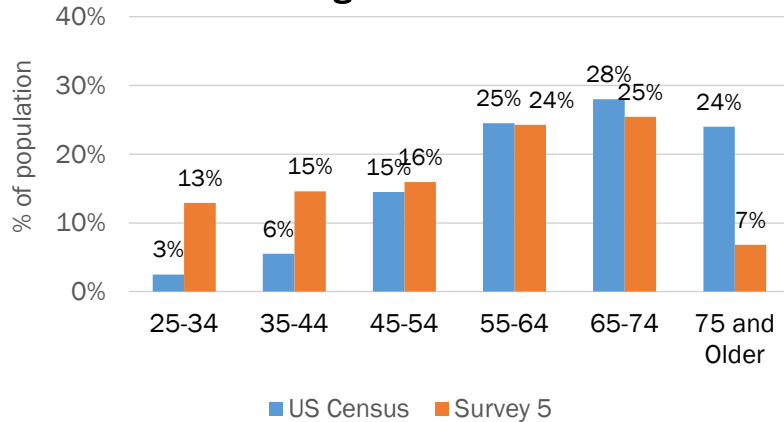
\*Indicates statistically greater at 90% confidence level

33. Which of the following have you experienced as a result of bills related to your cancer treatment? Please select all that apply.

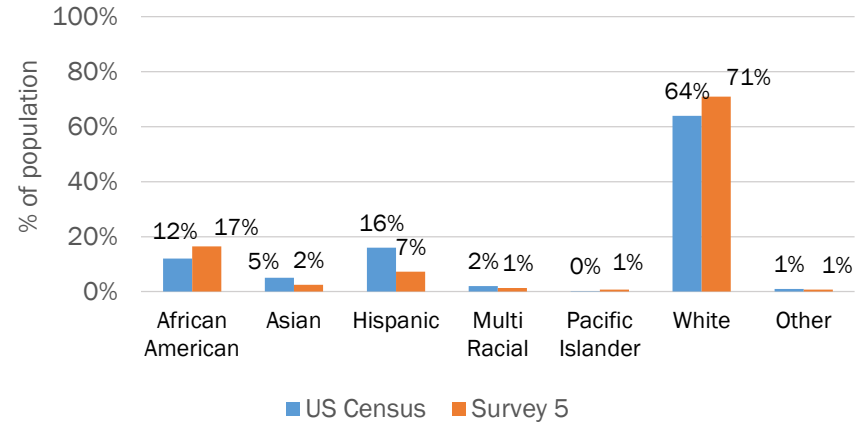
## Survey 5: Symptoms and Side Effects

# Survey 5: Symptoms and Quality of Life

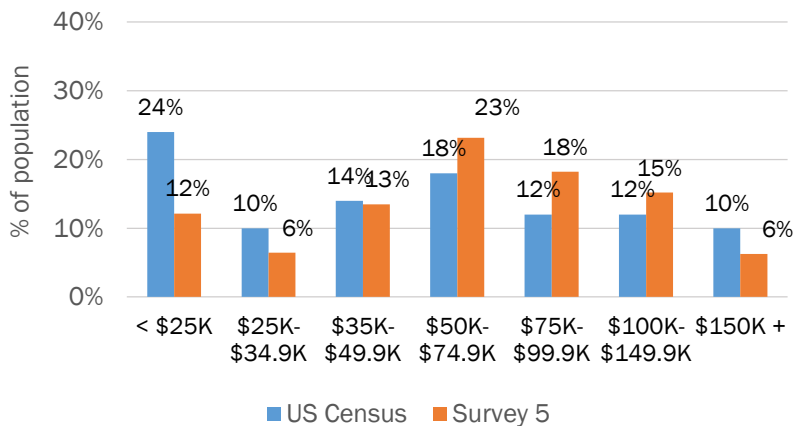
## Age Distribution



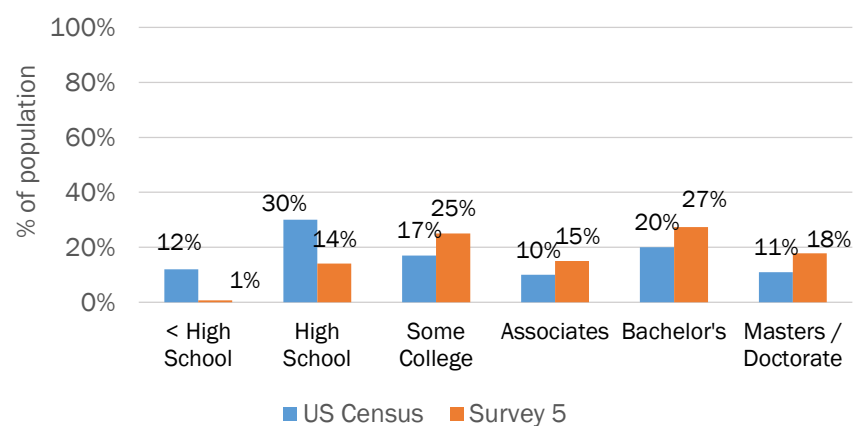
## Ethnic Distribution



## Income Distribution



## Education Distribution

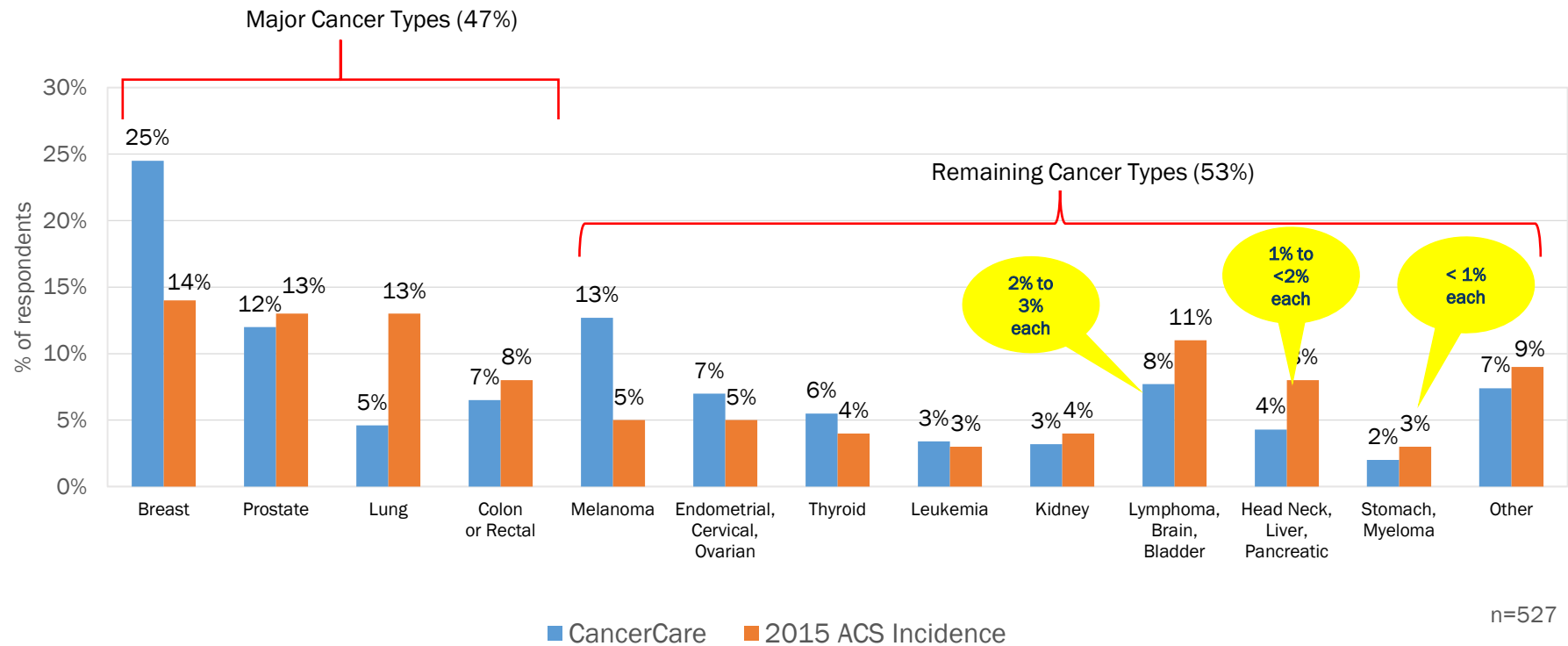


n=527

Respondents to this survey were diagnosed with a range of cancer types. By design, participants were selected to achieve a roughly 50/50 split between those presenting with one of the four most common cancer types (breast, prostate, lung, and colorectal) and all others. Non-melanoma skin cancer was excluded from the sample.



