MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

2020-2021 Public Experience Research Findings

November 23, 2021

Thank you to our sponsors and collaborators

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Thank you to our sponsors and collaborators (continued)

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Executive Summary: Background

In 2018, the results from our Massachusetts tracking survey made clear that we needed to think differently about the public engagement for serious illness care improvement. We had found no change in health care proxy rates between 2016 and 2018. We were not meaningfully different than the rest of the country on anything we could compare (and, in truth, advance care planning rates have stagnated nationwide for years, if not decades). Disparities by race, ethnicity, and income remained. Our previous open-ended qualitative research found confusion and misunderstanding about the language we used to describe the broad bucket of activities that we collectively call advance care planning (ACP). It was also clear that the public almost exclusively associates the entire field of serious illness care/ACP with the end of life and death. The default assumption is of Do Not Resuscitate orders, 'pull the plug' decisions, and what we have come to refer to as true end-of-life planning: funeral planning, place of death wishes, legacy planning and other near or after death preparation and logistics.

So, we changed tack. In 2018, we embarked on a messaging research project to better understand how the public 'hears' the language we use to describe advance care planning and create simple, universal messaging concepts to promote engagement. We were hoping to increase engagement among the people ***least*** likely to do advance care planning actions and ***most at risk*** for poor serious illness and end of life outcomes. These include Black and Latinx people, and people with lower income and education, among others. We were also hoping to find messaging that would encourage people to do these behaviors earlier. There remains broad consensus among our stakeholders that advance care planning actions are happening too late in an illness trajectory to improve care and reduce avoidable suffering. So, we explored language that avoided 'end of life' or 'death' as an experiment in whether we could help shift the frame further upstream. We tested many different types of 'calls to action' – completing advance directives, to talking with loved ones and doctors – as well as the many 'reasons why.'

Executive Summary: Background (continued)

The resulting research produced clear, actionable recommendations: tactical language that resonated universally, and especially among the segments of the public least likely to have already engaged in advance care planning. The research also produced a wealth of knowledge about approaches and language to avoid. For example, the use of 'loved ones' felt alienating to people who didn't have close family members to choose as a proxy. A focus on 'rights' made people feel defensive and 'conversations' can feel really heavy and daunting. The results once again highlighted the power of the 'death' mental trap: for the younger and healthier (or even the seriously ill who are still in active treatment) they just don't think they need ACP…yet.

But the biggest red flag was the basic believability of what we were asking people to do. For example, the idea that people would engage in advance care planning behaviors for 'peace of mind' was actively rejected by some people, notably those with lower incomes. They noted that conversations cannot ease the worries of affording care, taking time off work to be a caregiver, the pain and anguish of watching a loved one suffer. Planning cannot ease the burden of unmet needs and inequitable treatment. The message back to us was clear: we cannot overpromise, and we must acknowledge how these calls to action butt up against the reality of interacting with the health care system.

Executive Summary: Background (continued)

In the end, this research left us with more questions than answers. Then came Covid and our health care community's acknowledgement of both the historic – and very current – inequities in health care access, treatment, and outcomes. Our lens, too, shifted. In 2018, we approached our messaging research with a simple question: how to best promote advance care planning to the public, especially underserved and marginalized communities most likely to experience poor outcomes? But what if that was the wrong question? What if the 'right' question is this: what are people's lived experiences in health care settings, the challenges faced by people and caregivers dealing with serious illnesses and what does that understanding tell us about what we should prioritize saying, doing, and asking them to do; how would that understanding impact the behaviors we're trying to 'sell' and how we sell them? And what if improving serious illness care is less about what ***the public*** should do, which implicitly offloads responsibility on to them, and more about what ***health systems*** and clinicians should do, which is, in the end, where the power for change truly rests?

This is not to say that we must wait for the perfect, patient-centered health care system before we can do anything. We just have to move forward with the reality of lived experiences – especially the inherent power imbalance between patients and clinicians - in mind. We designed our research with this lens.

Executive Summary: Findings

Advance care planning rates remained largely unchanged in the last three to four years, despite the media attention focused on ACP in the early months of the Covid-19 pandemic. Compared to 2017 nationwide, advance directive completion rates fell slightly in 2021 as did conversations with loved ones. While conversations with clinicians rose slightly in the US (and quite substantially in Massachusetts compared to 2018), Black and Hispanic adults are now less likely to want to talk to a doctor about their wishes for care than they were in 2017. Seriously ill people aren't engaging in ACP at meaningfully higher rates compared to the non-seriously ill.

Despite the low or falling engagement in advance care planning, most people strongly believe in one of the core principles that underlies this behavior: that quality care can only be provided when clinicians really know patients and their priorities. When presented with many different options about what clinicians should say or what quality care looks like, clear consensus emerged on what people want most from their health care: a sense of mutual respect, collaboration and partnership, of dignity and humanity, infused with kindness, openness, empathy and without judgement. People are willing to put up with a lot in terms of inconvenience for clinicians who treat them like a whole person.

When comparing different public 'calls to action,' people nearly unanimously recognize that speaking up about what matters and what works for them (and picking the right doctor in the first place) is the most impactful thing that they can do among traditional ACP/shared decision-making behaviors. But while it is impactful, people also know it's hard. Because the clinician's response is not in their control. And they can't always switch doctors. Their lived reality of negative health care experiences holds them back**. Negative experiences erode trust and undermine the belief that it's worth it to try and speak up.**

Negative experiences are more frequent for people with serious illnesses and disabilities, people with lower incomes, and Black and Hispanic people. While race, income and disability/diagnoses lead the perceived reasons behind unfair treatment, negative experiences are also attributed to many other aspects of people's identities: age, language, insurance, weight, beliefs, appearance and more…

Executive Summary: Findings (continued)

On the other hand, traditional consumer-controlled ACP and end-of-life planning is seen as believable and relatively easy to do, but compared to having the right doctor and speaking up about what matters, these actions are seen as **relatively low-value by most** (not to mention that calls to complete proxies are seen as part of end-of-life planning, even when explicitly separated). This is probably one reason why we've seen little movement on ACP documentation over the years –it doesn't get to the core of what people feel they need, either now or for a future serious illness situation. Age – unrelated to illness –is the biggest driver in ACP engagement, suggestive of cultural patterns of behavior that are largely unmoored from any clinical situation. What's more, document completion can be a barrier to engaging in conversations with clinicians; some people have done their planning and therefore don't feel the need to talk. And then we see that many people have done their documents and remain worried about decision making, either their own decisions if seriously ill or if their proxy has to step in.

Taken as a whole, these findings suggest that, while there is value to traditional advance care planning programs (and such programs would be wise to capitalize on the perceived ease of these actions and not weigh them down too heavily with emotional or logistical challenges), the greater ***potential*** impact lies in focusing on relational aspects of care, communication and shared decision making long before any serious illness diagnosis. This could take many forms with opportunities to focus both on the public/patient side and the clinician/system side. From public engagement campaigns that seek to empower, give permission and guidance on how to speak up and about what, to system-level quality measurement programs or skills training and incentives that emphasizes relational aspects of care, patients feeling heard and understood, cultural humility, listening and trust-building.

2020-2021 Consumer Research Overview: Process

Phase 1: Start with the Community

(August-December '20)

- Collaborate with community-based organizations and networks of patients, families, and caregivers to ensure our questions and language capture what really matters most about experiences with serious illness care

Phase 2: Gather the Data

(February-March '21)

- National, large-scale, representative, quantitative survey of American adults
- Massachusetts oversample
- Use University of Chicago's NORC AmeriSpeak Panel

Phase 3: Humanize the Data and Validate Findings

(April-August '21)

- Qualitative research via two online communities (July and August)
- Delve deeper on experiences, test messaging concepts, and contextualize calls to action in the lived experience of health care interactions and other life priorities

Hypothesis: start by looking back to people's experiences in order to move forward to better communication and care

- A key part of improving serious illness care involves improving communication
- We asked: what makes good serious illness communication?
  - —People who are willing to speak up and share what matters most
  - —Clinicians who stop to take the time to ask, and listen, to the person/patient in front of them
- We hypothesized that people's experiences of **being listened to in the past** will influence how much they are willing to speak up when it truly matters
- Which, if true, suggests that a critical way to improve serious illness care is to **address listening and communication long before a serious illness diagnosis**

Sample Questions

- Health care experiences: involvement in decision-making, being listened to, treated with dignity and respect, trust in clinicians, fear of speaking up
- Traditional advance care planning behaviors
- Opinions on improvements in serious illness care, worries about serious illness

Major Survey Findings

Survey Methodology

Who

- N = 1854 adults over the age of 18 nationally; oversampled Massachusetts residents
- Oversampled specific demographic groups: Blacks, Hispanics, people with serious illness, disabilities, low-income, and caregivers
- “Involved” caregivers answered questions about their care recipient
- **NOTE**: we reported findings for Asian adults in our demographic breakdowns, but small sample size warrants cautious interpretation

When & How

- April 20th – May 17th, 2021
- NORC AmeriSpeak Panel
- Hybrid online and phone data collection; conducted in English and Spanish
- All data were weighted to ensure results are reflective of U.S. Census population

Testing

- Newly designed questions on health care experiences and improvements and worries about serious illness care
- Explored, created, and refined with advocates, researchers and community partners
- Formal cognitive testing with people from specific demographic groups

Source: NORC AmeriSpeak Methodology Report

Defining Serious Illness

Diagnosis: diabetes, lung disease, heart disease or stroke, cancer, dementia, depression/anxiety/other serious mental health problem, chronic kidney disease

&

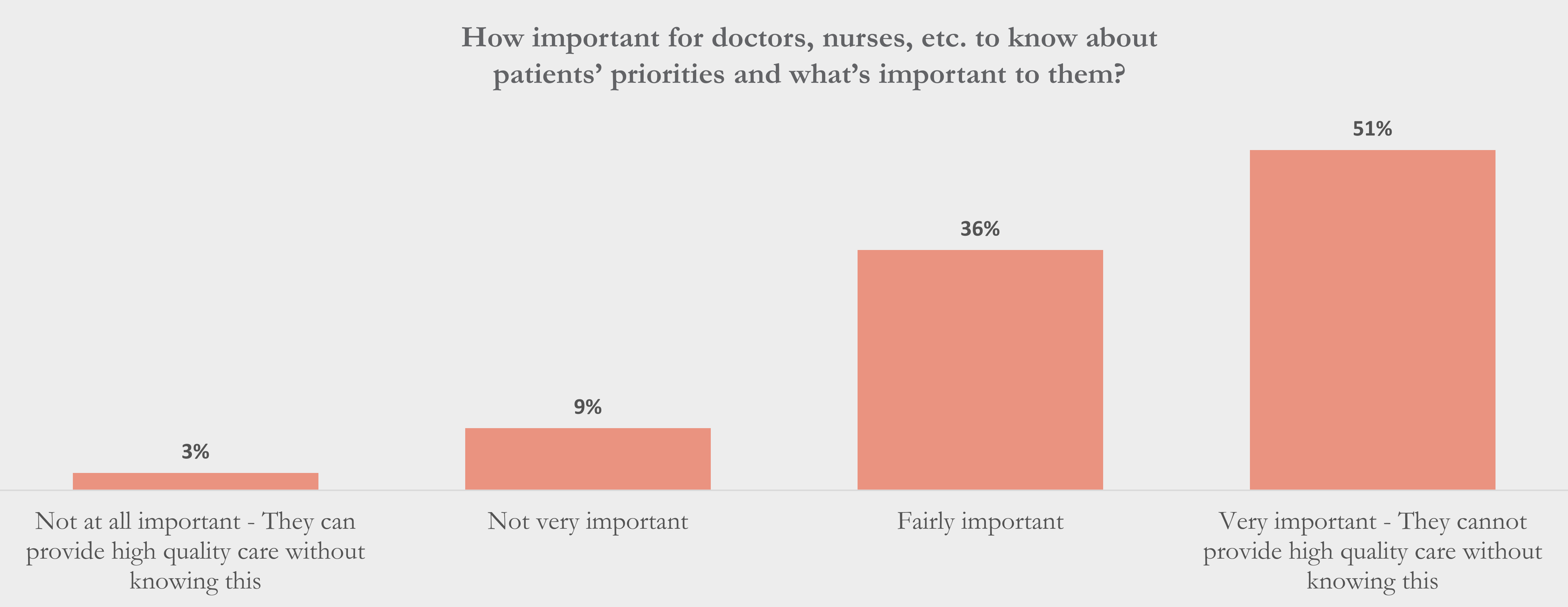
Have been feeling sick enough in the last year that it's been getting harder to do your normal levels of work and activity

⇩

20% of survey respondents

Source: MCSIC Survey Instrument

87% of adults think it's important for clinicians to know their patients' priorities and what's important to them in order to provide high quality care.

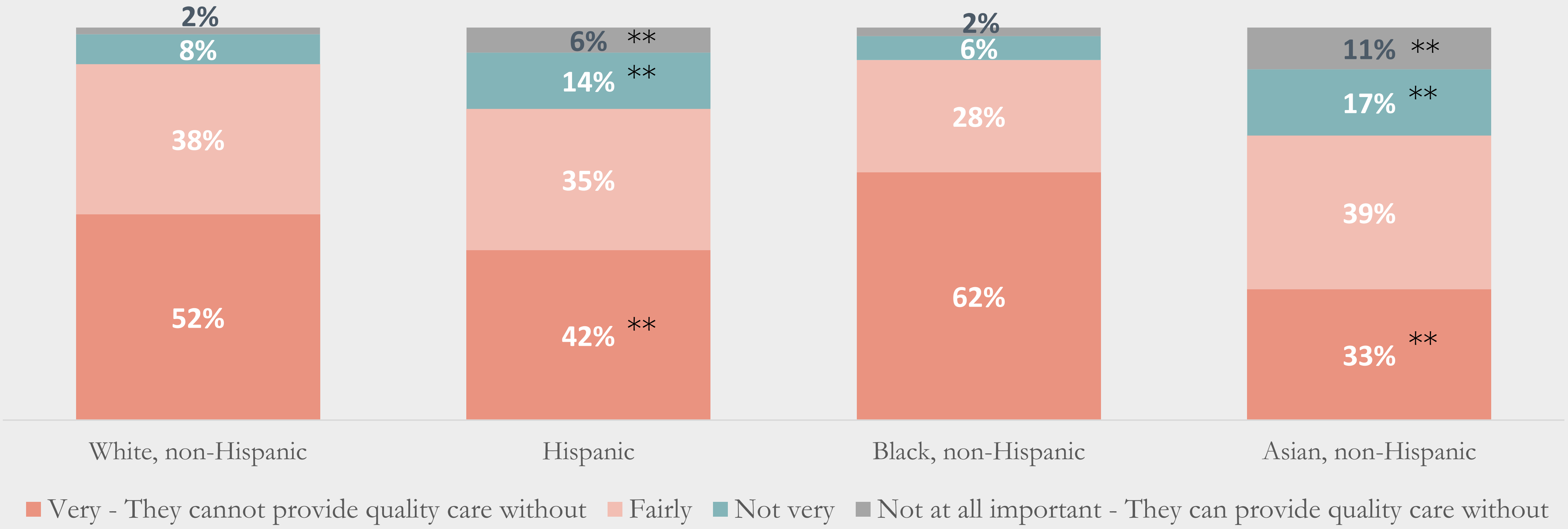


n = 1854. Totals may not add to 100% due to rounding error and don't know/refused or skipped answers

35. How important is it for doctors, nurses, or other health professionals to know about their patients' priorities and what's important to them?

