



**SIXTH
ANNUAL
SUMMIT**



**Prioritizing Equity & Inclusion
in Serious Illness Care**

Summit Materials

October 14, 2021



MASSACHUSETTS COALITION FOR
SERIOUS ILLNESS CARE

2020-2021 Research Highlights

Thank you to our sponsors and collaborators

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Thank you sponsors!



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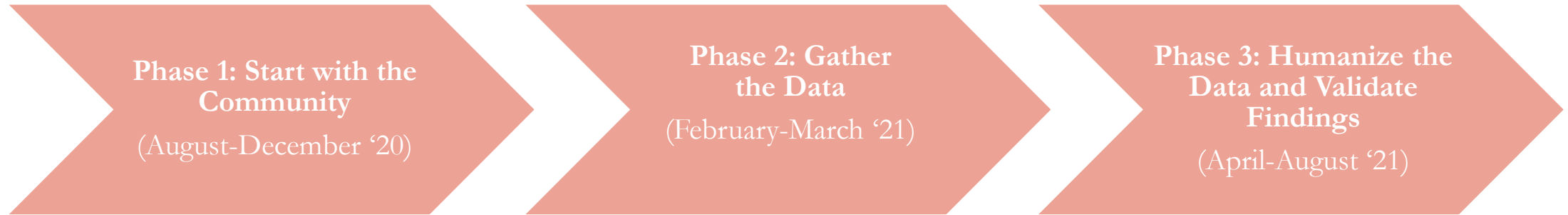


CAPE COD
HEALTHCARE



Hebrew
SeniorLife

2020-2021 Consumer Research Overview: Process



- 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

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

- 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



Major Quantitative 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

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

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
- Conducted cognitive testing with people from specific demographic groups



Defining Serious Illness

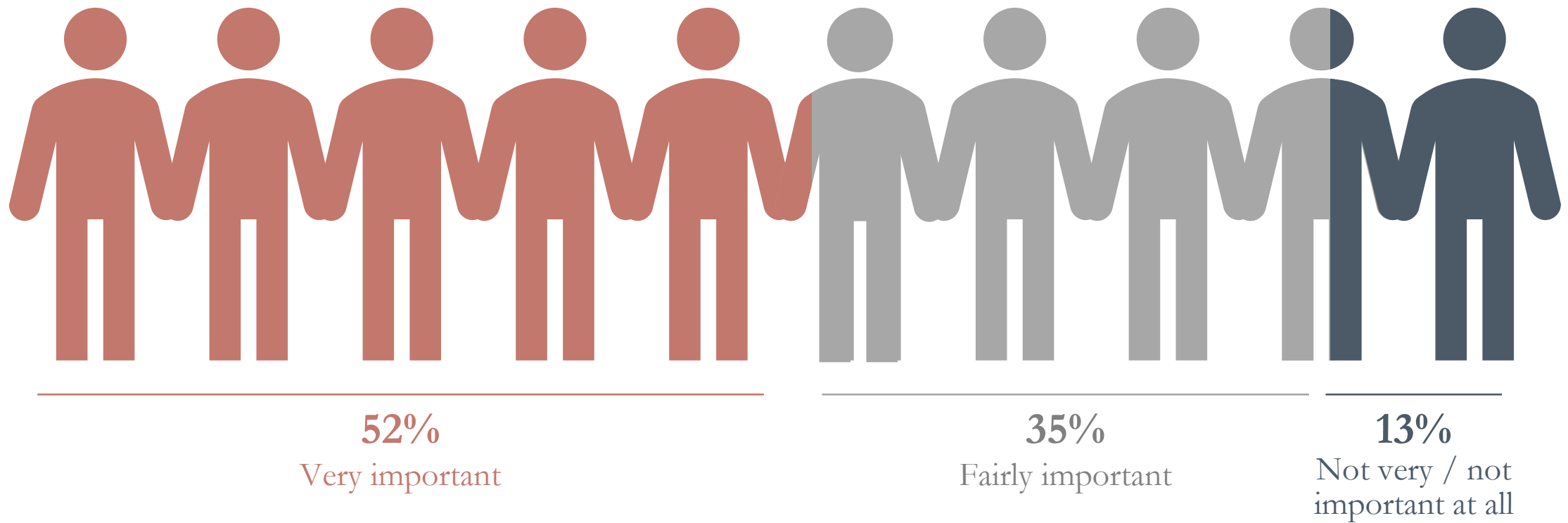
Diagnosis: diabetes, lung disease, heart disease or stroke, cancer, dementia, depression/anxiety/other serious mental health problem, chronic kidney disease