## Distribution of Respondents by Cancer Type – Survey 5

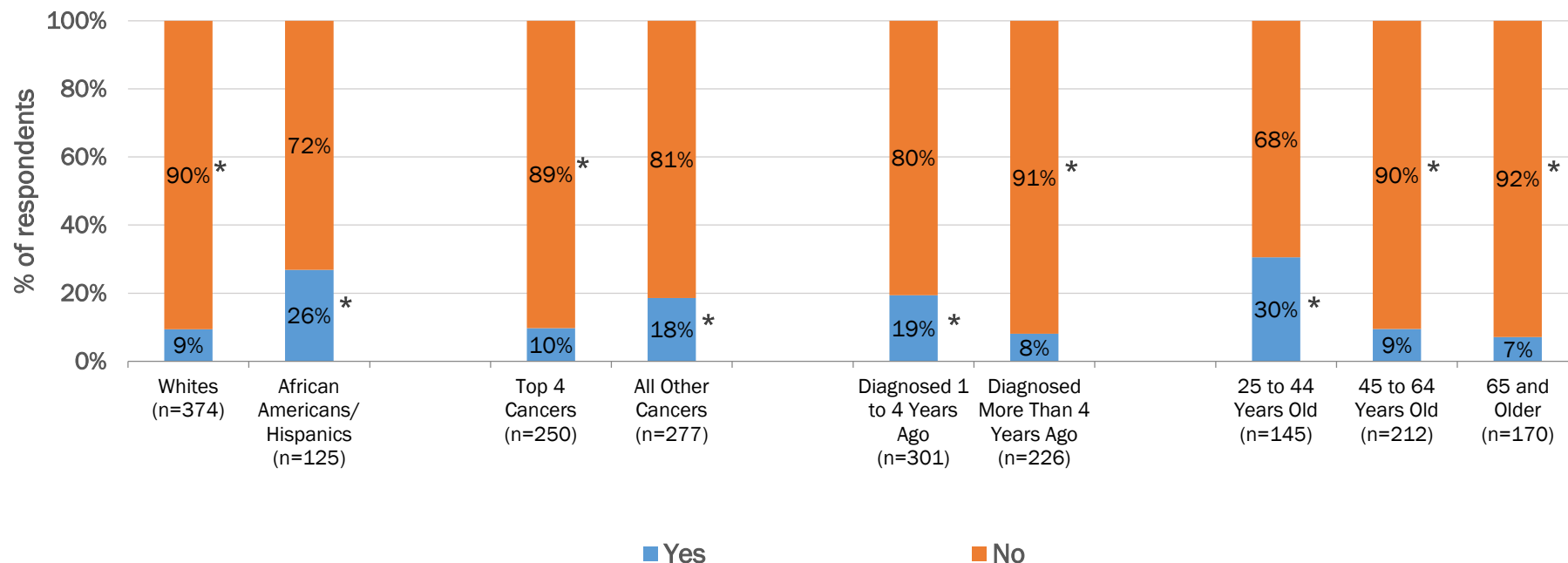


5. What type of cancer were you most recently diagnosed with?

Note: percentages may be off by 1% due to rounding

Participation in clinical trials was much higher in this study population than the U.S. cancer patient average of 3%. One-quarter of African American / Hispanic patients reported participating in a trial, as did 30% of those aged 25 to 44 years. (Note that 53% of the 25- to 44-year-old respondents identified as African American/Hispanic.) Those with less common cancers were more likely to be on a trial than those who had breast, prostate, lung, or colon cancers. Also, those patients diagnosed within the past 4 years were more than twice as likely to be part of a clinical trial than those who were diagnosed more than 4 years ago.

## Clinical Trial Participation



\*Indicates statistically greater at 90% confidence level

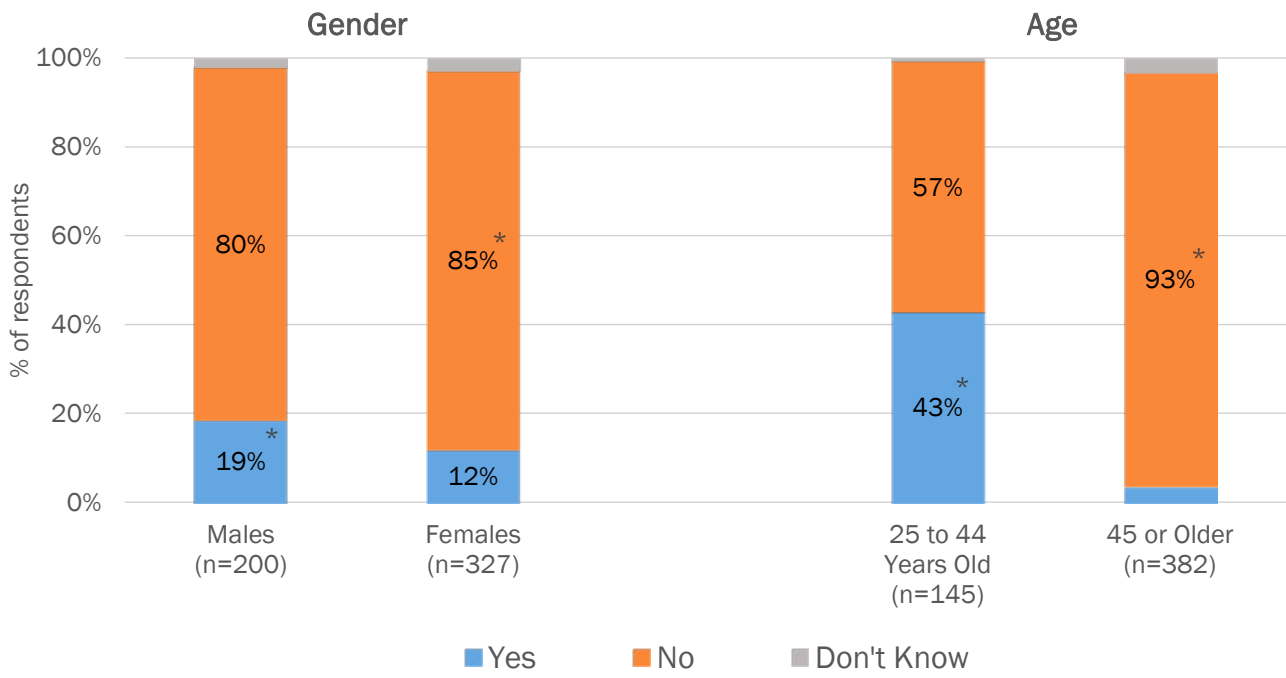
9. Have you ever been part of a clinical trial for cancer treatment?



Use of the “distress thermometer” varied greatly across patient populations though was quite low on average. Patients who were under 45 years of age reported being 10 times more likely to be asked to complete the distress thermometer form than were those 45 years or older. Those treated at community cancer centers were significantly more likely to have used the distress thermometer (22%), as were those in active treatment (29%) or on maintenance therapy (19%).



### Use of “Distress Thermometer Form”



### Distress Thermometer Form

During the past week, how distressed have you been?

Please indicate your level of distress on the thermometer and check the causes of your distress.

Extreme distress

10  
9  
8  
7  
6  
5  
4  
3  
2  
1  
0  
No distress

Practical problems

☐ Housing  
☐ Insurance  
☐ Work/school  
☐ Transportation  
☐ Child care

Family problems

☐ Partner  
☐ Children

Emotional problems

☐ Worry  
☐ Sadness  
☐ Depression  
☐ Nervousness

Spiritual/religious concerns

☐ Relating to God  
☐ Loss of faith  
☐ Other problems

Physical problems

☐ Pain  
☐ Nausea  
☐ Fatigue  
☐ Sleep  
☐ Getting around  
☐ Bathing/dressing  
☐ Breathing  
☐ Mouth sores  
☐ Eating  
☐ Indigestion  
☐ Constipation/diarrhea  
☐ Bowel changes  
☐ Changes in nutrition  
☐ Fevers  
☐ Skin dry/itchy  
☐ Nose dry/congested  
☐ Tingling in hands/feet  
☐ Feeling swollen  
☐ Sexual problems

\* Indicates statistically greater at 90% confidence level

40. Have you ever been asked to complete the “Distress Thermometer” form, which is pictured below?

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57

Moderate-to-severe fatigue was the symptom experienced most often, with 25% of men and 46% of women indicating that it interfered with day-to-day activities. Overall, women were much more likely to report experiencing symptoms and side effects and to report that they interfered with their day-to-day activities. Those in active treatment and those on maintenance therapy experienced these symptoms and their impact at similar levels.