Black and White adults feel the strongest about health care providers needing to understand their patients’ priorities to provide quality care.

How important is it for doctors, nurses, or other health professionals to know about their patients’ priorities and what’s important to them?



U.S. National General Population Results

n = 1218-288-193-50 Totals may not add to 100% due to rounding error and don’t know/refused or skipped answers
35. How important is it for doctors, nurses, or other health professionals to know about their patients’ priorities and what’s important to them?
**Indicates significantly difference than the reference category, non-Hispanic White (95% confidence)

People with serious illness report lower levels of understanding by their clinicians in some important areas of their lives.

Generally speaking, how well do you feel that doctors, nurses and other health professionals understand… (Fairly + Very Well)	Serious Illness?	
	No	Yes
Your life priorities	71%	**61%****
The activities that bring you joy and meaning	62%	**52%****
Your health goals	79%	**69%****
Your financial situation	46%	42%
The most important relationships in your life	50%	47%
Your faith or spirituality	39%	37%
Your culture	53%	52%
Sample Size	1487	367

10. Generally speaking, how well do you feel that doctors, nurses and other health professionals understand…
** Indicates significantly different than those without Serious Illness, respectively (95% confidence)

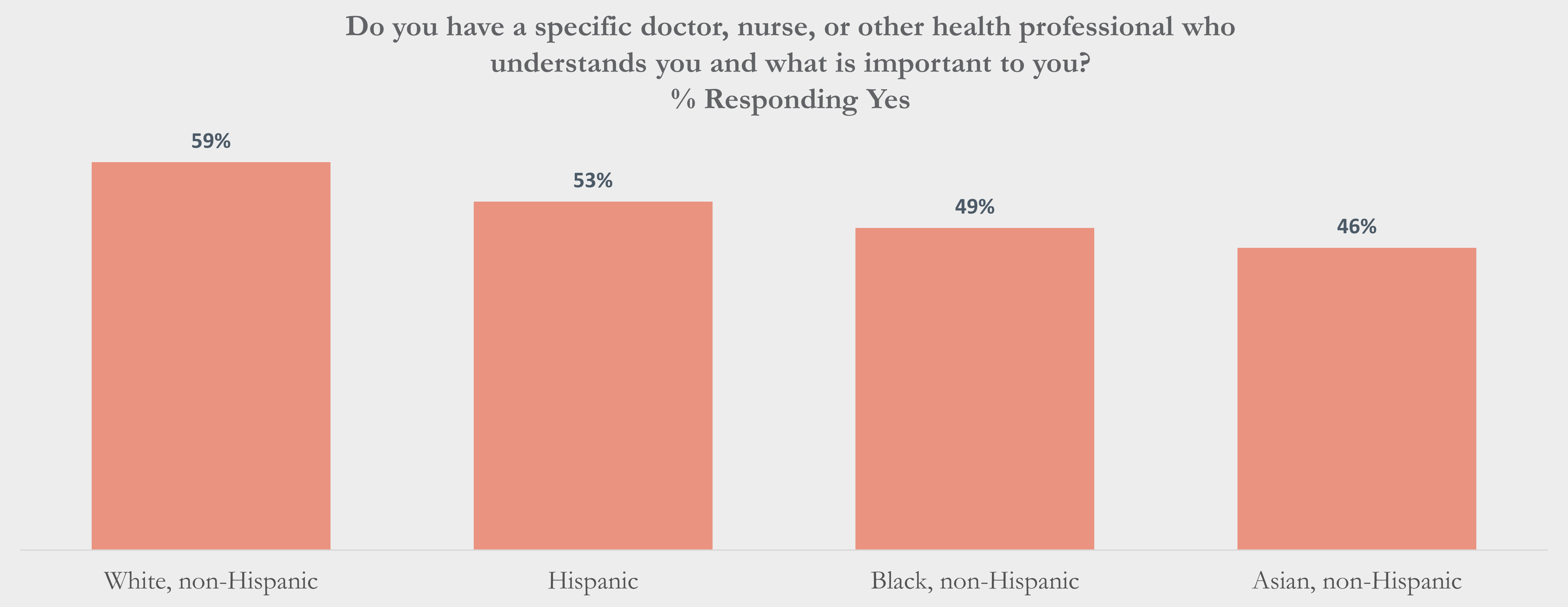
Perceived understanding of health goals is fairly consistent across all adults; on other areas, Asian adults are significantly less likely than others to say their doctors and nurses understand them well.

Generally speaking, how well do you feel that doctors, nurses and other health professionals understand… (Fairly + Very Well)	Race/Ethnicity			
	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic
Your life priorities	72%	64%	71%	**59%** **
The activities that bring you joy and meaning	61%	62%	64%	48%
Your health goals	79%	74%	77%	75%
Your financial situation	46%	47%	44%	36%
The most important relationships in your life	50%	50%	55%	**33%** **
Your faith or spirituality	35%	44%	**56%** **	25%
Your culture	56%	49%	50%	**42%** **
Sample Size	1218	288	193	50

10. Generally speaking, how well do you feel that doctors, nurses and other health professionals understand…

** Indicates significantly higher than the reference category, non-Hispanic White (95% confidence

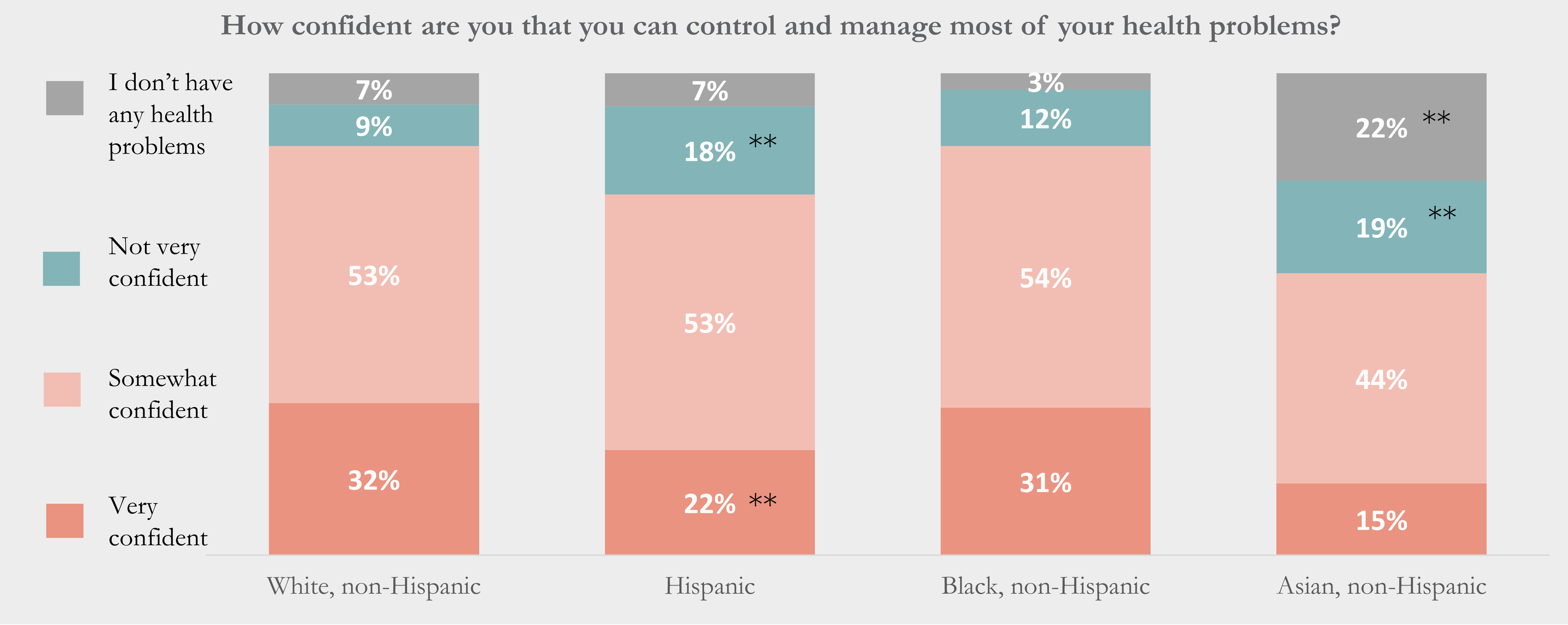
With only modest differences by race and ethnicity, White respondents are slightly more likely to say they have a medical provider who understands them well.



n = 1212-286-192-50

11. Do you have a specific doctor, nurse, or other health professional who understands you and what is important to you?

Patient confidence is highest among White and Black adults, lower for Hispanic and Asian adults.



n = 1218-287-193-50

12. How confident are you that you can control and manage most of your health problems?

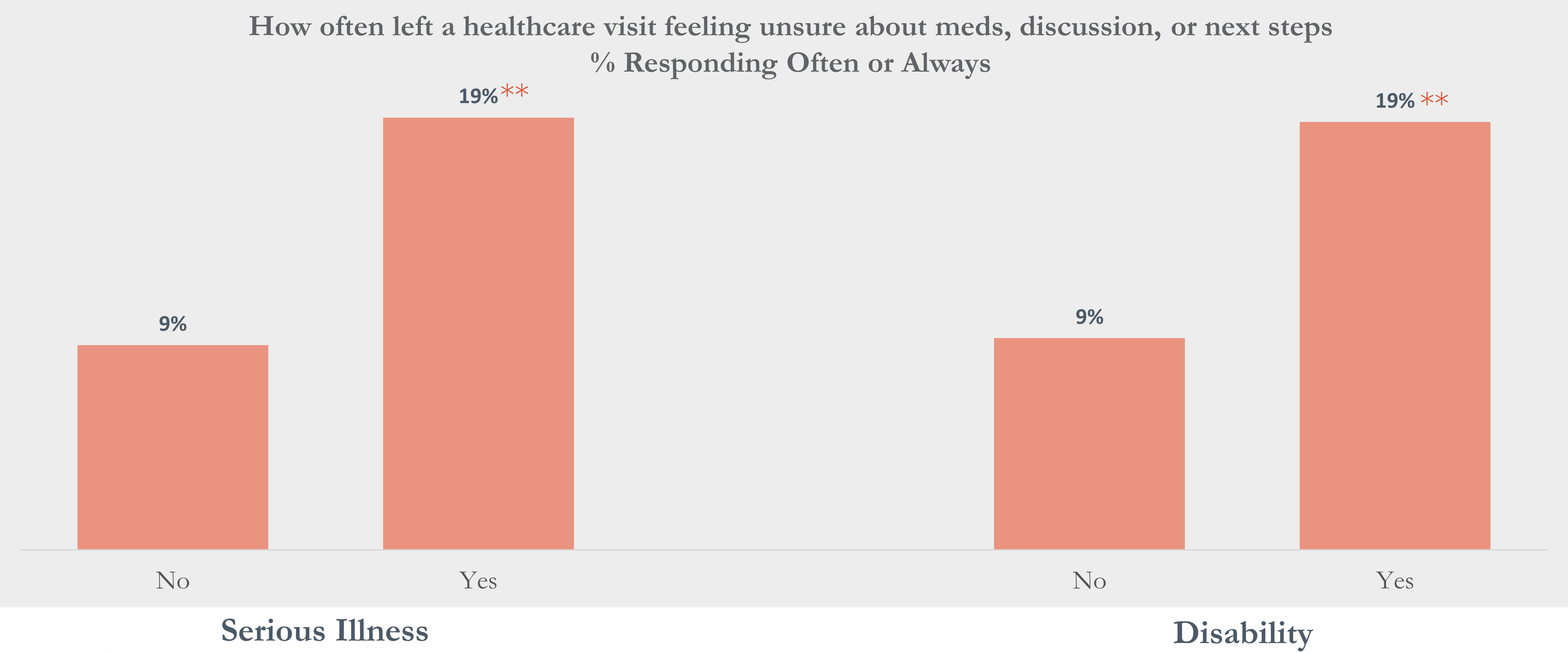
** Indicates significantly higher than the reference category, non-Hispanic White (95% confidence)

There were few differences in the perception of provider effort levels in engaging in shared decision making across White, Hispanic and Black adults; Asian adults reported significantly less effort. There were no differences across income levels, disability or serious illness (not shown).

How much effort would you say doctors, nurses, etc. make to… (Shown = "A lot of effort")	Race/Ethnicity			
	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic
Help you understand your health issues?	38%	32%	41%	19% **
Listen to the things that matter most to you about your health issues?	34%	29%	37%	26%
Include what matters most to you in making decisions about your care and treatments?	36%	35%	38%	17% **
Sample Size	1218	288	193	50

6-7-8. Generally speaking, how much effort would you say doctors, nurses, and other health professionals make to…?
** Indicates significantly different than the reference category, non-Hispanic White (95% confidence)

People with serious illness and people with disability are about twice as likely to report having left a health care visit feeling unsure about the visit, outcomes, or next steps.

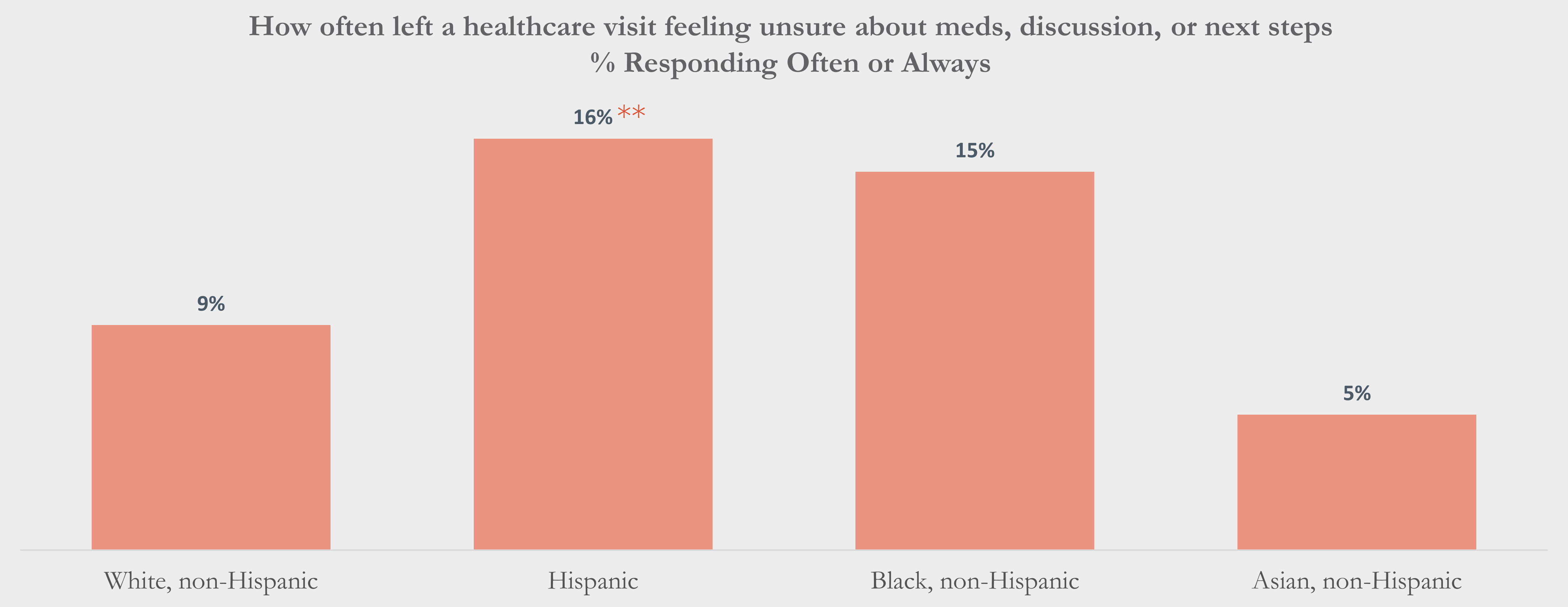


n = 1487-367-1503-351

9. How often have you left a health care visit feeling unsure about your medicines, what was discussed, or what to do next?