&

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



87% of adults believe it is important for clinicians to know their patients' priorities and what's important to them to provide high quality care



Yet for people with serious illness, they share that clinicians are less likely to know their life priorities and health goals

 Life priorities

 Activities that bring joy & meaning

 Health goals



Exploring health care experiences involved asking about both positive and negative experiences in the past

Positive

- Help you **understand your health issues**
- Listen to things that matter most about your health
- Include **what matters most in making decisions** about care
- Understand your life priorities, activities that bring joy and meaning, health goals...
- Trust clinicians to **do what is right for you**
- Treat you with **dignity and respect**

Negative

- Left a visit **feeling unsure about medications or next steps**
- Have you **been afraid to ask questions, speak up, or disagree** because worried it may impact your care
- **Talked down to you** or make you feel inferior
- **Treated unfairly** by a clinician, and why



People with serious illness, and people with low-income are much more likely to be afraid that asking questions or disagreeing may impact their care

*How often have you been **afraid to ask questions, speak up, or disagree with doctors, nurses, and other health professionals because you're worried it may impact your care?***

(% responding most or all of the time)

Serious Illness: 21%

<\$30K: 25%

No serious Illness: 11%

>\$100K: 8%



People with serious illness, Blacks, and Hispanics are much more likely to have been talked down to or made to feel inferior

*How often do doctors, nurses, and other health professionals **talk down to you or make you feel inferior?***

(% responding most or all of the time)