## Common Symptoms and Side Effects

	Moderate to Severe Symptoms		Symptoms Most Interfering With Day-to-Day Activities	
	Male (n=200)	Female (n=327)	Male (n=174)	Female (n=298)
Fatigue	41%	61%	25%	46%
Anxiety	30%	43%	12%	20%
Difficulty exercising and staying physically active	29%	37%	10%	16%
Sexual/intimate relations problems	27%	16%	8%	3%
Weight gain or loss	25%	36%	4%	9%
Decreased appetite	23%	28%	8%	7%
Hair loss	22%	40%	5%	7%
Diarrhea	21%	17%	9%	7%
Nausea or vomiting	15%	25%	7%	15%

Indicates statistically different at 90% confidence level

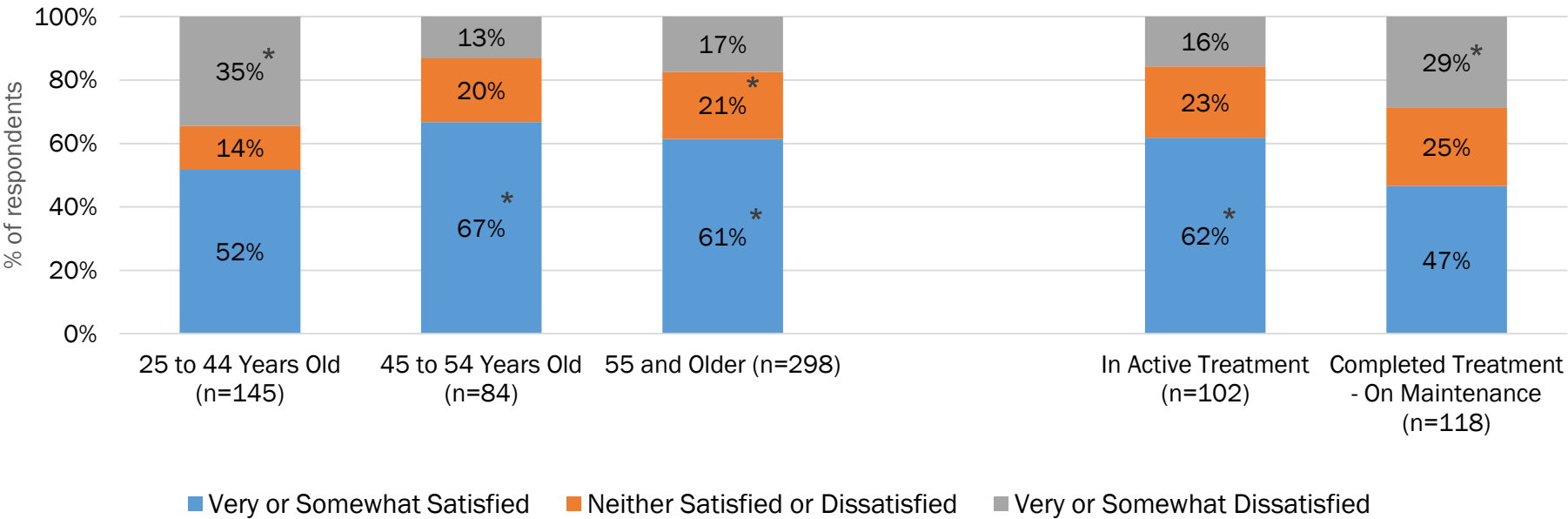
10. Following is a list of symptoms and side effects. Please indicate those that you have experienced moderately to severely due to your cancer and/or its treatment

11. Of the moderate to severe symptoms/side effects you selected, which ones most interfere with your day-to-day activities?

Among survey respondents, satisfaction with the way their care team prepared them for cancer-related symptoms and side effects was relatively low, and 13% to 35% reported they were very or somewhat dissatisfied. Younger patients and those on maintenance therapy were most likely to be dissatisfied.



Satisfaction With Preparation By Care Team for Symptoms and Side Effects

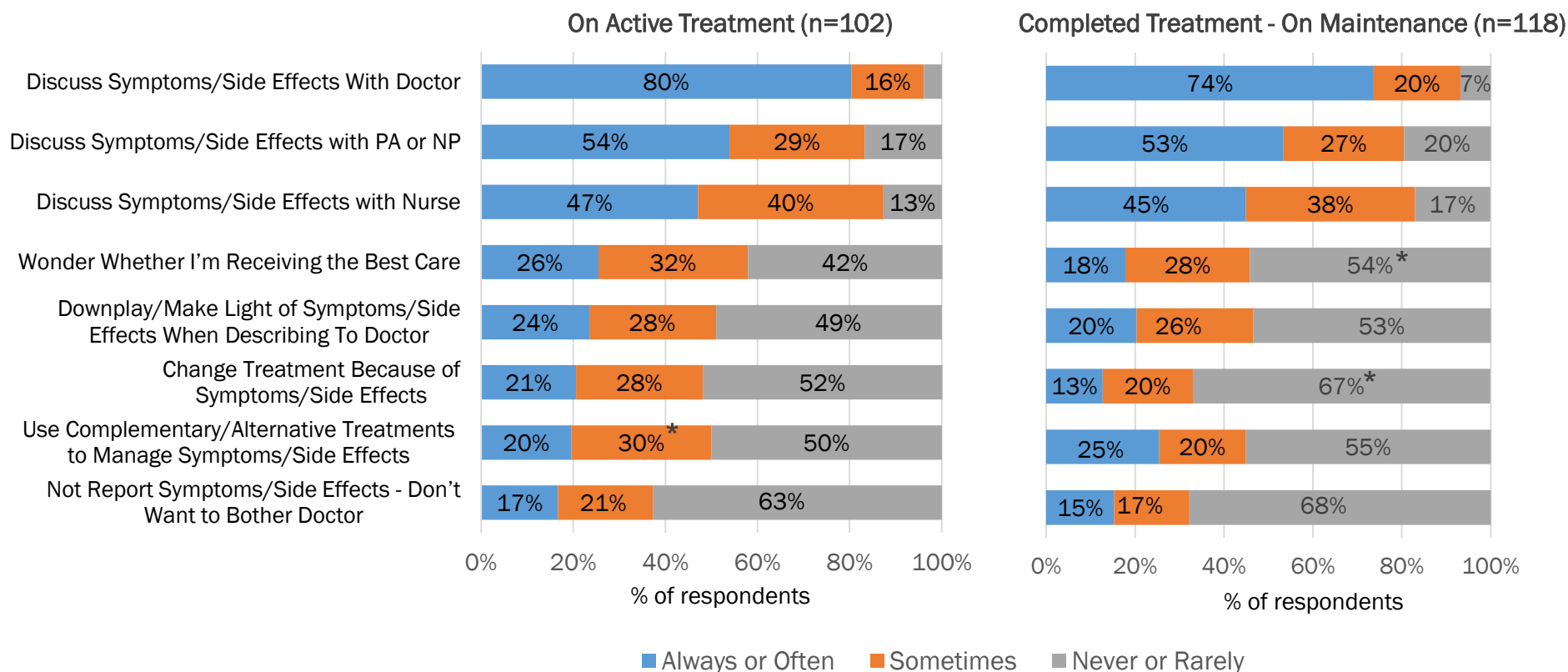


\*Indicates statistically greater at 90% confidence level

14. How satisfied are you with the way your clinical care team prepared you for the symptoms and side effects you experienced?

In response to experiencing symptoms and side effects, patients had discussions most often with their doctors and to a lesser extent with PA/NPs or nurses. Those in active treatment or on maintenance therapy responded very similarly to these survey questions. Of note, about one-half of respondents wondered whether they were receiving the best care. One-half also said they downplayed their symptoms and side effects when describing them to their doctor, and nearly 40% said they did not report symptoms or side effects because they did not want to bother the doctor.

## Responses to Symptoms and Side Effects



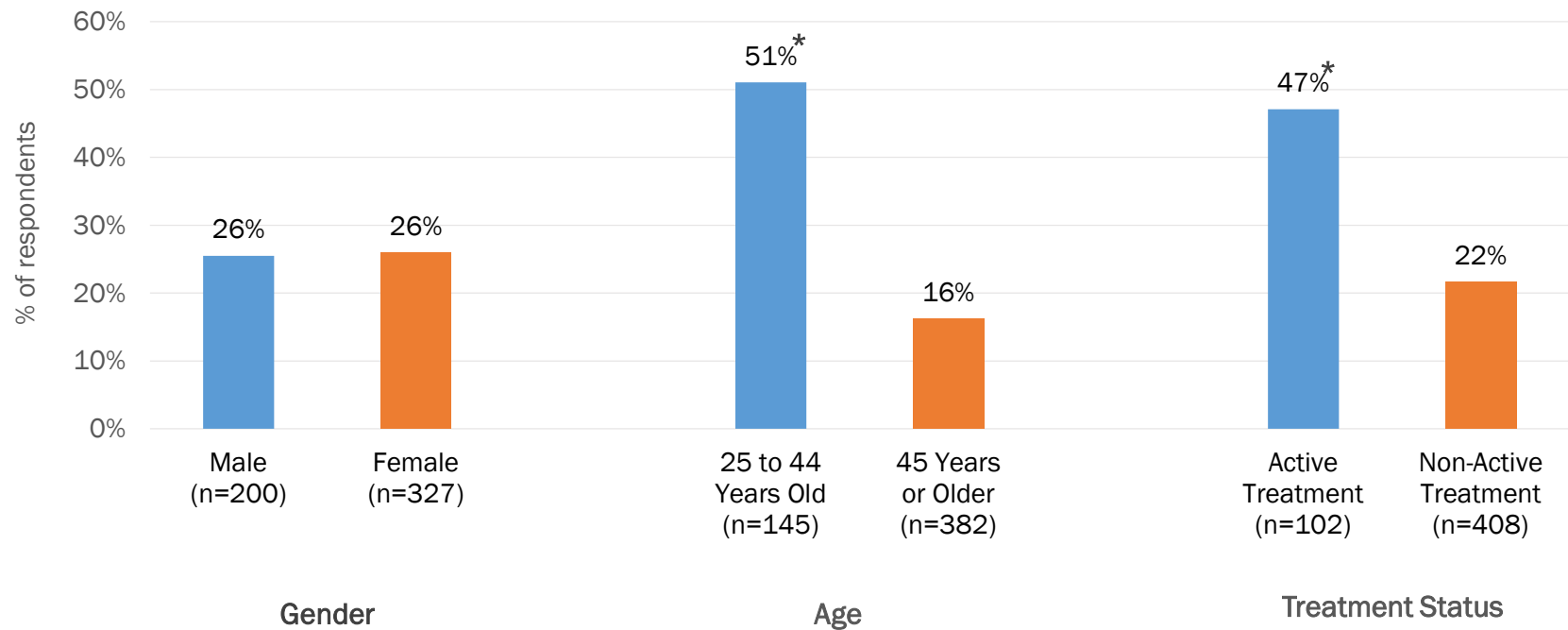
\*Indicates statistically greater at 90% confidence level

20. How often do/did you take the following actions?

One-quarter of both men and women who responded to the survey reported they had used cancer-specific counseling/support services. Those respondents aged 25 to 44 years old and those in active treatment were twice as likely to have used these services.