** Indicates significantly different from the reference category, No Serious Illness/No Disability, respectively (95% confidence)

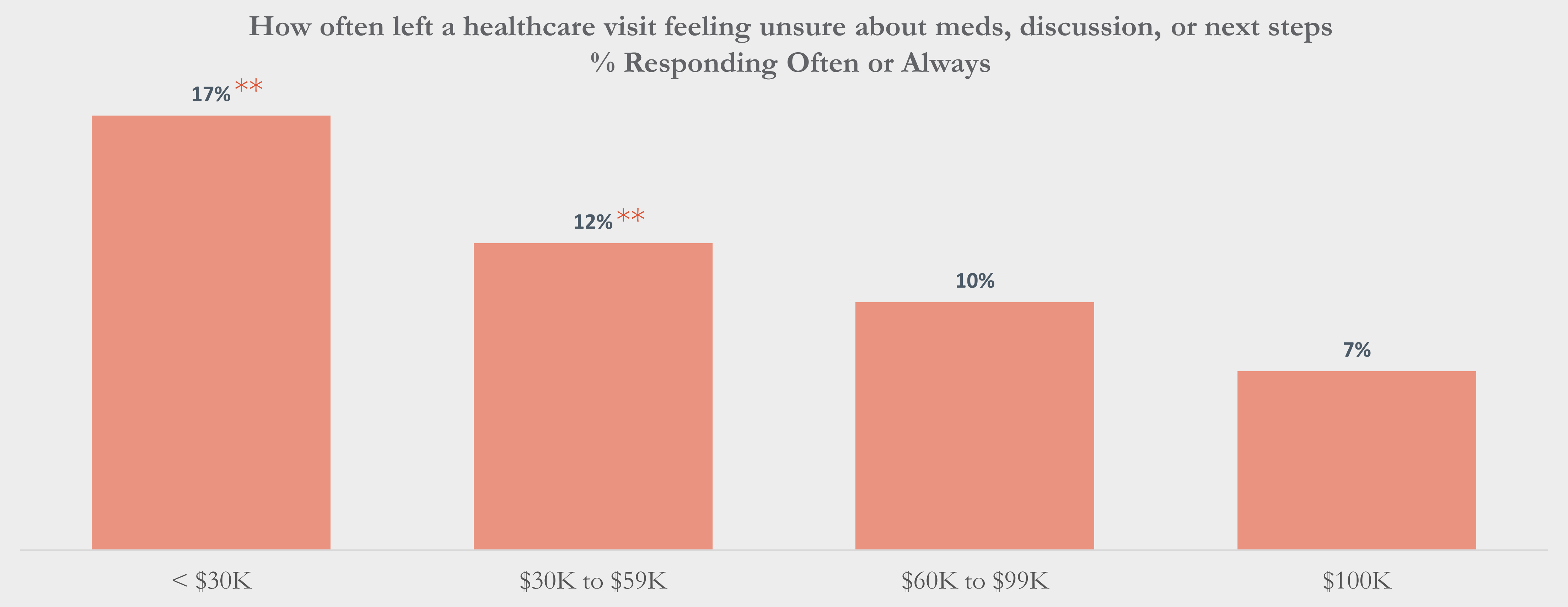
Hispanic and Black respondents also report a higher incidence of feeling unsure following a recent medical visit.



U.S. National General Population Results

n = 1218-288-193-50
9. How often have you left a health care visit feeling unsure about your medicines, what was discussed, or what to do next?
** Indicates significantly different than the reference category, non-Hispanic White (95% confidence)

Feeling unsure following health care visits is also significantly higher among lower-income respondents.



U.S. National General Population Results

n = 437-526-464-427

9. How often have you left a health care visit feeling unsure about your medicines, what was discussed, or what to do next?

** Indicates significantly different than reference category, $100K+ (95% confidence)

People with serious illnesses, Black and Hispanic adults, and people with lower income report less trust and less feeling like they are treated with dignity and respect

How often… (% Most or Almost all of the time)	Serious Illness?		Race/Ethnicity				Household Income			
	No	Yes	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic	< $30K	$30K - $59K	$60K - $99K	$100K+
…Do you trust doctors, nurses, and other health professionals to do what is right for you?	76%	67%**	78%	68%**	66%**	76%	63%**	74%	79%	77%
…Do doctors, nurses, and other health professionals treat you with dignity and respect?	84%	81%	88%	72%**	81%	81%	79%**	81%**	85%	88%
Sample Size	1487	367	1218	288	193	50	437	526	464	427

13-14-15-16. How often / how much of the time…

** indicate significant difference from the reference category (No Serious Illness, White, non-Hispanic, $100K+ income) (95% confidence)

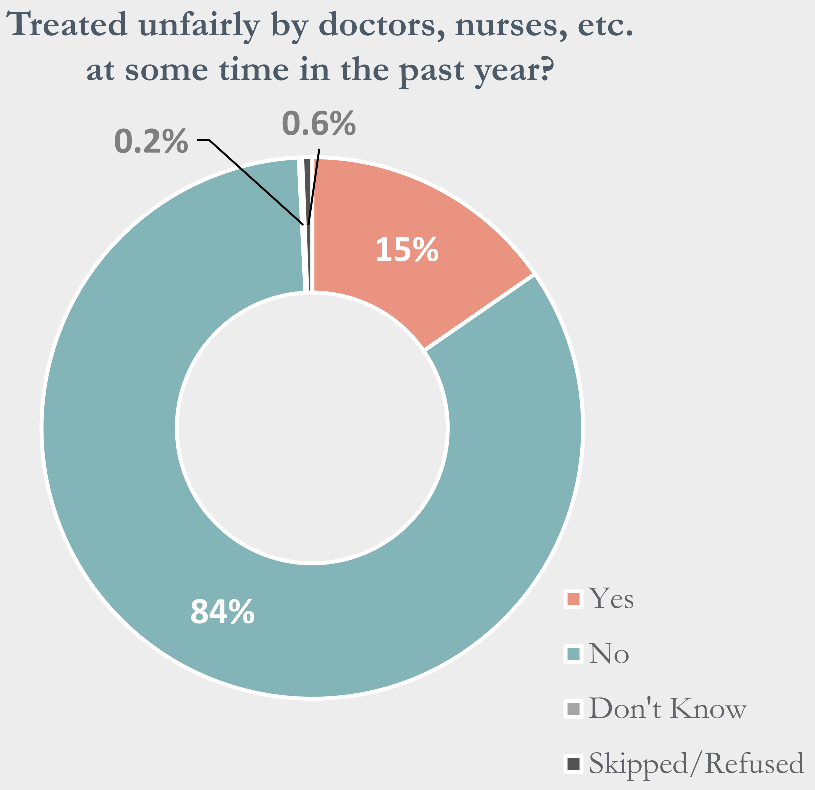
Adults with serious illnesses, Black and Hispanic adults, and people with lower incomes report more frequent negative experiences.

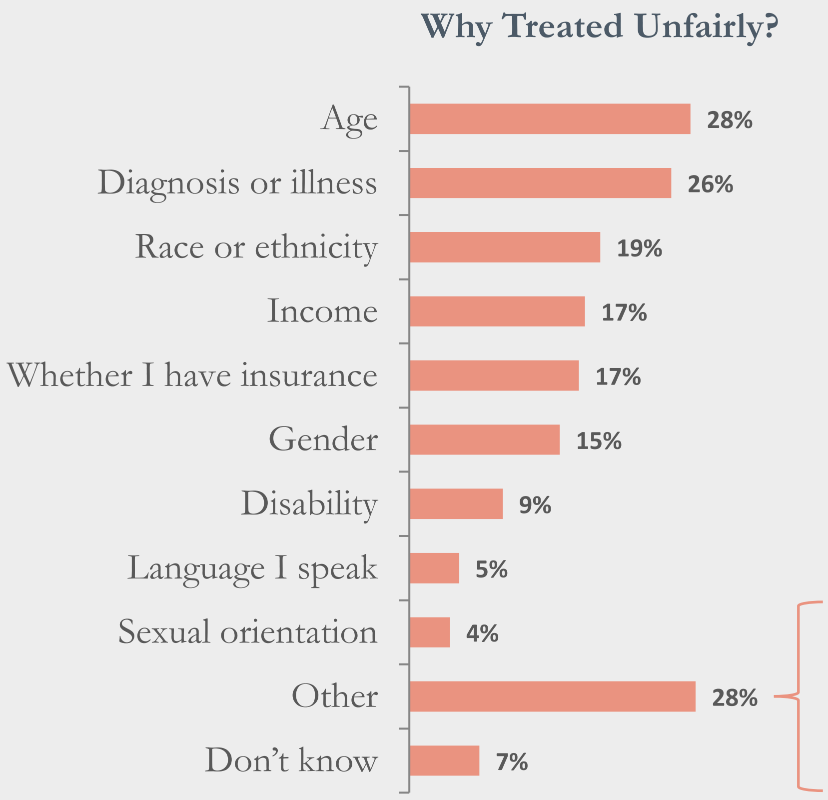
How often… (% Most or Almost all of the time)	Serious Illness?		Race/Ethnicity				Household Income			
	No	Yes	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic	< $30K	$30K - $59K	$60K - $99K	$100K+
…Have you been afraid to ask questions, speak up, or disagree with doctors, nurses, etc. because you're worried it may impact your care?	11%	21%**	10%	18%**	17%**	11%	23%**	14%**	9%	8%
…Do doctors, nurses, and other health professionals talk down to you or make you feel inferior?	9%	13%**	6%	14%	18%	17%	17%	8%	9%	7%
Sample Size	1487	367	1218	288	193	50	437	526	464	427

13-14-15-16. How often / how much of the time…

** indicate significant difference from the reference category (No Serious Illness, White, non-Hispanic, $100K+ income) (95% confidence)

Age and illness, along with race and income, lead the list of perceived reasons behind receiving unfair treatment by health professionals. But there are many other reasons, too.





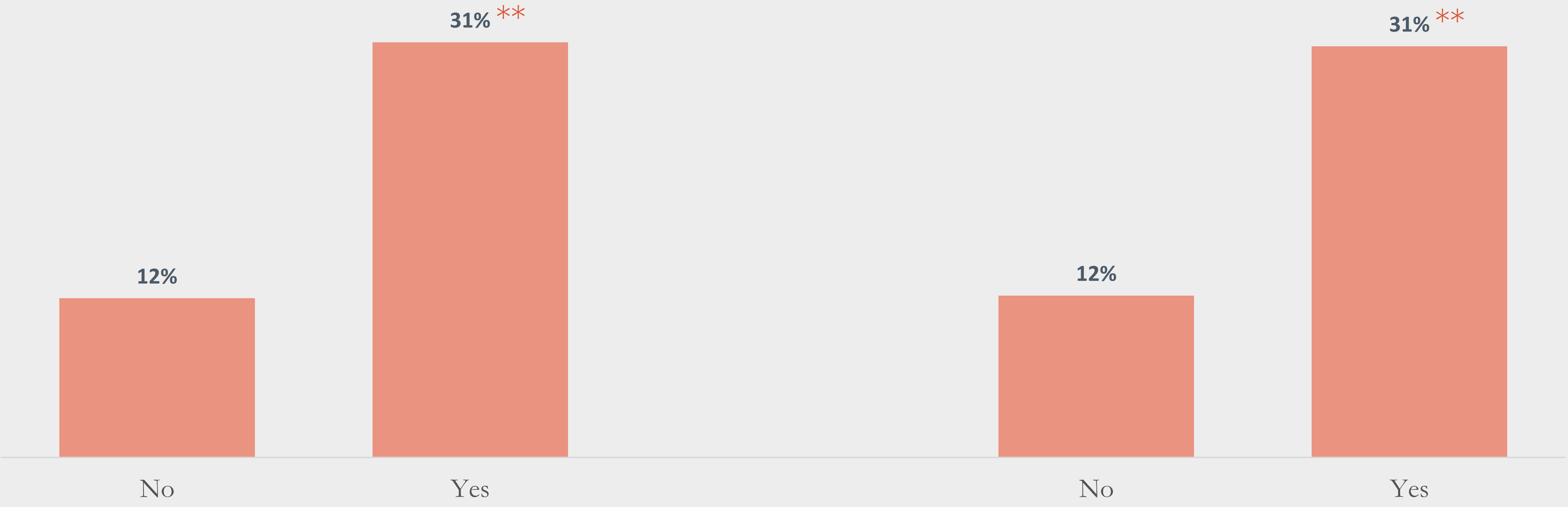
- Weight
- Beliefs (e.g. holistic)
- Intelligence
- Behavior (e.g. substance use)
- Appearance

n = 1854-290

17. Was there a time in the last 12 months when you felt that you were treated unfairly by doctors, nurses, or other health professionals?
18. What do you think are the main reasons for being treated unfairly? (Check all that apply)

Both people with serious illness and disability are significantly more likely to recall a time within the past year when they were treated unfairly by clinicians.