Serious Illness: 13%

No serious Illness: 9%

White: 6%

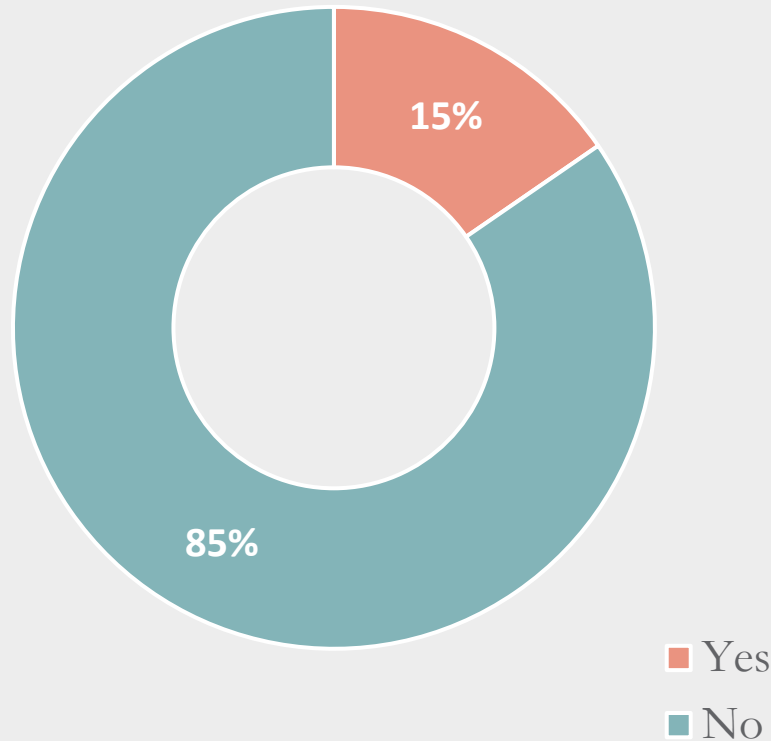
Hispanic: 15%

Black: 19%

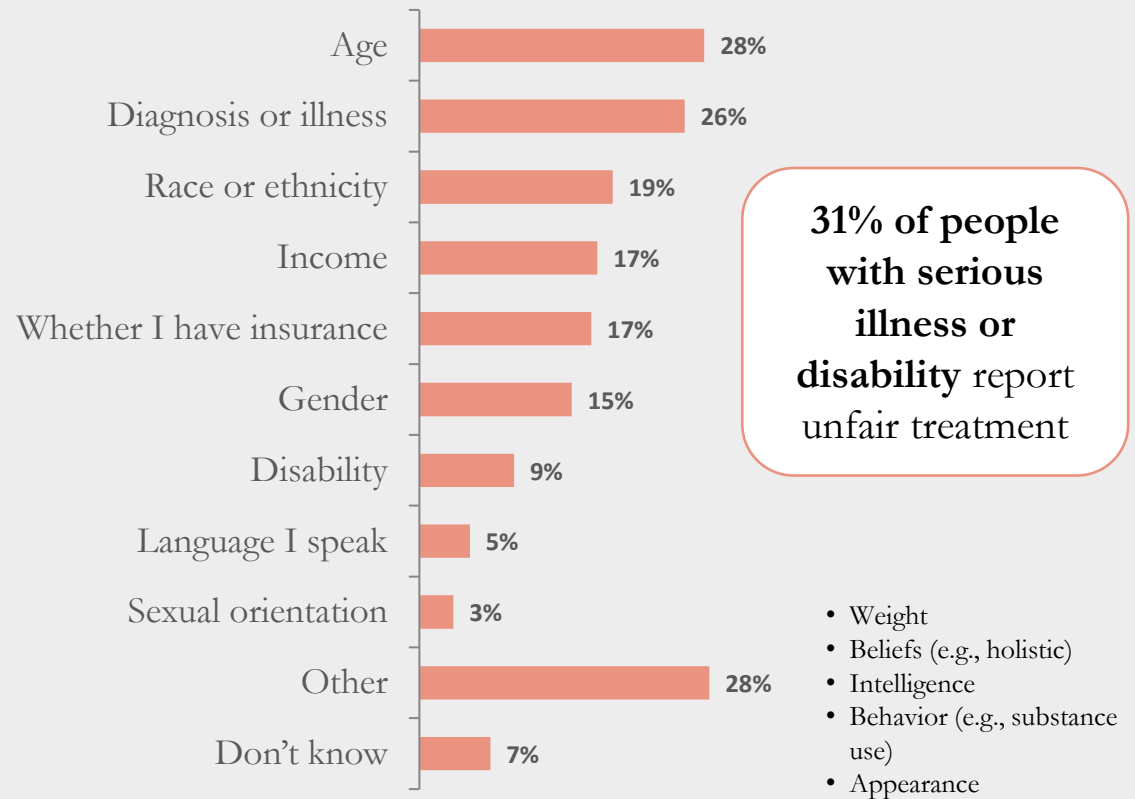


People with serious illness and/or disability are much more likely to have been treated unfairly by health professionals

Treated unfairly by doctors, nurses, etc. at some time in the past year?



Why Treated Unfairly?

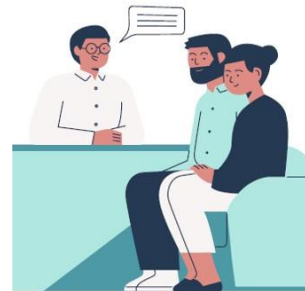


Next, we began to re-explore Advance Care Planning behaviors



Conversations
with family/
loved ones***

Conversations
with clinicians



Documentation

***Good reminder: for a minority of people, referring to family and even 'loved ones' can be alienating. For consistency, we asked questions identically to previous surveys so we could compare over time. Were this not the case, we'd ask differently...



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



Conversations with family/loved ones

Documentation



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%



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

Conversations with clinicians



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%

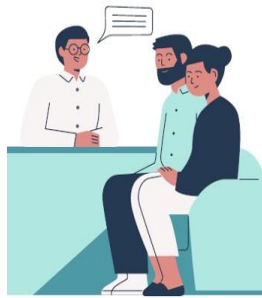


People with serious illness are more likely to have had conversations across the board, but the rates are still relatively low; rates of documentation are the same as people without serious illness



Conversations with family/loved ones

Conversations with clinicians



Documentation

Advance Care Planning Actions	Serious Illness	
	Yes	No
Had a serious conversation with spouse, parent, child, other loved one.. about wishes for your medical care if you become seriously ill?	63%	54%
Had a serious conversation with a spouse, parent, child, other loved one...about who will make decisions about your medical care?	62%	53%
Had a serious conversation with a doctor, nurse, etc. about wishes for your medical care if you become seriously ill?	35%	20%
If no, would you want to talk to a doctor, nurse, etc. about your wishes for your medical care if you became seriously ill?	51%	45%
Had a serious conversation with a doctor, nurse, etc. about who will make decisions about your medical care?	34%	20%
Written document that describes your wishes for care if seriously ill?	29%	35%
Documented health care proxy?/Written document names a health care decision maker?	32%	36%