### Use of Cancer Specific Counseling/Support Services

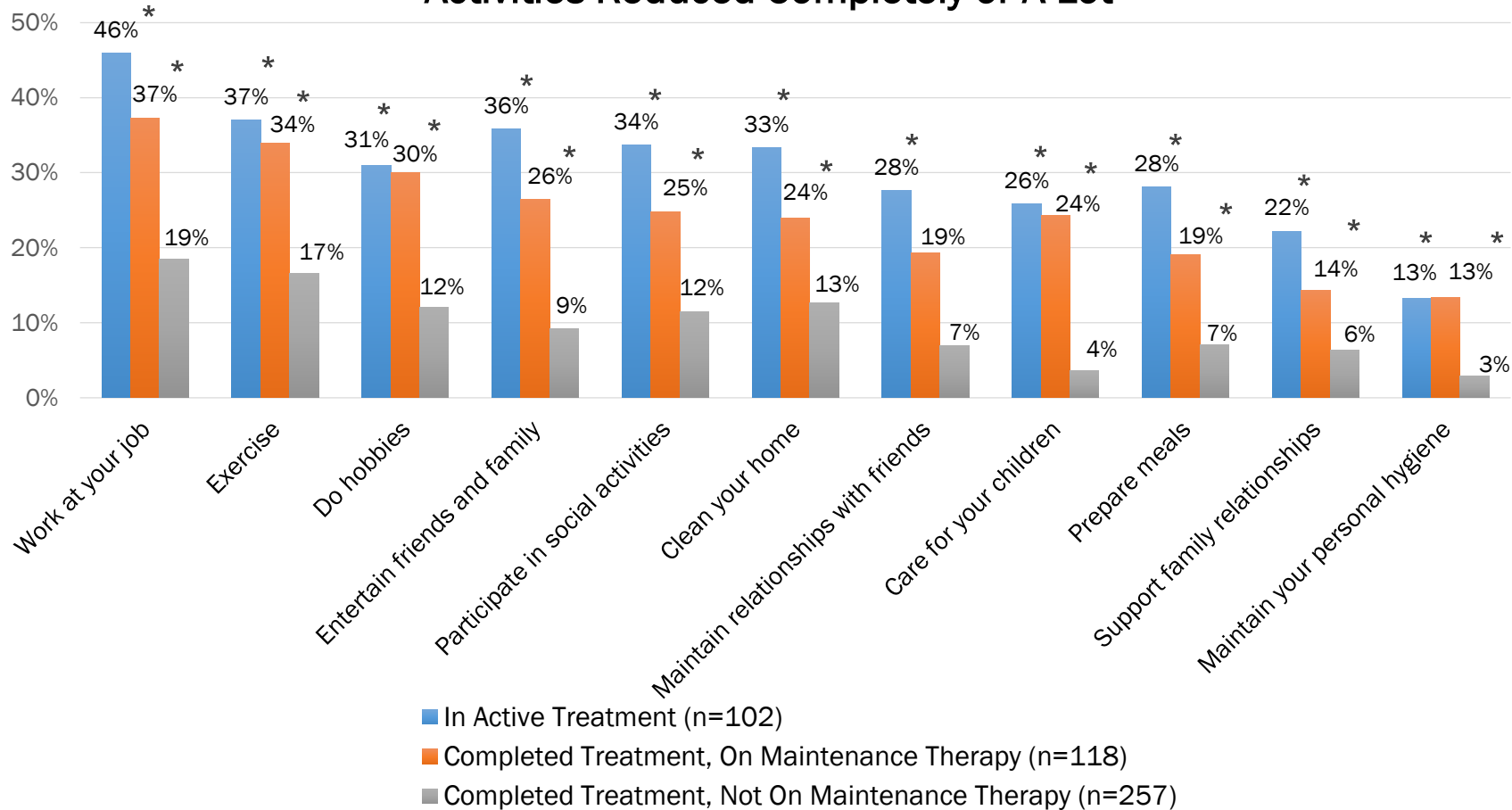


*\*Indicates statistically greater at 90% confidence level*

36. Have you ever used cancer-specific counseling/support services (such as social workers, psychologists or psychiatrists who specialize in oncology) to help you cope with your symptoms/side effects?

As a result of having cancer, for one-quarter to one-third of respondents, the ability to perform day-to-day activities was dramatically compromised. For many, this was true even when treatment had been completed, regardless of whether or not they were on maintenance therapy.

## Activities Reduced Completely or A Lot



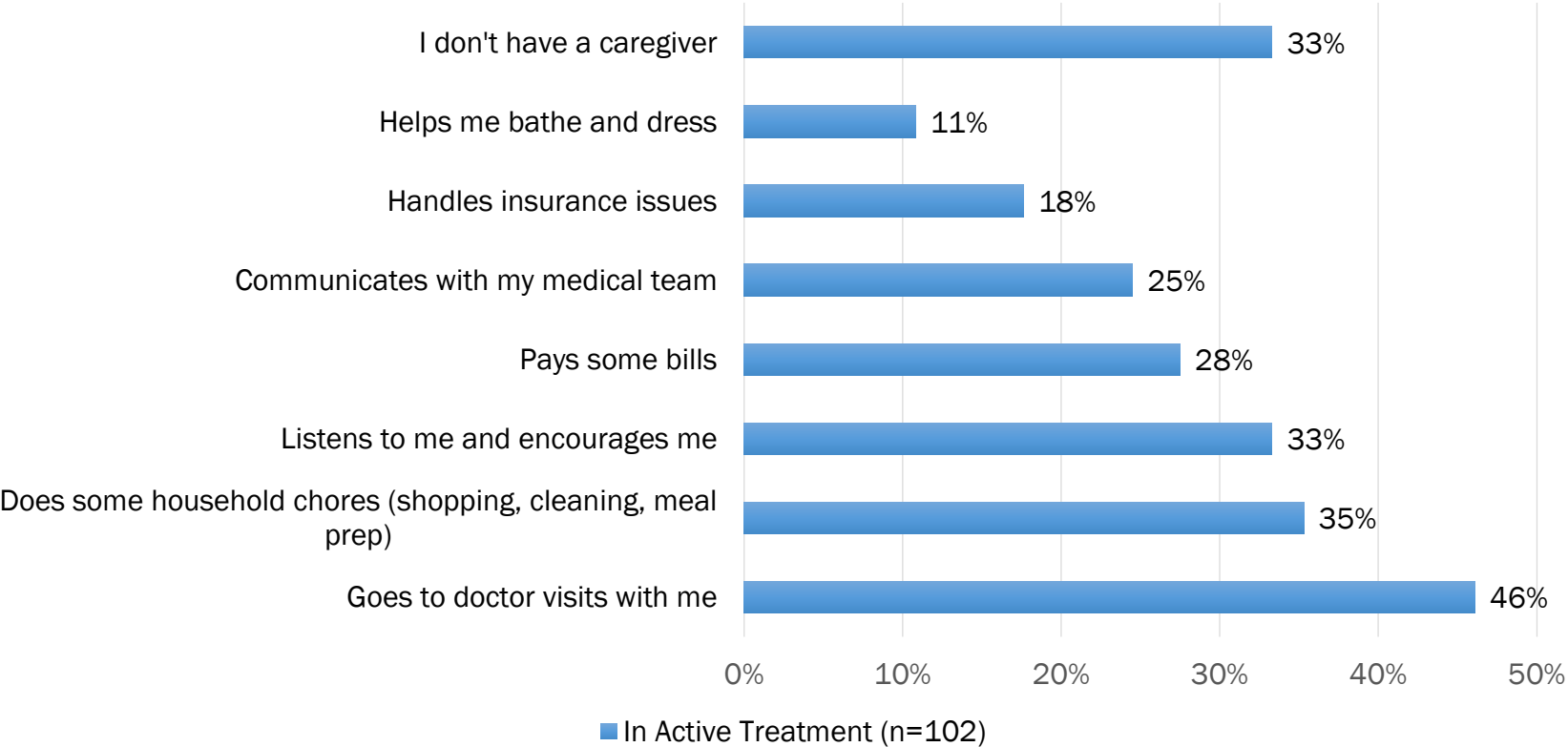
\*Indicates statistically greater at 90% confidence level

43. How much has your ability to do the following activities been reduced as a result of having cancer?

One-third of patients in active treatment reported not having a caregiver. Among those that did, nearly half said their caregiver accompanied them to doctor visits. Other activities included doing household chores, providing emotional support, paying some bills, and communicating with the medical team.