Was there a time in the last 12 months when you felt that you were treated unfairly by doctors, nurses, or other health professionals? (% Responding Yes)



Serious Illness

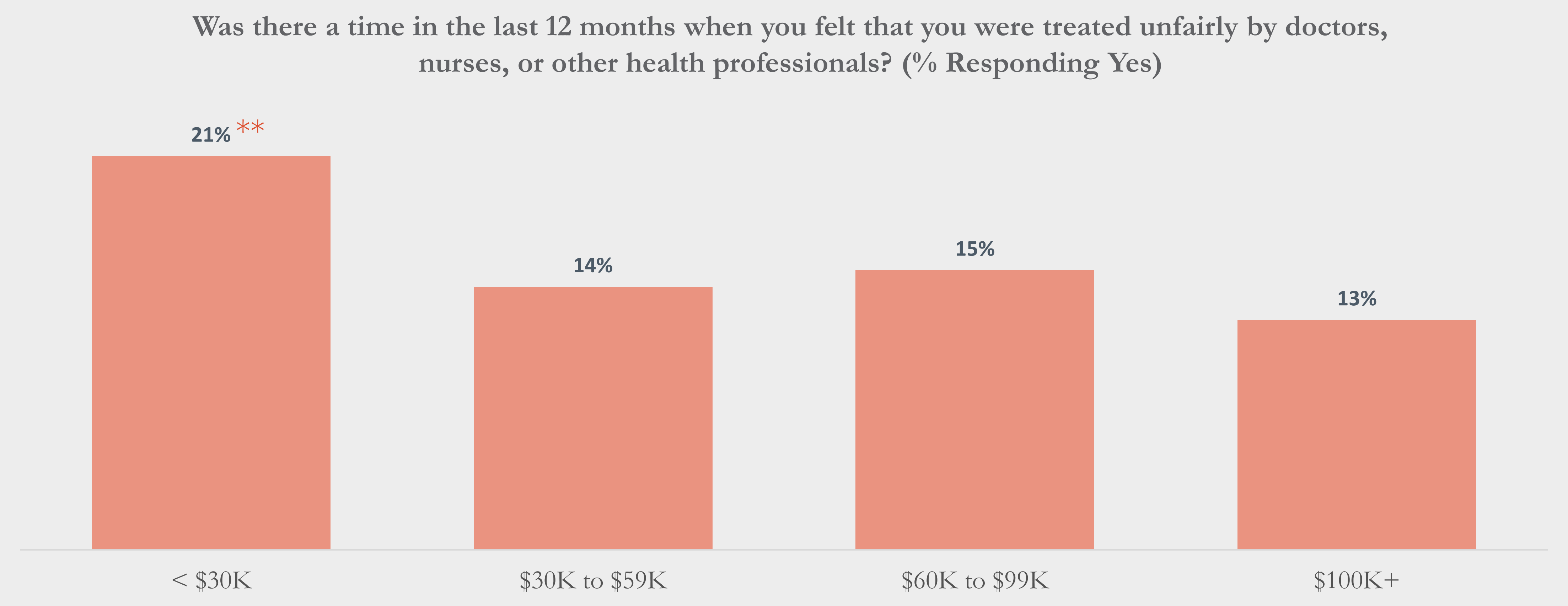
Disability

n = 1487-367-1496-351

17. Was there a time in the last 12 months when you felt that you were treated unfairly by doctors, nurses, or other health professionals?

** Indicates significantly different from the reference categories (No Serious Illness/No Disability, respectively) (95% confidence)

Recollection of being treated unfairly during a health care visit is highest among the lowest-income respondents, where one-in-five report such an instance within the past year.

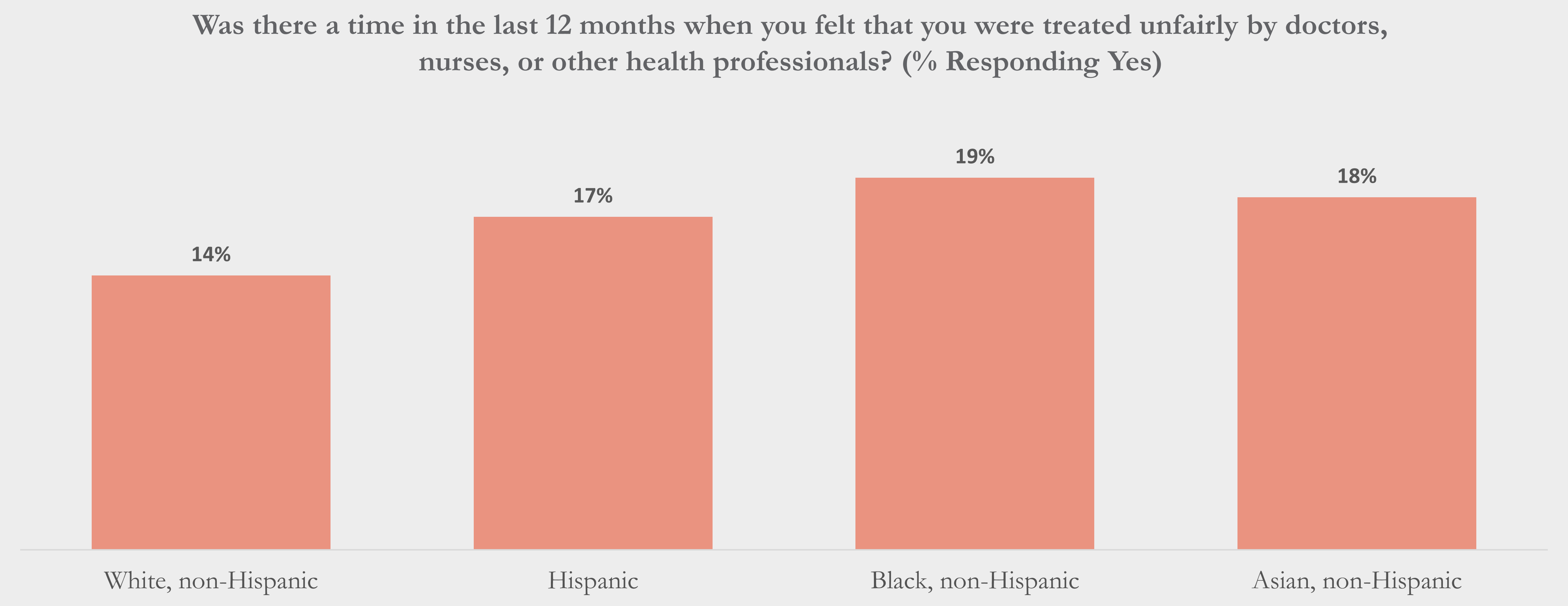


n = 437-526-464-427

17. Was there a time in the last 12 months when you felt that you were treated unfairly by doctors, nurses, or other health professionals?

**indicates significant difference from the reference category $100K+ (95% confidence)

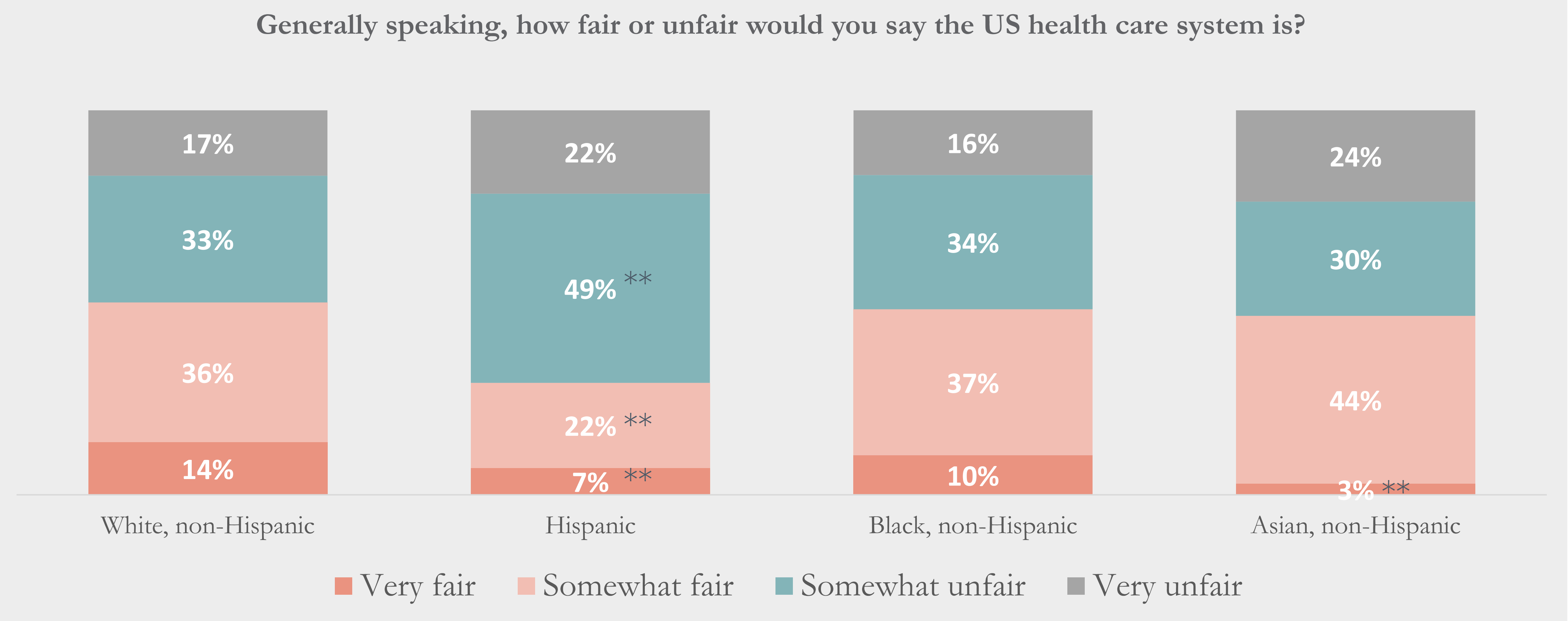
Recollection of being treated unfairly is statistically similar across White, Black, Hispanic, and Asian adults.



U.S. National General Population Results

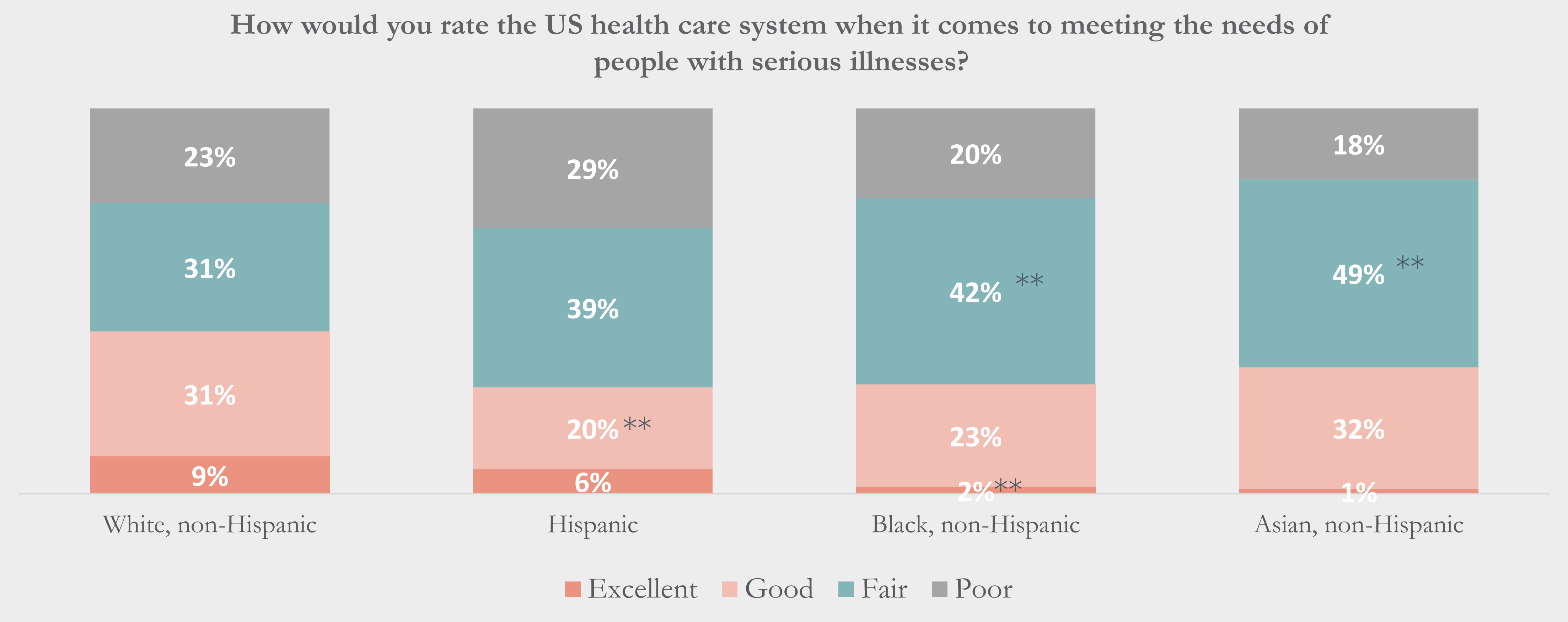
n = 1218-288-193-50
17. Was there a time in the last 12 months when you felt that you were treated unfairly by doctors, nurses, or other health professionals?

Hispanic respondents have a relatively unfavorable view of the fairness of health care in the U.S.



n = 1213-286-191-50; totals may not add to 100% due to rounding error and don't know/refused or skipped answers
32. Generally speaking, how fair or unfair would you say the US health care system is?
**Indicates significant difference from the reference category (White, non-Hispanic) (95% confidence)

White adults give relatively higher marks on the ability of the US health care system to meet the needs of people with serious illness.



n = 1145-270-175-50; totals may not add to 100% due to rounding error and don't know/refused or skipped answers
33. How would you rate the US health care system when it comes to meeting the needs of people with serious illnesses?
** Indicates significant difference from the reference category (non-Hispanic White) (95% confidence)

There are several contrasts in perceived improvement needed by race/ethnicity. Black and Hispanic adults place higher importance on several areas, especially eliminating racism improving access to the best treatments. *(data corrected 11.23.11)*

Improvements needed to better support seriously ill (% Quite a Bit + A Great Deal)	Race/Ethnicity			
	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic
Reducing cost of treatments and medicines	59%	63%	52%	53%
More access to health insurance	44%	**54%** **	51%	39%
More support for mental health	44%	47%	54%	39%
Eliminating racism and discrimination	39%	**50%** **	**61%** **	31%
More access to the best treatment options	31%	**48%** **	**49%** **	35%
More support in people's own language	22%	**39%** **	**35%** **	27%
Helping with basic needs (housing, food, utils, transport)	25%	**37%** **	**42%** **	36%
More spiritual care support	24%	31%	31%	22%
More options for care at home	26%	31%	31%	32%
More support for family/friend caretakers	21%	**31%** **	**31%** **	**39%** **
More assistance ensuring residence meets their needs	21%	**30%** **	**35%** **	27%
More support coordinating different docs, appts, meds	21%	27%	**32%** **	27%
More assistance with daily activities	18%	**30%** **	23%	23%
Sample Size	1218	288	193	50

34. In your opinion, how much improvement is needed in the following areas to better meet the needs for people with serious illness?
** Indicates significant difference from the reference category (non-Hispanic White) (95% confidence)

Conversations with loved ones and documentation was largely flat, with some small increases and decreases, in both the US and Massachusetts.

Advance Care Planning: Family/loved ones + documents	US		Massachusetts	
	2017	2021	2018	2021
Had a serious conversation with spouse, parent, child, other loved one.. about **wishes for your medical care if you become seriously ill?**	54%	55%	46%	**54%** **
Had a serious conversation with a spouse, parent, child, other loved one…about who will **make decisions about your medical care?**	62%	**54%** **	60%	**54%** **
Documented health care proxy?/Written document names a health care **decision maker**?	41%	**33%** **	41%	37%
Written document that describes your **wishes for care if seriously ill**?	34%	30%	n/a	32%

36-37-38-39-40-41. Have you / Would you / Do you…

***Indicates significant difference from reference category (2017 or 2018) (95% confidence)

Conversations with clinicians about wishes for care increased, especially in Massachusetts.