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



Advance Care Planning Actions	White		Black		Hispanic	
	2017	2021	2017	2021	2017	2021
Had a serious conversation with spouse, parent, child, other loved one.. about wishes for your medical care if you become seriously ill?	61%	62%	35%	42%	41%	45%
Had a serious conversation with a spouse, parent, child, other loved one.. about who will make decisions about your medical care?	67%	59%	54%	41%	51%	51%
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%
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%
Had a serious conversation with a doctor, nurse, etc. about who will make decisions about your medical care?	24%	22%	22%	21%	23%	28%
Written document that describes your wishes for care if seriously ill?	40%	35%	24%	20%	21%	20%
Documented health care proxy?/Written document names a health care decision maker?	47%	38%	36%	24%	30%	24%



Major Qualitative Findings

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 (communication, relationships, decision-making)

TEST

Test 12 conversation statements, 4 quality care definitions and 5 care models descriptions 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



July Part 1: Explore and Test

Constellation of attitudes, perceptions and expectations

PROFITS

COVID

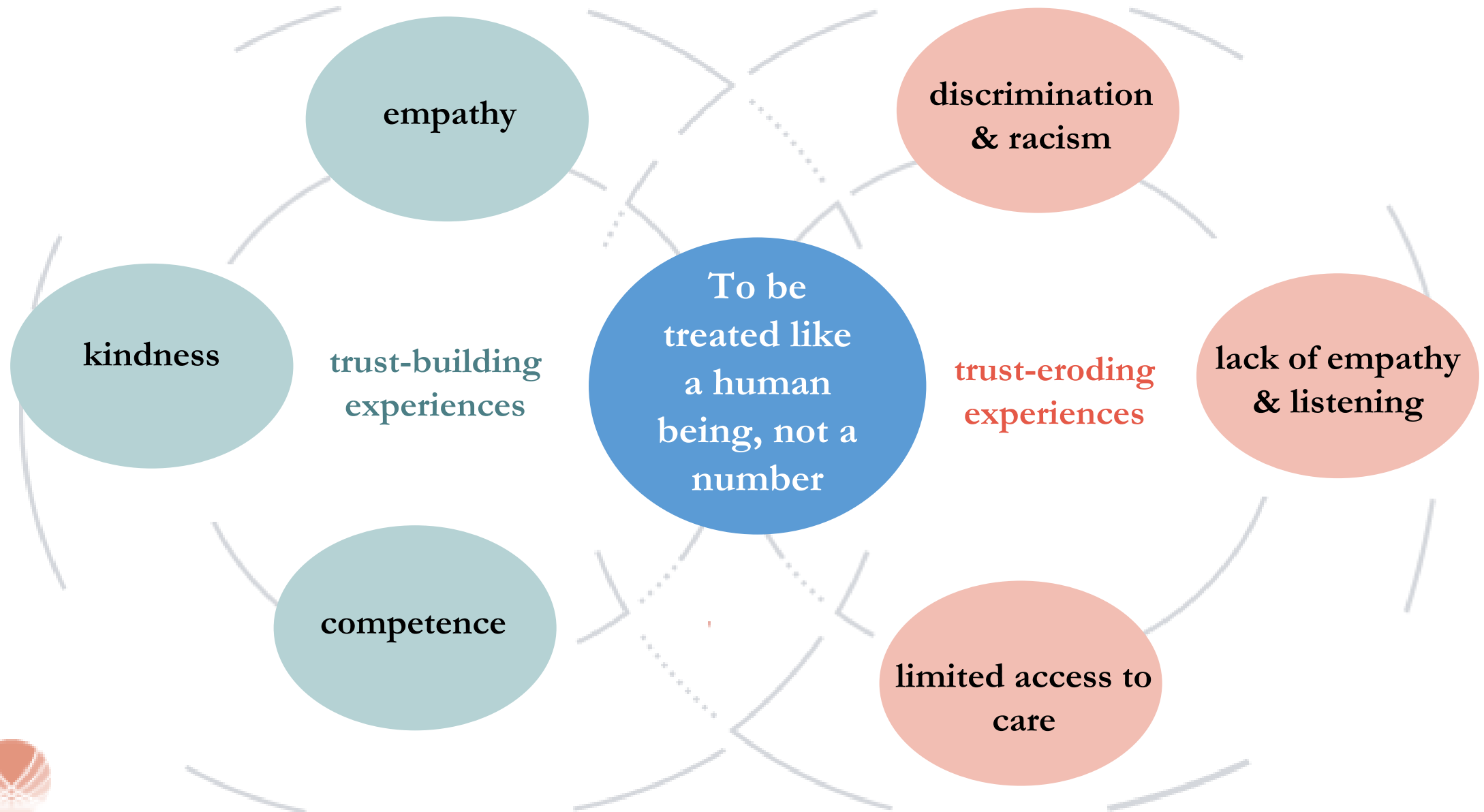
EMPATHY

WELL-BEING

TRUST



Trust in the health care system builds and erodes constantly



The 12 Conversations Statements 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.



People overwhelmingly selected a collaborative approach to care, 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.



Additional Insights

medical costs

People worry that disclosing concerns about medical costs can alter/affect their care and treatment options.

expertise

People expect/want expert and competent doctors, but for some statements of expertise conveyed arrogance.

time

Clinicians talking about valuing a patient's time is not necessarily believable.



4 Quality Care definitions were tested, and once again a collaborative approach to care resonated most overall

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...



What does this all mean?

Being treated like a whole person is
the real differentiator.

August Part 2: Validate

4 different “Calls to Action” were 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...



Overall, “You Can Speak Up” universally seen as having the greatest impact, if more difficult compared to other actions

	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	●	●	●	●	●	●	●



Speaking up about what matters
(and picking the right doctor) is recognized