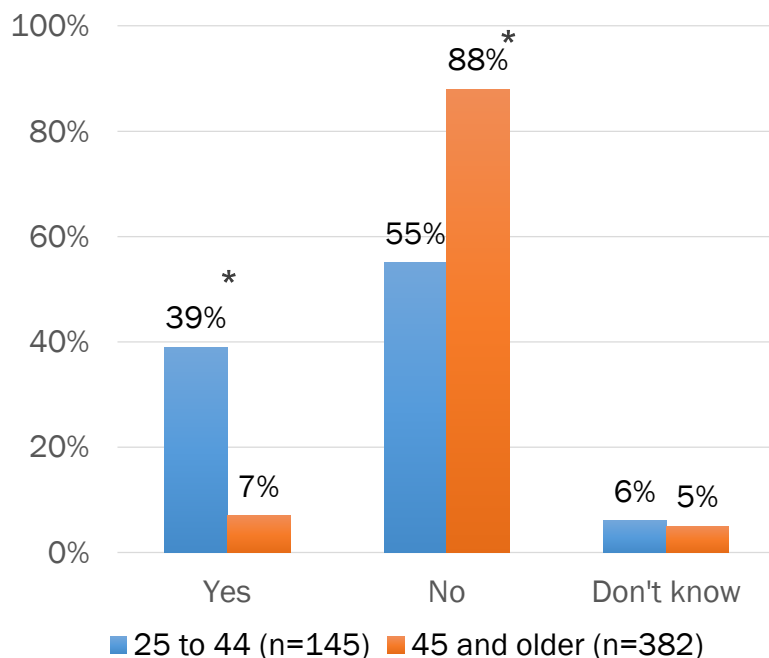
### Caregiver Activities



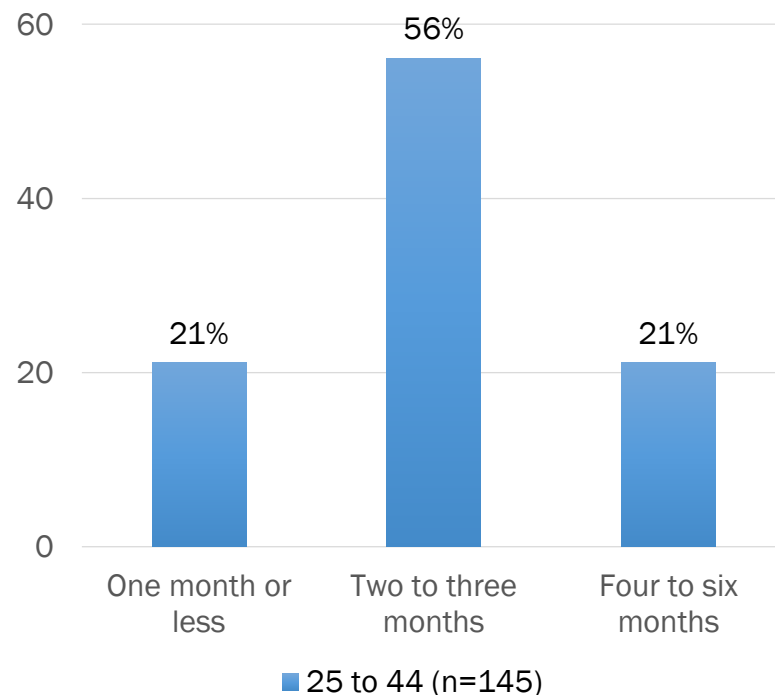
41. Please indicate the ways your caregiver helps make your quality of life better.

Among those ages 25 to 44, 39% of respondents indicated that their insurance company required they follow a step-therapy process to manage symptoms/side effects. For a majority of these patients, this required using a non-preferred medicine for 2 to 3 months.

### Insurance Company Required Step Therapy



### Step Therapy: Required Time for Using Mandated Medicine



23. Has your insurance company ever required you to follow "step therapy" to manage any symptoms/side effects you experienced?

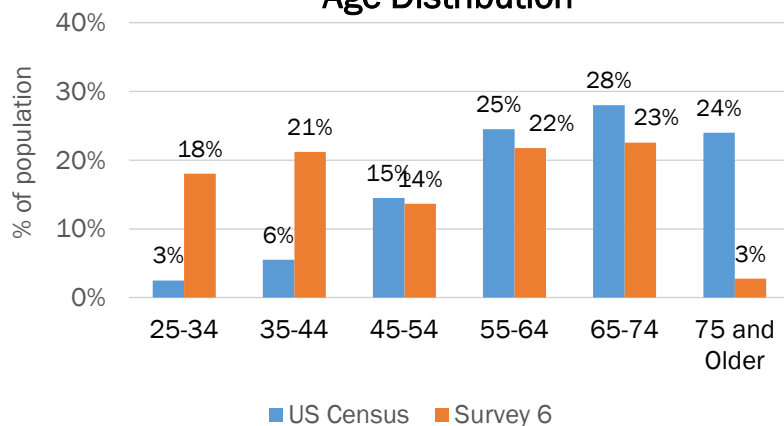
24. How long did you have to use the first medicine before you could have the one you and/or your doctor preferred to manage your symptoms/side effects?