Advance Care Planning: Clinician conversations	US		Massachusetts	
	2017	2021	2018	2021
Had a serious conversation with a doctor, nurse, etc. about who will make decisions about your medical care?	23%	22%	27%	**32%** **
Had a serious conversation with a doctor, nurse, etc. about wishes for your medical care if you become seriously ill?	18%	**23%** **	14%	**32%** **
If no, would you want to talk to a doctor, nurse, etc. about your wishes for your medical care if you became seriously ill?	57%	**46%** **	58%	**48%** **

36-37-38-39-40-41. Have you / Would you / Do you…

***Indicates significant difference from reference category (2017 or 2018) (95% confidence)

Racial and ethnic disparities persist in advance care planning engagement, and some have grown significantly. Notably, in the percent of Black & Hispanic respondents who would want to talk to a clinician about wishes for care.

Advanced Care Planning Actions	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian, non-Hispanic	
	2017	2021	2017	2021	2017	2021	2017	2021
Had a serious conversation with spouse, parent, child, etc. about wishes for your medical care if you become seriously ill?	61%	62%	35%	42%	41%	45%	n/a	47%
Had a serious conversation with a spouse, parent, child, etc. about who will make decisions about your medical care?	67%	**59%****	54%	**41%****	51%	51%	n/a	38%
Had a serious conversation with a doctor, nurse, etc. about wishes for your medical care if you become seriously ill?	18%	**23%****	17%	20%	17%	26%	n/a	15%
If no, would you want to talk to a doctor, nurse, etc. about your wishes for your medical care if you became seriously ill?*	55%	49%	63%	**42%****	59%	**38%****	n/a	45%
Had a serious conversation with a doctor, nurse, etc. about who will make decisions about your medical care?	24%	22%	22%	21%	23%	28%	n/a	14%
Documented health care proxy?	47%	**38%****	36%	24%	30%	24%	n/a	19%
Documented wishes for medical care?	40%	35%	24%	20%	21%	20%	n/a	22%
Sample Size	1140 * 878	1218 * 918	387 * 285	193 * 145	401 * 307	288 * 201	n/a	50 * 39

36-37-38-39-40-41. Have you / Would you / Do you…

indicates significant difference ***within* each group compared to the 2017 reference category (95% confidence)

While there are some moderate variations by race and ethnicity, the top reason for ACP inaction is consistent for all: They just haven't thought about it.

Reasons for not documenting wishes for medical care	Race/Ethnicity			
	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic
You haven't thought about it (e.g. too young, too healthy).	43%	44%	42%	46%
Family / decision-makers will know what you want.	35%	33%	28%	22%
There are too many other things to worry about right now.	33%	**20%** **	32%	40%
You don't know how to begin or would need help to do it.	28%	25%	27%	36%
You don't want to think about sickness and death.	24%	22%	33%	16%
Don't think documents will make any difference in care.	7%	9%	8%	3%
You have never heard of it.	4%	**14%** **	5%	**14%** **
Want doctors to make the decisions for you when needed.	5%	5%	8%	6%
Don't have anyone that you can make responsible for this	4%	4%	**11%** **	3%
Not something people in your culture, religion, or family do.	1%	**8%** **	**14%** **	**22%** **
Worried having these documents will mean worse care.	5%	7%	6%	3%
Other	8%	5%	10%	4%
Sample Size	743	190	134	35

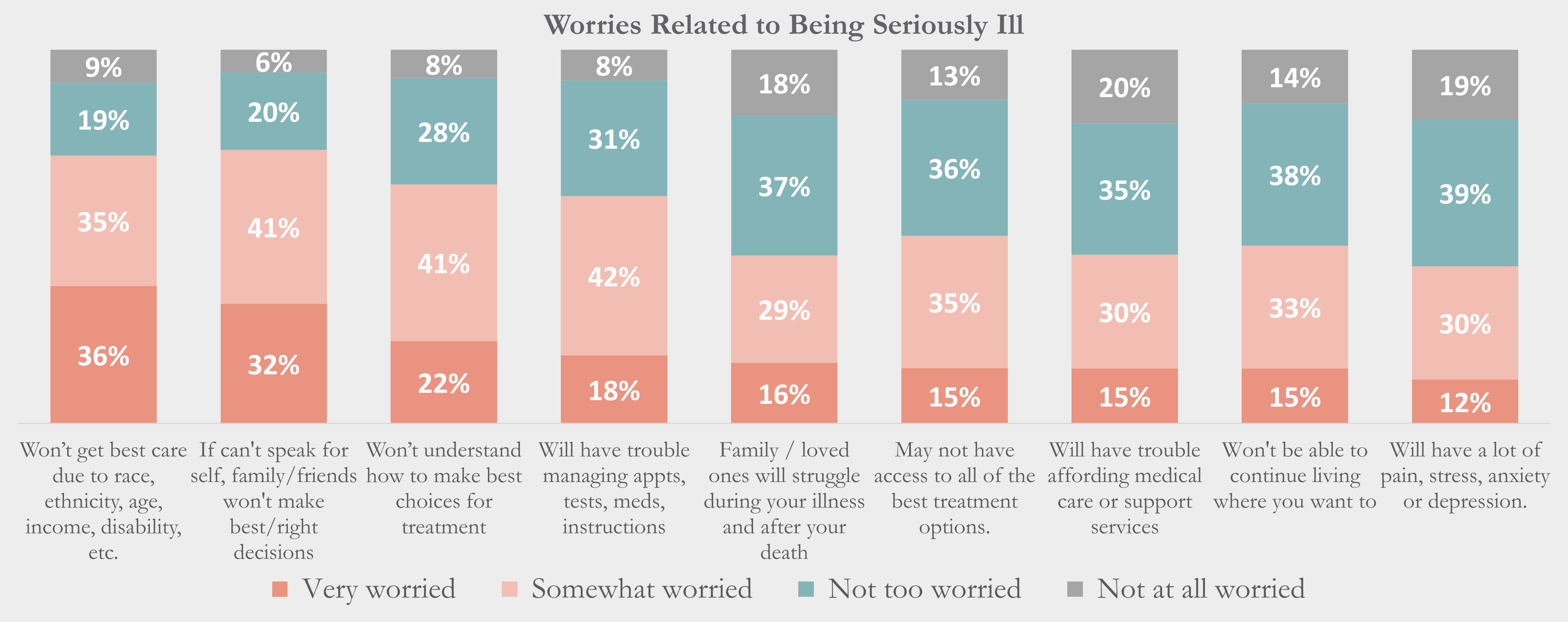
42. There are different reasons why people may not have their wishes for medical care written down. Are any of the following a reason you have not written down your wishes for your medical care [if you became seriously ill]? Check all that apply.
**Indicates significant difference from the reference category, non-Hispanic White (95% confidence)

People with serious illness are more likely to have had conversations across the board, but the rates are still relatively low. Only a third had conversations with their doctors; little difference in documentation between the seriously ill and all others.

Advanced Care Planning Actions / Interest	Serious Illness?	
	No	Yes
Had a serious conversation with spouse, parent, child, etc. about wishes for your medical care if you become seriously ill?	54%	**63%** **
Had a serious conversation with a spouse, parent, child, etc. about who will make decisions about your medical care?	53%	**62%** **
Had a serious conversation with a doctor, nurse, etc. about wishes for your medical care if you become seriously ill	20%	**35%** **
Would you want to talk to a doctor, nurse, etc. about your wishes for your medical care if you became seriously ill?*	45%	51%
Had a serious conversation with a doctor, nurse, etc. about who will make decisions about your medical care?	20%	**34%** **
Documented health care proxy?	32%	36%
Documented wishes for medical care?	29%	35%
Sample Size	1487 * 1149	367 * 232

36-37-38-39-40-41. Have you / Would you / Do you…
**Indicates significant difference the reference category, No Serious Illness (95% confidence)

Not getting the best care and proxies making good decisions topped the list of worries around serious illness.

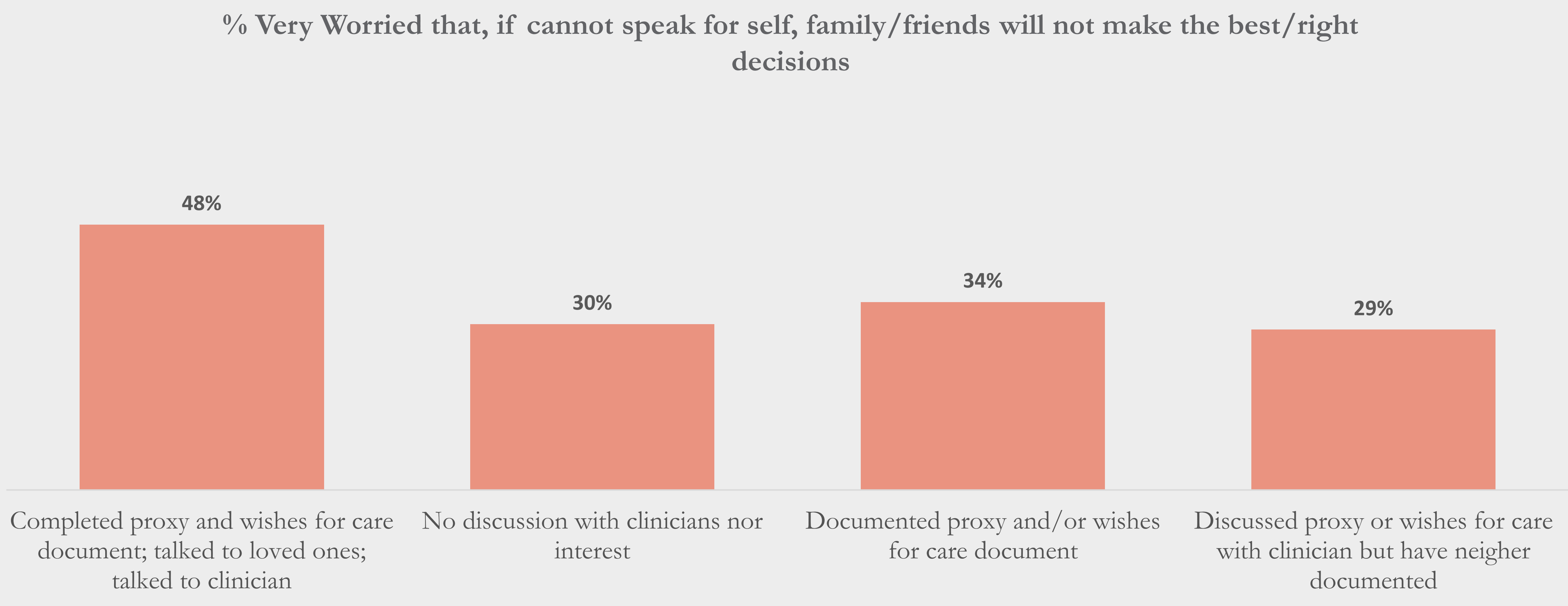


U.S. National General Population Results

n = 1854

43. How worried are you about the following [if you were to become seriously ill]?

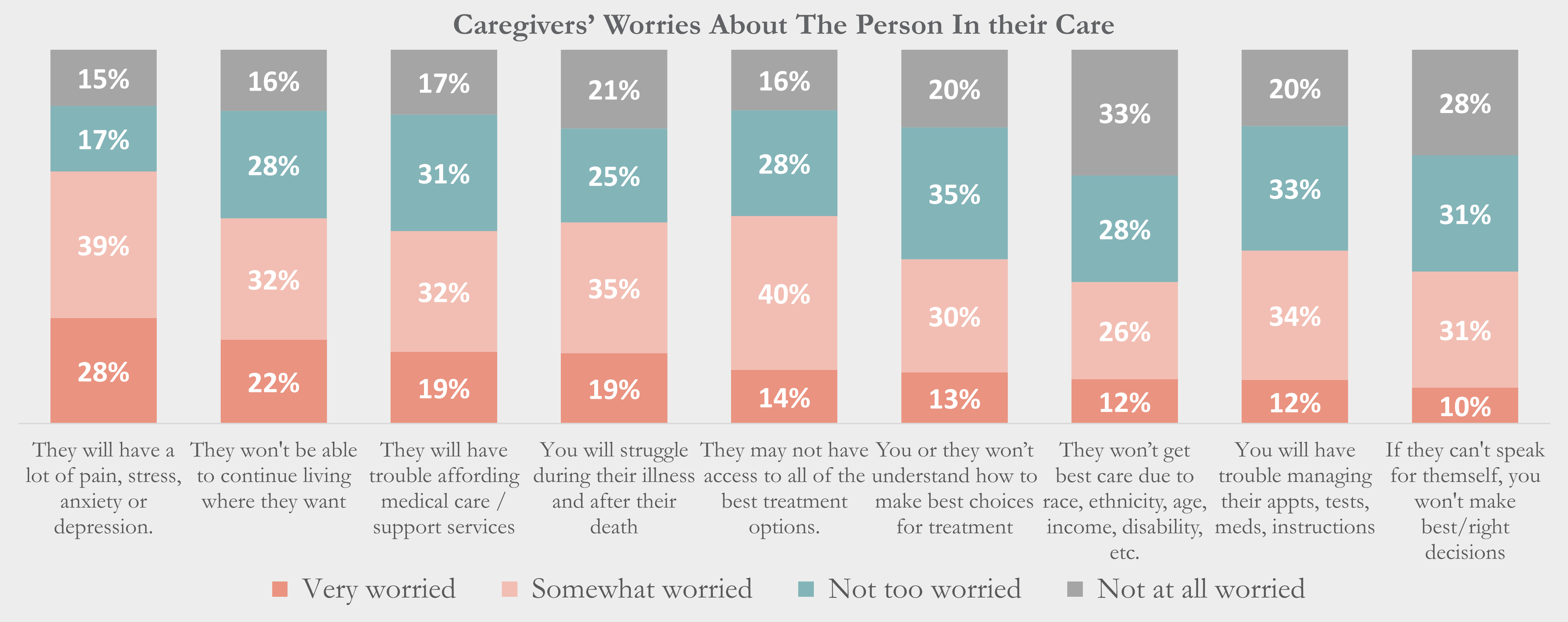
Worry about proxy decision making was high, but it important to note that, the most worried adults are the ones who have actually completed all ACP actions…



n = 1218-288-193-50

17. Was there a time in the last 12 months when you felt that you were treated unfairly by doctors, nurses, or other health professionals?

And caregivers are least worried about decision making. They are much more worried about the physical and emotional suffering of the person they are caring for.