as the most impactful and valuable action.



In closing...

**“Please keep pushing to make care better for people,
to raise your standards,
and to improve anything you can...”**

What Matters in Action

A different kind of homework on quality improvement

*HPM 253: Improvement in Quality of Health Care
July 27 – August 14, 2020*

Assignment 1: Customer Needs Assessment Instructions

Due date: Friday, August 14, 2020 by 2 pm

1. Identify a patient (or family caregiver) who is bright and insightful. Pick someone who has experienced a long-term and/or serious health care concern. You may choose a family member, patient or friend. Examples might include an aunt who was the caregiver of an Alzheimer's patient, a patient in your practice with diabetes, or a friend who is a cancer survivor.
2. Schedule a 45-minute time to interview him/her, either in person or by telephone.
3. Begin by asking the person to think broadly about their situation. Ask him/her to talk about what it is like to be a person in their situation, with his/her particular disease or health concern. How does it affect his/her life? What are the main fears, frustrations, inconveniences, and uncertainties he/she faces? What makes it hard to be a person in their situation? What helps him/her overcome difficulties in dealing with the situation?
4. Now, move to health care specific issues. Ask him/her to think about a specific time when health was a problem and when he/she saw a health care provider about it. Ask him/her to describe the time in specific detail. What were the fears, frustrations, inconveniences, and uncertainties? What did he/she wish had happened that did not happen? What was the hardest part about being a patient in the health care system? What positive surprises did he/she experience?
 - Do let them talk and move off into other health and life events if they wish. Be mindful of and try to minimize interruptions. Follow up for details if the responses are general. When he/she finishes one health event move on to another, until they run out of steam.
 - Do not defend yourself or the health care system. You are there to learn. You are not there to explain, teach or be judgmental.
5. When you have completed the interviews, combine the results into a non-duplicated list of needs. Group those needs into like categories and label each category. Then finish by writing up your thoughts about how the interview went and what could have made it go better. What made it challenging or worthwhile? What did you learn that you could carry over to quality improvement work? Your narrative should be no longer than 1-2 pages.