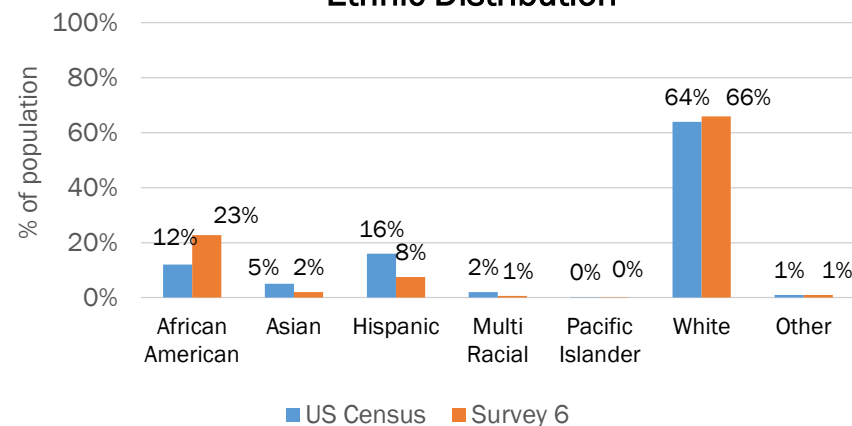
## Survey 6: Survivorship

# Survey 6: Survivorship

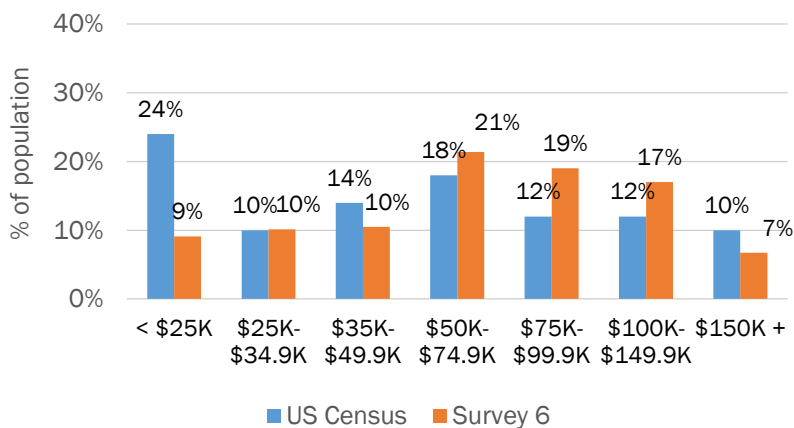
## Age Distribution



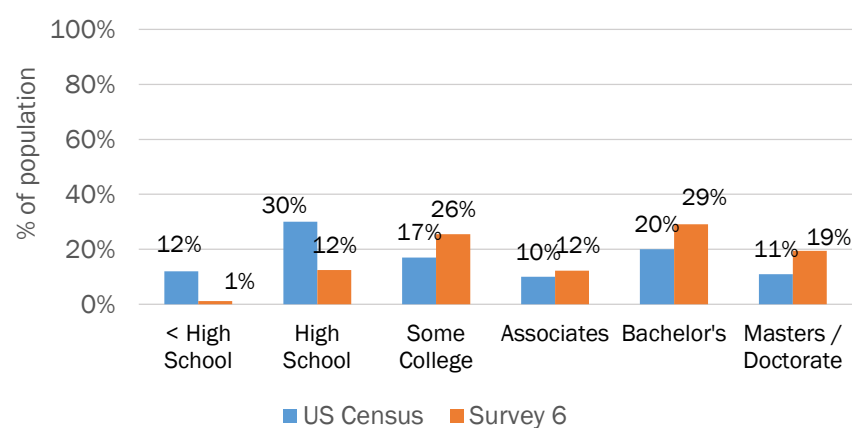
## Ethnic Distribution



## Income Distribution



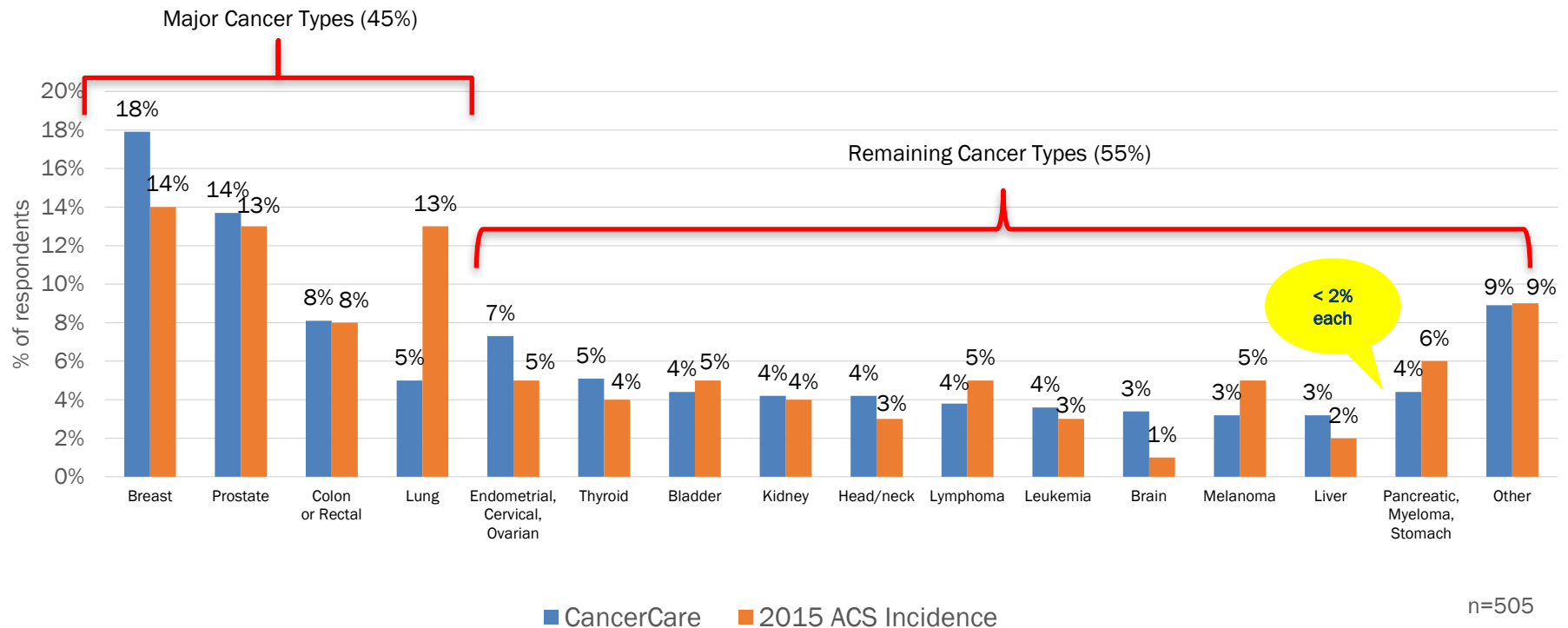
## Education Distribution



n=505

Respondents to this survey were diagnosed with a range of cancer types. By design, participants were selected to achieve a roughly 50/50 split between those presenting with one of the four most common cancer types (breast, prostate, colorectal, lung) vs all others. Non-melanoma skin cancer was excluded from this sample.

## Distribution of Respondents by Cancer Type – Survey 6

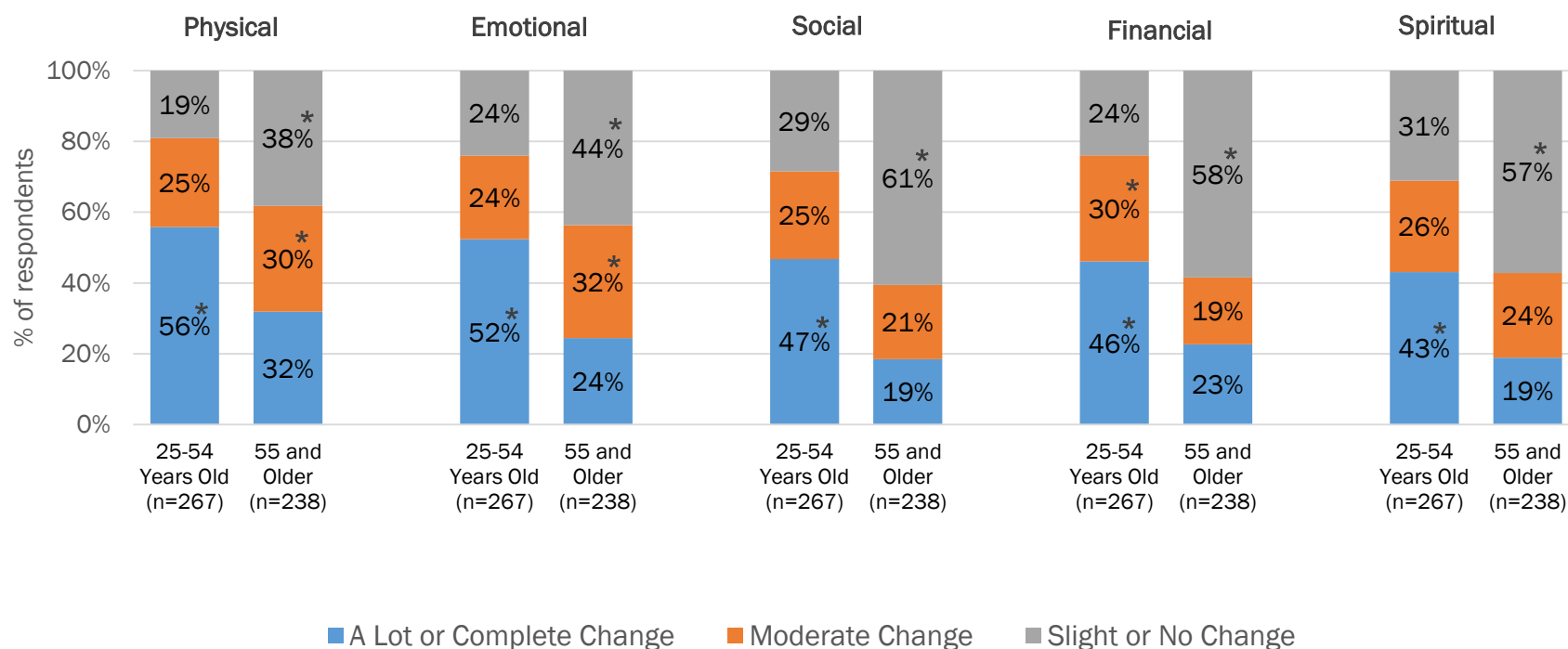


5. What type of cancer were you most recently diagnosed with?

Note: percentages may be off by 1% due to rounding

Having cancer changes lives, especially for those aged 25 to 54 years. About one-half of the respondents in this age bracket reported a lot or complete change in the physical, emotional, financial, social, and spiritual aspects of their lives. Another one-quarter reported moderate changes in these areas.

## Changes in Life Since Cancer Diagnosis



\*Indicates statistically greater at 90% confidence level

10. Compared to before you were first diagnosed with cancer, how much change has there been in the following aspects of your life?

Women who responded to the survey were much more likely than men to report that having cancer resulted in positive changes in their outlook on life and their relationships with family and friends. Those respondents treated in academic medical centers were also more likely to report these positive changes than those treated in community facilities.