U.S. National General Population Results

n = 401

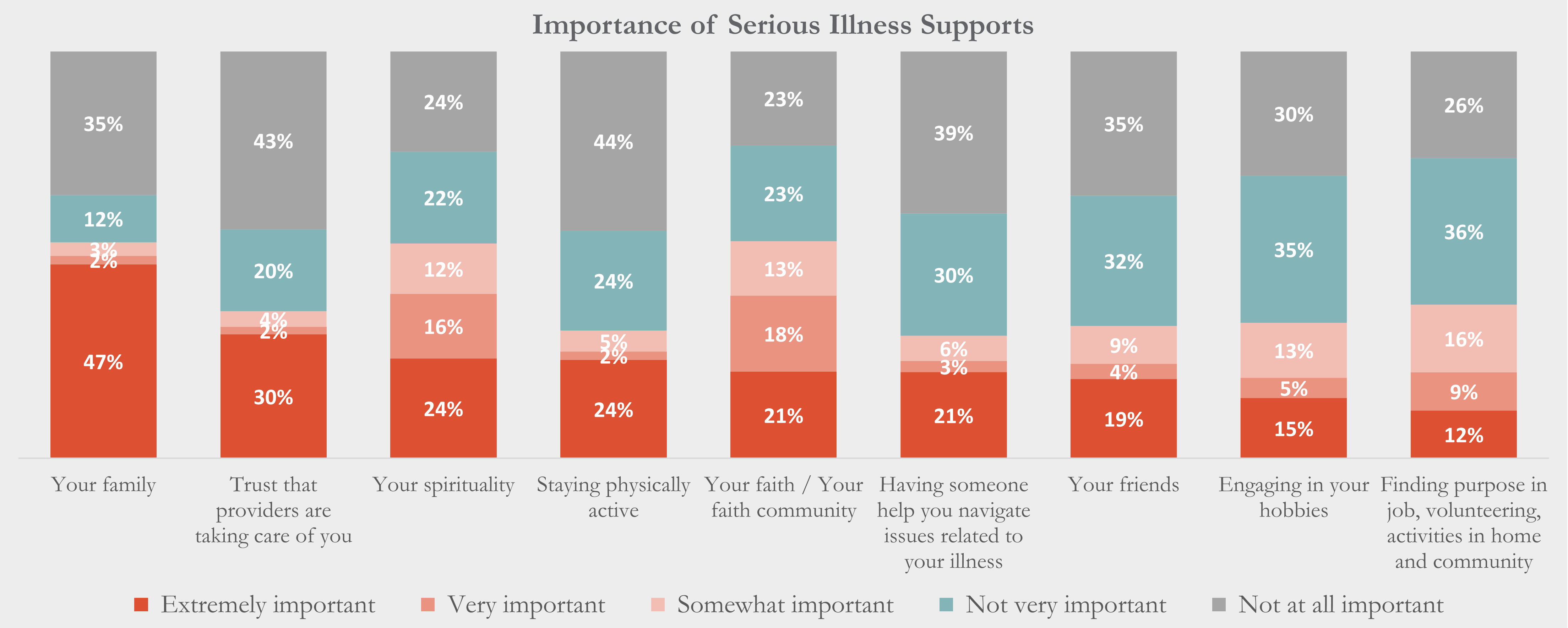
49. How worried are you about the following when it comes to [PERSON]?

When asked about worries about a serious illness, White adults are most worried about getting inferior care due to something about their identity, as are Hispanic adults, but not as strongly; Black respondents worry most about health care decisions, either by proxies or themselves, while Asian adults report less worries.

Worries related to becoming seriously ill (% Very Worried)	Race/Ethnicity			
	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic
If can't speak for self, family/friends won't make best/right decisions	36%	**26%** **	32%	**12%****
Won’t get best care due to race, ethnicity, age, income, disability, etc.	46%	**28%** **	**14%** **	**8%****
Won’t understand how to make best choices for treatment	22%	21%	26%	13%
Will have trouble managing appts, tests, meds, instructions	19%	14%	19%	12%
May not have access to all of the best treatment options.	16%	11%	13%	8%
Won't be able to continue living where you want to	15%	12%	22%	6%
Family / loved ones will struggle during your illness and after your death	16%	14%	23%	**4%****
Will have trouble affording medical care or support services	16%	10%	18%	**4%****
Will have a lot of pain, stress, anxiety or depression.	12%	11%	16%	3%
Sample Size	1218	288	193	50

43. How worried are you about the following [if you were to become seriously ill]?
** Indicates significant difference from the reference category, non-Hispanic White (95% confidence)

Family is by far the most important serious illness support, followed by trust in health care providers and spirituality.



U.S. National General Population Results

n = 1854

44. If you are seriously ill or were to become seriously ill, how important do you think each of the following are or would be in supporting you through your illness?

Black respondents rate several serious illness supports more important than other groups – including spirituality, trust in providers, and finding purpose in job/activities.

Importance of supports if you become seriously ill (% Very + Extremely Important)	Race/Ethnicity			
	White, non-Hispanic	Hispanic	Black, non-Hispanic	Asian, non-Hispanic
Your family	52%	44%	49%	42%
Your spirituality	41%	33%	**48%** **	32%
Your faith / Your faith community	42%	32%	43%	**25%** **
Trust that the providers are taking care of you	32%	29%	**42%** **	**16%** **
Staying physically active	22%	30%	**41%** **	21%
Having someone help you navigate issues related to your illness	22%	24%	31%	23%
Your friends	24%	21%	**30%** **	9%
Finding purpose in your job, volunteering, activities in your home and community	19%	18%	35%	14%
Engaging in your hobbies	17%	**24%** **	**30%** **	14%
Sample Size	1218	288	193	50

44. If you are seriously ill or were to become seriously ill, how important do you think each of the following are or would be in supporting you through your illness?

** Indicates significant difference from the reference category, non-Hispanic White (95% confidence)

Major Qualitative Findings

Qualitative Research Methodology

- **Online Communities**:
  - —Virtual collaborative spaces where participants can be engaged in structured daily activities/discussions facilitated by a trained moderator, over a period of weeks. Communities are asynchronous so people can participate at their own pace.
- **Recruitment:**
  - —Mix of adults 18+ from across the US, aligned with U.S. census
  - —Oversampled: Blacks, Hispanics, people with serious illness, disabilities, low-income, and caregivers

In-depth engagement with 580 adults via online community forums.

Part 1
June – July: 300 participants, 2 weeks

Part 2
August: 280 participants, 1 week

EXPLORE

Understand people's lived experiences with the health care system and with clinicians (focus on communication, relationships, decision-making)

TEST

Test 12 conversation statements and 4 quality care definitions to gauge resonance and relevance

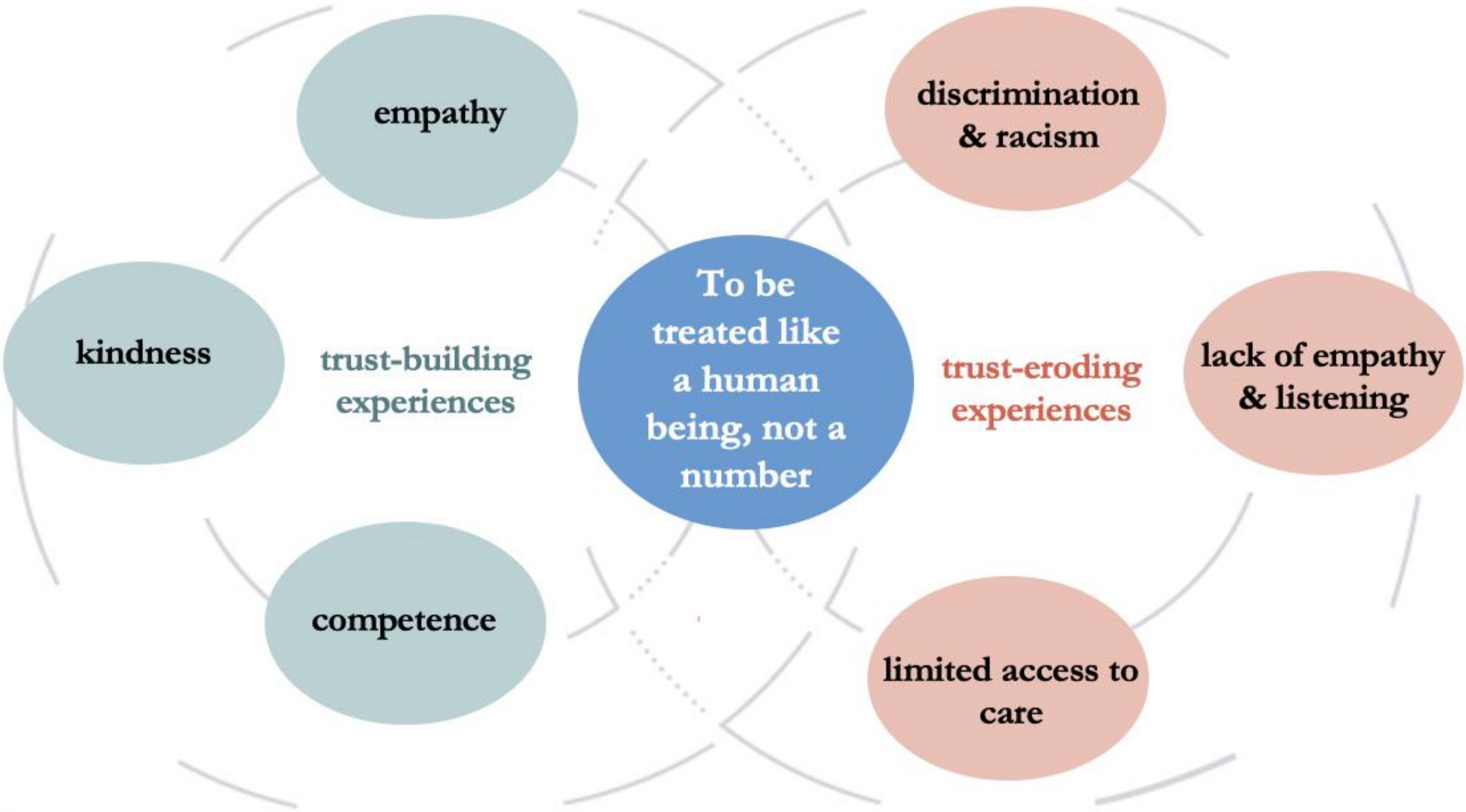
VALIDATE

Delve into survey questions we needed more insight on and use Part 1 findings to develop and test (ACP /shared decision-making) calls to action for believability, difficulty and impact

To test statements/descriptions, participants read through the content and used a highlighting tool to share which words/phrases resonated and which did not. We then engaged them in discussion about their feedback, asked them to select the statements that resonated the most and least or were perceived as most believable, difficult to do, and of greatest impact on their health and well-being and tell us why.

July Part 1: Explore and Test

Trust in the health care system builds and erodes constantly across the continuum of health care engagement. This is not a static or unchangeable process and through it all people most want to be treated like a human being.



empathy

kindness

competence

trust-building experiences

To be treated like a human being, not a number

trust-eroding experiences

discrimination & racism

lack of empathy & listening

limited access to care

Open-ended questions about health care experiences good and bad…

- Across all groups (Blacks, Hispanics, people with serious illness, disabilities, caregivers, people 65+) a noticeable contingent had **positive health care experiences** that stemmed from doctors and staff showing empathy, kindness, competency, efficiency, good communication, attentive listening, and making the effort to understand the individual as a human being.
- Most **negative health care experiences** were due to a mix of discrimination, lack of empathy, poor communication/listening skills, frustration/anxiety navigating and dealing with the health care system (e.g., insurance, cost, doctors' tardiness, misdiagnosis, pressure to accept treatments or procedures individuals do not necessarily want, disregard for the individual's mental health and overall wellbeing).
- There is a **strong perception that negative health care experiences are widespread** while positive experiences seem more isolated or 'the luck of the draw.'

Open-ended questions about health care experiences good and bad… (continued)

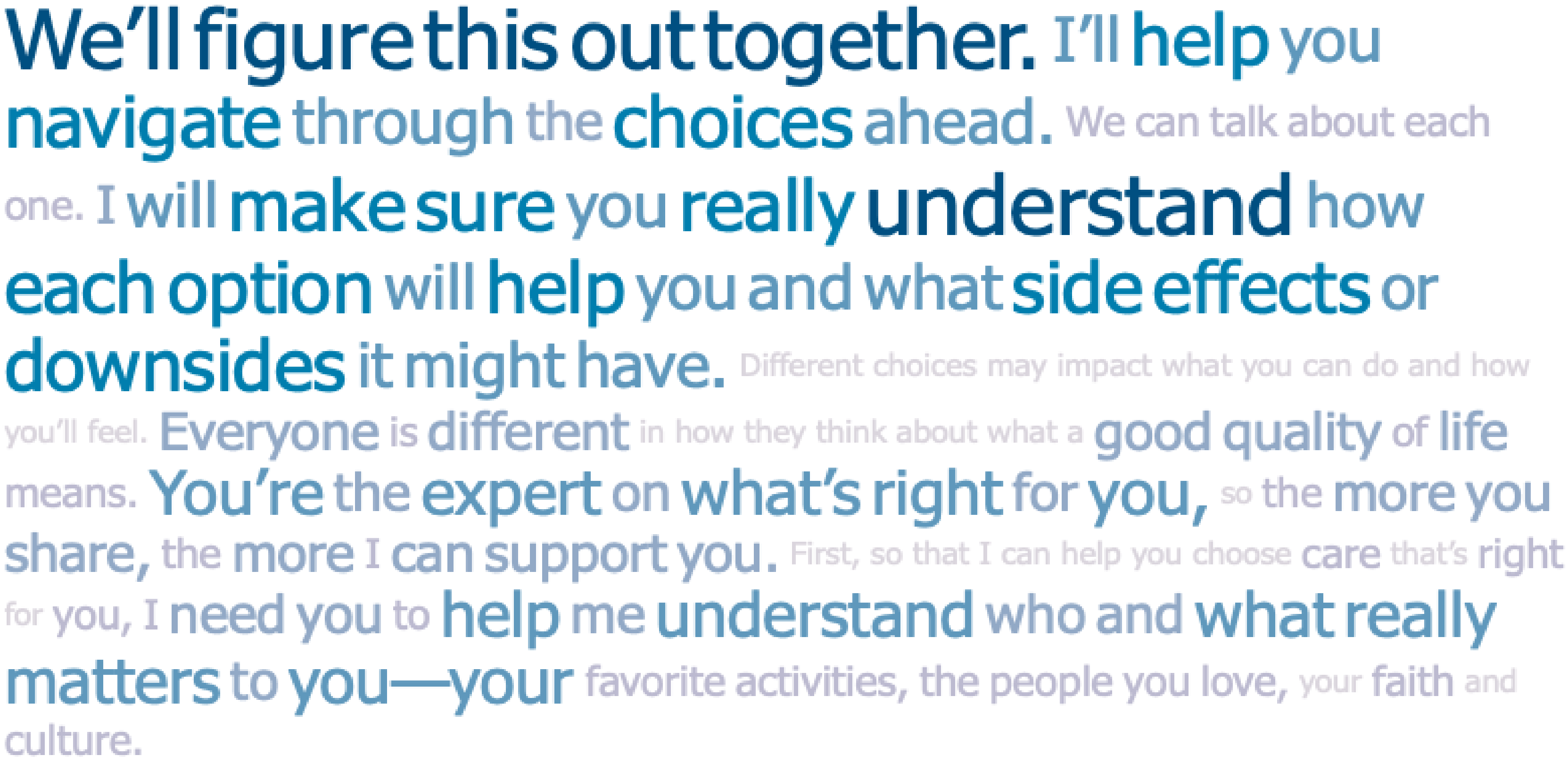
- **Most people perceive the health care system is focused on making money/profit** (e.g., privatization of health care, doctors obligated to meet quotas, high cost of care, etc.) hence the common belief that people are treated like a number and not like a human being.
- **While COVID exacerbated the negative**, many tolerated/accepted the challenges as something to be expected and appreciated and welcomed virtual/telehealth appointments (still preferring the in-person interactions) – there was not a strong indication that COVID lowered people's trust in the health care system. Some were grateful for the way their doctor/other health professionals made them feel safe (whether that was enforcing social distancing, masking, cleaning waiting rooms, etc.) and went above and beyond in terms of being accessible.
- **As people age, they feel more prepared and willing to advocate for themselves.** There is a sense of having more control and that they need to stand up for themselves and ask for what they need.