What Matters To You Day

NHS
Royal Free London
NHS Foundation Trust



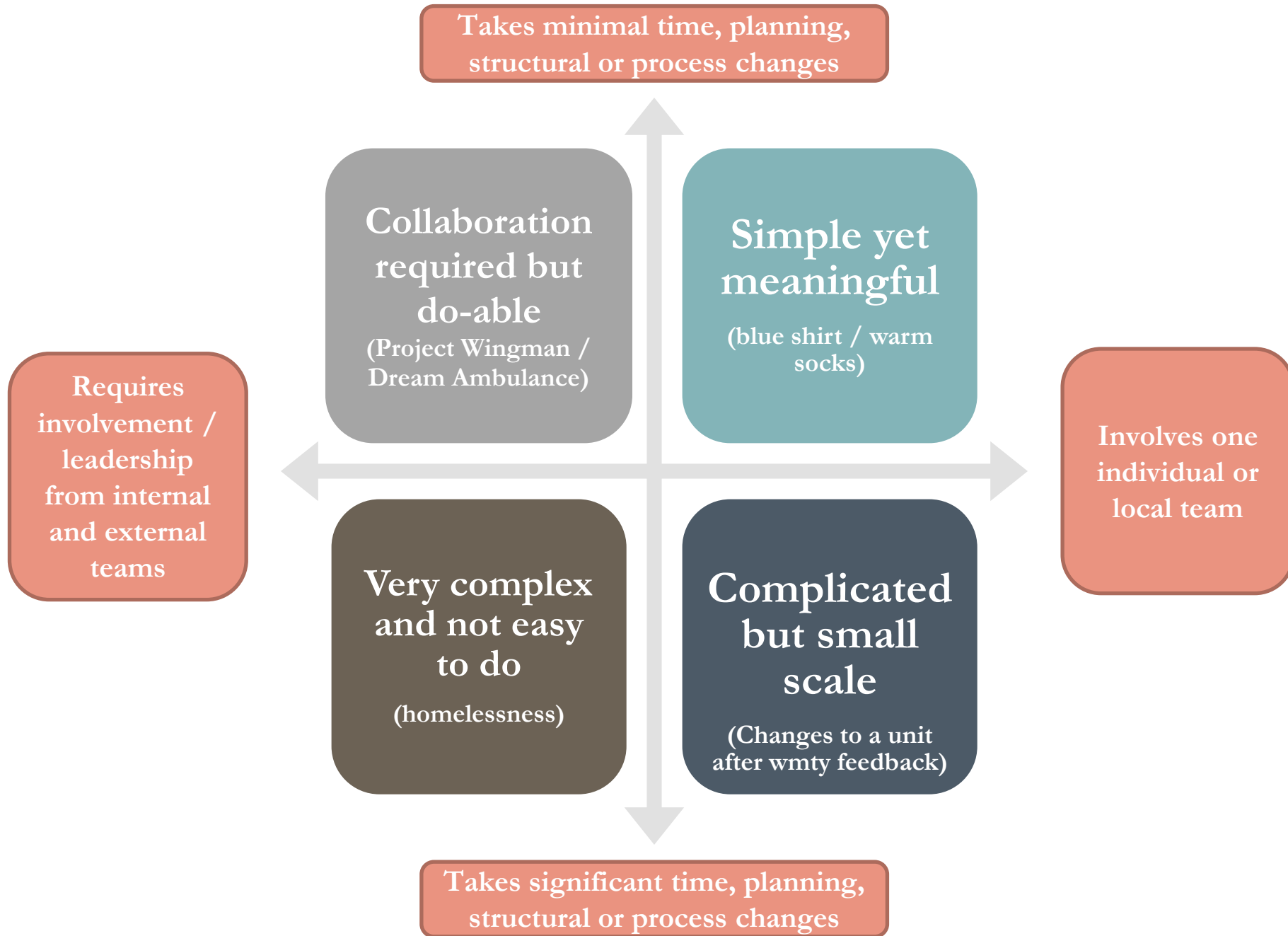
67% of staff reported asking What Matters to You changed the intervention they delivered

80% of staff shared the information that they learned with others on the care team

90% of staff reported that asking the question enhanced their conversation with patients and families



Learn more: <https://wmtty.world>



Age-Friendly Health Systems: What Matters Conversations



An initiative of The John A. Hartford Foundation and the Institute for Healthcare Improvement (IHI) in partnership with the American Hospital Association (AHA) and the Catholic Health Association of the United States (CHA).

"What Matters" to Older Adults? Toolkit

A toolkit for health systems to design better care with older adults but understanding "what matters" most to each adult.

 [Download the Toolkit](#)



Learn more: <http://www.ihl.org/Engage/Initiatives/Age-Friendly-Health-Systems/Pages/Resources.aspx>

Appendix

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.



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.