## The Impact of Cancer on Relationships

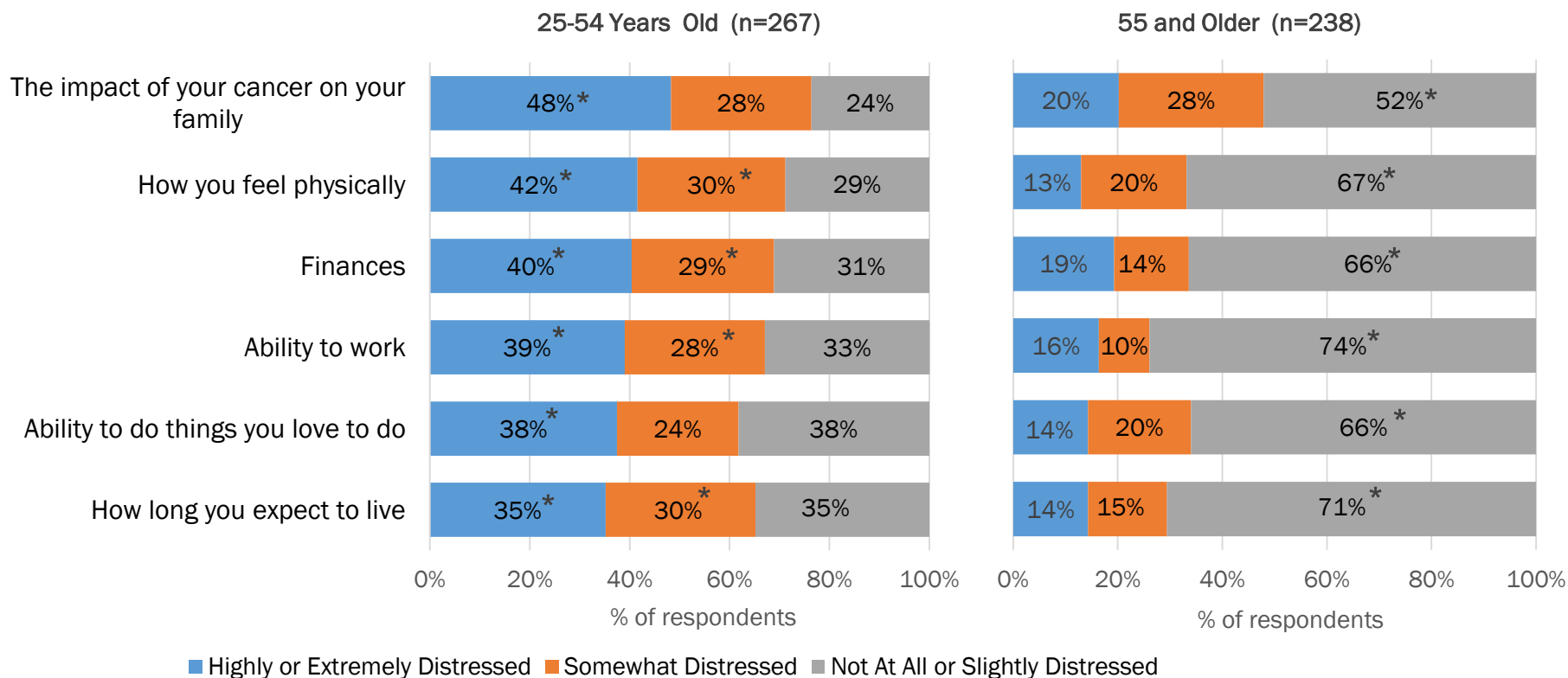
	Agree / Strongly Agree	
	Male (n=267)	Female (n=238)
My friends and loved ones have provided me with wonderful support and care.	62%	76%
For each new day, I feel more grateful than I did before I was diagnosed with cancer.	55%	69%
I appreciate my friends and family more than I did before my diagnosis.	49%	59%
I look for the 'good' in people and situations more than I used to.	46%	57%
Other people with cancer have been helpful in supporting and advising me.	39%	59%
My relationships have become stronger since I was diagnosed.	42%	52%
Since my diagnosis, I discovered friends I didn't know I had.	26%	35%

Indicates statistically greater at 90% confidence level

31. Please indicate how much you agree or disagree with the following statements:

For the vast majority of respondents, being diagnosed with cancer caused distress. The impact of cancer on their family was most often reported as being extremely stressful. In all aspects of life mentioned in this survey, respondents aged 25 to 54 years were significantly more likely than those aged 55 years and older to report being highly or extremely distressed.

## Cancer-Related Distress

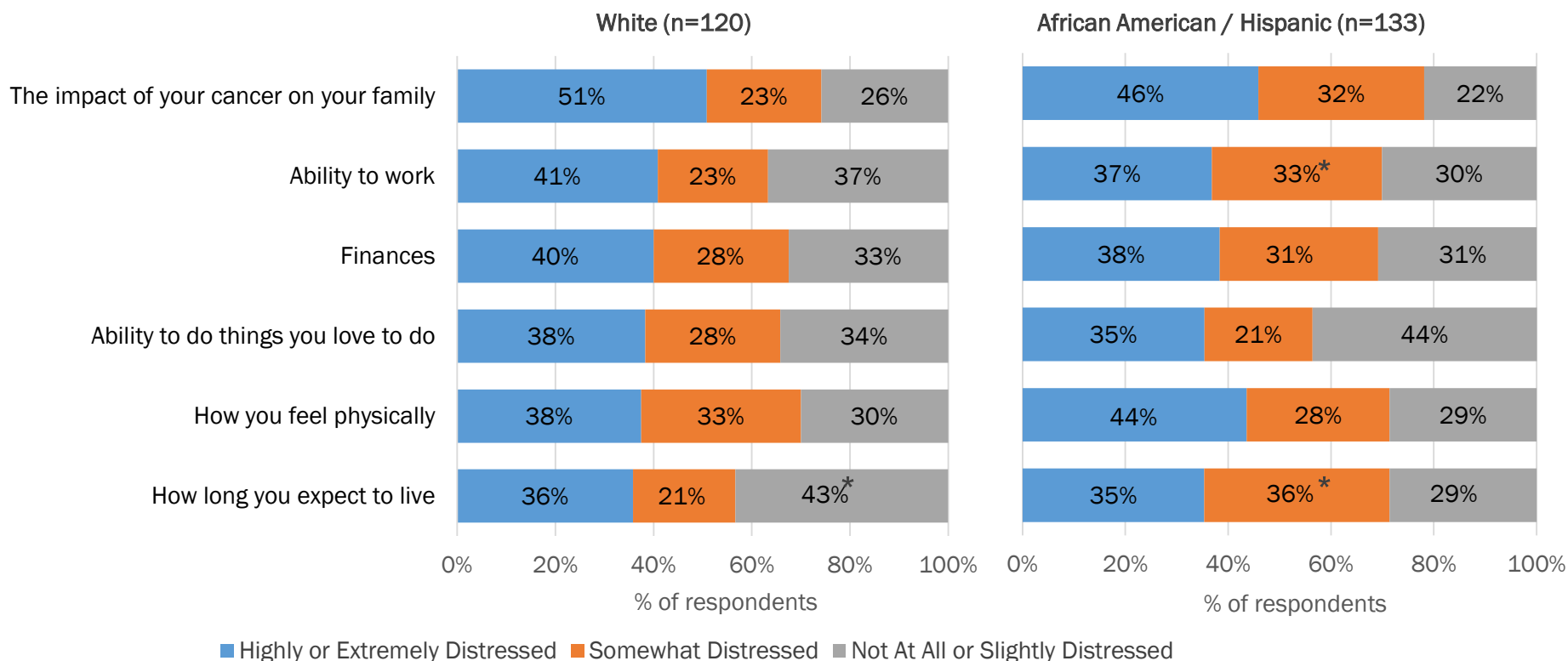


\*Indicates statistically greater at 90% confidence level

11. How distressed (anxious, extremely upset, or in emotional pain, for example) have you been due to the impact cancer has had on the following aspects of your life?

Respondents aged 25 to 54 years experienced similar levels of distress due to the impact of cancer, regardless of ethnicity. African Americans / Hispanics, however, were significantly more likely than whites to report being distressed about how long they expected to live.

## Cancer-Related Distress – Ages 25 to 54

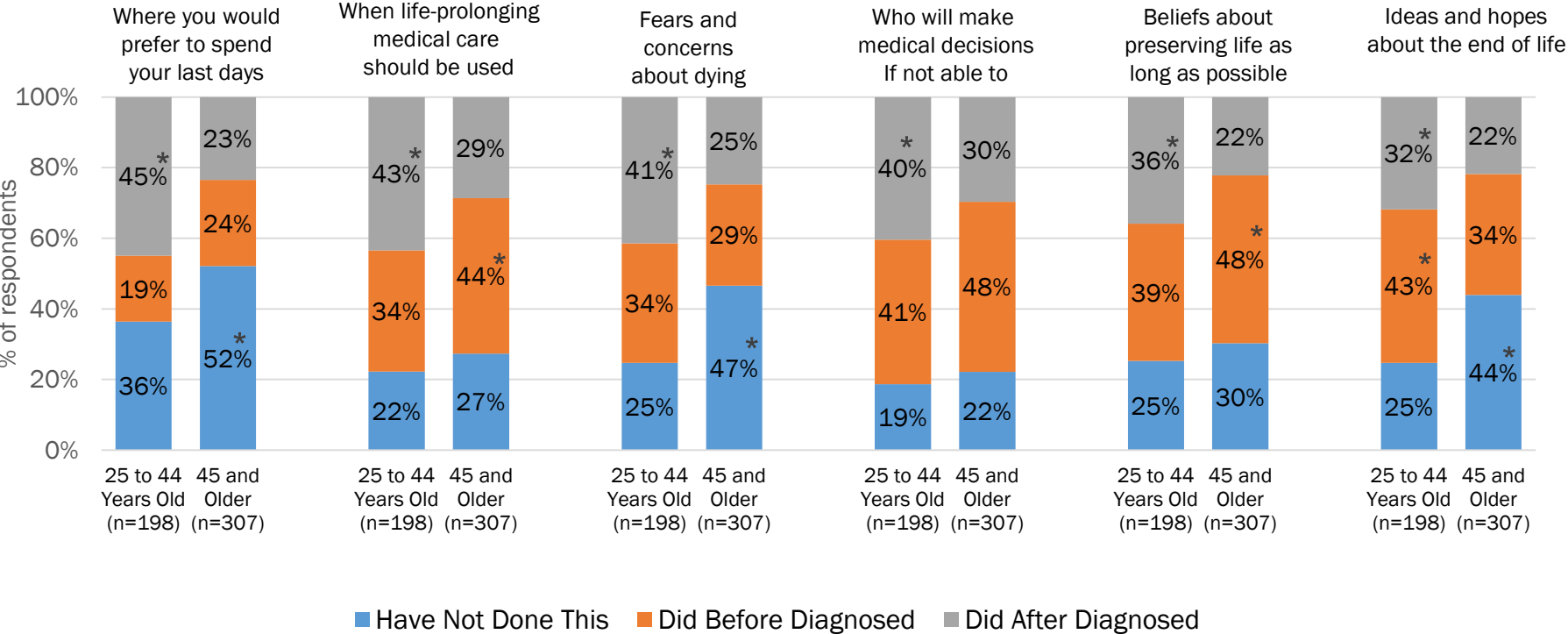


\*Indicates statistically greater at 90% confidence level

11. How distressed (anxious, extremely upset, or in emotional pain, for example) have you been due to the impact cancer has had on the following aspects of your life?