Conversations Statement* testing revealed insights into people's concerns, expectations and what they find believable about health care system interactions.

We'll figure this out together.	Let's make a plan for your care in case you can't speak for yourself one day.
I know that health care treatments can be expensive.	Treatments only work if they work for you.
I'm keeping up with the latest research, treatments and ideas.	Someone–me myself, or a member of my care team–will always call you back.
Your time matters to me.	I welcome all of your ideas and questions.
If you have any concerns, let me know.	Many patients are concerned that if they talk about challenges with health care costs, I will assume they can't afford treatments.
I get that, sometimes, life and other things can get in the way of your ability to get care.	I treat all my patients equally and recommend the kind of care I would recommend for family or close friends.

* 12 "conversation statements" that a clinician might say in an appointment, touching on decision making, advance care planning, bringing up costs, expertise and more. (The full text is included in the appendix.)

People overwhelmingly selected a collaborative approach to care as most important, summarized in this sentiment.



We'll figure this out together. I'll help you navigate through the choices ahead. We can talk about each one. I will make sure you really understand how each option will help you and what side effects or downsides it might have. Different choices may impact what you can do and how you'll feel. Everyone is different in how they think about what a good quality of life means. You're the expert on what's right for you, so the more you share, the more I can support you. First, so that I can help you choose care that's right for you, I need you to help me understand who and what really matters to you—your favorite activities, the people you love, your faith and culture.

Visual output example from highlighting exercise showing words and phrases thar resonated most with participants. Responses were also reviewed by Blacks, Hispanics, people with serious illness, disabilities and caregivers showing no meaningful differences.

Additional insights from conversation statement testing

medical costs	expertise	time
People worry that disclosing concerns about medical costs can alter/affect their care and treatment options. They want to be reassured that if they share concerns their doctor will not withhold choices that will help them.	People expect and want expert doctors, however statements of expertise were often perceived as arrogant, reinforcing power imbalance and suggesting that the clinician would not be collaborative.	Clinicians talking about valuing a patient's time is not necessarily believable due to people's common experience of feeling rushed through appointments, doctors running late, or made to wait for appointments.

Quality care definition* testing: again a collaborative approach to care resonated most overall, and a non-judgmental approach to care resonated most among Black, Hispanics, people with serious illness and disabilities

Resonated most **overall** and with caregivers	**Good quality care is collaborative with me**: it requires taking the time to learn about me so that my care is the best possible fit for me and to learn what is really going on, not just the symptoms but the root cause…
Resonated most among Blacks and Hispanics, people with serious illness and disabilities	**Good quality care is kind, empathetic, patient, non-judgmental, treating me (and everyone) as important and worthy of care**…
Neutral	Good quality care is from competent, knowledgeable doctors who know all the most effective treatments available…
Resonated least overall	Good quality care is timely, convenient, and coordinated…

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* The 4 Quality Care definitions were crafted using answers from earlier open-ended answers by participants. (The full text is included in the appendix.)

Quality Care definition testing: additional insights

- **Across all demographic groups there was consensus that quality care is empathetic, kind, patient, non-judgmental and collaborative "with me**." For many, this is the way it should be, while recognizing it's not always the case based on their experiences. Empathy was consistently referred to as an essential quality that defines the good/best health care professionals.
- **Quality care as timely and convenient touched a nerve.** Even though it sounds great, it is not realistic**.** It made many reflect on their experiences and how the health care system treats people like a number and lacks respect for the individual's time.
- **Most people felt neutral about quality care is from competent, knowledgeable doctors**. Once again highlighting that this should be a given.

Summary Reflection Part 1: People want partnership. And while timeliness and expertise are important, those are just table stakes. Being treated like a whole person is the real differentiator.

- **People want mutual respect, collaboration, and non-judgmental empathetic care from their clinicians.** Across the different testing exercises, people valued this kind of attitudinal/relational theme and language.
- **It rankles people to try and 'sell' what they perceive to be things that just meet their baseline expectation. Basic courtesies and human decency should not be positioned or marketed as novel, new and/or nice to have.** For many the concepts tested touched a nerve as they shared stories of doctors and other health professionals lacking empathy, ignoring concerns, keeping them waiting for significant periods of time, not following up and more.
  - This sentiment helps explain why participants downplayed expertise/competence, which they just expect as a given; (also: statements of expertise sounded arrogant to some, suggesting that clinician wouldn't be collaborative/respectful, which was the primarily desired value)
- We did hear from a good number of people (across all racial and ethnic groups) who shared their **stories of empowerment** – how they grew weary of less than satisfactory experiences with their doctor and/or other health professionals and made a change (changed doctors, switched to a new practice, etc.). Some had done this multiple times over – committed to finding a doctor (practice, etc.) that met and/or exceeded their expectations. Undoubtedly – these consumers inspired others in the online communities to do the same (which reinforces what we already knew about the **power of word of mouth** and the degree to which people rely on others with shared experiences for health care system guidance/advice).
- Even those who had made a change and are now happy with their doctor shared that **there are still trade offs**. They are willing to sacrifice some of their time (i.e., scheduling appointments with specialists several months out, waiting for a doctor who is running late, etc.) in return for high quality care. **The high-quality care (e.g., that doctor who "treats them as a human being," shows empathy, truly listens to them, advocates for them, treats the "whole patient," involves them in decision making, and ultimately makes them feel better) is what matters most.**

Summary Reflections Part 1 (continued)

- **Believability** – the degree to which people bought into the words/language/ideas varied within each demographic group based on their personal experiences. We heard from a vocal group who shared that in theory the concepts sounded great… but given their health care experiences, they questioned the reality of these concepts actually happening (e.g., doctors having ACP conversations about planning for the future didn't seem realistic when most doctors barely take time to discuss the present; or doctors saying your time matters to me when doctors are always late for appointments, etc.)
- It's no surprise that **cost factors into everything**. No matter the idea and the way we framed it (whether it was a specially trained team of doctors, nurses, specialists/palliative care, an advocate who worked for a nonprofit organization, or a dedicated resource employed by a hospital), people quickly asked about the cost and whether it truly could be covered by insurance.

August Part 2: Validate

Overview

- 280 people, age 25+ census matched; split into 3 groups (for testing purposes)
- Oversampled respondents of color, people with serious illness, disabilities, caregivers
- **Explored** a handful of quantitative survey questions that we needed more insight on
- **Tested**:
  - 4 “calls to action” (speak up; pick the right doctor; pick a proxy; do end of life planning)
  - Calls to action were tested in three separate ‘treatments’ – as a public health campaign; and within a simple letter from a doctor; and within an expanded letter from a doctor using language sourced from the July qualitative test
  - Participants rated each on **believability**, **difficulty**, and value to their **health/ well-being**

Insight into survey question: “How important is it for doctors, nurses, or other health professionals to know about their patient’s priorities and what’s important to them?”

- Yes, people really do feel strongly that doctors need to know a person and their priorities in order to provide high quality care; for those who don’t, it’s a question of believability.
  - In the survey, we knew this question would be influenced by social desirability bias; we wondered how much that was driving the strong, positive responses (52% of respondents said that it was ‘very important’ that clinicians know a patient and their priorities and could not provide high quality care otherwise; another 37% said it was fairly important)
  - So, we explored this question again with open ended ‘explain your answer’ requests
  - We found that answers did not seem to be strongly an artifact of the bias
  - Respondents said that while doctors don’t need to know every single detail of a person’s life, it’s important they have a fair understanding of what is important to the individual so they can structure a collaborative treatment plan. It’s also important that doctors not separate physical health from mental/emotional health in treating the whole person.
  - For those who answered that doctors don’t need to know a person/their priorities, the issue was simply that they didn’t believe doctors either had the time to get to know people and/or were not willing to listen.

Insight into survey question: "Generally speaking, how well do you feel that doctors, nurses and other health professionals understand your life priorities, your health goals, the activities that bring you joy and meaning, your financial situation, your culture etc…"

- In the survey, we were surprised how well people reported that their doctors knew them (e.g., ~80% said doctors know their health goals either very well or fairly well; 60-70% said their doctors knew their life priorities and the activities that gave them joy and meaning either very well or fairly well; about 50% said the same of their culture and relationships; and ~40% their faith and financial situation).
- So, we asked participants these questions again and then to explain their answers
- We found:
  - Most people think their doctors understand their health goals; discussing health goals seems to conflate with life priorities and activities that bring joy and meaning. For a majority, doctors mostly discuss health goals and at times conversations touch on other aspects such as life priorities and activities.
  - Conversations about non-medical/health aspects of people's lives are appreciated if there is a clear connection to their health and well-being. With limited time for appointments, some people don't want to waste time with things that may not be tied to their health.
  - Those who feel their doctors understand them tend to speak up. They are confident advocating for themselves and proactively sharing aspects of their lives they think are relevant to their health.
  - Some have experienced great relationships with doctors who demonstrate empathy and listening skills. The downside is when the doctor they trust leaves/retires; or the practice stops accepting their insurance and they have to settle for a different type of doctor experience or search until they find a doctor they feel good about.

Insight into survey question: (If haven't already) "Would you want to talk with a doctor, nurse etc. about your wishes for your medical care if you were seriously ill?"

- We also explored people's willingness to talk with doctors about their wishes for care.
- As in the survey, the vast majority of participants had not talked with their doctors about their wishes for care, even those with serious illnesses; many had specific reasons:
  - **All set, got advance directives in place.** Completing living wills, a power of attorney or DNRs (without necessarily having conversations) gives a sense of confidence that their wishes are official and will be respected.
  - **Don't have a regular doctor or one they trust.** They don't feel close enough with their doctors to have such a serious conversation – e.g., doctors leave practice, see doctor only for annual checkups, use urgent care.
  - **See no point because current doctor may not be the one to treat a serious illness**. They expect that if they become seriously ill, they will need to see specialists and may have to get care at a different hospital or facility.
  - **Trust family to take care of it.** Prefer to speak to family first and complete documents since doctors may change over time and family will have the legal power.
  - **Have not thought about it/are healthy.** May consider completing a living will and talking to doctor if their health condition changes, but not while healthy.
  - **Doctors have not brought it up.** The majority have not had doctors bring up these types of conversations and some people with a serious illness wondered why their doctors had not done so.

Call to action testing: set up/instructions

- Three separate communities three or four ‘calls to action’ in a different context
  - Community 1 saw them all as a public health campaign
  - Community 2 read them in a ‘simple’ letter from their doctor’s office
  - Community 3 read them as part of an ‘expanded’ letter from their doctor’s office, using much of the language about collaboration and empathy that tested best in July
  - ***NOTE****: we did not include the ‘you can look for the right doctor’ call to action in the doctor’s office letters; it was only seen by the people in the public health campaign test*

- Each person read the material, did a highlighting exercise and then rated them on:
  - **Believability**: how much you truly buy into what’s being said
  - **Difficulty**: the degree to which you can actually do what’s being said
  - **Impact**: looking into the future - the degree to which what’s being said is going to positively impact your health and wellbeing

Calls to action* tested

You can speak up and have a say in your care. Getting health care often involves choices that impact your life and wellbeing in different ways. Treatments only work if they work for you...

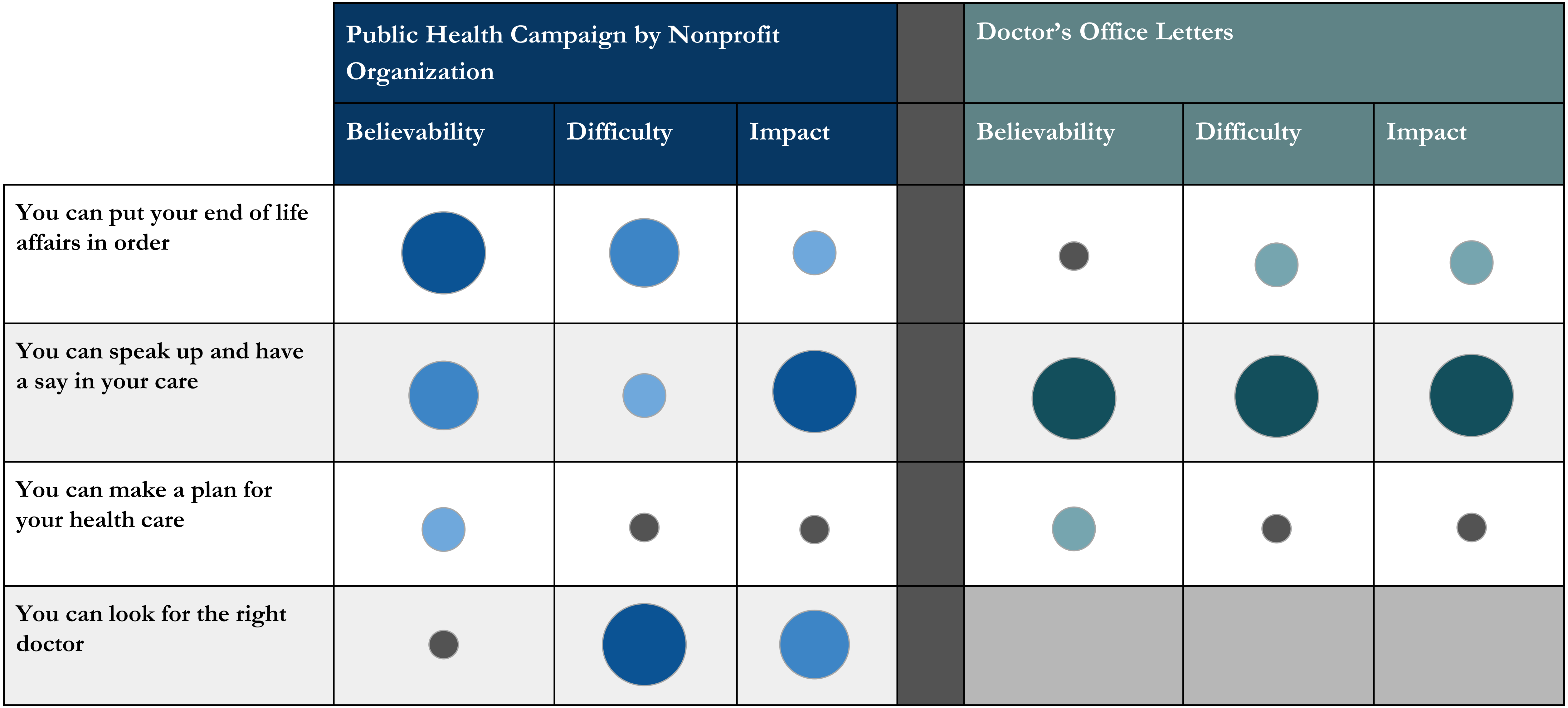
You can make a plan for your health care in case you cannot speak for yourself. Talk to a trusted person about becoming your health care proxy, a person who can make medical decisions for you if you can't. Share with that person what matters most and what your good days look like…