The onset of cancer prompted those respondents under 45 years to have various end-of-life-related conversations with family to a greater extent than it did those 45 years and older. Despite their cancer diagnosis, 20% to 50% of those aged 45 years and older had not communicated their wishes regarding key end-of-life issues to their family.

### Discussion Topics with Family Since Being Diagnosed with Cancer



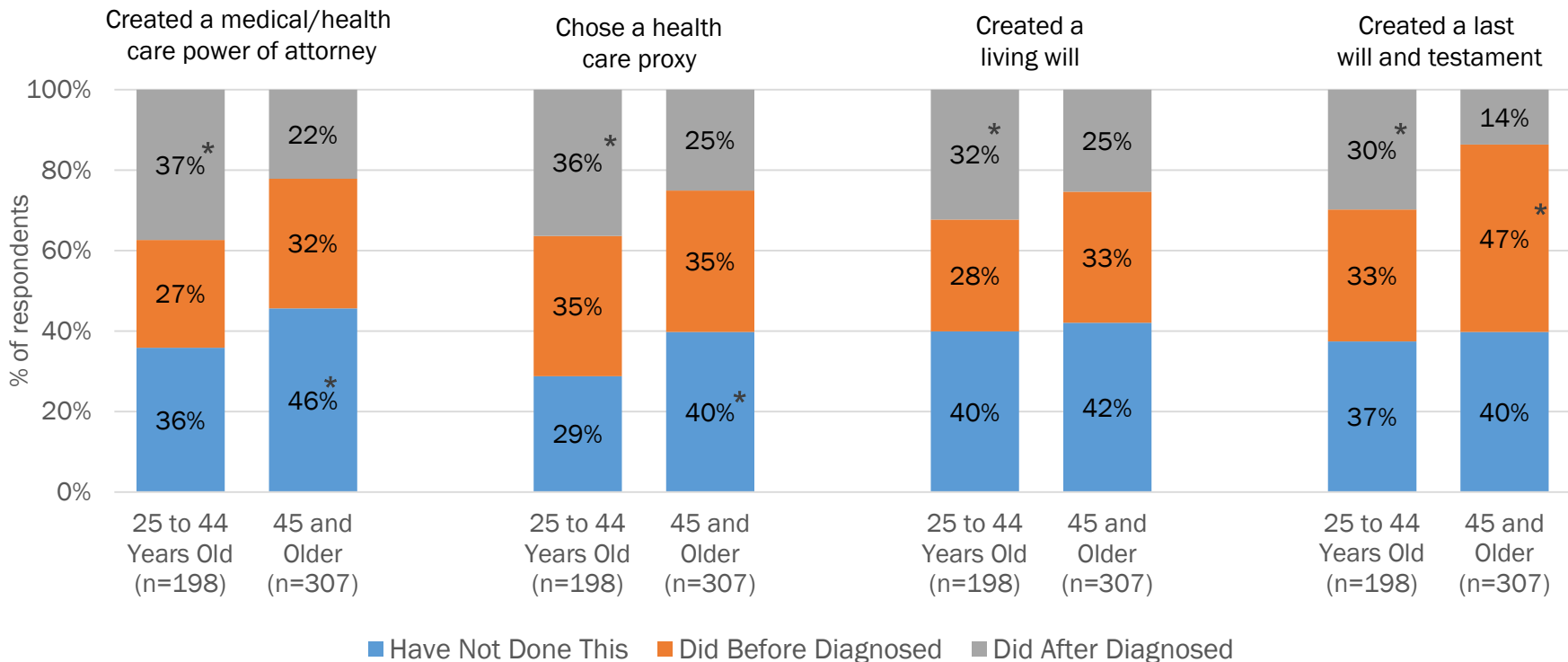
\*Indicates statistically greater at 90% confidence level

15. Please indicate whether you have spoken with your family or loved ones about the following topics and if you have, whether the conversations first occurred before or after you were diagnosed with cancer:



After being diagnosed with cancer, about one-third of those under 45 years created legal documents reflecting their end-of-life wishes. Despite a cancer diagnosis, 29% to 46% of respondents had not completed any of the legal documents queried, such as a medical power of attorney, healthcare proxy, living will, or last will and testament.

## Actions Taken by Those Diagnosed with Cancer

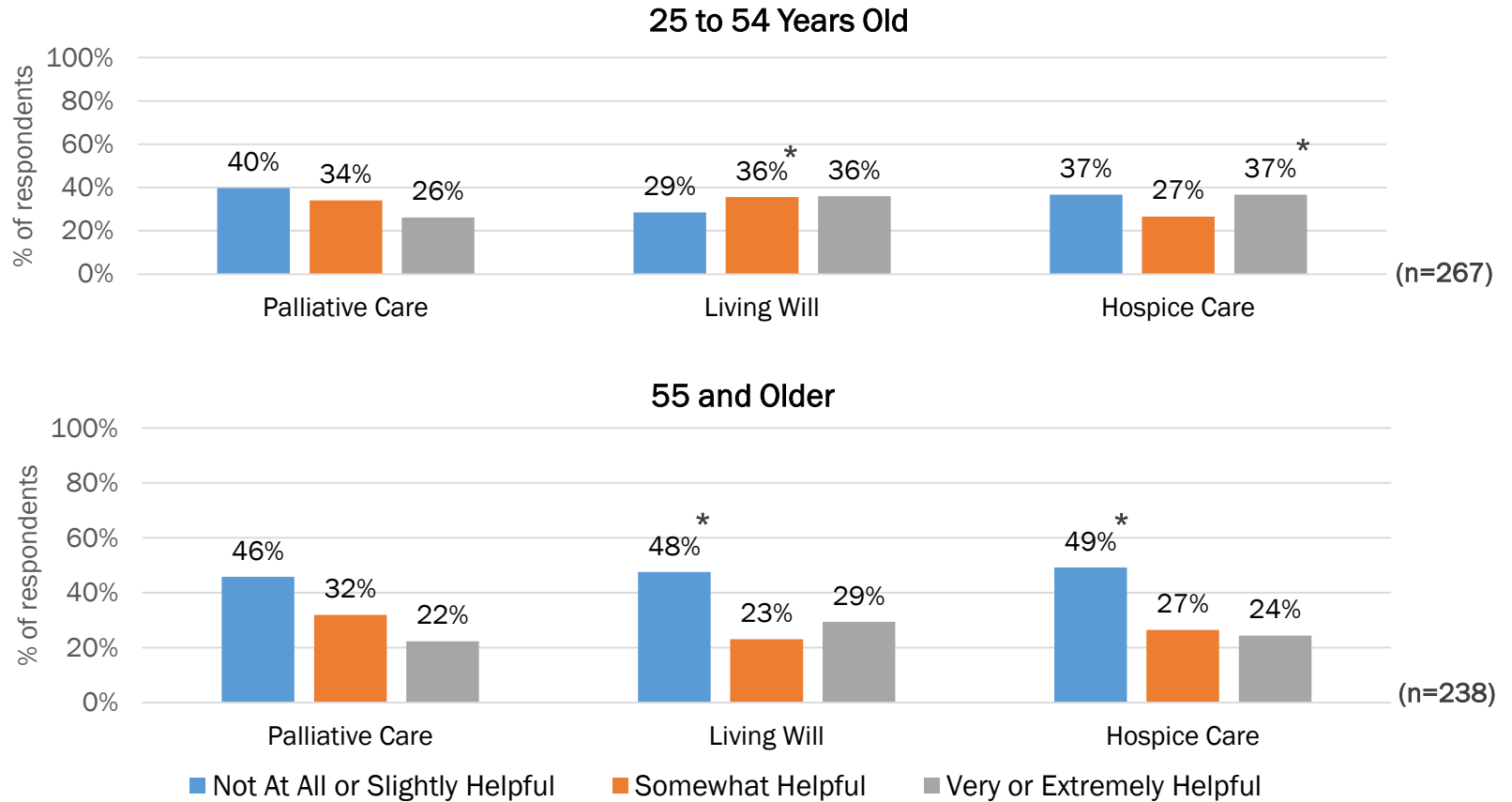


\*Indicates statistically greater at 90% confidence level

21. Please indicate if and when you have done the following.

From 22% to 37% of respondents indicated that additional information about Palliative Care, Living Wills, or Hospice Care would have been helpful to them. Those 55 years and older were significantly more likely to report that information on Living Wills and Hospice Care would not have been helpful. More than one-third of 25- to 54-year-old respondents said that more information on these topics would have been helpful.

## Usefulness of Information



\*Indicates statistically greater at 90% confidence level

30. How helpful would it be for you to receive additional information about each of the following?