You can put your end of life affairs in order. There are documents, instructions, and products such as life insurance, wills, and funeral directions, that will give the people around you the guidance and support they will need after you are gone…

You can look for the right doctor. A great doctor takes the time to treat you as a whole person, listens to what matters to you, is empathetic and non-judgmental, and gets to the root causes of your concerns to help improve your well-being…

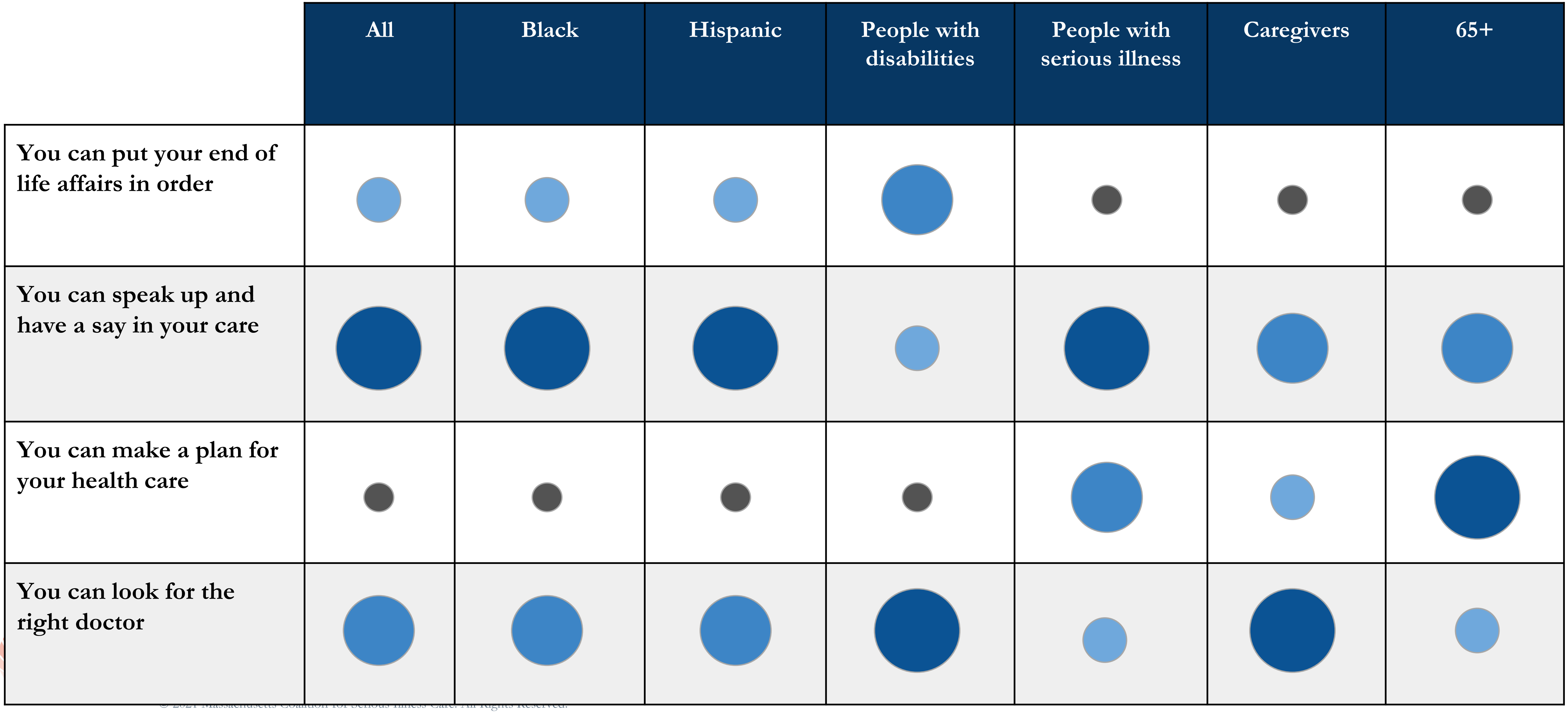
*** The full text is included in the appendix.**

Results Overall: "You Can Speak Up" universally seen as having the greatest impact, though more difficult than other actions, especially in the Doctor's Office Letter treatment.



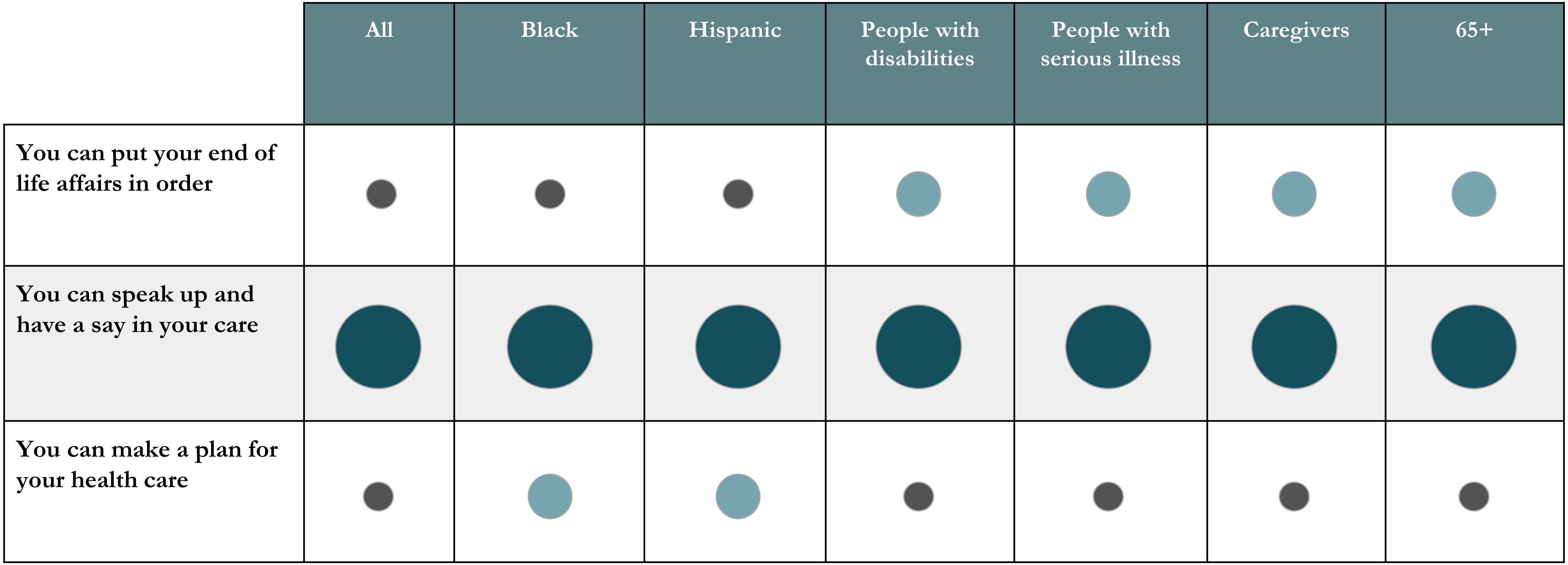
	Public Health Campaign by Nonprofit Organization				Doctor's Office Letters		
	Believability	Difficulty	Impact		Believability	Difficulty	Impact
You can put your end of life affairs in order	●	●	●		●	●	●
You can speak up and have a say in your care	●	●	●		●	●	●
You can make a plan for your health care	●	●	●		●	●	●
You can look for the right doctor	●	●	●				

Perceived impact by communities of focus: public health campaign treatment



	All	Black	Hispanic	People with disabilities	People with serious illness	Caregivers	65+
You can put your end of life affairs in order	●	●	●	●	●	●	●
You can speak up and have a say in your care	●	●	●	●	●	●	●
You can make a plan for your health care	●	●	●	●	●	●	●
You can look for the right doctor	●	●	●	●	●	●	●

Perceived impact by communities of focus: doctor's office letter treatment



	All	Black	Hispanic	People with disabilities	People with serious illness	Caregivers	65+
You can put your end of life affairs in order	●	●	●	●	●	●	●
You can speak up and have a say in your care	●	●	●	●	●	●	●
You can make a plan for your health care	●	●	●	●	●	●	●

Reflections on public calls to action

- **You can speak up and have a say in your care** messaging was believable and ***deemed to have the greatest positive impact overall and especially when presented as clinician communications;*** it was perceived as more difficult to do when delivered by health care providers and slightly less difficult to do when presented as marketing campaign language.
  - Respondents selected this as the most impactful action across all segments in the doctor's office letter treatment and for most segments in the public health campaign treatment including Black and Hispanic respondents, as well as people with serious illnesses
  - For people with disabilities and caregivers seeing the public health campaign test, where they saw the additional option of 'you can pick the right doctor,' it was this option that was seen as the most impactful, even though it was seen as ***more difficult*** and ***less believable*** than 'you can speak up'

- While believable and not difficult to do, **You can make a plan for your health care** (proxy) messaging was ***deemed to have the least impact*** and was often associated with getting end of life affairs in order (e.g., many respondents did not seem to think they were meaningfully different calls to action).
  - For people 65+ it was seen as having the greatest impact in the public health treatment, while maintaining it's perception as the least difficult to do (in the doctor's letter treatment, however 'you can make a plan' was seen as having the least impact); ***this may reflect confirmation bias***, as the vast majority (~80%) of people 65+ have done this action already
  - The perceived impact was relatively higher for people with serious illnesses (but still lower than 'you can speak up')
  - The perceived impact was relatively higher for Black and Hispanic participants and those with serious illness when delivered as a letter from a doctor's office (but again, lower than 'you can speak up')

Appendix

July Qualitative: 12 Conversation Statements

1. **I'm keeping up with the latest research, treatments and ideas**. Science is changing all the time, but I am an expert in your particular condition and am aware of up-to-date best practices and all the choices for your treatment. And if I don't know, I will ask my colleagues. If it turns out we don't offer one of those treatments or approaches here, we can talk about how to get it to you.
2. **We'll figure this out together.** I'll help you navigate through the choices ahead. We can talk about each one. I will make sure you really understand how each option will help you and what side effects or downsides it might have. Different choices may impact what you can do and how you'll feel. Everyone is different in how they think about what a good quality of life means. You're the expert on what's right for you, so the more you share, the more I can support you. First, so that I can help you choose care that's right for you, I need you to help me understand who and what really matters to you—your favorite activities, the people you love, your faith and culture.
3. **I welcome all of your ideas and questions;** If you hear or read about treatments from family, magazines or on the internet, or have ideas about alternative therapies, please share them with me. I won't always know about everything, but I will listen and figure out how we can incorporate your ideas into our decisions. Any ideas and questions you bring to our discussion can help me do my best job for you
4. **If you have any concerns, let me know.** If something ever doesn't seem right, or you see an error in your records or plans or think there is something wrong with your treatment, it's my and my team's responsibility to fix it. It's not your job to track all this stuff down.
5. **I know that health care and treatments can be expensive**. I wish that costs didn't need to be involved in making care choices. I will offer all the choices I think may help your condition, but some might only help a little bit, some might not help at all and some may cost you a lot of money. We'll take time to consider the options as we figure out what works best for you and support what matters most to you. I can't provide you with the best quality care unless we're working together.
6. **I get that, sometimes, life and other things can get in the way of your ability to get care.** If it's tough for you to make the time for visits or afford the transportation costs to get here or another center involved in your care, let's talk about it. There could be other options closer to home or we could even consider virtual options. Or if you have other worries such as immigration status, let me know and I will try to help.

July Qualitative: 12 Conversation Statements (Continued)

7. **I treat all my patients equally, and recommend the kind of care I would recommend for family or close friends**. People often ask me what I'd do if I myself, or my own mother, were the patient in their shoes. And I tell them it would be the same process: I take the time to explain how I would help my mom make decisions, based on what matters to her, her circumstances and priorities—just as I will do for you.
8. **Treatments only work if they work for you**. If you have too many pills to keep track of, need to run to different pharmacies to get them, or if appointments are too hard to fit into your life and it's too hard to come see me or your other doctors, let me know. I may not always be able to figure it out right away, but I will always listen and try to problem-solve with you. If I know about challenges, I can do better.
9. **Someone—me myself, or a member of my team—will always call you back**. Your questions and concerns matter to me and my team, so you never have to worry that they will go unanswered or unaddressed.
10. **Your time matters to me**. If I am late for our appointment, I will try to make it up. As much as possible, I will try to make sure that all your appointments are at the same time, on the same day. Or if it works better for you, we can try and use virtual visits or home visits so you don't have to travel to meet me in my office.
11. **Many patients are concerned that if they talk about challenges with health care costs, I will assume they can't afford treatments.** Even if you share concerns about treatment costs, I will not withhold choices that can help you. And then if costs are a challenge, we can work together to figure out what is best for you. That can mean using lower cost treatment options or I can connect you to our financial counselor to talk about how to deal with all the medical bills.
12. **Let's make a plan for your care in case you can't speak for yourself one day.** We can't plan for everything. But we can talk about what matters to you and what you'd want most if you couldn't make your own decisions. We may not be able to predict every choice that would need making, but you can give those you love the guiding principles to confidently make decisions for you if they have to. So let's talk about your values and preferences, and the care that's right for you. Conversations about things we can't control can actually help to give us a sense of control.

July Qualitative: 4 Quality Care Statements

- **Good quality care is collaborative with me: it requires taking the time to learn about me so that my care is the best possible fit for me and to learn what is really going on – not just the symptoms but the root cause**. It also means taking the time to help me understand what needs to be done and why, and allows me to weigh the risks and rewards of different courses of treatment, including honest considerations of cost. It means coming up with a plan together that works for me and my life. Good quality care means a relationship where doctors and patients are working together, trusting each other, and committed to my wellbeing.

- **Good quality care is kind, empathetic, patient, non-judgmental, treating me (and everyone) as important and worthy of care**: everyone – from the doctors to the office staff – really listens to me, believes me, treats me with dignity, respect, recognizing that I know myself better than anyone and not assuming anything about me. They work to really understand me, treat me like a whole person, not as a number, recognizing the big picture, including how I am feeling emotionally as well as my physical symptoms. It's really truly caring.

- **Good quality care is from competent, knowledgeable doctors who know all the most effective treatments available**. Doctors will keep up with the latest research and make me feel confident in their knowledge by, for example, answering questions about their expertise and giving me straight answers to my questions. While everyone is human, quality care has minimal mistakes. But it also means admitting when they do not know something and being honest about issues.

- **Good quality care is timely, convenient, and coordinated**: good quality means being able to see a doctor as soon as I need; it means teams of doctors work together and talk to each other, so I don't have to update everyone when something changes; visits and tests are scheduled around me and my life, like using many more virtual/telehealth visits whenever possible and then being on time when I do have to come in; outreach and follow-up is proactive to make sure I get everything on schedule; doctors read my chart and information so I don't have to repeat everything each time. Calls or online messages are returned quickly; refills and referrals are done without hassle, and results reported fast.